Trigeminal Neuralgia Association Australia Incorporated.

ABN 33 914 644 101

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

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

August 2010.

Recently we applied for funding under Volunteer Grants 2010 and I am happy to inform you that we have been successful in obtaining a small grant to help us cover some equipment purchasing costs. We would like to publicly thank **the Hon Jenny Macklin MP, Minister for Families, Housing, Community Services and Indigenous Affairs, and Senator the Hon Ursula Stephens, Parliamentary Secretary for Social Inclusion and the Voluntary Sector;** for their support and the letter of congratulations.

It is encouraging to read that " The Australian Government recognises that community organisations and their volunteers play a vital role in our local communities, donating their time, skills and understanding to our most vulnerable and disadvantaged Australians, helping out in times of crisis, preserving our environment and enriching our cultural life.
This grant funding is also a way the Government can help ease the financial pressure for non-profit organisations, assist their volunteers and encourage more people to get involved in their community. ''

I will be travelling to Mayo Clinic in Rochester, Minnesota USA at the end of this month to attend their TNA 8th National Conference as they celebrate their 20th Anniversary.
Ever since my first contact with them in 2000 to start the Sydney Support Group, we have maintained a close bond and developed a very warm friendship.

In 2006, the Founder of TNA USA, Mrs Claire Patterson, initiated the President's Pin event. The President's Pin is a pin that was presented to Claire by her Board of Directors honouring her pioneering work. Claire offered this pin as a symbol in bonding the various sister organizations globally. It so happens that it is my turn to be receiving the President's Pin on their 20th Anniversary. The significance of the President's Pin is the milestone we have achieved as a global effort in raising TN awareness.

My visit to Rochester also offers an opportunity to catch up with old friends whom I have met over the years at previous conferences, and via emails. However, my visit to Rochester is a short one as I am on my way to the 13th World Congress on Pain in Montreal which starts on August 29th. It will be an awesome learning time and I am greatly looking forward to it. Perhaps one day with more successful grants such expenses can be fully borne by the association. ☺ Meanwhile, please keep me in your prayers as I travel and learn.

I will be checking my email periodically, if you have matters which may need my attention please use my tna_Sydney at yahoo.com address and I will endeavour to get back to you as soon as possible. If you require immediate support please contact your local support group leader/s – their contact number can be found on the back page of the newsletter. In my absence, Jocelyn has kindly agreed to do the next 2 newsletters. Thank you Jocelyn ☺

Irene.

The New York Times

My Pain, My Brain

By MELANIE THERNSTROM
May 14, 2006

Who hasn't wished she could watch her brain at work and make changes to it, the way a painter steps back from a painting, studies it and decides to make the sky a different hue? If only we could spell-check our brain like a text, or reprogram it like a computer to eliminate glitches like pain, depression and learning disabilities. Would we one day become completely transparent to ourselves, and — fully conscious of consciousness — consciously create ourselves as we like?

The glitch I'd like to program out of my brain is chronic pain. For the past 10 years, I have been suffering from an arthritic condition that causes chronic pain in my neck that radiates into the right side of my face and right shoulder and arm. Sometimes I picture the pain — soggy, moldy, dark or perhaps ashy, like those alarming pictures of smokers' lungs. Wherever the pain is located, it must look awful by now, after a decade of dominating my brain. I'd like to replace my forehead with a Plexiglas window, set up a camera and film my brain and (since this is my brain, I'm the director) redirect it. Cut. Those areas that are generating pain — cool it. Those areas that are supposed to be alleviating pain — hello? I need you! Down-regulate pain-perception circuitry, as scientists say. Up-regulate pain-modulation circuitry. Now.

Recently, I had a glimpse of what that reprogramming would look like. I was lying on my back in a large white plastic f.M.R.I. machine that uses ingenious new software, peering up through 3-D goggles at a small screen. I was experiencing a clinical demonstration of a new technology — real-time functional neuroimaging — used in a Stanford University study, now in its second phase, that allows subjects to see their own brain activity while feeling pain and to try to change that brain activity to control their pain.

Over six sessions, volunteers are being asked to try to increase and decrease their pain while watching the activation of a part of their brain involved in pain perception and modulation. This real-time imaging lets them assess how well they are succeeding. Dr. Sean Mackey, the study's senior investigator and the director of the Neuroimaging and Pain Lab at Stanford, explained that the results of the study's first phase, which were recently published in the prestigious Proceedings of the National Academy of Sciences, showed that while looking at the brain, subjects can learn to control its activation in a way that regulates their pain. While this may be likened to biofeedback, traditional biofeedback provides indirect measures of brain activity through information about heart rate, skin temperature and other autonomic functions, or even EEG waves. Mackey's approach allows subjects to interact with the brain itself.

"It is the mind-body problem — right there on the screen," one of Mackey's collaborators, Christopher deCharms, a neurophysiologist and a principal investigator of the study, told me later. "We are doing something that people have wanted to do for thousands of years. Descartes said, 'I think, therefore I am.' Now we're watching that process as it unfolds."

Suddenly, the machine made a deep rattling sound, and an image flickered before me: my brain. I am looking at my own brain, as it thinks my own thoughts, including these thoughts.

How does it work? I want to ask. Just as people were once puzzled by Freud's talking cure (how does describing problems solve them?), the Stanford study makes us wonder: How can one part of our brain control another by looking at it? Who is the "me" controlling my brain, then? It seems to deepen the mind-body problem, widening the old Cartesian divide by splitting the self into subject and agent.

But most of all I want to know: Will I be able to learn it?

For most of history, the idea of watching the mind at work was as fantastical as documenting a ghost. You could break into the haunted house — slice the brain open — but all you would find would be the house itself, the brain's architecture, not its invisible occupant. Photographing it with X-rays resulted only in pictures of the shell of the house, the skull. The invention of the CT scan and magnetic resonance imaging (M.R.I.) were great advances because they reveal tissue as well as bones — the wallpaper as well as the walls — but the ghost still didn't show up. Consciousness remained elusive.

A newer form of M.R.I., functional magnetic resonance imaging (f.M.R.I.), used with increasingly sophisticated software, is accomplishing this, taking "movies" of brain activity. Researchers are able to watch the brain work, as the films show parts of the brain becoming active under various stimuli by detecting areas of increased blood flow connected with the faster firing of nerve cells. These films are difficult to read; researchers puzzle over the new images like Columbus staring at the gray shoreline, thinking, India? Most of the brain is uncharted, the nature of the terrain unclear. But the voyage has been made; the technology exists. Pain — a complex perception occupying the elusive space spanning sensation, emotion and cognition — is a particularly promising area of imaging research because, researchers say, it has the potential to make great progress in a short time.

Perhaps more than any other aspect of human existence, persistent pain is experienced as something we cannot control but desperately wish we could. Acute pain serves the evolutionary function of warning us of tissue damage, but chronic pain does nothing except undo us. Pain is the primary complaint that sends people to the doctor. Of the 50-odd million sufferers in the United States, half cannot get adequate relief from their chronic pain. Many do not even have a diagnosis.

Unlike acute pain, chronic pain is now thought to be a disease of the central nervous system that may or may not correlate with any tissue damage but involves an errant reprogramming in the brain and spinal cord. The brain can generate terrible pain in a wound that is long healed, in a body that is numb and paralyzed or — in the case of phantom-limb pain — in a limb that no longer even exists.

Although there have been many theories about how pain works in the brain, it is only through neuroimaging that the process has actually been observed. It is now clear that there is no single pain center in the brain. Rather, pain is a complex, adaptive network involving 5 to 10 areas of the brain transmitting information back and forth.

This network has two pain systems: pain perception and pain modulation, which involve both overlapping and distinct brain structures. The pain-modulatory system constantly interacts with the pain-perception system, inhibiting its activity. Much chronic pain is thought to involve either an overactive pain-perception circuit or an underactive pain-modulation circuit.

Like everyone who suffers from chronic pain, I find it hard to believe that I have a pain-modulation circuit. The aspect of my pain I feel most certain about is that it is not voluntary: I cannot modulate it. And this belief is reinforced every single day that I suffer from pain, which is every day. Yet I know that pain is not a fact, like a broken bone; it's a perception, like hunger, about a physical state ("an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage," as the International Association for the Study of Pain defines it). And it's a mercurial perception; under certain circumstances the pain-modulatory system works like a spell and the brain completely blocks out pain.

Soldiers, athletes, martyrs and pilgrims engage in battles, athletic feats or acts of devotion without being distracted by the pain of injuries. When the teenage surfer Bethany Hamilton's arm was bitten off by a shark, she felt pressure, but "I didn't feel any pain — I'm really lucky, because if I felt pain, things might

not have gone as well," she said (articulating one reason the modulatory system evolved: if she had thrashed about in pain, she would have bled until she drowned).

In addition to being activated by stress, the pain-modulatory system is triggered by belief. The brain will shut down pain if it believes it has been given pain relief, even when it hasn't (the placebo effect), and it will augment pain if it believes you are being hurt, even if you aren't (the nocebo effect). The brain's modulatory system relies on endogenous endorphins, its own opiatelike substances. The nature of a placebo has long been a source of speculation and debate, but neuroimaging studies have shown the way a placebo actually helps to activate the pain-modulatory system.

In a recently published study led by Dr. Jon-Kar Zubieta at the University of Michigan Medical School, the brains of 14 men were imaged after a stinging saltwater solution was injected into their jaws. They were then each given a placebo and told that it would positively relieve their pain. The men immediately felt better — and the screen showed how. Parts of the brain that release endogenous opiates lighted up. In other words, fake opiates caused the brain to dispense real ones. Like some New Age dictum, philosophy becomes chemistry; believing becomes reality; the mind unites with the body.

Other studies have shown that opiates and other medications rely on a placebo to achieve part of their effect. When subjects are covertly given strong opiates like morphine, they don't work nearly as well as they do if the subjects are told they are being given a powerful pain reliever. Even real medications require some of the brain's own bounty.

Conversely, thinking about pain creates pain. In studies at Oxford University, Irene Tracey has shown that asking subjects to think about their chronic pain, for example, increases activation in their pain-perception circuits. Distraction, on the other hand, is a great analgesic; when Tracey's volunteers were asked to engage in a complicated counting task while being subjected to a painful heat stimulus, she could watch the pain-perception matrix decrease while cognitive parts of the brain involved in counting lighted up. At McGill University, Catherine Bushnell has shown that simply listening to tones while being subjected to a heat stimulus decreased activity in the pain-perception circuit. +++

"There is an interesting irony to pain," comments Christopher deCharms, who worked with Mackey designing and carrying out the Stanford study. We were talking in his office at Omneuron, a Menlo Park medical-technology company he founded three years ago to develop clinical applications of neuroimaging. "Everyone is born with a system designed to turn off pain. There isn't an obvious mechanism to turn off other diseases like Parkinson's. With pain, the system is there, but we don't have control over the dial."

The goal of the Stanford technique is to teach people to control their dials — to activate their modulatory systems without requiring the extreme stress of fleeing from a shark or the deception of a placebo. The hope of neuroimaging therapy (as deCharms calls the Stanford technique) is that repeated practice will strengthen and eventually change the ineffective modulatory system to eliminate chronic pain, the way long-term physical therapy can change muscular weakness. The scan would thus be more than a research tool: the scan itself would be the treatment, and the subject his or her own researcher.

Only once do I recall having a glimmer of my own pain-modulatory system at work: a hidden power that emerged, dispensed with pain and then returned to some forgotten fold in my brain, where I have never been able to locate it again. The event did not take place on a battlefield or a marathon course or in a temple; it was in a basement of the Stanford University medical center three years ago. At the time, Mackey had designed an earlier study that did not use imaging technology but focused on how suggestion alters pain perception. Although I was not formally enrolled in the study, I asked if I could undergo a clinical demonstration. My experience illustrated the power of suggestion in an unexpected fashion.

A metal probe attached to the underbelly of my arm heated up and cooled down at set intervals. I was told that although the heat probe would feel uncomfortable, my skin would not be burned. During one exposure, I was instructed to think of the pain as positively as possible, during another to think of it as negatively. After each sequence, I was asked to rate my pain on a 0-to-10 scale, with 10 being the worst pain I could imagine.

Although I discovered that I could make the pain fluctuate depending on whether I was imagining that I was sunbathing or was the victim of an inquisition, I still rated all the pain as low — ranging from a 1 to a 3. If 10 was being slowly burned alive, I felt I should at least be begging for mercy to justify a rating of 5. So I insisted that Mackey turn up the dial so I could get a real response. But even during the moments when I was actively trying to imagine the pain as negatively as possible, it remained in a mental box of "not even burned," which kept it from really hurting: hurting, that is, the way a burn would.

As it turned out, I got a second-degree burn that later darkened into a square mark. Mackey was more than a little dismayed as we watched the reddening skin pucker, but I was thrilled. Naturally the protocol had been carefully designed not to injure anyone, yet in my case that protection had failed because of the very phenomenon it was designed to study: expectation — the effect of the mind on pain or placebo.

I had recently spent several weeks observing Mackey in the university's pain clinic, where he is associate director. I was so convinced that Mackey — then a tall sandy-haired 39-year-old with a deep interest in technology (he got a Ph.D. in electrical engineering before he went to medical school) and an air of radiant integrity — would not burn me that my brain had not perceived the stimulus as a threat and generated pain. I admired him, I trusted him, I was positive that he wouldn't hurt me. And, ipso facto, he hadn't.

Mackey's genius as a practitioner, I thought, lay partly in his ability to similarly inspire patients. "When I started working with pain patients, I realized how much of the treatment involved trying to reverse learned helplessness," he said — to rally them out of the despair ingrained from years of unremitting pain and cajole their minds to chip in its own analgesic to their therapies. "The purpose of this study is to show patients their mind matters," Mackey said.

The mark of the burn is barely visible now, but for a couple of years afterward, at times when my chronic pain was making me miserable, the sight of it would both encourage and reproach me. Here is the ultimate proof that my mind can control pain, I would think, yet I didn't know how to make it wake up and do so. I could take the edge off the pain by conjuring positive images, but the effects didn't last, and I never again had the remarkable placebo response that masked a second-degree burn. In fact, a mild burn from spilling tea on my hand one day brought tears to my eyes.

When the real-time neuroimaging study began, I couldn't wait to try it.

The area of the brain that the scanner focuses on is the **rostral anterior cingulate cortex** (rACC). The rACC (a quarter-size patch in the middle-front of the brain, the cingular cortex) plays a critical role in the awareness of the nastiness of pain: the feeling of dislike for it, a loathing so intense that you are immediately compelled to try to make it stop. Indeed, the pain of pain, you might say, its defining element, is the way in which the sensation is suffused with a particular unpleasantness researchers refer to as dysphoria. Since pain is a perception, it's not pain if you don't experience it as hurting. You can feel hot or cold or pressure, and note them simply as stimuli, but when they exceed a certain intensity, the rACC kicks in, and suddenly they become painful, riveting your attention and causing you to recoil.

Many pain-reducing techniques aim to manipulate the conscious awareness of pain. Distraction, placebo, meditation, imagining pleasant scenes and hypnosis all result in a reduction of rACC activation

when they work. Patients who have undergone a radical surgical treatment occasionally used for pain (as well as for mental illness) called a cingulotomy, in which the rACC is partly destroyed, report that they are still aware of pain but that they don't "mind" it anymore. Their emotional response has receded.

The image I saw while lying in the f.M.R.I. machine at the time of the recent Stanford study was not literally my rACC but a visual analogue of it that is easier to see: a 3-D image of a fire. The flames represent the degree of activation in your rACC: when it is low, the flames are low; when rACC activation is high, the flames flare. The study involves five 13-minute scanning runs, each consisting of five cycles of a 30-second rest followed by a 1-minute interval in which you try to increase rACC activation and then a 1-minute interval in which you try to decrease rACC activation.

Before my scan began, I was prepped in different mental strategies for increasing and modulating my pain. Everyone's brain works a bit differently, though, so subjects have to experiment in the scanner to see what is most effective for them. For some, trying to distract themselves from their pain works best; for others, focusing on their pain — like embracing a Zen koan — seems to be what triggers their pain-modulatory system. When deCharms used neuroimaging therapy on himself to try to alleviate his chronic neck pain, he concentrated on the pain itself and felt it "suddenly melt away." He said that a patient described the feeling as being "like a runner's high" (a state that has been shown to involve the release of endogenous endorphins).

Increase Your Pain, the screen commanded, as the first run began. I tried to recall the mental strategies in which I had been prepped for increasing pain: Dwell on how hopeless, depressed or lonely you felt when your pain was most severe. Sense that the pain is causing long-term damage.

Dwelling on the hopeless loneliness of my pain certainly made the flames of my rACC spark. The mental image that I found increased my pain the most, however, was the one that matched the visual analogue of the rACC: Picture a hot flame on your painful area. Try to make the flame grow in the painful area, and imagine it actually burning your flesh.

Having recently read Ariel Glucklich's extraordinary "Sacred Pain," I had plenty of details of the burning of heretics and witches available to me. I had only to imagine the smell of sizzling hair to make the flames of my rACC explode.

Decrease Pain, the screen commanded.

The suggested pain-reduction strategies, however, did little to quell the flames on the screen. I pictured suffocating the pain with banal positive imagery: flowing water or honey, something soft and gentle, but my mind kept slipping back to the progress of the auto-da-fé, and the rACC fire flared.

Feel that sensation, but tell yourself that it is just a completely harmless, short-term tactile sensation.

Pilgrims and devotees all around the world choose to inflict pain upon themselves during sacred rites — from being nailed to crosses to dangling from hooks. For them, pain is an occasion for euphoria, not dysphoria. There are many historical records of the equanimity saints and martyrs often possessed during torture. The second-century Jewish martyr Rabbi Akiva, for example, continued to recite a prayer with a smile on his lips while the flesh was being combed from his bones. "All my life," he explained to the puzzled Roman general orchestrating his execution, "when I said the words 'You shall love the Lord your God with all your heart, with all your soul, and with all your might,' I was saddened, for I thought, When shall I be able to fulfill this command? Now that I am giving my life and my resolution remains firm, should I not smile?"

As Glucklich writes, the conviction that pain is a spiritual opportunity seems paradoxically anesthetizing — or, as a scientist would say, religious states of conviction can robustly activate the pain-modulatory system.

During my next Decrease Pain interval, instead of trying to picture a vacation, I imagined myself as a martyr, lucidly reciting Though I walk through the valley of the shadow of death while being burned at the stake. My rACC activation — I noted — respectfully quieted. Then I remembered that the 23rd Psalm seems to have Christian associations, and since I was presumably being tortured for being half-Jewish, a Jewish prayer might be more appropriate. Unless, that is, I was being accused of witchcraft, in which case, I might be generally disillusioned with Judeo-Christian prayer. As I tried to settle on a fantasy, I noticed that my rACC stayed low: Irene Tracey's theory of the modulating effects of distraction. By the last run, I had the strategies down — heretic-martyr: rACC down; heretic-victim: rACC up.

The results of the scan, Mackey showed me, revealed significant brain control. A week later, I was scanned again, this time in the offices of Omneuron. I could feel that it was easier to control my rACC with less reliance on elaborate fantasy; I was interacting more directly with my brain.

This learning effect was clearly seen in the recent Stanford study (which was financed in part by the National Institutes of Health). The first phase of the study looked at 12 subjects with chronic pain and 36 healthy subjects. (The healthy participants were subjected to a painful heat stimulus in the scanner and tried to modulate their responses. The chronic-pain patients, however, simply worked to reduce their own pain.) The chronic-pain patients who underwent neuroimaging training reported an average decrease of 64 percent in pain rating by the end of the study. (Healthy subjects also reported a significant increase in their ability to control the pain.)

"One big concern we had," Mackey says, "is, Were we creating the world's most expensive placebo?" To ensure against that, Mackey trained a control group in pain-reduction techniques without using the scanner (as in his previous study) to see if that was as effective as employing a $2 million machine. Mackey also tried scanning subjects without showing them their brain images or tricking subjects by feeding them images of irrelevant parts of the brain or feeding them someone else's brain images. "None of these worked," Mackey says, "or worked nearly as well." Traditional biofeedback also compared unfavorably; changes in pain ratings of subjects in the experimental group were three times as large as in the biofeedback control group.

The second phase of the study, which is now under way, is designed to assess whether neuroimaging therapy offers long-term practical benefits to a larger group of chronic-pain patients. After the six sessions designed to teach them to regulate their pain, they will be observed for at least six months. The idea is to see whether they can fundamentally change their modulation system so that it can reduce pain all the time without constantly and consciously thinking about it. If so, the technique would not simply provide shelter from the storm of pain; it would bring about climate change.

"I believe the technique may make lasting changes because the brain is a machine designed to learn," deCharms says. The brain is soft-wired (plastic) rather than hard-wired: whenever you learn something new, new neural connections are believed to form and old, unused ones to wither away. (Researchers refer to this as activity-dependent neuroplasticity.) In other words, if you actively engage a certain brain region, you can alter it.

Many diseases of the central nervous system involve inappropriate levels of activation in particular brain regions that change the way they operate (negative neuroplasticity). Some regions experience atrophy, while other regions become hyperactive. (For example, epilepsy involves hyperactivity of cells; stroke, Parkinson's and other diseases involve the atrophy of nerve cells.) With chronic pain, it is believed that additional nerve cells, recruited for transmitting pain, create more pain pathways in the nervous system, while nerve cells that normally inhibit or slow the signalling, decrease or change function.

In addition, chronic pain results in a significant loss of other kinds of brain cells. A. Vania Apkarian at Northwestern University found that while the brain of a healthy person shrinks 2.5 percent a year, in a person with chronic back pain, it shrinks an additional 1.3 percent annually in the areas that involve rational thinking. I know chronic pain interferes with my concentration at times, but I never imagined that it could be truly impairing it! The Stanford technique may mitigate this harm by teaching people how to increase the efficacy of the healthy cells.

Moreover, the technique may offer a particular advantage over drug therapy. It is very difficult to design drugs to fix a problem in a specific region of the brain because the receptors that drugs target, like the opiate receptors, generally appear in multiple systems throughout the brain (which is partly why drugs almost always have side-effects). Neuroimaging therapy, on the other hand, is designed to teach control of a localized brain region.

"The technique gives people a tool they didn't know they had," Mackey says, "cognitive control over neuroplasticity. We don't fully understand how this feedback mechanism is working, but it provides tangible evidence that people can change something in their own brains, which can be very empowering. It takes Buddhist monks 30 years of sitting on a mountain learning to control their brains through meditation — we're trying to jump-start that process." As to how exactly it works — how the decision-making parts of the brain (the prefrontal regions of the cortex) cause the change in the rACC — "Heck if I know!" he says. "How do we get the brain to do anything? We can map out the anatomical circuits involved and the general functions of those circuits, but we can't tell you the mechanism by which any cognitive decision is translated into action."

If neuroimaging therapy could treat pain, could it rewire the brain to fix other diseases, like depression, stroke and learning disabilities, or exercise the brain in ways that would make it cleverer and more adept at certain skills? Neuroimaging has shown, for example, that the part of the brains of London cabdrivers that regulates spatial relations is larger than usual and that learning to juggle creates visible changes in parts of the brain involved with motor coordination during three months of training. I'm constantly getting lost and dropping things. Could I exercise and strengthen those areas more quickly by, say, thinking about maps in the scanner than by driving around London?

"What is the limit to neuroimaging therapy?" deCharms muses. "Could you learn to target the reward or serotonin system and up-regulate happiness? Could you augment psychotherapy by allowing the patient and the therapist to watch the brain?" — an idea Omneuron is already exploring, by bringing therapists and patients to the scanner and imaging patients' brains as they undergo the sessions. "After all, talk therapy is about learning to understand thought processes — to understand neural substrates and change them," he says.

How deep can the insights that functional imaging might offer really go?

What I'd like to do most is not fix problems or improve skills but use imaging as a vehicle for self-transparency. Instead of puzzling about my motivations, I'd like to be able to read my mind completely, like a book: for imaging to be the Plexiglas window through which I could finally see the ghost.

"Hmm," Dr. Scott Fishman, chief of the pain-medicine division at the University of California, Davis, said dubiously when I brought up this notion. "I'm not sure that functional imaging is actually looking at the mind. The mind is like a virtual organ — it doesn't have a physical address that we know about. Functional imaging provides a two-dimensional snapshot of a three-dimensional or a four-dimensional event of this entity of the mind. Right now, imaging is just looking at the brain; we have to be honest about that." Imaging shows the level of activation of different parts of the brain, from which we can extrapolate something about the mind, he points out, "but what we really need to see is how the parts talk to each other — and the complex nuances of their language."

The brain has more than a hundred billion neurons. All functional imaging can tell us now is that a few hundred million of them in various areas become more active at certain times. It's as if you were trying to conduct a symphony by watching a silent film of the concert. You would see the players in the bass section active at one moment, vigorously gesturing, and then the rest of the orchestra would join in, but you couldn't hear the notes or how they form strands of melody and harmony and meld together to create the ethereal experience.

"Consciousness is not neurons firing — consciousness is a transcendent emergent phenomenon that depends on the firing of neurons," says Dr. Daniel Carr, an eminent pain researcher who is now the C.E.O. of Javelin Pharmaceuticals. "The gears of a watch rotate and keep time, but the turning of the gears is not time. The question is, Is neuroimaging a picture of the experience of consciousness or is it a picture of a mechanism associated with that experience? Can there actually be a picture of an experience? Does a picture of a funeral or a wedding show you experiences? Or is there an unbridgeable gap there because you need to already understand the experience in order to interpret the photos? If a higher being told us how consciousness works, could we understand the explanation?"

I hope the above article has stirred your interest. Brain imaging for pain using functional MRI has a lot of interest in Pain research these days. I am working on inviting one such imaging expert to our 2011 conference. – Irene.

Weather forecast - the Australia way

It was April and the Aboriginals in a remote part of Northern Australia asked their new elder if the coming winter was going to be cold or mild.
Since he was an elder in a modern community he had never been taught the old secrets. When he looked at the sky he couldn't tell what the winter was going to be like.

Nevertheless, to be on the safe side, he told his tribe that the winter was indeed going to be cold and that the members of the tribe should collect firewood to be prepared. But being a practical leader, after several days he had an idea.
He walked out to the telephone booth on the highway, called the Bureau of Meteorology and asked, 'Is the coming winter in this area going to be cold?'

The meteorologist responded, 'It looks like this winter is going to be quite cold.'

So the elder went back to his people and told them to collect even more wood in order to be prepared.
A week later he called the Bureau of Meteorology again. 'Does it still look like it is going to be a very cold winter?'
The meteorologist again replied, 'Yes, it's going to be a very cold winter.'
The elder again went back to his community and ordered them to collect every scrap of firewood they could find.
Two weeks later the elder called the Bureau again. 'Are you absolutely sure that the winter is going to be very cold?' he asked.
'Absolutely,' the man replied. 'It's looking more and more like it is going to be one of the coldest winters ever.'
'How can you be so sure?' the elder asked.

The weatherman replied, 'Our satellites have reported that the Aboriginals in the north are collecting firewood like crazy, and that's always a sure sign.'

http://www.ncbi.nlm.nih.gov/pubmed/7699385
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An epidemic in Cuba of optic neuropathy, sensorineural deafness, peripheral sensory neuropathy and dorsolateral myeloneuropathy.

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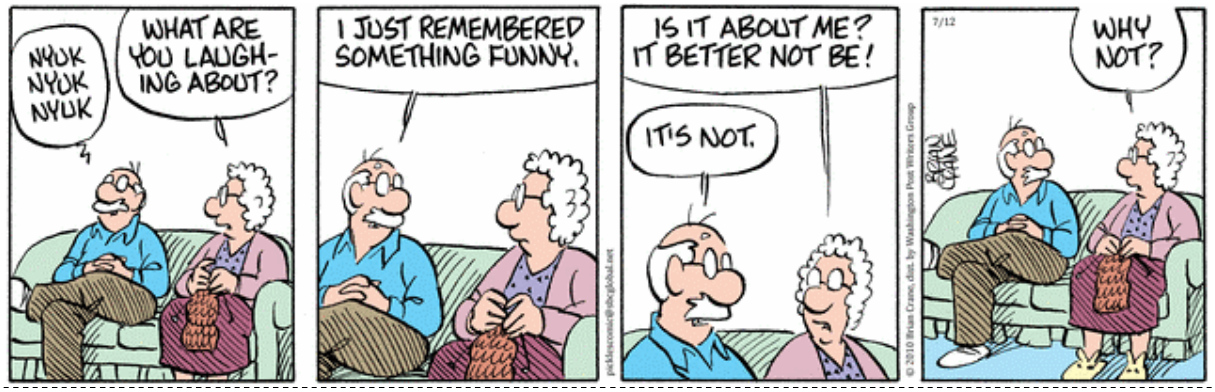
Abstract
An epidemic outbreak of peripheral neuropathy affected Cuba in 1992-93 resulting in 50,862 cases (national cumulative incidence rate (CIR) 461.4 per 100,000). Clinical forms included retrobulbar optic neuropathy, sensory and dysautonomic peripheral neuropathy, dorsolateral myeloneuropathy, sensorineural deafness, dysphonia and dysphagia, spastic paraparesis, and mixed forms.
For epidemiological purposes, cases were classified as optic forms (CIR 242.39) or peripheral forms (CIR 219.25). Increased risk was found among smokers (odds ratio (OR) 4.9), those with history of missing meals (OR 4.7) resulting in lower intake of animal protein, fat, and foods that contain B-vitamins, combined drinking and smoking (OR 3.5), weight loss (OR 2.8), excessive sugar consumption (OR 2.7) and heavy drinking (OR 2.3). Optic neuropathy was characterized by decreased vision, bilateral and symmetric central or cecocentral scotomata, and loss of color vision due to selective lesion of the maculopapillary bundles. Peripheral neuropathy was a distal axonopathy lesion affecting predominantly large myelinated axons. Deafness produced selective high frequency (4-8 kHz) hearing loss. Myelopathy lesions combined dorsal column deficits and pyramidal involvement of lower limbs with spastic bladder. Clinical features were those of Strachan syndrome and beriberi. Intensive search for neurotoxic agents, in particular organophosphorus esters, chronic cyanide, and trichloroethylene intoxication, yielded negative results.
Treatment of patients with B-group vitamins and folate produced rewarding results. Most patients improved significantly and less than 0.1% of them remained with sequelae; there were no fatal cases. Supplementation of multivitamins to the entire Cuban population resulted in curbing of the epidemic. Overt malnutrition was not present, but a deficit of micronutrients, in particular thiamine, cobalamine, folate and sulfur amino acids appears to have been a primary determinant of this epidemic.

PMID: 7699385 [PubMed - indexed for MEDLINE]



Things that only the illogical Irish would say:

'You three are a right pair if ever I saw one!'
'How come every time you ring a wrong number it's never engaged?'
'Spread out in a bunch.'
'Hello, Mary, how's your new false teeth?' asked Bridget. 'I'm leaving them out till I get used to them!' said Mary.

Meeting Reports

SYDNEY SUPPORT GROUP

Toongabbie Public School

3rd July 2010

Present: Irene W, Peter & Rose H., Jocelyn S , Kim K, Marion A, Stuart & Gundel B, Frank M, Jan McL , Ray C , Vera R , Laurel R & Jan

Apologies: Stephanie R, Henry & Jeanette B, Ann & Laurie P, Marj & Ken F, Hilary & Keith W, Lloyd & Elizabeth T.
Kim S, Celia C, & Julie C who have all just undergone MVD, so we look forward to seeing their happy faces soon!
Julie C rang me later in the month to say she is now pain free after her MVD, and she hopes to be at the CBD meeting to share her good news and experience.

Meanwhile our thoughts are with: Lloyd and Elizabeth, Lloyd recovering in hospital; Hilary and Keith; Hilary still recovering from back surgery.

Due to a prior booking of the Hall, we were relegated (or is that promoted?) to the Staff room, which was very comfortable. Irene W opened the meeting at 1.45 and welcomed new member Laurel & her friend Jan.

Laurel has had facial pain for 12 years following Rhinoplasty (nose surgery) in 1998 which damaged her orbital nerve. Within 6 months of this surgery she developed pain on her left side, but it was not diagnosed immediately. She had a partial nerve block which lasted a week, but made her paralysed and she was constantly dribbling. Then she had a complete nerve block that lasted about 6-8 weeks She gets constant sharp, shooting pain and feels like she has been hit on the head with a hammer. She had a couple of years of remission, when we had milder winters, but as soon as there is a cold snap it seems to knock her about.
Irene explained that in Dr Burchiel's Classification for Facial Pain – "**Trigeminal neuropathic pain**" results from unintentional injury to the trigeminal nerve from trauma or surgery; and surgical therapies for trigeminal neuralgia should be avoided as they would not help in such cases.

Excerpt: **Trigeminal Neuralgia: Definition and Classification :** Jorge L. Eller, M.D.; Ahmed M. Raslan, M.D.; Kim J. Burchiel, M.D.

[Pain in the distribution of the trigeminal nerve in patients with a history of injury to the trigeminal system identifies a specific subset of cases. The patients in these cases are suffering from a form of neuropathic pain involving the trigeminal system, as opposed to the idiopathic forms of TN (TN1 and TN2). This group of patients is divided into two subsets. The first, trigeminal neuropathic pain, includes patients who have suffered unintentional injury to the trigeminal system as a result of facial trauma; oral surgery; ear, nose, and throat surgery; skull base surgery; posterior fossa surgery; or stroke. The second, trigeminal deafferentation pain, includes patients who received intentional injury to their trigeminal system, such as neurectomy, gangliolysis, rhizotomy, nucleotomy, tractotomy, or other denervating procedures. Trigeminal neuropathic pain mostly constitutes an unremitting throbbing or burning in the affected area…]

Due to her pain, Laurel had to give up her TAFE teaching job. Her pain is constant and she is on 800mg Tegretol (less in the summer months) & Mersyndol. She tried Lyrica but it made her feel weird, nauseous and drowsy. She saw Dr Dexter, to explore her options, but he said an MVD is not suitable for her condition.

Peter shared his update with his peripheral nerve stimulatoion, which was implanted for his post herpetic neuralgia. He has recently had it tuned and feels it is working better. He could sympathise with Laurel as he had the same "bag of cement on your head" feelings.

Jan expressed concern that her sister could be getting symptoms of TN. She has pain low level left developing in the temple and triggered by cold.

KimK then introduced our guest speaker Dr. Sun. Dr Sun is from China and is visiting her daughter Mei, who has kindly come along to interpret for us. Dr. Sun then introduced herself …

" I am a doctor. In my hospital I have seen many patients like you and I have compassion for you. Today I would like to introduce to you a sort of holistic approach, a self help Traditional Chinese therapy for healing from the inside.
In China, we apply the combination of Chinese herbals, acupuncture, medications (drugs) or surgeries, to achieve an overall better result."
The theory behind Acupuncture is that the energy flows through the meridians and when pathways are blocked, pain results. Acupuncture - inserts fine needles - unblock these pathways.
Although pain is in one area, needles are placed in other parts of the body, to clear the blockage.
Traditional Chinese medicine attempts to diagnose the underlying cause by examining the colour of the tongue, pulse at wrist. Dr. Sun also mentioned that there is a cross reference ie: left face = right wrist. Chinese medicine believes that heat blocks the pathways and so people suffering pain should avoid spicy food & alcohol. As everybody is different and have differing occupations, Drs may use different techniques to treat.

Dr Sun explained the self-help method as the " 3-1-2 meridians" practice
She also said that all the senior citizens in China practise these 3 methods to maintain a healthier life style.

3 - Acupuncture Points
1 - Tummy breathing
2 - Relaxation.

3 Acupuncture Points
Dr Sun then demonstrated for us the 3 Acupressure points that we can do on ourselves as often as we can, whenever we can.
i) The first acupuncture point - on the fleshy part of hand (near the base of the thumb and first finger) can help prevent flu, constipation, relieve toothache, headache, pain in the arm, elbow, shoulders etc. Dr. Sun walked around the room and literally had all of us squealing in pain as she presses into the acu -point
ii) The second acu –point is 3 fingers width from the base of the wrist and is right in the centre of the 2 tendons which runs down the wrist. This is a life saving point as it relates to the vital organs such as heart & respiratory system.
iii) The third acu – point is 4 finger width below the kneecap, and it relieves facial & back pain, flu symptoms and helps with liver function, bladder, prostate & period pain.

1 - Dr showed us the deep tummy breathing, with Kim K as the patient. There are 9 meridians in your tummy & this breathing exercise helps to balance the Yin & Yang, while massage the 9 meridian. " lying down on your back breath in through your mouth while pushing out the tummy as far as you can, then exhale."

2- We were shown how to stand & squat , which should be repeated 20-100 times per day. But Dr. Sun advises not to force yourself, and only to squat as far as you can. She also suggested that elder folks should find a table or something steady to hang on to for balance.

We should all do "3-1-2" every day. The advantages of doing these routines are- no special equipment required, no medication, no side effects, it is flexible, in that it can be done anytime, anywhere. This is very popular in China with the elder folks.
Dr Sun wished us good health & happiness and concluded a very informative talk. Kim presented her with a small gift and we all enjoyed cake & a cuppa.

The above are notes taken by Marion and myself; any error is strictly ours.

Frank reports that door collection for 3 July= $ 37.50
Hall Rent =$33.00; Gift for Guest Speaker $22. Balance = $100.60

Next meeting here at **Toongabbie Public School at 1.30 on Saturday 4th September 2010,** which will be our 11th birthday celebration!

Irene.

Please note**: Our 4th December** meeting will be a combined Toongabbie and Sydney CBD meeting here in Toongabbie. This is a special time of the year to share blessings of Christmas and warmth of friendship. Special guest is Santa: Dr. Mark Dexter giving a talk on " how to read your MRI."
We extend this invitation to all members especially those from Canberra - **O! Come All Ye Faithful**! for **Santa Clause is coming to town**.

Brisbane Support Group

30 Ridley Rd Bridgeman Downs

10 July 2010

Present: Leonie G, Margaret and Colin B, Eileen and Henry C, Neil F, Jeff and Lorraine B, Helen W, Rod W, Noela W, Jill L, Br. Leo, John and Margaret H, Neil F
A**pologies**: Tony M, Doreen T

My apologies for the shortness and lack of detail in the notes from this meeting; 21 month old Eamonn attended the meeting with me and as a result I was unable to take detailed notes while watching him and conducting the meeting. My apologies also if some of the detail is incorrect. Leonie J

Tony M: - Tony sent his apologies for this meeting as he was away on a fishing trip. He informed me he has been a lot better lately and as a result was well enough to be able to go away on this trip. He is also well enough that he has been able to return to work in recent months. This is fantastic news Tony we are so happy to hear your great news.

Corry G: - Leonie's Mum Corry has been better but is still holding in there. The cold weather in the south seems to be causing some havoc with her pain levels. Lets hope that cold weather eases a little soon and the pain along with it.

Lorraine B: - Has had to stop taking Tegretol due to liver problems. Is on 150mg Lyrica and 100mg Endep. She has a Vitamin B12 shot regularly. The Lyrica unfortunately gives Lorraine a rash so she is not keen on taking it. Her tongue has been burning lately.

Noela W: - Was good until recently. The colder weather seems to be affecting the pain.

Helen W: - Has been working on reducing her Tegretol dosage from 200 – 100 at night. She is also on treatment for osteoporosis.

Margaret B: - Was going well but recently has been getting shocks about 1-2 times a week. She has reluctantly upped her Tegretol to 500 for the moment. She finds she is often unable to think straight.

There were a number nods of agreement/acknowledgement (I know how you feel) around the room when this comment was made.
Jill L: - Has been good. Is on Tegretol as Lyrica made her sleepy. Tegretol seems to be more effective too. She takes Endep also. Jill has not been in any real pain since around February. B12-(Neo-Cobalamin).

Margaret H: - Has been good. Unlike many others Margarets pain seems better in Winter than Summer. She will not change her meds though as they seem to be doing the job. She is 800mg Tegretol a day and Methylcobalamin monthly.

Henry C: - Has has a relapse lately and attributes it to the cold weather. He was on 200 Tegretol for a short period due to the pain but has weaned himself off it again.

Br. Leo: - Has been the same but is ok. He finds some relief from the Anaesthesia Dolorosa with a hot water bottle.

Neil F: - Has not been good. This is why he has been absent from meetings this year.

Gold coin donations: $36.00

Next Meeting: Saturday September 13th 2010

Leonie

SUNSHINE COATS SUPPORT GROUP

Kawana Library, Nanyima Street, Buddina.
1.00pm. 17 July 2010

Apologies: David G, Lloyd K, Sherryl M, Keith B.

Present: Max H, Trixie B, Jill L, Andrea F, Jean W, Teresa M, Peter & Pearl B, Glenis N.

Jean welcomed everybody to the meeting, old and new faces.

General Business: Teresa has resigned from group leader. Jean is looking for someone to come forward to assist Jean. (*SGL appointment is by the Association after assessment)*

Phone reports:
David G: His TN is still biting, not back on his medication at the moment. David is aware of the ongoing zaps.
Lloyd K is feeling fine.

Meeting reports:

Max H is Pain free at the moment, off all medications but getting a few pins and needles. (Great to hear Max.) He isn't sure what he has done to make it go away, but he is now able to shave without any pain. This is after five years of being on Tegretol.

Jill L: Another person that isn't in any pain at the moment. Jill is still taking 200 mg Tegretol per day. She is able to touch her face without any buzzing, has been able to do that for about 2-3 weeks now. Weather/wind doesn't affect her. Jill has been attending the Brisbane meetings as well, which she finds very helpful.
(Jean took the time to remind members that the methylcobalamin injections that Brisbane are having, are vitamin B12).

Peter R: Great news, the reason that Peter and Pearl couldn't come to last meeting was because they have just become Grandparents to twins (little boys). Congratulations!!! Peter has been pretty good. He is tempted to stop his medication 200 mg Tegretol. At the moment he is in very little pain, but still has his B12 injections monthly and is still on the soy program.

Andrea F: Andrea has been using soy products for a couple of years. She has been to a Caloundra dentist, every thing is very good. Fantastic news, Andrea is going to see Dr Dexter for a consultation next week on Thursday. Her pain seems to have settled into a few light pains. At the moment Andrea is taking Tegretol 200mg. The group reminded Andrea to take her pain diary and any previous brain MRI's to Sydney. (Good luck Andrea, you are in great hands).

Glenis N: First time visit for Glenis. Her medications are:- Lyrica 600mg and Norspan 20mg pain patches, that are changed weekly. She hasn't been diagnosed with TN. Her right side is affected, the Trigeminal nerve was damaged from a bleed in the brain. The pain is constant- prickly, burning,shock feelings and soreness in the lip and eye. Glenis attends the pain clinic at the Nambour hospital. In the past she had a Lidocaine infusion- after 3 days it hadn't made any difference, so stopped infusions. She is on a new medication Endep 10mg. Feels that has helped a little, but it has interfered with her Warfarin. At the moment she is getting her blood tested weekly to try and level everything out. It has been five years since her haemorrhage with the residual affect being that her teeth are numb, bottom lip OK, top lip not and doesn't have any feeling in her teeth. (Our thoughts and concern are with you).

Trixie B is fine and has no pain to report. She is a little sensitive around the scar area.

Jean W: Going to see Dr Dexter on the 29th July. She had a CT scan and since the Doctor didn't call her, assumed that she had to put up with the pain. On a good day she feels as though she has a hang over. She had to go to the doctor again for another complaint and since she was still in considerable pain asked what could be done. Her doctor looked at the scan results and advised that there was only an Arachnoid cyst, nothing to worry about. Jean pointed out that was what was causing some of the problems last time. Her Trigeminal nerve goes over the cyst. They can't put any Teflon there, they can't remove the cyst because it is close to the optic nerve and may cause blindness. This is why she is going to see Dr Dexter to see if anything can be done.

Teresa M: Been to see chiropractor that specialises in upper cervical chiropractic, because her upper neck is out of alignment. Her CT scan showed that the C1-C3 vertebrae are all off centre. She is going to see him for treatment.

Jean pointed out that in the last newsletter there medications that were referred to, were a little different to the one's that we may be used to.

Translations are as follows: Information taken from Insights :page 184-85).

Carbamazapine = Tegretol
Phenytoin = Dilantin, Epanutin.
Clonazepam = Rivotril, Klonopin.
Valproate = Depakene, Depakote, Epilim, Convulex.
Gabapentin = Neurontin
Oxcarbazepine = Trileptal.
Topiramate: **Topomax**

The question the support group would like to ask is "What is Topiramate"?
Topiramate is also known by most as Topomax (some even call it Dopemax because of its side effect). It is a drug used mainly for (preventing) migraine - Irene.

A couple of the classified ads were read out, providing a few chuckles.

Jean thanked Teresa for her long time support as group leader. Before that, she did the advertising and treasurer, besides other things. Teresa was presented with a small gift and thank-you card that the members signed. *I hope folks also remember to thank Jean - Irene.*
Jean took the time to thank everybody for coming and invited everyone to join us for afternoon tea.

Meetings donations $28.50

Next meeting 18 September 2010.

Jean

Canberra Support Group
Canberra Labour Club Belconnen
24 July 2010

Present: Richard M, Susan M, Devi W, Jan G.
Apologies: Brian W, Chris R, Cathleen T, Kerri G.

Meeting opened at 10.45 am.

Jan reported that **Brian W** was still pain free over three years after his glycerol injection. He had discovered that Dr T was recovering and now working one day a week from the Canberra Hospital.

Jan had received a phone call from a friend of a sufferer with many questions about surgery. Jan had felt that Irene would be better able to answer and suggested an email be sent. She believed that Irene had received and answered the email.

Cathleen was not in pain at present and continuing with B12 as she felt it was helpful.

Kerri had mistaken the time of the meeting so offered her apology. Her doctor has increased the dosage of her medication which was helping but also making it difficult to concentrate, which was a problem at work. Her doctor hoped to reduce her dosage soon.

Richard now has pain in the jaw but wondered if his jaw was out of alignment due to chewing on one side. His dentist had informed him that he could apply for Enhanced Primary care if a dental problem was affecting a medical condition. There would be some costs involved.

Jan continued to be mostly pain free and hoped the cold winds due soon did not have the usual result of triggering an attack.

Devi arrived having been delayed by traffic and road works. She looked so much better than the last time she had been able to attend the support group meeting; and she attributed this to acupuncture. She had been told it was not a cure but twice a week sessions had certainly helped. It had also been suggested that she eat kidney beans every day to build up the nerves. She does feel much better. She was attending the pain clinic as Gabapentin was then subsidised.

The meeting then closed at 11.20am.

Next Meeting is on the 25th of September.

Jan

Perhaps you folks could plan to travel to Toongabbie together and join us on the 4th of December for a special support group meeting. – Irene.

2010 Meeting Dates

State	GROUP	Date & Time	Venue	Group Leader/s
ACT	**Canberra**	**25 September 10.30-12.30**	**Barbara Byrne Room Labour Club, Belconnen**	Jan Goleby ☏ 02 6254 6640
NSW	**Sydney**	**4 September 1:30pm – 4:00 pm**	**Toongabbie Public School** Cnr Fitzwilliam & Binalong Roads	Kim Koh ☏02 97431279
	Sydney CBD	**2 October 10:00am –12:30pm**	**St. James Parish Hall,** Level ONE, 169 Phillip St. Sydney CBD	Irene Wood ☏ 0413 363 143
QLD	**Brisbane**	**13 September 1.30-4.00pm**	**30 Ridley Road BRIDGEMAN DOWN**	Leonie Gall ☏ 0407 55 44 07 Tony MacPherson ☏ 07 3822 2286
	Sunshine Coast	**18 September 1:00 pm**	**Kawana Library,** Nanyima Street, Buddina	Jean Williams ☏ 07 54911978
	Townsville	**21 August 1.00 – 4:00pm**	**Carville Senior's Villa** 35 – 37 Diprose St **PIMLICO**	Sera Ansell ☏ 07 47516415
S.A	**Adelaide**	**26 September 2:00pm – 4:00pm**	**Burnside Town Hall Civic Centre** Cnr Portrush/Greenhill Road	Graham/ Liz Boyer ☏ 08 8392 2781
TAS	**Hobart**	**21st August 2:00 – 4:00 pm**	**Glenorchy Library** Enter via **Barry and Cadell Streets**	Helen Tyzack ☏ 03 6245 0429 Ros Wilkinson ☏ 03 6234 7989
VIC	**Melbourne**	**7 August 1:30pm – 4:00pm**	**"Ringwood Room" Ringwood Library, RINGWOOD**	Evelyn Diradji ☏03 9802 6034

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