Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

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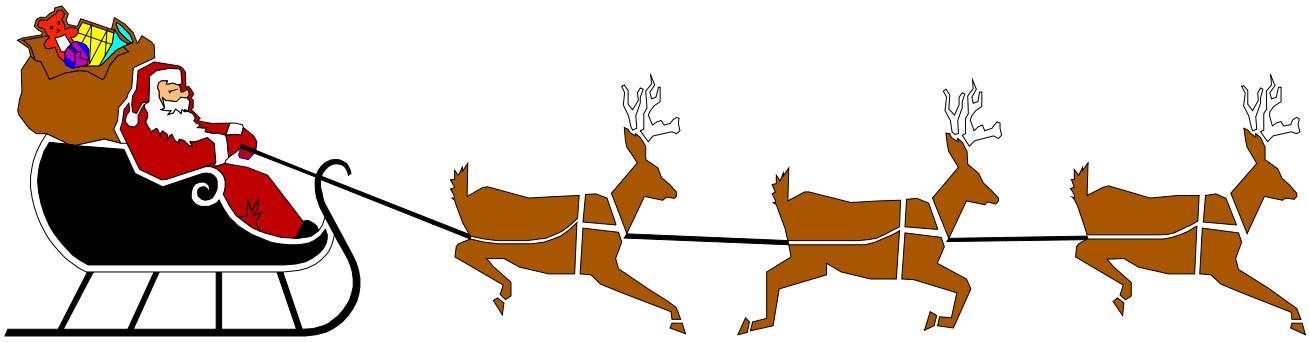
NEWSLETTER DECEMBER 2009

If undelivered please return to:
Chris Hewlett
51 Killen Road, RD 2
Katikati, 3178
New Zealand



Patron	Hon. Steve Chadwick MP		
President	Bob Stothart	4/326 The Terrace, Wellington, 6011	Ph: (04) 385 0240 Email: stothart@ihug.co.nz
National Coordinator	Jenny Murray	27 Grenville Street, New Plymouth, 4310	Ph/Fax: (06) 751 1014 Email: jenny.gbs.nz@clear.net.nz
Secretary	Tony Pearson	113 Weka Road, Mariri, RD 2, Upper Moutere, Nelson, 7175	Ph/fax: (03) 526 6076 Email: tonypearson@xtra.co.nz
Treasurer	Peter Scott	P.O. Box 4162, Palmerston North, 4442	Ph: (06) 357 8436 Email: peterscott@clear.net.nz
Newsletter Editor	Chris Hewlett	51 Killen Road, RD 2, Katikati, 3178	Ph: (07) 549 0931 Email: chrispy57@gmail.com
Medical Advisor	Gareth Parry ONZM.MDO.FRACP.ChB		
Web Site	**Support** **Education** **Research**		**www.gbsnz.org.nz**

Editors Note

A couple of new cases of GBS have been reported since the last newsletter. We wish these new sufferers a speedy recovery and sincerely hope they will be home for Christmas.

Planning for next year's AGM is well under way. Details are revealed later in the magazine.

There have been lots of interesting articles popping up on the internet with regard to swine flu vaccinations. Some in favour, some not, but as yet I have had no response from the writers re permission to reprint. I am hopeful that will happen before the next issue.

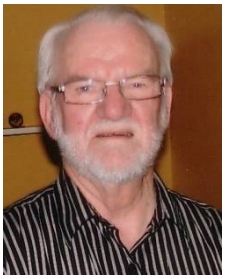
Terry's garden tip re used coffee grounds has been working a treat and the number of slugs taking up residence in my cabbages etc has dramatically reduced. Apparently the worms like them as well which might explain the huge ones I've been seeing lately.

Please keep your stories coming in and any other articles you think might be of interest to the group. Thanks to all those who have contributed so far.

I wish you all a very Merry Christmas and a Happy New Year.

Chris

Presidents Paragraph:



A recent Listener carried an extensive piece on campylobacter but nowhere was Guillain Barré Syndrome mentioned. However, there seems to be a growing understanding about how to safeguard against infection from this particular nasty. Members who attended the national conference in Auckland this year will recall the presentation from Dr Donald Campbell of the Food Safety Authority about campylobacter and he said that education about food handling, particularly uncooked chicken, was making a difference in the incidence of severe gastroenteritis illnesses. I mention this because about 40% of GBS and CIDP cases are precipitated by campylobacter. It is a case of being forever vigilant to avoid this horrible, sickening bacteria.

Because GBS/CIDP are rare diseases we will never be a regular high profile, front page news item but we can and should always be aware and alert to poor food handling practices. If you see low standards in public places avoid them forever.

Along with my wife Margaret and Peter and Robin Scott we put up a stall at the Nurses Annual Conference here in Wellington and handed out a whole lot of brochures and pamphlets. It was heartening to talk to many of those gathered who had nursed GBS/CIDP patients and to share their understanding about this perplexing neurological condition. I thought we made a small impact and I'm sure we left an impression that here is a support group with its eye on the ball. We'll be looking for other, similar opportunities.
On a more cheerful note, enjoy Christmas, take care and greet the New Year with courage and optimism.

Further to Bob's comments on Food Safety for those of you who have internet access take a look at this link. A very interesting article.

http://www.nytimes.com/2009/10/04/health/04meat.html?_r=1&partner=rss&emc=rss&src=igw

Secretary's Jottings

As Vivienne and I eagerly await the arrival of our third grandchild – courtesy of our younger daughter and her partner – I am minded to think back over the last eight years since our arrival in New Zealand – my how time flies!! I arrived as a keen immigrant to this great country but nevertheless somewhat nervous on the medical front having only just received a (somewhat forced) sign off from my neuro consultant to allow me to fly after 3 consecutive attacks of GBS (CIDP) over the previous 18 months in the UK. Was I crazy I asked myself to leave the tried and tested UK medical system, that had got me thro' the attacks, to risk a medical set up I knew nothing about in a comparatively tiny commonwealth country and to walk away from a strongly supportive UK Support Group and to throw myself on the mercy of a NZ Group that – as far as I could determine at that stage - involved just one lady called Jenny. Well – if I have learned anything in my time here it's "don't jump to conclusions"!

True our medical and hospital service has its shortcomings but, overwhelmingly, I hear from Group members that – once they have been diagnosed (and there, of course, is the key to GBS – the world over!) then the treatment and care they have received is praiseworthy. And as for that one "lady" – while she remains the pin wheel of the Group I now know that she is ably supported by a raft of "official" and unofficial helpers that make up the strength of the Group today. Yes there is still a lot we can do but – and here is the second thing I have learned - " Rome wasn't built in a day" and, just perhaps, the rush, tear and deadline setting I was used to in my London job may not generate the lasting results we need here.

So my worries were groundless, at least from a GBS perspective, and all I have to worry about now as "certificated kiwi" is understanding the MMP Electoral system – grasping the implications of the Treaty of Waitangi on the social and economic future of this country and wondering why – against all the obvious signs that this country and its people are having a tough financial time at present – the kiwi dollar is one of the strongest and most regularly internationally traded currencies in the world!

Mind you these momentous issues are nothing in comparison to the headache I have caused our Treasurer to have over the last month or so! In the last newsletter I asked our Editor to include a "Yellow Sheet" inviting readers who were not already financial members to join our happy band. We did indeed receive a few additional new members BUT a goodly number of you misinterpreted my objectives and paid up again – even though you were already financial.

So…… With the new membership year commencing on December 1st – I will, with Peter's help, try to ensure that those who have already paid for 09/10 are not chased again and receive your new membership card without further delay.

And finally….. So you think you know all about GBS do you because you have gone through the ordeal yourself or helped someone through it and sat through several Conferences?– well how about S.I.D.P. and Anti Mag ???? Both of these variants have occurred in NZ during the last few months to new sufferers and, surprise surprise, the medics reference to them generated a few blank faces BUT guess who we turned to for help – and guess who knew exactly what they were – no prizes, of course, for it was none other than our valued Medical Advisor Dr Gareth Parry. I won't labour you with an explanation at this point but have asked our Editor – if she has room- to include Gareth's description elsewhere in the Newsletter – suffice it to say that when SIDP was explained it rang a bell and I went back to my own case notes – and guess what – it's what I was diagnosed with – although it didn't register at the time! As for the Anti Mag variant – rarer than Hen's Teeth I gather BUT if you know someone who has it (because it's chronic) PLEASE let me know – there is a gentleman down this way who would love to share experiences and prognosis for the future. As an aside those of you at the Conference may recall Gareth describing a "new" GBS treatment he was trialing in the USA involving the drug Rituximab which was not then available in NZ – Well Nelson/Marlborough DHB have just funded a course of treatment with this drug – it's one of the VERY few that Anti Mag responds too!!

Well, as another busy year draws to a close, I guess like many of you, we are making plans to make the best of the summer months with family and visitors (only 4 sets of overseas visitors on our schedule so far!) and I hope you are able to have a good time even if our old friend GBS is making life somewhat tougher than you may wish – as my old Dad used to say

"*Nil desperandum carborundum*" – which roughly translated – he assured me – means "*don't let it grind you down*" !!

As always take care

Tony

GBS DICTIONARY

By Gareth Parry

S.I.D.P.

The 'S' of SIDP is for subacute. As has been stated, some people use the term to distinguish between GBS, that progresses for up to 4 weeks, and CIDP that needs to progress for at least 8 weeks. In my opinion SIDP is just a form of CIDP. Almost all SIDP patients will need some form of treatment for a relatively long period of time, typically a minimum of months. Prognosis may be a bit better than typical CIDP.

ANTI MAG

Myelin-associated glycoprotein (MAG) is an essential component of myelin that holds the layers of myelin together. Antibodies against this molecule lead to decompaction of the myelin - instead of being tightly wound around the axon it becomes loose and that leads to degeneration of the myelin sheath. Thus, it is a demyelinating neuropathy as is CIDP but it is not inflammatory. Since it is not inflammatory the typical approaches to treating CIDP do not work very well, if at all. Steroids definitely do not help. IVIg might help a little bit because it does bind antibodies in the blood but the effect is minimal and short-lived.

PLEX also helps a little but as sole treatment is not very effective which is why I typically use PLEX along with chemo. PLEX removes the antibodies while the chemo stops them being formed again. This approach is sometimes effective but even then it is not dramatic.

Rituximab is a fairly new drug that targets the cells that produce the antibodies. A recent study showed that it was effective in anti-MAG neuropathies but it is not a cure. Many patients do not need to be treated. MAG neuropathy usually comes on late in life (70's and beyond) and can be quite mild, causing nothing other than a little imbalance. When it comes on at a younger age it is more likely to need treatment because it does progress and the younger onset gives it more time to produce disability. One conundrum is that treatment is much more effective if given early but you don't want to treat too early because the treatments carry some risk and may not be necessary. I usually reserve treatment for people under the age of 70 although I will treat older people who are in excellent health and likely to live another decade or more. This a very rare neuropathy, constituting perhaps 5% of CIDP-like neuropathies.

Take your brain out for a walk

Two new studies spell out benefits for people recovering from stroke as well as for those 50 and older.

Walking is good for your head. Sure, we knew about the improvements it can provide to aerobic capacity, not to mention muscles and joints, but two recently released studies show that walking can enhance brain function too.

Walking or other repetitive exercise can change the brain in a number of ways, says Prof Gary Small, of the University of California's Semel Institute for Neuroscience and Human Behavior. The heart pumps more blood, affecting not only muscles but also the brain. "Your brain needs blood, because in the blood are nutrients and oxygen, which are good for the cells and will make the brain healthier," he says. "The vessels that deliver the nutrients also branch out and become more effective."

The act of doing a movement over and over can also stimulate the brain's neurocircuits, he adds, resulting in activity in various regions of the brain. That activity may decrease over time as the body becomes more efficient at the activity. But other stimulation can have an effect - while a person walks outside with a friend, for example, the brain is guiding a number of activities, such as taking and observing.

In one study, stroke patients put through a walking programme could walk better and faster afterward and the repetitive movements also activated areas of their brain. Researchers expected to see most activity in the cortex, which governs motor skills, but instead much activity was seen in the subcortical region, which, says lead author Dr Andreas Luft professor of neurorehabilitation at the University of Zurich in Switzerland, "has some role in walking, but maybe we've underestimated it. We're actually putting this idea back as a potential mechanism of how walking is controlled."

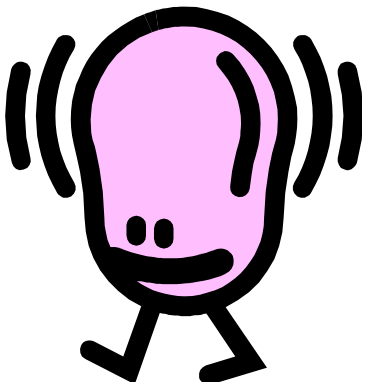
About half of 71 study subjects with some movement disability were asked to walk on a safety-rigged treadmill three times a week for up to 40 minutes, increasing intensity to a moderate level as the study progressed. The others did assisted stretching exercises for the same amount of time. All were tested in the beginning and after six months for speed and aerobic capacity; about half in each group were given functional magnetic resonance imaging tests before and after to determine brain activity. The walking group increased its speed by 51%, while the stretching group improved by 11 %. The walkers' fitness levels also increased, with aerobic capacity rising about 18%, while the stretching group's fitness levels decreased slightly.

Functional MRI tests revealed intensified activity in the subcortical region in the walking group, which surprised the researchers (the stretching group showed no change). "We found that change can not only happen in the superficial layers of the brain, but in the deeper brain levels as well," says Prof Luft.

"The movement repetition that typically goes on in a physical therapy session is very low," says Dr Daniel Hanley, a professor of neurology at Johns Hopkins Medical Institutions and a co-author of the study, which was conducted at Johns Hopkins, the University of Maryland and the Department of Veterans Affairs, Maryland VA Medical Center. "We did a lot of repetition with the same leg, and we think that is associated with the brain changes." The researchers believe the brain is either relearning how to walk, or reprogramming itself to compensate for regions damaged by the stroke.

In the other study, a walking regimen boosted cognitive scores in adults who were encouraged to exercise at home for 24 weeks in a moderately intense regimen (most chose walking). Researchers at the University of Melbourne in Australia did randomised tests on 170 adults aged 50 and older who didn't have dementia but were considered at increased risk due to memory problems. All participants received education materials on memory loss, stress management, diet, alcohol consumption and smoking, but not on physical activity. Half - the control group - were not encouraged to exercise. The others were asked to exercise for three 50-minute sessions per week. Cognitive function was measured over 18 months with the Alzheimer Disease Assessment Scale-Cognitive Subscale, which measures cognitive dysfunction in people with Alzheimer's and other forms of dementia. Those in the exercise group showed a small improvement in cognitive scores compared to the control group and also displayed better delayed recall. Researchers believe the progress is significant, considering participants engaged in only moderate amounts of physical activity.

Jeanine Stein is the health correspondent for the Los Angeles Times.



A Personal Encounter...

A Day of Celebration

By Bob Gregory

Guillain Barré Syndrome arrives suddenly and entirely unbidden into busy lives, transforming stricken individuals from their familiar world of normality into a strange and different place, where they become dependent patients and/or clients, unable to take care of their own needs and becoming generally incapable, at least for a time. The damage to the peripheral nervous system creates strange and frightening physiological sensations, blocked internal connections, and ravages one's physical body.

Psychologically and emotionally, GBS leaves indelible marks, for one endures a major and profound trauma to the self. Most, fortunately, are able to get well and perhaps even, if lucky and gifted with patience, stronger and more aware and appreciative of the importance of such positive activities as "smelling the roses" each day thereafter.

For me, GBS started over 20 years ago, and quickly disrupted my life, even though it took over a year to get a diagnosis confirmed by two neurologists and subsequent personal understanding of what was wrong. The funny electrical sensations, the fatigue, and the "brain dead" feelings gradually left me over the next decade or so, and my patience in dealing with denial; anger, acceptance, and moving on were eventually rewarded. But the huge impact of the disease left its mark.

Following recent retirement from my job and past career, I wanted to get into something new, something different, something rewarding. I wanted to reject forever that "brain dead" feeling, and test my capabilities to learn and find alternatives.

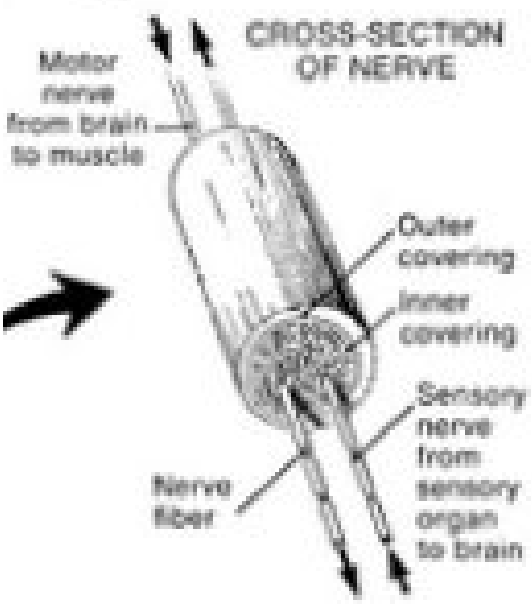
From childhood, I always wanted to get into "ham" radio, and so I decided that might be a suitable project, something new about which I knew very little. Accordingly I began studying the complexities of reception and transmission of radio waves, antennas, atmospheric conditions, electricity, transistors and diodes, and so much more of the special lore common to amateur radio operators. Over several months, I attended the local NZART meetings where I was welcomed and advised and given access to their excellent specialist library, read the magazines and books available at the local library, talked with and listened to various experts, and listened in on a 2 metre radio to the "rag chewing" of local hams. I was surprised at the enormous scope of knowledge required, and by the depth of information available on so many topics that were quite mysterious. I studied hard, putting my brain up against the plethora of complex bits of information.

Eventually, the big day came and I sat down and took the formal written examination. I was fortunate enough to pass the first time, and I have now been assigned a unique call sign – giving me the privilege of being able to transmit as a ham operator. The country code is ZL, the 2 stands for the region of New Zealand I live in, and the final three letters, when coupled with the ZL2, are unique to me. Quite naturally, I chose and was rewarded with a special sign that would mark and celebrate my involvements with the Guillain Barré Syndrome. My call sign is ZL2GBS and I am proud of that! I have just received my certificate today, and I have yet to make my very first call - but you and I know full well that we GBS'ers are special and we know better than most, about caring and smelling the flowers! Celebrate, enjoy, and make the most of each and every day.

Life summarized in ..... 4 bottles

Nerve Pain in GBS

I had been searching for stuff for the next magazine and I found this picture in an old book on women's health that I have.



It shows a view of the nerve and I noticed that there appears to be two nerves that could be involved in GBS. One says it's the motor nerve from brain to muscle; the other is the sensory nerve from sensory organ to brain.

My question is, is this the reason that some people experience pain and some do not with GBS. Can the motor nerve be affected and not the sensory nerve?

Dr Parry Replied:

This is very insightful and quite complex question that I will try to address in less than 10 pages. Maybe it is time to talk about pain in GBS again at the next meeting.

When they first emerge from the spinal cord the sensory and the motor nerve fibers are completely separate. They join just as they emerge from the spinal column. Once they emerge from the spinal column the sensory and motor nerves are intimately mixed together and anything that affects one is likely to affect the other

- The initial pain that occurs in GBS is due to inflammation and swelling in these nerves within the spine but outside the spinal cord itself. The inflammation activates specific pain nerve fibers in the nerve sheath. It is really not much different from inflammation causing pain anywhere. If you get arthritis (inflammation of the joints lining) you get joint pain; if you get appendicitis (inflammation of the appendix) you get abdominal pain, etc. This early pain in GBS tends to be felt in the general region of the spine or the upper parts of the limbs - between the shoulder blades, low back, hips and thighs, shoulders and upper arms. It subsides as the inflammation subsides, generally over a few days to a week or two. It tends to be of an aching quality. This pain occurs regardless of whether the motor nerves or the sensory nerves are involved.
- The second pain tends to come on as the first subsides. It feels different in quality; it is burning, shooting, stabbing although sometimes also feels aching. It is felt farther down the limb, usually in the hands and feet but can involve the entire area of the limbs and even the torso. This pain is caused by damage to the sensory nerves, usually outside the spinal column; i.e., after the motor and sensory nerves get mixed together. It typically lasts for a few weeks but can last for months and may even be permanent if the GBS is severe.
- It is not entirely clear why some patients get pain and others don't but it is generally related to severity. The more inflammation there is the more early pain there is and the more nerve damage occurs so the later pain is also more common and more severe. Some people with mild GBS can still get quite severe early pain but they almost never get the late pain because there is very little nerve damage.

This is the brief version and probably raises more questions than it gives answers.

I attach a brief article I wrote and that we probably published in the newsletter a couple of years ago.

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PAIN IN THE GUILLAIN-BARRE SYNDROME

By Dr G Parry

Guillain-Barré syndrome (GBS) is a disorder in which the dramatic nature of the paralysis overshadows all other features. Pain is not given much attention but is an integral part of the disease; in some studies, pain has been reported in more than 80% of patients. It has been my experience that pain is frequently underappreciated and undertreated by physicians. At one extreme, I have talked to patients who have been told that they cannot have pain because pain does not occur in GBS. Pain may occur during the acute phase of the illness and may even predate the onset of the weakness or it may occur during recovery and rehabilitation. Because of space limitations, I will not discuss the emotional pain but close attention to anxiety and depression in both patients and their loved ones is a critical part of overall management of GBS. Nor will I discuss the pain which may occur during the rehabilitation process.

1. Pain during the acute phase of the illness:

Pain may be the first symptom of GBS or may develop together with the weakness. It typically is located in the region of the spine and the upper parts of the limbs. For example, there may be pain between the shoulder blades, in the low back and buttocks or around the hips and shoulders. The pain is often difficult to describe but tends to have an aching or cramping quality. There may be stabs of pain with movement. It is not at one clearly localized point but is somewhat diffuse and seems to be deep in the body rather than on the surface. It is usually no more than a nuisance but may be severe, particularly in patients with rapidly progressive and severe paralysis. In such patients, who may be on a ventilator and unable to communicate easily, it is very important to ask specifically if pain is present. This is the most neglected type of pain seen in GBS since the doctors are concentrating on the life-threatening aspects of the disease. However, when severe it may cause dangerous heart irregularities and changes in blood pressure and aggressive treatment with strong analgesics such as morphine may be needed. Care must be taken with the use of these narcotics in patients with reduced respiratory function since they may cause respiratory failure. If the patient is already on a ventilator there is little cause for concern. This pain may resolve rapidly during treatment with plasmapheresis. It also improves with steroids such as prednisone. It is also important to realize that immobility causes pain which can be alleviated by frequent turning and passive movement of paralysed limbs so experienced high quality nursing is very important.

2. Pain during recovery:

As recovery from paralysis progresses, the pain discussed above usually subsides but may be replaced by a different type of pain. This new pain tends to be localized in the lower part of the limbs, particularly in the feet. The pain is less often of the aching/cramping quality and is more burning, stabbing or shooting. It may be associated with marked sensitivity to touch so that even the light touch of the bed sheets is perceived as pain. It is also exacerbated by exercise and weight-bearing so it may interfere with rehabilitation. This is called “neuropathic pain” and it responds rather poorly to narcotic analgesics although they should still be used in severe cases. Best responses are seen with certain antidepressant drugs such as amitriptyline (Elavil) and nortriptyline (Pamelor) or with anticonvulsant drugs like gabapentin (Neurontin) and carbamazepine (Tegretol). High doses are usually necessary and response may not be immediate. In my experience, the commonest cause of failure of these drugs is that the dose is not high enough and is not used for long enough. Most patients will experience side effects if the drugs are used in sufficient doses to relieve pain but the benefit should outweigh those side effects. Another problem is patient expectations; treatment is expected to reduce the pain but will seldom abolish it. If a patient is expecting to be pain free and there is only a 50% reduction in pain intensity that will be regarded as a treatment failure and yet that is about the best that can be expected. Nontraditional treatments such as acupuncture may also help. Neuropathic pain also subsides with time but may persist for months or years and occasionally some pain may persist permanently.

In summary, pain of some degree occurs in most patients suffering from GBS and may occur at any stage of the illness. It is frequently ignored and usually is undertreated. Fortunately, in most patients it is mild and, even when severe; it usually improves spontaneously or with treatment

A Personal Encounter...

ARRON'S EXPERIENCE OF GUILLAIN-BARRE SYNDROME

(Written by Theresa and first published in our magazine in 1999)

GBS - a viral infection mimics the chemical compound and myelin sheath around the nerves, the immune system attacks the virus and the nervous system - causing paralysis.

Arron had the 48hr flue one weekend but by Monday morning he seemed to have recovered so he went to work all OK. He had a few dizzy spells during the week but nothing to worry about. Then Saturday morning he woke up with tingling fingers and feet. It worsened; he began to walk funny so he went to the doctor who said 'take some aspirin and rest'. That night he had back pain and at midnight was crying in pain so we went to emergency.

We spent the whole night in emergency. It was 8 am after 3-4 doctors looking at Arron and some believing he was making it up before the most senior person came alone and thought it may have been Guillain Barré. After I had dressed him to leave (because we were both fed up and angry at having had to wait the whole night before someone would help us) they admitted him for a lumbar puncture and sent a very moody wife home. I went back to the hospital. After some sleep, Arron had deteriorated. He was in intensive care, very very scared and the paralysis began to travel up his arms and legs. Over the next 2 days he stabilised while on a drip of immunoglobulin, so they sent him to a normal ward. But, he couldn't move his arms and couldn't ring the bell for attention so he couldn't feed himself and didn't eat. Then he wet himself because he couldn't contact a nurse. With the help of his boss, Barrie, we moved him to the private ward, but they moved him straight to intensive care again because his breathing had become worse. He didn't sleep for the first week. Four patients died and were wheeled out. Alarms went off all night. After a couple more days he became unable to swallow, talk or breathe and eventually asked to be put on a ventilator. His eyes were terrified and he begged me to help him but there was nothing I could do. If I cried he got upset. I was there 14 hours a day, only going home to sleep briefly. The house was awful without him around, so dead - like the life had gone completely and I began to hate being there.
So, they knocked him unconscious and ventilated him, also connecting him to every other life support machine he wasn't already on.

We expected it to be a simple procedure. However, while I was in the waiting room a new doctor I hadn't seen before came in to tell me they were going to transfer him to Charing Cross Hospital. I panicked thinking the hospital was actually in Charing Cross which was Central London, very difficult to get to, expensive to park (if parking could be found at all) and the drive in rush hour traffic would be horrific. I cried and shook. I called Arron's boss who tried to calm me down. He said Price-Waterhouse-Coopers (Arron's work) would pay for the car parking and not to worry. Eventually my uncle arrived and told me the hospital was in Hammersmith - not very far (straight down the M4 about half an hour's drive depending on the traffic). Arron was totally unconscious; he had no idea of what was happening. The doctors/nurses promised not to wake him at Charing Cross until I was there so I could explain where he was and why. The ambulance people arrived, transferred him to a stretcher and off he went looking 'dead' and leaving me in a hysterical state. I followed them out to the ambulance where they said he might be able to hear me so I should say good-bye and give him a kiss. I climbed in the ambulance and whispered that everything would be OK and I loved him. In a state of shock I stood on the footpath and watched the ambulance drive off, not knowing if I would ever see him again. I had to fight from fainting, I shook but didn't cry. The worst experience of my life was happening. Was I in a dream? Was this really happening? Did I have the strength to get through?

My Uncle Peter took me to dinner, then to the hospital. At the intensive care unit we were met with a solid door and an entry telephone. We rang the bell but they wouldn't let us in. I asked how he was and was told he was awake and fine. Awake?? - They promised not to wake him until I was there. Why wouldn't they let me in? I started to yell at them. I was incredibly angry that I couldn't see Arron. I was shaking and couldn't breathe very well. We were told to sit in the waiting room. Sit? - I couldn't sit still. I paced back and forth until about an hour later they let us in. Arron was asleep again. I became even angrier! He looked

dreadful. He looked as if he could have been dead. All the life was gone. No more strong solid husband for me to rely on. My best friend was gone.

The next day I arrived before 7 am. When I saw all the machines I was overwhelmed. Something swept through me and I felt myself falling. I landed on the chair and the nurse gave me some water. Arron was surrounded by machines. He was still unconscious. Alarms kept going off. There was constant beeping. The nurse gave him injections. A doctor took me aside and explained what the machines were. I asked if Arron would die. He said he expected to see him every day like he expected to see me. Arron had a 5% chance of dying, but then I could die in an accident on the way to the hospital. He was realistic with me. For 4 days Arron remained unconscious. I called my parents from a mobile at the hospital usually around 4 am their time. Eventually I asked mum to come over because I was in a state, hadn't eaten for days, and couldn't think straight. I told her to hurry and get here before Arron died. My mother and Arron's mother arrived from New Zealand within hours of each other. Arron had begun to wake at various times, but he could not speak because of the ventilator. We had the alphabet written out and when he wanted to tell us something I would point to the letters and he would nod or shake his head. The first time we used this system, he wouldn't agree to any of the letters and became frustrated. Eventually when a nurse tried to help we realised I had missed the 'W' off the alphabet and that was what he wanted!! The strong drugs affected him and he would ask weird things such as was he in a wheelchair? No he was lying on a bed but it did have wheels. One morning I arrived and read the question he had asked during the night - 'Am I dead?'

That made me very sad. He must have been terrified. I wanted to be by his side 24 hours, but had to get some sleep. I generally left the hospital at 11 pm to go home and left the house in the morning at 6.30 am to get back to the hospital.

At first all Arron's food was given to him via a tube through the nose. But for some reason Arron bled from the nose and mouth constantly for 4 days. I would use the yankasucker to suck away all the blood and saliva which collected. Bottles of blood would fill up to be taken away. I continued to ask why he was bleeding but was only told it was OK. Eventually they took all tubes out of his mouth and nose. They gave him a tracheotomy (put a ventilator straight into his throat), put the food tube straight into Arron's stomach and packed his nose to stop the blood. Then Arron had plasmapheresis which means he was connected to a machine by 8 lines in each thigh and his blood was taken out, cleaned (the white blood cells taken out) and put back. Throughout each 2.5 hour session Arron would be in terrifying pain, although he could not speak or make a sound, his face screwed up in agony. He would ask to be knocked out for each session, but although they gave him more drugs, they would not give him enough. I would cause a scene on his behalf each time. Eventually they told me I was not allowed in the ward from 12 - 2 p.m each day (which was a rule for all relatives) and they would give him the plasmapheresis at that time! Finally the sessions stopped. They hadn't worked at all. The tubes came out of Arron's thigh, blood spurted everywhere.

On numerous occasions the ventilator tube would pop off Arron's neck, stopping him from breathing. I would usually jam it back on, but Arron was terrified when he was left alone because one time it popped off and although the alarms rang he had to lie there not breathing for a minute or two until a nurse came back into the room.

The following weeks Arron had severe pain in his hands and feet. If anyone touched them his face would screw up and he would bang his head against the pillow. (His head was the only hing he could move). They overfed him and his stomach looked 6 months pregnant. This caused further complications. His diaphragm would push up into his lungs and stop him breathing.
3 Times this happened. Arron would gasp for air, sweat profusely, his face would go red, then white, and finally he would be unconscious. It was one of the most terrifying things to watch. Like watching someone drown. I would panic. Doctors and nurses would rush around giving him injections to bring down his blood pressure. They would take him off the ventilator and bag him manually to get more oxygen into his lungs. After an hour or two, Arron would slowly come back to normal. Another complication was Arron's heart which stopped 3 times and continued to miss beats. The most serious occasion was around 7-8pm one night. His eyes rolled back in his head and then he was gone. A dead body. Doctors and nurses surrounded the bed. Alarms continued to go off. I stood at the end of the bed, hopping from one foot to the other, taking deep breaths. They gave him injections and fussed over him. Quite dramatic. When it was over I

went to find mum. She had disappeared. I found her rather upset in the ITU relative waiting room. We stayed all night that night; just to make sure Arron was OK.

A week later Arron began to improve. The doctors finally granted us our wish to go back to Ashford hospital. Closer to home and a smaller more friendly hospital. Our mothers flew back to NZ. I started a new part time job to keep my mind off everything. Arron had physiotherapy twice per day. Many times Ian, the physiotherapist, would spend time shaking Arron's chest to remove phlegm which collected because of the ventilator and was unable to be coughed away by Arron. Movement began to come back into his arms. Each day Arron would be hoisted into a supportive chair to give him a break from the bed. He would come off the ventilator for 10 minutes at a time to teach himself how to breathe again. Each day he would try to extend the time off the ventilator. Then, one day, (at the same time Lisa was praying for him in NZ and following my prayer to Mother Teresa the night before) he stayed off the ventilator all day! It was very sudden and shocked the nurses. They left his tracky in for another week just to make sure he didn't need it again, and then took it out altogether. The first few times he coughed were rather frightening. He had no muscles and found it nearly impossible to cough, he barked and gasped for air while the nurses thumped and squeezed his chest.

Arron began to eat soft foods, but didn't like the pureed hospital food, so I bought him baby food and would feed him myself every day. Our friends lent him their TV/Video which was a life saver because Arron couldn't do anything at all for himself except watch TB. The worst thing was boredom. Hour after hour he would just lie there waiting for the day to end and another day to start.

Arron was transferred to the stroke ward where he began to rehabilitate. Often the nurses would hoist him into a chair and I would wheel him to the shower and shower him. On the days I wasn't there, if the nurses were too busy to shower him, he would miss out on physiotherapy and have nothing to do all day. Our friends visited once per week.

After a few more weeks Arron could move a lot more. He learned to slide himself on a transfer board from the bed to a wheelchair. I took him to the supermarket next door every day because there was nowhere else to go. Twice I took our cat to see him. Pets were encouraged in that particular ward, to assist rehabilitation.

In June it was his birthday. I was allowed to take him to a hotel for the night (but only just). I had arranged for all of his work colleagues and our friends to turn up at the hotel for a surprise lunch. We had a wonderful time, but Arron didn't like being dropped back at the hospital!

Soon Arron learnt how to transfer from his wheelchair into the car, so I could take him places. Unfortunately he couldn't come home because he couldn't climb up the stairs to get into our house!

The physiotherapist worked really hard with Arron to teach him how to get up stairs backwards on his bottom! Arron would sweat and the effort would be exhausting. Finally he was confident and was allowed home on weekends. It was strange having Arron home in a wheelchair. I would have to lift him in and out of the bath (our shower is over the bath) which often strained my back. For Arron it was wonderful to be home. Our cat loved chasing the wheelchair up and down the hallway.

After 3 weeks, the nurses allowed Arron home permanently. He had pushed for that decision. I was terrified. He would be totally my responsibility. If anything happened to him, I would be to blame. It would mean worrying about him while I was at work. Wondering if he was lying on the floor, waiting for me to get home to help. Then once I was at home I couldn't relax because I would have to do everything for him. I didn't think I was capable. Didn't think I could do it, but needed to for Arron's sake. His hands were not working at all. He could only stand in front of his wheelchair for a couple of minutes. I worried that he would try to make lunch and cut his fingers off. I worried that he would fall between the wheelchair and the toilet when trying to transfer. No-one came to see if he was OK during the day. The hospital said we lived in the wrong location and the council didn't have district nurses or anything else of that nature.
I desperately wanted to hire someone ourselves to drop in and see him and make him lunch, but Arron insisted he was not a baby. He had no idea of how it felt; just saw it as an attack on him. He wanted to learn to do everything again for himself. I had to give him injections each night. Dress him, shower him, feed him, pass him things he needed constantly such as the TV remote, help him in and out of the wheelchair,

make sure all the correct pills were out for h him to take each day etc. At times I wished we were back in NZ with some help. I was angry with the nurses for allowing him home too soon. I would call him from work, but he couldn't get to the telephone fast enough and it would switch onto the answer phone. I would panic. Couldn't concentrate on work.

I guess in many ways I was over-reacting, but I had never been in a situation like that before. I wasn't really thinking sensibly. Arron continued to improve. Sometimes he would get frustrated. One of the worst things for him was getting in and out of the house. He was incredibly self-conscious about having to struggle on his bottom very very slowly up and down the communal stairs. An ambulance would pick him up 4 times per week and take him to physiotherapy.

Eventually he learned to walk on crutches. He was rather wobbly and would often bang into the walls. He had splints to keep his feet from dropping when he lifted his legs. We laughed a lot at his attempts. We joked that he was a baby learning to walk for the first time! After a few more months he reduced to one crutch. He still needed the splints and his right hand did not work very well, so he couldn't do up buttons or write. He started to work 3 days per week and have physiotherapy 2 days. This was to prevent boredom and because we were afraid his company would not keep his job open for too much longer. The ambulance crew decided Arron could get his own way to physio. This was frustrating because I was at work and the only way would have been a 25 minute walk for Arron, over a dangerous blind bridge with no footpath and to the bus stop to wait for buses that rarely turn up! We bought an automatic car with power-steering for him to drive to physio. We knew he shouldn't have been driving and that the insurance wouldn't cover him, however we had no choice. After the first couple of attempts of bunny-hopping, his driving was fine.

Throughout the whole ordeal Arron has been incredibly strong. His faith has never faltered. He has proven how with sheer determination and willpower one can overcome life's tragic circumstances. I am so proud of how he endured his illness, never complaining or giving in to defeat.

Arron continues to improve slowly. It is 9 months since he first contracted Guillain Barré Syndrome. His feet and right hand remain in the same condition. We are told it could take 2 years for him to fully recover.

GBS - Getting Better Slowly.

10 Years On....

Arron and Theresa Story continues

Update - November 09

We are living in NZ, Arron is 35 and it has been 10 years since he had GBS. We now have 3 children aged 6, 4 and 1. Arron is getting on with a very normal life, working hard, doing well in his computer career. His feet continue to be a slight problem, and ache when standing/walking for too long, but he no longer wears splints since he discovered wearing 'light-weight' shoes. He even chases the kids around (the doctors said he would probably never run). He does have drop foot though, so has to lift his knees higher than the average person. Occasionally when tired he will trip over, and has once broken two toes, and another time injured his ankle badly, surprisingly these have been more recent occurrences (playing paint-ball on a farm!) and to be expected really. We have learned to appreciate life and value each day we have, never knowing when something so dramatic can suddenly happen. We do not live in fear though. We thank God for the gift of healing, for competent doctors and caring health-care.

Theresa

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Gardening Tips: Things to do in the garden this month

Continue to feed and water your tomato and strawberry plants as well as other fruiting veges. This will help produce large flavoursome fruit.

Trim back and feed your flowering shrubs just after they have finished flowering. By doing this, your shrubs will develop luscious new growth, retain a good shape, and produce plenty of flowers during the next flowering period.

As you dead head your roses, come down to an outfacing 5 or 7 leaflet and thin out some of the canes that grow towards the middle of the plant. Feed your roses at the end of the month and spray with 'Yates Shield' or 'Yates Guardall' to protect all the new growth from Blackspot and aphids.

May the gardening 'bug' be with you!

Terry Watton
Paeroa Garden Centre

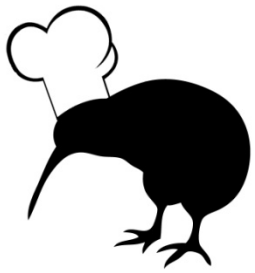
Something from the Kitchen

With an abundance of Silver beet in my garden I thought I'd share my favourite quiche recipe with you. This is such a versatile vege and so easy to grow – even by a challenged gardener like me.

Herb and Silver beet Quiche

Line a 23cm quiche dish with shortcrust pastry. (this can be baked blind and cooled but I never bother)

Filling:
60gm (¼ cup) butter
1 small onion, thinly sliced and separated into rings
3 bacon rashers, chopped
500gm silver beet (or spinach)
1 cup sliced mushrooms (optional)
eggs lightly beaten
150ml (⅔ cup)
½ teaspoon salt
¼ teaspoon black pepper
1 teaspoon dried thyme
½ teaspoon dried basil
2 teaspoons chopped fresh parsley
60gm (½ cup) grated cheese



Method:
Preheat oven to 200°C/400°F
In a large frying pan, melt the butter over moderate heat. When the foam subsides add the onion and cook stirring occasionally for 5 to 7 minutes or until soft and translucent but not brown. Add bacon and mushrooms and fry, stirring occasionally, for 5 minutes.
Add the silver beet, and, stirring frequently, cook the mixture for another 3 to 5 minutes or until the silver beet is heated through and the ingredients are well mixed. Spoon the mixture into the quiche dish.
Combine the eggs, cream, salt, pepper, thyme, basil and parsley. Stir in the cheese, mix well and pour over the silver beet.
Bake for 30 minutes or until the filling has set and the top is browned.

Notice Board

AGM: Saturday 1st May 2010 Palmerston North

Venue: - Psychology Department - Massey University. **Organiser:** John Podd

Time: 1300hrs or 1pm for those non-military people.

John has organised a room that will hold 40 people, and has coffee & tea making available - and toilets. Lift access is available close to the room. He is working on reserved parking at the moment.
A map (via email) is available from Jenny or me with the Psychology Dept on it.

Come along and hear what your Trust Members have been up to on your behalf and bring along your thoughts and ideas to help continue to grow and strengthen the Group

Trustee Meeting:

This will be held prior to the AGM at 12 o'clock.

Apologies to either meeting to the Secretary please.

Facebook.

There has been a group formed on Facebook for GBS Survivors. If you put the phrase below in your search engine it will take you there:
Facebook.Guillain-Barré Syndrome Survivors
Sorry I can't get a direct link to work

Situation Vacant

We are still looking for a Publicity Officer.
Responsibilities include keeping the support network in the public eye; communicating regularly with departments of neurology in hospitals, liaising with media and generally putting our good news stories out in the public etc.
If you have the experience, the time, the passion and skills for this role please contact: Bob Stothart
stothart@ihug.co.nz

International Conference Philadelphia November 2010

Bob and Margaret have offered to lead a group (or an individual, or couple) to this conference. Contact them direct if you wish to go. It is a great opportunity to meet fellow suffers and learn more about GBS from the many renowned medical personnel who will be speaking there (incl[illegible]ng our