



Guillain – Barré Syndrome Support Group New Zealand Trust

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NEWSLETTER MARCH 2014

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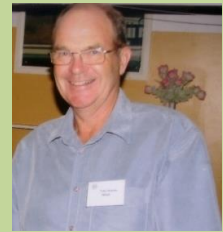
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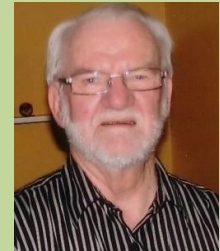
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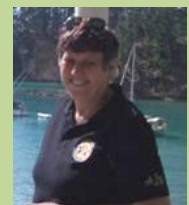
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Editor's Note



It is hard to believe we are nearly a quarter of the way through the year already. There have been a few new cases of GBS reported to us and I think in most cases we have been able to provide support to these people and their families.

The Treasurer has reported a slow response to the renewal of subs with over 50% still outstanding. Without your continued support we as a group cannot provide ongoing support to new patients. We have no other major source of funding so we are very reliant on your generosity to continue being a member of the group so I hope those of you that haven't quite got around tuit will do so this month. I have included the renewal form again and those of you who receive a hard copy will have a red sticker on their address label as a reminder.

With the AGM fast approaching it is time to consider if you can offer your time or support to the group. Hospital visitors, a publicity officer are two of the positions we need to fill. Also due to ill health our current President has had to relinquish the reins and we will have to find someone to fill that role. I am happy to continue on as your editor but if any of you want to take on the job I won't be offended. It is easy to get stale in a job and new ideas and a fresh approach to the task are always good.

With winter fast approaching the old question of whether or not to have a flu jab will I'm sure raise its ugly head. If you have had GBS in the past 12 months it is probably not advisable to have one, otherwise you should weigh up your own situation, consult with your Doctor and then decide if it is right for you.

Help is required to man the desk at the Auckland Brain Day on 29 March. I initially put my hand up then I realized I had double booked myself so I had to withdraw my help. Information on this is further on in the magazine.

See you at the AGM?

Chris

Presidents Paragraph:

Due to ill health our President has been unable to contribute this issue. We all wish him a speedy recovery.

Obituary - Zelda Menzies

I wish to advise that our mother Zelda Menzies passed away on the 10th December 2013. I would like to thank you all very much for the continued support that mum received while she was suffering from this hideous disease. Many thanks.
Phil and Gai Menzies



I first met Zelda at the Conference in Auckland. She was there with her carer Joy and despite her health issues Zelda had a real zest for life. She was always happy to visit those in Rotorua Hospital who contracted GBS and while her health permitted she would come to Tauranga for our coffee group meetings. Zelda made a real contribution to our group and she will be sorely missed.

Chris Hewlett - Editor





Secretary's Jottings

Well there went Summer! – certainly the coldest most changeable summer months I can recall since we arrived in New Zealand. We have just returned from a 3000Km “tikki” tour of the South Island with some long standing friends from the UK. Whilst they were impressed with the scenery they were not so enamoured with the weather that we encountered – 32 degrees on the open top bus tour of Christchurch and two days later 5 degrees in Queenstown!

These friends were on holiday with us in France back in 2000 when I had my first CIDP encounter so they were familiar with our Syndrome – they told me when they arrived last month that a good friend of theirs in England had just been diagnosed with the Miller Fisher variant and knowing what GBS was about were able to put her in contact with the UK Support Group.

The UK Group have recently undergone big changes – they have converted their structure into a registered charity (something we did several years ago!) and have changed their name to GAIN- Guillain-Barre and Associated Inflammatory Neuropathies. Their web site is now www.gaincharity.org.uk but the link on our website will automatically direct you to their new site. I know the USA Group made a similar name change last year to incorporate CIDP into their title but I am unconvinced there is a need for us to follow suite – our MAB will probably disagree with me but to the ordinary layman they are all versions of GBS!

We have been advised of another “success” in gaining accident compensation from ACC for GBS following a Flu vaccination. It took two and a half years of legal wrangling to have cover approved. I will follow up on the details of the situation (only the second that has come to our attention in the last 10 years) to ascertain if there are any “guidelines” that future sufferers might follow to strengthen their case with ACC. Sadly the fact is that for most the related cause of their GBS encounter is not clearly defined and so the potentially serious financial consequences of contracting and recovering from the Syndrome do not qualify for ACC compensation.

As most of you know our family subscribes to the Listener and whilst Vivienne enjoys the book and art articles and reviews I tend to be more interested in the health reports (neither of us puts much faith in the political reviews!!) Late last year a short item caught my notice about the potential benefits and risks of Chlorine – which, apparently, is produced naturally in our bodies – yes the same substance that we keep under the sink! And to quote the article:-
“What we know now is that white cells go through the body, find unwanted bugs, eat them and squirt chlorine on them to kill them....but....it's becoming increasingly apparent that in the wrong place at the wrong time it can be destructive – bleach has been implicated in inflammatory illnesses such as heart disease, cystic fibrosis, rheumatoid arthritis and even cancer”

This from a Professor at Otago University!

... It made me wonder about a possible GBS “trigger” ???

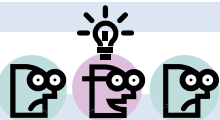
Anyway enough from Professor Pearson! – The AGM notice will be found elsewhere in this Newsletter. Yes I know AGM's are boring – or can be – but they are an essential part of the management of every organisation so even if you cannot or do not wish to attend in person please ensure you are financial and cast your Proxy vote.

As always
Take Care

Tony

Odds and (the inevitable) Sods

Somewhere to
snippets of



post anonymous
experience

Cleaning teeth with the 'wrong' hand ! Gums battered, takes ages. Then when the 'right' hand recovers, re-teaching it all over again.

Feet ! Its always 'feet,feet,feet'. When re-learning to drive 'where the hell is my right foot now !'

Bloody balance !
Any ideas for a tricycle ?

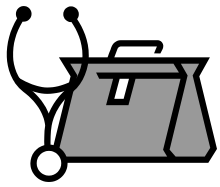


GBS UK

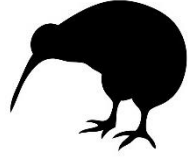
has formally changed its name, become a registered charity and has a new web site.

It will now be known as “**G.A.I.N**”
(Guillain-Barré & Associated
Inflammatory Neuropathies)

<http://www.gaincharity.org.uk>



Letters to the Medical Advisory Board



Is restless leg syndrome has anything to do with my GBS??

My wife has noticed some nights I have been twitching badly from the waist down.

I have just had a visit to my GP and he wasn't very helpful when I asking him the same thing. He suggested I took a medication used for Parkinsons syndrome. However I would rather not take any medication unless necessary.

If you can help that would be appreciated.

Dr Parry Replies:

RLS is very unlikely to be related to GBS. Patients with residual pain after the GBS can get symptoms. Similar to RLS but that is really voluntary movement of the feet and legs to make the pain feel better. In RLS the movements seem to be unconscious and uncontrollable. Parkinsons medications such as pramipexole, ropinirole and L dopa can be miraculously helpful if the symptoms are distressing, especially if they are disturbing sleep. No harm will come from the symptoms so if they are not particularly bothersome it is fine to just live with them.



And from our Facebook Page:

My 25 year old brother has been suffering from GBS since 16th april 2013. The diagnosis was very late in last week of May. He reached his acute stage within one week and suffered total paralysis. His cranial nerves were severely affected that he started drooling severely and tongue bite was also present. But his eyes were not affected. After a spontaneous recovery of 10 months till now, He is walking slowly without support.

His major concern is severe drooling which is affecting his daily routine and social life. We have tried Glycopyrrolate with some success but the side effects were very bothersome that he had to drop on the medicine. Trihexyphenidyl did not work and caused side effects.

I request any help to reduce drooling with either non drug remedies or drugs with minimum side effects. I will be grateful to any viable help.

Dr Parry Replies:

The drooling is due to residual weakness of the facial and pharyngeal (throat) muscles. It will improve slowly as the strength returns. There are number of strategies that can be effective but all carry some risk of side effects and not all are reliably effective. Unfortunately, it is just a matter of trying different things.

1. The most effective strategy is to inject botulinum toxin (Botox) into the salivary glands. This can be challenging in NZ because Botox is not approved for this indication but some neurologists have been successful in getting approval. The advantage of this strategy is that there are no adverse effects outside the area of injection. The main risk is that it makes the mouth too dry. The effects wear off after a few months. On very rare occasions Botox can make swallowing worse because the drug can spread beyond the salivary gland area.
2. Atropine mouth washes can also be effective and well tolerated.
3. Take care to try to minimize the amount swallowed to avoid the side effects.
4. Amitriptyline can also be effective and is usually my first choice. This drug is an antidepressant that has been around for decades and one of its most troublesome side effects when used for depression was dry mouth. In depression we use the drug as a single large dose at bedtime but when treating drooling I prefer to use smaller doses of 10 mg 2-3 times daily. The drug may cause mild sedation but that usually is temporary. It can also cause constipation.

Since I know nothing about the patient other than the little given in this e-mail I need to emphasize the importance of discussing these treatment options with the treating physician.

Vitamins, minerals and other dietary supplements in GBS and CIDP

Gareth Parry

Other than questions about vaccination, questions about dietary supplements are the most common posed by my GBS and CIDP patients. Various surveys indicate that 75%-85% of the general population take some form of dietary supplement at some time during their adult lives. The percentage for patients who have a chronic illness or have suffered a potentially life-threatening illness like GBS is likely to be even higher. By far the most frequent questions surround the B-group vitamins, probably because of the wide knowledge that these vitamins are essential to nerve health. The bad news is that there is absolutely no evidence that any of these strategies ward off disease or help recovery from an existing disease. Specifically, no dietary supplements help CIDP or improve recovery from GBS. The good news is that, in the great majority of cases, these agents are safe so that the only blow to the welfare of the individuals taking them is to their wallet. This brief review is not meant to be comprehensive and I will focus on the B-group vitamins since these generate the most questions in my practice, both in NZ and in the US. I will highlight those supplements that are known to be harmful.

B-group vitamins: B vitamins, particularly B1 or thiamine, B3 or niacin, B6 or pyridoxine and B12 or cobalamin, are essential for proper nerve health and deficiencies of these vitamins can cause neuropathy. However, they are so prevalent in even the poorest of diets in the developed world that dietary deficiency is almost unheard of except in specific disease states. It is true that very strict vegans, who consume no animal products of any kind, can rarely develop vitamin B12 deficiency. B1, B3 and B6 are abundant in many vegetables and grains and even the strictest vegan would still have a diet rich in these vitamins. Also, patients can develop vitamin deficiency after major gastric surgery, particularly the bypass surgery that is becoming increasingly used to manage severe obesity. B1 is a ubiquitous vitamin found in fruit, vegetables, grains and meat and dietary deficiency is almost unheard of, except in cases of gross malnutrition such as occurred in concentration camps during the 2nd world war. The Recommended Daily Allowance (RDA) is 2 mg. In NZ, B1 deficiency is seen in severely malnourished alcoholics and, rarely, in individuals with intractable vomiting associated with pregnancy (severe morning sickness) and possibly chemotherapy. In such individuals there is damage to the central and peripheral nervous systems causing optic nerve damage, memory loss and severe incoordination as well as neuropathy. There are no known toxic effects of B1. B3 is also ubiquitous, being present in almost all foods and is particularly rich in meat, fish, seeds and nuts. B3 dietary deficiency is seen only in cases of gross malnutrition. The RDA is 12-18 mg. Deficiency causes diffuse effects on many organs, particularly the brain, skin and gut with neuropathy being a relatively minor effect. There are no known toxic effects of B3. B6 is also found in a wide variety of food stuffs and dietary deficiency is confined to gross malnutrition. The RDA is 5 mg. There are a number of drugs that interfere with B6 metabolism and can cause a clinically significant deficiency. Most notable is isoniazid which is widely used to treat tuberculosis. The primary manifestation of B6 deficiency is neuropathy but other organs can be affected. **Most importantly, excessive B6 can cause neuropathy.** Doses in excess of 200 mg daily are unquestionably toxic but some studies have suggested that doses of as little as 50 mg daily can cause neuropathy if taken for long enough periods of time. Some commercially available formulations, such as Vitabase B-complex 100 and others, contain as much as 100 mg B6 so this, in association with a normal diet, could easily result in a potentially toxic intake. I recommend that no patient takes more than 20 mg daily in the form of supplements so carefully check the amount of B6 in any supplement that you are taking to make sure you are not getting too much. B12 is primarily found in meat, particularly liver, and fish which is why strict vegans may develop dietary deficiency. The RDA is tiny, only 2-3 micrograms, which is why true dietary deficiency is so rare. However, absorption of B12 from the gut requires a chemical called intrinsic factor (IF) which is produced by the stomach. There is an autoimmune disease in which antibodies are formed against the cells that produce IF so that B12 cannot be absorbed, despite being plentiful in the diet, and patients with IF deficiency develop diseases associated with B12 deficiency. The main effect is on the spinal cord but neuropathy may occur. If B12 deficiency is suspected the vitamin can be assayed in the blood; if no deficiency is found there is no medical need for supplementation. There are no known toxic effects.

Other vitamins: Vitamin D is well recognized to be important for bone health but also has important effects on the immune system. Vitamin D deficiency is known to make multiple sclerosis (MS) worse and vitamin D supplements has been shown in several studies to improve MS. CIDP has many immunological similarities to MS and it makes sense that CIDP may worsen with vitamin D deficiency although no studies have been done to show this. Vitamin D is made in the body by the action of the sun on the skin and vitamin D levels in the blood fall over the course of the winter. In the northern US, where I have worked for the last 20 years, the winters are so long that I recommend to my CIDP patients that they take 2000 international units of vitamin D daily over the course of the winter. Whether that is necessary in NZ is questionable but certainly would do no harm. There are no harmful effects of vitamin D on nerves. **However, very high doses of vitamin D (greater than 10,000 units daily) are theoretically harmful to the kidneys since they may increase calcium levels and may cause kidney stones.**

Vitamins, minerals and other dietary supplements in GBS and CIDP

Gareth Parry

Minerals: Trace amount of minerals are necessary for a number of metabolic processes but there is no evidence that supplemental minerals are necessary for good health since they are abundant in many foods. **The one mineral that has the potential to cause harm is zinc.** Zinc is often used to reduce the risk of colds and flu during the autumn and winter. However, too much zinc intake results in excessive excretion of copper in the urine leading to copper deficiency. Copper deficiency causes damage to the spinal cord and peripheral nerves.

Other supplements: A quick survey of the internet reveals many food supplements that purport to boost immunity, improve nerve and muscle function and generally improve health. Evidence for these benefits is entirely lacking but most of these mixtures of proteins, amino acids, vitamins and minerals are harmless.

In summary, taking vitamins, minerals and food supplements provides no health benefits in individuals with an adequate diet but generally do no harm. There are rare disease states and a few other situations (veganism, stomach surgery) that can cause deficiency but these are easy to recognize and blood tests are readily available to determine if deficiency exists. Excessive amounts of vitamin B6 (pyridoxine) and zinc are known to cause nerve damage and these should be used with great caution by patients with CIDP or who are recovering from GBS.

Books to Read and Links to other GBS Stories

Guillain-Barré Syndrome – From Diagnosis to Recovery

by GJ Parry, MB, ChB, FRACP
and Joel S Steinberg, MD, PhD

The perfect book for those new to GBS who want to learn more about this Syndrome.

No Laughing Matter

by Joseph Heller and Speed Vogel

This is an interesting account of Joseph's battle with GBS written as remembered by him and by his good friend Speed Vogel.

Blue Water White Water

by Robert C Samuels

This is Robert's harrowing story of his GBS experience. It is frightening at times, humourous at others and well worth the read. Incidentally he was in hospital the same time as Joseph Heller.

<http://trevorsammut.blogspot.co.nz/>

This link takes you to Trevors blog and is an interesting read.

<http://www.youtube.com/watch?v=xzRxHOQ3zsg>

This link was sent to us by the GBS-CIDP Foundation International and tells Jane's story



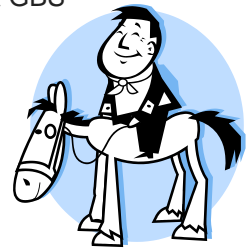
Personal Encounter - Margaret Dempsey

It is 21 years since I spent 6 months in Middlemore Hospital with GBS and as an early Member, (No. 22) of the Group I have read every Newsletter since, but have never contributed. After all this time, however, I realize that I have never seen reference to horse riding as a means of therapy for balance and as a strong advocate of the help it gave me, feel I should share that part of my rehabilitation with members.

Christmas week 1992 found me in Middlemore ICU for 9 weeks and ultimately 6 months, but those who have been through GBS will realize, that was almost 'the beginning'. I still feel the 2½ years of rehab was the most difficult part in learning to walk again, as I was warned by the physiotherapists. Having been paralysed up to and including my eyelids, I had had a long way to go.

During transition between ICU and the rehab ward, I spent some time in a medical ward, where I was treated at weekends by a physiotherapist just returned from working overseas. Our connections were very short at the time and Jeanette subsequently took a position as Charge Physiotherapist at the Ambury Park Riding Therapy School in Mangere. Having been discharged from hospital in June and very wheelchair bound, I had reached the point of some movement and carrying on hydrotherapy at our local heated pool. That therapy was in itself a huge success, walking against the water – after my husband had literally pushed me into the pool, my only access. I'm sure all readers can see the mental picture!

Towards the end of 1993 I had a call from Jeanette, telling me what she was doing and about a GBS patient she was working with at Ambury Park with some success. Would I be interested in coming over to see what they had to offer, as she felt the horse riding could well help my balance? It turned out to be one of the best decisions I ever made in relation to my tottering gait. Initially I was given a small, unbelievably quiet horse and just mounting him from the "stand" was a shaking experience, but as every rider has a helper – and Jeanette in this case – confidence did rise over time. We attended weekly sessions of up to an hour, from memory, walking around the arena to begin with and later extending to the grounds outside. As I am only 1.52m tall (how can I use that word?), just sitting astride a horse was an exercise in itself, but as weeks went on I progressed from the inside arena to walking, turning, crossing the areas ... and even talking! My balance was improving by the weeks until by mushroom time around April, I was spying the fungi from above, pointing them out to my following husband carrying the paper bag and feeling very pleased with myself. Those few months probably did more for my general balance than much of the walking I did each day – just one more house up the street each day (making sure I had enough energy to get back again) and so on. Even now to walk on a floating marina remains a little scary, but there is no doubt that riding therapy was a great way to go and I would recommend it to anyone who is able to take advantage of it.

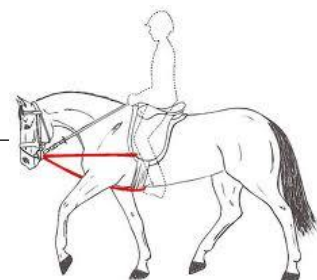


Now 84, I have led a very active life and over the past 6 years have had the privilege of returning the favour of the years of help my husband gave me by looking after him following several strokes. He lost that battle in November, but without his import at that time, I would have taken much longer in my rehabilitation. One can have nothing but endless praise, too, for the wonderful help of every aspect of medical help given over time.

I hope the above can help some patients, Chris and enable them to enjoy the experience as well. It was very rewarding.

Below is a link to the NZ Riding for the Disabled Website. If you are interested in this you will be able to find a school near you if you are interested in giving it a go.

<http://www.rda.org.nz/>



My GBS Experience: Carol's story

My story starts on the 24th February 2011. I am a registered nurse and an independent vaccinator. I had been employed by the local health board CMDHB to vaccinate staff with the flu vaccinations. The vaccine included the swine flu vaccine. From memory this was the 3rd year that the vaccines were available. As part of our training programme, us nurses had to give each other the new Intanza flu vaccine. This was a smaller volume of vaccine given just under the skin surface, this would give a more vigorous reaction and was intended to impart a full immunity to the three winter flu virus's in the vaccine.

I had an unusually strong reaction to this vaccine. An almost unbearable severe itch, swollen reddened arm. This lasted for 7 days which was unusually long and intense. It was expected that this would normally last 2 days this varying between people.

I seemed to be well and healthy for the next two weeks, I usually enjoyed good health, attending regular Karate lessons where I also taught Karate and was training to sit for my black belt.

Two weeks later I woke with the most terrible stiff and painful back, I could not sit only stand, this lasted about a day. I also remember standing in the garage and feeling pins and needles happening on the soles of my feet. I was incredulous and ran in to tell my husband. Over that day the pins and needles intensified, now affecting most of my legs. As a nurse I knew this was VERY BAD! I was petrified with the thoughts of this was not possibly happening to me. There was too much information and knowledge spinning around in my head. I was too scared to tell my husband. Sometimes it's better not to know at all. I told him a little so he knew what to do if I could no longer stand by myself.

Over the next couple of days I could hardly walk, I was falling over, my balance was gone, I needed walls to hold me up. My legs and now most of my body felt like it was buzzing or vibrating.

When I tried to walk my leg muscles kind of stopped working and I just stood there till I lost balance. I couldn't stand up from a chair without help. Somewhere about day three?, the toes on my left foot had no feeling at all. Then I was VERY VERY scared.

I remember searching all the information I could find on line. I knew it was Guillain Barré. That's the problem when you are a nurse, you know too much, self - diagnose and try to self- treat. I couldn't get a Drs appt. as he was fully booked. I had to wait 2 days. Only small changes in symptoms. The pins and needles had spread to my whole body, even my face, I had pins and needles in my tongue and throat. That made it hard to eat. I had pins and needles in my brain. My brain was foggy and thinking was very slow. Following the visit to the Dr I was sent to the hospital for assessment.

Assessments at the hospital showed interesting but baffling differences to the Guillian Barré that most Drs have had experience with. I no longer had numb toes, I had no reflexes in my legs. I did not show protein in the lumbar puncture spinal fluids. I still had serious nerve symptoms of buzzing vibrating limbs, pins and needles everywhere, shooting pains running down my limbs, falling over and loss of balance, fatigue. Further nerve conduction studies were normal. So with children to feed and sort out at home I begged to be discharged.

I tried hard to hide all the symptoms. I managed to turn up for work the next day. My colleagues did my work for me. I sat and did very little. Luckily workloads were light.

Specialist report stated possible Guillian Barré, suggestive of irritability of the sensory nerves. My understanding following discussions with him is that I have managed to be struck down with one of the rarest forms of Guillian Barre, affecting the sensory nerves seldom seen therefore making diagnosis difficult.

Symptoms now included descending waves of cold prickles down my body especially brought on by standing in the wind, inability to have hot sunshine on my skin, unable to have hot showers, or cold, clothing on skin can be a torment, my husband is too hot to be close to in bed. Nerve pains deep and hard to bear making driving the car difficult. Surprisingly the worst symptom is pressure from lying down on the bed. Within a few minutes of going to bed at night having to change position as pressure causes pain deep inside my legs that once there, seems to last a long time.

Every night is difficult to get enough sleep.

Now I wanted to find out more information and also visited the Dr to ask for an ACC form to be filled out. Then there were several months of ACC asking for more time to gain information, Finally the claim was declined. Surprisingly they stated I had menopause symptoms. Well yes I have menopause but that is a very distinctly different set of symptoms and are unrelated to those caused by the Guillian Barré symptoms.

MY GBS Experience: Carol's story

My belief and understanding is that the flu vaccine caused my symptoms. I was well before the vaccine. I needed to prove that point.

I rang a lawyer specialising in ACC claims. He accepted my claim and stated he would only be paid if we won and ACC accepted liability for the treatment injury. He appealed to the disputes tribunal for reassessment of the declined claim.

The case was heard before the disputes tribunal. The case was again declined, as the adjudicator focussed on the menopause statement in the specialist report. She bypassed evidence from the specialist supporting the link between having the vaccine and becoming ill.

The lawyer was noticeably unhappy with this decision stating we could prove a link between the flu vaccine and symptoms of Guillian Barré. He appealed to the district court for the case to be heard. One week before the hearing the lawyer received a letter stating that ACC have approved cover.

This has taken two and a half years to win a land mark case. I needed to prove the truth of the matter. My belief and understanding is that the flu vaccine caused my symptoms. I was well before the vaccine. I needed to prove that point. I also needed to let the world know my story. There are others out there with symptoms similar to mine. I needed to fight for their rights for future claims as well.

With all Guillian Barré affected people there are ongoing issues that need to be addressed, such as

- How do we plan for our retirement with a vastly reduced income through this illness?
- How do we get recovery time and not end up bankrupt?
- Who will look after us and how will they get paid?

My illness caused me to have 7 months off work unpaid. I did not have medical insurance. I thought I was invincible. I have only been able to work part time for 2 years. I still have pain nearly 24/7, I refuse tranquillizers, sedation. I take evening primrose oil it helps calm the nerve irritability. I take B vitamins. My being ill has caused great havoc in our family. Too many times we couldn't buy groceries or pay bills. We are now facing a bankruptcy.

I have learned to be stronger than I thought I could be. I have found if you don't push your limits then there is no possibility to achieve more. I have learned to sit and let my always active mind relax by bone carving in my garage and letting the soul fly free while I carve. My hands have always remained strong. I am very grateful for that. When there are times pain is with me, I then find the need to carve and create something beautiful. It balances the world. It makes me happy.

*We don't know how STRONG
we are until being strong is
the only CHOICE we have.*



BOP/WAIKATO Coffee Group Meeting

Standing: : Rod Bellerby, Chris Hewlett, Gordon and Celia Stephenson, Judy Deed, John Dixon, Jan Gribble, Ken Ardern, Fran and Grant McKay, Barry Deed

Sitting: Julia Ardern, Marty Hewlett, Sue Dixon

Kneeling: Meike Schmidt-Meiburg

Our meetings just keep getting better and better.
Thank you all for coming.

An interesting statistic from our group is that twice as many men as women have been the victims.

The 12th AGM: 12.30pm Sunday 4th May 2014.

Auto Lodge Motor Inn 193 Devon Street East

New Plymouth

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all financial members of the Trust in early April. Everyone is welcome to attend the meeting but only financial members are eligible to speak and vote at the meeting

Members who are unable to attend the meeting may nominate a Proxy to vote for them, either our President Ken Daniels or another member of their choice.

Nominations for membership of the Trust Board are always welcome and should be lodged with the Secretary as soon as possible but no later than Wednesday 30th April. Nominations should be signed by the candidate who will need to be, or become, a member of the Trust and supported by a Proposer and Secunder who must also be members, together with a brief C.V. of the candidate. If no nominations are received prior to the meeting the Board may accept oral nominations at the meeting.

If you have any questions about the forthcoming AGM please direct them to the Secretary Tony Pearson on 03 526 6076 or tonypearson@xtra.co.nz

If you are planning to come to the AGM could you please let Tony know for catering purposes. Ed

Help Wanted for Brain Day - Auckland Saturday 29th March

For the last few years John and Margaret Davies assisted by Maurice and Kath Vickers have manned the GBS desk at the Auckland Brain Day. John will be away on the day of this year's event – Saturday 29th March from 0900hrs to 1600hrs (9am – 4pm for those non- military people) at the Auckland University Owen Glen Business School.

Maurice and Kath are willing to man the desk again this year but we need two or three others to help share the load.

You don't have to be a GBS expert just willing to chat to people about the syndrome in general and hand out brochures to those interested.

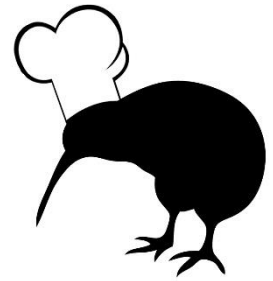
If you feel you would be able to assist Maurice and Kath please let me know and I will put you in touch with them.

Many Thanks

Tony Pearson



Something from the Kitchen



Blueberry Muffins:

Ingredients:

2 cups flour
1 dessert spoon custard powder
3 tsp Baking powder
1 cup sugar
 $\frac{3}{4}$ cup blueberries
2 eggs
 $\frac{3}{4}$ cup milk
 $\frac{3}{4}$ cup oil

Method:

Sift flour, custard powder and baking powder.
Add sugar and blueberries.
In a separate bowl, beat eggs milk and oil together and add to first mixture.
Spoon into greased muffin tins and bake in moderate to hot oven 15-20 mins.

Topping (Optional):

Mix $\frac{1}{4}$ cup lemon juice with $\frac{1}{3}$ cup white sugar and the rind of one lemon.
Heat until sugar is dissolved.
Pour a tablespoon of syrup over each muffin, whilst both muffins and syrup are warm.

Sweet Blueberry Sauce

Ingredients:

1 tbsp butter	$\frac{1}{4}$ cup water
1 cup frozen berries	Pinch of cinnamon
1 tbsp lemon juice	5 tbsp icing sugar
1 tbsp flour	$\frac{1}{2}$ tsp gelatin

Method:

Heat butter in a pan so that it melts. Add the berries, lemon juice and cinnamon.
Stir until melted.
Mix in the flour and icing sugar as well as gelatin.
Lastly add the water and bring to the boil for a couple of minutes.
Season/add more sugar to taste and cool.

Serve on top of cheese cake or with waffles.



Bay of Plenty / Waikato Coffee Group.

Venue: The Raft, 65 Chapel Street, Tauranga

Date and Time: Friday 23rd May 2014 11.30am



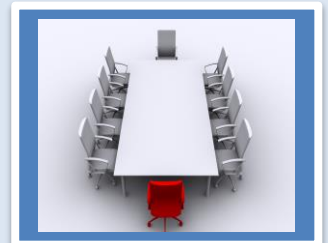
2014 AGM

The 2014 AGM is to be held in NEW PLYMOUTH

On: Sunday May 4th

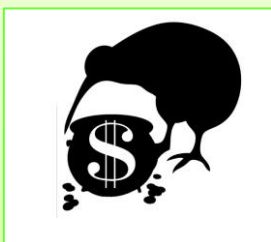
Time: 12.30pm, but preceded by a finger food buffet from 12 noon

Venue: Auto Lodge Motor Inn, Devon Street East
9.30 am ahead of the AGM



SUBS ARE OVER DUE

PLEASE POST YOURS TODAY.



Wanted



Publicity Officer

If you think you have what it takes to promote our Support Group please contact Ken Daniels or Tony Pearson.

Their contact details are on the front page of the magazine and they'd love to hear from you.

Guillain Barré Syndrome Support Group Trust N.Z.

Registered Charity No CC20639 www.gbsnz.org.nz

INVOICE

2013-2014 MEMBERSHIP ANNUAL SUBSCRIPTION

Subscriptions for membership of the Group for the financial year commencing on 1st December 2013 are now due and your ongoing support would be appreciated to help further the important roles the Group plays in supporting new and existing sufferers of this devastating syndrome.

Please detach the bottom section of this page, complete the information requested and send with your remittance to the address detailed below.

Subscription Rates

Single Annual \$15.00

Single Life \$150.00

Medical Group \$75.00

*Subscriptions can be paid Direct Credit the Group's Bank Account
Taranaki Savings Bank (TSB) Moturoa Branch New Plymouth
Bank Account No:- 15 3949 0339362 00*

Be sure to reference your name on the transfer

You can also now receive the Group's Newsletter by e-mail (thus helping us with the cost of stationery and postage) if you would like to take up this option and have not already notified our Editor Chris Hewlett please e-mail her at (chrispy57@gmail.com) or add your e-mail details below and we will arrange for this to happen.

Thank you on behalf of the Board of Trustees.

**Please detach and post this remittance advice with your subscription to:-
Peter Scott PO Box 4162 Palmerston North 4442**

NAME(s).....

MEMBERSHIP NUMBER(s) (if known).....

SUBSCRIPTION(s) PAID

DONATION

TOTAL =====



If your address or contact details have changed recently please make a note of the new details here.....

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