

Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

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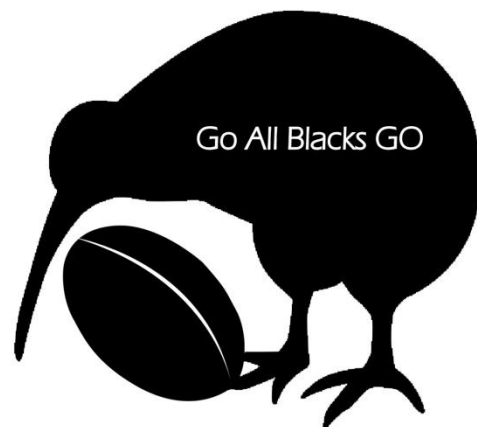


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NEWSLETTER SEPTEMBER 2011

If undelivered please return to:

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Editors Note

Winter has left us and thankfully we have not been notified of a huge number of new GBS cases. To those of you who have been unlucky enough to get this scary condition I hope that the Support Group has and can continue to offer you hope and encouragement on your long journey to recovery. Remember we have a Facebook Page, which is taking a little while to get up and running but there are a few on there who are keen to offer their support, encouragement and tips they have found to make life easier during the recovery process.



If you want to receive your newsletter by email only and haven't already let me know please do so. It is a big saving on the Groups funds with the ever increasing costs of printing and postage.

Jenny lent me her folders of all the Support Group Newsletters and I have scanned them all as PDF files so we now have a digital copy of them all. If for any reason you would like an old issue let me know and I will email it on to you.

A couple of States in America have been hit with outbreaks of GBS, some cases linked to Campylobacter. I have reproduced a couple of these articles in the magazine.

My work place has taken on the 10,000 steps a day challenge. We have split into 3 teams of 4 and are doing a virtual walk from Cape Reinga to Wellington over a 10 week period. We are due to arrive in the Capital on the Sunday of Labour weekend. I am finding it quite a challenge. The reason being - FATIGUE. I'm finding I am going to bed quite early during the week and by Friday night I am utterly exhausted and in bed asleep by 8pm. Despite this I am enjoying the challenge and hopefully I won't crash and burn.....

Chris



Presidents Paragraph:

An old aunt of mine had a calendar on her wall adorned with little bits of philosophy and pithy sayings to make you think. One I have always remembered is "I had no shoes and I complained until I met a man who had no feet." The saying has stayed with me across the decades and even when I was really down with GBS I remembered that there were people worse off than me. As I write this I think of the people in Christchurch and the endless earth movements they have had to endure. I think of family loss and my heart goes out to the occupants of the city. The ripple effects are on-going: the loss of property, people, belongings, memories and water, sewage and systems has been extremely difficult to endure.

It is the second day of spring (as I write), the cloudless Wellington sky, the granddaughter playing netball in the sun, people walking along the waterfront, international rugby teams arriving in the country, an air of expectation and anticipation abounds. A time for renewed hope and aspiration.

Our greatest service as an organisation, I believe, is to visit those afflicted with GBS or CIDP in hospital and to reassure them that they will get better. Their eyes change and they gather hope unto themselves. Eventually they recover and move from the people with no feet to the people with no shoes. And then they are taking their first tentative steps before striding forward with renewed hope. In time, the people of Christchurch will stride forth in their new city.

Professor Gareth Parry has been in touch with me and is in the process of inviting suitably qualified people to form a Medical Advisory Board. This group will include neurologists, physiotherapists and rehabilitation specialists and their function will be to provide accurate medical advice, to seek grant funds, to contribute to our conferences and write for publication. As soon as the Medical Advisory Board is formed I will publicise the fact. They will add lustre and status to our support group: as an organisation we will have new shoes.

Bob Stothart



Secretary's Jottings

Well I'm writing this sat in my study at our house near Motueka in the midst of a "once in a lifetime storm" on August 15th 2011. Nelson is – of course - avoiding most of the weather – admittedly we were down to 6 degrees midday and are now (about 10pm around 4 degrees) – which is pretty rough for us – but not nearly as rough as down south .., BUT .. the point is within 48 hours I shall be in Spain at 32 degrees – BLISS – probably not!! - but a LOT warmer than here. So yes an early input for the Newsletter but one that has got me thinking back to my time in the UK when good old GBS came "a knocking"

I was a pretty important financial EXECUTIVE – even though I say it myself!! – high powered team about me in the central London office – people jumping to attention in our subsidiaries around the world when I turned up to "review" their financial performance –Business Class air travel around the world – flash hotels – you can imagine the scenario I am sure!! . And at 55 I had set things up (not without a little pushing from my 10 year younger BOSS I have to admit) to retire – and then ...all of a sudden I was a VERY unsure "older male" bedridden in hospital with this "THING" that had hit me and rendered me as helpless as a baby – except intellectually – and I sure had some scary thoughts at that time!! . Neither My British Airways Gold card nor my Shangila Hotel Executive Suite membership could help!! – I was in DEEP TROUBLE and nobody seemed to know what was wrong with me – except my Neurological Consultant – who fortunately for me was a student of the top GBS Neuro guy in the UK Richard Hughes - who said – as I shuffled on two sticks into his consulting rooms in Stevenage (just north of London) .. "I bet I know what you've got!!!" – and so I met GBS – or in my case CIDP. No respecter of corporate importance, gender, age, ethnic background or state of health. And the rest – as they say – is history. AND LONG MAY IT REMAIN SO!! – but although HE may have known what ailed me – I still didn't have a clue – couldn't even pronounce what I had got!! . I eventually learnt -from the homework of my sister in Canada on the internet – that the UK had a support group and HOSPITAL VISITORS!! – oh if only I had known that as I lay in my hospital bed wondering if I was going to make it or not!! . A visit from a fellow GBS'er at that time would have been worth gold dust but nobody in the Hospital advised me of the UK network of visitors or the existence of the support group – just as it is in New Zealand.

Every major hospital in the UK – some 70 plus of them - has at least one, and often several, dedicated HOSPITAL VISITORS who are prepared to share their experiences, and more important, confirm their recovery from GBS. That is where we need to take New Zealand. So don't be shy in coming forward – you just might be able to make a world of difference to a new GBS'er who thinks they are all alone in experiencing this horrible situation.

And so to other business. The Board will meet in November to review progress on a number of issues that were discussed at the Conference and AGM. It is a matter of satisfaction to me that our membership gets so involved in our operations, with ongoing constructive input. If you have any points you would like to raise please e mail me – we have, as a Board, no monopoly on good ideas and constructive criticism is well received and will be acted upon.

The next issue of the Newsletter will include a request for subs – in the form of an invoice. An attempt to economise on postage and become more efficient. I look forward to the renewal of existing financial members and, just perhaps, a few new members who enjoy this publication but, as yet, have not been moved to lend their financial and moral support to this dedicated group.

As some of you may remember I read the Listener – recently two interesting articles appeared – the first on the Restless Legs Syndrome ... how similar that seemed to my own legs twitching in bed!! And another on the effects of STRESS on our health. As I have previously mentioned I am sure STRESS brought on my GBS – but there seems precious little research into this as a potential GBS initiator. Perhaps when Dr Parry settles here in Nelson (due early in the New Year) I can persuade him to investigate this further.





Secretary's Jottings continued.....

Some of you will remember Jon Anda's story. Jon decided to have a Stem Cell transplant earlier this year as a potential solution to his seemingly un-resolvable CIDP Anti-Mag condition. All is not well post the operation with Jon and I have asked him to provide and update for the next Newsletter.

Work continues on the 101 booklet on assistance with post GBS conditions from Government institutions. If you have any significant positive or negative experience with ACC/WINZ/Enable etc – PLEASE let me know.

I am sure we all would wish to offer our support and goodwill to those GBS'ers who have the misfortune to be caught up in the Canterbury situation – it is almost impossible for me – sat up here in “sunny” Nelson to understand the difficulties those of you in Christchurch are going thro' – if there is any way we can help PLEASE let us know – but regrettably I have to advise you that I do not know any “BIG WIGS” in the EQC or Insurance Companies that just might be able to speed up financial resolution for you guys.

Back in October – I'll publish my “suntan” on our website Facebook site!! – just joking!!

As always take care

Tony

Publicity Officer's Plug



Since the last newsletter *Kai Tiaki Nursing New Zealand* published an article I wrote on caring for a GBS/CIDP patient. Many thanks to all those who helped make the piece come together. The Health & Disability Commission has reproduced the article on its website and you can read it here:

http://www.gbsnz.org.nz/_data/assets/pdf_file/0003/23547/Nursing_a_GBS_patient.pdf
and
<http://www.hdc.org.nz/media/182635/gbskaitiaki11.pdf>.

Once again I'd like to invite any members and newsletter readers out there to get in touch if you have an idea for a story I could have a go at getting into the media to help raise awareness of this illness and raise the profile of the support group. Please drop me a line at maria.gbsnz@gmail.com anytime. Also if you have a personal story you want to share with the group but need someone to help you tell it I'm your girl.

Thanks to those members who got in touch after the last newsletter in regard to topics I plan to follow up, such as an attempt to “piggyback” on food safety campaigns in the media this summer with a story about New Zealand's slightly higher incidence of GBS put down to our higher incidence of campylobacter. I'll be getting back in touch with those who contacted me about this soon. If you believe the trigger for your GBS or CIDP was campylobacter or another food-borne illness I'd be keen to hear from you.

Lastly, I'd encourage more people to join our Guillain-Barré/CIDP support group on Facebook. The group has 24 members at the moment but the more the merrier – it's a great forum to seek advice and support each other along the road to recovery.

Maria



Obituaries:

Joe Gilligan. Joe who had GBS many years ago, died on 19th July 2011 at the age of 90 at the Thornleigh Rest home in New Plymouth. He was a dear old guy - his wife died many years ago. They had no children. Our sincere condolences to Joe's family.



Myrtle MacDougal – Timaru Myrtle passed away a day after her 87th birthday. Myrtle contracted GBS at the age of 79. She made a good recovery and was able to once again enjoy her twilight years. Our deepest sympathies to Myrtle's family.

As a tribute to Myrtle I have reprinted her story in the magazine. Ed



Dr Lindsay Haas

By Bob Stothart

It is with a sad heart I record the passing of Dr Lindsay Haas, Neurologist, Wellington Hospital. Lindsay was a strong supporter of our Support Group, not up front but modestly behind the scenes offering wisdom and assistance from the beginning. I have known Lindsay for decades as a member of our ski club but more particularly from the time he treated me when I was helpless with GBS. It was Lindsay I went to for advice when Margaret and I undertook the organisation of the first national conference. He suggested speakers, potential sponsors, commented on how to organise the day and generally gave us his backing. We returned each time we organised the conference for Lindsay's opinion on what we were planning. His ideas and suggestions were always beneficial and we will miss him immensely. He also generously provided accommodation for Gareth Parry on his regular visits to Wellington.

Lindsay was my regular contact at Wellington hospital and he'd ring often for me to visit a patient. He was a skier (adventurous if not stylish), a devotee of the arts, gathering a large collection, a conversationalist and he was great company. Lindsay will be greatly missed at Wellington Hospital where he was admired by his colleagues. One of his endearing characteristics was his ability to develop strong friendships and the large attendance at his funeral at Old St Pauls in Wellington was testament to the esteem with which he was held.

Rest in peace Lindsay. Rest in peace.



The Late Myrtle Macdougall's Experience of GBS

Myrtle recently passed away aged 87

My name is Myrtle Macdougall. I am 79 years old, and last year I shifted from just north of Auckland to South Canterbury. In August 2002, I had been working in the garden and developed a niggly pain in my back, and, thinking it was muscular, went for some massages. The pain gradually became worse until I could not lie in bed anymore and spent the night sitting in an easy chair where I could relax and sleep, if I could.

One morning I awoke to feel my face felt lop-sided: all pulled around towards the right. That day I went for a massage and the lady agreed with me that we needed further investigation for the pain. She had me at the doctor within the hour and he tested me for a mini stroke. There was no sign of a stroke. He said "you have Bell's Palsy" (half the face is paralysed: a nervous condition which can strike anyone at any age – but 90% is recoverable. The doctor also phoned the Hospital for me to be X-rayed. This showed up two compressed fractures of the lower spine due to osteoporosis.

My doctor referred me to the Pain Clinic and also to the A.T & R (Assessment, Treatment and Rehabilitation) specialist at the local hospital. It was four to five weeks before I had an appointment with either of these specialists but I was assured I was "in the system". My doctor was only allowed to prescribe Panadene for the pain at maximum dosage.

During this wait, I was visibly deteriorating, working in the kitchen I experienced one major blackout and two minor ones, resulting in three falls, fortunately no injury. I lost all desire for food. I was not having very much food at all. Another morning I awoke and felt that my right leg (from my knee to my groin) did not belong to me. When I tried to walk my feet would not do as I wanted them to do. I was tripping over my feet and my gait was very unsteady.

My husband has a wheelchair for use about the house so I took to that as I felt it was the safest way to get around without falling. Another day I awoke with pins and needles in my fingers and toes, quite a numbness and cold. If I could see what I was doing I could concentrate and manage the task but for anything I could not see my fingers were useless.

Time passed. We had no idea what was wrong. I was seriously deteriorating with little food and little sleep. On 8 October 2002, the first doctor examined me relating to the Bells Palsy. He sent me for a hearing test and made an appointment with the eye specialist. Most of the time from first developing Bell's Palsy, they taped my left eye shut and that was such a relief. The eye specialist decided to stitch my left eyelids together, half way across the eye – not very nice as the eye was so tender and sensitive, it hurt and left me with a very black eye. I was hoping to have the stitches out the following week, but during that time I tore them apart during the night and they had to be done again.

On 12 November 2002, I saw the Pain Clinic specialist. He put me on some very strong pain tablets and arranged for me to have a four hour drip at the Outpatients next day. This doctor kept in touch with me quite often to check my progress.

On 25 November 2002, the A.T & R specialist saw me. She questioned me about my symptoms and I was replying while the assistant was taking my blood pressure while I was sitting down. I was told to stand up and the reading was about 20 units down and the lower reading was very, very low.

The next day the District Nurse came to the house to take my blood pressure. The lower reading did not even register. No wonder I was falling. I was blacking out! Next day, Friday 30 November, I was in hospital – probably for my own protection.

When I went into the hospital I could not walk, nor could I eat. On the Monday I was thoroughly examined. It was thought I had Guillain Barré

But while I did not have all the symptoms, there were extras as well. On the way back to my bed I was vomiting with weakness. I was not allowed to move without a nurse.

After about three weeks in hospital I realized that I was not relying on the medication to ease the back pain, so I asked if I could cut the pills out, but promised to ask for the panadene if I needed it. The back was tender and sometimes uncomfortable, but not in pain.



The Late Myrtle Macdougall's Experience of GBS continued....

Milestone No 1.

The Pain Clinic people looked in every other day to see how the pain was affecting me and also to encourage me to stand and try to walk with whatever help I needed. I ate whatever I could keep down – especially at meal times. The main treatment was rest with the physiotherapist helping me to regain strength in my legs so I could walk and get up from chairs etc.

Before any treatment was commenced I had to go to Christchurch Hospital for a 'nerve conduction test' to confirm that I did have Guillain Barré Syndrome. The tests were positive. I was put on the treatment immediately. Two hour drips for five consecutive days – three at Christchurch hospital and two back at Timaru hospital.

At Timaru the dose of Prednisone was doubled to 80mg. My response was satisfactory. They let me out on Christmas Day and Boxing Day and then home until the following Sunday night. Doctors examinations and assessments on the Monday so I had to be there, very pleased with me and I was discharged on 31 December 2002 after 32 days in hospital.

The hospital treatment was wonderful; I could not fault it in any way. The staff taught me to walk and to eat again. They sent me home with a walker however it was not long before I could manage without it for support. Even going outside, as long as I could see the surface of the ground or path, I was alright. Within a month I was walking around a small residential block and concentrating on using my ankles, legs close together and feet pointing straight ahead. I am still doing the daily walk. One of the first things I wanted to take over was kitchen duties – and I did, but I had to have rests every so often and then carry on again. When standing at the bench I had a bend in my knees and it was an effort to 'stand tall' and work. To begin with my back got very sore, and I had to consciously think and make an effort all the time. I am eating well and have put on all the weight I lost, but the flab from the prednisone is still as much as ever – hopefully this will reduce over time.

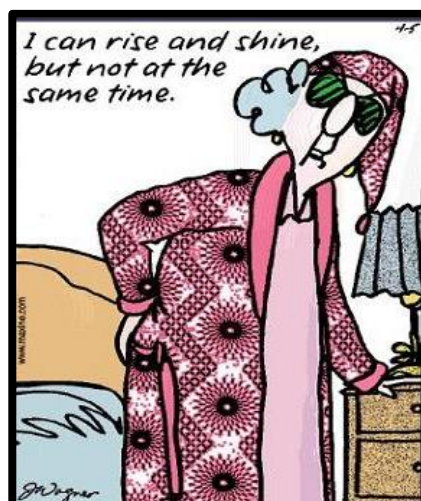
I see the specialist at the hospital every four to six weeks which is good. I am coming off the prednisone and will have to take things gradually for a few months. Hopefully some of the side effects will start to disappear. My very swollen ankles are coming down. The hospital gave me surgical elastic stockings and I think they are helping.

I am trying to walk up steps normally. Instead of 1/1, 2/2 I am trying to 1,2,3,4, and also walk back down again. It is improving but I have to be careful.

I am back driving the car and am gaining more confidence. Traveling is no problem but I like a small cushion behind my back for support on long distances.

My fingers and toes still have pins and needles. I have to be very careful of heat and protect them from being accidentally burned on hot surfaces or in very hot water.

I found when I came home from the hospital that I was very clumsy, misjudging, knocking and dropping things, but I am getting more control now.



Atypical types GBS and CIDP

A presentation by
Dr Gareth Parry

Atypical demyelinating neuropathies

- Chronic demyelinating neuropathies:
 - Paraproteinemic neuropathies
 - Multifocal motor neuropathy
 - Lewis-Sumner syndrome
- Variants of GBS:
 - Miller Fisher variant of GBS
 - Acute sensory neuronopathy

Paraproteinemic neuropathies

- CIDP with an abnormal paraprotein.
- Demyelinating neuropathy with specific anti-nerve antibodies (MAG/SGPG)

Paraproteinemic neuropathies

- There are 2 main types of protein circulating in the blood.
 - The most abundant is albumen.
 - Globulins are the most important from an immunological perspective because they constitute antibodies, both antibodies for fighting disease but also antibodies that cause diseases.
- Globulins can be separated out using electrophoresis into different classes – IgA, IgG and IgM are the most important.

Paraproteinemic neuropathies

- Occasionally a clone of white blood cells derived from the bone marrow escape normal control mechanisms and begin producing excessive amounts of a single immunoglobulin. These are called paraproteins.
- The abnormal clone of WBC's may be malignant (multiple myeloma or plasmacytoma) but the majority of cases are relatively benign (MGUS).
- Every patient with a paraprotein should be tested for multiple myeloma and plasmacytoma.
- These are not auto-immune diseases like CIDP or GBS.

Paraproteinemic neuropathies

- IgG proteins are the most common but least specific: ~10% of healthy people >70 years of age have an IgG paraprotein.
- Patients with otherwise typical CIDP may have IgG paraproteins and probably behave no differently from typical CIDP; treatment and prognosis are the same.

Paraproteinemic neuropathies

- IgM paraproteins are less common but are more specific; there are much more likely to be specific antibodies attacking the myelin sheath of the nerves.
- The best understood of these neuropathies is **anti-MAG neuropathy**, in which specific antibodies attack a component of the myelin sheath (Myelin-Associated Glycoprotein) which is the "glue" that holds the layers of the sheath together.

Paraproteinemic neuropathies

- Anti-MAG neuropathy is initially purely sensory but weakness does develop later.
- Sensory ataxia is the most disabling feature.
- The neuropathy evolves extremely slowly over years to decades. Patients often do not get the specific diagnosis for more than 10 years and by that stage treatment is unlikely to help.
- Usually a disease of people >70.
- Younger patients tend to have a more rapidly progressive disease.

Paraproteinemic neuropathies

- Prognosis is guarded. Progression is inexorable but usually slow.
- Because this is not an auto-immune disease it does not respond to steroids (prednisone).
- PLEX removes globulins from the circulation and occasionally may help but benefit is transient.
- IVIg may also produce minimal and transient benefit.

Atypical types GBS and CDP

A presentation by
Dr Gareth Parry

Paraproteinemic neuropathies

- Rituximab kills the antibody producing cells and is the only drug that has shown to help these patients but the benefit is uncertain and minor.
- Chemotherapy is occasionally helpful but is very toxic.
- Stem cell transplants hold some promise but have high risk.
- To be effective, any treatment needs to be started early.

Multifocal motor neuropathy

- MMN first described in 1985 (Parry).
- Pure motor demyelinating disease that superficially resembles motor neuron disease.
- Extremely restricted in its distribution, affecting only a few nerves (2-3).
- Hands are most commonly affected.

Multifocal motor neuropathy

- Initial symptoms are often cramps and muscle twitching. Weakness quickly follows and there is usually muscle atrophy.
- There may be some vague sensory symptoms but there is no objective sensory loss and the sensory nerve conduction studies are normal.
- Evolution of weakness is usually slow and may be step-wise.
- There may be specific anti-nerve antibodies.

Multifocal motor neuropathy

- Treatment with IVIg is beneficial in about 80% of cases but it does not cure the disease and probably needs to be administered life-long.
- Steroids and PLEX are not helpful and may even make patients worse.
- Treatment should not be given unless there is disability.
- Sufficient treatment should be given to maintain function, not necessarily to try to return the patient to normal function.
- Rituximab and chemotherapy have been used with occasional benefit but are higher risk strategies.

Lewis-Sumner syndrome

- First described in 1983.
- Very similar to MMN but has overt sensory involvement.
- Treatment is essentially the same as MMN but steroids may help.

Miller Fisher syndrome

- Initially described by Dr Fisher in 1956.
- Consists of ophthalmoplegia, ataxia and areflexia:
 - Patients cannot move their eyes properly so they get double vision and they also get drooping of the eyelids.
 - Coordination is impaired, particularly causing loss of balance but also clumsiness of the hands.
 - Reflexes are lost or diminished.
- There may also be mild difficulty with swallowing and speech.
- There is no weakness.

Miller Fisher syndrome

- Usually a post-infectious illness (C. jejuni).
- Evolves acutely over less than 4 weeks to nadir.
- CSF protein is elevated.
- Specific antibodies (Gq1b) are elevated in the blood in about 90% of patients.
- The disease is more common in Japan where it constitutes nearly 25% of GBS cases compared to ~5% of cases in North America. This strongly suggests a genetic predisposition to this type of GBS.

Miller Fisher syndrome

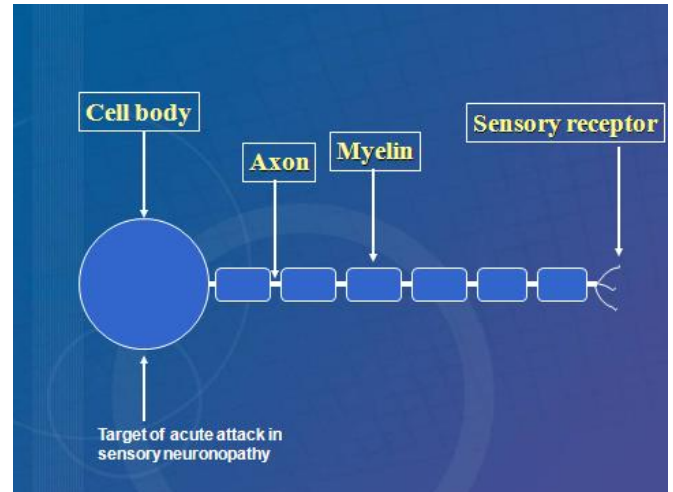
- Usually a very benign illness. Full recovery is almost invariable.
- There is no good *scientific* evidence that treatment is necessary or beneficial. However, anecdotal evidence suggests that both IVIg and PLEX shorten the duration of the illness, as in typical GBS.
- Benefit of treatment must be weighed against potential risks. It is reasonable to treat patients who have bulbar involvement or cannot walk safely.

Atypical types GBS and CDP

A presentation by
Dr Gareth Parry

Acute sensory neuronopathy

- Usually a post-infectious illness.
- Evolves acutely over less than 4 weeks to nadir.
- Primary manifestation is sensory ataxia (loss of balance).
- Numbness, tingling and pain may occur.
- Occasional autonomic involvement.
- There is no weakness.



Acute sensory neuronopathy

- Prognosis is guarded:
 - Mild cases make partial functional recovery.
 - Severe cases usually have permanent disability.
- There is no evidence that treatment is beneficial.
- Immunotherapy, usually IVIg, is usually tried and may be effective if administered very early, within 2-3 days of symptom onset.

Pam's GBS Encounter.....

Hi, I am Pam and I had GBS 2 years ago – after having a flu injection. 4 weeks on ICU trying to work out what was wrong, then 8 months in hospital. I couldn't talk, walk, breath. I was like a cabbage. My family wrote a diary for me. I cry when I read it. I was so sick I nearly lost my life, but with the support of my family, friends and nursing staff I pulled through.

You have to leave your dignity at the door and have a terrible feeling of utter helplessness.

I have no feeling in my feet and am very tired. I have to pace myself as to what I can do. My head knows I can do things, but my body will not co-operate and I suffer from frequent cramps. It is very frustrating. But I am alive after escaping a

near miss in the Christchurch earthquake. That has unsettled my nerves so much I am having counseling.

I am unsteady on my feet and my hands are also unsteady. I used to do a lot of craft work but I now find this almost impossible. But I am alive!

Why do they '*push*' for you to have a flu injection? So many of my friends refuse because of what happened to me! They even get Texts on their mobiles to get one!!

Pam Jeffery



Judith Connors's Encounter with GBS

My name is Judith and I'm 62 years of age. Below is a summary of my GBS experience.

What Happened to me between Dec 2000 and June 2011.

Dec 2000 Sold tavern business

April 2001 Husband has massive stroke, put into care until he died August 2005.

Sept 2001 I have bronchitis

Dec 2001 GBS. Cause or Result of bronchitis or stress over husband? I will never know.
On going problems: Poor balance and fatigue.

AFTER THAT

Osteoporosis
Polimyalgia

Dec 2009 Tripped over supermarket trolley resulting in double fracture right humerus.

June 2011 Slipped in shower. Two lessons learnt from this:
1. Always check your medic alarm
2. Always check your rubber shower mat is not covered in mould and soap grime.
Renew regularly.

VOLUNTEER WORK:

Secretary Levin Stroke Support Group.

LOVE:

On top of the world when I met my male friend in Dec 2010. He made me feel young and that I could do anything. He had to go to Auckland for work (I am in Levin). Hope HE comes back.

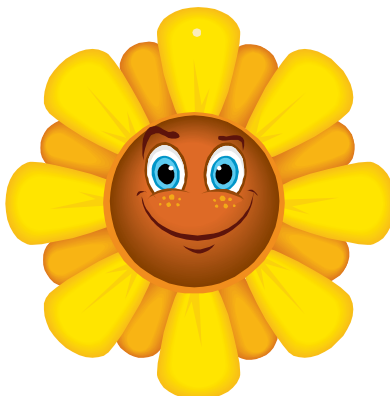
FAVOURITE SONG:

One Day at a Time.

LIFE GOES ON:

Roll on 2013. In the meantime I hope JK doesn't expect me to go back to work.

KEEP SMILING.



Outbreak of GBS in Arizona linked to Campylobacter

Reprinted with the kind permission of the author JoNel Aleccia, contributor on msnbc.com

A cluster of cases of a rare illness that can lead to nerve damage and paralysis has been identified along a small stretch of the United States-Mexico border. An outbreak of food poisoning is the likely culprit, health officials in the two countries said. At least two dozen people in Yuma County, Ariz., and San Luis Rio Colorado, Sonora, Mexico, have been diagnosed with Guillain-Barré Syndrome in the past month, with some left drastically impaired by the illness that triggers the body's auto-immune reaction. "It's really attacking the nerves," said Shoana Anderson, office chief of infectious disease at the Arizona Department of Health Services. "All of the patients I've seen are not able to walk."

Most of the victims, including 17 from Mexico and seven from the U.S., are adults who range in age from 40 to 70, although younger people also have been affected, Anderson said. Some patients have muscle weakness in their upper bodies as well as in their legs, she added. It's not clear how quickly they may recover.

Guillain-Barré Syndrome, or GBS, typically affects only about 1 in 100,000 people, according to government health statistics, so a cluster of 24 cases is cause for alarm, officials said. Although the condition often resolves on its own, recovery can be long and painful. And in rare cases, the illness can cause permanent disability and even death.

The sudden spate of GBS cases in the southwest looks to be the result of an outbreak of infections with Campylobacter bacteria, a common diarrheal food borne illness typically caused by eating raw or undercooked poultry or meat, unpasteurized milk or contaminated water. It can also be spread by animals such as cattle and dogs.

At least four of the GBS patients have been confirmed to be infected with Campylobacter bacteria, meaning there's a good chance the others were, too, officials said.

"It's pretty convincing," said Dr. Tim F. Jones, a national food borne illness expert and the state epidemiologist for Tennessee. The germ can be hard to detect because it has to be cultured from stool specimens, he added.

GBS is serious complication of infection

GBS is the most serious complication of Campylobacter infection, with about 40 percent of the 3,000 to 4,000 cases seen in the U.S. each year attributed to that bacterium. Campylobacter is one of the most common causes of diarrheal illness in the U.S., infecting an estimated 2.4 million people each year, according to the federal Centers for Disease Control and Prevention.

But the bug typically causes sporadic infections, not widespread outbreaks, so that also drew the attention of health officials in Arizona and Mexico, along with representatives from the CDC.

The two countries are conducting a rare bi-national investigation, watching for new cases of GBS reported to doctors and hospitals and for new evidence of Campylobacter outbreaks.

Some U.S. states are reporting higher than normal rates of Campylobacter infections. In Wyoming, for instance, the state has confirmed 34 cases since June 1, four times as many as usual. No cases of GBS have been detected there, health officials said.

In Arizona and Mexico, health officials are pushing to determine the source of the Campylobacter infections through interviews with victims and other epidemiological research.

"Our big push is to figure out what's causing this," said Anderson. "It's really important that to us to stop the underlying infection."

Campylobacter infection, which can lead to GBS, is not spread from person to person, but through contact with contaminated food and other objects. To avoid infection, people should wash hands thoroughly after preparing food, before eating and after using the bathroom. Also wash hands after contact with pets.

Make sure to cook all poultry products thoroughly, so that they're no longer pink and they reach an internal temperature of 165 degrees Fahrenheit. Use separate cutting boards to prepare meat and vegetables and wash all cutting boards, countertops and utensils with soap and hot water after preparing meat or other animal products.



Campylobacter increase in Wyoming; any relation to Arizona?

This article was taken from "barfblog – safe food from farm to fork" and reproduced with the kind permission of the author Dr. Douglas Powell

Posted: July 14th, 2011 - 6:46pm by **Doug Powell**

[The Wyoming Department of Health](#) is reporting a four-fold increase statewide in Campylobacter infections this summer, with at least 29 people sickened and six hospitalized. Nearly three-quarters of the patients are male.

"While the increase in these infections appears to be sporadic with no single common source, it's clear that animal-related illness is at least partially driving the increase," said Kelly Weidenbach, epidemiologist with the department's Infectious Disease Epidemiology Program.

In rare cases people may develop serious complications such as Guillain-Barré syndrome. The syndrome occurs when the immune system is triggered to attack the body's nerves. It can lead to paralysis and usually requires intensive care.

Public health officials attempt to interview each person with the Campylobacter infection. Among patients interviewed to date, exposure to animals, especially cattle and dogs, has been common.

"In many cases, the animals were noted to be ill with diarrhea when the person had contact with them," Weidenbach said. "Several have been ranchers or individuals who recently attended a cattle branding and who were accidentally exposed to fecal material."



That sounds different from the [Arizona campylobacter increase](#). But who knows.

<http://barfblog.foodsafety.ksu.edu/blog/149602/11/07/25/guillain-barre-syndrome-victims-rise-arizona-mexico-campylobacter-outbreak>

WEBSITE CO-ORDINATOR

For the past few years Lil Morgan has very successfully organized our Website. But due to the need to build a new house and sort a new direction after years of farm management Lil and her man need to focus on matters closer to home.

So we need someone to step into Lil's shoes. You don't have to be a "Techi" or a "Geek" - all that stuff is done by Ben – an employee of the Rare Diseases Organisation – but you do need to be comfortable with your computer – essentially Word and E Mail –and be a bit organized.

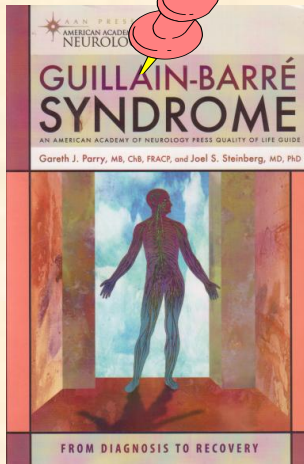
The job involves passing stuff to Ben to update our site – latest stories – changes in Trustees etc etc – all provided by me, Chris, Bob "et al" and generally being familiar with the site. I gather we have a Facebook site as well – but don't ask me about that!!

If you would like to give something back to the Group and are keen to have a go – give me a call. I am "holding the fort" in the meantime but in actual fact there is nothing that needs doing right now!

Tony – 03 526 6076 – tonypearson@xtra.co.nz



Notice Board



Jenny now has a new stock of Gareth and Joel's book.

Cost \$35 plus p&p

Written in an "easy to read and understand" format for the layman, it covers a wide range of topics including symptoms and diagnosis, caregiver guidelines, rehabilitation and much more.

If you or any of your family members want a greater understanding of GBS then I strongly recommend this book.



Moving House? Don't forget to give us your new address.

**More Personal Stories
Wanted
For Publication Please.
Email or Post to the Editor**

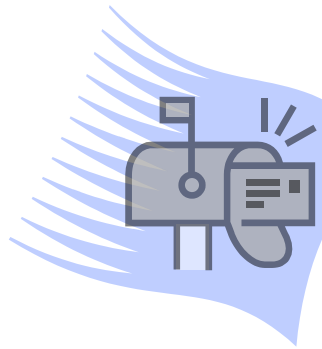
NZ Facebook Support Group

Lil has set up a support Group on Facebook under the section 'common interest and health and well being'. If you are on Facebook join up and start some discussion going.

Guillain-Barré/CIDP Support Group

The GBS/CIDP Foundation International's magazine is now available online. Anybody who wants access to this magazine can get it online at:

www.gbs-cidp.org



Want to receive your magazine by Email?

Just email the Editor and your colour copy will be on its way.

Not only would you be saving a tree but also be helping to reduce the costs of publishing and posting the magazine.

BOP Coffee Morning

Everyone welcome

Tuesday 27th September

The Manor Café

514 Cambridge Road, Tauriko, Tauranga

Time: 10.30am

Please let Chris know if you can make it.

07 5490931 or email: chrispy57@gmail.com

Hope to see you there.

