Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

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NEWSLETTER DECEMBER 2012

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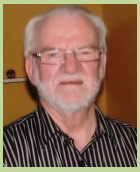
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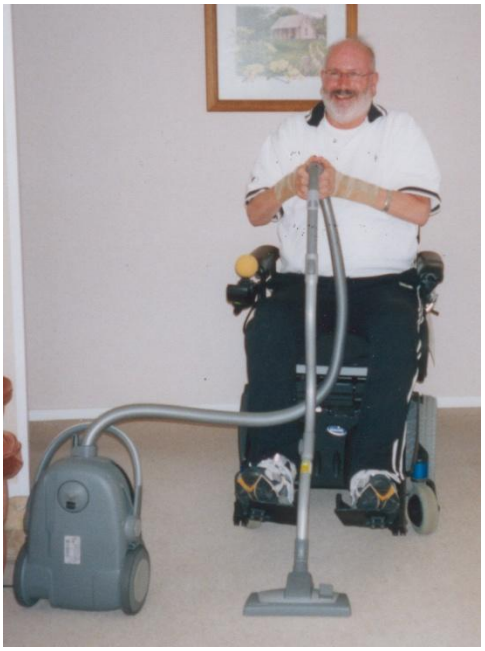


Grant McKay has gone from house husband to king of the road.

He is loving his new found independence and freedom.

Codicil to an existing Will

If you have already made a Will you can still help the Guillain Barré Syndrome Support Group by adding a codicil to your Will.

If you would like further information or would like to talk to a Trustee of the Group about making a bequest to the Charity please contact us on 03 526 6076.

We do advise consulting with your legal advisor before completing this codicil form
Please take this form to your legal advisor

I …… (Name)

of ……

…… (Address)

Declare this to be a …….. (first/second) codicil to my Will dated ……/……/…….
In addition to any legacies given in my said Will I give to the Guillain Barré Syndrome Support Group New Zealand Trust, of 113 Weka Road, Mariri, RD2, Upper Moutere, Nelson 7175 (or any other premises which the Support Group may hereafter occupy) a charity registered in New Zealand No. CC20639,
A share of …….. of my estate or the sum of NZ$ …… and/or
…….. (a specific sum)
to be used for general purposes and I declare that the receipt of the Treasurer or duly authorized officer shall be full and sufficient discharge. *
In all other aspects I confirm my said Will and all other codicils thereto.
**please complete as required and cross out those options not required.*

Signed ……

Signed by the above named in our presence and witnessed by us in the presence of him/her and each other

Witnessed by:	***Witnessed by:***
Signature……	Signature……..
Name ……	Name……..
Address……..	Address……..
……	……..
……	……..
Occupation……	Occupation……...
Date…../…../……..	Date…../…../……..

A very big thank you to Marie Oliver who left $100 to the Support Group in her will. We appreciate this very generous gesture

Obituaries

Since the last newsletter we have received word on the passing of some of our members.

George Wadsworth	died 4th September.
Henry C Senior	died October aged 91 years
Pat Baker	died 9th October.
Marie Oliver	died September aged 90.

We send our heartfelt sympathy to the families of these members.

Editors Note

11 years and 3 days after getting GBS I found myself incapacitated once again and reliant on friends and family for my well being. Once stitched up, my ears suffered badly, as those who think I am too old to be doing a bit of off road motorcycling told me so. My cousins response to my aunt was "And she's how old". Back on crutches and confined to keeping my leg elevated for the next few weeks, I shall try and not go crazy with boredom. At least I have had the magazine to produce. Might not be doing any dancing at the work Christmas party this year, which some may say is a good thing.

Annual subs are now due and a form is included in this magazine. Please get these into Peter sooner rather than later. Due to costs and the small income the Trust has to operate on we can longer send to those members who are not financial.

We have had another successful Bay of Plenty get together, with 17 people (including partners and friends) coming to our Christmas luncheon. Thank you everyone for making these such fun and successful events over the year. If anyone in would like to organise something in their area I am happy to help get you started. All you need is a suitable venue, the desire to meet fellow sufferers and a liking for coffee and cake. These events can be put on our Face Book and Web pages for maximum exposure.

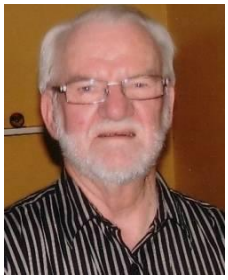
We have had a few cases of GBS reported in the BOP/Waikato area lately. Talking with others at our luncheon this seems to be the time of year for outbreaks in our regions which makes us ask the question WHY? Is it because immune systems are down after winter or what? Can our medical board provide a theory?

Our best wishes for a speedy recovery go out to these people and their families.

I wish you all a very merry Christmas and happy New Year

Chris

Presidents Paragraph:



My wife Margaret and I attended a Neurological Foundation presentation at the Wellington Opera House recently. It was part of the foundation's Progress Through Research programme which they have presented in Auckland, Wellington, Christchurch and Dunedin. The Wellinton occasion was MC'ed by Kevin Milne in a lively and entertaining manner contributing to an informative and valuable evening. Speakers included Dr Jon Simcock and Auckland neurologist, Associate Professor Bronwen Connor a researcher from Auckland and Associate Professor Anne La Flamme of the Malaghan Institute. While GBS was not mentioned there was much discussion about other neurological conditions. What was really significant was the quality of research being undertaken in New Zealand, including stem cell research and the significant progress that is being made on a number of disabling conditions. We all benefit from this internationally recognised research.

I was not able to attend the GBS/CIDP International Foundation's symposium in Fort Worth in October but speaking with Professor Gareth Parry who was there, he told me there were about 400 delegates 200 of whom were first time attenders. In other words half of those there had encountered GBS or CIDP and wanted to understand more about their particular malady by attending the symposium. I would leap for joy if our conference, being held next April in Wellington, attracted a 50% response from people who had never been before. This is the only conference on GBS/CIDP held in New Zealand and we work hard to assemble a programme of informative speakers. If you possibly can, regular attender or first timer, come to the conference and I guarantee you will benefit from it.

Bob

Secretary's Jottings

"From the very beginning the medical staff gave us literature from the GBS Support Group and encouraged us to make contact. **So I did and spoke to a very helpful lady and joined the online Facebook group. I was instantly overwhelmed by the kindness and support shown to me by members of the group who had had GBS or still had it or CIDP and then continued to offer us support throughout Martin's illness"**

The above is an extract from a story in the Autumn Edition of the UK GBS newsletter "In the Know" from a Mum about her teenage son's encounter with GBS in January of this year. The Italics of the first sentence are mine but it was just that simple statement that made me sit up! – so ….. if it can happen in the UK then WHY OH WHY does it not seem to be happening in New Zealand. We all know we can do the help and support bit ONCE we have made contact but so often the contact is by a chance encounter/contact with another GBS'er – who someone who knows one – or by the diligence of the sufferer (or more often their carer) searching the web .
We can keep sending out literature to medical centre's and we can develop our "educational visits" to nursing and other medical staff but this is something we have tried for many years and, generally it is met with a (at best) lukewarm response from the medical hierarchy. The KEY ??? – well I think it lies in the nationwide development of the Hospital Visitor network much as has been done by the UK Group. As with so many things in this country it's not "What you know" but "Who you know" and I am certain that once the medical teams that deal with GBS patients get to know a "local" face and recognize a capable and sensible authorised member of the Support Group who can provide focused support based on experience to their patient without threatening the team's medical competency THAT'S when we will see a change in the number of contacts stemming from information about the Group passed to their patients by the medical teams.

The April 2013 Conference kicks off on the Friday afternoon with the first of what I hope will be many gatherings around the country to provide the skills and guidance to those who are willing to volunteer for this most important role. I look forward to joining that first gathering and meeting you there.

Since the last Newsletter I have lost a good friend, John Mason. John and I met at our local Sailing Club here in Motueka soon after I arrived in NZ. It turned out that we had grown up in the UK not so far apart – John in Hampshire and me on the Isle of Wight – just a short boat trip apart! John was initially diagnosed with CIDP a year or so ago but the "standard" treatments did not seem to be helping ,in fact quite the contrary and it was not until Dr Gareth Parry got involved during one of his periodic visits to Nelson that our local medics accepted John was afflicted by something unrelated to GBS and began to try other remedies – but sadly to no avail. Throughout his illness John remained alert and willingly helped me put together the paper on the availability of financial and other assistance to GBS sufferer's – the last Newsletter contained an article from John about his (generally positive) experiences of working with WINZ to alleviate some of the financial burden that inevitably comes with a prolonged illness. I shall miss you my friend.
The past few months have been quiet as far as new GBS/CIDP cases in the Top of the South coming to my attention. You will notice I am NOT saying there have not been any cases – just I haven't heard about them – Am I beginning to sound like a stuck gramophone record ?!
Thanks to the good offices of the NZ Organisation for Rare Diseases (NZORD) and its CEO John Forman we (that is Chris, Lil, Ken and myself) have been WEBUCATED.
NZORD's Webmaster Ben Chapman was keen to pass on some of the responsibilities for the structure and operation of our website to the Group (a policy that is being applied to all Group's who operate their websites under the NZORD's auspices). As I mentioned in the last Newsletter such skills don't necessarily come naturally and so it was agreed we should assemble in Wellington for a day's tutorial. So now, hopefully, we can pretty much run our website within the Group. Ben is still helping us develop the "new look" 2nd generation website and will continue to handle some of the tricky "geeky" bits of stuff that the system's servers require – but if you spot a gaff on the site let any of us "Webexperts" know – because it will be our fault!

If you are planning to come to the Conference in April it would be a GREAT help to me to get you registrations in as soon as possible. There is a surprising amount of administration involved in setting up delegate information and whilst none of it is Rocket Science it does take time and if I have to rush things at the last minute then the inevitable errors will occur. Currently I am dealing with a potential delegate from Nepal – I leave you to guess at the bureaucratic mountain of paperwork that is accumulating in order to get him a visa to visit NZ!
I have applied to Lottery for funding assistance to help defray some of the costs of the event – the last two Conferences have left a hole in Peter's accounts – and whilst we do have a strong Balance Sheet it is not a situation that can be tolerated indefinitely – so fingers crossed please.
And finally, the latest Communicator from GBS/CIDP International contains a letter from a spritely 93 year old (got GBS at 70) who continues to apply to his life an expression given to him by his therapist whilst recovering from GBS:
"inch by inch anything is a cinch"
Not a bad concept!
As always
take care

Tony

Ironman challenge a 'personal crusade to show CIDP who's boss'

- By Maria De Cort

A Hawke's Bay woman who was once told she may never again walk unaided is embarking on her toughest challenge to date, training to complete the Kellogg's Nutrigrain Ironman New Zealand next March.

Kathy Eggers is a 39-year-old mother of three, part-time nurse and "newbie triathlete", living with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP).

Five-and-a-half years ago when Kathy was first diagnosed the disease attacked her peripheral nervous system to the point where she lost control and feeling of her arms and legs until full quadriplegic paralysis set in.

Several times since her first "encounter" with CIDP she has had to relearn how to feed herself, walk, write, care for herself and her family.

As her medical team devised an intensive treatment regime to stabilise and then control the disease, Kathy used sport and physical activity as her main rehabilitation therapy.

"Goals were set initially to master sitting, then standing, leading onto walking a few steps, to then reaching my letterbox, which then turned into ¼ block, then 1km and so forth. My first duathlon was in April 2008 – exactly a year from when I became unwell. I could barely feel my lower legs, let alone my feet, but I completed the 2km run, 11km cycle followed by 2km run, which was more like a 'waddle'."

Since then, and still continuing with a rigorous treatment regime including regular blood transfusions, immunosuppressants and other medications, and through several relapses that saw her immobilised again, Kathy has clocked up an impressive track record of multisport events for a woman told by specialists at the time of diagnosis that she may never walk unaided.

Having run her first half marathon in August 2009, she has gone on to complete two half ironman competitions and a full marathon, as well as regularly competing in duathlons, triathlons, lake swims and mountain races. In the lead up to next March's Ironman she will compete in the Taupo Half Ironman on 8 December as well as several provincial triathlon events.

Kathy says she decided to take on the ultimate multisport challenge, an Ironman, as a "personal crusade to show CIDP who's boss" but added motivation for doing the event is "because I can, for those who, due to illness, can't".

"CIDP is such a rare disease and is still considered a medical mystery, which can affect anyone at any time in their life, and for which the majority of sufferers never regain their former state of health. I am doing this event to raise awareness of CIDP and GBS and doing it for those who, due to ill health, can't!"

Kathy says the Ironman – which involves a 3.8km swim in Lake Taupo, 180km cycle leg and a full marathon (42.2km) to finish – will be "gruelling to say the least, but so is living with or through GBS or CIDP".

"I hope to inspire those living with CIDP and GBS that anything is possible, while encouraging others to set goals and step out of their comfort zones in making their dreams come true!"

Kathy is using the race as an awareness raiser and has been fortunate to have Kellogg's select her as one of three athletes to sponsor for the event (the others being Prime News presenter Charlotte Bellis, a fellow rookie, and a 27-year-old Auckland firefighter and semi-pro triathlete coming back from injury). Kellogg's generous sponsorship includes paying Kathy's entry fee, financial support towards coaching and training, kitting Kathy out with race gear (on which the GBS logo will find pride of place) and utilising its PR team to get Kathy's story out to the world.

Look out in the *NZ Woman's Weekly* due out 10 December for a feature on Kathy and if you are going to be in Taupo on 8 December or March next year – be sure to have your cheerleading pompoms and banners ready and voice at full strength! The rest of us will be there in spirit – "Go Kathy!"

My GBS Experience - Paddy Rule

My GBS experience started in November 1998. I was 56 years old and working fulltime as a receptionist for an osteopath. In October I had a bout of flu, as I'm asthmatic, ended up with a chest infection for two to three weeks, got over that OK.

My husband and I decided to have a night away at Waiheke Island, a favourite place of mine. Had a very enjoyable time, went out for dinner and next day went for a long walk. Coming back to our cottage, there was a very steep hill and I had a lot of trouble walking up it. I thought it must have been that I was still short of breath.

The following Tuesday, my grandson was at a school camp and I had gone down to help on a bush walk in the Huia Ranges. This again was very steep, but I had done it many times with no trouble. The track was very slippery after rain and I found it very hard going, falling many times. I kept using my inhaler as again, I thought I must be short of breath. I had to go to work later that afternoon, by this time my feet were feeling all tingly. At the end of the clinic I asked the osteopath if he would check my back as I thought I may have hurt it after all my falls, but my back was fine.

Next morning I started work early and my employer asked how my feet were. By this time tingling was travelling up my legs and also in my hands. He told me to see my GP as soon as I had finished work. I did this and by the time I saw him the feeling of pins and needles was to the top of my legs and arms. I had a doctor who is extremely good at diagnosing and straight away said he thought I had GBS. I had never heard of it. He made me an appointment to see a Neurologist the next day. I saw this Doctor and he immediately admitted me to hospital. By this time I couldn't walk without help and was numb up to my waist and in a lot of pain. Had a lumbar puncture done, which confirmed GBS. I was very fortunate as the paralysis stopped at my diaphragm so I didn't need life support. I could use my hands a little but had no strength in them.

My stay in hospital was not a good experience. Most of the staff had no idea what GBS was. I was in a 6 bed ward, 5 men and myself. The men were very kind, cutting up my food etc. I had no physio or any suggestions to help me move a little easier. Unless I was hanging onto someone I fell all the time. I was told I would get over it and nobody dies from GBS. Finally I asked if I could go home as I could get more help there. I was told to take panadol for pain and was discharged.

On the way home a car cut into our lane nearly hitting us. My husband had to brake hard and my head jerked forward and back sharply.

Good to be home and family were wonderful. I had to sleep in an armchair as the pain was bad lying down. A day or two after coming home I started to get severe headaches. The pain went up to my neck across my skull and was nearly unbearable. My husband took me back to outpatients to see the Neurologist and he almost inferred it was all in my mind. That was quite a low time. I had been going down to A & E nearly every day and pethidine was the only thing that helped. My own Doctor who had been on leave, came back and he was the one who helped me the most. He put me on a drug that people who suffer from migraines use. I could inject myself and the relief I got was wonderful.

Slowly I started to get back to normal. Walking was still very hard and I was always falling. I went back to work which was good. I started knitting to get my hands moving and eventually this did help, although the grandchildren didn't think much of my efforts
The head pain finally went but it was a good two years before the leg pain eased and even then I would be asleep and my legs would go into spasms. It would stop if I stood up.

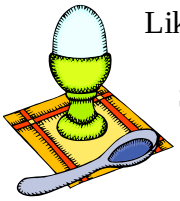
Many funny things happened during this time. One time we thought it would be nice to have a family weekend camping. We owned a little caravan so off all the family went to a beachside camp. The camp owners were very kind and gave me a key to a mobility shower and toilet complex they had, as this was a very slow business for me. My husband got hold of a porta pottie for me to use at night which he put in the awning. First night out to the awning I go. I manage to get down but because it was very low I couldn't get up. Not enough strength in my arms or legs to push up. I didn't want to yell out and wake up all the camp so I sat and waited to be rescued. After about an hour my husband finally realised that I wasn't in the other bed and came and searching for me. After that experience I woke him at night if I needed to venture out to the awning. It was good for a laugh the next day with the family.

I am fine again now but still have numbness in my feet especially the toes and they are very sensitive. I can't go barefoot anymore. Still that is nothing much to put up with.

Life is still good and I am blessed with wonderful children and grandchildren.

Handy Hints

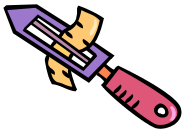
Paddy Rule sent in these handy hints which they found very helpful after her husband had a stroke and left him with a paralysed arm. They could be of assistance to GBS patients with little hand strength.



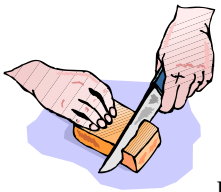
Like Boiled eggs but very hard to manage with one hand?

Solution: Get a solid square of timber (about the size of a bread and butter plate) and a wooden eggcup. Screw eggcup onto the board which makes it very sturdy and it doesn't move.

To Help in the kitchen:



Get a solid piece of timber and put several tin tacks through the timber from the bottom. This device is great for peeling potatoes, carrots etc. The tacks hold the veges in place and away you go with the peeler.



Trouble finding a knife sharp enough to cut meat when you have no strength to apply enough pressure?

Try purchasing a lead cutting knife. This is very similar to the rocker knife but much sharper. You can purchase them at craft shops that sell glass and lead for stained glass making.

My GBS Experience - Garry Crabbe

How I got GBS started from getting a common cold which started about the middle of December 2007. In the end the cold went to my chest, so I went to my local Doctor who prescribed Augmentin. Anyway, that was for 21 tabs which finished on the 24th of December. No sooner had I these tabs when I noticed the symptoms of tingling in my fingers and toes. But nowhere else.

At the time I just thought it was this tingling feeling from just coming off Augmentin, but as time went on I noticed that I was starting to feel weaker by the day. On the day that I was sent to Wellington Hospital A & E I couldn't walk properly at all. That was Saturday afternoon.

I was admitted to E Ward Sunday the 30th of Dec. That night they took me up to Theatre to perform a Lumbar puncture which I wouldn't wish on anyone.

I noticed after Sunday that I went downhill as far as talking, smiling or anything that I was used to doing.

They started me on Blood Plasma drips on Sunday for 3 days.

And going by the nurses I hit rock bottom on Wednesday the 2nd.

One thing I do have to say is that the Staff in Ward E Neurological Wellington were fantastic.

So there you go. Prior to this I never ever heard of GBS and I do have to say it sure did scare me big time. Prior to getting GBS I was very fit and active. So there we are. It will be great hearing from Mr. Bob Stothart.

I was given some info from Wellington Hospital i.e. After GBS was won.

Regards Gary

Something from the Kitchen

Cookies and Cream Truffles

Serves: Makes about 14 balls

Ingredients:

500gms Oreo biscuits
250 gms cream cheese, softened
400gms milk chocolate
100gms white chocolate

Method:

1. Crush cookies in a blender.
2. Pour into a bowl, add cream cheese and mix well until there are no traces of white.
3. Roll mixture into balls, place on a baking paper lined tray and refrigerate for 45 minutes
4. Break milk chocolate into small pieces and put in a microwaveable container. Melt gradually stirring every 20 seconds until smooth.
5. Coat balls thoroughly with melted chocolate. Place back into fridge to cool.
6. Finally melt remaining white chocolate and using a fork drizzle melted white chocolate over balls.

GBS Members from the BOP/Waikato area enjoying a Xmas lunch get together.

Rosemary McBride
Meike Schmidt-Meiburg
Marty Hewlett
Lauren McBride

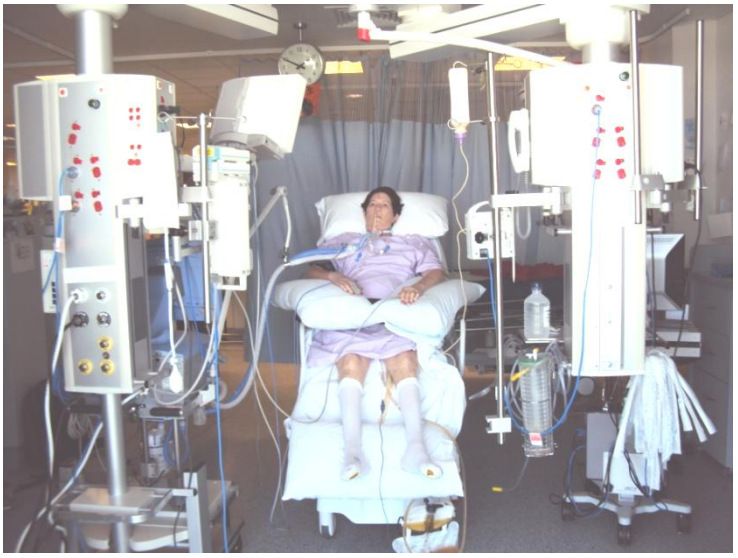
Fran and Grant McKay
Jan Gribble
Celia and Gordon Stephenson
Carmen Woodhouse
Jan Morrow

Ray Morrow
Woody Woodhouse
Glenda Ryan
Chris Hewlett
Barry and Judy Deed

MARILYN TURNWALD

GBS SURVNOR-EXTRAORDINAIRE

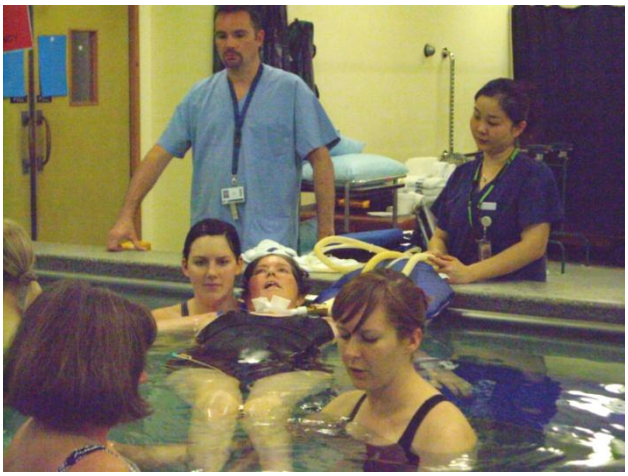
When the pins and needles first started in my hands and feet I ignored them, as we were flying out to Australia on the 7th of January 2011 for a family reunion. I said to my husband that I could hardly walk the long corridor down to the airport gate, so I had a feeling something was wrong. We were being met at Brisbane airport by my sister who is a charge nurse in ICU at the Royal Brisbane Hospital. She took one look at the way I was walking and after I described my symptoms she knew exactly what was wrong with me. I was in ICU within hours. So much for the reunion!



I had never heard of Guillain-Barré Syndrome, so I had no idea of the long road that awaited me. Within 3 days I was intubated and put on a ventilator as I could no longer breathe for myself; my muscles had entirely lost all power and all I could do was just follow people with my eyes. I underwent numerous CT and MRI scans as well as two lumbar punctures. (On the 'fun scale' of 1-10, they rate about minus 30). The high body temperatures were incredible and they covered me in ice packs to cool me down. The disease process also affected my heart muscle – my heart rate would drop really low before it would pick up again. At one point, my heart stopped altogether and I suffered an asystolic cardiac arrest. To prevent this happening again, I had a cardiac pacemaker inserted.

Because I was going to be on life-support for quite some time, the doctors inserted a tracheostomy into the front of my neck to connect to the ventilator, so that the tube in my mouth could be removed, to prevent any long-term complications.

The nightmares and the hallucinations from all the pain-relief and sedation drugs took a lot of getting used to. Because I could not fully close my eyes and they were in danger of being damaged, which they were anyway, at night they were taped shut but with the hallucinatory drugs this was a terrifying experience. During that time I was given 2 courses of intagram and two plasma exchanges. The boredom of those days, of being unable to talk or communicate were intolerable. Trying to communicate by blinking at an alphabet chart is frustrating to all involved. After much wrangling with our travel insurance company I was flown back to New Zealand on the 23rd of March, loaded into the back of the aircraft with the passenger meals along with a Doctor and a nurse. I was in ICU at Waikato hospital for another 3 months and was followed under the watchful eye of neurologist Dr Chris Lynch whose knowledge of GBS is incredible. One of his early comments was "you really got hammered" and I guess it was then I realised how sick I was. My church had set up a daily prayer group for me, so at 5 o'clock each day four people would come to see me, and this I found very comforting. I only hope God will forgive me for all the "why me's" and 'how could you do this to me?' that I sent his way. Initial recovery from GBS is extremely slow so nothing seemed to happen in ICU towards my getting better. Trips downstairs to the hydrotherapy pool were like a major military exercise with a doctor, nurse, ventilator technician and 3 physios all in the water with me holding me afloat. Eventually I moved to HDU where the speech therapists started to work on my vocal cords and the physiotherapists began on my very flaccid muscles. I was then transferred to A4, then



MARILYN TURNWALD

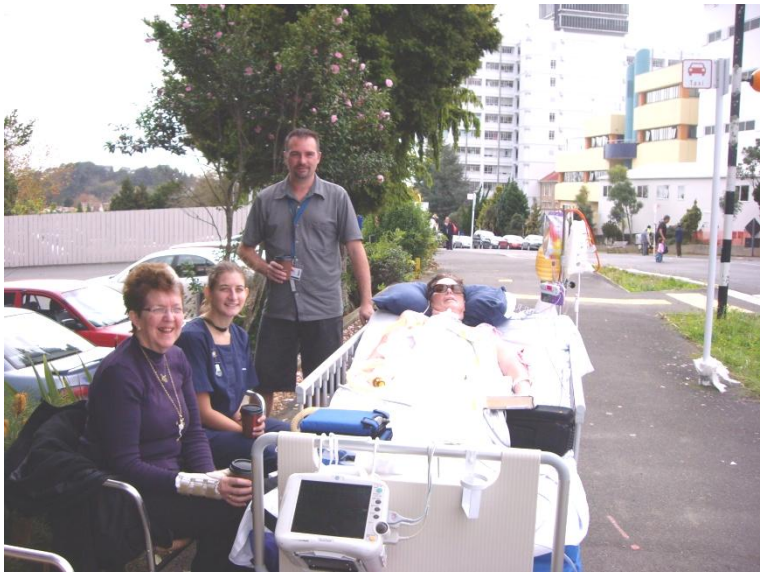
GBS SURVNOR-EXTRAORDINAIRE

Neurology, and then finally to the rehabilitation ward on ward 55. I was in that ward for so long that when I finally left, the staff gave me a small party to send me on my way.

I needed surgery to close the hole in my neck from the tracheostomy site, and I still apparently have an enlarged spleen. In hospital, one loses all dignity, but the nursing care in both the Royal Brisbane Hospital and Waikato Hospital has been superb.

After 11 months in hospital I am slowly getting closer to walking, although I still have the pins and needles in my hands and feet, and the lower half of my face is paralysed with Bulbar palsy. I am hoping to have all feeling back in my feet within 6 months and only the tips of my fingers tingle now.

Because of my inability to fight 'bugs' I picked up a very nasty little critter 'microbacterium' abscessus bacteraemia/sepsis'. Another lot of surgery to remove the pacemaker and found the bug was happily breeding in behind it. It took Dr. Karalus months to finally send it on its way, but the combination of strong drugs that I had to take have left me with a severe hearing impediment and I now require hearing aids.



I came out of hospital two weeks short of 12 months. I was in a wheelchair but am now able to get around with a walking stick. I have a great physiotherapist at the hospital gym and still regularly see the eye department as my sight has also been compromised. I have given up any thought of going back to work and haven't dared to drive my car as my feet and lower limbs are still quite numb.

We refer to the past 2 years as the years from hell, but in all this time, my husband and 3 children have borne this burden with wonderful resilience as has my ICU trained big sister and for this I love them all dearly. I am certainly well on the very slow road to recovery although there are still a few hurdles to 'jump over' and I am very grateful to Drs. Lynch, Karalus and Adiga for their ongoing care and support and to the incredible nursing staff at the Royal Brisbane and Waikato hospitals. Also a huge thank you to Gordon Stephenson and his wife Celia who visited me often all the way from Putaruru offering words of encouragement. Without everyone's care and dedication, I would not be here today.

The GBS/CIDP Foundation International have advised us that they are getting a number magazines to New Zealand address's returned. If you have not been receiving their Newsletter and wish to do so please make sure they have your correct address. You can contact Shawn Coates direct (Shawn.coates@gbs-cidp.org) and she will take care of it personally or go on the website www.gbs-cidp.org and fill out a contact form and note that it is an address correction.

Guillain-Barre Syndrome -
How is it treated and what is the outcome?

This is the fourth in a series of 5 articles on GBS written by Dr. Gareth Parry to give an overview of the illness.

GBS is an acute paralytic illness that can lead to death unless appropriately managed and yet the majority of patients will survive and return to a productive life. The primary role of management consists of supporting the patient during the acute stage of the illness to allow recovery to take place. While important, manipulation of the disease process itself to accelerate recovery, should not take precedence.

Supportive care:

Once the diagnosis is established a patient with GBS needs to be managed in a hospital setting. Not all patients need to be managed in an intensive care unit (ICU) but such facilities need to be available. The primary needs are the ability to monitor cardiac rhythm and respiratory function. Ideally heartbeat, blood pressure and oxygen saturation (the amount of oxygen in the blood) should be continuously monitored since these constitute the greatest risk during the first 24-48 after the onset of the weakness. If there is fluctuation of blood pressure, an irregular heart rate or reduction of oxygen saturation immediate admission to the ICU is essential for medical management. Similarly, breathing function needs to be assessed, not continuously but frequently, and if it is declining admission to the ICU is essential in case artificial ventilation is needed. With meticulous supportive care of cardiac and respiratory function about 95% of GBS patients will survive even without specific treatment of the disease state as outlined below.

1. **Management of breathing:** About 25%-30% of patients will develop abnormalities of respiratory function but not all of those will require artificial ventilation. If artificial ventilation is required a tube is inserted through the nose and passed into the trachea (windpipe) and a machine pumps air into the lungs. If artificial ventilation is required for more than about 48 hours a tracheostomy will be necessary; a tube is inserted through in incision in the lower part of the neck just above the breastbone. Artificial ventilation can be continued indefinitely until the muscles of the diaphragm recover sufficiently to support natural breathing.
2. **Management of cardiac function:** If serious abnormalities of heart rhythm occur medication to stabilize it or even a temporary pacemaker may be needed but this is very rare. Marked fluctuation of blood pressure may occur but seldom needs treatment. However, awareness of the risk of a severe fall in blood pressure when the patient first gets out of bed is important; many patients have becoming dizzy and fallen or even blacked out completely when first taken to physical therapy.
3. **Management of bowel and bladder function:** Bladder problems are common in GBS and most patients who are unable to walk will have a catheter placed in the bladder. Incomplete bladder emptying increases the risk of infection as does the presence of a catheter and this needs to be carefully monitored. A high fiber diet should be given to those still able to eat and limited use of laxatives may be necessary to prevent constipation.
4. **Preventing blood clots:** Blood clots may form in the veins of the legs and pelvis of patients who are unable to walk and these may travel to the lungs causing the life threatening condition of pulmonary embolism. To reduce this risk such patients will receive injections of low dose heparin, a blood thinner that reduces clot formation.
5. **Pain management:** Pain management during the early stages of GBS can be challenging. Inadequately controlled pain obviously can have a major impact on the comfort of the patient and can also exacerbate autonomic instability, leading to potentially serious heart rhythm and blood pressure problems. However, effective treatment of pain may necessitate medication that can further suppress breathing function in patient in whom it may already be compromised. The patient and family member must be made partners in this decision. Some patients may choose to tolerate the pain rather than risk having to go onto the ventilator. Simple analgesics such as ibuprofen, naproxen or paracetamol may be tried but are seldom helpful. If the pain is of sufficient severity to need medication some form of narcotic such as morphine or its derivatives will usually be necessary and it is these medications that can suppress respiration. Medications such as amitriptyline and gabapentin

that are used to treat the chronic neuropathic pain that sometimes follows the acute paralysis (see part 2 of this series) can also be tried and may be helpful but are seldom sufficient on their own.

6. **Rehabilitation:** The process of rehabilitation begins at the earliest stages of the disease. When the muscles are extremely weak this may consist only of passive movement to ensure that flexibility of the muscles and joints is maintained until the nerves recover their function. Later, more active movement will be incorporated into the physical therapy program. Occupational and physical therapists are amongst the most important members of the GBS management team and participate in care from the ICU all the way to discharge home and even beyond.

Treatment of the disease process:

GBS is an autoimmune disease in which antibodies attack the peripheral nerves. Treatment of this abnormal immune attack was initially tried with steroid medications such as prednisone but subsequent research showed that this was ineffective. In fact, patients who received steroids fared slightly worse than those who did not. Steroids have many side effects and should not be used in GBS. Paradoxically, they can be extremely useful in CIDP as will be discussed in a later installment.

In the early 1980's plasmapheresis(PLEX) was tried and several large studies confirmed its benefit. Experimental studies in animals showed that there was an antibody in the blood of patients with GBS that could produce inflammation and nerve damage when injected into the nerves of animals. It was postulated that removal of the antibodies by PLEX should accelerate recovery in GBS patients.The early studies done in Europe and the United States showed that patients who received this treatment spent less time in the ICU and less time in hospital than those who were not treated. PLEX quickly became the standard of care for GBS patients, at least for those with impaired ability to walk. The PLEX procedure consists of inserting a large catheter into a vein, usually in the region of the neck. Blood is withdrawn and run through a machine that separates the cells from the plasma. The cells are then returned to the patient along with donor plasma or a synthetic plasma substitute. Since the antibodies reside in the plasma fraction, they are removed and can no longer attack the nerve and the natural process of healing can begin sooner, leading to more rapid recovery. Unfortunately, PLEX does not affect mortality or the degree of recovery, just the rapidity of recovery.

In the early 1990's PLEX was largely superseded by intravenous infusions of immunoglobulin (IVIg). Immunoglobulins are the proteins in the blood that include antibodies, such as those attacking the nerves in GBS, and Igis derived from donated blood plasma. The exact reason this treatment works is not entirely clear but it is thought that the antibodies in the donated Ig bind the harmful antibodies that the GBS patient is producing, thus preventing them from attacking the nerves. Experimental studies in patients with GBS showed that IVIg was at least as effective, possibly superior to PLEX. The main advantage of IVIg over PLEX is ease of administration and patient tolerance. IVIg can be easily administered through a vein in the arm and does not require expensive equipment. Also, PLEX can occasionally worsen the heart rhythm and blood pressure abnormalities and this does not occur with IVIg. IVIg is administered at a dose of 2 gm/kg divided into daily doses given over 5 days. Anecdotal evidence suggests that some patients who remain very weak after the first dose of IVIg may benefit from a second dose. A small study failed to confirm that benefit but larger studies are planned.

Antibody attack on the nerve requires a chemical from the blood called complement and it has been suggested that inhibition of complement may reduce injury to the nerves and speed recovery. There are complement inhibitors available that are safe and further studies are planned to determine whether they can improve outcome and are more effective than IVIg or can be used as supplementary treatment.

Not everyone with GBS needs to be treated. None of the studies included patients who were still able to walk; prognosis in these patients is so good that the risks of the treatment, even though they are small, are not justified. If a patient is still able to walk but is progressing rapidly it is not wise to wait until he cannot walk to start treatment. Patients with the Miller Fisher form of GBS, a rare variant that affects the eyes and balance but does not cause weakness, also do not need to be treated unless the balance is so bad that they cannot walk safely because prognosis is so good without treatment.

Guillain-Barre Syndrome -
How is it treated and what is the outcome?

It is important to start treatment as early as possible. Treatment administered more than two weeks after the onset of weakness is probably not effective and even treatment given between one and two weeks after weakness onset is of questionable benefit. This is why early diagnosis is so important.

Long term outcome with GBS:

From its earliest recognition as a distinct disorder, the excellent prognosis of GBS has been repeatedly emphasized. It was this good outcome that led Guillain and colleagues to recognize that is was distinct from polio. In all GBS patients progressive worsening of the paralysis stops within 4 weeks of onset. There is then a period of plateau that may last a few days to a week or two and then improvement occurs. In rare cases, complete recovery may be seen within a few weeks but more commonly there is a slower return of function of many weeks or months. Sensation is not as severely affected in GBS but paradoxically, if it is affected, it recovers more slowly. Reflexes are the last to return but this has no importance for the GBS patient; it is simply a sign for the neurologist to assess. Autonomic abnormalities are short lived, usually resolving within the course of an acute hospital stay.

The excellence of the prognosis has probably been a little exaggerated. Compared to polio it does have a superb prognosis since recovery from severe paralysis in polio never occurs. The majority of GBS patients, about 70%, do return to normal strength. Many of these do actually return to fully normal function, returning to all former physical activities and employment. However, some will be found to have subtle residual findings on careful neurological examination and the nerve conduction studies may remain abnormal. These subtle abnormalities may have important function consequences; some elite athletes have been unable to return to their former level of athletic performance despite apparent full neurological recovery. Residual fatigue in patients who have fully recovered strength also is a problem. One Dutch study showed that about 80% of their GBS patients had residual fatigue that persisted for years. Our own much smaller study in Minnesota indicated that about 60% had residual fatigue. Some of the patients in both studies did have residual weakness and sensory loss as well but some seemed to have completely recovered their neurological function but were limited by fatigue. The basis for residual fatigue is unknown and unfortunately it does not respond well to stimulant medications. Weight loss and conditioning exercises do seem to be of benefit. It is important to ensure that residual fatigue does not have another cause. Depression may manifest only as fatigue and is quite common after GBS. Many systemic illnesses such as anemia, low thyroid function, diabetes, etc, can also cause fatigue. Although GBS does not increase the risk of these disorders they should be considered as they may be treatable. Sleep disorders are also quite common and may contribute to fatigue.

What about the 30% of patients whose neurological function does not return to normal? Firstly, some patients (about 5%) still die from the complications of GBS, usually pneumonia or pulmonary embolism but a few from heart rhythm disturbances. Others improve but do not ever return to normal. These are patients whose GBS was severe, almost always with severe associated axonal degeneration (see part 1 of this series). Many are completely paralysed and ventilator dependent at the lowest point of their illness. Even in these severely involved patients some recovery occurs and it may be quite dramatic but is slow and incomplete. Cranial functions such as facial strength, speech and swallowing almost always recover although mild facial weakness may persist. Breathing also always improves; in 40 years I have seen only one patient who remained on a ventilator after 2 years. Limb strength improves more slowly and to a smaller extent. Proximal muscles, those closest to the spine, recover before the muscles of the hands and feet. Persistent foot drop is the commonest residual effect. Loss of sensation in the feet and, rarely, in the hands may also persist. One of the most distressing residual symptoms in these severely involved patients is pain. This is both the neuropathic pain that arises from the nerve damage and pain from joints and surrounding structures due to overuse and instability because of the weak muscles.

The degree and rapidity of recovery is directly related to the severity of the initial weakness and the severity of the axonal degeneration and these can be accurately assessed at the time of the initial illness. Thus, it is possible to predict at that early time where an individual patient is going to be in 1-2 years. However, it is not always wise to provide that information to the patient when they are still trying to deal emotionally with a life changing event. Also, these predictions are not always correct. I recommend that emphasis be placed on the almost invariable improvement and address the degree and timing of improvement during the period of rehabilitation.

NOTICE BOARD

Support Kathy Eggers when she competes in the

Taupo Ironman

March 2013

WANTED

We are looking for a name for our magazine.

Have you any novel, exciting ideas?

If so send them in to the Secretary Tony Pearson.

His contact details are on the front page of the magazine.

Bay of Plenty / Waikato Coffee Group.

Venue: Robert Harris Coffee Shop Matamata. Across the road from the Information Centre. Easy access.

Date & Time: Friday 18th February 2013 at 12.30

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Have you made or found a device that helps with day to with other members.
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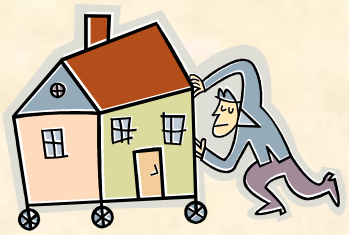

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We thank you for your continued support.

GBS BI-ANNUAL CONFERENCE 2013

FRIDAY 26th April 2013 to SATURDAY 28TH APRIL 2013
Brentwood Hotel Wellington

Get your registration in today and be part of this wonderful event and gain a better understanding of GBS/CIDP and the road to recovery.

Guillain-Barre Syndrome Support Group of New Zealand

CONFERENCE PROGRAMME

April 26 – 28, 2013

Brentwood Hotel, Kilbirnie, Wellington

FRIDAY 26 April

2-00pm Training for Hospital Visitors and Local Coordinators
4-00pm Registration
5-30pm Wine, Cheese and Chat with conference members
(Own arrangements for dinner)

SATURDAY 27 April

8-30am Official Welcome and Conference Opening by Steve Chadwick, Patron, followed by Presidential welcome to the Members of the Medical Advisory Board.
9-00am Keynote Address: Gareth Parry: GBS Overview

9-45am **Morning Tea**

10-15am Keynote: Annette ICU
10-45am A personal encounter with ICU: Lil Morgan
11-00am Keynote Address: Suzy Mudge: rehabilitation
11-45am A personal encounter: rehabilitation

12-00noon **LUNCH**

1-30pm Keynote Address Michael Baker: campylobactor
2-15pm A Personal Encounter
2-30pm Keynote: pain

3-00pm **Afternoon Tea**

3-30pm Keynote: fatigue
4-00pm A personal encounter with pain and fatigue: Pralene
4-30pm Ask The Experts

7-00pm **Conference Dinner (optional)**

SUNDAY 28 April

8-30am Meeting of the Trust
8-30am Meeting of the Medical Advisory Board
9-30am AGM of the New Zealand Support Group

Organised by the Guillain-Barré Syndrome Support Group of New Zealand Trust
Enquiries to Bob Stothart **stothart@ihug.co.nz**
Registered Charity No CC20639
www.gbsnz.org.nz

REGISTRATION FORM

Guillain-Barré CIDP Conference
Friday 26th April – Sunday 28 April 2013

Name……
Address……
……
Phone……..
Email…….

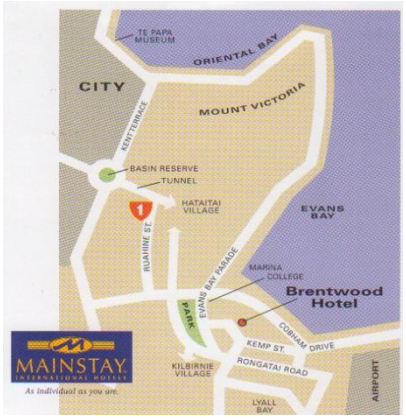
Please enclose registration fee with this form and post to: Tony Pearson, Skylark Ridge, 113 Weka Road, Mairiri, RD2, Upper Moutere, Nelson, 7175

$100.00 full registration……
$80.00 for Saturday only……..
$50.00 for second person in a family……
$30.00 for full-time students…….
$40.00 for conference dinner, this is optional…….
TOTAL $……

A $20.00 late fee will be required for registration after 12 April 2013

Make cheques payable to Guillain-Barré Syndrome Support Group and cross, Not Transferable

Reserve your own accommodation, quote reference73929 and mention GBS Conference to get special rates at the Brentwood Hotel. (Phone: 04 920 0400). Please specify any disability requirements.



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INVOICE

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Subscriptions for membership of the Group for the financial year commencing on 1st December 2012 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.

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