

Guillain-Barré Syndrome

SUPPORT GROUP NEW ZEALAND TRUST

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NEWSLETTER SEPTEMBER 2012

If undelivered please return to:

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Editors Note



Thanks to everyone for their contributions to this magazine. I think you will

all enjoy this months' read. In fact I believe it will take you longer to read than it takes me to read our local paper.

The conference looks to be an actioned packed event with many keynote speakers confirming their attendance. It is also a great opportunity to meet and talk with fellow sufferers and renew friendships so I hope that many of

you will take the opportunity to attend. The registration form is enclosed in this newsletter and is available on the web site.

<http://www.gbsnz.org.nz/conference>

We have had a few new cases of GBS reported to us and Jenny has been able to provide them with information and contacts to help them in their recovery. It is partly due to the subs you pay that makes these resources available so if you haven't joined or renewed I would just like to remind you to do so, so that we as a group can continue to help those that get GBS/CIDP.

I am trying a new print layout so would be interested in your feedback. Those who get the newsletter by email will not notice a change. All in an attempt to improve the magazine.

As always I would love to receive the story of your GBS/CIDP journey so put pen to paper and send it to me.

Last but not least, this will be your last newsletter if you are not financial.

Chris



Presidents Paragraph:



It has been suggested that this Newsletter

should have a more 'catchy' name. Jenny Murray began the Newsletter as a means of keeping people informed, of publishing people's personal stories of their encounter with GBS and she did a great job in gathering bits and pieces of news and information and posting it out to us. It was greatly appreciated by all recipients. The role of Editor was passed over to Chris and she has expanded the content while maintaining the basic news and information about GBS in New Zealand. I have always thought that Newsletter is a rather ordinary name for this vehicle of communication. Could we not come up with something a trifle

more catchy? The American organisation calls their newsletter, The Communicator and our British friends call their magazine Reaching Out. We have endless possibilities for a name: Aspirations, Korero, Inspirations, The Myalin Sheath, Connections and more. So here is an opportunity for fertile and creative minds to come up with suggestions, so get your thinking caps on. Inundate me with ideas; fill my emails with wonderful, quirky, apt and or totally appropriate suggestions for a name. I'll cogitate upon these and invite the Board members to vote for their preferred option, so go to it.

Keep saving for the Conference being held in Wellington, next April (details elsewhere in this

Newsletter). We have worked really hard to assemble a great list of presenters and to make the conference accessible to everyone. I know we live in tough financial times and our planning has taken this into account, keeping costs to an absolute minimum. You will benefit from attending. I say that without reservation as the gathering of up-to-date information about GBS/CIDP, the talking to people with similar afflictions, the renewal of friendships and the general feeling of goodwill is a powerful therapeutic balm. Be there if you can.

Bob

Secretary's Jottings



Watching the news over the last few

evenings and seeing our Prime Minister in his "silly shirt" with the other Pacific Forum leaders in the Cook Islands I was prompted to wonder if GBS/CIDP is something Cook Islanders suffer from and, on a wider scale back here in New Zealand, I wonder if we have any idea of the incidence of our Syndrome amongst Maori and Pacific Islanders resident in NZ? We don't have an "ethnic background" as part of our membership data base but just basing an assumption on surnames I would say that at least 95% of our members are "Pakeha". I suspect the statistics do exist somewhere in Hospital records but - if my own experience of trying to extract GBS statistics from our own Nelson Hospital is anything to go by - it would take a mammoth research project to acquire the data.

I don't know about anyone else but I really enjoyed the articles in our last Newsletter from members of our MAB - very readable for a layperson. We have yet to realize I think what a terrific resource we now have access to in the MAB. GBS as we all recognise affects everyone differently and whilst I am sure there are many classic presentations of GBS and CIDP it seem to me that increasingly they manifest themselves in more complicated ways leading to slow diagnosis or complications in the recovery process. It is in just such situations that being able to access the experience and expertise of the MAB may bring some clarity and comfort to new and ongoing sufferers. We are in the process of developing a protocol for MAB access but in the meantime if you or any of your friends or family are

concerned with or confused by a GBS situation that does not seem to fit the "normal" pattern contact Jenny or any member of the Board with your concerns or question and you can be sure it will be passed on to the MAB. Vivienne and I manned a GBS stand at the Nelson Brain Day back in July - it was nothing like as hectic as we have heard the Auckland and Wellington events were but we were able to hand out a fair number of information pamphlets and to exchange some useful ideas with other volunteers manning their respective stands - I am biased of course but I thought our stand was the best "presented" with our striking banner and smart table cloth!

We do not have a resident Neurologist in any of the Top of the South Hospitals at present (only Gareth when he is back in Nelson) and so have to travel to Wellington or Christchurch or line up for the next visit of an Auckland Neurologist who comes to Nelson once in a while however I have managed to establish the names of the most "active" players in both Marlborough and Nelson Hospitals who deal GBS cases and have delivered a full set of information pamphlets to them together with contact cards with a request they be passed on to their GBS and CIDP patients - only time will tell if they assist.

Conference 2013 flyers are now about and Registration is open. I for one intend to "sign up" for the Friday afternoon Hospital Visitor training session - I have done quite a bit of Hospital visiting but having some guidelines on approach and content of a visit will be good. If you have a mind to volunteer for Hospital visiting - and it can be a very rewarding experience - then this session is a must.

On the day to day operations front the development of our new look website is progressing slowly - due mainly to tardiness on my part rather than any lack of activity on Lil Morgan's as she has already put in a great deal of work on structure and content. I understand the importance of having a great website - I just find it difficult to get my mind around the technical concepts of establishing it. Our annual registration with the Charities Commission has been accepted along with details of Board changes. A fair number of new financial membership have been recorded as people indicate their wish to continue to receive the Newsletter and keep in contact with the Group (remember this Newsletter is the last non financial members will receive!)

As always
Take care

Tony



My GBS Experience - Jan Gribble

Written March 2012

Three months from the onset of GBS, I managed to cut and file my fingernails. A big deal for me as it meant that I could hold and use scissors and a nailfile. My hands are still like tingling hacky sacks but at least I can do something all by myself. I can also shower and dress myself with someone near at hand. Buttons and necklaces are still a challenge. The nerves in my face are still painful so always give gentle hugs to a GBS patient.

My encounter with GBS began before Christmas, 2011. Life was good. I loved my job as a teacher and had holiday plans of getting the house and garden shipshape plus doing beadwork. My sister-in-law was having the family Christmas in Auckland and my job was to make the pudding. We were planning a trip to England to meet a new grandchild, due in May. All was to change. I ignored a few warning signs such as tingling feet, trouble getting up from kneeling, aching muscles and joints plus walking crookedly. I also started sleeping during the day. I put it all down to 'flu or "end-of-termitis." I had a shower on Sunday 18 December. I was aching everywhere and I was pleased that I had made a doctor's appointment for Monday. Once dressed, I cleaned my teeth and found that I could not spit. I looked in the mirror and found that my whole face had twisted and was paralysed. I had no frown or smile, nor could I close one eye. Our country town has no weekend Doctor so I rang the triage nurse who told me to go to Anglesea Clinic in Hamilton, 32 Kms away. The Doctor there saw me straight away as they thought I might have had a stroke. From there I was taken to Waikato by ambulance. The Doctor there was terrific and tried every test she could think of plus a head scan and chest x-ray. She then admitted me and referred me to a neurologist who saw me on Monday. He suspected GBS as I admitted to a throat infection a few weeks previously. This diagnosis was confirmed by a lumbar puncture and an electro conductive study. Treatment was started that night with over three hours of intravenous immunoglobulin and continued over the next four nights. By now, family and friends were learning a lot about this previously unknown syndrome. My speech was slurred and my blood pressure very high. I was being carefully monitored for any sign of lung or heart collapse. It was becoming obvious that this was a long term illness. I slept a lot, ate soft food and sometime after Christmas Day, I was transferred to Ward 58, the Rehabilitation Ward. My legs sometimes buckled and on one fall I twisted an ankle.

A turning point for me was when the Physiotherapist arranged for me to have a visitor whose symptoms were far worse than mine. Marilyn suggested hydrotherapy. I asked the Occupational Therapists who asked Physios who asked Doctors and back down the line until permission was granted and appointments made. At last I could move limbs and stretch muscles in the water. Progress was made when I

could move my legs and sit up on the side of my bed. Also I could read a little once I could separate pages. Right from the third day I was determined to knit a shawl for my new grandchild. I had put the pattern and wool out ready to start in the holidays. To compensate for the lack of fine motor control in the fingers I just used bigger needles. I think I fell asleep about every 5/10 stitches, but this really helped my hands. I built up upper body strength doing lengths of the corridor in a wheelchair. When asked what my goals were my seemingly frivolous but heartfelt reply was to spit and smile which did happen. My face came back first. Not only could I smile but I could close my eyes and speak properly. My forehead remained frown free for longer but I finally felt like "Me. I will never forget hearing a friend's stricken whisper to another friend "Was that Jan?" when I was wheeled past her in the early days.



Everyone has a different GBS story and I am telling mine in the hope it will help someone. For example, I still have trouble with hot food and liquids. I must be the only person who has been cold all the time this summer, especially my hands. After ten weeks I was finally able to roll over in bed. After 12 weeks I still have numb "fencepost" legs especially when I am due for a rest. They always tingle and are often cold. Despite numbness, my feet and hands are quick to feel pain.

Any small item in my shoes or slippers causes pain as does catching my fingers on anything. Just like "The Princess and the Pea" pain is magnified. My back tightens by the end of the day and I feel as if I am clamped into a turtle shell. If I start to overdo things I get a headache, stabbing pains in feet and hands and my ankle swells. I rest with my feet up and recharge my batteries.

I came home after almost nine weeks in the hospital and had support from the START programme. I have appreciated the visits and support with showers and exercises. A real frustration has been being isolated on a farm and relying on family to get items. After three months it is a treat to go anywhere but it is very tiring meeting people and catching up. I can now write my signature and do legible writing and printing.

My goals for six months are to be back driving a car and to be back at work. Instead of me attempting overseas travel, all of the family are coming home for Christmas and a beach holiday. Here's hoping both the weather and Christmas will be better than last year. The hardest part of having GBS is explaining what I have to people. I now look well and most folk have no understanding of the fatigue factor.

At least I now have the need, and time to put my feet up. To do otherwise will delay recovery. My choice is to progress as much as I can taking the fatigue factor very seriously.

My GBS Experience - Memorable Moments and Intimate Incidents.

By Gordon Stephenson

My 81st birthday October 2005

10 days later, wobbly legs, and off to Waikato hospital.

Total and complete paralysis, eyes shut, unable to breathe, heart stopped twice.

Brain in a haze, but incredibly vivid hallucinations.

Shocks like my farm electric fence unit, administered by my friendly sadist neurologist who is now a member of our GBS advisory panel.

Wife and family incredibly devoted to a non-responsive body. The strange state of zero communication, later overcome by itching my left hand.

In and out of ICU and HDU. Devoted nurses whom I am unable to even see. They even removed my beard without my knowledge!

Jibbalani, Nigerian physio, moving my limbs with infinite care.

Strong hands turning me in bed.

Hoisted vertically in a harness, and seeing this sack of apparently water-filled skeleton dangling below.

My first bath in a water filled stretcher.

This remains a mystery, but I somehow indicated to the ICU nurses that what I longed for was to see grass and trees again. A troop of nurses, bless them, wheeled me out with all my tubes and bits, to be in the sun under a tree. Just at that moment the family arrived, and said 'that can only be Gordon'

Into a ward to start recovery, and restless nights.

10 weeks after admittance, into the Rehab Ward. Wonderful treatment, so positive.

Christmas, and the ward nurses gave up their own private room for my family to celebrate with me.

Work work work. Wheelchair. Almost sweating to move along corridor.

Walking is so complicated. Even swallowing had to be taught.

Swimming and meeting Meike Schmit there, she is now on the GBS committee.

Family taking me out in wheelchair to visit Hamilton Lake. Watching toddlers there learning to walk, making it look so easy.

Falling is no worry for them Opening a conference at Waikato University being wheeled on stage in my chair.

After nearly 6 months, ready for home.

Kind friend put up hand rails in all critical places in the house.

My wife Celia wheeling me between bedroom and sitting room, via our lawn, because the house has three sets of two steps between levels.

Being tipped out of wheelchair one evening as we entered French-doors into bedroom, in the rain. Hilarious efforts to get this useless body onto the bed.

Celia having to see to all body functions. The huge burden placed upon her. Daughter coming to help with shower. Using hair dryer to dry and warm body.

Our spare room converted to a 'gym'. Mornings spent there on floor lifting 'domestic weights' and standing on a bouncer holding rails. The effort. Two hours sleep after.

Slow recovery. Crutches. Walk 10 metres and return. Then 20 metres days later. Slowly putting the distance up.

Being helped on to the farm quad for my first ride on the farm.

In fear and trepidation, taking a driving test after 15 months and passing. But automatic only, not manual and not a good driver.

Unable to do up laces for 5 years.

The need to wear track pants because fingers will not undo fly zips.

Cleaning teeth only possible with left hand till last year.

Still unable to do up buttons. Celia releases me from my shirt each evening.

Walking any distance needs my two trusty Leki Sticks.

Typing takes as long to correct as to actually type.

Looking drunk when walking.

Out blotto for one hour after lunch. Bliss!

Balance is stupid, hopeless at night, can trip on a blade of grass.

Courtesy and kindness shown by everyone to a rather dodderly old man. Even the traffic stops.

In spite of everything, living a very full life. Too much to do to indulge in any self pity.

You have to laugh!



Gordon (right) chats with Dr Gareth Parry at the 2011 Conference

Line-up of experts to address GBS national conference

By Maria De Cort

The sixth national conference organised by the Guillain-Barré Syndrome Support Group of New Zealand will be held from 26 to 28 April 2013 at the Brentwood Hotel in Kilbirnie, Wellington.

Guillain-Barré Syndrome (GBS) is a rare autoimmune disorder, where the body's own immune system turns on itself and attacks the peripheral nervous system causing temporary muscle weakness, sometimes to the point of severe paralysis, sensory loss and pain. Often triggered by a preceding illness, GBS has an incidence of 1-2 people per 100,000 or about 40-80 New Zealanders a year. CIDP is a chronic or ongoing neuropathy that closely resembles GBS.

Three members of the recently established GBS NZ Medical Advisory Board (MAB) will present keynote addresses at a conference.

The national support group's new advisory board is headed up by long-time medical advisor for the GBS NZ support group and a world authority on Guillain Barré Syndrome, Dr Gareth Parry. The New Zealand-born neurologist, who is Professor Emeritus of the Department of Neurology, University of Minnesota, USA, has studied GBS and its variants for the best part of four decades and authored two books on GBS, one for neurologists and one for patients.

Dr Parry is joined on the MAB by Dr Suzie Mudge, Neuro Rehab Results Director and physiotherapist, and senior lecturer and researcher in the Health and Rehabilitation Research Institute, AUT University; Waikato Hospital neurologist and neurophysiologist Dr Chris Lynch; Auckland City Hospital neurologist with a subspecialty interest in peripheral nerve diseases Dr Dean Kilfoyle; ICU consultant Dr Annette Forrest; and Pathology Registrar at Auckland District Health Board Dr Pralene Maharaj.

Drs Parry, Mudge and Forrest will all give keynote presentations at the biennial conference.

The biennial conference is for people with Guillain-Barré Syndrome (GBS) and its variants such as Miller-Fisher Syndrome, acute motor axonal neuropathy (AMAN) and others as well as patients with chronic disorders such as Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) and related disorders.

The 2013 GBS/CIDP conference is open to current and former GBS/CIDP patients, and their families and caregivers. It will also appeal to neurologists, physiotherapists, occupational therapists, nurses and general practitioners.

The conference, which will be officially opened by former MP Steve Chadwick, Patron of GBS New Zealand, includes a keynote presentation by Associate Professor Michael Baker from the University of Otago, Wellington based on his world-first study looking at the link between campylobacter and GBS. There will also be presentations by former patients, an experts' forum with Q & A time, a hospital visitors' training workshop and group discussion sessions.

For more information or to register visit the GBS NZ Support Group's website at www.gbsnz.org.nz.



Attendees at the 2011 conference take part in the popular Group discussion session.

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: campylobacter
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-Barre Syndrome Support Group of New Zealand Trust
Enquiries to Bob Stothart stothart@ihug.co.nz
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Guillain-Barre syndrome – How is it diagnosed?

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

GBS is generally easy to diagnose once the diagnosis is considered. There are very few acute paralytic illnesses that occur in this era, at least in developed countries. The characteristic clinical syndrome of acutely evolving weakness, often preceded by sensory symptoms presents few diagnostic challenges. The clinical findings of weakness and loss of reflexes usually clinches the diagnosis. Mild cases may elude diagnosis but probably little harm results from that. Perhaps the greatest concern is the possibility of delayed diagnosis. A patient presenting with nonspecific sensory symptoms as outlined in Part 2 of this series may be reassured that nothing serious is going on and may neglect the subsequent development of weakness until it is severe. Since treatment is most effective when administered early this may result in a poorer outcome than if treatment had been started promptly.

The tests that are done to establish a definite diagnosis are nerve conduction studies (usually referred to as EMG) and examination of the cerebrospinal fluid (CSF) obtained through lumbar puncture.

Nerve conduction studies and electromyography:

Peripheral nerves are simply biological electrical cables that transmit information from the brain and spinal cord (the central nervous system or CNS) to muscles, and from skin and other sensory receptors back the CNS. The electrical cable is known as the axon and like any electrical cable, an insulating sheath is needed for the system to function normally; without insulation the electrical current will diffuse away from the axon and conduction failure will result. In nerves the myelin sheath constitutes that insulation. In most cases, GBS is a disease in which an immune (inflammatory) attack is mounted against the myelin sheath causing demyelination. The loss insulation causes abnormal conduction of electrical signals. In severe cases conduction is blocked completely; the electrical impulse travels part way along the nerve but fails completely at a site of demyelination. In less severe cases the impulses do get through the area of demyelination but do so very slowly. Thus, the two electrophysiological hallmarks of demyelinating GBS, the commonest form, are conduction block and conduction slowing. These abnormalities can be demonstrated in patients through the technique of nerve conduction studies (NCS). GBS also damages axons, either as a secondary phenomenon or, less commonly, because the axon is the primary target of the inflammatory attack (as described in the first two parts of this series). The prognosis for recovery in GBS is primarily a function of the severity and extent of axonal injury. NCS, supplemented by electromyography enable assessment of the degree of axonal degeneration.

NCS are done by delivering electrical shocks at one or more sites along the course of the nerves. Because GBS is a patchy disease, at least in its early stages when NCS are most important, several nerves may need to be studied, focusing on sites of maximal weakness. Because GBS is mainly a motor disease, affecting strength much more than sensation, NCS focus on motor nerves. Shocks are delivered to the nerve from the surface of the limb and the electrical response is recorded from the muscle it supplies. The response is amplified and displayed on a screen. The instrument (electromyograph) measures that time it takes for the response to travel from the site of the shock to the muscle and the examiner measures the distance so that speed of conduction can be calculated.

Conduction speed is normally greater than 50 meters/second in the arms and 40 meters/second in the legs but in GBS affected nerves will usually conduct at speeds below 30 m/s. The size of the response is also measured at each stimulus site. If the size of the response elicited by stimulation at a site close to the muscle is much bigger than the size further up the limb this indicates that some of the electrical impulses are blocked between the two stimulus sites (conduction block). If the size of the response elicited by stimulation close to the muscles is reduced this indicates axon loss. It is sometimes more difficult to activate the nerves in GBS and the intensity of the electrical current needs to be increased, adding to the discomfort of the procedure. Occasionally the nerves are completely inexcitable, a particularly ominous prognostic sign. Thus, motor NCS in GBS are primarily done to confirm the suspected diagnosis and are expected to show conduction slowing and conduction block. Secondly, they give prognostic information; if the size of the response is less than 10% of normal and particularly if the nerves are inexcitable it is likely that recovery will be slow and incomplete and the patient will be unable to walk a year after the onset of the illness. Conversely, if the size of the responses is normal, even if weakness is very severe, recovery is likely to be complete and rapid.

Sensation is affected in GBS but sensory NCS add little to either the diagnostic value of the procedure or to prognosis. They are primarily done to exclude diseases that can mimic GBS.

The second component of the electrical testing in GBS patients is electromyography (EMG). The entire procedure is most commonly referred to as EMG. The true EMG portion of the procedure entails insertion of a needle into several muscles. The needle is simply a small aerial that records the electrical activity of the muscles when they are relaxed and when they are activated. It is of minimal use as a diagnostic test but

Guillain-Barre syndrome - How is it diagnosed?

Part Three Continued.....

can give important information about the degree of axonal injury and, therefore, prognosis. It is not usually done in the first 1-2 weeks of the illness because it takes time for the abnormalities to become manifest; this is why patients may be asked to return for further testing 3-4 weeks after the onset of weakness. If the patient is already improving this part of the test may be omitted completely.

Although NCS and EMG testing is always uncomfortable and is occasionally very painful it is completely harmless. There is no damage to the nerves or muscles from the procedure and, apart from some mild aching at sites of stimulation or needle insertion, there are no after-effects.

Lumbar puncture:

Few procedures in medicine are more replete with horror stories than the lumbar puncture (LP) but these stories are largely urban myths. Reports of infection (meningitis) from the procedure are greatly exaggerated and rarely, if ever, occur in the modern era. Significant bleeding is equally rare. Reports of paralysis are simply untrue; LP is often done for diseases that cause paralysis and paralysis attributed to the procedure is, in fact, due to the illness for which the LP is being done. Even the reports of pain from the procedure itself are exaggerated. There is some discomfort but frank pain is rare and is seen mainly in obese patients and those with spinal arthritis or who have had spinal surgery. To do the lumbar puncture the patient lies on one side and draws the knees up as close to the chest as possible, leaning forward to hug the knees. This curves the spine and opens up the space between the vertebra, making the procedure easier. The skin over the lower back is carefully cleansed with antiseptic and local anaesthetic is injected. A fine caliber but long needle is inserted between the vertebra and advanced until it enters the fluid-filled space (called the caudal sac) surrounding the nerves as they emerge from the spinal cord. A few milliliters of CSF is removed for analysis and the needle is removed. Occasionally as the needle is advanced it will hit one of the nerves causing a sharp stab of pain that can be quite severe but is usually brief and disappears with repositioning of the needle. Thus, the procedure itself is usually no more than uncomfortable and somewhat anxiety-provoking.

The problem with the LP is the after-effects. About 25% of patients experience headache that typically comes on about 24-48 hours later. Mostly it is mild and responds to simple analgesics such as aspirin or paracetamol. Unfortunately about 5% of patients develop a severe headache which is much worse when sitting or standing and may be associated with nausea and even vomiting. The headache is due to low pressure in the CSF as a result of continued slow leakage of fluid through the puncture site. If this happens it may be necessary to do what is called a "blood patch". The patient's own blood is removed and injected into the area of the lumbar puncture where it congeals and plugs the small hole in the lining of thecaudal sac, preventing further leakage. Once this is done the headache subsides over a few days. The risk of this "post-spinal headache" can be minimized by meticulous hydration both before and after the procedure as well as caffeine; caffeinated soft drinks constitute simple way of achieving this. We also traditionally ask the patient to remain lying flat for 30 minutes or so after the procedure even though this of unproven benefit.

Since the lumbar puncture is unpleasant and occasionally causes severe headache what information is derived to make it worthwhile? The name "Guillain-Barre syndrome" was given to this disorder because of the almost unique findings seen when spinal fluid was analyzed. Guillain and his colleagues noted that the spinal fluid protein concentration was markedly increased while the number of inflammatory cells in the fluid was normal. The commonest paralytic illness of that era was polio and CSF analysis in polio shows only mild elevation of protein but a marked increase in the number of inflammatory cells. While polio is now rare in developed countries several other viral infections (most notably West Nile virus which is currently sweeping the United States) can produce a similar paralytic illness with the same CSF appearance as polio. Distinction of these disorders from GBS is important since management is different.

In summary, the diagnosis of GBS is usually straightforward once it is considered and can promptly be confirmed through EMG/NCS and LP. These are unpleasant but safe tests that can be done easily at all hospitals with a neurologist. Early diagnosis is important because treatment is most effective if administered early.



Getting back on track

By Pralene Maharaj

Pralene is a member of our Medical Advisory Board, and understands only too well the trials and tribulations of GBS. She will be a guest speaker at the 2013 Conference.



Saying that contracting Guillain–Barré Syndrome changed everything for me is the understatement of the century!

Like with many ambitious people in their 20s, I had mapped out my life and was well on my way to making those plans a reality. I was a doctor and had just been accepted on to a specialist training program. I had a great family and friends. I was financially stable, building the foundations of a good life, and everything was heading in the right direction.

And within a matter of days, I was lying in an ICU bed diagnosed with GBS, only able to blink my eyes.

Of all the emotions and thoughts going through my head as I lay there, these few stand out:

- The only place I wanted to be right then was my parent's house, because it was the safest place I could think of.
- I wanted to gulp down litres of iced water! In particular, iced water from the water cooler in the ICU that they'd dip my mouth swabs in!
- I would never again sit around on the couch and waste away hours that I could spend being outside, walking, running or dancing.
- I didn't want to be a doctor anymore.

As for the last point, I had a variety of reasons, which over time I realised were feeble.

The truth was that I was scared I would no longer cope with the physical demands of being a doctor given my disabilities; of not being as competent and efficient as I had been prior to getting GBS; of being compared to the fully mobile, able-bodied person I was; of patients' perceptions that a physically disabled doctor could not be as "good" as a "normal" doctor and subconsciously assuming physical disability goes hand in hand with intellectual disability.

However in spite of these fears, I couldn't escape the fact that being a doctor had been my dream since I was 2 years old, when I would go to my dad's practice and spend the day talking to his patients in the waiting room.

I was determined not to live a half-life, and not let this experience change the future I'd envisioned for myself, and which I'd worked so hard for. And even if I didn't quite get there, it would not have been from a lack of trying.

Easier said than done...and I knew there was a long and tough road ahead!

I put absolutely everything I had into my rehabilitation, setting progressive milestones, and pushing myself to achieve them (at times, along with a lot of whinging!). As it turns out, being an obsessive compulsive, A-type personality can be a good thing!

It's not an exaggeration that I had to essentially relearn basic activities all over again... like walking, speaking, eating, driving etc. The acts that had been second nature and which most of us take for granted were suddenly those which I found myself aiming to achieve again. Understandably, it was a tough, scary and often frustrating experience.

However, thanks to a determined and positive attitude, amazing healthcare professionals, incredible family and friends, and a good sense of humour (you have to laugh, especially at yourself!), I went from being completely dependent on everyone around me to getting back on track, and independent again.

On the professional front, the biggest hurdle that I've overcome was returning to work as a doctor at Auckland Hospital last year, the same place I'd spent 3 months on a ventilator in 2006.

And more recently, another achievement was finally returning to work at North Shore Hospital, which is where I had been working on the day I fell ill.

I arrived at my office at North Shore Hospital on this Monday morning a few weeks ago, and logged on to the computer system. I chuckled to myself to see my homepage exactly the way I had left it almost 6 years ago, with the list of patients I'd seen on my last day of work before I was admitted to the emergency department with GBS. As far as the computer system was concerned, it was just my next day at work... without any hint

Getting back on track

By Pralene Maharaj

of the enormity of what had happened between that day (6 October 2006) and this Monday morning (13 August 2012).

Obviously everything had changed, but equally at that moment, nothing had.

It actually was just my next day at work (with a bit of an adventure along the way to getting there). And I was so happy to be back!!

It isn't easy to wholly articulate the sense of accomplishment I feel. Returning to this hospital, and continuing my training after all the obstacles I've faced makes it a hugely rewarding achievement.

It's been great walking through the wards and passages and being stopped by people congratulating me on returning. Sure, there's the odd confused look when people see my walker

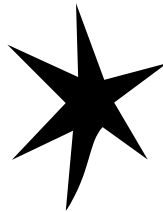
and do a double-take at my name badge. However, those moments are surpassed by the well-wishes.

In all honesty, some of the concerns I mentioned before about returning to work still occasionally worry me.

But the reality is that I now possess something that most doctors cannot ever completely have: true empathy; an understanding of the anxieties, the fears, the questions, the uncertainties, and the real impact severe long-term disability has on a life.

And I hope to apply that daily to be not just as good as I was previously, but better!

P.S Even now at age 32, Mum and Dad's house is still the best place to be!



Bay of Plenty members enjoyed another get together in June.

Back from left: Meike Schmidt-Meiburg, Lauren McBride, Deb Allison, Grant McKay, Chris Hewlett

Front from left: Rosemary McBride, Jan Gribble

Coming to Terms with GBS/CIDP and Seeking Financial Support from WINZ by John Mason

Having suddenly been told that you have either GBS or CIDP is a major shock in itself and of course this can cause further problems financially. All I want to do in this document is to try and pass on what I did and the support and help I got from my local WINZ office after being diagnosed with CIDP.

After my diagnoses, I had no idea what CIDP was, let alone how I was going to handle it and what possible pitfalls lay ahead. It became obvious within a short time that regardless of the problem I was in for a major increase in my weekly expenditure. I know that in one week alone I had two visits to my GP and three trips to my local hospital. At the time that was \$60 for my GP, \$9 for prescription and a total of 300 kilometres (\$60 for petrol) to get to and from the hospital. I had heard through the grapevine that WINZ did provide financial support to cover additional costs such as Doctors fees, prescriptions and travel costs.

Of course the biggest problem to overcome is one's own pride. At first, I did feel as if I was taking advantage of the system, but you have to remember that you have paid your taxes like most good citizens. The money you have paid for many years is really an insurance premium to cover you in the bad times. (There are more than a few people who rely on WINZ for money, they have not contributed to and expect society to provide for them). Any help you get is an entitlement, as you have paid for it over many years. A key thing with support from WINZ is that any benefit paid to a beneficiary is based on **“Actual Income from investments etc and not from Assets or the amount of money you might have in Investments”**.

To start with you need to make an appointment to discuss your situation with someone at your local WINZ office. I would suggest that you ask to talk with the person who deals with people who have disabilities or illness. I made the mistake of taking the first available person and had a bit of a run around. I was then asked to go back and talk with a person who dealt with disability/sickness beneficiaries. Now I always ask to see a specific person and if they try and put me onto someone else I state that I am not here to waste my time or the time of WINZ staff going through the details of my illness. Do not be put off by the official

attitude of some of the staff. You have to remember that they are dealing with all sorts everyday and they have to protect the public purse.

In my own particular case I was informed by WINZ staff that I was entitled to a disability benefit and allowance. At my interview with them they supplied me with the necessary forms and requested that I get the forms signed by my GP. My GP also wrote a letter to say that my wife was not in a position to work as I needed assistance at home to carry out some very basic tasks for me.

Knowing that I would be able to get financial support from WINZ towards my living costs made the weight of having CIDP easier to bare. Of course there are limits to the amount of assistance one can get, but anything, when you are ill and not capable of earning is a help. There is quite a range of items you can get assistance with, but you will need to discuss with your WINZ Case Manager what is appropriate for you. In my own particular case, I received a basic Disability benefit that was adjusted depending on the income my wife and I received from our investments. In addition to this we received a Disability Allowance and this was based on actual spend, averaged out over a year. There is a maximum payable on this allowance and will be up to a maximum of approximately \$60 per week. Since I started receiving the Disability Benefit and Allowance from WINZ my financial circumstances have changed on a number of occasions. Each time they do I make an appointment with my local WINZ office to discuss any changes to ensure that I am not overpaid or underpaid my benefits.

I have always found WINZ to be particularly helpful and the key to this is to be honest with them and ensure you have a good record of all income and expenditure. I have drawn up some basic forms for this purpose and keep them updated every time I see my Doctor, pay for prescriptions or drive to the hospital. In addition to these records I keep all receipts for Doctors and medicines and Hospital appointment cards. Keeping good records will ensure that your dealing with WINZ will be easier.

Further reading on help available from State Institutions is on our website. Click on the link below:

[http://www.gbsnz.org.nz/Support State Institutions](http://www.gbsnz.org.nz/Support%20State%20Institutions)

If you don't have access to a computer and would like a copy of this document contact The Editor.

Fit body, Fit brain

By MARGO WHITE

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Margo White is a freelance journalist.*

The evidence is compelling, says Professor Winston Byblow, Director of the Movement Neuroscience Laboratory at the University of Auckland; a good level of cardiovascular fitness will slow down the inevitable shrinking of the hippocampus. It's estimated that, once we're over 40, our grey matter depletes at a rate of around 5% each decade.

The benefit of exercise is not only evidenced in animal studies that have looked, in intimate detail, at the brains of rodents, but also (non invasively) in the observable changes in humans, either by measuring cognitive abilities, or through brain imaging techniques.

"The misconception is that if you don't want to lose your memory, you do crossword puzzles and Sudoku, but there's little evidence that doing those activities improves your cognitive abilities," Professor Byblow says. "It makes you better at doing crossword puzzles and Sudoku but there's limited evidence that there's much transfer."

However, there is strong evidence that swimming, running, walking the dog, even rigorous housework and gardening (anything that gets the pulse up for 30-45 minutes per day) will help preserve our executive function – that is, the brain's processing speed, the speed of our reactions, our ability to remember phone numbers long enough to dial them.

"We've seen this time and time again, in dozens of really good studies, with control groups in which half the participants do exercise and the other half do a controlled activity like stretching. And if you compare that evidence with say, cognitive exercises, overwhelmingly, physical activity has been shown to far outweigh the benefits of any of those training programmes. So I say to people, put down the crossword and pick up the dog lead."

What is less clear is why this is the case; exercise is a complicated physiological stimulus and it's difficult to identify the precise mechanisms involved. While it is possible that exercise promotes neurogenesis (the development of more neurons), the evidence is mixed and controversial, says Professor Byblow. Besides which, most physical and cognitive tasks don't rely on neurons alone, but having synapses fit enough to make connections between them.

What we do know, however, is that the brain requires a massive amount of oxygen and glucose. "The brain is a bit of a furnace. It consumes 20% of the oxygen the body receives, and 25% of glucose, but it's only 2% of body weight, so it's a pretty hungry organ."

We also know that, as we get older our cerebral blood flow decreases. Not so long ago it was thought that this was because, as we get older, we are less neutrally active so our brains don't need the same levels of oxygen and glucose. However, scientists now know this isn't the case.

"When you look at how the brains of older adults are functioning, and we can do that with fMRI scans (functional magnetic resonance imaging – the measure of brain activity by observing change in blood flow), the older adult brain shows greater activity to perform cognitive tasks at an equivalent level as a younger person", Professor Byblow explains. "There's more widespread activation".

Again, it is unclear what exactly this increased activation reflects. It's possible that as our ageing synapses become more sluggish, our brains compensate by calling on more areas of the brain. At least that's a theory. What we do know is that physical fitness – from swimming, running, walking – can make a difference of 17% in terms of blood flow to the brain which is equivalent, in terms of

blood-flow, of a 10-year reduction in your age. In other words, the circulatory system of the 70 year old with a high level of cardiovascular fitness would be that of the sedentary 60 year old.

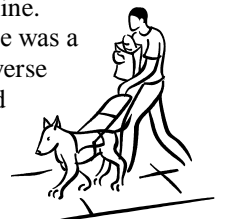
Perhaps it's time to reframe the idea that cognitive decline is directly related to how old we are, he says. "I think a more feasible working hypothesis, is that reductions in cognitive function and brain blood flow, aren't only related to age, but our level of physical activity – we tend to do less as we get older. But we've seen that in the key areas in the brain that are prone to shrinkage, exercise will not only slow the shrinkage down, but it can be even be reversed in older adults."

There is no evidence that exercise will protect people from a neurodegenerative disease such as Alzheimer's, which is still likely to be determined by our genes. But if exercise can't entirely outwit our genes, it seems it might stall them for a while.

"Carriers of the APOE gene which predisposes certain individuals to Alzheimer's, and even those with early Alzheimer's still derive benefits in terms of cognitive function from regular physical activity such as walking.

"Exercise is more a prevention than a cure – whether it's neurodegeneration or simply our memory starting to fail, what we've seen, time and time again, is that regular physical activity will, better than anything else we can find, slow the rate of that decline.

Let's face it, if there was a drug that would reverse brain shrinkage and help us maintain our cognitive abilities as we get older, chances are we'd be taking it. In this case the drug happens to be exercise".



Something from the Kitchen



CREAMY BROCCOLI MACARONI

120 gms Blue Vein Cheese Crumbled
120 gms Uncooked Macaroni
200 mls Low Pat Milk
3 tsp Cornflour
1 Chicken Stock Cube
1 Head Broccoli Florets (Blanched 2 Minutes)
1 Onion Diced Finely
1 Red Pepper Seeded & Sliced
1 cup sliced Mushrooms
1/2 tsp Minced Garlic
4 tsp Margarine

Cook macaroni in boiling salted water, drain and set aside.

In a large saucepan heat margarine, sautee onion, garlic, mushroom and red pepper gently.

In a small bowl, mix cornflour and milk together, add to onion mixture, crumble stock cube into saucepan, stir until thickened, add cheese, stir until cheese has melted, add broccoli and macaroni and stir to combine.

Pour mixture into a sprayed shallow casserole dish and heat in oven for 20 minutes at 180C.

A lovely accompaniment to crumbed fish.



Great Lake Taupo Cycle Ride



Terry Watton would like to organise a team of riders to do this event and raise the awareness of GBS in New Zealand.

It is held in November, so if you are keen please contact Terry



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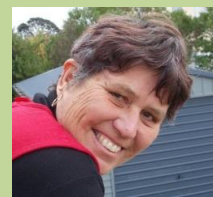
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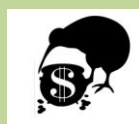
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**IF YOU HAVE A RED 'UF' ON YOUR ADDRESS LABEL
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Those NEW MEMBERS who join before the end of this financial year (30/11/12) will be deemed to be financial until 30/11/2013.

Your subscription (and it's only \$10) not only pays for the newsletter but enables the Trust to send information packages to new sufferers of GBS and many hospitals around the country.

Please continue to support GBS and post your renewal to the Treasurer today.



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Please send to the Editor.

E Mail: chrispy57@gmail.com or

Mail to Chris Hewlett

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Don't forget to
let the Secretary
and/or Editor
know your new
details.



Boy of Plenty Coffee Group.

Next meeting: Friday September 14th 10.30am

Venue: Villa Ridge Café – 528 Cambridge Road, Tauriko, Tauranga

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.

Wanted

Your personal story whether you be a sufferer or a caregiver we would love to hear from you.

Please send to the Editor.

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