Guillain – Barré Syndrome Support Group New Zealand Trust

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NEWSLETTER SEPTEMBER 2013

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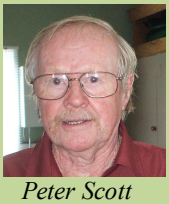
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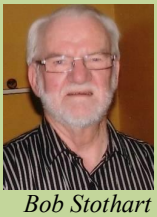
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Chris Hewlett

We welcome Kathryn Quick and Penny Sender to the Medical Advisory Board.

They graciously accepted Dr Gareth Parryôs invitation to join up.

Remember
If any members have any questions for the MAB please send them to the Editor and they will be forwarded on.

What's in your Magazine this month.....

Editor's Note

Winter has been very mild in the sunny Bay of Plenty and as far as we know there have not been too many new cases of GBS. That has to be a good thing.

Our coffee group seems to be going from strength to strength and it was good to see new faces at our August get together. Lil Morgan organized one in the Gisborne area. Sadly only one other person turned up but that has not daunted them and they are meeting again in October. Details further on in the magazine.

Rotorua was mentioned as an alternative site for the 2015 Conference so the Board would like some feedback from you, the members, if you would like to stick with the Wellington venue or try somewhere new. Personally I am all for giving Rotorua a try.

I need some more personal stories for the magazine. So someone please put pen to paper or flick me an email with your journey.

We always have a very long grace period for those people who havenôt paid their subs, but this will be the last newsletter you receive if you have fallen into that category. You will have a red sticker on the front of your magazine if you are currently unfinancial. Please continue to support the group and send your payment to our treasurer Peter Scott.

Our Face Book page has been growing in numbers lately, several new members being from overseas. Despite the growing numbers the actual postings donôt seem to be increasing so Iôm not sure how successful this site really is. Post some feedbacké é é .

So thatôs it. Enjoy the rest of the magazine and keep making slow and steady progress on the road to recovery.

Chris

Deaths

It is with sadness that we report the passing of two of our members, Barbara Wildbore and Jacquie Kerslake. Our sincere condolences to their families.

Presidents Paragraph:

I recently had the opportunity to visit one of my 7 sons who was teaching in Sichuan province in China. After spending a couple of days in Chengdu, a city of more than 14 million people, we traveled to his home in the remote town of Mianyang where there were only 4 million residents. The density and activity of such populations is amazing. As sometimes happens when you get away from your normal surroundings, you start thinking of how different life can be in different societies. The following facts made me think:

- Most people in China today do not have uncles, aunts, or cousins. This is because most are from single child families as were their parents.
- Although hospitals appear to be growing in number and quality, it is difficult for suffers of illnesses like GBS to quickly access the high level of care that we get in this country.
- When GBS suffers in China are in hospital or at home recovering, they generally do not have the level of family networks available for support that we do in New Zealand. Many children for example live at considerable distances from parents and may only have a working spouse to care for them in the rehab stages.
- A majority of Chinese live in apartment buildings. These buildings can be large and crowded according to our standards and ñgreenò areas are relatively few and far between. I saw a physiotherapist one day (I was lost at the time!) working with clients in a small park where they were practicing walking around a path one at a time with the physio holding on. A great sight but the temperatures were in the mid 40ôs!

So whatôs this all got to do with our support group? Can I suggest that despite all of the difficulties we seem to encounter with access to treatment, housing, family support and therapy, we should bear a thought for those GBS/CIDP suffers in other countries who are without some of the benefits we share.

Ken Daniels

Left to right: Shanti Singh, Jean White, Chris Hewlett, Judy Deed, Jan Gribble, Barry Deed, Christine Wilton, Meike Schmidt-Meiburg, Richard Wilton, Grant McKay, Fran McKay.

Secretary's Jottings

Have you had a look at the new website? www.gbsnz.org.nz ... really great .. many many thanks for all the work that Lil Morgan our website Co-ordinator and our webmaster Ben Chapman from the NZ Rare Disease Organisation have put in to make the site brighter and more accessible. Whilst we still have some way to go before we can hope to emulate the websites of the UK and USA Groups (assuming of course that we want to!) we have made great strides into the digital world for promoting information on GBS and its derivatives. If you have any suggestions for further improvements let me know. Incidentally the UK group now reckon their website is their most important point of contact for those seeking help and information and their very active Facebook Forum has over 2000 members!! And yes Chris and Lil ï I have an I Pad coming as a birthday present and once it arrives I will join our Facebook site!

Well Spring has apparently sprung ï at least the Daffodils are out ï although arriving back from a couple of weeks in Noosa to a rather chilly and wet Nelson ï it didnôt feel so ñSpringyò. Thank you to those of you who responded to my pre-holiday rush around to get in late subscriptions. Remember Newsletters will cease coming if you havenôt paid your sub for this year yet.

Talking of Spring ï and thinking of Summer - did anyone catch the article in the August Listener about the trial that is just starting in Australia and New Zealand to try to ascertain if there is a link between Vitamin D deficiency and the risk of developing Multiple Sclerosis (which was described as a disorder in which the immune system starts to attack the myelin sheath that coats the nerve fibres ï sound familiar ????). The study will involve more than 300 people who have had a single episode of demyelisation but who havenôt been diagnosed with M.S. ï anyone taking part? It will last for three years ï so a while to wait for the results but it could have an important bearing on GBS/CIDP incidences in this part of the world where interestingly ñ New Zealanders are showing low levels of vitamin D levels compared to people in the USA and UK partly, it is thought, because winter sunlight in the south does not have enough of the right UVB rays to make vitamin Dò. Supplements may or may not be the answer!

A few new cases of GBS/CIDP in the Top of the South over the winter months ï and, thanks to good medical care and a positive attitude on the part of the patients, all making good progress ñback up the hillò. However a disappointing tale of a poor attitude from our local WINZ office when they received a request for financial support from a local single guy without any family support (already in Hospital for 6 weeks and likely to be there for 3 months or more) and insisted that he make himself available for an apple picking job ï climbing ladders!!!- and even sent in the bailiffs to Hospital to ensure he wasnôt telling fibs about his ability to work. Fortunately his Consultant intervened and told the local WINZ Head of Department just what GBS involved ï and the appropriate support was then forthcoming. I think I need to drop in a few leaflets to our local office!!

In a recent copy of the Kai Tiaki Nursing Journal there was an article on the management of post-operative pain in hospitals ï written by a trainee nurse who had experienced poor care in this respect. The article made it clear that there are many ways in which nurses can measure and interpret patient pain but, depressingly, acknowledged that often these were ignored or disregarded as an ñoverstatement/exaggerationò of the patientôs real condition. Clearly if - in a GBS case- the patient or carer is able to express a need for pain relief to be administered this should be firmly communicated to the staff responsible. What is not so obvious is that when, as in the many stories I have read in the Newsletter, intense pain is being experienced by the patient who is completely unable to communicate how do carers or nursing staff know there is pain and how to assess and manage it? Probably it just comes down to the fact that it is important, as we all know, that as wide a publicity as may be possible be given within professional circles to the very likely event of this being the case for ICU GBS patients. Interestingly this is a subject that the UK based Cochrane Neuromuscular Disease Group of the world renowned Cochrane Collaboration is also looking at.

To end on a happier note we have just had a major triumph locally ï our local Community Association ï of which I am also Secretary ï after a 3 year battle with a major NZ company who were bent on a commercial sale - have managed to raise in excess of $700,000 to buy an iconic piece of coastal land in Tasman which will now pass into public ownership for ever.

It just shows that were there is a will there is a way. Something a lot of GBSôers will know from personal experience!

As always take care ï roll on summer

A Personal Encounter: John Moynihan

In 1975at age 46 in excellent health, never got colds or flu (nor did my wife, our sons or welfare children). Don't drink but sneeze frequently all year.

Woke up one morning with pins and needles and numbness in my toes and fingers. It progressed to my knees by 2pm. Next morning pins and needles to my ankles, progressed to mid-thigh by 2pm. Third day pins and needles to mid-calf and pins and needles in my feet. They also felt numb and spongy. Next morning flew from Invercargill to Napier for the paraplegic games. I was carer for my wife, a double amputee and another other disabled person. On the third day there, by mid-morning, pushing wheelchairs, fetching shot-puts, discus and javelins, I said to my wife, "I can't carry on, and I'm more disabled than anyone here. I caught a plane back to Invercargill that afternoon and entered hospital. My speech was affected, kept telling me I sounded upset. That continued intermittently for 15 years.

About 5 times a day I would be interrogated by two doctors, always different ones. Always the same questions and always that dammed sharp article dragged the length of my foot – it felt like a red hot knife slicing through my foot. After several days of this, five times a day, I yelled at them, "Don't do that again!". On about the third day I said it feels like several layers of nerves are affected. One doctor muttered to the other "he's describing it exactly'. Each pair of doctors I asked, "Is it rare, is it serious, has it got a name?" The answer was always "no". They then latched onto the fact I operated a borer treatment business with the best equipment in the country. They fixated on dieldrin poisoning. I told them dieldrin symptoms are quite distinctive and I haven't got any of them. They took a biopsy out of the muscle mid-leg. Within 24hrs I was suicidal with the agony – that was Friday night. "You'll have to live with it", the nurse said, "They won't take you to theatre till Monday". When they lanced it there was nothing there, but the agony went on for two more days. Meanwhile the symptoms got slowly worse and worse; I could hardly talk or eat, couldn't get out of bed or hold a urinal. No one ever mentioned GBS.

After 6 weeks I was still hardly able to talk but could struggle from one side to the other. At seven weeks I badgered staff till they bought me a wheelchair. "You can't use that", to which I replied, "You don't know what I can do!" The following week I asked for a walking frame. The nineth week I was walking the corridors holding onto the handrails. For many months after I got out, people would come up to me in the shops and on the street saying, "I saw you at the hospital, you were so determined to walk".

After about ten and a half weeks I got out of hospital I desperately needed to pick up the reins. We had no money coming in and three small children and a wheelchair bound wife. Everyone I spoke to I had to reassure them I was not drunk, I was getting over some bug that affected my muscles. Incidentally I don't drink alcohol.

On the third day home the hospital rang my wife in a big panic – ring an ambulance and get back to the hospital urgently! My wife said he is not here, he's working, still got those awful collywobbles. They had finally, after two months, identified the bug they gave me with the biopsy. I had beaten the bug, I was back working after a fashion. I had only one pair of shoes I could walk in. I was soon back dancing in those shoes and in stocking feet to the amusement of onlookers. I couldn't have driven a vehicle without hand controls, so my wife's car served us both. It was 17½ years before I could safely use foot controls and 23 years before I could walk fast along a street. Up till then, if I tried to walk fast I would be intensely willing my feet to walk. Any repetitive movement like a cycling machine or hammering framing nails in is still a no-no, but it gets done just the same.

It was many years before I heard the term Guillian Barré Syndrome. In the 1980's I was told several times I had Tapanui Flu – maybe. Long periods of lethargy. I have also been told I try to do too much – a fool to work so hard. The spirit is willing but the flesh is weak.

Now at 84 I have been assured by a doctor I have post GBS, aggravated by 14 months of stress.

There you have it. It has taken me years to get it down on paper – but it's done.

A Personal Encounter: Ross Bonnell

My encounter with what was diagnosed as GBS began at the end of March 2012. On Friday 23rd as I finished work for the day I noticed my left foot felt like it had a touch of cramp in it which eventually went away. Everything felt alright until Sunday when everything changed. After struggling to get out of bed I managed to walk and went to let the cat out. As I stepped down to do this I fell over and struggled to stand again. Once on the move everything felt okay. After a second fall I began to think that maybe I had, had a very mild stroke. My wife was still asleep so I had to wake her up and tell her what had happened. She said we needed to ring for an ambulance. Once they arrived they checked me over and decided I needed to be checked by a doctor at the after hourôs clinic. As I stepped out the door to walk to the ambulance I lost my balance, but was saved by the medic. It was then decided that I needed to go to Lower Hutt Hospital (A & E Department). Over the whole of Sunday tests and x-rays were done. The final test was a Lumbar Puncture and this confirmed that I had GBS. On Sunday night I was admitted to the ICU ward of Hutt Hospital where treatment of Intravenous Immunaglobin was commenced. After spending the night in ICU I was transferred to a general ward and treatment continued.

By Wednesday afternoon I became very unwell and so was back to the ICU Ward where in the early hours of Thursday morning they placed a tube down my throat. Hutt Hospital ICU at that time did not have facilities for long term patients so on Friday 30/3 I was transferred to Wellingtonôs ICU unit and on Sunday they performed a Tracheostomy (this replaced the tube in my throat and this was more comfortable). There I stayed for the next month and a half connected to a ventilator.

Since I had a tracheostomy I could not use my voice to communicate on how I was feeling and what was needed. Since I was an ICU long term patient, it was decided I needed a day out, and was taken to Oriental Bay. This trip I was connected to a portable ventilator and took an ambulance and driver, 2 nurses, 1 nurse aid and my wife to make it possible. A fun time was had by all.

As I slowly got better my time on the ventilator was decreased and I started to do more breathing by myself. Once weaned fully of the ventilator I was transferred back to Hutt Hospital for a week then to the Rehabilitation Ward.

It was there I stayed for the next two and a bit months, getting my body to do the everyday things we take for granted.

Being able to eat without someone helping you, showering and dressing myself, and finally being able to walk with the aid of a walking frame. By the beginning of August 2012 I was well enough to be discharged from Rehab and return home.

Over the many months I have been at home I am now able to do jobs I used to do. i.e. mowing the lawns, gardening, painting and cooking. I am also driving and have done a few solo drives by myself.

I am not working and finding a job that suits is a big challenge at the moment.

Getting a Brain Boost Through Exercise

As appeared in the Neurological Foundation's Headlines Newsletter

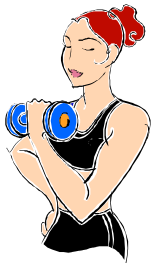
Two new experiments, one involving people and the other animals, suggest that regular exercise can substantially improve memory, although different types of exercise seem to affect the brain quite differently. The news may offer consolation for the growing numbers of us who are entering age groups most at risk for cognitive decline.

It was back in the 1990s that scientists at the Salk Institute for Biological Studies in California first discovered exercise bulks up the brain. In ground-breaking experiments they showed that mice given access to running wheels produced far more cells in an area of the brain controlling memory creation than animals that didn't run. The exercised animals then performed better on memory tests than their sedentary lab mates. Since then scientists have been working to understand precisely how, at a molecular level, exercise improves memory, as well as whether all types of exercise, including weight training, are beneficial. The new studies provide some additional and inspiring clarity on those issues, as well as, incidentally, on how you can get lab rats to weight train.

For the human study, published in *The Journal of Aging Research,* scientists at the University of British Columbia recruited women aged 70 to 80 who had been found to have mild cognitive impairment, a condition that makes a person's memory and thinking more muddled than would be expected at a given age. Mild cognitive impairment is also a recognised risk factor for increasing dementia. Seniors with the condition develop Alzheimer's disease at much higher rates than those of the same age with sharper memories. Earlier, the same group of researchers had found that after weight training, older women with mild cognitive impairment improved their associative memory, or the ability to recall things in context ï a stranger's name and how you were introduced, for instance.

Now the scientists wanted to look at more essential types of memory and at endurance exercise as well. So they randomly assigned their volunteers to six months of supervised exercise. Some of the women lifted weights twice a week. Others briskly walked. And some, as a control measure, skipped endurance exercise and instead stretched and toned. At the start and end of the six months the women completed a battery of tests designed to study their verbal and spatial memory. Verbal memory is, among other things, your ability to remember words and spatial memory is your remembrance of where things once were placed in space. Both deteriorate with age, a loss that is exaggerated in people with mild cognitive impairment. In this study, after six months, the women in the toning group scored worse on memory tests than they had at the start of the study. Their cognitive impairment had grown. But the women who had exercised, either by walking or weight training, performed better on almost all of the cognitive tests after six months than they had before. There were, however, differences. While both exercise groups improved almost equally on spatial memory, the women who had walked showed greater gains in verbal memory than the women who had lifted weights.

What these findings suggest, the authors conclude, is that endurance training and weight training may have different physiological effects within the brain and cause improvements in different types of memory. The idea tallies nicely with the results of the other recent study of exercise and memory in which lab rats either ran on wheels or, to the extent possible, lifted weights. Specifically, the researchers taped weights to the animals' tails and had them repeatedly climb little ladders to simulate resistance training.



After six weeks, the animals in both exercise groups scored better on memory tests than they had before they trained. But it was what was going on in their bodies and brains that was revelatory. The scientists found that the runners' brains showed increased levels of protein known as BDNF, or brain-derived neurotrophic factor, which is known to support the health of existing neurons and coax the creation of new brain cells. The rat weight-trainers' brains did not show increased levels of BDNF. The tail trainers, however did have

Getting a Brain Boost Through Exercise continued...

As appeared in the Neurological Foundation's Headlines Newsletter

significantly higher levels of another protein, insulin-like growth factor, in their brains and blood than the runners did. This substance, too, promotes cell division and growth and most likely helps fragile new-born neurons to survive.

What all of this new research suggests, says Teresa Liu-Ambrose, an associate professor in the Brain Research Centre at the University of British Columbia who oversaw the experiments with older women, is that for most robust brain health, it is probably advisable to incorporate both aerobic and resistance training. It seems that each type of exercise ñselectively targets different aspects of cognitionò, she says, probably by sparking the release of different proteins in the body and brain.

But, she continues, no need to worry if you choose to concentrate solely on aerobic or resistance training, at least in terms of memory improvements. The differences in the effects of each type of exercise were subtle, she says, while the effects of exercise ï any exercise ï on overall cognitive function were profound.

ñWhen we started these experiments,: she says, ñmost of us thought that, at best, weôd see less declineò in memory function among the volunteers who exercised, which still would have represented success. But beyond merely stemming peopleôs memory loss, ñwe saw actual improvementsò, an outcome that, if youôre still wondering about exercising, is worth remembering.

GBS Recoverer Seeks Support for ADHB Position

In 1996 I was in a coma for 21 days, paralysed for 4 months and in wheelchair rehabilitation for 2 years. Thanks to the highly trained staff at Auckland Hospital I survived to stand as a candidate today. Sadly, not everyone benefits from that concentrated level of patient-focus. I want to join the Board to make sure that patient's needs are put at the heart of ADHB's thinking.

Iôm seeking you help with my campaign as I want to represent patients and pay back to society c/- the Auckland District Health Board, with my wealth of experiences and recent service work I do for the community.

Also after years of governance work since my GBS, some paid but mostly volunteer, getting on to ADHB enables me to utilize these skills as I head towards the retirement era.

Refer my campaign link: - http://cityvision.org.nz/candidates/will-ilolahia-auckland-district-health-board

All I need is if you can pass on this link or my email, to members who live in the Auckland District area and hopefully they will be able to vote for me and if possible spread the word?

I do hope you can help.

Will óIlolahia

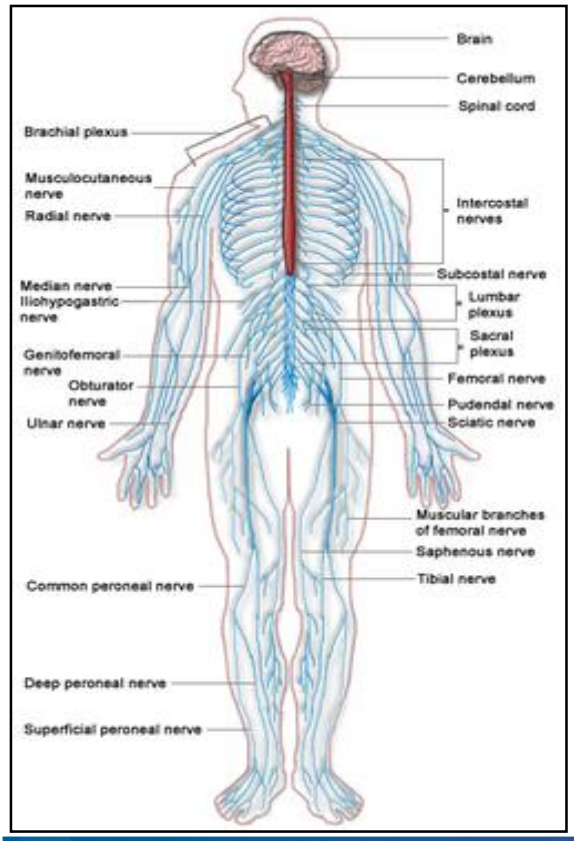
Guillain-Barre Syndrome
A brief overview

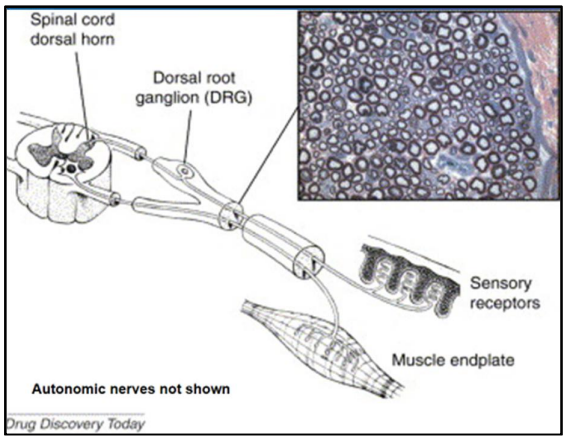
Gareth J. Parry
University of Minnesota
Consultant Neurologist
Wellington Hospital

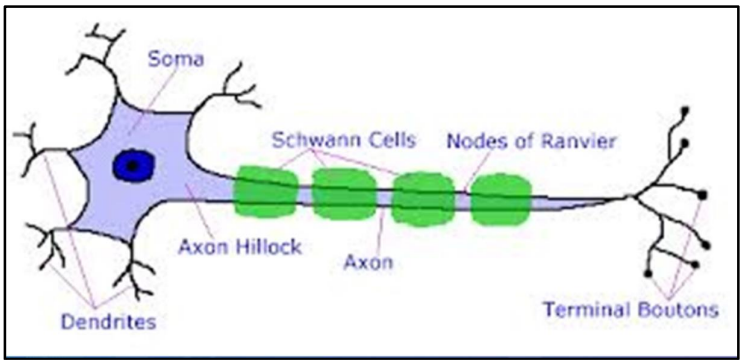
- What is GBS?
- What causes GBS?
- How does GBS affect you?
- How is GBS diagnosed?
- What is the treatment for GBS?
- What is the outcome after GBS?

What is GBS?

- GBS is a neurological disease:
  - Peripheral neuropathy.
  - *Demyelination* vs. *Axonal degeneration*.
- GBS is an autoimmune disease.
- GBS is an inflammatory disease.







GBS as an autoimmune disease

- About 70% of GBS cases follow an identifiable triggering event, usually infection:
  - Commonest event is a respiratory infection ("flu").
    - No relationship between the severity of the infection and the risk of developing GBS or its subsequent severity.
    - Infecting organism is seldom identified (CMV, mycoplasma)
  - Diarrhoea is the next most common antecedent event.
    - C. jejuni is the commonest identified cause of GBS overall.
  - GBS rarely occurs following vaccination.

GBS as an autoimmune disease

- The common thread that links these antecedent events is stimulation of the immune response.
- C. jejuni has been shown to share certain proteins with peripheral nerve proteins (antigens) and it is known that the immune response to the C. jejuni bacterium then involves the nerve because of this *"molecular mimicry"*.
- It is thought that the same mechanism may be operating following other infections but no common antigen has been found.

GBS as an inflammatory disease

- The effector cells of the immune response are the white blood cells which are the inflammatory cells that fight infections.
- Intense inflammation of peripheral nerves is the earliest pathological event in GBS.

How does GBS affect you?

- Many patients first notice mild sensory symptoms, usually distally; i.e., in the feet and/or hands.
- Weakness begins simultaneously or a day or two later and quickly comes to predominate.
  - Just as likely to be distal or proximal in the limbs
  - Usually affects legs first and ascends to the upper limbs
  - Rarely begins with bulbar muscles (face, speech and swallowing)
  - May begin with double vision due to weakness of eye muscles (MFS)
- Muscle cramps and fasciculations (twitching) may occasionally be noted.

Clinical presentation of GBS

- Early pain occurs in about 30% of patients.
  - Deep, aching, cramp-like pain
  - Located proximally (low back, between shoulder blades)
  - May be severe enough to need narcotics (rarely)
- Significant pain may distract from the diagnosis because of the (incorrect) perception that pain does not occur in GBS.
- Treatment of pain with narcotics may exacerbate respiratory symptoms.

Clinical presentation of GBS

- Autonomic nerves are frequently involved but usually asymptomatic:
  - Postural dizziness in those still standing/walking
  - Occasionally rapid and/or irregular heart beat may cause light-headedness
  - Abnormal sweating and temperature of the hands and feet
  - Difficulty urinating (ICU patients are almost always catheterized)
  - Constipation usually not manifest until after a week or so but early attention makes management easier
- Degree of autonomic involvement proportional to the severity of weakness.
- Although usually asymptomatic, autonomic involvement is an important cause of death in GBS patients.

Clinical presentation of GBS

Neurological examination:

- Confirms weakness.
- Sensory loss is absent or minimal.
- Rapid heart beat, particularly if also irregular, necessitates admission to ICU even if breathing is unaffected.
- *Absent or diminished reflexes are almost invariable and is a critical finding, even at the earliest stages of the disease.*

How is GBS diagnosed?

- Clinical suspicion
- EMG/NCS
- CSF examination
- Exclude other conditions in occasional atypical cases
- Lung function tests and ECG are not diagnostic tests but are critical for management.

Diagnosis of GBS

- Any patient presenting with these symptoms is easy to diagnosis.
- Delayed diagnosis is common, usually because all of the symptoms have not yet appeared.

Electromyography (EMG) and nerve conduction studies (NCS)

What is usually known as EMG is actually 2 separate procedures:

- NCS consists of administering electric shocks over the course of nerves and recording the responses from muscles (motor NCS) and from sensory nerves (sensory NCS).
- EMG consists of inserting needle into a number of muscles and recording electrical activity at rest and during contraction of the muscles.

Electromyography (EMG) and nerve conduction studies (NCS)

Motor NCS:

- Comprise the cornerstone on which an accurate diagnosis is based.
- Are used to classify the type of GBS:
  - AIDP in which the primary target is the myelin sheath
  - AMAN in which the primary target is the motor axon.
- Provide invaluable prognostic information:
  - Low amplitude (<10% of normal) of the motor response indicates a high probability of remaining chair or bed bound at a year.

Electromyography (EMG) and nerve conduction studies (NCS)

Motor NCS:

- Speed of conduction is slow in AIDP (<40m/sec in arms and <30 m/sec in legs).
- Conduction block in AIDP.
- Low amplitude responses indicate degree of axon loss:
  - Primary abnormality in AMAN.
  - Secondary axonal degeneration in AIDP.
- May be "normal" early in the course of the disease.
- Abnormalities may be patchy so multiple nerves need to be studied.
- Occasional need to repeat the study in non-diagnostic cases.

Electromyography (EMG) and nerve conduction studies (NCS)

Sensory NCS:

- Of little use in diagnosis of GBS.
- Primarily used to exclude other diagnoses:
  - Severe involvement of sensory nerves indicates a different diagnosis, particularly if motor NCS are normal.

Electromyography (EMG) and nerve conduction studies (NCS)

EMG:

- Of little use in diagnosis of GBS.
- May have some prognostic utility 2-3 weeks after onset of weakness in assessing severity of axon loss, particularly in proximal muscles.

Cerebrospinal fluid (CSF) examination

- CSF is the fluid that bathes the brain (*cerebrum*) and spinal cord.
- Nerve roots exiting the spinal cord traverse the CSF on their way to the limbs.
- The primary site of pathology in GBS is the nerve root and inflammation in nerve roots leads to protein leakage into the CSF, resulting in the characteristic high CSF protein.
- The inflammation remains largely confined to the nerve roots so inflammatory cells are not seen in significant numbers.
- This almost unique combination of high protein but few cells (albuminocytologic dissociation) led Guillain and colleagues to distinguish this condition from polio.

Cerebrospinal fluid (CSF) examination

- CSF is obtained by inserting a needle under local anesthetic into the lower spine, between vertebral the bones, and draining a small amount of the fluid.
- Despite urban myth, the procedure is:
  - Only minimally painful in most patients.
  - Never causes paralysis.
  - Rarely causes infection or hemorrhage.
- Causes headache in ~25% of patients which is severe in ~5%.

How is GBS treated?

- Most important treatment is supportive:
  - Even without specific immune therapy ~70% of GBS make a good recovery.
  - Prior to the development of good supportive care the mortality of GBS was about 25%

Supportive care in GBS

- Acute supportive care:
  - Support breathing
  - Prevent infections
  - Prevent blood clots
  - Pain management
  - Emotional support
- Chronic supportive care:
  - Physical therapy
  - Occupational therapy
  - Pain management
  - Emotional support

Immunotherapy in GBS

- Intravenous immunoglobulin (IVIg).
- Plasma exchange (PLEX).
- Do NOT use steroids.

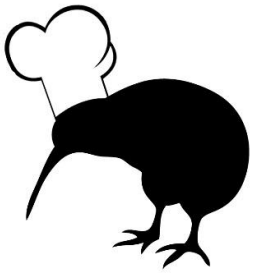
Immunotherapy in GBS

- IVIg and PLEX about equally effective.
- IVIg easier to administer.
- IVIg may be safer (but not in major studies).
- Treatment does not prevent deterioration or improve mortality.
- Treatment accelerates recovery:
  - Less time in the hospital.
  - Less time in rehab.

What is the outcome after GBS?

- About 70% of patients fully recover strength.
- Typically takes several months but may take up to 2 years.
- Patients who recover slowly usually recover incompletely.
- About 55% to 80% of patients have long term residual fatigue.
- About 5% of patients die from the complications of GBS (pneumonia, pulmonary embolism, cardiac arrhythmia).

Something from the Kitchen



Apple Date and Walnut Cake

Combine:
2 medium apples peeled and finely diced (use food processor)
1 cup chopped dates
1 cup boiling water
1 tsp baking powder.

Cream: 125gm butter, 1 cup sugar, 1 egg

Mix into apple mixture along with ½c chopped walnuts and 1½ c flour.

Put into a prepared 20cm round cake tin and sprinkle over topping:
¼ c chopped walnuts
2tbsp melted butter
2tbsp brown sugar

Cook in moderate oven for about 40 minutes.

Dangerous Chocolate Cake in a Mug

Ingredients:

4tbsp self - raising flour
2 tbsp cocoa powder
4 tbsp sugar
1 egg
3 tbsp milk
3 tbsp oil
1 tsp vanilla
3 tbsp choc chips (optional)
1 large mug

Add dry ingredients in your largest mug and mix well.
Add eggs, mix thoroughly.
Pour in milk and oil. Mix well.
Add essence and choc chips.
Cook in microwave for 3 minutes.
Cake will rise well ï donôt worry just enjoy.

Bay of Plenty / Waikato Coffee Group.

Venue: Villa Ridge Café
528 Cambridge Road, Tauriko

Date: Friday November 22nd
Time: 12.30

Gisborne Coffee Group.

Venue: Café Villaggio
57 Balance Street, Gisborne

Date: Friday October 18th
Time: 12 Noon

Feed Back Wanted

The Board has been asked to consider holding the 2015 Conference in **Rotorua.**

They would like to hear from members if they would prefer this option or stay with the previous venue in Wellington.

Send your preference to the Secretary Tony Pearson. His details are on the front page of the magazine. Please take the time to have your say.

2014 AGM

The 2014 AGM is to be held in

NEW PLYMOUTH

On

Sunday May 4th

Mark this date on your calendar.

Wanted

Publicity Officer

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

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