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Guillain – Barré Syndrome Support Group New Zealand Trust

Registered N.Z. Charity No. CC20639 Charities Act 2005

NEWSLETTER MARCH 2016



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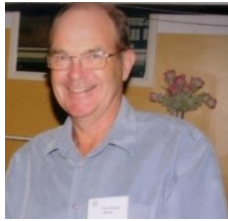
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Ken Daniels

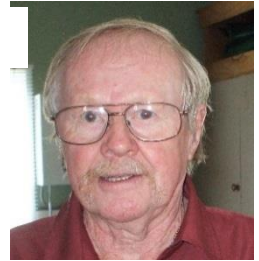
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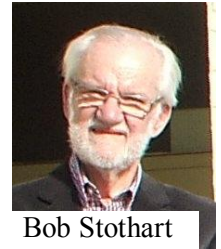
Chris Hewlett



Doug Young



John Davies



Bob Stothart



Dr. Pralene Maharaj



Dr. John Podd



Meike Schmidt-Meiburg

Notification of 2016 AGM

**The 14th AGM: 1300hrs Saturday 14th May 2016.
De Havilland Room Wellington Airport**

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

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

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



Editor's Note

Well we are well into the New Year and I am pleased to say that here in the sunny Bay of Plenty we have not been told of any new cases of GBS.

Members have been busy organizing themselves and holding coffee group meetings and more are set to take place in the coming months. More details of these in the magazine. Please make contact with the organisers if you wish to attend.

The AGM is coming up in May and the Board is looking for new members. Please offer your services if you are keen to come onboard.

Subs were due in December and some are still outstanding. If you have not renewed please fill out the renewal form attached and send to the Treasurer.

As always please send in your story if you have not already.

Enjoy the magazine and keep making small improvements on the slow road to recovery.

Chris



Presidents Report:

According to the World Health Organisation over a billion people are estimated to live with some form of disability. This corresponds to about 15% of the world's population. Furthermore, the rates of disability are increasing in part due to ageing populations and an increase in chronic health conditions. Some of these disabilities are caused by problems at birth while others result from disease, illnesses of various kinds, bad lifestyle choices or accident.



GBS, CIDP and other related illnesses can cause varying degrees of disability. Living in our modern world there are some things that can minimise the personal impact of these illnesses.

I found it interesting when digging a bit deeper into the recommendations of the WHO that they ask all countries to:

Promote strategies to ensure that people with disabilities are knowledgeable about their own health conditions, and that health-care, personnel support and protection of their rights and dignity are protected.

Our support group I believe tries to do all of these things. The advice available through our Medical Advisory team and articles published in this magazine and on our website gives knowledge about our particular illness and any resulting disabilities both temporary and permanent. The postings on our Facebook page and in emails and our 2 yearly conferences give knowledge and support to members and their families.

Thanks for supporting the Guillain-Barre Support Group. Thanks for supporting all people with disabilities and giving them knowledge and hope.

Ken Daniels



Secretary's Jottings

So.... STRESS: As I mentioned in my input to the last Newsletter I am pretty certain that Stress was the trigger that set me on the path to GBS. BUT – an interesting development!! – for the last 6 months Vivienne and I have been dealing with the sale of our present home and the re-building of our new one – lots of weekend jobs and late evenings during the week to keep abreast of the Builder and keep the present place up to “show home”

standards for viewings BUT ... it's Physical stress – we go to bed pooped! But it's not like the MENTAL stress that I was under in my commercial world back in London which culminated in my contracting GBS!! – NOW THERE'S A THOUGHT!! As my dad always told me “hard work never hurt anyone!!”

Do you holiday in the Pacific Islands?? – we have had one holiday there and hoped to have a few more but ZIKA ?? – and by golly it seems to be a GBS trigger – Our Chief Medical Advisor Dr Gareth Parry has written a paper on this which will appear in the medical journals in due course and he has contributed an item elsewhere in this Newsletter on the issue. A pretty small risk in my book – but we have all succumbed to a “pretty small risk” haven't we!!

So this year marks the 100th Anniversary of the discovery of GBS by those two French Doctors – and we still don't have a CURE - but do have a pretty good handle on what triggers the occurrence of this Rare Disease. The UK Group - of which I remain a member – are having a “celebration” of this anniversary in Glasgow Scotland in June of this year – and by co-incidence Vivienne and I will be there to say Hi from Kiwi land and I hope to make contact with a number of our International links. I am sure we can celebrate this anniversary at next year's Conference.

As our website and Face book page become more central to our links with new and ongoing GBS sufferers it is interesting to note that this year I have had several links to NZ GBS'ers passed to me from the USA Group- They do have a very good website with LOTS of interactive stuff and lots of Fundraising ideas.

I took on the Hospital Visitors Co-ordination Role almost by default as no one else put their hand up. We have had a really good 12 months of supporting those new GBS'ers that asked for support (and not all do!!) so a BIG thanks you our Hospital Visitors (many of them new to the role) for your efforts this year. We need more volunteers for this role especially in the South Island.

Which brings us to the AGM!! A formal Notice of meeting appears elsewhere in the Newsletter and in a non Conference year the AGM tends to be less well supported by members so to make it easier for “out of towners” we will be holding it at Wellington Airport using one of their meeting rooms – Wellingtonians, of course, have your very good bus service (the “Flyer”) to whisk you to the venue – so no excuses! The AGM will be preceded by a Board meeting of Trustees which will address the usual operational issues of the Group but this year there is a NEW Agenda item:-

“THE CHANGING OF THE GUARD” !!!!!

The majority of our present Board have served for a number of years – and good and loyal service that has been - but we feel that it is time for some “NEW BLOOD” with renewed energy, ideas and commitment to the aims of the Group to join the Board. If there is interest from members then a number of existing Board members have confirmed they are willing to step down – remaining Trustees of the Group but not active Board members. I recall at the last Conference a “first time” attender (and I genuinely can't remember who it was) telling me in no uncertain terms that a change in Board make up was long overdue! If that person was YOU now is the time to put your hand up. Board duties are not onerous with the Treasurer and Secretary shouldering most of the day to day routine stuff – and Board member's expenses, travel costs etc, are covered by the Group so it need not be a “financial” burden. Contact me if you feel you have the qualities/experience and drive to take the Group forward into the next “100Years”

As always, take care

Tony

OBITUARY - Gordon Stephenson

I met Gordon when we were both on Ward 58, the Rehab-ward in Waikato Hospital, early 2006. He came into hospital mid October 2005, and I followed 2 months later. One day a nurse asked me: "There is somebody next door, he has got GBS too, would you like to meet him?" (she had to ask for privacy issues). "Oh, yes, sure!!!" I was all excited. The nurse asked him the same thing, and he must have felt the same. It didn't take long, and a wheelchair driven by Gordon, then 81 years young, came into my room. Gordon's face beamed, he was 40 years older than me and happy to meet me, and a bit ahead in what he could do at the time. I was still lying in bed, just learning to use me arms and hands again, and gaining strength. From then on we were "partners in crime" and we were constantly trying to be better than the other, and learning new things before the other did, all in a fun way. The best times we had were our pool sessions, which the officials decided we could have at the same time. Imagine, we came in by wheel-chair, and had to be hoisted into the pool, but then - we could walk along the sides of the pool, or float - aided by long noodles wrapped around necks, or swim! We had so much fun, plotting - should we pull the red string/bell, hanging in the middle of the pool, so the staff would have to write an "incident report"?!!?! We never did.... we were well behaved.



We were discharged, I beat him by 2 weeks, in February and March 2006, but we stayed in touch, ringing each other for catch-ups every so often, and meeting at the Waikato GBS coffee-groups or AGM's over the next 10 years.

I am glad I met Gordon when I did! Having a fellow patient with GBS in hospital at the same time - I would wish it on everyone!! The feeling, 'you are not alone in this world with this illness', 'it can happen to other people too', was great. Then meeting more ex-patients at the coffee-mornings and AGM's would just confirm that.

But of course Gordon was more than fellow patient with GBS, as we found out at his 'Celebration of Life': we had met Celia and some of his 4 children and 11 grandchildren, but not his 8 great grandchildren over the years.

Gordon and Celia came together from England, he went share-milking before he bought his farm in Waotu in 1964. He served on and has chaired many local, regional and national organisations, such as Federated Farmers, the Maungatautari Ecological Island Trust, Environmental Council, National Wetlands Trust, Waikato Conservation Board, Lincoln University Council, Landcare Trust, South Waikato branch of Forest and Bird, the National Executive of Forest and Bird, he joined the local Tramping club, and fell in love with the NZ bush. We found out that he initiated a seven year campaign that resulted in the establishment of the QE II National Trust!

Gordon was very much involved and interested in everything around him, right till December 2015. His drive and vision for good farming and good environmental management will be a huge loss to agriculture.

(from his daughter Lynn's speech:

Gordon had an inherent love of life, a sense of fairness and respect, and a love of farming and the land itself. He was trained to think creatively and to lead by example and to always strive for the best possible outcome.

He was a family man and practical visionary.

When a mature tree falls in the bush, it leaves a light well, and all the saplings spring up to take its place... Let us follow that example.)

Gordon, we will miss you, and our thoughts are with Celia Lynn, Keith, Janet, Paul and your families in this sad time.

Meike



Dr Chris Lynch with Gordon his wife Celia and Meike

Auckland Coffee and Chat

28 February 2016

On a very warm late summer Sunday afternoon, six people met at my home in Glenfield to talk about their various experiences of GBS and to discuss what this new Auckland coffee group could aim to achieve. The five diagnosed and one spouse/carer discussed their likely predisposing factors to getting GBS, the time of year it happened, time spent in rehab, medical personnel responses, going back to work and how having a loved one diagnosed with the syndrome affects family and caregivers.

Experiences ranged from sixteen years ago to one person having just been discharged from a rehab/care home and from very mild to seriously ill.

Since these factors are somewhat different for every case, it helped having the opportunity to speak about personal aspects of this GBS journey.

Aims of our group:

- To allow people to tell their own story
- To remind people that there is a support group available
- To distribute GBS/CIDP literature
- To contribute to the Neurological stand on Brain Awareness day
- To hold a GBS/CIDP story-writing session
- To create a video documentary of patients/carers' stories



While there were six participants that day, three others expressed interest but sent apologies as they were not able to come. We thought this was a promising start and plan to hold about 3 meetings a year, perhaps in a hall or café depending on how far people have to travel and numbers attending with the next meeting to be held in June. A previous group has been set up for people in the Auckland area, but as that one has folded some time ago, we wanted to try a new initiative.

We welcome further enquiries.

Please contact Sharon or Eileen at the numbers below.

Sharon: 473 1128 or 021 300313 or sharondixon@orcon.net.nz

Eileen: 021 1133607 or eileenmagnajacobsen@hotmail.com

ANNUAL SUBS ARE NOW OVER DUE

If you receive your magazine by post and the address label is printed in **RED** then your subs are overdue. Please complete the attached invoice and send to the Treasurer Peter Scott.

If you receive your newsletter by E Mail I will remind you in the Email.

The group relies on your continuing support through this subscription to produce CD's, pamphlets, run conferences and offer ongoing support to GBS sufferers.

Your continued support is very much appreciated.

Zika virus infection and Guillan-Barre Syndrome: Should New Zealanders be worried?

By Dr Gareth Parry

Zika virus is a member of the flavivirus species, a group of viruses that causes several human diseases, mainly in tropical regions of the world. Zika virus was identified in Africa nearly 70 years ago and for many years has been recognized as a cause of a mild illness very much like influenza. Affected patients develop mild fever, rash, headache and pains in the joints and muscles. In most cases the illness lasts a few days and resolves without leaving any subsequent effects. Over recent years the virus has spread east through Asia and into the Pacific and the Americas. The virus has recently mutated making it more infective but the illness it causes remains mild. Studies have shown that only 20% of infected individuals develop any clinical disease which is similar to many viruses including polio and West Nile fever. Zika virus, like dengue fever and several other flavivirus-related illnesses, is transmitted by a specific group of mosquitoes of the *Aedes* genus. This mosquito is widely distributed in tropical areas including Africa, Asia, the Pacific and Central and South America. It is also found in tropical and subtropical regions of Australia. It has recently been identified in Washington DC where the mosquitoes have survived four winters, suggesting that the mosquito is becoming cold adapted. This species of mosquito has not been found in NZ; all New Zealanders infected with the Zika have contracted it overseas, mainly in the Pacific. In the absence of the appropriate mosquito vector it is highly unlikely that it could be spread to other individuals although human to human sexual transmission has been documented. It is possible that the virus could expand its host range to include endemic NZ mosquitoes or that the *Aedes* mosquito could become endemic in NZ by way of imports from Australia or the Pacific.

In infected humans the virus has been identified in the amniotic fluid (the fluid surrounding the developing fetus) and it is suspected as the cause of microcephaly, a small head size due to poor development of the brain, leading to mental and physical retardation. A marked increase in microcephaly has been seen in several countries, particularly in Central and South America, that have seen a simultaneous increase in cases of Zika virus infection. Health authorities worldwide are warning women who may become or plan to become pregnant to show extreme care to avoid exposure to Zika.

As with microcephaly, countries that have seen a marked increase in Zika virus infections have seen a coincident increase in GBS cases. In French Polynesia there were 73 cases of GBS in a population of 270,000, a 10-20 fold increase in GBS over that expected. For comparison, NZ has a GBS incidence of 2-2.5 cases per 100,000 population each year while many other countries see even lower rates, close to 1.5/100,000/year. Similar increases in GBS have been seen in several Central and South American countries. One report noted a mortality rate of over 50% but this has not been confirmed by others and may represent the poor standard of care in impoverished areas that typically see most cases of Zika. The association between Zika virus infection and GBS does not prove that the association is causative; it is possible that some other infection has increased simultaneously. However, it seems highly likely that it is the Zika virus itself is causing these cases of GBS. At the moment little is known of the exact nature of GBS associated with Zika virus infection and more research is needed.

So should New Zealanders be worried? In my opinion – no. The likelihood of Zika virus establishing a foothold in NZ is low mainly because the vector, the *Aedes* mosquito, is not found here. The risk of direct human-to-human transmission is also low, the single case of sexual transmission notwithstanding. New Zealanders travelling to areas where Zika virus does exist should be cautious and use insect repellent and mosquito nets to minimize the risk of exposure. If they are unfortunate enough to develop ‘flu-like’ symptoms during or after a visit to a Zika virus endemic area they should be on the lookout for neurological symptoms in the 1-3 week interval after infection and consult a doctor immediately, emphasizing that they may have been exposed to the virus and that the neurological symptoms may be due to GBS. Remember, treatment for GBS is most effective if started within the first week of onset of symptoms so early diagnosis and treatment are crucial.

Should individuals with GBS in the past or with CIDP be worried? It is unlikely that a past GBS sufferer exposed to Zika virus is at any increased risk of developing another GBS attack. It is more difficult to predict what might happen if a CIDP patient were exposed. CIDP may relapse following any viral infection although the risk is small. A similar risk may be seen with Zika virus but there is simply too little information to be able to predict with accuracy.

Zika virus update

The Ministry of Health has extended its Pacific travel advice around the Zika virus to include Tonga as well as Samoa as an area of active transmission.

Media release

29 January 2016

The Ministry of Health has extended its Pacific travel advice around the Zika virus to include Tonga as well as Samoa as an area of active transmission.

Tonga has reported one recent case of Zika virus within Tonga.

Additionally, the Ministry has received the first Zika notifications for 2016, involving nine travellers who have recently arrived from the South Pacific.

Four of the travellers have been in Tonga, four in Samoa, one is still to be reported.

Four of the travellers are female. In two of those cases, the potential for pregnancy has been ruled out.

Further tests are underway for the two remaining women.

Although Zika is generally regarded as a mild illness, it has previously been recognised as having additional complications in a small number of cases.

One of the travellers, a 47 year old Waikato man, has been admitted to Waikato Hospital with symptoms indicative of Guillain-Barre, a condition which can cause paralysis but from which most patients make a full recovery. The patient is in a stable condition.

All the other eight individuals have recovered.

Dr Don Mackie, the Ministry's Chief Medical Officer, says the notifications should be seen in the context of a large number of travellers in the region.

In 2014 there were 57 Zika notifications; last year there were nine (provisionally).

"We will be providing advice to incoming travellers and the Ministry is updating its information for health professionals. There remains robust mosquito surveillance and monitoring at our borders."

Health messaging advising travellers on what they should do if they get sick within a month of returning to New Zealand is displayed at all our international airports and [available in a health advice card format](#), Dr Mackie says.

The health advice cards are also available on Ministry of Health website and are available in Tongan and Samoan.

We are working with border agencies and airlines to find ways to enhance and increase the visibility of the messaging.

"If travelling in Zika infected areas, women who are pregnant or plan to become pregnant should consult with their healthcare provider. All travellers should take appropriate precautions to avoid mosquito bites."

Dr Mackie said as an additional precaution, the Ministry was also recommending that women returning from Zika infected areas who might wish to become pregnant should use an effective contraceptive for a period of three weeks after their return.

Updates on Zika notifications will now be provided weekly – they are currently published each month [on the ESR website](#). From now on they will be published on Thursday afternoon for the next month.

Updated information and traveller advice is available on:

- [Safe Travel: Zika virus](#)
- [Ministry of Health: Zika virus information for the public](#)
- [Ministry of Health: Zika virus information for health professionals](#)

Anyone wanting more information should call Healthline 0800 611 116.

GBS – A Very Personal Encounter

David Meyer

I have what?

Multifocal Motor Neuropathy (MMN) is a rare condition that causes weakness without significant loss of sensation. The disorder affects less than 1 person per 100,000 people. Men are almost twice as likely as women to develop the illness and most people contract the disease between the ages of 35 and 70. With very rare exceptions, MMN does not shorten life, or cause major problems with breathing or swallowing. However, it can cause a great deal of dysfunction and disability and the disorder appears to persist indefinitely and rarely goes into a long-term remission.

Around approximately 2001 -2002 the 3 outside fingers on my left hand started to curl and my thumb became weak (couldn't give anyone the thumbs up). I was having physio for something else at the time and mentioned it to my physio. Strengthening exercises were put into place but after about 3 weeks it was obvious these were not working. Over the course of the next 12 – 18 months I had several visits to various specialist as well scans of my spine. In 2003 I involved my GP a bit more and she suggested I see a Neurologist. I chose to go for a private consultation rather than join the “free” hospital list in order to get a quicker diagnosis. As a result of this visit I was sent for an EMG at the hospital. From this test there was not enough data to make a diagnosis so life carried on as normal. Approximately twelve months later I received a call to have another EMG. By this stage I had learned tricks that helped me cope with my bent fingers and I did not want to go through another EMG when in my own mind nothing had changed, so as far as I was concerned there would still not be a diagnosis. So with these things in mind I declined this test and I guess now I will never know if it would have shown anything different that could have improved my situation.

So for the next 9-10 years nothing really changed and I was more concerned about my arthritic knee. In May 2013 I finally got the knee replacement I had been dreaming about for about 10+ years. This went well and I stringently followed recovery instructions. It was during my physio rehab at the hospital that I started to notice that my calf muscles were getting very tight when under pressure and I was also becoming fatigued quickly. I also noticed the fingers on my right hand were also starting to curl and my thumb was weak as well. I sometimes felt a bit wobbly although at the time I put it down to my op. So back to my GP and she sent me back to the neurologist (I paid to jump the queue again) and was referred back to the hospital for more EMG. As a result of these tests a diagnosis of MMN was made. I totally misunderstood the description. I thought I had Motor Neuron which really alarmed me and my partner. After about a week I caught up with the neurologist again and this time did a better job of listening to his explanation and also realised that MMN is quite rare – 1 in 100,000. I couldn't believe my luck - hahaha. I was prescribed a 4 day loading dose of 39gms/day Intragram in November of 2013 and this was to be followed by further infusions every 2nd Monday & Tuesday. I noticed a small change in my strength around 10 days later. Not long after this the fingers on my right hand started to straighten. Life was starting to look good again. This continued for the next little while until some steroids were introduced. Prednisolone I think it was. I had recently read in some research that steroids were not good for MMN and made this known but was advised this was not the case. I decided to go ahead and accept steroids as I felt I needed to know for sure one way or the other. My research was proven to be correct. I started to go downhill and as well as this my infusions were pushed out to every 3 weeks and all of a sudden I was not doing so well. Then I had another EMG and the results showed I had not improved and this resulted in my infusions being stopped despite my debating that you don't get better I was gobsmacked to say the least.

From this point I went downhill and went through days of doubt and even believing that my days of mobility were numbered. I almost succeeded in convincing myself I had Motor Neurone (MND). I couldn't work and was worried that might become permanent and I was not ready for that yet. I have to say it was a horrible space I was in for nearly a month. I should mention that my reflexes were still strong and I could still drive. I just couldn't stand or walk unassisted and definitely couldn't get back up if I fell. It was a mission to get up off the chair or whatever I was sitting on

Then something happened that helped me turn the corner. My partner encouraged me to make a cake for the nurses at the ward where my infusions used to take place. (Something I often did when I was a regular patient) I thought this was a good idea as it would give me an outing that I probably needed and a change of scenery and I thought it would be nice to catch up with friendly faces again. When I took the cake in a couple of other patients that I had gotten to know were there so I had a chat with them as well. One of these people has CIDP and I had a very lengthy chat with them. I was full of dislike for my Neuro as I blamed

GBS – A Very Personal Encounter *continued*.....

them for the situation I was in and I made my thoughts quite clear about this. The person I was talking to must have had sore ears by the time I had finished but through it all remained calm and slowly but surely settled me down and caused my thought path to take a turn with their positivity and suggestions. Hell here was someone that had spent 7 months in hospital because of their condition and was still able to be positive about it all. Time for David to have another look at himself I thought. They suggested I join the GBS support group but I was a bit reluctant too as I did not have GBS and felt I didn't belong.

During the drive home I started to question the path I had been taking and by the time I got home I was ready for some positivity and made a decision to work away at getting my infusions started again. I started with my GP and the short story is after a lot of lobbying from her, my partner and another person from the hospital, I received another appointment which resulted in my infusions starting again. Bliss in our house again.

At about this time I responded to a request on a Facebook MMN group I had joined, about free IVIG for a trial period that GAIN had posted. But it was in England. I mentioned that I wished I was closer so I could volunteer and we had a bit of a chat and they advised there was a GBS group in NZ that maybe it might be good to join it - and this time I did. It was only a few months before the Rotorua conference and we signed up for this.

At the conference I met and talked to Dr Gareth Parry. I knew who he was as in my research I had found he was the person who discovered MMN (sometimes referred to as Parry's disease) in the 1980's. I was over the moon. Here was someone who had a vast experience of dealing with MMN. My confidence shot through the roof. I told everyone about it regardless of whether they wanted to know or not. At my next visit to my Neuro, I requested a visit for a second opinion with Dr Parry and a short time later travelled to Wellington for this. My diagnosis was confirmed and a recommendation to increase the amount of Intragam to 48gms/day twice a fortnight was made. My Neuro agreed to this and that is the dosage I currently get every second Monday and Tuesday. It has made a big difference to my mobility and life in general. I can even mow my lawn again and have started back at the gym just doing rowing, cycling, walking on the treadmill and if I'm game a short stint on the cross trainer. I still get quite fatigued especially if I am quite active, which I like to be. And these 30 degree days are not MMN friendly either.

I still occasionally "run out" of juice but nowhere near like I used to, which makes me weak and makes me want to sleep a lot but this only lasts for around 2 days and once the most recent treatment kicks in I'm up and away again. I think a lot more about what I'm doing to try and conserve energy ; for example if I'm at one end of the bench and need something from the other end I look at what else I can take in either direction to cut down on movement.

Unlike CIDP and GBS sufferers I don't experience pain but cramps can be a constant companion and often in areas you don't realise there are muscles, which make it hard to try and stretch the cramp out. Quite often the cramp will just "sit" there for hours before it suddenly grabs you when you drop your guard.

I see people in my age group running and jogging with ease and am sometimes a little envious of this but I have accepted that I can no longer be as mobile as them and walking is the fastest speed I can ever travel again and that I need crutches from time to time especially if a lengthy walk or stand around is happening and that if I trip and fall I need help in getting back to my feet.

One day my infusions may stop because they no longer work or caused a blot clot or some other reason and I may end up in a wheelchair. But those are only things I'm aware of and don't dwell on.

And I'm forever grateful to my partner who is so supportive but gives me the space to get on with it. My family and friends understanding and general interest in my progress is also appreciated. And of course the visit to the ward with the cake which I firmly believe was the starting point in my attitude change and acceptance that it was OK to ask for and accept other people's help.(stop being so proud).

My partner and I also got a lot out of the Rotorua conference and I recommend it to others who haven't been yet. We also attended a GBS lunch/coffee meeting for Hawkes Bay just before Christmas which was well worthwhile.

My current treatment programme is working well and life is great although I no longer work.

We are already planning for next year's conference.

See you there.

Further Reading:

<http://www.gbs-cidp.org/variants/mmn-overview/multifocal-motor-neuropathy-mmn-progress-challenges/>

FATIGUE AFTER GBS – CONFERENCE PRESENTATION

Dr Suzie Mudge,
Physiotherapist, Neuro Rehab Results
Senior Research Fellow, AUT University

What is fatigue?



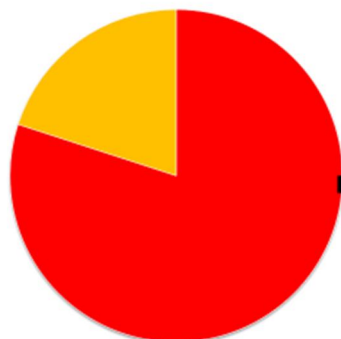
Subjective fatigue: a sense of reduced energy

Objective fatigue: reduced work capacity in response to activity



All of us have experienced fatigue. There are two types of fatigue that can be distinguished: Firstly subjective fatigue which is a sense of reduced energy. It is important to state that fatigue is normal, however it becomes pathological when it is out of proportion to the activity, it doesn't resolve after rest or is present following sleep. It is hard to measure subjective fatigue, but you can rate how you are feeling by using a scale. Secondly objective fatigue is much easier to measure or observe. And we can see it all the time at the end of a sports game or event when players tire. Of course, not just athletes experience it; we all experience it too as a result of activity. Again this is a normal response, but can become excessive under certain conditions.

How common is fatigue?



Up to 80%
GBS/CIDP report
severe fatigue

Merkies et al, 1999; Ranjani et al, 2014

Up to 80% of people with GBS/CIDP report severe fatigue

As well as that, 80% of people with GBS/CIDP rated fatigue as one of the three most disabling symptoms

Fatigue is not related to motor recovery, sensory changes or time since onset; eg high proportion of people who had made a good physical recovery still report severe fatigue (these figures are consistent with reports of fatigue in other neurological conditions eg MS)

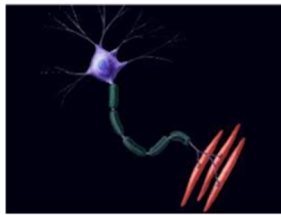
What causes fatigue?



So what else can effect fatigue? These are all factors that mostly impact on subjective fatigue or the feeling of fatigue.

FATIGUE AFTER GBS – CONFERENCE PRESENTATION

What causes fatigue?



Motor unit = nerve cell + muscle fibres

- Fewer motor units
- Compensate by increasing in size
- Because there are fewer, they get 'overworked'

Drenthen et al, 2023

Our muscles are made up of thousands of motor units. Following GBS/CIDP, some recent research has shown that there is a loss of motor units. Our bodies can compensate by increasing the size of the motor units, so each individual motor unit gets stronger. But it is possible that because there are fewer motor units, they all have to work harder and therefore are at risk of becoming overworked, therefore leading to fatigue. This is possibly more related to objective fatigue.

(Drenthen's study used motor unit number estimation, which was correlated to degree of fatigue. Previous studies have used conventional nerve conduction studies, which have not been correlated with fatigue, confounding possibly occurring due to reinnervation. Motor units are larger, though there are fewer.)

Balancing Fatigue and Overload



But how do we exercise without ending up like this?

The Balancing Act...



One really useful analogy is to think of your energy as a water bottle. You have a finite amount of energy. You might argue, 'why should I exercise?' and use up my precious energy?!

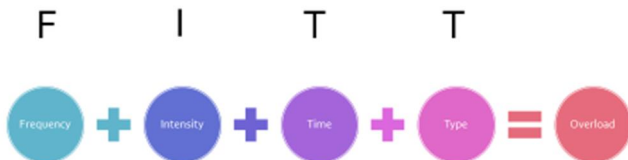
But you should think of exercise as one of the ways to make the bottle bigger with the capacity to store more energy. You need to use some of your energy in order to increase the size of your water bottle.

But what you want to avoid is emptying your bottle completely at one exercise session!

FATIGUE AFTER GBS – CONFERENCE PRESENTATION

Be cautious...

- Start slowly: 1-2 times/week
- Progress gradually
 - Progress one thing at a time using FITT principles



Fitt principles tell us there are several ways to overload our systems and increase our fitness.

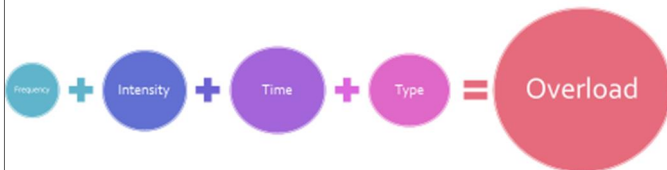
Frequency is how many times per week you exercise

Intensity is how hard you work

Time is the duration of time you spend exercising at each session

Type is the different types of exercise (aerobic, strength, yoga etc)

FITT



A gradual approach to exercise is to only increase one thing at a time. So if you increase both the intensity and the time, you get too much overload!

FITT



So just choose one thing to increase (in this case intensity) so you get a small amount of overload, then next time, you can increase something else.

Fatigue is normal with exercise!

- Everybody experiences fatigue
- But need to watch for excessive fatigue
 - Out of proportion to activity
 - Lasting for a long time
- If you experience these, then need to modify an aspect of exercise (use FITT principle)

If you don't experience any fatigue with exercise, then the benefits will be minimal!

Other strategies to try



I'm guessing that some of these strategies, you will have already worked out yourself, but I'm hoping that you might find something additional that helps!

FATIGUE AFTER GBS – CONFERENCE PRESENTATION

Conserve and Balance Energy

- Prioritise important activities
- Reduce unnecessary energy use
- Balancing rest and activity
 - Sleep at night
 - Rest during the day
 - May need to plan and be organised
 - Once you work out a routine, stick to it

View your energy as a limited resource, so work out what are the most important activities that you would like to do.

Think about the activities you do and consider whether there are ways to reduce energy use (eg avoid multiple trips)

It's important to try to find the right balance between rest and activity. Firstly this means doing what you can to ensure you get a good night's sleep (Minimise what causes you disturbances during night: eg. noise, temperature)

Schedule and take rests during the day. A rest doesn't necessarily mean a sleep; it could be a quiet activity in between two more active tasks.

It might be necessary to create and stick to a schedule. Avoid boom and bust cycles

Other ways to help manage fatigue:

- Communication
 - Ask for or accept help
 - Let people know how you are feeling
 - Learn from others
- Healthy eating
- 'Trial and error'

Communication – ask for help or accept help offered! Can just be with little things – get someone else to do your laundry and spend your energy on something more pleasurable! Events such as this weekend give you the opportunity to listen to the experiences of others and hear what works for others.

Good nutrition is important for giving you optimal energy levels. Not necessary to follow a specific diet, but follow healthy eating principles (lots of fruit and veges, less sugar, less fat,)

Summary


- Fatigue is persistent after GBS/CIDP
- Many ways to help manage fatigue
 - Remember the water bottle for exercise
 - Healthy diet
 - Balance activity/rest
 - Prioritise



GBS – A Very Personal Encounter

I am a neurophysiotherapist working at a rehabilitation Centre in Auckland. I have rehabilitated several GBS patients over the years; the nurses at work even call me a "GBS specialist". My 15 year old son contracted GBS 2 months ago whilst travelling overseas. I noticed that his gait was looking funny and he was hyperextending his knees for support. The next day he was struggling to get up off the floor and upon testing his balance he couldn't stand on one leg and had difficulty tandem walking. I took him straight to a neurologist who diagnosed him promptly with the clinical signs and confirmed that the next day with a nerve conduction test. At that stage my son was needing support to walk. He was treated with IV Ig and has made good recovery. Fortunately his respiratory muscles were not affected.

Being on the other side as a carer, I found it really hard to come in terms with the diagnosis and couldn't stop crying. Seeing my son go through the chills and fever as a reaction to IV Ig made me feel helpless. As a mother I was worried for him day and night thinking whether he would be able to play the piano again swim, bike or run as before. As a physiotherapist I motivate and reassure my patients and their carers but being in that position myself made me realise the impact of the disease in whole. I believe that anybody who has gone through the journey of GBS is a true survivor!



**Be stubborn
about your
goals, and
flexible about
your methods.**

Waikato Bay Of Plenty February Get Together.

We had a change of pace for our February meeting and incorporated a cycle ride along a new cycle track just out of Te Puke. 5 hardy cyclists turned up on an overcast day and braved the elements. We had to apologise to the rest of the attendees as we were rather late getting to lunch and I think some were beginning to wonder if they had the right day and place. Thank you for your patience.



Cyclists: *Grant McKay, Chris Hewlett, Meike Schmidt-Meiburg, Barry and Judy Deed*



Lunch goes: *Barry and Judy Deed, David and Yvonne Powell, Grant and Fran McKay, Robin Campbell and her sister Barbara, Chris Hewlett, Meike Schmidt-Meiburg.*

NOTICEBOARD

Hawkes Bay Coffee Group

An informal luncheon will be held for coffee and chit chat with others who have been down the GBS track.

Where: Golflands, Mangaterere,

When: Saturday 9th April

Time: 12.30pm

Spread the word among your HB friends. All welcome to attend.

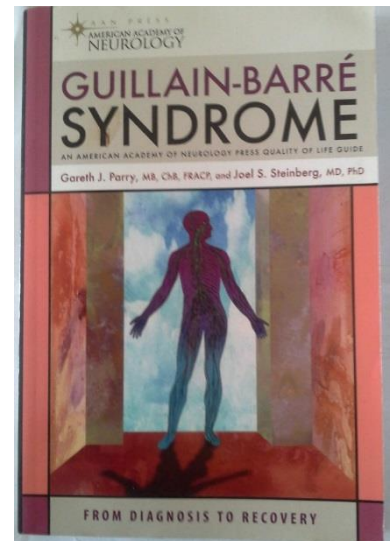
Ph: Lil 06 837 5696

What's Your Story ?

Urgently needed are your stories to publish in your magazine.

Please take the time to write about your GBS/CIDP (and or other Variants) and post or email to me – your editor. Details on the front of the newsletter.

Bob Stothart is happy to assist anybody to write their story. Contact him by **email:**
stothart@ihug.co.nz



We have copies of this book in stock again. Contact Tony Pearson for your copy. Just \$25

Email: tonypearson@xtra.co.nz
Ph: 03 526 6076

WAIKATO/BAY OF PLENTY COFFEE GROUP

May 2016



Where: Okoroire Hotel
18 Somerville Road, Okoroire

<http://www.okohotel.com/>

When: Wednesday 11th May

Time: 11.30 am onwards

**See you there.
Everybody welcome.**

PUBLICITY OFFICER WANTED

We are looking for someone who would like to take on this role.

If you think you have what it takes please contact:

Ken Daniels: espin.karori@xtra.co.nz

Or

Tony Pearson: tonypearson@xtra.co.nz



Guillain Barré Syndrome Support Group Trust N.Z.

Registered Charity No CC20639 www.gbsnz.org.nz

INVOICE

2015-2016 MEMBERSHIP ANNUAL SUBSCRIPTION

Subscriptions for membership of the Group for the financial year commencing on 1st December 2015 are now due and your ongoing support would be appreciated to help further the important roles the Group plays in supporting new and existing sufferers of this devastating syndrome.

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

Subscription Rates

Single Annual \$15.00

Single Life \$150.00

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

Be sure to reference your name on the transfer

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

Thank you on behalf of the Board of Trustees.

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

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