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## Guillain – Barré Syndrome Support Group New Zealand Trust

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

### NEWSLETTER September 2023



|                          |                                   |  |   |
|--------------------------|-----------------------------------|--|---|
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### **We Need Your Continuing Support. Can you help us by making a small Donation?**

We rely on donations from members and supporters to cover the operational costs of the group which is run by unpaid volunteers, all GBS/CIDP/Variants survivors or members of their families or carers.

#### **BANK TRANSFER INFORMATION**

**Bank Account Number – 15 3949 0339362 00**



**TSB – Moturoa Branch New Plymouth**

Please be sure to put your NAME in the reference area of the form so we can issue you with a receipt.

**AUTOMATIC PAYMENT:** Another way that you may like to consider is using internet banking to make small but regular monthly donations to the Group – a \$5 per month would give the Group \$60 a year – a really helpful donation.



## Medical Advisory Board



|   |   |
|---|---|
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Doug Young  
Tony Pearson  
Tony Pearson  
Daniel Leadbeater  
Tony Pearson  
Dr Suzie Mudge  
Dr Gareth Parry

## Editor's Note – Ansie Nortje



I hope that you will enjoy our spring newsletter and that you will find the information in it helpful.

Included in this edition are the May 2023 slides of Dr Suzie Mudge's presentation of her research topic on GBS, physical activity, fatigue and a few other things. As highlighted, physical activity has a range of benefits, all related to our overall wellbeing. According to the Mental Health Foundation of New Zealand, wellbeing means that we have the tools, support and environments we need to be who we are, and to build and sustain lives worth living. The five ways to wellbeing that they mention are: connect / *me whakawhanaunga*; give / *tukua*; take notice / *me aro tonu*; keep learning / *me ako tonu*; and be active / *me kori tonu*. For more information, refer to [https://mentalhealth.org.nz > five-ways-to-wellbeing](https://mentalhealth.org.nz/five-ways-to-wellbeing). Dr Mudge is currently working on a more user-friendly hand-out of her research findings, which will be published in a future newsletter.

I will be retiring from my role as newsletter editor at the end of 2023. If you are interested in taking up this task from 2024, please contact Tony Pearson (see his article Situations Vacant).

Thank you to everyone who has contributed to this newsletter, as well as to all of you who continue to be part of our Support Group.

*Ansie*

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## President's Report – Doug Young



Welcome to our Springtime newsletter for 2023.

The neighbour's lambs are running around their paddock this morning, indications that warmer weather is on its way and it gives a positive feeling to things. Along with Father's Day in the mix.

The last three months have been business as usual. I see it as a consolidation period where we catch up on the outstanding items from the AGM and any issues affecting the running of the Support Group. Simple items like changing the signatories of the bank account with Peter's retirement, is a minor logistical nightmare for Tony and Peter to sort out with TSB requiring time and patience.

I need to thank Meike and her team (Joanne) for the last regional meeting during May at the Ngatea District Hall. Twenty-seven people turned up and Gareth's team all felt they had a great day out. When we run these meetings it's well worth the effort of turning up to them.

It's good to see we are making progress in the research area, where Suzie Mudge is close to presenting her findings from the Fatigue research project and presenting it in a way that will be useful to everyone involved in the recovery phase from GBS. Also, Eileen McManus' project which requires as many ex-sufferers as possible to become involved, check out how to do this further on in this newsletter.

To those of you who are regular IVIg users, we are aware of some concerns with the change over from Intragam to Privigen in regards to the time it takes to administer the new medication. Gareth is investigating this for you as to the reasons why it takes longer. He will report back shortly.

That's it from the President, don't forget to make that small monthly donation to keep "The Wheels of GBS Recovery Process" going.

Regards to you all

Doug Young President.

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## Secretary's Jottings – Tony Pearson



Thank you to those couple of members who returned the GBS Book by Dr Parry – with three I have managed to buy in NZ, less one already sold to a new member, we now have four in stock! I will have a look at what is on offer in the USA, but these are always expensive - so if you still have a book and might be able to manage without it – I'm your man!

How's your Te Reo? I have to admit I am struggling with the plethora of Māori names that are being promulgated by the various Ministries that my reading takes me too:

Manatu Hauroa.....Ministry of Health; Te Whata Ora ..... Health New Zealand;

Te Aka Whai Ora....Māori Health Authority; Whaikaha ..... Ministry of Disabled People.

I guess in time we will become accustomed to these names and I suppose that is the object of the exercise but personally I would find it much more helpful if the English word preceded the Māori equivalent but that's probably a reflection of my advanced age and ethnic background. AND.. just in case you are wondering what the difference is between Manatu Hauroa and Te Whata Ora:

*"The Ministry of Health is focused on policy, strategy and regulation whilst Health NZ has taken over the planning and commissioning of services and the functions of the 20 DHB's to remove duplication and provide true national planning".* So now you know!

One of the latest actions of Manatu Hauroa is to develop a Rare Disorders Strategy for dealing with the many obstacles that people with rare diseases (and GBS is definitely within that catchment group!) face when trying to access the present health system. Whilst many of the aspirations of the draft strategy are admirable (and self-evident) such as a timely and accurate diagnosis, early treatment and adequate support systems, I can't help wondering if a more immediate focus on training and retaining more relevantly qualified health professionals wouldn't go a long way to solving present frustrations within our rare disorders community. Enough on this topic from a "grumpy old man"!!

Writing this on the first day of Spring – bright and sunny but a chilly wind – I thought with holiday season on the horizon some advice from the UK GBS Group GAIN to its members might be interesting:

**1. Holiday Vaccinations – are they safe for GBS'ers to have?:** Modern vaccines are incredibly safe and it's up to you to judge if the risks of catching the potential holiday infection outweigh the VERY small risk of triggering a GBS relapse and whilst most vaccinations do have some mild side effects (which might be more noticeable by those with a CIDP condition) they usually last only a few days.

**2. Do I have to declare my condition to the holiday insurance company?:** The simple answer is YES, if you have a CIDP or MMN condition as it is classed as a "pre-existing" condition but if you had GBS or Miller Fisher a while ago you probably do not, although questions on past hospitalisations/medications may require a more precise answer.

We all know that GBS is no respecter of sex, age or race, but in the now many years I have been National Co-ordinator for case referrals I have had very few Māori but in the last month there have been two! Both young males - previously fit and active - both put into ICU after a rapid decline: the first was discharged from rehab last week after just a four-week journey; the second who's attack started about the same time is still in a serious condition in ICU (one eyelid blinking only!) and facing a long recovery road ahead – no rhyme nor reason to that!

Like many CIDP'ers I was not able to pinpoint the "trigger" that caused my immune system to react at the time I was hospitalised (three times), but over the years since I have come to believe that it was work stress at that time that caused my immune system overload. It has therefore been interesting to read that an immunology researcher at Melbourne University, who was interested in the evidence that suggested the immune and nervous systems "talk" to each other, has been able to demonstrate (with mice) that applying stress to an individual stopped the immune cells (our T and B lymphocytes) from moving around the body – an essential feature allowing the cells to get to the right location to mount a response against an infection or tumour. Repeatedly subjecting the body to a stressful situation seemed to prevent the immune system from doing its job. BUT, as far as I am aware, GBS attacks are caused by the immune system going into "Overdrive" - or at least becoming "super-efficient" - when dealing with what they believe is an "infection" of our nerve's myelin sheath or the axon of the nerve itself. So maybe it WAS something else that set me off down the path of IVIg and Steroid familiarity? Has any other member attributed their GBS trigger to stress? As always, stay safe *Tony*

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## SITUATIONS VACANT – Tony Pearson

Our request for help in managing our website has been answered by Chris Lynch, the son of our identically named neurologist MAB member who will assist Chris Hewlett with some of the more “Techi” aspects of the operation. Thankyou both for stepping up.

We have not had any response to our request for Fundraising Committee Support members, so I will repeat the request carried in the last Newsletter.

### FUNDRAISING COMMITTEE MEMBER

Two of our Board members Doug Young and John Podd have been tasked with forming a sub-committee to developing ideas for raising funds to help support Group operations. Without a regular subscription income, we rely on donations to meet the day to day running costs of the Group which amount to about \$6000 per year. We are seeking help from a member or members who have some experience in this area to join that subcommittee to come up with some viable options to pursue. This does NOT include major PROJECT fundraising e.g., from Lottery or the RATA Foundation, but rather smaller scale membership focussed ideas to provide a modest but regular income flow for the Group. Discussions will be held via Facebook/Zoom or Phone. If you would like to help out by joining Doug and John in pooling ideas – or even if you have a single suggestion or idea – please contact Doug on [deyoungs@xtra.co.nz](mailto:deyoungs@xtra.co.nz) (03) 230 4060.

### NEWSLETTER EDITOR

For the last few years our Board Member Ansie Nortje has organised and edited our quarterly Newsletter. Ansie would now like to step back so we need a new Editor to come forward please from the membership. The Newsletter is completed in MS WORD – so a programme that should be familiar to most of the membership. Content is supplied by members of the Board, organisers of coffee group meetings and from other members of the Group who have stories of their GBS/CIDP journeys they are happy to share.

The Editor is responsible for compiling these inputs into the familiar format which includes the usual information on Board members and MAB members – contact data etc – a fixed/regular content – a task that involves 15 to 20 hours dedication 4 times a year. The Editor usually adds a “selfie” comment and if so-minded, a few “artistic” flourishes! We aim to publish a Newsletter at the end of March, June, September and December. Distribution of the final pdf version is by e-mail or post and systems are well established to accomplish this. All expenses of production and distribution are, of course, covered by the Group.

So.... if you have a modicum of experience and/or enthusiasm to have a go at this – Ansie will assist and guide you through your “first shot” - please let me know. [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz)

I am aware that a number of members have come from an “Office” background – or are indeed still engaged in publishing type activities, so PLEASE step forward and perhaps derive a degree of satisfaction of “giving back” to the Group that helped you in your hour of need – or is indeed still doing that. Thankyou.

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## From a Patient Perspective

### Cyclocross and CIDP – by Daniel Leadbeater



Recently I made a comment to Tony regarding entering the Cyclocross National Champions Age Group race held in August in Christchurch. I should have known better as, not one to miss an opportunity, Tony asked me to put some pictures together for the newsletter.

What is cyclocross you may ask? Cyclocross is a slightly unusual cycling discipline where riders race around a circular track on road type bikes equipped with knobbly tyres. On the course are obstacles such as stairs, sand pits, and barriers where the rider will usually dismount the bike, cross the obstacle with as much grace and finesse as they can muster, remount their bike, and carry on racing. The aim is to complete as many circuits of the approximately 3km course as possible within 50 minutes. It is a great spectator sport and tends to attract people who enjoy ‘type 2 fun’.

I was drawn to the sport on the suggestion of a friend while on the long and reoccurring recovery from my CIDP diagnosis. Though perhaps an odd choice, as the race is on a circuit course, I can participate actively without the feeling of being ‘dropped’ from a group ride. A ‘race within a race’ will often develop and as there are multiple races in the season, groups of riders will compete amongst themselves rather than for an overall ‘win’. If the legs are simply not behaving, I can ride a few laps of the course and retire from the field to engage in some banter from the sidelines.

From my efforts at Nationals, I can now proudly proclaim that I am ranked 12<sup>th</sup> in New Zealand Masters 1. While there may have only been 13 people registered in this particular category (the elite category featured all of the very fit people there to compete for the national jersey), and the only person I beat failed to make it to the start line, I still finished ahead of everyone who didn’t race that day. This tends to exemplify my general attitude towards living with CIDP. I may not win the race, but I will have a good time out doing what I can, when I can. Through my face in jumping the barriers may suggest otherwise, I was having a great time racing myself around the course.

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## **Performance Report to the Charities Commission – by Tony Pearson**

As a Registered Charity, the GBS Support Group is required to lodge a publicly available report on its performance during the past financial year with the Charities Commission. This covers not only financial issues, but also a written report on how we performed against the targets that we set ourselves at the outset of the year. The following is a summary of the report I lodged, with Board approval, a month or so ago for the 2022 year:

### **Financials:**

We received \$12,000 in donations towards our operating costs – significantly larger than normal thanks to two large donations from generous benefactors and a further \$4000 to be dedicated to Research activities. Operating costs were held down to \$7000 mainly the costs of producing and distributing the quarterly Newsletters and costs associated with holding the AGM in Wellington and Regional meetings during the year. We made a Research grant during the year of \$17,000 for the Fatigue Study led by our MAB member Suzzie Mudge facilitated through Auckland University.

At the end of the year (30<sup>th</sup> Nov 2022) we had a balance of \$31,000 in our Operating Bank account and \$99,000 in the Research Funds bank account.

### **Performance:**

1. We met all requests for information, Brochures and Books and such was the demand that we are having to re-print our Brochure stock and are hunting for additional supplies of the GBS book.
2. Newsletters were sent out each quarter as planned.
3. The Facebook and Websites were maintained and kept up to date and proved to be a very useful and active source of information and advice for members. As is often the case our website suffered a few “glitches” during the year, but these were resolved in a timely fashion by our website managers.
4. Hospital Visits of course were not possible during COVID restrictions but with the easing of these in the year visits re-commenced were possible.
5. Regular coffee gatherings were held around the country and Regional Meetings were held in Auckland and Christchurch.
6. Our investment in Research continued within the financial restrictions of the original \$95,000 grant and a \$17,000 grant was made for research into Fatigue amongst GBS’ers.
7. Our Medical Advisory Board continues to be active with members attending Regional Meetings and giving advice via our website.
8. As planned, three Board meetings have been held via the Zoom medium in the year along with the “Face to Face” Board and AGM in Wellington in June 2022. Regrettably a planned Zoom extension of the AGM failed for technical reasons.

If you have any specific questions about our financial or “activity” performance, don’t hesitate to contact me at [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz).

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# From the Medical Advisory Board

## Presentation slides on GBS and Fatigue – May 2023 Regional Meeting

by Dr Suzie Mudge

### PHYSICAL ACTIVITY, FATIGUE and a few other things...

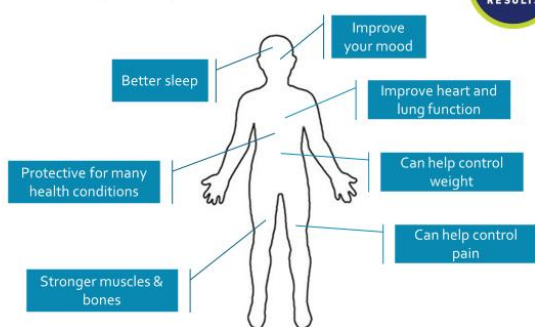
Dr Suzie Mudge  
Physiotherapist, Neuro Rehab Results & Senior Research Fellow, AUT

Presentation to GBS Support Group  
Ngatea, May 6, 2023

#### Outline

- Benefits of physical activity
- Research study results
- How to get the most out of physical activity

#### Activity helps



#### What about exercise with GBS & CIDP?

- Same benefits still apply
- Precautions/Risks
  - Muscular injuries
  - Exacerbation of fatigue

Markvardsen et al, 2018; Garssen et al, 2004; Janssen et al, 2018; Forsberg et al, 2015; Martin 2013; Arsenault et al, 2016

#### What is fatigue?



Subjective fatigue: a sense of reduced energy

Objective fatigue: reduced work capacity in response to activity



#### Fatigue



Fatigue is normal

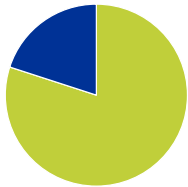


It is pathological when it is

Out of proportion to activity  
Doesn't resolve with rest  
Is present after sleep



## Fatigue after GBS



60-80% people (GBS + CIDP) report severe fatigue

- Not related to amount of recovery
- Persisting

Drory et al, 2012; Forsberg et al, 2015; de Vries et al 2010

## Can we change fatigue?



- Physical activity helps decrease fatigue in MS, PD
- Less clear after GBS
  - Small number of studies
  - Majority of studies conducted early after GBS onset
  - Most studies use a supervised exercise regime

de Vries et al, 2010; Mott, 2014; Cruickshank et al, 2015; Bussman et al, 2007

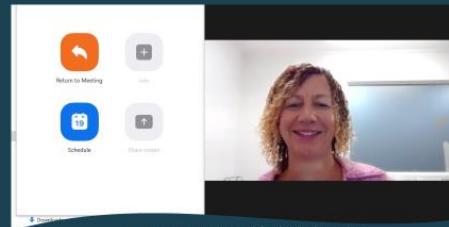


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## Physical Activity for Fatigue after GBS

Suzie Mudge, Greta Smith, Gareth Parry

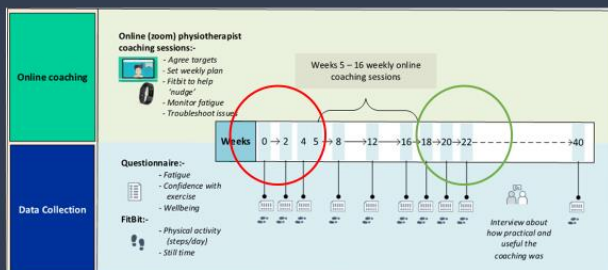


## Programme

- Remote sessions with physiotherapist
- 12 weeks
- Coaching to increase physical activity
- Individualised to each participant
  - Agree targets
  - Set weekly plan
  - Monitor fatigue
  - Troubleshoot issues



## Methods



## Participants

- 8 participants completed the programme
  - 4 male, 4 female
  - Ages: 58 - 81 years old
  - Fatigue severity score: 4.6 - 6.9
  - Steps/day: 1,554 - 9,888
  - Time since diagnosis: 2-12 years

## What did we find

Everybody was positive about the programme. 



Fatigue

Six participants reported less fatigue after the programme.

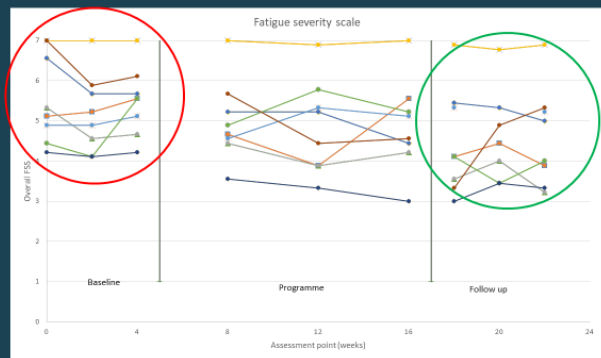


Physical activity  
(steps/day)

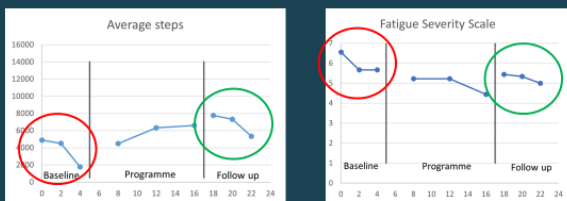
Five participants made a goal to increase activity during the programme.

Three participants showed clear increases of activity on fitbit. The other two did not but described doing more activities.

## Fatigue



## A picture of one participant



Feeling heard

Supported

It was personal

Personal connection matters

What participants thought was important about the programme.

Insights

Strategies

Things I've learnt

Fatigue

What participants thought was important about the programme

Keeping on track

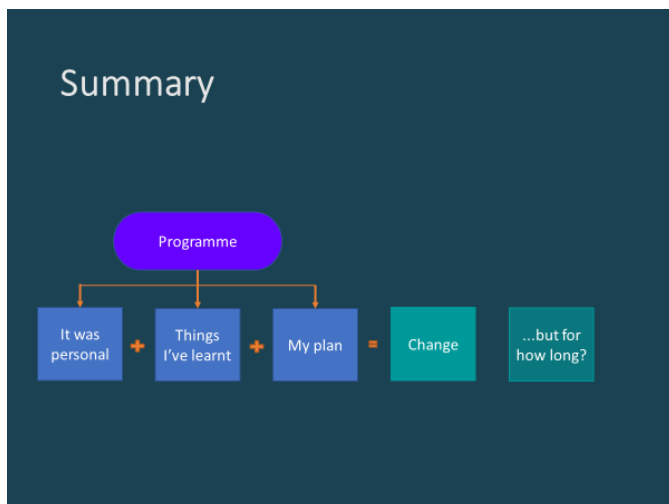
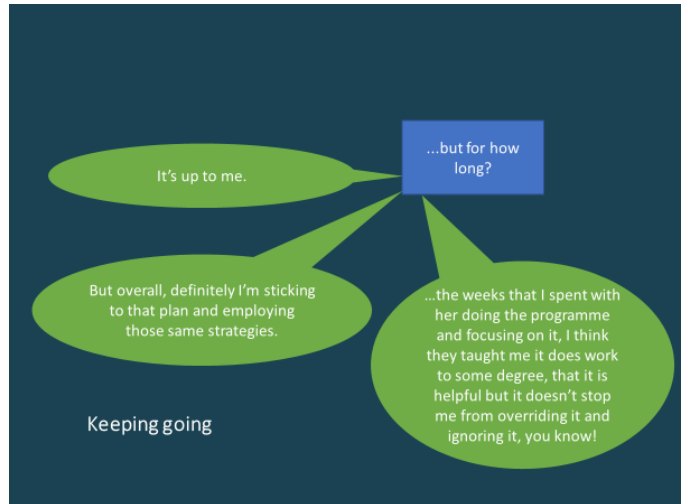
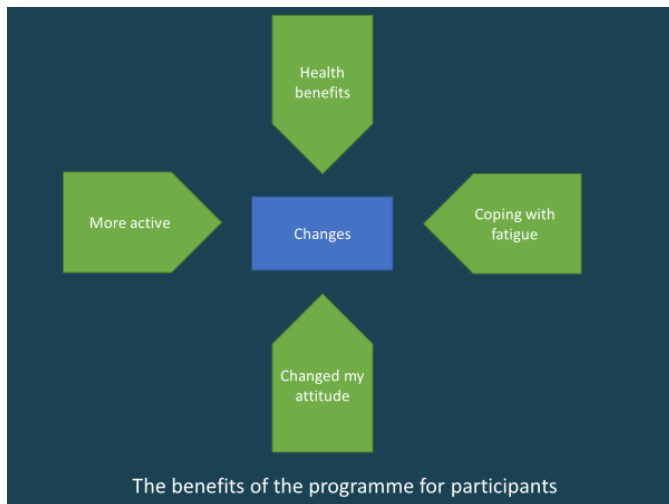
Feedback used for action

My plan

Aiming for the target

Making it part of my routine

What participants thought was important about the programme



## Understanding fatigue

- General features of fatigue
- Options for managing fatigue
- Try out strategies
- What works best for me



## Resources

<https://www.mssociety.org.uk/about-ms/signs-and-symptoms/fatigue>  
<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/tiredness>  
 MS energise app

## Activity helps reduce fatigue

## Balancing activity and fatigue

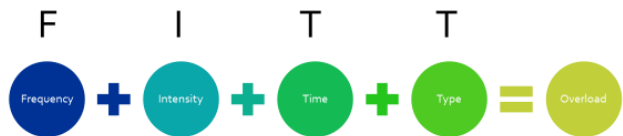


### TIPS

- Start small
- Progress gradually
- Monitor fatigue

## Use FITT principles

- FITT principles – use to start exercise
  - 1-2 times/week
  - Light intensity
  - Short duration
  - One type
- Progress **one** thing at a time using FITT principles
- If you have too much fatigue after exercise, use FITT to reduce



## Remember 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 fatigue with activity, then you need to modify an aspect of exercise (use FITT principles)

## Set targets



- Specific target
  - Steps/day
  - Exercise sessions/week
  - Take a 1 hour rest every day after lunch
  - Get a house cleaner

## Make plans

- What do you need to do to meet target?
  - Schedule in diary
  - Set a reminder on phone
  - Get your sneakers out night before
  - Contingency plans
- Write your plan down



## Support helps

- Exercise buddy
- Encouragement from family/friend
- Someone who can listen
- Support group



## Other fatigue management options

- Good sleep hygiene
  - <https://www.healthnavigator.org.nz/healthy-living/s/sleep-tips/>
- Structure your day
  - Balance high and low energy demanding activities
- Schedule a rest
- Make gradual changes
- Good nutrition

## Summary

- Fatigue is very common after GBS/CIDP
- Fatigue can be improved
- Activity is an important part of managing fatigue
  - Start small and go slow
- Try out different strategies to find what works best for you



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## Acknowledgements

- Participants
- Advisory Group
- Funding
  - Neuromuscular Research Fund
  - GBS support group
  - AUT Faculty Development Fund



## From the Medical Advisory Board

### Presentation slides on GBS in Aotearoa/NZ – May 2023 Regional Meeting

by Dr Gareth Parry

## GBS in Aotearoa/NZ

What does it look like here?



## GBS in NZ

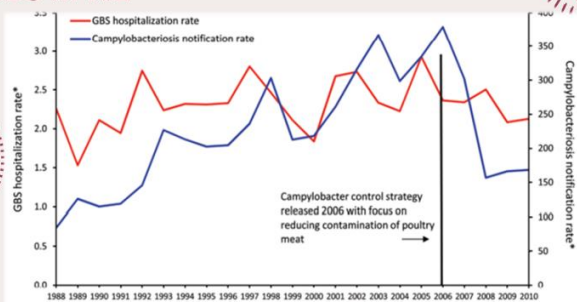
- Early 2000's in Auckland there seemed to be an unusual number of variant forms of GBS, especially amongst Māori and Pasifika:
  - Miller Fisher Syndrome (MFS).
  - Pharyngo-cervico-brachial (PCB).
- Was this just random variation or was there a different pattern of disease seen in NZ, mainly affecting people of Polynesian origin?

## GBS in NZ

- 2012 a report was published indicating that NZ had the highest incidence of GBS in the developed world, based on a survey of GBS cases occurring between 1988-2010.
- The average incidence during that 23-year epoch was 2.32/100,000/yr (1.53-2.93) compared to incidences of 1.5-2.0 in several studies in other developed nations.
- The increased incidence of cases was attributed to our high rates of *C. jejuni* gastroenteritis, a known trigger for GBS.



## GBS in NZ



## GBS in NZ

- In 2019 we decided that we should try to determine what GBS actually looked like in NZ.
- The start of the study was delayed by COVID and the need to obtain ethics approval and funding but it was finally launched in mid-2022.

## GBS in NZ

- The questions we chose to address were:
  - Why is GBS more common in NZ?
  - Does GBS affect Māori and Pasifika differently?
  - Is GBS more severe in NZ than in other developed countries?
  - What factors affect recovery from GBS?
  - [Is TPE a more effective treatment for severe GBS than IVIg?]

## GBS in NZ

- What have we achieved so far?
  - We have collected GBS cases back to the beginning of 2017 (retrospective cases) by mining MOH hospital discharge data.
  - We continue to collect new GBS cases (prospective cases) as they occur.
  - We have obtained data from ~300 cases (~260 retrospective and 40 prospective).

## GBS in NZ

- What have we found so far?
  - GBS may not be more common in NZ.
    - Only 542 of the 610 retrospective cases collected over the 4 years 2017-2021, coded in the MOH database as GBS actually had it.
      - ~20 had CIDP that presented acutely and initially diagnosed as GBS
      - The remainder had a wide range of other diagnoses including other neuropathies, stroke, myasthenia gravis, etc and some turned out to have no identifiable neurological disease.
      - The 2012 study had taken the MOH data as accurate and did not review individual patient records.

## GBS in NZ

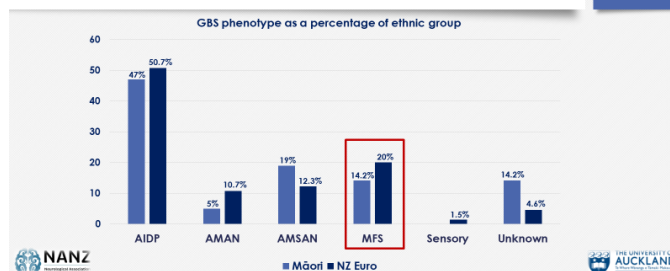
- What have we found so far?
  - If we do a rough calculation using the accurate data we find:
    - \*\*542 cases over 5 years = 110 cases/year =  $2.11/100,000/yr$
    - \*\*610 cases over 5 years = 122 cases/year =  $2.35/100,000/yr$
  - Thus, if the annual incidence is 2.11 that is not a lot more than findings from other developed countries whereas the figure of 2.35 is almost exactly what the previous NZ study had found.

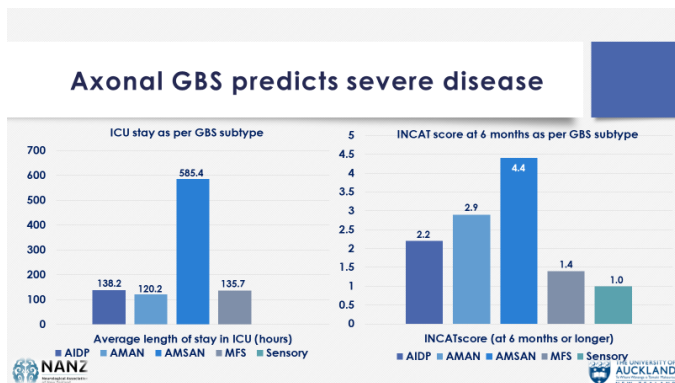
[\*\*Assuming a population of 5.2 million (2021 census figures)]

## GBS in NZ

- What have we found so far?
  - AMAN/AMSAN are more common in NZ than in other developed countries.
  - AMAN/AMSAN predict poor outcome with longer ICU stay and poorer functional scores at 6 months.
  - MFS is more common in NZ than in other developed countries (~15% vs ~5%) but it was slightly more common in NZ Europeans than in Māori (20% vs 14%).
  - Insufficient Pasifika cases to say whether MFS is more common in these patients.
  - Very few cases of PCB variant.

## MFS is prevalent in New Zealand





### GBS in NZ

- What have we found so far?
  - GBS is more severe in NZ.
  - Gastroenteritis is more common in NZ Europeans compared to Māori (19% vs 5%).
  - Māori are in the ICU for longer than NZ Europeans (260 hours vs 150 hours) and have poorer recovery.
  - Metabolic syndrome (obesity, hypertension, diabetes, gout, high cholesterol) is associated with slower recovery (320 hours in ICU vs 120).

### GBS in NZ

- What have we found so far?
  - Is TPE more effective than IVlg in severe cases?
  - We have no idea because not a single case has been referred for this segment of the study.

### GBS in NZ

- Caveats:
  - We still have relatively few patients (~300 of our target of ~1000).
  - Māori and Pasifika are under-represented.
  - We have few Auckland region patients.
  - We have few prospective patients (~40) and many data points cannot be found in the retrospective patients.

## PAST EVENTS

### Waikato/Bay of Plenty get-together of Wednesday 9 August



We had a lovely few hours catching up again with our friends and getting to know our new members. I mentioned the research project by Drs Eileen McManus and Gareth Parry again, and hopefully everyone will get in contact with them, to be part of this exciting project!

*by Meike Schmidt-Meiburg*

**Back row L-R:** Charmaine Barry, Chris Hewlett, Jill Keals, Grant McKay, Peter Barry, Mike Logan and Lyn Neels, Bob Keals, Meike Schmidt-Meiburg

**Middle row L-R:** Janice Boon, Fran McKay, Karen Soppet, Christine Wilton

**Front row L-R:** Jan Gribble, Fiona Green, Rex Soppet, Emma and Phil Wolfe

**Also present:** Tom Boon and Marty Hewlett

### Auckland North/West get-together of Sunday 27 August

A good chat swapping anecdotes and experiences with regulars Lorraine and Brian and new-comers Paul and Devi McNeill. Paul was diagnosed with GBS early 2023 and making good progress.

*by Eileen Jacobsen*

# NOTICEBOARD – UPCOMING EVENTS

## Bay of Plenty/Waikato Coffee Group



The forthcoming dates for our eating/drinking/chatting get-togethers are:

**Wednesday 4 October 2023** from 10.30 am at Cafe Nineteen, Fairview Estate Country Club, 34 Sharp Rd, Aongatete, Katikati. (07-549 3412, they close at 4pm.) Please let me know that you are coming or not by 2 October

**Thursday 30 November 2023** from 10.30 at the Willow Glen Cafe, 934 Gordonton Road, Hamilton 3281.

[www.willowglen.nz](http://www.willowglen.nz). Check out their menu (07 824 3691, they close at 4 pm.)

If you would like to take part in our Secret Santa, please bring a gift along to the value \$10, suitable for either your male and female friends.

Please let me know by Tuesday 28 November if you are coming or not.

(07) 86 73 163 or 027 325 0369 or [schmidtfarm@xtra.co.nz](mailto:schmidtfarm@xtra.co.nz)

Looking forward to another good catch-up with you all, Meike :)

## Auckland Coffee Groups



### Auckland North & West:

**When:** Sunday 26 November 2023

**Time:** 2pm

**Where:** Kings Garden Café  
Kings Plant Barn  
11 Porana Road, Takapuna

New members most welcome.

**Please RSVP Eileen at**

[eileenmagnajacobsen@hotmail.com](mailto:eileenmagnajacobsen@hotmail.com) Mob: 021 113 3607

### Auckland Botany:

**When:** Wednesday 22 November 2023

**Time:** From 10:30am

**Where:** Columbus Coffee at Mitre10, Botany, Auckland  
9 Bishop Dunn Place, Flatbush  
(off Ti Irirangi Drive)

Come and join us for a get together and a natter over coffee and/or tea, eats also available.

**Please contact Rex if you have any questions**

[rexbuckley@xtra.co.nz](mailto:rexbuckley@xtra.co.nz) Mob: 027 296 3297

## What's Your Story?

Would you consider telling us about your experience for publication in this - your magazine? Please take the time to write about your GBS/CIDP/Variant and send to the editor.

## Wellington Coffee Group



I am looking for a person/s to organise and host - at a venue of your choice - future Coffee gatherings in the Wellington area. If you are interested, I would love to hear from you.

**Ansie's contact details:**

[gbs.newsletter@gmail.com](mailto:gbs.newsletter@gmail.com)

Mob: 027 332 8546

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