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## **Guillain – Barré Syndrome Support Group New Zealand Trust**

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

### **NEWSLETTER December 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



<b>Dr. Gareth Parry (Chair)</b> ONZM, MB, ChB, FRACP Emeritus Professor, Department of Neurology, University of Minnesota, USA. Clinical Senior Lecturer, Otago University, Wellington Visiting Neurologist, Wellington Hospital. Medical Advisory Board: GBS/CIDP Foundation International	<b>Dr. Annette Forrest</b> ICU Consultant MBChB, BPharm, Dip Ag & Vet Pharm PGDIP Aeroretrieval Masters Aviation Medicine CAA Medical Examiner PGDIP Occupational Health
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Ian Gordon  
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Medical Advisory Panel

## Editor's Note – Ansie Nortje



As usual, this newsletter contains helpful information and food for thought. Speaking of which, December is the time for annual reflection and the opportunity to think about how satisfied we are with our lives, and where to go next.

Life tends to slow down over the festive season, we enjoy celebrations and focus on relationships, and we are often surprised at how quickly another year has passed.

We now have time to reflect on questions such as:

- What were the two or three greatest lessons that I have learned?
- Which healthy habits have I followed the past year?
- Did I make any new relationships that enriched my life?

On a personal note, as mentioned in the previous newsletter, I have decided to resign as Board Member and as newsletter editor. I wish to thank you all for the opportunity I had to be in these roles, and I wish you all a Merry Christmas and a Happy New Year.

*Ansie*

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## President's Report – Doug Young



Hello everyone

The December newsletter for 2023 is here, along with Summer.

Let's not forget to add Christmas into the mix as well, hopefully the Santa suit still fits for those of us delivering presents to children & grandchildren on the eve of the big day.

The last three months have been business as usual with people bevering away in the background.

Tony with about ten items to handle at once for his normal day. Peter and Brian tidying up the accounts hand over process. The interesting one is the work going on with Suzie Mudge and her Fatigue Study report on its findings as shown in the last newsletter. It's now becoming an active page on our website for everyone to access for information and advice on managing fatigue. It should be ready for release in the new year. As president, I cannot say enough about the time and effort Suzie and her team have put into this project. It will have a very beneficial outcome for us.

Our current headaches are finding some IT literate person to manage our website in an overview capacity and communicate with our website supplier. Also finding a replacement for Ansie as the News Letter Editor. These are both a work in progress.

On that note I need to offer a huge vote of thanks to Ansie Nortje for filling the editor's role over the last four years, along with her able assistant Louis. It is a time-consuming role to have within the organisation, and I am sure Ansie has given up a lot of her time and energy to make sure the deadlines for publication have been met. On behalf of all of GBS Newsletter recipients, and the Board of Trustees - Ansie, thank you for this. As you and Louis wind down your involvement with the support group over the next few months we are going to miss you both. Please accept our best wishes for the future and always stay in touch.

As President, I wish all readers a very Merry Christmas and a Happy New Year and that you get to enjoy some time with family & friends. And the summer due, plays its part as we expect.

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.





## Secretary's Jottings – Tony Pearson



As I write this piece for the Newsletter, I am waiting with “baited breath” (NOT!!) to learn if this country has finally got a functioning Government again more than a month after we all voted. I AM keen to see if this new crowd really DO have a will to solve the many serious problems this country is facing in its education and health arenas. At the end of the day, I guess it all comes down to having enough \$’s to fund the changes/improvements that are frankly self-evident to most of us. In the meantime, we continue to have to rely on the “good offices” and selfless input of those in the medical and teaching professions to keep the systems reasonably on track – in my book they deserve a BIG thankyou from all of us. – Enough “ranting” from me!

A BIG thankyou is also due to our Auckland member Mike Whyte and his business The Print Guys for not only re-printing our stock of Brochures at a very special “mates-rate”, but also for re-jigging the whole of their technical layout to “future proof” the content against printing software changes. Dr Parry had given them all the once over prior to this exercise so we are now in good shape to continue supporting new GBS’ers for a few years to come. I have also been able to acquire 6 more copies of Dr Parry’s book “From Diagnosis to Recovery” and two members have returned copies they had previously purchased for others to use – thankyou. The books, of course, have doubled in price and now cost \$40 a copy from Ebay or Fishpond!

There have been some interesting statistics about GBS appearing in various reports/surveys over the past few months:

From an MPI report of the 118 GBS reported cases hospitalised in 2022, some 18 were under 20-years old, 30 were 20-50 and 70 were over 50 with 23 of those being 70+. GBS can therefore impact on all ages, but as we know seems more prevalent in the aging population. Some 30% of those cases were triggered by Campylobacter infections.

A survey published by the American Academy of Neurology concludes that getting COVID increases the risk of a GBS attack, whilst receiving a vaccination would appear to DECREASE that risk - a finding they felt “may re-assure vaccine hesitant patients”. A small number of GBS’ers in this country would dispute that result as they feel that it was the Vaccine that triggered their GBS attack - although ACC has only accepted one case as far as I know - but for the vast majority of us vaccination would seem to be wise. Certainly, I shall be lining up for booster No.5 in early December.

A submission from the Neurological Alliance of New Zealand to the incoming Minister of Health (yet to be announced) will point out that this country currently has only 36 Neurologists against an estimated 88 required to cope with the demand from our population – no wonder we have to wait so long for a diagnosis or consultation!

As some of you will know, we have lost three Board members with Matt Peacey, Peter Scott and now Ansie Nortje resigning from the Board. That we will miss their selfless contribution to the work of the Group goes without saying and we shall sorely miss their contributions to our Board discussions and their administrative contributions to our efforts, but life moves on and we are actively seeking to fill those positions and will keep you informed of progress. It is perhaps of cold comfort to know that the UK GBS Support Group – of which I am a member - have also gone through a “change” period losing their Chairman, Treasurer and 2 of their full-time office staff – but they too are in “replacement” mode.

Having just watched the news, I now know that we DO have a government ready to go and whilst we will see how things develop, I was saddened to see that one of the Institutions that will be getting the “chop” is the Māori Health Authority. I was never convinced that NZ could afford two Health Authorities, but I did see the establishment of a dedicated “workforce” that would deal with Māori health issues in a way that was valued and accepted by Māori as a good thing. I know as part of the nurse training programme the practice of Tikanga – patterns of appropriate behaviour, including customs and rights - is taught but, I guess, I do subscribe to the view that a Māori nurse is more likely to understand the complexities of Māori health extending as it does beyond the physical being and medical diagnosis of a patient. So, whilst I accept that our policies and delivery of care are relevant, regardless of the patient’s ethnicity, we do perhaps need to recognise that it may be necessary to do things differently for some groups to achieve similar or the same outcomes as others. It is about need – not ethnicity. Perhaps the new Government will work not just towards increasing our desperately short-staffed NZ nursing population, but also to increase the percentage of Māori nurses (just 7.5% currently) to better address the 17% Māori population currently in NZ.

So, as we advance towards Christmas, I would wish you a good break with family and friends, stay healthy and join with me in looking forward to an active and rewarding 2024. As always, stay safe *Tony*

## SITUATIONS VACANT – Tony Pearson

### WEBSITE MANAGER

Our celebrations of finding a volunteer to help us with our website and IT issues were short lived as he has now withdrawn, so a renewed request is included as follows:

Our present Website Manager has retired from his position to concentrate on his growing personal business. We urgently need a volunteer to fill this position which requires a modicum of IT capability and a general familiarity with the way websites work. All the technicalities of website design/re-design/problem resolution are subcontracted to an offshore provider, but “in-house” we manage the loading of data to the website such as past newsletters, information on forthcoming meetings and coffee group gatherings together with any information updates from our MAB. So..... if you are comfortable with working with your laptop/desktop/iPad and communications by e-mail and the occasional Zoom meeting and want to contribute to this important internet presence of the Group, please contact Tony [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz) 027 687 1953. A full handover of the job will be organised and our previous Web manager has confirmed he will always be willing to provide backup advice as necessary.

### 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. **To avoid the need to re-instate an annual subscription for membership of the Group** 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 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.

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. **If no one steps forward to take on this role, publication of the Newsletter will cease until the position is filled which will be a great shame, as the Newsletter forms an important part of our membership communications.** 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 at [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz) Thankyou.



## From a Patient Perspective

### A GBS Patient's Report on treatment and recovery at Middlemore Hospital

The Journey of Patrick Tam, as relayed to Tony Pearson

As part of my "job" as National Co-ordinator for Hospital Visiting, I receive a lot of contact from discharged patients seeking rehab recovery advice etc. Regrettably sometimes those comments do not reflect favourably on the care they received in Hospital for a whole variety of reason – so it is uplifting to hear from a patient about the excellent care and information about GBS that he received in Middlemore Hospital recently. The following is Patrick's verbatim comments:

*Middlemore doctors did inform me about your GBS Support Group and they did mention that your group provides excellent support to GBS patients. In fact, the one doctor who treated me in ICU had GBS himself and he only had good words for your Support Group.*

*I'm 68, about to turn 69 in December. I had to celebrate my birthday while in ICU last year but the doctors, nurses and carers tried to make it something special for me while still connected to machines, etc. I've decided to retire but being an engineer, I find it difficult to do nothing so I have emersed myself in some DIY projects which I had planned before getting GBS.*

*Personally, I found Middlemore excellent with my care and recovery. I think a lot comes down to attitude because while in the Rehab ward I came across some patients who seemed to be quite negative about things and felt that not enough was being done for them. I was very positive and I felt that if I don't apply myself properly in rehab, I would not be able to recover properly or as quickly as possible. The first day in the Rehab ward I was taught to transfer myself from my bed to a wheelchair and will admit that was very hard because of my balance and the stiffness in my muscles. The nurses and carers smiled when they saw how determined I was to get mobile in the wheelchair because I had to learn how to use it. After 3 days I was given the two-wheel walking frame and two days later the four-wheel walking frame. It was really hard but I pushed myself and I requested that they teach me how to climb up a flight of stairs because I have stairs to contend with if I go home. In two days, I was able walk up 20 steps of the staircase outside the Rehab ward, but like a small child would do so it was one step at a time leading with the stronger leg. My positivity and motivation seemed to influence some of the other patients in the ward because they seemed to be chirpier and smiling rather than sad and feeling sorry for themselves. The doctors were amazed that in two and half weeks I was able to learn to do so many things that we would normally do like toileting, showering and getting mobile again. On the 26<sup>th</sup> January 2023, I was discharged from Middlemore to continue with rehab and assistance from the therapists from the stroke support group of Middlemore and I progressed so much quicker at home without actually trying. I was told that was going to happen by the chief physio at Middlemore. I was very fortunate that the physiotherapist who came to my home was very experienced and understood the difference that GBS and stroke patients need in their rehab and recovery.*

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### GBS AND RESUMPTION OF DRIVING - Tony Pearson / Dr Gareth Parry

The following advice was given by Dr Parry over the website "Q and A" link a month or so ago. I thought it was sufficiently important for members to be aware of the requirement. I wasn't aware of this and commenced driving again (in England) when I felt "ready". I guess apart from the risk of accidents resulting from a less than 100% control of the vehicle, the question of liability and insurance also rears its head. I will arrange to add this item to our Q and A section on the website. - *Tony Pearson*

**Question:** When can you drive again after having GBS?

**Answer:** I asked the Occupational Therapy Department at Christchurch Hospital for their advice and this is what they said. "A return to driving requires medical clearance, at a minimum from the GP who will consider if there are any residual difficulties that may impact on driving such as upper limb weakness, reduced hand grip or reduced ability to quickly and accurately move your foot when seated."

*Fatigue and endurance also need to be considered and these can be difficult for the GP to assess in the office. Having up to date information from your physiotherapist and occupational therapist can assist the GP to make a decision. If they are unsure, you will be asked to do an Occupational Therapy Driving Assessment. It is recommended that any recommendation/clearance to drive is provided in writing for your records." The short answer is that you should check with your GP. If he/she is not happy to give you the clearance, you should get a referral to the local OT people to get the formal assessment. - Dr Gareth Parry*

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## **From the Medical Advisory Board**



### **Two short updates on current research projects**

#### **GBS FATIGUE STUDY - Dr Suzie Mudge**

Eight participants completed the activity focussed coaching programme and nearly all had less fatigue after participating in the programme. Participants found it useful to try different strategies and felt they developed knowledge and skills to manage fatigue over the course of the programme. Participants thought it would have been useful to have more information about fatigue earlier in their recovery and so we are developing some simple resources about fatigue that we will share with you shortly.

#### **THE GUILLAIN-BARRE SYNDROME (GBS) PHENOTYPE IN AOTEAROA/NEW ZEALAND (AONZ): HOW ETHNICITY, SOCIOECONOMICS AND INFECTION INFLUENCE GBS OUTCOMES – Dr Eileen McManus**

This GBS study started in Feb 2022 and is ongoing. Some of the aims include a) describing how GBS affects New Zealanders, b) examining the causes of GBS in AoNZ, c) examining the impact of ethnicity and co-existing illnesses and socio-economic status on disease severity and outcome, and d) studying the impact of the SARS-CoV-2 pandemic on GBS incidence in AoNZ.

To date we have 802 GBS cases enrolled (from 2017 – 2023) and we continue to collect prospective GBS patients. As data collection is incomplete, we have not conducted statistical analysis, but potential interesting findings include a) higher than expected Miller Fisher Syndrome cases in AoNZ, b) higher than expected metabolic syndrome in our GBS patients. Metabolic syndrome is a cluster of common abnormalities, including insulin resistance, impaired glucose tolerance, abdominal obesity, reduced high-density lipoprotein (HDL)-cholesterol levels, elevated triglycerides, and hypertension. Metabolic syndrome increases risk of heart disease, stroke and type 2 diabetes.

We have also found higher than anticipated incorrect coding of GBS cases at the time of discharge from hospital with many CIDP cases coded as GBS, as well as some individuals with nonspecific symptoms suspected to be GBS but not confirmed.

Our data collection will continue until 2025. If you are interested in participating in this study, please contact Dr Eileen McManus at [emcm373@aucklanduni.ac.nz](mailto:emcm373@aucklanduni.ac.nz)





# From a Patient Perspective

## An Experience of GBS – by Ian Gordon

*When your determination changes, everything else will begin to move in the direction you desire. The moment you resolve to be victorious, every nerve and fibre in your being will immediately orient itself toward your success. On the other hand, if you think “This is never going to work out,” then at that instant every cell in your being will be deflated and give up the fight, and then everything really will move in the direction of failure. (Dr Daisaku Ikeda).*

My name is Ian, I’m retired, and live in Auckland’s Waitakere region with my wife of 40 years. On an early morning in August of this year, I was getting out of bed when quite suddenly and without warning, my legs collapsed from under me. Until that moment, I had considered myself a healthy 66-year-old with few or any previous conditions. A call to the Healthline people suggested I go immediately to my nearest emergency department, and a few hours later, I found myself in the Waitakere ICU, unable to walk or even hold the weight of a cup of tea in my hands. I wasn’t afraid, but rather, bewildered by my condition which was quickly worsening and subsequently diagnosed as Guillain-Barre. Trying to sleep that night with agonisingly high pain levels was impossible and no amount of pain relief, including morphine, seemed to work. The second night wasn’t much better, and I confess to allowing my negative self to think that death at this time would be preferable.

On the 3rd day, one of the medical staff assured me, “It’s good pain. Your nerves are trying to reconnect.” Those words were enough to lift my spirits and with the advent of a doctor who seemed to know more than most about GB, I was better able to grasp what I was up against.

Transferred to North Shore Hospital, I began to focus on my recovery, but little sleep over several nights had left me greatly fatigued. And so, when the doctor suggested I begin physiotherapy, I declined, stating I wasn’t yet up to it. “Do you want to get well?”, she asked. It was a harsh question, but in that moment, I realised I needed to win over myself. That, I reasoned, would come with the determination to set goals, and take action to achieve them. Thus, I began to move my life forward in the best possible direction at a pace I decided on.

This initially took the form of resolving to somehow attend a party being hosted by one of my friends that was scheduled for the end of the week - just days away. Although physically impractical at the time, I told my care team, who in turn insisted that I would have to prove I could get in and out of a wheelchair by myself, then unaided, safely to and from a car.

That became the focus of efforts to regain my strength and movement, and I became known in the ward for my positivity and doing all I could to quicken my recovery.

The day before the party, staff accompanied me downstairs to the hospital car park and watched as I safely transferred myself to and from the wheelchair to the car. Victory!

Attending that gathering the next day was amazing. Just being around regular people I knew as friends, and people who weren’t wearing uniforms or masks was the very best tonic - my energy levels soared. I went back to my cubicle at the hospital that afternoon even more determined and told my care team of my next target. “We don’t want to pour cold water on your enthusiasm, but you’re here to get well. You’re going to need time to recover,” I was told. “Yes, I understand, and I appreciate your concern, but come Friday next week, I’m going to be released and go home,” I replied. Because I couldn’t yet walk unaided and given Friday was just a week away, they appeared somewhat sceptical.

Two days later I was informed that a space had become available in the rehabilitation ward. Prefect! When staff expressed their surprise at how quickly my body was healing, I asked what I would need to achieve to be released? After some discussion, it was suggested that if I could get to the rehabilitation ward gym, some 300 metres away, safely, and unassisted, that would be sufficient. By Thursday that week, I had walked to the gym AND back again, a total of 600 metres - all this after being completely unable to move just 12 days earlier. The next day, which coincided with the first day of spring, Friday September 1st, they gave me my discharge papers.

It was a joy to be back home, only now, I could set my sights on functioning independently, showering and dressing myself, and graduating from the walking frame to crutches. It was time for my next target.

My youngest daughter was flying up from Wellington in just 2 weeks' time and I would greet her as if nothing had ever happened to me. Sure enough, I was able to walk and balance without crutches or assistance, and although she knew I'd been in hospital, looking at me walking normally, she confessed she wouldn't have known I'd been unwell.

I'm now fully recovered, but I've learned so much from having GB. Knowing what it's like to be incapacitated, understanding what people who experience extreme pain must endure, and even feelings of hopelessness. In truth, I'm grateful for these insights into those otherwise unfamiliar worlds that have imparted a degree of empathy I lacked before.

Finally, I wish to acknowledge, my greatest supporter, my wife, who has steadfastly stood beside me, through the rollercoaster of suffering and joys. Thanks to her care, I was able to freely confront my challenges, accomplish my goals and keep moving forward to achieve them.

This valuable experience has also reminded me that while life may not always go as we intended, regardless of circumstance, it is we who decide its course, and it is we who make it worthwhile.



## **Making the Most of the GBS|CIDP Foundation International Symposium**

by Clive Phillips



**On the main stage**

In October I had the opportunity to travel to Washington DC for the GBS|CIDP Foundation International Symposium. The Symposium is a biannual event that brings together over 400 members of the GBS, CIDP and MMN community from across the globe. Attendees included those who have been impacted by the conditions, their friends and relatives, members of the medical research community and representatives from a wide range of organisations. These included pharmaceutical companies, patient advocacy groups and manufacturers of adaptive devices.

Across three days the symposium saw a wide range of events from updates on the latest in research, to patients sharing their stories and Q and A sessions with expert neurologists. This was mixed with sessions on physical therapy, yoga, you name it, if it helped patients it was discussed.

In addition to sessions aimed at all attendees, there were a number of condition specific breakout sessions. These gave people the chance to really focus in on what was most important for them. For me as someone living with MMN, it was wonderful to find another 19 people with the condition attending. A record for the event which has been going for at least 30 years.

As well as attending the sessions, I also had the privilege of chairing a couple of Q and A sessions and of giving a short presentation to everyone attending the event. This enabled me to explain the purpose of the Making the Most of Now project I founded a couple of years ago to raise awareness of MMN and funds for research into it. It was also a wonderful platform to promote the Ride the World for MMN which takes place next February during MMN Awareness Month.

The Ride the World for MMN will be the third Ride for MMN event in as many years. The aim of it is to encourage people to get active in February and collectively clock up at least 40,000km in the month, the equivalent of riding around the earth's circumference. This equates to one kilometre for every person with MMN in the world.

Accompanying the presentations was a large exhibition space where a wide range of organisations had information stands. This allowed you to spend time one to one with everyone from Foundation staff to advocacy groups. Again, I was lucky enough to have a stand where I was able to chat to people interested in my project, sell merchandise that raised money for MMN research and could get people signed up for the Ride the World for MMN.

Last but by no means least, in addition to the formal conference sessions there was plenty of opportunity to catch up with old friends and to make new ones over a coffee or a beer. This was undoubtedly the highlight for me as it was so good to learn from others and to hear their stories. As if this wasn't enough there was even the chance to participate in a quiz, a host of games and if you had the energy and leg function to dance the night away at the closing event.



Talking Bikes and MMN on my exhibition stand



Yes, I really was outside the Capitol Building!

Many of the presentations were recorded and will be available online next year as part of the foundations virtual summit which takes place in years when they don't run an in-person symposium. The next symposium will be in Denver, Colorado in 2025 and I for one will definitely be going again if I can. I would wholeheartedly recommend it to anyone in our community who wants to connect with other from all across the globe and keep abreast of the latest research developments and trends in our world.

More details about the Ride the World for MMN in February can be found at <https://p2p.onecause.com/ride-the-world-for-mmn24/home> and you can keep an eye out for my updates on my website (<https://makingthemostofnow.co.nz/>) and social media sites.

*(Editor: See the YouTube channel of the GBS CIDP Foundation International at <https://www.youtube.com/@gbscidporg/videos> and particularly this video featuring Clive just prior to the symposium: <https://www.youtube.com/watch?v=s9IYX-qT8kg>.)*





## BEQUESTS – by Tony Pearson

A Bequest is a very valuable way of contributing to the ongoing work of the Group and to be effective, any bequest you wish to make should be through a Will in writing.

If you have already made a Will but would like to include a gift to the Group this can be made by a simple addition called a CODICIL as below.

If you would like further information or would like to talk to a Trustee of the Group about making a bequest to the Charity, please contact us on (03) 540 3217.

### Codicil to an existing Will

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

I ..... (Name)

of .....

..... (Address)

Declare this to be a ..... (first/second) codicil to my Will dated ...../...../.....

In addition to any legacies given in my said Will I give to the Guillain Barré Syndrome Support Group New Zealand Trust, of 30 Higgs Road, Mapua, Nelson 7005 (or any other premises which the Support Group may hereafter occupy) a charity registered in New Zealand No. CC20639,

A share of ..... of my estate or the sum of NZ\$ ..... and/or

..... (a specific sum)

to be used for general purposes and I declare that the receipt of the Treasurer or duly authorized officer shall be full and sufficient discharge. \*

In all other aspects I confirm my said Will and all other codicils thereto.

*\*please complete as required and cross out those options not required.*

Signed .....

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

**Witnessed by:**

Signature.....

.....

Address.....

.....

.....

Occupation.....

Date...../...../.....

**Witnessed by:**

Signature..... Name

Name.....

Address.....

.....

.....

Occupation.....

Date...../...../.....







## From the Medical Advisory Board



### Questions & Answers from the Panel Discussion May 2023 Regional Meeting

Panel: Drs Gareth Parry, Chris Lynch (Neurologists) and Dr Suzie Mudge (Physiotherapist)

*Transcribed by Meike Schmidt-Meiburg*

**QUESTION 1:** *I had GBS in 2009 and weaned myself off Gabapentin and the Fentanyl Patch and have just used Paracetamol for pain relief. Due to old age and stress with my husband's health, I was wondering if Gabapentin is still the best drug for nerve pain or is there something new out.*

**ANSWER:** There is nothing much that is new in the treatment of pain following GBS. There are several different classes of drugs that can be effective in taking the edge off the pain. Gabapentin and the closely related drug, pregabalin, are examples of drugs that can be effective. Tricyclic antidepressants such as nortriptyline and amitriptyline are also effective but tend to have more side effects. Some of the drugs used to treat epilepsy can also help pain. Finally, cannabis can also be mildly effective and has helped some individuals so is worth considering if your doctor is willing to prescribe it. The key is to work with your doctor to find the drug that is most effective for you and that has the fewest side effects.

Do not neglect non-medicine strategies; e.g., exercise can also help relieve pain, as can massage and cold packs.

It is important to consider the possibility that the pain may be related to something else such as arthritis. It is unlikely that any of these strategies will make the pain disappear completely, but they may make the pain more tolerable.

**QUESTION 2:** *In a case where a patient has been diagnosed with CIDP, and if the hallmarks are more consistent with MMN, is there anything to be gained from asking their Neurologist to double check the diagnosis or is there little benefit from knowing which it might really be.*

**ANSWER:** Multifocal Motor Neuropathy (MMN) affects the motor nerves only, causing weakness, cramps and muscle twitching, and is multifocal which means that it is patchy in its distribution, a nerve or a few nerves here or there. Sensory symptoms like numbness or tingling do not occur. CIDP affects both sides usually to a similar degree and almost always has some sensory symptoms although they may be quite minor. There are rare cases of CIDP that are pure motor, and some people think that this is a form of MMN and should not be treated with steroids.

It is important to know which it is because steroids are effective for treating CIDP but don't help MMN and may even make it worse. So yes, it is important to discuss your concern that you might have MMN with your neurologist.

**QUESTION 3:** *If the diagnosis was actually MMN rather than CIDP, is Methotrexate still considered an appropriate treatment for MMN?*

**ANSWER:** The only proven treatment for MMN is IVIg. Some people think that Cyclophosphamide can help, but it is an anti-cancer drug with all of the side effects that cancer chemotherapy can have, so it should be used very cautiously in MMN. There is no evidence that methotrexate is useful for MMN but it may help CIDP.

**QUESTION 4:** *I had the flu vaccine last year in May 2022, after contracting GBS in December 2021. The vaccine knocked me back 4 months of gains I made in leg strength, and lasted for about a month. I am very wary of having the Flu vaccine again. Recommendations and thoughts please for a 68-year-old retired man?*

**ANSWER:** The international GBS group recommends that you should not get any vaccinations in the first year after having GBS, so you probably had it too early. Beyond a year, you should always balance the benefit of any vaccination with the risk. The risk of getting the Flu, COVID or some other infection is much greater than any reactions from the vaccine. The Flu season is upon us, hospitals are filling up. If the illness gave you a setback, go slow when starting again.

**QUESTION 5:** *Is it advisable to continue with COVID vaccinations 6 monthly for GBS survivors?*

**ANSWER:** New vaccines contain new contents. The Flu vaccine gets yearly reviewed. Dr. Lynch will get a COVID booster to protect himself, his staff, and patients. The Flu has been with us for more than 100 years now. Fifty million people estimated died of the Flu in 1918. COVID won't disappear. If you have GBS, you should get both the flu vaccine and any recommended COVID booster, just as the general population should. The Astra Zeneca and Johnson & Johnson vaccines have triggered a few GBS cases, so probably the Pfizer vaccine would be preferable.

**QUESTION 6:** *How many weeks are advised to have between a Flu shot and a COVID booster?*

**ANSWER:** You can get them at the same time.

**QUESTION 7:** *Can Alzheimer's be detected in the eyes?*

**ANSWER:** Researchers found cells called microglia in the retinas of patients with mild brain impairment. That included people who showed no cognitive decline or only very mild symptoms. That indicates those cells could be a key marker in diagnosing Alzheimer's disease early. Dr. Lynch said that research test is not definitive.

**QUESTION 8:** *Do any results taken from a lumbar puncture help in the early detection of Alzheimer's or dementia? If GBS patients had a lumbar puncture, can we go back to those results and check certain figures with the view on early detection of Alzheimer's or dementia?*

**ANSWER:** The CSF that was taken when you had your lumbar puncture is not kept after you have been discharged from the hospital, so it would not be available to test later. The research on retinal changes and CSF abnormalities in very early Alzheimer's disease is still in its very preliminary stages.

**QUESTION 9:** *Is there any news for CIDP patients, what to do for lower backache, just Panadol?*

**ANSWER:** CIDP is the chronic version of GBS. It is usually chronically progressive over several months but occasionally, in about 10%-15% of cases, it comes on acutely and looks just like GBS, but then relapses later. Both GBS and CIDP respond well to IVIg and plasma exchange. GBS patients don't respond to steroid treatment, but CIDP patients respond well. Occasionally CIDP patients don't respond to either IVIg or steroids and there have been some reports of these patients responding to rituximab in this situation. If your CIDP is not responding satisfactorily to the primary treatments, it is worth discussing this possibility with your neurologist. Rituximab is quite expensive and it can be difficult to get PHARMAC to fund it, but we have had some success. Although rituximab is expensive, about \$10,000 a year, it is a lot less expensive than IVIg which costs about 10 times that amount.

Back pain is extremely common in the general population and it is probably no more common in CIDP patients. It should be treated the same way, regardless of whether you have CIDP. Most back pain gets better by itself. Exercise is always good! If that doesn't help, see a physio or GP. Some people go to massage, osteopath, chiropractor, whatever works, the absolute last resort is an operation for back pain alone. Anti-inflammatories (Ibuprofen, Voltaren, Naproxen, Diclofenac) are better short-term for pain relief than Panadol. In NZ you can see a physio without a referral from the GP. "Be as active as you can" is good!!

**QUESTION 10:** *Will they change IVIg medication to something new?*

**ANSWER:** In NZ intravenous Immunoglobulin (IVIg) is prepared from a pool of immunoglobulins (antibodies) from the plasma of thousands of healthy donors. Immunoglobulins are made by the immune system of healthy people for the purpose of fighting infections. There is a new IVIg product that is as good. Because no two batches of IVIg are exactly the same it is possible, although very unlikely, that you could have a reaction if you switch products. If that happens, it may be necessary to try a different batch.

**QUESTION 11:** *A lady had GBS in 2014, now her skin is numb from the knees down to the ankle on both legs.*

**ANSWER:** If this is a new symptom, it is unlikely to be related to GBS occurring nearly 10 years ago. It could be coming from a pinched nerve in the back, most likely from the 5<sup>th</sup> lumbar nerves. Most commonly this affects only one side but it can be on both sides. Wait a week or two. If there is no improvement then see your GP.

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## NOTICE OF SECRETARY'S PO BOX CLOSURE - Tony Pearson

Please note that the Group's PO Box has been closed. Could all members now please use my home address for communications to the Secretary/National Co-ordinator:

**30 Higgs Road  
Mapua  
7005**

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## PAST EVENTS

### Auckland Botany get-together of Wednesday 22 November 2023



It was wonderful to meet Jane and Lois and her husband Gordon for the first time. Wonderful to have Meike all the way from the farm at Waitakaruru visiting us. Lots and lots of natter took place and Meike produced some Christmas chocolates. A lovely touch. Meike also brought up the Fatigue Brochure and talked about the study by Eileen McManus. A couple of the group are going to be zoomed this coming week! - Rex Buckley

**L-R:** Martin, Rex, Lance, Jane, Meike, Lois, Rex, Karen, Rosemary, Char, Peter (Photographer: Gordon)

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# NOTICEBOARD – UPCOMING EVENTS

## Bay of Plenty/Waikato Coffee Group



**Forthcoming dates for our 2024  
eating/drinking/chatting get-togethers**

Meike will be in contact with members regarding the  
upcoming events for 2024.

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

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

## Auckland Coffee Groups



### Auckland North & West:

Dates for 2024 on the following Sundays,  
unless advised otherwise

**When:** 25 February, 26 May, 25 August, 24 November  
**Time:** all at 2pm

**Where:** Kings Garden Café, at the back of  
Kings Plant Barn

11 Porana Road, Takapuna 1025

We usually display the Auckland GBS Support Group banner,  
so we are easy to find in this busy cafe (and we reserve a table  
a little apart from the others so it's not too noisy ☺).

**Please RSVP Eileen at**

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

### Auckland Botany:

**When:** Wednesday 21 February 2024

**Time:** From 10:30am

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

All welcome to come and natter from wherever you may  
be. Merry Christmas Everyone and a Happy New Year.

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

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



## Wellington Coffee Group



We are 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, we would love to hear  
from you.

**Tony's contact details:**

[tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz)

Phone: (03) 540 3217

### 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.

Want to receive your newsletter in **colour** rather than a printed black & white version?  
Receive it by email and save a tree  
Please contact the Editor to update your delivery option.