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Guillain – Barré Syndrome Support Group New Zealand Trust

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

NEWSLETTER July 2023



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Te Whatarangi Dixon

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



Dr. Gareth Parry (Chair) 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	Dr. Annette Forrest ICU Consultant MBChB, BPharm, Dip Ag & Vet Pharm PGDIP Aeroretrieval Masters Aviation Medicine CAA Medical Examiner PGDIP Occupational Health
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Editor's Note – Ansie Nortje



The year is speeding along and as Doug mentioned in his President's report, we are well into the flu and cold season. Luckily, we have so many positive things and highlights to focus on, such as the pleasure of spending time with family living overseas who we have not seen for quite a few years.

To our retiring Treasurer Peter Scott, we salute you for your service! Peter knows the financial side of our organisation inside out after the many years he was in the position. Tony has contributed a fitting tribute in this newsletter. A warm word of welcome to our new Treasurer Brian Sheridan.

On behalf of us all, I want to acknowledge retiring Board member Matthew Peacey's work and solution focussed contributions to our Group. We will miss you Matt, but we do understand your demanding work situation and we wish you and your family all the best for the future.

As usual, there is a lot of interesting information in this newsletter. Please note the request of Drs Eileen McManus and Gareth Parry to participate in their GBS phenotype study in Aotearoa/NZ. Also note the volunteer assistance request from Tony Pearson.

Lastly, a warm welcome to our new Authorised Hospital Visitors: Kathy Eggars, Megan Dunn and Kathryn Banks. We look forward to working with you.

Take care and stay warm!

Ansie

President's Report – Doug Young



Welcome all to our Newsletter for June 2023.

The winter blues are here along with flues and colds around my household, but nothing too aggressive. Hopefully you all will avoid the worst of them this year.

Coming out of our AGM in Wellington on the 15th April, we retain the familiar mix of people serving on our Board. We have lost Matthew Peacey, therefore now have four vacancies to fill. However, some good news, we have gained Brian Sheridan as our replacement Treasurer for Peter Scott so that important position is filled, albeit Brian is not a Board member. Therefore, as President I believe we still have a strong body of people to conduct the business of the Support Group with.

As you will see in Tony's report there was a lot of business done in a short period of time, having to conduct a Board meeting alongside the AGM as well. My thanks to everyone who turned out and for the assistance they gave us. Unfortunately, the Zoom portion of the AGM did not perform well with technical hitches preventing members viewing online. As chairman of the meeting, I was as frustrated with the situation as were our members trying to join in. I apologise to those involved. We will get it sorted for next year as I believe it is a great way for members who cannot travel for whatever reason to be present and join in. Since the AGM, the Board held our 3-monthly Zoom meeting on the 16th June and it's proved a busy time for your Board members, so enjoy the contributions they have made to this newsletter, especially Gareth's team with their progress reports on the research they are involved in. It's exciting stuff when it involves our members as well, who can contribute to the research and impact on the results.

Our move as a Board to using more of the small sub-committee approach to try and speed up our progress on dealing with current issues, along with reducing our meeting times. Plus involving members from outside the Board for inputs & ideas to bridge the generation gap as I call it, is a work in progress that has a good feel to it.

It's all positive stuff at the moment, so enjoy your read and thank you Ansie and Louis for providing the glue that brings us together every 3 months.

Regards to you all

Doug Young President.

Secretary's Jottings – Tony Pearson



Well, I'm writing this on pretty much the shortest day of the year and what a gloomy day it is, especially for the two "new" GBS'ers who have contacted me today, but at least weather wise down here in so called "Sunny" Nelson we seem to have missed the deluge that is once again hitting the North Island's East Coast, although we are under an Orange Warning situation. With luck things will improve both weatherwise and for them.

Firstly, a thank you to those members who responded to my request for "Claw Hand" experiences – if things transpire as planned there should be an Article from our MAB member Kat Quick on that not so rare GBS complication. Regrettably, it would seem that only a few of you were prepared to give up a cup of coffee to make a regular \$5 donation to Group funds – I could go on about the bad effects of coffee, but perhaps a better thought is that when the cost of living stabilises, more of you may be able to support the Group's efforts.

As most of you know, I have over the past years been quite closely involved with the Burwood Hospital and the NZ Spinal Trust who have helped facilitate our Regional Meetings there. Many GBS'ers have done their rehabilitation at Burwood but the Hospital's main focus is dealing with patients who have suffered Spinal Cord Impairment (SCI). These patients fall into two categories – those who have suffered SCI through an accident and those who's SCI had developed through an illness. None of you will be surprised to learn that the financial/equipment support available to ACC clients is vastly superior to that available to DHB patients and that difference in quantitative support has a direct impact on the qualitative experience of the patient during recovery and ongoing living with the disability. The NZ Spinal Trust have decided "enough is enough" and have started a campaign – which they recognise might take years to bring to fruition – to make the treatment of these two categories of patients equal – or at least more equitable than at present. I know most of us do get better – well nearly better – but we do have members who have lost their employment through incomplete recovery and have had to manage with the limited support that the DHB/WINZ system provides during a long recovery or ongoing impediments to a normal life. I fear their aspiration might be a "bridge to far" if their aims for SCI patients were to be expanded across the wide spectrum of "illnesses" – a cost New Zealand could not contemplate – but nevertheless I admire their willingness to have a go. A "watching brief" I think, to see how we might support and potentially benefit from this initiative for our less fortunate members.

When you got GBS (or one of its variants) did you ask, "Why Me"? – I know I did! And, of course, there is no logical answer but "fate". However, reading the Obituary of Rabbi Harold Kushner who wrote the bestselling book entitled "When Bad Things Happen to Good People" – inspired by his grief at the loss of his young son to an incurable rare disease – I learned that there is a better question we should all have asked ... "How do I go on" and from that develop positive plans and actions to recover from the disaster that has befallen us. I think this would be a good message for our AHV's to carry with them on their visits to newly diagnosed patients.

Do you give blood? – apparently some 17,000 Kiwis do regularly, but demand is outstripping supply especially for that "liquid gold" Plasma – which many of us will have cause to thank for a halting of our GBS decline via IVIg infusions and, of course, many of you continue to rely on for managing your CIDP or MMN. I understand some 38,000 more donors are needed according to the NZ Blood Service and whilst Plasma donations can only be managed at our main city locations, "regular" blood donation can be made countrywide. New donors need to under 71 years old – any type of blood will be gratefully received. If you can meet the criteria – check at www.nzblood.co.nz – I urge you to do so. Even if I was young enough I couldn't because I came from the "Mad Cow Diseased" UK, although this restriction may be changed in the future as Australia has already done. You "youngsters" can also band together at your places of higher learning by initiating a "Project Plasma" group that I referred to in my last Newsletter – contact me if you think you might be able to help.

All our Top of the South coffee group have signed up to participate in Dr Eileen McManus' nationwide GBS survey. I am awaiting to hear that the survey has "Ethics Approval" and will then dispatch information which I hope our loyal band of AHV's will be able to distribute to newly diagnosed patients to encourage them to join. It will no doubt take some time to gather the information but I for one will be very interested to see if it can provide some firm data on the relationship between receiving a COVID vaccine (or getting COVID) and a follow-on diagnosis of GBS.

As always, stay safe *Tony*

From the Medical Advisory Board

Research Report – July 2023

by Drs Eileen McManus and Gareth Parry

The GBS phenotype in Aotearoa/NZ: How ethnicity, socioeconomics and infection influence GBS outcomes



Excellent progress continues to be made on this study. Since our last report in March, the number of patients whose data had been collected has increased from about 250 to nearly 400. We still have a long way to go to our target of about 1000 patients, but the response from GBS patients has been fantastic and we are very optimistic that the goal will be reached.

The preliminary results from the 223 patients whose data we have analysed so far, indicate that the commonest form of GBS, known as acute inflammatory demyelinating polyneuropathy (AIDP), which constitutes 80%-90% of GBS cases in other developed countries, is relatively less common in NZ (~60%). Variants such as the Miller Fisher Syndrome (MFS) and the axonal forms, acute motor axonal neuropathy (AMAN) and acute motor and sensory axonal neuropathy (AMSAN) are relatively more common in NZ, about 3-4 times more common than in other developed countries. This may be related to the very high rates of *Campylobacter* gastroenteritis, a known trigger for GBS. Also, since the axonal forms of GBS tend to have poorer recovery, this observation may explain why GBS cases here seem to be more severe although we do not yet have enough outcome data to confirm that suspicion.

We thank all of you who have agreed to participate in the study and urge anyone who has not been enrolled to contact Dr McManus at emcm373@aucklanduni.ac.nz.

VOLUNTEER ASSISTANCE REQUEST – by Tony Pearson

We are looking for assistance from the membership in two areas of our activities:

1. **WEBSITE MANAGER:** Our present Website Manager is retiring from his position to concentrate on his growing personal business. We 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 /redesign/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 027 687 1953. A full handover of the job will be organised and our existing Web manager has confirmed he will always be willing to provide backup advice as necessary.
 2. **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. 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 03 230 4060.
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Report on the Regional Meeting held in Ngatea on 6 May 2023

by Meike Schmidt-Meiburg

We had a great turnout with 23 former GBS patients and their partners present, and fortunate to listen to interesting and informative presentations from three members of our Medical Advisory Board, being



Drs Lynch, Mudge and Parry

Dr Gareth Parry (The NZ GBS research project, on behalf of Eileen McManus), Dr Suzie Mudge (Fatigue in GBS) and Dr Chris Lynch (GBS - following COVID and COVID vaccination).



Dr Mudge presenting her study on Fatigue in GBS

The food technology/hospitality students of the local HPC college prepared a yummy morning tea and lunch, so we could catch up with everyone over some refreshments. After lunch we were able to ask questions in the panel discussion. Many thanks to our three presenters for giving up their Saturday and coming to support our day, and also to everyone for coming along and attending :)



The three presenters (seated on the left) together with all the attendees

(Editor: Slides of the three presentations, and a transcript of the panel Q&A session will be published in future newsletters.)



From the Medical Advisory Board

What's handy to know about hands?

By Kat Quick (Physiotherapist)

It's reasonably common for people with Guillain-Barré Syndrome (GBS) or Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) to experience weakness in their hands. Muscles can become paralysed as a result of the disorder, and then further deconditioning may occur if the paralysis limits the completion of day-to-day activities. Figure 1 shows some of the symptoms a person with GBS or CIDP may experience in their hands.

Key goals of early physiotherapy and occupational therapy are to maintain muscle length and joint range of movement, to prevent contractures (a contracture is defined “as a [muscle](#) or other [tissue](#) that has become permanently shorter causing a body part, especially a joint, to be the wrong shape¹”), for example, contractures of the hand may look like clawing of the hand.

In most instances, preventing the development of hand contractures involves relatively straightforward interventions. If early treatment has not commenced and the hand becomes contracted, this may result in long-term difficulties that are hard to reverse (including pain, poor function, and risk of developing pressure sores). In severe cases of hand contracture, surgical intervention may be necessary. Surgery will usually involve a lengthy recovery period and is not without risks. It is important to remember that development of contractures is avoidable, early identification and consistency are key to their prevention.

The multidisciplinary team will develop a programme based on a person's strength, range of movement, muscle tone, sensation, and pain. The most common treatment approaches are usually:



1. Active exercises (to increase strength and stamina)



2. Passive stretching (when another person helps to move the hand/fingers to stop them becoming too stiff)



3. Splinting (when an external support is used to help the hand/fingers to rest in optimal positions)



4. Functional task practice (such as using hands for day-to-day activities that might involve dexterity and grip).

Treatment programme should be completed under the supervision of a physiotherapy or occupational therapist to prevent any complications. For example, if splints are worn incorrectly the person may be at risk of developing a pressure sore, or if joints are over stretched this may lead to pain and joint damage. There is not a “one size that fits all” approach to treatment for people with GBS or CIDP as everyone's needs will be assessed on an individual basis. Your rehabilitation team will develop your programme with all your needs in mind.

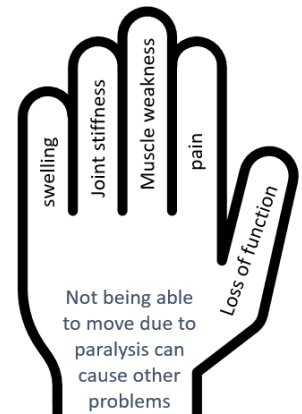


Figure 1: Possible difficulties experienced in the hands due to GBS/CIDP

¹ <https://dictionary.cambridge.org/dictionary/english/contracture>

INTRODUCING OUR NEW AUTHORISED HOSPITAL VISITORS

by Tony Pearson

I am delighted to introduce three newly authorised Hospital Visitors to our membership:



Kathy Eggers - Kathy works in the health sector and is based in Napier where she has been involved in the Gabrielle recovery effort not only on her families' own farm in the affected area, but working with the wider community to try and get back to normality – a long job I suspect. Kathy is a Life member of the Group and a CIDP survivor and will cover the Napier and Hastings Hospitals and the general Hawkes Bay area for the Group. It will be interesting to see if there is a “spike” in GBS cases in that region with cases being triggered by stress or infection but based on what we see in the media they seem to be a pretty resilient bunch over there.



Megan Dunn - Megan has that enviable condition on her side - YOUTH - and that, without doubt, has helped her make a good recovery from her GBS attack in 2020 after a five-month stint in Burwood Hospital. Originally from Christchurch where as a “pre-teen”, she experienced the two earthquakes, Megan has recently finished her studies in Dunedin and is now based in Auckland working in the Retail sector and will assist our existing AHV's in that city and area to help new patients, particularly those in the younger age bracket who sometimes have difficulty in relating their condition to us aged AHV's that pop in to see them!



Kathryn Banks - With the sad passing of Jenny Murray and subsequently her cousin Royce Woods, New Plymouth and its environs have been without AHV cover for a few years now, but thankfully Kathryn has volunteered to fill that gap. A CIDP'er from 2018, still on regular IVIg top ups, Kathryn is a teacher by profession and lives with her husband in New Plymouth. She will look after visits to the Taranaki Base Hospital and those GBS/CIDP'ers in that local area which, beautiful though it may be, sadly lacks a permanent Neurological support team at this time so that patients often have to travel to Waikato for treatment.

Welcome aboard ladies, the Group and I are VERY grateful for your willingness to “give back”.



PETER ROBERT WYNNE SCOTT
TREASURER EXTRAORDINAIRE 2001-2023

by Tony Pearson



Peter became a GBS'er in May 1996 at the ripe old age of 59 whilst he was working at an Accountancy Firm in Palmerston North. Feeling unwell after a bout of food poisoning from a chicken lunch, he went to his GP who prescribed antibiotics, but still feeling unwell and after falling on steps at the office he returned to the GP who prescribed more antibiotics and pain killers and sent him home. On arrival Peter had trouble opening the garage door and later in the evening fell over and Robin, with a neighbour's help, managed to get him into bed but then found he couldn't get out in the morning – so the ambulance was called and Peter went to hospital where a Lumbar Puncture confirmed GBS and

the ICU team set to work - reading the manual as none of them had seen GBS before – to get Peter – paralysed from the neck down - back to rights. After 21 days he was moved to the High Dependency Ward and then onto Re-Hab – but only on weekdays – at weekends Re-Hab closed so Peter was relocated to just about every other ward (except Maternity he says) with the Geriatric and Cardiac wards being the low points – No TV to watch Rugby!!

Extensive modifications to their house were necessary before Peter could leave Hospital and return home but it was some two and a half years before he was able to discard the wheelchair returning to Re-hab every weekday during that time and needing Robin and a carer to help perform routine daily activities using a hoist and sleeping in a modified hospital bed in the spare room – the only one with a doorway wide enough for the wheelchair to pass through.

Robin read the Women's Weekly – a VERY popular periodical of those days - and like a number of other GBS patients read Jenny Murray's letter to the editor in late 1997 about her sister Dulcie's GBS and asking if others in NZ had experienced this very rare disease – and from that article the Support Group, and Peter and Robin's association with it began.

After Peter became mobile, he was asked to take on a position with a firm he had previously worked for and continued working from home for them for a number of years, getting about with the aid of sticks. The earliest reference to his role within the Group that I can find was at an informal gathering in the Paeroa home of Terry Watton (our first President) in August 2000 where Peter was referred to as an Area Representative and it was not until 2001 when Jenny Murray, despairing of the local New Plymouth accountant she was using to “do the books”, persuaded Peter to take them on.

Peter was a Founder member of the Board of Trustees of the Group when it formally became a Charity in February 2001 and has continued to serve as a Trustee for 21 years – with Dr Gareth Parry MB and Dr John Podd PhD joining him in that distinction. Peter was formally nominated as the Group's Treasurer in September of that year at the Board's first meeting held at Auckland Hospital.

I first met Peter at the next meeting of the Board of Trustees held at Massey University in May 2002 – and came away having been voted onto the Board as South Island representative although Vivienne and I only really went along to say thank you for all the help and support we had received from the Group (aka Jenny) when we emigrated to NZ bringing my UK-contracted CIDP with me.

It was at that meeting that I first became aware of Peter's qualities as a Treasurer – always a stickler for details, he had perused the recently established Trust Deed and along with support from our then Patron Sir William Birch formalised membership of the Trust by the introduced \$10 fee as a qualification for voting rights. At the next AGM in 2003 the Audited Accounts were presented on time – a first I believe – and with my election as Secretary at that meeting my subsequent Minutes were duly vetted and proof-read by Peter – as they have been ever since.

Peter's commitment to the Group continued to grow as he took on board the organising and accounting for our annual and then biennial Conferences – no mean feat when the great unknown is the number of delegates likely to support the event whose costs have to be committed in advance – perhaps one of the reasons for Peter's “thinning on top” as the years have gone by.

Peter's careful management of our funds have ensured that whilst our finances will always be precarious – dependent as we are nowadays solely on donations from members and benefactors – we are in a good financial position and with the aid of several major donors have been able to sponsor 3 separate lines of GBS Research here in New Zealand. Yes, getting Peter to release some of his precious funds can be a battle, but when he does, you know he is satisfied with the validity of the request.

And finally, as they say “behind every successful man there is a committed woman” – such is the case with Peter.

Robin and Peter met in Feilding in 1960 and married in 1965. They lived in Otorohanga and Dannevirke and Feilding again before settling in 1980 in Palmerston North. Robin has been a Carer, a Mentor and on occasions a “Calmer” for Peter in respect of his association with GBS medically and professionally over the years, and the Group owes you a real debt of thanks Robin for your support to Peter in the great work he has done for the Group.

It has been a real pleasure to know you both and I hope we shall continue to enjoy your company at Group gatherings well into the future.

Tony Pearson Secretary June 2023 - on behalf of the Board of Trustees.

From the Medical Advisory Board

What does the change in IVIg product mean for CIDP and MMN patients?

by Dr Gareth Parry



In July 2023 the NZ Blood Bank will begin to switch IVIg product from Intragam P 6% solution to Privigen NZ 10% solution. Both products are manufactured by CSL Behring from donated NZ plasma. The active ingredient in both products is the same but there are slight differences in the stabilizers used leading to an improved shelf life and easier storage for Privigen. Many CIDP and MMN patients who are being treated with IVIg are worried that this might affect their treatment. So, what does this change really mean for these patients?

1. **Why is the NZ Blood Service switching from Intragam to Privigen?** There are several reasons for the switch. Firstly, CSL Behring wants to have their production facility aligned with other facilities internationally. Secondly, because Privigen is a more concentrated solution of immunoglobulin (Ig) than Intragam, a smaller volume can be delivered to administer the same dose of the active Ig. The higher concentration may also allow subcutaneous (under the skin rather than into a vein) delivery in some individuals. Finally, Privigen can be stored at room temperature and for longer periods of time, making it easier, and therefore less expensive, to store the product.
 2. **Are the 2 products equally effective?** The active component in the 2 products is identical, apart from the concentration and they should have identical beneficial effects in CIDP and MMN patients. I am not aware of any head-to-head studies testing this but there is no reason to suspect that there would be any difference in efficacy.
 3. **Are the 2 products equally safe and tolerable?** The only difference in the products is the concentration of the active component and the stabilizing chemical. Because the Ig concentration is higher in Privigen it is possible that some infusion reactions could be more noticeable, particularly headache, but the rare serious adverse effects such as allergic reactions, and blood clots should not differ between products.
 4. **Will there be any difference in the infusion protocol?** When patients are first switched from Intragam to Privigen, the manufacturer’s recommendation is that the initial infusion rate should be no more than 0.3 ml/kg body weight/hour. After the 1st hour the infusion rate can be increased. It is almost certain that the prescribing neurologist will adhere to this infusion schedule so that the duration of each infusion will be longer than the current duration with Intragam. Once it has been established that a patient is tolerating the new product the prescribing neurologist may permit a faster initial infusion rate and a faster escalation of the rate but that will be determined by individual prescribers based on individual patients’ reaction to the infusion.
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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...../...../.....



REPORT ON THE BOARD AND AGM HELD IN WELLINGTON APRIL 2023

by Tony Pearson

For once COVID and Air New Zealand co-operated to allow the Board to assemble at the usual time of year and without delayed arrivals at the splendid Miramar Golf Club Conference venue alongside Wellington Airport – unfortunately the Internet was NOT so co-operative – see later! This is the one opportunity a year for the Board to meet in person and whilst Zoom meetings are functional and cost saving there is no substitute for an across the table discussion and debate across the wide range of issues affecting the Group.

BOARD MEETING



Brian Sheridan

With our long serving Treasurer Peter Scott advising that he wished finally to retire from that role in the coming year we were delighted to welcome Brian Sheridan, a qualified and practicing accountant from Auckland who has volunteered to take over from Peter in due course. Brian is in the final stages of recovering from a severe GBS attack back in 2019 and, like many of us, wishes to “give back” to the Group for the support he has received during that recovery. Brian has significant accounting experience of the Charities/Not for Profit sector and so comes ideally qualified to help us AND has a somewhat more up-to-date IT capability than many of us “old stagers” can boast.

Approval was given for our latest AHV recruit Megan Dunn to be authorised to represent the Group – see elsewhere in this Newsletter for a little background on Megan. Dr Parry updated the Board on the progress of the nationwide study of GBS patients being led by Dr Eileen McManus. Final Ethics approval is now in progress which will allow Eileen to research the medical background of those NZ GBS’ers who put their hand up to be included. Three hundred have indicated a willingness to join so far with a target of 1500 for the survey as a whole. Significant funding has been obtained for the study which was initiated by a \$16,000 “starter” grant from the Group. Eileen will work with Clive Phillips on a much more limited study of MMN patients in NZ. Clive continues to raise funds for MMN research thro’ his biking activities and has so far raised more than \$100,000 which will be managed thro’ the USA Group.

Matt Peacey, our Nelson Trustee has decided to retire from the Board due to the pressure of work generated by his growing business interests. Matt has been our Website Manager and general IT “go to” person for the last few years and we have initiated a search for a member willing to take on this role – see the advertisement elsewhere in this Newsletter. The Board continues to investigate viable methods of raising donated funds for the Group and this activity together with our attempts to develop a YouTube training introduction for new Authorised Hospital Visitors are ongoing “Work in Progress” tasks. With over 200 members now on our 20-year-old Access database the time has come to update our IT management of this information base and means of communicating with members. Ansie and Brian will lead an investigation into current “user friendly” available alternatives. If you have any experience/expertise in this area they would be delighted to hear from you – let me know and I will put you in contact with them. Our Brochure re-print plans have hit a technical snag, again caused by the age of the print programmes initially used to generate these documents back in the UK, and we are re-structuring all seven Brochures to prepare them for a pre-print and to “future proof” their composition for ongoing re-prints.

AGM



Doug Young, Robin Scott

An IT hiccup meant that those members planning to join the AGM on Zoom were shut out leaving only a sparse number of attendees in person at the AGM. Doug introduced Brian Sheridan to the meeting and outlined the handover plans with Peter Scott as far as the Treasurer’s role was concerned. Peter, a Founder member of the Group, was thanked for his significant contribution of 21 years as Treasurer keeping the Group finances on the “straight and narrow” and his lady wife Robin was presented with a bouquet of flowers as a token of the Board’s appreciation of the “behind the scenes” support she has given Peter over the years. Peter continued his trend of good financial management by presenting a robust set of Accounts for the last financial year with a small \$5000 surplus from the years activities being declared.

A report on the November Regional meeting in Christchurch was presented and the plans for the forthcoming Regional meeting in the Waikato region was outlined. Reports on Website and Facebook site activities indicated a good level of engagement both with members and others in NZ and further afield. Dr Parry reported on the various Research projects underway under the Group umbrella with the Fatigue study monitoring stage now completed and the results being compiled for future publication – initial feedback is of a very positive impact of the exercise routine on the management of the fatigue issue suffered by the participants. The nationwide survey of GBS patients is about to get underway in earnest and smaller parallel survey of MMN patients in NZ is being initiated. The Group continues to respond to calls for help and information from new patients and after a quiet period caused by the COVID lockdowns AHV visit activity is picking up again.

The meeting was apprised of the various fund-raising ideas researched by the Board, without any bearing much fruit and some new ideas were tabled and will be followed up but the Group remains dependent on members' donations and a couple of grants from charitable foundations to maintain its operations. In spite of this, it was decided to continue with the current practice of no membership subscriptions but this will be reviewed in the future as part of the hand-over of Treasurer's responsibilities.

Doug presented his President's Report to the meeting and this is included elsewhere in this Newsletter.

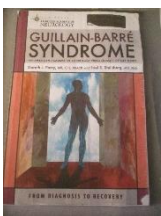
The meeting accepted with regret the resignation of Peter and Matt as Trustees and confirmed the re-appointment of Chris Hewlett and Meike Schmidt-Meiberg as returning Trustees and the appointment of Te Watarangi Dixon as a Trustee following his co-option as a Board member earlier in the year. The roles of President (Doug), Secretary (Tony) and Treasurer (Peter) were re-confirmed.

The Group will remain subscription free for the coming year but as our dependency on the ever-decreasing pool of donations becomes more tenuous we may have to review this policy next year.

Doug advised the meeting of the - so far - successful experiment of inviting members from various areas in the country to join the Board meeting discussions and offer thoughts and suggestions on the issues being aired. This is a "win-win" deal for the Group as we benefit from the often-younger input of our membership whilst not expecting those members to commit to ongoing time and effort obligations that being a formal Board member involves.

All in all, a constructive and enjoyable meeting followed by an equally enjoyable informal lunch afterwards. Thankyou Peter for organising.

RETURN OF GARETH'S BOOKS – by Tony Pearson



Once again, we have run out of Dr Parry's splendid book on GBS "From Diagnosis to Recovery" and they are increasingly difficult and expensive to source from global book depositories. SO..... If you have purchased one in the past, and no doubt really valued its contents, but no longer feel the need for it to grace your bookshelves and it is in reasonable condition would you consider returning it to the Group so that we may top up our stock to lend or sell to new patients who can benefit from the easily readable advice that it contains as you did.

If so please let me know at tonypearson@xtra.co.nz or 03 540 3217 and I will arrange to send you an NZ post envelope to enable you to return it to me – or you can simply post it to me at 30 Higgs Road, Mapua, Nelson 7005. We will happily refund the price you paid for the book but, of course, donations are always valued.

PAST EVENTS



Auckland Botany Coffee Meeting of 10 May

A wonderful natter was held among the plants on a lovely morning at Mitre 10 Botany. It was great to see Karen and Rex Soppet and Martin Walker for the first time.

Also in attendance were Lance Beste, Peter and Charmaine Barry and Rosemary and Rex Buckley.

by Rex Buckley

Waikato/Bay of Plenty get-together of Thursday 8 June



We had a lovely day at Hampton Downs, and it is always interesting to look at the racing cars and soak up the atmosphere :)

We welcomed a new couple to the group, and exchanged our stories, progress, tips and confirmed: GBS, "Getting Better Slowly" is the key!

by Meike Schmidt-Meiburg

Back row L-R: Meike Schmidt-Meiburg, Barry Deed, Grant McKay, Bob and Jill Keals, Mike Logan and Lyn Neels

Middle row L-R: Rex Soppet, Fran McKay, Julia Ardern, Michael Cameron

Front row L-R: Karen Soppet, Judy Deed, Roberta Cameron. (Peter and Charmaine Barry had left)

Top of the South Coffee Meeting of Sunday 7 May



Thirteen members (one who recently joined, still in recovery and using a wheelchair) sat down for a meeting in the BORED ROOM at the Zumo coffee house in Nelson at 1030hrs on May 7th. Zumo is a famous venue in Nelson with a long "coffee" history and the Bored Room provides an excellent quieter (and somewhat posh!) space for a chat – but still within an easy reach of a coffee and a muffin. We hadn't met for a while so it was good to catch up with old friends and meet new ones – with a delegation from Marlborough providing "over the hill" input. A quick round the table

recap of our GBS history brought everyone up to speed with our background and the group had a good mix of GBS and CIDP conditions. An animated exchange of experiences and advice was also accompanied by a number of more "technical" questions to be passed on to our Nelson resident MAB Head Dr Gareth Parry who was away up north supporting the Waikato/Bay of Plenty Regional meeting. All questions subsequently answered and passed on to the relevant initiator. As usual the chit chat lasted over the allotted 2 hours and we departed the premises to the smell of newly roasted coffee beans with several folk planning to meet up later with each other and a general consensus that we need to do this more often with unanimous agreement it should be as a celebration of the abandonment of the wheelchair by our new member. *by Tony Pearson*



Lorraine, Suzanne, Eileen, Brian

Auckland North/West Coffee Meeting of 28 May

After the usual greetings and catch-up on news, the four of us discussed highlights from the Waikato/Bay of Plenty Regional Meeting held a few weeks earlier. Brian participated in Dr Suzy Mudge's research project on Fatigue in GBS and found it helpful. Dr Chris Lynch had spoken about GBS following Covid-19 and Covid-19 vaccination. Lorraine recommended checking out The Long Covid Handbook by Medinger and Altman. Tony Pearson encouraged us to join Dr Parry and Eileen McManus' research project on GBS in NZ, as they are still accepting participants. *by Eileen Jacobsen*

NOTICEBOARD – UPCOMING EVENTS

Bay of Plenty/Waikato Coffee Group



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

Wednesday 9 August 2023 from 10.30 am at The Old Forge Kitchen, 9 Alexandra Road, Te Aroha West.
<http://www.theoldforgekitchen.co.nz/> Check out their menu, (07 884 8338, they close at 3 pm).
Please let me know that you are coming or not by 7 August.

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. 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.

Please let me know 2 days before each meeting that you are coming or not, so I can confirm numbers with the venue. They will have their lunch-time a-la-carte menu and cabinet food available too.

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

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

Auckland Coffee Groups



Auckland North & West:

When: Sunday 27 August 2023

Time: 2pm

Where: Kings Plant Barn Café
11/13 Porana Road, Takapuna

New members most welcome.

Please RSVP Eileen at

eileenmagnajacobsen@hotmail.com Mob: 021 113 3607

Auckland Botany:

When: Wednesday 23 August 2023 and
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 Mob: 027 296 3297

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

Mob: 027 332 8546

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.