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Guillain – Barré Syndrome Support Group New Zealand Trust

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

NEWSLETTER December 2022



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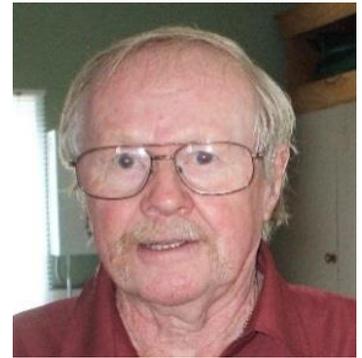
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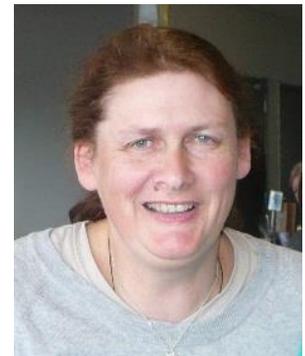
Dr Ansie Nortje



Chris Hewlett



Te Whatarangi Dixon



Meike Schmidt-Meiburg

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

TSB – Moturoa Branch New Plymouth

Bank Account Number – 15 3949 0339362 00

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



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



<p>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</p>	<p>Dr. Annette Forrest ICU Consultant MBChB, BPharm, Dip Ag & Vet Pharm PGDIP Aeroretrieval Masters Aviation Medicine CAA Medical Examiner PGDIP Occupational Health</p>
<p>Dr. Chris Lynch BMedSci, MB ChB, MD, FRACP Neurologist and Neurophysiologist at Waikato Hospital Honorary Senior Clinical Lecturer at the Auckland Medical School, Waikato Campus</p>	<p>Dr. Suzie Mudge Dip Phys, MHSc, PhD Director & Physiotherapist: Neuro Rehab Results Senior Lecturer/Senior Research Officer Health and Rehabilitation Research Institute, AUT University</p>
<p>Dr. Dean Kilfoyle Neurologist, Auckland City Hospital, Auckland DHB</p>	<p>Dr. David Gow M.D., MB ChB, FRCP (UK), FRACP. Neurologist with Southern DHB</p>
<p>Dr. Jennifer Taylor MB, ChB, FRACP Consultant Neurologist, Wellington Hospital</p>	<p>Dr. Vic du Plessis Neurologist and rehabilitation specialist. Part time consultant neurologist, Dunedin</p>
<p>Karen Clark Master of Nursing Clinical Nurse Specialist, Neurology Waikato Hospital</p>	<p>Kylie Kerr Occupational Therapist Burwood Spinal Unit, Christchurch</p>
<p>Kathryn Quick Physiotherapist</p>	<p>Te Whatarangi Dixon BHSc (Physiotherapy) MNZSP QE Health, Rotorua</p>

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Editor's Note – Ansie Nortje



'Year's end is neither an end nor a beginning but a going on, with all the wisdom that experience can instil in us'. Hal Borland.

It is amazing to think that another year is almost over. Looking back, there are so many things that we as a group have achieved, for example, the coffee groups we held; the support we provided to each other; and the research work that we continue to support and subsidise. I want to acknowledge the contributions each of you have made during 2022.

A warm welcome to our newest Board member, Te Whatarangi Dixon - we look forward to working with him as Board member.

Further to Tony's observations about CIDP / chronic conditions at the end of his report on the Christchurch Regional Meeting, I would like to invite members with such conditions in particular to share their experiences in our newsletter. Your contributions are always welcome, and a big thank you to all who have contributed in the past.

I wish you all the best for the festive time ahead. May you have a Merry Christmas and a prosperous New Year.

Ansie

President's Report – Doug Young



Welcome once again to the December 2022 edition of the GBS Support Group's quarterly newsletter.

I will start with wishing you all an enjoyable and safe time for the fast-approaching festive season just over the horizon.

Looking back at this time last year, with the uncertainty that prevailed back then, it's great to see such a positive outlook from people for the coming holiday season. I am predicting lots of sunshine and warm weather to come with it of course. So, your families and friends can gather around to enjoy the time together post COVID. Please make the most of it.

As President of the Board, I would like to welcome our newest co-opted Board member, Te Whatarangi Dixon to the group of trustees. Te Whatarangi is a physiotherapist and is also a member of Gareth's Medical Advisory Board team. He brings a valuable skill set onto the Board especially around patient recovery and rehabilitation.

Our GBS Board held its last Zoom meeting on the 6th September, business arising from this meeting are in Tony's report further on.

My brief overview & comments from the meeting are:

As a group we continue to achieve a lot, now seeing results starting to come out of the seeding research grants to the projects that Gareth is involved in. Please read his report on the continuing progress of these projects, it is very interesting stuff.

Gareth has some outstanding project leaders involved in this research, Dr Eileen McManus from Waikato Hospital is one, and Dr Suzie Mudge from North Shore another. As a group we are all indebted to these people.

We continue to assess other organizations similar to ourselves to form partnerships with, for information sharing and lobbying for increased government support for rare diseases like ours.

Regional Meetings: You will see Tony and the Christchurch team had a very successful meeting on the 20th November at Burwood Hospital. What a wonderful facility and our thanks go out to the Burwood Admin team Leah Milthorpe & Josh Caldwell of the Spinal trust for making it a successful event.

Enjoy your read, and I look forward to reporting on further progress of the Group in March 2023.

Regards

Doug Young

President



Secretary's Jottings – Tony Pearson



Barely a day goes by when we are not regaled by the media about the dire state of our medical system – be that ED waiting times, closure of Care Homes or lack of mental health support facilities.

Most of us realise that there is no “quick fix” for these problems and besides LOTS of dollars to upgrade facilities it will take years to train the various levels of medical professionals we need to run the systems. Sure, overseas recruitment will help in the short term but medical professional staff shortages are a worldwide problem and little old NZ at the bottom of the world is well back in the recruitment queue!

Existing medical teams are under huge pressure – you can see it in their faces at all levels of capability. Getting to see a GP can involve significant delays – and a Neurologist?? – well pack a bag for a long wait! In this environment the role of Support Groups like ours becomes even more important. Barely a week goes by that I don't get a call from an often highly stressed person who thinks they or their loved ones have GBS/CIDP symptoms but is unable to get in front of a knowledgeable GP or even less chance to see a Neurologist to have some form of confirmatory diagnosis. We can't substitute for that medical expertise but we can offer emotional support both over the phone or by a personal visit, suggest ways in which their current distress/discomfort might be eased, provide information of the underlying issues that GBS involves and how it is likely to resolve and – in dire cases - what to do to get seen pronto by a medical team that may be able to speed up that diagnosis! Time and time again I hear “if I just knew what I had got I feel I can deal with it” – uncertainty breeds stress!

COVID, of course, has added another dimension to symptom confusion. There are a few (but very few) confirmed cases of COVID itself or its vaccine being a trigger for GBS both worldwide and in NZ, BUT there are quite a few folk here who are experiencing weird and painful neurological conditions that are seriously impacting on their quality of life. Did the vaccine trigger my GBS? – Having got COVID, am I now dealing with CIDP or Long COVID? We will get answers to these questions in due course and a LOT of research is going on around the world, but in the meantime we GBS Support Group members can do our bit to provide what support we can.

Other news:-

As the “rouges gallery” at the start of this newsletter shows, we have a new Trustee of the Group, Board member Te Whatarangi Dixon. Some of you may have met him at the Hamilton Regional meeting back in May 2021. Whatarangi is a Māori Physiotherapist and at the time of the Hamilton meeting was based in Rotorua at the QE2 Hospital. Recently he has “absconded” to Adelaide to support his wife who is studying for a Doctorate but will be back! He brings a unique and highly skilled approach to GBS physiotherapy treatment – has had GBS himself twice!! – and is a nice bloke! We are delighted to have him onboard and he will join our ongoing discussion via Zoom at our quarterly Board meetings.

Regional Meetings: Our Christchurch meeting has just taken place – a report is elsewhere in this newsletter - and the next will take place in the first half of 2023. Rotorua and Hamilton are both in the frame so watch this space (and the website of course!!).

Enough for now. As always – Take care and stay alert to avoid COVID – we may have had enough of it – but it's not done with us yet. Is another booster on the cards?? – who knows – well I hope someone in authority does, but no mention publicly yet!

Tony



Editor: Links to explore:

GBS/CIDP Foundation International: <https://www.gbs-cidp.org/>

The Foundation's YouTube Channel: <https://www.youtube.com/@gbscidporg/videos>

From the Medical Advisory Board

Research Report - by Dr Gareth Parry



One of the most exciting developments in the GBS/CIDP field in NZ in recent years has been our forays into the research arena. This has been made possible by the generous support of the membership of the GBS Support Group Trust, for which we are extremely grateful. The members have supported the research both through their donations to the Trust and their willingness to participate in these research projects. The funds received from the Trust have enabled us gain preliminary data which has led to larger grants from sources such as the GBS/CIDP Foundation International and the NZ Health Research Council. Thank you.

1. **Benefit of supervised graded exercise in ameliorating post-GBS fatigue.** This project is being led by Dr Suzie Mudge and is supported in part by a grant from the Trust. Subjects are those who have had GBS at least 2 years prior to enrolment in the study and who still have residual fatigue that interferes with day-to-day activities. They take part in a virtually monitored and administered exercise program that is monitored by way of interviews with a physiotherapist and also by way of an activity monitor (such as a Fitbit) that measures the number of paces taken in a 24-hour period. The study is fully enrolled, and all subjects have completed the exercise programme. The data is currently being analysed but preliminary impressions are that the programme was well accepted and appears to have been beneficial.
 2. **GBS in the time of COVID.** Infection is the commonest trigger for GBS and there was concern that the COVID pandemic would result in surge of cases. Another known, but uncommon trigger is vaccination so there was further concern that the aggressive vaccination programmes instituted world-wide would also emerge as a trigger, analogous to the 7x increase in GBS cases in the US following the swine flu vaccination programmes of 1976. NZ is in an almost unique situation of having undergone rigorous lockdowns to control the spread of the virus and also be virtue of the extremely high vaccination rates. We are, therefore, studying GBS rates and characteristics during the years since COVID infections have reached our shores in February 2020. Preliminary data suggests that GBS rates actually diminished during the pandemic and provide reassurance that the COVID vaccine does not seem to be a GBS trigger. This project is led by Dr Eileen McManus who is donating her time as we currently have no funds to support it.
 3. **GBS in New Zealand: how ethnicity, infection & socioeconomics influence GBS outcomes.** GBS is more common in NZ than any other developed country and clinical experience suggests that it is different, being more severe, having more residual effects, being more likely to follow gastroenteritis, more likely to be of the axonal variety and more likely to be a variant form. These characteristics seem to be more pronounced in Māori and Pasifika. We have, therefore, started a study to see whether these clinical impressions are based in reality and to identify factors that lead to these observations. We are studying cases that have occurred since January 1, 2016, and will go forward through the end of 2025. We have enrolled a little over 100 patients so far, but we would like to enrol at least 1000 so we have a long way to go. This project is led by Dr Eileen McManus at Waikato Hospital and is supported by a grant from the GBS/CIDP Foundation International. If anyone is interested in participating, they can contact her at emcm373@aucklanduni.ac.nz. She will send you a consent form for you to sign so that we can access your GBS medical records.
 4. **Is therapeutic plasma exchange (TPE) preferable to intravenous immunoglobulin (IVIg) in severe GBS?** The most common treatment for GBS is IVIg, regardless of GBS type or severity but plasma exchange is also effective. For the most part both treatments appear similarly effective when patients with all levels of severity are included. However, some data suggest that plasma exchange is more effective in people with the more severe forms of GBS. We have, therefore, launched a clinical trial to compare outcomes in GBS patients with severe disease who are treated with IVIg or TPE. This study is also led by Dr Eileen McManus and is supported in part by a grant from the GBS Support Group (NZ).
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Report on the Christchurch Regional Meeting held on Sunday 20 November 2022 at Burwood Hospital

by Tony Pearson



Based in the modern venue of the Burwood Hospital – the main Rehab facility for GBS’ers from Central and Lower South Island - and facilitated by an admin team from Burwood who could not have been more helpful in both initial arrangements and sorting “IT glitches” on the day we were well set up. Sourcing the Panel of Experts proved a little more complicated with the absence of two of our South Island MAB members, but with the help of Dr Parry’s persuasive abilities and the willingness of members of the Burwood medical team to give up a day of the precious leave time things were sorted.

Dr Parry led the team, Dr Zoe Woodward a Christchurch Neurologist with GBS expertise supported him and Dana Campbell (OT) and Brendon Vercoe (Physio) from the Burwood team joined the panel. At the last-minute, Brendon’s family contracted COVID so we enjoyed his input via Zoom!

Following established practice, the morning was spent on presentations of GBS and CIDP from the neurologists, and Dana reviewed her OT functions at the Hospital. Doug and Gareth summarised the support the Group is giving to the several research projects underway in NZ into aspects of GBS treatment and support.

A short, light lunch break was followed by the Q and A session which lasted until we had the close the session at 1530hrs. The meeting was undoubtedly a success for the 16 members



who made the effort to attend. I was hoping for more support from the Canterbury Community but it was not to be. Attendees included a young GBS’er still undergoing rehab at the Hospital and who was able to allay her and her husband’s fears about the impact of her GBS episode on their future family plans – their minds put at rest by Dr Parry – priceless!!



Discussions ranged across COVID issues – inevitable I guess - with a report from a member who, after a long and sustained battle has got ACC to recognise his claim for the COVID vaccine inducing neuropathy issues. Medicinal Cannabis use was recognised as a potential life quality improver, and alternatives to the standard regular IVIg treatment for long term CIDP'ers were discussed with members recounting their success – and not so successful experiences of these.

I will submit a summary of the Questions and Panel answers that arose at the meeting for a future newsletter, but I think what stands out is that the

resolution of the ongoing disabling effects of CIDP remains the key issue for a support group such as ours. Yes, acute GBS is not a pleasant experience but for most it's a "on-off" and given time – weeks/months /years – it is done and dusted but for many CIDP'ers, it's a life changing event and one that, at least currently, has no practical end in sight. Let's hope current research can come up with an answer!

Thank you, Doug, for chairing the meeting and Gareth, for your "bulwark" support to our efforts and your willingness to share your wealth of knowledge with our members. I must also acknowledge my faithful loyal supporter Vivienne, always happy to back me up – a good tea lady, door welcomer and clearing up staff as required. Thank you, my love!

A Patient Experience

My GBS Journey by Mark Hooton

My journey with GBS started with the feeling of stones in my shoes one Friday night during the weekly beer at the local RSA. Numbness steadily rose both up my legs, as well as from finger tips to my wrists over a period of five weeks. GP visits were to no avail, walking got extremely difficult with only a shuffle possible. An appointment was then made at my local hospital. On the morning of this appointment, a hot bath seemed in order to ease the symptoms, but this turned out to be a bad decision. Stroke symptoms came on rapidly, with droopy mouth, etc., following which my doctor sent me to hospital immediately. Upon arrival, a lumbar puncture showed very little and the stroke ward was the logical place for me. My blood pressure of 200 over 160 was a major concern to the staff.

The doctors' daily rounds were joined by junior medical staff and after five days a junior doctor - after testing the numbness with a pin - asked to see the outcome of opening my mouth, which resulted in one eye closing at the same time. The junior doctor then mentioned to the doctor "GBS", which was something he remembered a family member having from years past. As luck would have it, I was later seen by a visiting doctor who put electrodes on my toes and thighs, fingers and elbows, resulting in my diagnosis. Plasma products were administered intravenously over four days, followed by three months of rehabilitation, resulting in me learning to walk again.

Forward ten odd years, then COVID appeared. After much consideration to be able to remain in the mainstream public, and following advice from GBS personnel and several doctors, I decided to get vaccinated. My GBS has steadily returned to my upper thighs during exercise and standing still for a few minutes as well. Constant exercise can result in a painful feeling under the skin, only eased with rest. When I got COVID along with many others, it was nothing near the condition of GBS. In all honesty, I'm not sure the vaccine was a bright idea, although I am in a far better condition than some of us. Rest and a positive attitude seem to me the best way to battle our condition, if we are lucky enough to be able to.

*Merry
Christmas*

PAST EVENTS

Waikato/Bay of Plenty get-together of 22 November

We had a very enjoyable get-together at The Village Café in Whatawhata, catching up with friends, and meeting new ones. Santa was in attendance, and we had a Secret Santa gift exchange.

We also gained three new members, one who got GBS after the first COVID vaccination, one got GBS after the first booster (had previously received shots one and two, no problems), and one had a positive COVID test and got GBS symptoms the following day.



Standing L-R: Marty Hewlett, Meike Schmidt-Meiburg, Chris Hewlett, Charmain and Peter Barry, Lyn Neels, Michael Logan, Fran and Grant McKay, Alison Hutchins, Tom and Janice Boon, Julia Ardern, Karen Soppet, Phil and Emma Wolfe, Judy Deed.

Seated L-R: John and Sue Dixon, David and Yvonne Powell, Rex and Linda Bannister, Adam Plumstead, Rex Soppet, Barry Deed.

At our recent meeting on Tuesday, we asked around and from 26 attendees, six ex-GBS patients had COVID once, one had it three times, and four partners had it once, all of whom were vaccinated. Hopefully NZ won't get too many new GBS cases with the approaching summer and holiday season.

We had a good year, meeting up for a bike ride and our bi-monthly get-togethers!!! I wish you and your families a Merry Christmas and all the best for the New Year 2023, health and happiness, and I'm looking forward to catching up with you all next year again!! Till then, many greetings - *Meike* :) :) :

Auckland North-West get-together of 5 November

Due to a little misunderstanding, we had a small gathering in the park instead of in the Neuro Connection facilities.

Lorraine, Brian and I discussed therapies that we found helpful in recovering from GBS, especially now that the acute stage is over for all of us – for Brian three years since onset, for Lorraine six years and for me (Eileen) 22 years! A couple of types mentioned were hydrotherapy, especially as it's non-weight bearing and going for walks and gradually increasing the distance, but not over-doing anything! I have also come across ANF therapy recently which has helped me heal from knee swelling & pain relating to a sprained ankle. (I find, even after all these years post GBS, that my muscle tone & strength has never quite returned to what it was before and I can still be vulnerable to injury.) *Eileen Jacobson*

Wellington get-together of 26 November

We had a small gathering, as many members were unable to attend. However, we had the opportunity of getting to know a new member and his partner, who shared with us their remarkable GBS journey, the beginning of which spanned an entire year in the rehabilitation ward. *Ansie Nortje*





NOTICEBOARD – UPCOMING EVENTS



Bay of Plenty/Waikato Cycling / Walking Group

When: Tuesday 17 January 2023
Time: From 10:30am onwards, meet at 10am
Where: From Leamington towards Lake Karapiro

Hi everybody, bring your bicycle, Nordic walking sticks and a shared picnic lunch, chairs, plates and cutlery, cups and drinks, etc., walkers welcome too!!!

Or just come and join us for the picnic :)

Coming from Cambridge end, drive into Leamington. The main street is called "Shakespeare Road". Turn left into "Browning Street". We will meet at the corner of "Browning and Carlyle Streets".

If you get lost, phone Grant for directions: 021 865 620. Please confirm that you are coming, then we'll wait for you.

Bay of Plenty/Waikato Coffee Group



When: Tuesday 7 March 2023
Time: From 11:00am onwards
Where: The RSA, 99 Beach Road, Waihi Beach (07)8635689

Check out their website and menu. The kitchen opens at 11:30, the bar at 11 am. You can order from the menu or get something from the cabinet.

Please let me know if you are coming or not by 5 March at (07) 86 73 163 or 027 325 0369 or schmidtfarm@xtra.co.nz

Many thanks and greetings, Meike

Wellington Coffee Group



When: Saturday 18 March 2023
Time: 3-5pm

Where: 124 Navigation Drive, Whitby, Porirua
Ansie and Louis invite you to join us at our home for a good coffee (or tea!) and home-baked nibbles. Please confirm by Saturday 11 March. New members most welcome!

Ansie's contact details:
gbs.newsletter@gmail.com
Mob: 027 332 8546

Auckland Coffee Groups



Auckland North/West:
When: Sunday 26 February 2023
Time: 2pm
Where: Yet to be confirmed

New members most welcome.

Please RSVP Eileen at
eileenmagnajacobsen@hotmail.com Mob: 021 113 3607

Auckland Botany:
When: Wednesday 08 February 2023
Time: 10:30am
Where: Columbus Coffee at Mitre10, Botany, Auckland
9 Bishop Dunn Place, Flatbush, 2013

Coffee, tea, menu or cabinet food (scones, muffins). All welcome, come and have a chat.

Please contact Rex if you have any questions
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.



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.