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Guillain – Barré Syndrome Support Group New Zealand Trust

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

NEWSLETTER March 2024



If undelivered, please return to:
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David Meyer



Brian Sheridan



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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Karen Clark Master of Nursing Clinical Nurse Specialist, Neurology Waikato Hospital	Kylie Kerr Occupational Therapist Burwood Spinal Unit, Christchurch
Kathryn Quick Physiotherapist	Te Whatarangi Dixon BHSc (Physiotherapy) MNZSP QE Health, Rotorua

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Editor's Note

Hello all. As your new Editor, I would like to thank both Ansie and Louis in having made the handover of the role so very smooth for me. My name is Carol Smart. I am a retiree, bookkeeper, artist, married, with two sons and three grandchildren. We live in Maungaraki, a suburb of Lower Hutt. I have lived in Wellington all my life but are making the move soon to New Plymouth. A new life phase which at times is exciting if not a little daunting.



My connection with GBS came about through my Dad contracting CIDP. The organisation's members at that time were so helpful to both my Dad and me as our family navigated the illness. I have remained a member of the group ever since.

I do hope you all had a marvellous holiday season. It seems a lifetime ago now. Here we are, March already. Autumn. The year is rapidly marching on, and here in Wellington, the mornings are a little cooler and darker.

As usual, this newsletter contains helpful information and food for thought.

Carol

President's Report – Doug Young

Hello everyone

Welcome to the March 2024 edition everyone, especially any first-time readers.



This becomes a special edition as we have managed to achieve a seamless transition from one editor to another without missing the three-monthly publication cycle. Ansie has been replaced by Carol Smart from Lower Hutt, who has kindly volunteered for the role. Carol has had previous association with the Support Group, therefore is aware of the very important part this position plays in our organisation. As President I extend our many thanks on behalf of the Board and the membership to Carol for filling this position. And again, to Ansie in the background, assisting Carol with the handover and publication of her first edition.

March is a busy month for the Board with preparation for the AGM on the 6th of April in Wellington - at what has become our venue of choice - the Miramar Golf Club. The meeting starts at 11.30 am. I encourage all members to try and join us and be involved with proceedings where possible. Zoom attendance will be available again this year. A light lunch will be available afterwards for those who attend. Details can be found further on in the publication.

Our three-monthly Zoom Board meeting held on 5th of March was a lively affair and a lot of business was dealt with. Tony's report, further on, details the business carried out. I welcome David Meyer to the Board as a co-opted member until the AGM confirms his appointment. This meeting highlighted the input our board support team members can inject into the discussions held on various items on the agenda. I thank Rex and Daniel for the work they have been doing in the background which in turn supports our Board members.

Other important issues dealt with over the last 3 months were - the Web-site management person. Meike has enlisted a young lady from her neighbourhood who is specialising in Web platform building and is now looking after any changes or problems encountered on the site. Many thanks Meike. Also, Bonnie Capper from Auckland who expressed interest in the Editor's role and is now on the reserves call up list, thanks

Bonnie. Brian Sheridan, our new treasurer, is settling into the role and is busy setting up the AGM along with Tony, producing the annual accounts. Also, with the administration of incorporation changes for Charitable Trusts and its effects on us to get his head around. So please spare a thought for Brian come AGM time. Gareth Parry and his team are progressing the research projects with the usual enthusiasm, as can be seen from his up-to-date report.

So, it's a busy start to the year. That's it from the President. Don't forget to make that small monthly donation to keep "The Wheels Of GBS Recovery Process" going.

Enjoy your read.

Regards to you all
Doug Young
President.

Secretary's Jottings – Tony Pearson

We live in uncertain times!

Internationally the wars in Ukraine and Gaza have the potential to immerse the world in conflict, whilst political wrangling in many countries and the looming possibility of a Trump-led USA are breeding grounds of instability. Here in NZ our new Government – whether you support them or not – is shaking up our institutions and causing concern throughout our already strained health, social support, and educational professions. I'm not saying it is bad per se, but it is unsettling, and this causes STRESS!



We all know that one of the recognised "triggers" of a GBS attack is campylobacter poisoning from, say, eating under-cooked chicken but increasingly new cases that I talk to and meet cannot recall a specific potential "trigger" and I am beginning to wonder if my own "self-diagnosis" of Stress being the trigger of my own GBS 20 years ago wasn't so far off the mark and increasingly, is contributing, if not causing, a GBS attack.

A GBS or CIDP diagnosis brings its own stress about the unknown consequences, both health-wise and its impact on family life – be that social or financial. That's where the Group can step up and help with information, answers to questions, a hospital or home visit or simply a re-assuring chat on the phone. "Been there – Done that – Got the T shirt" is perhaps not quite our mantra but the appearance of an upright and healthy-looking ex GBS'er, happy to impart some knowledge from first-hand experience, is reassuring for a patient flat on their back in ICU or a HD ward or struggling with a re-hab programme led by a PHYSIO "Terrorist". With our range of Brochures, a good website full of useful information and in giving access to seek specific information from our Medical Advisory Board, together with our Authorised Hospital Visitors group we can and do fulfil a most important role in helping New Zealanders thro' their GBS journey.

You may have noticed two new faces on the "mug-shot" page of the Board of Trustees. Brian Sheridan is our new Treasurer and has taken over the reins from Peter Scott who for 20+ years kept our books in order. Big boots to fill maybe but as a fully qualified and practicing NZ Accountant, Brian is up to the task I am sure. David Meyer is a long-timer of the Group and also a member of that rare GBS variant MMN and so a regular receiver of Ivig "top ups" so he brings to the Board not only a lot of previous organisational experience but a specific perspective on our "Variants". You are both most welcome additions to the Board, gentlemen.

And, talking of Ivig, the initial concerns about the medication switch between the tried and tested Intragram dosage and the new Privigen formulae seem to have settled down with regular users advising no additional side/after effects other than the mild headaches and fatigue they have got used to, but also – if their system can tolerate it – an option to increase dosage rate and hence shorten the time they are in the Medical

Outpatients Dept receiving their top up. If you are a regular Ivig'er and your experience does not align with this, I am sure our MAB would be happy to consider and advise – let me know.

Another long-time MMN'er is our own Nelsonian biking enthusiast Clive Phillips. Clive amazed us all with his fund-raising drive a year or so back, raising over US\$100,000 and providing the impetus to start a properly funded research project through the GBS-CIDP USA Group into the causes and effects of MMN. Not one to rest on his laurels, Clive is well on the way to repeating that funding effort with his "Ride the World" drive. We wish him the best of luck.

I'm not sure about the rest of the country but down here in the Top of the South we are experiencing another COVID wave. It would be nice to be able to say that this is "old hat" now and drops into the annual Flu box but that doesn't seem to be the case with some folk handling it well, whilst others are really knocked back by it. So, keep up the vaccinations and if you test +ve demand anti-virals if you are eligible – they really work.

Finally, would you please note that as a cost saving measure for the Group, I no longer have a PO Box. If you want to mail me, use my home address – 30 Higgs Road, Mapua, 7005

As always – Stay Safe.
Tony

SITUATIONS VACANT – Tony Pearson

1. BOARD MEMBER

With the recent addition of two new male members to the Board it would be nice to improve our female complement. Being a Board member is not an onerous job and only requires attendance at three Zoom, weekday evening meetings and one "eye to eye" meeting ahead of the AGM in Wellington each year. These generally last about 2 hours. Having a bit of experience in corporate or social organisations helps but is not essential. Experience of life and managing GBS/CIDP either as a patient or a carer more so.

If you are interested in helping the Group, please get in contact with the Secretary.

2. AUTHORISED HOSPITAL VISITORS

To replace recent resignations, we need to find members who are willing to become an Authorised Hospital Visitor in the Palmerston North/Fielding area, also the Wellington/Hutt districts. We have an established training programme and supportive aids to ensure you will be properly equipped to make visits. Our AHV's are probably our biggest asset in terms of assisting new patients in their recovery journey and it is a very rewarding undertaking. If you are interested in exploring possibilities, please contact the Secretary

COVID Vaccinations and GBS – Is there anything new? - Dr Gareth Parry ONZM MB ChB FRACP

A recent publication from a multinational group that included NZ researchers reported on adverse effects that had occurred amongst more than 99 million individuals who had received one of the COVID vaccines. There were nearly 243 million doses of the different vaccines administered. The report built on previous data from smaller studies and confirmed the extraordinary safety profile of all the vaccines. There was, however, a small excess of cases of GBS following vaccination. This risk was restricted to the AstraZeneca vaccine (AZV) and was tiny. More than 23 million doses of AZV were administered and 76 GBS events would have been expected in the 42 days following vaccination based on a chance association alone whereas 190 GBS events were seen. This has been reported as there being a 2.5 times greater risk of getting GBS following the vaccine which is true as far as it goes. However, that increased risk is still extremely small and is outweighed by the benefit that accrues from receiving the vaccine. The Pfizer vaccine, the one most widely used in NZ, was not associated with an increased risk of developing GBS.

This report does not address the risk to patients who have previously had GBS. However, one previous study of a nationwide COVID vaccination programme in Israel showed that no individual who had had GBS previously had recurrence following the COVID vaccine. Furthermore, experience with other vaccines suggests that GBS patients are no more likely to get a new episode of GBS following vaccination than they had been previously.

The take-home message from this important report is that the COVID vaccines are extraordinarily safe and individuals who have had GBS and who have CIDP should feel safe in taking future COVID vaccine boosters which are likely to be recommended as part of an annual vaccination programme.

A Request for Volunteers

The research “The Guillain-Barre Syndrome (GBS) phenotype in Aotearoa/New Zealand: how ethnicity, socioeconomics and infection influence GBS” aims to study the clinical characteristics, severity, long term outcomes and risk factors associated with GBS. We aim to look at the importance of ethnicity, infection, coexisting illnesses, and socioeconomic status. By identifying characteristics of GBS that predict less satisfactory outcomes we hope to be able to address these factors to shorten the duration of disability and to make a better long-term recovery

To date, we have recruited 804 patients. 734 of these are patients who had experienced GBS prior to the onset of the study and 70 are new patients who have developed GBS since we began the research. We are particularly eager to identify more of the new patients as this makes it easier to obtain all the necessary data. We will continue to recruit until the end of 2025. Any physician in NZ can refer patients to the study. Also, any patient who has ever had GBS can self-refer to the study i.e., there is no date restriction. GBS diagnosed in any year is welcome.

This research is supported by generous grants from the GBS Support Group NZ Trust and from the GBS/CIDP Foundation International and we are grateful for that support. We are also grateful to the many patients who have volunteered to participate in this research – we could not have done this work without you.

To volunteer to participate or for further details about the research please contact Dr Eileen Mc Manus emcm373@aucklanduni.ac.nz

A Refreshing look at Covid 19 and GBS

Dr Chris Lynch
BMedSci, MB ChB, MD, FRACP

My Perspective

- Reference to recent literature
 - Mechanisms of Covid and Neurological disease
 - Covid and GBS
 - GBS and vaccination

Covid Pandemic in Midlands Region: Community / Non-Hospital 2020-2023

- Estimate 50% of neurological care: non-hospital neurology specialists
 - Nerve testing
 - Outpatient appointments

Covid Pandemic in Midlands Region: Community / Non-Hospital 2020-2023

- 4 GBS
- 1 AMAN
- 6 post vaccination radiculopathy/plexopathy



Neuromuscular complications of coronavirus disease-19

Joome Suh and Anthony A. Amato

Purpose of review

Since its outbreak in Wuhan, China in late 2019, coronavirus disease-19 (COVID-19) has become a global pandemic. The number of affected cases and deaths continues to rise. Primarily a respiratory illness, COVID-19 is now known to affect various organ systems including peripheral nerve and skeletal muscle. The purpose of this review is to discuss the scope of neuromuscular manifestations and complications of COVID-19.

Recent findings

Several neuromuscular conditions, including Guillain-Barré syndrome, rhabdomyolysis, and myositis, have been reported in patients infected with COVID-19, but even with a temporal association, a causal relationship remains unproven. Direct invasion of neurons or myocytes by the virus, and immune-mediated injury have been speculated but not consistently demonstrated. In addition to potentially causing the above conditions, COVID-19 can trigger exacerbations of preexisting neuromuscular conditions such as myasthenia gravis, and severe infections can lead to critical illness myopathy/polyneuropathy.

Summary

COVID-19 appears to be potentially associated with a wide range of neuromuscular manifestations and complications. Further studies are needed to examine these possible associations, understand the pathogenesis, and develop preventive and treatment strategies.

Keywords

coronavirus disease-19, myasthenia gravis, myopathy, neuropathy, severe acute respiratory syndrome coronavirus 2

Neuromuscular Complications

- GBS
- Radiculopathy
- Plexopathy
- Isolated cranial nerve palsy (eg Bells palsy)
- Myositis

PostScript

Parsonage-Turner syndrome following COVID-19 vaccination

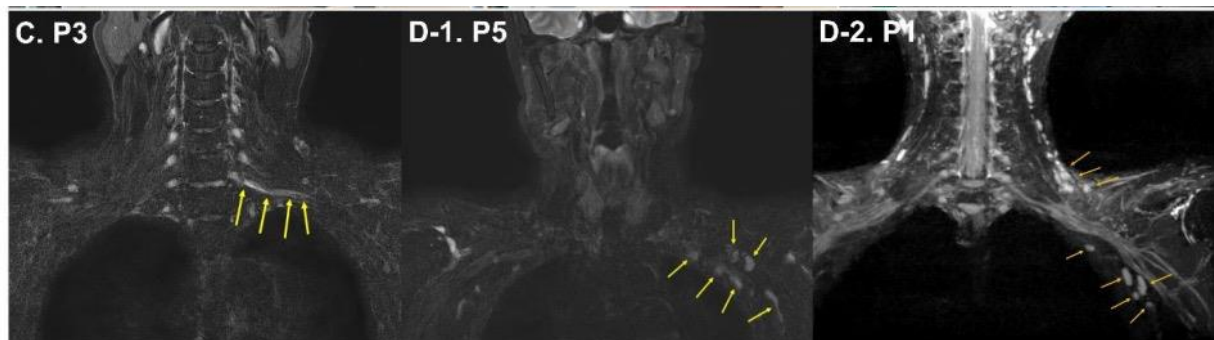
referral hospitals (Seoul, South Korea) between June and October 2021. We collected and analysed the detailed clinical information as follows: the type and order

All but two developed PTS after receipt of the first dose of COVID-19 vaccine. The interval from the vaccination to symptom onset and nadir ranged between 2 days and

Table 1 Summary of clinical characteristics

No	Sex/age (years)	Vaccine (dose)	Laterality	Days from vaccination to symptom onset/ nadir	Weakest muscle strength at nadir (MRC)	MRI	CSF analysis*	Treatment	Outcome
1	M/31	Janssen	Ipsilateral	6/7	III	Prominent ipsilateral axillary and cervical lymph nodes	WBC 0, protein 70	None	Full recovery by week 1
2	M/37	Janssen	Ipsilateral	14/14	IV+	Normal	ND	Oral prednisolone, gabapentin	Near-full recovery by week 10
3	M/71	AstraZeneca (first dose)	Ipsilateral	16/35	III	Signal changes and enlargement from the C8 root to the inferior trunk, prominent ipsilateral cervical and axillary lymph nodes	WBC 2, protein 57	Oral prednisolone, gabapentin	Poor recovery by week 15
4	M/63	AstraZeneca (first dose)	Ipsilateral	14/14	III	ND	ND	None	Poor recovery by week 4, lost to follow-up thereafter
5	F/65	AstraZeneca (first dose)	Ipsilateral	5/6	III	Prominent ipsilateral axillary lymph nodes	ND	None	Full recovery by week 2 months
6	M/61	AstraZeneca (second dose)	Ipsilateral	2/3	II	Signal changes and enlargement from the C8 root to the inferior trunk and medial cord, prominent cervical and axillary lymph nodes	ND	Oral prednisolone	Partial recovery by month 5
7	F/31	Cross-vaccination (AstraZeneca and then Pfizer)†	Ipsilateral	2/10	IV	Prominent ipsilateral axillary and cervical lymph nodes	ND	None	Full recovery by week 3
8	F/50	Pfizer (first dose)	Contralateral	4/16	III	Normal	ND	NSAIDs, fentanyl patch, IVMP	Good response to IVMP
9	M/58	Pfizer (first dose)	Ipsilateral	5/30	II	ND	ND	Oral prednisolone, pregabalin	Poor recovery by week 8
10	F/23	Pfizer (first dose)	Ipsilateral	10/11	V	ND (ipsilateral axillary lymphadenopathy in ultrasonography)	ND	Oral prednisolone, pregabalin	Partial recovery by week 6
11	F/81	Pfizer (first dose)	Bilateral	15 NA	IV	Normal	ND	Pregabalin, nortriptyline, NSAIDs	Poor recovery by month 6
12	M/39	Moderna (first dose)	Ipsilateral	7/14	IV	Prominent ipsilateral axillary lymph nodes	WBC 1, protein 76	IVMP followed by oral prednisolone, gabapentin	Poor recovery by week 8

*Values were expressed as cells/ μ L (WBC) and mg/dL (protein).
†Parsonage-Turner syndrome occurred 2 days after Pfizer vaccination following initial AstraZeneca vaccination.
CSF, cerebrospinal fluid; F, female; IVMP, intravenous methylprednisolone; M, male; MRC, Medical Research Council; ND, not done; NSAIDs, non-steroidal anti-inflammatory drugs; WBC, white blood cell.





Guillain-Barré syndrome in an era of global infections and 21st century vaccination

Michael P. Lunn

Purpose of review

Guillain-Barre syndrome is sometimes a severe and disabling postinfectious neuromuscular paralysis that is causally associated with a number of well defined infections, and occasionally with immunization. The severe acute respiratory syndrome coronavirus 2 (Sars-CoV-2) pandemic and the worldwide immunization programme provoked fears of an epidemic of coronavirus disease 2019 (COVID-19) related disease. As we emerge from the pandemic this review summarises some of the huge volume of publications about Guillain-Barre syndrome (GBS), COVID-19 and immunisation against it.

Recent findings

In the early months of COVID-19, there were concerns of significant numbers of cases of GBS resulting from SARS-CoV-2 infection. Large epidemiological studies have provided reassurance that the association of GBS with COVID-19 is small or absent. Despite considerable efforts, plausible pathogenic mechanisms aligned with our understanding of GBS causation have not been identified. Reliable data from national surveillance of COVID-19 vaccinations have shown GBS to occur at about 5.8 cases per million first doses of adenovirus vectored COVID-19 vaccines, otherwise not distinguishable from incident naturally occurring cases. However, this risk is far outweighed by the protective benefits of vaccination in the at-risk older deciles of age.

Summary

With no obvious link of GBS to COVID-19 epitopes, in particular the spike (S-)protein, but a clearly demonstrable causation in some susceptible individuals from the global rollout of novel adenovirus vectored vaccine technologies, adenoviruses are of significant interest in the pathogenesis of GBS as well as vectors in their many expanding pharmaceutical applications.

Keywords

adenovirus vectors, coronavirus disease 2019, Guillain-Barre syndrome, severe acute respiratory syndrome coronavirus 2, vaccination



Mechanisms of coronavirus infectious disease 2019-related neurologic diseases

Robyn S. Klein

snfl and sGFAP

Original research

Brain neuronal and glial damage during acute COVID-19 infection in absence of clinical neurological manifestations

Domenico Plantone , Sara Locci, Laura Bergantini, Carlo Manco, Rosa Cortese,
Martina Meocci, Dalila Cavallaro, Miriana d'Alessandro, Elena Bargagli,
Nicola De Stefano

Recommendations: Covid

- Covid Booster
- Masks
- Hand washing



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...../...../.....



PAST EVENTS

Auckland Botany get-together 21 February 2024



Lovely to see you all at the Coffee morning and to meet Patrick and his wife. (I must apologise that I did not write Patrick's wife name down) and Leigh for the first time. Ana was unable to come at the last minute but hopes to be at the next.

Martin informs me that he is on the mend.

Thanks Meike for the photo.

Bay of Plenty Waikato Get-Together



We had a great meeting in Matamata and some good discussions about a lot of topics :)

Standing from left to right: Meike Schmidt-Meiburg, Bob Keals, Janice Boon, Chris Hewlett, Karen Soppet, Jan Gribble, Alison Hutchins, Michael Logan, Barry Deed.

Sitting from left to right: Jill Keals, Roberta Cameron, Fiona Green, Rex Soppet, Judy Deed, Julia Ardern.
Photographer: Marty Hewlett.



Photographer: Marty Hewlett.

NOTICEBOARD – UPCOMING EVENTS

The 22nd AGM of the GBS Support Group Trust will take place at 1130 hrs Saturday 6th April 2024 at the Miramar Links Conference Venue at the Miramar Golf Club, 1 Stewart Duff Drive Wellington

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all members of the Trust in March. Everyone is welcome to attend the meeting and members are eligible to speak and vote at the meeting. We are planning for the meeting to be broadcast live on Zoom. Members will be advised of the link to enable them to join the Zoom meeting with the formal Notice.

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

If you have any questions about the forthcoming AGM please direct them to the Secretary Tony Pearson on 03 540 3217 or tonypearson@xtra.co.nz

CHRISTCHURCH

A Coffee and Chat meeting will be held on Sunday 19th May at Café Edge, 59 Edgeware Road, St Albans from 1000-1200hrs. This is a really nice Café where we have met before. It would help if you could let me know if you plan to attend – but not essential. Tony tonypearson@xtra.co.nz 027 687 1953



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
Phone: (03) 540 3217

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 PlantBarn, 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 Mob: 021 113 3607

Auckland Botany:

When: Wednesday 29 May 2024

Time: From 10.30 am

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.

Please contact Rex if you have any questions

rexbuckley@xtra.co.nz Mob: 027 296 3297

Bay of Plenty/Waikato Coffee Group



The next get together will be at the Mixture Eatery,
Tamahere Country Club, 70 Tamahere Drive, Tamahere,
Friday 3rd May 2024 from 10.30 am

Please let Meike know your intentions by Wednesday 1
May.

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

What's Your Story ?

Would you consider telling us about your experience for publication in this - your newsletter?

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.