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Guillain – Barré Syndrome Support Group New Zealand Trust

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

NEWSLETTER March 2022



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

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

BANK TRANSFER INFORMATION

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 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

Our lovely summer is starting to change into autumn, bringing shorter days and cooler weather. Alongside this, our borders have started to re-open, highlighting that we always have the strength to overcome crisis in life.



'The new dawn blooms as we free it. For there is always light if only we're brave enough to see it; if only we're brave enough to be it'. (National Youth Poet Laureate Amanda Gorman.)

In this issue, Doug updates us in his President's report about activities and progress we made during the first quarter of the year; Tony highlights in his secretary's jottings various aspects related to our support group, including the evolution of the new Health NZ all-encompassing government agency; and Dr Gareth Parry provided us with yet a further COVID-19 update. Many congratulations to our patron, the Hon. Steve Chadwick for the prestigious award bestowed upon her – more about this in Tony Pearson's article. Please also note that there are still "vacancies" for the GBS fatigue study (details in Dr Suzie Mudge's article in this newsletter).

Thank you to all the presenters, organisers and attendees of the very successful Auckland Regional Meeting held on 19 February. Included in this newsletter are the slides of Dr Parry's presentation "GBS/CIDP – What's New?" Further presentations will follow in future newsletters.

Lastly, I want to wish you all a Happy Easter season.

Ansie

GBS SUPPORT GROUP NZ ANNUAL GENERAL MEETING

**The 20th AGM of the GBS Support Group Trust will take place at
1100hrs Saturday 18th June 2022 at the
Miramar Links Conference Venue at the Miramar Golf Club,
1 Stewart Duff Drive, Wellington**

With the uncertainty surrounding the current Omicron-Covid outbreak, the Board has decided to postpone the AGM – originally scheduled for early April - until later in the year when the risk of exposure to the virus at the meeting should have diminished.

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all members of the Trust in May. Everyone is welcome to attend the meeting and members are eligible to speak and vote at the meeting. The meeting will also 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

President's Report – Doug Young



Welcome to the March 2022 edition of the GBS Support Group quarterly newsletter. What a stunning summer we are having and now continuing into autumn as well. With some improvement in our freedom of movement I hope all had a pleasant festive season with NZ based family and friends. We did, but still missed out on our two grandsons in Brisbane, however that's all go shortly. So hopefully all our members are making the same positive plans for the future.

The Board held our Zoom meeting 1st February, Tony has covered the details in his report further on in the publication.

My overview of the last three months' progress is:

- a. seeing the research projects we have assisted with funding, actually getting underway. You will enjoy reading about these by other contributors to this newsletter.
- b. Auckland Regional Meeting held on 19th February at Tui Glen Henderson. This was a very successful meeting and I extend my thanks to all who participated, both the organisers (Meike who ran the meeting and organised the food, Tom Hoey Chairman of the Neuro Connection Foundation and provider of the great venue and Eileen Jacobson our main Auckland contact person at present), as well as the MAB members who attended and presented (Suzie Mudge, Chris Lynch and Gareth). Finally, all the Auckland members who braved the Covid restrictions and attended, I am sure they all felt it was a worthwhile event and gained some insight into GBS and its effects.

Other ongoing Business:

1. The re-development of our Authorized Hospital Visitors training program is developing in the background.
2. Fundraising continues to be a priority

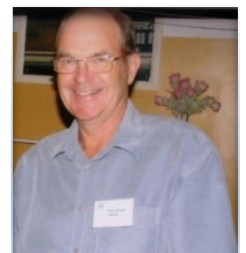
Enjoy your read, and I look forward to reporting on further progress of the group after our AGM in June.

Regards

Doug Young

President

Secretary's Jottings – Tony Pearson



None of you will be surprised that it's been a couple of months of many phone calls from worried GBS'ers about potential impacts of boosters causing relapses, etc., and also from some, admittedly a few, who are concerned that their present condition – which to them seems very like GBS - has been triggered by the vaccination. Thankfully with the support of the MAB most of the concerns about setting off a relapse have been allayed. As for the Vaccine triggering GBS - well I think it's too early to have any definite outcomes on this and whilst the numbers in NZ are small, that's not a lot of consolation if you are one of that number. Hopefully a meeting with a competent Neurologist and proper follow-up treatment can resolve any dilemma for individuals. The evolution of the new Health NZ all-encompassing government agency is progressing with the appointment of interim CEOs to both the main NZ Health and the Māori Health Authority - both very experienced ladies from the health sector. The size of the new organisation is staggering (at least in New Zealand terms) with 80,000 employees and an annual budget of \$20 billion – so no sign of any “glass ceiling” in this workplace for Chief Executives – let's just hope they can “crack” (no pun intended!) the transition without a disruption to ongoing healthcare!

An exciting development was Grant Robertson's announcement of a proposal that could extend the eligibility of claimants for ACC support to health disability sufferers – making a real possibility that GBS'ers may now become eligible for WINZ assistance as an “accident”. Definitely a “watch this space” item as far as I am concerned!

With no sign of any “re-think” on a Cannabis referendum it is disappointing to read in the Listener that progress on expanding the range of properly regulated and standardised products for prescription medication appears to be bogged down in the regulations that were meant to facilitate the improvement in options for users and their GP’s. Currently, only a limited range produced by a Canadian manufacturer is approved. Products that are in regular prescription use in Germany, UK, Australia have been rejected by our regulators and whilst just one NZ company has been granted a license to manufacture, none of its products has so far been approved. And guess what this restriction does to the legal price!

As this Newsletter goes to press, we in the Top of the South are hunkering down waiting for the Omicron “wave” to strike. I believe the Board has made as wise decision to delay the Annual General Meeting gathering in Wellington until June. Let’s hope we are though the worst by then.

Stay Safe.

Tony

Our Patron

by Tony Pearson



Some of our long-standing members may recall that we got our Patron – the Hon. Steve Chadwick – Mayor of Rotorua by default!

At one of our early Conferences we had invited the then Minister of Health Annette King as guest speaker but she sent her “regrets” as she was too busy with more important things than the GBS Support Group – so she sent her Deputy Steve Chadwick – who was already a member of the Group having a sister in Australia suffering from GBS. In 2004 Steve accepted the position of Patron to the Group following the retirement of our first Patron Sir William Birch – himself a GBS’er – and the rest – as they say – is history!

Steve has been a hugely supportive Patron and has welcomed us to a number of Conferences in her hometown of Rotorua. Her late husband John helped me re-write our current Trust Deed back in 2009 on a “pro-bono” and in plain speak language (brilliant for a Lawyer!).

Well, Steve’s work for services to local government and as an MP for her country (not to mention her support to our Group!) has been recognised by the award of a QSO – Companion of the Queen’s Service Order in this year’s New Year’s Honours list. Our heartfelt congratulations Steve, VERY well deserved.

Steve has been a “hands on” Patron launching many of our Conferences over the years and has supported local GBS’ers in Rotorua like Jackson Lee – who some of you will have met at the recent Auckland Regional Meeting - and she knows the most recent addition to our Medical Advisory Board Te Whatarangi Dixon – a Physio based in Rotorua who himself has had GBS twice!!

So as a Group, we have more than our fair share of nationally recognised celebrities, with Dr Parry – a Companion of the New Zealand Order of Merit (ONZM) – for services to Neurology and now joined by Steve’s QSO and we must not forget our Founder Jenny Murray’s Queen’s Service Medal so richly deserved for her unlimited commitment to GBS’ers in this country.

And finally Steve, we are so pleased to hear that you have made a good recovery from your recent brush with Covid-19 last month and it is a reminder to us all that Covid is no respecter of rank nor status but, as you reported, staying fit, getting vaccinated, taking all the sensible precautions, and having good medical support can win thro’ this “B” thing!

From the Medical Advisory Board



COVID infection, COVID vaccination and GBS – what is the latest?

by Dr Gareth Parry



There is very little new to report about GBS with either COVID infection or vaccination.

First, an update on COVID-19 infection itself. As of 13 March, nearly 460 million people are known to have been affected worldwide but the real number is certainly much higher since many cases have few or no symptoms and are not getting tested, especially in under-developed countries. There have been over 6 million reported deaths, again almost certainly many fewer than have really occurred. One estimate is of 19 million deaths. In the US, where COVID denialism and vaccine antipathy are rampant, about 25% of the total population has been documented to have been infected and nearly 1 million have died. In NZ, where >94% of the population is double-vaccinated, there have been ~350,000 cases (~6% of the population) and ~100 people have died. As you are all well aware, the dramatic rise in NZ cases is related to the Omicron variant that has recently reached our shores with almost 200,000 cases reported in the last 10 days. The omicron variant continues to be associated with milder illness and there have been only 23 deaths in that same 10-day period.

GBS continues to be reported following the COVID-19 infection but there is nothing to suggest that the risk is greater than with almost any other infection. That is, GBS is often triggered by any of a multitude of infections and COVID-19 is no exception, but the risk is small. GBS following COVID seems to have the same characteristics as GBS following other infections. Importantly, the frequency of GBS in NZ seems to have gone down since the onset of the pandemic. Researchers at the Wellington Hospital are working with the Ministry of Health to confirm or refute this but if it is true, it speaks to the very low risk of COVID as a trigger for GBS.

GBS following COVID vaccines also continues to be reported. That does not mean that the vaccine caused the GBS, although it may have, but GBS has occurred within 6 weeks of receiving the vaccine. As of 31 January, there had been ~9.5 million doses of the Pfizer vaccine given in NZ and ~6500 doses of the Astra-Zeneca vaccine. 357 people have had a serious adverse effect (SAE) to the Pfizer vaccine, including 22 reported cases of GBS, and 13 people have had an SAE with the A-Z vaccine with no reported cases of GBS. There have been some anecdotal reports of neurological symptoms occurring in GBS patients after being vaccinated but there have been no established cases of GBS recurrence with the vaccines.

This is all extremely reassuring, and the recommendations remain the same. The risk of getting GBS following COVID infection, although low, are much higher than the risk of getting GBS following the vaccine so get vaccinated and boosted.

CIDP patients can also take heart from the reported data from NZ and farther afield. I have not come across reports of relapse in CIDP with either COVID-19 infection or the vaccines. I am aware of one report of an extremely rare variant of CIDP called CANOMAD being unmasked by COVID infection, but it is very unlikely that the infection caused the disease. CIDP treatment also has very little impact on COVID-19 outcomes. The two commonest CIDP treatments, steroid medications such as prednisone and intravenous immunoglobulin are sometimes used in severe COVID disease and seem to improve the outcomes. The usual CIDP treatments also should have no impact on the effectiveness of the vaccines although rituximab, a rarely used CIDP treatment, theoretically could make the vaccine less effective. Vaccination can probably be given at any time during the IVIg treatment cycle but perhaps giving the vaccine a week before the next IVIg dose is scheduled might be a good idea – talk to your treating doctor about this.

So, the recommendation for CIDP patients is also to get vaccinated, continue your CIDP treatment and practice sensible infection control and avoidance strategies.



From the Medical Advisory Board



PRESENTATION SLIDES FROM THE AUCKLAND ONE DAY
REGIONAL MEETING HELD ON 19 February 2022
by Dr Gareth Parry

GBS/CIDP – What's New?

Gareth Parry (Dean Kilfoyle)
GBS Society Meeting
Auckland, February 2022

What's happening with COVID?

- >400 million people known to have been affected worldwide.
- Real number is certainly much higher since many cases have few or no symptoms and are not getting tested.
- Nearly 6 million deaths.
- In the US, where COVID denialism and vaccine antipathy are rampant, about 25% of the total population has been documented to have been infected and nearly 1 million have died.
- In NZ, where >94% of the population is double-vaccinated, there have been ~16,000 cases (~0.3% of the population) and ~50 people have died.

COVID-19 – your questions:

Does COVID-19 infection cause GBS/CIDP?	
Does COVID-19 vaccination cause GBS/CIDP?	
Will my GBS/CIDP treatments increase my risk of COVID-19?	
Will my GBS/CIDP treatments impair my response to vaccine?	
Should I get the vaccine?	
Have/will the MAB get vaccinated?	
I'm sick of hearing about COVID-19 , is there any other news?	

Don't shoot the messenger

- You can disagree with me
- You are entitled to your own opinion but not your own facts
- What I think is best for my patients is based on my interpretation of the available scientific evidence to date
- Recognizing all health decisions are a balance of risk and benefit
- Endorsed by MAB
- What I will advise for myself, my family and my friends



COVID-19 – your (short) answers:

Does COVID-19 infection cause GBS/CIDP?	Maybe a little
Does COVID-19 vaccination cause GBS/CIDP?	Maybe
Will my GBS/CIDP treatments increase my risk of COVID-19?	Not much
Will my GBS/CIDP treatments impair my response to vaccine?	Not much
Should I get the vaccine?	Definitely
Have/will the MAB get vaccinated?	Definitely
I'm sick of hearing about COVID-19 , is there any other news?	Sure!

Does COVID-19 cause GBS/CIDP?

- Any infection can cause GBS (CIDP not so much)
 - Possibility of a casual relationship between GBS and any infection is considered only if GBS begins within 6 weeks infection
- Has GBS occurred in the 6 weeks following COVID infection?
 - Yes, ~200 cases worldwide have been reported to have occurred during the 6 weeks following COVID infection through the end of 2021.
- Has GBS *recurrence* occurred in the 6 weeks following COVID infection?
 - Yes, 1 reported case (patient had already had 2 episodes)
- It is not certain whether this is “subsequence” or “consequence”.
- Even if it is consequence the risk is tiny (about 200 in 400 million)

That's sounds alarming....

- First 6 months of pandemic 15 million cases COVID
 - We would have expected > 100 cases of GBS if COVID hadn't happened
- OK, but what about asymptomatic or untested COVID?
 - If so, then we should have seen an increase in GBS numbers in 2020 vs 2019
 - UK did not: GBS numbers went down compared to 2019
 - In NZ the number of GBS cases that have occurred since the start of the pandemic appears to have fallen markedly.

Does COVID-19 cause GBS/CIDP?

- "Not particularly"
- Any infection can cause GBS
 - Including COVID
 - But no more readily than any other viral infection
- Public awareness of infection control is effective at reducing GBS (see the campylobacter story)

Does COVID-19 vaccination cause GBS/CIDP?

- “Possibly”
- ~10 **billion** doses worldwide so far and ~25 million doses are being given daily.
 - With the Pfizer vaccine (the one given to NZ’ers so far) the number of GBS cases occurring following the vaccine was no greater than the number that would be expected if vaccination had not been given.
 - With the Astra-Zeneca vaccine (recently available in NZ), 38 extra cases of GBS occurred for every **10 million vaccine doses given**; i.e., 38 more than would have been expected if vaccination had not been given.
 - ~100 cases of GBS have been described following the J&J vaccine out of ~12 million doses given over 4 months:
 - Not yet documented that they were GBS (many self-reported or reported by non-neurologists).
 - No published cases of CIDP relapse

Does COVID-19 vaccination cause GBS/CIDP?

- 20 GBS cases reported to Medsafe (as of 12 Jan).
- We would expect to see many more cases by a chance association alone.
- Given the number of people worldwide who have received a COVID vaccine and the time that has elapsed we would know by now if there was a risk.

Will my treatment increase my risk of severe COVID?

- “Not much” or “minor”
- (More relevant for CIDP patients)
- IVIG – no
- PLEX – has been used as *treatment* for critical COVID
- Steroids: probably not; steroids are used to treat severe COVID.
- Azathioprine/Methotrexate/Cyclosporin/Rituximab
 - Inconsistent small increased risk – probably mostly due to the underlying health condition (eg transplants, lupus). As CIDP does not affect other body organs the pure treatment risk is likely quite small.
- Advice
 - Good infection control measures. Mask in crowds.
 - Do NOT stop your treatment

Will my GBS/CIDP treatments impair my response to vaccine?

- “No”
- Small print
 - To the best of our knowledge so far
 - Rituximab

Should I get the vaccine?

- “Definitely”
- The pandemic is not over (India!!, Sydney?, recent upsurge in NZ with Omicron)
- NZ is **not** invulnerable
- The vaccine is extremely safe and effective
- The vaccine has been fully tested/approved
- Balance of risk vs benefit
 - Odds of getting GBS after vaccine: 1/800,000
 - Odds of dying if you get COVID: 1/50
 - Even here in NZ benefit >>> risk

Will the MAB members get vaccinated

- We all have.
- No serious side effects.

Other news

- Second IVIg dose in severe GBS
 - 2nd full 2g/kg dose within 7-9 days of the usual first dose
 - Did not improve any outcome measure
 - 4% vs 0% rate of pulmonary embolism
 - 2nd full dose quickly after first is not helpful, possibly dangerous
 - Reminder that IVIg is not entirely harmless
- Recurrent GBS
 - 3% of 400 patients with GBS in Bosnia/Serbia were 2nd attack
 - Average interval 12yrs.

Other news

GBS research in NZ:

- Fatigue following GBS.
 - The effects of a graded exercise programme (Dr Suzie Mudge).
- What does GBS look like in NZ?
 - Māori/Pasifika seem to get more MFS and PCB forms.
 - More GBS in NZ seems to be triggered by diarrhoea.
 - GBS in NZ seems to be more severe and to have poorer recovery.
 - We have launched a nationwide study to see if these clinical observations are accurate.
 - All patients who have had GBS since Jan1, 2017, and who develop GBS in the next 3 years will be invited to participate in the study.

Other news

GBS research in NZ:

- What is the better treatment for severe GBS, IVIg or TPE?
 - Some data suggests that TPE is superior.
 - We have started a study to try to answer the question. Auckland, Hamilton and Waikato are participating.
- GBS in the time of COVID:
 - NZ should expect to see about 10 new cases nationally every month.
 - The random observations of neurologists at 4 major centres (Auckland, Hamilton, Wellington and Dunedin) suggests that this number may be much lower since the start of 2020.
 - We are working with the MoH to determine the number of GBS cases that have been seen nationwide from Jan 1, 2019 (i.e., a year before COVID reached our shores) through to the end of 2021.

References

- GBS after COVID. J Neurology 2021;268(4)
- COVID and GBS in UK. Brain 2021;144(2)
- Recurrent GBS after COVID. Pathogens 2020;9(11)
- GBS after vaccine. <https://pubmed.ncbi.nlm.nih.gov/33824169/>
- Second IVIg. Lancet Neurology 2021;20(4)
- Zipper treatment. J Child Neurol 2019;34(5)
- Recurrent GBS. Neurology India 2019;67(6)



Clive Phillips' Bike Ride

By Tony Pearson



Clive on the trail

It was hardly a “ride” – I think a round trip of 1,132 Kms counts for more than that – my 14 year old “bike mad” grandson informs me “it’s called BIKE PACKING grandad”! But whatever its name, it was a great effort Clive – very well done and whilst I know it was not the top to tail of NZ that you had originally planned, I think under our present nationwide “medical” crisis it was a major achievement to have done it in 10 days – and , if the technology of your website is to be believed, you climbed cumulatively more than 14,000 metres! – unbelievable – that is eight times up our local Mt Arthur.

Good luck with your ongoing fund-raising efforts for MMN – I know you are hoping for more – and don’t stop contributing folks! – I think you recognise that here in NZ and

around the world fund raising entities are struggling as a direct result of the worldwide pandemic – let’s hope for better times in the years to come.

As part of our effort to support our “local” hero – Dr Parry and I – accompanied by our photographer (my loyal wife Vivienne) made the trip out to Tapawera - about a 45min (car) ride from Nelson to welcome Clive who was about halfway along his last and homebound leg and to provide him with “enroute” sustenance in the form of coffee and cake – an essential part of this “bike packing” lark I understand – at least judging by the activities of a large group of Hawkes Bay bikers – down here on holiday and also enroute to Nelson and indulging in similar fare at the café.

Clive arrived remarkably fit and fresh and looked more than capable of doing a 2nd circuit, but did admit that some sections of the ride were tougher than he had anticipated, but he achieved it with remarkably little physical niggles and amazingly no mechanical breakdowns of his trusty “steed”.



Gareth Parry, Clive Phillips and Tony Pearson

Now all this would be praiseworthy of any fit chap BUT, hang on, this guy ain’t so well as he might look because he suffers from a serious GBS variant called MMN (Multifocal Motor Neuropathy) and is one of a few in New Zealand but, of course, more worldwide. His condition requires Clive to have regular “top ups” of IVIg and he was doing the ride between his regular appointments for infusions. There is little understanding of this rare variant and Clive’s objective for this ride was to raise awareness of the condition and garner funds to assist research into its causes and management.

The USA GBS-CIDP Foundation were so inspired by Clive’s drive and determination that they have established an MMN Awareness group and set up a Research Funds to progress investigation into MMN and declared February as MMN month – with fund-raising efforts throughout the USA – and indeed worldwide – so quite a feather in your cap Clive!



Participants for GBS Fatigue Study

By Dr Suzie Mudge

Do you experience fatigue so that it interferes with your daily activities and want to take part in an intervention designed to reduce fatigue? We are still looking for more participants to take part in a research study looking at whether an intervention that includes physical activity will reduce fatigue after Guillain-Barré Syndrome.



The researchers are Dr Suzie Mudge, Dr Gareth Parry and Greta Smith and this study is hosted at AUT University. The intervention is delivered via zoom so you can take part from anywhere in NZ. It is tailored to your specific situation, so accounts for the activity you like doing, how much fatigue you have and other circumstances that are important to you. For more details about the study, please contact Greta Smith greta.smith@aut.ac.nz.

PAST EVENTS

Waikato/Bay of Plenty get-together of 8 Feb 2022 in Gordonton at the Willow Glen Cafe

by Meike Schmidt-Meiburg



We had great fun catching up, keeping cool (with ice cream!), chatting and laughing, making plans (to go up North, the South Island and planning a cruise and trip overseas), discussing the upcoming Auckland Regional Meeting, our next bike ride and lunch dates.

Sitting L-R: Emma Wolfe, Rex Soppet, Lyn Neels.

Standing L-R: Meike Schmidt-Meiburg, Barry Deed, Tom Boon, Judy Deed, Janice Boon, Chris Hewlett, Fiona Green, Min and Warren Turnwald, Julia Ardern, Karen Soppet, Jan Gribble, Michael Logan, Phil Wolfe. Photographer: Marty Hewlett.

NOTICEBOARD – UPCOMING EVENTS

(Given the ongoing circumstances around the COVID-19 pandemic, please note that any upcoming event will be subject to any restrictions on gatherings which may apply at that time. It is ultimately also up to the organiser and participants at that time to make a common-sense decision whether or not to proceed.)

Bay of Plenty/Waikato Coffee Group



When: Thursday 05 May 2022

Time: From 10:30am

Where: Café Nineteen, Fairview Estate Country Club
34 Sharp Rd, Aongatete, Katikati. Tel (07) 549 3412
They close at 4pm.

Please let me know if you will be attending or not by 03 May so I can confirm numbers with the venue. They will have their lunch-time a-la-carte menu and cabinet food available too.

(07) 867-3163 or 027 325 0369 or schmidtfarm@xtra.co.nz.

Many thanks and greetings, hopefully see you all then,
Meike :)

Wellington Coffee Group



Due to the present COVID situation, there is currently no scheduled Coffee Meeting. Stay safe.

**Please contact Ansie if you have
any questions**
Mob: 027 332 8546

Auckland Coffee Group



Due to the present COVID situation, there is currently no scheduled Coffee Meeting. Stay safe.

**Please contact Eileen if you have
any questions**
Mob: 021 113 3607

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.