Guillain Barré Syndrome Support Group NZ Trust

Connections

President's Report

Welcome to the March 2025 edition everyone.

An almost 5-month period for us to bring you all up to speed on, as plenty has happened which you will see as you read on.

Roz, our editor, has received lots of input from the board members and others for this edition. Therefore, should make interesting reading for one and all.

Our 3 Monthly Zoom Board meeting held on 11th March was the usual lively affair, and a lot of business was dealt with. Tony's report further on gives details of the business carried out.

With the planned regional meeting in Dunedin on the 4th of May not far away, everyone is busy putting the program details together. I am looking forward to this, the first ever such meeting for the deep South, since the organization's inception.

Following hard on its heals is the AGM scheduled for Auckland on May the 24th at the Manukau City Library, Meeting Rooms. Again a lot of work for Tony and Brian in particular to bring this together.

Then there is the normal business going on in the background. With Gareth's team continuing to work on their current research project with Eileen working through the large amount of information she gathered in, to produce the statistics in a format that is useful for all involved. We as a support group are helping her achieve this with additional funding required to do so.

Let's not forget the succession planning being an ongoing event as well, with people who have the skills we need, putting themselves forward and expressing an interest in a Board position.

That's it from the President, don't forget to make that small monthly donation to keep "The Wheels" of the GBS Recovery Process going.

Please note the names of our Major donors/sponsor's mentioned in the publication.

Enjoy your read

Doug Young

President

GBS NZ Board Activities

Since the last Newsletter we have had a couple of Zoom Board meetings – a medium we are all now pretty comfortable with - although Brian's last effort of recording the meeting and getting the

Zoom equivalent of A.I. to transcribe the Minutes demonstrated – I hope – that I am not out of a job yet!

Roz our new Editor is settling in well but as a Board we are concerned about the ongoing cost of the Snail Mail element of distributing the Newsletter to those recipients who have not elected to receive it digitally – it costs about $1500 per year for photocopying – paper – envelopes and stamps – something our scarce resources could do without - SO.. we are on a drive to persuade you "Snail Mailers" to jump into the digital era!

Following the Auckland Regional meeting in October last year the Board held a "Retreat" to focus on matters impacting on the development of the Group. In part this was initiated by the requirements of the Charities Commission imposing a formal review of our Governance regulations. This boiled down to an assessment of our Service Performance – we awarded ourselves an A-against their standards! However, our Cultural Responsiveness and Health and Safety practices did not fair so well and are currently receiving attention via a sub-committee of the Board to come up with appropriate rules/practices that can sensibly apply to our operations.

An objective (we hope) review of our Financial Management and Member Communication practices concluded we have things about right given the voluntary/charitable nature of our operations but we recognised we need to upgrade our membership database systems to provide a more informed access to the make up of our members relationship with their GBS experience – this is now underway and may result in a request to you as a member for the voluntary disclosure of additional information about yourself/your GBS condition. You will be kept informed of developments.

With a Board largely made up of "elder" members the question of Succession was addressed and with the addition of one new "younger" Board member and the expressions of interest in joining the Board from a couple of other "youthful" members of the Group the outlook is somewhat less concerning. Both the President (Doug) and myself as Secretary have agreed to serve thro' to the 2026 AGM but at that point we will step down to allow "new blood" to take over – if you have aspirations in those arenas PLEASE step forward!

Future Gatherings: - As you will read in this Newsletter the Dunedin Regional Meeting will take place on May 4th and the AGM in Auckland on May 24th. We are planning the second of our biannual Regional meetings – probably in Hamilton - in October but are open to suggestions for other venues.

As a result of my "urging" we have started to investigate the pros and cons of developing an Advocacy protocol for our AHV's – in simple terms this involves a discussion about whether or not our AHV's should attempt to "intervene" in Hospital decisions about the treatment of patients they are supporting. My "interest" was caused by several incidents (including one at Nelson Hospital) where "staff" were being encouraged (by the "powers that be") to discharge GBS patients from Rehab facilities before (perhaps) they were ready and capable of looking after themselves at home.

Fortunately – and without rustling TOO many medical feathers all these incidents were resolved in the patient's best interests but it started me wondering what our role in this area might "officially" be. It is a minefield of course and the USA Group has declined to venture into it with the UK Group – like us - giving it careful consideration – a Work in Progress!

Tony – Secretary to the Board.

Update from the Regions

Hi everybody in the Waikato/Bay of Plenty,
It was lovely to see you all for a good catch up and meet 3 new survivors with their partners in Katikati, welcome!!

Our next get together will be at the:

Matte Black Cafe
Gordonton
1063 Gordonton Road
Waikato
on Thursday 15.5.2025
from 10.30 am onwards

Please let me know if you are coming or not by Tuesday 13.5.2025, schmidtfarm@xtra.co.nz or 07 86 73 163or 027 325 03 69, the staff need some warning for setting up the tables, thankyou...and then I don't have to chase you ;)

Looking forward to catching up with you all!

Many greetings, Meike :)

Lower Hutt Wellington Coffee Group
At very short notice a small group of members joined me for a coffee and chat on Friday 21st February at the Art Gallery Café in Lower Hutt whilst I awaited the outcome of a further hand operation of my friend Apii Vaikai who's story was related in the last Newsletter.

It was sunny but windy – hence sheltering in the corner! Lots of topics covered including the design of Orthotics to assist foot drop issues – but remain stylish! Jan undertook to try and revive the Wellington Coffee Group which has not met for a while after Louis and Ansie moved on.

From left to right:-Me, Carol, Noel, Phillip, Katrina and Jan.

The Auckland Botany Coffee Group meets every three months at:

Columbus Coffee at Mitre 10 MEGA Botany,
9 Bishop Dunn Place
Flat Bush
Auckland 2013

Please let me know if you are coming or not, rbuckley@xtra.co.nz

Rex Buckley

Farewell to Dr John Podd

John resigned from the Board in September 2024 after some 20+ years of service to the Group. In keeping with the way he conducted himself at all of the meetings I attended John has asked that "no fuss" be made about his resignation. John was a "no fuss" sort of guy – he was happy to let other more "voluble" members of the Board lead debates but every now and then would add a quiet or "pithy" comment or word of wisdom that would make us stop and think – he had sound judgement and his wise advice will be missed by those of us who worked with him over those many years.

Thankyou John – the Group owes you a LARGE Debt of gratitude.

Tony

In Memorium

I am sad to announce the death of **Margaret Stothart** on January 11th, 2025, at the age of 90. Margaret had been a stalwart supporter of the NZ GBS Support Group Trust since its inception in2001. Margaret's husband, Bob, developed GBS in the late 1970s at a time when there was little knowledge about the disease and no support for its survivors. When Jenny Murray created our support group in the late 1990s Margaret and Bob jumped on board with enthusiasm. While Bob served on the Board of Directors of the Trust and was its President from 2007-2014, Margaret busied herself with less conspicuous but equally important activities, especially those associated with the National Conferences and later with the Wellington regional conferences. She could be found, along with Viv Pearson, manning the registration desk and organising the behind-the-scenes activities. She was a woman of energy and enthusiasm, and it showed in her work for the organisation. Margaret will be deeply missed by her family and all those who knew her.

Bob and Margaret Stothart on Registration duties at a GBS Conference

Dunedin Regional Meeting

Sunday 4th May 2025
Catholic Social Services,
42 Macandrew Road,
South Dunedin, Dunedin 9012
(wheelchair friendly ramps)

9.45 am **Introduction and Welcome**
Doug Young
President
GBS Support Group NZ Trust

10 – 10.20 am **GBS: Why the Immune System Attacks**
Dr. Anthony Garvey
Neurologist
Dunedin Hospital

10.20 – 10.40 am **Physiotherapy in GBS, Enhancing recovery across all stages**
Nicole Vercoe
Physiotherapist
GBS Board member

10.40 – 11.10 am Morning tea break

11.10 – 11.30 am **Pills and Potions: potential perils of dietary supplements**
Dr. Gareth Parry
Neurologist
Head of the GBS Support Group NZ Trust Medical Advisory Board

11.30– 12 am **Patient stories (max of 3)**

Noon – 1.30 pm **Lunch**

1.30 – 3.00 pm **Panel discussion and audience questions:**

Dr. Gareth Parry, Dr. Anthony Garvey, Nicole Vercoe

Please register for this event by contacting the secretary Tony Pearson at tonypearson@xtra.co.nz, any questions please ring him on 027 687 1953or 03 540 3217, and pay your registration fee of $30/pp online (to cover hall hire, morning tea and lunch), stating your name and Dunedin Reg. Mtg.: GBS Support Group NZ Trust, 15 – 3949 – 033 93 62 – 000. The meeting is open to members of the group together with all other interested parties.

We are looking forward to welcoming you all for this very informative event!!

Please send Tony an email asap. that you have paid your registration fee, by 27.4.2025at the latest, with your name, address, phone no., are you the patient or the carer, and if you have/had GBS/CIDP or ? or are you an interested party, would you be willing to share your story briefly before lunch, thank you.

Mailing address: 30 Higgs Road, Mapua 7005 Our website: www.gbsnz.org.nz

Secretary's Jottings

As the AGM at the end of May approaches – admittedly a little later this year than usual – I find myself reflecting on "numbers" –Over the past year 54 new GBS'ers in New Zealand have contacted the group-either directly or thro the Website/Facebook site. If I recall (and Dr Parry may correct me) we can expect New Zealand to have about 150- 200 new cases of GBS each year – based on a world-wide statistical average (although I think NZ runs usually a bit higher than that "average"). So that means barely one third of new GBS'ers in NZ make contact with us. Add to this that barely half of those who do become members of the Group respond to my "welcome how can we help" message and its starts to get a bit depressing – where are we going wrong??

BUT – something I have learned since arriving in NZ some 20+years ago is a re-appreciation of numbers. As the Company Secretary of a large multi-national industrial group in the UK before emigrating I had to plan for several hundred shareholders arriving for our London AGM – at the end of May in Auckland if we get 25 members to our AGM I shall be VERY happy – more of course would make me ecstatic! – and the same applies to our forthcoming Dunedin Regional Meeting - but that is not – I now realise – the point . If as a Group we can help 20 to 30 new GBS'ers a year come to terms and/or understand what they have to deal with and expect or direct them to services that can help them then I am very content – more would be great but its 20 to 30 who have had good input from us – and by that I also mean the input from our AHV's and our MAB's invaluable contribution - that make the year's effort worthwhile.

AND – I have yet to meet anyone who has attended those gatherings who has told me it was a waste of their time! The chance to come face to face and ask personal relevant questions of some of the foremost neurological experts in the country (which might otherwise take 4 or 5 months on a waiting list for a brief 15 minute consultation) along with the opportunity to learn something new about our shared "infliction" coupled with a really GOOD social interaction can't be over exaggerated! If I've twanged a chord with you – make the effort to attend!

Over the past year I have joined (as the NZ representative of our Group) an International GBS forum arranged by the USA Group. We meet on Zoom ever couple of months with representatives from across the world – roughly in our (12 hour) time zone- Europe, Singapore, India, Japan, Australia etc etc and it has put my concerns about our coverage in NZ into perspective –the enthusiasm that the representatives display for helping their countrymen is humbling – imagine being a GBS representative in India (population 1.4 Billion) or Japan (population 125 million) – both countries with vastly different levels of medical support but nevertheless they are doing their level best to help those in need. – a salutary lesson to dispel "self-pity" but it engenders a definite "end of term report " of Must try harder!

To other matters - No doubt some of you will have read about the sterling efforts of the parents of a young lad from Christchurch who contracted GBS back in 2017 – diagnosed in Nelson when he was on holiday – to get him support for his future life in a wheelchair based on a claim that a delayed recognition of the cause of his condition had caused severe neurological damage resulting in a poorer recovery than might otherwise have been the case. ACC have contested the claim thro' to the Court of Appeal and have prevailed with the court agreeing that "medically and scientifically there was no data to support the conclusion that treatment started 8 to 12hours earlier would have made any difference to the outcome". One has to wonder that the 10's – maybe 100's of thousands of dollars ACC have spent on lawyers might have been better applied to supporting the lad for the rest of his incapacitated life but I suppose extending ACC support to "non accidents" is not realistically or financially possible.

On a more personal note I have recently had to have minor surgery on my shin (Cancer related) which has necessitated me having to resort– over the last 3 weeks - to using crutches under threat from my surgeon and even more seriously from my wife!! - to take the weight off the leg. Apart from

the sheer frustration of using the damn things – which never stand upright and always catch on chair legs etc -it has given me a real insight and new found respect for all of you who have to use them, or other walking aids, full time to have mobility at all.

That will do me for now from my "soap box". As always Take Care - Tony

The 23rd AGM of the GBS Support Group Trust

AGM meeting details
1230hrs
Saturday 24th May 2025
Commercial Meeting Room
Manukau Library
3 Osterley Way
Manukau City Centre
Auckland 2104

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all members of the Trust in early May. 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 027 6871953 or tonypearson@xtra.co.nz

GBS outbreak in Pune, India

Earlier this year, an unusual number of cases of GBS was noted in the city of Pune, India, a city of about 7 million people located about 150 km SE of Mumbai. In a population of that size roughly 150 cases of GBS would be expected annually but nearly 200 cases were reported in the first 6 weeks of the year alone.

The increased numbers continued into March before beginning to wane. The cause of the outbreak has been traced to contamination of the water supply with Campylobacter jejuni, the commonest known trigger for GBS worldwide but particularly in under-developed countries. Water contamination is not a new problem in India, and it is not entirely clear why this outbreak has occurred. Since most of the cases have been reported from the periphery of the city where there is a high concentration of shanty towns and where the sewer system is being strained by increased migration from impoverished rural areas, this is the likely culprit.

It is also possible that there has been mutation of C. jejuni strains since only a small number have been shown to have the propensity to trigger GBS. There is nothing to suggest that this represents a global increase in the risk of getting GBS; it is a strictly local phenomenon.

Donation Request

Donate a Coffee a Month to keep the GBS Support Group going.

All members will know that the Group is run by unpaid volunteers – all past GBS/CIDP patients or supporters -who are willing to give their time freely as a "Thank You" to the help provided by the Group in their time of need.

Not everyone is in a position to give up their time in this way BUT there is a way **everyone** can help support the Group.

Operating the Group is not without a cost – about $6000 to $7000 a year to provide and dispatch Brochures and information to new GBS'ers, publish the quarterly Newsletter, - organise the AGM and other members meetings, run the website as well as the usual "office" costs of the Group.

Whilst we are grateful for the occasional generous contributions of a few members and their related organisations it would be comforting to know that we have an ongoing source of funds from our membership. We scrapped annual subs some years back, along with many other medical groups, and we are reluctant to re-introduce them

BUT if even half of our 200 strong membership were willing to donate the equivalent of a cup of coffee per month to the group it would virtually solve the financial concern.

PLEASE consider making a **regular $5 per month** donation to the Group via your bank and make your own personal contribution to keeping the Group going in the future

The Group's Bank Account with the TSB is No. 15 3949 0339362 00 Please use your Surname and REGDONATE as a Reference.

Your donation qualifies for a NZ donation tax credit because Guillain Barre Syndrome Support Group New Zealand Trust is an approved charity by Inland Revenue. You can claim 33.33 cents forevery dollar (in excess of $5) you've donated to Guillain Barre Syndrome Support Group New Zealand Trust. We will issue you with an approved receipt for your donation after 31 March each year.

YOU MAY HOWEVER PREFER TO MAKE A BEQUEST –

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, registered at 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

Note from the Editor

Please feel free to email me at rozvickerman@gmail.com with any comments or requests. Please visit our website for more information www.gbsnz.org.nz about our Board Members

GBS NZ Officers

Patron:
Hon Steve Chadwick
President:
Doug Young
Ph (03) 230 4060
Email: deyoungs@xtra.co.nz

Secretary:
Tony Pearson
Ph: (03) 540 3217
Email: tonypearson@xtra.co.nz
Treasurer:
Brian Sheridan
Ph: (027) 281 1160
Email: brians@jdw.co.nz
Medical Advisor:
Dr Gareth Parry ONZM MB ChB FRACP
Other Board members:
Nicole Vercoe
Meike Schmidt-Meiburg
David Meyer
Chris Hewlett

Medical Advisory Board

Dr. Gareth Parry (Chair) ONZM, MB, ChB, FRACP

Dr. Suzie Mudge Dip Phys, MHSc, PhD
Director &Physiotherapist: Neuro Rehab Results

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

Senior Lecturer/Senior Research Officer
Health and Rehabilitation Research Institute,
AUT University

Dr. Dean Kilfoyle MB ChB, FRACP
Neurologist and Neurophysiologist
Auckland City Hospital
Auckland DHB

Dr. Chris Lynch BMedSci, MB ChB, MD, FRACP
Neurologist Midland Neurology Hamilton
Honorary Senior Clinical Lecturer at the Auckland Medical School
Waikato Campus

Dr. David Gow M.D., MB ChB, FRCP(UK), FRACP.
Neurologist with Southern DHB

Nicole Vercoe
Physiotherapist . Clinical Manager Laura Fergusson Brain Injury Trust

We would like to acknowledge our supporters.

ARA LODGE No 348 IC CHARITABLE TRUST BOARD

PARRY FOUNDATION

We are most grateful for the continued support - it is truly appreciated.

Contact Us
Get Connected With
03 5403217
027 687 1953
support@gbsnz.org.nz

Our Legal Status

The Guillain Barre Syndrome Support Group Trust is a registered Charitable Trust No. CC20639 and details of the Trust, it's Trustees and Accounts can be found on the Charities Commission website

Information published in this newsletter is for educational purposes only, and should not be considered as medical advice, diagnosis or treatment of Guillain-Barré Syndrome, CIPD, related neuropathies or any other medical condition.

Guillain Barré Syndrome
Support Group NZ Trust