Guillain Barré Syndrome
Support Group NZ Trust

Presidents Report

Welcome to the November 2024 edition everyone.

It has been a very busy 3 months period for most of our board members and I thank them for their efforts in their respective portfolio's.

This becomes another special edition since we sent you the June Bulletin, as a flyer, to keep you up-to date with our Newsletter Editor situation. As after only one edition we lost Carol Smart due a sudden health issue which wouldn't allow her to continue. Hence the advertisement in the June Bulletin.

I now welcome Roz Vickerman to the team. Roz is a relatively new member who has answered our call for an Editor and at very short notice with Tony's assistance has managed to pull this edition together for us. A very big thank you to Roz from everyone, especially the Board.

Roz has included her work experience resume within the Newsletter.

Our 3 Monthly Zoom Board meeting held on the 24th September was a lively affair, and a lot of business was dealt with. Tony's report further on gives brief details of the business carried out.

I have to welcome Nicole Vercoe to the Board as a co-opted member until the AGM confirms her appointment. Welcome Nicole.

This meeting again highlighted the input our board support team members can inject into the discussions held on various items on the agenda. I thank Rex & Daniel for the work they have been doing in the background which in turn supports our Board members. Roz Vickerman, Kathy Eggers and Charmaine Barry also joined us.

The important issues dealt with over the last 3 months were our vacant Board positions, in finding people with the required skill sets willing to fill those slots. At this point in time, we believe we have a number of suitable candidates in "the wings" for those positions.

By the time this Newsletter goes to print we will have had the Auckland regional meeting on the 20th October which should be included here.

Then there is our Special Board meeting on the following Monday.

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

After the Board and AGM "Face to Face" meetings in Wellington, in April, the Board has met twice more on Zoom and whilst I would be the first to admit that this means of communication - which came to prominence for most of us during the Covid restrictions – has proved most useful and cost effective I still don't think it beats Face-to-Face communication- but then I am from the "wrong generation"!!

Perhaps the most significant events of the past few months have been the willingness of members to step up to help out with the operational management of the Group.

Nicole Vercoe, a Christchurch member and a qualified Physio with her own business had been supporting Board meetings for some while and has decided to join the Board and was duly co-opted at the July 24 meeting.

Nicole has a young family and with Brendon, her husband, lives in the Burwood region of Christchurch and will bring an added depth of professionalism and youth to the Board – Welcome Nicole!

Two more lady members - Roz Vickerman and Kathy Eggers have also put their hands up to assist.

Roz, semi-retired and based in Cromwell has a background in the Pharmaceutical industry and will join as a Board Support member and has also agreed to have a shot at Editing our Newsletter.

Kathy, a specialist nurse, in the Bay of Plenty will also join the as a Board Support member.

Left to Right:

Nicole Vercoe, Roz Vickerman, Kathy Eggers

By way of explanation a Board Support member is not formally a Trustee/Board member of the Group but is invited to join in the Zoom Board meetings to contribute their personal skills and experience to Board discussions as and when their personal life permits and has proved to be of particular value in broadening the knowledge base underlying Board deliberations.

If all things go forward smoothly both ladies have indicated that they would be willing to join the Board as full time Trustees of the Group should the AGM in April 2025 so wish.

Update from the Regions

Auckland Regional Meeting

27 former GBS, CIDP and Miller-Fisher syndrome patients from Auckland and surrounding areas followed the invitation, together with their family members, and attended the Auckland Regional meeting. Dr. Dean Kilfoyle and Dr. Gareth Parry gave interesting and informative presentations (COVID/vaccination update; The NZ GBS research project (led by Dr. Eileen McManus); Pain and its management).

After a yummy lunch Dr. Suzie Mudge and Dr. Parry made themselves available to answer questions from the floor in a panel discussion. During morning tea and lunch breaks we were able to connect with our friends and meet new attendees. These events are always a highlight in the year, and we thank Drs. Kilfoyle, Mudge and Parry for giving up their Sunday and present us with new available information on a range of topics!!

Hi Everybody in the Waikato/Bay of Plenty

We had lots of laughs and good catch ups with everyone at our recent get together in Hamilton in September.

Standing from left to right: Meike Schmidt-Meiburg, Rex Bannister, Alison Hutchins, Jill and Bob Keals, Lyn Neels and Michael Logan, Fran and Grant McKay, Karen Soppet, Barry Deed.

Sitting from left to right: Jan Gribble, Linda Bannister, Judy Deed, Rex Soppet.

Yvonne and David Powell

The members of the Waikato/Bay of Plenty GBS support group were sad to hear of David Powell's passing in June 2024, and then very shocked by Yvonne's passing shortly afterwards in August.

Yvonne had GBS in May 2014 and joined our group a few months later with David. Both have been very active and respected members of our local support group. They have attended all our regular coffee get-togethers, Regional meetings and also made themselves available as accredited hospital visitors, making contact with new GBS patients in Waikato Hospital and their families. We will miss them.

Our next get together will be at the:

Old Forge Kitchen, 9 Alexandra Road, Te Aroha West on Thursday 21. November 2024 from 10.30 am onwards.

Please let me know if you are coming or not by Tuesday 19.11.2024, schmidtfarm@xtra.co.nz or 07 86 73 163or 027 325 03 69, the staff need some warning for setting up the tables, thankyou... ;)

If you would like to take part in the Secret Santa, please bring a gift to the value of $10, suitable for either your male or female friend.

Looking forward to catching up with you all!

Many greetings, Meike :) Hohoho

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

The next meeting will be on Wednesday, 20 November 2024 at 10.30 am.

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

Rex Buckley

The Power of Support Groups

A great article from the HealthNZ Counties Manukau news feed - thank you Rex Buckley:

https://www.countiesmanukau.health.nz/news/stand-by-me-the-power-of-support-groups/

Dunedin Regional Meeting

Following the successful meeting in Auckland last week the Board has decided to "come south" and hold the next Regional Meeting in Dunedin. Details of venue and timing are now being sorted but put the date in your diary **Southlanders Sunday 4th May 2025**

Secretary's Jottings

Over the first few days of the school holidays, we had our 16 year old grandson to stay and it is great to have a strong healthy lad about to help with all those garden/construction jobs, that used to be easy but now seem to require a lot more effort. I couldn't help noticing that during the time he spent on his "device/phone" whilst he was multi-tasking by engaging in the adult's conversation, how quickly – with just a few strokes and taps on the phone - he was able to come up with the answers to questions that arose during the course our conversations and this has led me to wonder if the focus of our Group's existence has shifted.

There is SO MUCH information out there on the web – including specifically about GBS and its variants – with most of it available from reputable sources – that, more often than not, I find requests for assistance from us that arrive on MY device is not for a batch of simple guides about the nature and treatment of GBS etc but rather seeking input on how to deal with "complications" in how the syndrome is presenting, emotional side effects for the patient, and quite often the family of supporters, and increasingly how to navigate the seemingly "hardnosed" policies of Hospital officials when it comes to rehabilitation duration or discharge status or simply where to go for a diagnosis appointment that isn't going to be in the next decade.

I suppose all this comes under the heading of ADVOCACY and from what I can see this is also the main benefit that our Facebook site provides – a forum to ask those questions that only current and past patients have experience of to provide a helpful or constructive answer.

This same "detachment' seems to be true when it comes to requests for a Hospital Visitor which are becoming fewer and fewer – why talk to a human when A.I. has the answer? I think I can confidently say that those folk that DO ask for an AHV to visit are universally grateful for the face-to-face exchange of concerns and advice based on "been there and done that" which we can offer.

So where does that lead us? Advocacy is a profession – we are a bunch of willing and enthusiastic amateurs (and of course VERY nice people!!) but do we have the skills to provide the service and advice that increasingly we are being asked to provide. Sure we have the invaluable medical advice available to us from our Medical Advisory Board but should we be engaging in more formal training of our representatives and AHV's not just in helping to allay concerns with the presentation of the Syndrome but also to advise confidently and knowledgeably about a patient's rights for fair and reasonable treatment from our health system.

I am NOT talking about the care provided by the nurses, physios and all the other support staff (including the 'oh so important' tea lady) – all of whom invariably do the very best they can working within an overloaded system BUT RATHER the medical bureaucrats who set the targets for patient "turnaround", expenditure limits for in house support services and post discharge care and support. To these people - I would like to say GRRRRR!!~!!! I am forced – as I have often advised patient's family and supporters– to rely on POLITE PERSISTENCE to make my point and hopefully gain my objective.

AND Finally – before I get off my soap box! – wouldn't it be great if instead of bickering and point scoring off each other our politicians (of all persuasions) could agree on a common goal to get our creaking Health Service back into shape – train the necessary professional to staff it and provide an equality of service that meets the need of all New Zealanders no matter their age, creed or ethnic background – now THAT'S a party I would vote for!

OH!! – just seen a PINK PIG fly past my study window!
All for now

Tony (aka – "grumpy old man")

Apii's Story

Enabling Good Lives: Life changed in a blink of an eye.

Mother Nature threw Apii Vaikai a huge curveball in 2020 and put him on a very unexpected, and near-death journey. When Apii was 17 he and his family moved to Aitutaki in the Cook Islands. He had a good job and enjoyed an idyllic life fishing, diving and growing vegetables. Eventually the island became too small and Apii saved enough to return to New Zealand.

When the 25-year-old arrived in Auckland he was in for a few surprises. "The pies were cheap, but I had to learn how to use an EFTPos machine as we didn't have one on the island," he says. He spent the next three years working in a factory, before a holiday in Nelson tempted him out of the city." I loved the place, sea on one side and mountains on the other, so I decided to move South". Apii worked at a nursery, then completed an outdoor education course. He returned to Auckland briefly when his dad became unwell, but it wasn't long before he was back in Nelson, this time doing building work and gib installation.

In 2020 life took a dramatic turn for Apii. First, COVID-19 came along and like many people, Apii was laid off from his job. Then he fell ill. "I woke up one day and my feet felt numb," he says. "I didn't think too much about it and went fishing at Duncan Bay. By the time I got back to the car I couldn't lift my feet up. I drove home and stopped at a petrol station, opened the door and nearly fell out. The numbness had moved up my feet to my legs, so I thought I had better go to the hospital."

After many tests, Nelson Hospital doctors told Apii he was experiencing Guillain-Barré Syndrome (GBS), a rare autoimmune disorder in which the immune system attacks the nerves. Apii was placed in a treatment and rehabilitation ward, and it was hoped, with treatment, his condition would stabilise. "At this stage I couldn't move my hands, but I thought it would stop progressing and I would get better." After three days on the ward, Apii was still deteriorating, and struggling to breathe, so he was moved to the Intensive Care Unit where doctors fitted a tracheostomy tube and put him on a ventilator. He couldn't talk, eat, or drink, and had no sense of taste or smell. He could only move his eyeballs and blink. He remained like this for about a year.

"I remember staring out the window and watching the trees. I saw them with no leaves, then the leaves grew again, then I saw them lose their leaves again. That's all I could see," says Apii. His family visited, and he remembers the kindness of the nurses who would wipe his cheek when he shed a tear.

Apii's condition was life threatening, and he thought he was at the point of no return. "When I felt this was the end, I prayed". Apii was being closely monitored and the next day his 'numbers' went up. "They went on increasing and my breathing started to improve. I thought 'I should've prayed months ago!'. With a portable tracheostomy fitted Apii could now be taken to the shower. Although he wasn't allowed to drink or eat anything, the nurses put tiny drops of water on his gums. "I didn't realise water tasted so good. It's the small things we take for granted."

Slowly everything began getting better. He had a 'Swedish nose' fitted to his 'trachy and gradually his rusty voice was able to make a few squeaks.

Apii celebrated his 45th birthday in hospital with cake, although he could only manage a little puréed food. Finally, he had his tracheostomy and feeding tube removed and Apii's senses were overwhelmed. "I sipped a banana milkshake and was amazed by the taste. My sense of smell became really strong: a nurse's perfume and coffee on someone's breath."

Apii's recovery had just begun when in 2021 the omicron wave of COVID-19 meant he had to move into the community as the hospital rehabilitation ward was used to isolate affected patients. He found a place in a modern, sunny, Live Life Disability Support Service house, where he has continued physiotherapy to strengthen his muscles and improve his mobility. "I made a list of what I wanted to achieve: to go fishing, have a little garden and do a course – although I chickened out of that one."

Apii has had great support from within the service, and also from Tony Pearson, who is the national secretary of the New Zealand Guillain-Barré Syndrome Support Group. Tony arranged to get Apii a computer, with the help of the Fifeshire Foundation, so he

could become more 'connected' and has been by his side throughout. "He takes me to the pool for hydrotherapy sessions and helped me with a mobility scooter." It was also suggested Apii might like to visit the Nelson Whakatū Menzshed.

"I was afraid because I can't hold a hammer, or a machine and I thought it won't work for me. But when I got there, I had an interview and they said, 'go for it, get amongst it all'."

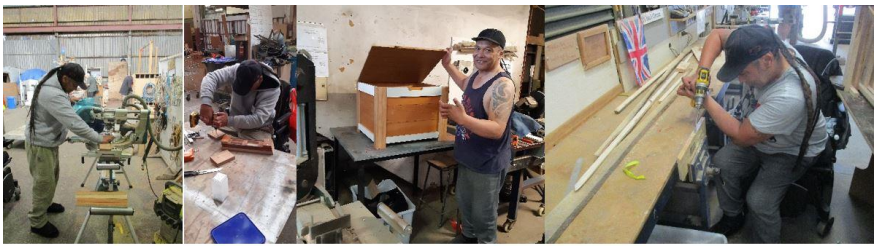
Apii made a toolbox and other small projects and was so happy with the results he couldn't wait to get back there "I didn't think I would be able to use a drop saw but I had a go. I just needed to press a button, and it worked."

Apii's physical mobility and his independence is continuing to improve. He can take himself to the Menzshed on his scooter, visit friends, go fishing, and cook and feed himself meals. "I feel I have control now. I can stabilise my emotions and thoughts. I have become empowered - if I want to do something I have the power to do it."

Reflecting on the years since his illness, Apii appreciates the things he used to take for granted. "The first couple of years were frustrating as I wasn't able to do anything myself, but as my physical health improved, so did my mental health."

"When you are in a situation like this or have been through something, leave it in the past. Be strong, be positive and try not to dwell on problems, as that takes you to a bad place. Now I just want to keep busy and focus on things other than my illness. Everyone has to have a purpose in life. At times I felt I didn't. But now my purpose in life, is to live."

Apii Vaikai is back doing what he loves - working with wood at the Menzshed.



The above article was written by Lee Nicholson a Registered Nurse with the Enabling Good Lives Service in Nelson and reproduced with that organisation's and Apii's permission.

FOOTNOTE FROM TONY (Oct 2024)

Apii's rehabilitation continues, and he has had the first of at least two tendon release operations to rectify his Claw Hands which will facilitate his being able to hold and grip crutches and so move on to the next phase of standing and walking. Last week he moved to independent living in a Kainga Ora house in Nelson – still wheelchair bound but with excellent support from the local staff of MSD, Nelson Marlborough Health Needs Assessment Service AND, believe it or not, friendly and constructive engagement from the Nelson branch of WINZ.

Apii still has a way to go to get fully back into the workforce however with his usual optimism and positive outlook on life is now using his computer to design raised garden boxes for his new premises to be built at the Menzshed!

It has and, I am sure will continue to be, a pleasure helping Apii recover from GBS even if he is only GETTING BETTER SLOWLY and along the way I have learned so much about navigating the support available (or not) to our disabled community.

Thank You and Congratulations

The GBS Support Group NZ Trust would like to extend their sincere thanks to Erin and honour her time with a scholarship.

Erin has been responsible for our website support administration this year and been a pleasure to work alongside.

No task was ever too much trouble for her.

We wish her all the very best for her future endeavors and for her studies at uni. We are sure she will do very well.

PACHA Report

Federation of Primary Health Aotearoa New Zealand (PACHA)

This organisation was formed in 2018 by NZ's primary health and community care leaders representing PHO's, pharmacy, midwifery, allied health (Physio's OT etc), nursing and others. It is believed to be the main body representing this sector and is Independently Chaired by none other than our Patron the Hon Steve Chadwick.

At a press conference back in June, Steve accompanied by the Executive Director of the group' commented that it was pleasing to see some new investment in the budget into the primary health sector, but disappointing to have free prescriptions removed as it would be detrimental to the health status of the very population we are trying to serve. New money for training new doctors is a step in the right direction but does nothing to

relieve the pressures on other health practitioners within the primary and community sectors.

The boost of $1.7 billion over 4 years to the Pharmac budget was also welcomed.

Steve added that a well-resourced and supported primary and community health sector makes the overall health system robust, effective, and successful. It ensures a long-term future for the voice of community providers on a sustainable pathway.

We wish Steve every success in pushing the case for these key personnel in our health system but recognise that in the current political environment it maybe that the "accountants" voices are louder than the "medics"– time will tell.

Situations Vacant

BOARD MEMBERS WANTED

The ladies have answered the call, and we have received 2 applications to join the Board so its time Gentlemen for some of you to step forward and help us run the Group. As a first step – to test the waters so to speak – why not consider joining the Board Support Team – a small voluntary group of members that "sit in" on our Zoom Board meetings and, where their experience helps, make suggestions to the Board about organisational matters without any commitment to join the Board or take on any Exec duties. If you would like to give it a whirl contact the Secretary on tonypearson@xtra.co.nz

AUTHORISED HOSPITAL VISITORS

To replace recent resignations, we need to find members who are willing to become an Authorised Hospital Visitor in 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 on tonypearson@xtra.co.nz

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Note from the Editor

My name is Roz Vickerman. I came across this support group when I was diagnosed with the Miller Fisher variant in Auckland hospital 2 days after Covid Positive. This was in April last year.

I have since had 2 more full episodes - one after Covid positive again and the other after Influenza A positive. I now know this variant well!

I am a semi-retired CEO having had a global career, spanning decades, in the commercial world of pharmaceutical and medical device companies.

We will get back into a rhythm of more consistent updates - please feel free to email me at rozvickerman@gmail.com with any comments or requests.

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

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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

Guillain Barré Syndrome
Support Group NZ Trust