

**Minutes of the 20<sup>th</sup> Annual General Meeting of the Guillain Barré  
Syndrome Support Group New Zealand Trust held at 1100 hours on  
Saturday 18<sup>th</sup> June 2022 at the Miramar Links Conference Venue  
Wellington**

**Present:-** Doug Young (President), Peter Scott (Treasurer), Tony Pearson (Secretary), and Trustees Chris Hewlett, Meike Schmidt-Meiburg, John Podd, Matt Peacey.

Doug welcomed the 7 members attending including the Head of our MAB Dr Gareth Parry and also the 6 members who had joined the meeting via the Zoom link and, with Tony confirming that the meeting was quorate, commenced the business of the meeting. Tony advised that 8 Proxy votes had been correctly lodged- 5 to Doug and 3 to Meike. Doug advised those members attending via Zoom that they were able to register their votes during the course of the meeting using the 'Chat' facility- with Matt recording votes so cast.

Before commencing the formal business of the meeting Doug introduced our Patron Steve Chadwick to members and explained that Steve, who had attended the Board meeting ahead of the AGM, had to leave shortly to catch a flight to Rotorua where she was due to speak at another formal engagement. Doug asked Steve to give the meeting a brief update on her recent appointment as Chair of the Federation of Primary Healthcare Aotearoa organization.

Steve explained that the Federation had been formed to bring together organisations and stakeholders from across the health care sector and to be the voice of and for primary health. The sector has 36,000 members including GPs, Midwives and all Allied health workers such as Physios and OTs, together with Pharmacy, nurses and Aged care staff amongst others. The essential focus of the role of her Board will be to find a place within the new Health Sector reforms where her executive can fairly represent and lobby for the membership and key to this will be the establishment of Local Networks. The Primary sector has always had to struggle for funds and this will also be a focus of the Federation. Many other organisations within the health sector will be in similar situations. The reforms planned have a huge agenda and it could take 2 years to see how it all unfolds. The National party have agreed to support the change so it should not be subject to political disruption. The Executive Director of the Federation is based in Nelson and Steve undertook to arrange for Gareth and Tony to meet her so they will know where to go to keep up to date with relevant developments. Steve wished everyone well and apologized for having to leave early due to a disruption of her planned flights home.

Doug thanked Steve for her presentation and making the effort to attend the Board and AGM. He noted that she will move out of her role as Mayor of Rotorua back into the Health sector where she started her career as a midwife but now in a much more influential role. Doug advised we would wish her to continue as our Patron for the foreseeable future and Steve confirmed she was happy to do so.

**1. Apologies:**

Apologies had been received from:- Ansie Nortje Mike Whyte and Margaret Stothart.

**2. Minutes of the last AGM held in Wellington on 10<sup>th</sup> April 2021.**

The minutes had been previously circulated to all members and Doug asked they be accepted as a true record. Vivienne Pearson proposed they be taken as read and be accepted as a correct record. The was motion seconded by Chris Hewlett and the members present and on Zoom signified their unanimous agreement.

**3. Matters Arising:-**

**A. Report on Regional Meetings and future plans:**

Doug advised he had attended the Auckland Regional meeting in February and inspite of Covid concerns across the Auckland region over 30 members attended along with Gareth and members of the MAB. Doug asked Meike to comment on the meeting and she reported that, following presentations by the MAB, the general discussions between the Panel and members was, as usual, the highlight of the session and as has been the case with previous Regional meetings had to be brought to a close by the moderator. Gareth confirmed his view that it was a successful meeting and, given the Covid environment, surprisingly well attended by the membership and extended his appreciation and thanks to Meike for her organisation and management of the meeting.

The Board is considering future meetings with the next perhaps in Christchurch at the Burwood Hospital venue and after that probably a return to Auckland but with Hamilton also a possibility based on the popularity of the last meeting there. Details to be advised in due course.

**B. Website site activity report:** Matt reported that we had about 200 users a month and based on the time they were spending on the site the indications were that they were finding the information they were seeking. After the Home page the most popular was the GBS explanation page and then the Questions to Medical Experts. Matt asked if we could ask our AHVø who visit patients if they could enquire from those patients if they had used the website and if so did they have any comments or suggestions for improvements to its content or ease of access. Tony to follow up. Ken Daniels ó present on Zoom - said he found the website very good to access and the content was detailed and useful although he felt a nice picture on the Home page might be appreciated by new searchers.

**C. Facebook Site activity report:** Mieke reported there were 396 members currently on the site In the last month 6 new members were accepted and 5 declined membership. 220 members are active of which 70% are female 30 male and all age groups from 18 to 65 are represented. Most popular time is 7.00pm on a Monday.69% of members are from New Zealand with the balance from the USA and the UK. Most New Zealand members live in Auckland followed by Christchurch, Wellington. Rotorua, Hamilton and then spread around the country. Activity on the site has slowed after a very intense period involving questions on both the Covid and Flu vaccines and their interaction with GBS.

**D. Research Project Update:** Gareth reported that we have 4 current and active Research projects all involved in GBS with a potential new project looking at CIDP issues. Two of the active projects have been partially funded by the Group and much appreciated by the lead researchers Eileen McManus and Suzie Mudge. Suzie's study on Fatigue is nearly fully enrolled ó 2 more participants required. Eileen's project looking into the relative effectiveness of Ivig vs Plex treatment on severe GBS cases is currently on hold due to the arrival of her new child but will resume in due course. The third study of particular interest to Gareth concerned the recording of NZ nationwide GBS cases with particular reference to its incidence within the M ori population and this study has recently received international funding which is very good news not only financially but in terms of the raised profile of NZ based research. The Onga Onga study has moved into the testing phase with local subjects offering themselves to be stung by Onga Onga and recording their re-actions. Preparations are in hand to submit the findings so far for a Peer Review. The next phase is to continue working with the Cawthron Institute to seek further funding to progress the isolation of the molecule responsible for the numbing effect. Realistically this sort of development could take a further 5 to 10 years to bring to fruition but without the Group's financial start up funding it would not have happened.

A further statistical study is looking into the premise that the incidence of GBS in NZ has actually decreased during the Covid pandemic with researchers based in Wellington and Waikato looking at this. At this time no further funding requests to the Group are envisaged ó but not discounted!

Doug reminded members that the funds granted by the Group had come from the Jones Research Fund ó set up some years ago following a significant bequest from a deceased member's estate. Steve commented that it was good to see research taking place in NZ ó certainly not the case when she attended an AGM in Wellington in 2008. Steve then bid her farewells and left the meeting.

**4. President's Report. (Copy Attached):** Doug presented his report ó his 6<sup>th</sup> as President - to the meeting noting that whilst the AGM had been delayed it did mean that some members felt more comfortable about attending in person although the past two years had seen the Zoom media become the meeting ònormö and with Matt's help meant that members could join this meeting remotely if they wished. Doug thanked all of his fellow Board members for the diligent undertaking of their various roles in the organisation, The Medical Advisory Board for their professional support and advice and in particular Dr Parry for his tireless support to the Group. The work of our Hospital Visitors had been curtailed in the year because of Covid restrictions in Hospitals but has continued to meet urgent requirements. How this aspect of the Group's work will evolve under the new twin Hospital Board organisation remains to be seen but our Patron Steve Chadwick has offered assistance if issues arise. Membership continues to grow ó now 245 ó and donation support is good although everyone is encouraged to help with what they can afford. The Board is researching several ideas to boost fundraising. Our Newsletter continues to be the main form of communication with

the membership but the Website and Facebook page are increasing important for interacting with new GBSers and their supporters/carers and the country wide coffee groups provide a face to face forum for members to enjoy each other's company and share experiences. Sincere thanks are due for the ongoing financial support that the ARA Lodge No. 3481C and the Parry Foundation provide to the Group, underwriting our ongoing operations. Thanks also to a young member Laike Moes from Levin who raised some \$2000 from her half marathon effort and donated half to the Group ó a great effort. Doug expressed condolences to all members who had lost partners during the year. Funding NZ based research into various GBS issues has been a major achievement of the past year particularly as it has kicked started several projects that have advanced to the stage where international funders are now prepared to add their financial clout. Our Nelson member Clive Phillips deserves a special mention for his biking marathon efforts which have raised over US\$70,000 to spearhead research by our USA sister group into the causes and treatment of the GBS variant MMN. The Auckland Regional meeting was an undoubted success and we hope that our relationship with the Neuro Connection Foundation who provided the Tui Glen venue for the meeting will develop into a most useful facility for our members. Doug noted we have two vacancies on the Board and urged members to consider helping the Group by offering their services. Having our Patron the Hon Steve Chadwick present at the AGM is a special treat and he wished her well in her new appointment. Doug closed by thanking his most important supporter and mentor ó his wife Terry-Ann.

#### **5. Presentation of the Accounts for the Year to 30.11.21.**

Peter presented his accounts for the year noting that he would report against the figures in the traditional format rather than the specialist format required by the Charities Commission for the Annual Return to that organisation. Receipts comprise mainly of Donations from the ARA, Parry Foundation and a number of general donations together with a small amount of bank interest which was reduced this year from previously due to the low bank rate and reduced deposits which had been depleted by the Research grants made in the year. Expenditure is mainly in line with previous years. Postage is down reflecting the purchase last years of a supply of pre-stamped envelopes. Regional meeting and Trustees travel costs are down reflecting a reduced level of expenditure of the Hamilton and Wellington meetings. Total expenditure for the year was just under \$6000 leaving an overall surplus for the year of some \$3000. The Balance sheet shows that our main operating asset is cash deposits together with stocks of books, stamps and badges and payment in advance for website services as required by our contract with the provider. The Group has no outstanding liabilities. The Research Fund stands at \$110,000 after receiving some \$7000 in donations and interest in the year and after making a \$16,000 payment towards the Waikato DHB research grant approved by the Board.

There were no questions arising on the Accounts which had been approved previously by the Board as required by the Trust Deed.

## **6. Election of Officers.**

Doug asked Tony to run through the procedures required for the Election of Trustees. Tony advised that in accordance with the rotational rules of the Trust Deed requiring one third of Trustees to resign each year, the Trustees who were required to resign this year were Doug Young and Tony Pearson together with Ansie Nortje who was co-opted and voted onto the Board last year and now joins the rotational system as a Trustee. These 3 persons, being eligible, offer themselves for re-election. No further nominations for election to the Board had been received prior to the meeting and none were forthcoming at the meeting. Doug handed over the Chair of the meeting to Peter who proposed that Doug Young, Ansie Nortje and Tony Pearson be re-elected en bloc as Trustees of the Board. Matt seconded the motion and all present confirmed their unanimous assent verbally and Zoom attendees by raising their hands. Doug advised the Board would confirm Officer appointments as follows:- Doug Young-President, Peter Scott ó Treasurer and Tony Pearson as Secretary. John Podd asked if there was any limit to the number of years service of the President. Tony confirmed there was none.

## **7. Membership Subscriptions**

In response to Doug's request for a recommendation on the level of subscriptions for the coming year Peter confirmed he was content for membership of the Group to remain free. He felt even though the subscription level was previously at a very low level it would be a disincentive to membership particularly for those people who had recovered from their GBS and may no longer see a need for Group involvement. Therefore we would need to continue to rely on donations to fund our ongoing operations. Vivienne asked how secure was the annual donation from the ARA Lodge? Doug said this was very important but not guaranteed. Finding funding grants for an operation as small as ours was almost impossible and alternative fund-raising was difficult for a Group like ours spread thinly across the country. Peter said he would like to see a push to persuade more members to sign up for a small monthly deposit which could provide a regular secure source of funds. Terry Ann asked if this was something we could push at our Regional Meetings and ask those present to commit to this sort of regular small donation reminding them that they were able to claim one third of this back from the IRD. To be followed up by the Board.

Meike asked if Lottery and similar funding organisations would assist. Gareth confirmed such funds were NOT available to cover a group's operating costs only for specific projects and that funding for medical projects was very limited.

## **8. General Business:**

**8.1 Primary Healthcare Aotearoa:** Steve Chadwick had reported on this at the start of the AGM prior to her early unavoidable departure.

**8.2. MMN Research Funding-raising:** Tony said we had hoped Clive Phillips would be able to attend the AGM remotely on Zoom but this had not transpired. Clive is a committed cycling addict who suffers from the GBS rare variant known as Multifocal Motor Neuropathy (MMN) and has set himself a goal of raising substantial funds to further dedicated research into the causes and treatment of this variant by seeking sponsorship of his biking activities. His original plan of transiting the length of NZ by bike was frustrated by Covid concerns but instead he completed a substantial and arduous circuit of the upper South Island and reported his progress on our Facebook site daily. He linked up with the USA GBS-CIDP Foundation International who promoted his cause across the States as we did here in New Zealand. His target was US\$100,000 which Gareth had advised was the minimum likely to generate the desired research interest and so far Clive has raised over US\$70,000 ó the majority from sponsors in the USA but also from New Zealand sources. Fundraising is still going on and Clive has published his future plans on our Facebook site. The USA Group will invite applications for research funding later this year and award funds in 2024. Clive has been appointed joint Chair of the MMN focus group of the Foundation to oversee future MMN activities. Whilst all funds will be channeled throø the Foundation the benefits of the research so enabled will help MMN sufferers around the world. David Meyer from Napier ó an MMN sufferer who was joining the meeting on Zoom - said it was heartening to hear the effort Clive was making on behalf of his fellow MMNøers. Doug said he was sure everyone in the NZ Group wished Clive good luck with his fundraising efforts ó a most creditable effort.

**8.3: Asia Pacific Group:** Tony reported that, unsurprisingly, Covid had put the concept plans on hold but that in spite of a request for an update from the Foundation International there have been no report on planned developments. He will keep on the case!

**8.4 Donation Fund Raising:** Doug advised the fund- raising sub committee had discussed a number of ideas for increasing income to the Group and the favourite at the moment was a òBeef calfö acquisition idea. The scheme was a popular fund-raising idea in NZ for Rugby Clubs and Schools but presented a number of problems for a charity such as ours in terms of tax and tracking requirements. He would be discussing possibilities with the Board after this meeting. If it proves viable the potential returns are significant but it involves a long term investment with risk.

**8.5 Area Representation at Board and AGM meetings:** Meike reported on a suggestion from her coffee group to increase representation from all parts of the country with active social groups by the nomination of 2 representative from each of those recognized groups who would join the Board meetings ó in person or by Zoom as appropriate and they could report back to their groups on proceedings. Gareth thought this would be a way of identifying future potential Trustees. Tony was concerned about the cost of facilitating attendance of these representatives at future AGMø if not by Zoom. Meike said that if we agreed to make the AGM a

Zoom only meeting this complication would not arise. There was general agreement on this but also a consensus that the Board should maintain its previously agreed position of meeting in person at least once a year.

Ken Daniels suggested we check with our constitution to ensure our plans involving extensive Zoom communication was permitted. Tony confirmed that the Deed did permit "electronic" communications which could include Zoom but will investigate further. ( Secretary's Note: Rule 6.4 of the Deed permits Board meetings by "simultaneous teleconferencing facilities" which I guess will include ZOOM

Doug asked Tony to add this suggestion to the next Board Agenda so we can explore the idea, and any potential issues, further.

8.6: Tony proposed a vote of thanks to Doug for leading the Group as President for the 6<sup>th</sup> successive year. The meeting enthusiastically endorsed this.

There being no further business Doug drew the meeting to a close at 1215 hrs hours, thanked members both present and on Zoom for their attendance and invited those present to join the Board for lunch.

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Signed as a True Record of Proceedings

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Date

Chairman