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Guillain – Barré Syndrome Support Group New Zealand Trust

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

NEWSLETTER September 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



It feels like yesterday when I went to Europe to visit family. Whilst there, I was fascinated by their public transport systems, and I spent hours traveling from place to place to ensure that I see and experience as much as possible. Highlights to me were visiting the numerous museums and cathedrals. Above all, being with family was the most precious. I spent most of my time in the Netherlands, absorbing the flat-contoured landscapes and could not help imagining how the Dutch would negotiate the hilly formations of Wellington on their (mostly non-electric) bicycles!

It is my privilege to continue as Board member following re-election and re-appointment during the AGM in Wellington earlier this year.

On behalf of all of us, I want to congratulate Dr David Gow, one of our Medical Advisory Board members, with his newly appointed position of Chief Medical Officer (CMO) for the Southern Health region.

I also want to acknowledge and congratulate our Patron, the Hon Steve Chadwick, who has been appointed Chair of the Federation of Primary Healthcare Aotearoa. Steve, we are pleased that you will remain our Patron, despite the big task ahead of you.

This newsletter includes Doug's President's report; Tony's information sharing and Board discussion update; the report on the AGM that was held in Wellington during June; Nicky Riches' GBS journey; as well updates about past and upcoming social events. The question-and-answer session from the Auckland Regional Meeting held in February 2022 inevitably contains several questions on COVID vaccines, but as we will no doubt continue with further COVID boosters for the foreseeable future, the particular questions remain largely relevant.

I wish you all a very pleasant Spring Season ahead.

Ansie

GBS Notice of Christchurch Regional meeting

SUNDAY 20th NOVEMBER 2022 10h30-16h00
BURWOOD HOSPITAL ROOM 2 LEVEL 2 MAIN BUILDING

Come along and meet Drs Gareth Parry from Nelson, Head of our Medical Advisory Board and Zoe Woodward, a Neurologist and Clinical Neurophysiologist practicing as a Consultant at Christchurch Public Hospital who will be supported by members of the Rehab team at Burwood, and also say hello to some of the Trustees of the Group. Hear short presentations about the latest developments in GBS/CIDP treatments and management and in an informal atmosphere discuss any issues of concern or interest with these experts and exchange experiences with other members.

There is a \$20 charge for attending and families are welcome (under 14 – no charge). The venue is, of course, wheelchair friendly with plenty of free parking. To assist with organisation please let Tony Pearson, the Secretary, know if you are hoping to attend the meeting and he will send you a registration form.

(tonypearson@xtra.co.nz, 03-540 3217 or 027 687 1953). Morning tea and a light sandwich lunch will be provided and the Burwood Hospital Café will be open for those who would like something more substantial. Our first meeting at this venue in 2019 was very well attended and enjoyed and valued by all who came, so come along and support the Group in this venture.

Tony

President's Report – Doug Young



Welcome to the September 2022 edition of the GBS Support Group's quarterly newsletter. There has been plenty of action over the last three months so I hope you enjoy the read.

As President I wish to thank you all for the support at the AGM in Wellington. Myself, Tony and Ansie stood down from the Board by rotation, all three of us were re-elected to the Board who then reappointed us to our former roles. It's my privilege to continue as your President at present. For us South Islanders what a stunning ski season it's been. I was in Queenstown three weeks ago and it was back to pre-COVID business as usual madness. It all felt so positive after two years of negativity, it was great to see it and get the feel of it all.

On a personal note, COVID finally caught up with us as a family, so we have been there and done that as well, fortunately with very minor symptoms and side effects for all involved. The Flu Bug we all had six weeks ago was far more punishing? One can only assume that two vaccines plus a booster did the job? Remember we always appreciate any contributions we can publish in the newsletter.

This quarter's overview of our actual activities follows:

Main Activities:

The AGM in Wellington on the 18th of June went well and Tony will give a review of both the AGM and Board meeting minutes further on in this newsletter. I wish to thank those of you who joined us via the Zoom Meeting "connection" set up by Matt Peacey. It certainly adds another dimension to running a meeting.

The highlight of the meeting was having our Patron Steve Chadwick present for part of the day (her busy schedule had her flying back to Rotorua in time for an evening engagement). However, Steve's input to the Board meeting was greatly appreciated, as she is a "Gold Mine" of information, advice and contacts for assistance in running an operation like ours.

Thankyou Steve, for making the Time for us.

The AGM outcomes highlighted the effort we have put into assisted funding of the research projects mentioned. I see a lot of positives coming out of this for GBS sufferers in the future along with the depth of talent we have within our health system who are capable of carrying out such projects. We have to make the effort to continue finding funding for these projects.

Authorized Hospital Visitors: as we know COVID restrictions greatly curtailed our activities in this area. Hopefully with the relaxing of COVID protocols over the next few months we will see an increase in the requests for this service.

Regional Meetings: Christchurch is next with a meeting organised for late November refer to the details elsewhere in this newsletter.

Coffee Groups: All areas are pushing ahead with their meetings which is great to see, it's only a couple of hours of your time to attend and it helps others.

Finally, a congratulatory note for Dr David Gow, one of Gareth's MAB team based in Dunedin. David has accepted the position of Chief Medical Officer (CMO) for the Southern Health region. We wish David well in his new role, while accepting we will see less of him at the "coal face", we know he is a strong supporter of a support group like ours. Thankyou David for all your good work done with our Southern Region GBS sufferers over the past 7 years.

Enjoy your read, and I look forward to reporting on further progress of the Group in December.

Regards
Doug Young
President



Secretary's Jottings – Tony Pearson

As you know I spend quite a lot of my time reading Magazines and Journals and, unsurprisingly, quite a lot of them have a medical bias particularly if they are focussing on neurological and autoimmune conditions. Regrettably however, more and more of my reading matter is going “on-line” which usually means I end up printing off interesting articles and saving them for bedtime reading – yes, I KNOW I could buy a Kindle or take my laptop to bed but I’m an old “fuddy duddy” and like paper! Anyway, after having surmounted the hurdles of logging in, I have managed to catch up on a couple of back issues of my complimentary copy of the online **Kaitiaki Nursing Journal** which contained some articles that I thought might be of interest to our membership.



The first focussed on COVID anxiety which in spite of our high immunisation rates and lower rates of severe symptoms in NZ, is becoming an increasingly prevalent condition in our population with the concerns not helped by the proliferation of dis-information and conspiracy theories posing as “fact”.



I guess there will always be an element of the population who are “worriers” but COVID – not just the fear of getting it but also when it is contracted – seems to have placed additional pressure on our already stressed Primary Care facilities where the burden of re-assuring an over stressed patient falls on the GPs and Practice Nurses. Certainly, I am aware that having had GBS or coping with CIDP has heightened the concerns of quite a few of our membership and it is hopefully comforting for them to know that our MAB is able to confirm that there is no evidence of our “Syndrome” placing most of us at any more risk than the general population.

So, we know GBS is an AUTOIMMUNE condition (apparently “ours” is just one of 80 recognised conditions!!) – but just what does that mean? Well according to an article in Kaitiaki, an autoimmune condition is identified by the presence of autoantibodies which attack the body’s own cells. Just how they get there is unclear – some can be clearly identified and treated whilst others have no clear identity but do respond well to suitable treatment. Whilst research has provided a considerable understanding of the mechanisms and genetics of some autoimmune conditions our understanding of the triggers for the condition to occur is poor – and GBS is no exception to that, although the presence of Campylobacter in our systems is now recognised as one of the most common triggers of a GBS attack. As far as I know GBS is not hereditary and it is more likely to be triggered by environmental conditions (smoking, diet etc) or, as I firmly believe in my case, STRESS (something to avoid – see preceding paragraph!). Current treatments involve non-specific immune-modulating drugs such as Corticosteroids but these have risks of side effects. The past two decades have seen huge gains in the management of autoimmune conditions through the development of medicine called Monoclonal Antibodies (with names ending in *iximab* or *izumab* – for GBS’ers a drug called Rituximab can be helpful if Pharmac agree to fund it!) which target molecules in the immune pathway, but these too are non-specific and have their own side effects. I recall a presentation given in Glasgow some years ago by the UK GBS Group where the Researcher likened our present medical approach to GBS as hitting it with a sledge hammer hoping to deal with it but in the process causing all sorts of other damage – “what we are aiming at” is to hit it with a Laser beam” – some way to go yet I fear, but fingers crossed!

There was a third article on the increasing use of “Biological Medicine” in New Zealand – but most of it went over my head - so I will perhaps ask our esteemed MAB to comment if they have any relevance to the management of GBS/CIDP or the Variants. What it did raise, in my mind at least, was just how safe these new medicines are – and who decides that they are safe. Well in NZ, that task is down to Medsafe and there have been a number of commentators during the development of COVID vaccine rollouts who have asked why we have had to wait for Medsafe approval of vaccines that are already being used worldwide and have been approved by the “Medsafes” of countries like the UK, Europe and the American FDA. Well back in July, Stuff published an interesting article by a guy called Ben Gray – an Associate Professor of Primary Health and General Practice at Otago University that recounted the failures of overseas regulators either as a result of “pressure” from the Drug Companies, keen to recoup their development costs, or a perceived need

to rush the medicine to a clamouring market. He concludes that Medsafe is a trustworthy regulator and whilst it is inevitably constrained in what it can do by the size of our population and there is a possibility that there are some delays in its process for approving medicines, it is accountable to Parliament and thereby to us.

More locally, a company called Medical Kiwi have recently opened a clinic here in Nelson (there is another in Christchurch) offering pain sufferers relief through cannabis products – grown in their own “world class” facilities outside Christchurch. Suitable prescriptions are provided after Online or Face to Face consultations with a GP. Whilst I wouldn’t deny that the use of medical cannabis (not to mention the “other stuff”) does seem to work for some in our fraternity, I remain concerned that this rapidly growing industry does not seem to have any established standards by which patients can place reliance on what their prescription contains. It will come I am sure, but not yet!

Briefly other news from Board discussion:

The Onga Onga project has progressed to the production of a “learned paper” on the research so far which is currently up for a Peer Review before, hopefully, being published in a Medical Journal perhaps in a few months’ time. Accidentally, we have learned that a similar Onga Onga based research is going on in Australia although their focus seems to be on establishing what causes the “sting” whilst ours is trying to isolate the “numbing” effect that follows the initial sting.

After a “trial” membership of some months, we have decided not to continue with our association with the Neurological Alliance – the aims of its member organisations seem more focused on gaining additional Government funding to enhance their administrative organisation allowing them to expand their services. We felt what we do, and how we do it, seems to work pretty well on a “Volunteer and Donation” basis and plan to continue as such.

A promising line of Fund Raising being discussed by the Board has floundered on the rocks of bureaucracy so our search will continue, but if you are able, some of you might consider signing up for a small (\$5) monthly donation to the Group via your Bank. A coffee a week is not too much of a sacrifice for the benefit of our mission, is it?

Elsewhere in this Newsletter, you will find details of our forthcoming Regional Meeting to be held at Burwood Hospital on Sunday 20th November. If you are in the Canterbury region, we shall be delighted to see you there.

As always stay safe.

Tony

THE NEURO CONNECTION FOUNDATION, HENDERSON, AUCKLAND

by Tony Pearson

As those members who attended the Auckland Regional Meeting held in February will know, our Auckland member Tom Hoey leads an organisation at the Tui Glen Centre which aims to assist in the recovery, readjustment and rehabilitation of Stroke patients after their discharge from Hospital care.

Tom believes that many of the practices and procedures used by his well-qualified staff would be beneficial to GBS/CIDP patients who wish to continue their rehabilitation journey after the support provided by the health service has ended.

Following a visit to the Centre by one of our Board members, Meike, it would seem that, from a non-medical viewpoint, the sessions undertaken by current stroke patients were along the lines of group physio routines and may well benefit members. An initial assessment is free and tailored ongoing involvement in regular sessions is at a modest cost.

As you know, the Group does not endorse any particular treatments outside the health system, but does recognise that some complimentary treatments and procedures can and do benefit recovering GBS/CIDPers. In that context, if you feel involvement with the Neuro Connection organisation may be beneficial to you, please make contact with the organisation at (03) 836 6830 or admin@neuroconnection.org.nz. Tom will be pleased to hear from you.

GBS Support Group NZ

Report on the AGM held in Wellington on June 18th 2022

by Tony Pearson



L-R: Peter Scott, Tony Pearson, John Podd, Doug Young, Chris Hewlett, Hon. Steve Chadwick, Meike Schmidt-Meiburg, Gareth Parry, Matthew Peacey, Ansie Nortje

A combination of members at the meeting together with those tuning in on Zoom resulted in a reasonably well attended meeting (as AGMs go – and I have been Secretary at a few!). I guess like all things the more you practise the better you perform, but certainly our expanding Zoom capability means that members can now actively participate in AGMs without the expense or inconvenience of leaving home – the way of the future I suspect.

AGMs are inevitably boring and institutional, but once you get thro' the regular stuff like membership fees (remaining at zero), accounts approval (we are comfortably in the black!) and Board elections (one new member

proposed) there are a few interesting developments to report!

Our Patron the Hon Steve Chadwick was in attendance and advised she will not be seeking re-election as Mayor of Rotorua, because she has been appointed Chair of the Federation of Primary Healthcare Aotearoa which acts as the co-ordinating voice and advocate for the 36,000 individuals involved in Primary Health Care in NZ (Doctors, Midwives, Physios, OT's, Pharmacies, Nurses and Aged Care staff along with many other allied professions). Establishing a proper status and funding within the new NZ dual Health Care system for the organisations and stakeholders it now represents, will be a huge task and likely to take several years as the new Health Boards settle down and define their roles and responsibilities. So, Steve has taken on a big and important task and we wish her well and we know she us up to its demands and we are also pleased to report she will remain our Patron for the foreseeable future.

The Auckland Regional Meeting back in February was very successful in spite of COVID restrictions with 30 local members attending. As is becoming the norm at these meetings the Q&A session with our MAB experts would have run on into the night if our organising Board member Meike had not reined it in.

Both our Website and Facebook platforms continue to perform well and reach out to some 500 (mainly) New Zealanders who live with GBS or one of its variants. Although much restricted by COVID regulations, our Approved Hospital Visitor activity has continued to provide face to face comfort and support where possible.



L-R: Tony Pearson, Doug Young, Peter Scott

Dr Parry reported on the exciting developments of four locally led research projects looking at various issues impacting on our GBS family. These projects have all been kick started with funding from our Group resources enabling the lead researchers to cast their net wider for international funds to finish the jobs. Fundraising requirements never diminish and have been well supported by the membership and other organisations, but two individual efforts deserve special mention. A young lady survivor of GBS, Laike

Moes, from Levin raised \$2000 by running a half marathon and split the proceeds between the Group and a mental health charity, while Nelson based Clive Phillips has raised (and is still raising) funds in excess of \$70,000 to support USA based research into the rare GBS variant MMN by his marathon bike riding epics. Very well done both of you.



Gareth Parry, Hon Steve Chadwick, John Podd, Vivian Pearson
effectively – watch this space!

In the future the Group is considering new fundraising initiatives (Research is a \$ hungry beast!) and whilst it is early days, we are exploring viable ways of encouraging wider membership engagement in the running of the Group particularly by our “younger” members who, whilst holding down busy jobs and family responsibilities, nevertheless have the know-how and experience that can benefit the Group and help it perform its objectives more efficiently and

Thank you to those members who made the effort to join the AGM either physically or electronically your contribution is always valued by the Board.

A Patient Experience

My GBS Journey by Nicky Riches



March 2020 was when NZ went into its first lockdown, but for me I will always remember it as the month that my life changed when I first experienced symptoms associated with GBS.

I am a solo mum to my 3 1/2-year-old son Cole and him and I spent the first couple of weeks of the March lockdown wandering the neighbourhood in the summer sunshine whilst I also tried to keep on top of my job as a Human Resources professional at a large energy firm in Taranaki.

I first noticed tingling like pins and needles in my legs and feet and then in my hands. I thought it was because I hadn't set my desk up correctly at home, so requested some better IT equipment from work. I then noticed I could walk less and less each day and I also struggled to do basic things like change Cole's nappy (he was one at the time) and unscrew the top of his bottle because I had lost all strength in my hands and wrists. I was so tired but I thought that was because I had a baby who was waking a few times a night. I would later realise it was part of the fatigue which has been an ongoing symptom

for the past 2 years. I also felt extreme sensitivity to pain, small things like bumping into something would cause me severe pain and at night it would feel like my skin was on fire which would prevent me from sleeping. I also noticed there were large parts of my body that were completely numb, a result of the nerve damage that was becoming more evident each day.

My GP was and still is incredibly supportive of my son and I, however when I went to see her the first couple of times, she struggled to make a diagnosis and originally thought it was fibromyalgia. As my condition deteriorated to the point that I couldn't lift Cole or walk up-stairs, I took myself to A&E and was lucky to be seen by an American doctor who had seen patients with GBS before and suspected this may be what it was. I had a lot of tests in hospital while they tried to understand what was happening, including a Lumber Puncture, MRI, CT scan and many blood tests. I don't recall ever seeing a neurologist in Taranaki hospital during that visit but I believe the hospital staff were communicating with one out of the region.

I was sent to Hamilton for some Nerve Conduction Testing and this is where they were able to confirm the diagnosis as GBS. They attributed my GBS to an auto-immune response to a gastrointestinal bug I had caught in early March 2020. Returning to New Plymouth it was a long time before I got to see a neurologist because we do not have one in the region and they were travelling very rarely during COVID. Unfortunately, every neurologist visit I had was fairly fruitless and I never felt there was much support provided or consideration given to the extreme life-changing disability and disadvantage that had resulted from having GBS. I think this was due to the fact that very few neurologists specialise in the condition.

I reached out to a friend of mine in the States who is a neurologist and she sent me some really useful information and instructed me to rest (although not easy with a 1-year-old!). The GBS book written by Gareth Parry was probably my most useful resource, as well as connecting with Tony from the Support Group who helped me immensely in not feeling alone in this strange experience. I also found the GBS/CIDP conference in Hamilton in 2021 extremely beneficial, as I connected with specialists and others who had suffered from something similar.

Obviously, one of the most frustrating things about GBS is that there is no simple treatment to support your recovery. As Tony told me early on, GBS can stand for 'Getting Better Slowly' and that is exactly what I have experienced in my journey. Along the way I have tried many things to help speed up my recovery including acupuncture, homeopathy, meditation, yoga and supplements. Although all of these have had some benefit, I understand that the nerve damage takes a long time to heal and it is not a race you can just speed up. I was also prescribed a series of different painkillers throughout my recovery but often opted not to take them to avoid the common side effects, and instead used Panadol regularly with limited effect. I did also receive a few funded hours support a week through an organisation called Accessibility, which allowed me a little bit of help around home which was very welcome.

Raising Cole on my own and not being able to rest has no doubt resulted in a longer recovery period and has meant I have had to get a lot of support from family and friends along the way and for their support I am forever grateful. There have definitely been moments in my recovery where I wasn't sure how we would get through and there are still times where my symptoms flare up which can put me in a negative headspace but ultimately, I know I'm heading in the right direction physically and that keeps me going.

Two- and a-bit years on and life is slowly returning to normal. Cole and I can enjoy our weekends together out and about, although we do both still have to have a lunchtime nap to recharge!

GBS has been a life-changing experience in so many ways. I wouldn't wish it on anyone but I have accepted that it has also taught me a lot about holistic health and wellness that I may not have otherwise known. I have also learnt that you have to advocate for yourself in the medical system because no one else will! I am optimistic that I continue to see small improvements in my condition each month and hope I will get close to my pre-GBS life in the near future.

From the Medical Advisory Board



QUESTION AND ANSWER SESSION FROM THE AUCKLAND ONE DAY REGIONAL MEETING HELD ON 19 FEBRUARY 2022

Presenters: Drs Gareth Parry and Chris Lynch (Neurologists) and Dr Suzie Mudge (Physiotherapist)

- 1. Question:** A short summary since my first vaccine. I had my first vaccine on 25.8.21 and started getting GBS symptoms 11 days later (back pain, numbness in feet and losing ability to walk unaided), was admitted to hospital five days from there. Diagnosed with GBS + SIADH + Bell's Palsy. Underwent IVIg infusion for five days. Was discharged on 21.9.21 with three weeks' home rehab. Still had and still have numbness around mouth and top lip. Had second vaccination on 13.11.21 and within ten days developed stiffness in my shoulders, upper arms, hips and knees. First thing in the morning found it difficult to walk, bend or get out of sitting position. Improved somewhat as the day went on. Diagnosed with Polymyalgia. Taking Prednisone which has helped enormously. Am slowly reducing the dose. I am not keen on having the booster vaccine.

Answer: *You have to weigh up the risk of getting Covid, how will the vaccine protect us and the fear of getting something like GBS again. Yes, you had a bad time, but we all will get COVID at some stage, you need to be vaccinated twice (you are), a booster is recommended because the vaccine wanes after 6 months, but you are still partly protected with two shots.*

Having had two different autoimmune conditions (GBS and Polymyalgia) suggests the possibility that you may have a tendency to develop conditions of this type in the future.

Of course, just because these events happened after the vaccine, it does not mean that they were caused by the vaccine. However, the occurrence a couple of weeks after the vaccine does suggest that the vaccination was the cause. Even if vaccination was the cause the balance of risk versus benefit may still favour getting the booster since the vaccine gives good protection from serious or even fatal infection with COVID.

The GBS/CIDP Foundation International has recommended that influenza vaccination should not be given if GBS has been triggered by a previous influenza vaccine but also if someone is within the first year of recovery from GBS, regardless of the trigger. However, this recommendation is not based on scientific evidence, but is just a commonsense approach. As always, the risk and benefits of getting the vaccine must be weighed against the risks of getting the disease for which the vaccine is being given.

- 2. Question:** Particularly with reference to CIDP (as this might relate more to chronic rather than acute disorder) - has there been any meaningful and credible research done on the effect of diet in autoimmune disorders. I've read about some research by Terry Wahls who claims to have had success treating MS with diet changes, and am curious whether this kind of research is considered to have any credibility and whether the experts think there could be benefit gained from a more natural, whole food, evolutionary diet.

Answer: *Diet for patients with auto-immune illness: there is no evidence that any particular diet is beneficial for patients with CIDP or, in fact, for any autoimmune disease. Some people feel that a specific diet is beneficial and there is certainly no harm in trying any diet but the success depends mainly on how strongly you believe in it; about 40% of people on placebos have a beneficial effect. If you believe something will work, it will, positive thinking. Most importantly, make sure nothing you take is harmful. For example, some vitamins can cause nerve damage if taken in large doses. Most important is: eat less, exercise more (not just for patients ☺).*

CIDP tends to go away eventually but it can take years. While it is active you may develop some degree of irreversible nerve damage which may be permanent. It is important to try to remove treatment from time to time to see if it is still needed. IVIg infusions are inconvenient and expensive, and carry a small risk of serious side effects as you get older. Steroids also carry risks with long-term use. There is little risk in trying to stop treatment every 3 years or so; if you get weaker you can start again.



Drs Lynch, Mudge and Parry

a yearly booster, but not as a mandate like this year. We have a pandemic now, a public health crisis.

3. Question: How many weeks after the booster is it safe to get the flu-shot?

Answer: *A few weeks apart.*

4. Question: Are we going to be continually required to get boosters and what effect could this have long term?

Answer: *The COVID virus won't go away. We will probably get offered a yearly booster, as a long-term recommendation.*

From next year we will get

5. Question: Might it be once per year in the future, like the flu shot, and constantly adjusted to new strains?

Answer: *We will probably get a COVID vaccine once per year towards winter. 1 in 50 people die from COVID. The virus mutates in time and usually the mutant forms are less dangerous. In 1918/19 at least 50 million people died of influenza but now we don't worry about it too much, because the virus is not as dangerous and the community as a whole has developed some immunity to it.*

6. Question: What is considered a mild case of GBS?

Answer: *When a patient goes into hospital, the doctors observe you, make sure they see how you react to GBS. For example, you can walk with flat feet slapping on the floor, you can grab, they watch what you can do, and what goes wrong when you try. If you are still able to walk without any support that would be considered a mild case.*

7. Question: GBS is considered a condition not a virus – when does it stop? Are the symptoms that I have at the moment the aftermath of GBS, not GBS itself?

Answer: *Something triggers the immune system, probably because something about the trigger resembles a molecule in the nerve, a process called molecular mimicry. If the trigger is a viral infection, the virus is eliminated by the immune system and the nerve damage that is GBS then takes some time to heal.*

8. Question: I have often wondered what is considered good relief for pain? What pills could one take?

Answer: *If the doctor treats for pain, the purpose is to improve your quality of life. If treatment for your pain does not improve the quality of your life, it is probably not worth continuing. For example, the side effects of the medications used to treat pain are sometimes worse than the pain itself. If the pain disturbs your sleep, then consider something to intervene with the pain. Pain and fatigue often go together. Many of the medications used to treat pain, such as gabapentin, pregabalin, nortriptyline and so on, can make your fatigue worse.*

9. Question: It's two years since contracting the worst strain of GBS. Hands are still a bit swollen with some feeling, legs from knees down still pins and needles! It's mainly my feet that have numbness. Pain is 24/7 and I'm using Gabapentin, Paracetamol, Nortriptyline and codeine when needed. Pain has eased in the last month. Is it okay to stop using Paracetamol and codeine? Will my condition improve or will I have numb & swollen feet forever?

Answer: Codeine and drugs like that are highly addictive and should not be taken over a long time, you get dependent, they are only good for acute patients, when they have massive pain! Codeine is an opiate, should you stop: yes, now!

There is no evidence that Paracetamol is good for neuropathic pain. Pain is going to improve. It can take up to 5 years. Prognosis: improvement will continue. Swollen feet: Gabapentin and pregabalin can cause swollen feet.

10. **Question:** Being a 67-year-old male with well-controlled Type 2 diabetes, I have been vaccinated yearly with the flu vaccine and more recently with the Pfizer vaccines including booster, all prior to me contracting GBS in mid-December 2021. With no discernible side-effects from any of the vaccines, how concerned should I be or not be, going forward, about further vaccines for flu and or additional boosters etc. I had the booster 3.12.21, got gastro, on 17.12. weakness in legs. 18.12. GBS diagnosed, triggered by gastro.

Answer: Get boosters regularly and flu shots when recommended.

11. **Question 11:** How does one get motivated to exercise?

Answer: Most patients don't do their home exercises at home. Some behavioural change principles: Set small goals, they need to be important to you. If you like doing it, and you get better at it, you will enjoy doing it, and improve with time. Maybe someone can walk with you, support each other, it's a support for you. Can you relate it to something you like doing, what can get in the way? If you are supposed to go for a run, but you hate it, you won't do it. If you enjoy going for a swim or a bike ride more, do that, do what you enjoy!

12. **Question:** I've had 3 vaccinations, wear a mask, should I still be worried?

Answer: You have done as much as you can and the challenge is to get back to your former life but you should do so as much as possible. Only you can decide how much risk are you comfortable with. We all face risks every day. You can step outside your house, and get run over by a car, but you still go out. You could drive to work, and someone drives into you but you still drive.

13. **Question:** Can stress make an auto-immune illness worse?

Answer: Possibly. Just because you can't prove it, it doesn't mean it doesn't exist. Young people do generally recover better than older patients.

14. Some general comments by members of the panel:

GBS can come on over as little as a few hours, but more often it evolves over a few days or a few weeks. It should not progress for longer than 4 weeks. If a GBS-like disease progresses for longer it is CIDP. Treatment for GBS is beneficial only if it's done within a week or possibly two weeks from the onset of weakness. If the treatment gets started after a few weeks, patient would have improved anyway, you can't say the patient got better because of the treatment.

It has got a psychological effect. If someone doesn't progress well in rehab, it can be because of anxiety or depression.

GBS is cruel, debilitating. It occurs in all ages, kids do get it too, but recover really well.

Plasma exchange and IVIg both work really well for most people. There is not much evidence that one is better than the other, but it has been suggested that plasma exchange is better for severely affected patients. We are doing some research in NZ to see if that is the case.

PAST EVENTS

Waikato/Bay of Plenty get-together of 23 August in Paeroa

It was great to see everyone, catch up, have some laughs, enjoy each other's company, yummy food and the



sun too!!

L-R Back Row:

Michael Cameron, Lyn Neels and Michael Logan, Barry Deed, David Powell, Chris Hewlett, Tom Boon, Peter and Charmaine Barry, Grant McKay, Rex Buckley.

L-R Front Row:

Judy Deed, Fiona Green, Roberta Cameron, Janice Boon, Jan Gribble, Yvonne Powell, Fran McKay, Phil and Emma Wolfe, Rosemary Buckley, Meike Schmidt-Meiburg.

First Auckland Botany get-together of 9 August at Columbus Coffee, Botany



Our first meeting of the Auckland Botany Coffee Group amongst the plants and succulents at Columbus Coffee @ Mitre10 Botany. Lots of valuable chat took place while eating and drinking coffee. How the time went by. A special thanks to Meike and the Powell's for traveling to be with us from the Waikato, it was wonderful to have you at our inaugural meeting in Auckland South.

L-R: David and Yvonne Powell, Peter and Charmaine Barry, Rex Buckley, Meike Schmidt-Meiburg and Rosemary Buckley

NOTICEBOARD – UPCOMING EVENTS

Bay of Plenty/Waikato Coffee Group



When: 22 November 2022

Time: From 10:30am

Where: The Village Café, 1 Rothwell Lane, Whatawhata
www.thevillage.kiwi (07) 829 8892 Closure at 3pm

Pre-Christmas Secret-Santa Get-Together

If you would like to take part in our Secret Santa, please bring a gift along to the value \$10, suitable for either your male and female friends.

Please let me know that you are coming or not, so I can confirm numbers with the venue by 21.11. They will have their lunch-time a-la-carte menu and cabinet food available too.

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

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

Wellington Coffee Group



When: Saturday 26 November 2022

Time: 3-5pm

Where: 124 Navigation Drive, Whitby, Porirua
Ansie and Louis invite you to join us at our home for a good coffee (or tea!) and home-baked nibbles. Please confirm by 23 November, new members most welcome!

Ansie's contact details:

gbs.newsletter@gmail.com

Mob: 027 332 8546

Auckland Coffee Groups



Auckland North/West:

When: Saturday 5 November 2022

Time: 2pm

Where: Neuro Connection, 2 Claude Brookes Drive, Henderson, Auckland

New members most welcome

Please contact Eileen if you have any questions

Mob: 021 113 3607

Auckland Botany:

When: Tuesday 11 October 2022

Time: 11:30am

Where: Columbus Coffee at Mitre10, Botany, Auckland
9 Bishop Dunn Place, Flatbush, Auckland

Put it on your calendar and come and join us, new members most welcome.

Please contact Rex if you have any questions

rexbuckley@xtra.co.nz

Mob: 027 296 3297

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.