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## Guillain – Barré Syndrome Support Group New Zealand Trust

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

### NEWSLETTER March 2023



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# Board of Trustees

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Doug Young

## Secretary



Tony Pearson

## Treasurer



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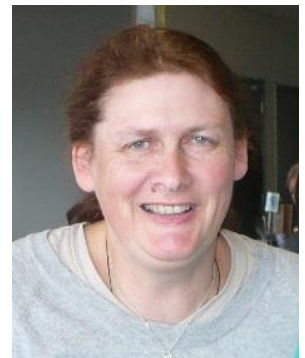
Dr Ansie Nortje



Chris Hewlett



Te Whatarangi Dixon



Meike Schmidt-Meiburg

## **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



**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



<b>Dr. Gareth Parry (Chair)</b> 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	<b>Dr. Annette Forrest</b> ICU Consultant MBChB, BPharm, Dip Ag & Vet Pharm PGDIP Aeroretrieval Masters Aviation Medicine CAA Medical Examiner PGDIP Occupational Health
<b>Dr. Chris Lynch</b> BMedSci, MB ChB, MD, FRACP Neurologist and Neurophysiologist at Waikato Hospital Honorary Senior Clinical Lecturer at the Auckland Medical School, Waikato Campus	<b>Dr. Suzie Mudge</b> Dip Phys, MHSc, PhD Director & Physiotherapist: Neuro Rehab Results Senior Lecturer/Senior Research Officer Health and Rehabilitation Research Institute, AUT University
<b>Dr. Dean Kilfoyle</b> Neurologist, Auckland City Hospital, Auckland DHB	<b>Dr. David Gow</b> M.D., MB ChB, FRCP (UK), FRACP. Neurologist with Southern DHB
<b>Dr. Jennifer Taylor</b> MB, ChB, FRACP Consultant Neurologist, Wellington Hospital	<b>Dr. Vic du Plessis</b> Neurologist and rehabilitation specialist. Part time consultant neurologist, Dunedin
<b>Karen Clark</b> Master of Nursing Clinical Nurse Specialist, Neurology Waikato Hospital	<b>Kylie Kerr</b> Occupational Therapist Burwood Spinal Unit, Christchurch
<b>Kathryn Quick</b> Physiotherapist	<b>Te Whatarangi Dixon</b> BHSc (Physiotherapy) MNZSP QE Health, Rotorua

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## Editor's Note – Ansie Nortje



In this edition, I want to acknowledge the impact of Cyclone Gabrielle and the recent flooding has had on many of us, our members, families, colleagues and friends. Such events highlight the importance of being resilient and of being supportive towards each other. Resilience is the ability to cope mentally and emotionally with a crisis. It is the capability to successfully adapt to challenging life experiences through mental, emotional and behavioural flexibility. In any crisis or challenging life event, support from the people around us, self-care, and a focus on what we can do, are important factors that contribute to our survival and personal growth.

*“When written in Chinese, the word 'crisis' is composed of two characters. One represents danger and the other represents opportunity”.* - **John F. Kennedy**

On behalf of all of us, I want to acknowledge the work our retiring Treasurer, Peter Scott, has done over the last 25 years. Peter, thank you, we are going to miss you, but we wish you all the best for the future.

In addition to our regular links of the GBS/CIDP Foundation International below, I would like to draw your attention to videos on Clive Phillips' latest bike ride to raise funds for MMN research (also see Tony Pearson's comments elsewhere in this newsletter):

[2023 Ride for MMN - YouTube](#) and [Help Raise MMN Awareness - YouTube](#)

See also a webinar video on MMN featuring both Clive and Dr Gareth Parry:

[Ask the Experts Webinar: Living with MMN Treatment and Care - YouTube](#)

GBS/CIDP Foundation International: <https://www.gbs-cidp.org/>

The Foundation's YouTube Channel: <https://www.youtube.com/@gbscidporg/videos>

Warm Easter wishes to you all.

*Ansie*

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## Regional Meeting for the Waikato/Bay of Plenty - Saturday 6 May at the Ngatea War Memorial Hall (Supper Room), Orchard West Road, Ngatea 3503

The GBS Support Group NZ Trust would like to invite you all to the Waikato/Bay of Plenty Regional Meeting on Saturday 6 May 2023 in Ngatea, Hauraki Plains, from 10 am – 4 pm. The supper room is easy to access by a wheel chair ramp.

In the morning there will be a series of short talks on GBS/CIDP from members of the Medical Advisory Board (Drs Gareth Parry, Suzie Mudge and Chris Lynch, experts in GBS and CIDP diagnosis and management). Topics will include a research update, COVID-19 and vaccination update, and management of pain and fatigue.

This will be followed by a panel discussion of issues facing GBS/CIDP patients. Most importantly, the entire afternoon will be used to provide attendees with the opportunity to ask questions of our GBS/CIDP experts. We are just finalising the programme and will publish it ASAP.

Please register for this event by contacting **Meike Schmidt-Meiburg** at [schmidtfarm@xtra.co.nz](mailto:schmidtfarm@xtra.co.nz), any questions please ring me on 07 86 73 163 or 027 325 03 69 and pay your registration fee of \$30/pp online (to cover hall hire, morning tea and lunch): GBS Support Group NZ Trust, 15-3949-0339362-000.

We look forward to welcoming you all for this bi-annual, very informative event!!

Please send me an email that you have paid your registration fee by May 1<sup>st</sup> at the latest, with your name, address, are you the patient or the carer, and if you have/had GBS/CIDP/or other variant. Thank you, Meike.

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## President's Report – Doug Young



Welcome all to our Newsletter for March 2023.

Another year has passed with a stunning summer for some, not so good for others. We have our AGM coming up in Wellington on the 15<sup>th</sup> April at the Miramar Golf Club next to Wellington Airport. There is a lot of business to get through in a short time.

Come along if you can, if not we will have a Zoom meeting facility available for those who would like to attend without having to travel.

The Board held our three-monthly Zoom meeting on the 7<sup>th</sup> March, and it overshot the one-hour time limit by a considerable margin due to additional items arising under additional business. Tony will provide insight to the additional items in his report further on in the publication.

However, I wish to comment on one item.

Peter Scott, our long serving Treasurer, has indicated that at 85 years young he believes it is time to “hand over the reins” to someone else. Peter has been treasurer since almost the Group’s inception, approximately 25 years. An accountant by profession, Peter has done an incredible job over these years. Managing our finances into the reasonably strong position we are in today, by being firm and prudent about how we spend our limited income. His years of experience ensures us newcomers don’t try and “reinvent the wheels” that haven’t worked in the past.

Peter has also managed our meeting proceedings with good knowledge of our Charitable Trust Deed, by which we are bound to operate within, as a Board.

Therefore, Peter’s position is one of the most important on the Board, and finding a suitably competent person with a similar set of skills is important for us as a Group. We have been fortunate to have a person from within our membership express an interest in the position who has similar skill-sets as Peter. As a Board we will be meeting with the candidate at our Board Meeting in Wellington prior to the AGM. This allows the interested party to review the job and meet all the Board members first hand for the first time. I am hoping for a positive outcome from this meeting so we can move forward from this point. This includes a smooth handover from Peter to the new treasurer over the following months. As you know, nothing happens too fast at Board level.

Enjoy your read and thank you Ansie, for putting it together under trying personal circumstances.

Regards to you all

Doug Young, President.

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**The 21st AGM of the GBS Support Group Trust will take place at  
1100hrs Saturday 15<sup>th</sup> April 2023 at the  
Miramar Links Conference Venue at the Miramar Golf Club  
1 Stewart Duff Drive Wellington**

Formal Notice, Agenda, Minutes and Proxy Forms will be circulated to all members of the Trust late March. Everyone is welcome to attend the meeting and members are eligible to speak and vote at the meeting. The meeting will also be broadcast live on Zoom. Members will be advised of the link to enable them to join the Zoom meeting with the formal Notice.

Members who are unable to attend the meeting may nominate a Proxy to vote for them, either our President Doug Young, or another member of their choice.

If you have any questions about the forthcoming AGM, please direct them to the Secretary **Tony Pearson** on 03 540 3217 or [tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz).

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## Secretary's Jottings – Tony Pearson



Well talk about the tale of two Islands! – For us here in South Island – “What Gabrielle???” – Nelson bathed in sunshine, just starting water restrictions and further south concern about drought conditions, but up north a different story! I wasn’t in NZ for Cyclone Bola but from what I can read, Gabrielle pretty much wreaked the same havoc in similar areas – at least as far as Hawkes Bay and surrounding regions are concerned. Watching the news, it is difficult to comprehend the devastation suffered by affected folk – particularly in rural areas. However, once I realised that it just wasn’t farms, orchards and vineyards impacted but also the towns of Gisborne and Napier as well I thought I would attempt to contact the 10 members we have in those towns. At the time of writing, four have responded with tales of road disruption, sharing accommodation and facilities, enforced overnight stays in Hamilton when receiving regular Plex/IVIg treatments (one member flown to her appointment in a neighbouring farmer’s plane!), but I have yet to hear from the others. So, Hilary, Phil, John, Collen, Paul, Beverley and Jeff do make contact and let us know you are OK – soggy maybe but safe and well.

Recovery is going to be a LONG, LONG, LONG haul, but I never ceased to be amazed at the Kiwi attitude that recognises that others are worse off than they are – provides unsolicited help to those in strife and how communities are almost made stronger by events like this. I chose the right country to emigrate to even if it’s weather can be somewhat more extreme than the Home Counties of England!

Some of you will have heard of IGOS (International GBS Outcomes Studies) which is an ongoing research project involving many learned folk studying 1,000 GBS patients across the world. In a recent paper looking at some 770 patients from the study group who had reported having an infection just prior to contracting GBS, 30% had *Campylobacter* poisoning and another 20% one form or another of common minor virus infections. Apparently, this was pretty much uniform across countries but the type of GBS that developed varied significantly between Asian and American/European countries. I’m not sure where NZ sits in this respect but most of you will have read about the recent recall of a variety of LISA’s hummus products that are potentially infected with contaminated tahini from Turkey. Whilst there have been no official reports of cases, a relatively high number of people have commented on social media about falling ill – some quite violently – after consuming these products in February. Thinking about the IGOS results above, one has to wonder what might transpire in terms of a GBS “spike” in the coming weeks/months here in NZ. AND, this morning I read on Stuff that there is a general health warning to all those valiant folk helping clean up the silt on the East Coast – it could be contaminated !! - so protect yourself from contact with it or it could lead to *campylobacter* or other related infections and we all know what might follow that!

COVID hasn’t gone away! Vivienne and I contracted it a couple of months back and our neighbours have just come out of home isolation, so it’s worth remaining cautious about contacts – especially large gatherings in enclosed spaces. What is clear to me is that the Anti-Viral medications that are available to us GBS’ers who contract COVID work wonders – at least for those folk in my “advanced age bracket” that I have spoken with.

As April approaches, the Board is gearing up for the AGM – and a formal Notice of Meeting is included elsewhere in the Newsletter. It will be held at the usual venue in Wellington but Zoom facilities will allow members around the country to join from the comfort of their own home. There are a number of new developments in the organisation of the Group to report, but I won’t steal the President’s thunder by letting the cat out of the bag at this time. Our regular Zoom Board meetings continue and are now including other members of the Group who are supporting the Board discussions as “advisors” and bringing an expanding viewpoint to our decision making – thank you to those involved. If you would like to add your constructive input to those meetings, please contact me and we can develop a relationship from there. Our special group of Authorised Hospital Visitors has been joined by Katherine Banks based in Taranaki and Kathy Eggers in Auckland. Thank you ladies for putting your hands up. Your contribution - like that of the rest of the team – is probably one of the most valued of all our services to newly diagnosed GBS patients.

A well-deserved pat on the back – or should that be wheels? – to Clive Phillips who has just completed 210Kms of the Alps to Ocean ride in South Island from dawn to dusk – his target was 300 Kms but was thwarted by a strong headwind – but still a marvellous effort in his ongoing drive (ride?) to raise funds for MMN research – a worthy effort, Clive!

Finally, something for our younger members – an idea from the USA Group – Project Plasma. They are trialling an idea – spread by the usual young persons’ social media mechanisms - of raising awareness of the

need for plasma donors amongst the student population of Colleges and Universities to increase the supply of IVIg medication. Might something like that work here? It would need a few guys and gals to lead the movement but if it proved to be viable, I am sure the NZ Blood Service would be interested in hearing about the possibilities. Have a look at [www.gbs-cidp.org/project-plasma](http://www.gbs-cidp.org/project-plasma) . Let me know if you might consider getting involved and I will take some advice from our MAB about a possible way forward. As always – stay safe.

Tony

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## From the Medical Advisory Board

### Research Report – March 2023

by Drs Suzie Mudge, Eileen McManus and Gareth Parry



#### **Impact of a physical activity programme on fatigue levels for people with GBS:**

The data collection for the fatigue project is now complete. We enrolled eight participants in the study, and all have now completed the intervention and data collection. We are currently underway with data analysis. Very early results suggest that most people had a decrease in fatigue over the course of the study. Participants were also very positive about their participation in the programme. We hope to present fuller results in May 2023. Those who are able to attend the Regional Meeting in Ngatea in early May, advertised elsewhere in the newsletter, are encouraged to come along and hear more detailed results.

#### **The GBS phenotype in Aotearoa/NZ: How ethnicity, socioeconomics and infection influence GBS outcomes:**

The work on the NZ-wide GBS project proceeds apace. We have now gathered information on nearly 250 patients. Our thanks to all of you who have agreed to participate; we could not have done it without your willingness to help. Most of the individuals we have identified had their GBS between 2020 and 2022 and we want to continue to add people dating back to the beginning of 2016, but we are eager to also identify more people who have GBS currently and going forward; the study will run through to the end of 2025. We are analysing this data with regard to environmental triggers, type of GBS, ethnicity, associated medical conditions and treatment given to see what impact these factors have on the outcome. This research will help to fill gaps in our knowledge of GBS that is specific to NZ and may help to explain why NZ has the highest rate of GBS in the developed world. We have already identified several previously unrecognized features of GBS in NZ. Firstly, the rare form of GBS called the Miller Fisher Syndrome, that affects the eyes, causing double vision, and also causes loss of balance is about twice as common in NZ than in other Western countries and seems to be more common in Māori than in NZ European. Secondly, Māori patients and those with the metabolic syndrome (obesity, diabetes, hypertension and high cholesterol) tend to more severely affected and need to stay in the intensive care unit (ICU) for longer. Thirdly, NZ Europeans are more likely to have their GBS triggered by diarrhoea than by respiratory infection. Finally, those patients who have the AMAN form of GBS that mainly affects the axons, rather than the myelin sheath, are more likely to have severe disease and stay in the ICU for longer and have poorer recovery at 6 months.

There is much more to be done. We are hoping to gather data on 700+ patients who had GBS during the 10 years from January 1, 2016 to December 31, 2025. If you are reading this newsletter and would be willing to participate, please contact Dr Eileen McManus ([emcm373@aucklanduni.ac.nz](mailto:emcm373@aucklanduni.ac.nz)).

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

by Tony Pearson

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 donations are tax deductible and the Treasurer will be able to issue you with an IRD acceptable receipt annually if you request it.

THANKYOU – Your Board

PS – It doesn’t take long to set it up – I have just done it in 1min and 51 seconds!! - have a go! *Tony*

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## “Claw Hands” - can you help with your own experience?

By Tony Pearson



For some time now I have been supporting a recovering GBS’er living in Nelson. Whilst his recovery has been slow following a severe GBS attack (2 sessions in ICU with “the works”) nearly 2 years ago, he is making progress with his upper body strength returned and his legs improving weekly with physio assistance using a walking frame and pool exercises BUT..... As you can see from the photos he has “Claw Hands” – these developed during his extensive bed-ridden state in hospital when, understandably, the rehab work was focused on getting him mobile again rather than the state of his hands – whatever the reason they are now

“locked” and the only potential solution – he is advised – is an operation to remove scar tissue in the joints and unlock the tendons (a non-medical man’s understanding of what is involved I hasten to add!!). Apparently, it’s not a guaranteed solution and will still require extensive physiotherapy afterwards to ensure the fingers regain their flexibility, but he wants to have a go at it.

Has anyone in the Group undergone such a procedure – or anything similar to cure/help improve this claw hand situation? PLEASE contact me if you have something to offer/advise

[tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz) 027 687 1953





# PAST EVENTS

## Auckland Coffee Group (North & West) meeting held on 26<sup>th</sup> February 2023

After reserving a table earlier, a small group of 5 met at the King's Plant Barn café at Porana Rd in Takapuna at 2pm Sunday 26<sup>th</sup> February.

As I arrived to set up with my bag of books, brochures and newsletters and the Auckland banner, two ladies at the next-door table recognised me and asked what I was doing. After explaining, they remembered another woman from our church who had also had GBS, years before I did, and that she had an awful time with it and still has residuals after all this time. Hmm..., another incidence of people having contact with or hearing of someone who has had an encounter with GBS or related syndrome. At that time the Support Group had probably not yet been set up.

Soon Lorraine and Sharon arrived and we chatted until Tracey and her husband Scott arrived. Tracey had experienced her first symptoms in early December 2022. Hospitalised initially at Middlemore, she was sent to Auckland City Hospital when her breathing was recognised as deteriorating and she needed to be in ICU. Today she was much improved though still at Rehab in Manukau and would need to return there after this visit. It was also good to have Scott's perspective as the 'significant other' and how this illness has impacted their whole family.

Next meeting will likely be Sunday 28<sup>th</sup> May 2pm also at King's Plant Barn Café, Porana Rd, Takapuna. Come and share your story too! You could be a great encouragement to another who is finding their 'new normal' after experiencing GBS/CIDP or related neuropathies.

Condolences to Sandra Close whose husband Richard (GBS) passed away in October 2022.  
Nola Neas has withdrawn from the Group after her husband Bill passed away May 2022.

*Eileen Jacobson*

## Waikato/Bay of Plenty get-together of 7<sup>th</sup> March at Waihi Beach



We had a good turnout for our first get-together for the year and had a lovely catch-up. Everyone enjoyed the extensive, flavoursome selection of the salad bar!

**L-R standing:** Michael Logan, Peter & Charmaine Barry, Yvonne Powell, Judy Deed, Chris Hewlett, Meike Schmidt-Meiburg, Janice Boon, Grant McKay, Mike Cameron, Barry Deed, David Powell.  
**L-R seated:** Lyn Neels, Roberta Cameron, Fran McKay.

**Photographer:** Marty Hewlett.

*Meike Schmidt-Meiburg*

# NOTICEBOARD – UPCOMING EVENTS

## Bay of Plenty/Waikato Coffee Group



**When:** Thursday 8 June 2023  
**Time:** From 10:30am onwards  
**Where:** The "The Hub / Aoraki Coffee", Hampton Downs Motorsport Park, 20 Hampton Down Road, Hampton Downs, Waikato. Tel (09) 930 9207

Located just off SH1, where the Hampton Downs Motorsport Park and information centre are.

Please let me know **by Monday 5 June** if you can make it or not, for letting the venue know, many thanks. Hopefully you can all come!!

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

Looking forward to another good catch-up with you all, Meike :)

## Wellington Coffee Group



**When:** Saturday 20 May 2023  
**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 Saturday 13 May.  
New members most welcome!

**Ansie's contact details:**  
[gbs.newsletter@gmail.com](mailto:gbs.newsletter@gmail.com)  
Mob: 027 332 8546

## Auckland Coffee Groups



### Auckland North & West:

**When:** Sunday 28 May 2023  
**Time:** 2pm  
**Where:** Kings Plant Barn Café  
11/13 Porana Road, Takapuna

New members most welcome.

**Please RSVP Eileen at**  
[eileenmagnajacobsen@hotmail.com](mailto:eileenmagnajacobsen@hotmail.com) Mob: 021 113 3607

### Auckland Botany:

**When:** Wednesday 10 May 2023  
**Time:** From 10:30am  
**Where:** Columbus Coffee at Mitre10, Botany, Auckland  
9 Bishop Dunn Place, Flatbush, 2013

It is situated in South Auckland, but we'd like to see and meet all GBSers, CIDPers and ? – from anywhere - all who would like to come plus partners to have a general 'old natter'. Please come, we would love to meet you. Plenty of parking, no steps.

**Please contact Rex if you have any questions**  
[rexbuckley@xtra.co.nz](mailto:rexbuckley@xtra.co.nz) Mob: 027 296 3297

## Top of the South Coffee Group



**When:** Sunday 7 May 2023  
**Time:** 10:30am  
**Where:** The BORED ROOM of the Zumo Café on Rutherford Street, Nelson (opposite the Torpedo 7 store).

Places around the BORED ROOM table are limited – but VERY comfortable!! - so if you want to book a spot please let me know. It will be a long overdue chance to catch up with fellow members in our area, meet new friends and exchange experiences. The venue is wheelchair friendly and if you need a lift to the get together also contact Tony Pearson.

**Tony's contact details:**  
[tonypearson@xtra.co.nz](mailto:tonypearson@xtra.co.nz)  
Mob: 027 687 1953 or (03) 540 3217

## 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.