

Your monthly update from GAIN



Raising awareness around GBS and CIDP

Rich's update

Rich Collins
Chief Executive

Hey there, hope everyone is doing well, and enjoying what is likely to be some short lived sunshine! Hopefully we will start to get some nicer weather as summer approaches.

It's been really busy here at GAIN HQ, preparing for GBS and CIDP Awareness Month and GAINmomentum. While it has been hectic, getting to meet with everyone in events and sessions so far has been amazing. It's also great to see what everyone has been up to, so please keep sharing your stories and pictures with us, we love seeing and reading them.

There are still lots of ways to get involved in Awareness Month and GAINmomentum, and you can see how on the next page.

We are also delighted to have Claire join us in the office on a permanent basis, more about her in the next edition of Lowdown.

Until then, take care, and speak soon



News

The clinical commissioning policy for immunoglobulin therapy in England was updated in April. The revised document covers the use of IVIG for some of the conditions that GAIN supports. This new version of the policy changes the 'hierarchy' of which conditions are prioritised, and instead states which conditions have IVIG routinely commissioned, and which don't. GBS, CIDP, and MMN are all classed as being routinely commissioned, but POEMS isn't. The document also outlines when IVIG should be given, and when it shouldn't for each condition. CIDP and MMN do not need prior approval before short term treatment (it is for long term), and for GBS, approval is not required before treatment (as long as it's within the eligibility criteria).

The government is consulting on changes to how they support disabled people and people with health conditions, particularly around financial payments. They are seeking views around the approaches they should consider around modernising the welfare system. This is an important consultation because many of the people impacted by GBS, CIDP, and other conditions depend on the state to support them during the most difficult times.

There are a few ways to get involved. Respond directly into the consultation by 22nd July at [Modernising support for independent living: the health and disability green paper - GOV.UK](#) (www.gov.uk), or email your comments to office@gaincharity.org.uk by 15th June and we can feed your thoughts into our response.

Awareness Month



As you will be aware, May is GBS and CIDP Awareness Month. We are asking everyone to share information about GBS and CIDP this month, so we hope that you are joining in, sharing your knowledge and experience with family and friends, and helping spread the word.

There are still lots of ways of getting involved. You can join one of the events listed below, you can share our factsheets, you can put up a poster, or you can wear one of our awareness ribbons.

To find out more head over to www.gaincharity.org.uk/awareness-month

Events

During GBS and CIDP Awareness Month we are running a number of online events, which we would love you to join.

On Thursday 16th May at 2pm, we have a regular GBS Get Together on Zoom

On Monday 20th May at 11am, we will be live in the Facebook Group discussing what people impacted by GBS and CIDP want and need

Thursday 23rd May is our CIDP Get Together on Zoom at 2pm

Finally, on Friday 31st May, we will be hosting a celebration of the GBS and CIDP Community at 12pm. Book on and join us to chat and share experiences of our amazing community.

More details can be found at www.gaincharity.org.uk/awareness-month

It's not too late to join in with GAINmomentum in May. Go to www.gaincharity.org.uk/gainmomentum to find out how

Our support for people impacted by GBS, CIDP, MMN, and other conditions



Don't forget that GAIN provides a wide range of support to people impacted by GBS, CIDP, MMN, and other conditions. If you need some support then please reach out to us using the details below

We provide:

- **Phone and Email Support**
- **Information, Guidance, and Advice**
- **Access to Peer Support with volunteers with lived experience**
- **Financial Grants**
- **Community Video Calls and Get Togethers**



Even if you just want a chat, get in touch, it's what we are here for

Get more information at www.gaincharity.org.uk



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