

A new monthly update to keep you in the loop



It's GBS & CIDP Awareness Month in May

Rich's update

Rich Collins
Chief Executive

Hi everyone, and welcome to the very first GAIN Update, your new monthly note from GAIN to fill the gap between copies of the quarterly newsletter, GAIN Lowdown. When I have been speaking to people, one of the things that keeps coming up is that most people want to hear more from us. While we don't want to send out too many things, I thought that a short update would be appreciated. So, from now on you will still get Lowdown every three months, but also a copy of Update in the months inbetween.

Anyway, lots in here including news and information, and we will be bringing you new content all the time. Don't forget to fill in the survey (see page 3). It really is your opportunity to comment on and influence the direction of your organisation. I need more responses, so please don't be shy in filling it in.

In the meantime, take care, and speak soon



News

The Lancet recently published new research that confirms that neurological conditions (which includes GBS, CIDP, MMN, and other related conditions) are now the leading cause of ill health and disability globally. Lots of organisations (including GAIN) are calling on the government to look at this research and improve services and support for people impacted by neurological conditions. You can read the research at [Global, regional, and national burden of disorders affecting the nervous system, 1990–2021: a systematic analysis for the Global Burden of Disease Study 2021 - The Lancet Neurology](#).

The Department of Health and Social Care (DHSC) has published its third Rare Disease Action Plan for England. It is structured around three priorities, helping patients get a diagnosis faster, increasing awareness among health professionals, and the better coordination of care. You can see the full plan at [England Rare Diseases Action Plan 2024: main report - GOV.UK \(www.gov.uk\)](#).

Finally, with an election on the horizon, lots of organisations are thinking about what they want to see in election manifestos. Please feel free to share your views about what you think should be prioritised.

GAINmomentum

Between 1st and 31st May we want you to do something every day (if you can) that makes you feel better. Tell people what you have done and help raise awareness of GBS and CIDP at the same time by telling people why you did it. There are lots of resources to help you do this on our website, including a tracker to record your activities, and factsheets to help share the message.

Go to www.gaincharity.org.uk/gainmomentum to find out more.



GBS/CIDP Foundation International

Do you know about the organisation GBS/CIDP Foundation International? Well, they are our international sister organisation who provide support and information for people impacted by GBD, CIDP, and other conditions around the world. We work closely with the Foundation, and think our members could benefit from some of their resources, like their Coffee Chat Video Calls, and their information packs.

Take a look at www.gbs-cidp.org



Survey

There is still time to take part in our survey

Our survey is still running for a few more weeks, so there is still time to let us know what you think of GAIN, what we do (or don't do so well), and what we should focus on in the future. It only takes a few minutes to complete, but your input is really important to us.

We need more responses, so please support your charity and scan the code or head over to <https://forms.office.com/e/ve2jBWC0TU>



May is GBS & CIDP Awareness Month

May is GBS and CIDP Awareness Month, and we hope that you will join us in celebrating the GBS/CIDP community and help us to spread the word about the impact of GBS and CIDP, as well as the work GAIN does. We want to reach as many people as possible, and will be holding some online events, as well as providing information across our social media and website.

If you'd like to help out by sharing your story or being involved in a webinar then please get in touch through the office.

GAIN's Trustees

There has been a number of changes to our Trustees over the last year, so we thought we'd give you a quick update on who they currently are. We will be focussing a bit more on our Trustees in future copies of GAIN Lowdown.

The current trustees are:

Carol Hooper – Chair

Paul Waine – Vice Chair

Sean Austin – Treasurer

James Wilson

Jatinder Paul

Jenny Willison

Lee Raynor

Steph Parker

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