

Keeping you up to date with what's happening around GBS, CIDP, MMN, and other Inflammatory Neuropathies

**New Local Get
Together Group in
Leeds**

**UK
Neurologist
gets top
award**

**My Neuro
Survey is
Live**



Rich's update

Rich Collins
Chief Executive

It's been hard to gauge what the summer is doing, with baking hot days followed by rain and cloud, but I'm hoping that you are having a great summer, and if you have gone away (or are going soon) that you have an amazing holiday.

We are still making a lot of changes at GAIN HQ, with better systems being developed with volunteers, new links with other organisations, and improved support being offered. I hope you are continuing to see the improvement! One of the biggest challenges I have set is to make sure we reach more people impacted by GBS, CIDP, and other conditions. It seems that this is working as the phone lines and emails are busier than ever.

We are really looking forward to our AGM and Big Get Together in November, and have started making plans for that. More on what's happening soon, I promise. In the meantime, take care, and speak soon



A handwritten signature of Rich Collins in black ink.

News

We were really pleased to see that Professor Mary Riley from University Of London Queens Square Institute of Neurology was awarded the 2024 Alan J Gebhart Prize by the Peripheral Nerve Society. You can read more at <https://pnsociety.com/congratulations-to-the-2024-pns-alan-j-gebhart-prize-recipients/>

This month we launched a new podcast where Rich (our CEO), and Al Bailey (an ex-professional rugby player with CIDP) talk to people who have been impacted by adversity. In the first episode they talk to Lynn Rogers, a professor of Neurology and endurance athlete who also happens to have CIDP. Listen on Apple, Amazon & Spotify. You can find more at www.gaincharity.org.uk/podcasts

Finally, if you missed it in the last issue, we will be holding our AGM and first Big Get Together in London on Saturday 2nd November. Put a note in your diary and watch out for more information coming very soon.

Local Groups

We've been thinking about Local Groups a lot recently. Back at the start of the year when we asked about what we should do and how we should engage with people, you told us that you wanted to see more local groups.

We are aware that there used to be lots of groups across the country, but most of these are gone now, and we want to see this change. We are currently working on some new systems and procedures, and while this is important, we also want to hear from you about where people want local groups, so we can get them in place.

So, if you are interested in running or attending a local group then drop us an email at office@gaincharity.org.uk, or ring 01529 469910 with your suggestions.

Lancashire and Cumbria Group

The Lancashire and Cumbria Group is still going strong, and meet quarterly in Catteral near Preston. The next meetings are on Saturday 7th September and Saturday 7th December. Contact Rosie to find out more via rosemarieh@gaincharity.org.uk

First Meeting of the Leeds GAIN Get Together Group



Jon Follows from Leeds wanted to start a local group in his area, so he did! The first meeting was in July and this is how it went.

A great first Leeds Get Together at St Aidan's RSPB reserve. We had a great chat in the sunshine sharing our experiences, challenges and ongoing recovery with GBS and CIDP. We've agreed to meet again, so if you're interested in coming along to the next Leeds one or fancy organising something in your local area, get in touch with Jon at jonf@gaincharity.org.uk

My Neuro Survey

We are working with the Neurological Alliances across the UK and Ireland to run the My Neuro Survey.

Everyone deserves access to the right care, treatment and support at the right time, no matter who you are or where you live. But too often we know this isn't the case for people with GBS, CIDP, or other Inflammatory Neuropathies.

The #MyNeuroSurvey gives you the opportunity to have your say. Please share your experiences and help improve services for everyone affected by neurological conditions now.



Go to <https://revealingreality.welcomesyourfeedback.net/s/3kl0s> click [here](#) or scan the QR code to access the survey and help us to support you, gather information and make things better.

Get more information at www.gaincharity.org.uk



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