



@gaincharity

# Update

November 2024  
No - 6

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# Rich's Update

**Rich Collins**  
Chief Executive



Hi there, everyone. How are we all doing? I hope that as the nights start to close in you are staying fit and well.

GAIN held its Annual General Meeting at the start of the month, along with our first Big Get Together. It was an amazing day spent with friends and colleagues, celebrating GAIN and our incredible GBS & CIDP Community.

We haven't got the space to do it justice this month, so you will have to wait for the next edition of GAIN Lowdown for a full rundown in December (I do like to build anticipation).

In the meantime we have been super busy providing support to people, and ensuring that we reach as many folk as possible. The phone lines continue to be busy, and I hope we are connecting with people. Let me know if you have any feedback. We are working on lots of new plans based on what you have told us, so watch this space as we head into the new year.

A handwritten signature in black ink that reads "Rich".

## News



Rich recently took to the airwaves to discuss a story with BBC Look North, along with featuring in an article on the BBC News website.

Ross Leslie from Northumberland developed GBS in 2023. Due to be discharged recently, he felt he was not yet ready to leave hospital as his recovery was not complete, and he felt he needed to improve further before discharge to be able to cope more at home.

Rich joined to discuss the importance of rehabilitation in people's long term recovery and that how, due to the unique nature of the condition, an arbitrary timeline cannot be placed on how long it takes for an individual to recover. Rich acknowledged the pressures the NHS currently face, and how people with GBS, or similar conditions, can advocate for themselves. It's a fascinating piece: [bbc.co.uk/news/articles/cwyg4pnjr380](https://www.bbc.com/news/articles/cwyg4pnjr380)

# Opportunity: Get involved in guiding pain research work at the University of Oxford

We were recently approached by Angie Lee, a pain and anaesthetics doctor and PhD student at the University of Oxford. Dr Lee wrote on behalf of the National Institute of Health and Research (NIHR) Oxford Health Biomedical Research Centre (BRC) with an opportunity for patients, carers or interested members of the public to be involved in pain research work at the University of Oxford. Some of you may find this opportunity interesting, and there is a paid element to the research.

## What is patient and public involvement in research?

Research provides evidence about what works best. Patient and public involvement (PPI) in research means research that is carried out 'with', 'by' or 'in partnership with' members of the public, rather than 'to', 'about' or 'for' them.

## You will be able to work with researchers to help shape:

What research takes place and how it is carried out, and how the results are shared and applied in practice.

## They are looking for:

Anyone who has experience of pain – as a patient and potential patient, people who use healthcare services, carers, and people from organisations that represent people who use services.

They seek up to 6 people to join their PPI group informing how pain research is conducted within the Oxford Biomedical Research Centre. This would be a commitment of 2-3 online meetings a year across 3 years, occasionally performing a task or activity such as reading and commenting on an abstract, or a focus group to provide your opinion on a proposal. They also warmly extend the opportunity for the PPI group to attend their face-to-face conference in summer or autumn 2025.

## Compensation

They will provide payment for your time, skills, and expertise at the following rates:

£12.50-£25.00 for involvement in a task or activity such as reading an abstract or participating in a focus group

£75 for involvement in approximately half a day's activity such as an online meeting or participating in a focus group with some preparation beforehand.

If you are interested in the opportunity, please contact [angeline.lee@ndph.ox.ac.uk](mailto:angeline.lee@ndph.ox.ac.uk)

**Please note: This is a project conducted independently of GAIN. We recognise it may suit our followers and service users, and therefore have shared it. However, we urge you take due diligence in any activities such as this to ensure your emotional, and physical, well-being.**



Hello! If you're not a member of the GAIN group on Facebook, allow me to briefly introduce myself. I'm Chris and I'm your new marketing executive.

Rich has suggested saving a full introduction for the main newsletter coming your way next month, but I wanted to take a brief second just to say hello and invite you to reach out with your stories.

Your input allows me to create compelling stories, videos and fact sheets that will help both grow GAIN's audience, and, perhaps most vitally, raise awareness of the conditions we support. If you would like to chat, or just want to know more, please reach out to [chris@gaincharity.org.uk](mailto:chris@gaincharity.org.uk). I'd love to talk.

We have some hugely exciting fundraising events coming up, and as subscribers to our newsletter, we are pleased to share these with you first.

General access to these events will be available from early 2025, so this is a great opportunity for you to jump on board early! If you're interested in claiming a free space at the following\*, please contact us via the links at the foot of this page!

- Swim Serpentine:  
Half Mile | One Mile | Two Mile
- Great Scottish Run
- Great North Run
- Great Manchester Run

We are also in the process of securing places within in the London Marathon. We cannot promise a place just yet, but if this interests you, please contact us.

\*Please note, though spaces are free at point of access, we request you commit to a minimum sponsorship. We have limited spaces at these events, so please get in touch early to discuss your place as they may already be claimed.

Get more information at [www.gaincharity.org.uk](http://www.gaincharity.org.uk)



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