



New clinical pathways

Member Survey

We want to hear from you

Welcoming our new Chief Executive

Celebrating People

We couldn't do it without you

Contents

03 A quick word from...

04 Celebrating people

06 New clinical pathways

08 Introducing Rich, our new CEO

09 GAINmomentum

10 Listening to you. Let us know your views

200 Club Winners

December

Deborah B.
David O.
Pamela P.

January

Audrey A.
Michael H.
Gordon S.

February

Sarah A.
Nick B.
David O.

GAIN - Guillain-Barré and Associated Inflammatory Neuropathies

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www.gaincharity.org.uk

A quick word from ...

A few thoughts from
GAIN's Chair and
Chief Executive

Carol Hooper Chair



WOW, how quickly time flies! So much has happened since my last update. It was an absolute delight to catch up with Glennys Sanders our founder and Patrons Richard Hughes and Sir Ian Macfadyen. Their thoughts and insights on the Charity are invaluable. Thank you to all three of them.

We've appointed our new CEO Rich, who is working tirelessly to get up to speed. He is already having an impact and the Board are delighted to have him on board. We've also appointed two new trustees Sean Austin and Steph Hartley. Both have a wealth of skills that complement our existing trustees. Next time I'll introduce you to the full board.

I've been amazed at the efforts of our volunteers, fundraisers and donors who are giving their time to support others and raise valuable funds. I cannot thank you enough.

It's been a busy few months and we are still very much in the transition phase. However, we have continued to deliver against our aims, and I am feeling confident and very excited about the journey ahead. The best is yet to come!

Rich Collins Chief Executive



It's been all change here at GAIN HQ, and it's great to have the opportunity to say hello. I've only been at GAIN since January, but it's been an interesting few months, meeting people and somehow ending up being signed up to run a marathon!!

It's been both humbling and life affirming to listen to the people we work with who have been impacted by GBS, CIDP, MMN, and other conditions. Being part of a really supportive community is amazing, and it's been great to be welcomed in by everyone.

Listening to views, and putting people at the centre of what we do is really important to me, so I hope you will share some of your thoughts and views with us as part of the engagement we are launching this month. You can find out more on page 10.

Oh, and if you really want to know anything more about me, then take a look at page 8. I look forward to meeting you all soon.

Celebrating People

Brian Macleod recently ran the Chicago Marathon, raising over £3,350 for GAIN. We asked Brian how the race went.

“I was all signed up for the Chicago Marathon in 2020 before being diagnosed with CIDP. There was no way I could have taken part after losing most of my strength and fitness, but thankfully 3 years on I was lucky enough to secure a place at the 2023 event.

The atmosphere was amazing, and the course was fantastic with cheering crowds, music and a real party atmosphere. While it got tougher as the miles piled on, I made it to the finish, and in a respectable sub-4-hour time. After crossing the line, I realised just what a journey it had been, even just to get to the start line in the first place after the previous few years.”

A huge thank you to Douch Family Funeral Directors who raised a sensational £2137.72 through fundraising events in 2023.



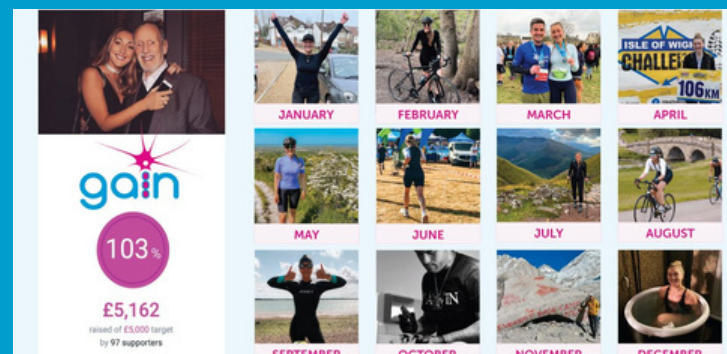
We were saddened to hear of the passing of George and Ruby Peak. George and Ruby were great supporters of GAIN, and will be very much missed. Our condolences to George and Ruby’s family and friends.



A massive thank you goes to everyone who has donated or is raising funds for us



Jodie Prior lost her Grandad, Colin, to GBS in 2020. As Colin was a man who liked to do things whole-heartedly, Jodie decided that to commemorate his life (and raise some money for GAIN) she would do something pretty spectacular. So last year Jodie undertook a challenge every month, including an ultra-marathon, an Olympic distant triathlon, and twelve days of ice baths! An absolutely amazing achievement and we’re sure that Colin would be really proud of Jodie. Jodie raised an incredible £5,161.76 for GAIN. Thanks Jodie.



You can read more about Jodie’s 12 challenges at <https://gaincharity.org.uk/12challenges/>

Meet Danielle McGuinness, who has raised over £11,000 for GAIN.

Join us in applauding Danielle, who I think you will agree is a true

#GAINhero

My fundraising journey with GAIN began five years ago whilst in recovery from Guillain-Barré Syndrome. Having been extremely poorly, ventilated and in an induced coma, my family had never heard of GBS and when the amazing staff at Royal Bournemouth Hospital passed my parents the contact details for GAIN, they jumped at the chance to get some all-important advice. When they called, they were so reassured that they weren't alone, they were sent information packs, and were offered a grant to help with travel and food costs whilst visiting me in hospital. They were also asked if they would like contact with someone who had lived experience of GBS who could help with any questions. My Mum and Dad were so grateful. When I was then able to talk and email, I contacted GAIN to thank them and tell them I wanted to begin raising awareness and fundraise for this fantastic charity. This is where it all began.

Over the past five years, I have raised over £11,400 and have spread the word far and wide across the UK. Each Easter and Christmas, it is a bit of a tradition that I host a GAIN Easter/Christmas Cake Day, where my workplace bake cakes, and take part in games and Raffle Draws. In September 2019 just after being discharged from hospital, I organised a Horse Racing Evening in a local social club which was a great night and gave me that fundraising bug. More recently, I organised my biggest event to date which was a Quiz and Horse Racing Night in a Bournemouth Hotel. What an incredible and fun evening where we raised £1,406. Around 90 people attended, including local people who also had or are in recovery from GBS. I have such a good support network of friends, family, colleagues and the GAIN community. My workplace, Cross Country Trains, have also been brilliant at supporting me in my fundraising and awareness venture. I chat regularly with passengers onboard who like to hear all about the charity.

I absolutely love the work I do for GAIN and will continue to come up with fun ideas to involve people and get GAIN's name out there. I feel like I am giving back to this wonderful charity who helped my family and I during our time of need. GAIN holds a very special place in my heart, now and always.



New Clinical Pathways

In January, our colleagues at the National Neurosciences Advisory Group (NNAG) and the Neurological Alliance published 'Optimal Clinical Pathway for Adults: Neurological Autoimmune Diseases.'

The document aims to make the diagnosis process better, and to ensure people get the most appropriate support and treatment to meet their needs.

The document was put together by a range of experts including representatives from GAIN and our Medical Advisory Board. It covers a whole range of conditions, including those that GAIN provides support around.



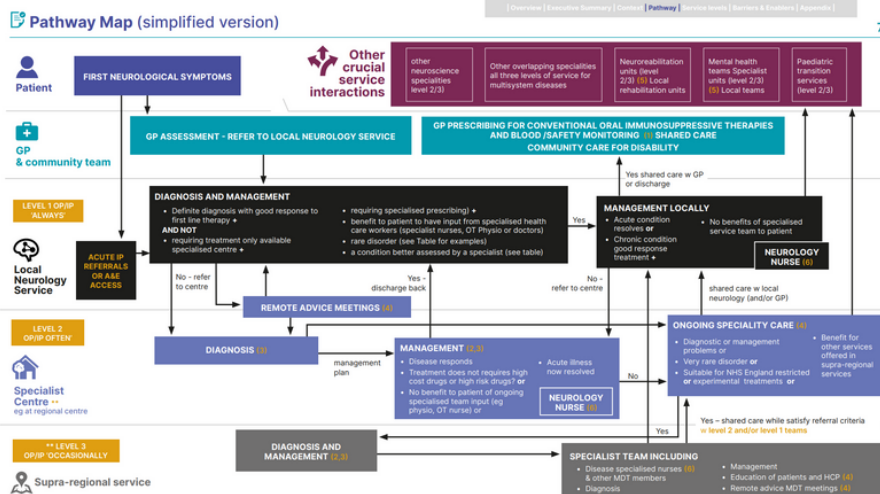
Optimal clinical pathway for adults: Neurological autoimmune diseases
National Neurosciences Advisory Group (NNAG)

Published: January 2024

The document is very detailed, and has really been designed for health professionals. However, we think there is a lot of really useful information in the document and wanted to share it with everyone.

The document highlights what the care pathway for someone with neurological symptoms should be, with a flowchart showing what happens next. This may be useful to share with your GP or Neurologist.

It is very complex, but we are currently working on a simple guide to go alongside the pathway, with a more understandable flowchart. We are hoping this will be available by the end of March.



You can find the clinical pathway document at

<https://tinyurl.com/AutoimmunePathway>

Keep an eye on our website and social media for our simplified guide and flowchart



Peer Support

Nothing can beat talking to someone who has been through the same thing as you, and this is why our peer support remains one of our most requested services.

GAIN has a bank of volunteers who are ready and willing to give you a phone call or meet over a video link, and share their lived experience of GBS, CIDP, MMN, or an associated inflammatory neuropathy, letting you know what to expect, and offering advice and guidance on next steps.

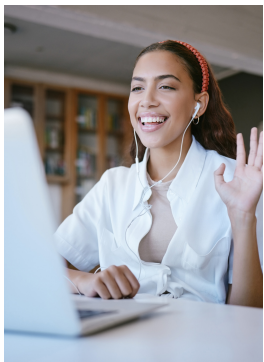
Whether you want information, or a friendly ear to talk to, get in touch with the GAIN office and we will match you up with someone who can help.

And if you fancy becoming a volunteer, then please get in touch - office@gaincharity.org.uk



Online Groups

Fancy a chat? Then join us each month on Zoom



Every month we log in to Zoom and have a catch up and a chat. The groups are friendly, no-judgemental and welcoming to everyone.

Whether you are new to the group or you attend every month there is always lively conversation, advice and support. So why not join us next month



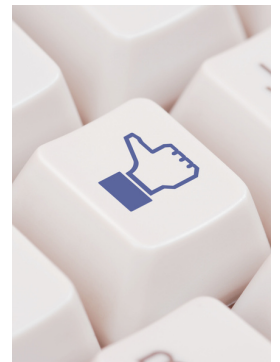
More at:
<https://gaincharity.org.uk/virtual-branch-meetings/>

Facebook Group

Did you know that we have a really vibrant Facebook Group?

Sometimes its really good to engage with others, share stories, or just see what other people's GBS and CIDP journeys are like.

Pop over to Facebook and join our group where you can be part of an amazing supportive community



The page can be found at:
<https://www.facebook.com/groups/727400487277814>



Rich Collins

GAIN's New Chief Executive

Rich Collins joined us as our new Chief Executive on 15th January. We thought it would be good for Rich to introduce himself, and say what he hopes to achieve at GAIN over the next few years.

Well, hello everyone. I'm Rich and it's great to be here at GAIN and having the opportunity to tell you a little bit about myself. I've been working across the community and statutory sector for around 30 years. I started off working in the community with people with learning disabilities and autism, before moving over to be a commissioner within health and social care. I led on some pretty big pieces of work, especially around long term and neurological conditions, and held some senior positions within councils. I moved back to the community sector around 10 years ago, where I have been working supporting charities and developing social policy

But that's all a bit boring. A bit about me, I love being outside and you can often find me up a mountain, running, on a bike, or in a kayak. I'm a big believer in working with and listening to people, so I really want everyone to be part of GAIN going forward, after all, this is your charity. I want to see us improve our offer to people, undertake more research, and become more prominent and influential. GAIN is a great charity, but we can all help to improve its impact.

I am here to make things better, but I can't do it without you. Please feel free to get in touch and share your views and your vision for GAIN. I really look forward to meeting as many people as possible and having a chat.



GAINmomentum

Are you ready to GAINmomentum?

GAINmomentum is all about being active, promoting physical and emotional wellbeing, and raising awareness of GBS, CIDP, and other associated inflammatory neuropathies.

The challenge is to do something active every day throughout May that makes you feel better, and to do a little more everyday so you continue to GAINmomentum.

So this May, join us for some fun and some activities, and we look forward to seeing what you get up to. Keep your eyes peeled for more info as we get closer to May.



Want to help GAIN out without it costing you a penny? Then simply start using easyfundraising.

Simply shop online and easyfundraising turns your shopping into donations for us. easyfundraising partners with over 7,000 brands who will donate part of what you spend to a cause of your choice. It won't cost you any extra. The cost is covered by the brand.

<https://www.easyfundraising.org.uk/causes/gaincharity/>

We get a lot of people asking us how they can support us by taking part in a running event.

Well one of the easiest things to do is to pop over to Run For Charity where you can find a list of events that you can sign up for. Simply click on the link below or search for us, click run for us, and we will be in touch to discuss events and entry fees. All you need to do then is get training.

<https://runforcharity.com/charity/guillainbarr--associated-inflammatory-neuropathies-gain>



Listening to you

It's really important to GAIN to hear from our members, our supporters, our fundraisers, our volunteers, and anybody else who cares about GBS, CIDP, and what we do.



That's why we are carrying out a listening exercise to understand what you think about GAIN, what we do, and how we do it. We want to know what we do well, what we can do better, and what we should concentrate on doing.

This will help us improve our offer to people, target our finances where they are needed most, and make sure we have the most impact possible.



There are lots of ways to take part:

- **Complete the survey on the next page and send it back to us**
- **Fill in the survey online by scanning the QR Code or going to <https://forms.office.com/e/ve2jBWC0TU>**
- **Arrange a 1:1 call or tell us your views by ringing 0800 374803**
- **Drop us an email with your thoughts, or send us a video or audio clip to office@gaincharity.org.uk**
- **WhatsApp us on 07878 090965**
- **DM us on our socials - @gaincharity**



1. Have you engaged with GAIN?

(Please choose one)

- Yes, in the last 12 months
- Yes, more than 12 months ago
- No
- Don't Know

2. How have you engaged with us?

(Please choose as many as you want)

- Contacted the office
- Received support
- Received peer support
- Requested a personal grant
- Received information
- Visited the website
- Volunteered
- Donated/Raised funds
- Something else (Please add)

3. Which one of these things is most important to you? (Please just choose one)

- Support
- Research
- Raising awareness

4. How well would you rate us on these things? (1-5 where 1 is terrible, and 5 is amazing)

Support ★ ★ ★ ★ ★

Research ★ ★ ★ ★ ★

Raising awareness ★ ★ ★ ★ ★

5. What do we do well?

(Please choose as many as you want)

- Provide support on the phone
- Arrange and provide peer support
- Provide online meetings
- Support local groups
- Send out information
- Provide information on the website
- Provide easy to understand information
- Social Media
- Fund research
- Carry out research
- Engage with people
- Engage with partners
- Promote GBS, CIDP and other conditions
- Something else (Please add)

6. What could we do better?

(Please choose as many as you want)

- Provide support on the phone
- Arrange and provide peer support
- Provide online meetings
- Provide local groups
- Send out information
- Provide information on the website
- Provide easy to understand information
- Social Media
- Fund research
- Carry out research
- Engage with people
- Engage with partners
- Promote GBS, CIDP and other conditions
- Something else (Please add)

7. What do you think we should focus on?

(Please choose as many as you want)

- Supporting people
- Supporting unpaid carers and families
- Physical Health
- Emotional/Mental Health
- Raising awareness
- Fundraising
- Researching treatments
- Researching causes
- Researching impact of conditions on people
- Working with health partners
- Working with charity partners
- Something else (Please add)

While you have our attention, is there anything else you want to tell us?

8. How would you like us to work with you?

(Please choose as many as you want)

- Website/online
- Paper copies/Mail
- Social Media
- Local Groups
- Online Groups
- 1:1/Personal meetings
- Videos
- Podcasts
- Webinars
- Information Sessions
- Newsletters
- Briefings
- Something else (Please add)

Thank you for completing our survey.

It's really appreciated.

Now please tear off this page and send it back to:

**Freepost, GAIN, Glennys Sanders House,
Pride Parkway, Sleaford, NG34 8GL**

Get more information at www.gaincharity.org.uk



Follow us on social media



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