



In your December issue:

**Big Get Together**  
**Rich goes to Amsterdam**  
**NHS 10 Year Strategy**  
**15 Years on - Jon's Story**  
**And much more!**



# LOWDOWN

December 2024

No. 7





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## 200 Club Winners

### September

Stephanie B  
Deborah B  
Carol H

### October

David O  
Pamela P  
Anne M

### November

Mike B  
Rosie H  
Debra H

Fancy seeing your name here and taking home a share of the winnings? Head over to [gaincharity.org.uk/200-club](http://gaincharity.org.uk/200-club) or give the office a call to learn more!

*Please note: the office will be closed from December 24th - January 2nd. The GAIN Facebook group will, as ever, remain open. We will be checking messages and emails over this period, but we may not be able to get back to you as quickly as normal*

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**Carol Hooper**  
Chair

## A Word From...



**Rich Collins**  
Chief Executive

As the holiday season approaches and the new year is in sight, it's provided the opportunity to reflect. Not just on the past 12 months but on my time since being impacted by GBS.

Why now? Well this time of year can do this to people but for me more so the improvements we have made as a charity this year have brought us much closer to those impacted by the conditions we support and I've been able to look back at the past 33 years and am extremely thankful for the life I have lived.

I owe my life and that of my son to the amazing medical and nursing team at Basildon Hospital. Although still in a wheelchair and unable to walk unaided, I was able to go home for Christmas dinner in 1991. However, my husband and I decided to spend the morning in the ward at the hospital with my new 'family', listening to the brass band walking the wards, eating chocolate and mince pies and enjoying being alive. This Christmas I will be spending it with my 92-year-old father, my 90-year-old in-laws, my husband, son and daughter-in-law and our 10 month old grandson.

His arrival was incredibly emotional. It was a new realisation and confirmation that my illness, whilst pregnant, hadn't affected my son's ability to become a father. The relief was immense.

In writing this message, it's a reminder to me and I'm sure others that GBS and the affects are with you not only physically but mentally for a long time. I know there are many of you still struggling with the effects of GBS and those of you with CIDP and MMN have different challenges to overcome.

At GAIN, we will continue to be here for you in whatever form that takes. So, if you are celebrating the festive season or if your focus remains on beating the condition I wish all of you Merry Christmas and here's to a happier and healthier new year.

And just like that, it's the end of another year. But what a year, my first with GAIN and the GBS & CIDP Community. It's been a real roller coaster that has kept me very busy, and always on my toes. I have had the joy of meeting so many of you, culminating with our AGM and Big Get Together in November.

What a day that was. I think I went through every single emotion possible, including having a proper cry as Claire and Jon spoke about their journeys and the impact of the GBS & CIDP Community. I am so appreciative of everyone who joined us in person or online, and to our wonderful speakers and contributors. A very special thanks to Maureen and Nancy from GBS/CIDP Foundation International for supporting the day. You can find out more about The Big Get Together on page 11. Now who is up for doing it again next year?

Since the last edition of Lowdown, we have been joined in the GAIN Team by Chris Morton, our new Marketing Executive (fancy title I know!) I was delighted to add Chris to the team, and he brings an amazing set of skills and experience to GAIN that will help us reach more people. Chris really wants to hear from our members so head over to page 10 to meet Chris and see how you can get in touch.

We are continuing to work with the NHS and other key partners in sharing the voice of our members, and it really feels like this work is beginning to have an impact. We will continue to seek to influence over the coming year, and will keep you updated as things progress.

That just leaves me to wish you a wonderful Christmas, and I look forward to catching up with you soon.

# News

## A Success for Backing the 1 and 6 - UK Neuro Forum

In the last issue, we encouraged you to get your voices heard in the #BackThe1in6 survey for My Neuro Alliance. Well we're glad to say your voices were indeed heard! A new UK Neuro Forum was confirmed by the Department of Health and Social Care on 28th November. The forum unites clinical leaders, organisations, and people with lived experience to help find ways to improve care and support for people affected by neurological conditions.

The forum will meet twice a year, with the first expected before the end of February 2025. Rich was in London for the launch, and GAIN is excited to be part of this initiative going forward.

For more, visit: [www.neural.org.uk/news/uk-government-launches-first-ever-forum-to-address-gaps-in-treatment-and-care-for-people-affected-by-neurological-conditions](http://www.neural.org.uk/news/uk-government-launches-first-ever-forum-to-address-gaps-in-treatment-and-care-for-people-affected-by-neurological-conditions)

## Civil Society Covenant with government

The Covenant is a new agreement that's intended to improve and reset the relationship between civil society and the government. NCVO are seeking input from organisations and groups of all sizes including charities, and GAIN have made our voices heard.

The new government are keen to work along side NCVO and civil society, so the Covenant is designed to support collaboration, ensure respect across different roles, support public bodies, build on existing agreements, and compliment existing arrangements in Scotland, Wales and Northern Ireland. By the time you receive this, the time for providing feedback will be closed. However, we urge you visit [ncvo.org.uk](http://ncvo.org.uk) to stay up to date, GAIN will play our part and keep you up to date with the latest news on social media.

### Research News: NICE to study Efgartigimod with Recombinant Human Hyaluronidase PH20 for Treating Chronic Inflammatory Demyelinating Polyneuropathy

The National Institute for Health and Care Excellence (NICE) has been asked to conduct an evaluation of the medication efgartigimod with recombinant human hyaluronidase PH20 for treating CIDP.

NICE intends to appraise this technology through its Single Technology Appraisal (STA) process.

We have replied on behalf of GAIN and our members as part of this and will be attending the scoping exercise in January. We will keep you updated with progress.

### National Voices Joint letter to the Chancellor ahead of the Autumn Budget

Ahead of the Autumn Budget, on 23 October, National Voices wrote to the Chancellor, Rt Hon Rachel Reeves, and Rt Hon Wes Streeting MP, the Secretary of State for Health and Social Care.

The letter, signed by 65 health and care organisations (including GAIN) highlighted the importance of working with people and communities and the VCSE organisations representing them to democratise decision making in health and care.

To read, visit: [www.nationalvoices.org.uk/publication/joint-letter-to-the-chancellor-ahead-of-the-autumn-budget/](http://www.nationalvoices.org.uk/publication/joint-letter-to-the-chancellor-ahead-of-the-autumn-budget/)

# CIDP Nurses Network

**Back in October our Chief Executive Rich was invited to attend the CIDP Nurses Network meeting in Birmingham, alongside one of our members, to talk to Neuromuscular Nurses about GAIN and the experience of living with CIDP. After a call out to members, Nigel Pickering agreed to come along to talk about his experience. Over to Rich to tell us about the day.**

It's always great to be invited to talk to clinicians, but I must say, it was especially good to talk to specialist nurses in October. Nigel and I travelled over to Birmingham and were warmly greeted by a group of around 30 specialist nurses from all around the UK. After an informal chat, I took the opportunity to explain who GAIN were and what we do. It was very interesting to find out that not all the attendees had heard of us before, and for some of those that had, it was only because we were listed on the agenda.

Whilst I could talk about GAIN and our GBS & CIDP Community all day, it was far more important to hear from Nigel, so after handing over to him, Nigel talked about his journey with CIDP, including the

barriers he had faced to treatment and support during the COVID-19 pandemic, and the impact of CIDP on him and his family. Nigel spoke with passion about his experience, and it was clear that some attendees were shocked to hear Nigel's story, especially the differences in experience to a patient like Nigel who had been in a regional hospital, as opposed to the specialist neurological centres they were attached to.

It was clear from the feedback and discussions that GAIN had a lot of allies in the room, and that hopefully attendees were able to return to their bases and inform patients about GAIN and what we do, as well as understanding a little bit more about the impact of CIDP on people and families.

I'd like to say a massive thank you to Nigel, for travelling over to Birmingham and sharing his experience. People like Nigel who share their lived experience are especially vital in helping us tell impactful stories.

I'd like to say thank you to all the attendees for making us welcome, listening, and for being so open with their comments.

Finally, a massive thank you to Takeda for sponsoring the event, getting us there, and ensuring that the voice of people impacted by CIDP was heard.

"It was clear from the feedback and discussions that GAIN had a lot of allies in the room"



# NHS Strategy Consultation:

## Key Highlights from our response to the NHS 10-Year Health Plan

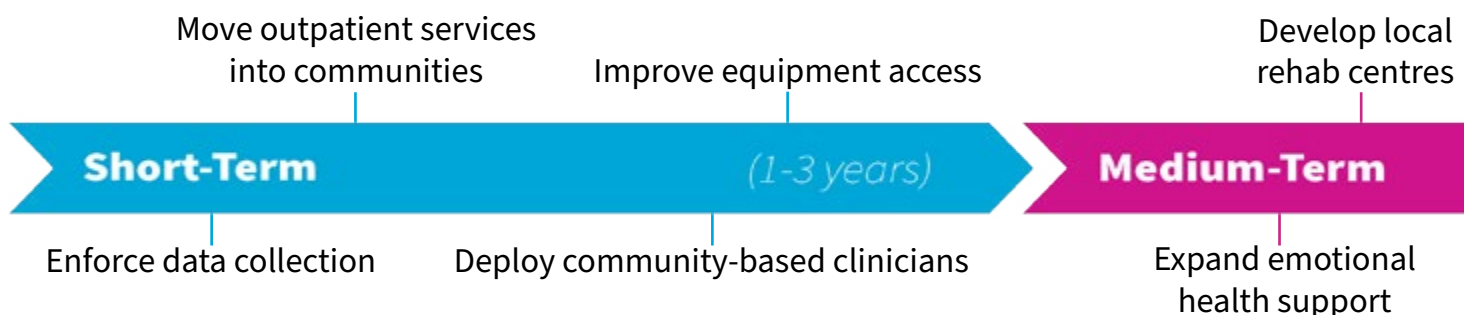
The NHS faces significant challenges, particularly in access, diagnosis, and equitable care. As an advocacy group, GAIN have outlined priorities to improve health outcomes and address disparities. We recently submitted a 10 page document with our contributions which is too much for this humble newsletter. Here's an overview of our recommendations based on the three shifts laid out in the consultation and you can read the full version on our website at [gaincharity.org.uk/NHS10](http://gaincharity.org.uk/NHS10).

### Moving Care to Communities

**We advocate for shifting services from hospitals to communities, emphasising localised, patient-centric care. Key proposals include:**

- Community-Based Diagnostics and Treatment mobile units and local clinics to improve access.
- Named Lead Clinicians: Assign geographically specific specialists
- Enhanced Community Rehabilitation: Establish local rehab centres and provide in-home services linked to patient recovery needs.
- Specialist Nursing Services: Deploy community neurological nurses similar to MS and neuromuscular nurse models.
- Integrated OT Support: Provide timely occupational therapy and adaptive tools to aid recovery and reduce hospital readmissions.
- Mental Health Focus: Offer trauma-informed emotional health support as a complement to physical rehabilitation.
- Better NHS-Community Links: Foster partnerships with community and voluntary sector organisations to optimise support.

### Potential Timeline



**By addressing these challenges and leveraging enablers like innovation, community partnerships, and government commitment, we can create a patient-focused, efficient NHS that meets diverse health needs effectively.**

## Harnessing Technology

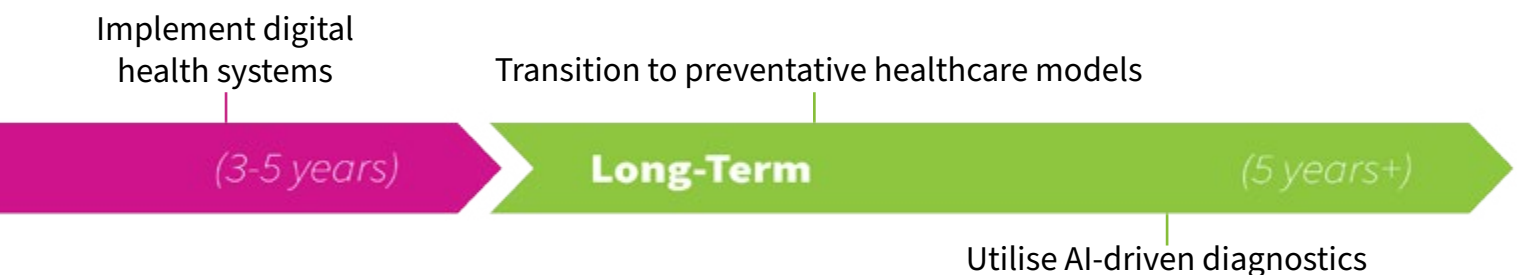
**Technology can revolutionise healthcare delivery, from diagnostics to ongoing management. Proposals include:**

- Digital Integration: Implement comprehensive digital health records and individual “digital passports” to ensure seamless care across systems.
- Remote Access: Expand telemedicine for consultations and rehabilitation, reducing travel burdens for patients.
- AI in Diagnostics: Use AI tools to support GPs and emergency staff in diagnosing rare conditions like GBS and CIDP more effectively.
- Enhanced Monitoring: Introduce wearable devices and apps for condition tracking and early intervention.
- Data Transparency: Improve NHS data collection and sharing to enable targeted interventions and community sector collaboration.

## Prevention and Early Intervention

**Preventing disease escalation is pivotal. Recommendations include:**

- GP and A&E Education: Equip frontline clinicians with the knowledge to recognise and treat rare conditions promptly.
- Universal Access to Rehab: Ensure equitable availability of neurological rehab, tailored to patient progress rather than arbitrary timeframes.
- Emotional Health Support: Provide specialist mental health interventions to prevent relapse and long-term disability.
- Community-Led Prevention: Empower the voluntary sector to deliver cost-effective, preventative care solutions.



**We've already seen the power your voices have when you backed the 1 in 6. Let's keep this going - Head to [change.nhs.uk](https://change.nhs.uk) to make your voice heard and help shape the NHS. In January 2025 they will contact everyone who has registered so far with more activities, so this is a great time to get involved.**

# Celebrating Our Community

Take on a challenge  
[gaincharity.org.uk/events](http://gaincharity.org.uk/events)

GAIN are lucky to have an incredible community of supporters who come together in so many different ways to help us support you. We thank the following for their kind support this quarter: Patrick L, Charlotte D, Gill C, Joshua M, James K, Cliff W, Julie W, Magdalena Z, Abi D, Thomas G, Kristi O, Johannes C & Tilly D. Here are some recent stories to inspire and move you.

## Mabel Lee

A BIRTHDAY GIFT FOR GAIN



“At the age of 18, I was diagnosed with Guillain-Barré Syndrome. I thought I was entering the unknown, but with GAIN, my family and I were provided with information, and someone to talk too every step of the way.

The awareness, funded research and overall aid GAIN have contributed to the community is immense and their work should not go unnoticed. The work they do help people like me and our loved ones not feel alone with these rare, life changing conditions.

So far, with the help of others, I have raised £1,316 which is only the beginning as I hope to raise more?”

Mabel’s Birthday fundraiser raised this incredible amount, so thank you, and Happy Birthday from everyone at Team GAIN!

## Florence & Ada

ON THE GREAT NORTH RUN

This was a special one for us. When Florence and Ada were just 18 months old, their Grandad was diagnosed with GBS.

It caused complete paralysis and saw him spend months on a ventilator in intensive care before even more months in hospital and rehab.

Recovery has been slow and painful but he continues to surprise and amaze his family over these last three-and-a-half years.

To celebrate their Grandad and help GAIN support others in a similar condition, the girls, now five years old did something incredible - they took on the Mini Great North Run!

Their little legs carried them for a 1.5km, and raised £805.52 for our charity, how great is that?

Thank you, Florence and Ada!





## Daniel Sanchez Marin

THREE PEAKS & 24 MILES

“I still remember the first symptoms of GBS in the summer of '23.

“It’s like walking with someone else’s feet,” I joked to my wife. It seemed funny—until the terrifying, dizzying loss of control set in. At the hospital, the doctor quickly diagnosed me. “Have you heard of Guillain-Barré?” she asked. “No,” I replied, as pins and needles buzzed through my legs.

That’s why I chose GAIN for the 3 Peaks Challenge—to raise awareness and funds for others facing this condition. Their work gives hope, and together, we can make a difference.”

Daniel, along with his colleagues at BMS Marine raised a phenomenal amount of £5,597.78, thank you team, and well done!



## ‘In Memory of Vinod’

Finally for this edition, we would like to thank the family of Vinod Rughooputh for thinking of GAIN during one of the hardest times a family can endure. They kindly provided the following for inclusion in this newsletter:

“Vinod was a very special and much-loved husband, father and grandfather. Born in Mauritius, he came to England in 1971 and trained as a nurse before later specialising as a psychiatric nurse.

Vinod was a resilient and very kind man with a strong work ethic. He welcomed everyone into his home and treated them like family. Being a brilliant cook, he could make a delicious meal out of anything. He had a passion for learning and was always reading or developing a new skill. He had a brilliant sense of humour, was incredibly loyal and was a father and grandfather figure to many.

He is missed and loved more than we can put into words.”

‘In Memory of Vinod’ raised £2,047.98. Please join us in a quiet moment of thought and appreciation to Vinod and his family.



## Meet Chris

Hello, everyone!

As Rich mentioned in his opening piece, I'm Chris your new Marketing Executive.

I won't take up too much of your time today, but since I'm looking to hear your stories over the coming weeks and months, it's only right if you hear mine so we know each other!

I'm coming to you from a marketing role in another charity here in sunny (as I type this my roof is dripping and I've just had to run outside to right a fallen bin) Scotland. I was looking to make a change and when I saw GAIN advertising for this role I jumped on it. Why?

When I was around 12 years old, a family member was diagnosed with GBS. I was reasonably shielded from this at the time and the little I did know I couldn't properly communicate to my peers.

To this day I still associate those fancy shell chocolates you get around Christmas - Guylain Seashells - with Guillain-Barré as that's what I took to calling it in school if someone asked. To be fair to young Chris, it wasn't a million miles away, and I only took light ribbing for my taste in fancy Belgian chocolates in the playground.

Later I'd learn more about GBS and the lasting impact it had on my family member. His journey back to physical health wasn't long, but his mental health? That was a different story.

He lived in fear of it coming back, and developed some substance issues that he was never able to bounce back from, or find the emotional support he needed.

During my interview with Rich and Steph, we talked about what I wanted to achieve. Highlighting the ongoing mental impact these conditions have were among my answers.

In GAIN's response to the NHS 10 Year Plan (page 6) we talk about the importance of offering trauma-informed emotional health support as a complement to physical rehabilitation. I hope my messaging can play a significant role in this.

To do this, I urgently need your help. At my fingers I've got stats, figures, and a Word Document of medical terms ready to be copy & pasted so I don't ever have to try and spell "efgartigimod" again.

What I don't have is your fantastic voices. I've got lots of wonderful stories, as seen in this very publication, but to launch campaigns, raise awareness, and grow our charity to the heights it should be, we need more.

If you're interested in sharing your story via text, audio over pictures, video, or a multimedia combination, please get in touch.

**chris@gaincharity.org.uk**  
**01529 469910**

### Chris' Highlights (so far)

**I can't believe it's already two months, it both feels shorter and longer (in a good way!)**

**Here's some of my highlights:**

**Travelling to London for the Big Get Together and meeting so many people in person for the first time**

**An exciting video project with the Lancashire and Cumbria group - more on that soon**

**The [REDACTED] but you'll see...**

**Joining the GBS & CIDP online Get Together sessions and hearing your experiences first hand**

**My first GAIN solo expedition for a cheque presentation in Fife (see the next monthly newsletter)**

**Having the opportunity to talk with incredible people on the other side of the world about upcoming campaigns**

# AGM and the Big Get Together

On November 2nd, the GAIN community gathered at the Radisson Blu, Canary Wharf, London for the Big Get Together. First though, there was official business to be taken care of in the form the Annual General Meeting. Here's what you need to know from the 2024 GAIN AGM (11:00 - 11:45)

For full AGM minutes, please visit: [gaincharity.org.uk/gain-policy-and-agm-minutes](https://gaincharity.org.uk/gain-policy-and-agm-minutes)

Rich and Carol warmly welcomed the attendees and explained the order of the day.

Carol reviewed the key points of the 2023/24 Trustees Annual Report, noting it was a year of significant change for GAIN. The staff team, including a new CEO, was refreshed, and there were changes at the Board level with new Trustees.

GAIN supported 191 people, with 24 receiving peer support from volunteers. Monthly Zoom meetings and the local support group in Lancashire and Cumbria thrived.

Over £22,000 in Personal Grants helped 23 people, and membership grew to 152 Voting Members. Carol highlighted contributions to clinical research, including £20,000 toward biomarker studies, and ongoing work with key partners like GBS/CIDP Foundation International. She also mentioned the 2024 engagement exercise influencing GAIN's operations and changes to communications.

Looking ahead, the focus will be on renewing the support offer, expanding reach, developing research, improving data management, and ensuring financial stability and continued growth.

Sean Austin (GAIN's Treasurer) updated on the annual accounts. Our gross income was reported as £303,906, and our expenditure was £216,979. GAIN's total net assets were £994,789. Members were able to vote on a series of motions, and the annual report and accounts were agreed. Jenny Willison and Lee Raynor were voted back in as Trustees, and three new Trustees (Sean Austin, Stephanie Parker, and James Wilson) were voted in.

The AGM closed with a fond farewell to departing trustee, Paul Waive, and a thanks to GBS/CIDP Foundation International for facilitating the events and Goodman Jones.





# the BIG GET TOGETHER

12:00-16:30 | November 2nd 2024  
Radisson Blu, Canary Wharf | London



After the November 2nd AGM, GAIN staff, trustees, members, volunteers and people living with the conditions we support gathered for the Big Get Together 2024.

How did the day go?

Read on to find out!



**2024 has been an incredibly exciting year for the GAIN family. We've seen new team members, trustees, a swathe of new volunteers, and new ways of working across the board.**

**One of the most exciting parts of the year though has to be The Big Get Together 2024.**

GAIN has held annual conferences in the past, but this is the first major event since COVID, and the first Big Get Together. It brought together a host of speakers from a wide range of disciplines and from across the globe.

So where better place to hold it than the nations capital?

After the AGM, we took our seats for what promised to be a day packed to burst with presentations, Q&A's, workshops and activities.

The afternoon started with GAIN's Chair, Carol, welcoming attendees both in the room and via Zoom before handing over to Chief Executive, Rich.

Rich shared an exciting vision for the future of GAIN and how that vision can be accomplished through strategy, support, research, and raising awareness. Attendees were able to add their thoughts about what GAIN should do and what our priorities should be

Next we had a forty minute session that felt closer to five. Our Medical Advisory Board stood up and introduced themselves to those in the room who may not be familiar with their work. They then took us through some breaking news in the research world surrounding treatments and trials.

All too soon it was over, but that just led onto a short but insightful piece by Maureen Neville and Nancy Di Salva of GBS/CIDP Foundation International. We think of them and GAIN as sister organisations so it was brilliant to have them here, in fact, the day just wouldn't have happened without their support!

The next panel was incredibly valuable for a lot of people in the room. We had Dr Stephanie Yin of Rare Minds presenting a piece on Emotional Health. We've mentioned mental health and emotional support several times in this publication, so it's fantastic we had someone like Dr Yin able to present on the day for over half an hour. There was a lot of note taking and head nodding throughout, so we're sure a lot of

important information was taken away.

Next, we had one of the most moving sessions of the day as Claire Shaw and Jon Follows stood up to present their lived experiences of GBS and CIDP. As Rich alluded to earlier, there was likely not a dry eye in the house.

That was the power of the day, one moment there's laughter, the next concentrated nodding, the next your fighting over the hankies.

There was time at the end for a free ranging Q&A session with a member of each panel in attendance, allowing people in the room and online to ask their burning questions.

Then all that was left to do was saying goodbye.

The day absolutely flew by and feedback so far has been overwhelmingly positive. This suggests there may be interest for another event in 2025.. watch this space is all we're saying.

Many attendees on the day mentioned that not only was this their first GAIN Get Together, it was the first time they had ever been in a room with people living with the same conditions and experiences as them.

Claire Shaw, a GAIN member living with CIDP said that it was "absolutely amazing to spend time with people who 'get it'" and encourages everyone to "come along next year, it's brilliant."

This is one of our favourite results from the day. We all know having a rare condition can feel lonely or isolating, even when you're surrounded by loved ones. Being able to provide a space to let our audience interact with people who are going through, or have been through, the same or similar experience is really special.

On the wall in our office are all the post-its and flipchart documents you filled in during the workshops. This information is going to be invaluable to us going forward and will ensure the goals of GAIN align with the needs of the people. Thank you all for an outstanding day.

**If you couldn't make it, or want to relive a particularly inspiring panel, the afternoon is available to stream now:  
[www.gaincharity.org.uk/bgt2024](http://www.gaincharity.org.uk/bgt2024)**

## Rich was in Europe after an invitation by GBS/CIDP Foundation International to join their European Volunteers Workshop. Here's what he thought about his time in Holland.

"I must say, I'd never been to Amsterdam before, and while this was a work trip, I was very much looking forward to seeing the much talked about canals, and maybe even some tulips! More fool me, as this trip turned out to be a full on set of incredibly interesting discussions and presentations, and all I got to see was the inside of a hotel and conference room.

Arriving late on Thursday, it was straight into a working dinner, but not before the dreaded ice breaker session. This was a real opportunity to finally meet colleagues from GBS/CIDP Foundation International in person, as well as new colleagues from across Europe, and old friends that I'd met at a previous event with EPODIN. There were representatives from all over Europe, from as far afield as Malta and Poland.

Friday saw an early start and straight into a series of updates from each of the European areas and volunteer groups. It was interesting to hear about the similar issues that were facing people impacted by GBS, CIDP, MMN, and other conditions from across Europe. The lack of consistent approaches, difficulties with diagnosis, access to treatment, and lack of understanding with clinicians appeared to be (disappointingly) universal.

Following on from these updates, we had a presentation from Dr Stephanie Yin from the UK organisation Rare Minds. Stephanie talked to us all about the impact of what we do on volunteers, and how we need to look after ourselves as well as supporting others. Stephanie's discussion was very impactful, so much so that we brought her to our Big Get Together in London.

In the afternoon we had an update on research, trials, and treatments from members of the Foundation's Global Medical Advisory Board. This was illuminating, and super interesting to link what was happening across Europe to what is happening here in the UK post Brexit. These updates were followed by a discussion between the clinicians and some of their patients. Through this discussion we got to see a very different side to the doctor's, and it was great to get their insight into the patient/clinician relationship.

On Saturday, we heard from a number of the event sponsors who represented different pharmaceutical companies. They spoke about European Policy, advocating, and how clinical trials work. We also heard about best practise in digital communication, and about different GBS/CIDP Foundation programmes.

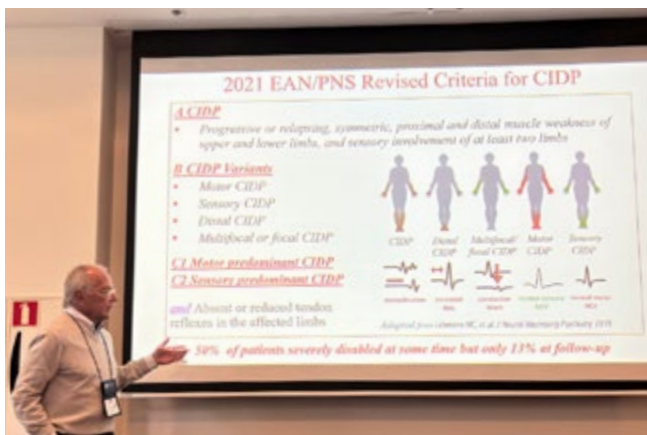


I had time on the train home to reflect on what an amazing few days I had spent with colleagues, and the new connections and friends I had made at the event. As one of the only people without lived experience at the event I did feel a little out of place and under qualified, but hopefully I was able to represent everyone effectively.

The trip was a great opportunity to build our connection with GBS/CIDP Foundation, and we do truly feel like sister organisations now. It was also great positive to build on relationships and networks across Europe and the world with other advocacy groups and with colleagues from across a variety of pharmaceutical companies.

One of the particular connections that I was able to make at the meeting was with John, an MMN patient from Gibraltar. John is a British Citizen, gets his medical input from a clinician who travels over from London, but has no local support in Gibraltar. It was good to meet John, and interesting to discuss how GAIN could support John and other people impacted by GBS and CIDP in Gibraltar.

And in case you were worried (I'm sure you weren't), while I didn't get to explore the canals on this trip, I was able to head back over to Amsterdam in November with my son and have a proper explore."



## Meet the Trustees - Lee Raynor

"I am a specialist medical lawyer and joined the GAIN board in 2016 having had both personal and professional experience of GBS and other inflammatory neuropathies.

My work involves acting on behalf of people who have sustained injuries of the utmost severity often requiring long-term hospitalisation and rehabilitation. This experience has shown me that there is often a gap between what is required by a patient post-discharge and what is offered through the NHS. I joined GAIN to address this treatment gap and to assist in the development of services that provide direct help to patients and their families.

There have been significant changes at GAIN over recent years with a new CEO, Chair, and strategic plan. These changes are very exciting, and I look forward to the future – I truly believe that we are positioning GAIN to be much more responsive to the needs of our members and those who seek our support.

I am currently a research student at Keble College, Oxford. My research considers the psychosexual effects of injuries and chronic conditions, how these are currently compensated, and how they can be better compensated. "

# MPs, Letter Writing, and Advocacy

In the last GAIN Lowdown, we encouraged you to write to your MP to raise awareness of our community and the issues we face. We included a draft letter that you were able to customise with your personal experiences, and it's been great hearing that many of you have taken that opportunity to make your voice heard ([gaincharity.org.uk/write-to-your-mp](https://gaincharity.org.uk/write-to-your-mp) for more)

Rich recently sent his own letters to Secretary of State for Health and Social Care, the Rt Hon Wes Streeting, and Secretary of State for Culture, Media and Sport, Rt Hon Lisa Nandy. Here is a brief snapshot of how he advocated for GAIN and our community. You can read the full letters via the link above.

18th October 2024  
RE: GAIN (Guillain-Barré and Associated Inflammatory Neuropathies)  
Dear Secretary of State....

Rich introduced GAIN to the **Secretary of State for Health** and Social Care as the UK's only charity supporting GBS, CIDP, and related conditions, highlighting our work.

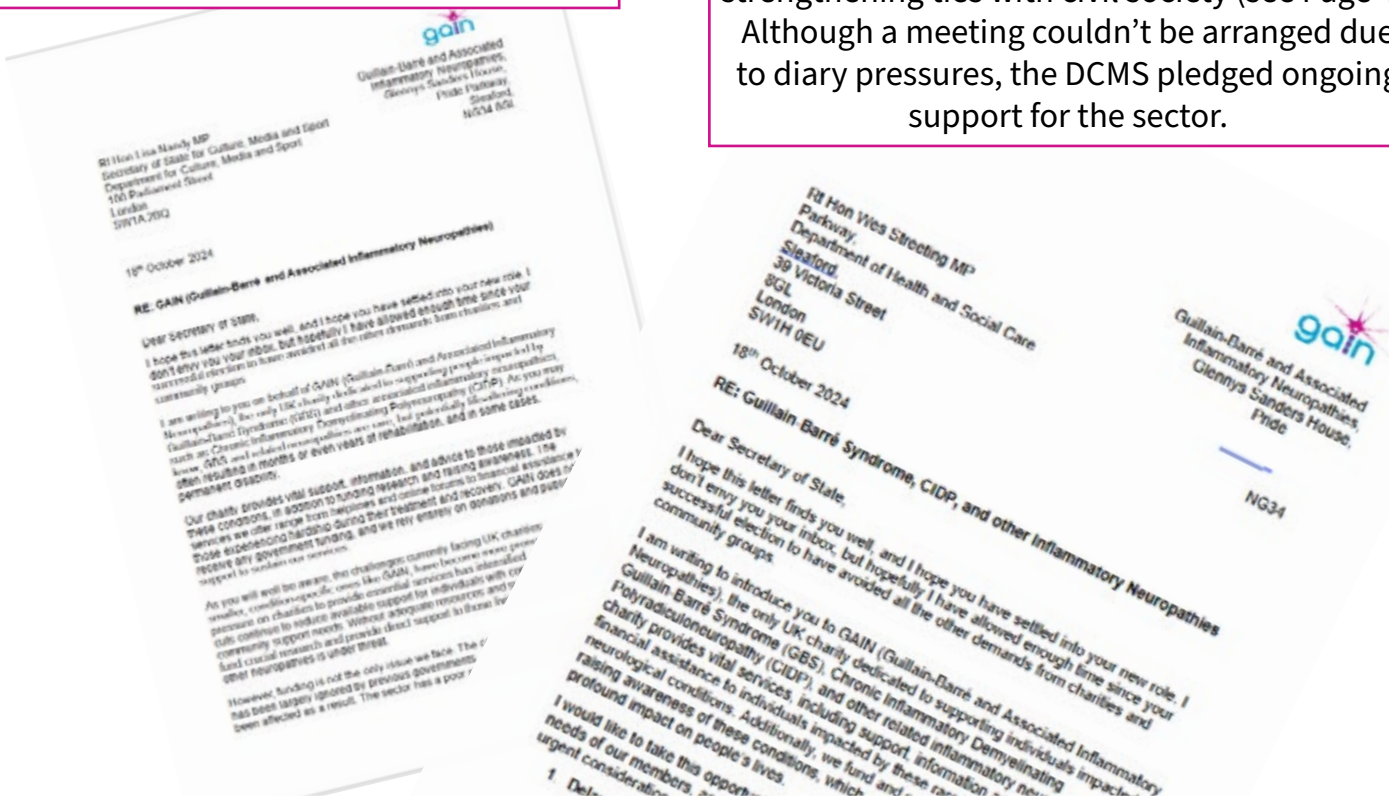
He outlined key issues, including delayed diagnosis, inconsistent treatments, lack of data, geographical inequalities, post-discharge support, and emotional care, as detailed in our suggestions for the NHS' 10 Year Plan (page 5).

Rich concluded by inviting collaboration to improve support for those affected and proposed a future meeting. No reply has been received so far.

When contacting the **Secretary of State for Culture, Media and Sport**, Rich again made GAIN's introductions.

Rich highlighted the challenges GAIN and the third sector face, emphasising the strain of providing essential services like research and support without government funding. He urged the Secretary of State to champion the sector while engaging with GAIN.

In early November, Rich received a reply from Stephanie Peacock MP, Minister for Sport, Media, Civil Society, and Youth. She expressed appreciation for GAIN's work, acknowledged the challenges small charities face, and assured that the Department for Culture, Media, and Sport is committed to supporting charities and strengthening ties with civil society (see Page 4). Although a meeting couldn't be arranged due to diary pressures, the DCMS pledged ongoing support for the sector.





# Your Story: Jon Shelton, 15 Years On

**The following is an editorialised version of Jon's story, we encourage you to visit our website to read the full unabridged piece via: [gaincharity.org.uk/JonsStory](https://gaincharity.org.uk/JonsStory)**

In 2009, at 48, I was diagnosed with a severe case of Acute Motor Axonal Neuropathy (AMAN), a variant of Guillain-Barré Syndrome (GBS). Back then, statistics suggested most GBS patients recovered fully, while 20% faced “residual issues.” I fall into the latter group. While I’ve improved significantly since my initial diagnosis, the condition still influences my daily life. Thankfully, it rarely prevents me from doing things—unless I forget and, for example, try to kick a football, inevitably landing in a heap!

When first diagnosed, I was paralysed from the neck down. After two Immunoglobulin treatments, Plasmapheresis, and Rituximab, my condition didn’t improve immediately. I spent over two months in the hospital and relied on carers for a year after returning home. Physiotherapy played a massive role, with swimming and gym sessions became my weekly routine but recovery from GBS is exasperatingly slow.

Fifteen years on, I’ve regained substantial functionality but residual issues remain. For instance, my left foot doesn’t lift properly, causing trips, especially when tired. My hands, while making a huge recovery, have lost muscle. Two fingers struggle to align properly and my thumbs work well but don’t lift up fully, so if I try to give the “thumbs up” sign it looks very much like a clenched fist, which isn’t the best look when one of your kids has done something good on the football pitch.

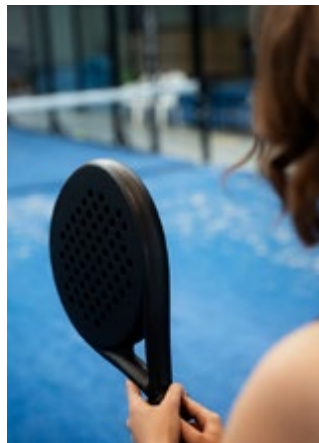
Sports became important to recovery. I focused on swimming early to build up muscle, and because it required less balance.

I was also running by now, and around this time my son, Tom (around 10) was taking part in junior triathlons. In the same centre Tom was training in was a space for adults. I thought it would be mega fit athletes, and yes there were plenty of those, but I was taken aback by how many people had just entered as a personal challenge and seeing some of them struggling with the swim.

After setting up my old mountain bike at home I started training in earnest. Because of that, I've now completed 6 sprint triathlons and a couple of 10k runs (best time being 1 hour 13 vs my PB of 38 minutes in my 20s). I'd say this period was about five years after GBS.

At five years, I surprised myself by returning to golf, a sport requiring balance and coordination. Swinging a club initially felt impossible, but persistence paid off and I eventually joined a club, gained a handicap, and entered competitions.

Moving to Spain in 2020, I discovered padel tennis, a racquet sport blending tennis and squash. Its small court and doubles format suit my limitations, and I now compete regularly—something I never thought I'd do again.



Over 12 years, improvements have been slow but undeniable. Whether due to nerve regeneration, retraining my body, or simple perseverance, the changes are clear. At 63, I can compete in racquet sports like

padel tennis and table tennis, though others, like squash, remain out of reach.

Has my mental wellbeing and lifestyle improved as a result of all this : without any doubt. My advice? Pursue what you can if you are able, whether it's pilates, swimming, or padel tennis. It's great socially as well.

Never give up,

Jon.

**Have you got a story to share? Please contact [office@gaincharity.org.uk](mailto:office@gaincharity.org.uk), we'd love to chat!**

What is Guillain-Barré Syndrome?



## New Blog Series On GBS

It's no secret that the conditions GAIN support are rare, and it's all too easy for us "in the know" to assume everyone knows what GBS, CIDP, and MMN are.

With that in mind, we've started a new blog over on the GAIN website that introduces these conditions in simple, accessible terms.

Our goal is to make the content as accessible as possible. Some readers may be seeking general information, while others could be newly diagnosed or supporting a loved one through their journey. In moments like that, the last thing anyone needs is a jargon-heavy document that makes you feel like you need a PhD to understand.

Instead, we're creating a straightforward, easy-to-understand guide to these conditions that anyone can follow.

These blogs will begin in December and will cover such topics as:

- What is Guillain-Barré Syndrome (GBS)?
- What are the symptoms of GBS?
- How is GBS treated?

We also know how hard it is explaining to friends and family just what you're going through, what you have been through, or even what to expect next. We hope these blogs will be a handy tool for you to share when you don't have the capacity or energy to explain it yourself.

If there is anything you would like to see, or you have any comments on the blogs then please do get in touch

[Read Now: gaincharity.org.uk/news](https://gaincharity.org.uk/news)



## Touching A Nerve



In this series of podcasts, Rich Collins (the GAIN Chief Executive) and Al Bailey (former professional Rugby player diagnosed with CIDP) talk to a whole host of folk from around the world who have been impacted by adversity or challenge, and who have come through the other side.

Episode 2 is currently streaming now, and features John Solosy who shares his experience of rowing 3,000 miles across the Atlantic for charity.  
Listen along: [gaincharity.org.uk/podcasts](https://gaincharity.org.uk/podcasts)

## Suggestion Box



Last time we told you about a virtual box for any ideas, thoughts, or suggestions you might have for GAIN. Well it's even easier to use now, simply go to:

[gaincharity.org.uk/suggestionbox](https://gaincharity.org.uk/suggestionbox)

to get in touch anonymously. You can still drop us an email at [ideas@gaincharity.org.uk](mailto:ideas@gaincharity.org.uk), or a message/voice note/video clip via WhatsApp on 07878 090965

## Last But Not Least: Events!

We have a number of event entry places coming up, some are in short supply so if you're interested, please get in touch: [gaincharity.org.uk/events](https://gaincharity.org.uk/events)

**Brighton Marathon | 6th April 2025**

**Great Manchester Run (Half Marathon) | 18th May 2025**

**Great North Run (Half Marathon) | 7th September 2025**

**Swim Serpentine | 20th September 2025**

**Great Scottish Run (Half Marathon) | 5th October 2025**



**Let's Keep In Touch**

**[gaincharity.org.uk](http://gaincharity.org.uk)**

**or join us on social media**

**@gaincharity**

