In your March issue:

Changes to Ig
Get Involved in Research
Jon In Philadelphia
MMN in Gibraltar
GAIN in Parliament
And much more!

LOWDOWN

March 2025
No. 8

In This Issue:

200 Club Winners

December
Tom O
Pamela P
Nova J

January
Norman D
Anne P
Pamela P

February
Nova J
Julie W
Graham H

Fancy seeing your name here and taking home a share of the winnings? Head over to

gaincharity.org.uk/200-club

or give the office a call to learn more!

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A Word From..

Carol Hooper
Chair

Well it has been a busy few months. We promised change and have started 2025 reviewing feedback and exploring new ways we can support and expand the services we already offer, as well as looking at new opportunities that will make a difference to those impacted by the conditions we support. More on these in due course.

For now, I have to mention the Neurological Alliance breakfast meeting Rich and myself were invited to attend which was held at the Houses of Parliament. The meeting aimed to raise awareness of neurological conditions to newly appointed MP's, and seek allies should 'we' need support and a voice in the House of Commons. Approximately 35 new MP's attended and as a result Rich and I will be back to London to meet with Steve Witherden, Labour MP for Montgomeryshire and Glyndwr who is keen to understand more on our conditions. I am also due to meet my local conservative MP Richard Holden to discuss our conditions and the work we do.

The meeting in London also brought together charities and organisations supporting neurological conditions and allowing a wonderful opportunity to network which was incredibly rewarding and has resulted in a couple of particularly beneficial connections.

It has been an incredibly fulfilling few months and I know Rich and the team are working hard to take action so you can all benefit from these behind the scenes activities. Until the next time.

Rich Collins
Chief Executive

A year ago, I was having a bit of a panic. I'd been in the Chief Executive job at GAIN for a month, and there was a big scary thing on the horizon. GAIN Lowdown.

While I have lots of experience with communication and engagement, I knew how important Lowdown is to the Inflammatory Neuropathies Community. I really didn't want to muck it up. So, I sat down with Claire, and we came up with a plan.

We wanted to make sure it was a useful and informative read, but we also wanted to make sure it had lots of stories in it. I also had two big demands, it had to be interactive, and it couldn't be boring.

Well, we got that edition out, and added in GAIN Update over the next few months, and we have been putting out regular newsletters since. It turned out to be not so scary, but is a whole lot of work. Hopefully you think it is worth it.

I'm so glad that I have been able to pass a lot of that work over to Chris, who is doing an amazing job to make sure Lowdown is as much loved as before.

In that first edition I was involved in, we published our first annual survey, so that we knew what you wanted from GAIN, and how well we are doing. In this edition we are publishing the follow up survey. Please fill it in and let me know how you think we are doing. Your views are really important to me, so please be honest.

Look forward to seeing the results.

News

Birmingham Get Together

GAIN are heading to Birmingham next week (as of when this newsletter drops) to meet Clive Phillips from Making the Most of Now. Clive and his team are taking on a huge 3,200km cycle around France to raise awareness and funds for MMN support - they're calling this event the Tour De MMN.

To celebrate this, GAIN and Making the Most of Now have organised a mini Get Together for anyone with GBS, CIDP, and MMN at the NEC Crowne Plaza, Birmingham, on Saturday 22nd March between 11:30 and 14:00. Entry is totally free, and you'll be able to meet others with similar conditions, as well as talk to Clive, and meet our ambassador, Ben Watson, Paralympic double-gold medallist.

Tickets are free and can be found at:
ticketsource.co.uk/gain

gaincharity.org.uk
makingthemostofnow.co.nz

Birmingham
Get Together

Do you have experience of an **Inflammatory Neuropathy** like **GBS**, **CIDP**, or **MMN**? Join us and people with shared experience for a chat and a bite to eat beside the National Cycling Show in the NEC!

WITH VERY SPECIAL GUESTS
BEN WATSON
Paralympic Double Gold-Medallist
CLIVE PHILLIPS
Founder of Making the Most of Now

Sat March 22nd, 2025 | 11:30 - 14:00
Crowne Plaza Birmingham NEC

Free Tickets
www.ticketsource.co.uk/gain

Concerns over the loss of a neurology framework for Scotland

The Neurological Alliance of Scotland recently submitted an open letter to Neil Gray MSP, Cabinet Secretary for NHS Recovery, Health and Social Care. The letter revolves around the end of the Neurological Care and Support Framework for Action in 2025, and urges urgent meetings with the Alliance to commit to a new framework or plan. 34 members endorsed this letter, of which GAIN was proudly one.

You can read the letter by visiting

www.scottishneurological.org.uk/news/news/policy-work/

Neurological conditions must be a research priority

In an open letter to the Rt Hon Peter Kyle MP Department for Science, Innovation and Technology, the Neurological Alliances of Scotland, England, Wales and Northern Ireland have urged the UK Government to prioritise investment into neurological condition research.

Recognising the 1 in 6 people in the UK with at least one neurological condition, the letter was shared to mark the start of Brain Awareness Week. GAIN was one of 78 endorsers. Keep an eye on our social media, and make sure to follow your local Neurological Alliance for updates.

Changes to Ig

If you've been following GAIN on social media, or received our last Update newsletter, you'll be aware that GAIN have been discussing the upcoming changes to how Immunoglobulin (Ig) is both sourced and distributed in England. As many people in our community rely on Ig for treatment, we thought it was important to present the information in a clear and simple way. Here's what is happening.

What is Ig and Why is it Important?

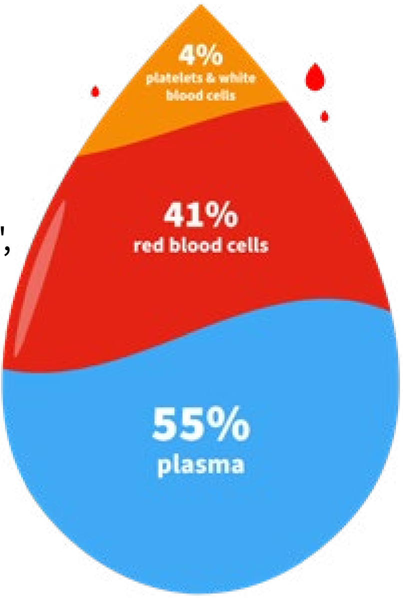
Immunoglobulin (Ig) comes in different forms, Intravenous Immunoglobulin (IVIg) being the most common and is infused into the blood through a vein, while Subcutaneous Immunoglobulin (SCIg) is injected under the skin.

In 2022/3, around 3,150 people across the GBS, CIDP, and MMN received it, so it plays a vital role in the treatment of these conditions.

What's Changing and Why?

We get Ig from a part of our blood called plasma (in fact, 55% of a regular blood donation is plasma - this is why it's so important to give blood if you are able). Until recently, the UK was unable to use domestically donated plasma for Ig production due to concerns over "Mad Cow Disease", therefore all plasma had to be imported. However, new guidelines now allow UK plasma to be used in Ig production.

To manage this transition and ensure a stable supply, NHS England has put in place new contracts with Ig manufacturers. Beginning in April 2025, these new contracts will secure better access to Ig at a lower cost. While this is largely a positive change, it does mean that some patients may need to switch to a different Ig product.



How Might This Impact You?

For patients with GBS, no major changes are expected. Emergency hospital treatment should remain the same.

For CIDP and MMN Patients, if your current Ig product is included in the new contract, nothing will change. However, if your treatment is not on the list, your clinician may need to switch you to an alternative. While most patients will adapt with no issues, others may find that a new treatment is less effective or has different side effects, in which case, your clinician will find an alternative, or source your original Ig where possible.

Need Support?

Changes to medical treatments can be stressful, and understanding how they impact you can be difficult. If you're worried, speak with your clinician, and we're always happy to chat here at GAIN.

GAIN in Parliament

Your Chair and Chief Executive represented GAIN and the Inflammatory Neuropathies Community at the Neurological Alliance's Parliamentary Neuro Reception.

We caught up with Rich and Carol to hear about their day at this landmark neurological event.

It was a very early start as Carol and Rich arrived at the Houses of Parliament for a breakfast event arranged and hosted by the Neurological Alliance. With around a hundred people attending from across the sector, the Neurological Alliance's membership was well represented, with GAIN showcasing our Community at the centre of the room. Speakers at the event included Professor Sir Stephen Powis (NHS England's National Medical Director) and Baroness Stephanie Fraser (Chief Executive of Cerebral Palsy Scotland and Parliamentary sponsor for the event). We also heard from some of the other Alliance members. With 1,400 people (including many GAIN members) joining the e-action to invite their MP to join the event, and 548 MPs receiving at least one email from a constituent about the event, we were delighted that a record-breaking 35 MPs or their representatives attended. This is the largest number of MPs to attend a Neurological Alliance event in its 30 year history!

Carol said "It was an inspiring morning at the Houses of Parliament, bringing together so many individuals and organisations from across the neurological community. Being about to represent GAIN was truly rewarding, especially being able to share our work with peers and MPs. The record-breaking attendance from MPs shows just how powerful our collective voice can be. Thank you to everyone who emailed their MP, and a huge thank you to the Neurological Alliance for arranging such a fantastic event, I can't wait to see what happens next!

Rich told us "It was great to catch up with colleagues from across the Neurological Sector, as we all came together to celebrate the work that we do and highlight the needs of people impacted by Neurological Conditions. It was rather surreal to walk over Westminster Bridge as the sun came up, before rolling out a GAIN banner in the Houses of Parliament and talking to MPs and colleagues about what GAIN does, and what people tell us they want and need. And with great interest from MPs, it really felt like people were listening. A really positive day with great prospects for the future."

It was a really good way to spend a morning, and an incredible way to spread the word about GAIN, Inflammatory Neuropathies, and Neurological Conditions. A massive thanks to Georgina and the team at the Neurological Alliance for arranging the event and for inviting Carol and Rich.

Parliament and Plasma

And that’s not all from Parliament, back in January, our Chief Executive Rich, was invited down to a special meeting with MPs in Parliament to discuss plasma, Ig treatments, blood and plasma donations, and the importance of Ig to the Inflammatory Neuropathies Community. Here are his thoughts on the day.

“It is always very humbling to be asked to go and represent our Community, and to speak on behalf of others. But I was really pleased to have received an invite from colleagues at NHS Blood and Transplant to come for a special round-table meeting with MPs, experts, NHS staff, and a few other representatives of patient organisations.

I arrived thinking this would be a large gathering where we wouldn’t really get a chance to speak, to find that it was actually a fairly small group of around 30 people. Our friends from NHS Blood and Transfusion led the meeting by talking about the really exciting news that we were due to receive the first batch of Ig treatments manufactured using plasma from UK donors for the first time in 30 years. They went on to talk about the strategy for increasing plasma donation in the UK, the importance of obtaining more plasma, and what this would mean for the long term ability to provide Ig treatments within the UK.

The floor was then opened for patient representatives and the NHS clinicians to talk about Ig, how important it was for the treatment of conditions like GBS, CIDP, and MMN, and some of the issues around supply.

The MPs and Lords who were in attendance listened in to the conversations intently, and it was really good to hear them ask some excellent questions, especially in terms of their constituents who depend on Ig products.

I was able to take the opportunity to highlight Inflammatory Neuropathies, and to talk about some of the needs of the community, and some of the issues linked to treatments and lack of consistency. I was also able to talk more broadly about the impact of these conditions on people’s lives. Many of the MPs hadn’t heard of GBS or CIDP before, so it was a real opportunity to enlighten them, and while clinicians didn’t agree with everything I had to share, we were able to agree on the importance of a more secure source of Ig treatments.”

Make sure to visit page 5 where we cover the upcoming changes to Ig and Plasma. Please also keep an eye on our website (gaincharity.org.uk) and social media channels @gaincharity to stay up to date with any new information we receive.

Celebrating Our Community

Take on a challenge
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 help you. We thank the following individuals for their kind support this quarter: Adam H, William B, Barry T, Vanessa Mc, Danielle B, Danielle Mc, Delia T, Sue F, Patricia E, Margaret L, Matthew L, Linda C, Graham C., and the following organisations: Grand Chapter Charity, Kippax Harriers, Squarepoint, Birchwood Golf Club & Hempstara

Tom Gilbert

SHEFFIELD 10K 2024

"There are two reasons I chose to support GAIN by running the Sheffield 10k in 2024. These are personal and family experience of GBS. In March 2023 I was diagnosed with GBS after feeling unwell and being hospitalised. Following the diagnosis of GBS I was treated via IVIg by the fantastic NHS. During this time GAIN's support to my wife and I helping us to understand the illness, implications and rehabilitation was invaluable. This followed the support GAIN provided to a grandparent who also had GBS in the past."

Tom raised a fantastic £733.88 to help GAIN, thank you Tom!

Kristi Oxborough

SWIM SERPENTINE

"Last year, I decided to fundraise in support of my colleague's son, who, while on his honeymoon last summer, fell ill and was later diagnosed with Guillain-Barré Syndrome (GBS). This was my first encounter with GBS, and to show my support, I participated in my first open water event, Swim Serpentine at Hyde Park in September. Through this challenge, I was able to raise £431.25 to support GBS research and raise awareness about this rare and life-changing condition."

Thank you Kristi for making your first open water event a challenge to help GAIN!

GAIN Hero! **Ruby Davis** LEICESTERSHIRE HALF MARATHON 2024

"My dad passed away in 2020, he had been diagnosed with terminal cancer and given his competitive nature, he was determined to try to beat it. In his attempt, he tried anything the doctors could offer him. Unfortunately, in the end, his immune system couldn't cope. He developed Guillain-Barré Syndrome and within 2 weeks he was gone. It was horrendous, coupled with the onset of COVID at the point when no doctors or nurses really knew how bad the situation was going to get. It meant my family were not able to spend much time with him in hospital and his funeral was a tiny gathering of mask clad close relatives.

I knew next to nothing about this syndrome, as it would seem, do most people. The more I read about it the more I wanted to raise some cash for this little-known auto-immune disease.

Running was my dad's hobby, not mine. In fact, I'd gone through the best part of 34 years hating running.

At first running was a real challenge, but it soon became a way to keep my dad, who was a keen runner, with me. I ran my first ever race, a 10k, in September last year, and feeling like I could push a little further I decided to try a half marathon this February. I knew raising money for GAIN would help spur me on and it was an honour to race on their, and my dad's behalf. I know he would be incredibly proud to be part of something which will improve understanding and hopefully help a lot of people - even though I'm sure he would have a cheeky smile on his face telling me it's a shame I couldn't have done it in under 2 hours… next time Dad!"

Ruby competed in the Leicestershire Half Marathon in 2hr 11mins which is really impressive since it was her first go and given that the course was pretty hilly and raised a spectacular £6,201.17!

'In Memory of Amratlal'

"Mr Amratlal Prajapati, loving husband, father of three children and grandfather of four will be deeply missed by all of us.

Despite the numerous personal and health challenges he faced throughout his life, including Guillain-Barré Syndrome and kidney failure, he maintained his sense of humour, kindness and generosity.

He prioritised his family and fulfilled his responsibilities with unwavering dedication; his absence leaves a profound void in our hearts and lives"

A collection in memory of Amratlal Prajapati raised £985.49.

Please join us as we think of Amratlal, his partner, children, and grandchildren, not to mention friends. We extend our heartfelt thanks to them for allowing us to share this piece in our newsletter.

CHALLENGE EVENTS FOR GAIN

Now you've read about some of our fundraising heroes, do you feel inspired to take on an epic challenge of your own? Well we've got amazing events coming up in which you can claim your space totally FREE! All you need to do is commit to a minimum sponsorship and the spot is yours (you'll also need to train, and take on a difficult event but you've got this!). So what have we got coming up?

RUN

great run

Half Marathon

18th May 2025
Great Manchester Run
limited places

7th Sept 2025
Great North Run
SOLD OUT

5th Oct 2025
Great Scottish Run
limited places

Take on a half in cities across the UK. Whether you're a seasoned running veteran and are going for a PB, or you've been running for a while and just want a goal, a half is a great challenge. Not only do you prove something to yourself, but you can also raise vital funds for GAIN!

Vitality London 10,000 | 10k - 28th Sept

A half is hard, which is why a lot of people like to take on a 10k first. The Vitality London 10,000 could be just the one for you. Not only is it a 10k, but it's the only 10k in the capital to finish outside Buckingham Palace. This is the sort of experience usually reserved for marathons, so this is an amazing and accessible run to which GAIN are over the moon to be able to offer places.

Note: Places in these events are limited, and some places may be snapped up quickly, so get in touch early if you want to reserve a spot: office@gaincharity.org.uk

SWIM

Swim Serpentine

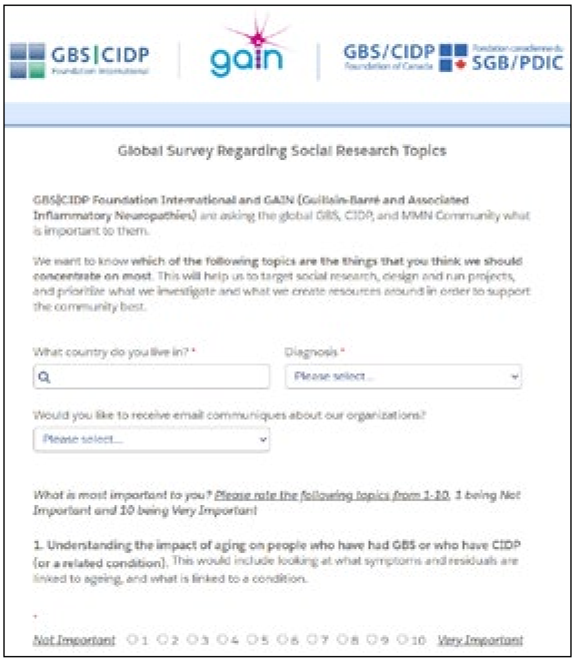
This is your chance to make a splash for cash and swim either **half a mile** or **one mile** along the Serpentine in London's Hyde Park! This is a really unique fundraiser and a chance to interact with and view a London landmark from a whole new angle.

20th Sept

Change the Future of Care and Support - Surveys

We have two hugely important ways you can directly help shape care, support, and awareness of rare conditions here in the UK, and globally. These are potentially game changing pieces of research, so please take a moment and read on.

GLOBAL SURVEY - For: GBS, CIDP, and MMN



Global Survey Regarding Social Research Topics

GBS|CIDP Foundation International and GAIN (Guillain-Barré and Associated Inflammatory Neuropathies) are asking the global GBS, CIDP, and MMN Community what is important to them.

We want to know **which of the following topics are the things that you think we should concentrate on most**. This will help us to target social research, design and run projects, and prioritize what we investigate and what we create resources around in order to support the community best.

What country do you live in? *

Diagnosis *

Please select...

Would you like to receive email communiques about our organizations?

Please select...

What is most important to you? Please rate the following topics from 1-10, 1 being Not Important and 10 being Very Important

1. Understanding the impact of aging on people who have had GBS or who have CIDP (or a related condition). This would include looking at what symptoms and residuals are linked to ageing, and what is linked to a condition.

Not Important ○1 ○2 ○3 ○4 ○5 ○6 ○7 ○8 ○9 ○10 Very Important

Working alongside GBS|CIDP Foundation International and GBS|CIDP Foundation of Canada, we are asking people with GBS, CIDP, and MMN around the world what is important to them. You'll be presented with 15 statements/areas of focus and we need you to identify which are most important to you.

This will then help us target social research, design and run projects, and prioritise what we investigate and what we create resources around in order to best support the community.

Expect to see questions about exploring the impact of diagnosis on families, mapping symptoms and residuals, determining the impact of grief, and more.

The results from this survey will be published and should be available from late May 2025.

UK SURVEY - For: CIDP

GAIN were fortunate enough to be invited to contribute to a major piece of work on CIDP being carried out by Argenx, one of the biggest biotechnology companies committed to researching autoimmune diseases.

We are carrying out this survey to better understand how Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) impacts the day-to-day life of people living with CIDP as well as their caregivers/husband/wife/partner.

We are looking to include those living with CIDP who are 18 or older, or if you are a caregiver or family member looking after an adult with CIDP. Your experiences can help advance our understanding of life with this condition.

The survey should take approximately 20 minutes to complete. All responses will be anonymous, remain confidential, and data will be securely stored in line with the Market Research Society Code of Conduct and General Data Protection Regulations (GDPR) in the UK.

Why Participate?

· Make a Difference: Your responses can help to improve care for people living with CIDP.
· Be Heard: Share your personal experiences and challenges to help shape the future of CIDP care.

This is your opportunity to share your experience! Keep an eye out for more details in the coming weeks. The survey will go live in April. To register your interest to participate or if you have any questions about this survey, please contact office@gaincharity.org.uk.

Last year, Rich met John Navarro at a GBS | CIDP Foundation International event, they had a great chat and kept in touch. John, 38, is from Gibraltar and has had a diagnosis of MMN for a year. He spent two and a half years before that searching for answers, and eight years with symptoms. Recently, John made a pop in the press during MMN Awareness Month. He kindly joined Chris via Zoom to share his story.

John Navarro had been living with a foot drop in his left foot. His Doctors chalked this up to two hernias in his lower back, and for six years, despite the foot drop getting progressively worse, John got on with life. Then he started getting the same weakness in his hands.

“Life and daily tasks became much harder as you can imagine. Then it got to the point where I couldn't grab cutlery properly, or grab a toothbrush properly, and so the hospital started pushing a little bit more for a different diagnosis while I started to worry a little bit more.”

He bounced between clinics with no real answer, and soon involved the Minister for Health, Gemma Arias-Vasquez (“there are only around 30,000 people and a very close knit community so it’s easier to do these things!”)

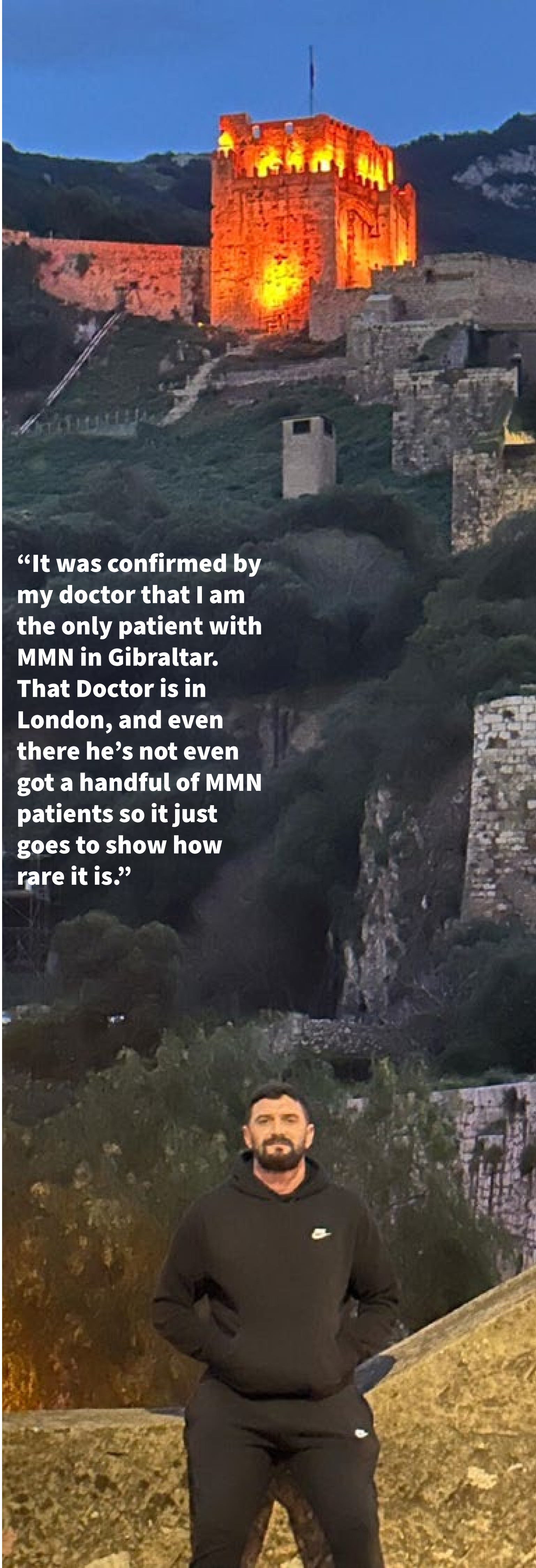
She took a great interest and got involved. He was quickly sent to another clinic a little farther away, but he was used to this, most of the clinics were already in Spain so he was happy travelling.

“I explained what was happening and before he had finished his tests, he said, ‘I know what's going on with you already’.

I left that clinic knowing that I had Multifocal Motor Neuropathy, and I've taken it from there. I was lucky to have this person who knew about MMN.”

Now he had an answer, treatment could begin.

“The attention that I’ve had from doctors and the care has been very, very good. And, perhaps because, we are in a smaller community, we haven't had any shortages of immunoglobulin. I have IVIg every four weeks now over two days.”



“It was confirmed by my doctor that I am the only patient with MMN in Gibraltar. That Doctor is in London, and even there he’s not even got a handful of MMN patients so it just goes to show how rare it is.”

“I also have a visiting specialist neurologist who flies over from London every six months, but if you have queries they’ll arrange a call. I’ve also got a local neurologist who is very attentive and if I’ve any questions I’ll send him an email. In fact, I emailed him a couple of weeks back and was in the process of WhatsApping my wife to update her when I received a call from him, so that goes to show the care has been second to none”

GAIN know all too well how isolating a rare condition can be, and John has one particularly unique distinction. “It was confirmed by my doctor that I am the only patient with MMN in Gibraltar. That Doctor is in London, and even there he’s not even got a handful of MMN patients so it just goes to show how rare it is.”

So how does John access peer support?

“I found I was missing a community because you want to talk to people going through the same thing you are, so I started a support group myself with help from a couple of other UK government patients.

I advertised it in some international groups, and within the first 24 hours we had about 50 members. Word of mouth is what keeps it growing and there’s a lot of information and questions in there. Everyone’s sharing stories, and there’s a lot of patient support, which is what we like.”

[Find the group on Facebook by searching Multifocal Motor Neuropathy Support UK]

At the start of this article, we mentioned press attention during MMN Awareness Month.

“I’ve been advocating for MMN since my diagnosis. I found the GBS | CIDP Foundation International and thanks to them I’ve been sharing my story online. But, perhaps because Gibraltar is a smaller community, I didn’t feel comfortable at first coming out locally.”

Well in February I thought, maybe I could light up the big iconic landmark that we have here in Gibraltar, other than the big rock - Moorish Castle. They light it up to raise awareness for other diseases and recognise certain people who pass away. So I thought, I’ll speak to the minister again and see if I can get them to light it orange for one evening.

However, to do that I knew I’d have to put my story out there on social media and local groups because there’d be no point in having the landmark lit with no context!

I got word that they’d accepted my idea so, with 4-5 days to prepare, I shared my story with the local community. It was really well received, overwhelming and emotional sometimes. I spoke on live TV, podcasts, and other media, so it’s been a busy month without expecting it!

As we left John to prepare for his next call, Chris asked if he had any final thoughts on the project, and if he had a message for others experiencing a rare condition like MMN.

“I hope that my actions have not only raised awareness for a moment, but also empower other people with rare conditions to speak out and raise awareness about them. People may not understand exactly what you're going through medically, but, psychologically we do understand, so don't hesitate to raise awareness for your condition.

But, always try to stay positive. No matter how hard it may be and try to just turn the curse into a blessing”

A huge thank you to John for taking the time to share his story with us.

Jon in Philadelphia

GAIN were excited to learn that one of our top volunteers, Jon Follows, had been invited by our friends in the GBS | CIDP Foundation International to fly out to their home base in Philadelphia in the United States. Representatives from the Foundation were at our Big Get Together in London last year and heard Jon talk about his experiences with CIDP. They were so impressed, they invited him to attend a three day Leadership Collaborative community workshop. Here's Jon with his story:

" From the 31st January to 2nd February I attended a 3 day 'Leadership Collaborative' community workshop hosted by the GBS|CIDP Foundation International in Philadelphia. The focus of the workshop was to improve the patient journey after being diagnosed in having Chronic Inflammatory Demyelinating Polyneuropathy.

20 patients from America, Canada, Italy and England (me), along with staff from the Foundation, came together to exchange our stories of having CIDP.

Why did I get invited? I have CIDP, but fortunately have made a quick and strong recovery and was invited to share my personal experience.

What followed was a very open and sometimes emotional discussion on our initial symptoms, which differed so much from a slow build up of pins and needles, to speedy paralysis, and diagnosis in hospital which included misdiagnosis of strokes, mistaking CIDP for anxiety and other wrong conditions which delay the necessary treatment.

above - Jon (far left)

It was really interesting to hear about the varying treatment available and everyone's differing on-going care , which showed how different CIDP can impact us. I was able to share some of my new anti-inflammatory lifestyle tips and bore them about how important our gut health is too!

We also discussed new ideas to help to address the ongoing challenges of this rare condition. I'm sure the Foundation will be sharing more on this soon!

And don't worry, I shouted about the great work of GAIN & our own community at every opportunity too!

For me, it was rewarding and beneficial to be in the same room as people who have the same condition as me, as we shared a common bond and understood what we are all going through straight away. It was really interesting to hear the differences in our symptoms, the care provision across the different countries and what we were now doing to minimise the ongoing condition. The emotional and social impacts, including the impact on our mental health shouldn't be forgotten.

I'll admit to being apprehensive about going - both on the travelling and the subject matter, but I am so pleased I had the opportunity to attend and be part of this new piece of research.

Although it started as a workshop with 20 strangers, we ended like friends.

I hope that these discussions and future work with the Global Medical Advisory Board will improve the journey for others in understanding, treating and living with CIDP. I can't wait to see what happens next...

- Jon Follows"

A huge thank you to Jon for taking the time to tell his story, and to the Foundation for organising this event. Jon's talk at the Big Get Together was certainly one of the highlights of the event, so we're thrilled that he had the chance to share his story with a global audience.

You can keep up with the Foundation's work over at **gbs-cidp.org**. Keep an eye on our social media to see what Jon is up to next, he's not resting after Philly, that's for sure!

Meet the Trustees

Sean Austin | Treasurer/ Chair of Finance Sub-Committee

"I developed CIDP in 2014. I had been aware for some time that something wasn't right but a sudden deterioration in my mobility prompted me to go to my GP. I was immediately (the same day) referred my local Neurology team at the Western General Hospital in Edinburgh where a diagnosis of CIDP was confirmed and an effective treatment plan was put in place.

Some years later, while researching my condition, I came across GAIN. Two things became apparent:

1. I was very lucky to get such a quick referral, diagnosis and treatment plan.
2. At that time, GAIN was "punching below its weight". (I had never heard of the organisation before!)

Having held a number of board level executive and non-executive positions, I thought I might be able to make a contribution to the GAIN board and I was lucky enough to be invited to join the Board about 15 months ago. I am now the Treasurer and I chair the Finance Sub-Committee.

It is an exciting time to be involved with GAIN. The appointment of a new CEO and team, a new Chair and a number of new trustees has reinvigorated the charity, and a new strategic plan means that we are already having much more impact in support of our members."

Story Time - Snapshots/Slice of Life

You may have seen us calling for stories recently on social media.

And what can we say, the response has been slightly overwhelming. Whether you've shared via a Teams or Zoom call, or penned a piece yourself and sent it to us for use, thank you! We know it can be hard to open up and share some of these intimate details with the world. Given how much more frequently we seem to be getting stories these days, we like to think it's because you know you can trust us to treat your information with respect, so again thank you for the trust.

However, the big world of social media is a hungry place, and we're always on the look out for more.

One thing that would be really useful is a snapshot or slice of your life story. An anecdote about something that happened in hospital that would have made your life better (*I wish someone would have massaged my hands),* or feel more respected as someone in a bed (*I wish they wouldn't stand and talk over the top of me like I'm not here*), or the concept of no small victories, *(I squeezed the toothpaste onto the brush myself this morning).* These don't need to be long, just grab your phone, and record a 30 second anecdote, and we can guarantee it will resonate with the GAIN community.

If you're interested, record a clip, and contact **office@gaincharity.org.uk**.

Keeping it Local

Local groups have been at the heart of GAIN for years, but since COVID we have seen most of them close down. You've told us that you want them back, so we have begun a process to develop a whole new set of Local Get Together's, as well as looking to restart some of the former groups.

As part of this work, Rich was invited up to Newcastle to talk to a group of local folk who had previously run a GAIN group, and really wanted to bring it back. Over to Rich for the rest of this story.

"I had been thrilled to receive an email from Paul in Newcastle about restarting the group and after several calls and emails, I jumped on a train up to see everyone. Unfortunately, incredible delays meant that I was stuck for 2 hours outside Durham, so only got a short time with everyone. However, it was amazing to hear about the history of the group, and look at how we GAIN can support it to come back reinvigorated. I look forward to seeing the next steps, and getting up for a proper visit soon."

If you want to know more about the Newcastle group, you can email Paul Mitchell via paulm.vol@gaincharity.org.uk.

Rich and Chris visit Cumbria

On Sunday 8th March - Rich took a little holiday from his own holiday in the Lakes while Chris grabbed a south bound train out of Glasgow. They assembled in Lancaster to drop in on the amazing Lancashire and Cumbria Group who were having their quarterly meeting.

One of the primary reasons was to share an update on an incredibly exciting project that we're not able to share here just yet, but *may* be able to spill the beans on in the next Lowdown. It was also just a great chance to hear from our community. Over the course of around three hours we had an open and honest conversation, with members sharing their experiences of GBS and CIDP, particularly in a health care setting. This was incredibly vital in helping us focus our work where it's needed, whether research, new services, or new ways to advocate for people. We walked away with a lot of fantastic suggestions (along with full stomachs from a veritable feast!).

It means a lot to be able to drop in on groups, and we thank them for allowing us into their space, along with a special thanks for their incredible fundraising efforts and top notch local support.

GAIN Survey 2025 - Your Voice

You will have already read in this edition about two major surveys taking place in the GBS, CIDP, and MMN world. This survey is unrelated to them, and instead focuses on us right here at GAIN. We're a listening organisation, so this is the time to make your voices heard and tell us what we do well, and what we could be doing better.

We carried out a similar survey last March to find out what you thought about GAIN and how we were performing. What your told us then helped shaped what we do now and how we have changed over these last twelve months.

In order to keep improving and making sure that we meet the needs of the GBS and CIDP Community, we are again asking if you can help by completing this survey. Once again it's all about your interactions with GAIN, how well we respond, how well we do (or not), and what we should be focusing on.

It shouldn't take you long to complete it (hopefully just a couple of minutes), but what you tell us really does help us to make things better. Please be honest, it's really important to us that you tell us what you really think and of course, many thanks for taking the time to share your views. To get involved just:

- Fill out the form over these next pages, tear, and return to us.
- Fill out the survey online at **forms.office.com/e/Zn0YPeuvG7** or scan:
- Arrange a 1:1 call by ringing: 01529 469910
- Record audio/video and send via WhatsApp to: 07878 090965
- Drop us an email: office@gaincharity.org.uk

GAIN Survey 2025

Returning your survey couldn't be easier. Simply fill out this form, carefully remove the pages, and pop it in an envelope addressed to "**FREEPOST GAIN**" - no stamps needed!

1/ Have you engaged with or contacted GAIN before?

(Please just choose one option)

☐ Yes, in the last 12 months
☐ Yes, longer ago than 12 months
☐ No
☐ I Don't know

2/ How have you engaged with us?

*(Please choose **as many** options as you want)*

☐ Contacted the office
☐ Donated/Raised funds
☐ Received information
☐ Received peer support
☐ Received support
☐ Requested a personal grant
☐ Visited the website
☐ Volunteered
☐ Other (please add)

3/ Have noticed any changes at GAIN over the last year?

(Please just choose one option)

☐ Yes, and I think things are better
☐ Yes, but I think things are worse
☐ No, things seem to be the same
☐ I Don't know

4/ Which one of these things is most important to you?

(Please just choose one option)

☐ Supporting people impacted by GBS, CIDP, MMN, & other Inflammatory Neuropathies
☐ Researching conditions and their impact on people and families
☐ Researching awareness about GBS, CIDP, MMN, & other Inflammatory Neuropathies
☐ Campaigning, and raising the voices and views of people impacted by GBS, CIDP, MMN, & other Inflammatory Neuropathies

For the next section, please fill each circle to show your rating out of five. For example:

● ○ ○ ○ ○ is terrible
● ● ● ● ● is amazing

5/ How well would you rate us on supporting people?

○ ○ ○ ○ ○

6/ How well would you rate us on funding and carrying out research?

○ ○ ○ ○ ○

7/ How well would you rate us on raising awareness?

○ ○ ○ ○ ○

8/ How well would you rate us on campaigning and advocating on behalf of the community?

○ ○ ○ ○ ○

9/ How would you rate us at communicating with you?

○ ○ ○ ○ ○

..and back to multiple choice

10/ What do we do well?

*(Please choose **as many** options as you want)*

☐ Arrange and provide peer support
☐ Carry out research
☐ Engage with people
☐ Fund research
☐ Promote GBS, CIDP, & other associated Inflammatory Neuropathies
☐ Provide easy to understand information
☐ Provide information on our website
☐ Provide online meetings
☐ Provide support on the phone
☐ Send out information
☐ Share news and developments
☐ Social media
☐ Support local groups
☐ Talk to the government
☐ Work with other organisations
☐ Other

P.T.O for Qs 11, 12, & 13

11/ What could we do better?

*(Please choose **as many** options as you want)*

☐ Arrange and provide peer support
☐ Carry out research
☐ Engage with people
☐ Fund research
☐ Promote GBS, CIDP, & other associated Inflammatory Neuropathies
☐ Provide easy to understand information
☐ Provide information on our website
☐ Provide online meetings
☐ Provide support on the phone
☐ Send out information
☐ Share news and developments
☐ Social media
☐ Support local groups
☐ Talk to the government
☐ Work with other organisations
☐ Other

12/ What do you think we should focus on

*(Please choose **as many** options as you want)*

☐ Emotional/Mental health
☐ Fundraising
☐ Physical health
☐ Raising awareness
☐ Researching causes
☐ Researching the impact of conditions on people
☐ Researching treatments
☐ Supporting clinical trials
☐ Supporting people
☐ Supporting unpaid carers and families
☐ Working with charity partners
☐ Working with health partners
☐ Working with government
☐ Working with pharmaceutical companies
☐ Other

13/ How would you like us to work with you?

*(Please choose **as many** options as you want)*

☐ 1:1/Personal meetings
☐ Blogs
☐ Briefings
☐ Information sessions
☐ Local groups
☐ Newsletters
☐ Online groups
☐ Paper copies/mail
☐ Podcasts
☐ Social media
☐ Videos
☐ Webinars
☐ Website/online
☐ Other

If you have any other comments on what we do, what we should do, or how we do it, email your thoughts to office@gaincharity.org.uk

gaincharity.org.uk

Email: office@gaincharity.org.uk
Phone: 01529 469910

@gaincharity

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