

Steph's Big Day Out



Our intrepid Trustee
climbs Ben Nevis

AGM & Big Get Together Book your places



Write to your MP
Tell them about GBS, CIDP
& GAIN

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James W.

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A quick word from ...

A few thoughts from
GAIN's Chair and
Chief Executive

Carol Hooper
Chair



I mentioned our fundraisers in our March edition, but after a summer of incredible achievements and given the importance of this income stream for our small charity, I think it's worthy of a specific mention again.

I completed the London Marathon back in the mid 90's and 2 years after recovering from GBS whilst pregnant with my son, so I know and appreciate what it takes to undertake these challenges.

Walks, runs, bike rides, mountain climbing, abseiling, swimming, it doesn't matter what it is or how far or how long it takes... I know it takes tremendous effort, positive mindset and belief, tons of training and dedication, and above all a will to succeed.

To everyone of our past, present and future fundraisers you are not only incredible individuals, you are an inspiration and the reason why our charity can continue. Without you doing what you do, raising the funds through sponsorship or donations, we could not continue to provide support.

You are such an integral part of our operation and you truly are making a difference to people's lives. You should feel good and proud. All of us here at GAIN are very proud to have you as part of the team.

Rich Collins
Chief Executive



These newsletters come around really quickly, and whenever I start putting them together, I worry about them coming across as dull.

Well hopefully my worries will become a thing of the past. We are currently in the process of recruiting a new member of the GAIN Team who will be focusing on Marketing, Engagement, and Communication. I'm hoping whoever gets the job will bring in some fresh ideas, and help us to continue with taking GAIN forward. I'll introduce them once they are in post.

In this edition of Lowdown (which I can't believe is my third!!) we continue to highlight our amazing GBS and CIDP Community, from our fundraisers to our trustees. We've put in another inspiring story from a member, and we showcase another #GAINHero.

Back in June, I was lucky enough to go over to Belgium to meet colleagues from across Europe, and to highlight the needs of the UK community in terms of CIDP. You can read about my trip on page 16.

Also, this month we are inviting you to write to your MP and tell them all about GBS, CIDP, and GAIN. Lets try and get some interest in our rare conditions and our community during this parliament.

Celebrating Our Community

Ben gets our London entry

We were lucky enough to secure one place for 2025, and after running our own ballot, Ben Edwards was lucky enough to get the place.

You can sponsor Ben and follow his Marathon journey at <https://2025tcslondonmarathon.enthuse.com/pf/ben-edwards-50400>.



A massive GAIN thank you to all our fundraisers

Tony S, Lydia D, Jess W, Dorothy M, Daniel S, Matthew P, Shona M, and Abi D

We'd also like to take this opportunity to thank all our monthly and annual donors

James goes above and beyond

At the beginning of 2023, James Harker's identical twin brother had GBS. To help other families who are dealing with GBS, James decided to take on the Welsh 3000's challenge, a 24 hour challenge to scale 14 peaks above 3000m.

James told us "We had never heard of GBS before, and we felt like we were going into the unknown. I understand how much other families out there will be suffering, and that's why I decided to raise money for GAIN, a wonderful charity that does so much to raise awareness and help those stricken with this terrible condition.

A massive GAIN thanks to James for his fundraising.



You can watch James' video of his adventure at <https://www.youtube.com/watch?v=Sbi3fBfhWoQ>

Steph goes up Ben Nevis for GAIN

Not only does Steph Parker give up her time and expertise as one of our amazing trustees, she is also an incredible GAIN fundraiser. Steph, who had GBS, climbed 'The Ben' in August this year. Steph said "It took 10 hours and I felt totally broken, but so pleased that I was able to do it."

A massive well done to Steph from all of us, and a huge thank you for the £2,124.66 that you were able to raise to help with GAIN's work.



This month's #GAINhero is Kenny Smith, who can be found out and about across the UK with his custom Trike



In 2014, Kenny began to feel ill, and over the course of a long weekend, he steadily declined until he was paralysed from his eyes down. Neither Kenny, nor his family knew that this would be the start of a three year stay in hospital, two and a half of them on a ventilator.

Following discharge, life had obviously changed for Kenny. However, he didn't let this keep him from one of his true loves, motorbikes. While he couldn't ride anymore, Kenny got together with some top notch custom builders who put together a unique trike that could accomodate Kenny's electric wheelchair.

Once built, and delivered Kenny was back on the road, enjoying the wind on his face and the roar of the engine. Now on the second version of the trike (following a crash!!), Kenny has been out and about across Scotland and beyond, visiting bike shows and events, and always promoting GAIN, raising awareness about GBS, and raising funds for GAIN.

Kenny, we applaud your spirit, your ingenuity, and your commitment to GAIN. Thank you from all of us within the GBS and CIDP community.

If you want a real treat, watch the amazing film 'Highway Star' about Kenny's story at <https://www.youtube.com/watch?v=ERshJ2MaQAA&t=269s>



Soroptimist International Blackpool and District support GAIN for Norma Parry

The amazing folk at Soroptimist International Blackpool and District have made an amazing donation of £1000 after one of the members, Norma Parry, was struck by GBS.

Norma says "I was diagnosed with GBS last December. 3 weeks in ICU in Blackpool followed, then 6 months in a Neuro Rehab Unit, before being transferred to Brainkind where I am currently, with a revised diagnosis of CIDP.

I have been a Soroptimist for over 20 years, but when my club offered to send this donation to Gain because of me, I was reduced to tears. I am not the sort of person who likes the limelight but on this occasion I want everyone to know that Soroptimist International, whilst being an organisation that promotes the welfare of women and girls, also promotes many other charities which do not get the recognition they deserve.



News

A letter to Wes Streeting

GAIN has joined up with National Voices and 109 other health and social care charities in writing to Wes Streeting, the new Secretary of State for Health and Social Care, congratulating him on his appointment and outlining the burning topics the sector is keen to discuss and highlight. As a collective, National Voices and its members felt the Secretary of State for Health and Social Care's assessment of the NHS as "broken" was both accurate and refreshing, as it voiced what many of the people we advocate for have felt over the last few years, as many have increasingly struggled to access the health and care they need.

You can read the joint letter, and find a full list of signatories, [here](#), or scan the QR code to find out more.



An update on the UK Plasma Strategy

As you will all know, plasma from blood is vital for the GBS and CIDP Community. As a result of CJD ('Mad Cow's Disease') we weren't allowed to collect plasma in the UK, and have been dependent on overseas supplies, especially from the US. This has caused issues in terms of cost and availability. However, the NHS Blood and Transplant (NHSBT) service have issued this update.

"Since April 2021, we have recovered an incredible 1,000,282 litres of plasma from both plasma and blood donations. The Department of Health and Social Care, NHSBT and NHS England, are working together on an ambition to create a long-term domestic supply of plasma in England.

In recent weeks, the last of the regulatory requirements required for the manufacture and distribution of UK Plasma derived medicines were received, and our first shipment of around 32,000 units of frozen UK Plasma was sent to the fractionator in Germany to begin the process of being turned into lifesaving plasma medicines for the first time in 25 years. The first UK patients will receive these medicines in early 2025. Every week we will now ship 30,000 units of frozen UK plasma to maintain a steady supply of medicine.

At NHSBT, we currently have three dedicated Plasma Donor Centres in Birmingham, Reading and Twickenham. We are focused on building a donor base, which has just exceeded 10,000 people, and continuing to collect plasma ready to make into medicines."

My Neuro Survey

Share your experiences and help improve neuro services by filling out #MyNeuroSurvey

The 2024 My Neuro Survey is now live, and we need as many people as possible to fill it in. This year's survey is all about sharing experiences and improving services.

Everyone deserves access to the right care, treatment and support at the right time, no matter who you are or where you live. But too often this isn't the case.

There are three versions of the survey this year, one for people with a neurological condition, one for carers, and one for children. This is the first time there has been a specific survey for carers, and we really want to hear from people who support others.

There are lots of ways to complete the survey. You can click on the link or scan the QR code below, or you can even request paper copies, fill it in over the phone, or get it in different languages. More details on how to access other versions of the survey can be found at <https://gaincharity.org.uk/my-neuro-survey/> or call the office on 01529 469910 for more information. What is important is that you fill it in and share your views.

By sharing your experiences you can help us and our colleagues within the UK Neurological Alliances to build a picture of treatment, care and support for people affected by neurological conditions throughout the UK and the Republic of Ireland.

The survey takes around 20 minutes to complete. It's completely anonymous and secure.

Please take part and make your voice heard.

Please complete the survey by 15 November 2024.

Scan the code to complete the survey or go to revealingreality.welcomesyourfeedback.net/s/3kl0se



1 in 6 people in the UK and the Republic of Ireland has a neurological condition. Help reach them all.

A photograph showing a young girl with curly hair and an elderly woman with white hair, both smiling and looking at something in the girl's hands. They appear to be in a kitchen or a similar setting.

#MyNeuroSurvey

A row of logos for various organizations: The Neurological Alliance, neurological alliance of Scotland, niNCA (Neurological Charities Alliance), Cŵsgrŵp Neurolegol Cymru, Wales Neurological Alliance, na? (Neurological Alliance of Ireland), and gain.

This year's AGM

Every year, GAIN has an Annual General Meeting. This year we will be in London on Saturday 2nd November

This year GAIN are hosting our AGM in London as part of a day celebrating the GBS and CIDP Community.

We would love as many people as possible to join us at 11am on Saturday 2nd November to hear about how the charity did last year and to explore plans for the year ahead.

Voting members can get involved by voting, asking questions, and getting involved in discussions. This is your opportunity to get really involved in the decision making of your charity.

The day continues at 1pm with the Big Get Together, our celebration of all things GBS and CIDP (see the next page for more details).

You can join us in London at the Radisson Blu Hotel in Canary Wharf. or join the AGM online. Tickets are available at <https://www.ticketsource.co.uk/gain> or by scanning the QR code below.



For those wanting to join online, further instructions will be sent out after you have registered.

Further information on voting and how to vote will be sent out to all registered voting members in October. If you'd like to join as a voting member or update your membership details go to www.gaincharity.org.uk/membership or contact the office on 01529 469910 or office@gaincharity.org.uk

Big Get Together

GAIN have joined up with GBS/CIDP Foundation International to host The Big Get Together 2024



Join us for our first BIG Get Together, a celebration of the GBS and CIDP Community in the UK, and a chance to look forward to the future.

We will be looking at what's next for GAIN, learning about the latest medical news, talking about our hopes and aspirations, highlighting emotional and mental health, and focusing on celebrating and looking ahead.

There will be lots of chances to chat and meet up with Trustees, staff from GAIN and the Foundation, members of the Medical Advisory Board, and members and volunteers from GAIN.

The Big Get Together is being held at the Radisson Blu Hotel at Canary Wharf in London, on Saturday 2nd November. You will be able to join us at the venue or we are hoping to have some limited coverage and accessibility online. Tickets are available at <https://www.ticketsource.co.uk/gain>

Write to your MP

Does your MP know about GBS and CIDP? Well we think they should.

Back in July, we had a general election in the UK. It seems like a long time ago now doesn't it!

Well, following the summer recess, MPs have returned to parliament, and we thought that this would be a great time to let them all now about Guillain-Barré Syndrome, CIDP, MMN, and other related conditions, as well as the issues associated with the conditions, and the work of GAIN.

It would be great if as many as people wrote to their MP (whether they are newly elected or have been your MP for a while) and raised awareness of our community and the issues that it faces.

To make it as easy as possible, we have put together a draft letter that you can use on the next page. You can also find it at www.gaincharity.org.uk/write-to-your-MP

To find details about your MP's address or email address we have also put some links on that page on the website.



If you'd like any help then get in touch with the office at office@gaincharity.org.uk or call 01529 469910.

Let us know that you have written to your MP, and let's see how many MPs we can reach.

RE: Support for GAIN (Guillain-Barré Syndrome and Associated Inflammatory Neuropathies)

Dear [MP's Name],

I am writing to you as one of your constituents to raise awareness about Guillain-Barré Syndrome (GBS), Chronic Inflammatory Demyelinating Polyneuropathy (CIDP), and other related inflammatory neuropathies, as well as to seek your support for GAIN (Guillain-Barré and Associated Inflammatory Neuropathies), the only UK charity dedicated to supporting people impacted by these life-changing conditions.

GBS and CIDP are rare but serious conditions that impact the peripheral nervous system, which can lead to severe and long-lasting disability. They affect around 1,500 people in the UK each year. These conditions can develop suddenly and without warning, leaving individuals and their families facing profound physical, emotional, and financial challenges. While some people recover fully, others live with long-term effects that can severely impact their quality of life.

GAIN plays a critical role in supporting people impacted by these conditions by providing essential information, advice, and emotional support. The charity also funds and conducts research to improve the understanding and treatment of GBS, CIDP, and related neuropathies. Moreover, GAIN works tirelessly to raise public awareness about these conditions to ensure that more people can receive timely diagnoses and appropriate care.

As a Member of Parliament, I urge you to champion the cause of those impacted by GBS, CIDP, and similar conditions by:

1. **Raising Awareness:** Please consider using your platform to highlight the challenges faced by those living with these rare conditions and to promote the work of GAIN
2. **Supporting Funding and Research Initiatives:** Advocate for increased government and NHS support for research and treatment related to GBS and CIDP
3. **Championing Patient Access:** Help ensure that people impacted by these conditions have timely access to the best possible diagnosis, treatments, support services, and rehabilitation, which can significantly impact their recovery and quality of life
4. **Meeting with GAIN:** I encourage you to meet with representatives from GAIN to learn more about their work and the challenges they face in supporting people impacted by these conditions. You can find out more about GAIN at www.gaincharity.org.uk

Your support could make a tremendous difference in the lives of individuals and families across the UK who are affected by these devastating conditions. Thank you for considering this request, and I look forward to hearing from you about how you can help raise awareness and support for this important cause.

Yours sincerely,

[Your Name]

[Your Signature if sending a hard copy]

Your Story

Victoria McDowall shares her story of what she thought was wedding planning stress, that actually turned out to be CIDP.



In October 2011, I realised that I had been feeling pins and needles all down the bottom half of my legs throughout that evening. I had been very tired, had blood tests which didn't show anything, and just thought I was stressed due to work and planning my wedding for July 2012.

The pins and needles did not go away, and I gradually became more fatigued and felt generally rubbish. By the time my wedding day arrived, I was feeling very run down and was unwell for all of my honeymoon. I was so weak when we got back that my new husband had to wheel me through the airport using a luggage trolley!

I was taken to hospital and referred to another hospital to see a neurologist. I was put through a barrage of scans and tests including a lumbar puncture, and was eventually diagnosed with CIDP.

Since then, I have tried out a few different makes of IVIG, suffering horrendous side effects including aseptic meningitis, eventually settling on a lower dose of Gamunex. It took a few years to iron out, but I am now able to work part time for the NHS. I continue to have IVIG every five weeks, and suffer with extreme fatigue and ongoing pain.

I think the biggest thing for me was accepting my life had changed. I have been on the waiting list for sub-cutaneous IG for seven years, and my neurologist is not the most helpful. Some people with CIDP are very lucky and have helpful neurologists. It is like getting blood out of a stone with mine!

I do not know anyone else with CIDP, so the only support I have is via GAIN and other online groups, for which I am grateful. I know the immune system is very complex, and I live in hope that there will be a possible answer in the future.

Does any of this sound familiar to you?

Do you relate to these real life stories?

Do have your own story to tell?

**Then get in touch with us at the GAIN
office using office@gaincharity.org.uk
or call 01529 469910**

**If you want to share your story via a
video or audio clip then send it via
WhatsApp to 07878 090965**



Meet the Trustees

Meet the people who help run your charity, our amazing Trustees

Jatinder Paul

Jatinder is a Solicitor (a Partner) at leading law firm, Irwin Mitchell LLP, and he specialises in assisting individuals who have developed serious life-changing illness and injuries through no fault of their own such as negligence caused by food poisoning following incidents across the globe. He has vast experience of handling complex and high profile cases for individuals who have catastrophic injuries / illnesses.

Jatinder cares passionately for his clients, who often require access to rehabilitation and funds for ongoing medical treatment, physiotherapy and care.

He has worked in this field for over 10 years and is often sign-posting his clients to charities such as GAIN to assist with their therapies and rehabilitation.

Jatinder became connected to GAIN through one of his clients, Mr William Marsh, who returned from the Dominican Republic in 2018 with food poisoning and developed GBS some days later. Before instructing Jatinder, William worked with GAIN to access statutory services and continues to work with his local authority in securing the services that he requires given that he remains paralysed and in need of considerable support.

Jatinder quickly realised the benefit that GAIN has to individuals who live with GBS and reached out to the charity to ascertain what more could be done to help others in the same situation. Jatinder enjoys working with the other trustees to develop the charity.

In 2016 Jatinder was named Young Professional of the Year at the Signature Awards in Birmingham. The Signature Awards celebrates the work of Asian professionals working in a range of industries including banking, accountancy and law. Jatinder is a recommended lawyer by the Legal 500, and he is an APIL Senior Litigator and Accidents and Illnesses Abroad Specialist. He often lectures at events organised for industry colleagues such as APIL, RSPH and PEOPIL.



Local Get Togethers

The Lancashire and Cumbria Group gets a visit from the Chief Executive

The latest meeting of the GAIN Lancashire and Cumbria Group was on Saturday 7th September, and Rich travelled up from Lincolnshire to introduce himself, and hear directly from the group.

A lively and busy meeting of 18 local people came together at Catterral Village Hall, and shared stories and experiences. Old friends caught up with each other, and new members arrived to receive support and reassurance from people who had been through GBS or CIDP before them.

Rich took the opportunity to talk to members of the group about his role, and how GAIN would support the group going forward. He spoke about his appreciation for the work the group had undertaken on behalf of GAIN for many years, and the value that Local Groups brought to the Charity.

After tea, cake, and a raffle (complete with tombola), the group presented Rich with an incredible donation of £150 from their fundraising.

After the meeting Rich told us “I can’t quite believe how amazing the folk in the Lancashire and Cumbria Group are. We couldn’t ask for a more supportive group. They completely represent our amazing GBS and CIDP Community, and I am so pleased that they invited me to join them. I can’t wait to visit again.”



The next meeting of the group is on Saturday 7th December. Dates for 2025 are 8th March, 7th June, 6th September, and 6th December. If you want to know more about the Lancs and Cumbria Group email Rosie on rosemarieh@gaincharity.org.uk

Rich's trip to Ghent

In June this year, our Chief Executive was invited over to Ghent in Belgium to meet with patients and colleagues from across Europe, and with representatives of argenx, a multinational pharmaceutical company. The two-day meeting was all about CIDP and the impact that the condition has on people and families. We asked Rich to tell us all about his trip to Belgium.



Getting up at 5am to jump on the Eurostar isn't my idea of fun, and a packed St. Pancras station full of football fans travelling to see England in the Euros made me think, why couldn't we have done this on zoom! However, two days spent with like minded colleagues, CIDP patients, and colleagues who are trying to improve lives really showed the power of coming together.

I was a little dubious about travelling at the expense of a pharmaceutical company, and arriving at their very fancy offices didn't help, but it was wonderful to be greeted by and meet in person my colleagues from other European GBS and CIDP organisations. Coffee and chat flowed easily as we discussed what we were hoping to achieve by getting together and setting out the parameters of the meeting. The focus was on the burden of CIDP, and we spent the rest of the day sharing experiences and learning how each other systems worked. As one of the only non-patient representatives, I was incredibly grateful to our members in the UK who had shared their experiences with me and Claire, and whose examples I was able to quote (all anonymously of course).



That evening, all the members of EPODIN (European Patients Organisations for Dysimmune Inflammatory Neuropathies), this includes GAIN of course, met for an Annual General Meeting and discuss the shared issues for people impacted by GBS, CIDP, and other conditions across Europe. Members were from the UK, France, Germany, Italy, Spain, and Romania.

It was amazing to share experiences, and hear about how other organisations were run, and what they did.

Rich's trip to Ghent (continued)

This meeting was followed by a working dinner with colleagues from argenx, including their Global CEO who joined us and showed a lot of interest in the needs of the CIDP community. I should say, argenx aren't doing this out of the goodness of their hearts. They are in the process of developing a new treatment for CIDP (the first for 30 years) so the information they are seeking to gather is to support that development. However, I was genuinely impressed by their openness, their dedication to the community, and to what they are seeking to achieve.



The second day in Ghent was all about sharing data and information. argenx have commissioned research that has captured information from CIDP patients and neurologists from across Europe, including the UK.

As a self-confessed data nerd, this made me very happy as the lack of data I have been able to find since I joined GAIN has been very limited. We were all able to test this data against our own experiences, and the information from patients that we have gathered.

All in, this was an incredibly rewarding few days. I learnt a lot, made some excellent connections, and the result of the day is the development of a research report that will be published (hopefully) later this year. I'll share this with everyone when it is available.

It was great to work with European colleagues and build on GAIN's reputation and place within the sector, and I was honoured to represent GAIN, the UK CIDP Community, and all of you.



Projects

Tell us what projects we should run and what we should focus on?

On a board in our office we have a long list of projects that we have been thinking about. These project ideas come from feedback from members, things we pick up in conversations when people ring us up, the themes that we see in our work, and sometimes just from the ideas going through our heads.

We think that an important part of our work is carrying out pieces of work that help improve lives, test things out, try new things, or explore new ideas to make things better.

Some of the things on the list include:

- **Emotional Health**
- **Physiotherapy**
- **The long term impact of residuals and symptoms**
- **Diet and lifestyle**
- **Exercise and movement**
- **Ageing and residuals**
- **Sexual Health**
- **The impact of stress**

**We want to know what you think? What are your thoughts on these ideas? Are there any particular projects we should run
Let us know via office@gaincharity.org.uk**



Suggestion Box

As hopefully you are aware by now, we consider ourselves to be a listening organisation. We are led by our members, and we are here for all people impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies.

In order to keep listening and to provide you with the opportunities to get involved in what we do, we want to keep hearing from you with your ideas and thoughts.

To help, we have created a new email for your ideas. Consider it as a virtual suggestion box. If you think of something, jot it down in an email and send it to ideas@gaincharity.org.uk. Alternatively drop us a message, voice note or video clip via WhatsApp to **07878 090965**





**Get more information at
www.gaincharity.org.uk**

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