

# Inflammatory Neuropathies UK

## INdepth

**March 2026**

**Annual Survey Edition**

**also IN this edition..**

**Our office move**

**Our big May challenge**

**Our fundraising heroes**

**And more**

**@InflamNeuroUK**



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## Introduction

### Carol Hooper | Chair of the Board

Well, what a frantic start to the year. Hopefully, a good sign of amazing things to come in 2026!

We completed our search for an Operations Manager and are so pleased that Tansy Miller has joined us bringing a wonderful skillset that is going to significantly benefit all of us and the charity. Welcome Tansy.

I've been out and about and travelled to Lancaster for the launch of Rosie's Project. What a wonderful welcome I received from members of the Lancashire & Cumbria support group and their families. Such an amazing initiative that will also bring huge benefits to Inflammatory Neuropathies UK.

Yesterday I attended the Essex support group in Billericay. Huge thanks to Rosie and Jenny for getting this up and running. I met some lovely people impacted by GBS and some who are still waiting for their conditions to be diagnosed. For all it was great to have the opportunity to talk, share information and just be there for each other. Another big step forward in creating the national community we are striving for.

And finally my training for May Awareness month is underway. I will be walking in the pool/swimming 10km to raise awareness and funds for the charity. Good exercise, better on my muscles and joints and all for a good cause win, win. I've completed 275 lengths so far (6875m and 4 hours in the water) and I'm feeling good about the challenge on the day. Why not join me **IN the water** with your own challenge?

### Rich Collins | Chief Executive

This Spring sees some more big changes at Inflammatory Neuropathies UK. As you will have seen last month that we were moving from Glennys Sanders House, to 3 Mill House in Sleaford. We are now settled into our new home, but it will take a while to get everything in the right place, and to get used to a new environment. Change can be difficult, but it can also be a good excuse to refresh and improve things.

This month has also seen another considerable development. I'm thrilled to say that Tansy Miller has joined us as our new Operations Manager. Tansy has significant experience of working across the charity sector with organisations like the MS Society and Trussell. She has a real passion for making a difference, and I know you will all welcome her with open arms.

With Tansy on board, we will be looking to push forward with our Strategic Plans which we unveiled back in October at the Big Get Together. We have been working on the action plans and key impact measures, and you will be seeing some of it coming to fruition already. There are more big plans in development so keep an eye on future additions of the newsletter for more.

And finally, you will know that for me, hearing from you all is incredibly important. When I first arrived in 2024, I started up an annual survey so that we could hear what you thought about the charity, and look to make things better. It's now time for the third edition of the Inflammatory Neuropathies UK annual survey. Head to page 22 to find out more. Whether you complete it online or and send in your response, please do take the time to do it. Without your views we don't know what you want or need. Remember, this is your charity, so please help guide it.

# IN charity news

We're over the moon to bring a special news section to the newsletter this month, we're INtroducing a new colleague, and new location! So let's meet..

## Tansy Miller

Hi everyone - delighted to meet you all! I'm thrilled to be here at Inflammatory Neuropathies UK as our new Operations Manager and have already been hearing about the fantastic work we're doing to support everyone affected by different forms of neuropathy.



It's clearly a really exciting time to join the organisation and be part of such a great team. I've been fortunate to work with some superb charities over the last thirty years including Trussell, the MS Society and Citizens Advice, where I was responsible for managing operations, leading staff and volunteers and coordinating a wide range of services.

Supporting people with neuropathic and health conditions is particularly close to my heart though as a close family member had MS, so I know how vital it is to get the right support at the right time. I very much look forward to getting out and about and meeting you all properly soon and working together to really make a positive impact for everyone in our Inflammatory Neuropathies community!

- Tansy

## Our new home

As Rich mentioned in his opening blurb - we're on the move. Or have been by the time you read this. Yes, we've packed up operations at Glennys Sanders House and moved to 3 Mill House in Sleaford. This places us at the heart of Sleaford and allows us to interact with our home base on a much more personal basis.

While Glennys Sanders House was a phenomenal home (it's named after our founder after all), it's just too big for our purposes. We were able to let the space out to a charity with a larger team, while renting a space more appropriate for our staffing and footfall.

This therefore opens up a new revenue stream, is a little more environmentally friendly (we don't need to heat a huge space over winter), and lets us work with the local Sleaford community.

Glennys was fully on board with the move, giving her blessing. And we're more than happy to say her name will remain on the original building going forward.

# **IN** the water

**And finally in charity news (well, the rest of this publication is technically charity news but go with us on this), we're so excited to reveal our May challenge - IN the water!**

Last year we asked you to light up the UK for Inflammatory Neuropathies, and you responded in droves, lighting landmarks and buildings in brilliant blue for GBS and CIDP Awareness Month. This year, we wanted to do it a little different and recognise all 40 of our supported Inflammatory Neuropathies during the month.

To keep it **IN**clusive, we have a couple of ways to get **IN**volved.

## **Get IN the water**

Swimming is one of the most accessible sports and activities to most living with an Inflammatory Neuropathy. It's low impact, doesn't require full sensation in feet/arms, and is a great way to keep fit.

In May, will you go **IN the water** and raise funds for us by swimming an amount of lengths you feel is a challenge for you? Whether it's one over the full month, or you're like our Chair of the Board, Carol Hooper ([www.justgiving.com/page/carol-hooper-1](http://www.justgiving.com/page/carol-hooper-1)), who is taking on a swimmers marathon in a day, go **IN the water** and help raise funds and awareness.

## **Go under the water**

Swimming not for you? We understand. Well there's a couple of other ways to join the fun.

If you're impacted by an Inflammatory Neuropathy, will you pledge to go under a cool (but no painfully cool!) shower blast each day? Tag your friends to get **IN**volved to help raise awareness, because, here's the other way to join in...

**If you're not impacted by an Inflammatory Neuropathy, or your friends aren't impacted, it's not always easy to understand the impact these conditions can have.**

Some of the conditions (though not all) cause severe tingling, numbness, and cause difficulties with fine motor tasks like typing, doing up a button, or chopping an onion.

Plunge your hands under a cold tap for a minute or two until nice and cold, and tingly (again, though - not painfully!), remove and dry them, and straight away try to send a message on your phone or button a shirt!

It's only a hint of what someone living with an Inflammatory Neuropathy might experience, but it's a start to understanding life with the condition.

**We'll have medals and awards for our top fundraisers. Learn more on our website and socials soon.**

### Part of Inflammatory Neuropathies UK's duty to you is to keep an eye on the latest news impacting our community.

We can then share it with you, help break down some of the more “jargon-y” articles, or discuss how a change in policy may impact your daily life. In some occasions, these turn into long form opinion blogs on our website, so please check in occasionally at [inflammatoryneuropathies.uk](http://inflammatoryneuropathies.uk).

If you've spotted an article about an Inflammatory Neuropathy that's left you scratching your head, please reach out and we can help break it down **IN simple terms**. Here's some of the latest news impacting our community:

#### Update on NICE appraisal on efgartigimod

You may recall that we have been keeping you up to date with the ongoing NICE appraisal of efgartigimod, a potential new treatment for CIDP. As you will be aware, NICE (National Institute for Health and Care Excellence) are the UK organisation that issues guidance for the NHS and for the health and care system. They are currently undergoing a process that looks at the clinical and cost effectiveness of efgartigimod to determine whether it will be approved for the treatment of CIDP in the UK. Last time we told you that we had submitted information into the process. The committee that is undertaking the appraisal has confirmed that their committee meeting to discuss the treatment will take part in March, and as expected patients will be involved and be heard on the day

It's good to see that the process is still moving forward, and that people's voices will be heard as part of the appraisal. We will of course keep you updated as this progresses.

*Project information | Efgartigimod with recombinant human hyaluronidase PH20 for treating chronic inflammatory demyelinating polyneuropathy [ID6409] | Guidance | NICE*

#### New Funding Boosts Research into Immune-Mediated Neuropathies

You'll know the name well if you're a long time Inflammatory Neuropathies UK supporter.

Professor Simon Rinaldi leads a research programme at the University of Oxford focused on how the immune system damages peripheral nerves in conditions including GBS and CIDP.

Another area of focus is MMN. Postdoctoral researcher Dr Nicolas Dubuisson is investigating why the immune system produces harmful antibodies that target motor nerves, causing progressive muscle weakness. By identifying the specific immune cells involved, researchers hope to develop longer-lasting – and potentially curative – treatments.

The work has been supported by several organisations, including the Royal Medical Academy of Belgium, Fédération Wallonie-Bruxelles, the Hospital Saint Luc Foundation, the Peripheral Nerve Society and the GBS|CIDP Foundation.

A new three-year grant of \$600,000 from the GBS|CIDP Foundation International will allow the team to expand the project, analysing patient samples in greater depth to better understand the immune mechanisms driving MMN.

## Latest on new GBS Treatment

We have been following the development of tanrurubart, a new potential treatment for Guillain-Barré Syndrome from Annexon.

We spotted some news on a number of sites that suggest that Annexon have submitted a Marketing Authorization Application (MAA) to the European Medicines Agency (EMA) for tanrurubart for the treatment of GBS.

Now while the EMA doesn't cover us here in the UK, submissions to the EMA tend to happen before submissions to NICE (our equivalent). So while this isn't the biggest news, it is still important as reports suggest that tanrurubart has been shown in clinical trials to 'rapidly stop neuroinflammation, enabling GBS patients to recover faster and more completely' from GBS.

There have been no new treatments for GBS for nearly 30 years, so we continue to wait in hope that this could be something that could be introduced to the UK in the future.

If we hear more, we will let you know.

## NICE Rare diseases quality standard(QS214)

Just before Rare Disease Day, NICE (National Institute for Health and Care Excellence) launched a new Quality Standard for Rare Diseases. Quality Standards are designed to improve the quality of care and services delivered and commissioned by the NHS and other providers.

The Quality Standard for Rare Diseases is made up of eight statements that lay out what people with a Rare Disease (which includes all Inflammatory Neuropathies) should expect in terms of services. These cover things like referrals, diagnosis, information, and access to services. It also states that everyone should have a named healthcare professional who coordinates or leads on their care and support.

This is a great step forward in ensuring that people with a Rare Disease know what to expect in terms of care and support, and to what standard they should expect. It doesn't mean instant change and improvement, but does give us something to build on and use to hold services to account. Inflammatory Neuropathies UK are delighted to see this standard in place, and are happy to endorse and support it.

To find out more head to [Overview | Rare diseases | Quality standards | NICE](#)

## Encouraging news in the Phase 3 CAPTIVATE trial

Dianthus Therapeutics has announced an early "go" decision in its Phase 3 CAPTIVATE trial of claseprubart for CIDP, following positive interim results. The decision was reached ahead of schedule after the study met its target, with 20 confirmed responders recorded among fewer than 40 participants in the first part of the trial.

No serious safety concerns linked to the treatment were reported, and the company plans to continue development using the 300mg dose while simplifying the next phase of the trial.

The results support ongoing progress of claseprubart as a potential new treatment option.



**Last year Inflammatory Neuropathies UK launched our Emotional Support Service for people impacted by these rare and life changing conditions.**

**If you haven't taken advantage of the sessions yet, let us tell you a little more.**

The emotional and mental impact of the conditions we support cannot be under-emphasised, but too often go unrecognised in favour of the physical symptoms.

Yes, the primary goal has to be stopping or halting the immune attack, but that shouldn't come at the expense of mental health.

The worry of recurrence. The fear of relationship and professional damage. The sleepless nights remembering intubation.

It's only natural you flinch every time you get pins-and-needles, but if it's a bit more than a flinch and you think you could do with talking to someone, we've got you.

Working with Rareminds, Inflammatory Neuropathies UK can offer anonymous, one-to-one support sessions with counsellors trained in rare conditions.



It's absolutely free at the point of access. That's what our fundraising heroes are doing it for.

To arrange an initial consultation, email [stephanie@rareminds.org](mailto:stephanie@rareminds.org), using the subject line "The Inflammatory Neuropathies UK Counselling Service" and they'll arrange a screening call.

We won't even know your name, we'll just get a notification someone has used the service.

Remember, our community spends hours in physio and rehab. We stretch. We twist. We lift. We rest.

That same principle can apply to our brains. It's just another organ after all, we can help strengthen it.

**If you or someone you know is struggling right now, there are trusted organisations across the UK offering free, confidential support.**

#### **Samaritans**

Call 116 123 (free) or visit [www.samaritans.org](http://www.samaritans.org)

#### **Shout**

Text SHOUT to 85258 or visit [giveusashout.org](http://giveusashout.org)

#### **Mind**

[www.mind.org.uk](http://www.mind.org.uk)

#### **NHS Every Mind Matters**

[nhs.uk/every-mind-matters](http://nhs.uk/every-mind-matters)

#### **CALM (Campaign Against Living Miserably)**

[www.thecalmzone.net](http://www.thecalmzone.net)

#### **Papyrus UK**

[www.papyrus-uk.org](http://www.papyrus-uk.org)

**If you are in immediate danger, call 999 or go to your nearest A&E department. Remember, you're not wasting anyone's time, these services are here to help when you need it.**

In February, there were two exciting events in the Scottish Parliament. A Rare Disease Day reception, and Scotland's Disability Summit. We sent our Scottish team member, Chris, across country to find out more.



I love representing our community in person when I can, but here just outside of Glasgow I don't always get the chance. So when two events that impact our community came along, I was on it like a flash.

First up was Genetic Alliance UK's Rare Disease Day reception at the Scottish Parliament.

The day started with a minor interrogation from the security team about my t-shirt and whether "Inflammatory Neuropathies UK" were a protest group (a good opportunity for some awareness raising, and a reminder to wear a button up shirt).

The event itself was very well attended with guests from all walks of the Rare Disease community.

Bob Doris MSP led the discussion, and invited speakers from Genetic Alliance UK along with Jenni Minto MSP.

Of course, the highlight of the day was 15 year old Emma, living with Williams Syndrome, who spoke with confidence about her experience of a rare condition.

It was an excellent event, and I encourage you to look at the full report [geneticalliance.org.uk/rare-disease-day/rare-disease-day-2026/](https://geneticalliance.org.uk/rare-disease-day/rare-disease-day-2026/)

After a quick run around Arthur's Seat (it's higher than you think), it was off home to recover before the main event on Saturday, The Scottish Disability Summit.

Imagine my surprise when we entered the parliament to be taken straight into the main Debating Chamber. Having spent hours of my life watching significant events in recent history unfold here (COVID, Independence for just two), it was quite a head spin to now be in the room itself.

The day started with a welcome from Presiding Officer, Rt Hon Alison Johnstone MSP, Jeremy Balfour MSP, Kaukab Stewart MSP, and The Traitors star, Meryl Williams.

Next - the meat of the day! We went into our breakout rooms to discuss what actually matters. I attended the Social Security workshop (led by Elena Whitham MSP), and let me tell you - ideas **flowed**.



From uniting the Blue Badges (why does every council area need its own system?), to looking at a system where people with conditions don't have to incessantly fill in the same details on forms over and over again just to get a basic standard of living. It was tremendously high energy stuff and I think change could really be on the horizon.

After the workshops was a quick chance to network over lunch, before retiring to the Debating Chamber to discuss, and vote on, what the priorities should be for the incoming government in May.

I might just be naive, but I left feeling very optimistic about the future for those living with disability or impairment in Scotland. Here's hoping I'm not!

## Nola Rowlands & Friends



On Wednesday 17th December 2025 on a very cold day, six girls from Class 13 at St James Primary School Cheltenham braved the elements and organised a charity bake sale as part of the school's end-of-term charity stalls.

The girls – Anushka, Ellie, Emilie, Molly, Nola and Olivia – baked and sold a wide range of treats including cupcakes, cookies and rocky roads, raising just over £50 on a very busy day and selling every single treat.

One of the chosen charities was Inflammatory Neuropathies UK, which is particularly close to the group's hearts as Nola's Grandpops, Iain Graham, was affected by GBS in 2011.

The girls were proud to support a charity. And would like to say a huge thank you to everyone who supported them and helped make the day such a success.

They raised a fantastic £50, woo-hoo!

## Charlie Litster



"A tingling in the fingers, a blink of an eye, and suddenly there's a stairlift being installed in the house.

That was the reality for my mum, Lindsay (hi mum!), who went from brisk walks with the dog to finding herself unwillingly lying on the sofa watching the nice chap install her new "Stannah".

Another person learned the hard way what the acronym CIDP means, and another life was limited by its effects.

Thankfully, through the miracle of science and the backing of Inflammatory Neuropathies UK, she's back doing (albeit slightly less brisk) walks, so I set out in December to raise money for the cause.

I cycled six hours a day solo along the length of Italy over three weeks (my knee still hasn't forgiven me...). It was tough – but I was proud to watch the donations roll in and smash

through my target over a glass of red in the evening.

Thanks to Inflammatory Neuropathies UK for everything you do!"

Charlie raised a monumental £3,251.71, what a job!

## Freddie Rogers



“Inflammatory Neuropathies UK means a lot to me for a very real reason. I had Guillain Barré Syndrome when I was 14 and it changed my life. I made a full recovery, but I still remember the fear and the uncertainty. I also remember how much support mattered to me and my family. I want to give something back to people who are going through this now. Inflammatory Neuropathies UK helps people feel less alone and better informed. It also helps families understand what is happening.

What drives me most is turning a difficult chapter into something useful. I want to show others that recovery is possible. I also want to honour the people who helped me when I needed it. Fundraising feels like a simple way to do that and to stand with everyone still facing these conditions today.”

Freddie raised a whopping £761.25, thank you!

## IN memory of Peter Sills September 1953 to July 2025



“I love this photograph.

The smile on Peter’s face reflects how much he was enjoying our special holiday in Australia, visiting our daughter and family. We had recently become grandparents to little ones there and were also looking forward the arrival of our son’s new baby, on our return home.

After a busy working life, it was truly wonderful to begin this new chapter and to look forward to so many happy times ahead.

Peter was certainly enjoying his much-deserved retirement. He volunteered as Chairman of our local Community Centre, where people can come together for a variety of activities. He was also a very keen member,

actor and Chairman of a local amateur dramatic group. He enjoyed organising two Bridge groups and playing the game while making new friends.

Being very sociable, he loved sharing a pint and a chat in our ‘local’ and was a valued member of the quiz team on Tuesday evenings.

Little did we know how all of this would sadly change so quickly and so drastically over a weekend in early September, 2024. This was when Peter fell victim to Guillain Barré and then CIDP , presenting him with the biggest challenge of his life.

He was so very brave throughout the journey and his positivity, together with his sense of humour and the little radio by his bedside, playing his beloved Classic FM, will long be remembered by all the amazing staff on the ICCU ward of New Cross Hospital in Wolverhampton. We continue to be very proud of him, and he is so greatly missed.

Thank you to so many people who raise awareness of these conditions, offer support and organise and take part in fundraising opportunities.

It is so appreciated.”

Thanks to Pat and Peter’s family and friends, Inflammatory Neuropathies UK received £2,945.17.

# IN their steps

## Fundraising with an Inflammatory Neuropathy

Hello all, my name is Danielle (Dani to most) and I had Guillain Barre Syndrome in January of 2019. I was very poorly, completely paralysed and ventilated in Intensive Care in Royal Bournemouth Hospital where I was for 4 months until I was medically fit to go home and continue Rehab. Fast forward 7 years and I am around 95% back to where I was before, the residual symptoms I have are fatigue and occasional nerve pain which I manage well. I feel extremely lucky and grateful for life and my health and appreciate everything my body did to get back to where I am.

Whilst I was placed in an induced coma, the wonderful staff in the hospital passed over details of Inflammatory Neuropathies UK to my parents and straight away my mum contacted them, they were amazing and supported my parents through the extremely difficult time they were facing. When I was back to a place where I was recovering and thinking forward to my future, I wanted to give back so I started fundraising and raising that all important awareness for Inflammatory Neuropathies UK. In the past 7 years I have raised around £13,500 which I am extremely proud of. This is through the hard work of my family, friends and colleagues and of course the continued support from Inflammatory Neuropathies UK.

I have hosted several different events to fundraise including Cake Sales, Quiz, Race Night, Raffle and Games. There are many ways to fundraise which don't always have to be attached to sporting events, as this can be difficult especially when in recovery.

I feel the success of your events starts with the advertising of it, ensure you have a good poster or post on social media promoting your event, getting it out there. Speak to people, spread via word of mouth and if you are comfortable then tell your story, this personalises things and gets people more involved naturally. Try

and source some free prizes from local businesses which in turn gets IN UK's name out there, so it is a win win.

Sometimes it can be daunting, and you don't know where to start when organising our event. Writing a list of things to do always works for me. Enlist the help of your friends, family and colleagues and set them tasks to do that can help you. Space out your tasks over time, do not overdo it, especially if you are still in the recovery phase. Remember that what you are doing is amazing and that you are not only fundraising, but you are spreading the word and flying the flag for Inflammatory Neuropathies UK.



My quiz and race night was a huge success, and I continually have people asking when the next one is, it was fun and everyone got involved and it was a nighttime event where people could let their hair down and dance the night away. I strongly recommend this type of event.

If anyone would like to chat about organising an event, need help or support then please feel free to ask the charity to pass on my details to you and I would be happy to help. Maybe some day we can do a joint event? That would be cool!

# INcoming and upcoming

Feeling inspired by our fundraising heroes? If you fancy taking on an event in aid of our work, here's what's coming up soon!

**3rd May 2026 | AJ Bell Great Birmingham Run – 10k**

**26th April | London Marathon – SOLD OUT**

**13th September | AJ Bell Great North Run – SOLD OUT**

**4th October 2026 | AJ Bell Great Scottish Run – Half Marathon**

“Having the crowd on your side and literally cheering every single step you take is something else! Having people cheering your name and shouting words of encouragement is simply amazing! Don't think either of us ever imagined just how amazing the day itself would be! Thank you so much Inflammatory Neuropathies UK!

We are both truly humbled, appreciative and again so so thankful for the opportunity”

We're proud to be able to give places to you, our fundraisers, in return for taking on these events for us. All we ask in return is that you raise a minimum sponsorship (to be discussed per event).. and do try to snap a few action photos for our social media!

# IN your speakers

We've been back on the airwaves recently with IN all honesty!

You can listen to our podcasts on Spotify, Amazon, Apple, and YouTube, and keep an eye out for clips on our socials.

We've enjoyed a wide range of guests and subjects recently. We've had two amazing MMN advocates in Joanna Mason and John Navarro. Jon Follows – our volunteer, CIDP advocate, and Yorkshire group leader joined us, along with David McIntosh of United Plasma Action, the team behind the Advoca app, and Dr Stephen Keddie, consultant neurologist.

If you've got an idea for a guest, why not reach out to us at [hello@inflammatoryneuropathies.uk](mailto:hello@inflammatoryneuropathies.uk), or if you've got a question or comment for us to read out on air, send it over and we might be able to answer with our guest!

The image displays four podcast episode covers for 'IN all honesty', a podcast about GBS, CIDP, MMN, and other Inflammatory Neuropathies. Each cover features a photo of the special guest and their title. The covers are arranged in a row, with the first three having a pink background and the fourth having a white background. Each cover includes the 'IN this together' logo and social media icons at the bottom.

- Ep. 10** with special guest **Joanna Mason**, MMN Advocate
- Ep. 9** with special guest **John Navarro**, MMN Advocate
- Ep. 7** with special guest **Dr. Stephen Keddie**, Consultant Neurologist
- Ep. 6** with special guest **Jon Follows**, Living with CIDP & Volunteer

# IN their voices

## Rosie's Project

**It's been almost two months since we premièred IN their voices (or as we know it in the community - Rosie's Project) to the stars, their friends and families, and a lot of new faces in Lancaster. We promised a little more about how the day went, so to start us off, here's Rosie herself.**



**"Saturday 24th January 2026 is a day I will not forget, it is one which finalised many years of dealing with numerous dead ends and so much disappointment in the struggle to bring the affectionately known 'Rosie's Project' to life. But now the hurdles had been jumped and finally for the five films produced it was première day. A day of anticipation for those whose journeys with GBS were to be seen for the first time.**

We, the stars of the films, our families and friends along with others from the Inflammatory Neuropathies UK community and officials from the charity gathered at The Storey, Lancaster for this auspicious event. Not knowing what to expect from the occasion or the films, I was in awe of both - each film gave a touching insight to personal journeys during very difficult and emotional times. I knew when I spotted tears on the faces of the audience that I had witnessed something rarely seen these days - compassion, from that I also knew we had all 'done a reet good job', as we say in Lancashire.

I have said this many times but Rosie's Project would not have been possible without the support of the members of the Lancashire & Cumbria branch who fundraised, supported and made personal donations and to those people I give a huge thank you. To Rich Collins, Chris Morton and Claire from Inflammatory Neuropathies UK a massive thank you is due for all the input, guidance, and advice in getting to the finish line. Going forward I pray the films will raise the required awareness of GBS and the charity and its support and guidance for everyone in need."

*- Rosie Hyslop*



**The day started with a little lunch and so many cups of tea and coffee we had to resupply the milk jug multiple times.**

The Inflammatory Neuropathies UK team were on hand early to make sure the stage was set (a huge thank you to The Storey staff who laid on a beautiful lunch spread as our guests arrived and helped set up the audio/visual for the day).

To kick us off, Rich welcomed our audience, and invited one young guest to announce lunch was served into the microphone. Mic test properly complete thanks to our young MC, we all had a good chat as seats filled.

Finally, we started the day with our Chair, Carol Hooper, launching the event before inviting Rosie up to say a few words.



Rosie was as big a star as ever, and gave a fantastic welcome and backstory to the videos. It's always great having her up front at an event and what more fitting event could we have asked for!

And then all that was left to do was dim the lights and roll the clips. Each video was followed by a little roundtable discussion to go over the individual experiences.

**“What a privilege Alan & I felt attending the launch of ‘Rosie’s Project’. What a wonderful group of people. Their touching stories will really make a difference to the charity and other people’s lives. The group epitomise what we are striving to achieve with our Inflammatory Neuropathies UK community, and I can’t thank them enough.”**

*- Carol Hooper*



After the videos were through, then the real conversation started. It was really valuable for us as a charity to learn more about these experiences as it helps us focus our work. But it's also an incredibly important piece of community support, because sure enough – every speaker and every comment was met with a sea of nodding heads and knowing smiles.

By the end of the afternoon (and how did it fly by so fast), we were totally out of posters and pens, with our audience taking away awareness material – if you see them in public, snap a picture!

A huge thank you to everyone who joined us on the day. It was truly an afternoon to remember.

**“Finally seeing the films on the big screen was magical, but not as amazing as seeing the reaction from everyone. What an incredible day, I was so pleased to have been there. Next, we need to show them to the world.”**

*- Rich Collins*

Look for InflammNeuroUK or Inflammatory Neuropathies UK on YouTube to see these clips in full. And if you're living with CIDP... well let's just say stay tuned.

## **IN review:** **MMN Awareness**

**MMN Awareness Month is over for another year, but our campaigning never ends. Let's take a look at February, what did we do, how did it go?**

We launched the month by completely refreshing our MMN Info Hub. That was a key job as we were told it was like reading "Double Dutch." So what better time to rewrite than MMN Awareness Month?

With a more accessible hub in place, it was time to attack socials. We had a wide poster campaign, with slogans like MMN – Takes Strength, Plasma Gives It Back (see the next page for more). If you'd like any of these, check our socials or get in touch.

And we launched a series of short information blogs about the condition to give a general overview about symptoms, diagnosis, and treatment.

We released two new episodes of IN all honesty (available where you get your podcasts) featuring John Navarro and Joanna Mason – two MMN advocates with very different but impactful stories.

We held our first MMN Online Get Together which went very well. While it wasn't a huge crowd, it did allow us to have some really good chats with familiar and new faces alike. We hope to keep these going so check our website for dates.

We also held an IN conversation event in our Facebook group. Again, not huge numbers (but that's par the condition – though we can do better in engaging the community and will!) but impactful takeaways and knowledge, plus it's an excellent chance for our wider community to learn a little more about a fellow condition.

Of course, MMN Awareness Month couldn't be mentioned without reviewing Making the Most of Now's No One Rides Alone!

For over a year, we've been working with Clive Phillips and his team. We were on the ground at the Birmingham Cycle Show. We worked getting the story into UK press. We released podcasts and promotional materials. We strategised about the movie release. And now, finally – the UK cinema tour is here. We were thrilled that Tansy was able to attend a screening, see her review overleaf.

We also had some incredible feedback (anonymised) from the month!

***"I learned more from your posts than I have from my consultant"***

This meant a lot to hear, but does raise an important point on the lack of information and support that can be available for those living with the condition. Clearly there's an urgent need for more advocacy and awareness. Which leads us to this final point.

We made a pledge to you.

As we planned for MMN Awareness Month, we had to face an uncomfortable truth: we haven't done enough for people affected by MMN over the years.

While we mention the condition and offer general support, we need to do far more.

This month was a starting point. We will talk about MMN more, share more stories, reach more people living with the condition, and make sure MMN receives the same focus as GBS and CIDP.

But this cannot stop when the month ends. So here's our promise: we will do better for people affected by MMN, and if you feel we're not doing our best – **hold us accountable.**

## Inflammatory Neuropathies UK

**MMN**  
impacts  
0.6 people  
per 100,000



**Rare, not INvisible**

#MMNAwarenessMonth

## Inflammatory Neuropathies UK

**Weak Grip. Strong Spirit.**

**Living with MMN takes strength.**

#MMNAwarenessMonth

**Living with MMN takes strength.**

**Blood and Plasma donations help return it**

**Inflammatory Neuropathies UK**

#MMNAwarenessMonth



## No One Rides Alone: Tansy's View

It was a very heartwarming and beautifully filmed documentary about the determination and passion of a cyclist affected by MMN (Clive Philips) and his journey to complete the Tour de France.

The film focusses on his inner journey as much as the external, and there are some very honest glimpses into the moments of self-doubt as he undertakes such a difficult challenge.

Along the way he and his fellow team of cyclists meet Paralympians, athletes and other patients affected by Inflammatory Neuropathies. The courage, honesty and inspiration that comes across in everyone's stories is a real highlight, as well as the wonderful camaraderie of being able to joke, cry and empathise with other people with the same condition. It was also a wonderful opportunity to meet Clive himself and we're all incredibly excited to see what challenge he'll pursue next!

Finally, what comes across most vividly for me through this film is the importance for anyone affected by these conditions of having a strong, positive support network. Whether its family, friends, volunteers or professionals, the message is clear- no-one should go through this journey alone, and with the right support in place we can achieve so much more together!

#MMNAwarenessMonth

**Inflammatory Neuropathies UK**

**MMN is INvisible**  
**Its impact isn't**

**learn more about the impact of MMN**  
[inflammatoryneuropathies.uk/MMN](http://inflammatoryneuropathies.uk/MMN)

## IN your words

**Imagine the day. It's an early start, you're due to drop off your partner's stepfather who had just been released from hospital following surgery, and by the end of the day it's you in hospital. Well Dai Colbeck doesn't need to use his imagination. He lived the experience, and is here to tell his story.**



When the alarm went off at 7:00 a.m., it felt like any other Friday. I was due to drive four hours to Cardiff to collect John, my partner (now wife) Louise's stepfather, and take him back home to mid-Wales, where Louise and her mum would meet us. John had just come out of hospital after surgery for a brain aneurysm. I had no idea my own day was about to take a turn.

I got out of bed and immediately felt a tingling numbness in my fingers and toes. I brushed it off as a bad sleeping position and carried on—shower, clothes, car keys, fuel, a quick garage coffee—and set off.

The drive to Cardiff was uneventful, but when I stepped out of the car something felt wrong. I couldn't walk at my usual pace; my legs were heavy and unsteady. Worried but determined, I made my way to the hospital, relieved to sit down again once John and I were back in the car.

The two-hour drive to his home passed quickly. Louise and her mum greeted us with tea and fussing, but as soon as I stood up again it was obvious something had changed. **My legs were weaker, barely holding my weight, and the heaviness had begun creeping into my arms.** Their concern shifted from John to me.

After eating—and pretending I wasn't worried—I struggled to walk the short

distance back to the car. Louise drove us home. It was only a two-hour journey, but it felt endless.

By the time we arrived, I could hardly manage the few steps to our front door before collapsing through it. An ambulance was called. The crew arrived quickly, assessed me, and took me to A&E at the Countess of Chester Hospital, where I was found to have extremely high blood pressure.

I was quickly surrounded by doctors and nurses, bombarded with questions and put through a battery of tests. When nothing conclusive appeared, I was moved to the majors department for further assessment. By the early hours of Saturday morning, I could barely lift my limbs. I drifted into a restless, uncomfortable sleep and woke to a day that remains mostly a blur.

Louise stayed by my side, worried that I hadn't eaten or drunk anything since the night before. Eventually, a doctor suggested Guillain-Barré syndrome—an autoimmune condition where the body attacks its own nervous system. It usually develops over days or weeks, not the few hours I'd experienced. A lumbar puncture was needed to confirm it, but after several failed and painful attempts the procedure was abandoned, and I slipped in and out of sleep.





By then, the nerve pain was intense. My breathing had become shallow, and swallowing was getting harder. The doctor who first suspected GBS explained that I would need to be placed in an induced coma. I didn't fully grasp what that meant, but I felt too weak and frightened to do anything but agree.

I was taken to intensive care, intubated, and kept in a coma for two weeks. It was the strangest period of my life—an entirely separate story of its own.

When I finally woke, my body felt as if it had been filled with sand. I had a tracheostomy, and a ventilator was breathing for me. I couldn't move anything except my head, and even that only slightly. My mouth felt stiff and unresponsive, though thankfully my eyes still worked. It was terrifying, but the staff reassured me constantly that recovery was possible, and that many people eventually regain full function—though it often takes six to twelve months.



As I write this, I'm just over three and a half years into my recovery. The 405 days I spent in hospital feel like another lifetime.

With relentless physiotherapy and unwavering support from my family, I can now walk a few steps with a frame.

My grip remains very weak, so I still need help washing and dressing, but I'm steadily regaining strength and mobility, taking every small improvement as a victory.

About eighteen months ago, everything was knocked off course once again by a diagnosis of partial heart failure. Shortly after that came a second blow: tonsil and lymph-node cancer. Thirty sessions of radiotherapy later, I'm grateful to be in remission. I've had to accept that my old life of motorcycles, hiking, and camping is behind me, but I'm still here and fighting to reclaim as much independence as I can.

It's obvious to anyone who's lived through GBS that every story shared here only scratches the surface. **Behind the words lie the emotions, the pain and discomfort, the determination, and all the blood, sweat, and tears that never quite make it onto the page.**



**A huge thank you to Dai for sharing his GBS story. 405 days in hospital is a significant amount of time and it's helpful to capture accounts like this for others going through a similar experience to let them know that progress and getting home is very possible.**

**If you would like to feature in a future newsletter or website blog, please send your story with some pictures (if you're happy to) to [hello@inflammatoryneuropathies.uk](mailto:hello@inflammatoryneuropathies.uk).**

**Much like Dai, your story may resonate with someone and help them know there can be a future after GBS.**

March is Make a Will Month, an important date in the diary for any charity and a reminder of how planning ahead can protect the people and causes that matter most to us.

Many people choose to leave the majority of their estate to family and friends, but some also decide to include a gift to a charity close to their heart. Leaving a gift in your will (often called a legacy gift) is a powerful way to ensure your compassion continues to make a difference long into the future.

By remembering Inflammatory Neuropathies UK in your will, you can help create a future where people impacted by rare Inflammatory Neuropathies are better understood, supported and empowered. These gifts help the charity plan ahead with confidence and continue vital work for the community.



Legacy gifts can support a wide range of important activities. They may help fund research into better treatments for conditions such as GBS like in the above photo. We have directly funded and supported field changing investigations thanks to previous gifts.

They may also provide emotional support to people newly diagnosed with CIDP, or enable practical help that

allows someone with MMN to remain independent at home.

There are different ways to include a gift in your will. Some people choose to leave a fixed amount of money, while others leave a percentage of their estate after other gifts have been distributed. Whatever the size, every gift can help strengthen support for people living with Inflammatory Neuropathies now and for generations to come.

If making or updating a will is something you've been considering, Make a Will Month is a great opportunity to take that step, and perhaps leave a lasting legacy of care and support.

## How to leave a gift

If you have an existing will in place, and/or have a trusted solicitor, simply reach out to them to discuss amending your will to include a gift.

If you don't have a plan in place. Now is the perfect time because we've partnered with Make a Will.

Make a Will Online is a simple, reliable, and secure way to put your wishes in writing. It's also free at point of access, you can of course choose to leave a kind donation to cover the fee but this is entirely optional

You can begin your free will at:  
**[inflammatoryneuropathies.uk/legacy-gift-in-wills](https://inflammatoryneuropathies.uk/legacy-gift-in-wills)**

If you have any questions or concerns about the Make a Will Online service, please don't hesitate to reach out to us. It's a big choice to leave a gift, and we want you to feel happy and comfortable in that choice.

# IN March

**It can feel like every month is an awareness month. However, when dealing with rare conditions, we need to take any opportunity to raise awareness.**

March is Autoimmune Awareness Month, and Brain Awareness Week (which will have just ended when this newsletter drops).

Autoimmune Awareness Month is observed every March to raise awareness of autoimmune diseases such as GBS and CIDP - along with the conditions strongly believed to be autoimmune like MMN.

There are over 80 known autoimmune conditions, including lupus, rheumatoid arthritis, multiple sclerosis, and psoriasis.

This is why we were proud to link up with Connect Immune Research. Getting our voice heard as a rare condition in a world of disease and illness is hard. But by joining forces with other charities and autoimmune research organisations, our collective voices can make a real difference.

Connect Immune Research is a partnership that wants to understand how immune conditions are linked. We want the scientific community to work together across autoimmunity specialisms to tackle multiple conditions at once. Understanding similarities and using existing knowledge of different conditions could help transform lives much faster than small groups of specialists working on separate conditions.

Here's a list of our fellow members, if you can - visit them on social media and learn a little more about these conditions. The more we know about each other - the better the support we can provide.

Alopecia UK  
Bowel Research UK  
British Thyroid Foundation  
Crohn's & Colitis UK  
Coeliac UK  
Inflammatory Neuropathies UK  
Juvenile Arthritis Research  
myaware  
National Axial Spondyloarthritis Society (NASS)  
the Psoriasis and Psoriatic Arthritis Alliance (PAPAA)  
Royal Free Charity  
The Wren Project

## What is an autoimmune condition?



Autoimmune conditions occur when the body's own immune system attacks healthy cells, tissues, and organs.

There are 80+ known autoimmune conditions, including type 1 diabetes.

In the UK more than one person in every 10 lives with one, or more, autoimmune condition.

Some autoimmune conditions can significantly impact day-to-day life.

There are currently no known cures for autoimmune conditions.

**Just some of the assets our collective group will be sharing through the month**

# Inflammatory Neuropathies UK Survey

Each year we carry out a survey to find out what you think about the charity, what we do well, what we could be doing better, and what we should be doing.

In order to keep improving and making sure we're doing the best job for the GBS, CIDP, MMN, and Inflammatory Neuropathies community, we are again looking for your opinions on Inflammatory Neuropathies UK.

2025 was a massive year for the charity. We changed our name, brand, added new services, and changed the way we interact with you in a lot of regards. But did we do that well and effectively? This is your chance to share your opinion.

It shouldn't take you long to complete it, just a few 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.

Thank you for sharing your opinion. This is your charity, so let's make sure it's working for you. After all, we're IN this together.

## 1. Have you engaged with or contacted Inflammatory Neuropathies UK before?

*(please just choose one option)*

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

## 2. How have you engaged with us?

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

- Contacted the office
- Donated/raised funds
- Joined a Facebook IN conversation event
- Joined a Zoom call
- Received information
- Received Peer Support
- Received Support
- Requested a Personal Grant
- Volunteered
- Visited the website
- Other

**If you'd rather complete the form online, simply visit:**

**[forms.office.com/e/TGuNxGGWWC](https://forms.office.com/e/TGuNxGGWWC)**

## 3. Compared to the year before, are things...

- Better?
- Worse?
- The same?
- I don't know

**4.** Please number these priorities in order of importance to you. 1 being most important.

- Supporting people impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies.
- Researching conditions and their impacts on people and families.
- Raising awareness about GBS, CIDP, MMN, and other Inflammatory Neuropathies.
- Campaigning and raising the voices and views of people impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies.

**5.** How well would you rate us on supporting people (where 1 is terrible and 5 is amazing)

1 5

**6.** How well would you rate us on funding and carrying out research? (where 1 is terrible and 5 is amazing)

1 5

**7.** How well would you rate us on raising awareness? (where 1 is terrible and 5 is amazing)

1 5

**8.** How well would you rate us on campaigning and advocating on behalf of the community? (where 1 is terrible and 5 is amazing)

**9.** How well would you rate us at communicating with you (where 1 is terrible and 5 is amazing)

1 5

**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 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

**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 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

**Continued overleaf.**

**Once complete, please send it free of charge to:  
'Freepost INFLAMMATORY NEUROPATHIES UK'**

**You can also fill in the form online:  
[forms.office.com/e/TGuNxGGWWC](https://forms.office.com/e/TGuNxGGWWC)**

**Or, if you prefer, give us a call or email with your responses.**

**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

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

**IN touch**

**We love to talk, if you have questions, comments, or queries, reach out to us:**

**01529 469910**

**[inflammatoryneuropathies.uk](http://inflammatoryneuropathies.uk)**

**[hello@inflammatoryneuropathies.uk](mailto:hello@inflammatoryneuropathies.uk)**

**@InflamNeuroUK**



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