Inflammatory Neuropathies UK

INdepth

June 2026

IN this edition...

@InflamNeuroUK

3 Mill House Carre Street
Sleaford | Lincolnshire | NG34 7TW

Registered Charity 1154843 & SCO39900

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INtroduction

Carol Hooper | Chair of the Board

Well, what a month! We're at the end of another May Awareness and I'm feeling pretty smug. I committed to walk in the pool/swim 10km to raise funds for the charity and I only went and did it!

I started well with a nice consistent pace. At length 250 I was joined by Gerald Shute who walked the last 150 lengths with me. Gerald suffers with CIDP, so it was a good challenge for him too and he was a great pacemaker. The last 50 lengths were really tough. I was running out of 'push' and could really feel it in my hips, but I got through. Totally exhausted at the end but so worthwhile.

I started at 6.45am and finished at 12.45pm. 6 hours pretty non-stop other than for water, bananas and nuts that kept me going.

Thanks to the support and donations of so many people, I've managed to raise £2700 (with gift aid) ….and thanks to everyone else who took part in '**IN the swim**'.

I'm now thinking of what I can do next year and already have thoughts.

Enjoy your summer.

Carol

Rich Collins | Chief Executive

Well May certainly was a busy month for all of us here at Inflammatory Neuropathies UK. It's only after GBS and CIDP Awareness month finishes that we can stop and reflect.
I must admit that I find May very stressful, with a lot of pressure on to make sure that what we do is useful, that our impact is positive, and that you, the incredible folk in the Inflammatory Neuropathies Community, are happy with what we are doing.

Looking back over the month, I think the pressure is all self-induced, and what we did this year was really good. The webinars and Get Togethers we put on had positive feedback, the posts across social media had a lot of impressions and engagement, and the reports and information we put out were well received.

There were a couple of additional obstacles thrown in during May. Chris, our Marketing Executive moved on, leaving a big gap in our creative output. And in addition, I moved house, which is possibly the biggest bit of terrible timing in the history of mankind! But still, we got a lot done, we spoke with a lot of people, and I think we made some real impact.

There were a few stand out moments for me. One was the launch of our new Benefits and Welfare service (big thanks to Tansy, our Operations Manager. You can find out more about the service at inflammatoryneuropathies.uk/finance)
I was also really happy for the launch of "Living with Inflammatory Neuropathies", our new report based on My Neuro Survey data. You can read it at inflammatoryneuropathies.uk/reports
And then there was the official opening of the new office with Glennys Sanders and Carol Hooper (see the cover). A great day with great people.

So, what did you think about this year's GBS and CIDP Awareness Month? We always welcome feedback, so if you have any thoughts drop us an email at hello@inflammatoryneuropathies.uk

In the meantime, take care and speak soon.
Rich

IN news

Efgartigimod

As you will be aware, we have been following the progress of the NICE evaluation of efgartigimod for the treatment of CIDP in the UK. Following on from the first committee meeting in March, NICE made a number of recommendations based on the outcome of the meeting. We have since replied to these findings, and a second committee meeting has been set for July this year. We again hope to be part of this meeting to continue to feed in the views of people impacted by CIDP.
We realise that this is a long process and many people are anxiously waiting on the findings. **We will obviously continue to keep you updated.**

Clinical Trials

We thought it was time to give an update around some of the clinical trials that are taking place at the moment. The information below was taken from clinicaltrials.gov. Please note that information may not be up to date, and participation in trials can be subject to many factors. If you want to know any more about any of those listed below, then please let us know.

MMN

A Clinical Study to Evaluate DNTH103 in Adults with Multifocal Motor Neuropathy (MOMENTUM) is recruiting in London and Oxford. **Talk to your consultant if you want to be involved.**

CIDP

A Study to Test the Efficacy and Safety of Riliprubart Against the Usual Treatment of Intravenous Immunoglobulin (IVIg) in People with Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) (VITALIZE) is currently recruiting in London, Inverness, and Oxford. **If you are interested, then talk to your consultant or contact us – rich@inflammatoryneuropathies.uk.**

A Study around Imeroprubart in Adult Participants with CIDP is currently recruiting in Bristol, Glasgow, Salford, and Southampton. **If you are interested in taking part, then reach out to your consultant.**

A Study to Assess the Efficacy and Safety of Empasiprubart in Adults with CIDP (emnergize) is registered in London but is not yet recruiting. Watch this space.
An Efficacy and Safety Study of Nipocalimab for Adults with CIDP is currently recruiting in Birmingham, Devon, Glasgow, and Sheffield. **Reach out to your consultant for more info. Efficacy and Safety Study of Nipocalimab for Adults with CIDP is currently recruiting in Oxford and Manchester.**

A Study to Assess Efficacy and Safety of Empasiprubart Versus IVIg in Adults With CIDP (emvigorate) is currently recruiting in Salford. Reach out to your consultant for more info.

Market Research

Exafield UK, a market research company, are currently running a study looking further into Multifocal Motor Neuropathy (MMN). They are looking to hear from patients diagnosed with MMN who have had or are currently receiving treatment (and their caregivers) to share their experiences.

It involves an online interview and an online task. Patients will receive up to £150 on completion of the study, and caregivers will receive £37.50 on completion of the study.

To take part email Evie Hawker on hawker@exafield.com with the subject MMN Study.

Please note that we are only sharing this opportunity and are not part of the work. That said, please indicate that you heard about the study from Inflammatory Neuropathies UK.

Active Surveys

We have been inundated with survey requests recently and have been sharing these via email and social media. But in case you missed any of them and want to take part, here are a select few you may want to respond to.

neuroquali

Plasma-Derived Medicines

People who rely on plasma-derived medicines (like IVIg and SCIg) have a powerful perspective, and PPTA want to hear from you.

PPTA has launched a global patient survey to better understand how patients view the medicines they depend on, including their awareness of how these therapies are made and the vital role plasma plays in making them possible.

Your input will help them better understand how you relate to your treatment. The insights gathered will help inform future education, advocacy, and awareness efforts to ensure patients and the public better understand the lifesaving impact of plasma donation.

If you have had IVIg or SCIg and want to take part, then head over to https://www.surveymonkey.com/r/IPAWpatientsurvey

CIDP Survey

Our friends at EPODIN (the European network of patient support groups) is undertaking the Neuroquali survey, which is looking at the impact of CIDP on people's lives.

If you are impacted by CIDP and want to share your views to help European wide research, head over to neuroquali.sanoia.com/?lang=en

EPODIN
European Patients Organization for Dysimmune & Inflammatory Neuropathies

IN June

Save lives, give blood!

June 8-15th marked National Blood Donor Week, so we've been supporting the NHS to raise awareness of the lifesaving importance of blood donation and encouraging those who've never donated to give it a go. We were out and about at both Tooting and Addenbrookes hospitals with their blood donors service to learn more.

For our community, blood donations are an absolutely vital lifeline, because with conditions like GBS, CIDP and MMN it is immunoglobulin via blood and plasma donation that reduces the severity and impact of symptoms. Someone with CIDP who receives typical treatment of a transfusion every 6 weeks would clearly require a large number of blood donations throughout their life.

But how many of us have wondered about what it takes to extract the immunoglobulin and get it to patients? The process is really impressive, with each unit of blood being matched by blood type before being cleaned, stored, and transported in a highly controlled environment.

Save lives
Give blood

Every blood donor gives about a pint per donation, along with a small sample for laboratory testing. Each donation is labelled with a unique barcode to track it throughout the process. The blood is kept on ice and transported to a processing centre, where it is centrifuged to separate it into red blood cells, platelets, and plasma.
Plasma may be further processed into components like cryoprecipitate, which helps with blood clotting. White blood cells are removed to reduce the risk of reactions, and the donated blood undergoes various tests to determine blood type (there are 8 different blood types) and to screen it for infectious diseases. If any test is positive, the donation is discarded and the donor is notified confidentially.

Units that pass testing are then stored until needed, although it can't be stored very long. Red blood cells can be stored for up to 35 days, platelets can be stored for up to 7 days and plasma can be stored for up to 3 years. So, the NHS only collects what they need. When the blood donation is used, every element that was separated can be utilised independently, meaning that a single blood donation can provide lifesaving care for up to three people! So, it really is a lifeline. However, the NHS blood and transplant service are in constant need of donors and desperately in need of more type O, B negative and black heritage donors.

People with certain health conditions can't give blood for obvious reasons, however family usually can, as well as friends and colleagues- so if you've never given blood, please do give it a try!
Just one hour of your time can save up to three lives. For more info, please visit www.blood.co.uk

IN their words

My Experience with Guillain-Barré Syndrome (GBS)

by Nicole Walczak

“After what I thought was winter flu, I developed a severe migraine that lasted around a month before losing feeling in my left arm. I went to hospital and, within two days, my condition deteriorated rapidly and I became paralysed from head to toe due to Guillain-Barré Syndrome (GBS).”

I spent Christmas and New Year in intensive care, and my birthday in February in rehabilitation. Recovery meant relearning things many people take for granted – how to eat, walk, talk and even breathe properly again. Leaving rehabilitation in April was a huge milestone, but recovery continued long afterwards. Over the following year I worked hard to rebuild my strength, return to the gym, regain confidence and eventually run again.

Although I am now close to full health, GBS has left lasting effects. I continue to live with chronic fatigue and Non-Epileptic Attack Disorder, alongside occasional aches and pains.

The illness also forced me to cancel travel plans I had been excited for, although I have since rebooked them for October 2026.

Despite everything, GBS showed me resilience I never knew I had. I am incredibly grateful for the support system around me – my family, friends and the healthcare professionals who helped me through the hardest period of my life. Some of the nurses who cared for me have become lifelong friends.

Since becoming ill, I have raised over £6,000 through fundraising, including online campaigns and organising a charity ball, with plans to continue supporting the GBS community in the future.

IN focus

GBS

Guillain-Barré Syndrome (GBS) is the most prevalent and probably most well-known of all the inflammatory neuropathies. It's an immune response where the body's immune system mistakenly attacks peripheral nerves and damages the network that carries messages between the brain, spinal cord, and the rest of the body. It usually starts very suddenly and has a deep and significant impact; most people require urgent hospitalisation and can spend months recovering in hospital.

The exact cause isn't fully understood, but most people develop it after an infection (like Campylobacter jejuni, the bacterium that causes gastroenteritis and viral infections like influenza, Epstein–Barr virus, cytomegalovirus, and even COVID-19). Although GBS can be severe, most people recover.

A 2023 study found that the reported incidence of GBS in the world among the studies included in the review is slightly higher than that previously reported and the highest incidence rates were associated with public health events of international concern, like COVID-19 and Zika virus outbreaks: In lay terms, any viral infection can trigger a heightened immune system response which is what in turn attacks the body's own nerves. This is what's happening in GBS.

Treatment usually involves immunotherapy — either intravenous immunoglobulin (IVIg) or plasma exchange — to stop the immune system from attacking the nerves. The myelin coating around nerves can regrow, so nerve fibres reconnect. But recovery can be frustratingly slow (think months or years) and residual symptoms can continue much longer. Nerves regenerate at a rate of just 1–3 mm per day, which means recovery can take years. So, things like energy levels, co-ordination, strength, pain and tingling symptoms all improve BUT with long stretches of time where nothing seems to be happening.

The nerves are also complex and carry all kinds of signals, so there are also some very unusual symptoms you might not expect, such as an erratic heartbeat, changes in blood pressure and difficulty regulating temperature. Other people develop facial weakness, and some of you may notice bladder problems or dizziness (vertigo).

However, one of the most common and significant aspects of living with Guillain-Barré syndrome is pain.

It can last a long time after recovery from hospital. Pain in GBS comes from irritated or inflamed nerves, because as the immune system attacks the myelin (the protective coating around nerves), those nerves send confused or exaggerated signals, so the pain is experienced as burning or tingling, deep, aching pain, or sharp, shooting "electric shock" sensations. It often worsens at night, making sleep difficult.
Treatments for pain vary, so as well as painkillers, solutions often involve things like nerve targeting medicines that calm overactive nerves, anti-inflammatories, and physiotherapy to ease musculoskeletal pain.
Sadly, living with pain takes a huge toll on our mental wellbeing and many people need support from a trained counsellor or therapist who understands what it's like to live with a condition like this.

Pain in GBS can be one of the most distressing aspects of the condition, but it does improve as the nerves heal.
Please don't forget that we have our fantastic free counselling service from Rareminds for anyone who is feeling unhappy, scared or depressed about their condition.
Fatigue is another frustrating symptom, it's not ordinary "tiredness" but a deep whole-body exhaustion that affects mood, cognitive ability and coordination.

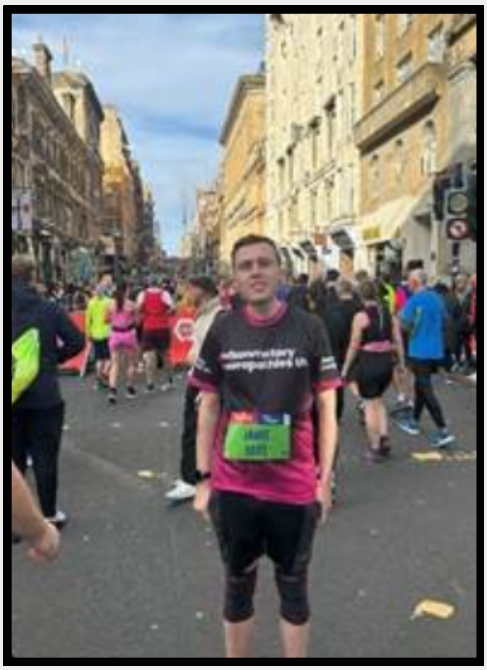
The reason fatigue is so common with GBS is that the immune system's attack on the nerves disrupts normal signalling, so every movement requires more effort. Even after the nerves begin to heal, the body may still be working overtime to reroute signals and repair damage. This combination creates a type of fatigue that feels disproportionate to activity levels — something many people describe as "hitting a wall".

Fatigue can be discouraging, especially when progress feels slow. We know that many of you worry that you're not recovering quickly enough, when in fact your body is healing from a major neurological event. Again, even when strength has returned, people often still experience persistent fatigue, reduced stamina, and cognitive fatigue, such as difficulty concentrating for long periods.
But there is hope! Anyone who's spent time with our wonderful community, whether as part of our Facebook group, online support group or in a direct conversation with a peer support volunteer will confirm that talking to other people who've 'been there' and who understand the ups and downs of a condition like this is invaluable in terms of practical and emotional support. Just knowing that every little improvement IS significant and IS a sign of recovery can help. 1mm of nerve growth a day might seem a miniscule amount and an almost imperceptible change in progress, but every little bit accumulates and over time real healing occurs! Meanwhile, from adaptations to make life easier, to the emotional impact, feeling understood, worries and anxieties, every conversation helps you feel less alone and can be a real source of support.
So, while it is definitely a rare condition you are absolutely not alone in dealing with it, do reach out, please keep talking, keep sharing and we'll get through this together with you.

IN aid of

We couldn't do what we do without the help of incredible supporters taking on challenges, events, or leaving a legacy gift. Let's catch up with those we are IN gratitude to.

Jamie Cameron



"In October, I ran the Glasgow half marathon in support of Inflammatory Neuropathies UK because their cause is very special to me. In 2006, I was diagnosed with Guillain-Barré syndrome, an experience that was not only life changing, but ultimately transformative leaving me with permanent restricted movement in my left arm. During my recovery, I realised how important it is to have access to clear information, specialist support, and a supportive community. IN UK is the largest UK based charity dedicated specifically to those who have suffered from Guillain-Barré and similar Neuropathy related illnesses. The work they do makes a real difference to people's lives and choosing them felt like a meaningful way to give back and support others who are navigating the same uncertainties I faced 20 years ago. Thanks to the generosity of friends, family, and colleagues, I was able to raise £750 — a reminder of the kindness people show when a cause is so important. "

Want to follow in Jamie's footsteps?
Great Scottish Run Half Marathon - 4 October 2026
Find out more at
https://www.inflammatoryneuropathies.uk/events

Christine Beattie

"I recently celebrated my 70th birthday – a milestone I once thought I would never see. Instead of gifts I decided to ask for donations to Inflammatory Neuropathies UK because of my life changing experience of having Guillain-Barré Syndrome.

I awoke one morning in March 2014 with a strange feeling in my feet and legs and within twenty minutes was unable to walk. After calling the Doctor out I was quickly taken to hospital and diagnosed with GBS.

Treatment was given promptly and, although I became paralysed, I did not need any help breathing. Six weeks later I was able to return home with mobility aids. GAIN charity, as it was then, were helpful with information about the condition and putting me in touch with other people in a similar position.

Nearly twelve years on I still suffer with all kinds of residual symptoms but am grateful to be able to do as much as I can. This was only possible because of amazing NHS professionals, support of friends, much prayer, and support from IN UK and fellow survivors." Christine raised £670.50 through birthday donations.

William Morrow

"I had never heard of Guillain Barre Syndrome (GBS) prior to December 2025.

My symptoms: tingling in fingers and feet, severe night back pain, loss of balance, and eventually collapsing of my knees spurred me to go urgently to the GP who immediately sent me to The Cleveland Clinic, where after numerous tests, GBS was diagnosed. I was put on a 5-day course of immunoglobulin and pain medication.

I was lucky to have had a mild case, caught early and received effective treatment followed by extensive physiotherapy to rebuild lost strength and balance, and happily I am fully recovered. While I don't know what caused the GBS, I do know that this rare syndrome can be serious, and not everyone recovers fully or quickly. Because of the low likelihood of contracting GBS, public awareness is limited. I wanted to support a charity working to help and inform victims and was happy to find Inflammatory Neuropathies UK."

Bill (William) donated £500.00 plus gift aid to Inflammatory Neuropathies UK

IN memory

Shona Fordyce (nee Lyttel)

Charity is one of the words I think of when I think of Shona. She was one of the most giving people I have ever met. She loved to help people and would often sacrifice time, her talents and her money to good causes.
Shona suffered with her neuropathy for over a decade. It was a slow drawn-out condition that took her mobility first and ultimately her life, but never her love of life or the immense love she had for her family and friends.
A strong and devout Christian who lived to share the love she had for Jesus with all.

Fiercely loyal, committed, the best listener, outrageously kind, gorgeous inside and out, funny, intelligent, loved to travel (which gave her friends all over the world), organised and disciplined.

She loved her naps, loved good food with a good film or tv show on but most of all she loved her time with her family - whether it was a phone call, a text or a visit.
She was taken too soon, and we all miss her so dearly and would do anything to have had more time with her. We hope by raising some money that others might be able to have longer with their loved ones. But funds need to be raised to do that.

Shona's family have so far raised £2,070.15

INdustry

Back in April, we sent our Chief Executive Rich Collins over to Milan for the International Plasma Protein Congress (IPPC).

It was a chance to hear the latest news from industry, catch up with colleagues from across Europe, and represent the voices of the Inflammatory Neuropathies Community. We asked Rich to give us an update. It seemed a long way to go to talk about plasma. But having discussed it with the Chair of the charity, and with colleagues from across Europe, I was convinced that attending the conference was worth the travel. And how right they were.

The two-day conference started with a Keynote Speech on 'The Impact of Plasma-Derived Therapies in Europe'. This was an incredibly in depth, deep dive into the value of plasma for patients. It sounds silly, as you know what IVIg means to you, but it was useful to hear the economic argument, and to see the data. And you know me, I love data.

It was incredibly useful to get a European wide perspective on plasma, and to compare how we do things in the UK, compared to our colleagues on the continent.

This session was followed by a panel about medicine supply chains, which included friend of IN UK, Jean-Philippe Plancon, from EPODIN. As a patient himself, Jean-Philippe was representing the community, and did an amazing job of expressing how important supply was, and what issues in getting treatments at the right time meant to people, including the consequences.

After further panel sessions and lots of coffee, we heard about legislation and reform, and its impact on access to treatments.

While this was focused on Europe, it does also affect the UK, so it was super useful to hear about what is coming and what we can do to input.

IPPC continued...

The first day finished with a session on strengthening access to plasma derived medicines across Europe, which included discussions on self-sufficiency (the UK is doing well here), stockpiling and its impact on other countries (we are quite bad at this), and how fragile supply can be.

This was moderated by Tomasz Kluszczynski, who has just written a white paper for EPODIN, the summary of which was published at the event, and which we fed into.

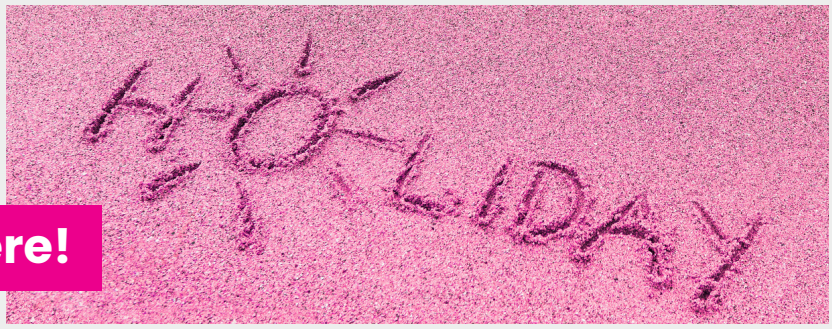
Day two was more focused towards industry, and while an F1 consultant gave the Keynote, I used the time to catch up with colleagues from EPODIN and share themes and issues that we had heard directly from patients. This was incredibly useful and eye-opening (who knew that in Romania they don't even tell you the brand of IVIg you are getting as its unlikely to ever be the same twice!)

There were useful sessions on innovation, donor health and safety (including input from NHS colleagues), and some amazing work from Egypt around plasma collection. I also had the opportunity to catch up with colleagues from NHS Blood and Transfusion and had the most in-depth conversation with them to date. Weird that I had to go to Milan to make this happen.

All in, this was a really useful two days in Italy, learning, sharing information, networking, and feeding into international work. A big thanks to the organisers who don't charge patient organisations to attend, and to everyone for being so open and supportive during the sessions.

I have brought back a lot of knowledge and look forward to putting it to use to continue to support the Charity and our Community.

IN travel



Holiday season is here!

While friends and family might be dreaming of sandy beaches, any of us impacted by an inflammatory neuropathy can find ourselves quietly wondering how on earth we'll manage the practicalities. Even the smallest trip can feel like preparing for an expedition. **But with the right planning, and the right support, holiday travel is possible and enjoyable!**

It starts with packing: the things to make where you stay easier, the cushions, the supports, all the portable versions of home that help unfamiliar places feel manageable. This might also mean keeping medications in your hand luggage, planning rest stops or choosing accommodation with reliable air-conditioning if heat worsens symptoms.

HOLIDAY RULE NO. 1: YOU CAN'T OVER PREPARE!

For some of us, the biggest worry isn't the journey itself but the crowds, the queues, and the fear of picking up another infection. That fear is real and valid but can be mitigated as much as possible. **Again, it often comes down to preparation, we've been hearing your top tips including choosing quieter travel times or requesting priority boarding on flights to avoid long waits in busy spaces.**

Many people don't realise that airports offer special assistance — wheelchairs, escorts, priority boarding — if you book in advance. And Non-Emergency Medical Transport (NEMT) services can provide trained medical staff who accompany you throughout the journey.

Travelling by train or ferry can also be a good option, as well as simply wearing a mask and carrying hand sanitiser wherever you go.

Heat & fatigue are another concern, we know that heat can be really debilitating. Pacing becomes even more important on holiday — planning outings for cooler parts of the day, building in rest breaks, and keeping hydrated (an excuse to try local juices or replenish with mineral water). And food is another important consideration! **While we all love to try local cuisines and different things it's probably useful to carry familiar snacks, avoid anything that could risk or trigger infection, remember your medication schedule is tied to meals or specific times, and always keep a small "just in case" kit of something you can eat when you're out and about.**

Before travelling, it's worth taking a few minutes to look up the nearest hospital or clinic, check how to contact emergency services, and confirm whether your medication is available locally. It's the kind of preparation you hope you'll never need — but it can bring enormous peace of mind. Finally, don't forget your travel insurance –because most inflammatory neuropathies are considered pre-existing conditions, it's essential to find travel insurance that covers you. Some insurers specialise in chronic or fluctuating conditions, and speaking to them directly often leads to better coverage. So, while travelling with an inflammatory neuropathy isn't simple, it also offers something precious: a chance to step outside the everyday. ***And everyone deserves a holiday!***

INformation Benefits

PIP – what is it?

We've probably all heard about PIP but if you're not claiming it, you might be wondering what it is and whether it's applicable to you. **Personal Independence Payment (PIP)** is money awarded to you for the extra care or mobility needs as a result of a disability or long-term health condition. PIP is not means tested – this means that your entitlement doesn't depend on your level of savings or income.

PIP is for people aged over 16 and under pension age, so if you're over pension age you will receive Attendance Allowance (and/or Pension Credit) instead.

To qualify, unless you're terminally ill, your care mobility needs must have lasted for the past three months and be expected to continue for the next nine months.

There are two parts ('components') to it: a daily living component, and a mobility component. You might qualify for one or both of them.

To get the daily living component your condition must limit your ability to carry out certain activities like preparing food, eating and drinking, managing your treatments, or washing/bathing.

To get the mobility component of PIP, your condition must limit your ability to carry out certain activities like walking, travelling, going on journeys and safely moving around unaided.

Facts & figures about PIP

Currently around 1800 people in the UK claim PIP for Guillain Barre Syndrome. Neurological conditions generally are under-represented in claims.

You can claim PIP regardless of whether you are in work, self-employed or unemployed.

- **Income – it doesn't matter what your income is.**
- **Savings – it makes no difference what savings you have.**
- **Also, your national insurance contributions, who you live with and whether or not you have carers are all irrelevant to a PIP claim.**

So how much is personal independence payment?

The lowest award you can get if your claim is successful is £29.20 a week, the maximum is £187.45 a week. The enhanced rate of the mobility component also gives you the option of getting a Motability vehicle instead of the cash.

How do I claim PIP?

In order to claim you need to contact the DWP. You'll need your National Insurance number, bank details, and GP information. You need to complete the form and attend a health assessment (usually by phone, video, or in person), after which the DWP takes around 20 weeks to make a decision. If it's a no, don't despair! Over 50% of people are rejected on application and over 50% of PIP appeals are successful. If you've been turned down, then ask for a Mandatory Reconsideration within one month. If that decision is unsuccessful you can appeal. Payments always start from the date you made your claim, and they should be backdated.

Free benefit check and advice

If you're unsure about PIP or other benefits you might be entitled to please contact us on hello@inflammatoryneuropathies.uk and we will be delighted to help. You can also read more about benefits and money advice on our website here: Finance | Inflammatory Neuropathies UK

IN neurology

ABN

In May, Rich & I (Tansy!) spent three days at the **2026 Association of British Neurologists (ABN)** Annual conference in Birmingham. Attended by hundreds of neurologists, clinicians, specialists, researchers, pharma companies and other health organisations, this was an amazingly energised, focussed, and lively conference. The ICC in Birmingham was buzzing from early morning to evening receptions.

Several sessions stood out for me: including some brilliant presentations on acute neurology, the primary–secondary care interface and an excellent session from our own MAB member, Tim Lavin on peripheral neuropathy in the general clinic.

There are some exciting developments taking place in stem cell research at the moment and some of the research papers were also particularly inspiring.

Rich and I were able to talk to dozens of neurologists about IN UK and what we do, many hadn't heard of us and were just delighted to know we're here and what we do, so that was incredibly encouraging. We certainly managed to spread the word and am sure many more patients will be referred more quickly to us in future.

Likewise, neurologists were able to ask us for things that would be useful to them in their work with patients, so all in all it was a really productive, busy and enlightening few days!

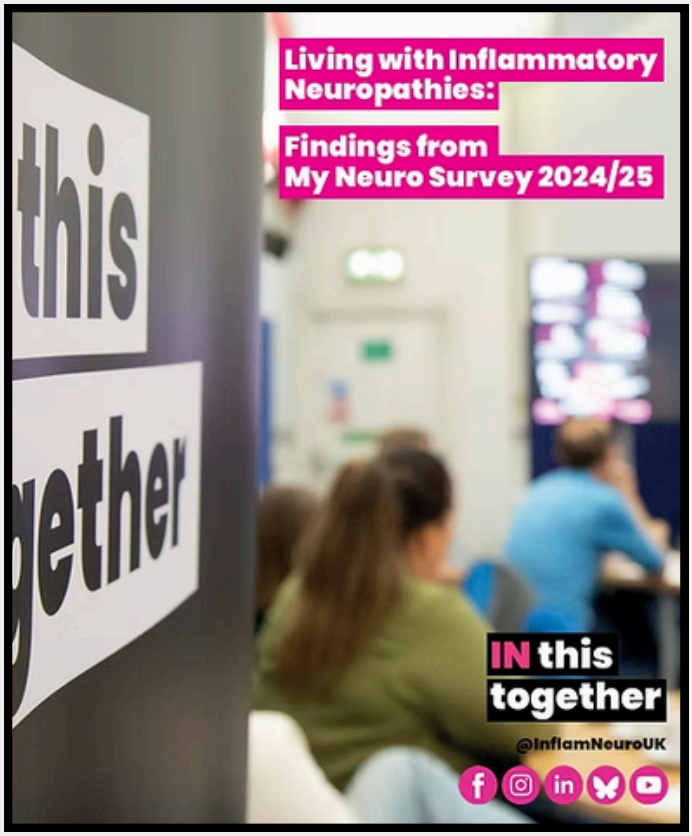
IN results

My Neuro Survey

We took a deep dive into the data from the latest My Neuro Survey, which gathered the experiences of more than 10,000 people living with neurological conditions across the UK, including hundreds of people impacted by Inflammatory Neuropathies. This data gives us a valuable insight into the challenges people face and, importantly, where we can make things better.

One of the most positive messages is that our community really got involved. **Inflammatory Neuropathies UK** was the sixth highest represented organisation in the survey, demonstrating just how willing people are to share their experiences and help drive change.
The survey highlighted that fatigue, pain, mobility difficulties, and sleep problems continue to have a significant impact on many people's lives. These challenges have an impact on work, lifestyle and hobbies, family life, and day to day activities. Despite this, people consistently showed resilience and a strong desire to stay active, informed, and involved.
One particularly encouraging finding was the enthusiasm for research, especially in terms of taking part in clinical trials. Lots of people said they would like to take part in research studies and clinical trials, showing a real commitment to helping improve treatments and understanding of these conditions in the future.

What My Neuro Survey Tells Us About Living with Inflammatory Neuropathies



However, it also showed that not many people get the opportunity to take part, something we need to look at more closely. The survey also highlighted areas where more support is needed, including better access to information, improved coordination of care and greater access to specialist services. These findings will help shape the future work of **Inflammatory Neuropathies UK.**

Most importantly, this report gives people impacted by Inflammatory Neuropathies a stronger voice. As always, we are committed to listening, learning and turning what the report has told us into action, so that together we can improve support, services, and opportunities for you, the Inflammatory Neuropathies Community.

IN support

Peer Support

We're highlighting our amazing peer support service and all the incredible volunteers delivering it to support our community. Peer support is our one-to-one buddying service where you can talk to a volunteer who has had the same or a similar condition to you, a friendly guide on this whole new path you're suddenly on.

Peer support is delivered by volunteers with lived experience, and everyone is a patient or parent supporting others impacted by an inflammatory neuropathy. We have 43 brilliant volunteers who offer one to one telephone, text, email or Zoom calls, on an ongoing informal basis set to your pace and needs. We match people by condition and other demographics as much as possible. We arrange the initial call or conversation but it's all completely private and completely confidential- some volunteers still chat to people who first got in touch years ago, others only need one or two conversations, it's up to you and the volunteer. There's no prescribed time limit or off-limit topic (although obviously we don't ever give medical advice).

To be put in touch with a peer support volunteer or find out more, please email
hello@inflammatoryneuropathies.uk

Many people tell us afterwards how refreshing it is to be able to have just talked honestly about all their symptoms, concerns, fears and queries without overburdening their own family or friends. In some cases, it's sharing humour, the random moments or simply celebrating small changes. Inflammatory neuropathies are so rare that many of us go our whole lives without meeting anyone else who has one - people accessing the service say to us again and again "I didn't realise before how much I needed this."

It's not about fixing anything or finding solutions as we can't advise but we can listen - it's about not facing anything alone. Our volunteers can also sometimes help with practical tips like managing fatigue, but mostly it's emotional reassurance, especially for those frightening days. And it can also offer incredible positivity, a real sense of optimism in hearing from people further along the road. As one volunteer said, 'it's changing the world, one conversation at a time'. So, if you or someone you love is on this journey, please reach out, and don't hesitate to ask for a session. Even if you don't know what to say yet, we're here for you!

IN fundraising

Bobby's Story | POEMS

Hope For POEMS

When I struggled to run playing football in January 2025, I never imagined that 12 months later I would be disabled and receiving regular chemotherapy injections.
It began as a tight right calf, not uncommon for a 41-year-old playing 5-a-side! I rested for a few weeks and then tried playing tennis, same issue, I simply couldn't run, my legs wouldn't function properly.

The next six months involved an array of people trying to diagnose what was wrong. Sports physios, osteopaths, GPs, A&E doctors and consultants all tried and throughout that time my condition only worsened.
By the time I saw a neurologist privately in July I needed a crutch to stand, I couldn't move my toes, I had numbness, tingling and swelling in my feet and my balance was poor. The neurologist said I had lower limb neuropathy and after an Electromyography (EMG) confirmed nerve damage, I was admitted to the Queen Elizabeth Hospital in Birmingham.
I'm incredibly grateful that my hospital consultant had heard of POEMS syndrome (Polyneuropathy, Organomegaly, Endocrinopathy, Monoclonal plasma cell disorder, Skin Changes) because he immediately requested a vascular endothelial growth factor (VEGF) blood test. I was treated for CIDP whilst we waited for the result and when it returned showing my VEGF levels were sky high, my consultant believed I had POEMS.

POEMS is incredibly rare. It affects 1 in 1 million people and in the UK just over 170 people have received the diagnosis in the last 20 years. It's so uncommon that it isn't formally recognised by the NHS. To confirm my diagnosis, I was admitted to the National Hospital for Neurology and Neurosurgery in London for a week of intensive tests, including a bone marrow biopsy. During this time, my condition continued to deteriorate. My legs and feet worsened, and my hands began to weaken. Thankfully, the biopsy confirmed POEMS, and I was able to begin treatment back in Birmingham before further damage was done.
Although POEMS isn't a blood cancer, the treatment is often similar. I began chemotherapy injections in October, and within two weeks I noticed real improvements. Strength returned to my upper legs and I became more mobile. However, nerve damage in my lower legs and feet could take years to recover.
It's been an incredibly difficult year not only for my wife and kids but also my wider family and friends who watched my health decline. I'm grateful to INUK for connecting me with peer support and free counselling sessions through Rare Minds which have been invaluable in helping me cope with such a rare condition.
As I write this in May I am looking forward to my little brother's wedding before my stem cell transplant begins in June. I am really pleased that we now have a fundraising campaign setup for research into this condition – thanks to the POEMS team at UCLH and INUK for making this possible. Only through research will our understanding and treatment of this condition improve across the world, please support if you can.

Further Information

To Donate

What is POEMS? Video

INflammatory Neuropathies UK Impact Report

This year has been a positive one for Inflammatory Neuropathies UK, with more people than ever before accessing our support, information, and services. This was highlighted in our new Impact Report.

HIGHLIGHTS

937 people supported
5,300 direct support activities
25 grants awarded
70,000 website visits

During 2025/26, we supported 937 people impacted by Inflammatory Neuropathies, a 57% increase on the previous year. We also completed more than 5,300 direct support activities, helping people access information, guidance, practical support, and connections with others who understand what they are going through.
Our Personal Grants programme continued to grow, with 25 grants awarded during the year. These grants provide valuable support to people facing financial challenges as a result of their condition.

More people are also finding us online. Over 70,000 people visited our website during the year, showing the increasing need for trusted, easy to understand information about Guillain-Barré Syndrome, CIDP, MMN, and other Inflammatory Neuropathies.
Our social media channels also continued to grow, reaching tens of thousands of people through awareness campaigns, lived experience stories, and practical information.
Importantly, feedback from our community remains very positive. People told us they value our approachable support, accessible information, awareness raising work, and our efforts to represent the voices of people impacted by Inflammatory Neuropathies.
The report also highlights what matters most to our community. People want greater awareness, more research, better emotional support, and more opportunities to connect with others. These priorities will help shape our work in the year ahead.
As demand for our services continues to grow, this report shows that Inflammatory Neuropathies UK is reaching more people, providing more support, and helping to ensure that nobody impacted by an Inflammatory Neuropathy has to face it alone.

You can read the report by scanning the QR code

or heading to
inflammatoryneuropathies.uk/reports

IN touch

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

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