Inflammatory Neuropathies UK

August 2026

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@InflamNeuroUK

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Chief Executive's Welcome

A note from Rich

Back when I worked for a council, we always saw August as an 'easy month'. People would be on holiday, the folk you did business with weren't around, politicians were on a break, and it was often a month when you could undertake reviews or write reports. A lot of my former colleagues think this is the case within the community sector as well, but the reality is that charities can't shut down for the summer.

Looking at our stats and figures, we continue to support more people each month, and this hasn't dropped over the summer. In fact, the phone is still ringing, the emails are still coming in, and people still need support and advice. GBS, CIDP, MMN and other conditions don't stop for the holidays, and neither do we. While others may be off on holiday, don't worry, we are still here and on hand when we are needed.

As you may be aware, our Marketing Executive, Chris, left Inflammatory Neuropathies UK earlier this year, and we have been managing our communications with a mixture of interim support and, well, let's face it, me. Well, I'm delighted to announce that we have been joined this month by Andrew Florence, the charity's new Marketing Executive. I'm sure you will join me in welcoming Andrew, who is already hard at work on the socials (and this newsletter), and I look forward to him adding his own unique voice to what we put out. There will be more about Andrew in next month's newsletter.

> "Charities can't shut down for the summer."

It's the big newsletter next month, and we look forward to sharing more news and stories with you then. But this month, we bring you details of a new Europe-wide report on Inflammatory Neuropathies, which I hope you will welcome as much as I did. Take a look and let us know what you think.

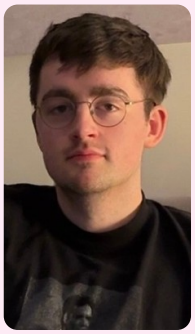
Back next month, but in the meantime take care and speak soon.

Warm wishes,

Rich

Rich Collins
Chief Executive

Welcome to Andrew Florence



Please join me in welcoming Andrew Florence, our new Marketing Executive.

There will be more from Andrew in the next edition of ***In Depth.***

Beyond the diagnosis:

Why the New Inflammatory Neuropathies Report Matters

Every so often, a report comes along that puts into words what people have been saying for years. The new White Paper on Dysimmune Inflammatory Neuropathies, or DINs, feels like one of those reports.

We have been working with EPODIN, the European network of Inflammatory Neuropathies patient organisations, for many years, and Rich recently headed to Brussels to hear more about their new White Paper and the thinking behind it.

The paper looks at Guillain-Barré Syndrome (**GBS**), Chronic Inflammatory Demyelinating Polyradiculoneuropathy (**CIDP**) and Multifocal Motor Neuropathy (**MMN**), using the umbrella term Dysimmune Inflammatory Neuropathies, or DINs. These conditions are different, but they share many of the same challenges: getting the right diagnosis, accessing appropriate treatment, managing fatigue and pain, rebuilding confidence and finding support for life beyond the clinic.

Inflammatory neuropathy patient leaders (including Rich!) from across Europe

What makes this report important is that it does not look only at tests, treatments and medical outcomes, it brings published research together with the experiences of people affected across Europe. If you have ever felt that the impact of an Inflammatory Neuropathy cannot be summed up by a test result, an appointment or a treatment plan, much of what follows will probably feel familiar.

The question is not simply, "Was treatment given?" It is also, "What happened to the person afterwards?" Did they regain their independence? Could they return to work? Were fatigue and pain taken seriously? Did they get the rehabilitation they needed? Were they able to take part in family and social life again? And, perhaps most importantly, were they listened to?

Getting the right diagnosis sooner.

One of the clearest messages in the paper is that diagnosis still takes too long for many people. The paper points to significant underdiagnosis across Europe and describes how symptoms such as weakness, fatigue, pain and sensory changes can overlap with other conditions.

For **CIDP**, it cites an average delay of more than 13 months from the first symptoms to a confirmed diagnosis. Delays are often longer for **MMN**, which can also be mistaken for other neurological conditions, delaying access to the treatment and support that may help. For **GBS**, where symptoms can progress very quickly, early recognition and treatment are especially important.

For anyone who has spent months being passed between appointments, being told it might be something else, or simply knowing that something was wrong without having an answer, those findings will not be surprising.

The paper calls for better awareness among healthcare professionals, clearer referral routes and more consistent access to specialist neurological expertise. In simple terms, people need to reach the right team, with the right knowledge, sooner.

Treatment is only part of the story.

The White Paper is also clear that good care cannot end with medicine. Rehabilitation is described as a core part of care, including physiotherapy, occupational therapy, psychological support and, where needed, speech and language or vocational rehabilitation. It should be tailored to the individual, taking account of fatigue, pain,

mobility, work, independence and the stage of recovery.

For one person it may be walking independently again. For another, it might be using their hands more easily, returning to work, managing fatigue well enough to see friends, or simply feeling confident leaving the house. The paper argues that these outcomes should count when we judge whether care is working.

Listening to lived experience.

This is perhaps the part that feels most important to us.

The report says patient organisations and people with lived experience should have a structured role in decisions about research, treatment guidelines, healthcare policy and access to medicines. It recommends that services focus on the outcomes that matter most to people, including fatigue, pain, quality of life, ability to work, independence and the impact on carers.

That is a big shift away from asking only what can be measured in a clinic.

People living with **GBS, CIDP** and **MMN** are experts in what these conditions mean in everyday life. Their experiences should not be an afterthought. They should help shape the services, treatments, research and policies designed to support them.

Reasons to look forward.

There is plenty in the report about what still needs to improve: earlier diagnosis, fairer access to immunoglobulin and newer treatments, stronger rehabilitation services, better plasma supply and more consistent care across different countries.

But there is also real cause for optimism.

Understanding of these conditions is growing. New targeted treatments are being developed. There is increasing recognition that rehabilitation and emotional wellbeing belong alongside medical treatment. And there is a stronger push to define success around the things that matter to people themselves.

For us, the report strengthens many of the messages our community has shared for years. Treatment matters, but so do recovery, confidence, independence, work, family life and being heard. The White Paper is a substantial read, but its central message is simple: better care starts by looking beyond the diagnosis and seeing the whole person.

And that is something we will continue working towards, together.

The White Paper is currently published as a preprint and has not yet undergone formal peer review.

You can read the full White Paper here:
https://doi.org/10.20944/preprints202607.0876.v1

Or scan the QR code here to go straight there.

IN this together

We're here for people impacted by GBS, CDP, MMN and other Inflammatory Neuropathies

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Information, support and guidance

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