Inflammatory Neuropathies UK

Driving Impact for the Inflammatory Neuropathies Community

Strategy Snapshot 2025–2035

We are the UK's only charity dedicated solely to supporting people impacted by:

- Guillain-Barré Syndrome (GBS)
- Chronic Inflammatory Demyelinating Polyneuropathy (CIDP)
- Multifocal Motor Neuropathy (MMN)
- and approximately 40 related Inflammatory Neuropathies

Inflammatory Neuropathies are rare, life-changing neurological conditions that can cause paralysis, long-term weakness, fatigue, sensory loss, and significant emotional and financial impact.

For many people, diagnosis is delayed. Information is inconsistent. Support is fragmented.

We exist to close that gap.

This is a snapshot of our ten-year strategy. so join us as we continue this amazing journey. After all, we are IN this together .

Who We Are

Founded in 1985 by Glennys Sanders following her own experience of Guillain-Barré Syndrome, we began as a volunteer-led support group around a kitchen table in Lincolnshire. Today, we are a respected national charity supporting thousands of people each year across the UK and Ireland.
We are an ambitious and forward-looking Charitable Incorporated Organisation with a small professional staff team, supported by committed volunteers and trustees, most of whom have lived experience of an Inflammatory Neuropathy.

Our Mission

The mission of Inflammatory Neuropathies UK is to effectively meet the needs of our Community; to be the voice of our Members; and to influence the approaches, practice, and policy around GBS, CIDP, MMN, and other Inflammatory Neuropathies.

Glennys Sanders, *our founder* **IN conversation** with Dr Claire Johnson, *PHD researcher*, who received Inflammatory Neuropathies UK funding.

"I was diagnosed with CIDP recently and the resources on your website were very helpful in the pre-diagnosis stage as well as in understanding treatment options" ***- from 2025 supporter survey***

Why We Exist

Inflammatory Neuropathies are rare conditions, but their impact is profound.

People may experience:

- Sudden paralysis or progressive weakness
- Long hospital stays and rehabilitation
- Uncertainty about relapse or remission
- Financial hardship
- Long-term physical and emotional effects

There is no comprehensive national dataset. Prevalence estimates suggest thousands are impacted, yet many remain unknown to support services like Inflammatory Neuropathies UK.

We know there is a gap between those living with these conditions and those receiving consistent, informed support.

We exist to close that gap.

We are here to:

- Provide trusted information and practical support
- Connect people with others who understand
- Fund research that improves outcomes
- Ensure our community's voice shapes healthcare and policy

Our Core Work is built around

Support

We provide practical, accessible support across the UK. Our support includes:

- Informed support through a dedicated advice and information helpline
- Specialist information resources online and in print
- Peer Support matching with trained volunteers
- Local and Online Get Togethers
- Personal Grants
- Emotional Support access
- A moderated online community of over 4,000 members

We do not provide medical advice, but we help people navigate complex systems and access the right support at the right time. For many, we are the first place they turn after diagnosis.

Raising Awareness

Through campaigns, digital engagement, conferences and professional networks, we highlight the reality of living with Inflammatory Neuropathies and the need for better support and recognition. We also know that if people do not know about us, we cannot support them. We work to increase awareness among:

- The public
- Healthcare professionals
- Policy makers
- Partner organisations

Research

Research changes lives.

We fund clinical research through grants and donations, supporting universities, hospitals and early-career researchers. We are now expanding into social research to better understand:

- Long-term impact and residual symptoms
- Emotional and mental health needs
- The experience of ageing with an inflammatory neuropathy
- Access to physiotherapy and rehabilitation
- Fear of relapse and uncertainty

We are also committed to improving data collection and usage so that future planning and policy are based on stronger evidence.

Advocacy & Influence

Inflammatory Neuropathies are part of a crowded neurological landscape. Smaller communities can easily be overlooked. We work to ensure our members are heard by:

- Responding to government consultations
- Engaging with NHS bodies and healthcare providers
- Contributing to national alliances and networks
- Amplifying lived experience

Our goal is not simply to support individuals, but to influence systems.

IN numbers: Our Impact in 2024–2025

599 people directly supported

128 people supported via online groups

56 peer support matches

£20,000 invested in clinical research

44,525 website visitors

4,186 Facebook community members

"Producing a response to the government's benefits plan on the day the news broke along with the messaging in the group about fighting for us is exactly what I needed to hear. It is reassuring knowing someone gives a damn"

Our 10-Year Ambition (2025–2035)

We are an ambitious organisation and over the next decade, we will grow sustainably, strengthen our voice, and expand our impact. Here's how we intend to deliver that aim.

Years 1–2: Strengthening Foundations

We will:

- Increase the number of people we support
- Increase the number of people we reach and engage with
- Reconstruct our Core Support Offer based on the needs of our Community
- Refresh our systems and practise
- Develop a financial strategy and improved financial model
- Develop more projects
- Improve our data
- Improve our communication

Years 3–5: Growing Reach and Influence

We will:

- Continue to increase the numbers of people we support
- Continue to increase the number and diversity of people we reach and engage with year on year
- Increase and diversify our income streams
- Provide more services and support
- Understand our Community more
- Begin a national conversation
- Grow our voice
- Continue to define and redefine the organisational systems and structures

Years 5–10: National Leadership

By 2035, we aim to:

- Reach everyone who needs us
- Be the first point of contact
- Have in place an up to date, full dataset
- Understand the burden of conditions
- Be much better known

"[Staff and volunteers]have all had time for me and I really appreciate that – I don't feel alone"

We will remain a charity that is Community-driven, Evidence-informed, Financially responsible, Bold in ambition, and compassionate in delivery.

This is a snapshot of a longer, more detailed Strategy which demonstrates what needs to happen, when it will occur, who is responsible, and how it will be funded. If you would like to read the full document, please contact us or visit our website.

We have big aspirations and the ability to deliver on them, so join us as we continue this amazing journey together:

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