

Inflammatory Neuropathies UK

**IN this Together:
Our impact in 2025/26**

IN this

together

Inflammatory Neuropathies UK Impact Report 25/26

Foreword From The Chief Executive

This year has been an amazing one for Inflammatory Neuropathies UK. Our first year following the rebrand from Guillain-Barré and Associated Inflammatory Neuropathies (GAIN), and it's one full of growth, learning, and connection.

Over the past 12 months, we have continued to support more people than ever before, strengthened our voice within healthcare and policy discussions, and expanded the reach of our information, awareness, and support work.

Behind every number in this report is a real person navigating the impact of Guillain-Barré syndrome (GBS), CIDP, MMN, and other Inflammatory Neuropathies. Many people tell us they feel isolated, unheard, or unsure where to turn. Our role is to help change that.

This year we saw:

- An increase in the number of people supported people supported
- An increase in activities completed
- Increased social media engagement
- More than 70,000 website users accessing information and support

This is amazing, but we also know there is still more to do.

Peer support referrals reduced during the year, and new membership numbers went down. These trends have helped shape our priorities going forward. We want to make it easier for people to find us, connect with others, and feel part of a supportive community.

The feedback from our community this year has been incredibly encouraging. People told us they value our approachable support, accessible information, awareness work, and growing advocacy role.

As a small charity, we are proud of the difference we continue to make with limited resources. None of this would be possible without the support of our volunteers, supporters, trustees, healthcare professionals, fundraisers, donors, and the wider Inflammatory Neuropathies Community.

Thank you for being part of this journey.

Rich

Rich Collins
Chief Executive





We know these conditions can have a huge physical, emotional, financial, and social impact. Many people face long recovery periods, uncertainty about treatment, challenges accessing healthcare, and the lasting impact of residual symptoms.

Our work focuses on:

- Providing practical and emotional support
- Delivering trusted and accessible information
- Raising awareness of Inflammatory Neuropathies, and the burden of the conditions
- Amplifying the voices of people with lived experience
- Supporting research and better care
- Working with healthcare professionals, policymakers, researchers, and partners to improve outcomes

We are here for our Community, we are here to support. We are all IN this together.

About Inflammatory

Neuropathies UK

Inflammatory Neuropathies UK is the national charity supporting people impacted by Inflammatory Neuropathies, including Guillain-Barré syndrome (GBS), Chronic Inflammatory Demyelinating Polyradiculoneuropathy (CIDP), Multifocal Motor Neuropathy (MMN), and around 40 other conditions.

We exist to ensure people impacted by these conditions are informed, supported, connected, and represented.





Why We Measure

Our Impact

Measuring impact helps us understand whether we are making a meaningful difference to people impacted by Inflammatory Neuropathies or not.

It allows us to:

- **Understand what matters most to the community**
- **Identify gaps and areas where people need more help**
- **Demonstrate the value of our work to supporters and funders**

- **Improve the services and support we provide**
- **Shape future priorities and strategy**

We use a combination of service data, digital engagement data, feedback, surveys, and conversations with the community to understand our impact.

This report combines data from across the organisation, alongside information from our Big Get Together, and feedback from our 2025/26 community survey.

WHAT WE DO

Information And

Support

We provide information, guidance, and support to people impacted by Inflammatory Neuropathies and their families.

This includes:

- Telephone and email support
- Peer support
- Online information and resources
- Virtual support sessions and online get togethers
- Social media support and community engagement
- Signposting and practical advice
- Personal Grants

Awareness And

Advocacy

We work to improve understanding of Inflammatory Neuropathies across healthcare, government, decision-makers, researchers, and the wider public.

This year we:

- Worked with national organisations and alliances
- Contributed to discussions around Principles of Care for CIDP

- Engaged with NICE consultations and rare disease quality standards

- Increased our awareness campaigning online

- Expanded our social media reach and engagement

Key awareness campaigns during the year included:

- GBS and CIDP Awareness Month
- Rare Disease Day
- Autoimmune Awareness Month
- Awareness content based on lived experience and symptoms

Research And

Partnerships

We continue to support research and work with healthcare professionals, researchers, charities, and industry partners to improve understanding and outcomes.

We know the community wants:

- Better understanding of the long-term impact of Inflammatory Neuropathies
- Improved treatments and access to clinical trials
- More research focused on lived experience and quality of life

These themes will continue to shape our future research priorities.

OUR IMPACT

Supporting More People

During 2025/26, we supported significantly more people than the previous year.



57%
more people supported



121%

increase in support delivered



67%

increase in Personal Grants awarded



63%

increase in direct support activities

Area	2025/26	Previous Yr
People supported	937	597
Personal grants awarded	25	15
Direct activities completed	5,349	3,285
Website users	70,091	44,525



Significant growth in website use and digital engagement



The data shows growing demand for practical support, information, and connection.

Your Voice, Your Impact



IN UK is far more approachable and feels like you are really getting to know your community and representing our needs well.



The content on your website and social media is really informative and engaging.



Digital Reach

And Awareness

Our online presence continued to grow throughout the year.

Measure **2025/26**

Social media followers **6,483**

Social media engagement **22,141**

Highlights include:



15%

Increase in social media followers



31%

Increase in social media engagement



80,000

Average monthly social media impressions



70,000+

website users during the year

Our website attracted more than 70,000 users during the year, showing the increasing demand for reliable information & support.

Listening To The

Community

We carried out a community survey during 2025/26 to better understand people's experiences and priorities.

The survey showed that people value the work we are doing.

Supporting people



4.1
out of 5

Communication : **4.2 / 5**

Raising awareness : **3.9 / 5**

Campaigning & advocacy : **3.9 / 5**

Research activity : **3.7 / 5**

People particularly valued:

- ✓ Our easy to understand information
- ✓ The peer support and emotional support that we provide
- ✓ Engagement with the community
- ✓ Awareness raising
- ✓ Website information and online resources
- ✓ Speaking up for people impacted by Inflammatory Neuropathies



Fundraising And

Financial Support

Despite a difficult fundraising environment nationally, annual fundraising income slightly **increased in 2025/26.**



What People Told Us

Matters Most

People consistently told us they want:



Better access to emotional and mental health support



More research into treatments and long-term impact



Greater awareness among healthcare professionals and the public



Stronger campaigning and advocacy



More opportunities to connect with others



Better information about clinical trials and specialist care

The survey also highlighted the importance of:

- ✓ Working with healthcare partners
- ✓ Working with government
- ✓ Supporting unpaid carers and families
- ✓ Ensuring lived experience shapes research and policy

We also saw an **increase in average donation size.** This was particularly encouraging and reflects the commitment and generosity of supporters.



What The

Future Holds

We have great plans, and the ability to deliver them.

This coming year ahead will focus on:

- Strengthening Peer Support
- Growing membership and community engagement
- Expanding support services
- Increasing awareness and campaigning work
- Developing clearer research priorities
- Improving how we measure long-term impact

We will continue to ensure the voices and experiences of people impacted by Inflammatory Neuropathies remain at the centre of everything we do.

Thank you to everyone who supported **Inflammatory Neuropathies UK** during 2025/26. Whether you shared your story, volunteered your time, donated, fundraised, attended an event, partnered with us, or reached out for support, you helped strengthen our community.

Together, we are building a future where nobody impacted by Inflammatory Neuropathies feels alone.

**IN this
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