

Inflammatory Neuropathies UK Trustee Role Description

About the role

- Voluntary role
- Reasonable expenses reimbursed
- Location: UK wide (Board meetings typically held online with occasional in-person meetings)
- Time commitment: Monthly one-hour meetings, annual AGM and Big Get Together, annual whole day session, with additional sessions as required. Overall, approximately 30-40 hours over 20 days per year

About Inflammatory Neuropathies UK

Inflammatory Neuropathies UK is the only UK charity wholly dedicated to supporting people impacted by Guillain-Barré Syndrome (GBS), CIDP, MMN and other Inflammatory Neuropathies. These are rare but life-altering autoimmune conditions.

The charity provides:

- Information and emotional support
- Personal grants
- Local and peer support groups
- Online forums and community spaces
- Fundraising for research
- Social research to improve understanding and services
- Support for families, carers and healthcare professionals

We work across the UK and are rooted in lived experience and peer support.

Role Purpose

As a Trustee, you will be part of the Board responsible for the overall governance and strategic direction of Inflammatory Neuropathies UK.

Trustees ensure the charity is well-run, financially sustainable, legally compliant and focused on delivering its charitable purposes.

Trustees share collective responsibility for decisions and must always act in the best interests of the charity and its beneficiaries.

Main Responsibilities

Governance and Strategy

- Contribute to setting and monitoring the charity's strategic direction
- Ensure activities align with the charity's charitable objectives
- Safeguard the charity's reputation and values
- Ensure effective systems of control and risk management are in place

Financial Oversight

- Ensure the charity is financially stable and sustainable
- Approve budgets, annual accounts and financial policies
- Monitor income generation, including fundraising for research and services

Compliance and Accountability

- Ensure compliance with charity law and relevant regulation
- Act in accordance with the governing document
- Ensure appropriate safeguarding measures are in place
- Promote equality, diversity, and inclusion in governance and services

Support and Challenge

- Provide constructive challenge and independent judgment
- Support and hold the Chief Executive to account
- Act as an ambassador for the charity where appropriate

Person Specification

We welcome applications from people with a wide range of backgrounds and experiences. Lived experience of GBS, CIDP, MMN or other Inflammatory Neuropathies (either personally or as a family member or carer) is highly valued, but not essential.

Essential

- Commitment to the mission of Inflammatory Neuropathies UK
- Understanding of, or willingness to learn about, trustee responsibilities
- Strategic thinking ability
- Good judgment and integrity
- Willingness to speak up and contribute constructively
- Commitment to equality, diversity and inclusion

Desirable (not all required)

Experience in one or more of the following areas:

- Charity governance
- Finance or accountancy
- Fundraising and income generation
- Health and social care
- Medical or research governance
- Digital and communications
- HR or organisational development
- Safeguarding
- Strategy Development, Deployment and Execution
- Public policy or advocacy
- Lived experience of Inflammatory Neuropathies

Time Commitment

- 12 Board meetings per year (typically monthly and 1 hour each)
- Participation in at least one sub-committee (if applicable)
- Annual General Meeting and Big Get Together
- Annual strategy session
- Occasional events or ambassadorial activity
- Preparation time for meetings (reading papers)

Term of Office

Trustees will serve terms in line with the constitution. A term of office is defined as the period between when a Trustee is first appointed by vote at an annual general meeting and when they retire. One third of all Trustees must retire at an annual general meeting. A Trustee can serve for four consecutive terms.

What You Will Gain

- The opportunity to make a meaningful difference to people living with rare, life-altering conditions
- Experience in charity governance and leadership
- The chance to contribute to research funding and service development
- Being part of a supportive, values-driven Board

Equality and Inclusion

Inflammatory Neuropathies UK is committed to building a diverse Board that reflects the communities we serve across the UK. We actively encourage applications from under-represented groups and will make reasonable adjustments to support accessibility.