Inflammatory Neuropathies UK

IN action

Our strategy

Delivering impact for the Inflammatory Neuropathies Community

2025 – 2035

INside table of contents

INtroducing...

IN time / IN support

IN the future

IN this together

IN numbers

IN the team

IN focus

IN action

@InflamNeuroUK

Registered Charity 1154843 & SCO39900
3 Mill House | Carre Street
Sleaford | Lincolnshire | NG34 7TW

01529 469910
inflammatoryneuropathies.uk
hello@inflammatoryneuropathies.uk

INtroducing

We are **Inflammatory Neuropathies UK,** the only UK charity completely dedicated to providing information and support to people impacted by Guillain-Barré Syndrome (*GBS*), Chronic Inflammatory Demyelinating Polyradiculoneuropathy (*CIDP*), Multifocal Motor Neuropathy (*MMN*), and other Inflammatory Neuropathies.

We are here to support, and to help people navigate the complex world of Inflammatory Neuropathies. After all, that's one of the main reasons why we exist. We try to make everything as simple as we can, by explaining, translating, and informing, so everything is as straightforward and clear as possible. We are also here to reassure during difficult times.

We offer personal grants, online forums, and much more. We support people through a community of volunteers with lived experience, ensuring people are there to help each other. We raise funds for research, and we advocate on behalf of our Community with the Government and other decision makers. We raise awareness about these life changing conditions with people, and with the medical community, so that we can make life better for people. We work right across the UK, and we can also offer advice and support to those living in the Republic of Ireland as well.

We are here for people whether they have one of these conditions, are supporting a friend or a family member, are a medical professional, or for those who would like to help us by raising funds.

We are in this together

Inflammatory Neuropathies UK is a well-respected national charity reaching and supporting thousands of people impacted by these life-changing conditions each year.

We are a membership organisation, driven by our Members and the Inflammatory Neuropathies Community. We want to ensure that people impacted by Inflammatory Neuropathies receive the best support, life chances, and outcomes as possible. We also want to see the burden of the conditions reduced.

We work to see people's experiences made better, especially in terms of diagnosis, treatment, and the long term management and impact of conditions. We are seeking to ensure that more people to know about Inflammatory Neuropathies, and for the voices of our Members and people impacted by these life changing conditions to be heard and to be listened to.

We are an ambitious and aspirational Charity, and are bold in our approaches to meeting the needs of our Community.

We are currently in a period of evolution, growth, and development, and understand that we need to take a more strategic approach to what we do and how we do it as we take the next steps forward on our journey to ensure that **Inflammatory Neuropathies UK** grows, thrives, and delivers.

IN simple terms

GBS is an autoimmune neurological condition that affects the nerves that control movement and senses (the peripheral nervous system). It can cause numbness and weakness, and some people may be completely paralysed or may require intensive care treatment. GBS impacts people in very different ways, and everyone's journey is different.

CIDP is a rare progressive condition that is characterised by gradually increasing sensory loss and weakness over a longer period of time. Long term treatment and support may be needed.

MMN is a rare, progressive condition that mainly impacts the motor nerves, causing weakness and potentially muscle problems, without significant sensory loss.

Who are we?

Inflammatory Neuropathies UK is a Charitable Incorporated Organisation (*CIO*) registered in England and Wales through the Charity Commission (1154843) and in Scotland through the Office of The Scottish Charity Regulator (SCO39900). We are registered as a section 167 organisation with The Charity Commission for Northern Ireland.

Our head office is in Sleaford in Lincolnshire, but we cover the whole of the UK and Ireland, including the Channel Islands, and the Isle of Man. We are not registered as a charity in the Republic of Ireland and do not act as one. However, people who live in the Republic of Ireland can contact us for support if they wish.

We have a small staff team of three staff members, around 30 active volunteers, and eight Trustees.

The objects of the CIO are to relieve the needs of people impacted by Inflammatory Neuropathies, their families and carers, in particular, but not exclusively by:

a) The provision of information, non-medical advice and other assistance;
b) The promotion of research into the causes, prevention and treatment of Inflammatory Neuropathies; and
c) Advancing the awareness of the public and of the medical professions concerning Inflammatory Neuropathies, their causes, prevention and treatment

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.

Our aims and objectives

Our aims and objectives are to:

- Provide appropriate support, information, advice and guidance to people impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies
- Raise awareness around conditions and the Charity with people impacted by Inflammatory Neuropathies, the general population, and the medical community
- Fund, facilitate and undertake clinical and social research into Inflammatory Neuropathies
- Influence government, policy makers, and the scientific community
- Advocate on behalf of our Members and the Inflammatory Neuropathies Community
- Effectively manage the Charity and its finances, and to fundraise to enable us to meet our aims and objectives

Our theory of change

To support our strategic planning we have put together a simple developmental Theory of Change, which lays out what the problem is that we are seeking to solve, what activities we will undertake to solve this problem, what the results of those activities will be, and what outcomes we are seeking for the people we support. This Theory of Change is the basis for this strategic plan *(see overleaf)*.

Inflammatory Neuropathies UK

Theory of Change

1 Problem

People impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies are negatively impacted by their conditions

2 Activity

Provide support, information, and advice | raise awareness | fund and facilitate research | and advocate and influence

3 Result

Improved quality of life | access to support, diagnosis, treatment and management of condition | understanding of own condition | and voice heard, listened to, and acted upon

4 Outcome

The negative impact of GBS, CIDP, MMN, or another Inflammatory Neuropathy affects people less.

IN time

our history

Inflammatory Neuropathies UK began its life as the Guillain-Barré Syndrome Support Group (*GBSSG*) in 1985.

Following her initial recovery from GBS, our Founder, Glennys Sanders, realised that there was no support for people impacted by GBS in the UK. During her lengthy rehabilitation, Glennys began making contact with clinicians, and establishing links across the country. Then in 1985, she placed an advert stating that she was holding a meeting to establish a group for people affected by GBS, and to her surprise she received a significant response.

From there Glennys established the GBSSG from her home near Sleaford in Lincolnshire, building a large group of local volunteers, appearing on local and national radio, and establishing a regular newsletter as well as an annual conference. The group finally outgrew Glennys' kitchen table, and rented a small office in nearby Ruskington.

The organisation established itself as a Charity in 1986, and was run entirely by volunteers. In 2013, a new Charitable Incorporated Organisation was set up named Guillain-Barré and Associated Inflammatory Neuropathies (*GAIN*). GBSSG transitioned into GAIN in 2014.

GAIN continued to grow and develop, and purchased its new base in Sleaford in 2017, a building that was named Glennys Sanders House after our Founder. GAIN continued in this form until 2024, when it began its current developmental phase under a new Chair and Chief Executive.

In May 2025 GAIN changed its name to **Inflammatory Neuropathies UK** in order to be more inclusive towards our whole Community, to support engagement and reach, and to build on its ongoing development.

Glennys unveiling her namesake building

IN support

Outcomes sought

The outcomes we are seeking to achieve are to:

- Improve the quality of life of people impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies.
- Improve the diagnosis, treatment, management, and support of people with an Inflammatory Neuropathy.
- Reduce the health, social, and economic inequalities affecting people impacted by Inflammatory Neuropathies.
- Increase the number of people who are aware of GBS, CIDP, MMN, and other Inflammatory Neuropathies; the impact of conditions on people's lives; and of the Charity.
- Increase and stabilise the funding that the Charity receives
- Increase the opportunities for people impacted by Inflammatory Neuropathies to be heard and listened to.

What we do

At the moment we provide a range of services for the whole of UK from our base in Sleaford. We provide services directly to people impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies, as well as supporting medical professionals and institutions, partner organisations. We also look to influence government and other decision and policy makers.

Our current offer

Our current offer is based around four key themes:

Support
Raising awareness
Research
Advocacy and influence

Inflammatory Neuropathies UK

Our Core Offer

Awareness

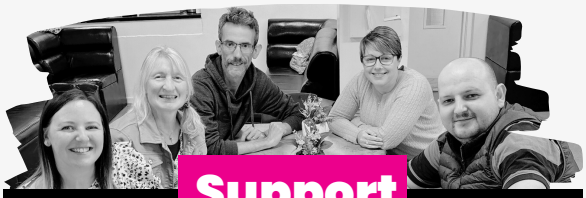
We INform people about these conditions by

- **Highlighting conditions with the public and medical professionals**
- **Sharing information about the charity with the public and medical professionals**

Advocacy & Influence

We advocate and INfluence by

- **Providing a voice for our members**
- **Listening to members, and collecting and sharing input**
- **Influencing government and policy makers**
- **Influencing the NHS and Pharma companies**



Support

1 2 3 4 **We get IN with people in need of help via**

- **Our Support Line**
- **Information, advice, and guidance**
- **Our Website**
- **Peer Support**
- **Online & Local Get Togethers**
- **Personal Grants**

Research

We hope to gain INsights into the conditions by

- **Funding clinical and social research**
- **Facilitating clinical and social research**
- **Undertaking social research**
- **Undertaking, supporting, and improving data collection and usage**

1. Leeds Local Get Together
2. CEO In conversation with Medical Professional at a conference
3. Research equipment from a funded project

Support

Our Core Support Offer involves:

Phoneline We provide an advice and information helpline (including a freephone number in both the UK and Ireland). The phoneline is available during office hours five days a week, with a messaging service available out of hours. Through the phone line we provide specialist information and advice about Inflammatory Neuropathies, general advice around living with a condition and accessing other types of support, and access to our other key support services. We do not provide any medical advice, but can refer specific questions to our Medical Advisory Board.

Information We provide a range of information resources to people impacted by Inflammatory Neuropathies. These include our website, factsheets, posters, social media resources, a range of printed resources, and specialist medical information developed by our Medical Advisory Board.

Peer Support We match people impacted by Inflammatory Neuropathies to our volunteers with lived experience of conditions and their impact. Volunteers are able to share their experience with people, and answer questions and queries.

Local Get Togethers We support a small number of local groups who meet regularly to share information and experiences, support each other, and meet socially. Currently we have groups in Lancashire and Cumbria, Yorkshire, and Newcastle.

Online Get Togethers We provide monthly virtual meetings on Zoom. These groups are always facilitated by a member of **Inflammatory Neuropathies UK**'s staff. The groups meet for an hour, and there is currently one group for GBS and its variants, and one group for CIDP and its variants.

Personal Grants We provide personal grants for people who are undergoing financial hardship. These grants provide financial support in terms of covering milage and parking costs for people who are in hospital, as well as funding specific pieces of equipment.

Facebook Group **Inflammatory Neuropathies UK** facilitates a closed Facebook Group for the Inflammatory Neuropathies Community. The group consists of over 4,100 people impacted by Inflammatory Neuropathies.

Raising awareness

Our current work around raising awareness includes:

Sharing information with the public We currently share information about conditions and their impact, and what the Charity does with our Community through social media and our website. Occasionally, our volunteers or a member of our Community may share information on our behalf. We run an awareness month in May each year.

Sharing information with clinicians and medical establishments At present, we share information with clinicians and with medical establishments when requested. Volunteers and Members may sometimes share information with their local clinicians and services on our behalf.

Research

Our current research work includes:

Clinical Research We fund clinical research through grants and donations. This is predominantly with universities, hospitals and research establishments. We also fund medical and clinical students, as well as their research.

Advocacy and influence

Our current work around advocacy and influence includes:

Member Voice We work to ensure that we listen to, capture and amplify the voices of our Members and the Inflammatory Neuropathies Community. This involves undertaking engagement and coproduction work, sharing opportunities with our Members (and with others), and ensuring that the voice of our Members is reflected in the work we do, and within our influencing work.

Influencing Government We seek to ensure that **Inflammatory Neuropathies UK** and our Members are represented and heard within government at the national level (UK, England, Scotland, Wales, Northern Ireland), international level (Ireland and EU), and at local and regional levels, and with decision makers across the board. This is in terms of consultations, research, and engagement, as well as around specific issues.

Influencing the NHS We seek to influence the NHS and health providers, as well as the pharmaceutical industry in terms of support, diagnosis, condition management, development, trials, and research.

IN the future

Our Potential Offer

While we are rightly proud of what we do, we always know that we can do more. Having talked to our Members, looked at our current offer, researched the needs of our Community, and discussed as a Board, we have identified a number of potential new opportunities to explore and develop.

Support

Our potential opportunities around our support offer include:

Improved direct support We want to make sure that we can support more people who come to us directly. In order to do this, we want to improve our core support offer so that we can advise and support around key areas such as finance, benefits, health processes, social care, and high-level emotional support.

Improved information offer Much of our information is outdated and written in language that is difficult to understand. This is especially true of our condition specific and medical information. We want to redevelop these resources, and ensure they are more accessible for everyone.

Local champions In the past, the Charity offered local representatives across the country. These were volunteers who could act as a local link for people impacted by Inflammatory Neuropathies. Whilst it is unlikely that we will need the types of support we previously had in place, people have told us that they would like access to people with experience and knowledge of local services and systems, as well as having someone they could meet in real life. This would link in with improving our Local Get Togethers.

Expanded Local Get Together network A key development for **Inflammatory Neuropathies UK** will be increasing the number and the scope of our Local Get Togethers, developing a larger network of groups across the UK and Ireland. This would involve recruiting, training and supporting additional volunteers to act as Local Facilitators.

Improved Online Get Together offer Feedback around our Online Get Togethers is that while they are well received, not everyone can attend during a working day, and that they don't meet often enough. We could hold more events each month, change

the times the events happen, and diversify the platforms we use. We could also look at alternative ways of meeting including via WhatsApp and other platforms.

Emotional Support A significant gap in support for people impacted by Inflammatory Neuropathies is around emotional support. While we aren't necessary responsible for this provision, and are not best placed to provide it directly, we could commission or support access to a direct service, or other key resources that could support individual and group emotional support needs.

We are currently trialling counselling and group support through a specialist provider. If this is successful we will look to roll this out as part of our core offer.

Physio and Rehab Support Another key gap is around physiotherapy and other rehabilitation services. Again, while this isn't necessary **Inflammatory Neuropathies UK**'s responsibility to provide, our Community is telling us that there is a need for these types of services. This is something we could commission or provide access to, especially in terms of lighter touch services and resources.

Raising awareness

Improved reach and engagement Our biggest obstacle to reaching more people is our reach and our engagement. If people don't know about us, then we cannot provide support. To improve awareness, we need to improve our reach. To do this we will further develop our social media channels, expand our website, and build on our messaging in order to ensure we can engage a larger and broader audience.

Campaigns We will develop and roll out a number of targeted and general campaigns each year in order to reach different audiences and spread different messages.

Research

Social Research While we have a history of funding and supporting clinical research, we have not routinely undertaken, facilitated, or funded social research. Our Members tell us that this is important to them, and that there are a large number of subject areas that we need to understand more, especially around how Inflammatory Neuropathies impact on people and their lives. Initial scoping work has given us some ideas to build on, specifically around:

- Mapping symptoms and residuals
- Investigating the fear of GBS returning
- Understanding the impact of aging on people with an Inflammatory Neuropathy
- Understanding how people impacted by an Inflammatory Neuropathy can be supported with their emotional and mental health
- Understanding the impact of physiotherapy for people impacted by GBS, CIDP, MMN, and variant conditions

Data Collection and Usage A key area for us is around improved data and information. Current data around Inflammatory Neuropathies is poor, with prevalence data our only real tool, and no usable national or international data available at any level. The data that we hold about our Members and the UK population impacted by Inflammatory Neuropathies is also incomplete, and does not allow us to look at population level information. This lack of data and information means that we cannot properly analyse need or demand, or best understand how Inflammatory Neuropathies impact people above an individual basis. We need to find ways of better collecting and using data across a number of levels.

Advocacy and influence

Louder Voice While we want to amplify the voices of our Members and the Inflammatory Neuropathies Community, and strive to do this where we can, we feel that we need to do lots more in this area. The Neurological Conditions sector is crowded with more than 400 different conditions, and it is very easy for smaller voices to be drowned out by larger ones. We need to make sure the voices of people impacted by Inflammatory Neuropathies are heard and are listened to.

Improved Presence across Networks **Inflammatory Neuropathies UK** are proud of being part of a number of alliances and infrastructure groups that help us to amplify our voice and create impact through a combined approach. However, we feel that we can do more within these groups, especially from a campaigning and policy perspective. We need to be more involved in setting and influencing agendas within these spaces and being an organisation that our peers turn to when they want quality and informed input.

Cross Party Representation At present, our voice at government level is insignificant. As a smaller organisation representing a relatively small membership and community of interest, we know that we are unlikely to have an All Party Parliamentary Group (APPG) put in place for Inflammatory Neuropathies, or any specific policy work undertaken around Inflammatory Neuropathies. However, we do want to ensure that Inflammatory Neuropathies are part of wider discussions, and our Member's voices are heard in Parliament, as well as on a regional and local level. To this end, we believe that we should seek allies across all parties within the House of Commons and the House of Lords, and within Holyrood, the Senedd, and at Stormont. We need to empower our Members to seek representatives from their local and national elected representatives.

Improved Influence While we are a small organisation, we believe we could and should have big influence due to the severity of the impact of Inflammatory Neuropathies on individuals and families, the significant cost of treatments and impacts on the state, and our potential position within alliances and infrastructure. We need to improve our influencing and ensure that our impact is felt beyond individual support, but also across national and international policy and practice.

IN this together

Why we do what we do

After forty years of supporting people impacted by GBS, CIDP, MMN, and other Inflammatory Neuropathies, we know why we do what we do, and what drives us forward every day. People.

However, in order to understand needs and demand, we need to demonstrate that as a Charity, there is a real need for us to exist, and to continue to fundraise and deliver support and services across the UK.

Commitment

All the staff, trustees, and volunteers who operate **Inflammatory Neuropathies UK** are committed to improving the lives of people impacted by Inflammatory Neuropathies, and reducing the negative impact of the conditions. This commitment to improve lives and impact is what drives the Charity forward, and comes from listening to the needs and wants of people, understanding the gaps in provision, and being driven by lived experience. Everyone involved with **Inflammatory Neuropathies UK** wants to see things better for people impacted by these conditions, and this is at the very heart of understanding why we do what we do, because we need to.

Community

We are so lucky to be supported by an amazing Inflammatory Neuropathies Community, not only in the UK and Ireland, but across the world. We believe that our Community is incredibly special, supporting each other, and sharing information and advice whenever they can. This Community manifests itself in a huge number of ways from the 4100 people on our private Facebook group, to the dozens of people who attend our monthly online Get Togethers. We have an incredibly close relationship with our Community, which is built on mutual trust, support and delivery. We know that when we need information, links, or input, then our Community will be there. And our Community know that **Inflammatory Neuropathies UK** will be there, whenever they need us most.

Members and client base

As we have highlighted, our own internal data is far from accurate. While we are actively working to improve the quality, scale, and scope of our own internal data, much of our legacy data is incomplete, and as result is unreliable. However, we are able to analyse our data to look at our membership numbers, as well as the numbers of people with each condition who are known to us.

Membership Numbers

no. voting members	no. of non-voting members	total no. of members
232	1556	1788

People known to us with...

GBS	CIDP	MMN
1070	274	11

other IN	total
30	1385

Needs and demand: numbers plus prevalence

We would love to be able to report on the number of people with GBS, CIDP, MMN, and other Inflammatory Neuropathies in the UK, but unfortunately there is no register, or universal method of capturing numbers which is used consistently. As a result, we only have prevalence numbers derived from clinical research which allows us to estimate the number of people who are impacted by these conditions.

Issues around how conditions impact people in different ways, also means that we can only further estimate the numbers of people. This is especially true as people 'had' GBS rather than 'having' it, and as a result we don't know the longer term impacts for different people due to residual and ongoing needs. Likewise, with CIDP and MMN, we don't know how many people who are diagnosed, have a condition that is well managed or in remission, so again, can't quantify impact as well. As a result, we can only estimate numbers impacted by these conditions using our own modelling tools.

GBS

	new cases per year (low)	new cases per year (high)	new cases per year (average)	total living with impact of GBS	total impacted directly by GBS
UK	669	1139	1004	3213	4217
England	565	1130	847	2712	3559
Scotland	54	109	82	261	343
Wales	31	62	47	149	196
N. Ireland	19	38	30	91	121
R.o.Ireland	51	103	77	247	324

CIDP

	new cases per year	total living with CIDP (low)	total living with CIDP (high)	total living with CIDP (average)
UK	602	3347	4686	4016
England	508	2825	3954	3389
Scotland	49	272	381	326
Wales	28	155	218	186
N. Ireland	17	95	133	115
R.o.Ireland	46	257	360	309

MMN

	total cases of MMN
UK	402
England	339
Scotland	33
Wales	19
N. Ireland	11
R.o.Ireland	31

Please note, figures in GBS, CIDP, and MMN tables are estimates based on available prevalence data and our own calculations

Learning from the data

As can be seen from the data outlined in this spread, the differences between prevalence information, and people known to us are stark. This shows that as an organisation we need to do more to reach and support the significant numbers of people likely impacted by Inflammatory Neuropathies, but who are not known to us.

IN numbers

We continually monitor and report on our impact. This is the key way we can see how well we are doing, how we are serving our Community, and how well we are delivering against our aims, objectives, and outcomes.

Here's how we performed between April 2024 and March 2025:

599 supported people

56 people with Peer Support volunteers matched

128 people supported via online groups

15 people supported by

£10,901 Personal Grants

IN the lab

"keep up the good work"

we funded

£20,000 of clinical research

on the INternet

Facebook Group Members **4,186**

Total Social Media followers **5,719**

Engagements across all socials **16,936**

44,525 website visitors

"keep building on the great work of the last 14 months"

"I think you are doing an amazing job -thank you"

INvolved

199 new members

59 voting

140 non-voting

members total

1,788 of

IN print

1,700 readers, which is approx. 12 newsletters sent to around 20,000 newsletters distributed. we believe we're engaging, via newsletters over 10,000 x a year

IN your opinion

Within our annual survey, people told us that they had seen a positive change in the charity since last year.

They also scored us above 4 (out of 5) across all areas of work

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

"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"

"What an excellent year it has been. Newsletters every month so I know what is happening with the charity and illness. I see Rich is always out meeting people, advocating, building a name. This is excellent. The more we shout the more people will know about GBS, the better the care."

"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"

"The only support I get really is through the magazines. I [also] enjoyed meeting other people who went through what I went through."

IN the team

Our model

Here at **Inflammatory Neuropathies UK**, we use a very basic and flexible structure, all based around the needs of the organisation and our Community. We do not feel that we need a large staffing structure to be able to manage our work. We have evolved a flattish structure that involves core roles that we need to deliver successfully, supported by a team of amazing volunteers and trustees.

If our model needs to be changed to deliver in a different way, we would always seek to use temporary resources or third parties to minimise risk to the organisation, unless there was a firm business case to change the structure, and a sustainable income stream to fund it.

Our working model is also fluid, having adopted remote working as part of recruitment strategies. While we retain an office presence, we will continue to operate some office based staff, but have a hybrid model to support recruitment, ensuring that we can secure the best resources to meet the needs of the organisation and our Community.

Staffing structure

Our current staffing structure is laid out below.

Chief Executive

The role of the Chief Executive is to lead and manage the Charity and the staff team, supporting the Board to deliver effectively.

The Chief Executive role includes:

- Operational responsibility and day to day management of the organisation
- Developing, managing and facilitating strategies to guide the organisation
- Advising the Board

- Managing and leading the staff and volunteer teams
- Representing and advocating on behalf of **Inflammatory Neuropathies UK** and our Community effectively and appropriately
- Managing partnerships and relationships with stakeholders

Information and Administration Officer

The Information and Administration Officer is vital to **Inflammatory Neuropathies UK**, carrying out our support function with people impacted by life-changing health conditions, as well as supporting the everyday running of the organisation.

The Information and Support Officer role includes:

- Providing support to people impacted by GBS, CIDP, MMN, and other related Inflammatory Neuropathies
- Providing Information, Advice, and Guidance
- Undertaking administrative tasks on behalf of the Charity, the Board, and the staff team
- Supporting and managing volunteers
- Acting as a first point of contact for the organisation

Marketing Executive

The Marketing Executive is an essential part of our Charity and the work that we do, carrying out vital engagement with people, as well as raising awareness across the Community.

The Marketing Executive role includes:

- Developing, maintaining and Implementing our Marketing, Engagement, and Communication Strategy
- Digital Marketing
- Content Creation
- Website Management
- Social Media Management
- Community engagement

Volunteers

At present we have 22 volunteers undertaking a number of roles on behalf of **Inflammatory Neuropathies UK**. These roles are:

Providing Peer Support Linking with people impacted by GBS, CIDP, MMN, or another Inflammatory Neuropathy, and providing information, advice, and guidance based on your own lived experience. This could be on the phone, or through a virtual meeting (MS Teams). On some occasions this may also be face to face

Supporting and Facilitating a Local Get Together Co-ordinating a Local Get Together in your area, and supporting those that join

Being a Local Champion Acting as an **Inflammatory Neuropathies UK** representative in your local area, linking into local clinical facilities and community groups and supporting local people impacted by GBS, CIDP, MMN, or another Inflammatory Neuropathy

Being an Online Champion Acting as an **Inflammatory Neuropathies UK** representative online, supporting people impacted by GBS, CIDP, MMN, or other

Inflammatory Neuropathies on online forums and meetings

Raising Awareness Supporting **Inflammatory Neuropathies UK**by actively raising awareness about GBS, CIDP, MMN, and Inflammatory Neuropathies, as well as the Charity itself

Research Support Supporting **Inflammatory Neuropathies UK**'s research work through data collection and related events

Trustees and governance

We have eight trustees who make up our Board. Our trustees have a wide range of experiences from across many sectors, and are able to support the organisation with their expertise, knowledge, and experience. Seven of our trustees have lived experience of an Inflammatory Neuropathy.

The Board is responsible for ensuring that the Charity is well managed, that we comply with all appropriate and relevant legislation and regulation, and that we look after our finances properly, putting them to the best use to meet the aims of the Charity. How **Inflammatory Neuropathies UK** is run and managed is laid out in our constitution.

As well as our Board, we have a **Finance Sub-Committee** which is made up of our **Treasurer**, **Chair** and one other trustee. The **Finance Sub-Committe** is responsible for oversight, direction, and guidance around financial issues, and to act on behalf of the Board in terms of financial scrutiny.

Trustees also sit on a number of **Task and Finish Groups** which are put in place to support specific workstreams, projects or developments.

Building and systems

Inflammatory Neuropathies UK is moving towards a more flexible working system. We are currently based out of Glennys Sanders House, a large office building based on Enterprise Park in Sleaford, Lincolnshire. However, we are seeking to move to a smaller serviced office that meets our needs better, and allows us to obtain an income from the building. As an organisation, we have adopted remote working as part of our working practices, but retain a base in Lincolnshire in order to provide storage, facilities, and resources to run the organisation.

In order to manage the organisation, we use a number of core systems and resources. These include:

Microsoft Office For emails, team communication, file storage and sharing, video calls, and project planning and management

Beacon For Customer Relationship Management

Xero For accountancy

Fundraising Platforms We use a variety of fundraising platforms to support fundraising and donations. These include Enthuse, Just Giving, GiveWheel, and PayPal Giving

Financial Platforms We use a variety of financial platforms to support financial transactions, sales, and donations. The include Stripe, Square, and Go Cardless

We bank with CAF Bank, Virgin Bank, and CCLA. We have investments through St. James Place. Our accountants and independent examiners are Moore Thompson LLP.

IN focus

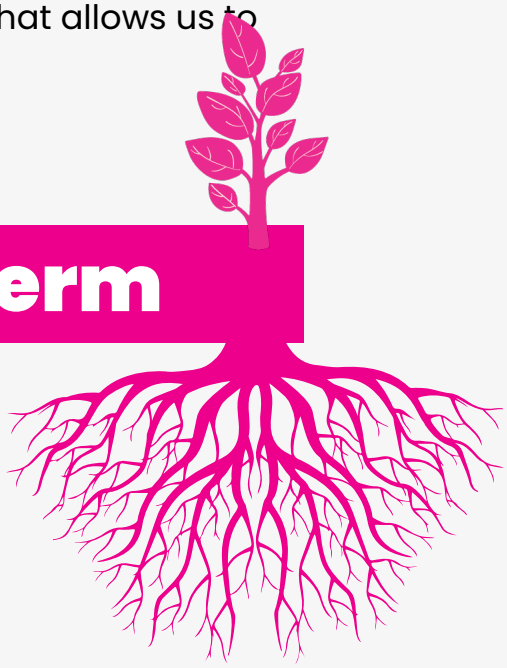
Our 10 year journey

We are a very ambitious organisation, and this is our proposed 10 year journey. It is the heart of our strategy and stems from our aims and objectives, through the needs of the Community we support, to the models and structures we have in place. This Golden Thread holds **Inflammatory Neuropathies UK** together, and allows us to create a planned way forward, as well as a detailed action plan based on what we will deliver.

IN the short term

We want to be a growing Charity with aspirational plans that allow us to spend part of our reserves to deliver for our community, while building up the reach and engagement that allows us to develop further.

IN the medium term



We want to be a stable and sustainable Charity with cash flow that covers all staffing and organisational costs, with income in place that allows us to deliver sustainable projects and fund research, whilst maintaining appropriate reserves.

IN the long term

We want to be a thriving Charity that is fully sustainable with increased income to match our spend, and where we deliver high quality outcomes and impact for our Community. We want to be known as the organisation that always meets the needs of its community, and is known amongst its peers as an example of good practice.

Our goals

We have a number of goals that will guide what we do over the next ten years.

These goals are based on the direction we want to take the Charity in, the opportunities that are presented to us, the needs our Community, and the needs of the Charity itself.

Short term goals (1-2 years)

Over the next two years, we will seek to:

Increase the number of people we support

We will ensure that we support more people and increase the impact of that support year on year.

Increase the number of people we reach and engage with

We will ensure that we are able to identify and interact with more people impacted by Inflammatory Neuropathies, and that we are more easily found and reached by those people who need us.

Reconstruct our Core Support Offer based on the needs of our Community

We will look at what we do, building on progress to date to ensure that our Core Support Offer reflects the needs of the Community and not the needs of the organisation or what we have historically provided.

Refresh our systems and practice

We will ensure that we continue to build our in-house systems and processes to deliver our functions effectively, efficiently, and flexibly.

Develop a financial strategy and improved financial model

We will build a new financial strategy to outline our approaches and actions to both income and outgoings, ensuring that we manage our funding effectively and in a sustainable manner. We will continue to update our financial models so that we also manage our finances appropriately.

Develop more projects

We will put in place new approaches and undertake more pilots and projects to identify the best ways to meet the needs of our Community.

Improve our data

We will seek to improve our data collection and management, ensuring that we have the information needed to support and understand our Community well.

Improve our communication

We will ensure that all our forms of communication are accessible, easy to understand, and approachable. This will be across all of our channels.

Medium term goals (3-5 years)

In years three to five, we will:

Continue to increase the numbers of people we support

We will ensure that we continue to support more people and increase the impact of that support every year.

Continue to increase the number and diversity of people we reach and engage with year on year

We will ensure that we continue to identify and interact with more people impacted by Inflammatory Neuropathies, and that we are more easily found and reached by those people who need us. This will include targeted work around people with different backgrounds and from diverse communities of interest.

Increase and diversify our income streams

We will seek to find more income streams, and to ensure that we have a mixed and varied income model, that supports long term sustainability.

Provide more services and support

We will continue to grow our service and support models, with different and varied models which match the needs of the Inflammatory Neuropathies Community.

Understand our Community more

We will seek to gather more information and data on our Community, building new tools and resources to analyse, utilise, and share in order to improve impact, interaction, and outcomes.

Begin a national conversation

We will build the profile of the organisation and the conditions we support to begin a national conversation around Inflammatory Neuropathies, the impact of the conditions, and the needs of the Community.

Grow our voice

We will look to have a larger, louder and more impactful voice on a national and international stage on behalf of our Community.

Continue to define and redefine the organisational systems and structures

We will ensure we always have in place a defined and sustainable structure and set of systems which are well managed and up to date, but which are intuitive, up to date, and meet the needs of the Charity.

Long term goals (5-10 years)

Our longer term goals, delivered in years five to ten, are to:

Reach everyone who needs us

We will reach, engage with, and support everyone with an Inflammatory Neuropathy who needs and wants our support.

Be the first point of contact

We will have the national and international relationships and partnerships in place that mean we are the first point of contact with regard to Inflammatory Neuropathies.

Have in place an up to date, full dataset

We will build and support systems so that we know the true numbers of people impacted by Inflammatory Neuropathies in the UK and Ireland.

Understand the burden of conditions

We will develop mapping and analysis so that we understand the burden of Inflammatory Neuropathies on all people impacted by them.

Be much better known

We will ensure that Inflammatory Neuropathies and **Inflammatory Neuropathies UK** have the same profile as other leading Neurological Conditions, and leading charities within the sector.

IN action

Our Action Plan

Our Strategic Action Plan demonstrates what needs to happen, when it will occur, who is responsible, and how it will be funded. This is a live document that we use daily, and is updated as and when required.

If you want to see the latest version, ask us for a copy via:
hello@inflammatoryneuropathies.uk

Inflammatory Neuropathies UK

@InflamNeuroUK

01529 469910
inflammatoryneuropathies.uk
hello@inflammatoryneuropathies.uk

Registered Charity 1154843 & SCO39900
3 Mill House | Carre Street | Sleaford |
Lincolnshire | NG34 7TW