



# Impact Report

2023/24



# ABOUT GAIN

GAIN (Guillain-Barré and Associated Inflammatory Neuropathies) is the only UK charity dedicated to supporting people impacted by Guillain-Barré Syndrome (GBS) and other related inflammatory neuropathies. GAIN is a well-respected national charity reaching and supporting thousands of people impacted by GBS, CIDP, MMN, and other life-changing conditions each year.

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 (Chronic Inflammatory Demyelinating Polyneuropathy) 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.

Around 1,300 people are impacted by GBS, CIDP, and related conditions each year, and for many people the impact on them and their families is significant.

GAIN provides support, information, and advice to people impacted by GBS and other related conditions. The charity also carries out and funds research, as well as raising awareness around these rare yet life changing conditions. GAIN does not receive any government funding, instead we rely on donations and funding from the public to provide services, and to seek access to new treatments and tools to support people's journeys through GBS, CIDP, and related conditions.

# Measuring Our Impact

People impacted by GBS, CIDP, and other inflammatory neuropathies are at the very centre of everything that we do. They are why we are here, and why we strive to be the best that we can be.

As a result, understanding what we do, and the impact that we make is vital to our work.

This report, is our first attempt at understanding and reporting our impact. It is safe to say that the information that we captured during 2023/24 could be better, and it doesn't give us the best information possible to measure our impact.

However, it is the best we can do, and we are making steps to improve our information. The data that we have got is drawn from our Customer Relationship Management System (CRM) and our existing financial information, as well as through other pieces of information that we hold or have gathered.



# What We Do

At present our core offer for people is:



Provide information and advice by phone, email, website, and other resources



Facilitate peer support which is provided by volunteers



Fund Personal Grants for equipment, or for help with travel to visit someone in hospital



Facilitate online Get Togethers



Facilitate an online Facebook Group

We also fund and carry out clinical and social research, as well as raising awareness around Guillain-Barré Syndrome, CIDP, MMN, and other related inflammatory neuropathies.

# What we are doing to improve our impact and impact reporting

We are currently going through a period of change, as we look at improving our core offer for people, and look at our organisational strategy going forward. We want to ensure that we provide the best services and the most impact that we can, and as part of our development, we will be looking at what we do, and how we can do it better.

In Spring 2024 we ran a survey to better understand what people thought of us, and what we do. We also asked where we could improve, and what we should focus on. This information will provide a baseline for understanding how we are doing, and whether or not we are improving.

It's really important to GAIN that we understand our impact, and the benefit that we deliver to people impacted by GBS, CIDP, and other inflammatory neuropathies.

However, to date, our impact measurement systems have been fairly basic, and we have been capturing outputs (numbers of people supported) as compared to the outcomes that we deliver for people (the impact of what we do for people, and what this means to them).

In 2024, we will be changing how we record and report our impact. Whilst we still want to know how many people we have supported and how we supported them, we also want to know the difference that we have made to people.

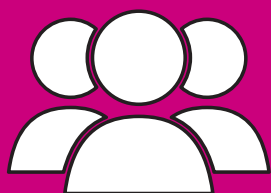
We will be introducing new ways of capturing information into our work, and using feedback from people to help us understand the benefits we provide. This will also help us improve what we do and how we do it.

This way of working will be new to us, so it may take a little time to introduce these changes, and embed them in how we work.

However, we promise that next year's impact report will be better, more detailed, and more informative.

# Our Impact

Between April 2023 and March 2024 we:



Supported 191 people



We provided information packs to 92 people



We matched 24 people with volunteers to receive peer support

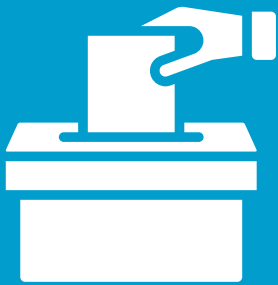


We supported 27 people with Personal Grants totalling £22,978



We provided 48 people with Physiotherapy packs

“Thank you for being there, you were my saviour when I was diagnosed”



We added 4 voting members to the charity meaning we had 152 voting members

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We added 326 non-voting members to the charity meaning we had 1143 non-voting members.



Our total membership was 1295

We sent out 4 newsletters to over 1000 people



We funded £20,000 of clinical research



Our website was visited by 43,624 people



Around 3900 people are members of our Facebook group

“GAIN has been a lifesaver for me. I have met online, and communicated with, the most wonderful, helpful, inspirational people.”

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Get more information at  
[www.gaincharity.org.uk](http://www.gaincharity.org.uk)

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