



NORTHERN IRELAND
**RARE DISEASE
PARTNERSHIP**

Rare
isn't rare!

More
than
110,000 in NI
affected

1 in
17

8,000
conditions and
counting

Only 5% of
conditions have
a treatment

30% of children
affected won't
reach their 5th
birthday

on average
5 years
to
diagnosis



1 in 17 people will be affected by a rare disease at
some point in their lives.
Individually we are RARE, together we are MANY!

Elevate
Working together to build
healthier communities

No one should be disadvantaged because of the rarity of their condition!



NIRDP is an umbrella group working to raise awareness, connect, educate and innovate on behalf of the entire rare disease community!

Comments from the community

"They helped me out, so get in touch if you need support. Took 35 years to find out what my rare disease actually was!"

"I appreciate your help, it's so frustrating to be at this end, wondering what is happening..."

Contact
info@nirdp.org.uk
www.nirdp.org.uk

Find us on:



CONTACT US FOR

Information, support, guidance and signposting.

Who – we support any individuals, family member, carer, friend or even health care professionals living or working with a rare condition in NI.

How – we accept referrals or self referrals through social media or our website, by email or phone.

We Can Provide:

- Information to support diagnosis
 - Emotional support/a listening ear
 - Connections to support organisation in the rare disease community
 - Benefit advice
 - Access to mental health services
- Practical support

Don't struggle alone... we're here to help!



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