What you tell us?

"Diagnosis Challenges
Undiagnosed, newly diagnosed, mis-diagnosis, delayed diagnosis"

"Emotional Impact
Bleak, lonely, soul destroying"

"Life Disruption
Life will never be the same, bomb going off, stunned"

"Isolation & Exclusion
Nobody knows about it, isolated, stranded, victimised"

"Uncertainty & Fear
Can't see the way ahead, difficult, stuck in time"

"Eyesight Issues
Vision problems adding to daily struggles, fear of deterioration, and impact on independence"

"Lack of Support & Guidance
No system, no guidelines, no leaflet, no information, no specialist"

"Practical Barriers
Nobody explains how/when? What to do if you need help? Where to go? How to get there? Who to ask?"

"Impact on Family
Impact on person and family, rest of world carries on, you have to find a new way to slot back in"

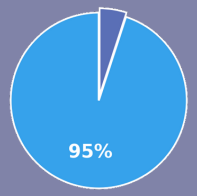
"Overall Struggle
A constant fight to navigate a system that doesn't understand rare conditions"

NORTHERN IRELAND
RARE DISEASE
PARTNERSHIP
www.nirdp.org.uk

KEY FACTS

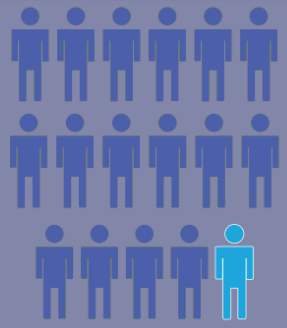
A RARE DISEASE = a life threatening or chronically debilitating disease, affecting not more than 1 person in 2,000

There are **10,000** rare diseases, with more being identified all the time



95% of rare disease do not have an available treatment

80% of rare diseases are genetic



1 in 17 of the population will be impacted by rare disease

30% of children with rare disease will not live to see their 5th birthday

That's over **100,000** people in Northern Ireland:

NORTHERN IRELAND
RARE DISEASE
PARTNERSHIP

Northern Ireland Rare Disease Partnership

Charity Number :105261

110,000

PEOPLE IN NI HAVE EXPERIENCE OF A RARE CONDITION

Contact Us

info@nirdp.org.uk

https://nirdp.org.uk/

Follow Us For More

What we do?

Connect- bring together individuals, families, carers and professionals.

Advocate- for better recognition and services.

Raise awareness- educate the public, professionals and policy makers.

Innovate- find new ways to improve lives.

Access our support hub:

Find a support group:

Working with?

As a partnership, we work together with Individuals, families, carers, professionals, and communities — because real change only happens when we join forces by:

- Understanding the totality of your experience, not only medical needs.
- Supporting you in accessing local or specialist services.

Others we work with :

- Department of Health.
- Your Health and Social Care Trust.
- Your council.
- Helplines NI.
- Rare Disease Organisations Forum NI.
- QUB and UU.
- Education Authority.
- Industry partners.
- All Party Group on Rare Disease at Stormont.
- Rare disease groups in the UK and Ireland.

Can you help?

Want to make a difference for those living with rare conditions?

- **Become a member** – stay informed and connected.
- **Share your story** – your experience matters.
- **Join a support group** – meet others who understand.
- **Volunteer** – your skills can help.
- **Fundraise or donate** – every effort counts.

Your time and generosity help us bring hope and support to families living with rare conditions.