

WHAT IS A RARE DISEASE?

A 'rare disease' is defined in Europe as a life-threatening or chronically debilitating disease affecting no more than 5 people per 10,000. There are an estimated 6-8,000 known rare diseases affecting up to 6% of the total EU population and perhaps up to 300,000 Irish people during their lives. Approximately 70-80% of rare diseases are genetic and are present throughout the person's entire life.

WHO WE ARE

The National Rare Diseases Office (NRDO) was established in June 2015 by the Health Services Executive (HSE). It is staffed by information scientists who have significant experience working with individuals and families affected by rare disorders.

WHAT WE DO

We provide current and reliable information about all rare diseases to people with rare diseases and their families as well as health care providers and researchers. Information includes:

- Specific disease information and clinical expertise
- Social care supports
- Patient support groups
- Rare Disease (RD) research and clinical trials, in Ireland and across Europe
- Policy information on rare diseases
- Non-directive information on the availability of rare disease specialists

WHAT WE CANNOT DO

We do not diagnose, treat or co-ordinate care for people with rare diseases - our role is limited to help people access reliable rare disease information. We do not offer the following services:

- Operate a rare diseases clinic
- Provide clinical advice or make a diagnosis
- Provide case management for individual cases
- Deal with complaints about specific individuals or services

RARE DISEASE INFORMATION LINE

We realise it can be difficult to find Rare Disease (RD) information. If our website does not have the details you are looking for please contact us via email or at our Rare Disease information line (details below) and we will help you find the RD information you seek. We want to give the most up to date and complete information therefore it may take a few days to answer your RD information query.

Contact Us

You can reach us at:

Rare Diseases Information Line:

Freephone 1800 240365 or 01 854 5065

(Mon-Thurs inclusive 9.30am -1.30pm)

Website: www.rarediseases.ie

Email: rare.diseases@mater.ie

General office queries: 01 809 7475

We are based at the Mater Misericordiae University Hospital
Dublin 7.

Please note that we do not have a public office or clinic.



NRDO

National Rare Diseases Office



National Clinical
Programme for
Rare Diseases