

NRDO

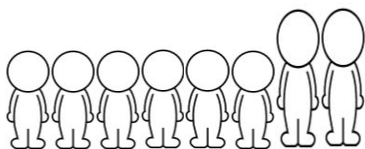
National Rare Diseases Office

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. Up to 6% of the total EU population and perhaps up to 300,000 Irish people develop a rare disease during their lives. Approximately, 70-80% of rare diseases are genetic and are present throughout the person's entire life.

**There are at least
6000 rare diseases**

**1 in 17 people will develop
a rare disease in their life**



**75%
of rare
diseases start in childhood**

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

Contact Us

It can be difficult to find information about rare diseases. We want to help you find the most up to date and complete information possible. We are based at the Mater Misericordiae University Hospital Dublin 7. Please note that we do not have a public office or clinic.

You can reach us at:

Rare Disease 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