



# Rare Diseases in Ireland

## What is a RARE DISEASE?

A disease that affects fewer than 1 in 2,000 people

**1 in 17 people**

live with a rare disease



**300,000** in Ireland



**6,000+** distinct rare diseases

**72%** genetic origin 



**70%** with first symptoms appearing in childhood

**5,100+** ultra-rare diseases each one affecting **< 5 people** in Ireland




## Rare diseases in children living in Ireland


**4.2%** children diagnosed with a rare disease **by age 17**

**~2,000** (3.7%) teens with a life-long rare disease **transition each year** to adult care

**11.8% mortality** by age 18 in those living with rare diseases

**58.6% deaths** in those **<15 years old** have an underlying rare disease

Children with rare diseases  use **25 times** more **hospital bed-days** as compared to their peers 

**51.9%** children's **hospital bed-days** are used by the **4.2%** living with a rare disease 

**Most rare diseases are life-long, chronic and disabling, and sometimes progressive and life-threatening.**

