Rare and orphan lung diseases

europeanlung.org/rare-and-orphan-lung-diseases/

A rare disease is defined as one that affects fewer than one person in every 2,000 people in Europe. Orphan diseases are those which are not widely researched, those where specific treatments are not available, and those which may only be of limited interest to scientists and doctors. Examples include primary ciliary dyskinesia, multiple cystic lung diseases and idiopathic eosinophilic pneumonias.

ELF EUROPEAN LUNG FOUNDATION

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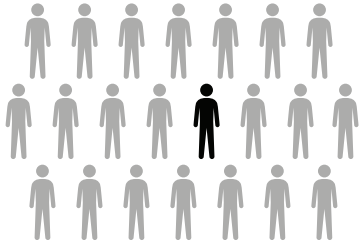
Areas for action

- New strategies are needed to encourage drug companies to develop treatments for rare and orphan diseases
- The time to be diagnosed needs to be urgently reduced to improve knowledge of the main features of rare diseases in healthcare professionals and this should be an ethical duty for all respiratory doctors
- There is a need to analyse the most effective strategies for encouraging drug companies to develop new treatments for rare and orphan diseases
- European reference networks should be further improved and registries and databases maintained



A **rare disease** is defined as one that affects fewer than **one person in every 2,000 people** in Europe

6,000

There are about **6000 rare diseases**, including well-characterised diseases as well as syndromes and anomalies

Around **80%** of rare diseases are **caused by genetic factors**

Orphan diseases are those which are **not widely researched and where specific treatment is not available**. They may be either common or rare

Infectious orphan diseases affect **1 billion people** worldwide and can cause disfigurement and lifelong disabilities

1 million people die each year from an **infectious orphan disease**

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