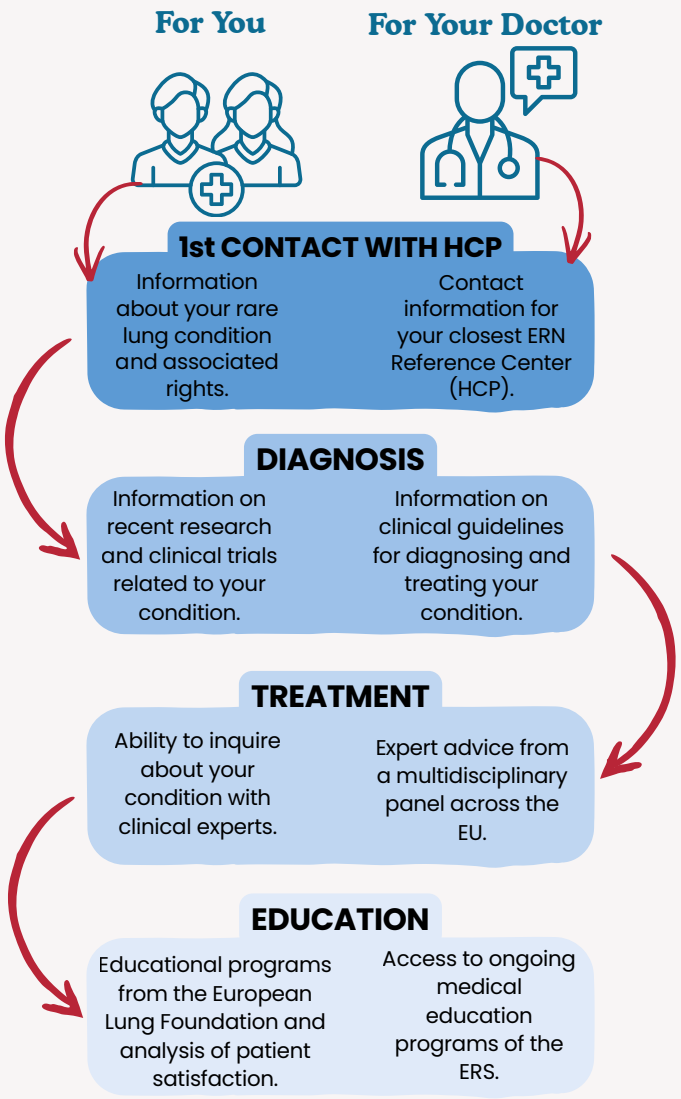
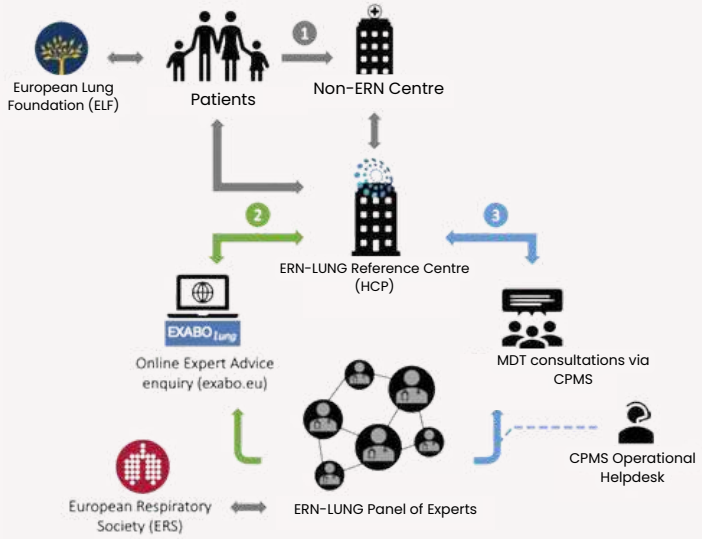
What can we do for patients and their local care team members?



Seeking expert opinion?

With the Online Expert Advice System **(EXABO - exabo.eu),** patients and clinicians can address a wide range of questions related to rare respiratory diseases by consulting ERN-LUNG experts who specialise in this field. If a patient's problem cannot be resolved through the national EXABO system, any physician can request a virtual consultation with ERN-LUNG reference centres via the Clinical Patient Management System (CPMS). This IT platform enables a multidisciplinary team (MDT) to discuss highly specialised patient cases in a secure environment.

The resulting recommendations are then communicated to the patient by their treating physician.



European Reference Networks | ERN-LUNG
RARE RESPIRATORY DISEASES
for rare or low prevalence complex diseases

INFO FLYER
ERN-LUNG

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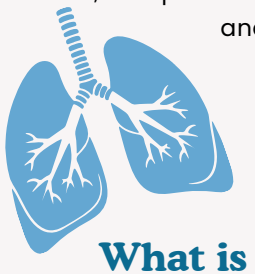
What are European Reference Networks?

European Reference Networks (ERNs) are virtual networks that connect centres of expertise across Europe. They aim to ensure that all patients with rare diseases have access to high-quality diagnosis, treatment, and care. This is achieved by centralising knowledge, clinical experience, medical research, training, and resources related to rare, low-prevalence, and complex diseases and conditions.



What is ERN-LUNG?

ERN-LUNG is the European Reference Network dedicated to rare respiratory diseases. It is a non-profit, patient-centric and scientific network of European Healthcare Providers (HCPs) and patient organisations. ERN-LUNG is committed, across Europe and globally, to reducing mortality associated with rare respiratory diseases and alleviating the burden these conditions place on patients of all ages. This commitment is pursued through excellence in patient care, advocacy, education, research, and knowledge sharing.

ERN-LUNG is currently made up of 79 Full Members in 25 countries (+Norway) and is organised into 10 Core Networks addressing a number of rare and complex pulmonary conditions. Additionally, ERN-LUNG is also divided into Functional Committees, which coordinate transversal activities that affect all of the current and future Core Networks.

ERN-LUNG SET-UP

CORE NETWORKS

CF	Cystic Fibrosis
PCD	Primary Ciliary Dyskinesia
BE	Bronchiectasis
PH	Pulmonary Hypertension
ILD	Interstitial Lung Disease
CLAD	Chronic Lung Allograft Dysfunction
MSTO	Mesothelioma
AATD	Alpha-1 AntiTrypsin Deficiency
ORLD	Other Rare Lung Diseases
SARC	Sarcoidosis

FUNCTIONAL COMMITEES

1	Research & Clinical Trials
2	Clinical Guidelines & Best Practice of Care
3	Registries & Biobanks
4	Communication & Outreach
5	Ethical Issues
6	Cross Border Care
7	Professional Training & Continued Medical Education
8	Patient Recorded Outcomes (PROs) & Quality of Life
9	Quality Management

Where can you find us?

ERN-LUNG is represented in a total of 30 countries, including non-EU countries, through full members, affiliated partners, and supporting partners. Across these countries, the network brings together 263 reference centres that provide expertise for different groups of rare respiratory diseases.

Patient involvement is embedded in all ERN-LUNG activities, with patient organisations actively contributing to decision-making through the European Patient Advocacy Group (ePAG) to ensure that the patient voice shapes the network's development and governance. There are currently 34 patient advocacy organisations (globally and in Europe).