



European
Reference
Networks

ERN-LUNG
RARE RESPIRATORY DISEASES
for rare or low prevalence
complex diseases



Funded by
the European Union

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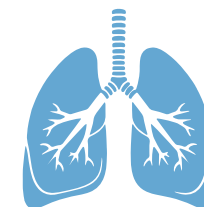
Easophageal Atresia Global
Support Groups (EAT)

Interested in joining the ERN-LUNG ORLD Core Network?

Contact the network coordination team at
info@ern-lung.eu for information on the application
process and to connect with network members.



ERN-LUNG Core Network: Other Rare Lung Diseases (ORLD)



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Requirements for joining the ERN-LUNG ORLD Core Network

ERN-LUNG comprises 10 Core Networks (CNs), each responsible for developing disease-specific action plans aligned with the network's overall strategy. Each CN defines minimum requirements for patient volume, multidisciplinary team composition, infrastructure, and clinical procedures.

There are no minimal patient numbers or procedures set for the ORLD Core Network. However, a multidisciplinary team is required to join ORLD.

Core Multidisciplinary Team

Adult Care

- Pulmonologist
- Radiologist
- Nurse
- Pathologist
- Physiotherapist
- Study Nurse
- Pediatrician
- Social Worker

- Surgeon
- Gynecologist
- Clinical Geneticist
- Thoracic Surgeon
- Physiologist
- Medical Secretary

Childcare (additionally required)

- Psychologist
- Neonatologist

ORLD current Activities:

- Networking and exchange on current issues identified by members
- Case conferences (via CPMS)
- Evaluating existing relevant guidelines and initiating guideline development
- Identifying requirements and initiating registries for (ultra-)rare lung diseases covered in ORLD

ERN-LUNG Actions

All other rare lung diseases not specifically grouped within one of the other disease-specific or group-specific Core Networks are invited to gather in this core network to cluster expertise and learn from the best. The main goals of this Core Network have been summarized by the leadership group as the provision of highly specialized patient-centered care, improvement of cross-border collaborations for continuity of care and reinforcing epidemiological information as well as sustaining research and training. Several diseases and disease groups have been selected as putative focal area of this Core Network, i.e. Congenital Lung Malformations, Disorders of the Respiratory Drive, Cystic Lung Diseases, Bronchopulmonary Dysplasia, Pulmonary involvement in Multiorgan Diseases and Undiagnosed Conditions. The sub-group formation is work in progress. All actions are discussed – and sometimes even initiated – by our patient representatives.

Where are our ORLD member institutions located?



Full Member Affiliated Partner Supporting Partner

