

European Reference Network for rare respiratory diseases : ERN-LUNG



Launched in 2017, the ERN-LUNG is one of the 24 ERNs, a network for rare diseases financed by the European Commission. Health systems in the European Union aim to provide high-quality and cost-effective care. This is particularly difficult however, in cases of rare (or low-prevalence) complex diseases which affect the daily lives of around 30 million EU citizens. European Reference Networks (ERNs) are virtual networks involving Healthcare providers (hospitals) across Europe. The Board of Member States is the formal body in charge of the approval and termination of networks and memberships. The Board is comprised of representatives of all EU countries. Thanks to the ERNs, patients with rare and complex conditions are able to benefit from the best treatment and advice available in the EU for their specific condition. Their doctors will have access to a highly specialized pool of colleagues from all over Europe.

Distribution of ERN-LUNG Healthcare Providers across Europe:



9 Core Networks (diseases):

- Cystic Fibrosis
- Pulmonary Hypertension
- Mesothelioma
- Interstitial lung diseases
- Primary Ciliary Dyskinesia
- Chronic lung allograft dysfunction
- Non cystic fibrosis bronchiectasis
- Alpha 1 antitrypsine deficiency
- Other Rare Lung Diseases

9 Functional Committees (priorities):

- Research & Clinical Trials
- Ethical Issues
- Registries & Biobanks
- PROs & Quality of Life
- Quality Management
- Guidelines & Best Practice of Care
- Communication & Outreach
- Cross-Border Care
- Training & Medical Education

The ERNs would greatly benefit from well-organized national reference networks, such as RespiFIL in France. If each EU-member state had a national reference center organization, the ERNs could just rely on those. As this is not the case everywhere yet, the ERNs have to make specific calls for HealthCare Providers (HCPs = hospitals) wanting to join the network. These HCPs have to prove minimal standards of care and a sufficient number of patients treated every year.

There are currently 91 Healthcare providers (hospitals) who are active members of ERN-LUNG, of which
60 full members responding to all criteria
18 affiliated partners responding to a majority of criteria
13 supporting partners: hospitals in countries who are not yet represented in the network (as well as all British hospitals, after Brexit).
 Interest to join ERN-LUNG is always very strong.

Find out more on www.ern-lung.eu

Network Coordination Team

is based in the Klinikum Goethe University of Goethe University Frankfurt (Germany) and Bicêtre, Assistance Publique Hôpitaux de Paris, Université Paris-Saclay (France)

Team members:

Thomas Wagner, coordinator (Frankfurt, KGU)
 Marc Humbert, vice-coordinator (Bicêtre, AP-HP)
 Olivia Steinmann (Frankfurt)
 Stephy Varghese (Frankfurt)
 Elisabeth Humbert-Dorfmüller (Frankfurt & Bicêtre)