

ERN on rare respiratory diseases (ERN-LUNG)

Rare and complex lung diseases require multidisciplinary care and psycho-social support. Their complexity can be due to the underlying genetic mechanism of the disease, or the secondary changes and damage done to other organ systems. Early diagnosis and access to specialist care improve outcomes for many of these conditions.

ERN LUNG (<https://ern-lung.eu/>) addresses all rare and complex diseases of the respiratory system, including Interstitial lung diseases (ILD), Cystic fibrosis (CF), Bronchiectasis (BE), Pulmonary hypertension (PH), Primary ciliary dyskinesia (PCD), Sarcoidosis (SARC), Alpha-1 antitrypsin deficiency (AATD), Mesothelioma (MSTO), Chronic lung allograft dysfunction (CLAD), and Other rare lung diseases (ORLD).

The network aims to improve expertise across Europe to advance standards of care, quality of life, and prognosis for the entire spectrum of rare pulmonary diseases. Members of ERN-LUNG develop and disseminate guidelines, promote common treatment approaches, enhance cross-border access to diagnosis and treatment, and assemble sufficiently large cohorts for clinical studies, clinical trial networks, drug development, and natural history studies.

Two registries have been built up in the past years: ERN-LUNG PRIME, with input from our Healthcare providers, and BREATHeREGISTRY, which is a patient-driven registry. Furthermore, the ERN-LUNG Academy has been training since 2023 a significant number of medical professionals who wish to get proof of knowledge on rare respiratory diseases, through Webinars and a practical stay in one of the network's expert centres.

ERN-LUNG provides patients with access to interdisciplinary teams, providing online second opinions on complex cases without requiring patients to travel. This is achieved through an online expert advice system, by online case panel discussions, and – if needed – by cross-border referral. Furthermore, the Undiagnosed patient's pathway has depicted a standard operating procedure, defining essential steps and criteria from the first contact to the healthcare system in primary care towards specialist centres and national reference networks, before the undiagnosed patient gets referred to ERN-LUNG.



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