

ERN on 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 improves outcomes for many of these conditions.

ERN LUNG addresses all rare and complex diseases of the respiratory system, including interstitial lung diseases (ILD); cystic fibrosis (CF); non-CF bronchiectasis (nCF-BE); pulmonary hypertension (PH); primary ciliary dyskinesia (PCD); alpha-1 antitrypsin deficiency (AATD); mesothelioma (MSTO); and chronic lung allograft dysfunction (CLAD).

The network seeks 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, initiate and support registries, and assemble sufficiently large cohorts for clinical studies, drug development and natural history studies.

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.

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