



ERN on respiratory diseases (ERN LUNG)

Complex lung diseases require multidisciplinary care along with psycho-social support. This complexity can be due to the underlying genetic mechanism of the disease, the secondary changes and damage done to other

organ systems. Early diagnosis and access to specialist care can improve outcomes for many of these conditions.

ERN-LUNG addresses a number of rare and complex pulmonary conditions, including idiopathic pulmonary fibrosis, cystic

fibrosis, non-cystic fibrosis bronchiectasis, pulmonary hypertension, PCD, AATD, mesothelioma, chronic lung allograft dysfunction, and ORLD.

The network seeks to improve expertise across Europe to advance standards of care, quality of life and prognosis across the spectrum of rare pulmonary diseases. Members are: developing and disseminating care guidelines; promoting common treatment approaches; enhancing cross-border access to diagnosis and treatment; initiating and supporting registries; and assembling sufficiently large

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cohorts for clinical studies, drug development and natural history studies.

ERN-LUNG provides patients with access to the interdisciplinary teams, providing online second opinions on complex cases without requiring patients to travel. This will see the expansion of an online expert advice system established through the EU-funded pilot project, ECORN-CF.

NETWORK COORDINATOR

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