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Coordinator: Prof. TOF Wagner
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Requirements for joining the ERN-LUNG CF 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.

Interested in joining the ERN-LUNG CF Core Network?

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

Network Coordination Team:

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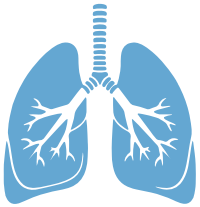
European Reference Networks | ERN-LUNG
RARE RESPIRATORY DISEASES
for rare or low prevalence complex diseases

Funded by the European Union

ERN-LUNG Core Network:

Cystic Fibrosis (CF)



July 2026

Indicator	Minimum Number required/HCP/year (Adults)
Minimum number of TOTAL patients (visited, treated, or followed) per year	100
Minimum number of NEW patients per year	0
Key diagnostic procedures per year	
Sweat test facility	Yes
Patient segregation / isolation facility	Yes
Sputum microbiology	Yes
Genetic counseling and testing	Yes

Competence Requirements
Clinical Follow up

- No. of patients diagnosed (total)
- No. of deaths
- No. of lung transplantations
- Age (median)
- Percentage of patients who performed at least 4 respiratory tract cultures in this year
- Percentage of non CFRD patients (aged >=10 yrs) who performed oral glucose tolerance test (OGTT) in this year
- Total no. of CF-specific clinical trials in which the HCP participated in this year
- Assessment of lung function (spirometry)
- Incidence of patients with acute dehydration in the first 12 months of life (number of dehydration / number of patients <12 months / per year)
- Percentage of malnourished patients with individualized treatment plan
- Annual chest Xray
- Annual visits

Children 6-17yrs // Adults >=18yrs

- Median highest measured lung function FEV1 value (lung transplants excluded), expressed as %, measured before bronchodilator
- Median Z-score of Body Mass Index (BMI)
- Intravenous antibiotics
- Inhaled antibiotic use
- Chronic pseudomonas infection
- Exocrine pancreatic insufficiency
- CF-related insulin-treated diabetes
- Pulmozyme inhalation use
- Percentage of patients on DNase

Core Multidisciplinary Team

Adult- and Childcare

- Pulmonologist
- Radiologist
- Nurse
- Physiotherapist
- Study Nurse
- Pediatrician
- Social Worker
- Microbiologist
- ENT Specialist
- Gynecologist
- Clinical Pharmacologist
- Clinical Geneticist
- Thoracic Surgeon
- Medical Secretary
- Nutritionist
- Psychologist
- Data Typist

ERN-LUNG Actions

The ERN-LUNG Cystic Fibrosis Core Network works closely with the European Cystic Fibrosis Society (ECFS) to develop high quality standards of care and best practice guidelines, and to accelerate research and orphan drug development through its well-established Clinical Trials Network (ECFS-CTN). The ECFS has been qualified by the European Medicines Agency (EMA) as an appropriate platform for the collection of CF data for Post Authorization Safety Studies and Post Authorization Efficacy Studies. Besides further elaboration of our CTN, our research priorities include the further development of Standards of Care and European SOPs for several frequently used diagnostic tools, the setup of Quality Control measures using a Delphi-procedure within the network, collaboration on set-up of eLearning on CF focusing on both patients and caregivers, and collaboration with EMA to pave the way for further treatment possibilities for patients with ultra-rare variants.

Where are our CF member institutions located?

Full Member Affiliated Partner Supporting Partner