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**Interested in joining the ERN-LUNG AATD
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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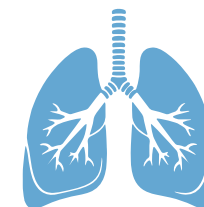
**European
Reference
Networks**

ERN-LUNG
RARE RESPIRATORY DISEASES
for rare or low prevalence
complex diseases



Funded by
the European Union

**ERN-LUNG Core Network:
Alpha-1 Antitrypsin
Deficiency (AATD)**



July 2026



Requirements for joining the ERN-LUNG AATD 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.

Indicator	Minimum Number required/HCP/year (Adults)
Minimum number of TOTAL patients (visited, treated, or followed) per year	45
Minimum number of NEW patients per year (identified as AATD patients)	15
Number of procedures per year	
Liver transplant	1
Intravenous alpha-1 antitrypsin augmentation	8

Core Multidisciplinary Team



Clinical Follow up

- FEV1% (mean, SD)
- Patients receiving AAT Augmentation Therapy (Total)
- Number of liver transplants
- Number of lung transplants
- Mortality
- Lung function (FEV1, DLCO, KCO, some patients RV and TLC too)
- QOL (SGRQ, CAT, Eq5D)

Human Resource Requirements



- Pulmonologist
- Radiologist
- Nurse
- Immunologist
- Hepatologist

ERN-LUNG Actions

The AATD Core has a Clinical Trials Network (CTN) existing since 1997. Besides continuing with drug trials in our CTN, our priority is to study the natural course of AATD for lung disease and for liver disease in collaboration with ERN RARE-LIVER (ERN on hepatological diseases). The main focus is currently on the EARCO initiative which stands for European Alpha-1 Research Collaboration. It is a pan-European network committed to promoting clinical research and education in AATD. The core project is the European AATD registry.

Where are our AATD member institutions located?



Full Member



Affiliated Partner



Supporting Partner

