



European
Reference
Networks

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



Funded by
the European Union

Lead Representative:

Inez Bronsveld
University Medical Center Utrecht,
NL

Deputy Representative:

Pierre-Régis Burgel
Cochin Hospital - APHP, FR

Patient Representative:

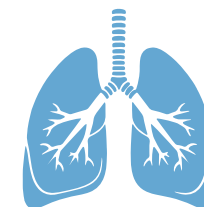
Elisabeth Jodlbauer-Riegler

Interested in joining the ERN-LUNG PCD Core Network?

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



ERN-LUNG Core Network: Primary Ciliary Dyskinesia (PCD)



Network Coordination Team:

Olivia Steinmann, MA
Elisabeth Humbert-Dorfmueller, MA
Thazhone Stephy Varghese, BDS, MBA
Lisa Rist, MSc, MA
Gergely Meszaros, MSc, JD
Janine Marx, PhD
Nathalie Assenheimer, MSc
Donata Eick, LLB, MSc
Hannah Scott, PhD
Kathryn Machray, PhD
Catherine Dilchert, MSc
Juliane Schmitt, MSc

ERN-LUNG Coordination Center:

University Hospital Frankfurt, Germany

info@ern-lung.eu

Coordinator: Prof. TOF Wagner

Vice Coordinator: Prof. Marc Humbert

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Requirements for joining the ERN-LUNG PCD 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
Minimum number of TOTAL patients (visited, treated, or followed) per year	30
Minimum number of NEW patients per year (identified as PCD patient)	5
Key diagnostic procedures per year	
Nasal brush biopsy or bronchial biopsy	70
HVMA or TEM:	70
Registry Participation	
https://www.pcdregistry.eu/	
ClinicalTrials.gov	
Identifier: NCT02419365	

Competence Requirements

- Clinical Follow up
- Body Mass Index (BMI)
- Lung Function



Core Multidisciplinary Team

- Pulmonologist
- Radiologist
- Physiotherapist
- Pediatrician
- Nutritionist

ERN-LUNG Actions

Within ERN-LUNG, we optimize current efforts to improve PCD patient care and quality of life. We will improve and formalize cross border patient care, with exchange of biological material for diagnostic purposes as the current main means in PCD. We will continuously update diagnostic and clinical PCD guidelines with support by the European Respiratory Society (CRC BEAT-PCD). Ongoing teaching and training activities will be updated according to regular training gap analyses. All centres participate in the International PCD Registry to facilitate evaluation of clinical outcomes and to enable large clinical studies. The recently established ERN-LUNG PCD Clinical Trial Network (CTN) chaired by Prof. Kim G Nielsen and co-chaired by Dr. Johanna Raidt and Bernard Maitre will foster clinical research and enable us to provide evidence-based therapy of PCD (<https://ern-lung.eu/our-expertise/disease-groups/pcd-about/pcd-clinical-trial-network/>).

Where are our PCD member institutions located?



 Full Member  Affiliated Partner  Supporting Partner

