

# ERN-LUNG

## European Reference Network for Rare Diseases of the Respiratory System

–

### An update



**European  
Reference  
Network**

for rare or low prevalence  
complex diseases

 **Network**  
Respiratory Diseases  
(ERN-LUNG)

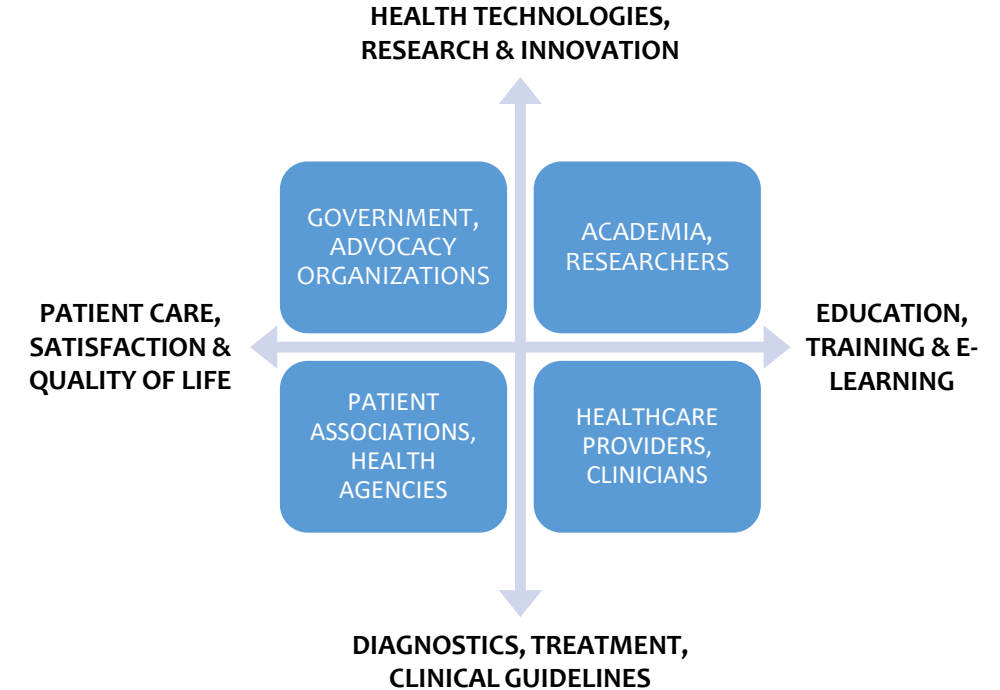
TOF Wagner

Coordinator

Frankfurt, Germany

# PURPOSE OF ERNs

- ERNs are networks involving centres of expertise, healthcare providers and laboratories across Europe. The overarching objective of European Reference Networks is that patients have an **improved access to quality diagnosis, care and treatment**.
- ERNs will help facilitate access to diagnosis and treatment **by providing easy access to knowledge and experience, medical research and training, and resources** in the area of rare or low prevalence complex diseases or conditions.

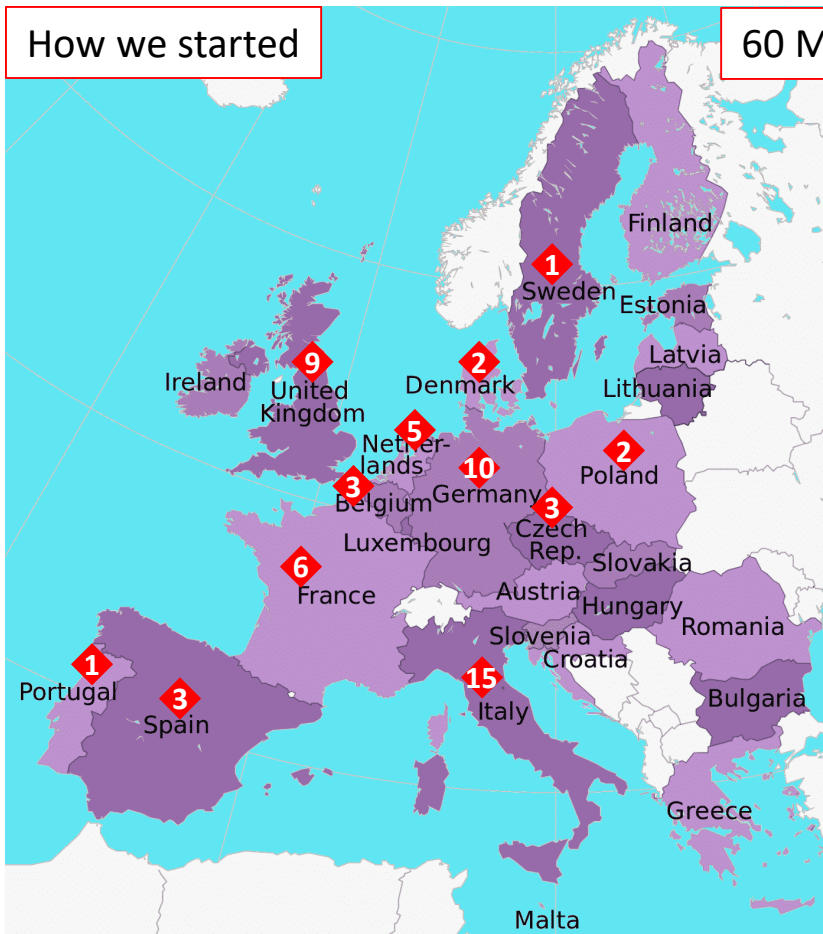




# ERN-LUNG

How we started

60 Members



## MSTO

- University of Antwerp
- Erasmus Medical Centre
- University Hospital San Luigi C
- Supporting Partner CHRU Lille
- Supporting Partner University
- Supporting Partner Thoraxklin

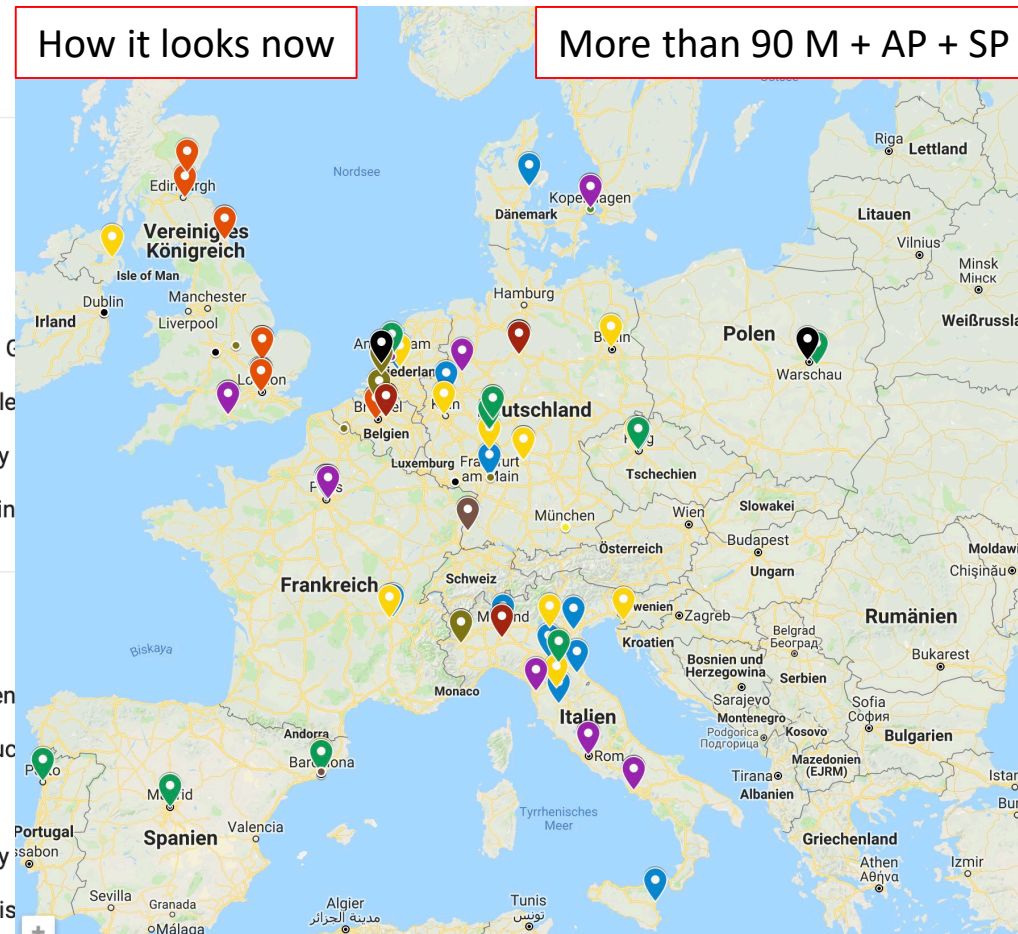


## AATD

- Leiden University Medical Cen
- Instytut Gruźlicy i Chorób Płuc
- Pavia University
- Supporting Partner University
- Supporting Partner Queen Elis
- Supporting Partner Beaumont Hospital ...
- Supporting Partner University Hospital S...

How it looks now

More than 90 M + AP + SP



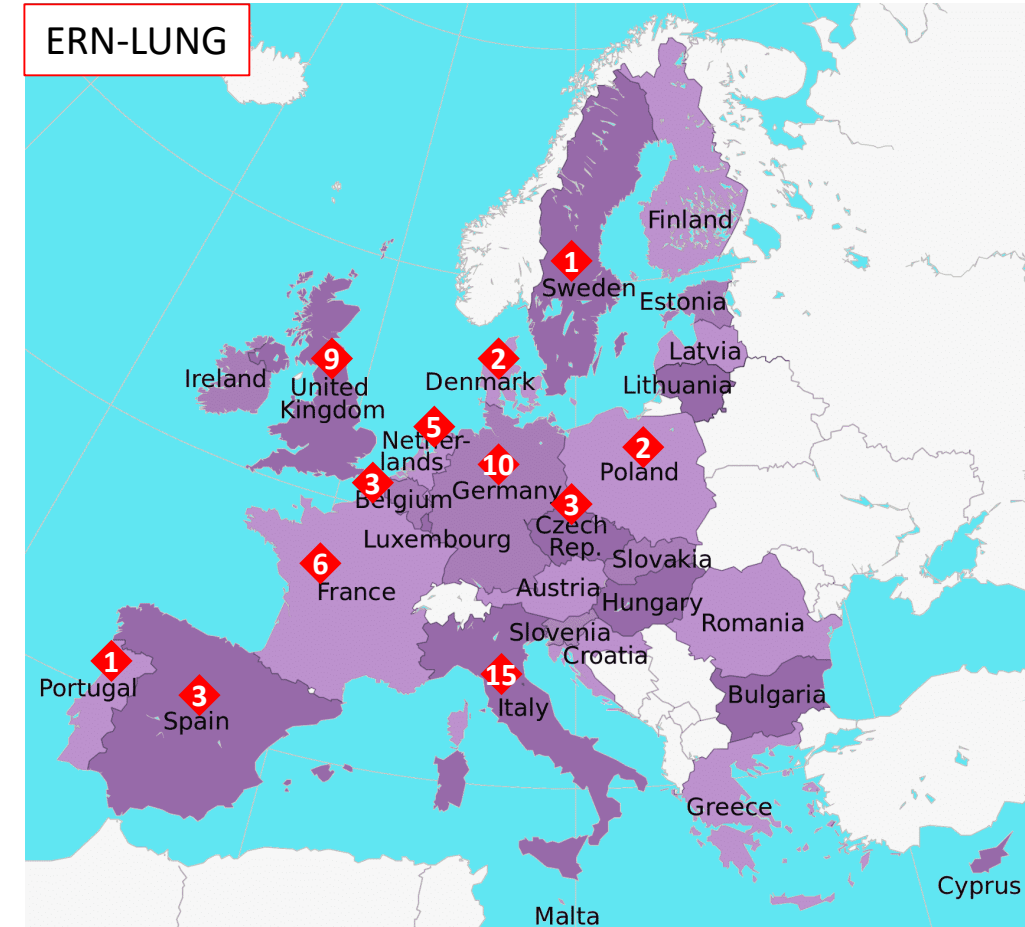
# ERN-LUNG

**MISSION:** To ensure and promote excellence in care and research to the benefit of patients affected by rare respiratory disease

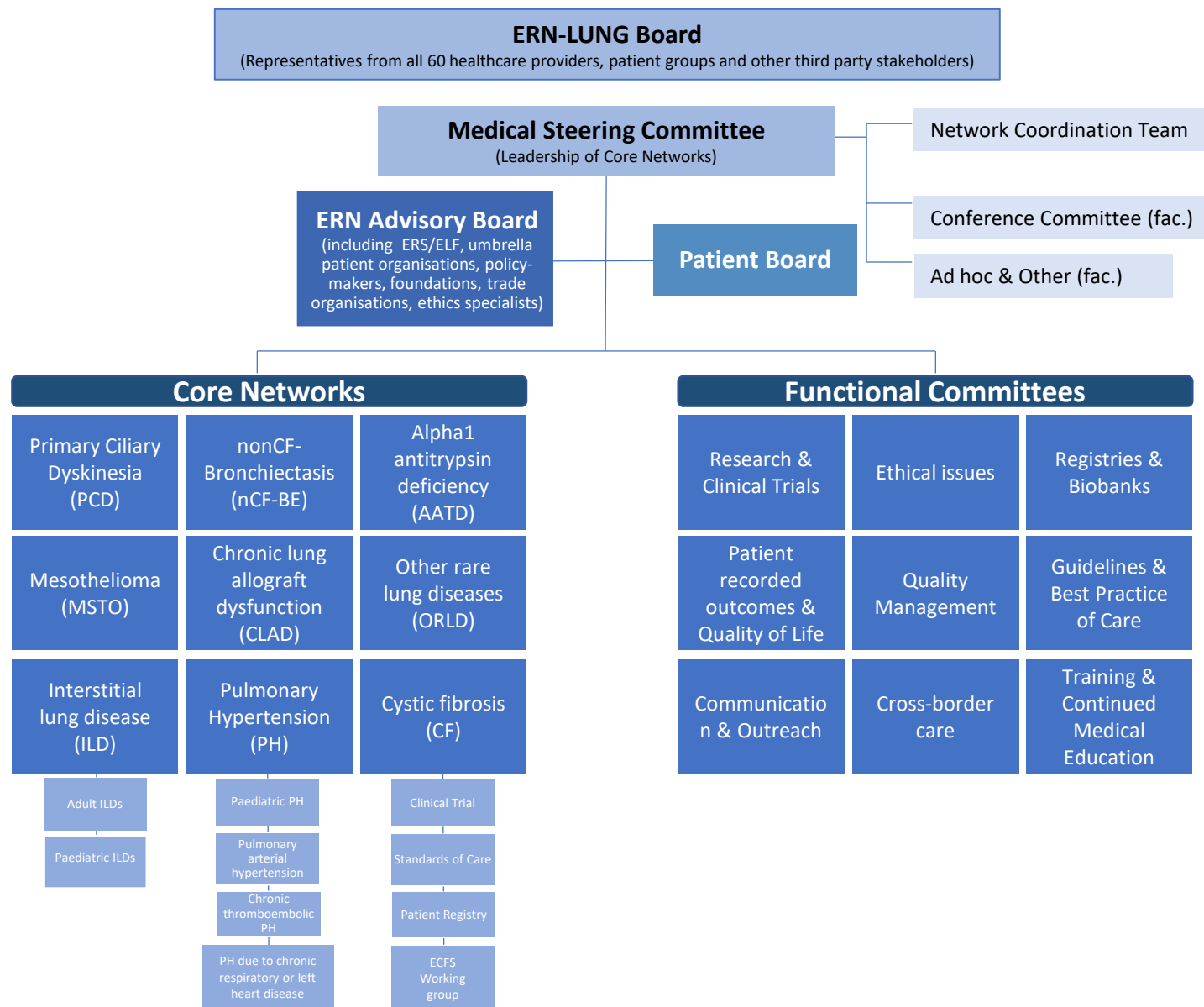
**VISION:** To be a European knowledge hub for rare respiratory diseases and to decrease morbidity and mortality from rare respiratory diseases in people of all ages

**OBJECTIVES:** 5-year plan of ERN-LUNG aims at fulfilling the following objectives

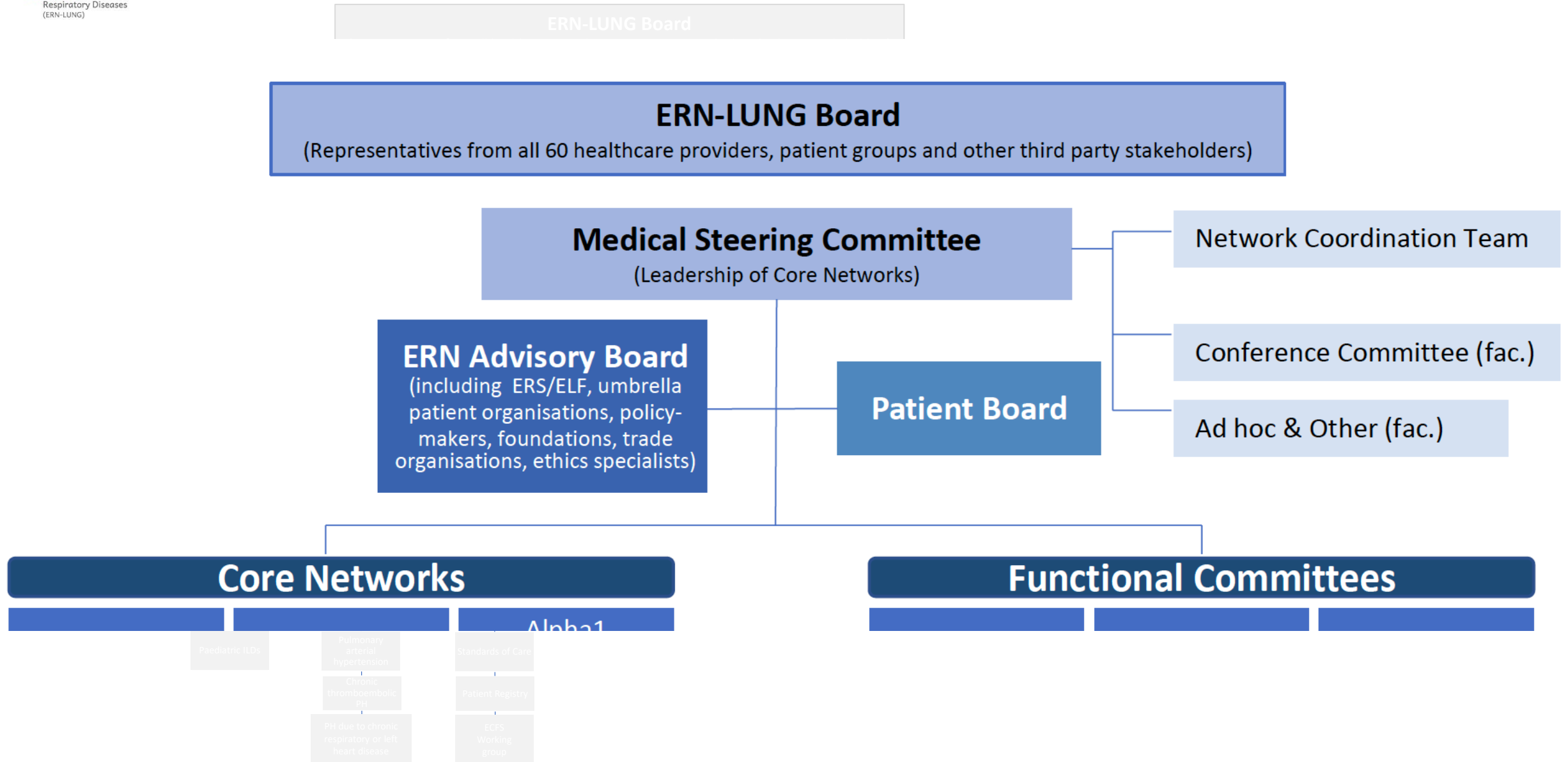
- Establishment of ERN-LUNG
- Improving cross-border care
- Strengthen research with registries and Clinical Trial Networks
- Easy access to quality information via online resources
- Training of patients and professionals



# ERN-LUNG STRUCTURE & GOVERNANCE

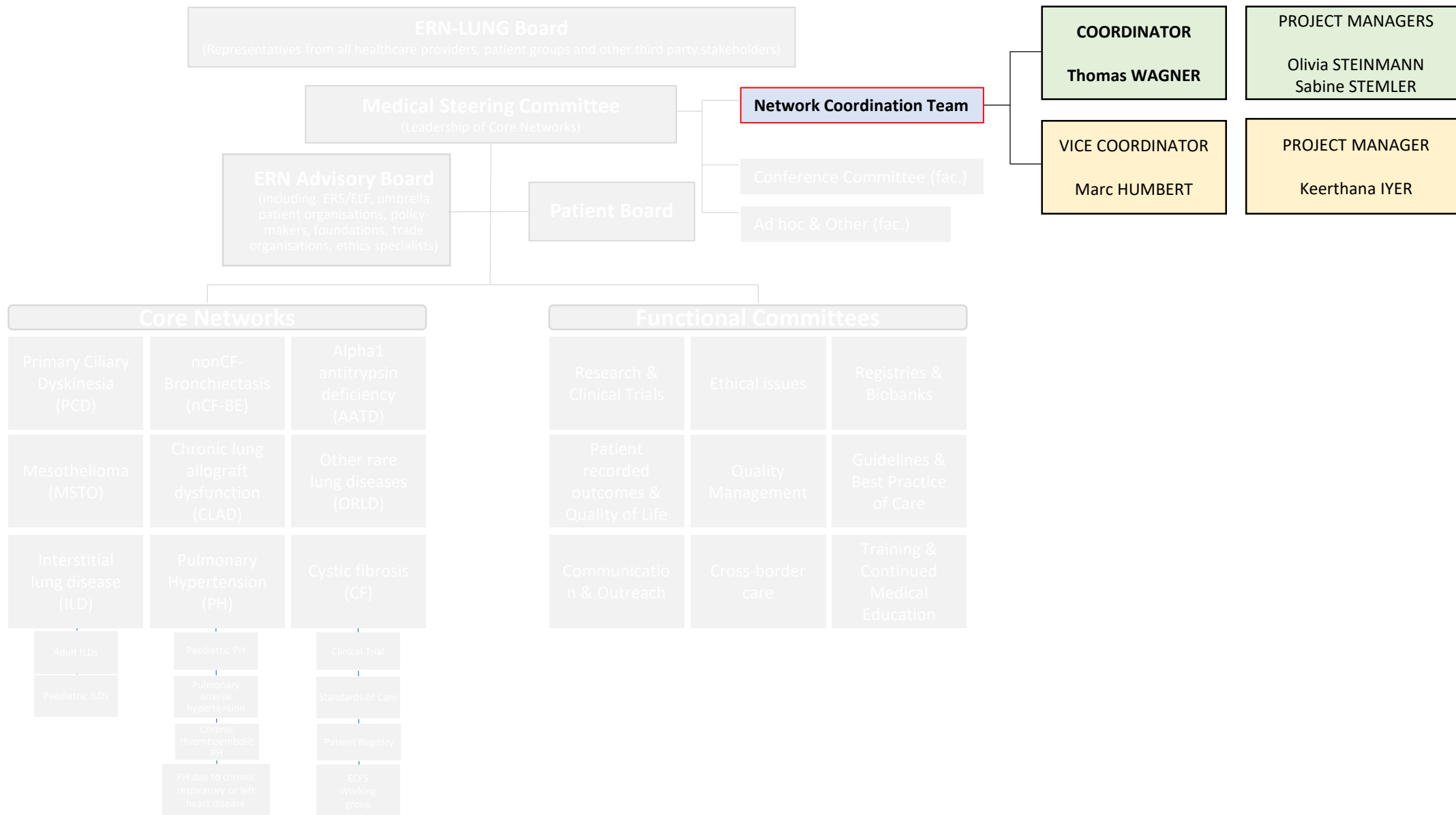


# ERN-LUNG STRUCTURE & GOVERNANCE





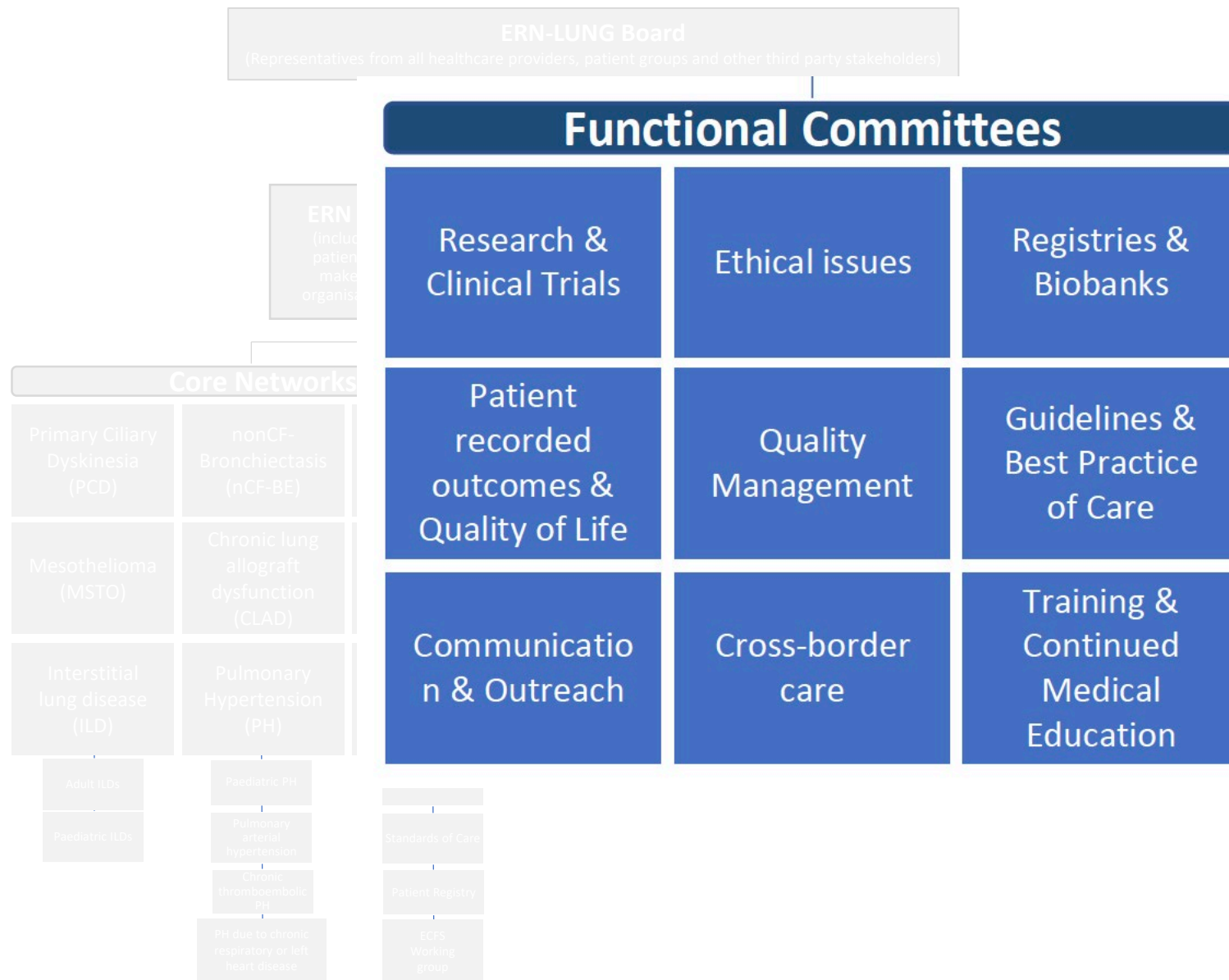
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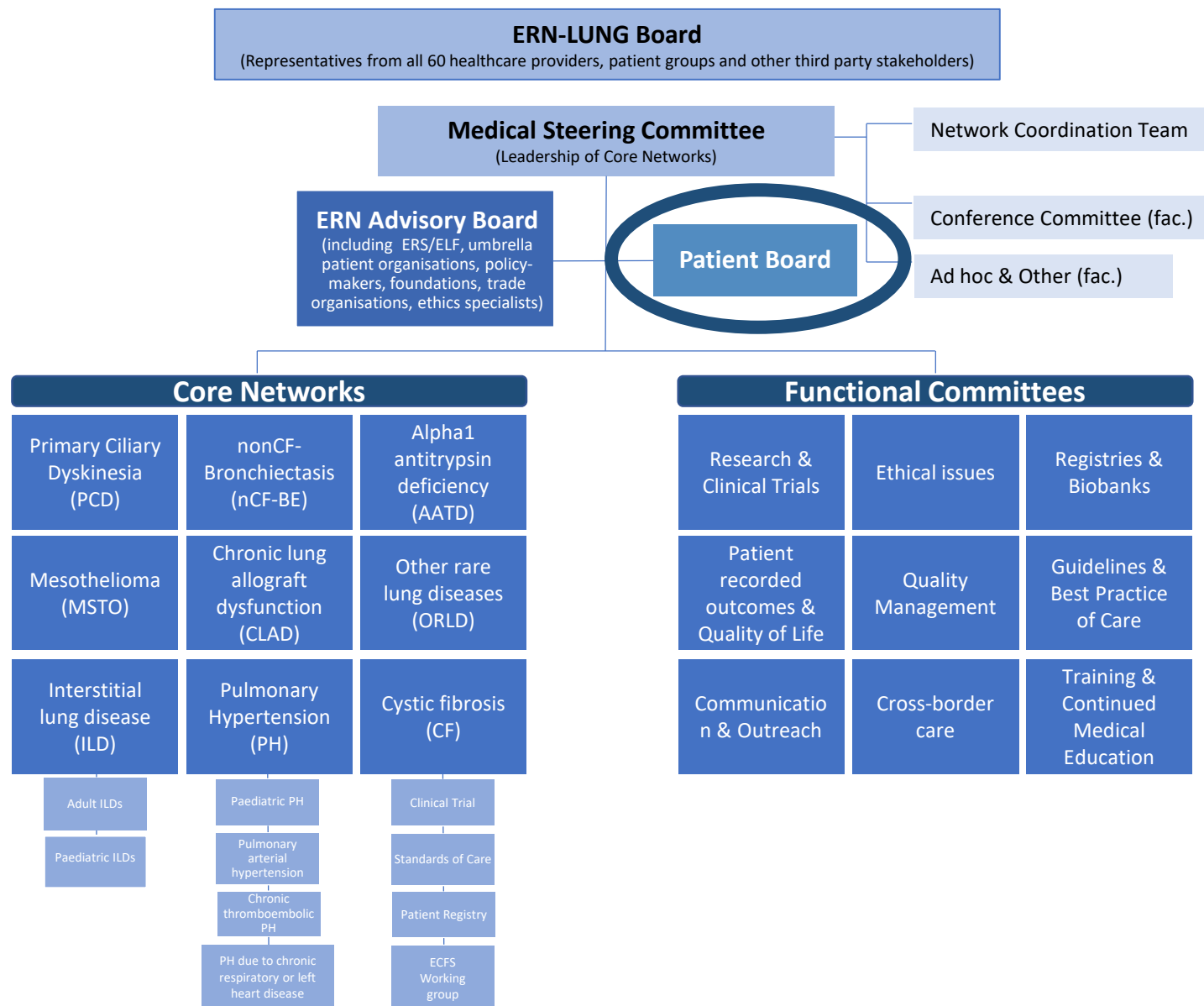
## ERN-LUNG STRUKTUREN & COOPERATION



# ERN-LUNG STRUCTURE & GOVERNANCE



# ERN-LUNG STRUCTURE & GOVERNANCE



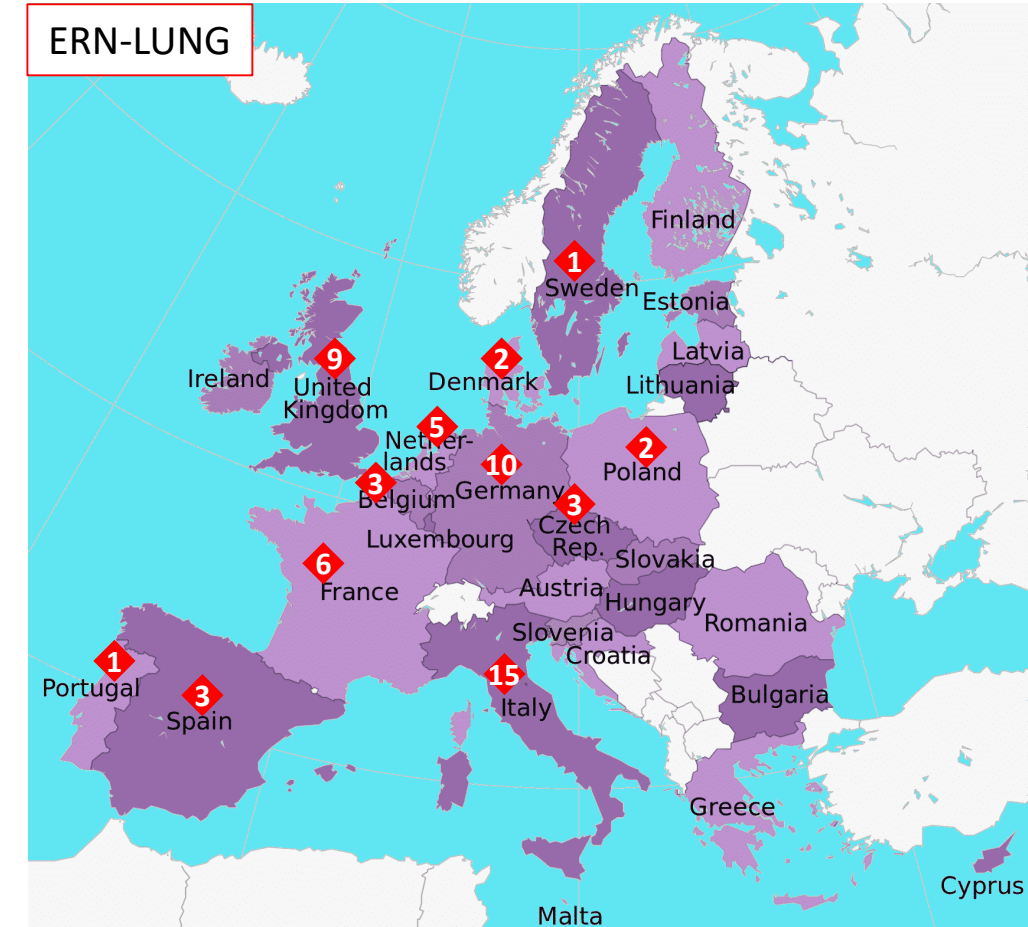
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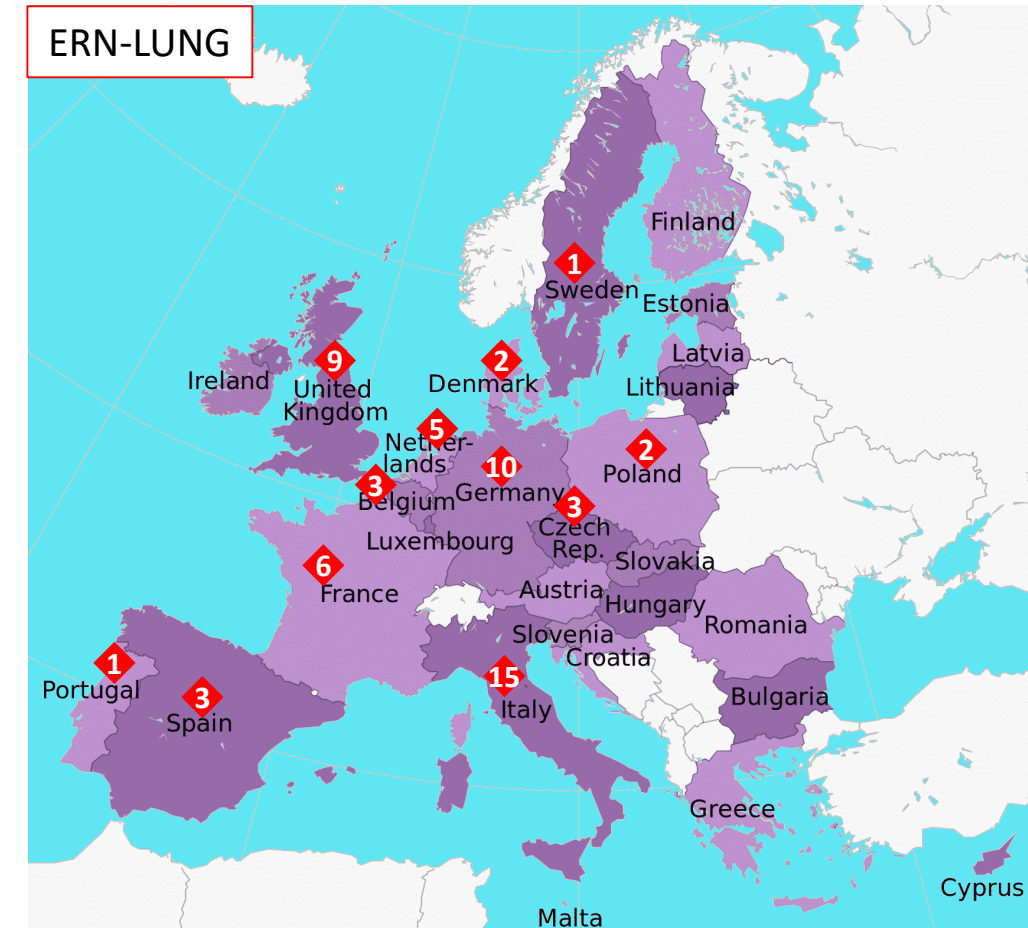
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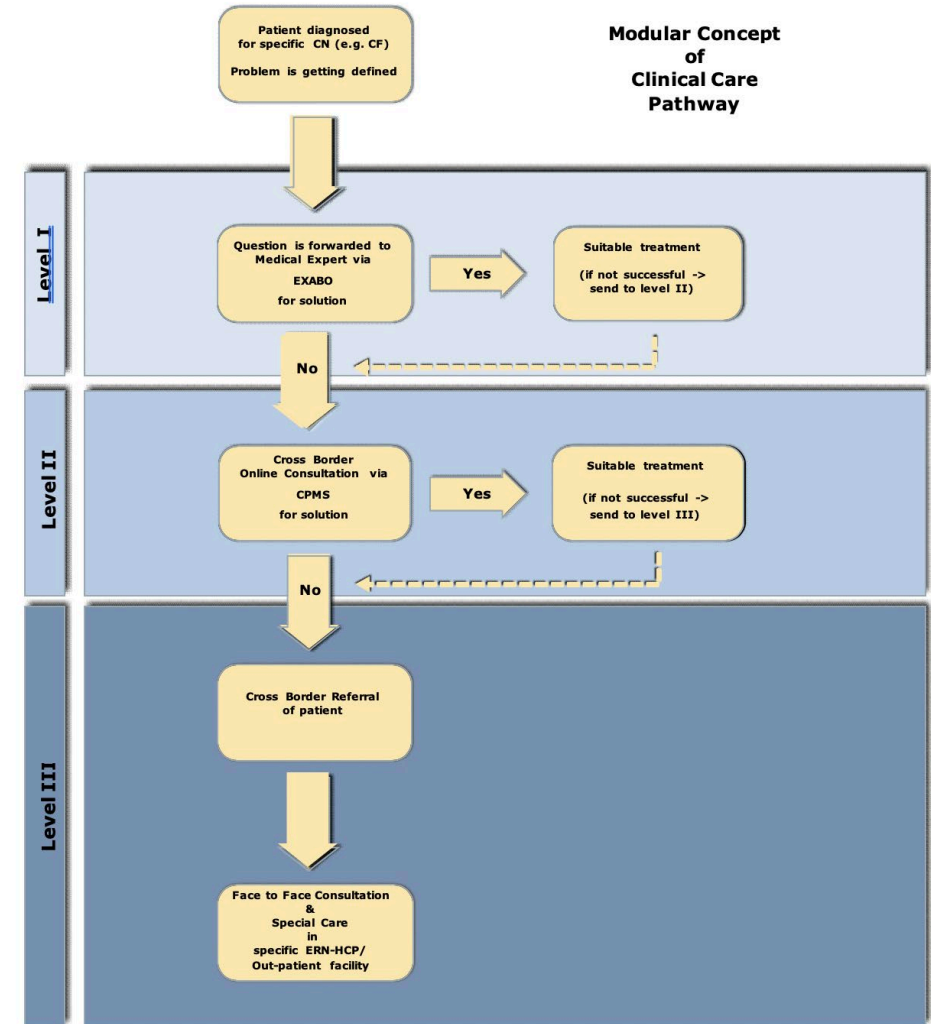


# ERN-LUNG Cross-border Care

For a patient, where cross-border referral is being considered by a member of ERN-LUNG, the following questions have to be answered with YES:

- I Has the problem been addressed within EXABO?  
*If NO, this has to be done.*
- II Has the problem been discussed during a cross-border teleconsultation (CPMS)?  
*If NO, this has to be done.*
- III Has the Panel of Experts of ERN-LUNG recommended cross-border referral to a specific center of expertise?  
*If NO, this has to be done.*
- IV Has the NCP of the country of residence of the patient been contacted?  
*If NO, this has to be done.*

**Only after having a clear YES for all four consecutive questions, the leading physician caring for the patient is endorsed by ERN-LUNG to state that the patient needs cross-border referral.**



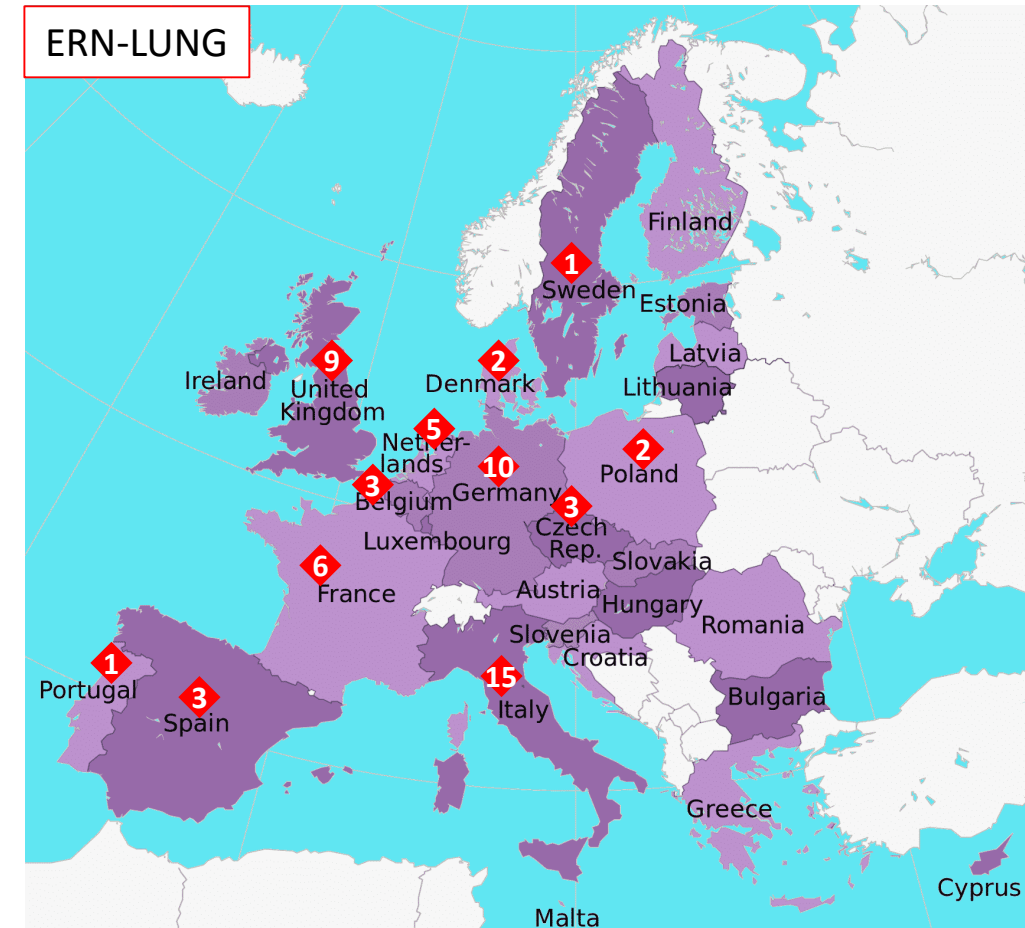
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# REGISTRIES AND CLINICAL TRIALS NETWORKS (CTNs)



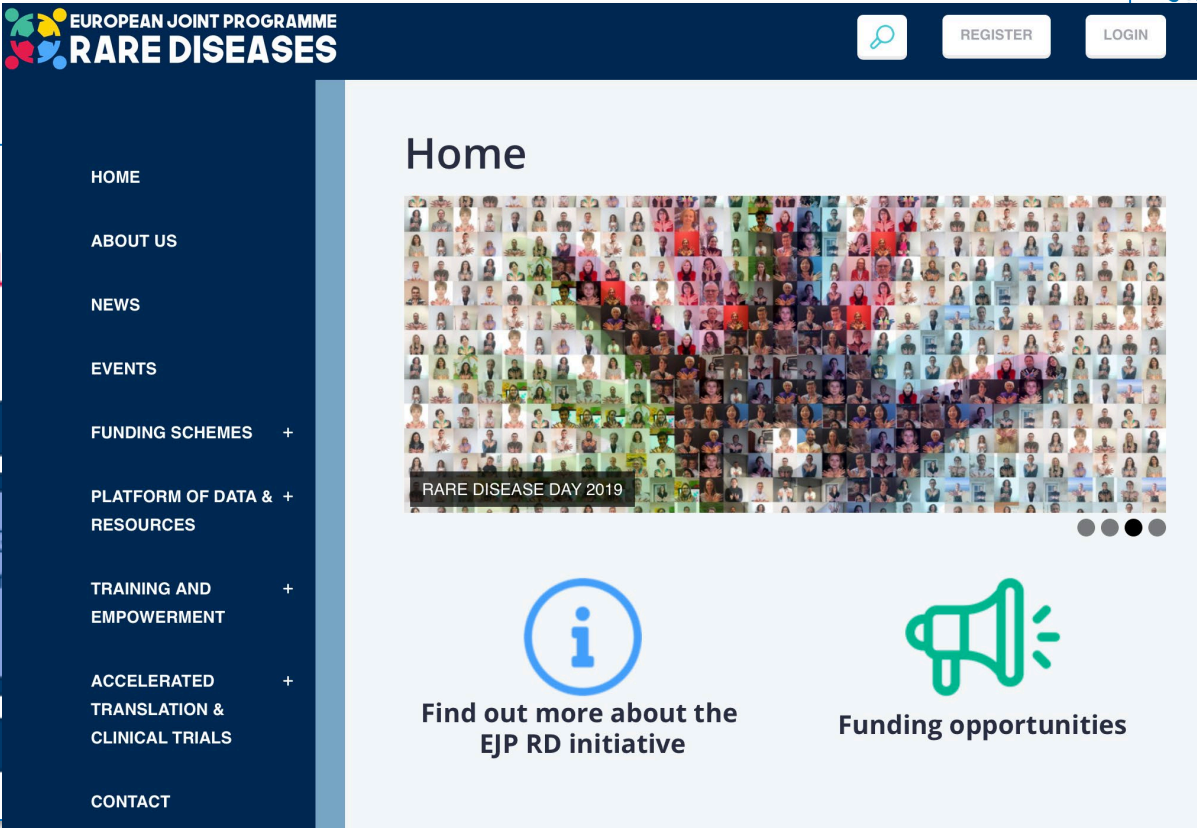
ERS Rare Lung Disease



ERDRI



ERN-LUNG Registry



EUROPEAN JOINT PROGRAMME RARE DISEASES

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RARE DISEASE DAY 2019

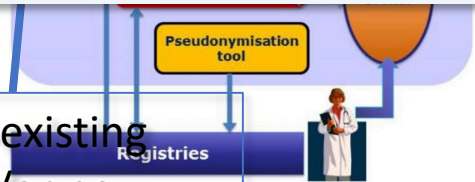
Find out more about the EJP RD initiative

Funding opportunities

All consultations

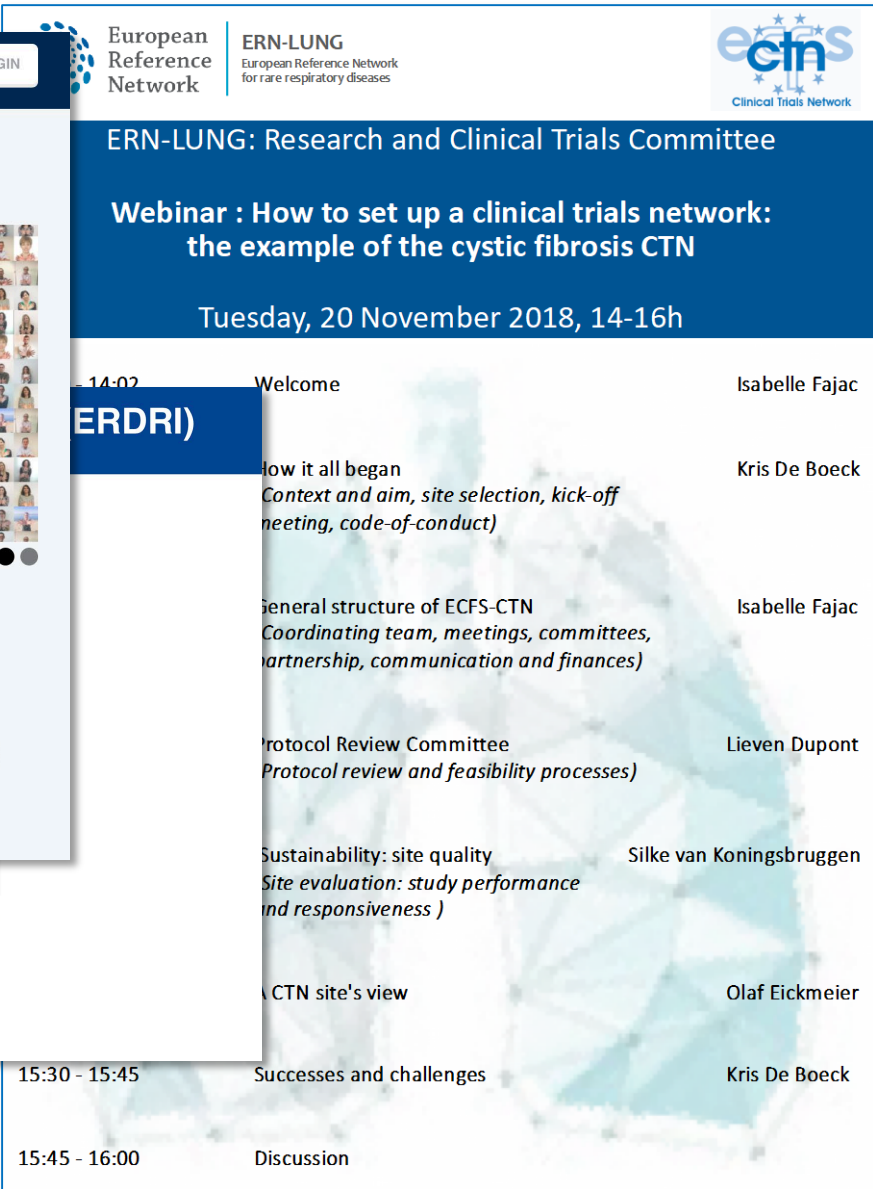
Patient recorded outcomes

Pre-existing and/or new Registries



Pseudonymisation tool

Registries



European Reference Network

ERN-LUNG  
European Reference Network for rare respiratory diseases

ERN-LUNG: Research and Clinical Trials Committee

Webinar : How to set up a clinical trials network: the example of the cystic fibrosis CTN

Tuesday, 20 November 2018, 14-16h

Time	Topic	Speaker
14:02	Welcome	Isabelle Fajac
14:02 - 14:15	How it all began Context and aim, site selection, kick-off meeting, code-of-conduct	Kris De Boeck
	General structure of ECFS-CTN Coordinating team, meetings, committees, partnership, communication and finances	Isabelle Fajac
14:15 - 14:30	Protocol Review Committee Protocol review and feasibility processes	Lieven Dupont
14:30 - 14:45	Sustainability: site quality Site evaluation: study performance and responsiveness	Silke van Koningsbruggen
14:45 - 15:00	CTN site's view	Olaf Eickmeier
15:30 - 15:45	Successes and challenges	Kris De Boeck
15:45 - 16:00	Discussion	

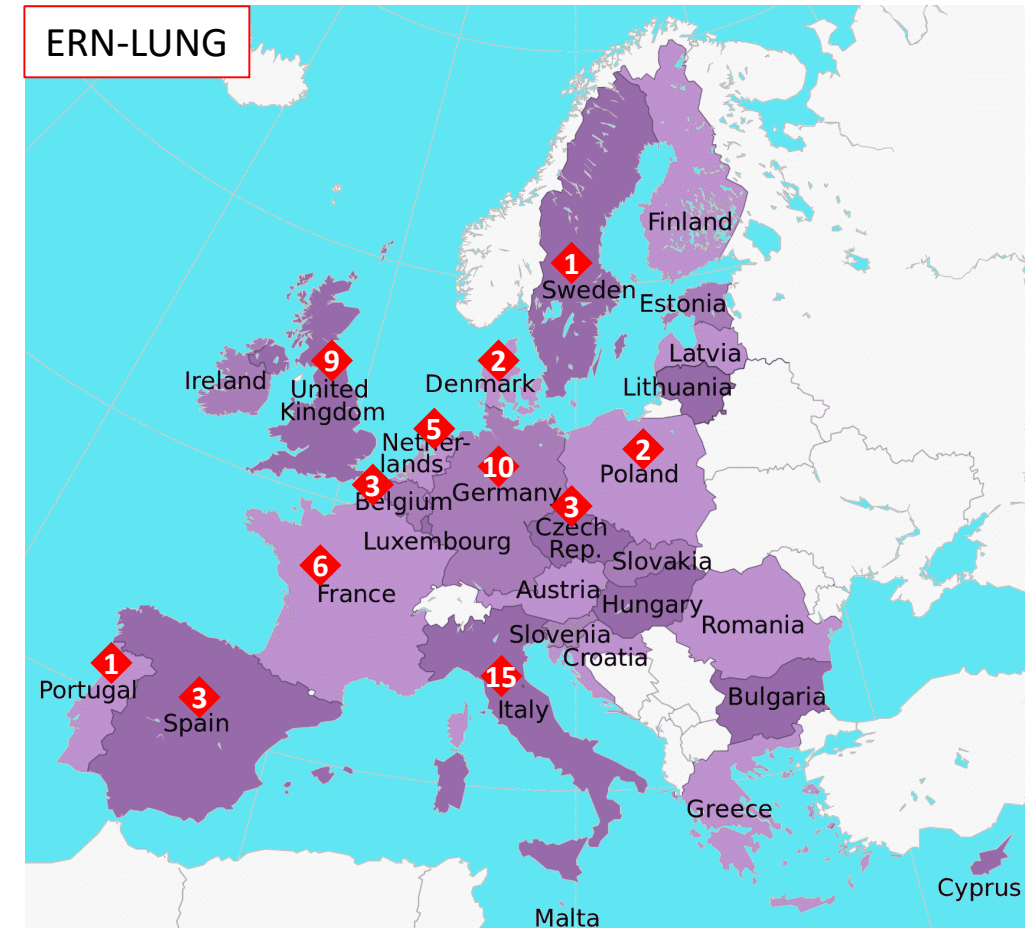
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# Expert Advisory Board ERN-LUNG EXABO

Exabo<sub>lung</sub>

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Expert Advice

Internal areaChange language

Ask question

1. Choose sector ✓

2. Choose language


3. Ask question

4. Personal data


Please select your preferred language for asking your question.

LanguageDeutsch


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Network  
Respiratory Diseases  
(ERN-LUNG)



Co-funded by  
the Health Programme  
of the European Union

About

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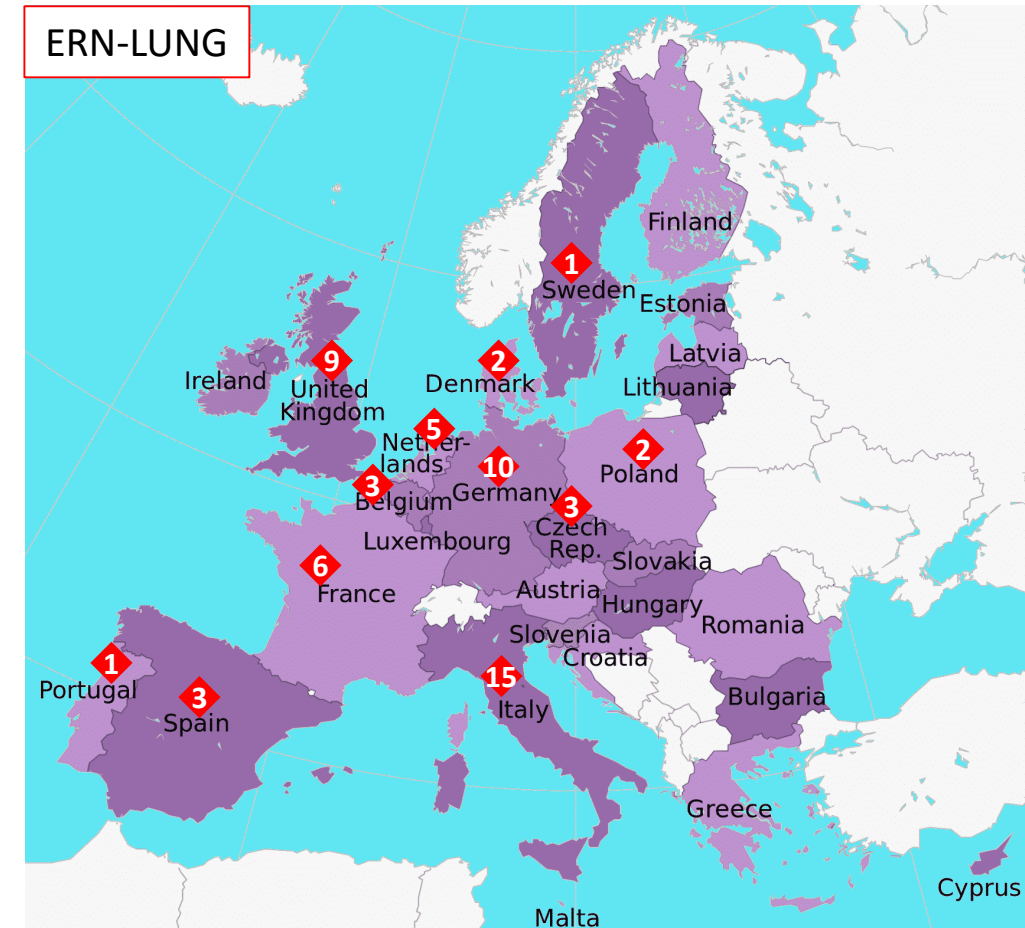
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ERN-LUNG is happy to be inclusive and we will collaborate with all HCPs who want to



# ERN-LUNG

[ERN-LUNG.eu](https://ERN-LUNG.eu)

[EXABO.eu](https://EXABO.eu)

[ejprarediseases.org](https://ejprarediseases.org)

[eu-rd-platform.jrc.ec.europa.eu](https://eu-rd-platform.jrc.ec.europa.eu)

