

PULMONARY HYPERTENSION (PH)

Lead Representative

Marc Humbert

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Deputy Representative

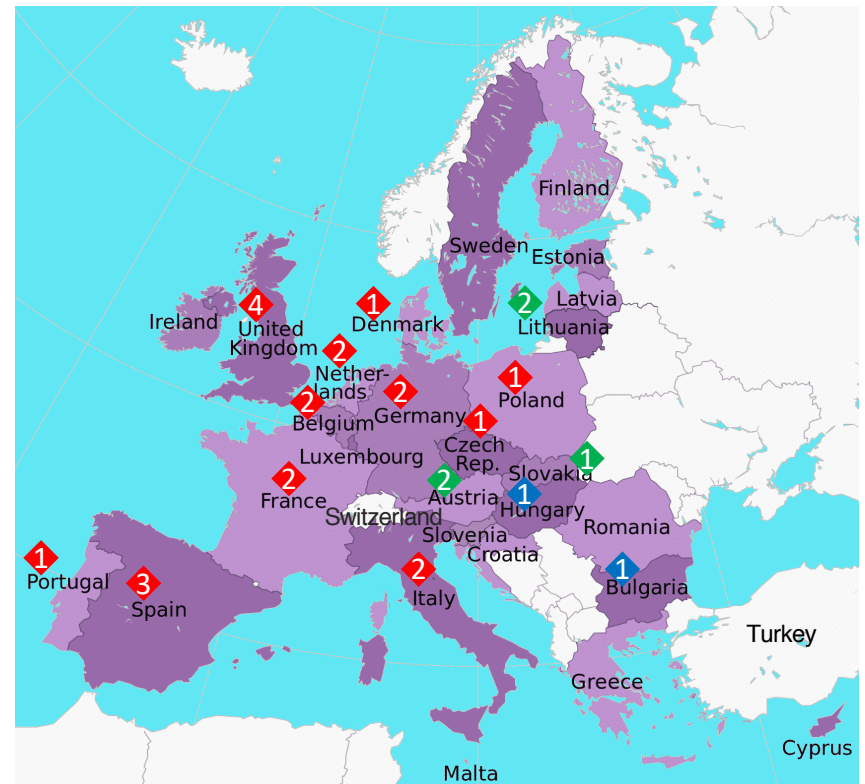
Nazzareno Galié

University of Bologna, IT

Patient Representative

Gergely Meszaros

PHA Europe, HU



Member HCP Affiliated Partner Patient Organization

Competency Requirements:

Minimum patient numbers & procedures

Indicator	Minimum # required / HCP / year	
	Adult	Children
Minimum number of TOTAL patients (visited, treated or followed) per year	200	30
Minimum number of NEW patients per year	50	10
Key diagnostic procedures per year		
Acute vasoreactivity challenge	20	10
Right heart catheterization	100	20
Pulmonary angiography	50	10
Doppler echocardiography	100	30
Ventilation/perfusion lung scan (V/Q lung scan)	50	0-10
Lung function tests with DLCO	100	20
Cardio-pulmonary exercise testing	20	0-10
6 min walking test	200	30
Biomarkers: BNP and troponin	200	30

Competency Requirements: Clinical Assessment

Hospital admissions
Mortality at 2 years
Pulmonary endarterectomy, in hospital mortality, in %
Survival (3 year survival data from national audit) for each of the 5 PH groups
Sepsis in patients on IV therapy with Hickman Catheter - UK quality measure
Proportion of patients with PAH/CTEPH who have a baseline NYHA/WHO functional class, exercise test (6 minute walk or cardiopulmonary exercise test), and right heart catheterization recorded before they begin any pulmonary hypertension drug therapy
Proportion of newly seen patients who underwent full screening programme
One-, two- and three-year survival of incident idiopathic, heritable and drug-induced PAH in the applicant center in the last 3 years
No. of patients under the applicant center treated with at least one PH drug therapy during each year in the last 3 years
Median survival of IPAH/HPAH/Drug-toxin induced (last 10 years)
Baseline WHO FC (%)
Baseline 6MWT (%)
RHC (%)

Competency Requirements:

Human resource requirements

Core team member HCP type	Extended team member HCP type
Pulmonologist	Paediatrician
Experienced lung radiologist	Lung pathologist
Geneticist	Psychiatrist
Thoracic surgeon	Social worker
Cardiologist	Palliative care
Hepatologist	
Gynaecologist	
Specialized nurses	
Psychologist	
Physiotherapist	
Medical secretary	
Study nurse	
Data typist	
Basic scientist	
Physiologist	
Transplantologist	
Interventional radiologist	
Patient representatives	