



Introducing the PULMONARY HYPERTENSION EXPERT PATIENT ACADEMY



Marc Humbert, MD, PhD

Dean of the Faculty of Medicine
and Professor of Respiratory Medicine
Le Kremlin-Bicêtre, France



Gergely Meszaros

Patient advocate,
Project Manager ERN-Lung, Hungary



Eva Otter

PAH patient, Support for PH-Patients,
PHA Austria, Austria



Mélanie Gallant-Dewavrin

Former PAH patient, lung transplant
recipient, Director, HTaPFrance, France



Pisana Ferrari

Former PAH patient, lung transplant
recipient, AfPH Secretary General,
Italy



Hall Skaara

PAH patient and Project Manager
PHA EUROPE, Norway



Louise Bouman

PAH patient and patient advocate,
Chair, PHA Netherlands,
Board member, AfPH, Netherlands



The PH Expert Patient Academy

Opening by Chairs (5 min): Marc Humbert and Gergely Meszaros

Welcome by AfPH and PHAE (5 min): AfPH (Mélanie Gallant-Dewavrin) and PHAE (Eva Otter)

The rationale of the project (10 min): Marc Humbert and Pisana Ferrari

Program overview (10 min): Hall Skaara

Sample content showcase (10 min): Louise Bouman

Patient engagement opportunities (10 min): Gergely Meszaros

Panel discussion (10 min): All

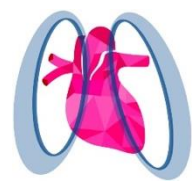


What Patients Need

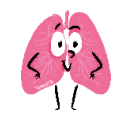
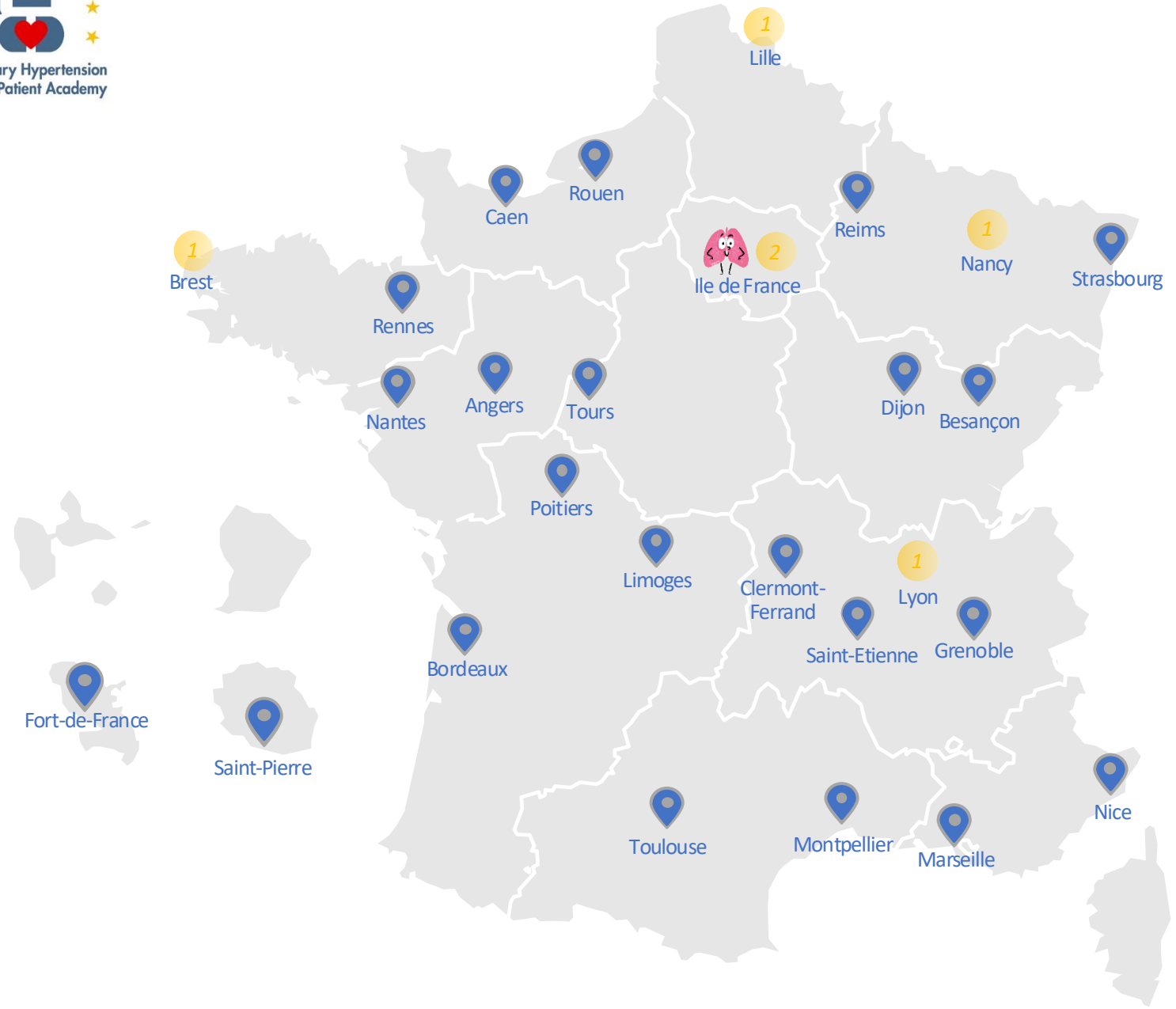
- Expert Provider Team
 - Via PH reference centers (PulmoTension since 2004, ERN-LUNG since 2017)
- Access to proper diagnostic modalities and tools
- Access to medications and interventions
 - Practical availability and cost
- Multiprofessional Support
 - Patient associations and support groups, palliative care
- Voice / Empowerment
 - Via patient-centered approach and PROMs



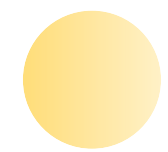
French PH Network PulmoTension : 2023 - 2027



PulmoTension
Centre de Référence de
l'Hypertension Pulmonaire



1 CRMR
coordonnateur



6 CRMR
constitutifs



22 CCMR



ERN-LUNG : 2023 – 2027

Mission – Vision - Objectives

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:

- Establishment and improvement of ERN-LUNG
- Improving cross-border care by offering (EXABO), teleconsultations (CPMS), and cross-border referral.
- Strengthen research with registries and Clinical Trials Networks (CTN)
- Easy access to quality information via online resources (homepage) and online advice platform (EXABO)
- Training of patients and professionals (ERN-LUNG Academy)
- Improving visibility of quality guidelines.
- Integrating services for undiagnosed patients (UDP) with respiratory symptoms and/or changes of function
- Improvement of standards of care, quality of life and prognosis for the whole spectrum of rare pulmonary diseases





ESC/ERS guidelines

JOURNAL ARTICLE GUIDELINES

2022 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension: Developed by the task force for the diagnosis and treatment of pulmonary hypertension of the European Society of Cardiology (ESC) and the European Respiratory Society (ERS). Endorsed by the International Society for Heart and Lung Transplantation (ISHLT) and the European Reference Network on rare respiratory diseases (ERN-LUNG). FREE

Marc Humbert, Gabor Kovacs, Marius M Hoeper, Roberto Badagliacca, Rolf M F Berger, Margarita Brida, Jørn Carlsen, Andrew J S Coats, Pilar Escribano-Subias, Pisana Ferrari, Diogenes S Ferreira, Hossein Ardeschir Ghofrani, George Giannakoulas, David G Kiely, Eckhard Mayer, Gergely Meszaros, Blin Nagavci, Karen M Olsson, Joanna Pepke-Zaba, Jennifer K Quint, Göran Rådegran, Gerald Simonneau, Olivier Sitbon, Thomy Tonia, Mark Toshner, Jean Luc Vachery, Anton Vonk Noordegraaf, Marion Delcroix, Stephan Rosenkranz ✉, ESC/ERS Scientific Document Group

- New! First time ever that patient representatives are included.
- Sets an important precedent for the future

ESC/ERS guidelines lay summary



- Also new!
- The same two patient representatives were involved in its development
- 11 languages

ALLIANCE FOR PULMONARY HYPERTENSION PHA EUROPE AND NATIONAL PATIENTS ASSOCIATIONS



Evolution of health care

- Shift from "for" to "with": the patient partnership Revolution
- Recognition also in PH clinical guidelines
- Patient lived experience provides insights clinical data cannot capture
- Patient priorities often differ from clinical priorities

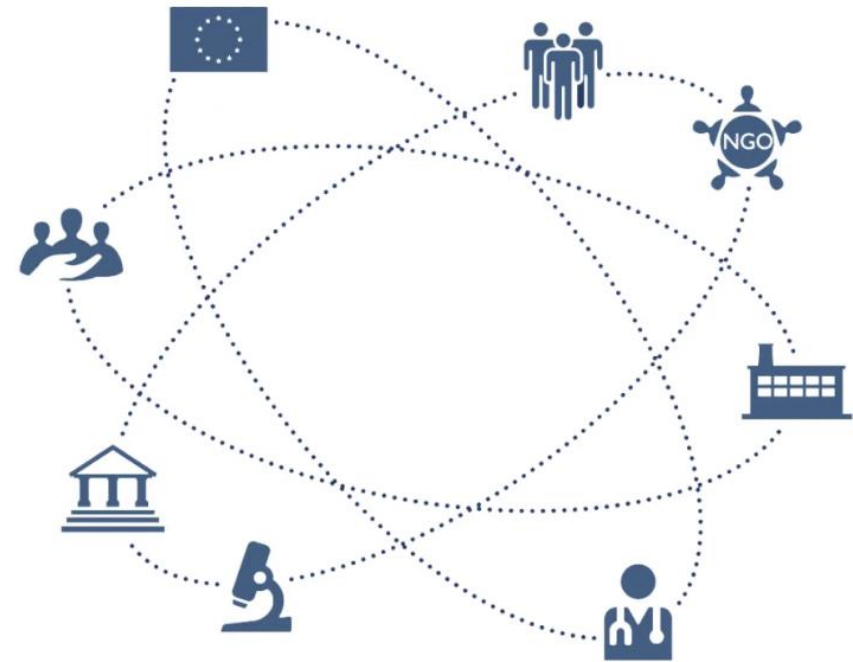
The Evidence: Better outcomes when patients actively shape care design



Growing patient involvement in health care

- EU institutions
- Scientific societies
- European Reference Networks (ERNs)
- Regulatory authorities (EMA, FDA)
- Health Technology Assessment bodies
- Health care industry
-

The challenge: Effective participation requires specialized knowledge and skills





The training gap

- European Patient's Academy on Therapeutic Innovation (EUPATI)
- European Patient Ambassador Program (EPAP)
- EURORDIS Open Academy

What's missing: Pulmonary hypertension-specific training

The need: PH advocates who can contribute professionally and confidently in technical environments





Introducing PHEPA

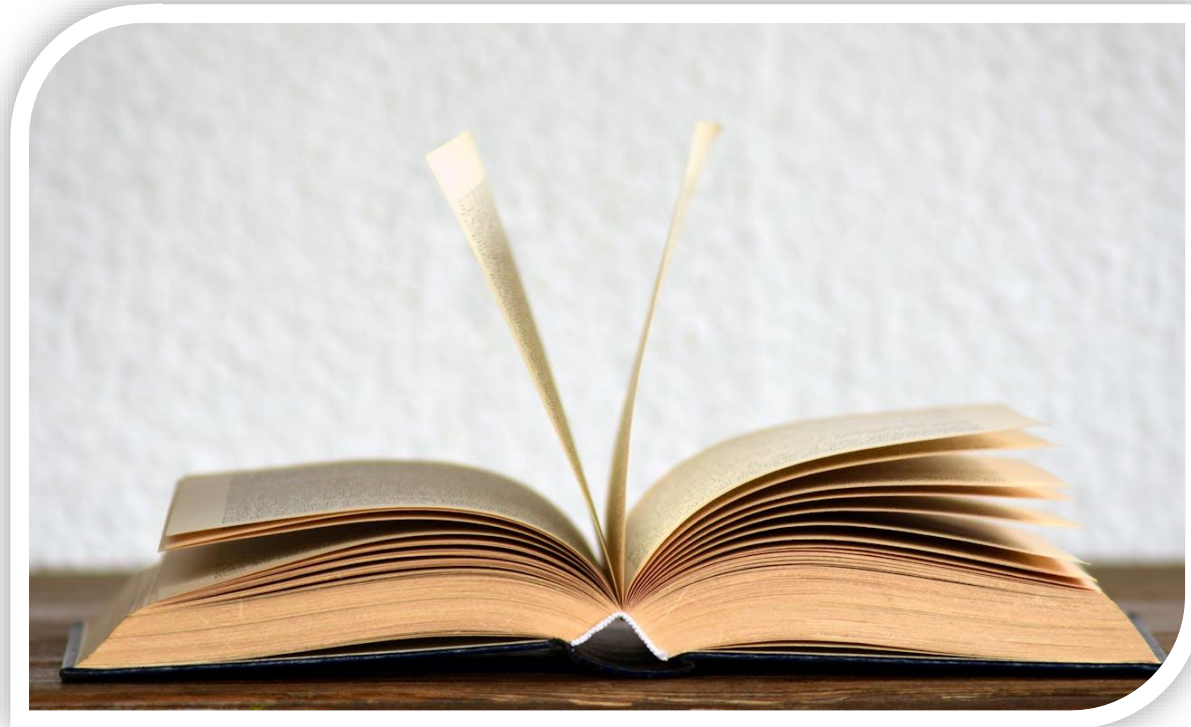
- Collaborative effort
- Comprehensive curriculum
- Fills a clear education gap
- Written by patients for patients
- Simple understandable language
- Reviewed by international experts
- Practical and actionable
- Free and accessible



How PHEPA Modules Are Built

Using Module 7 as an example:

- Title: Patient Reported Outcome Measurements (PROMs) and Quality Indicators (QIs)



How PHEPA Modules Are Built

Example: Module 7 Layout

- Always starting with estimated reading time and learning objectives
- Clear sections
- Structured headings
- They conclude with references and additional information

MODULE 7 Patient Reported Outcome Measurements (PROMs) and Quality Indicators (QIs)

Estimated reading time: 15 -20 minutes

Learning objectives:

- What PROs and PROMs are, why they are important for standard clinical care, clinical trials, HTA procedures and how and what to measure.
- Which PROMs are available for PH and how patients and patient organisations can contribute to the use of PROMs
- What are quality indicators, how are they developed and why are they important.

Introduction PROs and PROMs

Medical treatments are often judged by their impact on things like symptoms, complications, or survival. Some of these outcomes — such as hospital admissions or changes on a scan — can be measured by doctors. But there is growing awareness that treatments should not only be effective and safe, but also acceptable and meaningful to patients.

Medical tests alone cannot tell us how a patient feels, functions, or what they hope to achieve from a treatment. To measure this, we need input directly from patients — including their own experiences, goals, and quality of life.

This is why there is increasing attention on Patient-Reported Outcomes (PROs) — information that comes straight from patients about how their condition and its treatment affect their daily lives. To collect these insights in a structured way, we use Patient-Reported Outcome Measures (PROMs): tools such as surveys or questionnaires that patients complete themselves.

Why are Patient-Reported Outcomes so important?

Doctors often measure how well a treatment works using medical tests — like blood pressure, lung function, or exercise tests. But those numbers don't always show how a person feels in daily life.

This is where Patient-Reported Outcomes (PROs) are essential.

Imagine this situation:

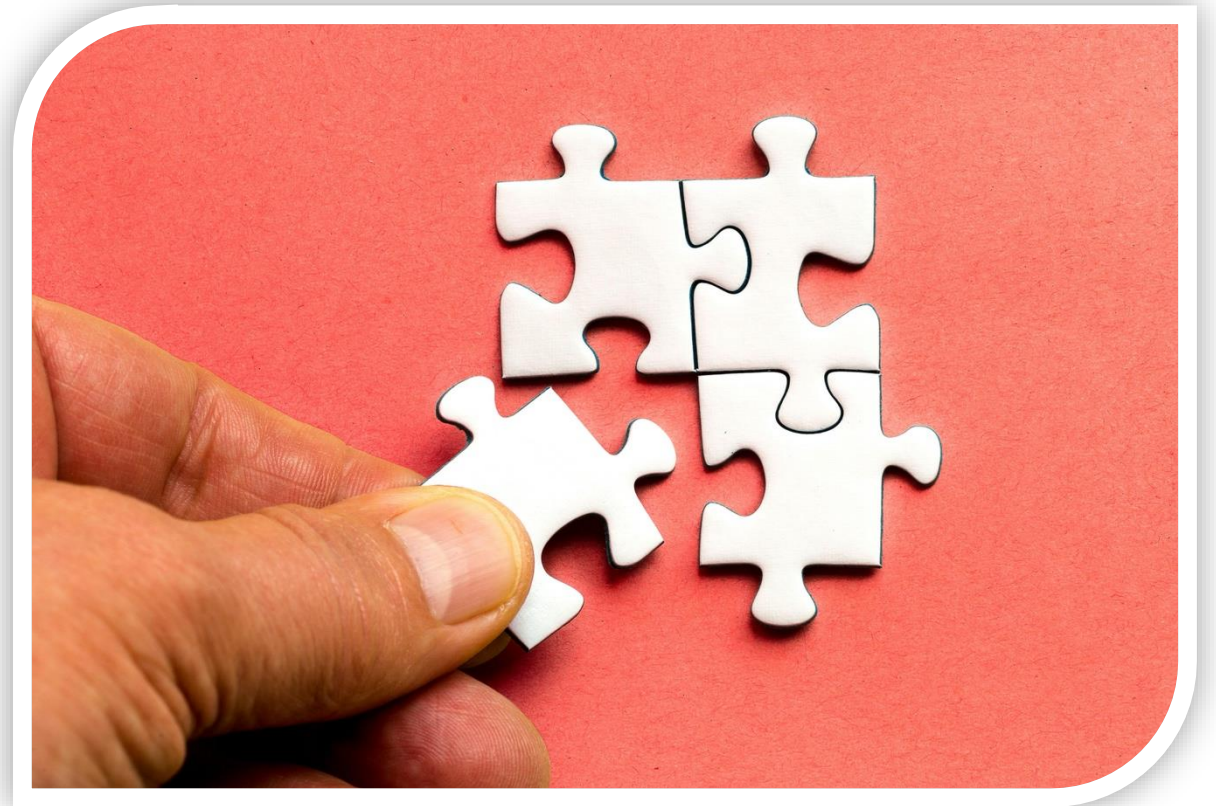
Two patients with pulmonary arterial hypertension (PAH) are given the same treatment. After a few months, their test results (like heart function or 6-minute walk distance) look very similar. But one of them says, "I feel much better — I can go for walks again!" while the other says, "I still feel exhausted and anxious all the time."



How PHEPA Modules Are Built

Example: Module 7 Layout

Let's work through the module together!





How PHEPA Modules Are Built

Every PHEPA module is built around three principles:

- Clarity — so it's easy to understand.
- Consistency — so it's easy to navigate.
- Credibility — so it's based on science.

Module 7 is simply one example of this approach.

And together, the modules create a structured pathway toward becoming an expert patient!



Who should participate

Someone living with the condition

Caregiver,
relative or
loved one

Friend,
schoolmate,
co-worker

Any other
individual
committed
to the cause
of PH

As inclusive as possible



Who would like to

- better understand the disease, the life of patients
- help a specific patient, the family, the PH community

ERN-Lung education landscape



European
Reference
Network

Respiratory Diseases
(ERN-LUNG)



Physicians



Patient
experts



Allied
professionals*



How to access the materials



Respiratory Diseases
(ERN-LUNG)

HOME CONTACT CPMS INTERNAL MEMBERS ERNs Lung-map FAQ LINKS INTRANET

ABOUT ERN-LUNG NETWORK FOR CLINICIANS FOR PATIENTS ERN-LUNG ACADEMY SEEKING EXPERT OPINION NEWS DONATE NOW



HOME » OUR EXPERTISE » EDUCATION & TRAINING » ERN-LUNG ACADEMY

ERN-LUNG ACADEMY



The ERN-LUNG Academy is a curriculum for medical staff at any stage of their career, who wishes to get a proof of knowledge on rare respiratory diseases. We wish to appeal to medical professionals: doctors, but also physiotherapists or specialized nurses.

What do we offer? Webinars and eCases, but also on-site training in ERN-LUNG Centers. The hospital can be freely chosen among our [member hospitals](#). The training will provide participants with a unique networking opportunity: get to know the best of the field they have chosen. We call for applications from participants of EU-member States from September to November of each year. **If you wish to apply, please send us a motivational email and your CV to [this address](#).** Classes start in January. For 2023, first year of the Academy, we recruited 43 participants from 13 EU Member States, and 3 non-EU States.

For 2024, we recruited 41 participants from 12 EU Member States and 5 non-EU States. For 2025, we recruited 56 participants from 14 EU Member States and 6 non-EU States.

For 2026, we recruited 71 participants from 15 EU Member States and 11 non-EU States. This year, we will also introduce a short exam based on the Webinars, in order to attest the



Youtube

Patient engagement opportunities - testing



The participants were attentive and understood the delivered educational content

The educational methods used were appropriate




The targeted audience was appropriate




Testing methods

- **Online Multiple-choice questions (MCQs) test**
- **Remote proctoring options:** Specialized companies offer secure online testing solutions.
- **In-person testing:** An in-person approach would be ideal from a security standpoint, but might be expensive.
- **Alternative assessment methods:** There are testing formats that naturally discourage cheating. Some possibilities:
 - Case study analysis: Candidates work through real PH scenarios, demonstrating applied knowledge
 - Problem-solving exercises: Practical situations requiring critical thinking rather than memorized facts
 - Portfolio-based assessment: Combination of written work, presentations, and practical demonstrations
 - Oral examinations: Via video call with multiple assessors

Multiple-choice questions (MCQs)



European Board for Accreditation
in Pneumology



SMART GUIDE:
HOW TO WRITE SUITABLE
MCQS

- Questions to be related to frequently used, relevant and important content
- Knowledge testing vs. theoretical facts
- Appropriate level of difficulty
- Concise and simple phrasing (double negative!)
- Avoid cues which helps guessing