

PH KNOWLEDGE SHARING PLATFORM 2025

A digital hub hosting all AfPH activities



PULMONARY HYPERTENSION
Knowledge Sharing Platform

Developed by the afph
ALLIANCE FOR PULMONARY
HYPERTENSION

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Pulmonary hypertension can affect anyone at any age

Explore the knowledge sharing platform

Find and share information that can improve the lives of pulmonary hypertension patients, their families, and their communities

▶ Check out our video

PH LIBRARY

- 900+ Expert-Curated Resources
- 200 new resources added 2025
- Content translatable into 40 languages
- Topics: pre-clinical research, clinical trials, diagnosis, treatments, surgery, QOL, health literacy, patient-doctor communication, E-health....

***IMPACT** - Only comprehensive multilingual PH repository worldwide (to the best of our knowledge!)*



WEBINARS

- 3 quarterly live events, last one today
- Topics included clinical trial results, PH GPS, WPHD, conference highlights, inhaled therapies, lung TX advances, early detection progress
- Slides & recordings online for ongoing access
- Speakers from 11 countries (HCPS and patient advocates)
- 3k views

IMPACT - Ongoing reference for patients, families & HCPs



Prof. Clemens Aigner
Professor of Thoracic Surgery and Head Department of Thoracic Surgery, Medical University Vienna, Austria



Prof. Harm Jan Bogaard
Professor of Experimental Pulmonary Medicine, Amsterdam UMC, The Netherlands



Ms. Louise Bouman
Patient, Chair of the Dutch PH Association and member of the Alliance for PH Board, The Netherlands



Ms. Colleen Brunetti
Patient, patient advocate and public speaker, USA



Ms. Pisana Ferrari
Patient and patient advocate President AIPH, Italian Pulmonary Hypertension Association, Secretary General AFPH, Italy



Prof. Ardeschir Ghofrani
Professor of Pulmonary Vascular Medicine, University of Giessen, Director PH Unit, University Hospital, Giessen, Germany



Ms. Dina Grajales
Patient, Patient advocate and President Sociedad Latino de Hipertension Pulmonar, Colombia



Prof. Luke Howard
Consultant Pulmonologist and Lead Clinician for the Pulmonary Hypertension Service, Imperial College London, United Kingdom



Dr. Hans Klose
Head of the Pulmonology Department at the University Medical Center, Hamburg-Eppendorf, Germany



Mr. Matt J. Granato
Strategic Advisor/President and Chief Executive Officer PHA, Pulmonary Hypertension Association, USA



Prof. Marc Humbert
Université Paris-Saclay, French PH Referral Centre, Hôpital Bicêtre, Le Kremlin-Bicêtre, Director of French PH National Reference Center, France



Mr. Gergely Meszaros
Patient advocate, Project manager at EDN-LUNG, Hungary



Prof. David Montani
Université Paris-Saclay, French PH Referral Centre, Hôpital Bicêtre, Le Kremlin-Bicêtre, France



Ms. Noriko Murakami
PH family member and advocate, President of PHA Japan, Japan



Ms. Karen Osborne
Chief Executive Officer Pulmonary Vascular Research Institute (PVRI), United Kingdom



Mr. Robert Pleticha
Patient Engagement Expert in Clinical Development at pharmaceutical, Medvetec, Spain



Mg. Phil. Ieva Plume
PH patient and patient advocate, Chief of PHA Latvia, Latvia



Prof. Sandeep Sahay
Associate Professor of Medicine, Director, PH program, Houston Methodist Hospital, Houston, Texas, USA



Andris Skride MD, PhD
Head of the PH division, P. Stradiņš Clinical university hospital, Riga, Latvia



Prof. Olivier Sitbon, MD, PhD
Université Paris-Saclay, French PH Referral Centre, Hôpital Bicêtre, Le Kremlin-Bicêtre, France



Ms. Wendy Vansteenkiste
PH patient and patient advocate, Patiëntenvereniging voor Pulmonale Hypertensie vzw, Belgium



Mr. Jan Verstraete
Project Manager of the Patient Expert Centre, Belgium

PEP TALKS

- NEW! Practical daily living strategies & essential advocacy skills
- 14 videos published (4 more coming soon)
- Speakers from 13 countries
- Diverse PH subtypes, age groups, treatment modalities, life situations
- Videos online for ongoing access
- 2.7 k views



Alena Adarbehova
Former PAH patient, lung transplant recipient,
Volunteer for the AIPH, Abu Dhabi-Vienna



Ioanna Alysandratos
PAH patient, President of the Hellenic Community
for PH and of the AIPH, Greece



Louise Bouman
PAH Patient, Chair of the Dutch PH association,
Member of the Board of the AIPH
The Netherlands



Mrs. Colleen Brunetti
PAH patient, patient advocate
and public speaker, USA



Tania Cicognini
PAH patient and patient advocate, Italy



Jen Cueva
PAH Patient and patient advocate, author, USA



Pisana Ferrari
Former PAH patient, lung transplant recipient,
patient advocate, President AIPH,
Italian PH Association, Secretary General AIPH, Italy



Mélanie Gallant Dewavrin
Former PAH patient, lung transplant recipient,
Director of the French PH Association H20France



Micheal Garrett
Husband and caregiver of a PH patient, USA



Dina Grajales
PAH Patient, President, Sociedad Latino
de Hipertension Pulmonar, Colombia



Derek Henderson
Former CTEPH patient, post PEA, Canada



Deger Kesimoglu
PAH Patient, volunteer for the Turkish
PAHSS: Patients' Association and AIPH
Turkey



Suzanne Lea
Former PAH Patient,
lung transplant recipient, UK



Caitlen Mellor
PAH Patient, The Netherlands



Richard Mindham
HF Patient and patient advocate, UK



Ayotunde Omitogun
Patient and patient advocate, Nigeria



Rishabh Radhakrishnan
Former CTEPH patient, post EPA, Singapore



Wendy Vansteenkiste
Patient and patient advocate, Chair of the
Patientvereniging voor Pulmonale
Hypertensie vzw, Belgium

IMPACT - Authentic patient-to-patient
knowledge sharing in accessible language

KEY METRICS 2023-25

900+
resources

22.000
Website
views

9.000
Visitors

127
countries

4.300
SM
followers