



# PULMONARY HYPERTENSION Mariposa Journal

WINTER 2025 • PHA EUROPE'S OFFICIAL JOURNAL • N. 35



early diagnosis • best treatment • better quality of life • finding a cure  
**PHAEUROPE** & *Global*  
PULMONARY HYPERTENSION ASSOCIATION

Wilhelmstraße 21 · A-1120 Vienna · AUSTRIA · [info@phaeurope.org](mailto:info@phaeurope.org) · [www.phaeurope.org](http://www.phaeurope.org)

# Editor's memo

WINTER EDITION • 2025

## REFLECTING ON A YEAR OF ADVOCACY, COLLABORATION, AND PATIENT VOICES

Dear Friends,

2025 has brought us many remarkable moments, and it is a pleasure to reflect on a year marked by strong advocacy, meaningful collaboration, and a continued commitment to ensuring that the voices of people living with pulmonary hypertension (PH) are heard wherever decisions are made. This winter edition of Mariposa looks back on a year in which PHAEUROPE remained highly active across scientific, policy, and patient advocacy arenas - always with patients at the centre.

One of the cornerstones of our year was, once again, the Annual PH European Conference (APHEC), held in Castelldefels, just outside Barcelona. APHEC continues to be a key meeting point for PHAEUROPE, bringing together member associations, patient advocates, experts, and partners for several days of learning, dialogue, and exchange. This year's meeting included our General Assembly, important governance processes, strategic discussions, meetings with our pharmaceutical partners, and a strong educational programme covering topics such as PH-ILD, diagnosis and follow-up, mental health, and the latest scientific developments in PH. A dedicated article in this issue provides a more detailed overview of APHEC 2025.

Throughout the year, PHAEUROPE also maintained a strong presence at major European and international conferences and policy forums. We contributed the patient perspective at events in the European Parliament and participated in key scientific and professional meetings, including ERN-LUNG activities, specialist PH conferences, global PH symposium updates, and major respiratory and patient congresses. These engagements help ensure that

patient experiences and priorities are reflected in research, clinical practice, and health policy. A comprehensive conference report later in this issue highlights these activities in more detail.

World Pulmonary Hypertension Day (WPHD) remained an important moment of global awareness and solidarity in 2025. While WPHD is covered in greater depth in the summer edition of Mariposa, it is worth noting once again the collective impact of patient-led awareness activities across regions and continents. World Pulmonary Hypertension Day (WPHD) in May and Pulmonary Hypertension Awareness Month in November were both key moments in PHAEUROPE's 2025 awareness activities. The WPHD campaign focused on the importance of early diagnosis, while PHAEUROPE's contribution to Awareness Month was a campaign that highlights the ongoing need to improve access to treatment for people living with pulmonary hypertension.

Another area of significant progress in 2025 was social media and digital engagement. PHAEUROPE's social media activities reached new levels this year, with strong growth in reach and engagement across all platforms. Awareness campaigns, advocacy messages, educational content, and patient stories contributed to increasing visibility for pulmonary hypertension and strengthening connections within and beyond the PH community. The social media report included in this issue provides further insight into this work.

It is also important to recognise that all of these activities were delivered by a very small team. In 2025, the work of PHAEUROPE was carried out by just four staff members. On behalf of the organisation, I would like to extend my sincere thanks to them for

their hard work, professionalism, and dedication throughout the year. Their commitment has been instrumental in ensuring that PHAEUROPE continues to deliver meaningful impact across a wide range of activities.

Underlying everything we do is a strong commitment to collaboration - across borders, disciplines, and organisations. In 2025, PHAEUROPE continued to strengthen partnerships within Europe and beyond, welcoming new associated members and expanding its global connections. These collaborations help broaden perspectives, amplify patient voices, and ensure that our work reflects the diversity of experiences within the PH community.

As you turn the pages of this winter edition of Mariposa, we hope it provides a clear picture of PHAEUROPE's activities over the past year and the many ways in which patients, advocates, experts, and partners continue to work together to improve care, access, and quality of life for people living with pulmonary hypertension.

With warm regards,

**Zdenka Bradac**  
President, PHAEUROPE

## CONTENTS

Editor's memo .....	p. 2	SERBIA.....	p. 95
Bel Air Center .....	p. 4	SLOVAKIA .....	p. 97
PHAE 2025 activities .....	p. 6	SLOVENIA .....	p. 99
PHAEurope's annual PH meeting .....	p. 11	SPAIN ANHP .....	p. 101
PHAEurope at conferences and key meetings .....	p. 14	SPAIN FCHP .....	p. 104
PHA Europe - Social media activities .....	p. 18	SPAIN HPE-ORG .....	p. 107
ARGENTINA .....	p. 24	SWEDEN .....	p. 109
AUSTRIA .....	p. 29	UKRAINE PHA .....	p. 110
BELARUS .....	p. 34	UKRAINE PHURDA .....	p. 111
BELGIUM .....	p. 37	USA .....	p. 114
BOSNIA AND HERZEGOVINA .....	p. 40	Media clippings .....	p. 117
BULGARIA BSPPH.....	p. 43	Austria .....	p. 117
BULGARIA PHA .....	p. 45	Belgium .....	p. 118
CROATIA .....	p. 47	Bosnia and Herzegovina .....	p. 118
CHINA .....	p. 50	Bulgaria BSPPH .....	p. 119
CZECH REPUBLIC.....	p. 51	Croatia .....	p. 119
GERMANY.....	p. 53	Czech Republic .....	p. 120
HUNGARY .....	p. 55	Hungary .....	p. 120
ISRAEL .....	p. 61	Latvia .....	p. 121
ITALY (AIPI).....	p. 62	The Netherlands .....	p. 122
ITALY (AMIP).....	p. 64	Norway .....	p. 122
JAPAN .....	p. 65	Poland .....	p. 123
LATIN AMERICA.....	p. 66	Slovakia .....	p. 123
LATVIA .....	p. 67	Spain ANHP .....	p. 124
THE NETHERLANDS .....	p. 72	Spain FCHP .....	p. 124
NIGERIA .....	p. 76	Spain HPE-ORG.....	p. 125
NORTH MACEDONIA .....	p. 77	Ukraine PHURDA .....	p. 126
NORWAY.....	p. 78	Sponsors .....	p. 127
POLAND.....	p. 81	AIMS OF PHA EUROPE.....	p. 128
PORTUGAL .....	p. 90	Members of PHA Europe and contact details.....	p. 129
ROMANIA .....	p. 92	Associated members of PHA Europe and contact details.....	p. 131

## BEL AIR CENTER



Bel Air Center has been a success since its grand opening in 2024, featuring a webinar by Prof. Marc Humbert and Prof. David Montani in connection with World PH Day on May 5th.

For those of you who are not familiar with our Bel Air Center, let me explain what it is:

Bel Air Center is a unique virtual PH conference center that employs the latest cutting-edge technology. It's open every day, year-round, catering to a global audience through our extensive translation features.

At its core, the platform offers engaging live presentations, along with a wide array of recorded presentations in multiple languages, accessible for viewing at any time.

Additionally, the center hosts a wealth of information and materials from PH associations worldwide and leading pharmaceutical companies.

For those who prefer auditory learning, we proudly feature the entire podcast series from PH Aware, including more than 500 episodes.

Moreover, you can browse our gallery showcasing artwork and contributions from PH patients, doctors, and various other stakeholders.

To foster connections, our social area allows you to chat and host video conferences with fellow members, creating a dynamic and interactive community.

Anyone can register to access the Bel Air Center. Simply go to the landing page: [www.belaircenter.info](http://www.belaircenter.info) and create a free account. Please provide as much information as possible during registration to help us tailor the platform and its content to your needs.

From our landing page, you can click on a link to access Bel Air Center. When you log in for the first time, you create a personal password that does not expire. You only need to enter this password the very first time; on subsequent visits, you will be taken directly into the Center when using the same computer.

The centre currently offers more than forty presentations covering various aspects of PH. One example is a talk by HTA specialist Neil Bertelsen, which provided an excellent introduction to the HTA process and how patient associations can get involved. This presentation is part of a series of three. Make sure to create your Bel Air Center user account to be notified about this and other interesting upcoming webinars.

Another feature of the presentation room is that some webinars have been dubbed into several languages. Simply click on the blue filter icon in the right-hand corner and select the desired language. The webinars available in that language will then be displayed. We will increasingly utilize this feature to make our excellent material accessible to a wider audience worldwide.

*Welcome to Bel Air Center! Make sure to create your free account and explore the center. It is open 24/7!*

**Hall Skaara**  
Project Manager



**AllRock Bio, Inc. is dedicated to advancing novel therapies to improve the lives of patients suffering from pulmonary hypertension, interstitial lung diseases, and other fibrotic conditions.**

Leveraging extensive expertise from drug development to commercialization, AllRock Bio's team is dedicated to advancing impactful therapies for cardiopulmonary diseases. AllRock Bio's lead drug, ROC-101, is an orally administered, potentially best-in-class pan-ROCK inhibitor. ROC-101 is initially being investigated in pulmonary arterial hypertension (PAH) and pulmonary hypertension with interstitial lung disease (ILD-PH).

ROC-101 potently inhibits both ROCK isoforms, ROCK1 and ROCK2. This pan-ROCK inhibition results in an anti-proliferative, anti-inflammatory and anti-fibrotic mechanism of action that potentially enables the treatment of PAH and ILD-PH. This mechanism for ROC-101 targets the pathologic process of pulmonary arterial remodeling seen in PAH and ILD-PH, and it also targets the pulmonary fibrosis seen in ILD-PH.

**WE USE BUSINESS TO  
FIGHT FOR  
SOCIAL JUSTICE**

We have long been a company that looks to do things differently; instead of maximizing shareholder returns, we reinvest around 50% of our profit in initiatives that give back to society. Back where it belongs.

Founded in Barcelona in 1959, we offer transformative solutions for debilitating life-threatening conditions, with an increasing focus on pulmonary vascular and interstitial lung diseases and rare neurological diseases.

Our business is not an end in itself, but a way to change lives.

We are Ferrer. Ferrer for good.

**ferrer**  
for good

Certified  
**B**  
Corporation

## PHAE 2025 activities

### Vienna - Austria, January 21st

#### CORPORATE MEETING

PHAEUROPE held its corporate meeting, during which it presented its business plan and discussed future directions and activities.



### Brussels - Belgium, February 4th - 5th

#### HEALTHY LUNGS FOR LIFE

Hall represented PHAEUROPE in the European Parliament together with our partners in the European Lung Health Group. This included presentations and lung function testing of Parliament employees.

### Virtual - February 6th

#### EU

Hall represented PHAEUROPE in the first of three webinars in which the EU presented the European Health Data Space (EHDS). PHAEUROPE has been part of a working group providing input to this initiative.



### Berlin - Germany, February 20th - 21st

#### INTERNATIONAL EXPERT MEETING

Reshaping Prostacyclin Therapy in Pulmonary Hyper-tension A scientific committee, such as I. Lang, M. Kurzyrna, K. Tello, and R. Steringer-Mascherbauer, met in Berlin. The focus of this conference was the progress in the development of the new implantable pump. The patient perspective was discussed by Eva.



### Paris - France, March 24th - 25th

#### ERN-LUNG

Hall participated in ERN-LUNG's annual board meeting in Paris and presented PHAEUROPE's Bel Air Center to the audience.



### Kaunas - Lithuania, May 9th

#### 5TH BALTIC PH CONFERENCE

Hall participated in the fifth Baltic PH Conference in Lithuania, where specialists from the Baltic countries met to discuss the latest advances and opportunities for collaboration.



### Brussels - Belgium, May 23rd - 25th

#### EPF

Hall participated in EPF's Annual General Meeting in Brussels. PHAEUROPE is a full member and voted on, and provided input to, the items on the agenda. The strategic plan for 2027-2031 was discussed on the second day.

### Dublin - Ireland, June 11th - 13th

#### ERS

Hall participated in an ERS Summit focused on prevention. This is particularly important in relation to lung diseases, and Hall provided input related to pulmonary hypertension and tertiary prevention.



### Amsterdam - The Netherlands, June 15th - 17th

#### PVRI

Hall represented PHAEUROPE at PVRI's Drug Discovery & Development Symposium in Amsterdam.

### Bologna - Italy, July 3rd - 5th

#### WORLD PH SYMPOSIUM UPDATE

Hall participated in the symposium update in Bologna and delivered a presentation entitled "From Patient Empowerment in Pulmonary Hypertension to PROMs: the Patient Perspective."



### Brussels - Belgium, September 1st

#### EU PARLIAMENT

Hall represented PHAEUROPE in the European Parliament and delivered a speech to Members of the European Parliament on living with a chronic respiratory disease and the importance of not overlooking the respiratory dimension in the new EU cardiovascular health plan.

### Amsterdam - The Netherlands, September 25th - 26th

#### GAAPP

Hall participated in GAAPP's annual conference. This was the first time PHAEUROPE was represented at the conference and it marks a closer collaboration between the two associations.



### Amsterdam - The Netherlands, September 27th

#### ELF

PHAEUROPE had several representatives at the ELF Networking Day. PHAEUROPE is actively involved in ELF through participation in several advisory groups and committees. PHAEUROPE representatives helped to facilitate and document the breakout sessions.

*Amsterdam - The Netherlands, September 28th - October 1st*

ERS

PHAEUROPE was well represented at the large ERS Congress. Representatives contributed as speakers in both studio sessions and regular sessions and participated in committees such as CRCs, ELF PAG, ELF PAC, and ELHG. The Congress also provided an excellent opportunity for networking.



*Barcelona - Spain, November 4th - 9th*

APHEC

PHAEUROPE's annual conference was held as usual in Castelldefels, outside Barcelona. Most of PHAEUROPE's members participated in a successful conference that included advisory board meetings, the AGM, pharmaceutical presentations, and presentations by leading PH specialists.

*Prague - Czech Republic, November 13th - 16th*

ELHG

Hall was part of the steering committee for the Respiratory Patient Academy organised by the European Lung Health Group (ELHG), of which PHAEUROPE is a member. Five representatives from PHAEUROPE's member associations participated in the academy.



**Fundación Contra la Hipertensión Pulmonar**

*Rome - Spain, November 20th*

FCHP

PHAEUROPE's President, Zdenka, represented the Spanish PH association FCHP at its anniversary event in Rome, delivering a speech to commemorate their important work.

*Virtual - November 21st*

ROMANIAN PATIENT ASSOCIATION

The Romanian patient association organised a patient meeting attended by both patients and doctors. Hall joined via Zoom and delivered a presentation on pulmonary hypertension and rehabilitation.



*Brussels - Belgium, November 25th - 27th*

EPF

Hall participated in EPF's congress entitled "Shaping the Future of Healthcare - Preparedness for Health Systems' Resilience."

# We are MSD

For 130 years, we have tackled some of the world's biggest health challenges and provided hope in the fight against disease, for both people and animals. Today, we continue our commitment to be the premier research-intensive biopharmaceutical company in pursuit of medical breakthroughs that benefit patients and society for today, tomorrow and generations to come.



[msd.com](https://www.msd.com)

Copyright © 2021 Merck & Co., Inc., Kenilworth, NJ, USA and its affiliates. All rights reserved.

## PHAEUROPE'S ANNUAL PH MEETING 2025

*Coming Together in Castelldefels*



PHAEUROPE's annual PH European Conference (APHEC) once again brought our community together in Castelldefels, just outside Barcelona, for several days of learning, discussion, collaboration, and social connection. As in previous years, the meeting was a highlight of the PHAEUROPE calendar, offering an important forum where patient advocates, experts, and partners could meet face to face. It is worth highlighting that the entire

practical organisation of the conference - including flights, transfers, accommodation, food and beverages, conference arrangements, and accounting - was handled by just two people: Tamara and Gerry. With Gerry's 45 years of experience in the tourism industry, their joint efforts ensured that APHEC ran smoothly and professionally, allowing participants to focus fully on the programme, discussions, and networking.



### GOVERNANCE, TRANSPARENCY, AND GROWTH

The conference opened with PHAEUROPE's General Assembly, where members and fellows gathered to review the organisation's activities, discuss priorities, and take part in elections. Two board members were up for election, resulting in a shift within the board, and one new auditor was elected. These processes are central to ensuring transparency, renewal, and strong governance within the organisation.

The General Assembly also included a dedicated social media report, highlighting the campaigns run in recent years and demonstrating impressive reach across all major platforms. The report clearly showed how social media has become an increasingly powerful tool for awareness raising, advocacy, and community engagement for PHAEUROPE.

An important part of the General Assembly was the staff report, which presented the work carried out since the previous APHEC. This gave members a comprehensive overview of PHAEUROPE's advocacy, education, policy engagement, partnerships, and project activities over the past year.

In addition, the General Assembly welcomed a new associated member: Sociedad Latina de Hipertensión Pulmonar, an umbrella organisation from South America. This new partnership further strengthens PHAEUROPE's global presence and underlines the importance of collaboration beyond Europe.



*Committed to transforming the lives of patients with pulmonary diseases*

- ❖ Inhaled moslicigat, Pulmo vant's first investigational candidate, is a **potential first-in-class, soluble guanylate cyclase (sGC) activator** with a novel mechanism of action currently being evaluated in a global **Phase 2 PHocus trial** (NCT06635850) in pulmonary hypertension associated with interstitial lung disease (PH-ILD).



For more information about our company or ongoing clinical trial, visit <https://pulmo vant.com> or <https://phocusstudy.com>

Moslicigat is an investigational product which has not been approved for use by the U.S. Food and Drug Administration or any regulatory authority.

## DIALOGUE WITH INDUSTRY PARTNERS AND CORPORATE PLANNING

A key part of APHEC is the dedicated pharma days, during which PHAEUROPE meets with the pharmaceutical companies it collaborates with. Each partner was given one hour to present updates on research, pipelines, and developments relevant to pulmonary hypertension. These sessions allow for open dialogue and questions, helping patient representatives stay informed while also ensuring that patient perspectives and unmet needs are clearly communicated.

PHAEUROPE also used the opportunity to hold a corporate meeting with its pharmaceutical partners, during which the organisation presented its business plan for the coming year. Sponsors provided constructive feedback, reflections, and suggestions, contributing to a valuable exchange that helps strengthen collaboration and align expectations.

## EDUCATION, EMPOWERMENT, AND NEW PERSPECTIVES

The educational programme offered a broad range of sessions aimed at strengthening knowledge and empowerment among participants. Topics included PH-ILD, screening and diagnosis, follow-up and long-term management, and the latest scientific updates in pulmonary hypertension. PH-ILD is an area of growing importance for PHAEUROPE, as it is for many pharmaceutical companies, and reflects the increasing recognition of this patient group's unmet needs. Continuing to include and represent people living with PH-ILD within our member associations is essential to ensuring comprehensive advocacy, equitable access to care, and a strong patient voice across the full spectrum of pulmonary hypertension.



One particularly engaging and practical session focused on echocardiography. A PH patient volunteered to undergo a live echocardiographic examination, which was performed and explained in real time by Professor Zvonimir A. Rako from the Giessen PH Center in Germany. This unique session gave participants valuable insight into how echocardiography is used in daily clinical practice to assess and monitor PH.

The scientific programme also included presentations by Professor Stefano D'Alto and Professor Hossein Ardeschir Ghofrani, both world-renowned pulmonary hypertension experts. PHAEUROPE is proud that leading specialists of this calibre take the time to join our annual meeting, share their expertise, and engage directly with the patient community.

Mental health was addressed in a dedicated session led by Dr. Beate Schrank, highlighting the psychological burden often experienced by people living with chronic and rare diseases. The session emphasised the importance of recognising mental health as an integral part of holistic PH care.

## COLLABORATION AND PATIENT ADVOCACY

Collaboration across borders and organisations was a recurring theme throughout the conference. A dedicated session with PH

Aware and Steve highlighted opportunities for closer cooperation with patient advocates and organisations in the United States.

The programme also included a presentation from GAAPP (Global Allergy & Airways Patient Platform), showcasing their work in patient advocacy, education, and global collaboration.

## NETWORKING AND SOCIAL EXPERIENCES

As always, APHEC was not only about formal sessions. Informal discussions during breaks, meals, and social activities created valuable opportunities for networking, peer support, and the sharing of lived experiences.

The programme also included a sightseeing excursion to Barcelona, led by a highly humorous and engaging guide. Beyond offering insight into the city's history and culture, the excursion provided a relaxed and enjoyable setting that strengthened the sense of community and "family feeling" among participants - an important part of what makes APHEC special.

## LOOKING AHEADS

The conference also included internal planning sessions focused on PHAEUROPE's future activities and priorities. Together with staff, partners, and member representatives, participants reflected on upcoming challenges and opportunities.



Once again, Castelldefels proved to be an ideal setting for PHAEUROPE's annual meeting — combining strong governance, high-quality education, strategic dialogue, and a warm, inclusive atmosphere.



**gossamerbio**

Gossamer Bio is a clinical-stage biopharmaceutical company focused on developing seralutinib, an investigational medicine for the treatment of pulmonary arterial hypertension (PAH) and pulmonary hypertension associated with interstitial lung disease (PH-ILD).

Our goal is to improve the lives of people with these rare diseases through innovative scientific research and support for patient advocacy groups.

For more information please visit:  
[www.gossamerbio.com](http://www.gossamerbio.com)

August 2025

## PHAEUROPE AT CONFERENCES AND KEY MEETINGS IN 2025

Throughout 2025, PHAEUROPE maintained a strong and visible presence at major European and international conferences, policy meetings, and specialist forums. These activities reflect our continued commitment to advocacy, collaboration, and the advancement of care for people living with pulmonary hypertension (PH), while ensuring that the patient perspective remains central in scientific, clinical, and policy discussions.

### ADVOCACY AND LUNG HEALTH AT EU LEVEL

Early in the year, PHAEUROPE was represented at several high-profile events in the European Parliament. Participation in the Healthy Lungs for Life exhibition and an event on raising standards of COPD care brought lung health firmly into the EU policy spotlight. Hundreds of parliamentarians, staff, visitors, and patient representatives underwent lung function testing, underlining the importance of prevention, early detection, and awareness.



PHAEUROPE used these opportunities to highlight both the value and the limitations of spirometry for PH, stressing that while spirometry cannot diagnose PH, it can indicate when further investigation is needed. Advocacy efforts also focused on the urgent need to prioritise respiratory diseases in EU policymaking, given their enormous societal and economic burden.

Later in the year, PHAEUROPE returned to the European Parliament for the event “Breathing Better – Scaling up EU Prevention Policies for Respiratory Health.” Policymakers, researchers, and patient representatives called for stronger prevention policies, cleaner air, early detection, and greater investment in respiratory research and care. PHAEUROPE contributed the patient perspective, emphasising life with pulmonary arterial hypertension, inequalities in access to treatment, the need for innovation – particularly for PH-ILD, where no approved treatments currently exist – and the direct impact of climate change on symptoms and quality of life.

### COLLABORATION WITHIN EUROPEAN NETWORKS

PHAEUROPE played an active role within European reference and patient networks throughout the year. At the 9th ERN-LUNG Annual Board Meeting in Paris, representatives from across Europe reviewed progress on registries, education, cross-border care, and future strategy. During the ePAG session, PHAEUROPE

presented the Bel Air Center – a virtual platform for education and collaboration between patients and professionals – which generated strong interest among participants.

The meeting highlighted advances in patient-reported outcomes, quality management, and clinical research collaboration, as well

as the importance of strengthening involvement from centres and healthcare professionals across all regions of Europe.

PHAEUROPE was also actively involved in the European Respiratory Patient Academy, organised by the European Lung Health Group. Several representatives from PHAEUROPE member associations participated, strengthening patient knowledge, advocacy skills, and capacity to engage meaningfully with clinicians, researchers, and policymakers.

### SCIENTIFIC EXCHANGE AND SPECIALIST MEETINGS

At the 5th Baltic PH Conference in Kaunas, Lithuania, PHAEUROPE was represented as the sole patient voice among clinicians and researchers from the Baltic region and beyond. The conference showcased strong cross-border collaboration between Lithuania, Latvia, and Estonia and covered topics such as right ventricular function, echocardiography, right heart catheterisation, PH subgroups, and emerging therapies – including the fourth treatment pathway with sotatercept. The inclusion of medical students and young researchers was particularly encouraging and points to a strong future for PH care in the region. Several sessions were recorded and later made available through the Bel Air Center to extend their educational reach.



Scientific advances were also at the forefront during the PVRI Drug Discovery & Development Symposium in Amsterdam. This international meeting focused on emerging therapies, including sotatercept and next-generation activin-pathway agents, inhaled kinase inhibitors, biomarkers, interventional devices, and catheter-based procedures. Discussions reflected growing optimism that PH treatment may be entering a disease-modifying era, while also addressing equity in clinical trials, sex differences in PH, and sustainability in research.

### GLOBAL PERSPECTIVES, EMPOWERMENT, AND PREVENTION

PHAEUROPE participated in the World PH Symposium Updates 2025, an interim meeting between the five-yearly World Symposia on Pulmonary Hypertension. The conference reviewed progress in clinical trials, endpoints, genetics, biomarkers, and novel

therapies. PHAEUROPE contributed directly to the programme by delivering a keynote presentation on patient empowerment and patient-reported outcome measures (PROMs), highlighting their importance in capturing lived experience and their continued underuse in routine care. The meeting also underscored persistent global inequalities in access to diagnosis, treatment, and patient empowerment.

Prevention was another key theme during 2025, notably at the ERS Presidential Summit on Prevention in Dublin. Discussions covered primary, secondary, and tertiary prevention across chronic respiratory diseases. For PH, where primary prevention is often not possible, the focus was on tertiary prevention: timely diagnosis, advanced therapies, rehabilitation, and environmental measures that preserve quality of life. Patient testimonies reinforced the message that prevention must be embedded across sectors and supported by adequate funding.

### HEALTH SYSTEM RESILIENCE AND THE PATIENT VOICE

Towards the end of the year, PHAEUROPE participated in the EPF Congress 2025, entitled “Shaping the Future of Healthcare – Preparedness for Health Systems’ Resilience.” The congress examined lessons from COVID-19 and ongoing vulnerabilities in European health systems, including workforce shortages, fragmented clinical research, supply chain weaknesses, misinformation, and inequalities in access to care.

Discussions highlighted the importance of trust, transparent communication, and meaningful patient involvement in preparedness planning. The second day focused on future



solutions, including digital health, artificial intelligence, and upcoming EU initiatives such as the Biotech Act and disease-specific health plans. A recurring message was that resilient health systems can only be achieved when patients are recognised as essential partners in shaping healthcare policy, research, and innovation.



### ERS CONGRESS AND NETWORKING

PHAEUROPE was well represented at the ELF Networking Day and the ERS Congress, which remain among the most important annual gatherings for the respiratory community. Representatives from PHAEUROPE contributed as speakers, participated in committee and working group meetings, and engaged actively across a wide range of scientific and policy sessions.

Beyond the formal programme, the ERS Congress provides exceptional networking opportunities. It brings together clinicians,

researchers, patient organisations, policymakers, and industry partners from across Europe and beyond. These interactions are invaluable for strengthening existing collaborations, establishing new partnerships, and ensuring that the patient perspective remains integrated into research, policy discussions, and future initiatives within the respiratory field.

### PHAEUROPE ANNUAL MEETING

In addition to international conferences, PHAEUROPE also held its annual meeting, which took place, as always, in Castelldefels, outside Barcelona. The meeting brought together member associations from across Europe and included the Annual General Meeting (AGM), strategic discussions, meetings with pharmaceutical partners, and presentations from leading PH specialists. While a separate report will cover this meeting in more detail, it remains a cornerstone event for internal collaboration, knowledge exchange, and alignment on PHAEUROPE's priorities and future activities.

### LOOKING AHEAD

Taken together, PHAEUROPE's conference participation in 2025 demonstrates the breadth and depth of our engagement – from EU-level advocacy and health system resilience to cutting-edge science, patient empowerment, and international collaboration. By ensuring that the patient voice is present wherever decisions are made, PHAEUROPE continues to work towards earlier diagnosis, better care, and improved quality of life for people living with pulmonary hypertension across Europe and beyond.



Shaping the Future  
of Healthcare



FOCUS ON  
PERSONALISED  
MEDICINE

OrphaCare is an international, up-and-coming company with a special focus on medical devices. The company organizes a comprehensive and competent patient support as well as distribution.

In addition, OrphaCare is acting as a manufacturer of a software medical product risk class I according to MDR<sup>1</sup>.

*At OrphaCare,  
we don't just  
talk about  
personalised  
medicine,  
WE LIVE IT!*



For further information visit us at:  
[www.orphacare.com](http://www.orphacare.com)

<sup>1</sup> EU Medical Device Regulation (MDR) 2017/745  
Map: © dikobrazly / iStockphoto.com. Foto: © alvarez / iStockphoto.com. Montage: Leitner: design.renateleitner.com



*AOP Health is the  
European pioneer  
for integrated  
therapies for rare  
diseases and  
in critical care.*

**Needs. Science. Trust.**

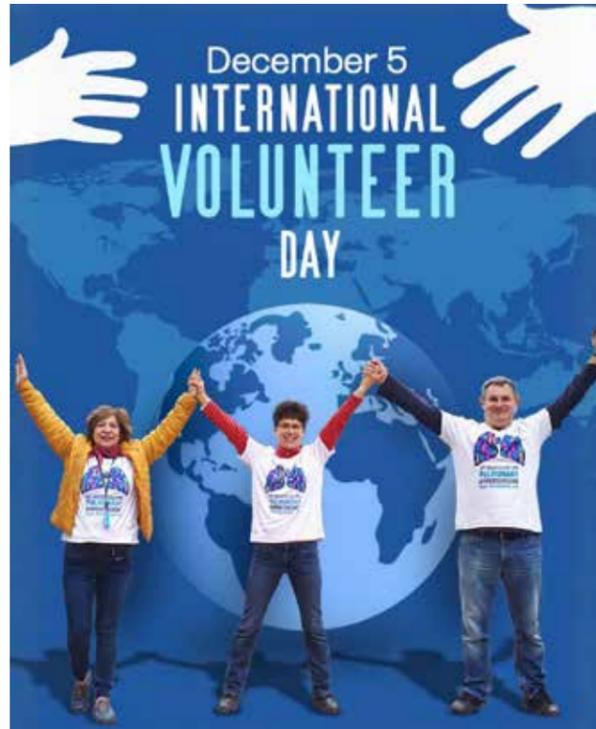
[www.aop-health.com](http://www.aop-health.com)



## PHA EUROPE – SOCIAL MEDIA ACTIVITIES 2025

Throughout 2025, PHAEUROPE continued to strengthen its role as a leading patient advocacy voice in the pulmonary hypertension (PH) community, delivering record-breaking results across all social media platforms while amplifying patient stories, awareness campaigns, and key international events on social media platforms.

The year was marked by extensive coverage of major European and global PH events, including APHEC 2025, the ERS Congress,



World Symposium on Pulmonary Hypertension (WSPH) updates, the ERS Presidential Summit on Prevention in Dublin, the PVRI Drug Discovery & Development Symposium 2025 in Amsterdam, and the EPF Congress in Brussels. At these events, PHAEUROPE was represented by its board members, patient advocates, and staff, consistently ensuring that the patient perspective remained visible and heard at all relevant scientific, policy, and advocacy forums and events.



A defining highlight of 2025 was the exceptional success of our awareness and storytelling campaigns, with PH patients at the center of all our campaigns and social media activities. Following the conclusion of World PH Day 2025 under the powerful slogan “Sometimes, It’s PH”—the most successful WPHD campaign to

date—PHAEUROPE shared more than 70 patient testimonials supported by strong, awareness-focused visuals. The campaign achieved outstanding organic reach and engagement, resonating widely across Europe and the whole world.



The second half of the year proved equally dynamic. Two major campaigns ran in parallel. Through the campaign titled “Without You, There Would Be No Us,” more than 30 patient stories of gratitude were shared, with patients thanking caregivers, family members, friends, healthcare professionals, pharmaceutical companies, associations, organizations, and all those whose support makes living with PH possible. At the same time, PHAEUROPE contributed to the November PH Awareness Campaign under the slogan “Access Means Life.” This original campaign featured 30+ patient testimonials highlighting both progress and ongoing challenges and disparities in access to care and treatment worldwide. Patients from almost all continents participated in our campaign. In November, PHAEUROPE also joined forces with the Pulmonary Hypertension Association (PHA) from the USA, actively sharing their social media materials for their Awareness Campaign and further strengthening transatlantic collaboration during PH Awareness Month.

November was particularly active on PHAEUROPE’s social media channels, coinciding with APHEC 2025 – the Annual PH European Conference, organized by PHAEUROPE in Castelldefels, Barcelona. Over five days, we provided daily coverage of conference activities, capturing key discussions, patient voices, expert insights, and community moments - running in parallel with the PH Awareness Campaign and further amplifying its impact.



Beyond campaigns, our platforms consistently delivered meaningful awareness content throughout the year. This included WPHD Around the World, showcasing activities of PHAEUROPE's member associations; the #goodPHnews series celebrating achievements and positive developments across the PH community; and posts marking key international health-related awareness dates. Through this content, we also regularly updated our audience on the latest developments in drug approvals, relevant clinical trials, and major breakthroughs in pulmonary hypertension diagnosis and treatment, ensuring that patients, caregivers, and advocates remained informed about advances shaping the future of PH care. Together, these



initiatives reinforced unity within our global PHfamily and ensured continuous visibility for patients' efforts and successes across Europe and beyond.

Collaboration remained a cornerstone of our social media activities in 2025. PHAEUROPE joined the Pulmonary Vascular Research Institute (PVRI) in developing and promoting their Patient Engagement & Empowerment Series, actively supporting the dissemination of patient-focused educational content across our platforms. We also partnered with the Global Allergy & Airways Patient Platform (GAAPP) in marking World Chronic Disease Day and World Lung Day, contributing to global awareness efforts that highlight the broader impact of chronic and respiratory diseases.

These sustained efforts resulted in a record-breaking social media performance in 2025. Across all social media platforms combined, PHAEUROPE achieved 9.4 million total impressions, 83,669 content interactions, and reached a community of 20,123 followers. Platform-specific results further highlight this success:

- FACEBOOK:**
  - 7.6 million total views
  - 69.7K content interactions
  - 1.6K new followers
- INSTAGRAM:**
  - 1.4 million reach
  - 5.5K content interactions
  - 387 new followers
- LINKEDIN:**
  - 127,000 impressions
  - 6,688 reactions
  - 145 comments
  - 122 reposts

Compared to previous years, nearly all key metrics showed significant growth, reflecting the strength of PHAEUROPE's patient-centered approach, compelling storytelling, and consistent engagement with the PH patient and scientific community.



As 2025 concludes, PHAEUROPE remains firmly committed to using its social media platforms as spaces of unity, advocacy, and hope—amplifying patient voices, highlighting breakthroughs in treatment and care, and reinforcing the message that access means life. Guided by a clear vision and supported by a strong and dedicated social media team, PHAEUROPE will continue to build on these achievements, further improving how PH patients, member associations, and advocates are represented online.

PHAEUROPE's social media team, led by Maleen Fischer, looks forward to the year ahead with confidence and determination, continuing to reflect the strength, resilience, and winning spirit of PH patients across Europe and beyond. To conclude, this year's results and success would not have been possible without you – PH patients and PHighters. Thank you for your support and courage.

*Maleen Fischer and the Social Media Team  
PHAEUROPE – For the Patients*



At J&J, we understand that pulmonary arterial hypertension (PAH) comes with many challenges, and not all are physical.

That's why we've created PH Human – an educational programme dedicated to empowering people living with PAH to help understand their condition and engage in their care, bringing loved ones and caregivers along on their journey.

Whether you are looking for tools to support productive conversations with your healthcare team like our **Breathe In, Speak Out Conversation Kit**, interested in understanding the standards of care you should expect to receive through our **PAH Patient Charter**, or you are simply searching for tips and tricks to **live well with PAH** – PH Human has a variety of resources and real-life experiences available to empower you to play an active role and make informed decisions in your care.

Find out more on  
**PHuman™**



**Hollie, 37**  
United Kingdom  
Entrepreneur  
Living with pulmonary arterial hypertension

CP-561853 | January 2026

Janssen Pharmaceutica NV © JP NV 2022.

# Inhibikase Therapeutics

 **GLOBAL ALLERGY & AIRWAYS**  
PATIENT PLATFORM

## Your PH Journey, Empowered.

Discover **PulmonesVitales.com** – your comprehensive guide to living well with pulmonary hypertension. Meet Aura, your digital companion for guidance, education, and support.

[Register now >](#)

 Now I know I'm not alone. I have clear information and a supportive community.  
**Mariana** ★★★★★

\*Available in Spanish. Use your browser translation for other languages.

Supported by  
 **GLOBAL ALLERGY & AIRWAYS**  
PATIENT PLATFORM

Powered by  
 **LHL**  
LIFE HEALTH LEADERS



 **PULMONES VITALES**

Johnson & Johnson



# ARGENTINA

Throughout 2025, HIPUA strengthened its work in information provision, support, and the defence of the rights of people living with Pulmonary Hypertension (PH), implementing actions focused on awareness-raising, education, psychosocial support, health policy advocacy, and territorial outreach. This journey reflects a sustained commitment to empowering the PH community and to contributing to the development of more equitable, accessible, and people-centred health systems.

## WORLD RARE DISEASE DAY

Within the framework of World Rare Disease Day 2025, HIPUA carried out a range of initiatives aimed at increasing the visibility of Pulmonary Hypertension, promoting early diagnosis, and facilitating timely access to available treatments. Actions included a social media communication campaign developed in collaboration with patients and families, featuring educational content on rare diseases in Argentina, as well as participation in the international campaign led by PHA Europe.

In addition, a virtual talk was held with leading specialists, who addressed therapeutic advances, ongoing clinical trials, and the review of common misconceptions surrounding PH. The day concluded with the testimony of a patient, whose personal experience provided a close and meaningful perspective for the participating community.



## RESPIRO2 MAGAZINE

Since 2019, HIPUA has maintained an editorial policy aimed at responding to the demand from patients and families for up-to-date, reliable, and accessible information. Within this framework, the free, biannual digital magazine RESPIRO2 is published as a tool for information, education, and empowerment.

The magazine brings together testimonies from people living with Pulmonary Hypertension alongside contributions from medical professionals of recognised expertise in Argentina, presented in clear and accessible language. During 2025, issues No. 12 and No. 13 were published, reaffirming HIPUA's commitment to disseminating high-quality content that strengthens the active participation of the PH community in their own care.

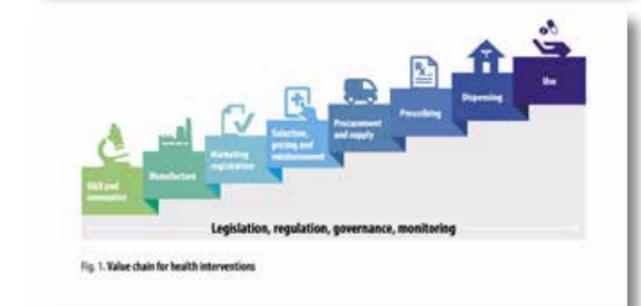
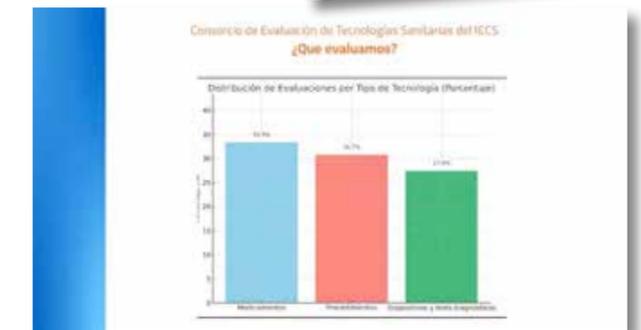


## PARTICIPATION IN TRAINING AND HEALTH POLICY DEBATE SPACES

Throughout the year, HIPUA actively participated in training and reflection initiatives related to health technology assessment and health decision-making.

In April, the organisation took part in a webinar organised by the Institute for Clinical Effectiveness and Health Policy (IECS), focused on the debate around health technologies and coverage decisions within the Argentine health system, in the context of discussions on the creation of a national health technology assessment agency. The event brought together more than 250 participants and fostered plural dialogue aimed at strengthening evidence-based decision-making processes.

HIPUA also participated in a conference organised by ISPOR Argentina, where health, academic, and technical leaders analysed challenges and potential models for the implementation of a national health technology assessment agency, with a focus on equity and system efficiency.



- Si su institución se enfrenta a decisiones relacionadas con:**
- Nuevas tecnologías y tratamientos de alto costo
  - Judicialización
  - Enfermedades huérfanas o catastróficas
  - Aumento de costos sanitarios

- Soluciones basadas en evidencia**
- Se pueden encontrar resultados como:
- Si existen o no beneficios concretos esperables con la aplicación de la nueva tecnología.
  - La comparación de las distintas alternativas terapéuticas en relación a sus costos y beneficios para la patología evaluada.
  - Evaluación de eficacia y seguridad para decisión de cobertura en casos individuales

## PSYCHOSOCIAL SUPPORT: "I TAKE FIVE MINUTES... I TAKE A BREATH"

Since its inception, HIPUA has developed emotional support spaces designed to promote the psychosocial well-being of people living with PH. The workshops are entitled "I take five minutes... I take a breath", held both in person and virtually, and aim to reduce isolation, strengthen self-esteem, encourage the exchange of experiences, and promote peer support networks.

These spaces are designed to help individuals face the disease from an active position, restoring their decision-making capacity and reinforcing their leading role, with an approach centred on life rather than solely on diagnosis.



## TRAINING ON RIGHTS AND ACCESS TO HEALTHCARE

In September, HIPUA participated in a training programme organised by CAEME (Argentine Chamber of Pharmaceutical Specialties), aimed at patient organisations and focused on health rights, therapeutic sovereignty, and responsible prescribing. The initiative enabled reflection on key issues such as access to medicines, freedom of prescription, informed consent, and the use of electronic prescriptions, strengthening HIPUA's institutional approach to patient rights.

## PARTICIPATION IN MULTI-STAKEHOLDER FORUMS

HIPUA was invited to participate in the AmCham Argentina Health Forum, a space that brought together representatives from the public, private, and academic sectors under the theme of sustainable and innovative healthcare. Topics addressed included financing, prevention, innovation, clinical research, and strategic partnerships, highlighting the importance of multi-stakeholder cooperation.



## ACCESSIBILITY AND DISABILITY

During 2025, the Government of the City of Buenos Aires presented the Manual of Good Practices in Universal Accessibility, developed with a rights-based approach and previously discussed within the framework of the Honorary Advisory Committee of COPIDIS, of which HIPUA is a member as a representative of people with visceral disabilities. The document provides guidelines for the design of accessible environments, services, and communications, promoting a more inclusive society.



## BREATHING ACROSS ARGENTINA

"Breathing Across Argentina" is HIPUA's federal programme aimed at reducing regional inequities in access to the diagnosis and treatment of Pulmonary Hypertension. Throughout the year, the initiative was implemented in the Central and Northwest (NOA) regions through meetings with patients, families, and healthcare professionals, visits to healthcare centres, and the distribution of educational materials.

This territorial work made it possible to identify structural barriers, strengthen local networks, support critical situations, and expand HIPUA's institutional presence beyond the metropolitan area, consolidating the programme as a strategic tool for promoting health equity.



**PARTICIPATION IN SCIENTIFIC MEETINGS**

HIPUA participated in the XXI Weekend on Heart Failure and Pulmonary Hypertension, organised by the Argentine Federation of Cardiology. This national scientific meeting brought together specialists from different disciplines to update knowledge and share experiences in the management of these conditions.

**NOVEMBER: PULMONARY HYPERTENSION AWARENESS MONTH**

During November, HIPUA joined the international campaign created by PHA Europe and contributed with the local campaign "Access to healthcare is life", highlighting the persistent challenges in access to early diagnosis, appropriate follow-up, and treatments, based on the voices of patients and families.



**INSTITUTIONAL REPRESENTATION AT COPIDIS**

HIPUA was once again appointed as a full member of the Honorary Advisory Committee of COPIDIS, representing people with visceral disabilities in the City of Buenos Aires, including people living with Pulmonary Hypertension. This appointment, valid until December 2027, reaffirms the organisation's institutional



commitment to the defence of rights and the promotion of equal opportunities, access to education, employment, and independent living.

**FREE SERVICES FOR THE COMMUNITY**

Finally, as it has done uninterruptedly since 2009, HIPUA continued to provide free support, guidance, and counselling services to people living with PH and their families across the country. Through its Legal Department, the organisation also supported cases related to access to treatments, disability certification, and other issues linked to the right to health, including free legal representation when necessary.



**AUSTRIA**

**RECOGNITION – 25 YEARS OF PH AUSTRIA – PULMONARY HYPERTENSION INITIATIVE**



On November 26, the Umbrella Association of Lower Austria Self-Help Groups (Dachverband NÖ Selbsthilfe), with financial support from the Office of the Lower Austrian Provincial Government, and the Austrian Health Insurance Fund (Österreichische Gesundheitskasse), invited guests to the Lower Austria Self-Help State Conference held in the Assembly Hall of the Lower Austrian Provincial Government building in St. Pölten. Representatives of public life honored the chairwomen and chairmen of the self-help organizations for their many years of voluntary service. The program was rounded off by the lecture „Courage to Aim High“ by former ski jumper Thomas Morgenstern.



**MAJOR FUNDRAISING CAMPAIGN VISIT TO THE RESEARCH LABORATORIES OF VIENNA GENERAL HOSPITAL (AKH)**

On June 2, Gerry Fischer and Eva Otter, both from PH Austria, as well as Univ.-Prof. Dr. Irene Lang and her research team, had an appointment with Peter N. Thier at the AKH. During his birthday celebration, which included a short presentation of the Lung Children's Research Association by Maleen Fischer, Peter raised an astonishing amount of money – which he personally doubled. In total, € 12,770,- was raised and handed over to Dr. Irene Lang's PH research team. Peter also had the opportunity to visit the research laboratory on-site and engage in insightful discussions.

**THANK-YOU EVENT – VERGISSMEINNICHT**

On April 23, the annual Vergissmeinnicht Thank- Event was held in the gardens of Schönbrunn Palace, attended by Jacqueline on our behalf. As a gesture of appreciation, the nonprofit partners of the initiative distributed 2,000 forget-me-not seed pots across Austria.



Launched by the Fundraising Association Austria together with the Austrian Chamber of Notaries, the Forget-Me-Not Initiative raises awareness of charitable bequests and inheritance law. Including charitable causes in one's will is a growing international trend, and in Austria, testamentary donations have doubled over the past decade—driven by the wish to leave a meaningful legacy behind.



## YOU ARE NOT ALONE – WE STAND WITH YOU

A POSTER OFFERING ENCOURAGEMENT FOR PATIENTS AND THEIR FAMILIES

PH Austria and AOP Health joined forces to create a shared sign of support for people affected by pulmonary hypertension. The result is the poster "You Are Not Alone – We Are Here for You," designed to encourage patients and their families and to convey solidarity, closeness, and support from both medical professionals and patient organizations.

The poster will be displayed in all specialized PH outpatient clinics across Austria and later in PH clinics throughout Europe, serving as a visible symbol of a strong support network. Heartfelt thanks go out to AOP Health, Mr. Manuel Brenner, and everyone involved in bringing this meaningful project to life.



## INFORMATION DAY IN ST. PÖLTEN

STRONGER TOGETHER WITH PH – A SUCCESSFUL EXCHANGE AFTER A LONG BREAK

The PH-Information-Day returned on April 2025, in St. Pölten, bringing together patients, relatives, and experts. Short lectures on diagnosis, modern therapies, and psychological resilience were complemented by open conversations in a warm, welcoming atmosphere. The strong feedback showed how essential such meetings are for providing knowledge, connection, and hope.

The program covered three key topics: Dr. Helena Schramm spoke about pulmonary hypertension and modern diagnostics, stressing the importance of early, precise detection. Prof. Dr. Julia Mascherbauer presented current CTEPH treatment options and recent medical advances. Clinical psychologist Mag. Johanna Groth focused on psychological resilience, offering practical advice on mindfulness, self-care, and the importance of social support.



## INFORMATION DAY IN GRAZ

On September 12, 2025, PH Austria's Information Day took place in Graz, hosted by Assoc. Prof. Dr. Gabor Kovacs and Univ. OA Priv.-Doz. Dr. Philipp Douschan. After an overview of PH Austria's projects by Eva Otter, Dr. Nikolaus Kneidinger introduced the PH center in Graz and its development.

Prof. Kovacs presented new medications and future perspectives for PH care, followed by Dr. Douschan's update on IRC/ARC and its benefits for patients. Dr. Valentina Basin concluded with insights into her research on the role of sexual hormones in pulmonary hypertension.

The event offered a valuable mix of information, research, and outlooks, ending with shared meals and conversations. Many thanks to our sponsors for making this day possible.



## INFORMATION DAY IN VELDEN

*Informative – highly qualified – well attended – emotional*

These words describe the meeting better than any other. With outstanding speakers such as senior physician Dr. Buchacher from Klinikum Klagenfurt, Univ.-Prof. Dr. Irene Lang, and Univ.-Prof. Dr. Christian Gerges, both from AKH Vienna, we were able to attract excellent speakers who enriched the event.

The presentations covered a wide range of topics – from risk stratification and therapy goals in PH to therapy algorithms in accordance with the recommendations of the WSPH, whose influence of genetics on the treatment of PH was particularly exciting.

A central topic was balloon angioplasty, a promising treatment option for numerous patients.

The Bell Air Center (BAC) platform also found its place in the program, with Hall and Eva vividly explaining the many possibilities of this innovative platform.



## INFORMATION DAY IN VIENNA

The Vienna Information Day on November 15, held at the Arcotel Wimberger, brought together patients, relatives, and interested visitors for the most important PH meeting of the year. After a welcome by PH Austria, leading experts, as Univ.-Prof. Dr. Irene Lang, Univ.-Prof. Dr. Christian Gerges and Dr. Lukasz Antoniewicz, AKH Vienna, presented the latest advances in therapies, emphasizing the need for individualized treatment and early combination strategies. Modern options for CTEPH were also discussed, including surgical, interventional, and medical approaches.

Beyond medical topics, the program focused on everyday life with PH. Lectures on resilience highlighted ways to strengthen mental well-being, while contributions on smoking and e-cigarettes underlined their risks for lung health. Nutritional guidance showed how a balanced diet and fluid management can support the cardiovascular system. By combining scientific insight with practical advice, the event provided participants with knowledge, motivation, and concrete tools for living with pulmonary hypertension.



## MILESTONE GATHERING – PART 1

### FIRST-EVER MEETING FOR PATIENTS ON INVASIVE THERAPY OFFERS HOPE, SUPPORT, AND CONNECTION

For the first time, patients requiring invasive therapy met at a specially organized gathering. The event offered a valuable space for exchange, understanding, and mutual support.

Accompanied by Univ.-Prof. Dr. Michael Freissmuth and Univ.-Prof. Dr. Irene Lang from the University of Vienna, as well as the OrphaCare team, participants received medical insights, practical guidance, and answers to individual questions. The open atmosphere and personal exchange were experienced as deeply enriching and relieving.

The success of this first meeting showed how essential such initiatives are. As the first part of a three-part series, future events will focus on topics such as nutrition, social life, travel, and psychological support—aimed at improving quality of life. Special thanks goes out to OrphaCare for making this gathering possible.



## MILESTONE GATHERING – PART 2

### LIVING WITH A PUMP – BACK IN THE MIDDLE OF LIFE

The second meeting in the series was another memorable afternoon, this time focusing on nutrition and travel with invasive therapy. Many patients shared that, after diagnosis, they withdrew from everyday life—afraid to travel, eat out, or enjoy normal experiences. This series aims to show that living with a pump means staying in the middle of life.



Participants discussed topics like weight gain, diarrhea, digestive issues, and practical healthy eating. Expert tips covered staying well-nourished on the go, medication storage, and smart snacks for long trips. Special thanks goes out to Claudia Englisch for the nutrition input and to Gerry Fischer, Chairman of PH Austria, for the travel talk—both tailored to participants' needs.

Most moving were the personal stories: first trips after diagnosis, overcoming fears, and rediscovering freedom. The message was clear: travel is possible, enjoyment is possible, and life can bring joy again—step by step, together.



## SCIENCE MEETS FUN

PH Austria organized a special event for young members aged 17 to 30, who were invited to attend with a companion. Assoc. Prof. Dr. Christina Binder (AKH Vienna) gave an engaging lecture on “Understanding Echocardiography,” followed by an open Q&A. The positive response was so strong that another meeting is already planned.



After a shared lunch at Hotel Wimberger, the day ended with a highlight: VIP visits to Comic Con Vienna, where participants met stars like Jamie Campbell Bower and Elijah Wood. Thanks to MSD's support, our young members gained valuable medical insights and enjoyed a carefree afternoon.



## 12TH VIENNA ZOO RUN: A GREAT SUCCESS

On June 11th, 2025, around 2,000 runners from over 30 countries took part in the 12th Vienna Zoo Run at Schönbrunn Zoo. The event raised approximately €40,000 for the Children's Lung Research Association and species conservation at the zoo.

Under the motto “Get breathless for PH,” participants completed the 6 km evening run through the zoo, creating a unique and joyful atmosphere. The event also included a moment of silence in remembrance of the tragedy in Graz. The Vienna Zoo Run was made possible thanks to the support of numerous sponsors and partners.

The next Vienna Zoo Run will take place on June 17th, 2026.





# BELARUS

## REPORT ON ACHIEVEMENTS IN 2025

Cardiopulmonology | Pulmonary Hypertension | Transplantation | Cardiology

### OVERVIEW OF ACTIVITIES IN 2025

In 2025, the key areas of professional and informational activity in cardiopulmonology were focused on the following priorities:

- **Pulmonary Hypertension (PH)** — development of modern approaches to diagnosis, risk stratification, and therapy, including innovative pharmacological strategies.
- **Lung Transplantation** — support and coverage of advances in high-technology surgery, particularly in the Republic of Belarus.
- **Cardiology** — integration of cardiological expertise into the management of patients with combined cardiac and pulmonary pathology, including secondary PH and post-transplant patients.

This report reflects the major events, scientific and clinical achievements of 2025, with emphasis on both Belarusian and international experience.

### PULMONARY HYPERTENSION: KEY ACHIEVEMENTS IN 2025

#### SCIENTIFIC AND CLINICAL ADVANCES

In 2025, the field of pulmonary hypertension demonstrated several important developments:

- **Continued progress in targeted PH therapy, including:**
  - combination treatment strategies,
  - early initiation of dual and triple therapy,
  - exploration of new molecular targets.
- **Increased focus on personalized medicine, including:**
  - patient phenotyping,
  - genomic and proteomic approaches,
  - individualized treatment selection based on clinical profiles.
- **Publication and discussion of studies addressing:**
  - pulmonary hypertension following COVID-19,
  - HIV-associated pulmonary hypertension,
  - rare and complex forms of PH, including chronic thromboembolic PH (CTEPH).



### INTERNATIONAL COLLABORATION AND KNOWLEDGE EXCHANGE - MAY 2025

The **5th Moscow Scientific and Practical Conference “Pulmonary Hypertension: Pathways to Ensuring High Quality of Life”** was held.

#### Key highlights included:

- Discussion of modern diagnostic and therapeutic algorithms for PH.
- Presentation of international clinical guidelines and real-world clinical cases.
- Strong emphasis on:
  - interdisciplinary collaboration between cardiologists and pulmonologists,
  - early diagnosis of PH,
  - improvement of patient quality of life and long-term outcomes.

Specialists from the **Republic of Belarus** participated in the conference, strengthening international cooperation and professional knowledge exchange.

### VISUAL AND EDUCATIONAL MATERIALS

Throughout the year, the following materials were actively utilized and disseminated:

- photographs from professional conferences,
- visual schemes of modern PH treatment strategies,
- infographics and clinical trial data,
- educational content for healthcare professionals.



### LUNG TRANSPLANTATION: ACHIEVEMENTS OF THE REPUBLIC OF BELARUS IN 2025

#### KEY CLINICAL MILESTONES

In 2025, Belarus reaffirmed its position as a regional leader in transplant medicine.

- A **successful lung transplantation** was performed in Minsk for a patient from Uzbekistan with combined cardiac pathology.
  - The surgery lasted **over 12 hours** and required a multidisciplinary surgical team.
  - The clinical outcome was positive, and the patient successfully completed postoperative rehabilitation.

In addition:

- **Dozens of lung transplantations** were performed nationwide during the year.
- Active transplantation programs also included:
  - heart transplantation,
  - liver transplantation,
  - kidney transplantation.

#### INFRASTRUCTURE AND TECHNOLOGICAL DEVELOPMENT

The **Minsk Scientific and Practical Center for Surgery and Transplantation** continued its dynamic development:

- expansion of thoracic and transplant surgery departments,
- active use of ECMO technology,
- performance of complex high-technology and combined surgical procedures,
- continuous improvement of postoperative patient management.



### VISUAL DOCUMENTATION

Visual materials included:

- photographs of surgical teams and operating rooms,
- images of patients in the postoperative recovery phase,
- screenshots of national and international media publications.

## CARDIOLOGY: INTEGRATION WITH PULMONARY HYPERTENSION AND TRANSPLANTATION

### ACHIEVEMENTS IN THE REPUBLIC OF BELARUS

In 2025, the cardiology sector demonstrated significant progress:

- expanded access to interventional and diagnostic cardiology services at the Republican Scientific and Practical Center "Cardiology",
- implementation of advanced imaging and functional diagnostic techniques,
- improved quality of care for patients with cardiovascular diseases.

### EDUCATIONAL INITIATIVES

- Ongoing training programs for general practitioners.
- Organization of regional and interdistrict seminars on arterial hypertension.
- Strengthened focus on early detection and prevention of cardiovascular diseases.

### CARDIOLOGY AND PULMONARY HYPERTENSION INTERFACE

Cardiological expertise plays a critical role in the management of PH patients:

- assessment of structural and functional cardiac changes,
- evaluation of right ventricular function,
- optimization of treatment strategies considering cardiopulmonary interactions,
- pre- and post-transplant cardiac management.



### REGISTRATION OF ADEMPAS (RIOCIQUAT)

In 2025, the medicinal product Adempas (riociguat) was officially registered in the Republic of Belarus:

- registered under its international nonproprietary name (INN): riociguat,
- became the third officially registered medication for pulmonary arterial hypertension in the country,
- significantly expanded therapeutic options for PH patients,
- aligned with international treatment guidelines for specific forms of pulmonary hypertension.

The registration of Adempas represents an important step toward improving access to modern PH therapy and enhancing patient prognosis.

### CONCLUSION

The year 2025 marked a significant phase in the advancement of:

- pulmonary hypertension diagnostics and treatment,
- lung and solid-organ transplantation in Belarus,
- integrated cardiology approaches for complex cardiopulmonary patients.

Active international collaboration, implementation of innovative technologies, and registration of new pharmacological therapies have contributed to improved quality of care and strengthened Belarus's position in the field of high-technology medicine.



## BELGIUM



### Stronger Together: Peer Support for Pulmonary Hypertension

*Pulmonary hypertension (PH) is a rare and often invisible disease that weighs heavily not only physically but also socially. Patients frequently face misunderstandings and loneliness. Peer contact offers recognition, support, and connection – no one understands better what you are going through than someone experiencing the same.*

### 1.1 EDUCATION

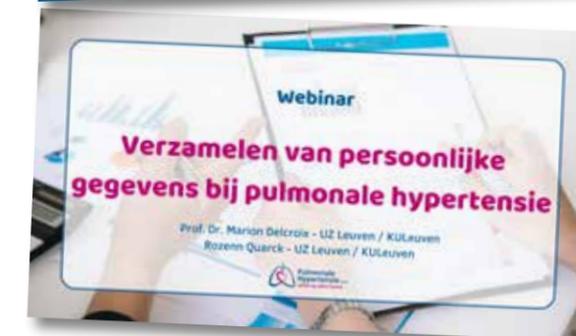
#### WEBINARS

UZ Leuven experts provided clear explanations about what happens with material and data used for research.

- Webinar 1: Collecting biological material
- Webinar 2: Collecting data

#### PH-PIP PROJECT

Together with HTAP Belgique and PEC, we are developing sustainable educational material. First results will appear in 2026.



### 1.2 ADVOCACY AND AWARENESS

#### PROJECT: DE WARMSTE WEEK

Under the theme Loneliness, we expanded our range of peer activities:

- **Small-scale meetings:** coffee, info sessions close to home
- **National family day:** increasing involvement of family and the wider environment.

Peer contact not only strengthens mutual support but also helps bring problems to light and defend patients' interests. Professionally recorded testimonies show you are not alone.



### REGIONAL MEETING DAYS

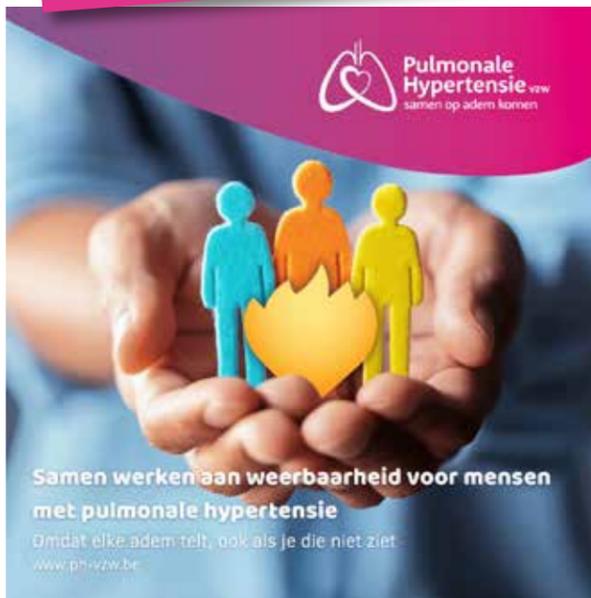
With coffee, treats, and warm conversations, we offered an accessible way to come together. Thanks to tailored transport, even less mobile patients could participate. Around 50 people found support and recognition.

### PH FAMILY DAY

On October 18th, participants enjoyed a boat trip, city visits, and pleasant moments in Vilvoorde and Brussels. It was a day full of connection and lasting memories.

### TESTIMONIES

A series of video testimonies from patients and caregivers openly share experiences, strength, and hope. These digital stories connect people and break through loneliness.



## 1.3 ACTIONS FOR A GOOD CAUSE

### PLAYMOBIL BY THE SEA EXPO

During the Playmobil by the Sea expo in Ostend, organized by Connect to Smile vzw, we raised €4,000. Visitors learned more about pulmonary hypertension, measured their lung capacity, and created a figurine. Next year, we will return as the chosen charity.

## 1.4 SUPPORTING SCIENTIFIC RESEARCH

### STRONGER TOGETHER FOR RESEARCH

Thanks to these actions and donations, we were once again able to donate €5,000 to KU Leuven for fundamental research into PH. In this way, we contribute step by step to better treatments – and hopefully one day, a cure.

**Key Message:** Peer contact, education, and collective actions make a real difference. Together, we break loneliness, strengthen the community, and support research.



Belgian patient association for pulmonary hypertension vzw (P.H. Belgium) - Kruisbeeldstraat 28, 9220 Hamme  
 BE 0475 321 180 - RPR Ghent, Dendermonde division  
 BE04-0682-3239-3031 - www.ph-vzw.be - info@ph-vzw.be



# BOSNIA AND HERZEGOVINA

## WE WILL NOT GIVE UP THE FIGHT FOR OUR LIVES

Another dynamic and intense year is behind us. The members of the Association of Citizens Suffering from Pulmonary Hypertension "Dah" in Bosnia and Herzegovina were also very active and very successful throughout 2025 in raising awareness of pulmonary hypertension in our country. This is evidenced by the numerous activities in which we were involved, as well as the great interest shown by the media in what we do. It is truly very difficult to list everything, and even harder to summarize it in a few journalistic columns.

## FOCUS – A BETTER POSITION FOR PATIENTS

Our activities each year begin and end with the marking of significant dates for ill and disenfranchised patients in our country, among whom are PH patients. At the very beginning of the year, we participated in the work of the Assembly of the Federation of Bosnia and Herzegovina Alliance for Rare Diseases, and in the second month we marked Rare Disease Day – RDD 2025, while in the last month of 2025 we marked the International Day of Persons with Disabilities. These events were realized in cooperation with alliances and associations whose focus is on patients who are denied some of their basic rights. The situation in this field does not change significantly. Year after year, we draw the public's attention to all the shortcomings of our healthcare system, pointing out the problems faced by people suffering from rare diseases such as pulmonary hypertension, or persons with disabilities, among whom are again those affected by this severe, rare, and incurable disease. We use every opportunity to present our proposals for resolving the accumulated problems due to which the weakest among us suffer. What hurts us the most is the fact that PH patients in our country do not have the same status or access to therapies, and that this depends solely on their place of residence.



This devastating fact is something we must change, because it is absurd that we live in the same country, suffer from the same disease, yet some patients have at least initial, basic therapy covered by the state, while others, apart from diuretics, have to purchase everything themselves. This is something we do not want to remain silent about and which is always the focus of our public appearances at such events.



We also had the opportunity to speak about our activities, our struggle, and the position of people suffering from pulmonary hypertension at the 2nd Annual Meeting of the GAAPP Regional Alliance of Eastern Europe (EEA). The meeting was attended by a representative of the "Dah" Association, Sabina Hodžić, who had the opportunity to present our Association, point out our problems, our goals, as well as our successes. She presented continuous activities aimed at raising awareness of pulmonary hypertension and improving the position of patients in our country. In addition to presenting news and plans of our Association, Sabina actively participated in discussions with partners, with whom she also agreed on further cooperation.



patients in finding solutions for treatment, research, and access to innovations that would enable patients to be at the center of medical development and decision-making, especially when it comes to pulmonary hypertension, an invisible disease faced by the patients gathered around our Association.

During the year, we also had a number of meetings with representatives of several pharmaceutical companies that showed great interest in our position and problems. Among them, we certainly want to highlight MSD, Glosarij CD, and Nobel, which supported PH patients in Bosnia and Herzegovina through concrete activities and donations, as well as the printing of our new leaflet

and brochure. Throughout all our meetings and encounters, we gained new, sincere allies in the fight for the lives of PH patients in Bosnia and Herzegovina, which gave us a new tailwind, new strength, and determination that giving up is not, and cannot be, an option.

This EEA meeting preceded the holding of the 6th International AAA Congress, which was attended on behalf of the "Dah" Association by Sabina Hodžić and Haris Badžić. On this occasion, they had the opportunity to acquire a range of new knowledge about ways of acting to strengthen the role of



## SPORTS ACTIVITIES FOR A STRONGER PATIENT VOICE

Of course, this year again did not pass without the support of our healthy forces, the professional and recreational athletes, who, through their participation in various events, spread the word about the position of people suffering from pulmonary hypertension in Bosnia and Herzegovina, and in this way, together with us, raised awareness of pulmonary hypertension. During 2025, there were sixteen such events, among which our goodwill ambassador, an outstanding athlete, a runner with an even greater heart, the one and only Enes Ibrahimagić. Nothing can stop our Enes. Perseverance, endurance, sportsmanship, and empathy for the sick and disenfranchised are the basic qualities that drive him and leave us breathless. He proved this through participation in 11 races during 2025 in our country, as well as





in Croatia and Malta, running with the markings of the European PH community, under extremely good but also extremely bad conditions, and through his participation spreading the word about pulmonary hypertension. We are grateful for such an ally, a young man who can be an example to others that through their activities they can always give a stamp of humanity and, in their own way, help in the realization of the goals of those who physically cannot.

In addition to Enes, breathless for PH this year were also other runners from Bihać: the unique Emina Čehajić Gradinović, Amar Čehajić, Anel Rahmanović, and Adnan Skalić, at many races during 2025, as well as Vedran Skulić from Croatia, who ran a 12-hour ultramarathon for PH, running it in Slovenia with PH markings.



We cannot and must not forget the mountaineers from Visoko, Akif Limo, Mahir Koljenović, and Edin Mehanović, who supported PH patients in our country with their ascents of Prenj, a beautiful mountain massif in Bosnia and Herzegovina, and drew the public's attention to our position. These were our first contacts and cooperation, but everything indicates that they certainly will not be the last. The mountaineering society "Visočica" can be proud of its members who dedicated their climbs to those who are breathless and without medication.

Of course, this year again we were not forgotten by our unique Ismet Škulj, who, during the summer, cycled from Bosnia and Herzegovina to Slovenia, spreading the word about our disease, our position, and our struggle. A man with the heart of a lion, resilient and strong, once again this year he showed and confirmed his dedication to the humane mission of raising awareness of pulmonary hypertension along the roads of Europe. Having such support is an indescribable gift, and what these healthy people do to help sick and disenfranchised PH patients in our country is invaluable, which is why great respect goes to all of them. We hope that their support will not be absent in the years ahead!

**Vera Hodžić,**

*President of the Association of Citizens Suffering from Pulmonary Hypertension "Dah" in Bosnia and Herzegovina*



## BULGARIA BSPPH

### WHEN BORDERS DO NOT STOP HOPE

On the 10th of September, Irena Metodieva was officially placed on the lung transplant waiting list in the United States—the first and crucial step toward her survival. Just one month later, on the 17th of October, a new chapter of her life began. After nearly a year of negotiations, the American lung transplant program accepted Irena and gave her a real chance for a future.

Since 2019, access for Bulgarian patients to lung transplantation in European clinics has been almost impossible. However, thanks to the tireless efforts of BSPPH, along with the support of many big-hearted people, a miracle happened—the National Health Insurance Fund approved funding of USD 700,000 for the life-saving operation. For several months now, Irena has been in the United States, preparing for her transplant.

The team led by Prof. Reda Girgis accepted the challenge of taking on Irena's case, despite her coming from Bulgaria. Prof. Girgis is a world-renowned specialist and Head of the Corewell Health Richard DeVos Heart and Lung Transplant Program in Grand Rapids, Michigan.

Today, Irena is feeling well and enjoying her new life, filled with hope. We continue to believe, to fight, and to stand by her side. Because life is the most precious thing we have.



### MARCH OF HOPE

On the 22nd of February, 2025, representatives of BSPPH traditionally took part in a march marking Rare Disease Day. The initiative has been organized for several years now and aims to raise awareness of the challenges faced by patients with rare diseases, as well as to draw public and institutional attention to the need to establish and financially secure a National Programme for Rare Diseases with a horizon to 2035.

The event brought together family members and patients with rare diseases, as well as those who make daily efforts and provide care to ensure that the lives of these patients are fulfilling and dignified. The "March of Hope" seeks to attract public and institutional attention to the needs and problems of people with rare diseases and to place on the public agenda the

necessity of adopting and financially securing a National Plan for Rare Diseases with a horizon to 2035.

Why is this important?

In Bulgaria, nearly 350,000 people live with rare diseases. They face daily challenges related to access to treatment, social inclusion, and professional realization. Through this march, the organizers aim to demonstrate that people with rare diseases are equal members of society and deserve support and understanding.



Joining this global network opens new opportunities for the exchange of experience, joint initiatives, and even stronger advocacy for patients' rights—both in Bulgaria and beyond.

Together with GAAPP, we will continue to fight for: easier access to diagnosis and treatment; the introduction of real and effective forms of home oxygen therapy; making lung transplantation a realistic option rather than a rare exception; and giving visibility to the issues faced by people who often remain “invisible” within the system.

This new step is clear proof that the voice of Bulgarian patients with pulmonary hypertension can be heard strongly and clearly on the global stage.



OTHER NEWS

MORE THAN SPORT: THE BULGARIAN LACROSSE TEAM PLAYS FOR PH AWARENESS

For the first time ever, Bulgaria took part in the European Lacrosse Championship, held from the 10th to the 20th of July, 2025 in Wrocław, Poland. But this wasn't just about sports. The national team played with purpose—proudly supporting BSPPH. By raising their sticks, they also raised awareness for a rare and serious disease that deserves more attention and solidarity. We celebrate Team Bulgaria—not just for their performance on the field, but for standing strong with the PH community.



# BULGARIA PHA

## EMPATHY WITHOUT BORDERS: PHA BULGARIA'S JOURNEY FROM LOCAL AWARENESS TO GLOBAL ADVOCACY

In 2025, in a powerful display of unity and commitment, the Pulmonary Hypertension Association (PHA) Bulgaria has been, once again, committed to raising awareness, fostering empathy, and building a supportive community for those affected by pulmonary hypertension (PH)—a rare and often invisible disease. Through a combination of local initiatives, national conferences, and international collaboration, PHA Bulgaria continues to ensure that no patient feels alone.

After our “Breathing Awareness Into Everyday Spaces Campaign” around World Pulmonary Hypertension Day, which was joined by the rare disease community, we organised our national patient conference.



## A NATIONAL CONFERENCE DEDICATED TO PATIENTS

On October 17-18, 2025, PHA Bulgaria organized the National Conference on Pulmonary Arterial Hypertension in Stara Zagora—a patient-centered event that brought together medical experts, patients, and advocates. Highlights included:

- Medical insights from Dr. Simona Markova on diagnosis and treatment, and from Dr. Diana Lekova-Nikova on PH in interstitial lung disease.
- A moving personal narrative from patient Teodor Oprenov titled “God, Why Me?”
- Psychological support strategies presented by therapist Stanislava Sabeva.
- Advocacy discussions led by Pavlina Grigorova on disability assessment challenges.
- Insights into rare related conditions, such as Tarlov cysts, by Monika Marinova.
- An inspiring recovery story from chairman Todor Mangarov following a thrombendarterectomy.

The conference reinforced the importance of knowledge-sharing, emotional support, and community building in the journey with PH.



### THE TAKEAWAY: EMPATHY IN ACTION

From local gyms to international forums, and from patient gatherings to scientific conferences, PHA Bulgaria’s work demonstrates that empathy is not just a feeling—it is a catalyst for change. By turning understanding into action, the association ensures that every patient’s voice is heard and valued.

PHA Bulgaria extends heartfelt gratitude to PHA Europe and all partners, supporters, and volunteers who make this vital work possible. Together, they are building a more compassionate and informed world—one breath, one conversation, and one connection at a time.



## CROATIA

*The year behind us was exceptionally dynamic, successful, and rich in activities that further strengthened our pulmonary hypertension (PH) patient community, while increasing the visibility and recognition of our work in Croatia and beyond. We are proud to present the key moments, projects, and achievements that marked this year.*

### SUPPORT FROM ZAGREB COUNTY – PROJECT “BLUE WINGS FOR BLUE HEROES II”

We are especially pleased that, for the second year, Zagreb County recognized the importance of our work and once again selected our project Blue Wings for Blue Heroes II for funding. This continued support is a strong affirmation of our commitment, quality, and responsibility toward the patients we represent.

This year, the funds were used to produce an educational and accessible podcast featuring **Dr. Mateja Janković Makek**, a leading pulmonary hypertension expert from the Reference Center at the University Hospital Center Zagreb.

Through a relaxed yet highly informative conversation, we addressed many important topics relevant to patients and their families.

#### Podcast link:

<https://youtu.be/kT-mAx99QqM>

The podcast is available on our website and social media channels and will soon be displayed on the screens of the Bel Air Center in Zagreb, further expanding PH awareness among the general public.

### A HISTORIC MILESTONE – FIRST BPA PROCEDURE IN CROATIA (UHC SPLIT)

This year marked a historic moment for the PH community in Croatia. **The first Balloon Pulmonary Angioplasty (BPA) procedure for a patient with chronic thromboembolic pulmonary hypertension (CTEPH)** was successfully performed at the University Hospital Center Split.

BPA is a minimally invasive endovascular procedure that opens narrowed or blocked pulmonary arteries, improving blood flow and alleviating symptoms in patients with CTEPH. Until now, all Croatian patients had to travel to Austria to access this treatment, which posed a significant additional burden.

Thanks to the dedication and high level of expertise of the cardiology team at UHC Split, this life-changing procedure is now available in Croatia for the first time.



This represents a major step forward for patients, medical professionals, and the healthcare system as a whole—bringing us closer to establishing a national center of excellence for CTEPH treatment.

Our heartfelt congratulations go out to the entire medical team on this outstanding achievement!

### HUMANITARIAN AND ARTISTIC PROJECT “4000 FOR 30” – THE POWER OF ART, UNITY, AND HEART

Significant public and media attention was drawn by the inspiring project “4000 for 30”, led by a renowned photographer and artist from Bjelovar. He cycled 4,000 kilometers, from the Vukovar Water Tower to the Eiffel Tower in Paris.

The journey commemorated an important anniversary in the history of the city of Vukovar and was dedicated to our association Blue Wings (Plava krila). Riding under our flag, he raised funds for our work via the GoGetFunding platform.

Filled with emotion, his photographs of landscapes across Croatia, Slovenia, Austria, Germany, and France reached



thousands of people, spreading awareness of pulmonary hypertension through a unique blend of art and humanitarian action.

On the 19th of December, an exhibition of the most beautiful photographs from the journey will open, with all proceeds from sales dedicated to supporting the work of the Blue Wings association.

<https://www.zvono.eu/vukovar---bjelovar-biciklom--ali-preko-pariza-802>



### AMBASSADORS – OUR DEDICATED RUNNERS “GET BREATHLESS FOR PH”

We are particularly proud of our ambassadors—dedicated runners who participate in races across Croatia and beyond, proudly wearing our “Get Breathless for PH” shirts.

With their enthusiasm, energy, and long-term commitment, they have become one of the most recognizable symbols of support for people living with pulmonary hypertension.

Their presence on race courses increases PH visibility, sparks conversations among citizens and athletes, and connects us with the sports and outdoor community, a community that has always shown us remarkable support.

We are deeply grateful to them for representing us with pride, smiles, and big hearts.



This meeting once again confirmed how collaboration between healthcare professionals and patients directly contributes to improving the quality of life of people living with PH.

### 4TH NATIONAL PULMONARY HYPERTENSION MEETING – MULTIDISCIPLINARY STRENGTH

On the 6th of December 2025, the 4th National Pulmonary Hypertension Meeting was held at Hotel Dubrovnik in Zagreb, once again bringing together leading experts from all Croatian PH centers—pulmonologists, cardiologists, rheumatologists, and young physicians who will carry forward the future care of patients.

The lectures highlighted the importance of a multidisciplinary approach, advances in diagnostics and treatment, and continuous education within the professional community.



### PANEL ON PHILANTHROPY AND GIVING – A STRONG PATIENT VOICE

On the 8th of December 2025, invited by Mladenka Majerić, a fundraising and leadership expert, we participated in a panel discussion focused on the social and legal frameworks for charitable giving in Croatia.

It was an inspiring and meaningful discussion about the challenges of philanthropy in our country, as well as an opportunity to emphasize how crucial systematic support is for the work of patient organizations.

We believe that, in the future, more representatives of public institutions will join these conversations, as lasting change is not possible without their active involvement.

Step by step, through joint efforts, we can strengthen the culture of giving and solidarity in Croatia.





# CHINA

In 2025, Sotatercept became available in Macao and Hong Kong in July, and by the end of the year, conditional approval was also possible in mainland China. For patients with pulmonary hypertension (PH) in China, this expanded treatment options in an important way. Yet, many still face barriers, as national insurance coverage has not yet been secured.

This progress brings both hope and caution. Some patients can now access these new treatments, while others continue to navigate gaps in healthcare resources and support within their communities.

Our community was proud to see Huang Huan, our Director and a former PH patient, who underwent a double lung transplant, representing patients at the Center for Drug Evaluation (CDE) conferences on drug safety and clinical trial design. These invitations highlight a growing recognition that lived patient experience is a form of expertise—and that our daily struggles with PH matter beyond the clinic.



In November, with support from PHA Europe, we participated in the global awareness campaign "Access Means Life." The campaign sparked strong interest among Chinese patients in learning how others around the world navigate access to medications and clinical trials. One participant said, "I hope one day we could talk with them face-to-face." Another shared, "I've met someone with PH on RedNote." These stories reminded us that we are not alone: strength, solidarity, and courage across borders are vital in reducing isolation within the PH community. Compared with five years ago, PH patients in China enjoy improved living conditions overall. Still, challenges remain—especially in rural areas, where limited drug options, shortages of specialized physicians, and uneven expertise continue to shape daily life. As we move into the new year, we look forward to deeper international collaboration and shared learning, helping ensure that progress translates not only into drug approvals but into real, meaningful access and better quality of life for all patients.



# CZECH REPUBLIC

## ACTIVITIES OF THE ASSOCIATION OF PATIENTS WITH PULMONARY HYPERTENSION (SPPH) IN CZECH REPUBLIC - 2025

The year 2025 was exceptionally significant for our Association of Patients with Pulmonary Hypertension (SPPH), as we celebrated the 20th anniversary of our founding, while continuing our core mission of raising awareness and supporting patients.

### REHABILITATION AND RECONDITION STAY

The well-being of our members remains our priority, so the highlight of the year was the week-long rehabilitation and recondition stay in Poděbrady. Poděbrady is a well-known wellness and spa town, famous for its mineral water rich in beneficial minerals. Patients had access to everyday physiotherapy group sessions tailored to their specific needs, providing physical support. Patients could also ask for an individual physiotherapy session if needed. Furthermore, they had the opportunity to use the swimming pool and enjoy swimming.



### THE ANNIVERSARY CELEBRATION: GENERAL MEETING AND TREE PLANTING

Our 20th anniversary was celebrated with a General Meeting, a key moment for reflection and planning, where patients, their families, caregivers, and friends were brought together. We were honored by the presence of the President of the Slovak Pulmonary Hypertension Patients Association (ZPPH), Mgr. Iveta Makovníková and her husband, showing the cross-



border collaboration within the PH community. Respected professors Prof. MUDr. Pavel Jansa, Ph.D. and Prof. MUDr. Pavel Lindner, Ph.D. and representatives of the pharmaceutical companies MSD and AOP, who consistently support our efforts, also honored us with their well-appreciated presence.

Another significant celebration of our anniversary was the planting of a symbolic tree. As November is also considered a Pulmonary Hypertension Awareness Month, it took place on November 26th in Kateřinská zahrada (Catherine's Garden), to raise awareness of this serious disease. The tree symbolizes hope, strength, and solidarity in the fight against PH. It is intended as a peaceful place, where patients can stop, take a breath, and draw strength from it. We can also see the tree as a symbol of large, healthy lungs, helping patients breathe in the moments, when every single breath becomes a struggle.

We feel grateful for the opportunity to celebrate two decades of the work of SPPH, and we are looking forward to continuing our PH path side by side with patients, as well as everything the future brings.



## GERMANY

### THE PULMONARY HYPERTENSION SELF-HELP GROUP WITH HEART AND IQ NOW ALSO ON INSTAGRAM

Recently, the self-help group can also be found on Instagram. As we want to adapt to modern changes and increasing digitalization, we decided that from now on Julia Beese will represent the group on Instagram.

The page is currently being built step by step. Over time, pulmonary hypertension will also be explained there, tips will be shared, and personal patient-to-patient contact will be offered. This allows us to continue reaching each patient where they are and to gain even more visibility in order to inform and support patients, relatives, and anyone interested.

On this platform, everyone has the opportunity to read along, comment, and interact, as the page is publicly accessible to everyone.

Link: [https://www.instagram.com/pulmonalehypertonie?igsh=dW9zYXZ1bDNwOTUx&utm\\_source=qr](https://www.instagram.com/pulmonalehypertonie?igsh=dW9zYXZ1bDNwOTUx&utm_source=qr)



### PHIL – AND HOW HE BECAME THE MASCOT OF “SELF-HELP WITH HEART & IQ”

In February 2017, Daniela Schiel founded the self-help group *Self-Help with Heart & IQ*.



The group photo featured the group's name and the color violet. Violet is the international color for pulmonary hypertension. This is likely because many people with PH develop purple-blue lips due to oxygen deficiency.

A small, slightly chubby zebra also kept appearing in the group's posts and reports.

Medical students are taught: *When you hear hoofbeats, think of horses, not zebras.*

This means that when symptoms occur, doctors are encouraged to first consider common illnesses rather than rare, exotic ones. Unfortunately, this often leads to

patients like us being overlooked, and the time until a correct diagnosis is made is prolonged.

For this reason, the zebra has become the international symbol for rare diseases.

The zebra combined with the color violet is therefore often found in pulmonary hypertension groups.

Just as no two zebras are alike, every PH patient is different. Many doctors have little experience with this rare disease.

The zebra of *Self-Help with Heart & IQ* has a unique distinguishing feature: its right ear is violet.

With this, we say: *We are zebras. We are rare and need special awareness and attention.*

PHiL got his name from the group's co-founder Ralf Schmiedel (†):

**PHiL = Pulmonary Hypertension in Life**

Our sadly deceased PHighter Manuela Lutama (†) gave our mascot its first tangible, cuddly form. Thus, a beloved companion and lucky charm for children and adults living with PH was born.

Our PHighter Ute Dietrich has since perfected PHIL over time. She also adopted the idea of differently colored ears for other rare diseases, helping to spread awareness of these conditions.

This led to the creation of hundreds of zebras—made with great care, detailed handcrafting, and a lot of heart—for patients with rare diseases.



Ute Dietrich, diagnosed with PH in 2018 due to the rare lung disease LAM (lymphangioleiomyomatosis), has made it her mission to raise awareness for rare diseases through public outreach—with a crochet hook.

One of her beautiful zebras even appeared on television in 2024 during the RTL Charity Marathon, where Esther Schweins supported a project for children with rare diseases.



PHIL is also present for all members on the Self-Help with Heart & IQ Facebook page—here in graphic form.

Especially in our group image, he repeatedly reflects current topics, such as keeping distance during the COVID era or highlighting special occasions.

I, Gabriele Köpper, am responsible for the graphic design of PHIL and our group logo.

Diagnosed with PAH and CTEPH in 2013, I am also an administrator of Self-Help with Heart & IQ.

Sabine Rossat also helps raise awareness of the rare disease pulmonary hypertension by applying PHIL graphics to mugs and other everyday items.

And so, the tangible, real-life PHIL and the graphic PHIL stand side by side for all group members—helping hand in hand, just as we do for one another as members of this community.



# HUNGARY

Last year, the main goals of Tüdőér Egylet was to advocate for the people living with pulmonary hypertension (PH), to raise awareness, to educate patients, and to strengthen national and international professional relationships.

## RAISING AWARENESS AND SHAPING MINDSET

### WORLD RARE DISEASE DAY- FEBRUARY

On February 22nd, we participated in the central event of the World Rare Disease Day, which was hosted in Budapest by RIROSZ (Hungarian Rare Disease Alliance) in cooperation with Semmelweis University. Our fellow members also came from the countryside to represent the Association together. With the help of our colorful posters and T-shirts, we addressed many interested people; we distributed information materials, and performed blood oxygen level and pulse measurements.



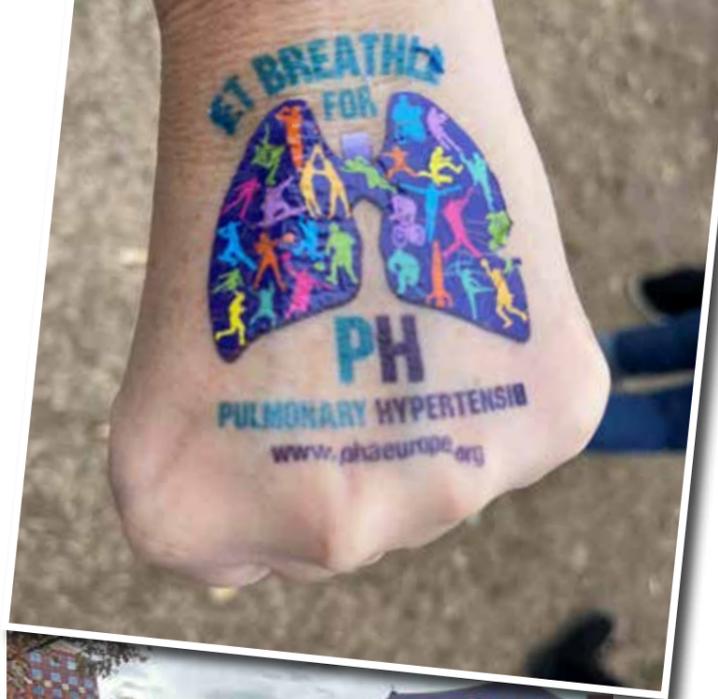
It was a special pleasure to meet with representatives of the National Scleroderma Non-Profit Association, as PH often develops in scleroderma - we also discussed future cooperation opportunities in this regard.



**SPAR BUDAPEST MARATHON- OCTOBER**

On October 11th, as a continuation of our tireless awareness-raising work, we once again participated in the SPAR Budapest Marathon, where PH patients and their relatives walked together 2,300 meters. Everyone looked at our team with appreciation, seeing how determined and cheerful we were.

We started the race with our President, Eszter Csabuda, at the forefront, and Gergely Mészáros, who is a dedicated patient advocate for the PH community, also walked with us. The atmosphere of the race was very motivating. We reached the finish line tired and quite out of breath, but we received the medals very happily.



**BÖRZSÖNY MOUNTAIN HIKE - OCTOBER**

On October 25th, a group of fellow patients and relatives undertook a hike to raise awareness of pulmonary hypertension. Fortunately, it was beautiful autumn weather that day. Young and old alike set off on a hike in the picturesque Börzsöny mountain. They overcame distance, altitude and shortness of breath, and as a reward, the forest dazzled everyone with its colors.



**COMMUNITY PROGRAMS AND LOCAL COLLABORATIONS**

**HEALTH PROMOTION OFFICES**

There are health promotion offices in our country, which aim to shape attitudes, increase health awareness, spread health-preserving behaviors, and organize and conduct health promotion programs. In cooperation with the office operating in our home district, Zugló, we participated in several walks. During these, we had the opportunity to raise awareness of the challenges of the people living with rare diseases and the importance of early diagnosis.



**CIVIL INFO DAY - OCTOBER**

At this event, various NGOs introduced themselves, and we had the opportunity to get to know other associations. In addition, representatives of the Bethlen Gábor Foundation and the National Cooperation Fund (NEA) gave a presentation about the application opportunities.

**PROFESSIONAL AND ADVOCACY REPRESENTATION**

**CONFERENCES AND FORUMS**

**AIPM Conference** – On May 29, 2025, the topics discussed included: pharmaceutical matters and financing, international pharmaceutical industry trends, healthcare digitalization, lessons learned from clinical trials, and the status of national health literacy.

We participated in the “Have a coffee with a Patient Organization” program, the aim of which was to allow professional participants to learn about the work of the associations, their goals, and to create new collaborations. We also built relationships with other civil organizations.



**NATIONAL HEALTH PICNIC – SEPTEMBER**

On the first Saturday of September, we participated in the 1st National Health Picnic, which was one of the most comprehensive public health events in Hungary. We presented interactively what it means to live with shortness of breath: visitors could experience the everyday life of PH patients through simple exercises. We also received several inquiries regarding patient journey management.





**AIPM Meetup** – On September 20th, 2025, we had a great opportunity to meet and network with representatives of other patient organizations, as well as to listen to useful presentations. It was stated here that patient organizations are an integral part of patient care. They are not competitors, but partners with doctors. They help educate patients, reduce the burden on doctors, and support research and advocacy.



**PAH Forum** – On September 12, 2025, high-quality presentations by leading experts from national PAH centers on the latest treatment guidelines.



**Congress of the Hungarian Health Economics Society** - On October 13, 2025, we, together with several other patient organizations, represented the voice of patients on health policy and pharmaceutical subsidy issues. In both, we were assured that hard work is being done to ensure that access to medicines is as smooth as possible.



**ABEP meetings** - We also had the opportunity to participate in a quarterly program (ABEP), where we listened to lectures on various topics useful to patient organizations. These quarterly meetings are organized by the Association of Innovative Pharmaceutical Manufacturers (AIPM), who, this year, also placed great emphasis on maintaining contact with patient organizations and providing assistance. They also provide our Association with the opportunity to appear in a patient organization publication for doctors, which helps to increase awareness of our rare disease and makes the value that the associations create visible.

**APHEC – EUROPEAN PH CONFERENCE**

At the beginning of November, at the invitation of PHA Europe, we attended the annual European PH Conference (APHEC) in Castelldefels, a suburb of Barcelona.

This year's APHEC brought together representatives from 40 member organisations from 35 countries, along with medical experts, researchers and other stakeholders – all united by a common mission: to amplify the voice of PH patients in Europe and around the world.

It is reassuring to see that several pharmaceutical companies are working to ensure that new types of treatment options will be available to people living with PH in the future.



**EUROPEAN RESPIRATORY PATIENT ACADEMY - EFA**

From our association, Dóra Erdélyi was participating in the first **European Respiratory Patient Academy**. This was a fantastic opportunity to build connections with fellow patient advocates, deepen knowledge in several fields, and strengthen advocacy skills in respiratory health.



**COOPERATION WITH OTHER ASSOCIATIONS**

June is Scleroderma Awareness Month, for which we were able to participate in the 20th anniversary national conference of the National Scleroderma Non-Profit Association. Our challenges are very similar and we also desire rehabilitation, nutritional advice and psychological support in addition to medications. Everything that can improve the quality of life.



September is Pulmonary Fibrosis Awareness Month. Our association participated as an invited guest at the doctor-patient meeting of the Hungarian Pulmonary Fibrosis Association, since PH often develops as a secondary disease in people affected by pulmonary fibrosis.



The Hungarian Transplant Federation organized the National Meeting of Transplant Recipients, so called Trapi Days, between 17-19 October.

When PH drug treatments are exhausted, often only a lung transplant can save the patients' lives, so there are several people in our association who are already living as organ transplant recipients.

The 2025 event celebrated a special anniversary: 10 years since the first lung transplant was performed in Hungary. We were delighted that our association was invited to this event, which is the largest Hungarian community and professional meeting of transplant recipients, where doctors, healthcare professionals, transplant patients and their family members share their knowledge, experiences – and stories of restarting life. We were especially honored that our association's activist, Dóra Erdélyi, was able to tell her story about how she, as a patient of a rare disease, who lived with PH, got diagnosed and then underwent the life-saving surgery, as well as her experiences during recovery and what kind of life she can live as a transplant recipient.

To give the audience a sense of what it feels like to be short of breath, each participant was given a nose clip and was asked to listen to the presentation while breathing through a straw. After a few seconds of practice, the room fell silent – because this cannot be described in words, it can only be experienced.



## PATIENT STORIES

In July, our fellow patient, Dóra Erdélyi, shared her story on the public television morning show, drawing attention to the importance of early diagnosis and timely treatment. In her case, medication treatment options were exhausted after a few years and a life-saving transplant saved her life.

In December, she was featured in an article in the magazine *Nők lapja*, where she also told readers about living with PH, transplantation, and recovery.



## INTERNATIONAL CAMPAIGNS

## WORLD RARE DISEASE DAY - FEBRUARY

We joined PHA Europe's global World Rare Disease Day campaign. The visual materials, which we were able to translate into Hungarian and publish on social media, were of great help, emphasizing the importance of early diagnosis and access to care.



## PH AWARENESS MONTH - NOVEMBER

We joined PHA Europe's "Access Means Life" campaign.

We shared personal stories and other information about access to treatment, medicines and proper care, and the desperate consequences that a lack of these things can have for anyone living with this serious, progressive and chronic disease

## APPLICATIONS AND OPERATION

Throughout the year, we continuously monitored national grant opportunities. Although our programs were deemed professionally eligible for support, we did not receive financial support due to a lack of resources. Despite this, we continued our activities with commitment.

## CLOSING THOUGHT

The events of the past year have reinforced our belief that community building, collaboration, and patient voice are essential to improving the quality of life for people living with pulmonary hypertension. Thank you to everyone who joined us – in person or online.

*Eszter Csabuda –Tüdőér Egylet*

[www.tudoer.hu](http://www.tudoer.hu)

<https://www.facebook.com/tudoer.egylet>



## ISRAEL

The final quarter of 2025 has been a season of significant breakthroughs and enhanced support for the pulmonary hypertension community in Israel. From policy victories to digital empowerment, here is a look at our recent milestones.

## A MAJOR VICTORY: SOTATERCEPT JOINS THE NATIONAL MEDICAL BASKET

We are thrilled to announce the successful inclusion of Sotatercept in Israel's national medical basket. This achievement is the result of tireless advocacy to ensure our patients have access to the latest life-altering treatments as quickly as possible.

To support this rollout, the Association has been active on several fronts:

- Navigating Access: We assisted patients in preparing and submitting applications to ensure they receive the medication they need.
- Clinical Feedback: We maintain a continuous dialogue with our partners, providing vital feedback on patient experiences, challenges, and treatment outcomes.
- Holistic Support: Recognizing the anxiety that comes with new treatments, we have established a dedicated support group. Our team provides detailed explanations on administration, side-effect management, and emotional support to create a „sense of calm” for those beginning this new journey.

## EMPOWERING VOICES THROUGH INNOVATION

In our commitment to better serve the community, Association fellow Maayan Steele recently participated in the „Empowering Patient Voices” enrichment program hosted by MSD.

This collaborative training focused on integrating cutting-edge AI tools into patient advocacy. These resources will allow us to streamline our communications, reach more patients, and provide even more effective, data-driven support for the PH community.

## STRENGTHENING THE TRANSPLANT JOURNEY

Navigating the complexities of a transplant is one of the most daunting challenges a patient can face. In partnership with the Israel Lung Transplant Association, we have expanded our specialized support program.

## Our recent efforts include:

- Bureaucracy Management: Developing tools and guidelines to help patients handle the administrative hurdles of the transplant process.
- Medical Roadmaps: Providing clear information on the timing and stages of the medical journey.
- Global Options: Conducting extensive research into the feasibility and timing of overseas transplants for those requiring options beyond our borders.





# ITALY (AIPI)

### ACTIVITY REPORT 2025

2025 has been a year of significant growth and engagement for AIPI, marked by strengthened community connections, expanded educational initiatives, and important advocacy milestones.

### PUBLICATIONS AND COMMUNICATION

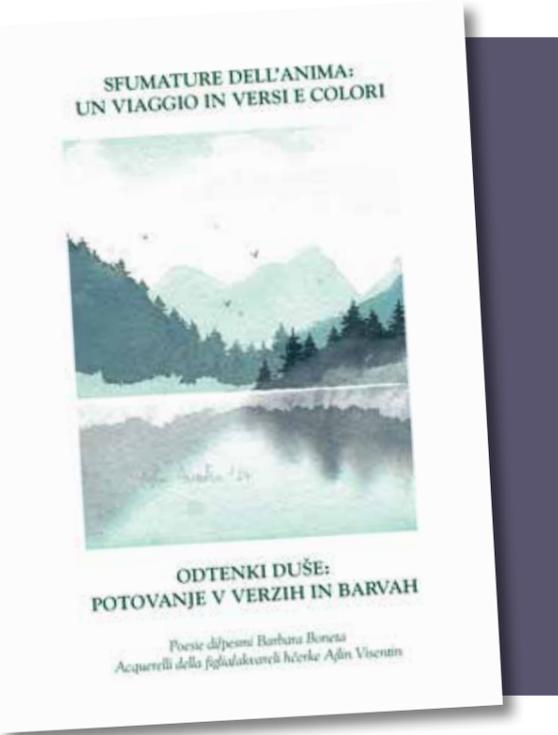
AIPI continued its commitment to keeping the Italian PH community informed through four editions of its quarterly newsletter AIPI News. The newsletter provides comprehensive coverage including the latest developments in the PH field both internationally and at the national level, updates about healthcare policies in Italy which can potentially affect patients (access to drugs, pensions, etc.), patient testimonials, articles submitted by patients on topics of general interest, recipes, and practical advice. This year we featured a number of patient stories that highlighted the diverse experiences and challenges faced by our community members. We also maintain an active presence on social media platforms and participate in social media patient groups, ensuring we reach our community through multiple channels.



In 2025 we also proudly launched a new publication in July 2025, and a second one is due to be issued shortly. The first is a touching collection of poems written by PAH patient Barbara Boneta, from Trieste, illustrated with beautiful watercolor drawings by her daughter Ailjn, a graduate of the Accademia delle Belle Arti of Udine. The publication was presented at two very well attended regional public events, contributing to raising awareness of PH. The second publication, which will be issued shortly, is a collection of patient stories published over the past 12 years in our quarterly newsletter, thoughtfully organized by key themes related to the patient journey.

### DIRECT PATIENT SUPPORT

AIPI provides concrete, hands-on support to patients through multiple channels. Our helplines offer direct assistance and guidance to patients and families in navigating the complexities of PH diagnosis and treatment, as well as practical logistics support such as travel arrangements and accommodation for medical visits to specialist centers. We also provide free legal advice to help patients understand their rights and navigate healthcare, employment, and disability benefit systems. Additionally, we



maintain a presence at the PH clinic at S. Orsola Hospital in Bologna once a week, ensuring patients have access to assistance during their visits.

### PATIENT ENGAGEMENT AND COMMUNITY BUILDING

Our community events brought patients together across Italy. In March, we hosted a patient meeting in Bologna, providing an invaluable opportunity for face-to-face connections and peer support.



Later in the year, a group of transplant patients organised an informal meeting in Udine, addressing the unique needs and experiences of this important patient subgroup. A special highlight of the year was the charity run in Sardinia, organized by one of our Board members, Marika Gattus, demonstrating how local initiative can raise both awareness and funds for the PH community.



### MEDICAL AND SCIENTIFIC ENGAGEMENT

AIPI strengthened its presence in the medical community through several key activities:

- **TRANSPLANT CONFERENCE, VARESE (MAY 15-16):** Our President represented AIPI at a conference organised by the University of Varese, where she was asked to speak on the topic of „Ethics and

communication in transplant: the patient perspective”.

- **NARRATIVE MEDICINE PROJECT, HELSINKI (MAY 29-31):** The findings of AIPI’s innovative Narrative medicine project, launched in 2024, were presented as a scientific poster titled „Application of the Narrative Medicine Palliative Care Model to Enhance Quality of Life in Patients with Pulmonary Arterial Hypertension” by Dr. Daniela Zuffetti, international narrative medicine expert, and our project leader, at the European Association for Palliative Care (EAPC) Congress, showcasing how structured patient stories can enhance medical understanding and care.



- **WORLD SYMPOSIUM FOR PH UPDATES, BOLOGNA (JULY 3-5):** Although our President was unable to attend the WSPH Updates conference in Bologna, we are grateful to Hall Skaara, a fellow PH advocate who is project manager at PHA Europe, who kindly presented her slides on the topic of „Patient empowerment and the role of PROMs from the patient perspective”.
- **ANNUAL PHA EUROPE CONFERENCE (NOVEMBER 5-9):** Marika Gattus, AIPI Board Member, attended the APHEC on behalf of AIPI, and wrote a detailed report for the December edition of AIPINews.

### PROFESSIONAL DEVELOPMENT AND NETWORKING

Recognizing the importance of advocacy skills, AIPI participated in the PH Patient Association Academy, organised by Johnson & Johnson Innovative Medicine, investing in our team’s professional development to better serve our community. We also engaged in networking activities, including an event in Milan (November 13), organised by Patients4Partners and admedicum, aimed at strengthening collaborations with other patient organizations and stakeholders. At the European level, AIPI actively participates in the Alliance for Pulmonary Hypertension’s events and activities, contributing to the broader European PH advocacy community.

### LOOKING FORWARD

These activities reflect AIPI’s commitment to a comprehensive approach to patient advocacy—combining peer support, medical engagement, educational initiatives, and direct patient assistance. As we move into 2026, we continue building on these foundations to better serve the Italian PH community.



# ITALY (AMIP)

## THE ACTIVITY OF THE ASSOCIATION OF PATIENTS WITH PULMONARY HYPERTENSION (AMIP) IN 2025 IN ITALY

This year, AMIP has been involved in various events. In particular, it has represented patients' issues at national and international scientific conferences held in Italy. It should be noted that the association's scientific committee has created the Italian Pulmonary Hypertension Network (IPHnet), which brings together more than 20 Italian hospitals, so at the national level the association to turn to, is us.

Our helplines, one dedicated exclusively to young people, have been ringing continuously... patients asking us for information on living day to day with the disease. We received more than 700 calls. In addition, we have been involved in institutional tables, both regional and national, because in Italy, there is currently great attention being paid to the issues of patients with rare diseases, and we have been able to offer our experience.



But that is not all; we also managed to participate in small local events (theatrical, musical, sporting) that allowed us to raise awareness about the condition and resiliently engage the patients. Unfortunately, the lack of volunteers did not allow us to focus more on what we care about most: organizing doctor/patient meetings in all the Regions. However, we did manage to hold three: one in Verona (Veneto), one in Milan (Lombardy), and one in Palermo (Sicily), which were all a great success.

We continue our daily efforts in favor of the patients, to whom we are managing to make it clear that being part of the European association will give them a stronger voice in all areas.

*Together, we can!*

Vittorio



# JAPAN

PHA Japan organized their 18th National Conference at Keio University Hospital in Tokyo on October 19th, 2025.

The main theme was about new drugs, including sotatercept, which was approved in April 2025.

PHA Japan held an online meeting entitled 'Have you ever heard of cardiac rehabilitation?' on January 17th, 2026.

As cardiac rehabilitation was permitted for PH patients in 2024, and would be covered by the National health insurance in Japan, we were excited to notify PH patients about this good news.





## LATIN AMERICA

### SOCIEDAD LATINA DE HIPERTENSIÓN PULMONAR - NEWS FROM COLOMBIA AND BEYOND

We are sharing images from our 10th Summit of Leaders of the Pulmonary Hypertension Patient Organizations, held in Medellín, Colombia.

Over the course of three days, we carried out a Summit unique in its kind in Latin America, commemorating the 20th anniversary of the Latin Society of Pulmonary Hypertension and its ongoing work for Pulmonary Arterial Hypertension (PAH) across the region. This important event took place within the framework of the Asoneumocito Medical and Scientific Congress of Colombia, with the participation of representatives from 13 countries and 16 patient organizations.

The program included:

- Scientific updates on pulmonary hypertension
- Leadership and advocacy training
- Management techniques for chronic respiratory diseases
- Exhibition of medical devices used in PAH treatment
- Leadership development workshops
- A visit to a PAH reference and research center

The training was key to strengthening leaders with both technical and human vision, and the networking with



physician researchers brought science closer to the patient's reality, fostering collaboration and better healthcare decisions. Strengthening the Latin American Pulmonary Hypertension Network consolidates a strong regional voice that directly impacts patients through more timely diagnoses, improved care, greater access to reliable information, and a more effective defense of their rights and quality of life.

On the fourth day, the Summit concluded with the "Race for Air" Athletic Run, promoting awareness and unity around respiratory health.

This Summit was supported by and benefited from the participation of leading physicians and researchers in pulmonary hypertension from Colombia and across Latin America.

#LATAMRESPIRA




## LATVIA

### BREAKING BARRIERS THROUGH ART AND AWARENESS: PHA LATVIA'S IMPACTFUL 2025



#### PHOTO EXHIBITION "THE SOUND OF THE FLOWERS"

Throughout 2025, PHA Latvia excelled in its public outreach and education efforts, making a lasting impact through a series of successful events across Latvia. One of the most notable highlights is the photo exhibition "The Sound of the Flowers", which will continue into 2026 due to high demand from various public institutions and businesses wishing to host it on their premises.

In May 2025, three photo sessions took place in Riga, involving a team of artists and 10 individuals with disabilities, including those with various forms of pulmonary arterial hypertension. This creative work culminated in the exhibition "The Sound of the Flowers", a photographic series aiming to raise awareness and celebrate beauty. The official opening ceremony of the exhibition was held on August 20, 2025, at "Galerija Centrs" in Riga. The event featured addresses from key figures, including The Chief Rare Diseases Specialist Prof. Andris Skride, and State Secretaries from both the Ministry of Welfare and the Ministry of Culture. One of the photo models and PAH patient, Arina Bazarbajeva, noted during the opening ceremony that it is crucial to recognize and understand "invisible disabilities". She emphasized that people with functional impairments are equal members of society who can live and work just like everyone else.

Ieva Plūme, the head of PHA Latvia and the exhibition's producer, explained the vision behind the project: **„With this art project, we wanted to break the stereotypes dictated by beauty and fashion standards. Our goal was to showcase not the diagnosis or weakness, but rather the personality, beauty, and human qualities of each model.“**

The exhibition received significant national media coverage, featuring prominently on the news broadcasts of two major national TV channels and in national radio news. Throughout the autumn and winter of 2025, the exhibition traveled and was displayed in various Latvian regions, even in very remote regions. **Since August, the series has been viewed by approximately 8,000 residents and tourists.**

To complement the exhibition, a series of ten short videos has been released on PHA Latvia's social media channels, offering a behind-the-scenes look at the journey and personality of each photography model.

The creative team of this project include: producer and author of concept Ieva Plume, photographer Agnese Zeltina, florist Antra Pugaine, stylist Lolita Graudina, and video operator Karlis Grebzdze. This project was financially co-funded by the European Social Fund Plus and the State of Latvia, alongside supporters of PHA Latvia.

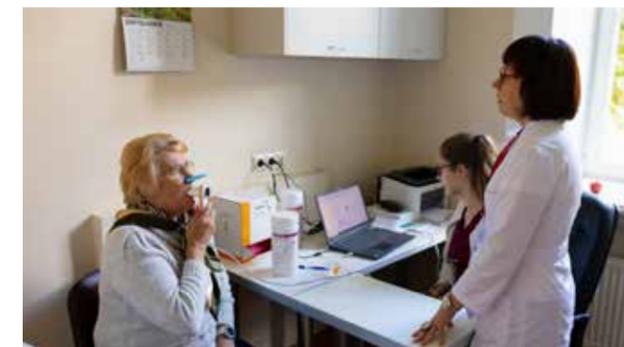


#### 4TH OXYGEN FESTIVAL MARKS WORLD LUNG DAY 2025

In celebration of World Lung Day 2025, the 4th Oxygen Festival took place on September 25th at the Riga 1st Hospital, welcoming 64 participants. The festival offered a comprehensive program focused on health and community support. Attendees had the opportunity to network, gain useful advice on pulmonary health, and attend a lecture by Dr. med., Prof. Andris Skride, who discussed the latest global treatment methods for pulmonary arterial hypertension. Dr. Skride's lecture is also available on the



organization's YouTube channel. Participants of the event actively engaged in health monitoring and physical activities, including the 6-minute walking test, pulmonary spirometry, and guided exercise and movement sessions. The event concluded with a creative workshop titled „My Autumn Taste”, where everyone prepared their own personalized spice blend. The 4th Oxygen Festival received financial support from the Society Integration Fund from the State Budget of Latvia, alongside contributions from various corporate sponsors.



#### MEDIA PRESENCE AND COMMUNITY CONNECTION

PHA Latvia successfully engaged in widespread national and regional media coverage, resulting in a public reach of over 350,000 people. PHA Latvia's mission was highlighted in four national television features, including a notable live appearance on the TV3 Morning Show and specialized features on the National news broadcasts. The conversation continued on the airwaves with ten radio appearances, ranging from in-depth discussions and news reports to an intimate personality portrait of PHA Latvia President Ieva Plume on the popular broadcast “Monopols”. Beyond broadcast media, the campaign's impact was further bolstered by 13 digital and print publications.

These included three major national features exploring life with PAH and individual patient stories, as well as eight regional reports that brought local attention to the “The Sound of the Flowers” exhibition and the “Wellbeing Walkings” initiative.

Parallel to this public outreach, keeping the community internally informed and connected remained a top priority. Throughout the year, PHA Latvia curated and distributed twelve monthly newsletters, ensuring members received consistent support and updates. To remain transparent and accessible to the wider public, these resources were also published as a digital archive on the PHA Latvia website: <https://www.phlatvia.lv/lv/veskopu-2025/>.





### ADVOCACY: SHAPING THE FUTURE OF PATIENT CARE

In addition to its public outreach, PHA Latvia was deeply committed to advocacy throughout 2025, actively shaping healthcare policy and support systems. The association submitted eight key documents to national institutions, focusing on critical improvements, such as state-funded rehabilitation and physiotherapy for PAH patients within the National Rare Diseases Plan 2026–2027. Further proposals were made to ensure state-funded pneumonia vaccinations for this specific patient group, alongside expert opinions on regulatory amendments concerning drug distribution and the enhancement of the adult disability system.

This influence was reinforced by PHA Latvia's active participation in 20 high-level sessions and working groups. These included meetings with the Parliament's Social and Labor Affairs Committee, the Subcommittee on Public Health, and the Ministry of Health. By participating in the National Rare Diseases Mirror Group and the working group for the upcoming National Rare Disease Plan, the association ensured that the voices and needs of PAH patients remained a priority at the highest legislative levels. On November 26, 2025, Ieva Plūme participated in a public discussion hosted by the State Medical Commission for the Assessment of Health Capacity and Working Ability. During the session, she voiced a critical perspective regarding the systemic gaps and the unmet needs of people with disabilities in the country.



The association's work is also grounded in evidence-based research. In 2025, a significant study titled „Social and Emotional Aspects of Pulmonary Hypertension” was conducted, providing a vital comparison with 2019 data. The findings, which were published on the association's website, were shared directly with Members of Parliament of Latvia and the Ministry of Health to highlight the real-world challenges patients face.

### INTERNATIONAL COOPERATION

In 2025, PHA Latvia significantly expanded its international presence through participation in European forums. From May 22nd to 24th, PHA Latvia's President Ieva Plūme and volunteer Ieva



Araja attended the **EURORDIS Annual Conference** held in Riga, which brought together rare disease advocates from across Europe to share expertise and advocate for patient-centered policies.

The commitment to international growth continued in November, as Ieva Plūme and Ieva Araja represented the association at the **PHA Europe Annual General Meeting and Conference** from November 5th to 8th. During this summit, they established closer ties with Northern European PH organizations, laying a strong foundation for future collaborative projects and cross-border initiatives aimed at improving the lives of those living with pulmonary hypertension.

### SUPPORT AND WELLBEING OF PATIENTS

Beyond policy and research, PHA Latvia remains dedicated to providing direct, personal support to its community. Throughout the year, the association delivered **43 help-line** consultations, offering guidance to PAH patients, their families, and individuals living with rare lung diseases, ensuring that no one had to navigate their journey alone.

Recognizing the vital role of physical health and emotional resilience, the association organized a series of **five therapeutic walks** led by a professional physiotherapist during the summer. These walks took place across five different regions of Latvia, bringing together a total of **147 participants**, including PAH patients, and people with various disabilities, to promote movement and social connection in a supportive environment. The “Wellbeing Walkings” initiative was supported by the European Social Fund Plus and the State of Latvia.

The year culminated in the “**Christmas Taste 2025**” celebration on December 13th — a heartwarming event led by the patients themselves. The festivities were opened by PHA Latvia Board member Linda Romanovska, whose moving and emotional wishes set the tone for the day. The community welcomed special guests from the „Santa Claus Academy,” who arrived with gifts provided by the PHA Latvia and our partner, the „Meness aptieka” pharmacy network. In a joyful tradition, guests received surprises by reciting festive Latvian folk beliefs. The celebration continued with featuring team relays, creative tasks, and dancing to favorite songs. Members enjoyed a rich holiday feast and a „sparkling” atmosphere of shared joy. A highlight of the day was a vibrant workshop led by PHA Latvia member Zane Lazdina,



where participants learned to create delicious, healthy, and colorful smoothies using all-natural ingredients, proving that a wellness-focused lifestyle can be both beautiful and tasty.

### STRENGTHENING ORGANIZATION: GROWTH AND STRATEGIC VISION

The association's work was carried out by three staff members and supported by seven volunteers, who contributed their time and expertise to the association throughout the year 2025. Their commitment remains a cornerstone of PHA Latvia's ability to reach and support the patient community.

A pivotal moment for the organization's future occurred during the **PHA Latvia Annual General Meeting** on August 16th, 2025, where members gathered to review achievements and set new goals. Most significantly, the meeting saw the establishment of the **Strategic Plan for 2026–2028 of organization**, a comprehensive roadmap designed to guide the association's



mission over the coming years. This strategic document is now publicly available: <https://www.phlatvia.lv/lv/merki-un-uzdevumi/> outlining the middle-term objectives for patient advocacy and support.

In 2025, the association also successfully implemented several high-impact projects backed by national and international funding. This included the “Support Program for People with Disabilities and Seniors,” a vital initiative co-funded by the European Union Social Fund Plus and the State of Latvia. Additionally, the project “Breath in One Rhythm!” was realized with the support of the Society Integration Foundation, further strengthening the bonds within the community and ensuring that the voice of PAH patients continues to be heard across all levels of society.

*Ieva Plūme,*  
**President of PHA Latvia**  
<https://www.facebook.com/phlatvia>  
<https://www.instagram.com/phbiedriba/>



# THE NETHERLANDS

## SUMMARY OF ACTIVITIES OF THE DUTCH PULMONARY HYPERTENSION FOUNDATION 2025

### REFLECTION ON THE DUTCH NATIONAL PH INFORMATION DAY

#### THEME: STRONGER TOGETHER

On Saturday, the 22nd of November, the Dutch Pulmonary Hypertension Foundation hosted its annual National PH Information Day in Nijkerk. With around 190 participants — patients, family members, physicians and nurses — the event once again proved to be an important moment for connection, learning, and support within the PH community.



#### A POWERFUL OPENING

The day was introduced by host Arieke van Liere, who used a simple ball of yarn to visualise the theme “Stronger Together.” As the yarn moved through the room, it symbolised how each person’s life thread can twist, stretch, or even break — yet becomes stronger when connected with others. It was a memorable and meaningful start that set the tone for the rest of the programme.

Louise Bouman, chair of the Dutch association, welcomed all attendees and emphasised how the presence of so many people shows the strength and resilience of the PH community. By the end of the day, that feeling had only deepened.

#### UPDATES IN TREATMENT: SOTATERCEPT, SERALUTINIB AND IMATINIB

Pulmonologist Dr. Jurjan Aman (Amsterdam UMC) provided an accessible overview of the latest developments in PH treatment. He focused mainly on sotatercept, a promising new therapy currently being studied. Unlike existing medications, which primarily dilate the

blood vessels, sotatercept targets the underlying cause: thickening of the vessel wall.

Although study results are encouraging, Dr. Aman emphasised that this is not a “miracle drug.” Not all patients respond equally well, and important questions remain about long-term safety and future reimbursement. At this stage, sotatercept is available only within clinical trials.

He also highlighted two additional investigational treatments aimed at reducing vessel-wall proliferation:

- **Seralutinib**, an inhaled therapy
- **Imatinib**, now being reassessed with a modified dosing strategy

Together, these developments offer a glimpse of new treatment pathways for the future.

#### UNDERSTANDING LOSS AND GRIEF

One of the most impactful sessions came from renowned grief expert **Prof. Dr. Manu Keirse**, who spoke passionately about the many dimensions of loss. Without slides or notes, he held the audience spellbound.

Prof. Keirse explained how loss affects everyone differently: patients may mourn the loss of future expectations; families may grieve the life they once shared; healthcare providers may feel they couldn’t do enough.

With vivid examples and gentle clarity, he showed how understanding grief helps people support one another more compassionately. Many attendees recognised their own experiences and shared them afterwards — a moment of genuine connection.



#### THE INVISIBLE LOAD OF PARTNERS

Author and caregiver advocate **Jessica van Hooff** led a session on the emotional and practical burden often carried by partners of people living with a chronic illness. Drawing on interviews from her book *De Partner*, she highlighted the need for greater recognition and support for partners, who often balance care, work, emotions, and daily life.

She encouraged open communication, seeking help early, and acknowledging that illness affects both the patient and their loved ones.

#### PH BASICS AND REHABILITATION INSIGHTS

For those newer to PH, Thys Mulder provided a clear introduction to the condition, explaining the different forms of PH, how symptoms emerge and what treatment options exist.

In another session, patient advocate Charlot van der Ven-van der Leest, physiotherapist Maryse Lamers, and treatment coach Sonja Willems shared insights into the rehabilitation programme at Radboudumc. Charlot’s positive, motivating story — including how she inspires others online — left a strong impression on the audience.



#### A DAY OF CONNECTION AND STRENGTH

As the afternoon came to a close, participants left with new insights, shared experiences, and meaningful conversations. The message of the day was unmistakable: **being together makes us stronger.**

#### THE PATIENT PERSPECTIVE IN PH CARE

In 2025, Louise Bouman, President of the Dutch Pulmonary Hypertension Association, shared the patient’s perspective at several key events, both national and international.

At the **IMPAHCT Symposium** in Barcelona, she highlighted the importance of early diagnosis and collaboration between patient organisations and healthcare professionals to improve patients’ quality of life — beyond medical treatment alone.

During **Innovation for Health 2025** in Rotterdam, Louise emphasised that true innovation must solve patients’ daily challenges.

“Healthcare is not just about surviving, but about living well. Medications should improve both life expectancy and quality of life.”



At an **ERS Industry Session in Amsterdam**, Louise and Gergely Meszaros (ERN-LUNG) stressed the value of patient-reported outcomes, simple human questions in consultations, and shared decision-making. Clinicians acknowledged challenges, such as time pressure and incomplete questionnaires, but agreed that listening to patients is essential for care that truly fits their lives.



During the **ERS Onsite Course – PH Academy**, Louise shared her personal journey with PAH, illustrating the long road to diagnosis, the daily impact, and what matters most in care. Key messages included: listening beyond symptoms, understanding the patient’s context, and early referral to expert centers.

At the **EMEAC Virtual Industry PAH Symposium**, Louise described how multidisciplinary teams, PH nurses, and patient organisations transform care: “Patient organisations turn individual experiences into collective strength — transforming the patient voice into action, progress, and better care.”

Across all these events, Louise demonstrated how the patient perspective strengthens collaboration, guides meaningful innovation, and ensures that PH care is truly patient-centred. Listening, understanding, and early action can make a profound difference in the lives of people living with PAH.

### CONSULTATION PREPARATION CARD: HELPING YOU FOCUS ON WHAT MATTERS MOST

People with pulmonary hypertension don’t only want to live longer — they want to live well. To support meaningful, patient-centred consultations, the Pulmonary Hypertension Foundation (Netherlands) has created a simple tool: the Consultation Preparation Card.

This one-page card helps you capture what truly matters before your appointment:

- your key questions
- current concerns or symptoms
- changes since your last visit
- your goals for daily life and wellbeing

Bringing the card to your consultation ensures your priorities are heard, even when time is limited.

You can download and print the card for free. No printer? Request a tin with 25 pre-printed cards by emailing: [info@stichtingpulmonalehypertensie.nl](mailto:info@stichtingpulmonalehypertensie.nl)

Better preparation leads to better conversations — and care that supports not just life itself, but the quality of living.

### THE DUTCH PULMONARY HYPERTENSION FOUNDATION AND PH IN THE MEDIA

#### 1. PAH: THE INVISIBLE DISEASE WITH MASSIVE IMPACT

Pulmonary arterial hypertension (PAH) is rare and invisible, yet its impact is enormous. Rob van der Aa, diagnosed at six, shared how fatigue, shortness of breath, and appearing “healthy” mask a



challenging daily reality. A 2024 lung transplant offered a second chance, though recovery was both physically and emotionally demanding.

Prof. Dr. Anton Vonk Noordegraaf highlights the social and psychological strain on patients and families. Early diagnosis is crucial, as timely treatment can slow disease progression and improve outcomes. Awareness and



understanding—within healthcare and society—make a real difference in helping patients live fuller lives.

#### 2. RARE DISEASE CAMPAIGN: INTERVIEW WITH DR. MENNO DOUWES AND LOUISE BOUMAN

PAH is a progressive lung disease that profoundly affects daily life. Louise Bouman, diagnosed in 2008, and Dr. Menno Douwes emphasize the importance of early recognition and intervention. Louise describes constant fatigue, breathlessness, and balancing medication with daily activities. For children with PAH, missing school or sports is a frequent challenge.

Despite these limitations, Louise stresses resilience and creativity:

“Even with PAH, it’s important to enjoy life. An electric bike lets me keep cycling — something I refuse to give up.” Early diagnosis, supportive care, and moments of normalcy are invaluable for patients and families alike.

#### 3. STRENGTHENING THE PATIENT VOICE IN DRUG DEVELOPMENT

Louise Bouman, Chair of the Dutch Pulmonary Hypertension Association, advocates for patient involvement in medicine development through the EUPATI NL programme. She ensures rare disease research reflects real patient needs.

“Collaboration with international networks is essential. For rare diseases, phase 3 studies require global participation to include enough patients.”

By connecting patients, researchers, and clinicians, Louise helps transform individual experiences into actionable insights, shaping treatments and policies that truly address the realities of living with PAH.

#### SCIENTIFIC ADVISORY BOARD: STRENGTHENING RESEARCH WITH PATIENT IMPACT

As the Dutch Pulmonary Hypertension Foundation continues to professionalise, it has established a **Scientific Advisory Board**

to support a transparent and high-quality research funding policy.

The board currently consists of **Dr. Anco Boonstra**, retired pulmonologist with long-standing experience in PH care, and **Dr. Michiel Alexander de Raaf**, former PH researcher and now alderman and deputy mayor. Both bring strong scientific expertise and a deep personal commitment to the PH community.

The advisory board independently reviews research grant applications and provides recommendations to the foundation’s board, which makes the final funding decisions. A key focus is patient impact — particularly studies that aim to improve quality of life for people living with PH.

By supporting meaningful research and guiding young investigators, the Scientific Advisory Board ensures that patient-funded research truly reflects patient priorities. As both members emphasise: it may be a small contribution compared to large funding bodies, but it plays a vital role in driving progress that matters most to patients.

#### EMBEDDING THE PATIENT PERSPECTIVE IN MEDICINES DEVELOPMENT

Appropriate care is impossible without the patient perspective. With the launch of the Dutch Patient-Centred Collaboration on Medicines (PSM) platform, patient organisations and pharmaceutical companies are working together to structurally embed this perspective throughout the entire life cycle of medicines.

The Dutch Pulmonary Hypertension Foundation has joined this initiative, which aims to build an open and equal partnership between stakeholders. Until mid-2026, participants will jointly explore the current state of patient involvement, identify areas for improvement, and develop practical solutions — starting with the new EU Health Technology Assessment (HTA) process. This first phase will result in shared insights, a practical framework, and concrete recommendations to ensure that patient input becomes a standard and meaningful part of medicines development and evaluation.





# NIGERIA

## CARDIAC COMMUNITY ADVOCACY AND SUPPORT INITIATIVE ACTIVITIES

In November 2025, Cardiac Community Advocacy and Support Initiative implemented a Pulmonary Hypertension (PH) awareness campaign titled “PH No Be Joke” to commemorate Pulmonary Hypertension Awareness Month.

“PH No Be Joke” is a Nigerian expression meaning “Pulmonary Hypertension is not a joke.” The campaign was designed to emphasize the seriousness of the condition and the urgent need for greater attention, early diagnosis, and improved care for people living with PH in Nigeria.

The campaign highlighted real-life patient stories, focusing on the daily challenges faced by individuals living with pulmonary hypertension in Nigeria. A recurring theme across the stories shared was the lack of access to PH medications, the high cost of the few available treatments, and the heavy burden of out-of-pocket payments on patients and their families.

To expand the reach of the campaign, patient stories and educational content were shared across Cardiac Community’s social media platforms. In addition, Cardiac Community engaged traditional and digital media by participating in radio discussions to speak about pulmonary hypertension, patient challenges, and existing gaps in access to care. The campaign messages were also amplified through online newspaper platforms, allowing the advocacy messages to reach a wider audience beyond social media.

In response to the challenges highlighted during the campaign, Cardiac Community supported patients through its PH Drug Aid initiative, enabling some individuals to access pulmonary hypertension medications currently available in Nigeria.

This intervention helped ease the financial burden on patients who can’t afford their medications.



# NORTH MACEDONIA

Throughout the year, we actively worked to raise awareness, support patients, and strengthen the sense of community around Pulmonary Hypertension. Our activities were dedicated to education, public visibility, and meaningful engagement, always with the goal of improving understanding and support for those living with this rare and serious condition.

One of the most important moments of the year was our participation in the **November Run Gevgelija**, as part of the global observance of **November as Pulmonary Hypertension Awareness Month**. By taking part in this event, we helped bring attention to PH, shared the voices of patients, and showed that they are not alone in their journey. The run symbolized endurance, hope, and unity—values that reflect the daily strength of people living with Pulmonary Hypertension.

Our greatest supporters are the runners who never stop running for patients with Pulmonary Hypertension. They proudly represent the PH community in almost every marathon in our country, and they also carry this message beyond our borders by running in marathons in other countries. With every kilometer completed, they raise awareness, spread compassion, and remind the public of the importance of early diagnosis, better treatment, and continuous support.

Their commitment, energy, and solidarity inspire us throughout the year and motivate us to continue our mission. Together—with patients, families, supporters, and runners—we are building a stronger, more visible community and are moving forward step by step toward a better future for everyone affected by Pulmonary Hypertension.





# NORWAY

In PAH Norway, we have workgroups active either online on Teams, or during physical meetings once a month.

Our main Objective in 2025 has been to get Pulmonary Arterial Hypertension acknowledged as a rare disease in Norway with its own diagnostic number, called an ORPHA code, as it has been in the EU.

Once recognized as such, we would then have more rights to rehabilitation, new vaccines and to general healthcare. This mattered especially when Covid Vaccines arrived, and we were put in the back of the queue to be prioritized for the vaccines, even behind healthy 65-year-olds. We have had quite a lot of help from Elisabeth Naess, our local

MSD representative, in Norway with this. It seems now that we are getting close to this goal in January of 2026.

At the end of February 2025, we attended the Rare disease Day in Oslo. It was both an event held in the evening, before the Rare Disease Day, where multiple people with rare diseases presented themselves and their stories, and a more general meeting on the 28th of February with the Norwegian Federation of Persons with Disabilities as the organizers. The main focus was, of course, how it is to live with rare diseases. There were 2 gold medalists, who participated in the Special Olympics present, who shared their stories. This was incredibly interesting and inspiring.



In March, several members of our group were participating in a 4 week rehabilitation programme at the Cathinka Guldberg Hospital in Oslo, which supplies a specialised rehabilitation programme for Patients with Pulmonary Hypertension. It includes lectures, training, dieticians, and psychologists. At the same time, we were also invited to a patient evening with patients who were at the hospital. Other PAH patients were invited to come for an informational meeting about our PAH workgroup, highlighting what we can do for PAH patients. We had a lovely pizza evening with information and free time for getting-to-know each other and got several new members to join our association—a great opportunity for advocacy!



In June, we all met physically before the summer to sum up our work and have lunch with our local Heart and Lung Association.

Also in June, Marit Nicholson attended the Norwegian meeting with the Heart and Lung Association as a representative for our group with PAH.

In October, we got a new board member, Inger Lise Sæther, who has been a PAH patient for many years, and who has a lot of knowledge about PAH.

In November, there were two large meetings/conferences, the APHEC in Barcelona, and the day before the APHEC meeting, on the 5th of November, Ann-Kathrin Bruheim attended the Patient Advocate Group meeting.



From November 6th to November 9th, Marit Nydal Nicholson and Ann-Kathrin Bruheim attended the APHEC in Castelldefels in Barcelona and got much input about new treatments for PAH, as well as about Interstitial Lung Disease, which so far has gotten much less attention.



Right after the conference in Barcelona, there was a new meeting in Prague with the European Respiratory Patient Academy.



There were so many interesting stories and fantastic opportunities to learn about advocating for our diseases, meeting new people and learning from others about how to advocate for our different diseases.

in Oslo about how far we had gotten in our pursuit to get PAH registered as a rare disease in Norway.

The good news is that the specialists in Rikshospitalet in Oslo have started the registration of one patient at the time, so we are seeing a small light at the end of the tunnel, thanks to our work.

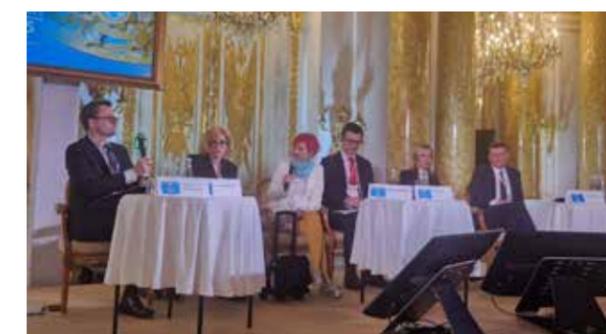
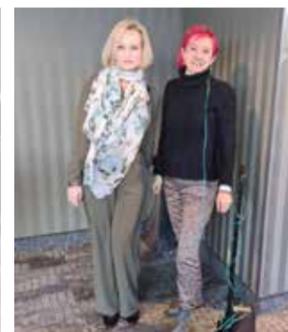
The next day, we had a meeting at the Heart and Lung hospital



# POLAND

At the beginning of January, a meeting was held at MSD, focusing on „The Life of Patients with Pulmonary Hypertension.“ The president of the association spoke to company employees about the difficulties of living with the disease. The purpose of the meeting was to understand the needs of the patients.

We then travelled to Warsaw to participate in the „Health Priorities“ conference. The president of the association, as a patient, spoke about the lives of patients with PAH and their challenges, then he appealed for urgent reimbursement of the drug. The Minister of Health and professors also attended the meeting.



In February, we participated in a two-day conference of the Polish Cardiac Society, during which we shared knowledge about the disease with cardiologists, students, rehabilitation specialists, and nurses. We also distributed information leaflets about our disease to the physicians.



The following day, a press conference organized by the „Eco Serce“ Association was held, discussing the report on drug programs and urgent reimbursement needs. Professor Marcin Kurzyzna spoke about the disease, and the president of the association discussed the need for changes in drug programs for children and adults.



On the Rare Disease Day, a meeting was held in Warsaw's Łazienki Park, and our association received an award – a crystal ball – for its overall work on behalf of patients.



On March 1st, 2025, another patient meeting was held in Gdańsk, organized by our association. Professor Ewa Lewicka welcomed the guests, and then representatives of the association presented their activities and goals. During the meeting, backpacks and teddy bears with the association's logo were distributed, which particularly delighted the younger participants. During the event, important health-related topics were discussed, such as pulmonary hypertension treatment strategies and the latest scientific findings, as well as clinical research—facts and myths. Participants also watched an educational film about the rehabilitation of patients with PAH, titled „Movement is Health.” A psychologist also participated in the meeting, providing advice on how to navigate the disease and overcome challenges. Patients had the opportunity



In February, a meeting with Minister Urszula Demkow was held, which was focused on the importance of drug reimbursement, changes to the drug program for adults and children, reimbursement for oxygen concentrators, and rehabilitation for patients. A comprehensive letter regarding urgent needs was submitted.



At the end of February, Auto Group Polska held a meeting during which we distributed leaflets about the disease to employees, and the company donated backpacks and teddy bears with the association's logo to celebrate Rare Disease Day.



to share their treatment stories, which enriched the atmosphere of the meeting and allowed for an exchange of experiences. During the break we invited everyone for lunch.



A recording of an educational film about the Hickman catheter pump featuring a patient treated with epoprostenol, who spoke about her life on the pump, was shown to uplift other patients and demonstrate that life with a Hickman catheter can be enjoyable.



On March 22nd, 2025, the second patient meeting was held in Szczecin. The aim of the meeting was to raise awareness about PAH. Participants had the opportunity to learn about the condition, current available treatments, and new directions and hopes. The topic of thromboembolic pulmonary hypertension (CTEPH) was also discussed. Short videos featuring patients were shown during the meeting, which provided valuable information by displaying a presentation on the use of a subcutaneous pump, explaining its operation, maintenance, and impact on quality of life. A highlight was an online connection with a patient who spoke about her experience with a Hickman catheter pump. A lecture by Dr. Dorota Wańkowska, a coach, also took place – she spoke about the role of

mental support, motivation, and building inner strength in living with a chronic illness. A valuable highlight of the program was a workshop with a physiotherapist, who presented specific exercises that can be performed at home – safe and tailored to patients' abilities. The meeting concluded in a pleasant atmosphere with a shared lunch, providing an opportunity for networking.



On April 5th, 2025, a meeting organized by the School of Coping with Disability took place in Wrocław. Many interesting topics were discussed, including the nutrition of people with chronic illnesses and disabilities. During the meeting, key aspects were discussed, such as reduced physical activity, swallowing disorders, home-based feeding tube therapy, and the problem of malnutrition. Our Association also spoke at the event, having been invited to give a lecture. We introduced the participants to the topic of pulmonary hypertension, emphasizing the symptoms of the disease, ways of recognizing it, and the importance of early diagnosis. The President of our Association then shared her personal experience and reports.



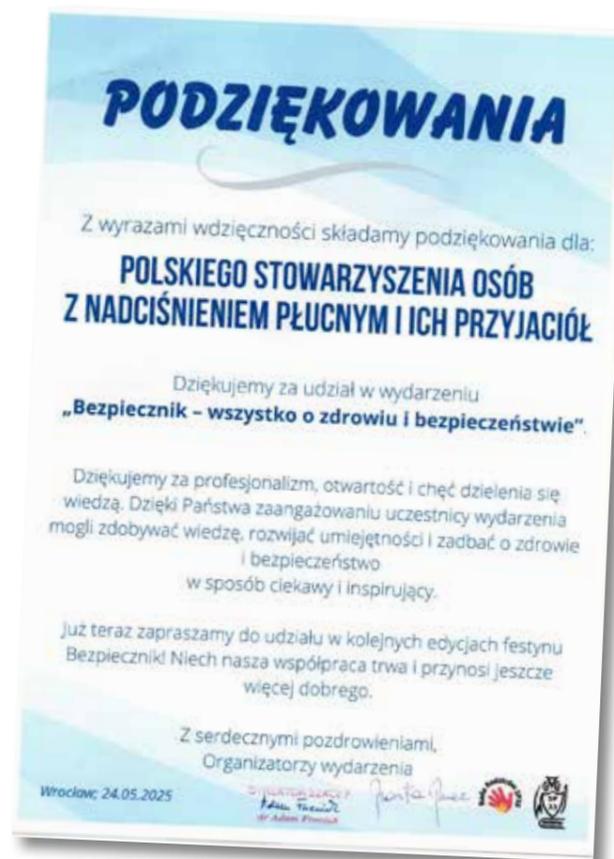
Wrocław Cardiology Conference – In April, we received an invitation to participate in the Wrocław conference. We had the opportunity to inform cardiologists about our condition. Family physicians, rehabilitation specialists, nurses, and students also visited our stand. During one workshop, we had the opportunity to talk to the students about the condition and how to recognize it for faster diagnosis.



Warsaw – Patient Focus Conference – The aim of the conference was to highlight the importance of collaboration between doctors and pharmacists. Unfortunately, patients often combine various medications, which can cause side effects.



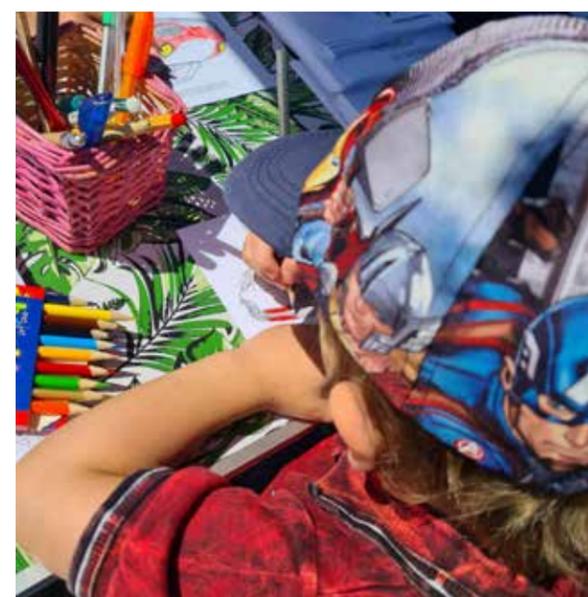
Educational campaign „Bezpiecznik – All About Health” – in May, we were invited to an educational campaign organized by a primary school. As always, our booth featured educational materials. Our booth was primarily attended by children eager to ask questions about heart and lung diseases.



In June 2025, the third Patients' Meeting took place at the Otwock Theatre. The meeting was led by Professor Maria Wieteska-Miłek. The meeting was opened by Otwock City Councilor Joanna Chmielewska. We discussed many interesting topics, including the practical aspects of parenteral prostacyclin use, modern therapies for pulmonary hypertension, the role of a multidisciplinary rapid response team in Poland in the diagnosis and treatment of acute pulmonary embolism, psychological intervention in pulmonary arterial hypertension, the risk of malnutrition in pulmonary hypertension, and quality of life as assessed by patients with pulmonary hypertension. During the coffee break, we invited patients to our stand, where we distributed guides, and those interested could learn how to perform subcutaneous injections and familiarize themselves with a Hickmann catheter pump. Otwock City Councilor Krystian Kiełtyka, a long-time supporter of our association, was also present. We also played a recording by Kinga Fukushima, author of the book „Deprived of Breath,” and videos featuring the stories of patients on pumps.



At the end of June, we had the pleasure of participating for the third time in the city's educational campaign „Poznań w formie” (Poznań fit), organized by the Poznań City Hall - Department of Health Promotion. In addition to our association members, our patients also actively participated in the event. The main goal



was to educate Poznań residents about pulmonary hypertension. We discussed the early symptoms of the disease and encouraged them to be mindful of their body's signals. We distributed hundreds of leaflets and gadgets, which were intended not only to attract attention but, above all, to remind everyone of the importance of a prompt diagnosis. A special element of the event was the „Quick Diagnosis of Pulmonary Hypertension” campaign. We also prepared materials aimed directly at primary care physicians. We asked residents to share them with their doctors – we believe this will help reach an even wider audience of specialists. There was also a children's corner, which, like last year, was extremely popular and became one of the most popular parts of the event. The youngest participants could draw, solve crosswords, puzzles, and mazes, all in an atmosphere of fun and laughter.



In July, the Federation of Polish Patients organized a training course entitled „Strengthening the Competencies of Patient Organization Representatives for Effective Advocacy and Watchdog Activities,” in which our association also participated. For four days, we learned how legal acts are developed and who can submit comments on various drafts. Two days were devoted to clinical trials—how the process works, who can participate, what randomization means, and what to consider when signing informed consent. At the end of the training, we learned how a bioethics committee operates and how to evaluate/amend and analyse applications.



From September 2nd to 4th, 2025, the prestigious Economic Forum took place in Karpacz, to which our association was invited. The Forum is one of the largest and most important economic and political events in Central and Eastern Europe. It is a place where, for over thirty years, people with a decisive influence on the fate of Poland, Europe, and the world have been meeting. This year, we also participated in the roundtable discussions. We highlighted the limited access to the latest drug therapy, Sotatercept, a life-saving drug, and its absence from the reimbursement list. We appealed for urgent access to the therapy. During the forum, we spoke with MP Witold Tumanowicz, to whom the association presented its problems. The MP promised us support and submitted an interpellation to the Ministry of Health on our behalf.



On September 8th, our association, along with several patients, went to the Parliamentary Group in the Sejm (lower house of parliament). The goal was to fight for urgent reimbursement for the drug. Professor Adam Torbicki delivered a presentation about the disease, and the association's president presented „The Life and Problems of Patients with Pulmonary Hypertension.” Dr. Olga Dzikowska-Diduch highlighted a very serious problem – the National Health Fund refusing to provide the drug in a life-saving procedure. Patients also appealed: „Every person deserves the chance to live in health, strength, and dignity.”... „The lack of access to Sotatercept makes my life a daily struggle for breath and energy...” „Don't take this chance away from us.” „This medication is not a luxury, it's the right to live in better health...” - with these words, our long-time patient Iwonna began her speech in the Sejm. Because we don't care about luxury. We care about a dignified life.



As part of the Ukrainian grant, we created a leaflet with short stories from our patients. The goal of the campaign was to emphasize the importance of not judging patients based on their appearance. We wanted to show that people with the disease also have a need to be beautiful, and this right should not be taken away from us.

On September 13th, our association once again participated in the educational campaign „Wrocław Health Promotion Days,” organized by the Wrocław City Hall, Department of Health Promotion. During the event, doctors spoke to passersby about pulmonary hypertension, explained the symptoms of the disease, pointed out what to look for, and measured blood pressure for those who volunteered. We also prepared a children's corner where children could participate in educational

games. Children happily drew questions and answered them, and received prizes for participating. We also distributed guides and short biographies of people with pulmonary hypertension to highlight the realities of living with this disease and encourage early diagnosis.



Press Connect Meeting - On October 11th, 2025, our association received an invitation to Warsaw for a Press Connect meeting. President Stanisław Maćkowiak, representing the National Orphan Forum, Dr. Jakub Gierczyński, and approximately 20 journalists were also invited to the meeting. The purpose of the meeting was to engage journalists in the topic of rare diseases, present the audit, and familiarize journalists with pulmonary hypertension.



In October, the 9th Congress, Vision of Health - Diagnosis and the Future - Patient at the Crossroads, took place. The association's president participated as a panellist. It was a heated debate with journalists, doctors, and officials. The aim of the debate was to draw attention to the lack of access to state-of-the-art PAH therapy, which is why we appealed for urgent reimbursement. The president pointed out that officials were blocking access to medications, violating patients' rights. After the debate, a gala dinner was held, during which our association received an award for its work.



Co-creation of the „Travel with PAH” guide – we had the great pleasure of co-creating an incredible guide on traveling with the disease.



Cardio-oncology conference in Wrocław – we participated in another conference in October. This time, we met with oncologists. We noted that cancer patients often remain without cardiologist care during treatment.



Pulmonary Circulation Association, October 17th-18th, is a conference for our doctors, to which our association has been invited for years. During this meeting, we delivered a lecture presenting the association's activities. During breaks, we had the opportunity to talk with our doctors and nurses. During the conference, an exhibition of heart disease patients, created by Agnieszka Wołcenko, president of the „Eco Serce” association, was on display in the hotel lobby. The exhibition generated enormous interest, aiming to demonstrate that one can find one's way in the face of illness and help others.



On Saturday, October 18th, 2025, the fourth patient meeting was held at the Novotel Wrocław Centrum hotel. Dr. Ewa Mroczek and members of the Association's Board welcomed participants, emphasizing the importance of community and ongoing patient education. This was followed by a series of expert presentations by patients: Dr. Maria Wieteska-Miłek discussed the risk of malnutrition in pulmonary hypertension, highlighting the often underestimated nutritional aspects of this condition. Association representatives presented the organization's activities and plans for the coming year. Dr. Ewa Mroczek presented the latest information on the development of therapy and research directions in pulmonary hypertension. Professor Anna Doboszyńska gave a short presentation on speech testing in patients with PAH. Dr. Łukasz Biel and Dr. Krzysztof Aleksandrowicz spoke about the role of physical activity in the lives of patients, emphasizing the importance of safe and controlled exercise. Anna Jelenik, a psycho-oncologist, delivered an incredibly moving lecture entitled „How to Be Sick and Not Go Crazy - What Can I Do for Myself.” Attendees watched Angelika's moving 10-minute story, „My Life with Hickman.” The star of the meeting was, of course, the writer Kinga Fukushima, who flew from Japan to Poland especially for us. She wrote the book „Deprived of Breath,” in which the main character has pulmonary hypertension. The author not only shared her experience but also signed books with personal dedications after the meeting. Blue friendship and solidarity bracelets were sold during the meeting. The meeting concluded with patient Marta Tomczyk, who, in her presentation, „The Pump Isn't as Scary as They Say - My Crazy Life on the Pump” spoke about everyday life with the pump and the strength that can be found in accepting the disease.



At the Annual PH European Conference in Barcelona from November 5th to 9th, 2025, we were represented by one of our members, Piotr Niewadzisz. Representatives from many countries, not just European ones, as well as pharmaceutical companies and academics involved in pulmonary hypertension, were present. The most important topics discussed included raising public awareness, improving the quality of life for patients, providing information on the latest research and its direction, and, of course, organizational matters. The groundbreaking drug Sotatercept, which was recently launched, was also an important topic for patients. We are pleased that we had the opportunity to participate in the conference.

Patient Organization Meeting – At the end of November, at the invitation of MSD, a two-day meeting of patient organization leaders took place. Topics discussed included: three crises in healthcare, challenges for drug policy – financing therapy in the healthcare system, legislative and financial barriers to access to innovative therapies, the role of communication in building trust, and AI in practice: how to gain efficiency and minimize risk. The president of our association was asked to summarize the conference on access to innovative therapy.



On December 2nd, we travelled to the capital to participate in a press conference at the Sejm. On behalf of patients, the president of the association thanked the Ministry of Health for the drug reimbursements provided so far, but appealed for an urgent reimbursement of the drug. Next, we went to the Sejm Chamber for

a meeting of the parliamentary group on rare diseases, where they discussed successes and pressing needs. After the presentations by doctors and MPs, other organizations also took the floor. We once again appealed to MPs for urgent reimbursement of Sotatercept and to not block the life-saving procedure with Sotatercept.



On Saturday, December 6th, a Christmas-themed patient meeting was held in Zabrze. A Christmas clip was shown on the main screen, imitating a burning fireplace, with Christmas music playing in the background. We asked everyone to wear something festive. The room was decorated with festive decorations, which included strings and lights. We also brought a Christmas tree. All of this created a beautiful and festive atmosphere in the hall. Guests were welcomed by Professor Wojciech Jacheć, MD, PhD, and Ilona Skoczylas, MD, PhD. As always, our association presented a presentation on its activities. Dr. Skoczylas discussed new developments in PAH treatment. Dr. Kamil Jonas then presented the results of clinical trials on the new drug Sotatercept. Professor Jacheć prepared an excellent presentation on catheterization. Professor Jacheć drew attention to the problem of switching patients to additional prostanoid therapy, so we presented research results indicating that prostanoids prolong life in patients. Meanwhile, patient Ania shared her experiences living „on a pump.” We also showed a film about a patient with a Hickman catheter and Professor Piotr Dąbrowiecki's film „Respiratory Tract Infections and Their Prevention.” At the meeting, we also sold friendship bracelets. During the coffee break, visitors could approach a table stocked with guides, various gadgets, pumps, and various types of injections. Experienced patients demonstrated how to properly perform injections. There was also time for patients, who shared their stories and advice. Over delicious freshly roasted coffee, the conversations were endless.





# PORTUGAL

The **APHP – Portuguese Pulmonary Hypertension Association** has significantly strengthened its role within the Pulmonary Hypertension (PH) community in Portugal. This period has been marked by meaningful institutional engagement, active participation in scientific, and patient-centred events, as well as new initiatives aimed at empowering patients and caregivers as key stakeholders in healthcare.

## STRENGTHENING COLLABORATION WITH PH REFERENCE CENTRES

A major milestone during this period was the **first official APHP meeting with 5 of the 6 national PH Reference Centres in our country**. This meeting represented an important step towards reinforcing dialogue between patients and healthcare providers, promoting mutual understanding, and contributing to more coordinated, patient-centred care pathways in Portugal.

## ACTIVE PARTICIPATION IN SCIENTIFIC AND PROFESSIONAL MEETINGS

In October, **APHP President Cátia Rodrigues**, together with **Dulce Barbosa**, PHAEurope fellow and PH patient, participated in the **Second Meeting of the Sociedade Portuguesa de Cardiologia** - Portuguese Society of Cardiology. The event brought together numerous healthcare professionals over two days and addressed a wide range of topics related to Pulmonary Hypertension. The meeting was supported by **MSD, AOP and Janssen**.

APHP’s intervention focused on the theme **“Bridging Minds”**, highlighting gaps and expectations between patients and healthcare professionals. The presentation explored:

- What healthcare professionals wish patients knew,
- What patients wish their doctors understood,
- and what both patients and PH specialists should better understand together.

This contribution reinforced the importance of shared decision-making, empathy and open communication in PH care.



## CAPACITY BUILDING AND PATIENT ASSOCIATION EMPOWERMENT

Dulce Barbosa also took part in the **first “Patient Association Campus – Unlocking Healthcare”**, organised by **Johnson & Johnson**. This initiative recognised the essential role of patient organisations in building more humane and responsive healthcare systems. The event provided a unique opportunity for training, capacity building, and the exchange of best practices among patient associations, caregivers and family members, strengthening their impact in everyday advocacy work.

## AMBASSADOR INITIATIVE AND COMMUNITY ENGAGEMENT

During this period, APHP also launched **regular meetings with APHP Ambassadors** — patients and caregivers who wish to play a more active role within the association. These ambassadors are involved in helping organize events, proposing fundraising ideas and creating opportunities for experience-sharing and peer support, reinforcing community cohesion and participation.



## AWARENESS CAMPAIGNS, FUNDRAISING AND PARTNERSHIPS

In November, APHP organised a highly attended online webinar, about CTEPH, which reached a wide audience and was considered a major success in terms of engagement and information sharing. In addition to this webinar, we also planned and organized another one on nutrition, which, due to factors beyond APHP’s control, was postponed to the first quarter of 2026.

Organized by the “Star Padel Babes”, APHP were invited to participate in a PH awareness campaign during a padel tournament in Coimbra, with part of the funds raised donated to the association — a strong example of community-based awareness and solidarity.

APHP also established a valuable partnership with Healthy Planet, a Portuguese brand focused on environmentally conscious home and personal care products, made possible by one of APHP’s ambassadors – Mónica Gonçalves. A percentage of sales from these products was donated to the association,



combining sustainability, social responsibility and patient advocacy.

These past months reflect APHP’s commitment to strengthening patient participation, fostering dialogue with healthcare professionals and building meaningful partnerships. By empowering patients and caregivers, engaging in scientific and educational initiatives, and promoting awareness and fundraising activities, APHP continues to work towards a more inclusive, informed and patient-centred approach to Pulmonary Hypertension care in Portugal.





# ROMANIA

## PULMONARY HYPERTENSION PATIENT ASSOCIATION ROMANIA 2025 - ACTIVITY SUMMARY

### A YEAR OF TRANSFORMATION AND GROWTH

The year 2025 marked a pivotal moment for PHA Romania, representing the first year of substantially expanded activity and impact. Building organizational capacity while maintaining patient-centered focus, we successfully organized four major events, conducted two comprehensive studies on pulmonary arterial hypertension (PAH) patient needs, and launched an ongoing focus group series examining the patient journey in Romania. This growth reflects our evolution from an emerging organization to an established patient advocacy voice.

### MAJOR EVENTS AND STAKEHOLDER ENGAGEMENT

Our 2025 event program brought together the full spectrum of stakeholders—medical specialists, policymakers, patients, and caregivers—to address critical gaps in PAH care and advocacy:

#### MAY 16 - PAH PATIENT WORKSHOP

This foundational event gathered medical specialists, representatives from the National Health Insurance House (CNAS), patients, and caregivers to discuss treatment access, reimbursement challenges, and support needs. The workshop established crucial dialogue channels between patients and healthcare system decision-makers.

#### MAY 26-29 - AER PROJECT LAUNCH (STAGE 1)

We initiated the „Efficient Access to Public Health System Resources for PAH Patients” (AER) project with a strategic meeting before the Health Commission of the Romanian Senate. This session conveyed the specific challenges faced by our patient community and laid groundwork for systemic advocacy efforts.

From May 26th to May 28th, the unique exhibition „AER at Height” was held in the Romanian Parliament, in the Senate. The project’s objective is to improve the diagnosis process, access to innovative therapies, and sustainable care for patients with pulmonary arterial hypertension (PAH).

The exhibition featured ten expressive collages and hiking articles, illustrating the unseen challenges of people living with PAH.

#### OCTOBER 22 - WEBINAR ON INTERDISCIPLINARY APPROACHES

On October 22nd, we hosted the webinar „Pulmonary Hypertension: Interdisciplinarity in Approaching Complex Cases,” bringing together medical experts from multiple specialties to discuss collaborative approaches to complex PAH patient management. This educational session emphasized the importance of coordinated care across cardiology, pulmonology, rheumatology, and other relevant disciplines.

#### NOVEMBER 21 - EUROPEAN DIALOGUE ON PAH

In partnership with MedUni Târgu Mureș, we organized a European dialogue bringing together specialists, patients, and caregivers to share perspectives on care coordination, emerging treatments, and quality of life improvements. This cross-border exchange enriched our understanding of best practices.

#### NOVEMBER 27 - AER PROJECT ANALYSIS (STAGE 2)

The second phase of our AER project provided detailed analysis of challenges faced by PAH patients in accessing diagnosis, treatment, and ongoing care within Romania’s healthcare system.



### RESEARCH AND EVIDENCE-BASED ADVOCACY

Understanding that effective advocacy requires solid evidence, we conducted two comprehensive studies as part of the AER project:

#### SITUATION ANALYSIS OF UNMET NEEDS (FEBRUARY 2025)

This study systematically identified gaps in current PAH patient care, covering diagnostic delays, treatment access barriers, psychosocial support deficiencies, and healthcare system navigation challenges.

#### PAH PATIENT GUIDE (MARCH 2025)

We developed Romania’s first comprehensive patient guide specifically for individuals with pulmonary hypertension, providing accessible information on disease understanding, treatment options, healthcare rights, and support resources.

Additionally, we produced the first dedicated brochure for PAH patients in Romania, created entirely by the association with support from AOP, ensuring patients have clear, accurate information at diagnosis and throughout their journey.

### UNDERSTANDING THE PATIENT JOURNEY

In November, we launched a landmark focus group series in collaboration with MSD, examining the complete patient journey from first symptoms through treatment initiation. This research identifies specific pain points that will shape our 2026 advocacy priorities, ensuring our efforts address the most pressing patient needs.

### INTERNATIONAL INTEGRATION AND CAPACITY BUILDING

PHA Romania significantly strengthened its position within the European rare disease community:

#### PHA EUROPE ANNUAL MEETING (5-9 NOVEMBER)

Our representatives attended the annual PHA Europe gathering, establishing valuable connections with member associations

across Europe and gaining insights into successful advocacy models and collaborative opportunities.

#### EFANET RESPIRATORY ACADEMY PRAGUE (NOVEMBER 13-16)

Participation in this specialized training provided comprehensive knowledge on advocacy strategies and patient empowerment techniques that we will implement starting in 2026, enhancing our organizational effectiveness.

#### NETWORK MEMBERSHIPS

We proudly achieved membership in two prestigious organizations:

- **GAAPP** (Global Allergy & Airways Patient Platform), connecting us with respiratory patient advocates worldwide
- **ERN-LUNG** (European Reference Network for Rare Lung Diseases), integrating us into specialized clinical and research networks.





### STRATEGIC PHARMACEUTICAL PARTNERSHIPS

We redefined our relationships with pharmaceutical industry partners (MSD, AOP) and established collaborative frameworks that maintain strict ethical boundaries, while also supporting patient education and advocacy. These partnerships, launching fully in 2026, will enable expanded patient programs while preserving our independence and patient-first mission.

### DIGITAL PRESENCE AND PATIENT ENGAGEMENT

Recognizing the importance of accessibility and community building, we significantly enhanced our digital infrastructure:

#### WEBSITE REDESIGN

Our completely redesigned website ([hipertensiunepulmonara.ro](http://hipertensiunepulmonara.ro)) provides improved navigation, comprehensive resources, and better accessibility for patients seeking information and support.

#### SOCIAL MEDIA EXPANSION

We established a LinkedIn presence for professional networking and advocacy outreach, while substantially increasing our Facebook activity with both member growth and regular patient-focused content.

#### DIRECT PATIENT COMMUNICATION

We created a dedicated WhatsApp group, enabling real-time communication, peer support, and rapid information sharing among patients. This platform has notably strengthened patient involvement in association projects and decision-making.

### ORGANIZATIONAL EVOLUTION

A significant operational milestone was our transition from collaborative implementation (working through COPAC, the association for patients with chronic diseases, in the first half of 2025) to direct implementation of all activities in the second half of the year. This evolution demonstrates our growing organizational capacity and sustainability.

### LOOKING FORWARD

With our 2026-2027 activity plan in advanced development stages, we are positioned to build upon this year's achievements. Our focus will remain on evidence-based advocacy, comprehensive patient support, international collaboration, and systemic healthcare improvements that benefit all Romanian patients living with pulmonary hypertension.

The transformation of 2025 provides a solid foundation for continued growth, deeper impact, and stronger patient voices in healthcare policy and practice.



## SERBIA

### PULMONARY HYPERTENSION SERBIA – KNOWLEDGE, COMMUNITY, AND HOPE AS THE FOUNDATION OF CONTINUOUS WORK

The association **Pulmonary Hypertension Serbia** continued its intensive, responsible, and dedicated activities throughout this quarter and focused on improving the position and quality of life of patients living with pulmonary hypertension in Serbia. Our work encompasses international cooperation, direct patient support, and active engagement with medical innovations that are transforming the lives of patients. Three key events from the past period best illustrate this mission.

### INTERNATIONAL COOPERATION AND KNOWLEDGE EXCHANGE – APHEC, NOVEMBER 2025

In November, Pulmonary Hypertension Serbia took part in APHEC, the annual assembly of **PH Europe**, one of the most important international gatherings in the field of pulmonary hypertension. The event brought together representatives from more than 40 countries from Europe and across the world, once again confirming its global relevance and the strength of a united effort to improve the lives of PH patients.

During the assembly, we had the opportunity to hear the latest professional insights in the field of pulmonary arterial hypertension (PAH), learn about innovations in therapy, and exchange experiences, news, and ideas with other patient organizations. Meetings with leading physicians and representatives of the pharmaceutical industry were of particular value, as their lectures were both highly educational and encouraging.

As every year, APHEC also carried a strong emotional dimension. Reunions with long-standing friends and partners in advocacy reminded us how vital solidarity and community are, while also



highlighting the significant progress achieved together over the years.

### INFO DAY FOR PH PATIENTS – BELGRADE, DECEMBER 13, 2025

As part of our ongoing support for patients, Pulmonary Hypertension Serbia organized an Info Day for PH patients on December 13, 2025, at the Falkensteiner Hotel Belgrade. The gathering took place in a warm and constructive atmosphere and was attended by around fifteen participants, including patients, as well as members of medical staff, which added special value to the meeting.

Info Days represent an important space for open discussion, exchange of experiences, and addressing everyday challenges of living with pulmonary hypertension. In an informal setting, over a



shared lunch, participants had the opportunity to connect, support one another, and receive practical and reliable information directly from healthcare professionals. Special emphasis was placed on strengthening cooperation between patients and medical experts, as well as on the importance of continuous communication.

During the meeting, future steps and activities of the association were discussed, including the continued, dedicated work on a petition aimed at improving treatment options for PH patients in Serbia. This Info Day once again confirmed the importance of such gatherings—because an informed, connected, and empowered patient is better equipped to face the challenges of the disease.



**INSPIRATION AND MEDICAL PROGRESS – “DISCOVERIES FOREVER” EVENT**

Alongside patient-focused activities and international collaboration, Pulmonary Hypertension Serbia also had the pleasure of attending the inspiring event organized by MSD, entitled “Discoveries Forever”, dedicated to medical ideas that change the world, the people behind them, and values that endure over time. One of the speakers was Arsen Ristić, who reflected on pulmonary hypertension in the past and today, highlighting the remarkable progress in diagnostics and treatment. His presentation clearly demonstrated how far medicine has come and how significant the advances have been for PH patients compared to previous years. The event also emphasized the exceptional effectiveness of innovative therapies and the fact that medicine has been experiencing continuous growth in recent years—not only in the field of pulmonary hypertension, but also in oncology, systemic diseases, and many other complex and severe conditions. What once seemed unimaginable is increasingly becoming reality thanks to science, research, and courageous ideas.



**LOOKING AHEAD**

All three events clearly illustrate the direction in which Pulmonary Hypertension Serbia is moving—guided by knowledge, cooperation, direct patient support, and strong belief in medical progress. With the experience gained from international assemblies, the trust and energy built through Info Days, and the hope brought by innovative therapies, we continue our work with responsibility, perseverance, and optimism. Our goal remains unchanged: a better, safer, and higher-quality life for all patients living with pulmonary hypertension in Serbia—today and in the future.



**SLOVAKIA**

**ACTIVITIES OF PHA SLOVAKIA IN 2025**

The year 2025 was marked by intensive efforts aimed at raising awareness of pulmonary arterial hypertension (PAH) and supporting patients in their fight for access to innovative treatment. Throughout the year, we carried out four major campaigns, numerous accompanying activities, and actively participated in professional and public discussions.

**RARE DISEASE DAY CAMPAIGN**

To mark Rare Disease Day, we prepared a social media campaign and organized a discussion forum titled “When Breath Runs Short” for third-year students of the Secondary Medical School in Lučenec. The event focused on PAH, its consequences, organ donation, and transplantation.



**“LET’S BREATHE TOGETHER” PROJECT**

In cooperation with the organization Rare Diseases, we launched a two-phase campaign titled “Let’s Breathe Together”.

- **The first phase** involved distributing wall calendars with portraits and short stories of patients to selected hospitals and clinics across Slovakia, aiming to raise awareness among both patients and healthcare professionals. We received an honorable mention in the Most Beautiful Calendar of the Year 2025 competition.
- **The second phase** focused on preparing a travelling exhibition, which has so far been installed in six hospitals and spa facilities and will continue throughout 2026.

The opening and christening of the Let’s Breathe Together exhibition was on a press conference in April. Full patient stories are available at [www.dychajmespolu.sk](http://www.dychajmespolu.sk).

In May our awareness raising was also supported by runners participating in several events, including the ČSOB Marathon, Wings for Life World Run 2025, Urban Challenge, and the two-day 360 km relay Vltava Run.

**PH AWARENESS MONTH – “ACCESS MEANS LIFE”**

We contributed three patient stories to the campaign and also shared stories from the *Let’s Breathe Together* project on social media. The campaign was closely linked to our efforts to secure innovative treatment. Several members of our Association provided interviews to the media.



## CAMPAIGN FOR INNOVATIVE TREATMENT

Ensuring access to innovative treatment remained one of our top priorities. After the categorization of the drug Winrevair was rejected, along with four exemption requests, we actively engaged in professional discussions and public initiatives.

We participated in a protest briefing, several conferences, two meetings at the Ministry of Health, and discussions at NIHO, which did not recommend the categorization. We supported two mass comments on the Medicines Act, which is currently under review. Patients with PAH joined the campaign by sharing their personal stories. We also took part in the “Waiting List” campaign organized by the Platform of Helping Organizations – Nezabudnutí.

## REHABILITATION AND EDUCATIONAL STAY

For our patients, we organized a six-day rehabilitation and educational stay at the Sliuč Spa. Participants made full use of spa treatments, mineral baths, healing springs, and therapeutic exercise. The program included a discussion with psychologist Mgr. Peter Bielik, who provides free counselling to our Association.

## EDUCATION AND PROFESSIONAL EVENTS

Representatives of our Association attended the APHEC conference in Barcelona. Participation in the 9th National Patients' Conference was also highly valuable, as it brought together representatives of the ministry, parliament, health insurance companies, providers, and patient organizations. The main message was clear: *Patients must be co-creators of health policies, not just their recipients.*

In October, we took part in the Congress of the Slovak Cardiology Society with an information booth.



## INTERNATIONAL COOPERATION

Chairwoman Iveta Makovníková accepted an invitation from the Czech PH Association to attend a weekend meeting marking its 20th anniversary. She presented the activities of ZPPH over the past 15 years and expressed gratitude for their support during the founding of our Association in Slovakia.

## END-OF-YEAR MEETING

We concluded the year with a working dinner for our partners, during which we reviewed the results of our activities and presented our plans for 2026. The meeting included constructive discussions and a commitment to continued cooperation.

*Iveta Makovníková,  
PHA Slovakia*



# SLOVENIA

## A YEAR OF CONNECTION, COURAGE, AND INTERNATIONAL RECOGNITION

The year 2025 was a year of consolidation, strengthened collaboration, and visible progress for the Association of Patients with Pulmonary Hypertension Slovenia, both nationally and internationally. Through well-designed projects, educational initiatives, and compelling patient stories, the Association continued to advance its core mission: improving awareness and early recognition of pulmonary hypertension, amplifying the patient voice, and contributing to better and more accessible care.

Throughout the year, a strong emphasis was placed on building meaningful connections—between patients, healthcare professionals, researchers, decision-makers, and the wider public. This combination of expertise, lived experience, and human support enabled the Association's work to extend beyond the traditional scope of comparable organizations.



## KEY AWARENESS-RAISING ACTIVITIES IN THE FIRST HALF OF THE YEAR

At the beginning of the year, the Association joined the observance of **Rare Disease Day**, drawing attention to the importance of early diagnosis of pulmonary hypertension within international initiatives. Special focus was also given to the **Without You, There Would Be No Us** campaign, which highlighted the contribution of Prof. Dr. Barbara Salobir in Slovenia to the development of comprehensive care for patients with pulmonary hypertension.

## A COMMUNITY THAT GIVES STRENGTH

In autumn, members of the Association gathered for an **excursion** to Radovljica. Alongside informal socializing, a walk through the historic town center, and a shared lunch, the event reinforced mutual bonds. Such gatherings are particularly meaningful for

patients, as they encourage the exchange of experiences, foster a sense of belonging, and provide essential psychosocial support when living with a rare disease.

A strong symbolic and emotional moment was also reflected in the Association's participation in the **Circle of Gratitude and Cooperation** event marking the 25th anniversary of the Slovenian Transplant Society. Held in Mengeš, the event brought together patients, donors, healthcare professionals, and numerous patient organizations, while reinforcing awareness of the importance of organ donation. The presence of the President of the Republic of Slovenia, Dr. Nataša

Pirc Musar, as an honorary patron, added special significance and conveyed a powerful message of support to patients with pulmonary hypertension, for whom lung or heart transplantation may represent the only long-term treatment option.



## THE PATIENT VOICE IN THE PROFESSIONAL ARENA

In 2025, the Association further strengthened the role of patients in professional and scientific dialogue. At the **European Respiratory Society** World Congress, Association member Nina Kobler presented the patient perspective on pulmonary hypertension and emphasized the importance of integrating patient experience into the development of modern, empathetic, and effective healthcare approaches.

The Association also contributed to the education of future healthcare professionals through active participation in the **11th Student Symposium of the Slovenian Pharmaceutical Society**. Expert lectures were complemented by a patient's personal story, offering students a more holistic understanding of the disease—beyond clinical guidelines and into everyday life.

In addition, the Association took part in the **Fajdiga Days** in Kranjska Gora, focusing on awareness-raising among primary care physicians. Practical demonstrations helped illustrate the physical limitations patients face and highlighted the importance of early recognition of pulmonary hypertension symptoms.



Board of PHA Europe reflects strong mutual trust and confirms that smaller organizations can play a significant role in shaping shared European objectives.

Nina Kobler, through the presentation of the **One Breathless Mission - Jonuka400** project, highlighted the value of media collaboration, personal patient stories, and creative approaches to awareness raising. Her contribution sparked constructive discussion on how patient organizations can more effectively engage the public, policymakers, and the healthcare community.

### LOOKING AHEAD

The year 2025 reaffirmed that the strength of the Association of Patients with Pulmonary Hypertension Slovenia lies in knowledge, collaboration, and compassion. The Association has established itself as a trusted partner within the professional community and the wider public, and as a space where patients feel heard, supported, and empowered.

Sincere thanks go to all supporters, collaborators, and friends of the Association who, through trust, energy, and openness, help shape our journey. With you, ideas become projects, projects become stories, and stories create change. We look forward to continued cooperation and shared steps ahead.

*We wish everyone a successful and inspiring 2026.*



### EUROPEAN ENGAGEMENT AT APHEC 2025

APHEC 2025 provided an opportunity for in-depth professional exchange, sharing of best practices, and further strengthening cooperation among national patient organizations.

The Slovenian Association was actively and meaningfully involved in the conference. Through her long-standing work—particularly in strategic communication and campaign development, including the **Without You, There Would Be No Us** campaign—Tadeja Ravnik contributed to discussions on the future direction of the organization and the strengthening of the patient role at the European level. Her election to the



## SPAIN ANHP

The year 2025 marked a milestone of special significance for the National Pulmonary Hypertension Association (ANHP): the celebration of our 20th anniversary. Two decades of commitment, support and continuous work have shaped a strong, united and resilient community that this year not only celebrated its journey, but also the real impact achieved in the lives of thousands of people living with pulmonary hypertension and their families.

This anniversary provided an opportunity to look back with pride, acknowledge the path we have taken, and at the same time renew our mission with a firm commitment to the future. Every action carried out throughout the year was imbued with this commemorative spirit, reinforcing our purpose of improving the quality of life of people affected by this rare and complex disease.

### SUPPORT, AWARENESS AND COLLABORATIVE WORK

Throughout the year, ANHP continued to provide comprehensive support to people living with pulmonary hypertension, as well as to their caregivers and families. This support was complemented by awareness-raising campaigns aimed both at the general public and at healthcare decision-makers, with the goal of giving visibility to a disease that still presents an average diagnostic delay in Spain of between one and a half and two years.

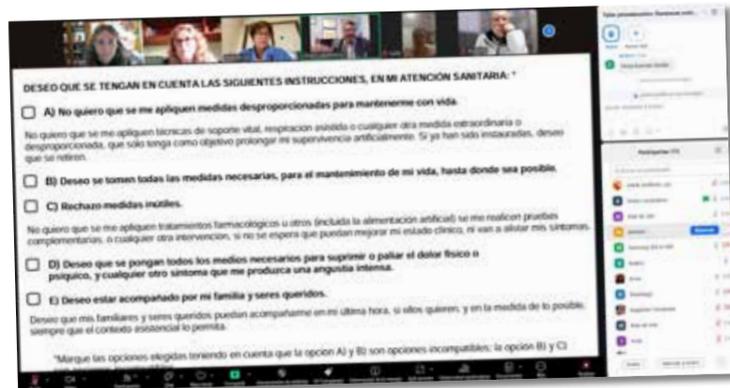
In 2025, several key campaigns were promoted, including Rare Disease Day (28 February), World Pulmonary Hypertension Day (5 May) and Pulmonary Hypertension Awareness Month in November. All of these initiatives were carried out in collaboration with other rare disease organizations, based on the conviction that networking multiplies impact. Our slogan #JuntosLlegamosMás (#TogetherWeGoFurther) reflects this philosophy of cooperation and solidarity.

Among the joint activities, a charity concert at the Valdebernar Cultural Centre (Madrid) stood out, as well as participation in information stands such as the one held at Universidad Rey Juan Carlos, where awareness of different rare diseases was promoted through participatory activities. In addition, ANHP was present in community media outlets, such as the radio programme "Vicalvaro te escucha", where the importance of early diagnosis, research and institutional support was addressed.



## TRAINING, PSYCHOSOCIAL SUPPORT AND EMPOWERMENT

Strengthening patients and caregivers has been another fundamental pillar of our work. In this regard, ANHP organised the psychosocial workshop “The Art of Caring (for Yourself): Well-being for Caregivers”, delivered by the association’s psychologist, as well as the webinar “Rights and Resources in Pulmonary Hypertension”, which addressed key issues such as disability assessment, dependency and work incapacity—processes that are often complex and emotionally demanding.



to Juan Izquierdo, a physiotherapist at Hospital Universitario 12 de Octubre (Madrid), for his commitment to rehabilitation and improving quality of life through cardiopulmonary exercise.

ANHP also recognised the essential role of Irene Delgado, patient and founder of the association, for her courage in creating a space of support and hope, as well as the work of Eva García, president since 2016, for her close leadership, experience as an expert patient and ongoing dedication.

Throughout the year, ANHP also supported and disseminated international campaigns promoted by PHA Europe, reinforcing alignment with shared messages and objectives at the European level.

## A COMMEMORATIVE EVENT CELEBRATING 20 YEARS OF HISTORY

On the 24th of May, ANHP celebrated its 20th anniversary with a commemorative event filled with emotion, remembrance and commitment. The event brought together patients, family members, healthcare professionals, partner organisations and institutional representatives in a gathering that honoured the past and projected hope for the future.



One of the most meaningful moments was the recognition of volunteers, whose commitment has been essential to the association’s development. Special acknowledgement was given to the community of El Espinar (Segovia), which for years has actively supported fundraising initiatives for projects focused on support, research and awareness.



Recognition was also given to the work carried out in the creation and consolidation of specialised pulmonary hypertension units, such as those at Hospital San Pedro de Alcántara (Cáceres) and Hospital Virgen de la Victoria (Málaga), highlighting the importance of specialised and equitable healthcare across the country.

Two particularly moving awards were proposed directly by patients. The first was presented to Raúl Rodríguez, a nurse specialised in pulmonary hypertension, in recognition of his professional and compassionate support for patients undergoing subcutaneous treprostinil treatment. The second was awarded



## COMMUNITY, CONTINUITY AND LOOKING TO THE FUTURE

Throughout the year, mutual support groups for patients were maintained, providing key spaces for sharing experiences, emotional strengthening, self-care and adherence to complex treatments. Likewise, the ANHP Breakfast Meetings were consolidated as spaces for dialogue and connection between patients, caregivers and healthcare professionals.



In 2025, continuity was given to the patient support project at Hospital Universitario 12 de Octubre in Madrid, supported by an agreement with the Community of Madrid and the Madrid Health Service. This project included monthly seminars in collaboration with the hospital’s pulmonary hypertension unit, as well as its presentation at specialised international forums.

The year concluded with the awareness campaign “Every Person Matters: Pulmonary Hypertension Has a Face”, aligned with European initiatives focused on equity in access to healthcare and treatments. Actions included institutional meetings to address barriers in disability assessment, participation in parliamentary forums and the organisation of events for patients and families in different regions of Spain.



After 20 years of work, the National Pulmonary Hypertension Association reaffirms its commitment to people living with this disease. We continue to move forward with the conviction that unity, visibility and collaborative work are the most powerful tools to transform realities and build a fairer and more hopeful future for the pulmonary hypertension community.





# SPAIN FCHP

## THE SPANISH PULMONARY HYPERTENSION FOUNDATION STRENGTHENS ITS COMMITMENT TO AWARENESS, RESEARCH AND PATIENT SUPPORT

In recent months, the **Spanish Pulmonary Hypertension Foundation (FCHP)** has carried out an intense range of activities reflecting its ongoing commitment to people affected by the disease, their families and the advancement of scientific knowledge.

One of the most significant institutional milestones was the **meeting with the President of the Government of Catalonia**, a key opportunity to convey the reality of Pulmonary Hypertension and to advance dialogue with public administrations in support of greater awareness and improved patient care.

The Foundation also celebrated its **17th Anniversary**, a landmark event that brought together patients, families, healthcare professionals, researchers, institutional representatives and partner organizations. **The following day, the 7th Pulmonary Hypertension Patient Conference was held**, further reinforcing the Foundation's commitment to patient education and empowerment.



This conference featured the participation of **Matt Granato, CEO and President of the Pulmonary Hypertension Association (PHA)**, and **Dr. Alejandro Cruz from Hospital Universitario 12 de Octubre**, who addressed key topics such as Pulmonary Hypertension, new treatment options, the importance of patient participation in clinical trials, and the role of genetics in the disease.

The programme also included a **nutrition workshop led by Silvia García** and a **psychology workshop delivered by the Foundation's psychologist, Rocío Cuenca**, creating a comprehensive and patient-centred approach. These were truly meaningful sessions, marked by shared experiences, learning and moments of deep connection.



Sport once again proved to be a powerful tool for awareness and solidarity through the **Velilla de San Antonio Charity Run**, a well-established event in the Foundation's calendar, as well as the **Charity Padel Tournament**, both initiatives combining community participation with support for FCHP projects.



In the scientific field, the Foundation took part in the **SECA Congress**, reinforcing its involvement in forums for knowledge exchange and professional development alongside specialists in the cardiovascular and respiratory fields.

Finally, Culture also played an important role with the launch of the charity album **"Empty Lungs"**, an initiative that uses music as a means of raising awareness and supporting Pulmonary Hypertension, bringing the disease closer to society from a different perspective.

Through all these initiatives, the Spanish Pulmonary Hypertension Foundation continues to move forward with the firm objective of **raising awareness of the disease, promoting research and supporting those living with Pulmonary Hypertension**, demonstrating that collective effort is essential to building a better future.



## SPAIN HPE-ORG

### PULMONARY HYPERTENSION SPAIN: A YEAR OF COMMITMENT, PARTICIPATION AND PROGRESS TOWARDS PERSON-CENTRED CARE

Over the last year, Pulmonary Hypertension Spain (HPE-ORG) has consolidated its role as a key player in defending the rights, supporting, and raising awareness of people living with pulmonary hypertension and other rare diseases. Through scientific conferences, psychosocial support programmes, strategic alliances and awareness-raising activities, the organisation has promoted a more humane, participatory, and equitable model of care.

### DIALOGUE BETWEEN PATIENTS AND PROFESSIONALS: REFERENCE CONFERENCES

One of the most notable milestones was the 16th Pulmonary Hypertension Conference held at the Hospital Clínic in Barcelona, a hybrid event that brought together patients, family members, and healthcare professionals. The programme addressed therapeutic advances, new molecules, the role of lung transplantation, and the demystification of misconceptions about the disease. The president of HPE-ORG, María Rodríguez, advocated for the real integration of the patient's perspective into clinical practice and participation in hospital committees as a way to promote earlier diagnoses.

The day concluded by reinforcing the idea of person-centred care based on collaboration.

Along the same lines, HPE-ORG's participation in high-level forums, such as the 11th Affective Effective Awards Forum. The debate on reference units for pulmonary hypertension has served to highlight the importance of measuring results, the patient experience, and the need for sustainable resources that guarantee equity throughout the territory.



**AWARENESS AND RIGHTS: GIVING A VOICE TO RARE DISEASES**

The organisation has actively participated in the Rare Disease Day and European Patient Rights Day, highlighting the importance of access to diagnosis, information, and participation in healthcare decisions. Under slogans such as ‘Share your colours’ and ‘The value of our experience’, HPE-ORG has encouraged citizens to get involved and recognise the fundamental role of patients as active agents in the healthcare system.

Of particular relevance was its participation in the 18th World Rare Disease Day in Catalonia, held at the Recinte Modernista de Sant Pau, where unity, visibility, and active participation were highlighted, as well as recognition of leading professionals in the treatment of pulmonary arterial hypertension.

**COMPREHENSIVE SUPPORT PROGRAMMES: SUPPORT BEYOND DIAGNOSIS**

Psychosocial support remains one of the pillars of the organisation. The **‘Learning to Breathe’** programme, active since 2017, continues to evolve with online training, support groups, emotional workshops, yoga and physiotherapy, ensuring equitable access tailored to the real needs of people with PAH.

This project is complemented by initiatives such as **‘Afternoon Gatherings’**, emotional support groups led by psychologists in collaboration with the University of Barcelona; the **welcome programme for new patients**, which offers guidance from the moment of diagnosis; and **the pilot meeting for patients and family members**, focused on strengthening communication and mutual understanding within the family environment.

**TRAINING, ETHICS AND COMMUNITY**

HPE-ORG has also promoted spaces for community reflection, such as the talk on advance directives and euthanasia held in Sant Feliu de Llobregat, which fostered a respectful dialogue on autonomy and end-of-life issues, or hospital conferences



aimed at patients and families, such as the one organised at the Río Hortega University Hospital in Valladolid during Awareness Month.

**PARTNERSHIPS FOR PROGRESS**

The agreement signed with the Spanish Society for Healthcare Quality (SECA) marks a decisive step towards raising awareness of the social and occupational impact of pulmonary arterial



hypertension, incorporating the patient’s perspective into healthcare quality policies and research.

**NATIONAL STUDY IMPACT OF PULMONARY HYPERTENSION ON WORK DISABILITY AND QUALITY OF LIFE IN SPAIN**

We would particularly like to highlight that during 2025, Pulmonary Hypertension Spain – Patient Organisation (HPE-ORG) has promoted a nationwide study aimed at analysing the impact of pulmonary hypertension on work disability and quality of life of those affected in Spain. The initiative, developed in collaboration with a scientific committee composed of Dr. Pilar Escribano, Isabel Blanco, and Dr. Manuel López Meseguer, has the endorsement of scientific societies, SEPAR, SEC, and SECA. Its objective is to generate scientific evidence that will improve social and occupational recognition of the disease and contribute to the definition of more

appropriate support measures. This project reinforces HPE-ORG’s commitment to research, knowledge generation, and the defence of the rights of people with pulmonary hypertension.

**LOOKING TO THE FUTURE**

All these actions reflect a firm commitment: that no person with pulmonary hypertension should feel alone and that their voice should be part of the decisions that affect their health. Pulmonary Hypertension Spain continues to work towards a more participatory healthcare model, based on evidence, empathy and collaboration between patients, professionals, and institutions.



**SWEDEN**

**PATIENT MEETING IN STOCKHOLM**

Together with the PH-team at Karolinska University Hospital, we organized a successful patient meeting for patients with PAH, CTEPH, and their relatives.

**THE PATIENT VOICE**

We have participated in a large number of meetings with both healthcare providers and the pharmaceutical industry. In these meetings, the perspectives of patients and their relatives are a natural and sought-after part, and our voice is taken seriously and is highly valued.

**NEW MEMBER SURVEY ON TIME FROM FIRST SYMPTOMS TO DIAGNOSIS**

We conducted a new member survey on the journey from symptoms to diagnosis. The results show that although treatment options continue to develop, the time from the first symptoms to diagnosis is still far too long for many.

**YOGA STUDY FOR PAH PATIENTS**

Together with Linköping University Hospital, we have planned a yoga study aimed at PAH patients. The study will begin in the first quarter of 2026.

**NEW WEBSITE**

We launched a new website with a more modern, cleaner design and updated content. The hope is that it will make it easier to find information and learn about the association’s work.

**THE ASSOCIATION IS GROWING**

During the year, PAH Sweden has continued to develop. The number of members has increased from 225 to 253, and the board has been strengthened by expanding from six to seven members. This gives us better conditions to move the association’s work forward.





## UKRAINE PHA

### THE YEAR 2025 BECAME A PERIOD OF STEADY, MEANINGFUL, AND TRULY VIBRANT WORK FOR THE UKRAINIAN ASSOCIATION OF PATIENTS WITH PULMONARY HYPERTENSION

Amid war, instability, and constant pressure on the healthcare system, the Association continued to focus on what matters most - staying close to patients, supporting them, and bringing them together around knowledge, communication, and mutual trust.

One of the key areas of activity throughout the year was educational and informational initiatives. Patients regularly participated in online webinars dedicated to diagnostics, modern approaches to treatment, rehabilitation, and legal protection of patients' rights. These events brought together physicians from specialized expert centers, rehabilitation professionals, and representatives of governmental institutions. The webinars became a space for open dialogue - a place where patients could ask questions, receive professional explanations, and feel that they do not have to walk the path of illness alone.

Throughout the year, the Association also continued the implementation of the free NT-proBNP testing project for patients with pulmonary hypertension. For many people, access to this test is critically important, as it allows for an objective assessment of their condition and timely adjustment of therapy. Over the course of the year, more than 250 patients underwent free testing. Behind this number are real stories, timely clinical decisions, and a more confident course of treatment.



Special attention was given to supporting physical activity and respiratory function. A series of online sessions with adapted breathing and physical exercises was organized for patients, taking into account the specific features of the disease. All sessions were recorded and published on the Association's

YouTube channel, allowing patients to practice at a convenient time and at their own pace.

An essential part of the Association's work remains amplifying the voices of patients themselves and fostering their involvement in the broader orphan disease community. During the year, patients with pulmonary hypertension actively participated in the School of the Orphan Patient, organized by the "Rare Diseases of Ukraine," of which our Association is also a member, as well as in the activities of the Youth Division of the

Charitable Foundation "Orphan Swallows." This involvement helps build not only knowledge, but also a sense of belonging, confidence, and shared strength.

The past year once again demonstrated that a patient organization is not only about projects, reports, and events. Above all, it is about people - people who support one another, share their experiences, learn to live with a diagnosis, and together defend the right to a dignified life and quality medical care. **It is this unity that becomes the strength that allows the community to move forward, even in the most challenging times.**



## UKRAINE PHURDA

### A YEAR OF ADVOCACY, SUPPORT, AND SYSTEMIC CHANGE

Over the past year, the Pulmonary Hypertension Ukrainian Rare Disease Association continued its mission to support patients with pulmonary hypertension, strengthen the patient voice in health policy, and advance respiratory health in Ukraine. Despite the ongoing war, limited resources, and constant challenges in the healthcare system, PHURDA remained active at national and international levels, combining patient-centered support with systemic advocacy, education, analytical work, and international cooperation.

### PATIENT SUPPORT AND COMMUNITY CARE

Patient support remained at the core of PHURDA's activities throughout the year. The organization works 24/7 to provide informational, legal, and psychological consultations to patients with pulmonary hypertension and their family members. A dedicated hotline (tel. +380 97 151 09 01) continued to operate as a vital support channel, as well as the Viber PH support chat "ЛГшки," which has become a safe space for mutual assistance, sharing experiences, and emotional support for patients from all over the country.

The PHURDA Psychological Support Project, supported by GAAPP, provided regular monthly closed online meetings for patients. These unrecorded sessions allowed for the discussion of sensitive personal issues.



During the year, special thematic meetings were also organized for patients, including an online meeting dedicated to Rare Disease Day, a session on legislative changes in Ukraine related to disability registration, and several meetings on available digital resources for patients, including medical platforms and AI-based tools.

Through collaboration with partner organizations, PHURDA also responded promptly to individual patient needs, facilitating access to life-saving medicines and support.

### ADVOCACY AND HEALTH POLICY ENGAGEMENT IN UKRAINE

PHURDA remained a strong advocate for patients' rights and access to treatment within the Ukrainian healthcare system. PHURDA representatives regularly participated in weekly meetings of the Ukrainian Respiratory Coalition, which PHURDA co-founded, ensuring coordination among patient organizations and the medical community.





Throughout the year, PHURDA was involved in key national policy discussions, including:

- A high-level discussion on the underfinancing of medicines from the state budget, with representatives of the Ministry of Health, the Ministry of Finance, and Medical Procurement of Ukraine
- The national forum “Reimbursement 2025. Partnership for Sustainable Development,” organized by the National Health Service of Ukraine
- The meeting “State–Patient–Producer: Search for Effective Solutions,” organized by the CF “Patients of Ukraine”
- A consultation meeting of the National Health Service of Ukraine with patient organizations on healthcare financing priorities for 2026

PHURDA continued its work as a member of the Working Group of the Ministry of Health of Ukraine on Rare Diseases and was also actively involved in the areas of transplantation and pulmonary hypertension, contributing to interdisciplinary dialogue and the development of comprehensive solutions for patients with severe and orphan conditions.

In partnership with the Foundation “Patients of Ukraine,” PHURDA also participated in joint advocacy for the co-financing of orphan disease areas, emphasizing the need for sustainable and predictable mechanisms of state support.

### EDUCATION, AWARENESS, AND ANALYTICAL ACTIVITIES

Educational activities remained an important strategic direction of PHURDA’s work. A series of webinars for patients and healthcare professionals were held within the PH Academy, aimed at raising awareness and promoting professional dialogue.

An important event of the year was the first internship of a young

specialist at the Pulmonary Hypertension Center in Lviv. This was an important step in forming a new generation of specialists and strengthening expert potential in the field of rare diseases.

In September, PHURDA implemented the Healthy Lungs for Life project in Lviv, which included educational lectures in schools, an online flash mob, and the placement of informational banners throughout the city. The campaign aimed to prevent smoking among adolescents and raise awareness about lung health and the impact of air pollution.

A separate focus of the year was active analytical work. PHURDA systematically collected information on the state of the environment in Ukraine, the impact of tobacco smoking on the population, and the situation of patients with PH-ILD, including those without therapy and living in conditions of social isolation. These data form the basis for further advocacy and the preparation of analytical materials.



### INTERNATIONAL COOPERATION AND REPRESENTATION

PHURDA actively represented the interests of Ukrainian patients at the international level, participating in regular meetings of PH PAG, PAG EPAP, and EEA, as well as in events such as ELF Networking Day, the ERS Congress, the 6th International AAA Congress in Sarajevo, and the IRC Workshop 2025 in Amsterdam.

Significant events of the year included participation in APHEC and training within the European Respiratory Patient Academy in Prague, which became platforms for the exchange of experience, professional discussion, and the presentation of the Ukrainian context at the European level.

An important step in organizational development was PHURDA’s membership in the European Federation of Allergy and Airways Diseases Patients’ Associations (EFA). This membership significantly expanded opportunities for international cooperation and advocacy for Ukrainian patients, especially in wartime conditions.



### SOLIDARITY, FUNDRAISING, AND SUSTAINABLE INITIATIVES

With support from Gossamer Bio employees, PHURDA achieved a critical infrastructure milestone by purchasing a defibrillator for the Pulmonary Hypertension Center in Lviv, directly improving emergency preparedness and patient safety.

PHURDA continued its long-term social and environmental initiatives, including the fundraising campaign “Cork for Life.” During the year, more than 8 tons of plastic caps were collected and recycled. The funds raised were directed toward patient support and organizational activities.

### LOOKING FORWARD

This year has demonstrated the effectiveness of PHURDA’s comprehensive approach, combining direct patient support, systemic advocacy, education, analytical work, and international cooperation. Through persistent daily work and strong partnerships, PHURDA continues to support people living with pulmonary hypertension in Ukraine, ensuring that their voices are heard, their needs are addressed, and their right to quality care is protected.

“We constantly tell our international partners the truth: without real support during the war, patients with pulmonary hypertension in Ukraine lose their chance at life. Solidarity is not just words. It is joint actions that provide treatment, protect patients’ rights, and save lives every day.”

European RESPIRATORY PATIENT

Oksana Kulish - Skåra  
Head of PHURDA



# USA



Over the past year, the Pulmonary Hypertension Association advanced its mission through coordinated efforts in public awareness, professional education, research and improved access to trusted information for people affected by pulmonary hypertension.

PH Awareness Month in November provided a focused opportunity to deepen public understanding of the condition and its impact. This year's campaign, "EmPHasize Your Health," highlighted whole-person health, including physical and emotional well-being, for people living with PH. The campaign encouraged symptom recognition, screening and informed conversations with health care providers through broad public education and community engagement. Educational resources, advocacy tools and community perspectives were shared through digital platforms, with expanded reach to higher-risk communities through collaboration with organizations focused on associated conditions, including the American Lung Association, Adult Congenital Heart Association, National Scleroderma Foundation and the Foundation for Sarcoidosis Research. These partnerships helped reach broader patient and provider audiences and reinforced the importance of understanding related conditions when identifying and managing PH. Programming throughout the month included webinars, O2breathe Walks and activities dedicated to chronic thromboembolic pulmonary hypertension. Collectively, these efforts invited the global PH community to share experiences, raise awareness and support earlier diagnosis, appropriate treatment and ongoing care.

PHA also strengthened access to information through the launch of a redesigned website, PHAssociation.org. Over the course of

the year, all site content was reviewed, updated and reorganized to improve clarity, accessibility and ease of use. The updated site offers expanded educational content, improved navigation and print-friendly features that allow information to be easily shared in clinical and community settings. Medical experts, patients and caregivers contributed to the review process to ensure information is accurate, relevant and practical.

In September, PHA hosted the Pulmonary Hypertension Professional Network Symposium in Seattle, the first time the



event was held outside Washington, D.C. More than 650 people attended, making it the largest symposium to date. The program focused on team-based care, emerging clinical challenges and long-term strategies to improve outcomes. Sessions also addressed policy and advocacy issues related to patient access to treatment, highlighting the role of clinicians and researchers in shaping systems of care.

Research remained a cornerstone of the association's work. This year marked the 10th anniversary of the Pulmonary Hypertension Association Registry. Established in 2015, the registry now includes



information from more than 3,500 patients and allows researchers to study PH across all groups and pediatric populations.

Over the past decade, the registry has expanded from six pilot sites to more than 100 PH Care Centers in the United States. The data have informed more than 50 research proposals, supported numerous conference presentations and contributed to more than 20 peer-reviewed publications. Collectively, this work has advanced understanding of PH, supported improvements in patient care and contributed to the development of new treatment approaches. In 2025, researchers published new findings on medication non-adherence in PH, highlighting ongoing challenges in care delivery. This milestone coincided with PHA surpassing \$10 million in research grants funded over the past 25 years.

Together, these efforts reflect a year of steady progress in awareness, access to information, research and professional education, reinforcing a continued commitment to improving care and quality of life for people affected by PH globally.



# Belgium



# Bulgaria BSPPH



# Bosnia and Herzegovina



# Croatia





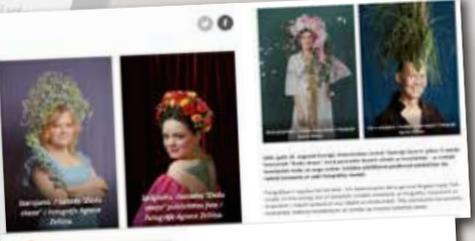
Czech Republic



Hungary



Latvia



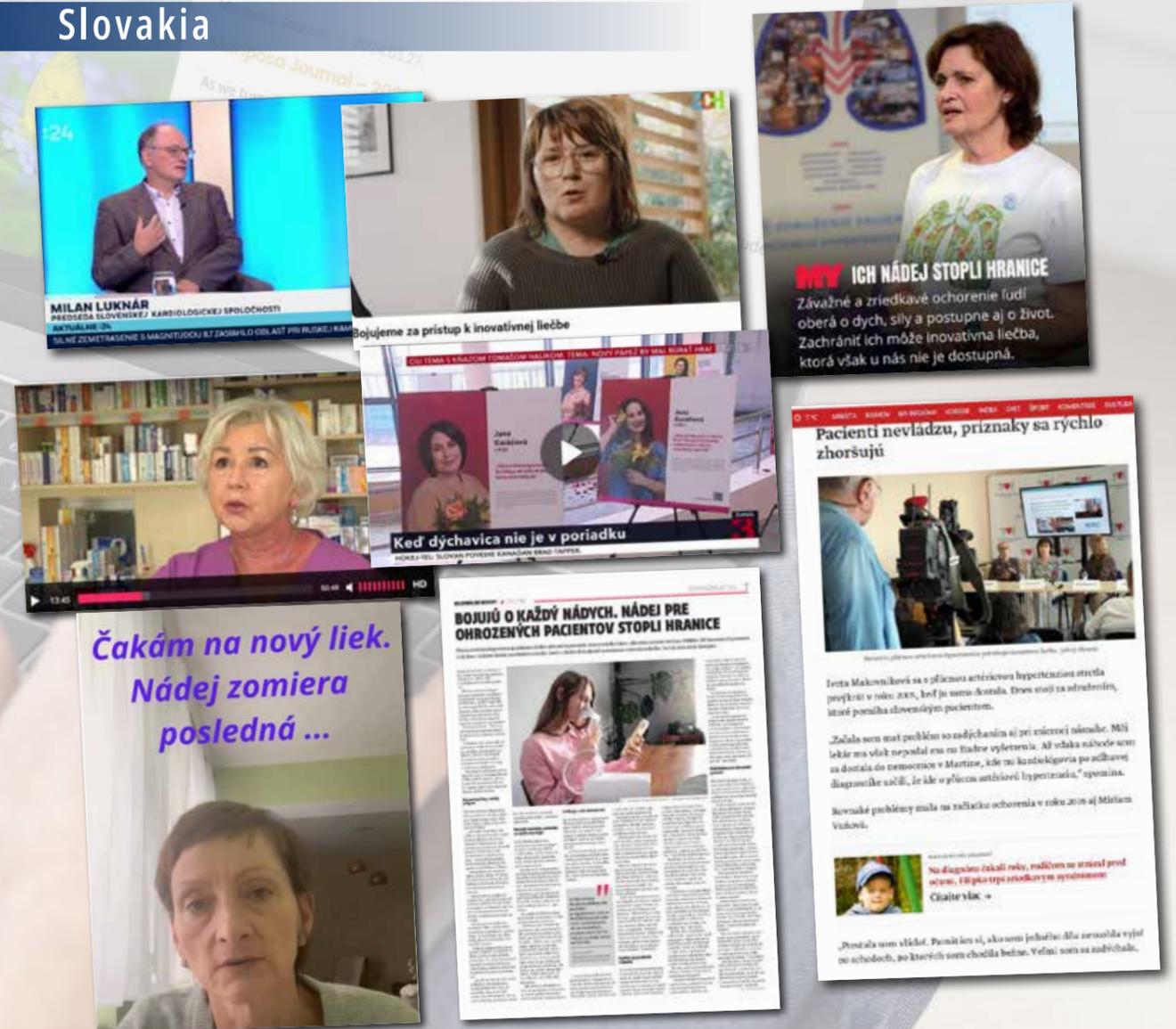
# Poland



# The Netherlands



# Slovakia

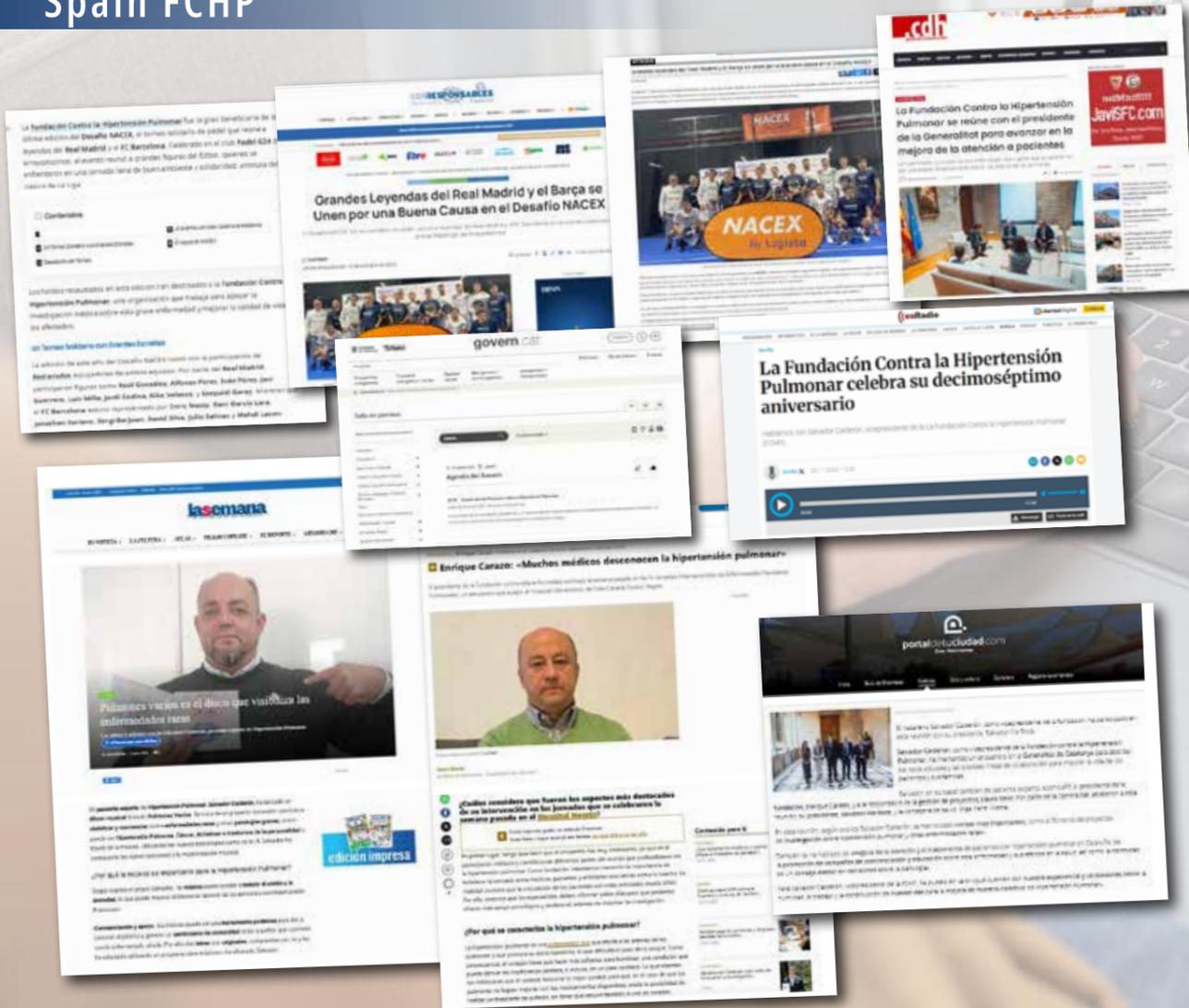


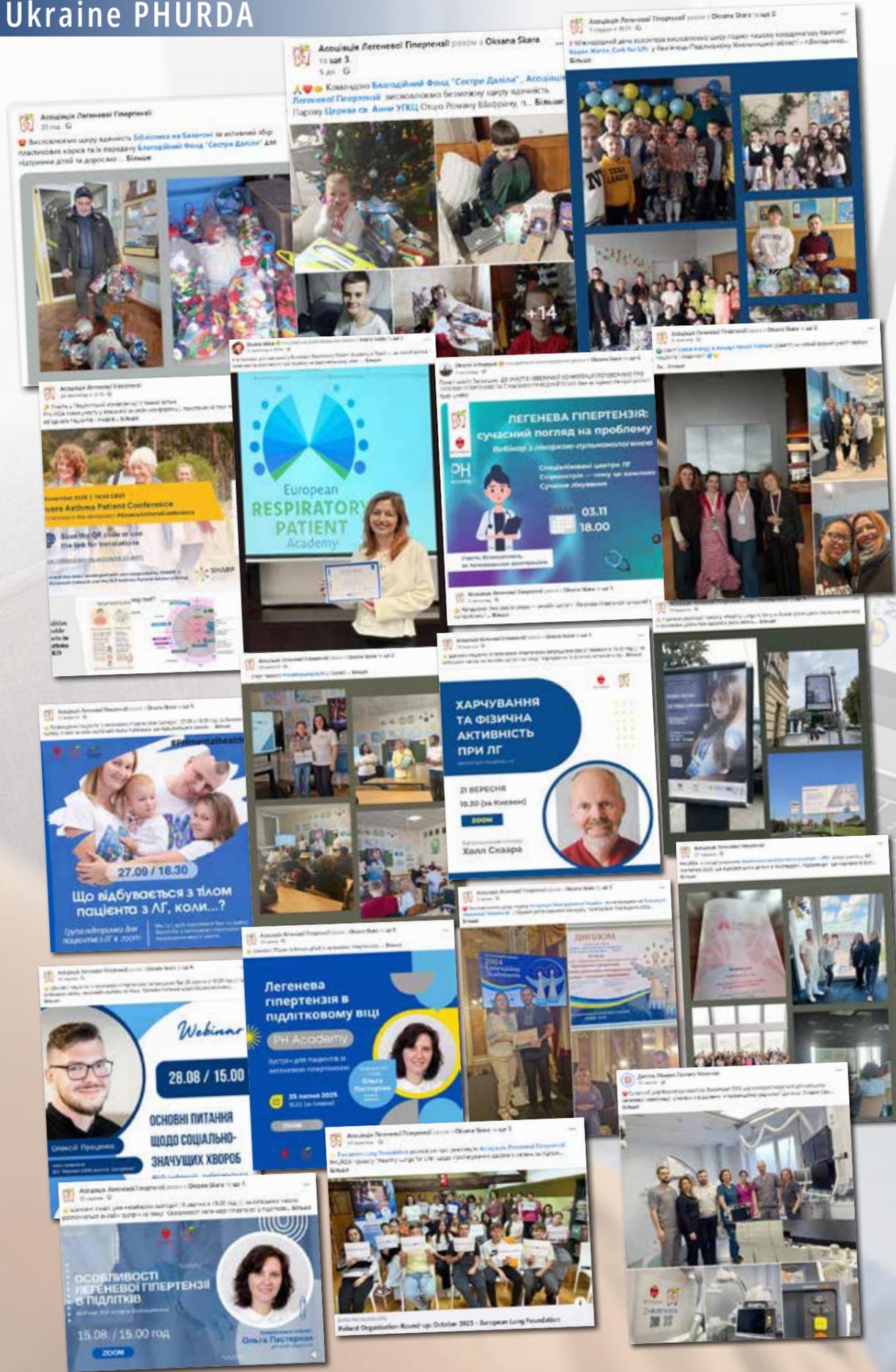
# Norway



Čakám na nový liek.  
Nádej zomiera  
posledná ...







• SPONSORS •

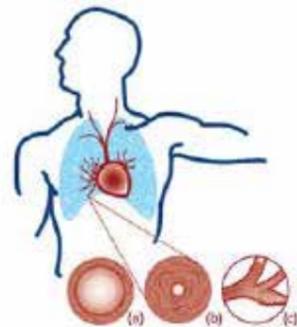


## AIMS OF PHA EUROPE

Pulmonary arterial hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria as an international nonprofit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hypertension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations, and public institutions worldwide and work towards achieving the best possible standards of care for all European pulmonary hypertension patients.

## WHAT IS PULMONARY ARTERIAL HYPERTENSION?

In patients with Pulmonary Arterial Hypertension, characteristic changes occur within the pulmonary circulation, which include thickening of the linings and obstruction of the small pulmonary blood vessels. They are both structurally and functionally abnormal. In severe cases, up to 80% of these very small blood vessels are rendered non-functional. As a result, the pressure in the pulmonary circulation rises well above normal, and this places strain on the right side of the heart. This strain can cause the heart to enlarge, and the patient may develop heart failure. This is a disease that can affect all ages and is more commonly seen in females. Pulmonary arterial hypertension has an estimated prevalence of about 50 per million population.



a) Cross section of normal pulmonary artery

b) Reduced lumen of pulmonary vessels due to cell proliferation and remodelling in advanced pulmonary arterial hypertension

c) Longitudinal section with pathological changes within the vessels (proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs

## TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

Over the past decade, a number of evolving therapies that either use complex delivery systems such as 24-hour intra-venous or subcutaneous drug infusion, drug inhalation and, more recently, oral medications, have transformed the outlook for PAH patients. PAH is a condition that can be rapidly progressive and needs careful, ongoing expert care and management. The disease can be insidious in its onset, with unexplained breathlessness and tiredness as its two main symptoms. If undiagnosed and/or inappropriately treated, the average life expectancy for these patients is estimated to be around 2-3 years. For those patients who fail to respond to medical therapies, double lung, or in some cases, heart and lung transplantation, may be appropriate.

## THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

While a cure for this aggressive and life-threatening disease is still some way off, there is much to be optimistic about. There are an ever-increasing number of therapies available for the effective treatment of pulmonary arterial hypertension, which improve the quality and length of life. The aim for the present should be to ensure that all patients with pulmonary arterial hypertension have access to centres of excellence in the diagnosis, management, and ongoing treatment of this disease.

## Members of PHA Europe and contact details

### AUSTRIA



**PH Austria**  
**Initiative Lungenhochdruck**  
Wilhelmstraße 21 - 1120 Wien  
[www.phaustria.org](http://www.phaustria.org)  
[info@phaustria.org](mailto:info@phaustria.org)

### ESTONIA



**Eesti Pulmonaalhüpertensiooni Ühing**  
[eessti.ph@gmail.com](mailto:eessti.ph@gmail.com)  
+37253004221

### BELARUS



**Aid to Patients with Pulmonary Hypertension**  
Zapadnaya str. 13 - 3  
Minsk, 220036  
[phbelarus@yandex.ru](mailto:phbelarus@yandex.ru)

### FINLAND



**Suomen PAH-potilasyhdistys ry. PHA Finland**  
c/o Sonja Koski  
Wilhelmstraße 21 - 1120 Wien  
[suomenpahry@gmail.com](mailto:suomenpahry@gmail.com)

### BELGIUM



**Belgische patiëntenvereniging voor Pulmonale Hypertensie vzw (P.H. België)**  
Kruisbeeldstraat 28, 9220 Hamme, Belgium  
[info@ph-vzw.be](mailto:info@ph-vzw.be)

### HUNGARY



**Tüdőér Egylet**  
19, Cházár András utca - 1146 Budapest  
[www.tudoer.hu](http://www.tudoer.hu)  
[csabuda.eszter@t-online.hu](mailto:csabuda.eszter@t-online.hu)

### BOSNIA AND HERZEGOVINA



**Udruženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini**  
Zlatnih ljiljana 33, 72220 Zavidovići, BiH  
[ugphbih@gmail.com](mailto:ugphbih@gmail.com)

### ITALY



**Associazione Ipertensione Polmonare Italiana Onlus**  
Via Cortazzis 5 - 33100 Udine, Italy  
<https://www.aipiitalia.it/>

### BULGARIA



**Pulmonary Hypertension Association**  
37 Hadji Dimitar str, ent. B, fl. 2, ap. 3  
5800 Pleven  
[www.phbulgaria.eu](http://www.phbulgaria.eu)  
[todormangarov@abv.bg](mailto:todormangarov@abv.bg)  
[info@phbulgaria.eu](mailto:info@phbulgaria.eu)

### ITALY



**Associazione Malati di Ipertensione Polmonare Onlus**  
Via Ardea 1/B - 00183 Rome  
[www.assoamip.net](http://www.assoamip.net)  
[info@assoamip.net](mailto:info@assoamip.net)

### BULGARIA



**The Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH**  
Pirinski prohod str., bl.24 A, entr. B, fl.3, ap.34 Sofia- 1680, Bulgaria  
[www.bspph.net](http://www.bspph.net)  
[bgspph@gmail.com](mailto:bgspph@gmail.com)

### KOSOVO



**SSH P KOSOVË**  
Based in Kosovo, Sterpce  
Phone number +383-45-211-835  
[kosovaphinfo@gmail.com](mailto:kosovaphinfo@gmail.com)

### CROATIA



**Plava krila - Udruga pacijenata oboljelih od plućne hipertenzije**  
Gorica Jamnička 23 - 10451 Pisarovina  
[infoplavakrila@gmail.com](mailto:infoplavakrila@gmail.com)  
[www.plavakrila.hr](http://www.plavakrila.hr)

### LATVIA



**PHA Latvia**  
Str. Celnieku 6a - 35, Salaspils - LV - 2121  
[www.phlatvia.lv/en/](http://www.phlatvia.lv/en/)  
[phbbiedriba@gmail.com](mailto:phbbiedriba@gmail.com)

### CZECH REPUBLIC



**Sdružení pacientů s plicní hypertenzí, z.s**  
Náměstí 14. října 1307/2, Praha 5, 150 00  
[www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)  
[info@plicni-hypertenze.cz](mailto:info@plicni-hypertenze.cz)

### LITHUANIA



**Žmonių sergančių plautine hipertenzija asociacija**  
Biržų g. 2, Papilys, LT-41221, Biržų raj., Lietuva  
[www.zspha.lt](http://www.zspha.lt)  
[info@zspha.lt](mailto:info@zspha.lt)

## Associated members of PHA Europe and contact details

### MOLDOVA



**Asociația Obstească**  
 „Asociația persoanelor cu hipertensiune pulmonară din Republica Moldova”  
 Moldova, MD-2024, str. Andrei Doga 34, ap. 43  
[roman.balmush@gmail.com](mailto:roman.balmush@gmail.com)

### NETHERLANDS



**The Netherlands**  
 Stichting Pulmonale Hypertensie  
 Postbus 418 2000 AK Haarlem  
<https://stichtingpulmonalehypertensie.nl/>  
[info@stichtingpulmonalehypertensie.nl](mailto:info@stichtingpulmonalehypertensie.nl)

### NORTH MACEDONIA



**APH Moment Plus Macedonia**  
 „Association for Pulmonary Hypertension Moment Plus Macedonia”  
 Tance Kamberov 29,1480 Gevgelija  
[phmomentplus@gmail.com](mailto:phmomentplus@gmail.com)

### NORWAY



**PHA Norway**  
 LHL PAH - Pulmonal hypertensjon  
 Vitaminveien 1A  
 0485 Oslo, Norway  
[www.lhl.no/trenger-du-hjelp/interessegrupper/lhl-pah](http://www.lhl.no/trenger-du-hjelp/interessegrupper/lhl-pah)  
[lhl.pah@lhl.no](mailto:lhl.pah@lhl.no)

### POLAND



**Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół**  
 street Wielicka 57e/5; 30-552 Kraków, Poland  
[www.phapolska.org](http://www.phapolska.org)  
[kontakt@phapolska.org](mailto:kontakt@phapolska.org)  
 President: Małgorzata Piekarska:  
[malgorzata.piekarska@phapolska.org](mailto:malgorzata.piekarska@phapolska.org)  
 Vice-President:  
[Izabela Łęga, izabela.lega@phapolska.org](mailto:Izabela.Lega.izabela.lega@phapolska.org)

### PORTUGAL



**Associação Portuguesa de Hipertensão Pulmonar**  
 Rua Dr Costa Simões, 59. 3050-226 Mealhada  
[www.aphp.pt](http://www.aphp.pt)  
[associacaohipertensaopulmonar@gmail.com](mailto:associacaohipertensaopulmonar@gmail.com)

### ROMANIA



**Association of pulmonary hypertension patients**  
 Sinaia/Prahova Carol I, nr 11 street  
<http://hipertensiunepulmonara.ro/>

### RUSSIAN FEDERATION



**Save and Protect**  
 Pobedi prospect 102 / office 45 - Kazan  
 Republic of Tatarstan, 420140  
<http://www.ph-association.ru/>  
[lilya-belle@yandex.r](mailto:lilya-belle@yandex.r)

### SERBIA



**Plućna Hipertenzija Srbija**  
 Ul. Kneza Mihaila 33  
 11000 Beograd  
[www.phserbia.rs](http://www.phserbia.rs)  
[office@phserbia.rs](mailto:office@phserbia.rs)

### SLOVAKIA



**Združenie pacientov s pľúcnou hypertenziou, o.z. Lučenská 31 - 990 01 Veľký Krtíš**  
[www.phaslovakia.org](http://www.phaslovakia.org)  
[phaslovakia@gmail.com](mailto:phaslovakia@gmail.com)

### SLOVENIA



**Društvo za pljučno hipertenzijo Slovenije**  
 Slovenska 29, 1000 Ljubljana  
[dbph.slovenije@gmail.com](mailto:dbph.slovenije@gmail.com)  
[www.facebook.com/PljucnaHipertenzija](https://www.facebook.com/PljucnaHipertenzija)

### SPAIN



**ANHP Asociación Nacional de Hipertensión Pulmonar**  
 Calle Villajimena nº 85, 1º 4 C.P.  
 28032 Madrid  
[www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)  
[informacion@hipertensionpulmonar.es](mailto:informacion@hipertensionpulmonar.es)

### SPAIN



**FCHP Fundación Contra la Hipertensión Pulmonar**  
 Calle Pablo Neruda, 39 28980 Parla - Madrid  
<http://www.fchp.es/es-info@fchp.es>  
<https://www.facebook.com/fundacionhp>  
<https://twitter.com/fundacionhp>  
<https://www.instagram.com/fundacionfchp/>  
<https://www.linkedin.com/company/fundaci%C3%B3n-contrala-hipertensi%C3%B3n-pulmonar>

### SPAIN



**Hipertensión Pulmonar España Organización de Pacientes (HPE-ORG)**  
 Sant Feliu de Llobregat  
 c/o Anselm Clavé no 33 3o 3a - CP 08980 Barcelona  
<http://www.hipertension-pulmonar.com>  
[presidencia@hpe-org.com](mailto:presidencia@hpe-org.com)

### SWEDEN



**PAH Sverige**  
 c/o Patrik Hassel  
 Kärrtorpsvägen, 37  
 121 55 Johanneshov  
[www.pah-sverige.se](http://www.pah-sverige.se)  
[patrik@pah-sverige.se](mailto:patrik@pah-sverige.se)

### UKRAINE



**Pulmonary Hypertension Ukrainian Rare Disease Association-PHURDA**  
 Hlyboka street 12, Lviv 79013  
[fond.poryatunok@gmail.com](mailto:fond.poryatunok@gmail.com)

### UKRAINE



**PHA Ukraine**  
 Rusanivskyy Blvd, 7, Off. 3, Kyiv, Ukraine, 02147  
[www.pha.org.ua](http://www.pha.org.ua)  
[info@pha.org.ua](mailto:info@pha.org.ua)

### ARGENTINA



**HIPUA Hipertension Pulmonar Argentina**  
 Juramento 2120 4º “11” – Ciudad Autónoma de Buenos Aires (CABA) CP:1428  
[hipertensionpulmonarargentina@gmail.com](mailto:hipertensionpulmonarargentina@gmail.com)

### CHINA



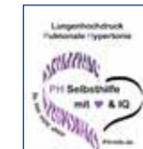
**iSEEK Pulmonary Hypertension Hope Center (PHA China)**  
 Rm.102B, NO.2 Block, NO5. Huayuanlu, Haidain District, Beijing, P.R.China  
[gloriahuan@hotmail.com](mailto:gloriahuan@hotmail.com) (for international communication)  
[huanghuan@iseek.org.cn](mailto:huanghuan@iseek.org.cn) (for Chinese)

### COLOMBIA



**Sociedad Latina de Hipertensión Pulmonar - Inicio**  
 Carrera 66 C 42-37 Código postal 110931 Bogotá- Colombia  
[admin@sociedadlatinahp.org](mailto:admin@sociedadlatinahp.org)  
[d.grajales@sociedadlatinahp.org](mailto:d.grajales@sociedadlatinahp.org)

### GERMANY



**Pulmonale Hypertonie Selbsthilfe**  
 Hafenstraße 122, 46242 Bottrop, Germany  
[daniela.schiel@pulmonale-hypertonie-selbsthilfe.de](mailto:daniela.schiel@pulmonale-hypertonie-selbsthilfe.de)

### ISRAEL



**PHA Israel**  
 13 HaShoshan Street - Beit Shemesh 9959013 Israel  
[www.phisrael.org.il](http://www.phisrael.org.il)  
[office@phisrael.org](mailto:office@phisrael.org)

### JAPAN



**PHA Japan**  
 Village A 209, 5-8 Tsukimino, Yamatoshi, Kanagawaken, 242-0002 Japan  
[npophajapan@gmail.com](mailto:npophajapan@gmail.com)

### NIGERIA



**Cardiac Community**  
 4a Idowu Olaitan StGbagada, Lagos 102216, Lagos, Nigeria  
[info@cardiaccommunity.org](mailto:info@cardiaccommunity.org)

### USA



**Pulmonary Hypertension Association**  
 1121 14th St NW, Suite 150 Washington D.C., 20005  
<https://phassociation.org/>



EDITOR & RESPONSIBLE FOR THE CONTENT:

PHA EUROPE  
Wilhelmstraße 21  
A-1120 Vienna  
Austria

[info@phaeurope.org](mailto:info@phaeurope.org) - [www.phaeurope.org](http://www.phaeurope.org)