

PULMONARY HYPERTENSION Mariposa Journal

SUMMER 2026 • PHA EUROPE'S OFFICIAL JOURNAL • N. 36



early diagnosis • best treatment • better quality of life • finding a cure

PHAEUROPE & *Global*
PULMONARY HYPERTENSION ASSOCIATION

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Editor's memo

SUMMER EDITION • 2026

Dear Friends, Colleagues, and Supporters,

Welcome to the Summer 2026 edition of Mariposa, dedicated to World Pulmonary Hypertension Day!

This year, our World PH Day campaign focused on the theme **"Hope in Every Trial,"** highlighting the importance of clinical research and the hope that new treatments bring to people living with pulmonary hypertension.

Throughout May, we ran an extensive social media campaign combining educational materials with the voices and experiences of patients from around the world. The campaign included 19 patient testimonials and more than 20 infographics covering pulmonary hypertension, clinical trials, treatment progress, innovation and the importance of patient involvement in research. More than 45 PH organisations worldwide took part by sharing, translating, and adapting the materials for their own communities.

The response was impressive. Across Facebook and Instagram, the campaign reached 4.5 million people, while content interactions increased by 190% compared with our 2025 World PH Day campaign. These results show that even a complex topic such as clinical trials can generate strong engagement when it is communicated in an understandable and patient-centred way.

Clinical trials were also the focus of our World PH Day webinar, **"Clinical Trials in Focus – Hope in Every Trial: Two Perspectives – One Goal."** Professor Ardeshtir Ghofrani presented the academic perspective, while Dr. Michelle Ghofrani from Liquidia Corporation explained how the pharmaceutical industry approaches the development of new medicines. Together, they gave us a fascinating insight into the long journey from scientific discovery to an approved treatment – and reminded us how important collaboration between researchers, industry and patients is in developing tomorrow's therapies.

But, as always, World PH Day is really brought to life by the activities of our member associations.

Once again, they showed remarkable creativity and commitment. In Ukraine, patients explored equine-assisted therapy at the Kyiv Hippodrome, learning how interaction with horses can support emotional and psychological rehabilitation. In Slovakia, patients celebrated the 10th anniversary of their traditional symbolic mountain march, this year joined by friends from the Czech PH community.

In Bulgaria, a successful fundraising initiative resulted in six oxygen concentrators being made available to patients. Croatia found a very different way to communicate our message with **The Scarf That Breathes** – a specially designed blue scarf symbolising breath, life, hope and solidarity with the PH community.

And sometimes, a small initiative can make a very strong impression. In Poland, Milenka, the daughter of a PH patient, decided to organise an educational event at her school, teaching other children about PH, empathy and understanding.

These are only a few examples. Throughout this edition of Mariposa, you will find many more activities – from educational meetings and awareness walks to media campaigns, sporting events and iconic buildings illuminated in support of the PH community.

What always impresses me about World PH Day is the enormous variety of ideas, but also the common purpose behind them. Whether an activity reaches a classroom, a city, or millions of people through social media, every effort helps make pulmonary hypertension more visible. This year's campaign also reminded us that patients are not only participants in research – they are partners in innovation, and their experiences and perspectives are essential in shaping the future of PH care.

Above all, this year's World PH Day reminded us that hope grows when we share our stories, listen to one another and work together towards a future where every person living with PH has access to better treatments and a better quality of life.

I would like to thank all our member associations, volunteers and everyone else who contributed to World PH Day 2026. A special thank you also goes to our industry partners for their continued

support of PHAEUROPE & Global and our member associations.

I hope you enjoy this special World PH Day edition of Mariposa!

Warm regards,

Zdenka Bradac

President of PHAEUROPE & Global

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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 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.

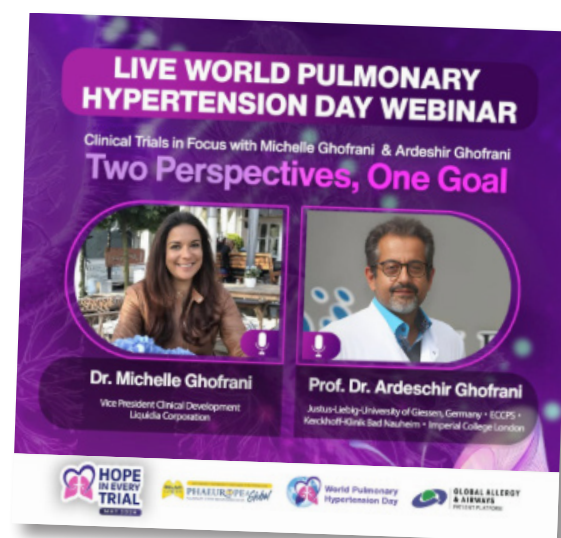
From our landing page, you can click on a link to access Bel Air Center. When you log in for the first time, you create a personal password that does not expire. You only need to enter this password the very first time; on subsequent visits, you will be taken directly into the Center when using the same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

The centre currently offers more than forty presentations covering various aspects of PH. One example is our World PH Day webinar Clinical Trials in Focus – Hope in Every Trial, presented by Professor Ardeschir Ghofrani and Dr. Michelle Ghofrani. The webinar explores how new PH treatments are developed and why clinical trials are essential for future advances.

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



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
PH Human™



Johnson & Johnson

Hollie, 37
United Kingdom
Entrepreneur
Living with pulmonary arterial hypertension

CP-561853 | January 2026

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Mariana ★★★★★

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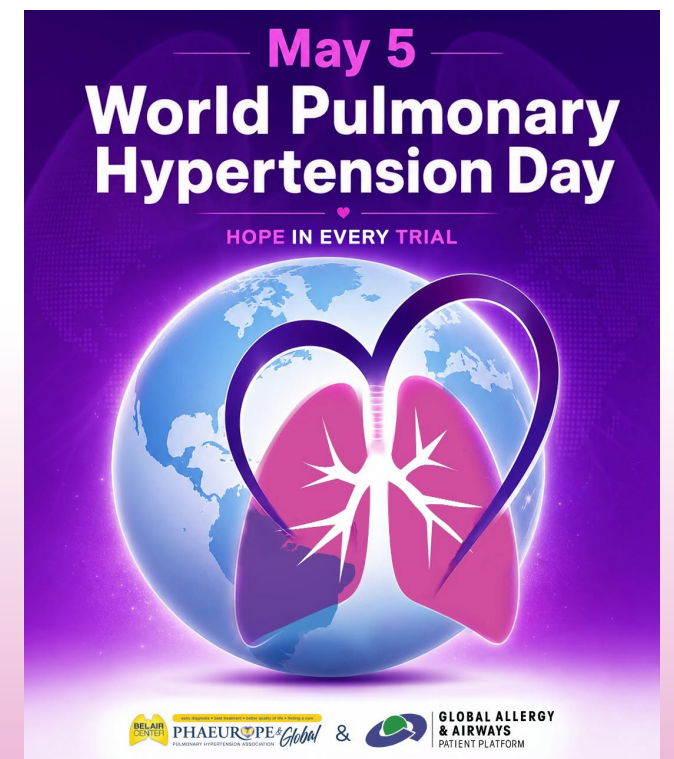
SOCIAL MEDIA



WORLD PH DAY 2026: HOPE IN EVERY TRIAL

World Pulmonary Hypertension Day 2026 carried a message that was different in tone, but equally powerful in meaning. While previous campaigns focused strongly on awareness, early diagnosis, access to care, PH symptoms, and the lived reality of pulmonary hypertension, this year's campaign opened a new and deeply important conversation: the role of clinical trials, innovation, and patient participation in shaping the future of PH care.

Under a symbolic slogan "Hope in Every Trial," the 2026 campaign placed clinical research at the heart of the global PH conversation. For many patients, clinical trials are often discussed only in highly medical settings, during expert conferences, or in difficult moments when existing therapies are no longer enough. This year, PHAEUROPE & Global brought that conversation closer to the community itself. Through the voices of patients from different parts of the world, the campaign helped translate a complex scientific topic into something personal, understandable, and profoundly human.



WORLD PH DAY 2026

Hope in Every Trial

Despite a smaller campaign footprint, 2026 delivered **markedly stronger engagement, follower growth, and audience response** than 2025.



The 2026 campaign may have been smaller in volume and scope than some previous editions, especially compared with the 2025 “Sometimes it’s PH” campaign, which included more than 70 patient stories and continued through much of June. Yet its impact was no less remarkable. Despite addressing a more delicate and complex topic, the campaign achieved significant results and showed that the global PH community is ready to engage with deeper, more challenging conversations when they are presented with clarity, trust, and humanity.

Clinical trials are not only about science. They are about possibility: the hope that tomorrow’s treatments may be more effective, more accessible, and more tailored to the needs of people living with PH. They are also about courage - the courage of patients who take part in research, the commitment of doctors and researchers who dedicate their work to innovation, and the responsibility of the global community to ensure that progress reaches everyone, not only those with the easiest access to specialist care.

Although World PH Day itself is marked on May 5, the campaign continued throughout May as a month-long global awareness effort. Built around 19 patient testimonials and more than 20 infographics, it combined personal stories with educational content on pulmonary hypertension, clinical trials, treatment progress, innovation, and the importance of patient involvement in research.

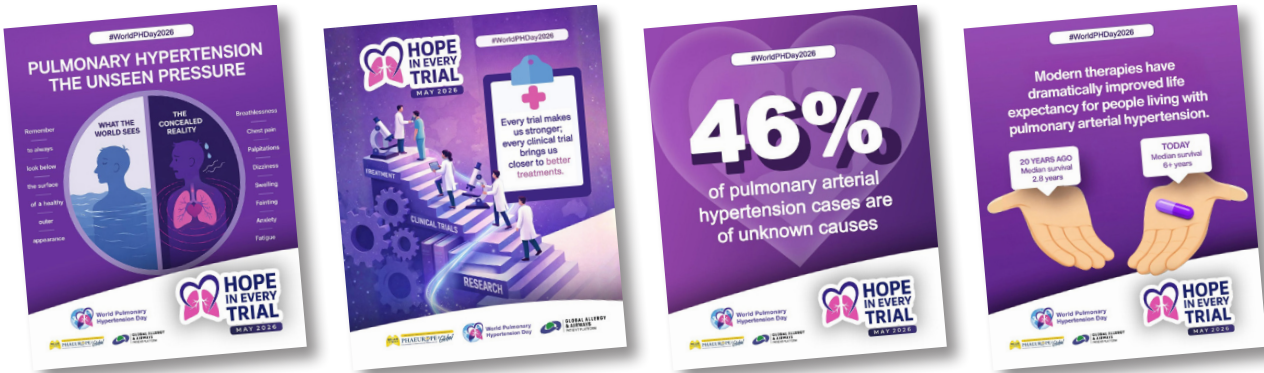
Across Facebook and Instagram, the campaign reached 4.5 million people. Even more importantly, engagement rose dramatically compared with the previous year’s larger campaign. Content interaction increased by 190% compared with “Sometimes it’s PH,” showing that this year’s message did not only reach people, it moved them to respond, react, share, and take part.

The increase in link clicks to both the PHAEUROPE website and worldphday.org was also significantly higher, confirming that the campaign encouraged audiences to seek more information and engage beyond social media.

At the center of the campaign were the patient testimonials. For the second consecutive year, World PH Day placed patients’ voices at the heart of the message. This has become one of the campaign’s greatest strengths: not speaking about patients, but with them; not reducing PH to statistics, but allowing the reality of life with PH to be seen through real experiences and faces.

This year, patients spoke about access to treatment, the need for innovation, the barriers that still exist in many countries, and the hope connected to clinical trials and future therapies. They reflected on the emotional weight of living with a rare and complex disease, but also on the importance of being included, heard, and represented in research. Their stories showed that clinical trials are not an abstract scientific process, but part of a wider journey toward better care, better treatment options, and a more equal future for all PH patients.

The response from patients around the world was deeply moving. PHAEUROPE & Global is sincerely grateful to all European associations whose members shared their stories, as well as to associations and patients from China, Latin America, North and South America, and Africa. We are also thankful to the patient



associations from the USA and Canada. The participation of patients from almost every continent once again confirmed the high level of trust that the global PH community places in the work of PHAEUROPE & Global. It also showed that this trust is one of the reasons the organization continues to grow - not only in numbers, but in relevance, reach, and responsibility.

The structure of the 2026 campaign followed a clear educational path. It began with essential information about pulmonary hypertension, including its definition, prevalence, complexity, and the five PH groups with understandable and engaging infographics. From there, the campaign moved toward the extraordinary progress that has been made over the past three decades, particularly in the field of pulmonary arterial hypertension treatment.

This progress is one of the strongest reasons for hope. In only a few decades, PH care has changed dramatically. Treatments have improved, understanding of the disease has deepened, and research has opened doors that were once unimaginable. Yet the campaign also made clear that progress does not happen on its own. It depends on research, collaboration, investment, clinical trials, and the willingness to include patients as partners in innovation.

A central message of “Hope in Every Trial” was that patients who

participate in clinical trials are not only receiving care, they are helping to build the future of care. Their participation contributes to the development of new and innovative therapies that may one day become available to many others. In this way, clinical trials become more than a scientific process. They are also an act of solidarity across time: today’s patient may help tomorrow’s patient breathe easier.

At the same time, the campaign did not ignore the inequalities that still exist. Patients from different regions of the world shared different perspectives, reminding us that access to clinical trials is not equal everywhere. Some patients live in countries where research opportunities are limited or unavailable. Others face barriers related to geography, information, referral pathways, specialist care, language, or awareness. The campaign highlighted

the need for more inclusive research and better representation of underrepresented patient groups, so that future treatments are developed with the full diversity of the PH community in mind.

As in previous years, ready-to-use materials were prepared in CANVA, allowing national associations to translate, adapt, and publish them in their own languages and local contexts. This approach once again proved essential. The success of World PH Day cannot be measured only by the results on PHAEUROPE & Global channels, because the campaign lived far beyond them. More than 45 PH organizations around the world took part in the campaign. By sharing prepared materials, adapting visuals, translating messages, and bringing the content to their own communities, these associations helped raise the campaign’s reach to an even higher level. Each shared post, each translated infographic, and each local adaptation strengthened the global message: there is hope in every trial, but that hope must be visible, understandable, and accessible to all.

This year, campaign materials were also shared by PHAEUROPE partners and sponsors, whose support helped expand the message beyond the immediate PH community. PHAEUROPE & Global gives special thanks to all sponsors who took part by sharing campaign content and helping raise awareness of pulmonary hypertension and clinical trials. Their contribution strengthened the visibility of the campaign and showed the



importance of shared responsibility in advancing PH awareness and care.

A thank you goes out to the Global Allergy & Airways Patient Platform, who joined this year's campaign.

Another important element of this year's World PH Day was the traditional WPHD webinar organized by PHAEUROPE & Global. The 2026 live webinar, titled "Two Perspectives, One Goal: Transforming PH Care Through Clinical Trials," brought together two distinguished speakers: Dr. Michelle Ghofrani and Prof. Dr. Ardeshir Ghofrani.

RECORDING NOW AVAILABLE!

World Pulmonary Hypertension Day Webinar

CLINICAL TRIALS IN FOCUS
with
Michelle Ghofrani & Ardeshir Ghofrani

Two Perspectives, One Goal.

Dr. Michelle Ghofrani
Vice President Clinical Development
Liquidia Corporation

Prof. Dr. Ardeshir Ghofrani
Justus-Liebig-University of Giessen, Germany
ECAPS • Kerckhoff-Klinik Bad Nauheim •
Imperial College London

GOOD NEWS!
The recording of our World PH Day webinar is now available in

Bel Air Center
— a premier online platform for PH patients.

Your trusted resource center for PH education & support.

Watch the webinar now on Bel Air Center >

The webinar offered a valuable exploration of clinical trials and their contribution to PH care from two complementary perspectives: clinical expertise and the pharmaceutical research field.

PHAEUROPE & Global is incredibly proud of the patients, associations, partners, sponsors, advocates, experts, and supporters, who made this campaign possible.

Most importantly, the campaign reaffirmed that patients are no longer only participants in research. They are partners in innovation. Their perspectives, experiences, needs, and expectations are vital to shaping the future of PH care.

"Hope in Every Trial" was not only a slogan. It was a reminder that every step forward in research carries the possibility of a different future. A future where innovative therapies are developed with patients, not only for them. A future where clinical trials are



more accessible and inclusive. A future where no patient is left behind because of where they live, what language they speak, or how visible their disease may be.

PH patients continue to face uncertainty, breathlessness, debilitating symptoms, and many barriers. But they also continue to bring courage, clarity, and hope to the global movement. Through their stories, advocacy, and willingness to take part in conversations that shape the future, they remind us that progress is not only measured in treatments approved, better outcomes, or trials completed. It is also measured in trust, participation, awareness, and solidarity.

Together, we are not only raising awareness. We are building the future of pulmonary hypertension care - one story, one trial, one partnership, and one act of hope at a time.

Thank You.
Maleen B. Fischer
Head of Digital Media



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WPHD WEBINAR

CLINICAL TRIALS IN FOCUS – HOPE IN EVERY TRIAL

This year's World PH Day webinar explored a topic that is of great importance to everyone living with pulmonary hypertension: the development of new treatments and the crucial role of clinical trials in bringing hope to patients.

The webinar, 'Clinical Trials in Focus – Hope in Every Trial: Two Perspectives – One Goal', brought together two internationally recognised experts with complementary perspectives. Professor Ardeschir Ghofrani, University Hospital Giessen, presented the academic perspective, while Dr. Michelle Ghofrani from Liquidia Corporation explained how the pharmaceutical industry approaches the development of new medicines. Together, they provided participants with a unique opportunity to better understand the long journey from scientific discovery to an approved treatment.

UNDERSTANDING THE DISEASE

Professor Ghofrani began by explaining how increasing knowledge of the biological mechanisms behind pulmonary

arterial hypertension (PAH) is opening the door to entirely new treatment approaches. While current therapies have significantly improved symptoms and quality of life, they primarily target the blood vessels' ability to dilate. Researchers are now focusing on therapies that may influence the underlying disease process itself, with the goal of slowing or even reversing vascular remodelling.

Participants also received an overview of the rapid progress being made in the field. Following the introduction of sotatercept as the first disease-mechanism-targeted therapy, several other promising approaches—including inhaled tyrosine kinase inhibitors, BMP9 mimetics and activin pathway inhibitors—are currently in clinical development.

HOW NEW MEDICINES ARE DEVELOPED

Dr. Michelle Ghofrani guided participants through the drug development process, illustrating how only a very small fraction of potential compounds eventually become approved medicines. She explained the many years of laboratory research, preclinical testing, clinical trials and regulatory review required before a new treatment reaches patients.



LIVE WORLD PULMONARY HYPERTENSION DAY WEBINAR
Clinical Trials in Focus with Michelle Ghofrani & Ardeschir Ghofrani
Two Perspectives, One Goal

Dr. Michelle Ghofrani
 Vice President Clinical Development
 Liquidia Corporation

Prof. Dr. Ardeschir Ghofrani
 Justus-Liebig-University of Giessen, Germany • ECCPS •
 Kerckhoff-Klinik Bad Nauheim • Imperial College London

MAY 5, 2026 | 18:00 CET
Bel Air Center Online Platform
 Watch the webinar at Bel Air Center • Login for free at belaircenter.info

HOPE IN EVERY TRIAL
 MAY 2026

PHAEUROPE & Global
 PULMONARY HYPERTENSION ASSOCIATION

World Pulmonary Hypertension Day

GLOBAL ALLERGY & AIRWAYS
 PATIENT PLATFORM

She also highlighted the importance of close collaboration between researchers, pharmaceutical companies, regulators and patient organisations. Patient input is increasingly recognised as an essential component throughout the development process—not only in designing meaningful clinical trials, but also in identifying outcomes that matter most to people living with pulmonary hypertension.

ADDRESSING CONCERNS ABOUT CLINICAL TRIALS

One of the most valuable parts of the webinar focused on a question many patients ask: Is it safe and ethical to participate in a placebo-controlled clinical trial?

The speakers explained that modern PAH studies differ considerably from those conducted decades ago. Today, most participants continue receiving their standard approved therapies while the investigational treatment or placebo is added on top. Placebo periods are generally relatively short, patients are monitored very closely, rescue treatment is available if needed, and almost all studies include an open-label extension where every participant has the opportunity to receive the investigational treatment.

The presenters also discussed evidence suggesting that participation in clinical trials may itself provide benefits through structured follow-up, regular assessments and optimisation of overall care.

LOOKING AHEAD

The webinar concluded with an inspiring discussion about the future of pulmonary hypertension research. Precision medicine, treatments targeting right ventricular function and therapies capable of reversing disease progression are all areas of active investigation. Although significant challenges remain, the pace of scientific progress has accelerated remarkably over the past few years, offering renewed hope for patients and families worldwide.

The webinar also reinforced an important message: successful drug development depends on strong collaboration between academic researchers, the pharmaceutical industry and patient organisations. By working together, these partners can accelerate innovation and ensure that future treatments address the needs and priorities of the people who matter most—patients.

PHAEUROPE & Global would like to thank Professor Ardeschir Ghofrani and Dr. Michelle Ghofrani for sharing their expertise and helping our community better understand the science, challenges and hope behind the next generation of pulmonary hypertension therapies.

*Hall Skaara,
Project Manager*



gossamer bio

A pair of hands holds a glowing, wireframe model of human lungs against a dark, starry background. The Gossamer Bio logo is at the top.

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

August 2025



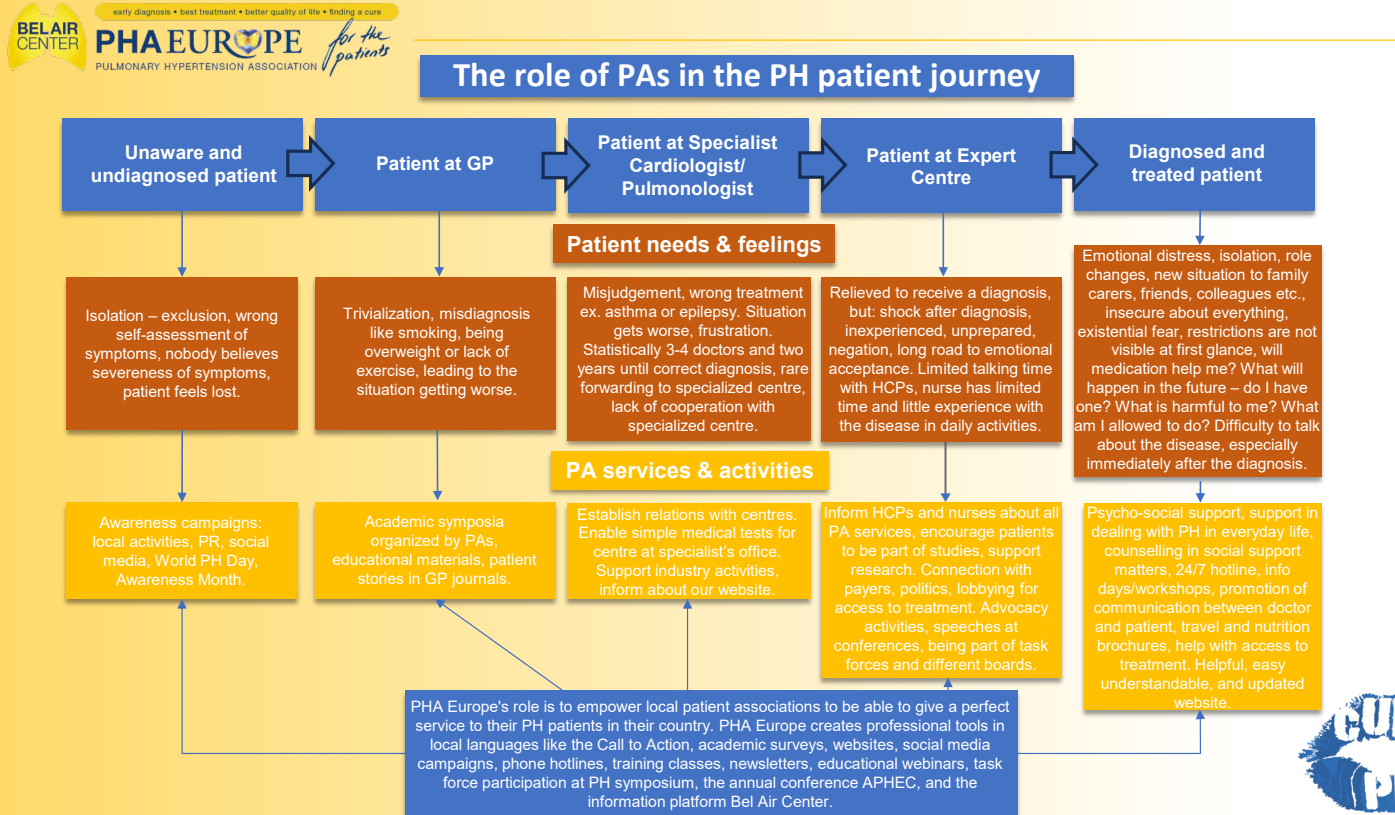
*Committed to transforming the lives of
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* EU Medical Device Regulation (MDR) 2017/745
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PH Network

Explore the PH Network

PH Network is a space for anyone curious, concerned or connected to pulmonary hypertension (PH) and pulmonary arterial hypertension (PAH).

Explore the PH Network:
ph-network.com

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ARGENTINA

ACTIVITY REPORT OF HIPUA FOR WORLD PULMONARY HYPERTENSION DAY

2026 Each year, World Pulmonary Hypertension Day provides an opportunity to raise awareness of this rare disease, increase public understanding, and strengthen the bonds that unite patients, families and healthcare professionals. In Argentina, HIPUA (Pulmonary Hypertension Argentina) turned this occasion into a full month of activities aimed at informing, supporting and empowering those living with the disease. The activities began on 5 May with a visit to Hospital El Cruce in Florencio Varela, one of the country's leading referral centres for Pulmonary Hypertension, Lung Transplantation and Pulmonary Thromboendarterectomy.



Together with Dr. Daniel Aimone and Dr. Marcelo Nahín, HIPUA organised an in-person meeting for patients and their families, where medical information was complemented by something equally valuable: the opportunity to share experiences and learn from others who are walking the same path.



On that same day, the 5th National Pulmonary Hypertension Meeting was held as a virtual event, bringing together people from different regions of the country. Specialists from leading healthcare centers addressed key aspects of the diagnosis, treatment, and follow-up of the disease, reaffirming the importance of education as a tool for improving quality of life.



The day concluded with the illumination of iconic landmarks across the city of Buenos Aires in purple, the international symbol of Pulmonary Hypertension. Among them were the Monument to Women, the newly restored Floralis Genérica, and the Space Tower, all joining the global awareness campaign that each year brings together patient organizations from around the world.

During the month, another edition of "I Take Five Minutes... I Take a Breather" was held, providing a space for patients and their families to come together and strengthen their emotional well-being. Through peer support and shared experiences, these gatherings aim to combat isolation, foster support networks, and provide tools to help people cope with the challenges of living with a chronic illness.



Activities continued in the province of Tucumán through the "Breathing for Argentina" project, a nationwide initiative that travels to pulmonary hypertension centers across the country to promote access to information, raise awareness, and provide support for people living with Pulmonary Hypertension.

May was also chosen as the occasion to launch "Patients as Protagonists", a project aimed at encouraging the active participation of people living with the disease. When patients share their experiences, they create a sense of connection, support others, and turn the knowledge they have gained into a collective tool capable of changing lives.





As a fitting conclusion to this busy month of activities, HIPUA launched “Living with Pulmonary Hypertension: Information That Supports You”, a new series of sessions organized by its Well-being and Active Living Departments. The first session, “Breathe in the Present”, provided patients and their families with mindfulness and self-care tools to help them manage stress, uncertainty, and the everyday challenges of living with the disease.

Finally, as a member of PHAEUROPE & Global, HIPUA joined the international “Hope in Every Trial” campaign this year—a social media initiative highlighting the vital role of clinical trials in advancing pulmonary hypertension research. We were proud

to contribute an inspiring story from Argentina through the experience of our dear Natalia, who shared the positive impact that participating in a clinical trial had on her life. We would also like to extend our sincere thanks to PHAEUROPE & Global for featuring Natalia as Argentina’s representative in this social media campaign.

Each of these activities reflects a deeply held conviction: no one should have to face Pulmonary Hypertension alone. Through education, support, and community building, we continue working to ensure that every patient finds not only answers, but also encouragement, hope, and a network of support to accompany them at every stage of their journey.



PH AUSTRIA AND THE CHILDREN'S HEART FESTIVAL

On the occasion of World Pulmonary Hypertension Day (WPHD), representatives of PH Austria participated in the Children's Heart Festival. The event brought together patients, families, healthcare professionals, researchers, and patient organizations to exchange experiences and raise awareness of congenital heart disease, pulmonary hypertension, transplantation, and other complex cardiovascular conditions in children.

Representing PH Austria, Eva Otter and Gerry Fischer attended the festival and had the opportunity to present a donation from the Lungenkinder (Lung Kids) Research Association. The donation was officially handed over to Prof. Georg Hansmann, who was recently appointed Director of Pediatric Cardiology at the Vienna Children's Heart Center, in support of his ongoing research and clinical projects.

The festival also featured patient symposia, educational sessions, and networking opportunities for families and advocacy organizations. PH Austria was pleased to contribute to this important event, which highlighted the value of collaboration between clinicians, researchers, patients, and patient organizations in improving the lives of children living with pulmonary hypertension and other serious heart and lung conditions.





THE 13TH VIENNA ZOO RUN

The 13th Vienna Zoo Run was once again a great success. The event, which was limited to 2,000 participants, sold out weeks in advance and created a fantastic atmosphere at Schönbrunn Zoo.

Under the motto “Get breathless for PH”, runners, families, groups of friends, and corporate teams came together to raise

awareness for pulmonary hypertension (PH). The unique course through the zoo and the shared commitment to a good cause made the event a truly memorable experience.

As every year, the net proceeds of the event will be donated equally to the Lungenkinder Research Association and Schönbrunn Zoo to support the protection of endangered species.



BELARUS

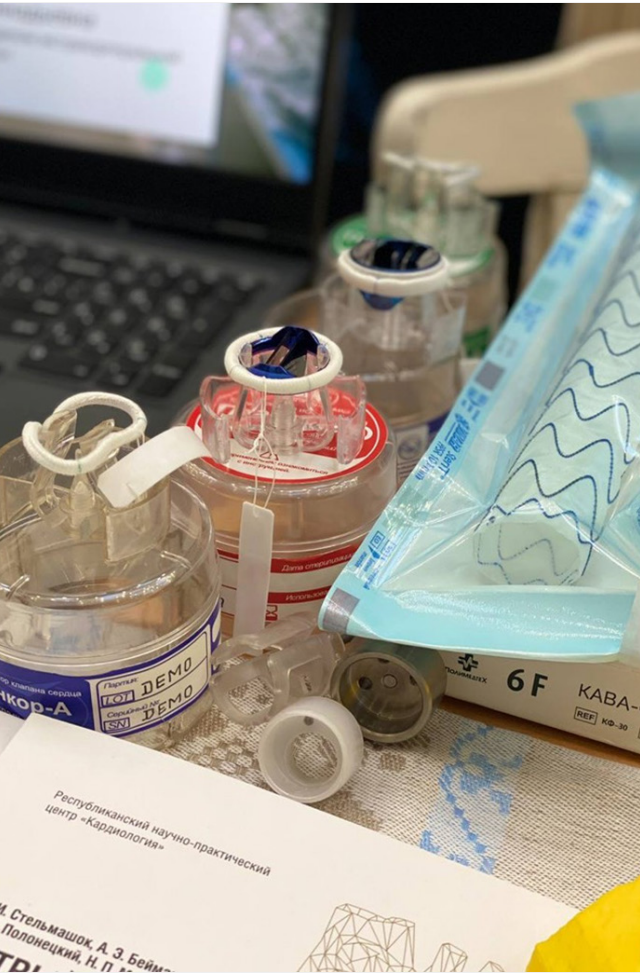
STRATEGIC PARTNERSHIP OF THE ASSOCIATION WITH THE RSPC „CARDIOLOGY” (BELARUS)

Instead of funding repetitive local public campaigns, this year the Association focused its efforts on a strategic partnership with the Republican Scientific and Practical Center (RSPC) „Cardiology.” Our joint work was aimed at raising awareness about pulmonary arterial hypertension (PAH) at both the state and expert levels. Our cooperation over the past year was marked by two key events:

1. PRESENTATION OF INNOVATIVE TREATMENT METHODS AT THE MINISTRY OF HEALTH EXHIBITION

As part of the official partnership with the Association, leading specialists from the RSPC „Cardiology” presented the center’s advanced achievements at a specialized exhibition at the Belarusian State Medical University (BSMU), held in conjunction with the final board meeting of the Ministry of Health. The joint stand showcased:

- **High-tech surgical treatment methods** for patients with pulmonary artery branch thromboembolism and chronic thromboembolic pulmonary hypertension (CTEPH).
- **Domestically produced** heart valves and vascular prostheses.
- **The application of innovative 3D technologies** for treating complex left ventricular pathologies.





2. INFORMATION AND EDUCATIONAL CAMPAIGN IN THE „MEDICAL BULLETIN“

To reduce diagnostic timelines and support the patient community, the Association backed a large-scale expert publication authored by the heads of the Republican Center for Pulmonary Arterial Hypertension—Doctor of Medical Sciences Elena Medvedeva and Candidate of Medical Sciences Tatiana Troyanova-Shchutskaya. The article, titled „Idiopathic Pulmonary Hypertension: Why it is a Diagnosis of Exclusion,“ was published in the Ministry of Health’s official publication, the „Medical Bulletin,“ and successfully conveyed the following key points to a broad audience of physicians:

- **Diagnostic difficulties:** Due to the non-specific nature of early symptoms, diagnosing Idiopathic Pulmonary Hypertension (IPH) remains one of the most challenging tasks.
- **The time factor:** On average, it takes about 2 years from the first manifestations of the disease to a confirmed diagnosis.
- **A diagnosis of exclusion:** Confirming the diagnosis requires the systematic exclusion of dozens of alternative diseases.
- **Risk groups:** The disease can develop at any age, but statistically, it is more commonly found in women.

The Association’s close collaboration with the country’s key medical experts has allowed for a responsible reallocation of resources, directing them toward long-term initiatives that systematically improve the quality of care for PAH patients in Belarus.



BELGIUM

WORLD PULMONARY HYPERTENSION DAY ACTIVITIES – PH BELGIUM (PH VZW)

Throughout the month of May, PH Belgium (PH vzw) organised a series of initiatives to raise awareness of pulmonary hypertension (PH), a rare and severe condition that is still too often diagnosed late. With a combination of in-person actions and online engagement, we aimed to reach as many people as possible, inform the public, and strengthen the sense of community among patients, families, and healthcare professionals.

BLUE LIPS CAMPAIGN AT UZ LEUVEN

This year, our Blue Lips campaign took place at University Hospital Leuven (UZ Leuven), where more than 10,000 staff members work every day to provide high-quality care. The goal was simple but essential: to make doctors, nurses, and other healthcare professionals more aware of the often subtle symptoms of pulmonary hypertension.

A photobooth was installed in the hospital, and staff members were invited to take a picture wearing symbolic blue lips. Each participant received a printed photo to take home, while the campaign wall gradually filled with all the images taken that day—creating a powerful visual statement of solidarity.

SPECIAL SUPPORT ON THE 11TH OF MAY

On the 11th of May, our campaign at the Gasthuisberg campus received special attention. **Bieke Verlinden**, alderwoman for Care, Welfare, and Cemeteries, visited the hospital to show her support for PH awareness. Together with our chairperson **Wendy Vansteenkiste**, she posed for a Blue Lips photo to mark World Pulmonary Hypertension Day. Her presence helped amplify the message and brought additional visibility to the campaign.



ADVOCATING FOR FASTER ACCESS TO INNOVATIVE THERAPIES

In connection with World PH Day, PH Belgium also met with **Kathleen Depoorter (N-VA)** to discuss policy measures that could improve early diagnosis and treatment for people living with PH.

A key topic was the **reimbursement of the ProBNP blood test**, an important tool for earlier detection of pulmonary hypertension. The discussion also highlighted the need for timely access to innovative therapies, which can significantly improve patient outcomes.

Depoorter publicly supported the Blue Lips campaign and shared the initiative on her LinkedIn page. The story was also covered by professional medical media, including **De Specialist** and **De Artsenkrant**.

MEDIA COVERAGE

The combined efforts of patients, healthcare professionals, and policymakers resulted in broad media attention. Several national and regional outlets reported on the campaign, including:

- Doctors, patients, and politicians paint their lips blue at UZ Leuven — **Het Laatste Nieuws**
- *Blue Lips campaign raises awareness of rare lung disease: "Often overlooked during examinations"* — **Het Nieuwsblad**
- *UZ Leuven and the patient association PH vzw raise awareness of pulmonary hypertension with a Blue Lips campaign* — **ROB TV**

This visibility helped reinforce the message that early recognition of PH symptoms is crucial for improving survival and quality of life.

BLUE LIPS ONLINE: A SYMBOL OF RECOGNITION AND HOPE

Alongside the hospital campaign, PH Belgium ran a month-long online awareness action under the motto: "Blue lips are not a beauty trend. They can be a warning sign."

The call to action was simple: take a photo wearing blue lips, share it on social media, and help raise awareness of pulmonary hypertension. The response was heartwarming.



Throughout May, photos appeared on Instagram and Facebook from patients, families, friends, and supporters across the country.

Each week, PH Belgium also shared educational posts about symptoms, diagnosis, and personal stories from people living with PH—bringing visibility to both the visible and invisible aspects of the disease.

CONCLUSION

The combination of physical and digital actions created a powerful and far-reaching awareness campaign. We are deeply grateful to all volunteers, participants, healthcare professionals, and supporters who contributed to this effort.

With these initiatives, we hope to have strengthened public understanding of pulmonary hypertension and to have supported earlier recognition of symptoms. PH Belgium remains committed to raising awareness, supporting patients, and advocating for better care.

We thank PHAEUROPE & Global for their continued support and international coordination.

On behalf of PH Belgium (PH vzw),
Wendy Vansteenkiste
Chairperson



BOSNIA AND HERZEGOVINA

PULMONARY HYPERTENSION IN THE PALM OF YOUR HAND

Marking World Pulmonary Hypertension Day (WPHD) 2026 was another opportunity for us to make our voice heard even louder. This year, we were especially vocal, because we managed to organize several events that attracted media attention, allowing us to continue raising awareness about pulmonary hypertension.

As has become our tradition, the observance of WPHD 2026 in Bosnia and Herzegovina began with the display of this year's global campaign visual on video billboards in two cities across the country. At highly visible locations and major intersections with heavy pedestrian and vehicle traffic, banners featuring the slogan "Hope in Every Trail" were displayed. Since the banners were particularly striking and featured images of people living with pulmonary hypertension, they attracted the attention of many passersby who wanted to learn more about the disease.

BUTTERFLIES OF HOPE

The campaign continued at the First Primary School in Zavidovići, where first- and fourth-grade students marked this very important date for us in their own special way. Their drawings of butterflies with outstretched wings symbolized the hope of all PH patients for positive outcomes from every clinical study aimed at treating our severe disease. Their colored pencils drew from the heart for all PH patients.

In this way, we not only included the youngest participants in the observance of WPHD in our country, but we also managed to create a wave across social media through their drawings. It became almost impossible to scroll through social networks without encountering one of these beautiful butterflies of hope. For this, we are immensely grateful to the students and their teachers, Samira Isić and Emira Skejić.



UNIMAGINABLE WITHOUT BOSNIAN AND HERZEGOVINIAN ATHLETES

Marking WPHD 2026 without the runners from Bihać and the long-distance cyclist from Zavidovići would be unimaginable. This was confirmed through sporting events that engaged all generations and helped spread awareness of pulmonary hypertension beyond the borders of our country.

Enes Ibrahimagić, a half-marathon and marathon runner, ran 21 kilometers at the beginning of May carrying the symbols of the European PH community in Croatia, in the unique and fascinating setting of the Željava Airbase Half Marathon. We have hope, hope in every study and we also have strength in people like Enes, who never gives up on us and continues to spread awareness of pulmonary hypertension throughout the region.



In addition to Enes, three more runners from Bihać joined us in marking WPHD. Emina Čehajić Gradinović, Amar Čehajić, and Adnan Skelić dedicated their participation in the first stage of the 2026 Plješevica Trail in Bosnia and Herzegovina to everyone living with pulmonary hypertension. In a true sporting spirit and under extremely unfavorable weather conditions, this trio was “out of breath for PH” on a 15-kilometer course with a cumulative elevation gain of 660 meters.



Ismet Škulj, a Bosnian recreational cyclist, dedicated his cycling tour from Bosnia and Herzegovina to Albania this year to people living with pulmonary hypertension as part of WPHD 2026. His journey lasted 15 days, during which he covered more than 1,000 kilometers on his bicycle. His route included stretches covered by snow and rain, with cold and wet conditions throughout, but none of this prevented him from carrying the symbols of the European PH community through four countries once again this year, spreading awareness of our disease and highlighting the situation of PH patients in Bosnia and Herzegovina.



THE FIRST CONFERENCE DEDICATED TO PULMONARY HYPERTENSION IN BOSNIA AND HERZEGOVINA

The highlight of the World Pulmonary Hypertension Day 2026 observance in Bosnia and Herzegovina was the organization of our first conference entitled “Pulmonary Hypertension in Bosnia and Herzegovina in the Palm of Your Hand.” The conference was designed to bring together cardiologists and pulmonologists, representatives of relevant institutions and decision-makers, as well as patients from across Bosnia and Herzegovina. Although all stakeholders were invited, representatives of government authorities and institutions did not respond to our invitation and were therefore absent. Their absence did not diminish the importance of the event nor call its realization into question.

The conference “Pulmonary Hypertension in Bosnia and Herzegovina in the Palm of Your Hand” was held in Sarajevo on May 15, 2026, and focused on the position of people living with pulmonary hypertension in our country. It resulted in concrete proposals and solutions aimed at improving the treatment of individuals affected by this rare, severe, incurable, and potentially progressive disease.

Particular emphasis was placed on the signing of the Declaration on Improving the Diagnosis, Treatment, and Quality of Life of Patients with Pulmonary Hypertension in Bosnia and Herzegovina. The Declaration identified the key challenges faced by patients, ranging from delayed diagnosis and limited access to

therapies to the lack of reference centers and systematic patient monitoring.

In addition to Vera Hodžić, President of the “DAH” Association, the Declaration was signed by distinguished experts from Mostar and Sarajevo, including Prof. Dr. Kristina Galić, pulmonologist; Prof. Dr. Edin Begić, cardiologist; Prim. Assoc. Prof. Dr. Alden Begić, cardiologist; Dr. Tanja Zovko, MD; and Prof. Dr. Fatima Gavrankapetanović Smailbegović, a representative in the House of Peoples of the Parliament of the Federation of Bosnia and Herzegovina, who had previously addressed our situation before one of the key political decision-making bodies in the Federation of Bosnia and Herzegovina.

The physicians emphasized the importance of early diagnosis, a multidisciplinary approach to treatment, and the availability of modern therapies. This view was also supported by Prof. Dr. Tamara Kovačević Preradović, a cardiologist from Banja Luka, who participated in the conference online.

These were precisely the topics that received the greatest attention and facilitated an exchange of experiences and proposals for improving pulmonary hypertension care in Bosnia and Herzegovina, with the goal of earlier recognition, better and faster diagnosis, and an improved quality of life for patients.

Vera Hodžić, President of the “DAH” Association, emphasized that PH patients in Bosnia and Herzegovina still do not have equal access to basic first-line therapies throughout the country. She particularly highlighted the need for access to modern therapies that are available in European countries, stressing that treatment of pulmonary hypertension according to European protocols and standards is not, and must not become, a privilege but rather a fundamental right of every PH patient in our country.

The conference concluded with a spontaneous dialogue between patients and physicians. Through the personal experiences shared by PH patients, it became crystal clear how people living with pulmonary hypertension in Bosnia and Herzegovina cope with the disease and the many challenges they face.



The conclusions of the conference, summarized in the signed Declaration and reinforced through the panel discussion, were unanimous: there is an urgent need to improve systemic support for patients through the establishment of a national patient registry, reference centers for pulmonary hypertension, continuous education of healthcare professionals, and the provision of therapies in accordance with European and international protocols and standards.

The fight for a better position for PH patients must become a shared responsibility of the healthcare system and society as a whole.

The conference “Pulmonary Hypertension in Bosnia and Herzegovina in the Palm of Your Hand” was organized by the Association of Citizens Living with Pulmonary Hypertension “DAH” in Bosnia and Herzegovina, with significant support from donors. The Association has already announced further steps aimed at improving the position of this small and disadvantaged group of patients who are fighting for their breath and their lives. However, achieving meaningful progress will require the involvement of decision-makers as well. Despite their absence from the conference, patients continue to regard them as partners in addressing the many challenges they face and in ensuring adequate treatment conditions and access to modern therapies for people living with pulmonary hypertension in Bosnia and Herzegovina.

Vera Hodžić

President of the Association of Citizens Living with Pulmonary Hypertension “DAH” – Bosnia and Herzegovina



BULGARIA BSPPH



BREATHING BLUE: BULGARIA'S LIGHT OF HOPE ON WORLD PULMONARY HYPERTENSION DAY

On May 5, the world marks World Pulmonary Hypertension Day — a day dedicated to one of the most severe and often late-diagnosed conditions, known as the “blue lips disease.” In Bulgaria, this day is not just a date on the calendar. It is a powerful call for solidarity, awareness, and above all — hope.

This year, under the global theme “Hope in Every Clinical Trial,” Bulgaria once again stood united with patients living with pulmonary hypertension (PH). As a symbol of compassion and support, the façade of the National Palace of Culture in Sofia was illuminated in blue on May 5. Three additional cities joined the initiative: Ruse lit up the Pantheon of National Revival Heroes, Plovdiv illuminated the Boris Hristov House of Culture, and Haskovo turned the bell tower on Yamacha Hill blue — each beam of light serving as a reminder that no patient should feel invisible.

In Bulgaria, approximately 500 people live with pulmonary hypertension. Behind this number stand faces, families, daily struggles, and quiet courage.

For the fourteenth consecutive year, the Bulgarian Society of Patients with Pulmonary Hypertension joined the global initiative, highlighting both the daily challenges patients face and the vital role of clinical trials and innovative therapies as a source of real hope.



This year, the campaign was supported by students from the Faculty of Medicine at Sofia University “St. Kliment Ohridski,” as well as graduating seniors from the 31st Secondary School “Ivan Vazov” in Sofia. On their graduation day, May 15, they

chose to send a message not only of new beginnings, but also of compassion and solidarity with people living with pulmonary hypertension.

Through their dedication and empathy, they showed that young people can be a powerful force for meaningful change, inspiring greater awareness and care for human life.



THE INVISIBLE ICEBERG

On May 5, the world marks World Pulmonary Hypertension Day. “Pulmonary hypertension resembles an iceberg,” explains Dr. Lyubomir Dimitrov, interventional cardiologist at the Pediatric Cardiology Clinic of the National Cardiology Hospital. “Doctors see only the tip, while beneath the surface remains a much larger group of undiagnosed patients. Unfortunately, there is still no non-invasive method to measure pulmonary artery pressure. Echocardiography can raise suspicion, but definitive diagnosis requires right heart catheterization.”

The complexity of diagnosis often delays treatment. And in a disease where time equals breath, delays cost dearly.

LIFE WITHOUT BREATH

“Pulmonary hypertension is an invisible disease that leaves you breathless,” says Natalia Maeva, Chairperson of BSPPH. “Even the simplest daily tasks — climbing stairs, moving an object — can completely exhaust you. The emotional burden is just as heavy: constant uncertainty, treatment side effects, frequent hospitalizations. Patients must continuously adapt to a changing ‘new normal’ and often depend on oxygen concentrators and costly supportive therapy. Access to clinical trials is essential, because innovative treatments bring real hope for improving quality of life.”

Her words echo the lived experiences of patients.

Irena Metodieva, a successfully transplanted PH patient, shares a message to the community:

“I would like to tell everyone in the PH community — be strong and believe in a better future. Support one another. Reach out your hands to each other. And may our society become more

informed, more understanding, and more caring toward the vulnerable.”

Milena Naneva adds:

“We must not give up despite the diagnosis. Years ago, I participated in a clinical trial. I know how important it is for patients from small countries like Bulgaria to be included in such research. Every step forward leads to a future where patients live longer and better lives.”



WHEN THE SYSTEM IS SILENT, HUMANITY SPEAKS

Beyond awareness, this year's campaign highlights a painful reality. BSPPH has once again urged the urgent removal of administrative barriers within the National Health Insurance Fund that prevent patients from receiving home oxygen concentrators. Although reimbursement criteria were officially published in October 2024, the mechanism remains non-functional in practice. No allocated budget, no effective procedural pathway — and patients continue to wait. While policy lags, society acts.



Through the donation initiative “Breathe,” BSPPH demonstrated that compassion can move faster than bureaucracy. Thanks to Nikola Rahnev and the team of Gorata.bg, three oxygen concentrators were donated. An additional fundraising campaign on the Pavel Andreev platform raised €3,200, enabling the purchase of three more devices.

Today, those machines are no longer equipment stored in boxes — they are already in the homes of people who depend on them. For many, they are not simply medical devices. They are the ability to take a deeper breath. To walk a few more steps. To spend another peaceful day with family. When institutions remain silent, humanity speaks. And sometimes, the most precious gift is oxygen.



BULGARIA PHA

PHA BULGARIA HIGHLIGHTS PULMONARY HYPERTENSION AT RARE DISEASE INFORMATION SEMINAR IN VARNA

PHA Bulgaria participated in an information seminar organized by the National Alliance of People with Rare Diseases in Varna, contributing to the awareness of pulmonary hypertension (PH) as a rare and life-threatening condition. The event brought together patients, healthcare professionals, and patient organizations to promote education, early diagnosis, and collaboration in the field of rare diseases.

A key part of the program was a lecture on pediatric pulmonary hypertension delivered by a pediatric pulmonologist. The presentation focused on the importance of early recognition and multidisciplinary care and included the discussion of an inspiring clinical case of a young child with advanced pulmonary hypertension who was considered a suitable candidate for lung transplantation. The case highlighted both the complexity of managing severe pediatric PH and the life-changing potential of timely referral to specialized transplant centers.

Throughout the seminar, PHA Bulgaria provided educational materials and information about pulmonary hypertension, engaging with patients and families to increase awareness of the disease and available support services.

The event was jointly organized by the National Alliance of People with Rare Diseases and PHA Bulgaria, with the main coordination led by Esra Nuri, a medical student and pulmonary hypertension patient. Her dedication and commitment played a key role in the successful organization of the seminar, demonstrating the valuable contribution that empowered patients can make to the rare disease community.

PHA Bulgaria remains committed to working alongside healthcare professionals, patient organizations, and the National Alliance of People with Rare Diseases to improve awareness, early diagnosis, and access to specialized care for people living with pulmonary hypertension in Bulgaria.



CHINA

RAISING AWARENESS AND CONNECTING PH COMMUNITIES

iSEEK Pulmonary Hypertension Hope Center has recently been involved in two initiatives to raise awareness and strengthen connections within the PH community.

RAISING AWARENESS THROUGH STUDENT ACTIVITIES

In collaboration with the China University of Political Science and Law, students organised a series of interactive sports games to raise awareness of pulmonary hypertension (PH). Activities included running, ring toss, balloon-blowing challenges and a PH knowledge quiz.

Inspired by the Breathless for PH concept, some activities gave students a chance to experience breathlessness after physical exertion and better understand some of the challenges faced by people living with PH.

The event also raised RMB 1,732.50 in support of iSEEK.



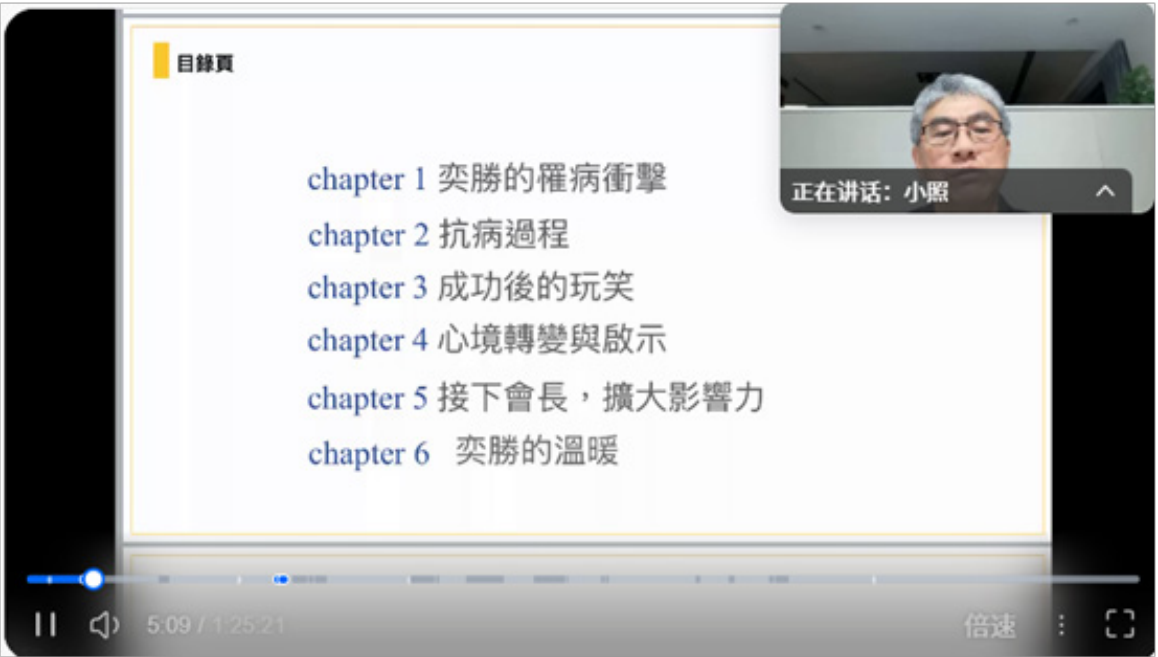
AN ONLINE EXCHANGE WITH TAIWAN'S IPAH COMMUNITY

iSEEK also held an online meeting with the Taiwan Idiopathic Pulmonary Arterial Hypertension Patient Association. Patients and advocates exchanged experiences on treatment, medication side effects, advocacy and lung transplantation.

The discussion also highlighted differences in treatment access. In mainland China, reimbursed PAH treatments are available to patients with different types of PAH, while in Taiwan, reimbursement is currently limited to idiopathic PAH. However, patients in Taiwan generally have higher levels of reimbursement and access to a wider range of treatment options, particularly prostacyclin-related therapies.

We were also touched to learn that the Chair of the Taiwan IPAH patient community is a caregiver and the father of a patient who died from IPAH. His experience reminded us that the impact of PH extends far beyond patients themselves. Caregivers also face significant physical and emotional challenges, and their health and well-being deserve greater attention. This highlighted the importance of not only medical treatment, but also social support and mental health support for both patients and caregivers.

Despite differences in healthcare systems and treatment access, the exchange showed how much patients, caregivers and advocates can learn from one another. Both organisations look forward to exploring further opportunities for cooperation and strengthening connections within the PH community.



CROATIA

WORLD PULMONARY HYPERTENSION DAY 2026 – CROATIA

The Croatian pulmonary hypertension patient association **Plava krila (Blue Wings)** marked World Pulmonary Hypertension Day 2026 with a diverse programme of awareness, education, and community activities that brought together patients, healthcare professionals, athletes, institutions, and supporters from across Croatia.

AWARENESS CAMPAIGN AND EARLY ACTIVITIES

Our awareness campaign began several months ahead of May, with our dedicated team of runners participating in the Sahara Trail, one of the world's most demanding desert races. Their achievement symbolised the resilience, determination, and strength demonstrated every day by people living with pulmonary hypertension. This event served as a powerful introduction to the months dedicated to raising awareness of PH.

PARTNERSHIPS AND EDUCATION

A significant milestone was reached in mid-May when we signed a cooperation agreement with Zagreb County, which selected our association for funding for the third consecutive year among a large number of applicants. Through the project **"Blue Wings for Blue Heroes"**, local authorities once again recognised the importance of supporting people living with pulmonary hypertension and their families, demonstrating a strong commitment to patient-centred healthcare and community engagement.

Education remains one of the cornerstones of our work. This year, we recorded a special podcast episode featuring **Dr Mislav Lozo, MD, PhD (University Hospital Centre Split)**. Dr Lozo and his team have pioneered the implementation of balloon pulmonary angioplasty (BPA) in Croatia for patients with chronic thromboembolic pulmonary hypertension (CTEPH). In the podcast, he discussed recent advances in PH treatment, highlighted the importance of early diagnosis, and shared insights into the development of specialised PH care in Croatia.



SPORT AND COMMUNITY ENGAGEMENT

Sport continues to be one of the most effective tools for raising awareness of pulmonary hypertension.

Plava krila participated as an official partner in an international Mini Handball Tournament that brought together more than 500 children from several countries.

Through educational materials and direct interaction with participants and their families, we introduced the PH community to a new audience and reinforced the message that every breath matters. During the event, face painting activities for both children and adults proved highly popular and significantly increased engagement and visibility of our awareness message. Another major highlight was our participation in the Plitvice Marathon, one of Croatia's most recognised running events. The 2026 edition gathered more than 900 runners from 50 countries, providing an exceptional international platform to raise awareness of pulmonary hypertension. Our runners proudly carried the PH message throughout the event, helping to extend awareness far beyond Croatia's borders.

On the day preceding the marathon, we organised a patient meeting and educational workshop. The programme included lectures on psychological wellbeing, coping strategies for living with a chronic disease, and motivational sessions designed to empower patients and their families. These gatherings remain invaluable opportunities for sharing experiences, strengthening peer support, and building resilience within the PH community. During the event, we also presented a special recognition award to Tomislav Smrček – Čonč, one of the most dedicated supporters of the pulmonary hypertension community in Croatia. As a symbol of gratitude, we presented him with a paddle, reflecting his extraordinary commitment to raising PH awareness through numerous sporting and humanitarian initiatives.

Over the years, Tomislav has supported our work through both joint and independent projects, including the remarkable **“Breathless Across the Adriatic”** expedition, during which he rowed the entire Croatian Adriatic coast in just six and a half days. He has also participated in the Via Adriatica Trail and other awareness campaigns, significantly contributing to the visibility of pulmonary hypertension and the challenges faced by those living with the condition.



PARTNERS AND SUPPORTERS

None of these activities would have been possible without the continued support of our long-term partners and sponsors. We are especially grateful to the **Croatian Society of Pulmonary Hypertension Foundation (HKD Foundation)**, **HTD**, **MSD**, and **Bauerfeind**, whose ongoing support enables us to deliver educational programmes, awareness campaigns, and patient-focused activities throughout the year.

We also acknowledge the support of **Kraš**, Croatia's oldest and most renowned confectionery company, which supported our sports activities by donating its iconic Bronhi candies. Known for its long-standing slogan “Bronhi – Breathing Made Easier,” this symbolic connection to our mission was particularly meaningful in the context of pulmonary hypertension awareness.

“THE SCARF THAT BREATHES” INITIATIVE

“The Scarf That Breathes” (Marama koja diše) is a new awareness initiative currently being developed by our association, aimed at increasing public understanding of pulmonary hypertension and highlighting the everyday challenges faced by people living with the disease.



The initiative is centred around a specially designed blue scarf symbolising breath, life, hope, and solidarity with the PH community. Through this campaign, we aim to engage patients, healthcare

professionals, athletes, public figures, supporters, and the wider public in raising awareness about pulmonary hypertension, early diagnosis, and patient support.

The project is currently in the preparation phase, including development of campaign materials, visual identity, promotional activities, and strategic partnerships. Once launched, “The Scarf That Breathes” will serve as a visible symbol of solidarity and a platform for sharing stories, promoting understanding, and encouraging public engagement.

We believe this initiative has strong potential to become a powerful awareness tool, increasing the visibility of pulmonary hypertension and strengthening support for the PH community in Croatia.

LOOKING AHEAD

World Pulmonary Hypertension Day 2026 once again demonstrated the strength of collaboration between patients, healthcare professionals, institutions, athletes, and supporters. Together, we continue to raise awareness, improve understanding of pulmonary hypertension, and ensure that the voices of people living with PH are heard throughout Croatia and beyond.



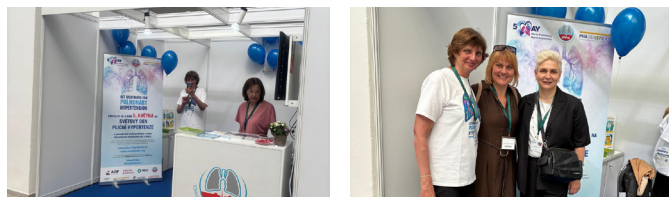
CZECH REPUBLIC

This year, on May 5, we once again celebrated World Pulmonary Hypertension Day (WPHD), which raises awareness about the challenges faced by patients living with this serious condition.

The main event in the Czech Republic took place in Brno, where patients, their families, friends, and supporters gathered on May 10th for a symbolic hike to Špilberk Castle. The hike was not only a pleasant gathering but also a reminder of the daily struggle patients with pulmonary hypertension face during everyday activities.

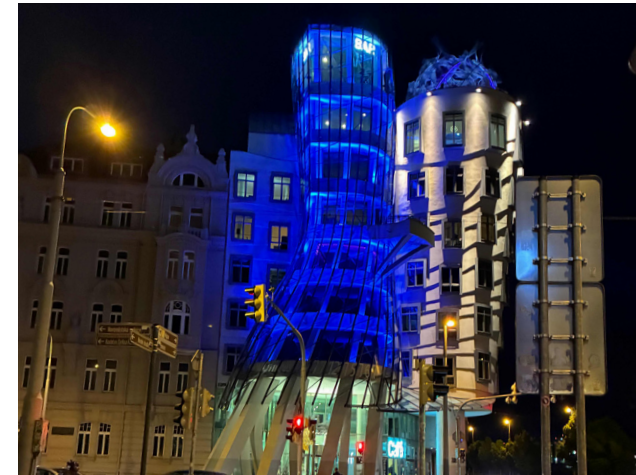
Blue balloons accompanied the participants along the way as a symbol of pulmonary hypertension and the patients' blue lips, which is one of PH symptoms. Those interested could also try inflating a balloon with a straw to step into the shoes of patients with pulmonary hypertension for a moment and feel just how challenging each breath could be. This symbolism helped many people better understand the limitations patients face every day.

As part of this year's WPHD, the Czech Association of Patients with Pulmonary Hypertension (SPPH) attended the cardiology conference in Brno, where we even had our own booth. During the conference, we had the opportunity to speak with doctors, medical staff, as well as prominent Czech cardiologists and professors. The conference included a traditional charity run, which is attended primarily by healthcare staff.



An important part of this year's World Pulmonary Hypertension Day was also the symbolic light-up of prominent buildings in blue, a color that symbolizes pulmonary hypertension and refers to cyanosis, which is the bluish coloration of the lips and other areas caused by a lack of oxygen. These included, for example, the Dancing House in Prague, the Husa na provázku Theater in Brno, the Omega Shopping Center and City Hall in Olomouc, and the Tomáš Baťa skyscraper in Zlín. This symbolic lighting helped raise public awareness.

World Pulmonary Hypertension Day was also featured in the Czech media as our patron Sabina Laurinová, Professor Jansa, and the president of our association, Milena Kaftanová, were interviewed. We would like to thank everyone who participated in this year's activities and helped raise awareness about pulmonary hypertension!



Zdroj: Facebook / Sdružení pacientů s plicní hypertenzí

08:20 SLABÝ Z AŽ SZ VÍTR, NA MORAVĚ A VE SLEZSKU MÍRNÝ SZ AŽ S VÍTR ZVOLNA ZESLÁBNĚ.

GERMANY

GERMANY: PATIENTS RAISING AWARENESS THROUGH COLLABORATION

To mark World PH Day, the German patient association PH-Selbsthilfe mit ♥ und IQ highlighted the importance of patient voices through several awareness initiatives.

One of the key projects was the patient brochure „Living with PAH”, created by patients for patients. It offers practical advice and personal experiences and is now available in PH centres across Germany.

Another highlight was the podcast „Together Strong: Self-Help and Research in the Fight Against Pulmonary Hypertension”, featuring patient advocates Katharina Reimer and Julia Beese, together with PH expert Prof. Dr. Hanno Leuchte. The episode shares personal stories about diagnosis and living with PH and the value of patient support.

Further collaborative projects are already planned, continuing the shared commitment to improving awareness and education for the PH community in Germany.



LEARN MORE:

PODCAST: Together Strong: Self-Help and Research in the Fight Against Pulmonary Hypertension

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PATIENT BROCHURE: Living with PAH



HUNGARY

On April 25, 2026, we organized the 14th PH Patient Meeting of the Tüdőér Egylet (Hungarian PH Association). We were happy to welcome many fellow patients, supporters and interested parties. The meeting not only provided an opportunity for personal conversations and exchange of experiences, but also for us to have more direct contact with our treating physicians and specialists.



The educational program began with a welcoming speech by Eszter Csabuda, the president of our association.

Afterwards, Dr. Erzsébet Boros, head of the department, gave a presentation on the rehabilitation options for reducing complex lymphedema. In PH patients, leg swelling can sometimes be caused not only by fluid retention, but also by lymphatic circulation disorders, so it was particularly useful to learn more about its causes and treatment options.

The video of the presentation is available here:
<https://www.youtube.com/watch?v=njfnT1UZ0bk&t=2s>



Then, Dr. Gergely Ágoston PhD, med. habil. head of the department, spoke about the most common side effects of medications used in the treatment of PH. This is an important topic for every patient, as almost everyone has encountered unpleasant symptoms during treatment. It was mentioned how important perseverance is, because it often takes time for our body to adapt to the medications, and to experience that in addition to their beneficial effects, possible discomforts subside or become more tolerable.

The video of the presentation can be found here:
<https://www.youtube.com/watch?v=79tAVDLRKxM&t=1073s>



Renáta Ocskó-Horváth explained the role of nurses in subcutaneous treprostinil therapy. She highlighted how important the work of healthcare specialists is in education, monitoring and everyday assistance. She presented practical information on pump use, as well as the benefits and difficulties of the therapy.

The patient presentations were a particularly inspiring part of the program. Our fellow patient Eszter Kőhalmi shared her personal experiences of everyday life with a medication pump.



Ádám Rakonczai told us how he experienced his diagnosis as a young man and how the disease changed his life and relationships. Csaba Konkoly showed us through practical examples the tactics and techniques he uses to plan his days in



order to minimize the discomfort caused by side effects. Dóra Erdélyi spoke briefly about her lymphatic circulation problem and in more detail about her experiences with sleep apnea and its treatment.



These personal stories were a good example of how to adapt to the “new normal” and the important role resilience plays in everyday life. The speakers jointly emphasized that living with treatment does not only mean taking medications and attending check-ups. Our own activity is equally important: regular exercise according to our capabilities, awareness and the effort to not only live with the disease, but to live with it as best as possible. Treatments can give us the opportunity to set goals and get closer to achieving them.

In closing, Dr. Kristóf Karlócai, Chief Physician, said a few thoughts.

The video about this program item can be watched here:
<https://www.youtube.com/watch?v=ARPDYD1fytA&t=18s>

We were delighted that Dr. Balázs Gieszer accepted our invitation and gave a presentation on the role of thoracic surgeons in the treatment of PH, as in some cases lung transplantation may be the only solution. Unfortunately, we cannot make this presentation available.



Following this, great interest was evoked by the presentation of Chief Physician Dr. Kristóf Karlócai, in which he emphasized that research activities are currently in progress in the treatment of PH in order to ensure that even more modern therapies will be available in the future. The video of the presentation is available here:

<https://www.youtube.com/watch?v=hAtbzIKrFNI>



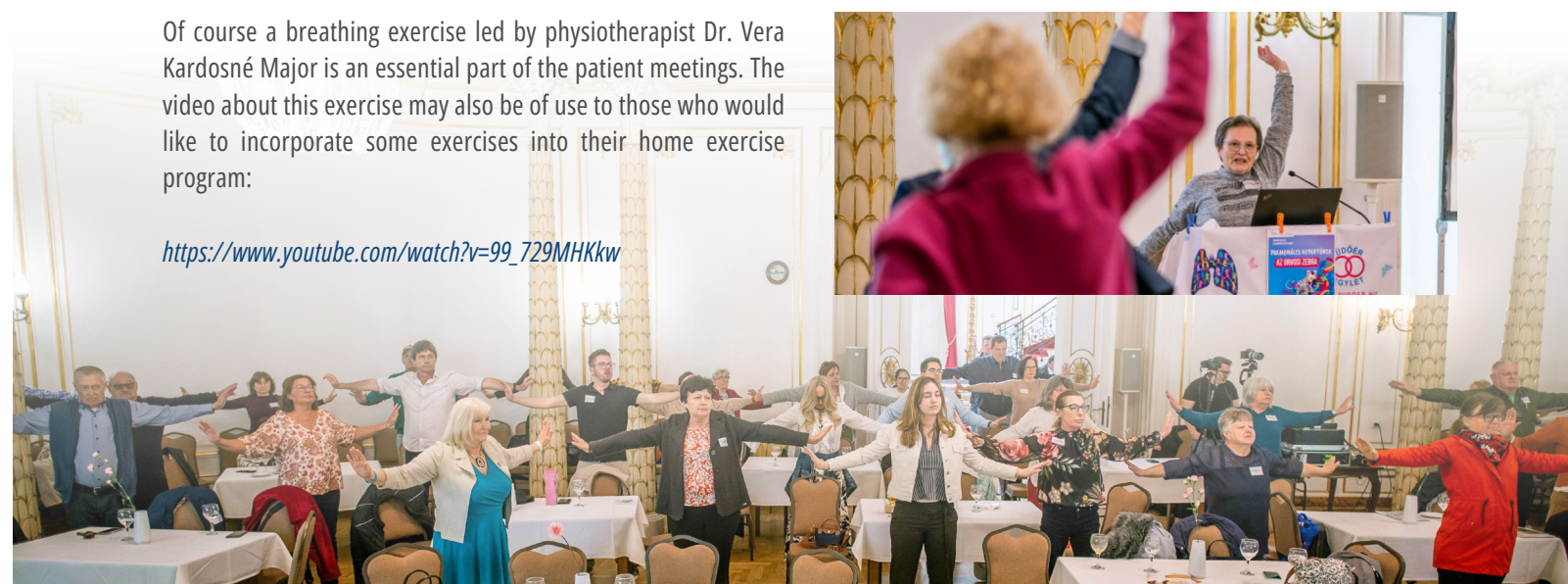
Of course a breathing exercise led by physiotherapist Dr. Vera Kardosné Major is an essential part of the patient meetings. The video about this exercise may also be of use to those who would like to incorporate some exercises into their home exercise program:

https://www.youtube.com/watch?v=99_729MHKkw

It was a pleasure to be together again, to talk with each other and share our experiences. The participants also took home a number of useful publications, including nutrition advice, travel guides for PH patients, a breathing exercise booklet, and two new publications that help to better understand treatment guidelines. All of these materials contribute to patients being more up-to-date and taking a more active role in their own care.



This year, we held our association's annual general meeting on May 19. Our president, Eszter Csabuda, reported on the activities of the previous year and illustrated with photographs the work of patients and volunteers, which was aimed to increase awareness of PH. Our association operates in difficult financial circumstances, so the cooperation and help of our supporters is still very much needed. Dr. Kristóf Karlócai, our treating physician, was also present at the general meeting, from whom we could also ask questions and discuss our individual problems this time as well.



In May, the month of World PH Day, we joined the international campaign of PHAEUROPE & Global. This year's theme focused on how we can find hope in every research. Our fellow patient, Dóra Erdélyi, summarized her experiences in Hungary and also talked about the hope that participating in a clinical trial brought her when existing treatments were no longer enough. This hope is not only for the participants in the research, but also for the fact that these treatments may thereby become available to others in the future. Living with PH, life is often a race against time, and clinical trials can give us time and a new chance to survive.



#WorldPHDay2026

A klinikai vizsgálatok többet jelentenek, mint innovatív kezelésekhez való hozzáférést. Lehetőségek arra, hogy átvegyük az irányítást egészségünk felett, és részesei legyünk annak a fejlődésnek, amely másokon is segíthet. Igen, a részvétel időt, vizsgálatokat és erőfeszítést igényel, de ugyanakkor beleszólhatunk a holnap terápiáinak alakításába. Számomra a vizsgálatban való részvétel nem csak az állapotomról szól – hanem arról is, hogy hozzájáruljak valami nagyobbhoz, és a reményről.

Dóra
PH Páciens, Magyarország






On May 23, 2026, our association was able to introduce itself at the Zuglói Civil Kavalkád (An event for the NGOs of Zuglói, Budapest). Since our headquarters are located in Zuglói,

strengthening local relations is important to us. The aim of the event was to bring civil organizations closer to the people and provide an opportunity to learn about their activities. We were able to talk at length about the work of our association, about PH itself, and why it is difficult and often still delayed to make a diagnosis. We also shared the challenges that people affected by PH live with, and how important support is to us so that patients can remain part of society to the fullest extent possible.

At our tent, we welcomed those interested with an immersive, attention-grabbing activity: the participants could create colorful works of art by blowing bubbles. We asked them to take a deep breath and let out the tension.

During the month of World PH Day, it is especially important for us to draw attention to the importance of breathing - the fundamental thing that most of us take for granted. The exhaled air appeared in a playful form on the paper, becoming a pattern of special colors and shapes. The idea of this communal creation came from a young artist from Zuglói.

Very enthusiastic little artists visited our tent while we raised awareness of our rare disease and provided information about the symptoms to their parents. Given the great success of the program, we would like to continue this activity at other awareness-raising events.

Hungary is currently undergoing significant changes, so there is still a lot of work ahead of us. We continue to work to effectively advocate for the PH patients and improve treatment options and their outcomes.

Eszter Csabuda –Tüdőér Egylet
www.tudoer.hu
<https://www.facebook.com/tudoer.egylet>



ISRAEL



A PLACE TO TURN: ONE FAMILY'S JOURNEY WITH PULMONARY HYPERTENSION

Aryeh Copperman, CEO of the Israeli Pulmonary Hypertension Association, has transformed his family's personal experience with pulmonary hypertension into a lifelong commitment to supporting patients.

Twenty-one years ago, Aryeh's wife was diagnosed with pulmonary hypertension during her fifth month of pregnancy. The diagnosis led to an extremely difficult decision: the pregnancy had to be terminated in order to save her life.

This experience brought Aryeh to the Israeli Pulmonary Hypertension Association, where he initially volunteered and eventually became CEO. Today, the association supports patients and families, raises awareness of pulmonary hypertension,

advocates for access to treatments, and helps patients navigate everyday challenges.

During the first half of 2026, the association increased its media activity and published several articles in Israel's national media. It also began a new collaboration with another lung disease association to strengthen advocacy and protect patients' rights.

Recently, Aryeh's wife underwent a successful lung transplant in Toronto, Canada. Despite continuing to support his wife through her recovery, Aryeh remains actively involved in the association's work.

"My goal is to make sure that no patient has to go through this journey alone," he says.



ITALY AIPI

AIPI'S FIRST SIX MONTHS OF 2026

The first half of 2026 was a particularly full one for AIPI, anchored by three milestones: our annual patient and family meeting in Bologna, the publication of our first two quarterly newsletters of the year, and the release of two new resources for our community. Alongside these, our members made their own mark, with patient and AIPI board member Marika Gattus taking part in several initiatives in support of PH awareness.

25-YEAR ANNIVERSARY OF AIPI

In 2026, AIPI celebrates a quarter of a century since it was founded in 2001. Over the past 25 years AIPI has built up a wide-ranging body of activity in support of PH patients and their families. On the information side, the association has held annual meetings with presentations from key scientific experts, published 92 editions of its quarterly newsletter and ten patient booklets covering everything from the basics of PH, its treatments and surgical options through to mental health and practical tips for everyday life. All the AIPI information resources are available online on its website. AIPI also provides news and regular updates of its activities on its social media channels (3,6k followers on Facebook). Patients and family members have also been able to rely on round-the-clock telephone helplines, organisational



support in arranging travel to medical appointments, as well as professional legal advice on pensions and welfare benefits, and direct financial support through the association's solidarity fund. AIPI has also worked to raise the profile of PH more broadly, through advocacy with national and local health authorities, awareness campaigns fronted by well-known testimonials from TV, cinema, arts, and sport, and representation of patient interests at congresses and other scientific and industry meetings.

ANNUAL PATIENT AND FAMILY MEETING

Our annual patient and family gathering took place in Bologna on 12 April 2026, and this year it doubled as a celebration of AIPI's 25th anniversary. President

Pisana Ferrari opened the day with a review of the association's activities in 2025, presented the 2025 budget and AIPI's plans for the current year, and — stepping in for Prof. Galiè, who was unable to attend for health reasons — gave a scientific update covering the history of PAH treatment as well as current and future therapies. Adelmo Mattioli, our welfare and pensions consultant, returned for his annual briefing, this time focused on 2026 updates to labour protections and disability benefits. Over lunch we



celebrated our 25 year anniversary with a cake and Prosecco. As always, the day closed with the traditional charity tombola.

NEW AIPI RESOURCES

On the publishing front, AIPI released two editions of its quarterly newsletter, AIPI news, and introduced to the public its two new volumes: a poetry collection by Barbara Boneta, a PAH patient living in Trieste, with beautiful watercolour paintings made by her daughter Ajlin, and a new collection of patient testimonials curated by Italian journalist Roselina Salemi. Both were presented at a public event in Trieste on 28 January and then launched at the annual meeting in Bologna on 12 April.



PH AWARENESS

Beyond the annual meeting, one of the highlights of the period was the Solo Women Run 2026, held in Cagliari, Sardinia, on Sunday, 8th of March, which brought together over 16,000 women in a solidarity event celebrating women's health and raising awareness of conditions that disproportionately affect them. Within this run, PH patient and AIPI board member Marika Gattus rallied a group of around 230 women, who took part wearing blue lipstick and carrying blue balloons to raise awareness of PAH and encourage others to „donate a breath” to those affected. Gattus wrote afterwards that the day was as much about caregivers as it was about patients themselves, and she summed up the spirit of the group with its motto — „we are just a drop, but drop by drop we can become a lake, a river, a sea” — pointing to 8 March as proof that this had been achieved. The „Dona un Respiro” group also used the occasion to collect a donation in support of AIPI's activities.

Marika Gattus's contributions to AIPI's activities continued beyond the run: she wrote about her experience of living with a rare disease in issue n. 91 of our newsletter, and in issue n. 92 recounted what it means to walk the Camino de Santiago while living with PAH.

Marika also attended the opening of the „Aria di Vita” campaign, promoted by MSD Italia under the patronage of AIPI and AMIP, which launched in Rome on 25 March and featured an original musical composition by renowned composer Maestro Enrico Melozzi, inspired by patients' experiences of living with PAH. And in June she represented IERFOP-ETS (European Institute for Research, Training and Vocational Guidance), the organisation she works for, at ExpoAid 2026, Italy's largest national event dedicated to disability and inclusion, held in Rimini.





ITALY (AMIP)

THE ACTIVITIES OF THE PULMONARY HYPERTENSION PATIENTS ASSOCIATION

In recent months, the Association's activities have focused on various meetings at the institutional level and with pharmaceutical companies, as well as supporting patients with all their needs (we were able to identify a psychologist dedicated to pulmonary hypertension).

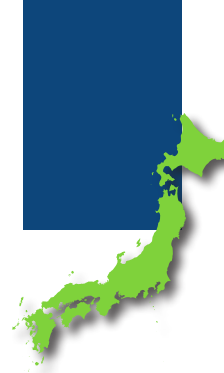
An important initiative was conducted with MSD Italia. Music maestro MELOZZI, well-known in Italy, composed the song „Aria di Vita” to give patients a voice. A giant saxophone was displayed in the train stations of Rome, Bologna, and Milan. The initiative received considerable media coverage ([link: https://www.youtube.com/watch?v=zUVEcfsgjg](https://www.youtube.com/watch?v=zUVEcfsgjg)).



Furthermore, with AOP Italia, we are conducting a survey to understand patient needs and are advancing the home delivery method for medications and aids, obviously without encountering the many challenges associated with the current regulations.

We are planning five doctor/patient meetings starting Saturday, October 3rd. They will take place in Verona, Pavia, Rome, Naples, and Palermo (we are also working on holding such a meeting in Sardinia).

Together, we can!



JAPAN

CONNECTING PATIENTS AND PHYSICIANS ACROSS EAST ASIA

The East Asia PH Patient Forum 2026 brought together physicians and patient organisations from Japan, Korea, Taiwan and China for regional exchange, collaboration and patient-family networking.

On Saturday, 30 May 2026, PHA Japan hosted the East Asia PH Patient Forum 2026 in collaboration with EASOPH (East Asia Pulmonary Hypertension Network) at the Kobe International Conference Center. The afternoon programme brought together physicians and patient-organisation representatives from Japan, Korea, Taiwan and China.

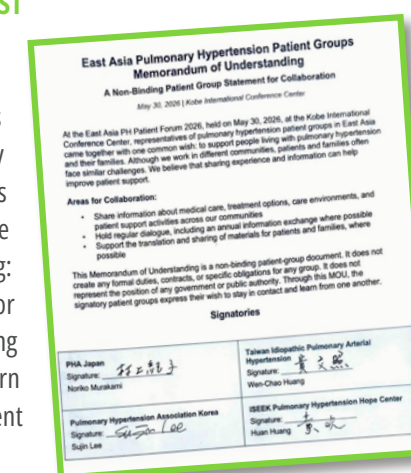
The forum opened with the latest updates from physicians and patient organisations across the four participating countries and regions. It then moved into a round-table discussion on common pulmonary hypertension challenges and the possibilities for patient support and collaboration across East Asia.



Taking place in May, a month that also marks **World Pulmonary Hypertension Day on 5 May**, the forum offered a timely opportunity to strengthen connections across the regional PH community.

A SHARED COMMITMENT ACROSS EAST ASIA

A central moment of the forum was the signing of the East Asia Pulmonary Hypertension Patient Groups Memorandum of Understanding. The document is explicitly non-binding: rather than creating formal duties or contracts, it records the participating groups' wish to remain in contact, learn from one another and improve patient support through practical exchange.



AREAS FOR COLLABORATION

- Share information about medical care, treatment options, care environments and patient-support activities across participating communities.
- Hold regular dialogue, including an annual information exchange where possible.
- Support the translation and sharing of materials for patients and families, where possible.

SIGNATORIES

PHA JAPAN

Noriko Murakami

TAIWAN IDIOPATHIC PULMONARY ARTERIAL HYPERTENSION

Wen-Chao Huang

PULMONARY HYPERTENSION ASSOCIATION KOREA

Sujin Lee

ISEEK PULMONARY HYPERTENSION HOPE CENTER

Huan Huang

KEEPING THE CONVERSATION GOING

The forum concluded with a patient and family networking session, reinforcing the event's focus on connection as well as information. By creating space for physicians, patient organisations, patients and families to meet within one programme, the forum provided a practical setting for exchange across borders.

The Memorandum of Understanding gives that exchange a simple structure for the future: continued dialogue, sharing useful information and materials, and learning from experiences across different communities whenever possible.

Held at the end of May, a symbolically important month for the global PH community, the forum and the subsequent signing of the Memorandum of Understanding between four patient associations from Japan, Taiwan, Korea and China represent a positive step forward for collaboration across the wider East Asia region.

LATIN AMERICA

May was a month of action, unity, and advocacy for the pulmonary hypertension community in Latin America.

At the Latin Society of Pulmonary Hypertension, we continued advancing our **#AdvocateToBreathe (#IncidirParaRespirar)** campaign, delivering messages of awareness, access, early diagnosis, and hope across different countries in the region. Several of our member organizations carried out in-person activities in countries such as Peru, Venezuela, and Colombia, among others, while others developed virtual initiatives to continue amplifying the voice of patients.

In addition, we successfully held the **4th Virtual Pulmonary Hypertension Marathon**, bringing together more than 200 participants from across Latin America, 19 speakers, and 6 hours of learning, science, advocacy, and hope.



We were also honored to join PHAEUROPE & Global's global campaign, **"Hope in Every Trial,"** an initiative that highlights the importance of clinical trials in creating new opportunities, innovative treatments, and hope for people living with pulmonary hypertension. We sincerely thank PHAEUROPE & Global for allowing us to be part of this valuable global campaign.

We extend our gratitude to our 20 member organizations, collaborators, patients, caregivers, healthcare professionals, leaders, and volunteers who made every activity possible and demonstrated that when we work together, we can go further.

We remain committed to advancing greater awareness, improved access to treatments, more research, and a better quality of life for all people living with pulmonary hypertension throughout our region.

#IncidirParaRespirar



(20 años) SOCIEDAD LATINA DE HIPERTENSION PULMONAR

¡GRACIAS! 4 TA MARATÓN VIRTUAL

A LAS 20 ORGANIZACIONES MIEMBRO DE LA SOCIEDAD LATINA DE HIPERTENSION PULMONAR

POR SU COMPROMISO, TRABAJO Y CORAZÓN EN LA LUCHA CONTRA LA HIPERTENSION PULMONAR

Logos of member organizations: FUNDACIÓN GRUPO DE APOYO PAT CARABOBO, RESPIROS PULMONAR, Fundación Ayudanos a Respirar, AFPIA, ONG AMISARE, ASHAP, abraf, APAV, ADHIPU, LABOR MÉDICA, HAPCHI, FUNDE, LHL, GLOBAL ALLERGY & AIRWAYS PATIENT PLATFORM.

4 TA MARATÓN VIRTUAL DE LA HIPERTENSION PULMONAR

(20 años) SOCIEDAD LATINA DE HIPERTENSION PULMONAR

GRACIAS

A LAS MÁS DE **200 PERSONAS CONECTADAS** DE LATINOAMÉRICA

Durante **6 horas de conexión**

13 Y 14 DE MAYO | **19 CONFERENCISTAS**

CUANDO NOS CONECTAMOS, TRANSFORMAMOS REALIDADES.

Juntos somos más fuertes, juntos llegamos más lejos.

Logos: 50 MAYO Día Mundial de la Hipertensión Pulmonar, LHL Latin Health Leaders, GLOBAL ALLERGY & AIRWAYS PATIENT PLATFORM.

Participant names: Nancy Rivas Elizondo, Luz Osorio, Maritza Rodríguez, Johanna Vanessa Castellanos Suárez, Dina Grajales, Amada Flores Rich, Paz Peraza, Romina González, Silvana Crespo, Saez, LHL, Gloria Grooscors, Rodrigo Ramirez, Xiomary Bermudez, Johanna Vanessa Ca, Flores Richert, Dina Grajales, Oscar Madrid, ANA FERNANDEZ, Paulina Saez, Rosa María Cruz navas, Luz Patricia Martinez, Laura Maurell, enrique linares, Edgar Ponce, Davis Orlando Romero Molina, Gaby Vásquez, luz patricia martinez, Ana Alvarez.

LATVIA

NEWS FROM PH ASSOCIATIONS

BRINGING „HOPE IN EVERY TRIAL”: CELEBRATING WORLD PH DAY 2026 IN LATVIA

This spring, the pulmonary hypertension community in Latvia came together for a very special World PH Day campaign titled “Hope in Every Trial”. From April 22nd to June 4th, 2026, the patients’ association PHA Latvia, in close collaboration with PHAEUROPE & Global and dedicated medical professionals, launched a heartwarming digital campaign on Facebook and Instagram. The main goal was to shine a light on the vital role of clinical trials in creating better treatments and bringing a brighter future for PH patients.

HEARTFELT STORIES AND EXPERT INSIGHTS

The true heart of this campaign was the incredible community involvement. We are deeply proud of and grateful to the five PAH patients: Aleksandrs, Zigrīda, Viktors, Laura, Ieva, who bravely shared their real-life testimonials about participating in clinical trials. Engaging so many patients to speak up was a huge success and touched many hearts.

Additionally, the campaign featured five educational video interviews with cardiologist Dr. Ricards Kaulins from Pauls Stradins Clinical University Hospital (PSKUS). Dr. Kaulins kindly explained the ABCs of clinical trials, helping to ease patients’ concerns and explain how clinical trials’ protocols work.

A BIG “THANK YOU” TO OUR TEAM

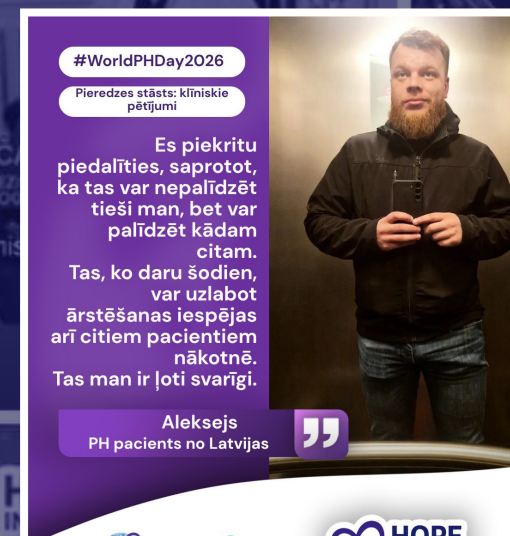
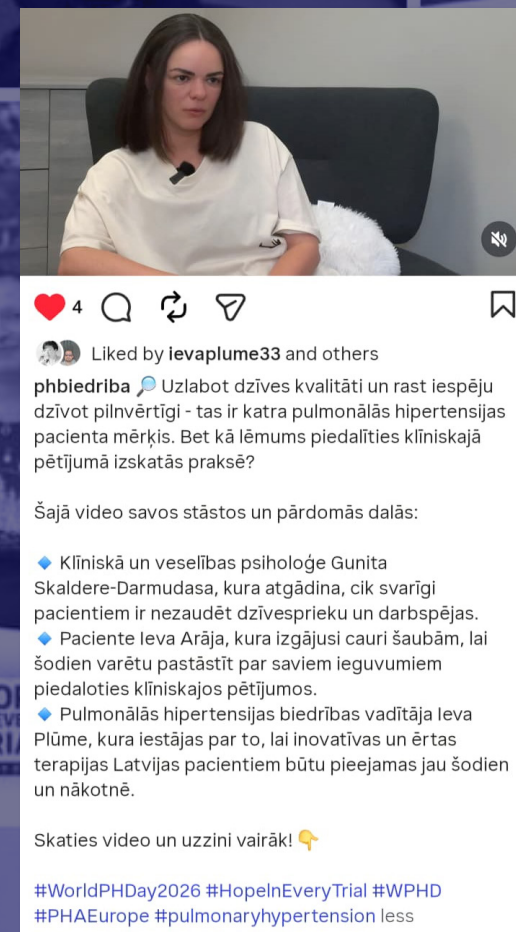
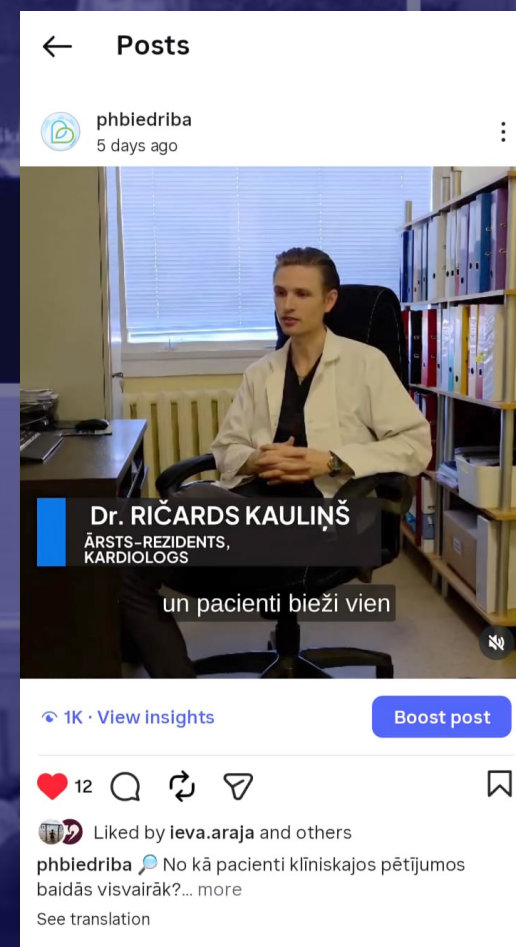
A special shout-out goes to PHA Latvia’s social media specialist, Ieva Aja. Thanks to her hard work and dedication, the association’s previous valuable materials like our educational booklet and 2023 videos were promoted alongside 19 translated information materials from PHAEUROPE & Global. Ieva did a fantastic job keeping our community informed and engaged every single day during the campaign.

THE CAMPAIGN IN NUMBERS

Our warm and educational messages reached far and wide, inspiring both our loyal followers and many new faces. Here is a quick look at our digital results across Facebook and Instagram:

- **Facebook:** with 7 original posts, 6 video reels, and 19 PHAEUROPE & Global materials, the campaign achieved an 25,192 impressions (with 70% coming from non-followers). Our reels alone got 6,815 views, and we had over 1,000 interactions.
 - **Instagram:** our content reached 838 accounts, gathering 2,703 views and 265 likes and reactions.
- The campaign wrapped up on June 4th with a final video showing the vital role of trials through the eyes of patients, caregivers, and the whole PH community. Thank you to everyone who watched, shared, and stood together with us. There truly is hope in every trial.

Authors of article: Ieva Plume, Ieva Aja.





THE NETHERLANDS

BRINGING FAMILIES TOGETHER: CHILDREN'S PH DAY IN THE NETHERLANDS

One of the highlights of our World Pulmonary Hypertension Day activities this year was the Children's PH Day, organized by the Dutch Pulmonary Hypertension Foundation in collaboration with the National Pediatric PH Expertise Center at the University Medical Center Groningen (UMCG).

The event brought together families of children living with pulmonary hypertension for a special day at the Dolfinarium in Harderwijk. Our goal was simple: to create a space where families could learn, connect, share experiences, and enjoy quality time together.

While the children participated in activities throughout the park and enjoyed a memorable dolphin show, parents attended educational sessions led by Professor Dr. Rolf Berger, one of the leading pediatric PH specialists in the Netherlands, and dietitian Jannie Ijbema. These sessions provided valuable insights into living with pediatric PH and offered parents the opportunity to ask questions and discuss practical challenges.

However, the most meaningful aspect of the day was the opportunity for families to meet one another. Parents exchanged experiences, shared advice, and found comfort in speaking with others who truly understand the realities of raising a child with pulmonary hypertension. For many participants, these connections were just as valuable as the medical information provided.

The feedback we received was overwhelmingly positive. Families left with new knowledge, practical tools, and a stronger sense of



community. Most importantly, the children enjoyed a carefree and joyful day filled with fun, laughter, and new friendships.

Events like Children's PH Day remind us how important it is to bring the PH community together. Beyond raising awareness, they strengthen the support network that patients and families rely on every day.

As one parent said at the end of the event:

„You really should have been here.”

The Dutch Pulmonary Hypertension Foundation is proud to continue creating opportunities for connection, education, and support for everyone affected by pulmonary hypertension.



BEHIND THE SCENES: A FIRST LOOK

A cosy campervan. Beautiful locations. Meaningful conversations. A relaxed atmosphere with room for recognition, honesty — and the occasional laugh.

That's exactly the feeling we wanted to capture with **Opgeladen („Recharged”)**, a new web series exploring what it really means to live with pulmonary hypertension. It's not just about the illness — it's about the people, the connections, and the moments that give you new energy.

For this series, we sat down with Charlotte (31 years), Eline (23 years) José (54), Sonny (40), and Piet Hein (65) — each bringing their own story, expertise, and perspective, but all sharing the same goal: supporting people living with PH through recognition, practical guidance, and hope.

The series will be released soon — but in the meantime, here's a sneak peek from behind the camera.





NIGERIA

The Walk4PH Community in Nigeria marked World Pulmonary Hypertension Day 2026 with a powerful awareness walk bringing together patients, healthcare professionals, advocates, volunteers, and supporters.

Under this year's theme, „Hope in Every Trial,” participants not only walked in solidarity with those affected by pulmonary hypertension (PH) but also helped raise awareness about the challenges faced by the PH community, including access to diagnosis, treatment, specialized care, and clinical trials.

The official World PH Day 2026 campaign materials by PHAEUROPE & Global were used effectively throughout the event, helping to amplify important messages for the PH community in Nigeria and across Africa. The campaign's visual identity reinforced the call for greater awareness, improved access to care, and continued hope for those living with PH.



One month later, the impact of Walk4PH 2026 continues to resonate. Every step taken, every conversation shared, and every voice raised contributed to a growing movement of hope, advocacy, and awareness.

Patient advocate Ayotunde Omitogun, who was featured in this year's World PH Day campaign developed by PHAEUROPE, expressed heartfelt thanks to the volunteers, PH patients, partners, and supporters who came together to make Nigeria's first PH Awareness Walkathon and World PH Day 2026 event a success.

We celebrate the dedication of our PH community in Nigeria. Together, across continents and communities, we continue working toward a future where no person living with PH is left behind.

We, at the Walk4PH Community Nigeria, are keeping hope alive and making every step count.



NORTH MACEDONIA

WORLD PULMONARY HYPERTENSION DAY MARKED WITH A COMMUNITY RUN AND AWARENESS EVENT

In recognition of World Pulmonary Hypertension Day, our organization successfully held an awareness event aimed at promoting understanding of pulmonary hypertension and supporting those affected by this rare and serious condition. The event brought together healthcare professionals, supporters, and members of the wider community in a shared effort to raise awareness and encourage solidarity.

The highlight of the day was a 7-kilometer awareness run, which attracted approximately 60 enthusiastic participants. Runners of different ages and backgrounds joined the event, demonstrating their support for people living with pulmonary hypertension and emphasizing the importance of physical activity, community engagement, and public awareness.

The run served not only as a sporting activity but also as a powerful symbol of perseverance and determination. For individuals living with pulmonary hypertension, everyday activities that many people take for granted can present significant challenges. By participating in the run, community members showed their commitment to standing alongside patients and helping bring greater visibility to a condition that often remains underrecognized.



To create a vibrant and welcoming atmosphere, a DJ provided music throughout the event, helping to energize participants and spectators alike. The music contributed to a positive environment that encouraged interaction, celebration, and community spirit. An information booth was also established at the event site, serving as a focal point for awareness-raising activities. Visitors had the opportunity to learn more about pulmonary hypertension, its symptoms, diagnosis, treatment options, and the daily realities faced by patients. Educational materials were distributed, and conversations with volunteers helped increase public understanding of the disease and the importance of early diagnosis and access to specialized care.

The event demonstrated the value of community-driven initiatives in promoting health awareness and supporting patients affected by rare diseases. Although modest in scale, the gathering successfully brought attention to pulmonary hypertension and fostered meaningful engagement among participants.

We would like to express our sincere gratitude to all runners, volunteers, supporters, and partners who contributed to the success of this year's World Pulmonary Hypertension Day event. Their participation and enthusiasm helped transform a simple awareness campaign into a meaningful opportunity to educate the public and strengthen community support for individuals living with pulmonary hypertension.

As we reflect on this successful event, we remain committed to continuing our efforts to raise awareness, advocate for patients' needs, and build a more informed and supportive society. Together, we can help ensure that pulmonary hypertension receives the attention it deserves and that those affected by the disease know they are not alone.



NORWAY

The Board of the Norwegian Association participated in Rare Disease Day. This is an event where patients, relatives, healthcare professionals, and organisations come together to raise awareness of rare diseases.

Many of the presentations particularly highlighted the importance of early and accurate diagnosis, equal access to treatment, and the need for increased research into rare conditions. Several speakers emphasised how important patient involvement is in the development of healthcare services, and how collaboration between specialist healthcare services, municipal healthcare services and patient organisations can contribute to better support and follow-up in everyday life.

Personal stories from patients and relatives provided strong and important perspectives on what it means to live with a rare diagnosis – including both the challenges and the ways people manage and cope with their condition.

We are also continuously working to ensure that all PAH patients have equal access to specialised rehabilitation, regardless of where in Norway they live. Norway has several regional health authorities, and we have experienced that they differ in terms of what rehabilitation services they offer.



We used the PAH Day on the 5th of May to focus on this issue by holding a meeting with LHL, doctors, and legal experts. With their support, we hope to be able to influence the system so that all PAH patients are offered the same opportunities for specialised rehabilitation.

We have also organised patient evenings for PAH patients. These have proven to be very popular. We serve pizza, provide information about the work we are doing on the Board, and encourage everyone to share their thoughts and suggestions. These gatherings have proven to be valuable, both socially and in terms of focusing on the disease itself, coping strategies and sharing experiences.

We have also started the process of having PAH officially registered as a rare disease in Norway, with its own ORPHA code. This is new in Norway and is important in terms of ensuring appropriate healthcare and follow-up. Furthermore, such a registry can provide a basis for recruitment to medical studies, the development of national quality registries, and increased knowledge and recognition internationally.



Best regards,
Marit, LHL PAH Norway

POLAND

BLUE DAY IN BIELSKO-BIAŁA! WE TALKED ABOUT PULMONARY HYPERTENSION!

On May 5th, members of our association took to the streets of Bielsko-Biała to spread awareness about pulmonary hypertension. We were met with overwhelming kindness from the residents. They were eager to talk with us and listen to us about this rare disease.

It was beautiful, creative, and much-needed! Above all, we wanted to bring awareness to this difficult topic. We also wanted to show how important mutual support is.

EDUCATION ON THE CITY STREETS

Our campaign was full of important conversations and valuable materials:

- Leaflets for passersby: We distributed materials with the most important facts about the disease. We discussed the symptoms to look out for and advised on which tests should be performed.
- „Ola Onko” Guides: We distributed special booklets. These guides covered an important topic: the impact of chemotherapy on leukemia and its connection with pulmonary hypertension.



AN IMPORTANT LESSON FOR THE YOUNGEST

We haven't forgotten about the children. We've prepared something special for them:

- The Tale of Johnny: This is a story about a boy suffering from pulmonary arterial hypertension (PAH). The story shows how lonely a sick child can be at school. It teaches that peers should be supported, not ridiculed or shunned.
- Creative Backpacks: We distributed backpacks with our association's logo to the children. The little ones could paint them themselves. It was a lot of fun!



GIFTS FOR OUR PATIENTS

At the end of the meeting, we prepared a pleasant surprise. We distributed beautiful blue cosmetic bags with the association's logo to the patients. Blue symbolizes our fight for clean lungs and easier breathing.

The event included singing – our patient's daughter played guitar for us, and we sang songs

A BEAUTIFUL CULMINATION OF THE DAY AND A BLUE EVENING

After the event, we all went for lunch together. Since the weather was beautiful that day, we went for a walk around the city. We admired the charming Bielsko-Biała market square and took lots of photos together. There was a lot of laughter and joy.

However, the real surprise awaited us in the evening. The city illuminated the bridge and fountain blue especially for us! This beautiful gesture and the view were breathtaking. It was a very moving moment for all of us.



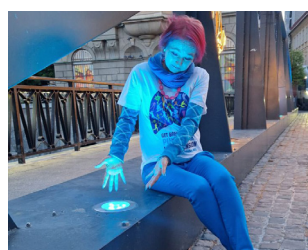
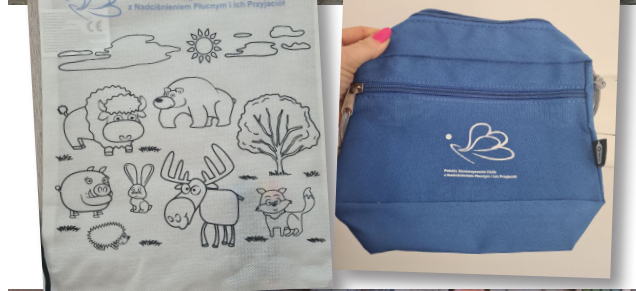
FIRST TIME IN GOŁAŃCZ! WORLD PULMONARY HYPERTENSION DAY IN BLUE

This year, our „Cities in Blue” campaign reached a new, unique location. For the first time in history, we gathered for World Pulmonary Hypertension Day in Gołańcz! All of this was made possible thanks to the generosity and openness of the local authorities.

A SPECIAL MEETING AND BLUE LIGHT

Our patient, Izabela Łęga, vice president of the association, traveled to Gołańcz with her mother. They had a beautiful mission to fulfill there.

The Mayor of the City and Commune of Gołańcz, Mr. Robert Torz, without hesitation, agreed to support our initiative. In solidarity with the sick, blue lights flashed across the city! Two important buildings were illuminated with the color of hope and clean



breath: the Gołańcz City and Commune Office building and the Gołańcz Cultural Center. Our patient met with the Mayor under these beautifully illuminated buildings. Mr. Robert Torz shared many warm words with our entire community. He wished us good health and emphasized his great joy in participating in such important initiatives.



A LITTLE HERO WITH A BIG HEART!

Milenka educates her peers in Oświęcim. On May 5th, on World Pulmonary Hypertension Day, something extraordinary happened. Milenka, the daughter of our patient, decided to organize a unique educational event! She conducted it at the Primary School with Integrated Departments No. 4 in Oświęcim. It's amazing how a young person can become a voice for such an important cause and teach others empathy and understanding.

A LESSON THAT TEACHES AND TOUCHES THE HEART

Milenka prepared a true lesson in sensitivity for her schoolmates. In a very simple and engaging way, she told them about pulmonary hypertension. She wanted the children to understand the challenges that sufferers face every day.

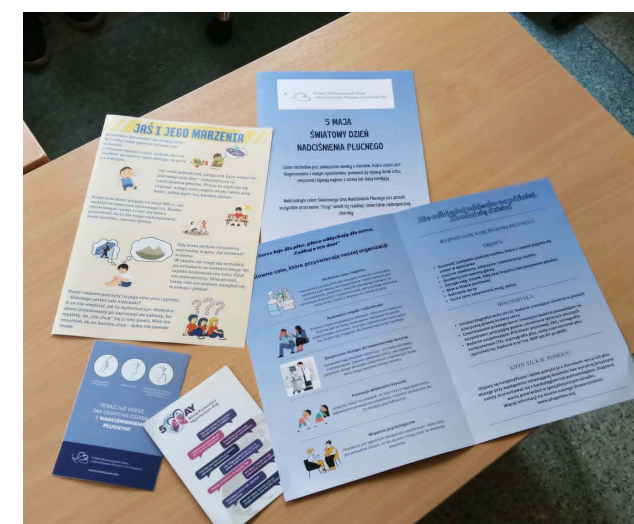
The highlight of the meeting was the straw test. This simple exercise involves breathing solely through a thin drinking straw. This allowed each child to briefly experience how difficult it is to breathe for someone with pulmonary hypertension. This short experiment showed the children why health and clean breathing are so valuable.

Educational gifts for children Milenka provided her peers with materials and surprises funded by the association:

- Information leaflets: She distributed materials for the children to take home so that their parents could also learn about the disease.
- Association backpacks: Each participant received a commemorative backpack, which brought much joy.

WORLD PULMONARY HYPERTENSION DAY DURING THE SCHOOL DAY IN SZYDŁOWIEC!

The school day at the John Paul II Public Primary School in Szydłowiec became a unique opportunity to do something good. We combined this joyful day with our awareness campaign for World Pulmonary Hypertension Day. It was a time full of smiles, learning, and great fellowship!



EDUCATION FROM THE YOUNGEST TO THE OLDEST

That day, the school hallways were visited by many wonderful guests. Among them were both young and adult residents of our area. However, we weren't alone! I had incredible support in spreading awareness about the disease. My young assistants, with enormous dedication and heart, helped me raise awareness in the local community. Together, we explained what pulmonary hypertension is and the importance of recognizing the symptoms quickly.

BLUE GIFTS AND MOMENTS OF JOY

Our stand was incredibly popular. We prepared a wealth of useful gadgets and educational materials for visitors, which sold out quickly: Knowledge packages: We distributed information leaflets with the most important facts about the disease. School gadgets: Everyone could receive a souvenir pen or lanyard. For creatives: The fabric bags for children to color in were a huge hit.

Thank you for your time, for every kind word, and for your incredible, positive energy. Thanks to you, we know that our mission is truly meaningful!



BIG HEARTS AT PRIMARY SCHOOL NO. 2 IN ZIĘBICE

World Pulmonary Hypertension Day at School Desks On May 5th, the day of World Pulmonary Hypertension Day, an extraordinary educational event took place at Primary School No. 2 in Ziębice. The main topic was pulmonary arterial hypertension (PAH) – a rare and serious disease, about which awareness was being built throughout the school community that day. Teachers and students participated with great enthusiasm, with particular emphasis on grades 1a, 2a, and 3a

To bring these difficult issues closer to the children, the youngest listened to a moving fairy tale about eight-year-old Johnny. The story of the boy, who, despite his illness, dreamed of things typical of his peers, allowed the students to understand the everyday challenges faced by people with disabilities. The fairy tale became a starting point for a conversation about



the importance of support and understanding for people whose disabilities are not always immediately apparent.

One of the most impactful parts of the program was the „straw test.” Both students and staff tried to breathe solely through a narrow tube. This simple experiment allowed participants to experience firsthand the effort involved in each breath of a person with pulmonary failure and the preciousness of our lungs.

The event concluded with an artistic performance. Students from grades 1a, 2a, and 3a created colorful educational posters that became a manifestation of solidarity with those with disabilities. Thanks to the combination of science and experience, Primary School No. 2 in Ziębice duly celebrated World Pulmonary Hypertension Day, teaching children empathy and sensitivity to the needs of others.



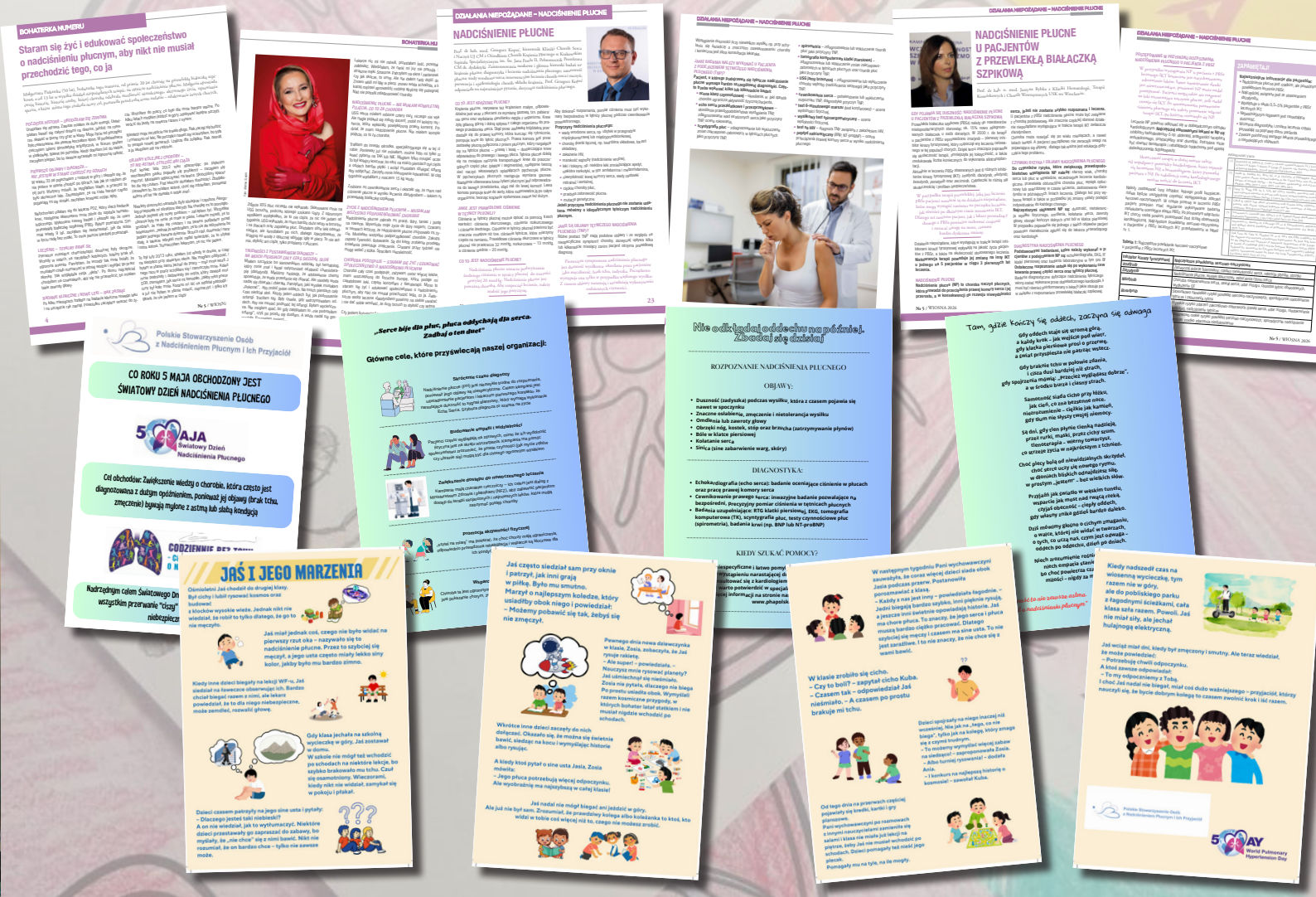
On the occasion of World Pulmonary Hypertension Day, the „Oli-Onko Hematology Guide” published an important and moving article by Małgorzata Piekarska, president of the Pulmonary Hypertension Association. The author shares her personal experience – she herself struggles daily with pulmonary hypertension, which developed as a result of leukemia.

This publication carries a fundamental, yet still too rarely discussed, message. Patients struggling with leukemia focus all their attention and treatment on hematology departments. In this process, circulatory symptoms can be easily overlooked. As a result, patients often remain without necessary cardiology care, and their declining performance is often incorrectly attributed solely to the effects of leukemia itself or chemotherapy. The morning also featured an article by Professor Grzegorz Kopec, who treats patients with pulmonary hypertension in Krakow on a daily basis, and

Professor Justyna Rybka (hematologist), who explains the impact of chemotherapy on pulmonary hypertension.

The cover featured the president of the Pulmonary Hypertension Association.

This guide aims to provide patients with clear guidance and medical direction. It is intended to advise hematology patients on the signals their bodies are sending them—such as increasing shortness of breath, chronic fatigue, or swelling—they should pay particular attention to. We want to equip patients with the knowledge that will allow them to promptly request a cardiology consultation and echocardiogram from their treating physician. Education, in this case, is a tool that saves health. We invite you to read this article, which teaches vigilance, breaks down barriers between medical specialties, and shows how to effectively care for themselves during and after cancer.





PORTUGAL

WORLD PH DAY 2026 IN PORTUGAL

BUILDING BRIDGES OF HOPE FOR PULMONARY HYPERTENSION

For the Portuguese Pulmonary Hypertension Association (APHP), **World Pulmonary Hypertension Day 2026** was much more than a single awareness moment. Throughout the month of May, APHP joined the **PHAEUROPE & Global campaign “Hope in Every Trial”**, combining it with our own national initiative, **“Pontes de Esperança para a HP” (Bridges of Hope for PH)** — a campaign built around education, connection, advocacy, and hope.

This year’s efforts aimed not only to raise awareness of pulmonary hypertension among the general public, but also to strengthen the bonds between patients, families, healthcare professionals, institutions, and all those who walk alongside the PH community.

GIVING PH A VOICE THROUGH NATIONAL MEDIA

Throughout May, pulmonary hypertension gained important national visibility through television and media coverage, helping to bring both the medical and patient perspectives closer to the public.

On the **4th of May**, the national television programme **Bom Dia Portugal (RTP1)** <https://fb.watch/HHOJ2R5rVI/> featured an interview with **Dr. Mário Santos**, Head of the Pulmonary Hypertension Unit at Hospital de Santo António and coordinator of the Pulmonary Hypertension Study Group of the Portuguese Society of Cardiology. The interview helped raise awareness for pulmonary hypertension, the challenges surrounding diagnosis, and the importance of specialised care and early recognition.



A second television feature aired on **May 10th** in **Jornal da Tarde (RTP1)** <https://www.rtp.pt/play/p16047/e928097/jornal-da-tarde> (min. 18:03 to 22:15), one of Portugal’s leading lunchtime news programmes, this time sharing the patient perspective through **Luísa Gonçalves**, a pulmonary hypertension patient from Madeira. In a deeply personal testimony, Luísa shared her diagnostic journey and the reality of regularly travelling from Madeira to Porto for specialised follow-up care, helping to shine a light on the daily challenges and resilience of people living with PH.

Together, these television appearances reached an estimated audience of over **half a million viewers**, contributing significantly to national awareness efforts.

In addition, APHP secured **multiple online and print media features**, generating an estimated **media circulation of more than 1.1 million impressions**, with an estimated media value equivalent of approximately **€72,883**.

A DAY OF LEARNING, SHARING AND COMMUNITY IN PORTO

The highlight of this year’s awareness campaign took place on the **16th of May**, when APHP held its national World PH Day event at **ICBAS – University of Porto**, under the theme **“Pontes de Esperança para a HP” (Bridges of Hope for PH)**.

The event brought together approximately **80 participants**, including patients, caregivers, family members, healthcare professionals, researchers, speakers, institutional representatives, industry partners, and friends of the PH community. Participants travelled from across the country — including **Madeira, Algarve, Santarém, Lisbon, Coimbra, Porto, Braga, Viana do Castelo, and Viseu** — reflecting the national reach and growing engagement of the Portuguese PH community.

The conference opened with the institutional presence of **Member of Parliament and physician Dr. Miguel Guimarães**, former President of the Portuguese Medical Association, whose participation reinforced the importance of advocacy, visibility, and continued efforts to improve quality of life for people living with pulmonary hypertension in Portugal.

Throughout the day, participants engaged in a diverse scientific and educational programme designed to bring together knowledge, lived experience, and meaningful dialogue.

One particularly memorable moment was the **“Respirar em Movimento” (Breathing in Movement)** session, led by sports physiologist **Cristine Schmidt**. After an introductory educational presentation on movement and pulmonary hypertension, participants moved outdoors for an adapted group exercise session combining breathing techniques, mobility, and light resistance exercises. Carefully adjusted to individual physical limitations and abilities, the session became a joyful and meaningful moment of connection between patients, families, and healthcare professionals — showing that movement, when adapted and supervised, can be both empowering and safe for people living with PH.



The programme also included highly valued sessions on **pediatric pulmonary hypertension, scientific innovation**, and one of the most emotional and engaging topics of the day: **pregnancy and contraception in pulmonary hypertension**, led by **Dr. Cristina Cruz**. The discussion sparked meaningful reflections among patients, many expressing hope that future scientific advances may create new possibilities for women living with PH, even if these changes may come too late for their own personal journeys.

Another particularly dynamic moment was the practical workshop dedicated to **parenteral therapies and infusion pumps**, led by **Nurse Carla Sá**. Through demonstrations, educational materials, and open discussion, patients and caregivers had the opportunity to ask questions and share personal experiences regarding life with infusion therapies. Conversations around treatment transitions — including experiences moving from epoprostenol to newer therapies such as selexipag or treprostinil — highlighted not only improvements in quality of life but also the significant psychological burden that infusion therapies can place on patients and families, while reinforcing hope for future therapeutic advances with fewer limitations.

The day also featured a successful **World caPHé session**, where patients and family members worked in separate groups to reflect on challenges, priorities, and opportunities for improving life with pulmonary hypertension. The discussions generated meaningful insights and practical reflections, reinforcing the importance of listening to lived experiences and co-creating solutions together.

To extend awareness beyond the event itself, APHP also developed and distributed **educational posters and leaflets to Portuguese PH reference centres**, helping reinforce patient information and visibility of pulmonary hypertension within healthcare settings.

The event concluded with APHP’s **General Assembly**, during which a **new board was elected**, welcoming four new members and reinforcing the association’s commitment to continued growth, patient advocacy, and future projects.



ROMANIA

WE BREATHE TOGETHER; WE FIGHT TOGETHER!

On May 8, the Romanian Pulmonary Hypertension Patients' Association, together with the "Victor Babeș" Hospital for Infectious Diseases and Pulmonology in Timișoara, and with the support of partners in the pharmaceutical industry, organized the first regional meeting of patients, doctors, and caregivers, titled "We Breathe Together, We Fight Together."

The event was attended by 29 patients and caregivers, along with doctors and nurses from the hospital, hospital management, and representatives of the association.

The event included several discussion sessions, as follows:

- Association representatives (Mr. Bogdan Burduja, Ms. Daniela Voinea, Ms. Anca Berendea, Mr. Florin Dumitrescu) spoke about the importance of patient associations, patients' active participation in association activities, educational programs, advocacy work, and the support provided by partners in the pharmaceutical industry;
- Physicians from the Pulmonary Hypertension Expert Center (Dr. Nicoleta Bertici, Dr. Ovidiu Mlădinescu Fira, Dr. Radu Lala, Dr. Irina Stan, Dr. Alexandru Crișan, Dr. Dana Biriș) delivered presentations tailored to doctor-patient communication, covering the following topics:



- New medical strategies for managing pulmonary hypertension (PH)—a multidisciplinary approach, featuring pulmonologists and cardiologists
- Physical exercise and physical therapy for patients with PH
- Psychological counselling for patients with chronic diseases (including PHT)
- Nutrition tailored to patients with PHT.

The most successful presentations—given their unique nature and the fact that such information is not readily available in most specialized medical facilities—were those covering physical therapy and exercise, as well as the discussions on psychological support.

The event was a success, with all participants expressing their delight at having been able to attend the first meeting of its kind.



A GROWING DIGITAL COMMUNITY

Throughout May, APHP maintained a strong digital awareness campaign across social media, combining educational content, campaign materials, event promotion, and patient-centred messages inspired by this year's "Hope in Every Trial" theme.

Across APHP social media channels, the campaign generated:

- 59,416 people reached
- 129,734 content views
- 6,312 interactions
- 3,565 profile visits
- 207 new followers

This year also marked the launch of APHP's **LinkedIn page**, representing an important new step in strengthening professional and institutional visibility.

HOPE GROWS STRONGER WHEN WE WALK TOGETHER

World PH Day 2026 reminded us that pulmonary hypertension may be a rare and challenging disease, but no one should face it alone.

More importantly, it reminded us that **bridges of hope are built when patients, families, and healthcare professionals walk side by side** — learning from one another, sharing experiences, and working together towards better care, greater awareness, and a better quality of life for everyone living with pulmonary hypertension.



The following day, on May 9, activities dedicated to World Pulmonary Hypertension Day continued with an awareness campaign aimed at raising awareness of pulmonary hypertension and the special needs of patients, held in Bistrița in partnership with the Via Transilvanica Association (viatransilvanica.com).

The event was organized as part of the “Good Day on Via Transilvanica” initiative and, together with the regional meeting on May 8, is part of the events dedicated to World Pulmonary Hypertension Day, held under the slogan

“EDUCATION • COMMUNITY • MOVEMENT.”



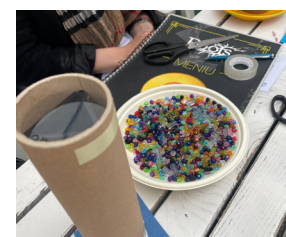
At this second event, under the motto “PH doesn’t stop us. We keep moving forward,” patients and volunteers demonstrated that resilience can transform any challenge into a beautiful experience.

The event’s program included an outdoor awareness and exercise activity, during which participants walked a 2-kilometer stretch of the Via Transilvanica, celebrating the freedom of the trails and the importance of exercise for health. For patients with PHT, every step is a victory, and this outing symbolizes the desire not to let the disease limit the joy of living.

The second part of the event featured the “Kaleidoscope of Hope” workshop, where, alongside Veronica Soare, participants—both patients and members of the general public—built kaleidoscopes, symbolically learning that life, even when it seems to consist of “shards” (difficult diagnoses), can create images of rare beauty if directed toward the light.

“May 9 marks the third part of our journey this year,” stated representatives of the Association. “After exploring our inner selves alongside psychologists and then building bridges of trust with doctors in Timișoara, we came to Bistrița to celebrate life in motion and the warm support of the volunteers, who help the ‘kaleidoscope’ spin every day.”

The event received support from prestigious organizations, underscoring the importance of solidarity in the fight against this rare condition (PHAEUROPE & Global, AOP Health, Vital Aire, Johnson & Johnson).





SERBIA

NEWS FROM PH ASSOCIATIONS

On the occasion of World Pulmonary Arterial Hypertension Day, the Pulmonary Hypertension Serbia Association held a panel discussion on May 28, 2026, entitled **“PH Yesterday, Today, Tomorrow.”**

The panel was accompanied by a press conference, during which the key messages of the event were presented, with a special emphasis on the importance of early diagnosis, access to modern therapies, and ensuring that treatment reaches patients as quickly as possible. We are also very pleased that the event received significant media attention, with coverage in more than 20 media outlets, including several national TV stations and prime-time broadcasts.

The panel brought together patients, family members, medical experts, representatives of the healthcare system, and decision-makers to open an honest discussion about the development of pulmonary hypertension treatment in Serbia, current challenges, and the future that brings new therapeutic options, improved diagnostics, and a better-organized patient pathway through the healthcare system.

We are especially pleased that the event was attended by a large number of people, both in the audience and among the speakers. The atmosphere was extremely positive, and the presentations and discussions showed how important it is to have patients, physicians, representatives of institutions, and all those who can contribute to improving the position of patients sitting at the same table.



The speakers at the panel were distinguished experts who, through their knowledge, experience, and many years of dedicated work, have made an enormous contribution to the development of pulmonary hypertension treatment in Serbia and the region: **Prof. Dr. Slavko Simeunović**, long-standing Head of Pediatric Cardiology at Tiršova Children's Hospital and Director of Profmedika Simeunović, as one of the pioneers of pulmonary hypertension treatment and management in the former Yugoslavia; **Prof. Dr. Arsen Ristić** from the University Clinical Center of Serbia, which includes the Reference Center for Pulmonary Hypertension; **Prof. Dr. Jovan Matijašević** from the Institute for Pulmonary Diseases of Vojvodina in Sremska Kamenica and the Reference Center for Pulmonary Hypertension; as well as **Dr. Ivan Stanković** from the Reference Center at the Clinical Hospital Center Zemun.

Another guest of the panel was **Dr. Željko Popadić**, representing the **National Health Insurance Fund of Serbia (RFZO)**, whose presence was particularly important, as it enabled discussion on access to therapies, procedures, waiting times, and future steps from the perspective of an institution that plays a key role in ensuring patients' right to treatment. With Dr. Željko Popadić, we also discussed the major progress made in the treatment of pulmonary hypertension in Serbia, especially compared with the situation some ten years ago, when specific therapies were not available to patients. Today, the situation is significantly different, and this progress represents an important result of the joint efforts of the medical profession, institutions, decision-makers, and patient associations.

The speakers addressed all important topics related to the lives of patients with pulmonary hypertension: from early diagnosis, timely initiation of therapy, and shortening the waiting time for treatment, to the availability of modern therapies, the role of reference centers, teamwork, and the need for the patient voice to be included in all important discussions about the future of treatment.

Today, we are pleased to say that Serbia has made a major step forward over the past decade in terms of therapy availability for patients with pulmonary hypertension. Among the available treatments is the first innovative therapy for pulmonary hypertension, representing an important step toward more modern treatment and a better future for patients.

It is also highly significant that one potent therapy, which until recently had been available only to adult patients, has recently become available to pediatric patients as well. This represents a major step forward for children and young people living with this serious and progressive disease, as it expands treatment possibilities and allows therapy to be tailored more individually to patients' needs.

Pulmonary hypertension is a disease in which time is extremely important. Early diagnosis, rapid initiation of therapy, and reducing the waiting time until treatment actually reaches the patient can significantly influence the course of the disease, quality of life, and long-term treatment outcomes.

We would like to thank all participants, speakers, patients, physicians, representatives of the healthcare system, and friends of the association who, through their presence and support, contributed to making this panel an important step in our shared fight for a better, safer, and more dignified life for patients with pulmonary hypertension.

PH Yesterday, Today, Tomorrow — from the fight for access to therapies to hope for more modern, faster, and better treatment for every patient.

Pulmonary Hypertension Serbia Association



SLOVAKIA

As part of the WPHD campaign, PHA Slovakia held several events this year.

Throughout May, we ran a social media campaign to support clinical trials and the need for innovative treatments, prepared by PHAEUROPE & Global. We also prepared and published several patient stories from Slovakia. Athletes also supported our campaign with their activities - a two-day 375 km relay race Vltava run and a physically demanding competition Urban Challenge.



In Slovakia, we have been fighting for the categorization of innovative treatment for the second year. This year's entire campaign was carried out in this spirit. On April 29, we prepared a press conference with experts on the topic "When time decides life". The speakers were top doctors Prof. Goncalvesová and Dr. Kafková from specialized PH centers in Bratislava and Košice. The President of the Rare Diseases Alliance, Assoc. Prof. Foltánová, spoke about the pitfalls of the upcoming amendment to the Drug Policy Act. President PHA Slovakia Iveta Makovníková spoke about the problems that patients struggle with and the need to accept innovative treatment. PAH patients present also shared their stories with the media.

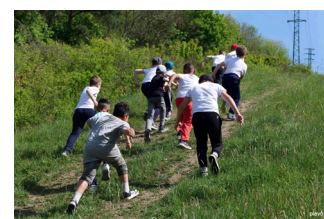


On May 5, four cities across Slovakia also marked World PH Day by illuminating seven landmark buildings in blue. Some cities also informed the public about World PH Day on their social networks.

This year, we decided to create the project "Children Need to Breathe Too," to support not only children with pulmonary hypertension, but all children, for whom ordinary breathing causes serious problems. The project was created in cooperation with the Primary School with Kindergarten in Dolná Strehová, where a member of our association Zuzana worked until recently. During April, students from the entire school were educated about PH and, under the guidance of their teachers, participated in an art competition. They prepared not only art works, but also greetings for sick children. The ten best artworks were exhibited at Imre Madách Castle, belonging to the Slovak National Museum. On May 5, a running competition was held as part of the project, in which the entire school participated. The event was not primarily about competition, although the winners were awarded, but to understand how children struggle with breathing during ordinary activities, to understand that breathing cannot be taken for granted. It was a wonderful day full of experiences, energy, joy and belonging. Finally, we took selected artwork, greetings, a short video from the activity and small gifts to the children at the Children's Cardiocenter in Bratislava to encourage them in their fight against the disease.

<https://www.youtube.com/watch?v=-R2kt-f1yGA>





On May 29-30, we continued the traditional symbolic march of patients with PH under the motto “I will stand up for you”. This year was the 10th anniversary. We started it with an information seminar on the eve of the march on the topic of innovative treatment. Our invitation was accepted by Dr. Regina Herčíková from Prague, who has been dedicated to patients with PH for years, but also actively works in the patient association. We also welcomed the members of the SPPH board of directors - chairwoman Milena Kaftanová and vice-chairwoman Miluša Šulcová, but also several members of the Czech association. The entire event was opened by the mayor of the municipality of Telgárt, who hosted our event. Dr. Herčíková spoke very interestingly about the positive impact of innovative treatment on patients in the Czech Republic. This treatment is not yet available in Slovakia, which worries most patients who are impatiently waiting for it. Chairwoman Milena Kaftanová provided an overview of the 20-year activity of the SPPH. Vice-chairwoman of the ZPPH Jana Guráňová finally addressed the audience with her story and the problems that accompanied her illness.



On May 30, the actual climb to Kráľova hoľa (King's Hill) (1946 m) with an elevation gain of 1079 m took place. In front of the Telgárt Hotel, a meeting and registration of participants took place, who received placards displaying photographs of patients. Attendance was high, with 115 participants taking part, among them 8 children aged 2-8 years. All were in a good mood with a determination to check their own fitness. Members of the Šumiačan folklore singing group also came to greet us, who accompanied the tourists on the hike with their symbolic Slovak song “Na Kráľovej holi”. This year, in addition to tourists, cyclists could also join the event. Some tourists did not manage to reach the top of Kráľova hoľa, but they managed to fight to the maximum, which we greatly appreciate. All the patients kept their fingers crossed for them. At least their photos reached a place that many of them may never be able to visit themselves. We prepared a unique visit to the Bell Museum for the patients and took them by bus to the Cottage under King's Hill, where they could enjoy the beauty of nature and meet cyclists on the return trip. The tourists were accompanied by a crew from the public television STVR and a report from the event will be published in the program Televíkend. The conclusion of the entire event was an informal evaluation of the event, thanking all participants for their support. The pleasant atmosphere was complemented by a raffle draw, of which there were plenty. We are pleased to have established a presence in this region as well.

<https://youtu.be/RfVQeeXahNo>

Iveta Makovníková
PHA Slovakia





SLOVENIA

NEWS FROM PH ASSOCIATIONS

REPORT ON THE EDUCATIONAL AND PROFESSIONAL MEETING FOR PULMONARY HYPERTENSION PATIENTS AND THEIR FAMILIES

Društvo za pljučno hipertenzijo Slovenije organized an educational and professional meeting for people living with pulmonary hypertension (PH), their family members, and association members. The purpose of the event was to provide participants with expert information about the disease, present opportunities for improving quality of life, and encourage networking and the exchange of experiences among patients and their families.

The program included lectures delivered by experts from various fields, covering key aspects of living with pulmonary hypertension. Participants received information on disease management, current treatment approaches, and emerging therapeutic options. Special attention was also given to physical activity and exercise within individual limitations, breathing techniques, nutrition, sleep, and the psychological challenges faced by patients.

The topic of family support was also addressed, as pulmonary hypertension significantly affects the daily lives of both patients and their loved ones. The lectures provided practical guidance for understanding the disease and coping with its impact.

The professional program was delivered by Assistant Professor Polona Mlakar, physiotherapists Mateja Noliml and Metka Medle, Sandra Pečnik, and Dr. Bernarda Logar Zakrajšek. The event was hosted and moderated by Katja Cimermančič.

An important part of the meeting was the concluding roundtable discussion, during which patients living with pulmonary hypertension shared their personal experiences. Tiana, Iztok, and Nina openly discussed the challenges they face in their daily lives and the adaptations that help them maintain the highest possible quality of life and level of activity. Their contributions provided valuable insights into the practical realities of living with pulmonary hypertension and encouraged open discussion and mutual support among participants.

The event contributed to increased awareness among patients and family members, strengthened their understanding of the disease, and further connected the pulmonary hypertension community. Participants gained valuable information, practical advice, and the opportunity to exchange experiences with others facing similar challenges.

For the association, this was one of the most important events of the year. It enabled stronger connections among members and participants, increased the visibility of the association, and resulted in the recruitment of several new members. Most importantly, it allowed us to get to know one another better and strengthen our sense of community. We aim to build on these foundations through continued networking, education, and the development of a strong support network for people living with pulmonary hypertension and their families.

PODCAST - PH: ZGODBE IN ZNANJE

This year, the Association has also placed a special emphasis on raising awareness and providing education through the podcast PH: Stories and Knowledge. The podcast addresses various aspects of living with pulmonary hypertension, bringing patients, their families and the wider public closer to topics ranging from treatment and physical activity to everyday challenges, support and the importance of community. Through conversations with healthcare professionals and people with personal experience of the disease, the Association aims to provide reliable information, practical advice and, above all, a sense of connection and support.

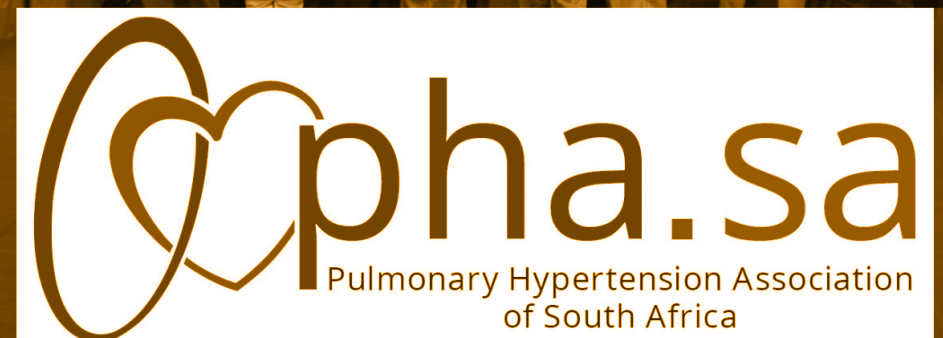
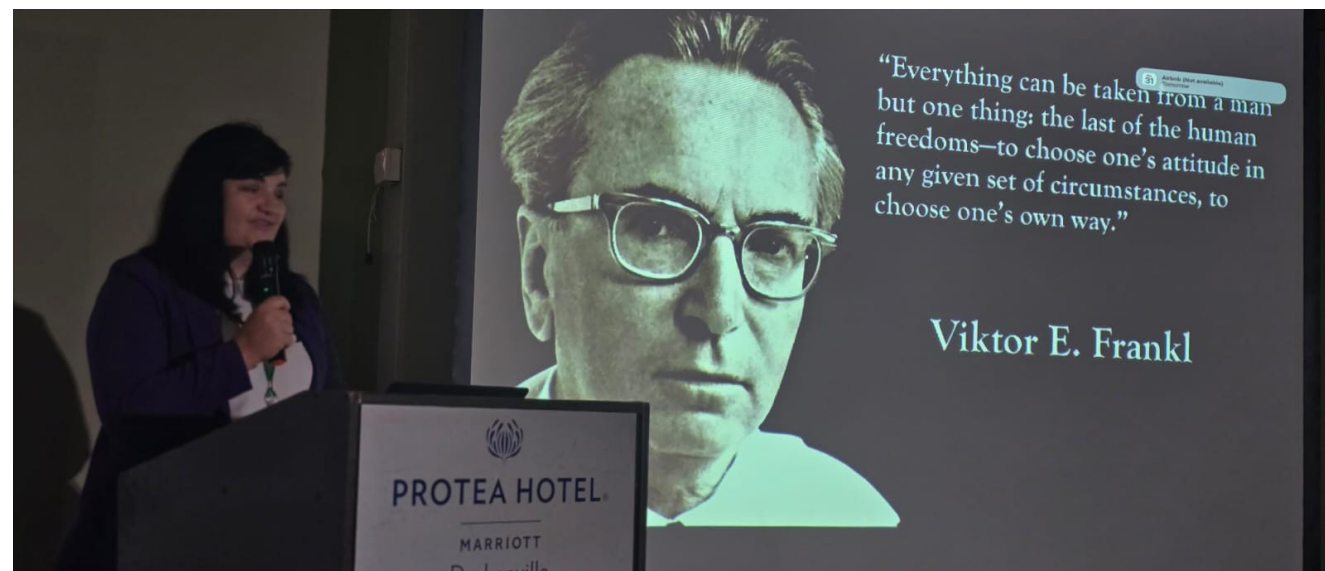




SOUTH AFRICA

Our Pulmonary Hypertension Association of South Africa has celebrated World PH Day with a PH Awareness conference hosted in Cape Town and Johannesburg on the 30th of May. We reached an even broader audience since the event was streamed online to patients all over South Africa. It was a PH Awareness event for patients, caregivers and the medical community to learn more about the condition and opportunity for patients to socialise. We had patients sharing their stories and unique journeys about life with PH. We had Prof Allwood sharing education around PH and the management of the condition, while a Cardio respiratory physio team shared about the importance of physical activity in PH. We could all also take part in some practical exercises.

This day really left us all with a sense of community, hope and armed with information to better tackle the PH journey together.



SPAIN ANHP

RAISE AWARENESS... WE ARE PULMONARY HYPERTENSION: "FEEL WHAT IS NOT SEEN"

In the context of World Pulmonary Hypertension (PH) Day, the National Association of Pulmonary Hypertension (ANHP) has developed throughout the month an intensive awareness campaign under the motto "Hipersensibilízate...somos Hipertensión Pulmonar" ("Raise Awareness... We are Pulmonary Hypertension"), an initiative that each year aims to raise visibility of this rare, serious and progressive disease that affects thousands of people in Spain.

Within this overarching slogan, the 2026 campaign has specifically focused on the message **"Feel what is not seen"**, highlighting the invisible nature of many of the limitations experienced by people living with pulmonary hypertension.

Through different awareness, information and participation actions, we have sought to bring society closer to the daily reality of those living with this disease and to foster greater empathy towards its physical, emotional and social impact.

As an organization that hosted the first World Pulmonary Hypertension Day in 2012, ANHP maintains a strong commitment to dissemination, patient support, and social and institutional advocacy. Throughout the month of May, we have carried out activities aimed at patients, families, healthcare professionals, public administrations and society as a whole, achieving significant reach both in-person and digitally.

CAMPAIGN HIGHLIGHTS

• DIGITAL CAMPAIGN "FEEL WHAT IS NOT SEEN"

Throughout May, we developed an intensive social media awareness campaign through testimonial videos, informational posts and collaborative actions aimed at increasing the visibility of pulmonary hypertension and the challenges faced by those living with it. In this regard, we also encouraged the creation of original content by our members through personal testimonies, videos and TikTok.

Through these posts, they shared invisible aspects of their daily lives

that reflect the true burden of the disease: from the complexity of medication routines or relying on oxygen therapy 24 hours a day, to the effort required to normalize everyday activities such as going to work or using public transport. We also highlighted the need to use disabled parking spaces and the emotional strain of feeling judged for having a disability that is not visible at first glance.

Together with our participation in initiatives promoted by PHAEUROPE & Global, we contributed to amplifying the awareness message at both national and international level. <https://hipertensionpulmonar.es/campanas/lanzamos-la-campana-hipersensibilízate-somos-hipertension-pulmonar-siente-lo-que-no-se-ve-para-dar-visibility-a-la-hipertension-pulmonar/>



• PODCAST "THE KIND FACE OF LIFE"

On May 5th, we launched the campaign activities by collaborating with the podcast "La cara amable de la vida" ("The Kind Face of Life"), a space dedicated to rare diseases. Two patients from our association took part in an episode focused on pulmonary hypertension, sharing their experiences and helping bring the harsh reality of this condition closer to society.



One of the guests delivered a deeply emotional dual testimony: first as a family member of her brother, who passed away due to pulmonary hypertension, and later as a patient herself after receiving her own diagnosis of genetically linked pulmonary hypertension. The second participant shared her journey living with the disease caused by toxic oil syndrome; a difficult path that led her to a lung transplant, speaking openly about the challenges of the process as well as the hope and positive transformation it brought to her life.

The interview was shared across our digital platforms throughout the month, achieving wide reach and contributing significantly to awareness of the disease. https://www.youtube.com/watch?v=hrUrBf_ZbM



• SYMBOLIC LANDMARK ILLUMINATIONS ACROSS SPAIN

On May 5th, once again, numerous iconic buildings and monuments across Spain were illuminated in blue as a sign of support and solidarity with people affected by pulmonary hypertension. This symbolic action, now a consolidated part of our annual campaign, continues to be a powerful tool for drawing attention to a still little-known disease. <https://www.google.com/maps/d/edit?mid=1gVxm7JZhwb7juwJ40cm-Q0oKW0VCj34&usp=sharing>

• IMMERSIVE EXPERIENCE "FEEL PULMONARY HYPERTENSION"

The activity "Feel Pulmonary Hypertension" once again played a central role in the campaign. On May 6th it was held at the General University Hospital of Toledo, and on May 9th at the Clinic Obert event at Hospital Clínic de Barcelona.

Through different immersive dynamics, participants were able to experience some of the daily difficulties faced by people living with pulmonary hypertension, fostering a better understanding of the disease and promoting empathy towards those who live with it.



• TRAINING ACTIVITIES FOR PATIENTS AND FAMILIES

Training and patient support also played a key role throughout May. On May 13th we held the online workshop **"Energy management in pulmonary hypertension"**, delivered by our psychologist, who provided practical tools to help manage fatigue, organize daily activities and improve emotional wellbeing.

In addition, on May 18th we held the online seminar **"Sleep hygiene"**, with participation from specialists in pulmonology, respiratory physiotherapy and psychology. The session addressed the importance of rest, the most common sleep disorders and their relationship with pulmonary hypertension.



• INSTITUTIONAL AWARENESS

On May 22nd, we delivered a training session for assessment teams from the Disability Assessment Centers of the Community of Madrid. The session deepened understanding of pulmonary hypertension and raised awareness of the limitations caused by a disease that is often invisible to those unfamiliar with it. The activity included both professionals from the association and a patient, providing both technical insight and lived experience.

• GENERAL ASSEMBLY AND ANNUAL MEMBERS' MEETING

On May 29th, the XXIV General Assembly and Annual Members' Meeting of ANHP took place in San Lorenzo de El Escorial, one of the most important events of the year for the organization, serving as a space for meeting, participation and strengthening of the association community.

Within this meeting, the in-person workshop **"Assessment and training of inspiratory muscles"** was delivered by a physiotherapist specialized in pulmonary hypertension. During the session, members learned about the importance of respiratory muscle training and practical tools to incorporate it into their daily lives.



• MAKING THE INVISIBLE VISIBLE

Throughout the campaign, we have worked to highlight that many of the consequences of pulmonary hypertension are not visible at first glance. Extreme fatigue, breathlessness, physical limitations and emotional impact are part of the daily reality of thousands of people, even though they are often unnoticed by those around them.

Through the message **"Feel what is not seen"**, we aimed to encourage society to look beyond appearances and better understand the reality of those living with this disease. Because only through knowledge and empathy can we move towards a more inclusive, aware and committed society for people living with rare diseases.

Because not everything that limits can be seen. But it can be felt.



SPAIN FCHP

WORLD PULMONARY HYPERTENSION DAY 2026 - FUNDACIÓN CONTRA LA HIPERTENSIÓN PULMONAR

A MONTH OF COMMITMENT TO RAISING AWARENESS OF PULMONARY HYPERTENSION

To mark **World Pulmonary Hypertension Day**, observed every **May 5**, the **Spanish Pulmonary Hypertension Foundation (Fundación contra la Hipertensión Pulmonar – FCHP)** organized an extensive programme of awareness, education, scientific outreach and patient support activities throughout April and May 2026. The campaign aimed to increase public awareness of this rare disease, promote early diagnosis, and bring the latest advances in research and treatment closer to patients, families and healthcare professionals.

The programme began on **24 April** with the **1st Castilla-La Mancha Pulmonary Hypertension Conference**, held at **Toledo University Hospital**. The event brought together healthcare professionals, patients and caregivers to discuss the current state of pulmonary hypertension, the challenges of early diagnosis and the latest therapeutic advances.

On the same day, the **Guadalhorce Primary School (CEIP Guadalhorce)** in **Pizarra (Málaga)** hosted a **Charity Fun Run and Fundraising Fair** in support of pulmonary hypertension research. The enthusiastic involvement of students, teachers and families not only helped raise funds but also increased awareness of this rare disease within the local community.



The Foundation's awareness campaign continued on **30 April** with the **Charity Fun Run at Gerardo Diego Primary School (CEIP Gerardo Diego)** in **Parla (Madrid)**. Once again, students, teachers and families came together for a day of sport and solidarity, demonstrating the educational community's commitment to supporting research and improving the lives of people living with pulmonary hypertension.

On **5 May, World Pulmonary Hypertension Day**, the Foundation launched a nationwide awareness campaign through social media, traditional media outlets and educational materials, highlighting the reality of living with pulmonary

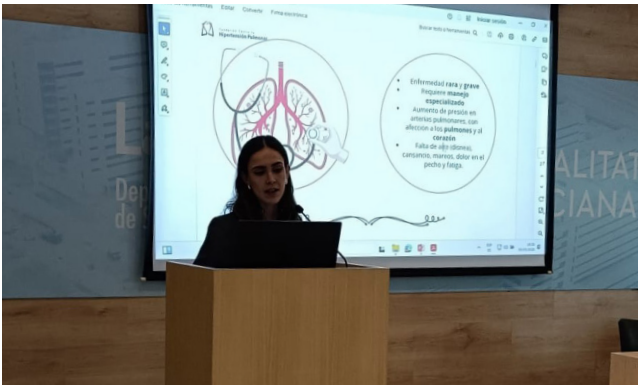
hypertension and the urgent need for greater awareness, earlier diagnosis and continued research. As part of the day's activities, **Enrique Carazo**, President of the **Spanish Pulmonary Hypertension Foundation (FCHP)**, was interviewed by **Radio Nacional de España (RNE)**, one of Spain's leading public broadcasters. During the interview, he spoke about the challenges faced by people living with pulmonary hypertension and emphasized the vital importance of public awareness, education and scientific outreach in achieving earlier diagnosis and improving patients' quality of life.

Also on **5 May**, a **Patient Meeting** was held at **Hospital Universitari i Politècnic La Fe in Valencia**, where patients, families and healthcare professionals shared knowledge, experiences and practical advice to improve quality of life.



One of the campaign's most symbolic initiatives was **„Light Up in Blue”**, during which numerous town halls, public buildings and iconic landmarks across Spain were illuminated in blue to show support for people living with pulmonary hypertension and to join the international movement raising awareness of the disease.

Research also played a central role in the campaign. On **6 May**, patients and families took part in an **Open Day at the Spanish National Research Council (CSIC)**, visiting the laboratory of **Dr. Eduardo Oliver**. The event provided participants with the opportunity to learn first-hand about ongoing research aimed at understanding the mechanisms of pulmonary hypertension and developing new therapeutic strategies.



Throughout May, the Foundation also collaborated in a series of **Patient Conferences** held at leading hospitals across Spain. These included the **2nd Pulmonary Hypertension Patient Conference at Costa del Sol University Hospital in Marbella on 7 May**, the **2nd Patient Conference at Salamanca University Hospital on 12 May**, the **1st Patient Conference at San Pedro de Alcántara Hospital in Cáceres on 19 May**, and the **1st Patient Conference at Virgen de la Arrixaca University Hospital in Murcia on 28 May**. These meetings provided updated medical information, encouraged dialogue between specialists and patients, and fostered peer support among families.

Educational activities continued on **20 May** with the webinar **„Pulmonary Hypertension in Children: Advances, New Treatments and Medical Devices”,** delivered by **Dr. María Jesús del Cerro**, one of Spain's leading specialists in paediatric pulmonary hypertension from **Ramón y Cajal University Hospital** in Madrid. The webinar attracted healthcare professionals and families interested in the latest developments in the diagnosis and treatment of paediatric pulmonary hypertension.

Fundación Contra la Hipertensión Pulmonar

"HIPERTENSIÓN PULMONAR EN NIÑOS: AVANCES, NUEVOS TRATAMIENTOS Y DISPOSITIVOS"

Dra. Mª Jesús del Cerro
Cardióloga pediátrica, unidad HP
Hospital Universitario Ramón y Cajal.

Día:
20 mayo 2026

Hora:
17:30- 18:30

La hipertensión pulmonar en niños es una enfermedad grave que afecta a la circulación pulmonar y al corazón. Los avances recientes incluyen nuevos tratamientos más eficaces, terapias personalizadas y dispositivos innovadores que mejoran el diagnóstico y el seguimiento. Todo ello está contribuyendo a aumentar la calidad de vida y el pronóstico de los pacientes pediátricos. ¡No te lo pierdas!

MANDA MAIL : INSCRIPCIONES@FCHP.ES

FORMATO ONLINE





The Foundation's commitment to scientific research was further demonstrated on 27 May with the announcement of the winner of the 2026 FCHP Pulmonary Hypertension Research Grant, an initiative designed to support innovative research projects that contribute to improving knowledge and treatment of the disease. en esta parte añadir que la ganadora de esta exitosa edición por la cantidad de proyectos presentados fue la

Doctora Olga Tura, del Institut d'Investigació Biomèdica de Girona Dr. Josep Trueta con el proyecto Título: Estudio del origen y características de la disfunción endotelial en la hipertensión pulmonar tromboembólica crónica (SIENA).

The campaign concluded on **29 May** with the Foundation's participation in the **CIBER Young Researchers Conference**, held in **San Lorenzo de El Escorial (Madrid)**, reaffirming its commitment to biomedical research and to supporting the next generation of scientists dedicated to pulmonary hypertension research. During the conference, **Enrique Carazo**, President of the **Spanish Pulmonary Hypertension Foundation (FCHP)**, participated as a speaker, providing the patient perspective and emphasizing the importance of collaboration between researchers, healthcare professionals and patient organisations to accelerate scientific progress and improve the quality of life of people living with pulmonary hypertension.

Alongside these events, the Foundation carried out an intensive communication campaign throughout the month, sharing patient and family stories on social media, promoting scientific research projects, engaging with the media, and highlighting its comprehensive support services, including psychological care, social work and patient guidance.

The **2026 World Pulmonary Hypertension Day** campaign once again demonstrated that collaboration between patients, families, healthcare professionals, researchers, public institutions, schools and partner organisations is essential to advancing the fight against pulmonary hypertension. Every conference, charity event and awareness initiative contributed to a shared goal: **to increase awareness of pulmonary hypertension, promote research and improve the quality of life of everyone living with this rare disease.**



SPAIN HPE-ORG

MORE VISIBLE THAN EVER: THE STRENGTH OF THE PATIENT ADVOCACY MOVEMENT ON WORLD PULMONARY HYPERTENSION DAY

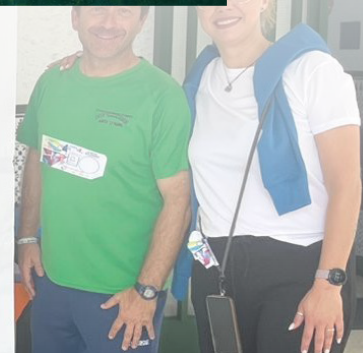
To mark World Pulmonary Hypertension Day, Hipertensión Pulmonar España has organised a packed and varied programme of activities across the country, with the aim of raising the profile of this rare condition, raising public awareness and strengthening the sense of community amongst those affected and their families.

The commemoration of this day has once again become a key moment for amplifying the community's voice, combining far-reaching digital initiatives with in-person events organised in various cities thanks to the direct involvement of members.



EUROPEAN SOCIAL MEDIA CAMPAIGN

One of the key aspects of this year's campaign has been participation in a coordinated online campaign at the European level, in collaboration with PHAEUROPE & Global. Under the shared hashtag #HopeinEveryTrial and a common image, this initiative has enabled us to unite our efforts and amplify our impact on social media.



Through posts, personal accounts, educational materials and audiovisual content, the campaign has succeeded in sparking conversation, raising awareness of the condition and reaching new audiences. The involvement of patients, families, healthcare professionals and organisations has been key to making this initiative an international success.

ACTIVITIES IN SPANISH CITIES

Throughout Spain, the Association has coordinated many activities in various cities, reflecting the commitment and involvement of the voluntary sector.

Guardo Town Council (Palencia) has once again played its part in marking World Pulmonary Hypertension Day by illuminating the ‘Fuente del Minero’ – the town’s most iconic building – in blue, and by supporting patients with pulmonary hypertension through allowing a significant march through the town’s streets, during which participants wore solidarity T-shirts.

Other activities also took place in the town of Guardo (Palencia), such as a Pilates class and an exhibition on pulmonary hypertension at the town’s Official Language School.



In Granada, the façade of the ‘San Cecilio University Clinical Hospital’ was illuminated in blue in support of patients suffering from this condition, as was the ‘Casa de Cultura’ in Churriana de la Vega, also in Granada.

In Valladolid, on 5 May, city buses from the ‘AUVASA’ company displayed information about World Pulmonary Hypertension Day on all their bus routes and at bus stop shelters to raise awareness of this condition.



Once again this year, Sant Feliu de Llobregat Town Council has shown its commitment to rare diseases during ‘La Fira’, the town’s local festival, by providing us with a shared space alongside several associations representing rare diseases in the municipality, where we were able to offer information about our association and about pulmonary hypertension to everyone who visited the information stand.



During the month of May, other sporting activities were also organised, such as a charity bowling session at ‘Bowling Ilusiona C.C. Splau’ in Cornellà, which was very well received by the participants, who played whilst wearing the charity T-shirt. Following this event, a second charity sports initiative was launched which, like the previous one, aimed to support and raise awareness of Pulmonary Hypertension; in this case, members of ‘CBS Gavà’ held a series of softball training sessions under the slogan ‘Make every swing count’.



In addition to the activities mentioned above, and as part of the celebrations for World Pulmonary Hypertension Day, we organised our General Assembly of members, held this year in the city of Zamora. This was a key opportunity to ensure that all voices are heard and that the Association works towards a common vision. A meeting was also held between patients and their families, which, as well as facilitating contact between patients, served as a space for support and the sharing of experiences.

All these activities have been made possible thanks to the Association’s coordination at national level, which has provided materials, strategic guidelines and ongoing support to the to the members involved in organising them.

NEW INITIATIVES AND INNOVATIVE FORMATS

This year has also been marked by the introduction of new initiatives that have enriched the celebrations. These include collaborations with new companies such as Ilusiona, CBS Gavà and AUVASA, which have joined our World Pulmonary Hypertension Day campaign to raise awareness of this condition,

and collaborations with healthcare professionals such as the Patient School at the Doctor Negrín University Hospital in Gran Canaria, which has enabled us to reach a wider and more diverse audience, as the event organised at this hospital was streamed live.

These initiatives have embraced more dynamic and participatory formats, encouraging interaction and raising awareness of the disease in both face-to-face and digital settings.



HIGH LEVELS OF PARTICIPATION AND THE CONSOLIDATION OF THE VOLUNTARY SECTOR

Participation in all activities has, once again this year, been very high, both online and in face-to-face events. This success builds on the positive trend of previous years and highlights the community's growing commitment.

The involvement of members, volunteers and partners has been fundamental to the delivery of the activities, demonstrating the strength and cohesion of the voluntary network.



Hipertensión Pulmonar España has given a very positive assessment of this year's campaign, highlighting in particular the collaboration at European level, the diversity of initiatives carried out across the country and the innovative nature of the proposals.

The Association thus reaffirms its commitment to continuing its work to raise the profile of pulmonary hypertension, improve the quality of life of those affected and continue to raise public awareness of this rare disease.



Mayo por la

HIPERTENSIÓN PULMONAR

VISIBILIZAR • INFORMAR • CONECTAR • EMPODERAR

Un mes lleno de actividades, encuentros y gestos que nos recuerdan que no estamos solos.

Seguimos caminando juntos.

DÍA MUNDIAL DE LA HIPERTENSIÓN PULMONAR

5 de mayo

COMUNIDAD Y APOYO

INFORMACIÓN RIGUROSA

EMPODERAMIENTO DEL PACIENTE

INVESTIGACIÓN Y ESPERANZA

HPE

www.hipertension-pulmonar.com

La visibilidad no es solo un día, es nuestro compromiso cada día.



SWEDEN

During the spring, we organized two patient meetings together with the PH teams in Lund and Uppsala. Around 100 patients and family members attended these events, providing valuable opportunities for learning, discussion, and connection.

We also held our annual camp for patients and relatives for the

eightth time. This year's camp was specifically aimed at patients aged 50 and above and their loved ones. As always, the camp offered meaningful conversations, shared experiences, and a strong sense of community. We would like to extend our sincere thanks to PHAEUROPE & Global and AOP Health for their valuable support in making this event possible.



UKRAINE PHA

As part of World Pulmonary Hypertension Day (WPHD) 2026, the Ukrainian Pulmonary Hypertension Association organized a series of activities aimed at raising awareness about pulmonary hypertension, supporting patients, and improving their quality of life.

In May, an online conference brought together patients, their family members, physicians, and specialists from the Pulmonary Hypertension Expert Center at the Strazhesko Institute of Cardiology (Kyiv). During the meeting, participants discussed current issues in the diagnosis and treatment of pulmonary hypertension, modern therapeutic options, and the importance of regular follow-up, physical activity, and psychological support for patients. The conference provided an open platform for communication with leading experts, allowing participants to ask questions and discuss practical aspects of living with pulmonary hypertension. Held in a warm and friendly atmosphere, the event once again demonstrated the importance of close cooperation between the patient community and medical experts.



As a continuation of WPHD 2026 activities, we explored the opportunities offered by equine-assisted therapy at the Kyiv Hippodrome. Participants learned more about interacting with horses, took part in preparing the animals for the sessions, and became acquainted with the basics of equine-assisted therapy as a method of emotional and psychological rehabilitation. Specialists from the equine therapy center explained the positive impact of communication with horses on emotional well-being, stress reduction, and the restoration of inner balance. They also discussed the possibilities and specific considerations of such activities for people living with pulmonary hypertension.

These activities once again highlighted that WPHD is not only an opportunity to draw attention to the challenges of a rare disease, but also an important platform for sharing knowledge, strengthening mutual support, and exploring new ways to maintain a high quality of life for patients. The Ukrainian

Pulmonary Hypertension Association will continue its efforts to develop educational, informational, and rehabilitation initiatives aimed at supporting people living with pulmonary hypertension.



UKRAINE PHURDA

BREATHE FREELY, LIVE ACTIVELY: PULMONARY HYPERTENSION DAY IN UKRAINE

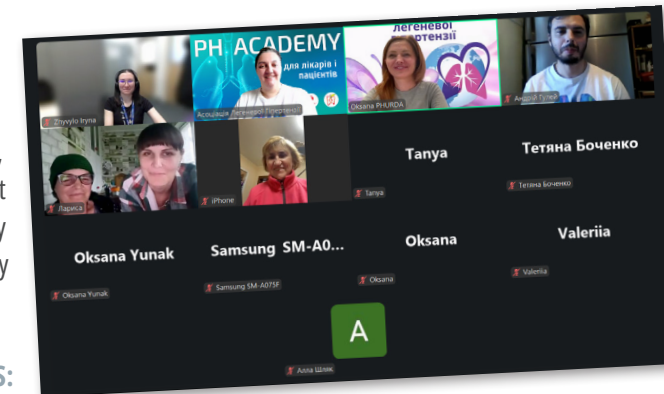
An awareness campaign, leading experts, and the voice of the patient community, came together to highlight the challenges of pulmonary hypertension and respiratory health in times of war.

VISIBILITY THAT SAVES LIVES: CITY LIGHT CAMPAIGN IN LVIV

One of the key objectives of this year's Pulmonary Hypertension Day was to bring the topic of respiratory health into the public space. Throughout May, residents and visitors of Lviv could see city light posters dedicated to pulmonary hypertension (PH), bronchial asthma, and other chronic respiratory diseases. This

public awareness campaign aimed to draw attention to the importance of early diagnosis and timely access to medical care.

Academy, an educational platform designed to help patients better understand their disease, modern treatment approaches, and opportunities to access high-quality healthcare.



In the context of war, where constant stress, environmental consequences of military actions, and limited access to healthcare continue to affect people's health, such awareness campaigns are more important than ever. They encourage people to recognize warning signs, seek medical attention promptly, and improve public awareness of respiratory diseases.




МІЖНАРОДНИЙ ДЕНЬ ЛЕГЕНЕВОЇ ГІПЕРТЕНЗІЇ

**Клінічні дослідження –
шлях до кращого майбутнього**



5 ТРАВНЯ

ЗНАННЯ. ДОСЛІДЖЕННЯ.
НАДІЯ. ЖИТТЯ.



Куліш Оксана

2026



PULMONARY HYPERTENSION DAY 2026: A NEW FORMAT FOR PATIENT ENGAGEMENT

The central event was the online meeting “Pulmonary Hypertension Day 2026.” Due to the ongoing security challenges caused by the war, large-scale public events remain difficult to organize. Therefore, the patient community has successfully transitioned to a modern digital format, enabling participation regardless of geographical location.

The main message of the event was that patients should not only receive healthcare but also become active participants in shaping healthcare policies, equal partners of the medical community, and drivers of meaningful systemic change.

The meeting focused on early diagnosis, access to innovative therapies, the daily challenges of living with pulmonary hypertension, and modern approaches to patient support. As 5 May is also World Asthma Day, a dedicated session addressed bronchial asthma and the importance of early disease control.

Particular attention was paid to the organization of medical care during wartime. Cardiologist Iryna Zhyvylo shared her practical experience of providing online consultations within the framework of cooperation with PHURDA and explained how telemedicine has become an essential tool for patients who cannot easily access face-to-face medical care.



CLINICAL TRIALS AND BREAKING MISCONCEPTIONS

One of the key topics of this year's programme was clinical research and the opportunities it offers to patients.

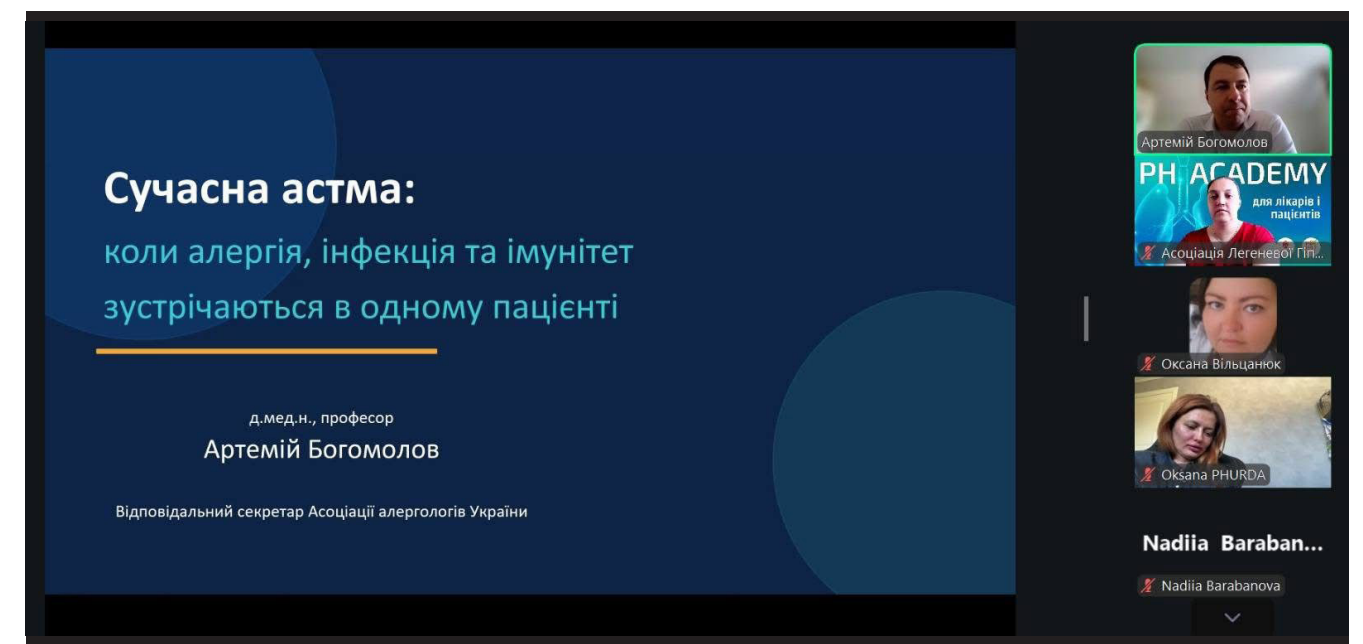
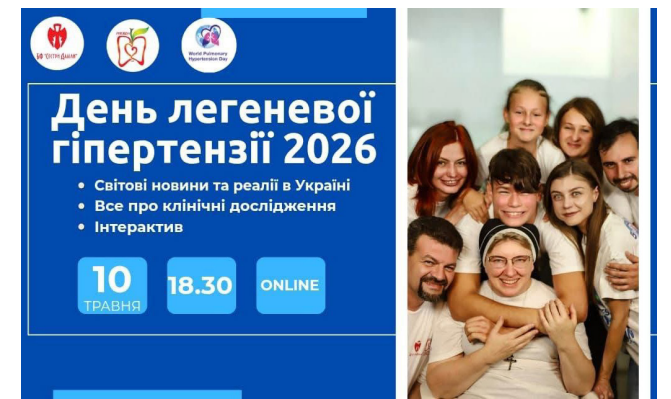
PHURDA's legal advisor Andrii Hulei explained where patients can find reliable and official information about clinical trials in Ukraine and internationally and discussed the legal aspects of participation in clinical research.

Special attention was given to compassionate use (early access) programmes, which may provide patients with severe diseases free access to innovative medicines. During wartime, these programmes are especially valuable because they help patients receive modern treatment when traditional healthcare pathways are limited.

Participants also discussed common myths surrounding clinical trials. Patients and healthcare professionals had the opportunity to ask questions, openly discuss their concerns, and receive professional, evidence-based answers from experts.

The Chair of PHURDA also participated in an online event organised jointly by URC and PHURDA to mark World Asthma Day and World Pulmonary Hypertension Awareness Day. In her presentation, she emphasized that addressing the challenges of respiratory diseases requires a comprehensive approach that brings together researchers, healthcare professionals, patient organisations, government institutions, and the pharmaceutical industry.

“Living with a chronic respiratory disease is not a sentence or a limitation. It is a way of life that can and should be managed effectively. Our goal is for every patient to feel not only the support of healthcare professionals but also the confidence and strength to take an active role in managing their own health”.





USA

PHA JOINS WORLD PH DAY CAMPAIGN FOCUSED ON CLINICAL TRIALS

The Pulmonary Hypertension Association joined this year's global World PH Day campaign, "Hope in Every Trial," which focused on clinical trials and how research can improve care for people with pulmonary hypertension.

As part of the observance, PHA shared information and resources to help patients and families better understand clinical trials, including why they matter, what participation may involve and how to learn more about available opportunities. PHA also encouraged people with PH to talk with their care teams about whether participating in a study or enrolling in the PHA Registry might be right for them. Patient stories and expert perspectives connected the campaign theme to real experiences in the PH community.

In a **Right Heart Blog** post, PHA advocate Jeff Harpp shared how clinical trials have shaped care for his son, Cash, who was diagnosed with PH in 2015 and has participated in several clinical trials. Jeff described the hope his family found through research, while also describing the travel, home health logistics and emotional weight that can come with trial participation.

"Participating in clinical trials brings hope, and that's the one thing we all cling to," Jeff said.

His family's story reflected the World PH Day theme by showing both sides of clinical trial participation: the possibility of progress and the practical challenges families must consider. Jeff encouraged families to understand the requirements before enrolling and to work with a PH care team they trust.

PHA also reshared **"Because Patients Said Yes: Trials That Changed PH Care,"** featuring Anna Hemnes, MD, who explained how clinical trials have helped shape current PH treatment. Hemnes emphasized that trial participation is a personal decision, and that improvement is never guaranteed. She also noted the broader impact of participation: "Every patient has the opportunity to help us and the world understand pulmonary vascular disease better."



"Participating in clinical trials brings hope, and that's the one thing we all cling to."

-Jeff Harpp

#HopeInEveryTrial
#WorldPHDay2026



"Everyone who participates in a clinical trial helps us understand more about the disease and how to treat it better."

-Anna Hemnes



PHA also shared the story of Benjaada Rim, a 22-year-old from Algeria who was diagnosed with PH at age 12 and has struggled to find specialized care in her country. Rim wrote about the limited treatment options available in Algeria, where she said only two of more than 14 medications available worldwide are accessible. Her story brought an international perspective to the campaign by showing why global awareness, research and access remain urgent needs for people with PH.

"I take every opportunity to raise awareness about this disease and advocate for patients like me," Rim said. "I truly believe that our voices will be heard."

Rim's story also showed how patients can turn personal experience into advocacy. She recently published a book



about her PH journey, using storytelling to raise awareness and help others better understand the realities of living with a rare condition.

PHA extended its activities beyond online education and awareness efforts through O₂breathe walks in Washington, D.C., and Southern California. The events brought patients, caregivers, families and supporters together to raise awareness, support the PH community and strengthen connections.

Together, the patient quotes, personal stories and community events reinforced why clinical trials matter. Progress in PH research depends on people: patients and families who consider participation, researchers and care teams seeking answers and advocates raising their voices for better access to care.



Austria

Ein Leben geg die Prognose

MIT DART JAHREN ERHÄLT KATHLEEN FISCHER DIE SCHWERE PULMONALE ARTERIELLE HYPERTENSION. I...
...tatsächlich ist es eine...
...die Prognose...
...das Leben...
...die Prognose...
...das Leben...
...die Prognose...
...das Leben...



PH-Austria feiert den Welt-Lungenhochdruck-Tag

Am 5. Mai wurde weltweit der World Pulmonary Hypertension Day (WPHD), der Welt-Lungenhochdruck-Tag, begangen.

Diese internationale Aktion...
...die Prognose...
...das Leben...
...die Prognose...
...das Leben...



PHAEUROPE Global
Pulmonary Hypertension Association

Mariposa Journal
Winter 2025 - REFLECTING ON A YEAR OF COLLABORATION, AND PATIENT ENGAGEMENT

the PHA Europe website
If you are new to the PHA Europe website, you will find information about the PHA Europe organisation.

Belgium

Kathleen Depoorter pleit voor snellere toegang tot innovatieve therapieën bij pulmonale hypertensie



UZ Leuven en patiëntenvereniging PH vzw vragen met blauwe lippen campagne meer aandacht voor pulmonale hypertensie



Blue Lips-campagne vraagt aandacht voor zeldzame longziekten: "Wak over het hoofd gezien tijd"

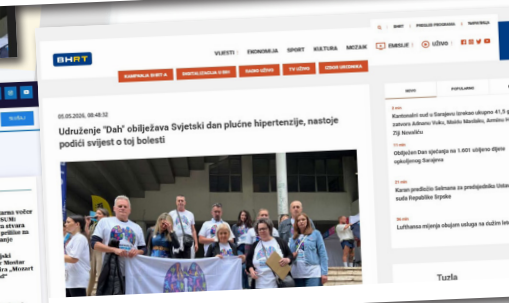


Nieuwsblad

Blue Lips-campagne vraagt aandacht voor zeldzame longziekten: "Wak over het hoofd gezien tijd"

Artsen, patiënten en politici kleuren hun lippen blauw in UZ Leuven

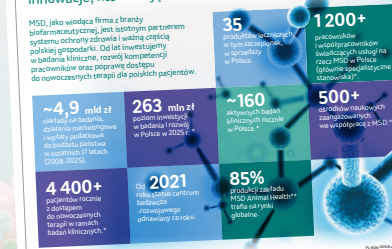
Patiëntenvereniging PH vzw en UZ Leuven vragen met een actie aandacht voor de weinig bekende, maar ernstige aandoening pulmonale hypertensie.



TEMAT NUMERU – PERSONALIZACJA LECZENIA

Badania kliniczne wykazały, że u pacjentów z chorobami układu krążenia, w tym z chorobami serca, wdrożenie terapii personalizowanych, które uwzględniają indywidualne cechy pacjenta, może przynieść korzyści. W tym celu lekarze powinni być świadomi, że nie wszyscy pacjenci respondują na ten sam sposób na ten sam lek. Istotnym czynnikiem jest wiek pacjenta, który może być istotnym czynnikiem w wyborze leku. W tym celu lekarze powinni być świadomi, że nie wszyscy pacjenci respondują na ten sam sposób na ten sam lek. Istotnym czynnikiem jest wiek pacjenta, który może być istotnym czynnikiem w wyborze leku.

35 lat MSD w Polsce. Innowacje, które mają znaczenie.

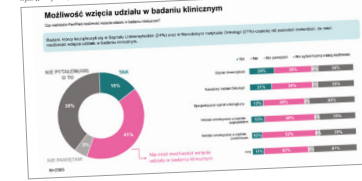


PRAWA PACJENTA



WYNIKI ANKIETY NA TEMAT EUROPEJSKIEGO KODEKSU OPIEKI ONKOLOGICZNEJ I PRZEPRAWY WYNIKÓW PACJENTÓW DOTYCZĄCYCH 6. PUNKTU – PRAWA PACJENTA DO INFORMACJI O BADAANIACH KLINICZNYCH

Niepełna połowa respondentów (47%) zdecydowała się na udział w badaniu klinicznym, podczas gdy 39% badanych nie wie, czy ich udział prowadzi taki rezultat. Największy udział respondentów (47%) nie miał możliwości wyboru udziału w badaniu klinicznym, a 39% ankietowanych nie opowiedziało się na temat możliwości. Tylko 15% badanych miało szansę zdecydować się na udział w badaniu klinicznym. Dwie trzecie badanych pacjentów (67%) stwierdziło, że nie przedstawił im możliwości wyboru udziału w badaniu klinicznym w tym czasie.



Zmieniamy życie pacjentów dzięki nauce™

Naszą misją jest odkrywanie, opracowywanie oraz dostarczanie innowacyjnych leków, które pomagają pacjentom przezwyciężyć poważne choroby.

Bristol Myers Squibb

Dowiedz się więcej na bms.com

JAŚ I JEGO MARZENIA

Ośmioletni Jaś chodził do drugiej klasy. Był cichy i lubił rysować kosmos oraz budować z klocków wysokie wieże. Jednak nikt nie wiedział, że robił to tylko dlatego, że go to nie męczyło.

Jaś miał jednak coś, czego nie było widać na pierwszy rzut oka – nazywało się to nadciśnienie płucne. Przez to szybciej się męczył, a jego usta często miały lekko siny kolor, jakby było mu bardzo zimno.

Kiedy inne dzieci biegały na lekcji WF-u, Jaś siedział na ławeczce obserwując ich. Bardzo chciał biegać razem z nimi, ale lekarz powiedział, że to dla niego niebezpieczne, może zemdleć, rozwalić głowę.

Gdy klasa jechała na szkolną wycieczkę w góry, Jaś zostawał w domu. W szkole nie mógł też wchodzić po schodach na niektóre lekcje, bo szybko brakowało mu tchu. Czuł się osamotniony. Wieczorami, kiedy nikt nie widział, zamykał się w pokoju i płakał.

Dzieci czasem patrzyły na jego sine usta i pytały: – Dlaczego jesteś taki niebieski? A on nie wiedział, jak to wytłumaczyć. Niektóre dzieci przestawały go zapraszać do zabawy, bo myślały, że „nie chce” się z nimi bawić. Nikt nie rozumiał, że on bardzo chce – tylko nie zawsze może.

Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół

CO ROKU 5 MAJA OBCHODZONY JEST ŚWIĄTOWY DZIEŃ NADCIŚNIENIA PŁUCNEGO

5 MAJA ŚWIĄTOWY DZIEŃ NADCIŚNIENIA PŁUCNEGO

Cel obchodów: Zwiększenie wiedzy o chorobie, która często jest diagnozowana z dużym opóźnieniem, ponieważ jej objawy (brak tchu, zmęczenie) bywają mylone z astmą lub słabą kondycją

CODZIENIE BEZ TCHU – CO POWINIŃMY WIEDZIEĆ O NADCIŚNIENIU PŁUCNYM?

Nadrzędnym celem Światowego Dnia Nadciśnienia Płucnego jest przede wszystkim przerwanie „ciszy” wokół tej rzadkiej i śmiertelnie niebezpiecznej choroby

Welcome to the PHA Europe Website

This website is for anyone who suffers from Pulmonary Hypertension (PH) as well as their friends and family. Here, you will find information about the condition, as well as about the PHA Europe organisation.

OUR HISTORY

Danas

Najnovije Politika Dijalog Kolumne Društvo

Beograd Novi Sad Kragujevac Niš

Danas online 29.05.2026. 21:31

Prati Danas.rs na Google-u

Više

Veliki pomaci u lečenju plućne hipertenzije u Srbiji - dostupne saviemene terapije



Veliki pomaci u lečenju plućne hipertenzije u Srbiji - dostupne saviemene terapije - Copyright Yashen Abdich / Alamy / Profimedia

Autor: Tanjug 30/05/2026 - 15:28

Plućna hipertenzija je ozbiljna, progresivna i potencijalno životno ugrožavajuća bole

f x e r

Lepa i Zdrava

Zdravlje

Plućna hipertenzija: nove terapije poboljšavaju život žen

u Srbiji

Redakcija Zdravlje 28.05.2026 0

Foto Izvor: Pexels / Mart production

Savremeni lekovi dostupni i mladim

od 18 godina značajno olakšavaju

svakodnevnicu obolelih žena i

omogućavaju bolju kontrolu bolesti

b92

Najnovije Info Istočni front

Aktuelno 30.05.2026. | 16:

AKTUELNO

Veliki pomaci u lečenju plućne hipertenzije u Srbiji, dostupne saviemene terapije

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heskavy	Spolná správa
29.06.2008 19:53	
Nagrodzón spravý >	
Dobráš spravý >	
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Aktualizácia TETRY	
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Komentáre	
Zahraničné spravý	
Sport	
Ekonomika	

PUČNICA ARTÉRIOVÁ HYPERTENZIA ZRUCKAVÁ, NO ŽAŽAVŔN

PRÍLOHA ARTÉRIOVÁ HYPERTENZIA (PHH)

Môj národný prírodný akút dyfaktívny, hruď 0 kolénne strany. Všetkých diagnóz Karologických kliniky Laskavého ľaduľu. Medzi ostatnými zástupcami v ocmu a celosvetovo kľúčová. Informovala o tom Generalisovaná vyšetrenia, že PHH je ochorenie, a na prítelene jej v nich môžu byť prvky prevažne soľná a doba ochorenia sa dá liečiť farmakologicky transplantáciou pľúc. Dostupné aj v jazyku prejavov v chorobe a celosvetovo poznáme 25 diagnostických kritérií postihuje viacšie ľudí.

Prvý krok pri diagnostike ochorenia vyžaduje kliniku - čísl. detských ochorení - nemeckú s gynie konkrétny test vzduchu ochorenia "konfiguračný" môže vyžvať nič choroby. PHH vzniká pri podrobení v PHH pacientov zástup. Pri podrobení v PHH pacientov sa potvrdí ochorenie a nastávajú sa

Pacient má spo

sedování, kontrolování a třídění m

VIDEO

A man with glasses and a white shirt is speaking, gesturing with his hands. He is seated in a brown upholstered chair against a light-colored wall. A framed picture is visible on the wall behind him.

K podozreniu na PAH sa lekári dostávajú najmä vtedy, keď bežné lieky na zlepšenie stavu pacienta sa ďalej zhoršuje. V súčasnosti trvá 1 – 3 roky. „Najdlhšie pacientka čakala na správnu diagnózu asi 10 rokov, až keď sa dala na „dobrú“ konšultáciu MUDr. Milana Lukinára, prezidenta Slovenskej kardiologickej spoločnosti. / Zdroj: www.kardiologia.sk /

Nenápadný začiatok a náročná diagnostika

[illegible][illegible][illegible]

**PERTEZNIA JE
JÉ OCHORENIE**

Príznaky, ako závažné ochorenie.
nauka, závažný, opuchy nôh, tlak na
stĺba a podľa predstavy
U univerzity Komenského a
ých chorôb Ewy Goncalvesovej
na strednej (talovej) končetine.

orenie malých plúcnych ciev, ktoré sa
prvým epizódou závažnej námahe. Tým sa
keď sa jej pýhľavkami. Dodala, že
v posledných štádiách
dávka závažnej leteľov, ktoré prináša
postupujú liečby. Rôzne prírodné
entov s touto chorobou a prevahne

TELEINTERVU
Ivetta Makyniková
OSLOBODENIE ZDROJŮ A PRÍČINŮ HYPERTENZIE
PRÍČINŮ HYPERTENZIE

Zuzana Bobšenová
pacientka s pľúcnou artériovou hypertenziou

[illegible]

Organizované a nízko nákladné

násipríklad poruchy funkcie ľavej srdcovej komory, ochorenia pľúc alebo chorôb pľúc, ako sú astma či pľúcna fibróza. Len zriedkavo sa vyskytuje jej špecifická forma – pľúcna arteriálna hypertenzia (PAH)

Organizované a nízko nákladné

Drobná astma (GOLD 1/2020)

Ochorenie sa často začína nešpecificky – dýchavičnosť po námahu. Pacienti s pľúcnou nemocou

sasť sk a nezabudnúť si

[illegible][illegible]

Journal

REPORTING ON A YEAR OF HYPERTENSION
CORPORATION, AND PATIENT

Pariposa Journal

2023 • PHE EUROPE'S OFFICIAL JOURNAL

the PHA Europe website

From Pulmonary Hypertension (PH)

PHA Europe

Spain HPE-OR

A collage of images. On the left, a close-up of a laptop keyboard with keys for 'F3', 'F4', '6', '^', '7', and '8'. In the center, a green and white bus with 'ALWASA' and '1379 WZ' on its front, driving on a city street. Above the bus, a document titled 'Pulmonary Hypertension Europe' is visible, featuring a logo and text about international cooperation and empowerment. In the bottom right corner, a small figure of a person in a black hat and purple outfit is visible.

[illegible][illegible]

WhatsApp chat conversation (Spanish):

- Jorge:** acordamos a 189 sus simpatizantes a la conmemoración del cincuenta aniversario del levantamiento.
- Historia:** Esta información sobre un supuesto acuerdo de la presión en los servicios de los polizontes y la detención previa no fundamental para.
- Jorge:** nada, no se lo he de dar credibilidad a esta información.
- Historia:** ¿pero...? ¿qué grado? ¿importante?
- Jorge:** (with heart, gift, and location icons) ¿pero...? ¿qué grado? ¿importante?
- Historia:** ¿pero...? ¿qué grado? ¿importante?
- Jorge:** Acorda en consecuencia.
- Historia:** Publicar

5 AÑO
Diez Muñetas por la
Hiperextensión Pulmonar

**HIPEREXTENSIÓN
PULMONAR**

señales de vivir con Hiperextensión Pulmonar:
 tos grave, inestable y sin cau-
 sas para encontrar nuevos tratamientos.

marcha solidaria a las 20:15 en la Iglesia Santa Bárbara hasta Lupa que
se foto de familia en la Fuente del Minero que se iluminará de color azul. Ver

MARCHA SOLIDARIA POR LA IGLESIA EN GUARDO

por un acuerdo que parte desde la HPE en
 Santa Bárbara y finaliza en la Fuente del Minero.

5 DE MAYO

**KOLESA DE SANTA
BÁRBARA**

20:15h

MASTER CLASS DE PILATES

centro de pilates Victory impartirá dos
 clases especiales con motivo del Día de la HAP

5 DE MAYO

CENTRO VICTORY

**11: CLASE 08:00h
2º CLASE 15:00h**

ILUMINACIÓN DE LA FUENTE DEL MINERO

en color azul como muestra de apoyo y
 sensibilización de la HAP

5 DE MAYO

**FUENTE DEL
MINERO**

21:15h

LA ESCUELA OFICIAL DE IDIOMAS

importante su curso de inglés con un
 enfoque de concienciación sobre la HAP

5 DE MAYO

**ESCUELA OFICIAL
DE IDIOMAS**

18:00h

***WorldPHDay2026**

**HOPE
FOR EVERY
TRIAL**
MAY 2026

**GLOBAL ALLIANCE
FOR HIV/AIDS
RESEARCH**



Ukraine PHURDA



SPONSORS

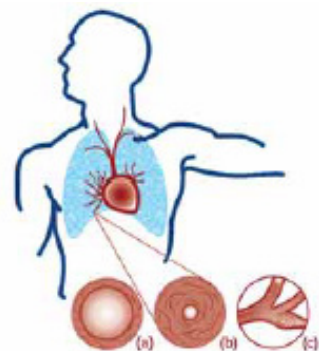


AIMS OF PHAEUROPE & Global

PHAEUROPE & Global was founded in 2003 to improve the lives of people affected by pulmonary hypertension (PH). Over the past 20 years, the role of patient associations has evolved from mainly providing peer support to becoming professional service centres for patients and their families. PHAEUROPE & Global supports its member associations in this development through information, education, training, exchange of best practices and capacity building. We also represent the patient voice internationally, working with healthcare professionals, policymakers, industry and other stakeholders to improve awareness, diagnosis, treatment, care and quality of life for people living with PH.

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 PHAEUROPE & Global and contact details

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BOSNIA AND HERZEGOVINA



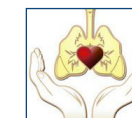
Udruženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini
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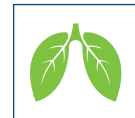
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PORTUGAL



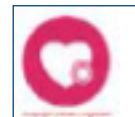
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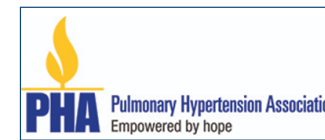
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