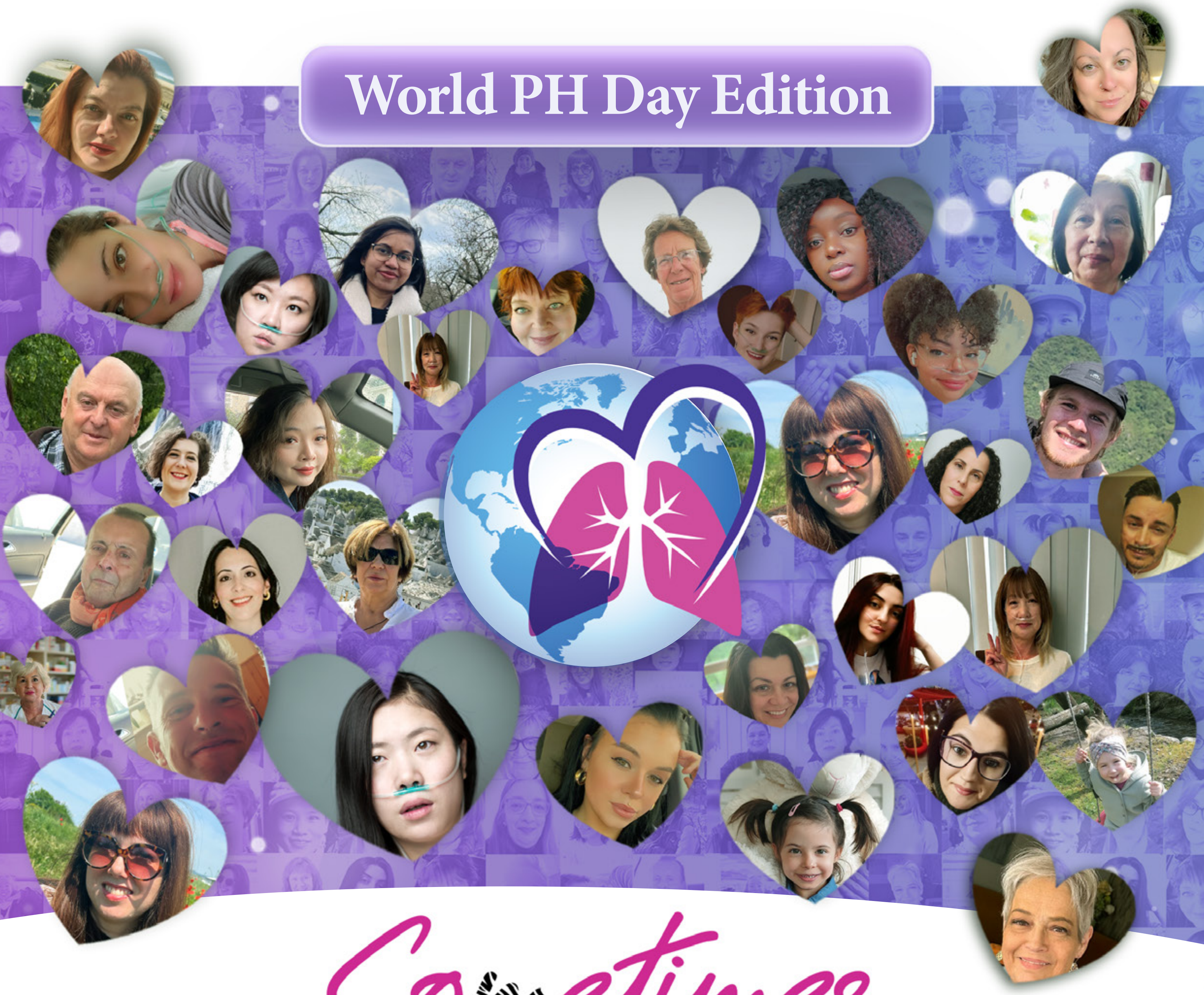
PULMONARY HYPERTENSION Mariposa Journal

SUMMER 2025 • PHA EUROPE’S OFFICIAL JOURNAL • N. 34

World PH Day Edition



Sometimes it’s pulmonary hypertension

BEL AIR CENTER
early diagnosis • best treatment • better quality of life • finding a cure
PHAEUROPE & Global
PULMONARY HYPERTENSION ASSOCIATION
Wilhelmstraße 21 • A-1120 Vienna • AUSTRIA • info@phaeurope.org • www.phaeurope.org

Editor's memo

SUMMER EDITION • 2025

Dear Friends, Colleagues, and Supporters,

Welcome to the Summer 2025 edition of Mariposa! This issue is fully dedicated to celebrating World PH Day 2025, a day when our community comes together to raise awareness and strengthen our voice for people living with pulmonary hypertension.

From Oslo to Lagos, Beijing to Washington, this year's events showed the extraordinary creativity and determination of our community. It is not possible to mention them all here, but let me share a few representative examples that reflect the diversity, spirit, and impact of World PH Day 2025. In Portugal, patients and families gathered in the historic town of Batalha for a weekend of connection, studies, and a neon walk. In Latvia, more than 130 people joined the Oxygen Festival for physiotherapy, health screenings, and open conversations in a "World Café." In the USA, advocates took their stories to Capitol Hill — and just one day later, a Congressman co-sponsored legislation to improve oxygen access, showing the impact of patient voices. In China, local groups combined baking and crafts with translated global stories, proving how solidarity crosses borders. In Austria, the Vienna Ferris Wheel and Ars Electronica lit up blue and violet, while Belgium's Blue Lips campaign turned a simple gesture into a symbol of recognition and hope. In North Macedonia, hundreds ran and then gathered for music in a show of unity, while in Ukraine, yoga, poetry, and youth advocacy reminded all that "we are more than PH." Bosnia and Herzegovina hosted the "Run for DAH" in Sarajevo, drawing 140 runners from across the Balkans. Meanwhile, in Norway, PH Norway joined the Coalition of Rare Diseases to push for faster access to precision medicine and clinical studies. And in Slovenia, Jona and Luka Kobler dedicated their record-breaking 102-hour sailing mission — an unofficial Guinness World Record — to raising awareness of PH, a feat that captured hearts and headlines. Alongside these national efforts, PHA Europe coordinated a major social media campaign under the slogan "Sometimes, it's PH." Built around 73 patient stories, the campaign was translated into 15+ languages, paired with educational infographics and other visuals, and reached 6.1 million impressions with 25,000+ engagements — all organically. PHA Europe's pages gained 700+ new followers on Facebook/Instagram and 54 on LinkedIn, with a median engagement ~18% higher than similar organisations. The now-iconic Zebra video once again helped explain misdiagnosis in a simple, powerful way.

A highlight of this year's programme was the World PH Day webinar hosted at the Bel Air Center: "Pulmonary Hypertension and Climate Change." Featuring Dr. Simon Clark, Dr. Mona Lichtblau, and Dr. Lucilla Piccari, and moderated by myself, the session explored how rising temperatures, wildfires, and pollution affect people with PH. Already viewed by more than 2,200 people, it underscored that climate change is not a distant threat — it is already worsening symptoms and disrupting fragile care systems.

A heartfelt thank you to all our member associations, partners, and volunteers who made this World PH Day such a success. Your energy, creativity, and commitment continue to inspire. A special thank you also goes to Maleen and BCHUB for the flawless execution of the WPHD campaign, and to Dora and Maleen for bringing everything together for this Mariposa edition.

Enjoy this special issue of Mariposa, filled with the highlights of World PH Day 2025 — from local events to global advocacy.

Warm regards,

Hall Skaara
Project Manager

CONTENTS

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. No password is required. You simply enter the email you provided during registration and request an access code. It will be sent to you within seconds, and you can then log in with your email address and the access code. (The use of an access code is only required occasionally for security reasons.)

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

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

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

Hall Skaara
Project Manager

Video recording of the webinar is available in the Bel Air Center Recorded Presentations room

Patient involvement in HTA training course

Neil Bertelsen,
BSc, MSc, MBA,

This training was sponsored by MSD

WPHD WEBINAR

Climate Change and Pulmonary Hypertension

On May 7, 2025, PHA Europe marked World PH Day with a webinar devoted to the urgent theme of climate change and its impact on people living with pulmonary hypertension. The event, held at PHA Europe's Bel Air Center, was moderated by Hall Skaara from PHA Europe and brought together an experienced panel: Dr. Simon Clark, who holds a PhD in atmospheric physics, and two PH specialists, Dr. Mona Lichtblau from the University Hospital Zurich and Dr. Lucilla Piccari from Hospital del Mar in Barcelona.

The discussion made clear that climate change is no longer a distant concern but a reality that already affects people with PH. Rising global temperatures and more frequent extreme weather events such as heatwaves, cold spells, and dust storms can worsen breathlessness, fatigue, and other PH symptoms. These environmental stressors are linked to more exacerbations, increased hospitalizations, and even higher mortality. Patients with PH often struggle to adapt physically to sudden changes in heat or humidity, and many find their ability to remain active reduced during periods of extreme weather.

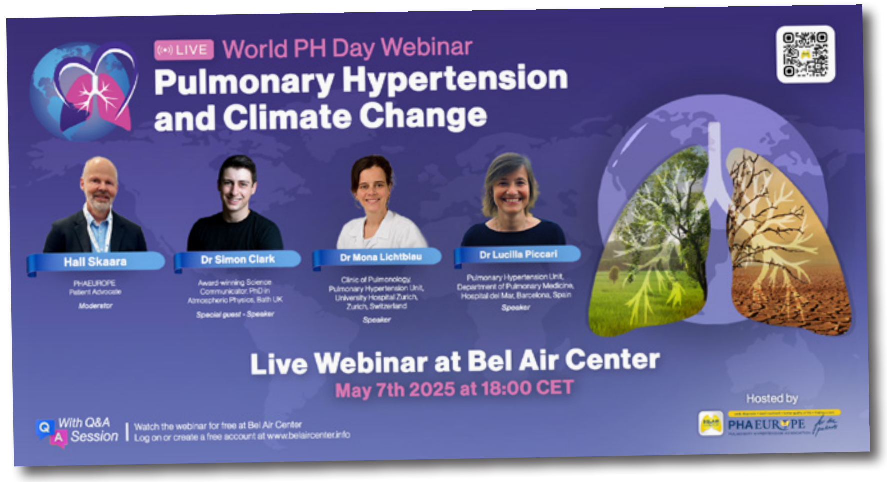
Dr. Lichtblau and Dr. Piccari explained that pollution compounds these challenges. Airborne particles and chemical exposures not only worsen existing disease but also increase the risk of developing pulmonary vascular complications. They pointed out that climate-related infectious diseases, food insecurity, and forced displacement may further contribute to the global burden of PH in the coming years. Another issue highlighted was the fragility of access to healthcare: natural disasters and environmental crises can disrupt the complex networks of care that people with PH depend on, leaving patients vulnerable when they most need stability.

Participants asked important and practical questions during the session. They wanted to know how PH patients can best cope with heatwaves or high pollution days, whether mental health is also affected by climate stress, and what role healthcare professionals and advocacy groups can play in helping people adapt. The panel emphasized that individuals could take steps, such as preparing for emergencies, paying attention to air quality, and protecting their mental health, but they also stressed that larger policy and advocacy efforts are essential.

The main conclusion of the webinar was that PH patients are and will continue to be affected by climate change. From direct effects on symptoms to indirect consequences through disrupted healthcare and environmental stress, the evidence is clear. For PHA Europe and the wider PH community, this is a call to raise awareness, strengthen advocacy, and ensure that the voices of patients are heard in the broader conversation about climate and health.

The webinar can be watched on demand in the presentation room at PHA Europe's Bel Air Center. A free Bel Air Center user account can be created via the landing page: www.belaircenter.info.

Hall Skaara
Project Manager


LIVE World PH Day Webinar
Pulmonary Hypertension and Climate Change

Hall Skaara
PHAEUROPE
Patient Advocate
Moderator

Dr Simon Clark
Award-winning Science Communicator, PhD in Atmospheric Physics, Bath UK
Special guest - Speaker

Dr Mona Lichtblau
Clinic of Pulmonology, Pulmonary Hypertension Unit, University Hospital Zurich, Zurich, Switzerland
Speaker

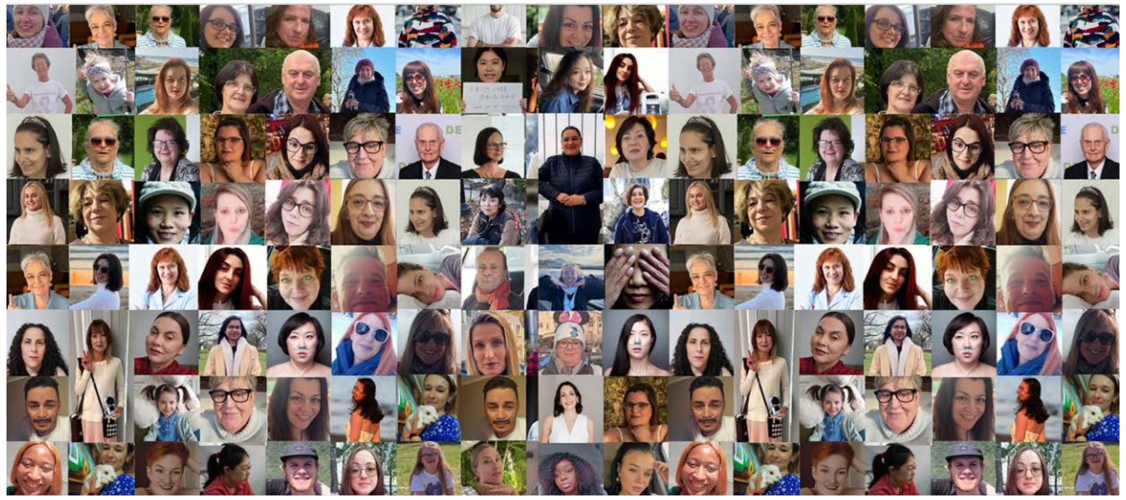
Dr Lucilla Piccari
Pulmonary Hypertension Unit, Department of Pulmonary Medicine, Hospital del Mar, Barcelona, Spain
Speaker

Live Webinar at Bel Air Center
May 7th 2025 at 18:00 CET

With Q&A Session | Watch the webinar for free at Bel Air Center
Log on or create a free account at www.belaircenter.info

Hosted by
PHAEUROPE

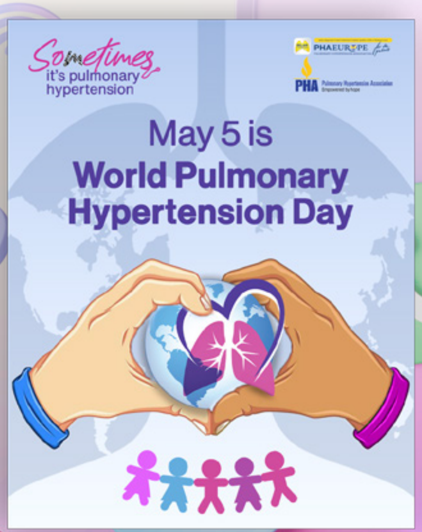
PHA EUROPE – SOCIAL MEDIA ACTIVITIES

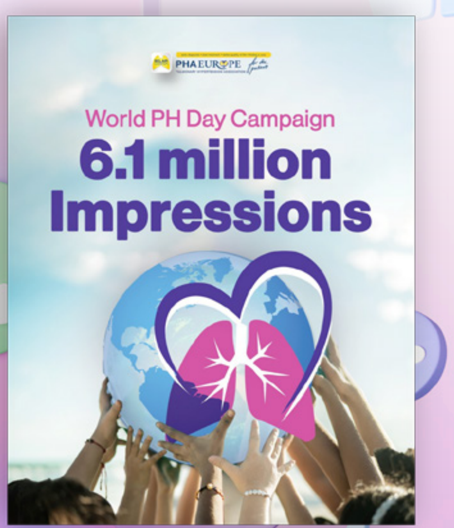


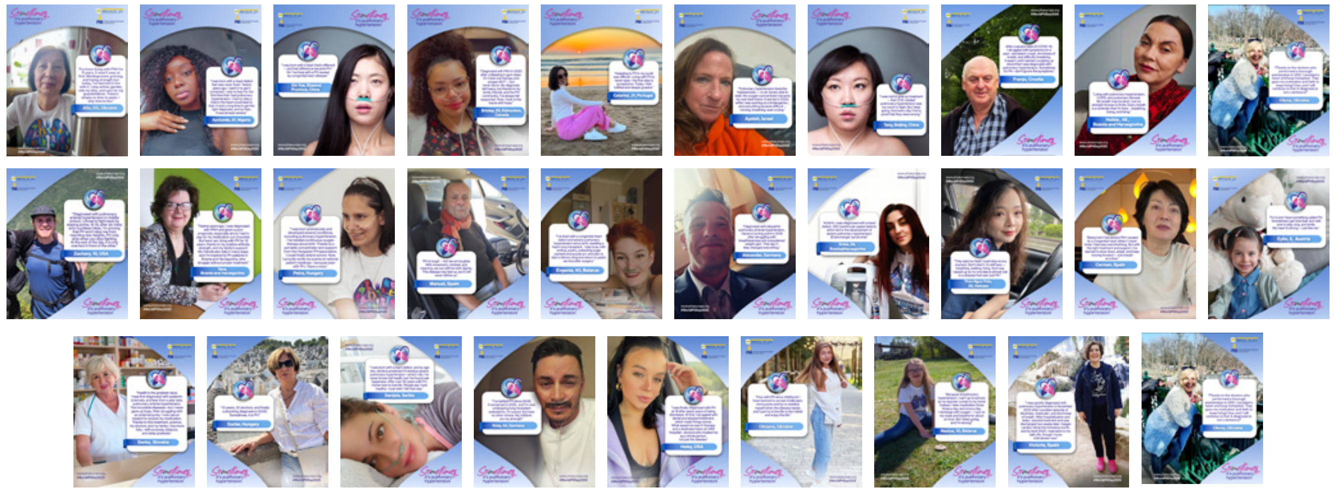
Sometimes it's pulmonary hypertension

WPHD 2025 reminded us that the most powerful awareness begins with personal stories. This year's campaign opened a window into the everyday reality of PH patients across the globe—offering a rare combination of global reach and deeply personal tone. Few campaigns manage to achieve both, but WPHD 2025 did exactly that. By turning shared struggles into a unified message of visibility and truth, the global PH community made this World PH Day not only impactful, but unforgettable. WPHD 2025 was a deeply personal and truly global milestone.

Under the slogan "Sometimes, it's PH" this year's social media campaign, lasting through May and June, drew on the powerful symbolism of the medical zebra, borrowing the slogan from the now famous video about PH and its misdiagnosis and diagnostic challenges—where rare and serious conditions, like pulmonary hypertension, are often mistaken for more common ones, just as a doctor, or anyone, might mistake the sound of hoofbeats from zebras, for those of horses. This theme echoed across more than 73 patient stories from almost every continent, revealing how often PH is misdiagnosed as anxiety, asthma, or simple fatigue, and how devastating those delays can be, only to later discover that "Sometimes, it's PH".



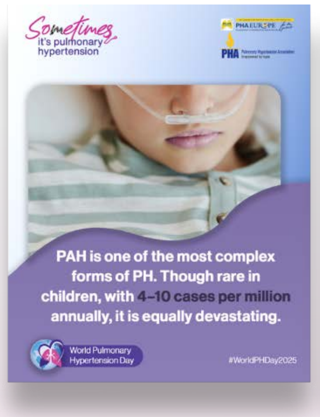


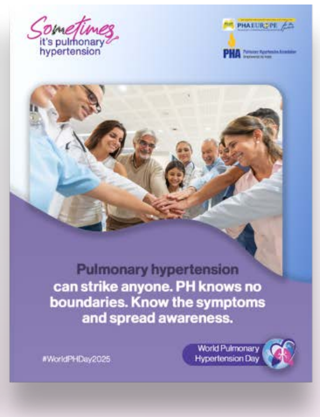


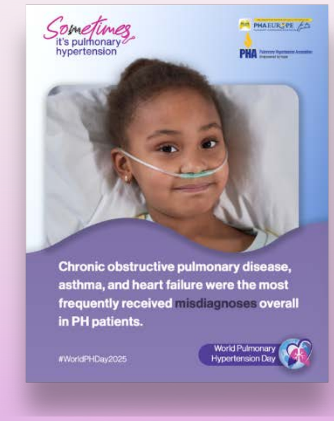
More than a campaign, WPHD 2025 became a shared space for patients to speak openly about their long journeys to diagnosis, their moments of fear and courage, and the challenges of living with a disease that often remains invisible to others. For the first time, this was not only a global effort, but a profoundly personal one; centered on the real stories of real people living with PH.

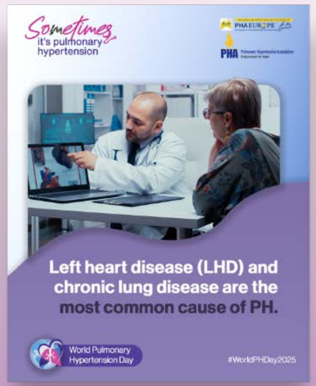
PHAEUROPE led this initiative as the umbrella association for national PH associations across Europe, while also connecting beyond. But this year, the support and participation extended even further than before. Almost all major PH associations across the globe joined forces, including those from the USA, Canada, South America, Nigeria, Israel, China, Japan, Vietnam, and the entire European membership. Each association not only helped amplify the message, but also contributed their own patients' voices—testimonies filled with resilience, pain, perseverance, and moments of clarity when the correct diagnosis finally arrived.

The campaign was built around three central pillars: patient stories, awareness and education posts, and visual engagement. At its core were 73 patient testimonials—powerful, candid accounts that shed light on the shared experience of being doubted, dismissed, or misdiagnosed, and the emotional weight of not knowing what's happening to your body. These stories, whether from young women navigating motherhood with PH, women in their middle age, men struggling to stay on their feet, or children and their parents facing the unknown, resonated across languages, regions, and generations. Though each was unique, many echoed the same confusion, the same fears, and, after countless wrong answers, the same final diagnosis: PH.









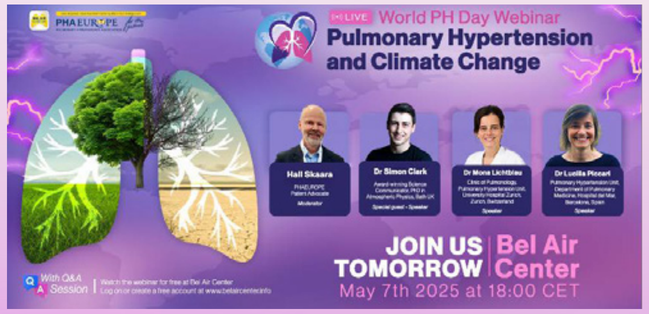
Complementing these stories were over 20 visual materials, including 9 educational infographics and 14 other informational posts and reels. The now-iconic Zebra awareness video was once again used to reinforce the message, helping global audiences understand that sometimes, what looks like something mild, is actually something much more serious. Translated into more than 15+ languages, all campaign materials were made editable and adaptable, allowing national associations to tailor them to their local context and ensure that the stories truly resonated with their communities.

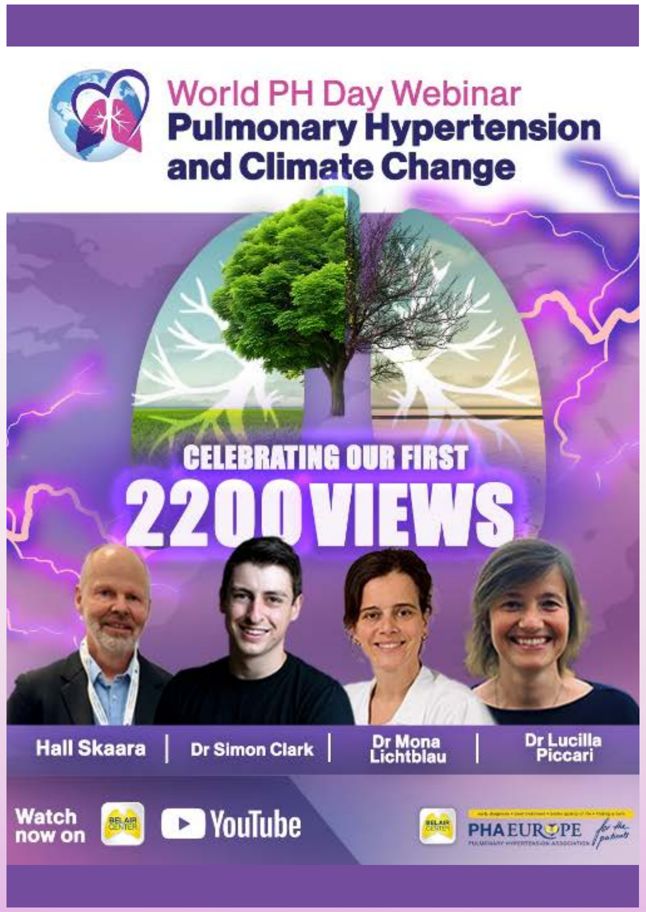
The impact of the 2025 campaign was extraordinary. With over 6.1 million impressions across platforms, more than 25,000 direct engagements, and an equal number of likes and shares, its reach extended far beyond social media, making this a campaign to remember.

In May and June alone, PHAEUROPE gained over 700 new followers on Facebook and Instagram, and 54 on LinkedIn, where it continues to lead as the most active PH page, boasting a median engagement rate of 8%, which is 18% higher than comparable organizations. On X, our organic reach climbed to 10,485 users, all without a single cent spent on promotion.

As is tradition, PHA Europe also hosted a dedicated WPHD webinar—but this year's topic broke new ground. The 2025 webinar, "Pulmonary Hypertension and Climate Change," featured Dr. Simon Clark, a well-known scientist, YouTube personality, and science communicator, alongside renowned PH experts Dr. Mona Lichtblau and Dr. Lucilla Piccari. The session was moderated by PHA Europe's Hall Skaara.

Already viewed by over 2,200 people on YouTube and still freely available via the Bel Air Center platform for the PH patients and stakeholders, the discussion explored the direct impact of environmental changes, such as rising temperatures, wildfires, and air pollution, on the lives and outcomes of people living with PH. The webinar underscored the urgent need for further research into these links and emphasized the importance of integrating climate risks into both clinical care and public health strategies.





The truth this campaign illuminated is simple, yet profound: sometimes, it's PH, and recognizing it can change, and save, lives. Thanks to the united voices of patients, caregivers, advocates, experts, and national associations around the world, WPHD 2025 became a movement defined by truth, solidarity, and deep emotional resonance.

PHAEUROPE is incredibly proud of our global community and everyone who supports the patients and patient associations along the way. What began as a campaign became a global movement—each voice unique, but all speaking the same urgent truth. Most importantly, the campaign empowered our community to speak up about their journeys, giving glimpses of authentic stories that remind all of us that behind statistics are faces. Patients deserve to be heard, believed, and treated, no matter who they are, where they live, or how healthy they may look.

The unity, bravery, and honesty shown throughout this campaign are a testament to a growing global movement—driven by patients, caregivers, advocates, and experts alike. Together, we are not just raising awareness; we are reshaping the future of pulmonary hypertension.

Yes, PH patients are breathless. And those who advocate for them—who speak, organize, and raise awareness—may sometimes share that feeling of breathlessness, in their own way, too. But above all, we continue to breathe in unity, walking together toward a future where no one has to face PH alone or unheard.

Maleen Fischer and the Social Media Team
PHA Europe – For the Patients

ARGENTINA

REPORT ON HIPUA ACTIVITIES FOR WORLD PH DAY

At HIPUA, we celebrate every World Pulmonary Hypertension Day with special activities and new projects:

As every year on May 5th, the Government of the City of Buenos Aires illuminated the following historical monuments in violet

- Torre Monumental
- Palacio de la Libertad
- Planetario
- Palacio Lezama

The 4th National Meeting on Pulmonary Hypertension was held on May 6th.

A completely virtual space—accessible from anywhere in Argentina via Zoom—aimed at patients and their families. Renowned national PH experts participated:

- **Dra. Lorena Maldonado** (Hospital Británico de Buenos Aires) opened the meeting with an update on key concepts based on the 7th World Symposium on Pulmonary Hypertension.
- **Dra. Daniela García Brasca** (Hospital Italiano de Córdoba) presented current treatments and future therapies.
- **Dra. Paula Kaplan** (Ramos Mejía Hospital, Buenos Aires) focused on essential daily care for people living with PH.
- **Dr. Luis Lema** (Model Cardiology Institute, Córdoba) spoke about the link between PH and pregnancy: a new paradigm after the 7th World Symposium?
- **Dr. Luis Gómez** (Fernández Hospital) addressed, for the first time in our meetings, the relationship between PH and genetics.

It was an ideal day to learn, clarify doubts, and strengthen empowerment toward a better quality of life.

4° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

6 de Mayo
18:00 hs

Por plataforma
zoom

Vacantes limitadas
Requiere inscripción previa

4° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

Acercándonos a un mejor conocimiento de la Hipertensión Pulmonar

Dra. Lorena Maldonado
Neumonóloga (Hospital Británico)

6 de Mayo
18:00 hs
zoom

Vacantes limitadas. Requiere inscripción previa.

4° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

Tratamientos actuales y futuros para la HP

Dra. Daniela García Brasca
Cardióloga (Hospital Italiano de Córdoba)

6 de Mayo
18:00 hs
zoom

Vacantes limitadas. Requiere inscripción previa.

4° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

Cuidados del paciente con Hipertensión Pulmonar

Dra. Paula Kaplan
Neumonóloga (Hospital Ramos Mejía - CABA)

6 de Mayo
18:00 hs
zoom

Vacantes limitadas. Requiere inscripción previa.

4° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

Embarazo y HP. ¿Cambio de paradigma a partir del 7° Simposio Mundial de HP?

Dr. Luis Lema
Cardiólogo (Instituto Modelo de Cardiología de Córdoba)

6 de Mayo
18:00 hs
zoom

Vacantes limitadas. Requiere inscripción previa.

4° Encuentro Nacional de Hipertensión Pulmonar para pacientes y familiares

Hipertensión Pulmonar y Genética

Dr. Luis Gómez
Cardiólogo (Hospital J.A.Fernández - CABA)

6 de Mayo
18:00 hs
zoom

Vacantes limitadas. Requiere inscripción previa.

Social Media Campaign

As part of PHA EUROPE, HIPUA joined the initiative “Sometimes it’s Pulmonary Hypertension.” It’s not asthma or panic attacks… it’s PULMONARY HYPERTENSION! We would like to thank PHA EUROPE for including Eleonora a representative of Argentina.

Sometimes it's pulmonary hypertension

Los sueños se hacen realidad cuando ponés tu corazón, pasión y dedicación en ellos. ¡Sí, podés lograrlo!... Solo cree en vos mismo.

Eleonora, Argentina

www.phaeurope.org
#WorldPHDay2025

“Breathing for Argentina”

In May, and in the context of World Day, HIPUA launched this project, traveling across the country to raise awareness, inform, and support patients and families.

Pulmonary hypertension is a rare and complex disease that affects pulmonary circulation, compromising oxygenation and causing symptoms such as dyspnea, fatigue, chest pain, and fainting. In Argentina, diagnosis takes an average of 16 months from the onset of the first symptoms, as they are often confused with other common respiratory diseases (asthma, COPD).

The goals of this initiative are:

- Improve access to diagnosis, treatment, and emotional support;
- Strengthen a national support network;
- Promote the inclusion of PH in public health policies.

Recognizing that each province has its own specificities — in infrastructure and resources — the tour helps identify specific barriers to medical access and develop support strategies tailored to each region. The journey has already reached Tucumán and Salta and will continue through other provinces in central and southern Argentina.

As part of World HP Day, we also resumed our meetings called "I take five minutes... I take a break."

This initiative, available both in-person and virtually, promotes emotional well-being through workshops designed to:

- Avoid isolation, reducing anxiety and depression;
- Share experiences, fears, and frustrations with others facing the same reality;
- Strengthen self-esteem, especially during difficult times;
- Build friendships among people who understand and accept each other.

The purpose is for each patient to take an active role in their illness, regain balance, and strengthen decision-making, focusing on life rather than the disease.

In summary, at HIPUA we transform World Pulmonary Hypertension Day into an opportunity to:

- Stay updated on medical advances and innovative treatments;
- Raise disease awareness and demystify its symptoms;
- Offer support, companionship, and a sense of belonging across the country;
- Empower every person to take ownership of their story and find strength in community.

AUSTRIA

THE VIENNA FERRIS WHEEL, ARS ELECTRONICA, AND THE LAUNCH OF THE OLDTIMER GUIDE

On May 5, 2025, WPHD, World Pulmonary Hypertension Day, was observed worldwide. This important occasion aims to raise awareness of pulmonary hypertension, a rare, often overlooked, and life-threatening disease. It can affect people of all ages, including children.

PH Austria once again used this day to send a strong message of support to those affected and to increase public awareness. The goal is to help recognize symptoms early, speed up diagnoses, and give hope to those living with the condition.

This was the reason why, on the night of May 5th, two major landmarks were symbolically illuminated.

The Vienna Ferris Wheel – Thanks to Managing Director Nora Lamac, one of Vienna's landmarks, the Giant Viennese Ferris Wheel, shined bright in vibrant blue and violet.

ARS ELECTRONICA

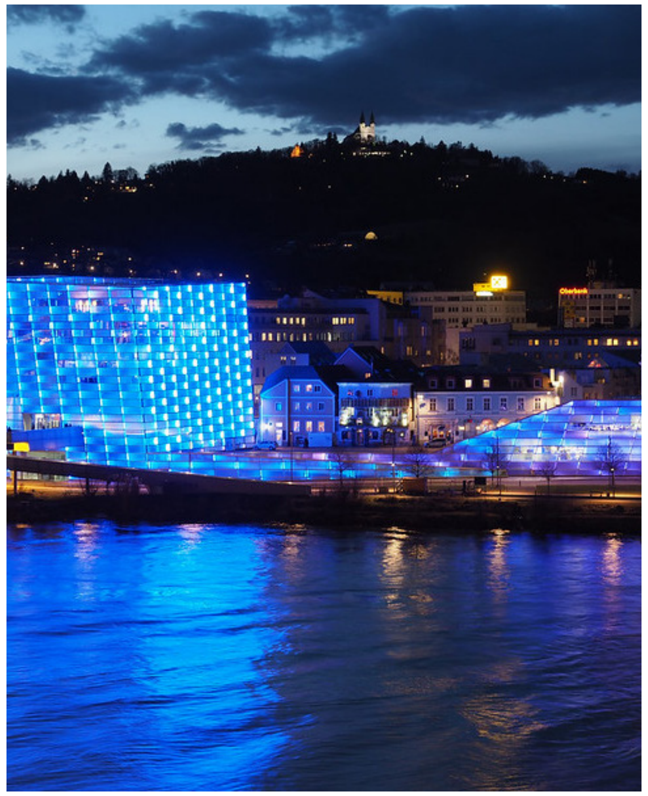
In the city of Linz, the **Ars Electronica Center** lit up in our colors of blue and violet on this day as well.

The light installations were intended as a visible sign of solidarity with all those affected, while also raising awareness of a disease that often remains hidden.

Numerous passers-by were moved and intrigued, with many stopping to take photos, aiming to learn more about the condition.

The illumination campaign was accompanied by information initiatives on social media and under the hashtag #WorldPHDay2025.

With actions like these, PH Austria sends a strong, high-profile message, giving an important voice to the roughly 900 people affected in Austria, as well as thousands more worldwide.



PH AUSTRIA AT THE LAUNCH OF THE OLDTIMER GUIDE 2025

On May 17, 2025, the 19th edition of the renowned *Oldtimer Guide* was presented in the impressive setting of Schloss Grafenegg during the Design Days, this year under the atmospheric motto *"Made in Austria."*

The event uniquely combined automotive elegance, Austrian design, and social responsibility. Amid lovingly restored vehicles and exciting exhibitors, PH Austria was also present with its own information booth. Eva Otter and Benita Fischer took the opportunity to provide visitors with in-depth insights into the rare but serious condition of pulmonary hypertension and to raise awareness.

We were especially pleased by the personal conversations on-site, the great interest shown by visitors, and the openness toward such a complex topic.

A particularly special moment was the classic car auction held during the event. A portion of the proceeds was generously donated to PH Austria – a sign of appreciation that deeply moved us.

We would like to sincerely thank the organizers of the *Oldtimer Guide*, especially for the valuable opportunity to make our work accessible to a wider audience.

A big thank-you also goes to MSD for their much-appreciated support.

BELARUS

As part of World Pulmonary Hypertension Day, an educational and creative event was held at the Molotkovichi Special School, organized with the participation of the Public Association Assistance to Patients with Pulmonary Hypertension.

The aim of the event was to raise awareness about pulmonary hypertension — a rare but serious disease that affects respiratory function and quality of life for thousands of people worldwide.

Participants included:

- Patients and their family members
- Teachers and school staff
- Specialists in adaptive physical education and rehabilitation
- Representatives of the public association
- Invited volunteers and organizers

The program featured the following activities:

1. CREATIVE DRAWING WORKSHOP
Conducted by an art studio led by Yulia Myalik, participants created images of blue butterflies — the international symbol of pulmonary hypertension, representing blue lungs and respiratory insufficiency.
A special highlight was the participation of a young patient, Anastasia, whose personal contribution became an important part of the event's symbolic message.

2. EDUCATIONAL LECTURE
Asya Birillo, a specialist in physical rehabilitation, delivered a lecture covering:

- Signs and symptoms of pulmonary hypertension
- Physical activity considerations for those diagnosed
- The importance of early diagnosis and patient support

3. ADAPTED PHYSICAL WARM-UP
Led by a teacher of adaptive physical education, the session included exercises tailored to the limitations faced by patients, emphasizing the importance of a gentle and thoughtful approach to physical activity.

BELGIUM

ACTIVITIES OF THE WORLD PULMONARY HYPERTENSION DAY – P.H. BELGIË

In May, in recognition of World Pulmonary Hypertension (PH) Day, we organized a series of initiatives to raise awareness about this rare and serious condition. Through both physical and online actions, we aimed to reach, inform, and connect as many people as possible around this important cause.

THE "TRIAL RUN" – 160 KM IN SUPPORT OF PH AWARENESS

On June 8th, a "Trial Run" took place: an impressive athletic feat in which a total of 160 kilometers was completed in relay.

The organizer, Lotje, first came into contact with Pulmonary Hypertension through the son of a colleague. It deeply moved her. As a colleague, she felt powerless to help—until the idea grew to combine action with something she could do: trail running.

With that in mind, she gathered 14 like-minded individuals—friends, colleagues, and sports enthusiasts with big hearts and strong legs. Some were seasoned runners, while others took on such a challenge for the first time. What united them was the drive to take action for people who have to fight every day just to breathe.

Together, they ran 100 miles in relay, from Hulst to Hamme, through the most beautiful trails, all the way to the headquarters of the patient association.

They didn't run just for sport, but for something much greater. With every mile, they aimed to raise awareness and collect funds for the patient association for people with Pulmonary Hypertension.

They ran for breath. For awareness. For connection. And for the difference we can make together.
For this initiative, we specially adapted our website to create a fundraising page *(https://ph-vzw.be/2025/04/10/samen-lopen-voor-adem/)*, which raised an impressive €2,755.85! In addition, we gained significant visibility through the organizers' Instagram page and social media, including posts from participants.

BLUE LIPS: A POWERFUL SYMBOL OF RECOGNITION AND HOPE

In May, we launched a special online campaign with the slogan: "Blue lips are not a beauty trend. They can be a warning sign." With this message, we aimed to raise awareness in a visual and accessible way about the visible, and invisible, signs of pulmonary hypertension.

The call to action was simple yet powerful: take a photo with blue lips, share it on social media, and help bring attention to our condition. And it worked! Throughout the month, photos of people with blue lips appeared on Instagram and Facebook, shared by patients, family members, friends, and supporters.

Each week, we also posted informative content about symptoms, diagnosis, and personal stories from fellow patients. The response was heartwarming, and engagement was strong. Even the godchild of our chairperson gave a presentation about PH in her classroom, and our board members proudly joined in by sharing their own blue-lipped photos.

The blue lips became a powerful symbol of recognition, solidarity, and hope. Because no matter how small an action may seem, together, we can make a visible difference!

CONCLUSION

The combination of physical and digital actions resulted in a powerful awareness campaign. We are proud of the dedication shown by all volunteers, participants, and supporters, and we hope that our efforts have contributed to greater awareness, understanding, and support for people with Pulmonary Hypertension.
We remain committed to increasing visibility and thank PHA Europe for their continued support and international coordination!

On behalf of VZW Pulmonale Hypertensie België,
Wendy Vansteenkiste
Chairwoman

Des lèvres bleues, ce n'est pas une tendance beauté. C'est peut-être un signal d'alarme.

#CurePH #WorldPHDay
#HypertensionPulmonaire @PHBelgium

Blauwe lippen zijn geen beautytrend. Ze kunnen een alarmsignaal zijn.

AANTAL
diagnoses van PAH en CTEPH*

*pulmonale arteriële hypertensie en chronische trombo-embolische pulmonale hypertensie

Des lèvres bleues, ce n'est pas une tendance beauté. C'est peut-être un signal d'alarme.

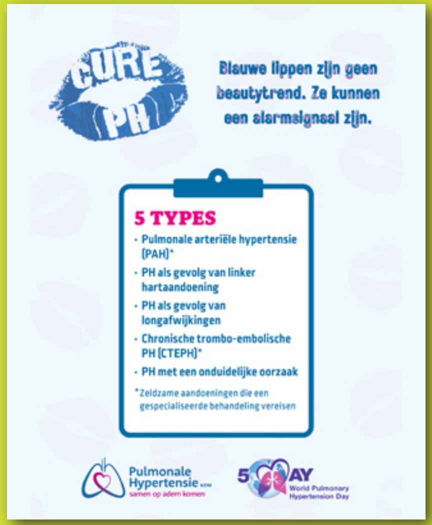
Qu'est-ce que l'HTaP?
L'HyperTension artérielle Pulmonaire est une élévation anormale de la pression sanguine dans les artères pulmonaires. Cette pression augmente le travail que doit fournir la partie droite du coeur, ce qui peut conduire à une insuffisance cardiaque. Cette maladie rare met la vie en danger et s'aggrave avec le temps.

Blauwe lippen zijn geen beautytrend. Ze kunnen een alarmsignaal zijn.

GEZONDE LONGSLAGADER

VERNAUWDE LONGSLAGADER
doordat gladde spiercellen in de wand van de kleine haarvaten zich ongecontroleerd vermeerderen (PAH)

BLOKKADE LONGSLAGADER
door een bloedprop in de grote hoofdaders; CTEPH is de enige vorm van PH die mogelijk te genezen is



Blauwe lippen zijn geen beautytrend. Ze kunnen een alarmsignaal zijn.

5 TYPES
- Pulmonale arteriële hypertensie (PAH)*
- PH als gevolg van linker hartaandoening
- PH als gevolg van longafwijkingen
- Chronische trombo-embolische PH (CTEPH)*
- PH met een onduidelijke oorzaak

*Zeldzame aandoeningen die een gespecialiseerde behandeling vereisen

Blauwe lippen zijn geen beautytrend. Ze kunnen een alarmsignaal zijn.

SYMPTOMEN

13%	hartkloppingen
15%	duizeligheid / flauwvallen
21%	gezwollen enkels
22%	pijn op de borst
27%	vermoeidheid
86%	kortademigheid

Des lèvres bleues, ce n'est pas une tendance beauté. C'est peut-être un signal d'alarme.

DIAGNOSTIC
en moyenne 2 ans

L'ESPÉRENCE DE VIE
en moyenne 2,8 ans
sans traitement

Un diagnostic précoce est fondamental pour améliorer la survie et la qualité de vie.

Blauwe lippen zijn geen beautytrend. Ze kunnen een alarmsignaal zijn.

GEEN ONDERSCHEID
in leeftijd, ras of geslacht

Des lèvres bleues, ce n'est pas une tendance beauté. C'est peut-être un signal d'alarme.

TRAITEMENT
dans des centres spécialisés

Le traitement est **complexe et coûteux** (p. ex. une pompe qui délivre des médicaments dans le sang par un cathéter 24H/24). Un suivi stricte et à vie est nécessaire. Parfois, une intervention chirurgicale (HTP-TEC) ou une transplantation (coeur-) poumons doit être réalisés.

BOSNIA AND HERZEGOVINA

RAISING AWARENESS OF PH IS A CONTINUOUS TASK

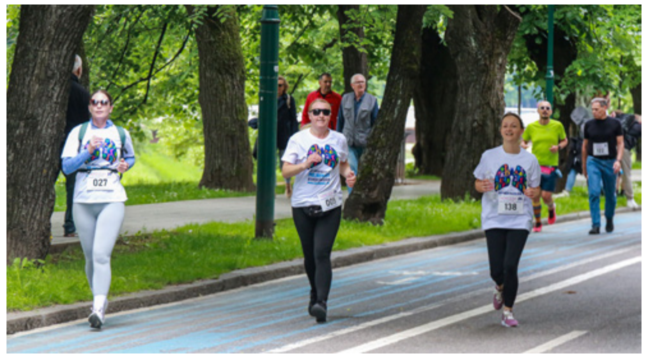
The commemoration of World Pulmonary Hypertension Day in Bosnia and Herzegovina began on May 5 with the publication of a video banner by the company „General Pro-Mark", which featured visuals of the campaign dedicated to pulmonary hypertension on the occasion of this day. The visuals were shown on a video banner in the very center of the town of Zavidovići for the entire month of May. In this way, we continued our cooperation with the company „General Pro-Mark", which provided us with this valuable space and thus supported those who live with this rare and serious disease every day. Our visual was not just a picture - it was a reminder that pulmonary hypertension is silent, invisible, but present, and that every support means a lot to us.

„INVISIBLE PULMONARY HYPERTENSION" – OUR NEW INFORMATION PROJECT

In addition, on World Pulmonary Hypertension Day 2025, the Association of Citizens with Pulmonary Hypertension „Dah" - in Bosnia and Herzegovina, with the support of sponsors, implemented an important informative project. Thanks to sponsorship, two brochures and one leaflet entitled „Invisible Pulmonary Hypertension" were printed. These information materials were created with the aim of raising public awareness of this rare but serious disease that often remains unrecognized.

The brochures and leaflet provide key information on symptoms, diagnosis, treatment options, and the daily challenges faced by sufferers. The materials are intended for the general public, but also for healthcare professionals, in order to improve understanding and strengthen early diagnosis.

Our Association continues its commitment to making invisible pulmonary hypertension visible, providing support to sufferers and informing the community.



ELEMENTARY SCHOOL STUDENTS MARKED WPHD 2025

Among other activities on World Pulmonary Hypertension Day (WPHD), we would like to highlight that students of grades II, III and V of the First Elementary School Zavidovići participated in an educational and creative activity dedicated to raising awareness of this rare and serious disease. The activity was realized thanks to the multi-year cooperation of the school and teachers with the Association of citizens suffering from pulmonary hypertension „Dah” - in Bosnia and Herzegovina.

Under the guidance of teachers Samira Isić and Emira Skejić, the students watched the zebra video „Sometimes it’s PH”, and, in a way adapted to them, they talked about what pulmonary hypertension is, how it affects the daily life of sufferers, and why the zebra, as a symbol of rare diseases, is important in promoting understanding and solidarity.

After the educational part, the children expressed their support and acquired knowledge through drawings on the topic „Pulmonary hypertension and zebras”. The creative and moving works of the students were published on the pages of our Association’s social networks with the aim of spreading the message about the importance of early recognition and support for people living with rare diseases such as pulmonary hypertension.

The school, teachers, students, and their parents showed empathy, openness, and willingness to be a voice of support for those who struggle with pulmonary hypertension every day through knowledge and creativity.

„WE RUN FOR BREATH” - WITH THE POWER OF STEPS FOR THOSE OUT OF BREATH

The central event marking WPHD 2025 in Bosnia and Herzegovina was the „Run for DAH” race, which was held in the beautiful surroundings of Wilson Promenade in Sarajevo, the capital of Bosnia and Herzegovina. On May 10, 2025, runners from Bosnia and Herzegovina, Montenegro, Slovenia, Croatia, Serbia, Germany, Austria, and the USA participated with the aim of raising awareness about pulmonary hypertension.

More than 140 runners of all generations joined this humanitarian event, sending a strong message of support to people facing this invisible but serious disease. The race was not of a competitive nature - its goal was symbolic, to run for those who cannot. In the end, the best received symbolic awards.

The event was accompanied by an extremely positive atmosphere, with numerous additional contents for visitors - from a music program and workshops for children, to promotional stands with educational materials and oxygen saturation measuring.

The organizers from the Association „Dečki u plavom” and the Association of Citizens Suffering from Pulmonary Hypertension „Dah” - in Bosnia and Herzegovina are grateful to all participants, volunteers, and partners for their support, emphasizing that every such activity is a step closer to better information, earlier diagnosis, and a better quality of life for those suffering from it.

The race „Let’s Run for DAH” showed how much unity and empathy can mean - because when a sufferer runs out of breath, there are runners to run for him. Of course, our Enes Ibrahimagić from Bihać was among the runners and thus added new kilometers to the list of over several hundred kilometers running out of breath for those suffering from pulmonary hypertension.

WE WERE ALSO PART OF THE PLJEŠEVIČKI TRAIL

We marked World Pulmonary Hypertension Day with the participation of Amar Čehajić, another of our runners from Bihać, in the II round of the Plješevička Trail League, which was held on May 17, 2025. Amar, who has run many kilometers for patients with pulmonary hypertension, this time, wore the symbols of the European PH community in the longest and most demanding race of the season. We must point out that in one day, two trail peaks with a length of 28 km with a total ascent of 1300 meters, were conquered. The strength and endurance of our runners, who got out of breath for pulmonary hypertension, left us out of breath this time as well. The significance and magnitude of such events is that a group of runners from Bihać does not run to raise awareness of our disease only during the WPHD celebration, but in all the races they participate in throughout the year, which deserves special respect from the entire PH community.

OUR STRUGGLE WAS HEARD THROUGHOUT BOSNIA AND HERZEGOVINA

And finally, the Association of Citizens Suffering from Pulmonary Hypertension „Dah” - in Bosnia and Herzegovina is very pleased to point out the extremely successful media interest on World Pulmonary Hypertension Day. More than 30 announcements in just one day, May 5, in various media and on online portals throughout Bosnia and Herzegovina, speak in favor of the increasing understanding and support that the public provides for our struggle.

This media response shows that our voice was heard - and that the common message of the patients, their families, doctors and friends reached the wider public. We are proud of this visibility, because we know how important it is in the fight for better treatment, timely diagnosis, and a dignified life for people living with pulmonary hypertension.

We would like to thank all journalists, editors, and media companies, who recognized the importance of this topic and gave us the space and opportunity to speak. This success further motivates us to continue with even greater energy and commitment.

Pulmonary hypertension does not have to be invisible - we proved that this May 5th!

Vera Hodžić,
president of the Association of citizens suffering from pulmonary hypertension „Dah" - in Bosnia and Herzegovina

BULGARIA BSPPH

PULMONARY ARTERIAL HYPERTENSION IS LIKE AN ICEBERG

On May 5, the world once again observed World Pulmonary Hypertension Day – a severe and often undiagnosed condition also known as „blue lips disease." Approximately 500 people in Bulgaria live with this illness. In solidarity with patients, from 8:00 pm to 11:00 pm on May 5, 2025 the facade of the National Palace of Culture in Sofia was illuminated in blue. Two more Bulgarian cities joined the initiative: in Burgas, the bridge in the Sea Garden was lit, and in Plovdiv, the Boris Hristov Cultural Center glowed blue.

SPORT OLYMPIC HALL FILLED WITH ENERGY, SPEED, AND SOLIDARITY

On May 17, the Racket Speed Club organized a badminton demonstration in support of patients with pulmonary hypertension. Participants were left breathless, showing solidarity with people living with this rare lung disease. 30 sports enthusiasts joined the „Breathless for PH" initiative of the Bulgarian society of the patients with pulmonary hypertension – an organization that has advocated for more than 13 years for those affected by this rare and insidious disease. Pulmonary hypertension impacts approximately 500 Bulgarians, with nearly 150 living with the rarest form: pulmonary arterial hypertension. Known as the „blue lips disease" due to low blood oxygen levels, it often forces patients into isolation from active life and society. Participants donated their time and energy for a high-intensity badminton workout. The event was held with support from the hosts Sport Olympic, the Bulgarian Pickleball Federation, and the Bulgarian Lacrosse Federation.

„I'm happy you're exercising for those who can't climb even a few stairs, and whose lives remain hidden from society," shared Natalia Maeva, chair of the patient organization and herself a transplant recipient, at the start of the session.

Special guest Irena Metodieva attended – whom we all believe will soon travel to the USA for a life-saving lung transplant. The session followed a high-intensity interval training (HIIT) format, which not only accelerates heart rate but activates hormonal and metabolic systems, promoting fat burning and muscle building. During peak exertion, heart rates reached 85–90%, with metabolism remaining elevated for hours afterward. Patients continue to highlight that Bulgaria remains indebted to those with pulmonary hypertension and severe lung diseases. The country lags significantly in the following: adopting innovative therapies, access to lung transplants, as well as home oxygen therapy.

MORE THAN A GAME: FIGHTING FOR BREATH

For the first time ever, Bulgaria took part in the European Lacrosse Championship, held from July 10 to 20, 2025, in Wrocław, Poland. But this was about more than just sports.

The national team played with purpose—proudly supporting the Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH). By raising their sticks, they also raised awareness for a rare and serious disease that deserves greater attention and solidarity.

The Bulgarian team —not only for their performance on the field but also for standing strong with the pulmonary hypertension community.

PATIENT WEBINAR "MYTHS ABOUT PULMONARY HYPERTENSION – MENTAL HEALTH"

The webinar was held on 21.05.2025. Dr. Lyubomir Dimitrov, an invasive cardiologist, Department of Paediatric Cardiology at the National Hospital of Cardiology and deputy chairperson of the Bulgarian Society of patients with Pulmonary Hypertension, spoke about the problems that doctors and patients with PH face. „All these patients should receive adequate medical care. We, I am talking about the doctors, the society, and the state, should provide them adequate treatment," the expert said.
A lecturer of the event was the psychologist Dr. Antonia Grigorova, who spoke more about the risk factors that affect the psychological state of patients with pulmonary hypertension. In addition, she spoke more about the risk factors that affect the psychological state of patients with pulmonary hypertension. She also offered a self-management program for patients with this rare disease, including how to build useful habits, how to solve problems, how to deal with anger, and how to communicate with family members.

BULGARIA PHA

EMPATHY WITHOUT BORDERS: HOW BULGARIA CELEBRATED WORLD PH DAY 2025

In a powerful demonstration of unity and awareness, the Pulmonary Hypertension Association (PHA) Bulgaria marked World Pulmonary Hypertension Day (WPHD) 2025 with a series of impactful events across gyms, conferences, and international forums. The message was clear: empathy is the first step to understanding, and no patient should feel alone.

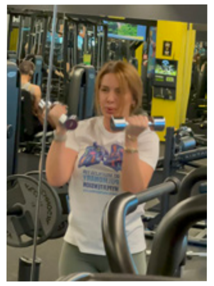
FROM FITNESS FLOORS TO ADVOCACY HALLS: RAISING AWARENESS WITH EVERY BREATH

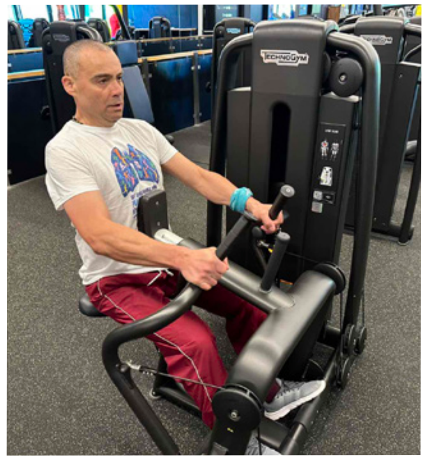
To mark 5 May, we partnered with Pulse and Fly fitness centres in Sofia to promote empathy and awareness for people living with pulmonary hypertension (PH).

Visitors participated in short breathing simulation challenges and spoke with our volunteers about life with PH.
Trainers and gym-goers shared messages of support for those living with rare lung diseases.

These events helped bridge the gap between the healthy public and the invisible daily struggles of patients with PH, reminding everyone that awareness begins with compassion.

The campaign was more than symbolic—it was experiential. Messages of solidarity poured in from participants who left with a deeper understanding of what it means to live with PH. The gym setting proved an innovative way to foster awareness and compassion in unexpected places.





SOLIDARITY IN THE RARE DISEASE COMMUNITY

PHA Bulgaria's message didn't go unheard. Several Bulgarian patient organizations extended heartfelt support, amplifying the campaign through their platforms. These included:

- Pulmonary Fibrosis Association Bulgaria
- Association of Kidney Disease Patients and Friends
- National Alliance of People with Rare Diseases
- Bulgarian Organization for People with Rheumatic Diseases
- Association of Patients Active in Healthcare

Their contributions reaffirmed the strength and unity of Bulgaria's rare disease community—a testament to the power of empathy across conditions.

CROSS-BORDER COLLABORATION: LEARNING AND SHARING IN FRANKFURT

Taking empathy global, PHA Bulgaria participated in the European PF Patient Advocate Forum in Frankfurt (24–27 April 2025), hosted by EU-PFF. While centered on pulmonary fibrosis, the event sparked important discussions that resonated with the PH community as well: delayed diagnoses, limited treatment access, and the emotional toll of chronic illness.

The forum created a vibrant space for idea-sharing and fostered promising new partnerships aimed at improving advocacy for rare lung diseases across Europe. The experience infused the Bulgarian team with renewed purpose and international support.

SCIENCE MEETS PATIENT VOICE: A STRONGER PRESENCE AT NATIONAL CONFERENCES

Partnering with the Pulmonary Fibrosis Association Bulgaria, PHA Bulgaria made waves at two major medical events:

- **Second BGBIP Symposium** *(4 April 2025, Sofia)*
Under the theme "Diagnostic and Therapeutic Potentials of Cryotechnique," this conference brought together interventional pulmonologists and medical researchers. This specialized symposium allowed us to engage with pulmonologists and interventional specialists on the patient experience with diagnostic procedures, especially lung biopsies. The joint booth highlighted patient perspectives on diagnostic procedures such as lung biopsies. Medical professionals welcomed the insight, with many emphasizing the growing need for patient inclusion in research design and clinical practice.

- **Fifth National Scientific Conference on Chronic Diseases** *(16–18 May 2025, Sofia)*
Focusing on chronic lung diseases, the conference was another platform for raising awareness. Our booth attracted researchers, clinicians, and students. We shared educational materials and patient testimonies about PH and PF. This joint initiative visibly demonstrated a unified patient voice in the respiratory field and promoted better understanding of rare lung diseases in the scientific community.

THE TAKEAWAY: UNITED IN EMPATHY

From local gyms to international stages, PHA Bulgaria's 2025 campaign showed that empathy is more than a feeling—it's a force for change. As patients and professionals come together, the rare disease community grows stronger, louder, and more visible.

PHA Bulgaria extends heartfelt thanks to PHA Europe and all partners for making this work possible. Together, we turn empathy into action and ensure that every patient voice is heard.

CHINA

WORLD PULMONARY HYPERTENSION DAY – SHARED VOICES, SHARED STRENGTH

This year, with the support of PHA Europe, we shared stories from PH patients around the world, bringing the Chinese PH community closer to the global conversation. Many found resonance: "I feel the same as her." Others expressed curiosity: "Why do they seem healthier than us?" Some offered heartfelt wishes: "Good luck to him (who is on the waiting list for a lung transplant)." Regardless of a country's level of development, misdiagnosis happens everywhere, connecting us as one family through shared challenges.

In China, the national centralized drug procurement program has lowered prices and expanded coverage for some patients, while others remain concerned about the effectiveness of generic medicines. Nationwide, equitable access to treatment remains a long-term challenge. In developed cities where access is better, mental health support has become a pressing need. Local patient groups have responded by organizing activities such as baking and handicrafts, offering comfort and connection to help relieve anxiety and sadness.

The photos from this year's event feature international PH awareness materials translated into Chinese, alongside warm moments of patients baking and crafting together — showing that care and solidarity truly cross borders.

CROATIA

MARKING PULMONARY HYPERTENSION DAY IN CROATIA: THE POWER OF UNITY, EDUCATION, AND SUPPORT

Every year, May is specially recognized in Croatia as the month for raising awareness about pulmonary hypertension (PH). This rare but challenging disease demands the collective strength of patients, families, medical professionals, and everyone involved in the fight against it. This year, our PH community came together for several unforgettable events that demonstrated how connected we are and how vital education and mutual support truly are.

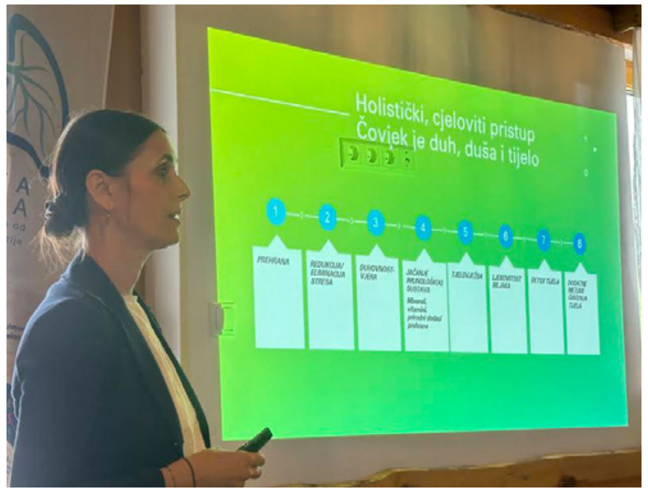
MAY 24: GATHERING AND LEARNING AT PLITVICE LAKES

The central event took place on May 24, in the stunning surroundings of Plitvice Lakes National Park. On that day, patients and their families gathered for an educational and social meeting. Pharmacist Sandra Pavić Drašković gave an engaging lecture on healthy nutrition, a key element in the daily support of PH patients. We learned how small changes in dietary habits can significantly impact overall health and quality of life.

After the educational part, we enjoyed a relaxed social gathering, and one of the most joyful moments was the **Paint and Breath** art workshop. Under the guidance of talented artist Mirjana Modrušan, we created beautiful images of the Plitvice Lakes — a symbol of our natural heritage and strength. This shared creative expression brought great joy and peace to everyone present.

MAY 25: „GET BREATHLESS FOR PH" RACE IN SABORSKO

The next day, the „Get Breathless for PH" race took place in Saborsko and partly along the Plitvice Lakes. Over 300 runners responded to the call to raise awareness of pulmonary hypertension and show support for patients. The race was both a physical challenge and an emotional event that reminded us of the importance of unity, support, and health awareness.



VIA ADRIATICA: 1100 KM WALKING WITHOUT BREATH FOR PULMONARY HYPERTENSION

Beyond local events, this year, we also realized an extraordinarily successful international project — **Via Adriatica: 1100 km Without Breath.** Tomislav and Charles, our brave walkers, dedicated this monumental feat to people living with PH in Croatia. They began their journey on Easter, April 20, and completed it on June 6, walking throughout May. To date, only 25 people have completed the challenging, yet breathtaking Via Adriatica trail.

Through the **GoGetFunding** platform, funds were raised for the association Plava krila (Blue Wings), making their adventure a direct support for our community. Throughout the journey, they shared photos, videos, and stories on social media, spreading awareness about pulmonary hypertension and encouraging understanding and empathy.

The project attracted significant media attention, and we even appeared on a TV program, once again emphasizing the importance of supporting PH patients and the need for education and collective action.

A STORY OF HUMANITY, STRENGTH, AND SUPPORT

All of these activities are more than just calendar events — they are living proof of how powerful community strength can be. Pulmonary hypertension often affects women, frequently disrupting their daily routines and complicating life plans, but together, we show that facing these challenges is not impossible.

Through education, creativity, sports, and solidarity, we are building a network of support that offers hope and inspiration to us all. Thank you to everyone who participated, organized, ran, painted, and walked for pulmonary hypertension — you are proof that together we can achieve more.

We invite everyone affected by this disease, along with their loved ones, to join us in future activities, because the power of unity and support truly changes lives.

MEDIA LINKS

https://www.facebook.com/share/p/1AafxcszEV/

https://www.mojportal.hr/magazin/bjelovarcanin-i-amerikanac-prehodat-ce-1100-km-svaki-korak-je-za-oboljele-od-plucne-hipertenzije/

[https://www.facebook.com/share/16PjLmHVHa/

https://ckzg.hr/2025/05/26/crveni-kriz-zagreb-uz-one-koji-ostaju-bez-daha-ali-ne-i-bez-podrske/

https://www.klikni.hr/aktualno/2025/06/06/hodali-48-dana-duz-hrvatske-obale-za-oboljele-od-plucne-bolesti/?fbclid=IwQ0xDSwKwMGRleHRuA2FlbQIxMQABHsoGc9K_QuMg_DJx3Xp_rnCmIRbBMT_yWfzP4hsAV2lhk6w656lXbk11Tbjh_aem_be9IHu9q4WC8tlQHASqvNw

https://www.mojportal.hr/magazin/conc-i-rooster-prehodali-1140-km-za-oboljele-od-plucne-hipertenzije-put-je-trajao-48-dana/?fbclid=IwQ0xDSwKwMX9leHRuA2FlbQIxMQABHgIOHrJ94LPcKS7ckr4iwIgMgZXzF9oPVzN9Yxl_MoBxQjATAH_d17I6v7es_aem_JdekLj7i56gMCYfUYIzCAw

https://www.facebook.com/share/1BpYr6mQHH/?mibextid=wwXIfr

https://hrvatskakucadisanja.hr/novosti/

CZECH REPUBLIC

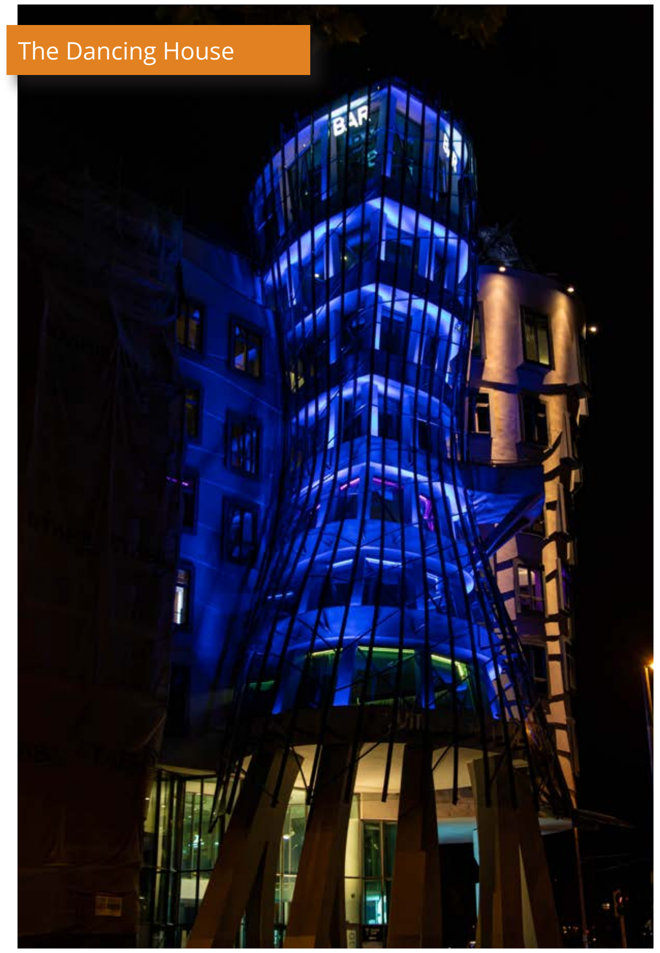
The gathering for World PH Day 2025 took place at Vítkov Hill in Prague and brought together patients, their families, members of our association, and employees of MSD s.r.o. - a major Czech biopharmaceutical company focused on research and development of treatments for serious diseases. As part of the awareness campaign, MSD illuminated their main building in the color blue and even displayed lungs as a symbol of PH on the building.

Several other landmarks across the Czech Republic were lit up in blue too, including: The Dancing House (Prague), Janáček Theatre (Brno), Husa na Provázku Theatre (Brno), Omega Shopping Centre (Brno), and Olomouc Town Hall (Olomouc).

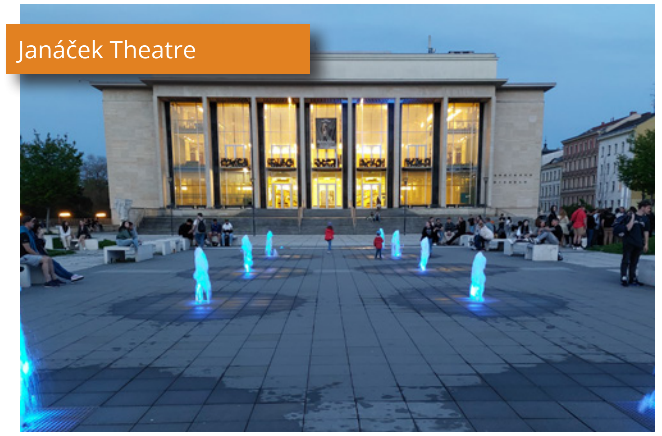
One of the activities during the event was a balloon exercise, which symbolized support for PH patients: healthy participants used straws to inflate balloons, simulating the experience of breathing with pulmonary hypertension. This activity aimed to raise awareness and understanding of the daily challenges faced by PH patients.


The MSD building


Omega shopping centre


The Dancing House


Husa na Provázku Theatre


Janáček Theatre


Olomouc Town Hall

GERMANY

FROM STRENGTH TO CREATIVITY: SABINE ROSSAT'S INSPIRING JOURNEY

In the quiet town of Kalbe/Milde, nestled in the heart of Saxony-Anhalt, Sabine Rossat, has transformed a personal battle into a powerful source of inspiration.

Since being diagnosed with pulmonary hypertension (PH) in 2019, a rare and serious lung disease, Sabine's life has changed dramatically. But instead of retreating, she leaned into creativity—and in 2024, opened her very own self-service hut: a charming little spot where locals and visitors alike can find her lovingly made crafts.

Her specialty? Handcrafted mugs, each one designed with care, warmth, and a touch of personality. They feature the zebra that highlighs the uniqueness and rarity of PH and was also in the forefront of thiy year's World PH Day Campaign.

But mugs are just the beginning—her hut also features homemade candles and other unique creations, making it a small but mighty symbol of resilience and artistic passion.

Sabine's story is more than just about crafts—it's about finding purpose and beauty despite life's challenges.

And indeed, through every mug and every candle, Sabine continues to pour out a little hope, one creation at a time.

HUNGARY

As every year, we have been preparing hard for World PH Day and a month full of awareness. We were delighted that this year's campaign featured patient stories. 3 of our fellow patients from Hungary shared their experiences of their PH diagnosis. The stories of patients from all over the world were also very touching, and our posts received a lot of views.

"10 év, 20 orvos, és végül egy sokkoló diagnózis 2006-ban. Van amikor PH."

Fiam születése után diagnosztizáltak pulmonális artériás hipertóniával, egy ritka, gyógyíthatatlan betegséggel. Küzdöttem, hogy gondozni tudjam a kisbabámat, mivel a tüneteimet összetévesztették a pánik betegséggel vagy a depresszióval. De a helyes diagnózissal, terápiával és az elszántsággal soha nem adtam fel. Harcoltam a családomért, és ma, 14 év pumpás terápiával később, jól vagyok, és segítek más pumpa használóknak mentorként.

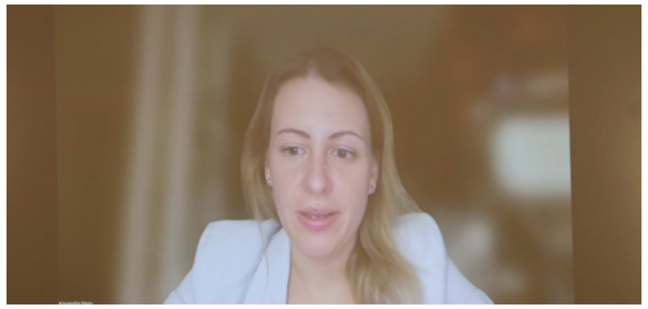
"Koraszülött voltam, és több betegségem is kialakult, köztük a pulmonális hipertónia. Születésem óta folyamatos oxigénterápiára volt szükségem. Egy hordozható koncentrátornak és a Tüdőér Egylet támogatásának köszönhetően végre járhattam iskolába. Jelenleg, büszkén szavalok verseket az országos betegtalálkozókon – mert még a PH-val is van hangom."

On April 26, 2025, we successfully hosted the National Meeting of PH Patients. We were happy that many people were able to participate, but we also thought with love of those who unfortunately could not manage to come. Fortunately, the recordings of the presentations were uploaded to YouTube, so everyone can recall/watch them.
https://www.youtube.com/@tudoervideo

Once again, we heard interesting and useful information on many topics. Not only our president Eszter Csabuda, but also the mayor of Zugló, András Rózsa, gave a short welcome speech. We were very happy to introduce ourselves to the mayor, because the association is headquartered in Zugló (District XIV), although we are a national organization. He promised that he would talk about us at the Zugló health roundtable forum, so that as many people as possible would learn about our disease.

The introduction was about modern PAH treatments in the lecture of Dr. Kristóf Karlócai, Chief Physician. Fortunately, despite the fact that PH is a rare disease, there are quite a few treatments available, and we can hope for an expansion of the range.

Next came Professor Dr. János Varga, who spoke about the importance of breathing exercises for pulmonary circulation. This was a kind of introduction to the final program point, the breathing exercises.



Afterwards, we listened to the touching personal story of Mrs. József Szalai, Katika, about how she faced this shocking diagnosis and how she learned to live with the disease.

PH has many forms, and some patients develop it due to lung diseases. In this regard, Dr. Alexandra Nagy spoke about pulmonary hypertension in the video of lung patients, as she was running the kilometers as a member of the Ultrabalaton team that runs around Lake Balaton.

We celebrated World PH Day, so we heard from Dóra Erdélyi about the current 2025 campaign, the importance of patient organizations, and which websites we can access reliable information from the Tüdőér Egylet and PHA Europe. We got to know the Bel Air Center and received help with registration.

Finally, Dr. Vera Kardosné Major gave us some exercises and we received a small booklet with exercises that we can do at home.

All present received a booklet that shows the excercises we practiced at our meeting.

AOP Health has prepared a travel guide for us, which contains useful tips that can help you if you want to travel as a PH patient.

Folders were also handed out about the Bel Air Center.

We ended the event with a light lunch and a chat! We hope everyone had a good time and found our presentations and booklets useful.

The weather in early May was not really favorable for our outdoor programs, but we finally managed to hold our awareness-raising event in the City Park on May 13th.

We participated in a Spring-Welcoming Literary Walk organized by the Zugló Health Development Office. The cardiovascular walking club meets once a month in the City Park, where we can listen to poems and interesting information about the authors while we walk a leisurely distance in the greenery. We were very lucky, as it had been raining in Zugló a few hours earlier, but by the time we left, the sun was shining brightly.

This time, we had the opportunity to talk about WORLD PH DAY, the symptoms of PH, and the importance of early diagnosis. We distributed informational materials to the participants.

We chose this poem to read because it expresses that even with a chronic illness, we should find unexpected joys amidst everyday challenges.

A Late Evening In May (extract)

It was late, I headed home, my soul
wrestling with thoughts of the day past,
I walked, along gardens and villas,
exhausted, sullen, downcast,
or was it my feet that carried me
dark branches looming overhead,
my two feet, two loyal servants
who by instinct my body led.

Suddenly a wave swept over me
on that late evening in May,
scents that hung heavy and dense
invisibly wafting away,
and in that sweet, exhaling darkness
the world adrift in vapors
surged toward me like an ocean of
lilacs, jasmine and acacias.

I lumbered slowly ahead,
tipsy, slightly wavering,
new seas sprang from the next garden,
new shrubs through the next railing,
and the scents permeated
my lungs, my heart, my mind,
I felt as though I'd grown wings
and left my weight behind.

How did I get home, I know not.
— My woes no fewer than before.
But since that day, I'd grown
to love life a little more,
amid work and troubles I await,
that it come, as I'm sure it might,
to brighten my weary moments,
some fortuitous delight.

Májusi éjszaka (részlet)

Késő volt, mentem haza, lelkem
az elmult nappal küszködött,
mentem, mogorván, kimerülve,
a kertek és villák között,
nem is én mentem, csak a lábam
vitt a fekete fák alatt,
két lábam, két hű állatom, mely
magától tudja az utat.

S egyszerre a májusi éjben
valami hullám megcsapott:
illatok szálltak láthatatlan,
sűrű és nehéz illatok,
a lélegző, édes sötétben
szinte párolgott a világ
és tengerként áradt felém az
orgona, jázmin és akác.

És részegen és imbolyogva
indultam nagylassan tovább,
s új tenger dőlt a szomszéd kertből,
új bokor az új rácson át,
s az illattól már illatos lett
tüdőm és szívem és agyam,
egész testem elnehezült
s azt érezte, hogy szárnya van.

Hogy értem haza, nem tudom már.
– A gondom ma se kevesebb.
De azóta egy kicsit újra
megszerettem az életet,
s munka és baj közt mindig várom,
hogy jön, hogy majd csak újra jön
valami fáradt pillanatból
valami váratlan öröm.

https://www.magyarulbabelben.net/works/hu/Szab%C3%B3_L%C5%91rinc-1900/M%C3%A1jusi_%C3%A9jszaka/en/82113-A_Late_Evening_In_May

We were also invited by the MSD office to raise awareness of pulmonary hypertension among their colleagues. We talked about the disease, presented the path to diagnosis, and the life with PH through personal stories. We presented our association in detail, talked about our World PH Day programs, and our future goals. The Hungarian Transplant Association also gave a presentation, and we discussed future collaborations with them.

We gave the interested parties a task: they had to reach the buffet by stairs and, in order to experience what a PH person feels every day, they were given a straw and a nose clip to do so. (Afterwards, they admitted that many of them couldn't take it anymore after the 1st floor.)

Our running ambassador Gyuri was also active. He completed 7 km in our association's T-shirt in not very favorable weather conditions to draw attention to pulmonary hypertension. He felt what it was like to gasp for breath, which PH patients often experience in their daily activities.

Press releases also drew attention to our national patient meeting and World PH Day.

On June 19th, our treating specialist Dr. Kristóf Karlócai summarized the information about the disease and treatments in the morning radio program. As those affected, our patients were able to talk about, among other things, how the diagnosis is usually made, how it can be processed, how it changes life, what difficulties the disease causes, how the association can help, why the association was established, and what its future goals are in addition to continuing its current activities.

We also mentioned that the disease is currently incurable and that although Hungarian patients have access to all available treatments, new therapies are also needed to continue on the path to making PH a well-managed chronic disease and ensuring that patients' quality of life is close to normal.

Eszter Csabuda –Tüdőér Egylet

www.tudoer.hu | *https://www.facebook.com/tudoer.egylet*

ISRAEL

RAMBAM PATIENT CONFERENCE: KNOWLEDGE, HOPE, AND PRACTICAL TOOLS FOR LIVING WITH A CHRONIC LUNG DISEASE

On Thursday, May 29, as part of PH Awareness campaign efforts, the Israel Association for Pulmonary Hypertension, together with the Rambam Health Care Campus in Haifa, hosted a special conference for patients living with chronic lung diseases, as well as for those undergoing evaluation for lung transplantation. The event brought together dozens of participants from across the country for a morning filled with enriching lectures, up-to-date medical information, and practical tools—all in one place.

Throughout the day, attendees heard from leading physicians and specialists in pulmonary Medicine, who spoke about the lung transplant evaluation process, respiratory rehabilitation, patients' rights, emotional support, and more. A strong emphasis was placed on providing practical strategies for managing advanced lung diseases, including innovative treatments and supportive technologies.

The conference was not only an opportunity to gain knowledge, but also a meaningful meeting point for patients, their families, and healthcare professionals. Personal and professional experiences were shared, strengthening the sense of support and community among participants.
Between sessions, guests enjoyed a complimentary lunch, offering a moment of refreshment and informal connection. Attendance was free of charge but required prior registration—highlighting the careful planning and genuine commitment to making quality information accessible to patients.

The conference was a powerful example of the importance of combining medicine, knowledge, and community resilience—and it left participants feeling newly empowered and hopeful for the future.

POST-TRANSPLANT MEDICATION AND LIFESTYLE: PRACTICAL WEBINAR EMPOWERS LUNG TRANSPLANT RECIPIENTS AND CANDIDATES

On Monday, April 21, 2025, a special webinar brought together over a hundred participants from Israel's transplant community for an informative and practical session focused on medications, supplements, and lifestyle considerations after lung transplantation.

The webinar, hosted by Lanshom – The Israeli Lung Disease Association and the Israeli Pulmonary Hypertension Association, in collaboration with the Pharmaceutical Association of Israel, was led by Dr. Ran Nisan of the clinical division of the Pharmaceutical Association.

Drawing from dozens of real questions raised by transplant recipients over the years, Dr. Nisan delivered a clear, structured, and accessible presentation designed to address common concerns and debunk persistent myths.

KEY TOPICS INCLUDED:
- When and how to take medications and how to safely integrate supplements
- Which supplements may be harmful to transplant recipients and which are beneficial
- Strategies to minimize side effects and avoid dangerous drug interactions
- Guidance on painkillers, sleep aids, nutrition, probiotics, and sun exposure

The session provided participants—lung, kidney, liver, heart, and bone marrow transplant recipients, candidates, and their families—with essential, up-to-date information in a supportive and welcoming format.

Held on Zoom and offered at no cost with prior registration, the event was part of an ongoing effort by patient organizations and medical professionals to empower transplant recipients with knowledge that supports long-term health and quality of life.

Feedback from participants emphasized the clarity and relevance of the content, with many expressing appreciation for the opportunity to receive expert advice tailored to their unique needs.

ITALY

At ICS Beethoven in Casaluce (CE), the spotlight shines on pulmonary hypertension.

“ASD PALLAVOLO CASALUCE AND AMIP ODV”

On May 5th, the world comes together to celebrate World Pulmonary Hypertension (PH) Day — a day that goes beyond medicine, beyond statistics, beyond definitions. It is a day that speaks of real lives, of struggling bodies, of weary hearts, of breaths that become daily battles. It is a day with a single purpose: to shine a light on a rare, invisible, and often forgotten disease.

Pulmonary hypertension is a progressive disease that affects the blood vessels of the lungs. A condition that reduces autonomy, freedom, and quality of life. But what hurts most is the time that passes without answers — a diagnosis that arrives late, when the damage is already advanced. Symptoms that are confused, ignored, or underestimated. Silent signals, often lost in the noise of a fast-paced life.

Yet behind every diagnosis are real people. Women and men, children and the elderly, who face an invisible challenge with courage every single day. This day is a strong and urgent call — an invitation to look deeper, a chance to stop and listen to those who have no voice.

It is a call to medicine: to promote training for general practitioners, to encourage timely referrals to specialist centers, and to recognize the signs of the disease before it’s too late.

It is a call to science: to continue advancing research, seeking innovative, sustainable, and accessible therapeutic solutions.

It is a call to politics: to place the health of rare disease patients at the center, investing resources, supporting orphan drugs, and guaranteeing social and employment protections.

Today is the time to look up.

World Pulmonary Hypertension Day teaches us that awareness is a collective responsibility. To learn, to speak, to share means saving time, energy, and lives. It means leaving no one behind and rejecting the idea that rarity equals insignificance.

Everyone living with pulmonary hypertension has the right to early diagnosis, appropriate care, psychological support, and recognition.

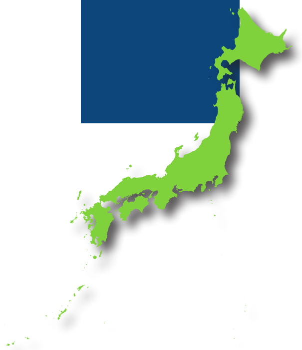
Because only together can we transform silence into listening.
Only together can we turn fragility into shared strength.
Only together can we build a world that is fairer, more inclusive, and more humane.

But let’s also talk about how this beautiful day came to be. A special thank-you goes to our sports association “Pallavolo Casaluce” and to AMIP (Italian Pulmonary Hypertension Patients Association), represented by our coach, Lello.

A wonderful day of Sport, Fun, Inclusion, Reflection, and Hope.

Together, we can!

Maria T.
Gioia M.



JAPAN

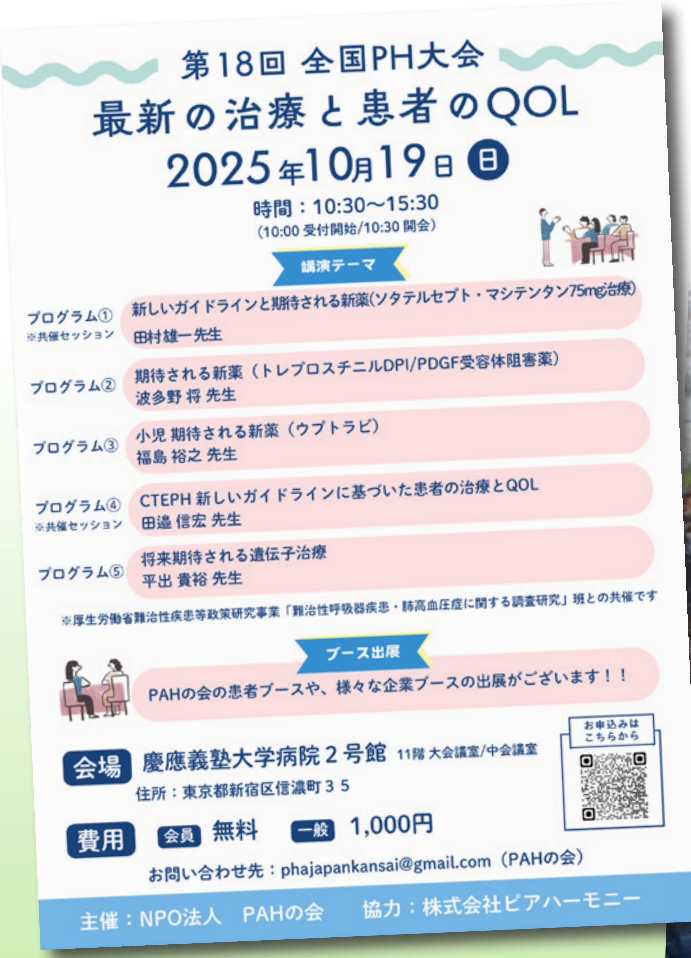
The global campaign of "Sometimes, it's PH" has demonstrated that PH patients face the same challenge everywhere. Japan is no exception.

Kiyoko told her story that started in 2002. She was then first diagnosed with pulmonary arterial hypertension (PAH). Years later, in 2015, her diagnosis was updated to chronic thromboembolic pulmonary hypertension (CTEPH). Despite the challenges, Kiyoko manages her condition with oral medication and oxygen therapy.

Now, she dedicates her time to supporting other patients, offering hope and understanding from her own experience. Her quiet strength and commitment to helping others shine through every day.

The Japanese association is very busy organizing the 18th National PH conference that will take place on the 19th of October in Tokyo.

PHA Japan and the Japanese Circulation Society is also working on publishing the Lay Summary of Pulmonary Hypertension Guidelines in Japanese that will help patients to better understand this rare disease.



第18回 全国PH大会
最新の治療と患者のQOL
2025年10月19日 日
時間：10:30〜15:30
（10:00 受付開始/10:30 開会）

講演テーマ

プログラム① ※共催セッション　新しいガイドラインと期待される新薬(ソタテルセプト・マシテンタン75mg治療)
田村雄一先生

プログラム②　期待される新薬（トレプロスチニルDPI/PDGF受容体阻害薬）
波多野 将 先生

プログラム③　小児 期待される新薬（ウプトラビ）
福島 裕之 先生

プログラム④ ※共催セッション　CTEPH 新しいガイドラインに基づいた患者の治療とQOL
田邉 信宏 先生

プログラム⑤　将来期待される遺伝子治療
平出 貴裕 先生

※厚生労働省難治性疾患等政策研究事業「難治性呼吸器疾患・肺高血圧症に関する調査研究」班との共催です

ブース出展

PAHの会の患者ブースや、様々な企業ブースの出展がございます！！

会場　慶應義塾大学病院２号館　11階 大会議室/中会議室
住所：東京都新宿区信濃町３５

お申込みはこちらから

費用　会員 無料　一般 1,000円

お問い合わせ先：phajapankansai@gmail.com（PAHの会）

主催：NPO法人　PAHの会　　協力：株式会社ピアハーモニー

LATVIA

On May 9, 2025, in honor of **World Pulmonary Hypertension Day**, Pauls Stradiņš Clinical University Hospital hosted the **Oxygen Festival, which was attended by 135 participants.** The event was led by **Ieva Plūme**, Chairperson of the Board of the Pulmonary Hypertension Society. **Dr. med. Dace Žentiņa**, a Board member of Stradiņš Hospital, gave a warm opening speech.

During the session **"Exercise and breathe with a physiotherapist,"** physiotherapist **Līna Puga** taught the audience exercises to improve well-being in daily life and provided individual consultations. Our social mentor, **Inga Zonberga**, was always available for conversations with participants. Additionally, a tactile and informative session on discrimination against people with disabilities was conducted by **Ivars Balodis**, Head of the association of disabled people and their friends "Apeirons," as well as **Liena Eisaka**, the communications manager of "Apeirons".

In a new format for our association – the **World Café** – festival participants discussed hobbies and future dreams, encouraged each other, and shared experiences on improving emotional health. The World Café moderators were Pulmonary Hypertension Association representatives **Linda Romanovska, Inga Zonberga, Līna Puga,** and **Arta Krūze**.

Līna Puga, physiotherapist, stated: "The physiotherapist's visit in a consultation format seemed to work well; we could both understand the patient's problem and provide advice. The World Café was a fantastic idea because people opened up, found common ground, and helped and encouraged each other – like in group therapy."

Throughout the day, medical assistants **Aiga Brazauska** and **Ilze Pūķe** performed over 100 express health tests, as there was significant interest in free tests from seniors, people with disabilities, hospital staff, and other interested individuals. Measuring oxygen saturation in the body and trying out oxygen therapy was available at the information booth of SIA "Miega slimību centrs".

Ieva Plūme gave several interviews to the media about pulmonary arterial hypertension, the severity of the disease and the need for earlier diagnosis, the Oxygen Festival's progress,

health literacy, and the necessity to educate seniors and people with disabilities about discrimination, as well as how to recognize it, and how to promote accessibility.

The festival organizers extend their gratitude to all staff and festival volunteers for their contribution and endurance: project manager **Marta Augucēviča**, event concept author Ieva Plūme, PHA representatives **Inga Zonberga, Linda Romanovska, Līna Puga**, and volunteers – **Ieva Arāja, Zane Lazdiņa, Arta Krūze**, and **Marks Plūme**! A special thanks to Pauls Stradiņš Clinical University Hospital for hosting and providing hospitality for the third Oxygen Festival!

Arta Krūze, Oxygen Festival volunteer, shared: "The Oxygen Festival was more than just an event – it was a moment of inspiration. For seniors and people with disabilities, it was an opportunity to check their health, learn about the association's work, and simply be together. I was touched by the moment when people wrote their dreams on paper – such a seemingly small step, yet so significant."

Environmental accessibility for people in wheelchairs was ensured at the event, with signs indicating event proceedings and the program. At registration, each interested person received information about the activities, and we explained the queueing order for express tests. Sign language interpretation was provided for people with hearing disabilities during the general part of the event, along with support for health tests and consultations.

This year, the World Pulmonary Hypertension Day 2025 event was supported by **Pulmonary Hypertension Association Europe, SIA "Hipnos"**, biopharmaceutical company **"Gossamer Bio Ltd.,"** and **Skrīveru Pārtikas Kombināts**.

NIGERIA

WORLD PULMONARY HYPERTENSION DAY 2025 EVENT ORGANIZED BY CARDIAC COMMUNITY ADVOCACY AND SUPPORT INITIATIVE

On May 12th, 2025, A Pulmonary Hypertension (PH) Awareness Event was held to commemorate World Pulmonary Hypertension Day. The theme was 'Sometimes, It's Pulmonary Hypertension'.
Organized by Cardiac Community the event focused on increasing public and medical awareness of Pulmonary Hypertension, a frequently underdiagnosed condition in Nigeria.
The program brought together healthcare professionals, advocates, medical students, and the public to deepen understanding of PH symptoms, management strategies, and the critical importance of early detection. We welcomed 107 participants. The opening speech was delivered by Mr. Agbaraojo.
First Dr. Oyewole Kushimo (Consultant Cardiologist, Lagos University Teaching Hospital) talked about Understanding Pulmonary Hypertension.
Next speakers were Dr. Peter Igoche (Pediatric Cardiologist, Limi Children's hospital, Abuja) and Dr. Temitope Quaye (Hematology Department, Lagos University Teaching Hospital (LUTH), Idi-Araba, Lagos) . Then Ayotunde Omitogun, Founder of Cardiac Community, shared her personal journey living with PH in Nigeria, underscoring the importance of advocacy and support networks.

The event was concluded with an Interactive Q&A Session where participants could ask specific questions, clarify doubts, and engage directly with the speakers.
Two national media outlets: The Guardian Nigeria and Punch Newspapers reported about the event. We are proud that the Social Media Reach for WPHD Campaign was over 30,000 views on all platforms.

OBJECTIVE OF THE EVENT

- Raise awareness of PH symptoms, risk factors, and management
- Highlighting the intersection of pulmonary hypertension and sickle cell disease in Nigeria, where SCD prevalence is highest globally.
- Promote early detection, timely diagnosis, and appropriate treatment

'SOMETIMES IT'S PH' CAMPAIGN

WPHD as a global awareness campaign unites all PH patients across the globe. Mary and Ayotunde from Nigeria share their personal journeys with PH, joining patients worldwide in expressing the same feelings of fear and anxiety caused by misdiagnoses and dismissal, as well as the relief that comes with finally receiving a correct diagnosis.
Mary recalls how years of breathlessness and fatigue, often mistaken for asthma, made school life difficult. Only after a right heart catheterization did she finally receive the correct diagnosis of pulmonary hypertension. Today, she focuses her energy on writing and creative work, finding new ways to live fully.
Ayotunde, born with a congenital heart defect, sought surgery more than a decade ago but was instead diagnosed with severe pulmonary hypertension—a disease she had never heard of and never imagined could result from her heart condition. Her story reflects the challenges of delayed diagnosis and the urgent need for greater awareness in Nigeria.

NORTH MACEDONIA

This year, we continued a heartfelt tradition that has been part of our association for over a decade. In honor of all those living with Pulmonary Hypertension (PH), and in memory of those who have lost their courageous battle with the disease, we organized a meaningful day filled with movement, music, and togetherness.

The day began with our annual **10km awareness run**, drawing in participants of all ages and backgrounds. With every step taken, we celebrated the strength of patients living with PH and honored those we've lost. The energy, determination, and sense of unity among the runners was truly inspiring — a powerful reminder that our association stands together in the fight against this challenging condition.

As the evening approached, we shifted the rhythm from running to music, gathering at a local bar for a **small but vibrant concert**. The atmosphere was electric, with everyone proudly wearing our signature **"Get Breathless" shirts** — a symbolic gesture of empathy for those who live each day battling shortness of breath and other symptoms of PH. The shirts weren't just attire; they were a message. A call to raise awareness and show support.

This event is more than just a run or a concert — it's a reflection of over ten years of commitment, love, and advocacy. We're proud to be part of a community that continues to show up, speak out, and support one another, year after year.

We thank everyone who participated, donated, or simply helped spread the word. Together, we're making a difference — one step, one song, and one story at a time.

NORWAY

At the world PH day, we attended a meeting with the Coalition of Rare Diseases in a round table conference in Oslo.

The meeting was to advocate for and increase the understanding and availability of treatments for rare diseases with advanced therapies (ATMP) and other types of precision medicine.

Proffessionals and patients from the main University Hospitals, the central organisations for the main disability organisations(FFO), Medical companies (Roche, MSD, Novartis, Sanofil), and Coalition of rare diseases and patient representatives, attended the meeting.

The goal of the meeting was to increase the cooperation between the private and public sector to make precision medicine more available for patients with rare diseases.
There were two main goals/objectives for the conference: one was to make access faster for patients with rare diseases to clinical studies in Norway, and the other was to gain faster access for patients with rare diseases to international studies.

Another goal was to connect these groups from public health, patient organisations, and industry and authorities, to get to know each other and know about each other, so that challenges and possibilities could be addressed.

Some national and international cooperations for paediatrics and cystic fibrosis fields were addressed with inspiring patients histories.

Ann-Kathrin Bruheim
PAH Norway

POLAND

WORLD PULMONARY HYPERTENSION DAY IN POLAND

For years, Poland has been trying to make information about our disease public. Unfortunately, we notice that many doctors are unable to diagnose the disease, and patients go to the hospital too late. That is why we are trying, with all our might, to speak loudly about pulmonary hypertension. We want to make our presence known on social media.

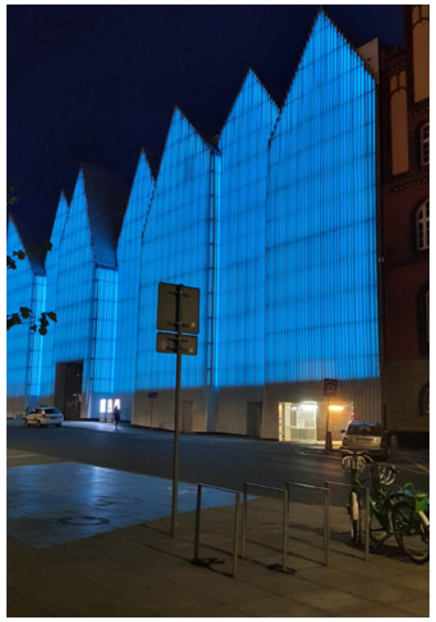
This year (like in previous years), we asked cities to light up their facilities in blue. Many cities joined the campaign. In the evening, some facilities lit up in blue in a gesture of solidarity with the sick. Our association went to the city of Bielsko Biała to stand on the bridge at 8 p.m., which was blue that day especially for us.

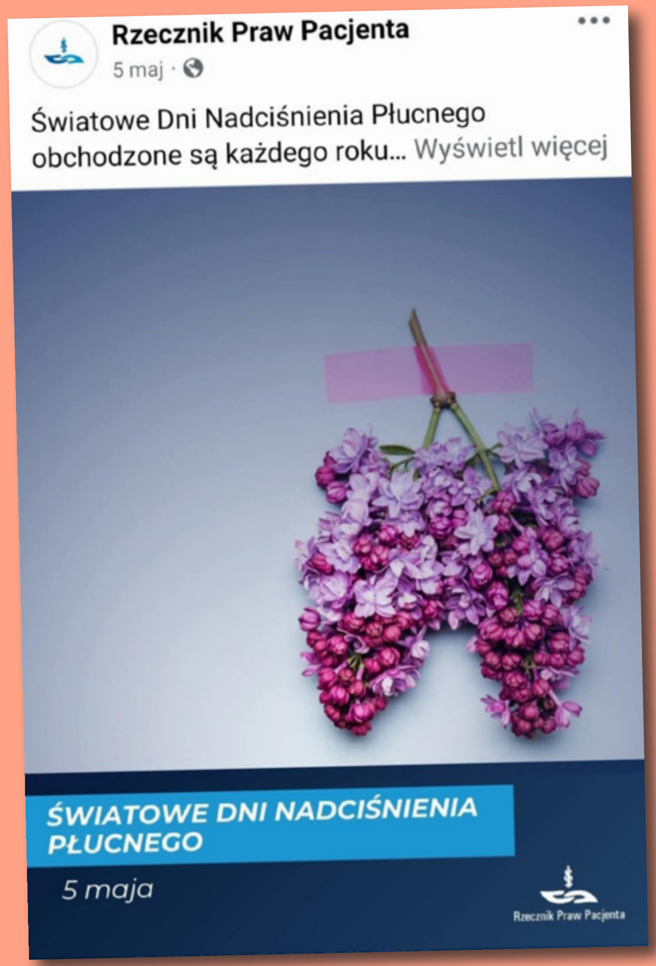
We tried to get many important people to write about us. The Patient Rights Ombudsman, Cardiologists, our doctors, our hospitals, city councilors, and cities joined the campaign. Our friendly associations, editors, who, at our request, wrote or shared our posts, educating the society at the same time, joined the campaign.

On the radio, at high noon, there was a programme dedicated to our disease, where the editor read information about pulmonary hypertension for a long time. In the city of Wągrowiec, in the cinema for a whole week, before each film screening, a board about the disease was shown. On the occasion of World PH Day, the car company AGP Polska donated water bottles with the association's logo. During the photo session in car showrooms, we told the employees about our disease.

On this important day for us, we signed an agreement with the badaniakliniczne.pl platform, so that our patients can have very quick access to new clinical trials, especially when the patient also has other diseases.

We also started a cooperation with the writer Kinga Fukushima from Poland, who has been living in Japan for years. Mrs. Kinga wrote a great book „Pozbawieni Oddechu", where the main character suffers from pulmonary arterial hypertension. Mrs. Kinga asked our association to review the book before it was published.

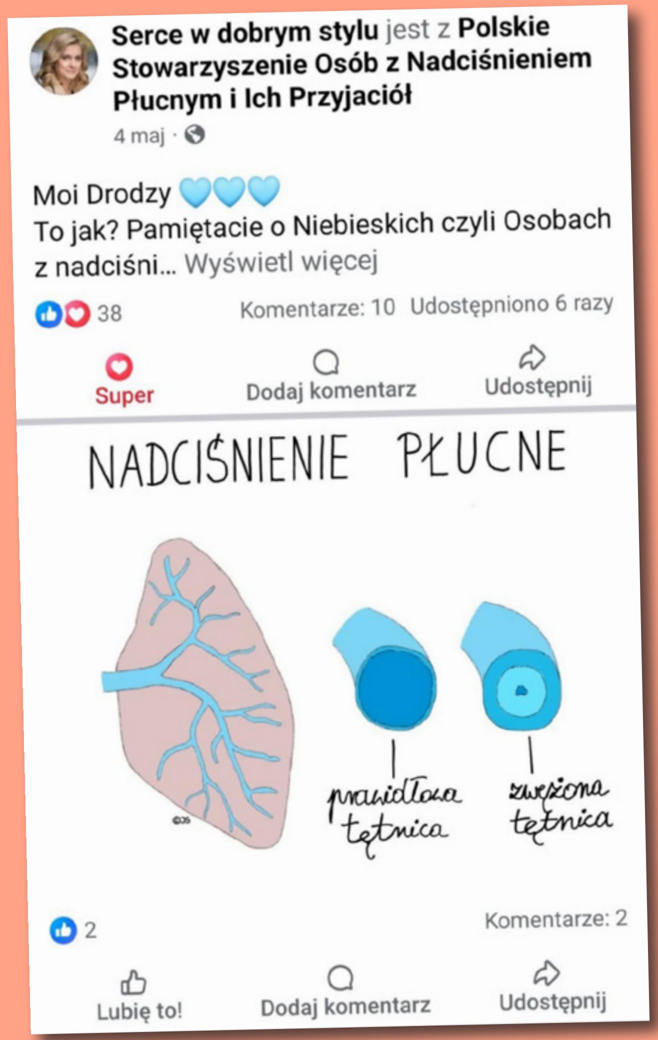




Rzecznik Praw Pacjenta
5 maj ·

Światowe Dni Nadciśnienia Płucnego obchodzone są każdego roku... Wyświetl więcej

ŚWIATOWE DNI NADCIŚNIENIA PŁUCNEGO
5 maja



Serce w dobrym stylu jest z **Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół**
4 maj ·

Moi Drodzy 💙💙💙
To jak? Pamiętacie o Niebieskich czyli Osobach z nadciśni... Wyświetl więcej

38 Komentarze: 10 Udostępniono 6 razy

Super Dodaj komentarz Udostępnij

NADCIŚNIENIE PŁUCNE

2 Komentarze: 2

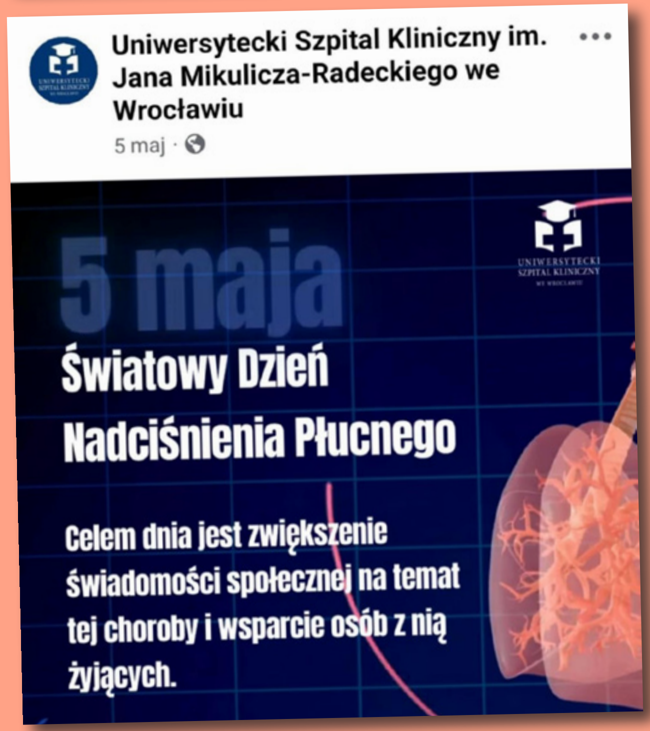
Lubię to! Dodaj komentarz Udostępnij

Długo i Szczęśliwie
5 maj ·

🦋Kiedyś choroba moda kobiet, dziś coraz częściej diagnozowana także... Wyświetl więcej

Informacje o tej witrynie

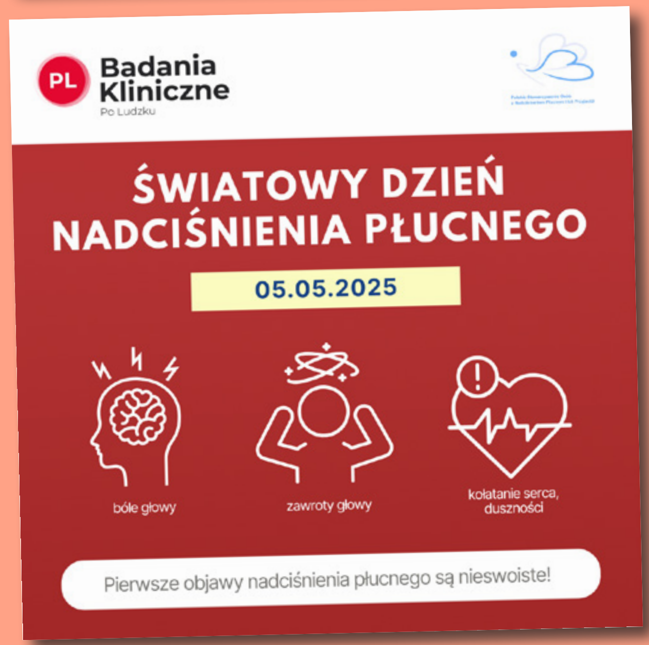
youtube.com
Tętnicze nadciśnienie płucne: kiedyś choroba młodych kobiet, coraz częściej także osób stars...



Uniwersytecki Szpital Kliniczny im. Jana Mikulicza-Radeckiego we Wrocławiu
5 maj ·

5 maja
Światowy Dzień Nadciśnienia Płucnego

Celem dnia jest zwiększenie świadomości społecznej na temat tej choroby i wsparcie osób z nią żyjących.



Badania Kliniczne Po Ludzku

ŚWIATOWY DZIEŃ NADCIŚNIENIA PŁUCNEGO
05.05.2025

Pierwsze objawy nadciśnienia płucnego są nieswoiste!

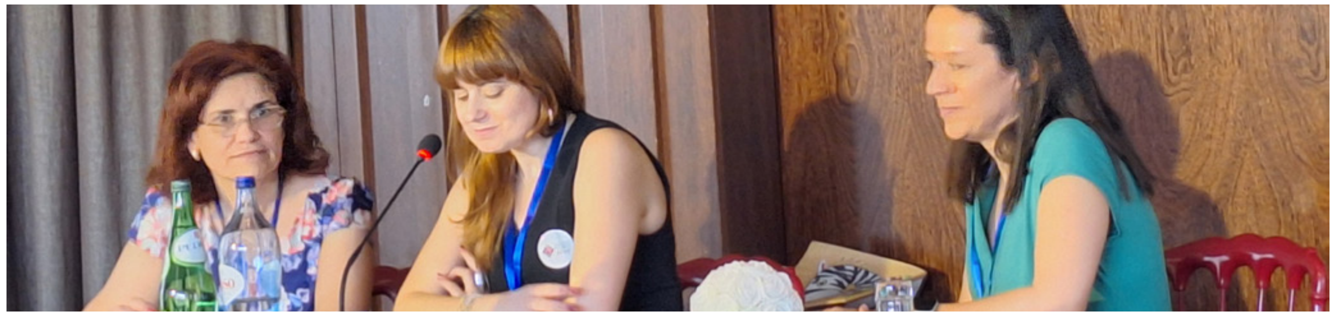
PORTUGAL

United in the "Battle" for PH – A Weekend of Connection, Awareness, and Hope

The weekend of May 17–18 began with a warm welcome in the town of Batalha (meaning Battle), where each participant received a folder containing informative literature, the full weekend program, and a piece of a puzzle. This puzzle served as an engaging icebreaker—each piece contributing to the construction of our WPHD (World PH Day) poster. The activity symbolized the power of unity: that only by working together can we build something meaningful and strong. It reminded us that every person plays an essential role in the fight against Pulmonary Hypertension.

Under the slogan United in Batalha/Battle for PH, the event brought together patients, families, friends, and healthcare professionals from five of Portugal's PH reference centers.
The event was a remarkable success.

Key highlights included the presentation of two insightful studies: one on PH literacy in Portugal, and the other on the impact of PH on patients' lives. A heartfelt conversation between our President and author Cristina Terencio about her book offered comfort and inspiration. Cristina generously donated all May book sales to the association in support of our work.



A communal lunch gave participants the opportunity to relax, chat, and truly connect. That evening, we lit up the streets of Batalha with a vibrant neon walk, led by an athlete from the local sports club, an unforgettable moment of solidarity and visibility. Day two continued with more health-focused talks, another group walk, and a visit to the historic Batalha Monastery. A final lunch was held, where each participant received a souvenir, and PH patients were presented with a small but meaningful gift.

The feedback has been overwhelmingly positive—from attendees and those following along through the growing media attention surrounding PH. The excellent collaboration between the association and healthcare professionals was also widely recognized. Strengthening and improving this partnership has been a long-standing goal, and we believe this event brought us closer than ever, reinforcing mutual trust and confidence in our mission.

Media & Awareness Initiatives in May

Several articles were published in health magazines and newspapers, both in print and online. Two television reports on national news were featured, a highlight in our PH awareness efforts.

Launch of “Ambassador of Hope” Programme

Our long term project “Ambassador of Hope” was soft-launched at WPHD. This programme is meant to empower patients, families, and healthcare professionals to become active advocates on a more regular basis for PH awareness. The participants are now being organized into three regional groups,- North, Centre and South,- each one aligned with the PH reference centers in their area. Their tasks include local awareness campaigns, fundraising, and event participation in community events. This ensures that awareness efforts are spread across the entire country, including less populated and rural areas, where visibility and access are often limited. The iniative has been met with great enthusiasm and strong attendance, and is already showing a meaningful impact.

ROMANIA

In May 2025, there were two events for the Romanian Association:

MAY 16TH - HTAP CONNECT

On May 16, a meeting between patients, doctors, authorities, and media representatives called „PHA Connect” was organized. The meeting took place in Bucharest.

Representatives of the National Health Insurance House, leaders of PH centers in Romania, representatives of the Association of Patients with Chronic Diseases in Romania, and the media responded to the organizers’ invitation.

The topics discussed were related to patient access to treatment and monitoring, early diagnosis possibilities, and PH in children.

Another important point was the presentation of the results of the study on the socio-medical needs of PH patients in Romania, conducted by COPAC and the PH patient association.

A deeply moving moment was the story of the first PAH patient present at the event, which was listened to with emotion by all those present.

The end of the day was reserved for discussions with patients, the presentation of special cases, and plans for organizing new meetings in cities where PHT treatment centers operate in Romania.

MAY 29TH - AER LA INALTIME

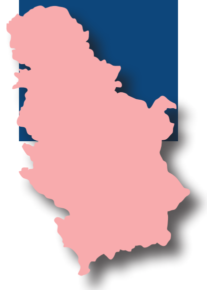
The AER project—Effective Access to Healthcare System Resources for Patients with Pulmonary Arterial Hypertension—is an initiative of the Romanian Association of Pulmonary Hypertension Patients. The project aims to enhance the diagnosis process, improve access to innovative therapies, and promote sustainable care for patients with pulmonary arterial hypertension (PAH).

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

Just as the right equipment is essential for setting out on a mountain trail, patients with pulmonary arterial hypertension need the right support, tools, and resources. The exhibition used the symbolism of mountain trails as a metaphor for the struggle for a normal life and equitable access to medical care.

„At over 8,000 meters in the Himalayas, thin air and extreme exertion are part of a conscious choice to take on a challenge. But here, at sea level, these difficulties can be a daily reality for other people. For patients with pulmonary hypertension, climbing a few steps can be equivalent to climbing a peak. These people climb their own Everest every day, in silence. I believe that, beyond empathy, their suffering, which is often invisible, requires real action and concrete support," said Alex Găvan, high-altitude mountaineer and collaborator on the AER project.

He emphasized to the Health Committee the importance of early diagnosis, access to modern treatments, and ongoing support.



SERBIA

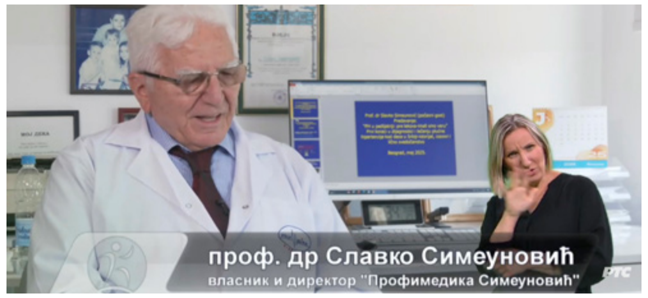
Belgrade marks World Pulmonary Hypertension Day and the 10th Anniversary of PH Serbia Association on May 26, 2025, hosting a remarkable conference dedicated to pulmonary hypertension (PH), symbolically marking both World Pulmonary Hypertension Day and PH Serbia's anniversary. The event gathered around 50 attendees from Serbia and the surrounding region, making it one of the most significant gatherings focused on this rare and complex disease.

Distinguished medical experts spoke at the event and were among the honored guests, including Prof. Dr. Slavko Simeunović, Prof. Dr. Arsen Ristić, Dr. Luka Babić, cardiac surgeon, and Prof. Jovan Matijašević, along with many others, whose presence enriched the event and contributed to the comprehensive scientific program.

A significant portion of the conference was devoted to innovative therapies, as well as the exchange of knowledge and experience in diagnosing and treating pulmonary hypertension. Special emphasis was placed on a multidisciplinary approach and the everyday clinical challenges that healthcare professionals face.

Guests from various parts of Serbia and the region were warmly welcomed as esteemed friends of the PH Serbia Association, which, thanks to the understanding and support of its donors, was able to host such an important event.

In addition to celebrating major anniversaries, this conference, once again, demonstrated the strength of unity and dedication in the fight against pulmonary hypertension.



SLOVAKIA

PHA Slovakia has been actively involved in the campaign for World PH Day this year. We were already actively preparing for the campaign in April. We published invitations to activities on social networks and athletes also supported us by participating in three running competitions.

The Rare Diseases Association, with which we have been cooperating for several years, prepared a podcast with President of the Slovak Society of Cardiology Milan Luknár on the issue of PAH. At the end of April, we launched a campaign on social networks using common graphics from PHAE.

On April 29, we prepared a press conference at the National Institute of Cardiovascular Diseases in Bratislava. The chairwoman Iveta Makovníková reported on the activities over the past 15 years. However, a hot topic was the need for innovative treatment for patients with PAH. Specialists in the treatment of PH, the head of the institute, doc. Eva Goncalvesová and President of the Slovak Society of Cardiology Dr. Milan Luknár, also spoke about these issues. For patients with PAH, this treatment is extremely important for a better quality of life and its prolongation. The last option is lung transplantation, but there are still few donors. The head of the University Hospital in Bratislava, Dr. Marta Hájková, head of the Center for Pre-Transplantation Preparation, spoke about lung transplantation as the last option of treatment. The output from this press conference was published in several public media.

On the 15th anniversary of the association's founding, the opening of the traveling exhibition *Let's Breathe Together* took place, which followed up on wall calendars distributed to selected specialist clinics in Slovakia. The aim of the exhibition is to spread awareness about PAH and find people who still do not have a correct diagnosis. The project was prepared by ZPPH in cooperation with the Rare Diseases Association. The exhibition will travel to Slovak hospitals until the end of 2026.

On May 15th, our runners took part in the 375 km long Vltava run relay race wearing *Get breathless for PH* T-shirts with portraits of patients on their backs. In addition to this run, they also represented us at *Wings for life* and *Urban* challenge.

The main event for World PH Day was the long-term project „I will stand up for you", in which we involve the general public. This year, we held the ninth annual symbolic climb to the mountain peaks in Slovakia. The climb to Veľký Javorník (1072 m) took place in the Slovak-Moravian Carpathians. Despite the rain and wind, 111 tourists of various age categories took part in the climb, starting from the young age of 1.5 years old. On the evening of the climb, an information seminar was traditionally held, which, this time, was dedicated to the activities of the association over the past 15 years. Lukáš, a PAH patient, who is waiting for a heart and lung transplant, spoke very emotionally about his desires. We also celebrated his 30th birthday.

SLOVENIA

REPORT ON EVENTS MARKING WORLD PULMONARY HYPERTENSION DAY

Pulmonary Hypertension Association of Slovenia organized an event on May 12, 2025 at Slovenski trg, Kranj. The event Every Breath Counts aimed to raise public awareness about pulmonary hypertension – a rare but serious disease that significantly impacts patients' quality of life. It took place in the city center of Kranj, between 1 PM and 6 PM, offering visitors the opportunity to:

- learn about the symptoms of the disease (shortness of breath, fatigue, dizziness),
- talk to doctors, patients, and members of the association,
- experience a simulation of breathing as a person with pulmonary hypertension through a modified six-minute walk test.

The event was supported by medical experts from the University Clinic Golnik:

- **Assoc. Prof. Dr. Boštjan Rituper**, **MD**, specialist in pulmonology
- **Asst. Prof. Dr. Barbara Salobir**, **MD**, specialist in internal medicine
- **Asst. Dr. Polona Mlakar**, **MD**, specialist in internal medicine
- **Anja Ilovar Bezjak, MD**
- **Andraž Jug, MD**

Through an interactive approach, we increased public recognition of the disease and encouraged reflection on the importance of early symptom detection. The event was well attended and received media coverage, further amplifying its impact.

The Pulmonary Hypertension Association of Slovenia participated in a free public health event organized by the Health Promotion Center of the Ljubljana Health Center on May 19, 2025. The event featured participation from various healthcare institutions and professionals offering:

- consultations on healthy lifestyles,
- preventive measurements and tests (blood pressure, blood sugar, etc.),
- individual advice tailored to different age groups.

Our presence focused on:

- raising awareness about pulmonary hypertension,
- engaging in discussions with visitors about symptoms and diagnosis,
- conducting an experiential simulation of breathing with "PH lungs" (using a nose clip and straws),
- encouraging the healthy population to understand the limitations faced by patients.

This event enabled us to extend our message to a broader audience, reaching people of all generations. By being part of a larger public health initiative, we contributed to greater recognition of pulmonary hypertension, even among those previously unfamiliar with the disease.

Šestminutni test hoje smo izvajali tudi danes v
📍Cukrarna

Zakaj?
Ker na ta način splošni javnosti najlažje približamo izzive, s katerimi se soočajo bolniki s pljučno hipertenzijo.
Vsak vdih šteje. In tega se zaveš šele takrat, ko ne moreš zares vdihniti s polnimi pljuči.

CONCLUSION

Both the organized event in Kranj and our participation in the broader public health initiative in Ljubljana were crucial to fulfilling the association's mission: **awareness, education, patient support, and increasing understanding of the disease in society.**

Through direct engagement with the public and the support of medical professionals, we successfully presented pulmonary hypertension, its symptoms, and the challenges patients face — with the ultimate goal of promoting earlier detection and faster intervention.

MEDIA OUTREACH IN MAY 2025

In addition to organizing and participating in awareness-raising events, the Pulmonary Hypertension Association of Slovenia was highly active and remarkably successful in media engagement throughout May.

We appeared in various national and local media, including:

- Television and radio broadcasts,
- Print and online magazines,
- Collaborations with social media influencers.

Our television and radio appearances were designed as in-depth, advisory-style conversations, providing not only medical insights but also personal experiences and emotional support. These segments allowed for interactive participation from viewers and listeners, who could call in or submit questions, making the dialogue more meaningful and engaging.

Several influencers amplified our key messages by sharing our content across social media platforms, significantly increasing our visibility and reach. This widespread media presence helped us engage a large and diverse audience, raising public awareness of pulmonary hypertension and improving the general understanding of the disease. Thanks to this strong media presence, we succeeded in delivering our mission to educate, inform, and support – not only through events but also through the power of public communication.

JONUKA400 – One Breathless Mission Succeeds: Jona and Luka Kobler Set (Unofficial for now) Guinness World Record

After 102 hours and 27 minutes of uninterrupted sailing, sixteen-year-old **Jona Kobler** and her father Luka Kobler have broken the **Guinness World Record** for the longest distance sailed by a double-handed dinghy crew – without external assistance and without setting foot on land. From Tuesday morning to Saturday afternoon, the duo covered **347 nautical miles** aboard their Beneteau First 14 SE, surpassing the previous record of **335 nautical miles**, set in 2021 by Uroš Kraševac and Maruša Močnik.

"We had an incredible few days on the boat. We were well organized, coordinated, and time flew by. Our goal was clear: to do something that held meaning – for us, for others, and for the message we wanted to share," said Jona Kobler at the conclusion of the voyage.

More Than Just a Record

The JONUKA400 – One Breathless Mission carried a powerful symbolic message. The Koblers dedicated their feat to raising awareness about **pulmonary arterial hypertension (PAH)** – a rare, life-threatening disease that leaves patients breathless, even with minimal exertion.
Their days at sea brought this reality to life in a tangible way. Prolonged periods of calm winds forced them to sail longer than expected, with progress coming slowly – a fitting metaphor for those living with PAH.

"Patients with pulmonary hypertension face their own kind of ,calm' every day," explained **Tadeja Ravnik**, president of the Slovenian Pulmonary Hypertension Society. *"The disease robs them of breath – a condition that can only be partially alleviated with timely diagnosis and proper treatment. It often makes it difficult to pursue even the simplest life goals."*

A Story of Connection – And What Comes Next

For Luka Kobler, the mission was about far more than a world record:

"What continues to amaze me is how many people helped create this beautiful, inspiring story. It might sound strange, but I experienced the whole challenge as the ultimate adventure. And this success – it's not just ours, it belongs to the entire team."
But the journey doesn't end here. **The JONUKA400 project – One Breathless Mission** will continue in fall 2025, when former record-holder **Uroš Kraševac** takes on the legendary **Mini Transat**, a solo transatlantic race sailed in tiny 6.5-meter boats. Alone at sea, with no advanced navigation or communication systems, each sailor must rely entirely on their own skills and determination.

The Breathless Mission Lives On

The legacy of JONUKA400 is a story of courage, collaboration, and resilience. And as it continues, its mission remains clear:
to raise awareness about pulmonary hypertension – a disease that takes your breath away, but not your will to live.

SPAIN ANHP

GET SENSITIZED: WE ARE PULMONARY HYPERTENSION

In the context of World Pulmonary Hypertension Day, commemorated every May 5th, the National Association of Pulmonary Hypertension (ANHP) has carried out an extensive awareness campaign throughout the month under the slogan "Get sensitized, we are Pulmonary Hypertension," with the aim of raising awareness about this rare and serious disease that affects more than 5,000 people in Spain.

As the organization behind the inaugural World PH Day in 2012, ANHP has upheld a strong commitment to raising awareness, supporting patients, and advocating for social and institutional change. This year's campaign focused on emotional connection, community involvement, and education, running from May 1st to 31st and achieving significant impact locally, nationally and internationally.

HIGHLIGHTED CAMPAIGN ACTIONS

1. Symbolic Lightings Across Spain

On May 5th, dozens of cities and towns throughout Spain joined the "Shine a Light on Pulmonary Hypertension" initiative by illuminating iconic buildings, fountains, and monuments in purple light. This initiative, now a well-established tradition in our annual campaign, aims to spark public curiosity and create opportunities for conversations about the disease.

2. Immersive Experience. "Feel Pulmonary Hypertension"

The same day, we organized an event at the esplanade of La Paz University Hospital in Madrid. Attendees were able to symbolically experience what it's like to live with PH through an interactive installation that simulated the breathing difficulties and constant tiredness associated with the disease.

3. Educational Sessions for Patients

We were involved in informative sessions held at Miguel Servet University Hospital (Zaragoza) and La Paz University Hospital (Madrid). On May 7th, we co-organized a workshop alongside the Pulmonary Hypertension Unit at Virgen de la Victoria Hospital (Málaga), aimed at patients and their families. Collaboration with healthcare professionals is a pillar for providing comprehensive support to patients.

4. Therapeutic Writing Workshop

On May 13th, an online emotional writing session was conducted by our psychologist. This workshop allowed patients and caregivers to express their experiences with the disease form a therapeutic perspective, helping to verbalize emotions and reinforce the feeling of community.

5. Member's Meetup in Madrid

On May 23rd, we organized a special social event for ANHP members, promoting the exchange of experiences and the reinforcement of mutual support among patients and families. During the gathering, we held a workshop on "Exercise for Patients with Pulmonary Hypertension" in collaboration with OXIMESA NIPPON GASES S.L., Carlos, the physiotherapist, helped us understand the importance of exercise for our condition, and we performed some exercises to improve respiratory muscle strength.

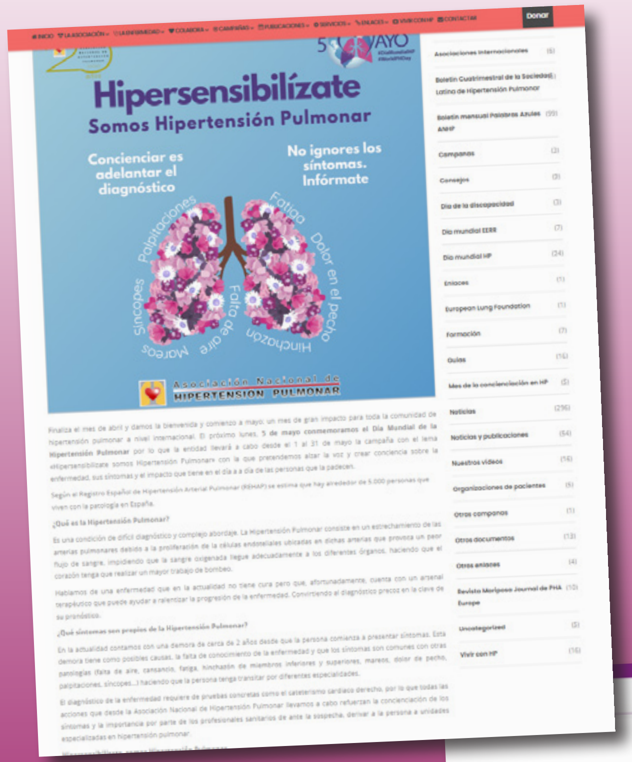
A MESSAGE THAT CROSSES BORDERS

Throughout the campaign, we have strengthened outreach on social media, digital platforms, and in the media, and actively supported the international campaign led by PHA Europe. As part of this network, we recognize the importance of coordinated and solidarity-driven action across the continent.

Pulmonary hypertension is a progressive disease, hard to identity and manage, affecting people of all ages- although it is more common in young women. The current average diagnostic delay ranges between 12 and 18 months, a delay that can seriously compromise prognosis. That is why we continue raising our voice to demand fair access to specialized centers across all the regions and to keep promoting awareness campaigns that inform society about the symptoms, impact, and real needs of those affected.

"Because Every BREATH Counts"

At ANHP, we believe that behind every diagnosis is a story of silent battle. Our 2025 campaign has been a demonstration of unity, visibility, and hope. We claim that every breath counts, which is why we will keep working every day so that pulmonary hypertension stops being an invisible disease.



Hipersensibilízate

Somos Hipertensión Pulmonar

Concienciar es adelantar el diagnóstico

No ignores los síntomas. Infórmate

Asociación Nacional de HIPERTENSION PULMONAR

Finaliza el mes de abril y damos la bienvenida y comienzo a mayo: un mes de gran impacto para toda la comunidad de hipertensión pulmonar a nivel internacional. El próximo lunes, **5 de mayo conmemoramos el Día Mundial de la Hipertensión Pulmonar** por lo que la entidad llevará a cabo desde el 1 al 31 de mayo la campaña con el lema «Hipersensibilízate somos Hipertensión Pulmonar» con la que pretendemos alzar la voz y crear conciencia sobre la enfermedad, sus síntomas y el impacto que tiene en el día a día de las personas que la padecen.

¿Qué es la Hipertensión Pulmonar?

¿Qué síntomas son propios de la Hipertensión Pulmonar?

El Hospital público La Paz muestra el día a día de un paciente con hipertensión pulmonar

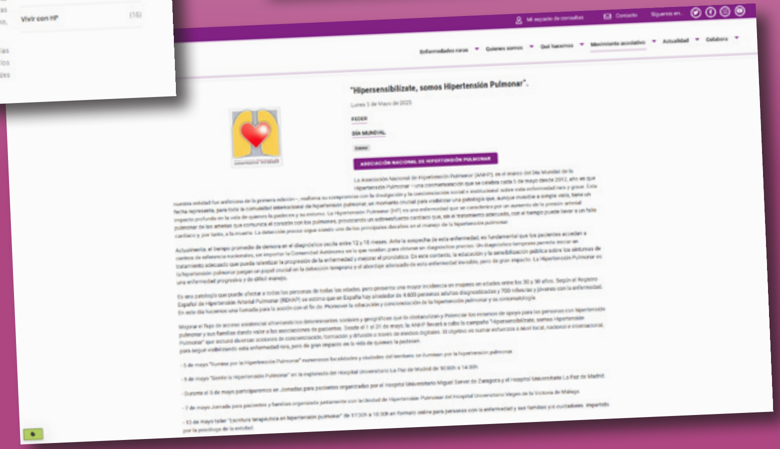
ESTA ENFERMEDAD AFECTA A APROXIMADAMENTE A UNA DE CADA 100.000 PERSONAS EN ESPAÑA

El Hospital Universitario La Paz, centro público de la Comunidad de Madrid, ha celebrado, con motivo del Día Mundial de la Hipertensión Pulmonar una jornada de sensibilización sobre esta patología, con charlas divulgativas y la instalación de una "habitación" simulada, donde mediante la realización de acciones cotidianas los ciudadanos han podido experimentar los síntomas que padece una persona con hipertensión pulmonar en su día a día. Una enfermedad crónica y progresiva que de no ser diagnosticada puede derivar en una insuficiencia cardiaca y el fallecimiento del paciente. Este hospital del Servicio Madrileño de Salud situado en la capital cuenta con una Unidad Multidisciplinar coordinada por el Servicio de Neumología que permite a los profesionales hacer un correcto diagnóstico y valoración de la enfermedad así como elegir el tratamiento más oportuno para esta enfermedad.

07 mayo 2025

Esta jornada celebrada en el Hospital Universitario La Paz ha sido organizada por profesionales de la Unidad de Hipertensión Pulmonar del Servicio de Neumología del hospital, junto con la Asociación Española de Hipertensión Pulmonar, la Fundación Contra la Hipertensión Pulmonar y la Asociación Española de Esclerosis Sistémica. Durante la misma se han realizado unas charlas divulgativas sobre la enfermedad y se ha instalado una habitación en la entrada del Hospital General, donde se podían realizar diferentes acciones de la vida cotidiana, con el fin de experimentar los síntomas que padece un enfermo de hipertensión pulmonar.

Durante esta jornada, los ciudadanos que se han acercado a la zona habilitada, han podido comprobar la fatiga y el cansancio que siente un enfermo de hipertensión pulmonar en su vida cotidiana. Allí, los visitantes han realizado tareas como hacer la cama, planchar, barrer o



"Hipersensibilízate, somos Hipertensión Pulmonar".

SPAIN FCHP

WORLD PULMONARY HYPERTENSION DAY 2025

From the Spanish Pulmonary Hypertension Foundation (FCHP), we commemorated this special day with a full schedule of scientific, institutional, social, and digital awareness activities to raise the profile of the disease and strengthen support for patients and their families.

HIGHLIGHTED ACTIVITIES:

- APRIL 29

- Marqués de Valdecilla University Hospital (Santander)
- Patient sessions on Pulmonary Hypertension

- MAY 5 – WORLD PH DAY

- La Fe University Hospital (Valencia)
- La Paz University Hospital (Madrid)
- Miguel Servet University Hospital (Zaragoza) Patient-focused educational sessions on PH
- 8:00 PM -» Landmark buildings illuminated in cities across Spain
- See map: *https://www.google.com/maps/d/u/0/edit?mid=1Tw5TrwJe2zoIsxOgPo3xyxsTDX-B0M0&ll=41.65289790313028%2C-4.728733749999998&z=17*

We also launched an awareness campaign on social media, sharing patient stories, expert voices, and key facts to raise understanding of life with Pulmonary Hypertension.

- MAY 6

- Principality of Asturias
- Institutional meeting with the Regional Minister of Health

- MAY 22

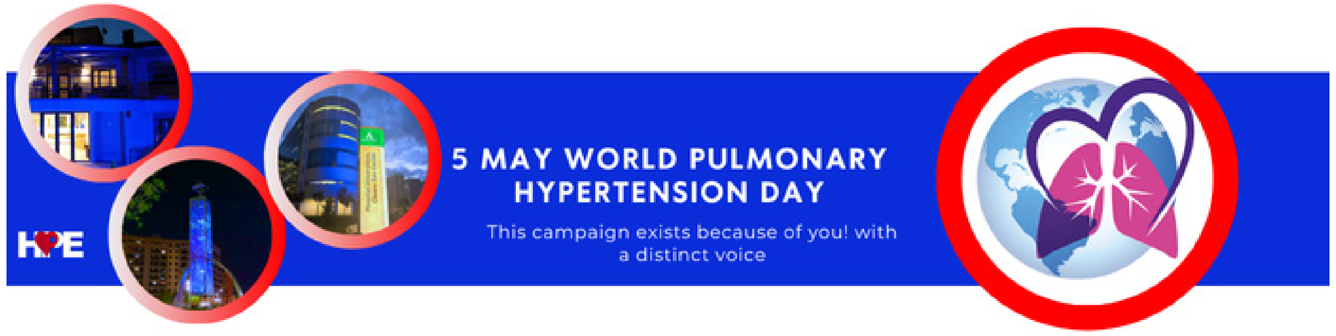
- Clinical University Hospital of Salamanca
- Patient session on Pulmonary Hypertension

- JUNE 5

- Official grant award ceremony by FCHP
- Dr. Eduardo Oliver (Spanish National Research Council - CSIC)
- Awarded project: "New circulating biomarkers for diagnosis and therapeutic monitoring in patients with Pulmonary Arterial Hypertension"

Thank you to everyone who took part, supported us, and helped raise awareness. We continue working together to promote research, visibility, and better quality of life for people living with Pulmonary Hypertension.

SPAIN HPE-ORG



HIPERTENSIÓN PULMONAR ESPAÑA ORG PACIENTES

"WITH A DISTINCT VOICE" - 5 MAY WPHDAY

On the occasion of the celebration of World Pulmonary Hypertension Day on 5 May, during the month of May, Hipertensión Pulmonar España Organización Pacientes has joined the Social Media campaign launched by PHA Europe together with PHA, and the entire Pulmonary Hypertension community worldwide, to raise awareness of this disease with the hashtags: *#pulmonaryhypertension #worldphday2025 #pulmonaryhypertension #pulmonaryhypertensionspain #hpe #pulmonaryhypertension #worldpulmonaryhypertensionday #pulmonaryhypertension2025 #pulmonaryhealth #rarediseases #visibilityhypertension*

In addition to the international campaign, HPE-ORG has run its own online social media campaign #Convozpropia (#WithaDistintcVoice), producing its own visuals and sharing the personal experiences of some of our partners and advice from the professionals who work with us on how to improve the quality of life for people affected by Pulmonary Hypertension through yoga, mindfulness and a healthy and balanced diet.

As in previous years, our organisation has involved our partners so that they are the ones who lead the implementation of face-to-face activities to give visibility to this disease in their own cities.

Thanks to this initiative, we have involved different city councils to illuminate buildings in blue in several cities in Spain, among them: the Fuente del Minero in Guardo, the Torre dels vents in Tarragona, the Cathedral of Sant Feliu de Llobregat, the House of Culture in Churriana de la Vega, the Hospital Universitario Clínico San Cecilio in Granada, and the Domus Vi residence in Lalín in Pontevedra. In all these cities, posters have been placed around the buildings, illuminated in blue, indicating the reason for the illumination to raise awareness about Pulmonary Hypertension.

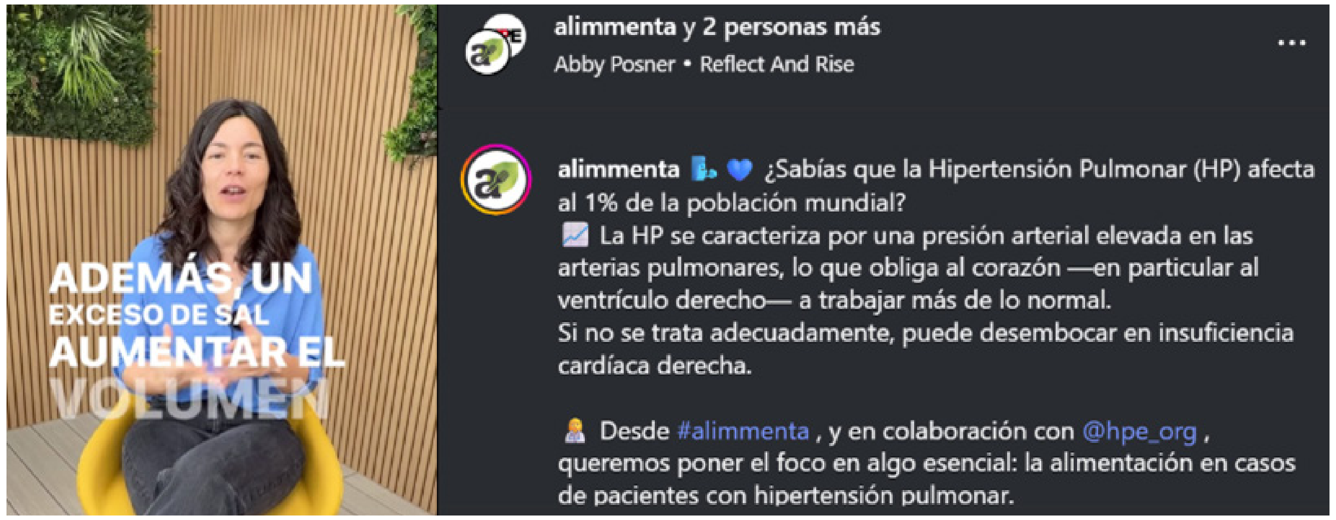
Our members have also carried out activities in collaboration with other entities. Our partner Carmen Buján organised a pilates class in collaboration with the Victory gymnasium in Guardo (Palencia), held an exhibition on pulmonary hypertension and the importance of giving visibility to minority diseases such as pulmonary hypertension at the official language school in Guardo (Palencia), and organised a solidarity walk in support of patients with pulmonary hypertension, supported by the Guardo Town Council (Palencia).

In addition, in Salamanca, our colleague Janeise Meneses organised a pilates class in collaboration with the AVIVA Foundation of Salamanca and a banner in favour of pulmonary hypertension was displayed during a basketball activity in collaboration with the same association. The AVIVA Foundation is a non-profit organisation whose aim is to defend the rights and improve the quality of life of people with disabilities and their families, oriented towards inclusion and participation in the community, who collaborate with HPE-ORG as we are united by disability. Finally, our colleague Lorea Ullibarriarana, affected by idiopathic PH, in active employment as a physiotherapist, once again dedicated the 5th of May to motivate her patients by celebrating the DMHP, turning her entire company to publicise and make PAH visible. She has carried out various handicrafts and activities in favour of PH together with the residents of the Domus Vi residence for the elderly in Lalín in Pontevedra.

Next to these activities, our colleague Maria was present at an information table provided by the City Council of Sant Feliu de Llobregat on the occasion of the celebration of 'La Fira' in this town, where she offered information about Pulmonary Hypertension and our association.

Among the activities carried out exclusively through social networks, we highlight the testimonies offered by our members about their experiences with pulmonary hypertension, and the advice on self-care offered by the professionals who accompany us on physical activity and breathing, mindfulness and healthy eating.

Furthermore, two free and open online workshops were offered, one on 'Digital Disconnection', which is so important nowadays, and one on the use of new culinary techniques to cook quickly without falling into bad eating habits.



alimmenta y 2 personas más
Abby Posner • Reflect And Rise

alimmenta 🩺💙 ¿Sabías que la Hipertensión Pulmonar (HP) afecta al 1% de la población mundial?
📈 La HP se caracteriza por una presión arterial elevada en las arterias pulmonares, lo que obliga al corazón —en particular al ventrículo derecho— a trabajar más de lo normal.
Si no se trata adecuadamente, puede desembocar en insuficiencia cardíaca derecha.

👩‍⚕️ Desde #alimmenta , y en colaboración con @hpe_org , queremos poner el foco en algo esencial: la alimentación en casos de pacientes con hipertensión pulmonar.

Thanks to the valuable support of the organising association, the activities have been a success, both in their coordination and execution, as well as in the participation and reach achieved. The World Pulmonary Hypertension Day campaign has allowed us to experience a remarkable growth in our social media, especially in the level of interaction with our publications. This increase reflects our ability to reach new audiences and directly convey the reality of living with pulmonary hypertension.

Likewise, various organisations have joined in the dissemination, amplifying our messages and sharing our content, which has contributed to increasing the visibility of this little-known disease.

Finally, we would like to highlight the satisfaction we have received from the results achieved, and the involvement of all the participants throughout different cities. Yet another year, we have achieved that, by the end of May, more people know about Pulmonary Hypertension, became aware of the seriousness of this condition, and approached both our organisation and the services we offer.

#CONVOZPROPIA

Taller gratuito

Desconexión digital

para mejorar tu salud mental

Miércoles 4 de junio

19:00h

Plataforma Zoom

#CONVOZPROPIA

Taller gratuito

COCINA SALUDABLE

en tiempo récord

Miércoles 11 de junio

19:00h

Plataforma Zoom

#CONVOZPROPIA

Sílvia Velasco
Paciente de
Hipertensión Pulmonar

#WordlPHDay2025

5 DE MAYO DIA MUNDIAL
DE LA HIPERTENSIÓN PULMONAR

Esta campaña existe gracias a ti!
Con voz propia

CENTRO MUNICIPAL DE CULTURA CHURRIANA
CHURRIANA DE LA VEGA, GRANADA

5 DE MAYO
CENTRO MUNICIPAL DE CULTURA
A LAS 21 H

EL CENTRO CULTURAL CHURRINA SE ILUMINARÁ DE AZÚL EN SOLIDARIDAD CON LOS AFECTADOS POR LA HIPERTENSIÓN PULMONAR

La Hipertensión Arterial Pulmonar (HAP) es una enfermedad rara, grave, progresiva, crónica y de manejo complicado, pudiendo ser diversos mecanismos fisiopatológicos, los que la desencadenan. La HAP se asocia con un importante incremento del riesgo de morbi-mortalidad cardiovascular y deterioro de la calidad de vida de los pacientes que la padecen, pues las personas afectadas se sienten cansadas, mareadas, con dificultad para respirar o que experimenten otros síntomas.

Ciertos cambios en las células que recubren las arterias pulmonares pueden causar que las paredes de las arterias se engrosan y endurezcan. Ello conlleva una reducción o bloqueo del flujo de sangre a través de las arterias pulmonares. Como resultado, la presión sanguínea en dichas arterias aumenta.

La hipertensión pulmonar puede afectar a cualquiera.
La HP no conoce fronteras.
Conoce los síntomas y ayuda a crear conciencia.

75%
DE LOS PACIENTES TIENEN UNA FORMA AVANZADA DE HP AL MOMENTO DEL DIAGNÓSTICO.

AFECTA A MAS MUJERES QUE A HOMBRES.DE CADA 5 DIAGNÓSTICOS 4 SON MUJERES

www.hipertension-pulmonar.com

#WorldPHDay2025

5 DE MAYO DIA MUNDIAL
DE LA HIPERTENSIÓN PULMONAR

Esta campaña existe gracias a ti!
Con voz propia

CENTRO VICTORY
MASTERCLASS DE PILATES

5 DE MAYO
CENTRO VICTORY
1° CLASE A LAS 09:15 H
2° CLASE A LAS 11:00 H

MARCHA SOLIDARIA POR LA HP
POR LAS CALLES DE GUARDO, DESDE LA IGLESIA DE SANTA BÁRBARA A LA FUENTE DEL MINERO

5 DE MAYO
IGLESIA DE SANTA BARBARA
A LAS 20:00 H

EL CENTRO VÍCTORY ORGANIZA UNA "MARCHA SOLIDARIA" POR LA HIPERTENSIÓN PULMONAR

La marcha partirá desde la Iglesia Santa Bárbara hasta el supermercado "Lupa" para dar visibilidad a la Hipertensión Pulmonar

5 DE MAYO
FUENTE DEL MINERO
A LAS 21:00 H

ILUMINACIÓN DE LA FUENTE DEL MINERO DE COLOR AZÚL, COLOR DE LA HAP

6 DE MAYO
ESCUELA OFICIAL DE IDIOMAS
A LAS 18:15 H

ESCUELA OFICIAL DE IDIOMAS
DARÁ SU CLASE DE INGLÉS CONCIENCIANDO DE LA HAP CON SUS CAMISETAS

www.hipertension-pulmonar.com

#WorldPHDay2025

SWEDEN

In May 2025, PAH Sweden organized a camp for patients with PAH and CTEPH for the seventh time. Every other year, we invite patients under the age of 50, and in alternating years, patients over 50. This year, it was the younger group who participated. For many of the participants, this was the first time they met and got to know others living with the same condition, and our evaluations show that the camp is highly appreciated. The camp takes place from Thursday to Sunday, and the days are filled with a mix of education, discussions, and excursions on the beautiful island of Fårö. We thank PH Europe for their contribution to the event!

UKRAINE PHA

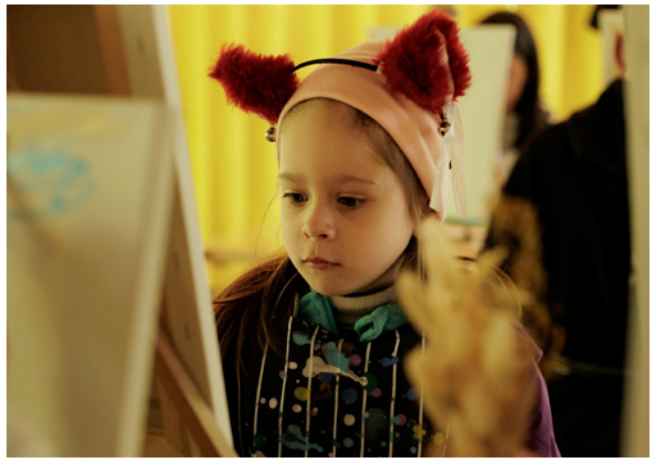
On May 10, 2025, Ukraine joined the global community in marking World Pulmonary Hypertension Day. In Kyiv, at a picturesque riverside location on the Dnipro River, patients with PH, their families, and partners gathered to declare to the world: **"We are more than PH."**

This day became an empowering event that united people and transformed a diagnosis into a supportive community. During the gathering, a physical activity workshop was held by Iryna Sydorchuk — an experienced yoga instructor, and a person living with pulmonary hypertension. Her story is truly inspiring, as she continues to live an active life despite her diagnosis. In addition, Iryna presented her own book of poetry, written from her personal experience of living with PH. Her poems deeply moved the participants, offering a powerful emotional reflection of shared pain and hope.

At the same time, an emotional art master class took place, where participants expressed their dreams, feelings, and inner strength through painting. The day was filled with conversations, warm embraces, stories of treatment and perseverance — creating a truly heartfelt, sincere, and inspiring atmosphere.

A special part of the event was the presentation of the youth initiative "Orphan Youth of Ukraine" — a project by the Public Union "Rare Diseases of Ukraine" aimed at empowering young people to actively advocate for the rights of patients with rare diseases. The initiative was introduced by Maksym Byskubskyi, with active participants including PH Association youth representatives Yuliia Berebenets and Anna Kovalova.

This day, once again, proved: we are not alone. We are a community that lives, dreams, and takes action. And we are definitely more than PH.



UKRAINE PHURDA

WE ARE HERE, WE ARE TOGETHER, WE ACT

Despite the challenges of war and instability, the Ukrainian community of patients with pulmonary hypertension remains united and active. We held an online meeting for World Pulmonary Hypertension Day to remember the past, feel each other's support, and look to the future with hope. The online meeting brought together patients, activists, doctors and friends. It became a place where memories were reminisced, experiences were shared, and new goals were outlined.

The meeting was opened by Oksana Kulish, a leader of the PH patient community in Ukraine. She gave a presentation on how the Ukrainian community has been involved in celebrating World PH Day in previous years — from educational events and flash mobs to information campaigns and participation in international initiatives.

"I remember the first flash mob in the center of Lviv for PH Day," recalls Oksana. — It was a desperate cry and a desire to be seen and helped. We didn't come out for the sake of a picture then — we came out for life. And every year there are more of us, and we can't be ignored."

TECHNOLOGIES THAT BRING THE FUTURE CLOSER

In the second part of the meeting, pulmonologist and digital expert Vitaliy Poberezhets shared the possibilities of using artificial intelligence (AI) in medicine. He told how the latest technologies can already today support doctors in making decisions, help with data analysis and monitoring the condition of patients.

"AI is not a replacement for a doctor, but an extension of him. It is a tool that gives a chance to detect the disease earlier, choose more accurate treatment, and even psychologically support the patient,"- Vitaliy noted.

This topic sparked a lively discussion among the participants — especially in the context of the challenges that Ukrainian medicine is facing during the war.

SMALL HEARTS - BIG SUPPORT

One of the most touching moments was the flash mob #BlueButterfly, which was joined by children from kindergartens and schools. They drew butterflies, created paper cutouts, shared photos in social media, and even danced - all in support of people with pulmonary hypertension.

"We sincerely thank the teachers who helped the children not just create postcards, but touch on the topic of empathy. This is already educating the future society - more attentive and humane."

PULMONARY HYPERTENSION - IT CAN BE ABOUT YOU

To increase the visibility of the disease in society, our team created a series of city lights under the slogan: "Pulmonary hypertension: danger is hidden under the appearance." The posters were placed in public places in Lviv and aroused great interest among passers-by.

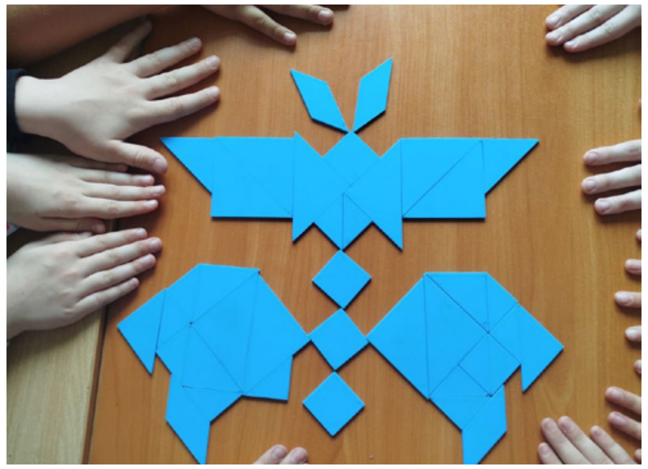
Also, Ukrainian patients became part of the pan-European PHA Europe campaign "Sometimes it's PH", becoming its faces and voices: "It is a great honor to be part of a campaign that changes perceptions. We are not victims. We are people with stories, experience and strength," shared one of the participants.

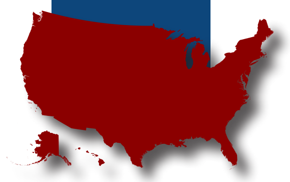
WHAT'S NEXT?

We are not stopping. The creation of educational videos, launching support groups, online consultations, campaigns for doctors, working with local communities, and international partners: all these are ahead.

Our goal is for every person with PH in Ukraine to know that they are not alone, and something is already being done for them.

We are grateful to everyone who was there. This is not just a fight against the disease. This is a fight for dignity, for the quality of life, for the future.





USA

PHA MARKS WORLD PH DAY WITH U.S. ADVOCACY AND AWARENESS EVENTS

The Pulmonary Hypertension Association joined this year's global World PH Day campaign, *"Sometimes It's Pulmonary Hypertension,"* to highlight the challenges patients face in receiving an accurate diagnosis. Led by PHA Europe, the campaign brought together PH organizations and advocates worldwide to coordinate efforts around awareness and education. To help spread the message online, PHA shared the Sometimes It's PH campaign video and released a downloadable World PH Day Toolkit with graphics and messaging for use on social media.

In the United States, PHA and its community of advocates observed World PH Day with a coordinated push for greater awareness and policy change. Participants shared personal stories with elected officials during virtual and in-person meetings on Capitol Hill, urging support for improved care and access for people living with pulmonary hypertension.

More than 30 patients, caregivers and health care professionals joined PHA's World PH Day on Capitol Hill event, meeting with U.S. lawmakers in Washington, D.C., on May 6 and engaging in virtual meetings on May 7. Advocates' requests included improving access to oxygen therapy, reducing out-of-pocket medication costs, preserving government health care funding and increasing federal investment in medical research.

One outcome came quickly: the day after meeting with PHA advocates, U.S. Representative Cleo Fields of Louisiana co-sponsored a proposed law to improve access to supplemental oxygen for people with severe lung conditions who rely on Medicare, a national insurance program.

Outside of its legislative efforts, PHA launched the "6-Minute Challenge," a virtual campaign inspired by the six-minute walk test used to assess PH severity. Participants were encouraged to commit to six minutes of activity each day throughout May, such as walking, stretching or low-impact exercise. The challenge was open to all fitness levels and aimed to promote movement and community engagement. On May 31, PHA recognized top participants, including individual fundraisers, team fundraisers and activity tracking champions, during a Facebook Live celebration.

PHA also hosted virtual support group meetings for people living with PH and their caregivers, with a focus on mental health and peer connection. The sessions offered a supportive space to share experiences, ask questions and connect with others who understand life with PH whether the participants were newly diagnosed or had been managing the condition for years.

Through advocacy, community-building and global outreach, World PH Day 2025 brought attention to the challenges of living with PH and the need for timely diagnosis and equitable access to care.

· MEDIA CLIPPINGS ·

Austria

Gemeinsam sind wir viele

Der rechte Ventrikel und die Trikuspidalklappe im Rampenlicht

12. Pneumo Aktuell

COPD: State of the Art

Vom reaktiven zum proaktiven Management – Präventivmaßnahmen werden in der Versorgung von COPD-Patientinnen immer wichtiger. Das unterstreichen auch die Aktualisierungen im GOLD-Report 2025: Sie betreffen u.a. den Fokus auf Prä-COPD bzw. PRISm, die Evaluierung von häufigen Komorbiditäten, das Einbeziehen von Umweltfaktoren und das Detektieren spezieller Phänotypen, für die Biologika im Behandlungsverlauf eine mögliche Therapieoption darstellen.

Update obstruktives Schlafapnoe-Syndrom

Prävalenz und Pathophysiologie

Die obstruktive Schlafapnoe (OSA) ist die häufigste schlafassoziierte Atemstörung, sie stört den Schlaf und beeinträchtigt seine Erholungsfunktion. Der Schweregrad wird durch den Apnoe-Hypopnoe-Index (AHI) definiert. Ein obstruktives Schlafapnoe-Syndrom (OSAS) liegt vor, wenn Patient:innen aufgrund der Apnoen bzw. Hypopnoen unter einem nicht erholsamen Schlaf mit vermehrter Tagesschläfrigkeit leiden. Die Prävalenz der OSA liegt bei Männern zwischen 4 und 49 %

OÄ Dr.ⁱⁿ Angelika Kugi

Abteilung für Innere Medizin, LKH Villach

Initiative

Chronisch obstruktive Lungenerkrankung

Ein aktueller Über

Frühzeitige Diagnose der PAH – Kardiologie im Fokus der Patientenjourney

PEOPLE &

Kunst, Karriere und Kulinarik

Update Asthma und COPD

«Von der reaktiven zur proaktiven Medizin»

Erschöpft, kurzatmig? Nicht alles ist Frühjahrsmüdigkeit!

Zum Welt-Lungenhochdruck-Tag am 5. Mai: Erfahren Sie, welche Beschwerden auf Lungenhochdruck hinweisen können

Lungenhochdruck im Blick

PH Austria fordert eine bessere Versorgung.

WIEN. Zum Welt-Lungenhochdruck-Tag am 5. Mai machte der Verein „PH Austria – Initiative Lungenhochdruck" auf die seltene, aber schwere Erkrankung Pulmonale Hypertonie (PH) aufmerksam, die auch

Referat

PULMONALE HYPERTONIE

A. Olschewski, Graz

V. Foris, Graz/Boston

H. Olschewski, Wien/Berlin

Update vom ERS International Congress 2024

Pathobiologie und Genetik der pulmonalen Hypertonie

Für die 7. Weltkonferenz für pulmonale Hypertonie (World Symposium on Pulmonary Hypertension; WSPH) 2024 beschäftigten sich

„Unser ganzes Leben ist weg"

Die „Adria", jener Wohnwagen, mit dem das Paar aus Wiener Neustadt (NÖ) durch Europa tourte, wurde in Spanien gestohlen. Für die schwerkranke Frau war das Fahrzeug ein mobiles Pflegeheim.

48. Jahrestagung der ÖGP

High-Risk-Lungenfibrose: optimales Zeitfenster für Lungentransplantation

Starke Frauen fürs Herz

Kindliche PH

Pulmonale Hypertonie im Kindesalter

Lungenhochdruck im Kindesalter unterscheidet sich von dem des Erwachsenenalters. Im Interview spricht OÄ Dr. Sulaima Albinni, Leiterin der Kinderherzambulanz der Medizinischen Universität Wien mit Schwerpunkt pulmonale Hypertonie (PH), über die Notwendigkeit einer angepassten Diagnostik sowie pathophysiologisch orientierte Therapiestrategien.

OÄ Dr. Sulaima Albinni, Wien

Opsumit

PAH-Therapie OPSUMIT (Macitentan)

Pulmonalarterielle Hypertonie

Risikostratifizierung und Behandlungsziele

Affentempo oder gemütliches Joggen beim Wiener Zoolauf

Auf die Plätze, fertig und los! Heute in einer Woche steigt der sechs Kilometer lange Klassiker im ganz besonderen Ambiente

Diese drei Läufer absolvierten den Lauf im Vorjahr in tierisch-coolen Kostümen.

Ein Jahr „Cardio-Café", die Podcast-Serie der ÖKG

Chronisch obstruktive Lungenerkrankung (COPD)

Ein aktueller Überblick

Bosnia and Herzegovina

radiosarajevo.ba

Foto: Dečki u plavom / Sarajevski maraton

U skladu s Rješenjem Ministarstva saobraćaja Kantona Sarajevo, ovog vikenda bit će održano šesto izdanje sportske manifestacije Sarajevski maraton, a građane očekuju privremene i parcijalne obustave saobraćaja duž trase utrke.

Manifestacija počinje u subotu, 10. maja 2025. godine, kada će na Vilsonovom šetalištu biti organizovane dječije utrke i humanitarna utrka "Trčimo za dah – powered by PROVIDENS". Ove utrke će se održavati između Mosta Suade i Olge i Mosta Vodoprivreda, u terminu od 10:00 do 12:00 sati.

FAKTOR

Plućna hipertenzija je podmukla bolest, gotovo neprimjetna, sve dok ne bude prekasno

Struka upozorava da se radi o bolesti koju je teško prepoznati na vrijeme

klix LIFESTYLE

Uskoro se obilježava Svjetski dan plućne hipertenzije: Evo šta znači i koji su najčešći simptomi

federalna.ba

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

vijesti.ba

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

Foto: Udruženje Dah

BiH Regija Svijet Ekonomija Kultura Sport

BOSNA I HERCEGOVINA

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

FENA Saopćenje, Foto/ Udruženje Dah

SARAJEVO, 4. maja (FENA) - Svjetski dan plućne hipertenzije obilježava se sutra, 5. maja. U svijetu gdje se bolesti najčešće prepoznaju po vidljivim znakovima i dramatičnim simptomima, plućna hipertenzija (PH) ostaje gotovo neprimjetna - sve dok ne bude prekasno. Ova rijetka i progresivna bolest sužava plućne arterije, otežava rad srca i pacijentima svakodnevicu pretvara u borbu za dah.

Sadržaj dostupan **isključivo pretplatnicima** FENA servisa. Za više informacija o načinu i uvjetima korištenja servisa kontaktirajte marketing@fena.ba .

FENA

Raport

BHDOKTOR

Tiha prijetnja koja dugo traje: Plućna bolest bez sistemske borbe je još opasnija

Večernji list

SVJETSKI DAN OVE BOLESTI

Plućna hipertenzija - tiha prijetnja bez sustavne podrške

radiosarajevo.ba

Žestoka poruka političarima oboljelih od plućne hipertenzije: "Naši životi zavise od vas"

FACE

NASLOVNICA FACE TV

Danas se održava humanitarna trka na 4K "Trčimo za dah"

10. maja 2025.

FACE PORTAL

05.05.2025. 05:00:00

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

TNT PORTAL

VIJESTI

Svjetski dan plućne hipertenzije – Lijek treba biti dostupan svim PH pacijentima

JU "Dom zdravlja" Zavidovići
16 min

Svjetski dan plućne hipertenzije – 05. maj
Danas je Svjetski dan plućne hipertenzije!
Plućna hipertenzija je stanje u kojem je krvni tlak u arterijama pluća (plućne arterije)
nenormalno visok. Brojne bolesti i poremećaji mogu uzrokovati plućnu hipertenziju.
Ljudi obično imaju kratak dah čak i pri blagom opterećenju (fizičkom naporu) i
gubitak energije, a neki ljudi osjećaju laganu vrtoglavicu ili umor. U dijagnostici se
koriste rendgenske snimke pluća i srca, elektrokardiografija (EKG) i ehokardiografija
(ultrazvuk), ali za potvrdu je potrebno izmjeriti krvni tlak u desnoj komorii i plućnoj
arteriji. Liječenje uzroka i primjena lijekova koji poboljšavaju protok krvi kroz pluća
usporavaju progresiju ove rijetke, teške i neizlječive bolesti.
U Bosni i Hercegovini je 2014.godine osnovano Udruženja građana oboljelih od
plućne hipertenzije „Dah" sa sjedištem u Zavidovićima i okuplja PH pacijente iz cijele
države.

Savez za rijetke bolesti Federacije BiH
34 min

💙 Svjetski dan plućne hipertenzije – 05. maj 💙
💜 Danas je Svjetski dan plućne hipertenzije! 💜
👉 Plućna hipertenzija je stanje u kojem je krvni tlak u arterijama pluća (plućne arterije) nenormalno visok. Brojne bolesti i poremećaji mogu uzrokovati plućnu hipertenziju. Ljudi obično imaju kratak dah čak i pri blagom opterećenju (fizičkom naporu) i gubitak energije, a neki ljudi osjećaju laganu vrtoglavicu ili umor. Rendgenske snimke pluća i srca, elektrokardiografija (EKG) i ehokardiografija (ultrazvuk) upućuju na dijagnozu, ali za potvrdu je potrebno izmjeriti krvni tlak u desnoj klijetki i plućnoj arteriji. Liječenje uzroka i primjena lijekova koji poboljšavaju protok krvi kroz pluća usporavaju progresiju ove rijetke, teške i neizlječive bolesti.
U Zavidovićima je sjedište Udruženje PPlućna hipertenzija BiHkoje je osnovano 2014. godine i okuplja 54 PH pacijenta iz cijele Bosne i Hercegovine.

bljesak.info

"TRČIMO ZA DAH"

Svjetski dan plućne hipertenzije: Oboljeli u BiH i dalje bez osnovnih lijekova

"Živimo u istoj državi, bolujemo od iste bolesti, trebamo istu terapiju, ali jedni pacijenti imaju lijek na teret entiteta ili kantona, a drugi nemaju, što ovisi o mjestu življenja."

radiosarajevo.ba

Žestoka poruka političarima oboljelih od plućne hipertenzije: "Naši životi zavise od vas"

"Za nas u Bosni i Hercegovini to su za sada puste želje. Bez adekvatnog liječenja i terapije, mi smo samo još jedna obespravljena i marginalizirana grupa pacijenata u ovoj državi koja je osuđena da se sama snalazi i bori za svoje živote, iako ponekad ne možemo ni disati", rekla je na kraju Vera Hodžić.

Udarne vijesti

Radio Sarajevo
Žestoka poruka političarima oboljelih od plućne hipertenzije: "Naši životi zavise od vas"
prije 11 minuta

Bljesak.info
Svjetski dan plućne hipertenzije: Oboljeli u BiH i dalje bez osnovnih lijekova
prije 38 minuta

vijesti.ba
Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške
prije 20 sati

ALJAZEERA

VIJESTI | Bosna i Hercegovina

Svjetski dan plućne hipertenzije: Podmukla, neizlječiva bolest koje nismo svjesni

Ova rijetka i progresivna bolest sužava plućne arterije, otežava rad srca i pacijentima svakodnevicu pretvara u borbu za dah.

M–XCLOUD

Svjetski dan plućne hipertenzije

OBIČAN RADIO

Svjetski dan plućne hipertenzije: U BiH i dalje nedostupni osnovni lijekovi za brojne pacijente

Magazin Plus

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

Bosnainfo

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

Televizija Sarajevo

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

RNU "Radio Brčko"
РНУ "Радио Брчко"

BiH: Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

TRKA ZA DAH

Novum.ba - NOVinar kojem se vjeruje

Svjetski dan plućne hipertenzije: Podmukla bolest, gotovo neprimjetna, sve dok ne bude prekasno

Videozapisi

zavidovicki.ba

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

Oboljeli od plućne hipertenzije uputili žestoku poruku političarima: "Naši životi zavise od vas"

bljesak.info

"Naši životi ovise o odlukama političara"

"Od inzistiranja da barem jedan lijek za plućnu hipertenziju treba biti dostupan svim PH pacijentima u Bosni i Hercegovini nećemo odustati jer drugu opciju nemamo. Naši životi ovise o odlukama političara koji sjede na strateškim mjestima i kreiraju zdravstvenu politiku, liste lijekova i slično, ne znajući kako bez terapija žive oboljeli od plućne hipertenzije", dodaje Hodžić.

Povodom Svjetskog dana plućne hipertenzije oboljeli ističu i hitnu potrebu za većom svješću, ranom dijagnozom i pravednim pristupom specijaliziranoj medicinskoj pomoći. Kao rijetka kardiopulmonalna bolest, plućna hipertenzija zahtijeva liječenje u stručnim centrima kako bi se osigurala optimalna njega. Posljednjih godina, nove terapije u svijetu ne samo da su poboljšale kvalitetu života pacijenata i ublažile simptome, već su također pridonijele smanjenju smrtnosti.

"Za nas u Bosni i Hercegovini to su za sada puste želje. Bez adekvatnog liječenja i terapije, mi smo samo još jedna obespravljena i marginalizirana grupa pacijenata u ovoj državi koja je osuđena da se sama snalazi i bori za svoje živote, iako ponekad ne možemo ni disati", rekla je na kraju Vera Hodžić.

Bolest je neizlječiva

Plućna hipertenzija je rijetko oboljenje krvnih žila pluća zbog kojeg strada i srce. To je i teško oboljenje u kojem je otežan protok krvi u plućima, pri čemu se povećava pritisak na desnu srčanu klijetku. Osim otežanog disanja, konstantnog umora, niske saturacije, aritmija, bolest može dovesti do iznenadnog prestanka rada srca i smrti. Bolest je neizlječiva, ali s odgovarajućom terapijom bolesniku se može produžiti i olakšati život. Postoji pet klasa bolesti, od kojih je najrjeđa primarna plućna hipertenzija od koje boluje vrlo mali broj osoba (od 5 do 50 na milijun).

faktor.ba

Plućna hipertenzija ostaje tiha prijetnja bez sistemske podrške

Bulgaria BSPPH

БНР 90

На 5 май отбелязваме Световния ден на пулмоналната хипертония – болестта на синит устни
публикувано на 02.05.25 в 16:44 | Автор: Стефка Павло

България се включва в глобалната кампания "Дари дъх", с която за 13-ти път у нас ще бъде отбелязан Световният ден на пулмоналната

Предавания — Тази сутрин

Трансплантация в чужбина: Защо НЗОК не покрива транспорта и престоя на пациента?

На болните се налага да събират средства от дарения за тези разходи

ЛЕЧЕНИЕ В ЧУЖБИНА

МАРИЯ САВКОВА 08:01 ч. 13.05.2025 г.

Преди месец ви разказахме за Ирена Методиева, която чака за белодробна трансплантация в САЩ.

02.05.2025 10:58

За 13-и път България е част от глобалната инициатива

София, 2 май 2025 г. – На 5 май светът ще отбе Световния ден на пулмоналната хипертония – тежко и често трудно диагностицирано заболяване, известно още като „болестта на сините устни". В България с него живеят около души.

В знак на солидарност с пациентите на 5 май 20:00 ч. до 23:00 ч. фасадата на Националния д на културата в София ще бъде осветена в синь Към инициативата се присъединяват и още дв български града: В Бургас ще бъде осветен мост Морската градина, а в Пловдив – Домът на културата „Борис Христов".

Пулмоналната хипертония (ПХ) е рядко белодро заболяване, което е потенциално фатално. При Високото налягане в белодробните артерии затруднява преноса на кислород. То води до хронична умора, задух и посиняване на устни, р крака. Симптомите често се бъркат с други заболявания, което забавя диагнозата до две три години от началото на първите симптоми. В напреднал стадий единствената опция за удължаване на живота остава белодробна трансплантация.

Medical News
НОВИНИ, РАБОТА, ОБУЧЕНИЕ

500 българи живеят с пулмонална хипертония

05/05/2025
КАТЕГОРИИ: ЗДРАВЕОПАЗВАНЕ, НОВИНИ
ЕТИКЕТИ: ПУЛМОНАЛНА ХИПЕРТОНИЯ

Croatia

Vikend ispunjen zajedništvom, inspiracijom i pokretom – obilježen Svjetski dan plućne hipertenzije u Saborskom i Plitvicama

HUMANITARCI BEZ PREMCA

Hodali 48 dana duž hrvatske obale za oboljele od plućne bolesti

Hod za oboljele od plućne hipertenzije je završio/Foto: Privatni album

HUMANITARNI HOD

Čonč i Rooster prehodali 1140 km za oboljele od plućne hipertenzije: "Put je trajao 48 dana..."

Czech Republic

Vitalia.cz » Zdraví » Nemoci a úrazy » Potíže s dechem, suchý kašel a únava mohou být příznakem plicní hypertenze

Potíže s dechem, suchý kašel a únava mohou být příznakem plicní hypertenze

ANNA DVOŘÁKOVÁ | 5. 5. 2025

PŘIDEJTE NÁZOR

Špatně se vám dýchá, nemůžete vyjít do schodů a býváte unavení? … může být vysoký tlak v plicích. Mezi další symptomy patří i modrá… hypertenzi mají v Česku tisíce lidí. Jde o vážné onemocnění, které… pomalu a často se zaměňuje s jinými chorobami, například s astmatem… Pokud se ale na něj přijde až v pokročilém stadiu, hrozí pacientům… zdravotní komplikace – v krajním případě i smrt. Současný pokrok… přitom skýtá naději na kvalitnější a delší život.

Blackout v Česku · Bitcoinová vládní krize · 80 let od konce války · Volby do Sněmovny · MediaHub · Další

Zloději dechu: astma či zákeřný plicní tlak. Mnozí netuší, že je dusí vážné nemoci

Premium · Fotogalerie 7

Ivana Lesková, 3. května 2025

Jste unavení a zadýcháváte se? Možná to svádíte na věk, stres či jarní únavu. Ale měli byste jít k lékaři. Může jít o projevy nejméně dvou vážných nemocí: vysokého plicního tlaku či astmatu. Mají shodné příznaky, ale rozdílné příčiny i léčbu. První zatěžuje srdce, druhá zužuje dýchací cesty. Na rizika upozorňují odborníci vždy 5. května ve Světový den plicní hypertenze a 6. května ve Světový den astmatu.

Svíjela se v křečích, omdlela: Denisu (40) nosil manžel do schodů kvůli nemoci plic

Autor: lc - 1. května 2025 • 10:09

Sdílej:

Špatně se vám dýchá, nemůžete vyjít do schodů a býváte unavení? Na vině může být vysoký tlak v plicích. Plicní hypertenzi mají v Česku tisíce lidí. Jedná se o vážné onemocnění, které postupuje pomalu a často se zaměňuje s jinými chorobami.

Vysoký tlak v plicích krade dech i normální život

24.4.2025 admin ZDRAVÍ 0

Na nemoc dne 5. května v Praze upozorní modře nasvícená budova Tančícího domu

Praha, 24. 4. 2025 – Špatně se vám dýchá, nemůžete vyjít do schodů a býváte unavení? Na vině může být vysoký tlak v plicích. Tzv. plicní hypertenzi mají v Česku tisíce lidí. Jedná se o vážné onemocnění, které postupuje pomalu a často se zaměňuje s jinými chorobami, například s astmatem. Pokud se ale na něj přijde až v pokročilém stadiu, hrozí

Vysoký tlak v plicích krade dech i normální život

29.4.2025 | Tisková zpráva | Aktuality z medicíny

Nemocní mohou žít lépe a déle – pokud se začnou léčit včas

Nemocní většinou končí v invalidním důchodu a jsou odkázáni na pomoc druhých. Současný p… plicní hypertenze přitom skýtá naději na kvalitnější a delší život. Důležité však je odhalit nemoc… na to upozorňují u příležitosti **Světového dne plicní hypertenze**, který připadá na **5. května**…

„Plicní hypertenze znamená zvýšení krevního tlaku v plicních cévách. Postihuje zhruba 1 % do… ve věku nad 60 let je ještě častější," popisuje **prof. MUDr. Pavel Jansa, Ph.D.** z **II. interní… kardiologie a angiologie Všeobecné fakultní nemocnice a 1. LF UK v Praze**. Nejčastějším… nemoci je dušnost, která se postupně zhoršuje. K ní se přidává suchý dráždivý kašel, únava, v… na hrudi. „V pozdějších fázích onemocnění začíná pacientům postupně selhávat pravá komora… při plicní hypertenzi dochází k její zvýšené námaze. Projevuje se to modravým zbarvením kůže… dolních končetin. Pacienti také mohou vykašlávat krev a omdlévat," doplňuje **prof. Jansa**.

Deník

AKTUÁLNĚ / Praha

Modré nasvícení budov v centru Prahy upozorní na zrádnou nemoc

Krátce

Cizinec vylezl na jednu ze soch s nožem v ruce

Dostali oznámení o ozbrojeném muži na Zličíně. Šlo o falešnou zprávu

Z domova

Zloději dechu: astma či zákeřný plicní tlak

Asi milion Čechů dusí vážné nemoci. Mnozí zatím netuší, co je příčinou potíží

Předpověď varuje před kroupami a nárazy větru

Na cestě do Polska hrozí kolony

Hungary

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Főoldal > Női Tükör > Légzőszervi megbetegedések > Egymillióból ötven embert fenyeget

Egymillióból ötven embert fenyeget

A pulmonális hipertónia (PH) a tüdő ritka és súlyos, nehezen felismerhető betegsége. A fizikai terhelhetőséget jelentősen korlátozó állapot tünetei nem kirívóak, így nehéz megmondani, hogy kinél utalnak valóban erre a problémára. Az időben érkező orvosi segítség mellett arra is szükség van, hogy jobban odafigyeljünk a PH-ban szenvedőkre, tegyük elviselhetőbbé a rájuk és szeretteikre nehezedő nyomást.

MÉG AJÁNLJUK

TSH: meddőség és visszatérő vetélések esetén

Felére fogyott két hónap alatt a világ legkövérebb nője

A gallium hőmérő biztonságos használata

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Egymillióból ötven embert fenyeget a tüdő egyik ritka, súlyos és nehezen felismerhető betegsége

Zuglói Egészségfejlesztési Iroda

May 12

https://www.egeszsegkalauz.hu/.../legzorendszeri.../ewqr0j2

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Egymillióból ötven embert fenyeget a tüdő egyik ritka, súlyos és nehezen felismerhető betegsége

BDPST 24

Címlap · Sztárvilág · Élet+Stílus · Otthon · Szórakozás · Sport

Főoldal / Címlap / Egymillióból ötven embert fenyeget, de melyik ötvenet?

EGYMILLIÓBÓL ÖTVEN EMBERT FENYEGET, DE MELYIK ÖTVENET?

A pulmonális hipertónia (PH) a tüdő ritka és súlyos, nehezen felismerhető betegsége. A fizikai terhelhetőséget jelentősen korlátozó állapot tünetei nem kirívóak, így nehéz megmondani, hogy kinél utalnak valóban erre a problémára. Az időben érkező orvosi segítség mellett arra is szükség van, hogy jobban odafigyeljünk a PH-ban szenvedőkre, tegyük elviselhetőbbé a rájuk és szeretteikre nehezedő nyomást. Május 5-e a PH világnapja, ami egyben alkalom és lehetőség is a segítségnyújtásra.

Patika Magazin Online

Egymillióból ötven embert fenyeget a pulmonális hipertónia, de melyik ötvenet?

ProfitLine

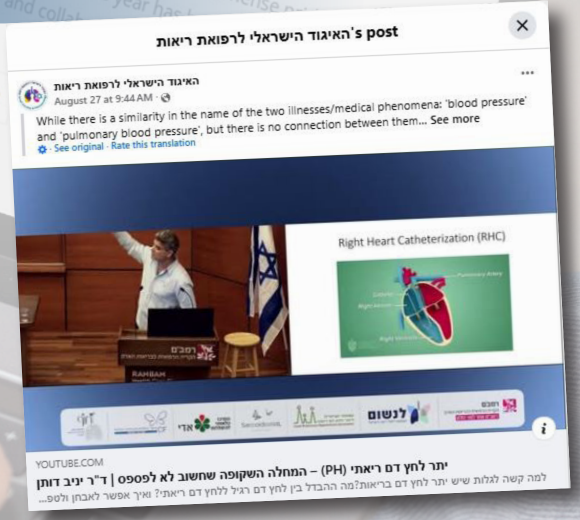
A pulmonális hipertónia (PH) a tüdő ritka betegsége: miről ismerhető fel?

AZ ÉGÉS AZ ELSŐDLEGES PROBLÉMA A DOHÁNYZÁSSAL

telex

Ennek a betegségnek a kutatásáért valaki egyszer még Nobel-díjat fog kapni

Israel



האיגוד הישראלי לרפואת ריאות's post

האיגוד הישראלי לרפואת ריאות

August 27 at 9:44 AM

While there is a similarity in the name of the two illnesses/medical phenomena: 'blood pressure' and 'pulmonary blood pressure', but there is no connection between them... See more

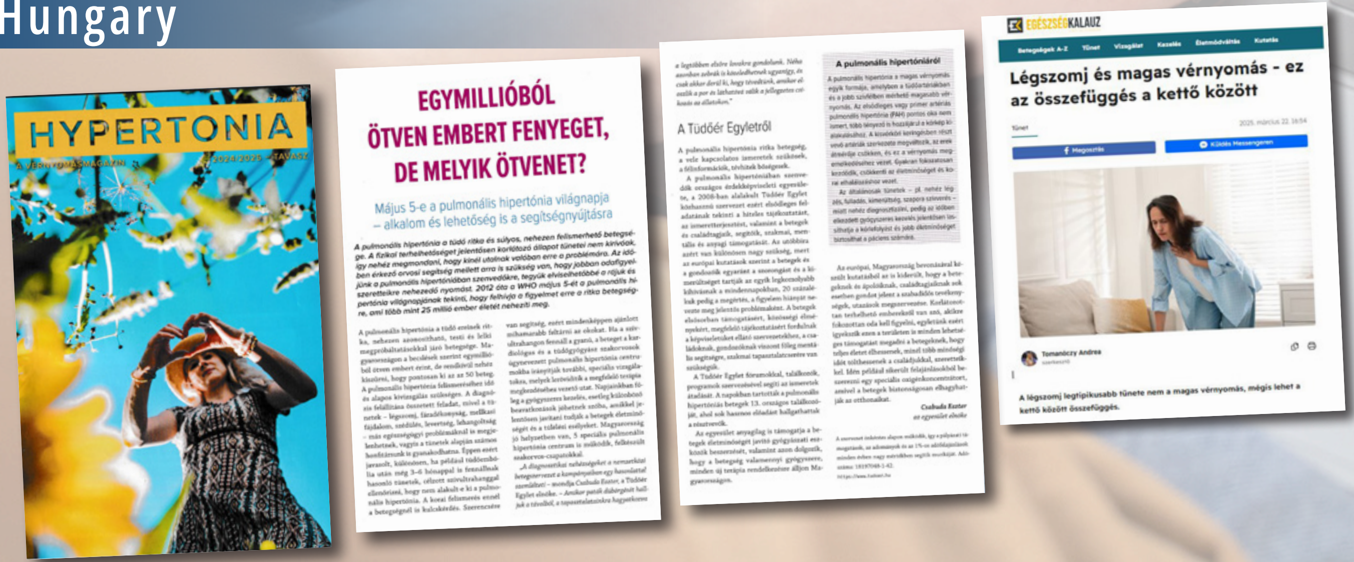
See original · Rate this translation

YOUTUBE.COM

יתר לחץ דם ריאתי (PH) – המחלה השקופה שחשוב לא לפספס | ד"ר יניב דותן

למה קשה לגלות שיש יתר לחץ דם בריאות?מה ההבדל בין לחץ דם רגיל ללחץ דם ריאתי? ואיך אפשר לאבחן ולטפ...

Hungary



HYPERTONIA

A VÉRNYOMÁSMAGAZIN · 2024/2025 · TAVASZ

EGYMILLIÓBÓL ÖTVEN EMBERT FENYEGET, DE MELYIK ÖTVENET?

Május 5-e a pulmonális hipertónia világnapja – alkalom és lehetőség is a segítségnyújtásra

A Tüdőér Egyletről

A pulmonális hipertóniáról

EGÉSZSÉGKALAUZ

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Légszomj és magas vérnyomás - ez az összefüggés a kettő között

Tomanóczy Andrea

A légszomj legtipikusabb tünete nem a magas vérnyomás, mégis lehet a kettő között összefüggés.

Latvia

SKĀBEKĻA festivāls

5 MAY World Pulmonary Hypertension Day

OXYGEN FESTIVAL IN LATVIA: MEDIA CLIPPING

Vai ir iespējams sadzīvot ar divām retām slimībām: iedzimtu sirdskaiti un plaušu hipertensiju? Atbilde: Pulmonālās hipertensijas biedrība vadītāja un Latvijas Reto slimību alianse valdes locekles Ieva Plūme stāstījumā. #WorldPHDay

TV3.LV

Vienas slimības nākamā blakne: Ievas Plūmes stāsts par dzīvi ar divām retām slimībām

Pulmonālās hipertensijas biedrība vadītāja Ieva Plūme šodien plkst. 17:00 TV3 #ZilonisStudijā ar kolēģiem no BKUS un Latvijas Reto slimību alianse runās par retām slimībām.

TV3 Latvija

24. Aprīlis

Šovakar (24.04.) 17:00 #ZilonisStudijā diskutēsim: RETĀS SLIMĪBAS: KĀ LAUZT MĪTUS UN MAZINĀT SABIEDRĪBAS

Pulmonālās hipertensijas biedrība

SKĀBEKĻA FESTIVĀLS

NĀC UZ SKĀBEKĻA FESTIVĀLU

💙💚 Šodien visā pasaulē atzīmē Pulmonālās hipertensijas dienu. Pulmonālās hipertensijas biedrība izsaka pateicību visiem Latvijas mediķiem un veselības aprūpes personām, kas ikdienā rūpējas par cilvēkiem ar plaušu hipertensiju 💚 Šīs sveicieni visiem pulmonālās arteriālās hipertensijas pacientiem, viņu ģimenēm un draugiem, kas sniedz atbalstu un sapratni 💚

#WorldPHDay
#pulmonaryhypertension
#PHAwareness
#PHCommunity

5.maijs ir Pasaules Pulmonālās hipertensijas diena

Ar pulmonālā hipertensiju slimo 31.5 miljoni

SKĀBEKĻA FESTIVĀLS TEVI GAIDA!

Skatīt reklāmas un ieskatus

Rādīt ierakstu augstāk

Vienas slimības nākamā blakne: Ievas Plūmes stāsts par dzīvi ar divām retām slimībām

Pasaulē patlaban ir zināmas aptuveni 7000 reto slimību diagnozes, un tās skar 6-8 % pasaules iedzīvotāju. Par savu personīgo pieredzi, sadzīvojot ar retu slimību diagnozēm, TV3 sarunu raidījumā "Zilonis studijā" dalās Latvijas Reto slimību alianses dibinātāja un valdes locekle Ieva Plūme.

Šogad Pasaules Pulmonālās hipertensijas dienas 2025 pasākumu atbalstīja Pulmonary Hypertension Association Europe, SIA "Hipnos", biofarmācijas uzņēmums "Gossamer Bio Ltd." un Skrīveru Pārtikas Kombināts.

Pasākuma telpās ir nodrošināta piekļūstamība cilvēkiem ar invaliditāti, vecākiem ar maziem bērniem un senioriem. Pasākumā tiks nodrošināta surdotulkošana.

Pēc statistikas datiem pasaulē pulmonālā hipertensija ir diagnosticēta vairāk nekā 25 miljoniem cilvēku. Eiropā ir ap 35 tūkstošiem plaušu hipertensijas pacientu. Balstoties uz SPKC datiem, Latvijā 2024. gadā nogalē bija reģistrētas 270 personas ar dažādu reto tipu plaušu hipertensiju un 35 hroniskās trombembolisko plaušu hipertensijas pacienti.

Nigeria

PUNCH business extra

NCDMB urges IOCs to engage local companies

Nigerian firm leads energy in FT Africa ranking

Telcos battle 33 outages in May

CBN sets 12-month deadline for new AML standards

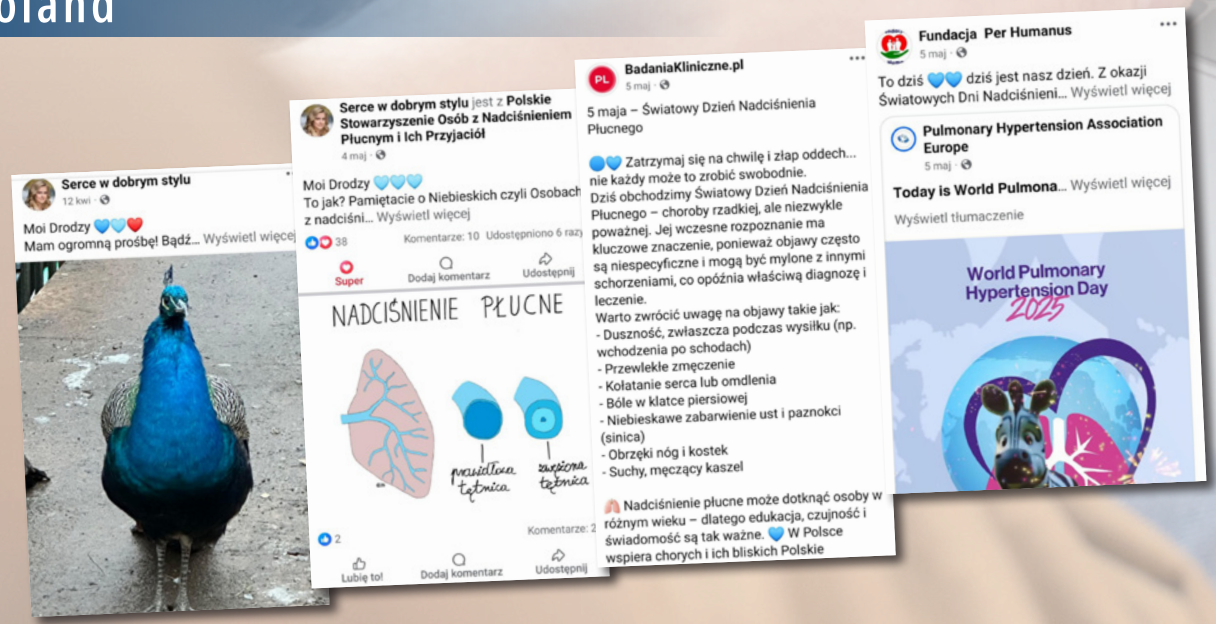
Keyamo, stakeholders set for aviation book launch

Public-private partnership vital for Africa – Terminal operator

NECA warns against overreliance on monetary tools

All stories continue on www.punchng.com

Poland



Serce w dobrym stylu
12 kwi
Moi Drodzy 💙🩵❤️
Mam ogromną prośbę! Bądź... Wyświetl więcej

Serce w dobrym stylu jest z **Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół**
4 maj
Moi Drodzy 🩵🩵🩵
To jak? Pamiętacie o Niebieskich czyli Osobach z nadciśni... Wyświetl więcej
38 Komentarze: 10 Udostępniono 6 razy
Super Dodaj komentarz Udostępnij

2 Komentarze: 2
Lubię to! Dodaj komentarz Udostępnij

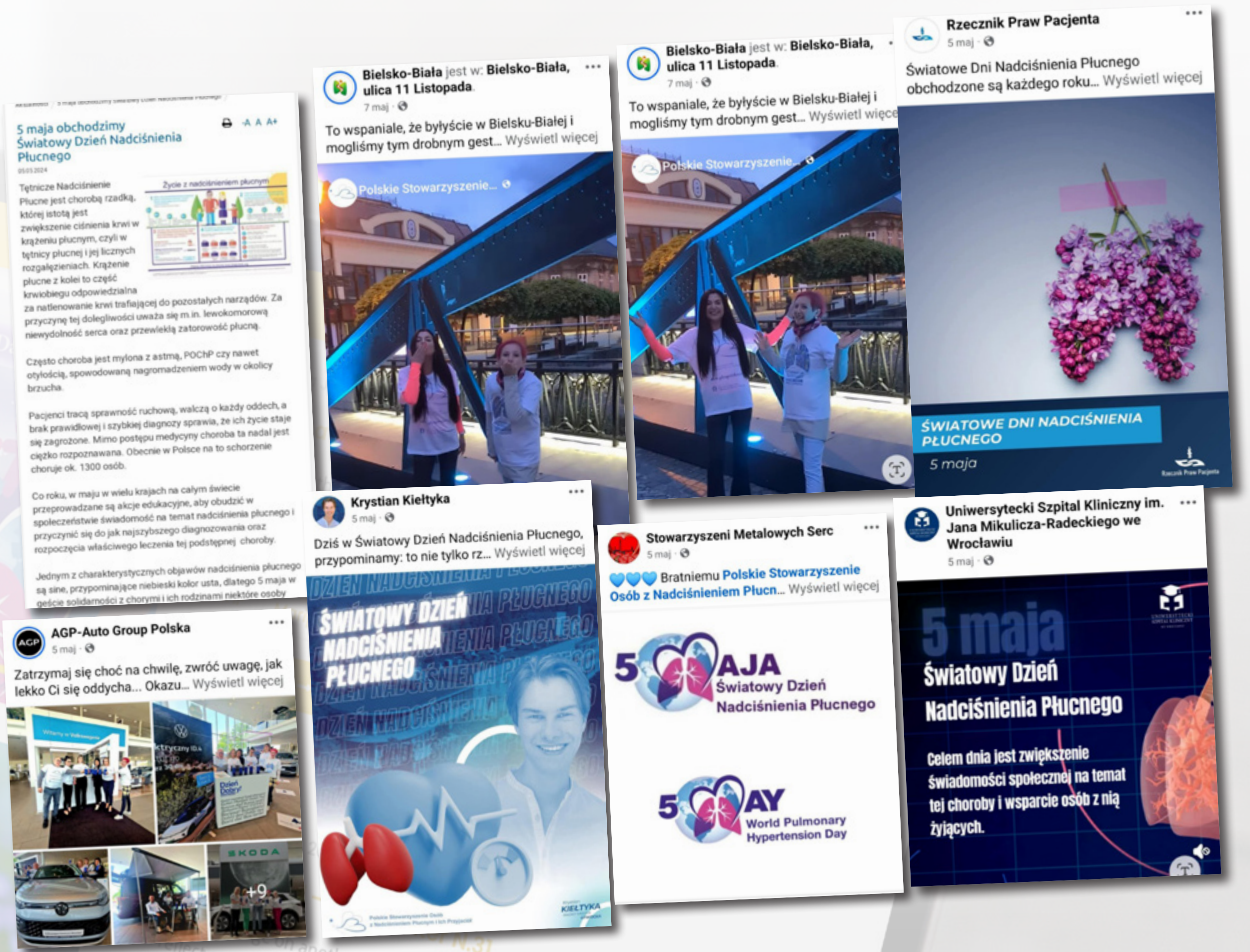
BadaniaKliniczne.pl
5 maj
5 maja – Światowy Dzień Nadciśnienia Płucnego

🔵💙 Zatrzymaj się na chwilę i złap oddech... nie każdy może to zrobić swobodnie.
Dziś obchodzimy Światowy Dzień Nadciśnienia Płucnego – choroby rzadkiej, ale niezwykle poważnej. Jej wczesne rozpoznanie ma kluczowe znaczenie, ponieważ objawy często są niespecyficzne i mogą być mylone z innymi schorzeniami, co opóźnia właściwą diagnozę i leczenie.
Warto zwrócić uwagę na objawy takie jak:
- Duszność, zwłaszcza podczas wysiłku (np. wchodzenia po schodach)
- Przewlekłe zmęczenie
- Kołatanie serca lub omdlenia
- Bóle w klatce piersiowej
- Niebieskawe zabarwienie ust i paznokci (sinica)
- Obrzęki nóg i kostek
- Suchy, męczący kaszel

🫁 Nadciśnienie płucne może dotknąć osoby w różnym wieku – dlatego edukacja, czujność i świadomość są tak ważne. 💙 W Polsce wspiera chorych i ich bliskich Polskie

Fundacja Per Humanus
5 maj
To dziś 🩵🩵 dziś jest nasz dzień. Z okazji Światowych Dni Nadciśnieni... Wyświetl więcej

Pulmonary Hypertension Association Europe
5 maj
Today is World Pulmona... Wyświetl więcej
Wyświetl tłumaczenie



5 maja obchodzimy Światowy Dzień Nadciśnienia Płucnego

Tętnicze Nadciśnienie Płucne jest chorobą rzadką, której istotą jest zwiększenie ciśnienia krwi w krążeniu płucnym, czyli w tętnicy płucnej i jej licznych rozgałęzieniach. Krążenie płucne z kolei to część krwiobiegu odpowiedzialna za natlenowanie krwi trafiającej do pozostałych narządów. Za przyczynę tej dolegliwości uważa się m.in. lewokomorową niewydolność serca oraz przewlekłą zatorowość płucną.

Często choroba jest mylona z astmą, POChP czy nawet otyłością, spowodowaną nagromadzeniem wody w okolicy brzucha.

Pacjenci tracą sprawność ruchową, walczą o każdy oddech, a brak prawidłowej i szybkiej diagnozy sprawia, że ich życie staje się zagrożone. Mimo postępu medycyny choroba ta nadal jest ciężko rozpoznawana. Obecnie w Polsce na to schorzenie choruje ok. 1300 osób.

Co roku, w maju w wielu krajach na całym świecie przeprowadzane są akcje edukacyjne, aby obudzić w społeczeństwie świadomość na temat nadciśnienia płucnego i przyczynić się do jak najszybszego diagnozowania oraz rozpoczęcia właściwego leczenia tej podstępnej choroby.

Jednym z charakterystycznych objawów nadciśnienia płucnego są sine, przypominające niebieski kolor usta, dlatego 5 maja w geście solidarności z chorymi i ich rodzinami niektóre osoby

Bielsko-Biała jest w: **Bielsko-Biała, ulica 11 Listopada**.
7 maj
To wspaniale, że byłyście w Bielsku-Białej i mogliśmy tym drobnym gest... Wyświetl więcej

Rzecznik Praw Pacjenta
5 maj
Światowe Dni Nadciśnienia Płucnego obchodzone są każdego roku... Wyświetl więcej

AGP-Auto Group Polska
5 maj
Zatrzymaj się choć na chwilę, zwróć uwagę, jak lekko Ci się oddycha... Okazu... Wyświetl więcej

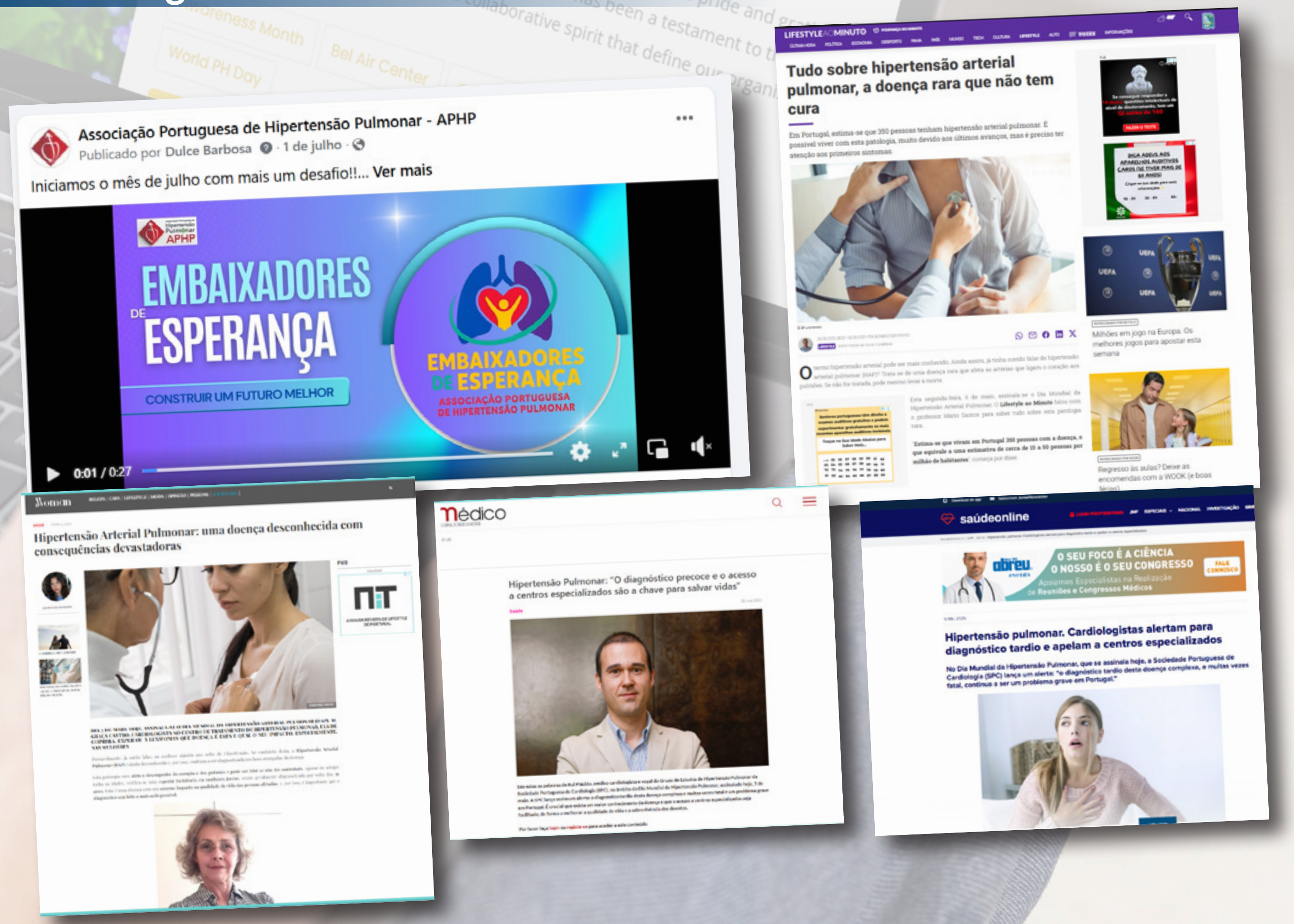
Krystian Kiełtyka
5 maj
Dziś w Światowy Dzień Nadciśnienia Płucnego, przypominamy: to nie tylko rz... Wyświetl więcej

Stowarzyszeni Metalowych Serc
5 maj
💙💙💙 Bratniemu Polskie Stowarzyszenie Osób z Nadciśnieniem Płucn... Wyświetl więcej

Uniwersytecki Szpital Kliniczny im. Jana Mikulicza-Radeckiego we Wrocławiu
5 maj

Celem dnia jest zwiększenie świadomości społecznej na temat tej choroby i wsparcie osób z nią żyjących.

Portugal



Associação Portuguesa de Hipertensão Pulmonar - APHP
Publicado por Dulce Barbosa · 1 de julho
Iniciamos o mês de julho com mais um desafio!!... Ver mais

Tudo sobre hipertensão arterial pulmonar, a doença rara que não tem cura

Em Portugal, estima-se que 350 pessoas tenham hipertensão arterial pulmonar. É possível viver com esta patologia, muito devido aos últimos avanços, mas é preciso ter atenção aos primeiros sintomas.

O termo hipertensão arterial pode ser mais conhecido. Ainda assim, já tinha ouvido falar de hipertensão arterial pulmonar (HAP)? Trata-se de uma doença rara que afeta as artérias que ligam o coração aos pulmões. Se não for tratada, pode mesmo levar à morte.

Esta segunda-feira, 5 de maio, assinala-se o Dia Mundial da Hipertensão Arterial Pulmonar. O **Lifestyle ao Minuto** falou com o professor Mário Santos para saber tudo sobre esta patologia rara.

"Estima-se que vivam em Portugal 350 pessoas com a doença, o que equivale a uma estimativa de cerca de 15 a 50 pessoas por milhão de habitantes", começa por dizer.

Milhões em jogo na Europa. Os melhores jogos para apostar esta semana

Regresso às aulas? Deixe as encomendas com a WOOK (e boas férias)

Hipertensão Arterial Pulmonar: uma doença desconhecida com consequências devastadoras

Hipertensão Pulmonar: "O diagnóstico precoce e o acesso a centros especializados são a chave para salvar vidas"

Hipertensão pulmonar. Cardiologistas alertam para diagnóstico tardio e apelam a centros especializados

No Dia Mundial da Hipertensão Pulmonar, que se assinala hoje, a Sociedade Portuguesa de Cardiologia (SPC) lança um alerta: "o diagnóstico tardio desta doença complexa, e muitas vezes fatal, continua a ser um problema grave em Portugal."

CISION mariana
ID: 117004007
06-05-2025
Meio: Imprensa
País: Portugal
Área: 365,41cm²
Âmbito: Femininas e Moda
Period.: Semanal
Pág: 32-33

Saúde A doença que afeta mulheres jovens

HIPERTENSÃO ARTERIAL

É uma doença rara mas pode atingir até pessoas saudáveis. Contudo, as mulheres entre os 30 e os 50 anos são as mais suscetíveis.

Texto: Inês Carvalho Esteves; Fotos: Shutterstock

Já deve ter ouvido falar de hipertensão, mas já conhece a Hipertensão Arterial Pulmonar (HAP)? É uma doença que afeta o desempenho do coração e dos pulmões e é mais rara e perigosa que a mais comum. Afeta bastante mulheres jovens e para conhecer melhor esta doença, falámos com a cardiologista e coordenadora da Unidade Funcional de Hipertensão Pulmonar do Hospital Garcia de Orta, Filipa Ferreira.

• Em que aspeto é que a Hipertensão Arterial Pulmonar (HAP) afeta o coração e os pulmões?

A HAP é uma doença rara, mas grave, que provoca um aumento da pressão nas artérias dos pulmões. Isso faz com que o coração direito, responsável por bombear o sangue para os pulmões, tenha que fazer um esforço muito maior. O coração direito tem uma capacidade muito limitada de conseguir vencer pressões mais altas e com o tempo, esse esforço excessivo leva a insuficiência cardíaca. Ou seja, afeta inicialmente os pulmões com uma repercussão no coração, dificultando a circulação e oxigenação do sangue.

• Pode afetar todas as idades, mas afeta mais mulheres jovens. Porque será?

A HAP pode surgir em qualquer idade, até em crianças. Tradicionalmente, era mais frequente em mulheres entre os 30 e os 50 anos, o que poderá estar relacionado com fatores hormonais e genéticos que tornam as mulheres mais suscetíveis. No entanto, este padrão tem vindo a mu-

A HAP provoca o aumento da pressão nas artérias

CISION mariana
ID: 117004007
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PULMONAR

dar sobretudo no que diz respeito à idade. Atualmente, o diagnóstico está a tornar-se mais comum em faixas etárias mais avançadas. Esta alteração pode dever-se ao facto de, em muitos casos, a HAP estar associada a outras doenças — como doenças do tecido conjuntivo, infeção por HIV ou doença hepática — que são mais prevalentes em pessoas mais velhas. Além disso, a exposição a certos fármacos, agentes de quimioterapia, drogas ou toxinas também pode estar na origem da doença, o que ajuda a explicar a ocorrência em diferentes idades.

• Como é que esta doença é detetada?

O sintoma mais comum e normalmente também o primeiro a aparecer é falta de ar ao fazer esforços. No entanto, pode haver outros sintomas associados, como cansaço, tonturas ou desmaios, inchaço das pernas e desconforto no peito. Como são sintomas inespecíficos, confundem-se facilmente com outras doenças cardíacas ou pulmonares e por isso o diagnóstico muitas vezes é tardio. O ecocardiograma é fundamental para levantar a suspeita e deve ser feito sempre que há sintomas sugestivos, mas o diagnóstico definitivo é feito através do cateterismo cardíaco direito, que permite medir diretamente a pressão nas artérias pulmonares.

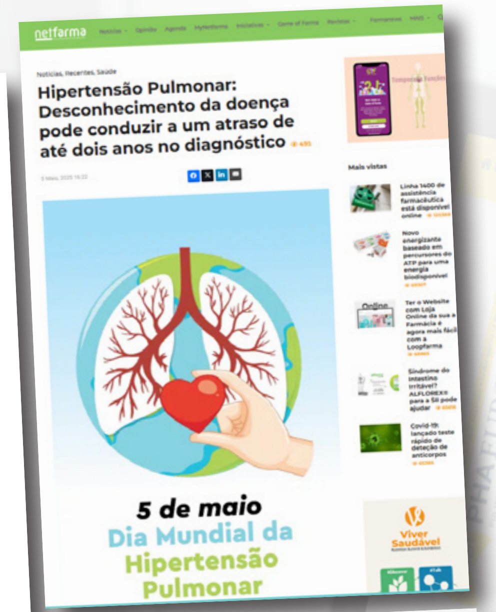
• Não há cura, mas qual é o prognóstico? Que tratamentos são feitos?

É verdade que ainda não há cura, mas os tratamentos evoluíram muito nos últimos anos e tem havido muita investigação nesta área. Hoje conseguimos melhorar muito a qualidade de vida dos doentes, melhorar os sintomas e prolongar a vida. O tratamento inclui, sobretudo, medicamentos específicos para dilatar os vasos dos pulmões que é uma terapêutica que está disponível apenas em centros de tratamento de hipertensão pulmonar. Em situações muito graves ou com resposta insatisfatória aos medicamentos, pode ser considerada a opção de transplante pulmonar.

Fármacos ou toxinas podem causar a doença

Diagnóstico complexo

É uma condição rara mas pode afetar jovens e até atletas, desafiando a ideia de que só atinge pessoas doentes ou idosas. Em alguns casos, a HAP é idiopática, ou seja, surge sem causa aparente, o que torna o diagnóstico ainda mais complexo.



netfarma

Notícias, Recentes, Saúde

Hipertensão Pulmonar: Desconhecimento da doença pode conduzir a um atraso de até dois anos no diagnóstico

SAPO JORNAIS

Tudo sobre hipertensão arterial pulmonar, a doença rara que não tem cura

Em Portugal, estima-se que 350 pessoas tenham hipertensão arterial pulmonar. É possível viver com esta patologia, muito devido aos últimos avanços, mas é preciso ter atenção aos primeiros sintomas.

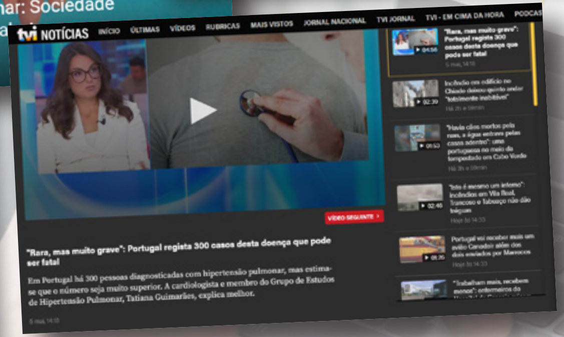
Hipertensão arterial pulmonar: Sociedade Portuguesa de Cardiologia a
diagnóstico tardio

sic notícias

15:35, 30 abr.2025

A VER Hipertensão arterial pulmonar: doença incurável afeta mais as mulheres jovens

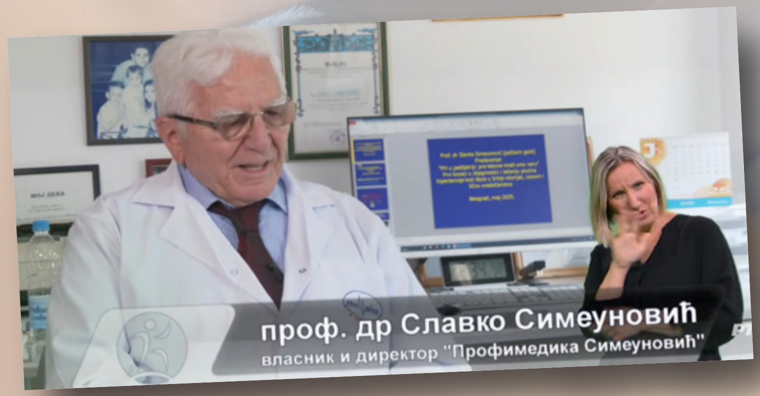
Associação Portuguesa de Hipertensão Pulmonar - APHP



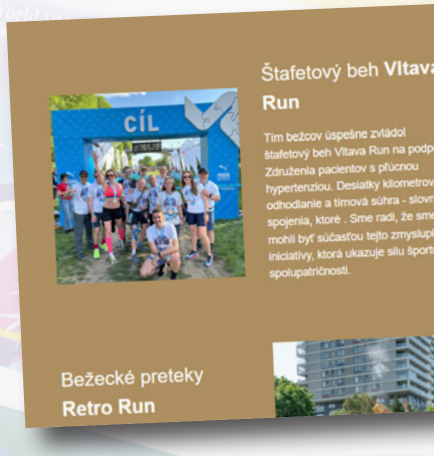
"Rara, mas muito grave": Portugal regista 300 casos desta doença que pode ser fatal

Em Portugal há 300 pessoas diagnosticadas com hipertensão pulmonar, mas estima-se que o número seja muito superior. A cardiologista e membro do Grupo de Estudos de Hipertensão Pulmonar, Tatiana Guimarães, explica melhor.

Serbia



Slovakia



Štafetový beh Vltava Run

Tím bežcov úspešne zvládol štafetový beh Vltava Run na podpor Združenia pacientov s pľúcnou hypertenziou. Desiatky kilometrov, odhodlanie a tímová súhra - slovné spojenia, ktoré . Sme radi, že sme mohli byť súčasťou tejto zmysluplnej iniciatívy, ktorá ukazuje silu športu a spolupatričnosti.

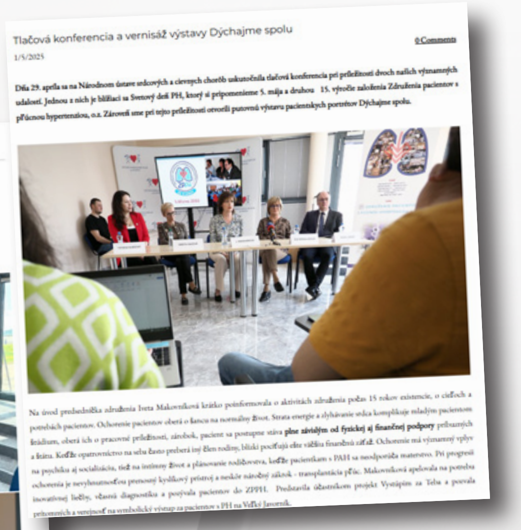
Bežecké preteky Retro Run

Príspevok od Národný ústav srdcových a cievnych chorôb, a. s.

Život s pľúcnou artériovou hypertenziou je každodenný boj. Ochorenie sa prejavuje zvýšeným tlakom v pľúcnych cievach, ktoré sa zužujú, tvoria sa v nich krvné zrazeniny alebo zanikajú, čo spôsobuje zvýšenú námahu srdca. Príznaky ako dýchavičnosť, únava, omdlievanie, opuchy nôh a brucha alebo tlak na hrudi sú spočiatku nenápadné, pripisované iným diagnózam aj psychike.

Link na reportáž TA3:
https://www.ta3.com/.../velmi-lahko-sa-zadychate...

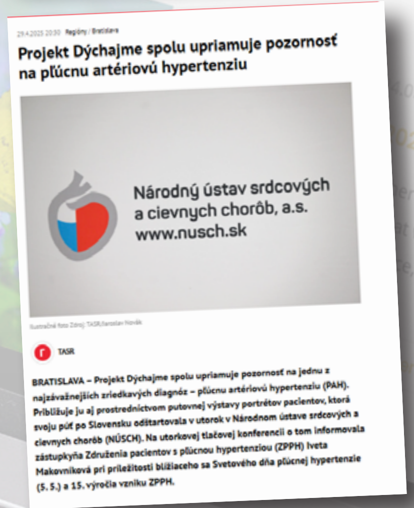
#tlacovakonferencia #plucnahypertenzia #pacienti #zdruzenie #zriedkavechoroby #ochorenie #odbornici #osveta #fotografie #vystava #krst #vernisaz #nusch_dkc



Tlačová konferencia a vernisáž výstavy Dýchajme spolu

1/5/2025

Dňa 29. apríla sa na Národnom ústave srdcových a cievnych chorôb uskutočnila tlačová konferencia pri príležitosti dvoch našich významných udalostí. Jednou z nich je blížiaci sa Svetový deň PH, ktorý si pripomenieme 5. mája a druhou 15. výročie založenia Združenia pacientov s pľúcnou hypertenziou, o.z. Zároveň sme pri tejto príležitosti otvorili putovnú výstavu pacientskych portrétov Dýchajme spolu.



Regióny / Bratislava

Projekt Dýchajme spolu upriamuje pozornosť na pľúcnu artériovú hypertenziu

TASR

BRATISLAVA – Projekt Dýchajme spolu upriamuje pozornosť na jednu z najzávažnejších zriedkavých diagnóz – pľúcnu artériovú hypertenziu (PAH). Približuje ju aj prostredníctvom putovnej výstavy portrétov pacientov, ktorá svoju púť po Slovensku odštartovala v utorok v Národnom ústave srdcových a cievnych chorôb (NÚSCH). Na utorkovej tlačovej konferencii o tom informovala zástupkyňa Združenia pacientov s pľúcnou hypertenziou (ZPPH) Iveta Makovníková pri príležitosti blížiaceho sa Svetového dňa pľúcnej hypertenzie (5. 5.) a 15. výročia vzniku ZPPH.

TERAZ.SK

Dýchajme spolu upriamuje pozornosť na pľúcnu artériovú hypertenziu

Primárka oddelenia zlyhávania a transplantácie srdca NÚSCH Eva Goncalvesová dodala, že pacienti s PAH sú liečení v špecializovaných centrách.

Pri príležitosti Svetového dňa pľúcnej hypertenzie spojili svoje sily Národný ústav srdcových a cievnych chorôb, a.s., Združenie pacientov s pľúcnou hypertenziou (ZPPH) a občianske združenie Zriedkavé choroby, aby prostredníctvom projektu *Dýchajme spolu* verejnosti pribl najzávažnejších zriedkavých diagnóz – Pľúcnu artériovú hypertenziu(PAH).

Veľmi ľahko sa zadýchate? Zbystrite, môže ísť o zriedkavé, no nevyliečiteľné ochorenie.

Veľmi ľahko sa zadýchate? Zbystrite, môže ísť o zriedkavé, no nevyliečiteľné ochorenie. Zisťovali sme viac | ta3

Viac info v tlačovej správe

Osvetový projekt Dýchajme spolu upozorňuje na závažné a zriedkavé ochorenie pľúc

Pri príležitosti Svetového dňa pľúcnej hypertenzie spojili svoje sily Národný ústav srdcových a cievnych chorôb, a.s. (NÚSCH, a.s.), Združenie pacientov s pľúcnou hypertenziou (ZPPH) a občianske združenie Zriedkavé choroby, aby prostredníctvom projektu Dýchajme spolu verejnosti priblížili jednu z najzávažnejších zriedkavých diagnóz – pľúcnu artériovú hypertenziu (PAH)

HS / SITA

30. 04. 2025 | Z domova | 4 min. čítania | 0 komentárov |

…ber z konferencie / Foto: Facebook

NAŽIVO

Pri výbuchu vo vnútrobloku bytových domov v juhoruskom meste Stavropol prišiel o život prvý námestník primátora tohto mesta Zaur Gurcijev, ktorý svojho času velil leteckým útokom na juhoukrajinské mesto Mariupol. Informovala stanica Rádio Sloboda (RFE/RL), ktorá dodala, že gubernátor Stavropolskej oblasti Vladimir Vladimirov potvrdil Gurcijevovu smrť, píše TASR. Podľa neho vyšetrovatelia pripúšťajú aj verziu, že šlo o pokus o atentát zo strany Ukrajiny.

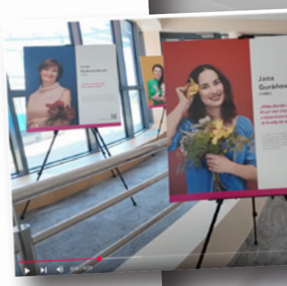
15:43

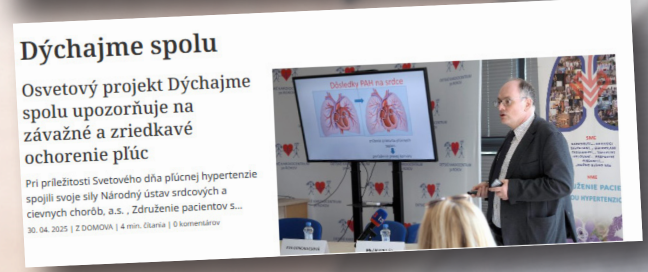
Desaťtisíce demonštrantov v nepálskom hlavnom meste Káthmandu požadovali obnovenie

Veľmi ľahko sa zadýchate? Zbystrite, môže ísť o zriedkavé, no nevyliečiteľné ochorenie. Zisťovali sme viac

ta3/Monika Hajko

2.5.2025 13:12



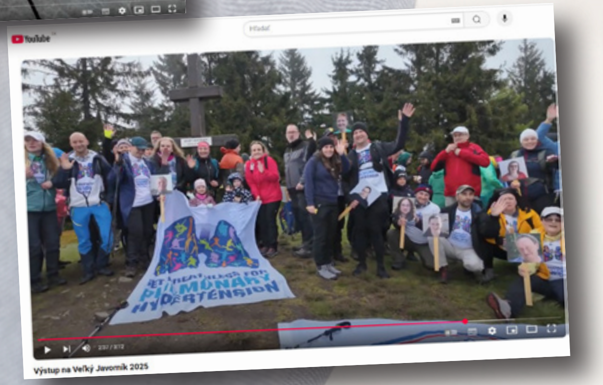


Dýchajme spolu

Osvetový projekt Dýchajme spolu upozorňuje na závažné a zriedkavé ochorenie pľúc

Pri príležitosti Svetového dňa pľúcnej hypertenzie spojili svoje sily Národný ústav srdcových a cievnych chorôb, a.s. , Združenie pacientov s...

30. 04. 2025 | Z DOMOVA | 4 min. čítania | 0 komentárov



Výstup na Veľký Javorník 2025

Slovenia

6-minutni test hoje z nosno ščipalko in slamico v ustih

Si predstavljate, da bi bilo že preobličenje postelje za vas neverjeten napor? Da ne bi zmogli prehoditi niti nekaj stopnic ali dohajati otrok na sprehodu? S tem se namreč soočajo bolniki s pljučno hipertenzijo. Ker so simptomi precej splošni in se jih lahko pripiše več boleznim, gre za zadihanost, utrujenost, tiščanje v prsih, omotico in otekanje nog, je pot do diagnoze in zdravljenja pogosto predolga. Da bi ljudje izkusili, kako je dihati s pljuči takšnega bolnika in bolezen hitreje prepoznali, je Društvo za pljučno hipertenzijo v središču Kranja mimoidočim pripravilo poseben test.

Iz 24UR: V Kranju poseben test

PLJUČNA HIPERTENZIJA

DANES V KRANJU POSEBEN TEST

Zdravje: pljučna hipertenzija

domžalec.si · Sledi

3. maj

Pljučna hipertenzija je redka, a resna bolezen, ki povzroča težko sapo, utrujenost, omotico, otekanje nog. … Prikaži več

DOMZALEC.SI

Svetovni dan pljučne hipertenzije - domžalec.si

Ob svetovnem dnevu pljučne hipertenzije v Društvu za pljučno hipertenzijo Slovenije se

3 komentarjev

Všeč mi je · Komentiraj · Deli z drugimi

LJUBLJANSKE NOVICE

Vredno objave – Društvo za pljučno hipertenzijo Slovenije so včeraj na Slovenskem trgu v Kranju pripravili dogodek 'Vsak vdih šteje'

Kranj, Svetovni dan pljučne hipertenzije, izkušnja bolnic

RTV 365

Misija brez sape

domžalec.si

Kako je dihati s pljuči bolnika? Mimoidoči v Kranju preizkusili šestminutni test hoje

Izjave posameznikov, ki so preizkusili šestminutni test hoje

Med.Over.Net

Kaj bi morali vedeti o bolezni, ki je pogosto zamenjana za astmo?

Ob svetovnem dnevu pljučne hipertenzije Društvo za pljučno hipertenzijo Slovenije pričenja kampanjo 'Prepoznajmo pljučno hipertenzijo', s katero želi povečati prepoznavnost bolezni med splošno javnostjo in spodbuditi k zgodnejšemu prepoznavanju simptomov.

Kaj je pljučna hipertenzija?

Forum

Naši strokovnjaki odgovarjajo na vaša vprašanja

Med.Over.Net

17. maj ob 15:17

Nikoli ne veš, koliko zraka boš lahko vdihnil, in le čakaš ali se ti bo zavrtelo ali ne

MED.OVER.NET

Pljučna hipertenzija: Nikoli ne veš, koliko zraka boš lahko vdihnil

Postavitev diagnoze pljučne hipertenzije prinaša dva glavna izziva. Prvi in pogosto najzahtevne…

Deljeno 5-krat

V Kranju je štel vsak vdih

Na Slovenskem trgu v Kranju je potekala ozaveščevalna akcija o pljučni hipertenziji z naslovom Vsak vdih šteje. Osrednja aktivnost dogodka, ki ga je pripravilo Društvo za pljučno hipertenzijo Slovenije, je bil prilagojeni šestminutni test hoje, pri katerem so lahko obiskovalci izkusili, kako težavno je dihanje za bolnike s pljučno hipertenzijo.

RTV 365

ŽIVETI S PLJUČNO HIPERTENZIJO

Živeti s pljučno hipertenzijo

GET BREATHLESS FOR PULMONARY HYPERTENSION

NOVICE

Misija brez sape

V torek, 17. junija 2025 ob 9.00 bo iz Marine Izola izplula zgodba o pogumu, vztrajnosti in povezovanju. 16-letna Jona in njen oče Luka Kobler se podajata na izjemen jadralski izziv, s katerim bosta poskušala postaviti Guinnessov svetovni rekord v najdaljši prejadrani razdalji v dvoje z jadrnico tipa dinghy – brez pomoči in brez dotika kopnega. Na podvig se odpravljata z jadrnico BENETEAU First 14 SE, njun cilj je prejadrati kar 400 navtičnih milj.

avdio.ognjisce.si

AVDIO ARHIV RADIA OGNJIŠČE

JONUKA400 - Misija brez sape

Jona in Luka Kobler, hči in oče, sta v sklopu projekta JONUKA400 - Misija brez sape postavila nov Guinnessov svetovni rekord v najdaljši neprekinjeni prejadrani razdalji v dvoje, brez pomoči in brez dotika kopnega. S podvigom oziroma jadranjem sta osveščala o redki in nevarni bolezni - pljučni arterijski hipertenziji.

Nataša Ličen

3. 7. 2025

Spain ANHP

Comunidad de Madrid

El Hospital público La Paz muestra el día a día de un paciente con hipertensión pulmonar

ESTA ENFERMEDAD AFECTA A APROXIMADAMENTE A UNA DE CADA 100.000 PERSONAS EN ESPAÑA

Hipersensibilízate

Somos Hipertensión Pulmonar

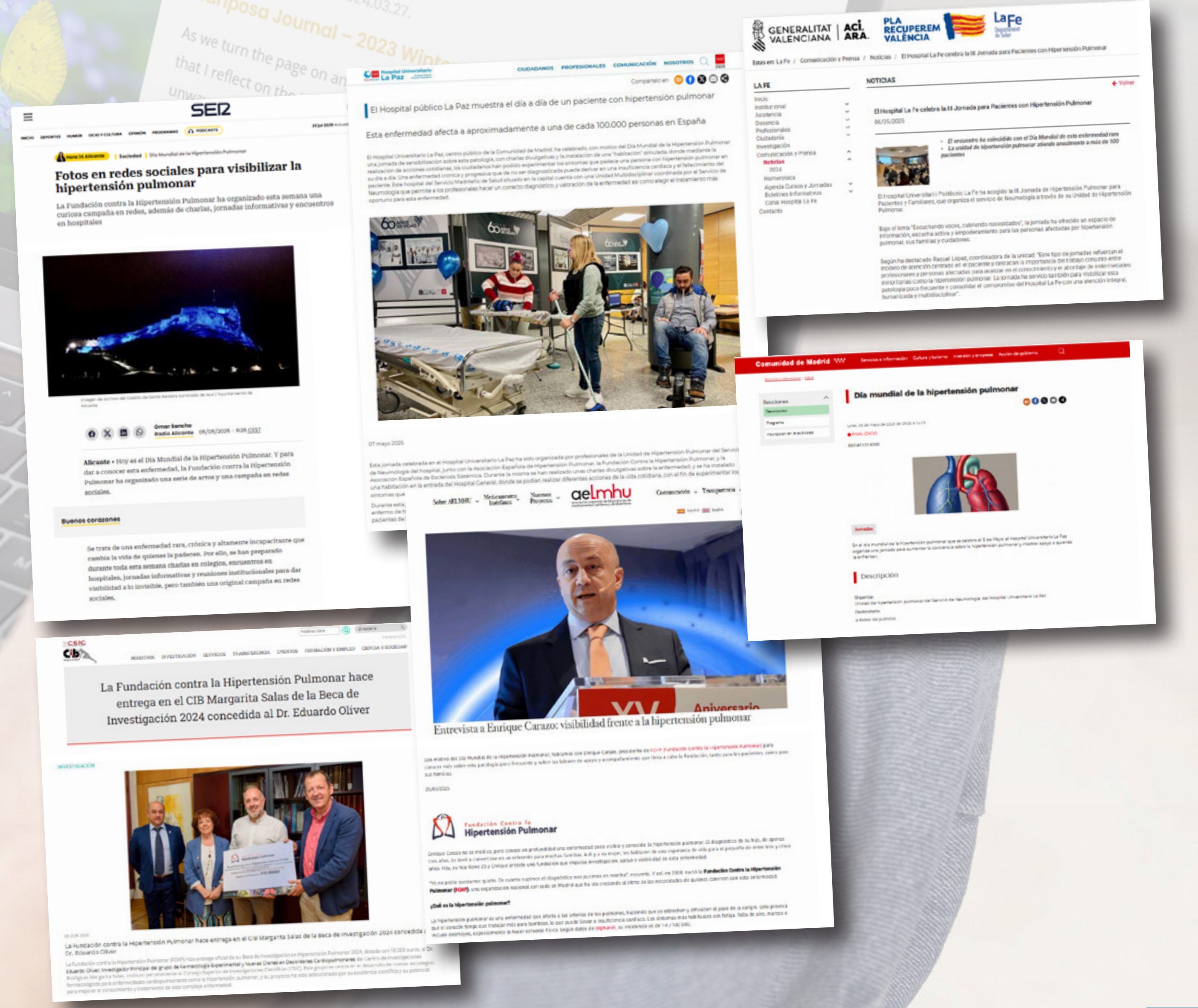
Concienciar es adelantar el diagnóstico

No ignores los síntomas. Infórmate

feder

"Hipersensibilízate, somos Hipertensión Pulmonar".

Spain FCHP



SER

Hora 14 Alicante | Sociedad | Día Mundial de la Hipertensión Pulmonar

Fotos en redes sociales para visibilizar la hipertensión pulmonar

La Fundación contra la Hipertensión Pulmonar ha organizado esta semana una curiosa campaña en redes, además de charlas, jornadas informativas y encuentros en hospitales

Omar Sancho, Radio Alicante, 06/05/2025

Alicante - Hoy es el Día Mundial de la Hipertensión Pulmonar. Y para dar a conocer esta enfermedad, la Fundación contra la Hipertensión Pulmonar ha organizado una serie de actos y una campaña en redes sociales.

Buenos corazones

Se trata de una enfermedad rara, crónica y altamente incapacitante que cambia la vida de quienes la padecen. Por ello, se han preparado durante toda esta semana charlas en colegios, encuentros en hospitales, jornadas informativas y reuniones institucionales para dar visibilidad a lo invisible, pero también una original campaña en redes sociales.

Hospital Universitario La Paz

El Hospital público La Paz muestra el día a día de un paciente con hipertensión pulmonar

Esta enfermedad afecta a aproximadamente a una de cada 100.000 personas en España

07 mayo 2025

GENERALITAT VALENCIANA | ACI. ARA. | PLA RECUPEREM VALÈNCIA | La Fe

NOTICIAS

El Hospital La Fe celebra la III Jornada para Pacientes con Hipertensión Pulmonar

06/05/2025

Comunidad de Madrid

Día mundial de la hipertensión pulmonar

Descripción

CSIC CIB

La Fundación contra la Hipertensión Pulmonar hace entrega en el CIB Margarita Salas de la Beca de Investigación 2024 concedida al Dr. Eduardo Oliver

aelmhu

Entrevista a Enrique Carazo: visibilidad frente a la hipertensión pulmonar

Fundación Contra la Hipertensión Pulmonar

¿Qué es la hipertensión pulmonar?

Spain HPE-ORG

#CONVOZPROPIA

Recomendaciones para pacientes recién diagnosticados

#WordlPHDay2025

"Cada respiración me hace más fuerte; es un recordatorio de que sigo aquí, sigo luchando y no me rindo."

Carmen, Spain

Sometimes it's pulmonary hypertension

El 73 % de los pacientes tiene menores ingresos familiares debido a la HAP.

El apoyo es esencial

73%

Hola, soy Carmen, estoy diagnosticada de hipertensión

Vivir con Hipertensión Pulmonar es posible

5 DE MAYO DÍA MUNDIAL DE LA HIPERTENSIÓN PULMONAR

Millones de personas conviven con la Hipertensión Pulmonar

EN CASOS DE HIPERTENSIÓN PULMONAR SERÁ CLAVE PROTEGER

Alicia Navarro
Psicóloga Clínica
Instructora de Mindfulness

Juntos somos más fuertes

¿Qué le dirías a alguien al que le acaban de diagnosticar?

¿Cómo cuidar la mente cuando se vive con Hipertensión Pulmonar?

Silvia Velasco
Paciente de Hipertensión Pulmonar

5 DE MAYO

Día Mundial de la Hipertensión Pulmonar

#convozpropia

Mayo, mes mundial de la Hipertensión Pulmonar

Taller gratuito

COCINA SALUDABLE

en tiempo récord

Miércoles 11 de junio
19:00h
Plataforma Zoom

Desconexión digital para mejorar tu salud mental

Miércoles 4 de junio
19:00h
Plataforma Zoom

Hipertensión Pulmonar España ORG Pacientes

Taller Abierto y Gratuito: Desconexión Digital para Mejorar la Salud Mental

PHAEUROPE @EuropePHA

Emilia, Spain

Manuel, Spain

Ayuntamiento de Guardo

Día Mundial de la Hipertensión Pulmonar (5 mayo)

Ukraine PHURDA

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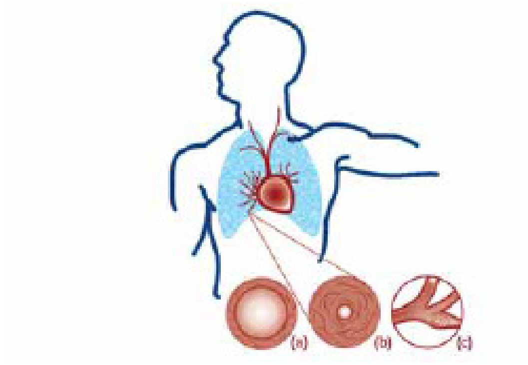
PULMONARY HYPERTENSION ASSOCIATION

AIMS OF PHA EUROPE

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

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

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



a) Cross section of normal pulmonary artery

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

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

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

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

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

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

Members of PHA Europe and contact details

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