PULMONARY HYPERTENSION

Mariposa Journal

WINTER 2024 • PHA EUROPE'S OFFICIAL JOURNAL • N. 33

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

BELAIR CENTER

PHA EUROPE
PULMONARY HYPERTENSION ASSOCIATION
for the patients

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Editor’s memo

WINTER EDITION • 2024

CELEBRATING GROWTH, COLLABORATION, AND INNOVATION IN THE PH COMMUNITY

Dear Friends,

As we approach the conclusion of another extraordinary year, it’s a pleasure to reflect on the milestones and shared achievements that have brought us closer as a community. The past year has been a time of growth, innovation, and unparalleled collaboration, and this issue of Mariposa captures the essence of what makes our pulmonary hypertension (PH) community so vibrant and resilient.

One of the highlights of 2024 was the Annual PH European Conference (APHEC), held in the picturesque city of Castelldefels, Barcelona. Bringing together over 70 delegates from 41 PH associations across 37 countries, APHEC provided an incredible platform for learning, networking, and empowerment. The conference saw the election of a new board, the induction of new members (welcome to Cyprus, Kosovo, Nigeria, and the USA!), and inspiring workshops and presentations. A heartfelt thank you goes to all the speakers, who generously provided their expertise free of charge, and to the sponsors, whose support made this event possible. This issue delves into APHEC’s rich program, including sessions on advocacy, health technology assessment, and the future of PH treatments.

This year’s World Pulmonary Hypertension Day (WPHD) once again demonstrated the power of a united global community. PHA Europe was proud to lead the flagship WPHD event in collaboration with PHA US, showcasing the strength of our shared mission to raise awareness and advocate for better outcomes for PH patients. With contributions and events spanning continents, WPHD reinforced its role as a true global event that connects and inspires all corners of the PH community.

Another significant achievement was PHA Europe’s participation in the 7th World Symposium on Pulmonary Hypertension (WSPH), held in Barcelona, Spain. The WSPH brought together global experts to advance the understanding and care of pulmonary hypertension. PHA Europe was honored to have a representative in one of the task forces, contributing to the discussions that culminated in the publication of proceedings in the European Heart Journal. These proceedings, which cover groundbreaking insights into PH diagnosis, treatment, and care, are an invaluable resource for clinicians, researchers, and advocates worldwide.

A further milestone was the official opening of the Bel Air Center, a groundbreaking virtual platform designed to educate and connect PH patients, caregivers, and stakeholders. The presentation library now boasts over 60 video presentations, with many subtitled in multiple languages and dubbed into several languages, including Croatian, French, German, Polish, Portuguese, Spanish and Swedish, to improve accessibility. While most presentations are in English, some are available in other original languages to better serve a diverse audience. We will continue expanding this library with content in numerous languages, making it a vital resource for the global PH community.
This year also featured a thought-provoking webinar by Prof. Ardeschir Ghofrani, who shared groundbreaking insights into current and emerging PH treatments. His expertise has been a cornerstone of our educational efforts, and this webinar, alongside his contributions to APHEC, reinforces the importance of innovation and personalized care in PH management.

Finally, it’s heartening to witness the expanding reach of Mariposa itself. PHA Europe has grown to include members from all over the world, spanning Europe, Africa, Asia, and the Americas. Additional associations, like those in Peru and Canada, contributed to the summer edition of Mariposa, sharing articles and photos from their vibrant WPHD events. These stories, along with those from our member associations, reflect the diverse experiences, innovative initiatives, and collective dedication of the global PH community.

As you turn the pages of this issue, I hope you feel the energy, dedication, and compassion that define the PH community. Thank you to our members, partners, and supporters for making 2024 a year to remember. Together, let’s continue to raise awareness, drive progress, and create a brighter future for all those affected by pulmonary hypertension.

Warm regards,

Hall Skaara
Project Manager

CONTENTS

BEL AIR CENTER

Bel Air Center has been a success since its grand opening, 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 almost 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 center currently offers over sixty presentations covering various aspects of PH, including high-quality training videos. For example, HTA specialist Neil Bertelsen delivers two insightful presentations that provide an excellent introduction to the HTA process and explain how patient associations can get involved. Additionally, we offer a valuable advocacy presentation that serves as a great resource for anyone engaging with the media.

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

Vienna - Austria • January 23rd - 24th

CORPORATE MEETING

PHA Europe ran its corporate meeting presenting its business plan and discussing future directions and activities.

London - England • January 31st - February 3rd

PVRI CONGRESS

Hall shared a stand with Matt from PHA at the congress, presenting PHA Europe's work.

Riyadh - Saudi Arabia • February 14th - 18th

SAPH2024

Hall was invited as a speaker at the annual Saudi Arabian conference to present PHA Europe and talk about the patient perspective.

Brussels - Belgium • February 26th - 27th

ELHG (EUROPEAN LUNG HEALTH GROUP)

Hall participated in a meeting with the members of ELHG, who met with high EU and EMA officials to discuss lung health issues.

Brussels - Belgium • April 13th - 14th

EPF

Hall participated in the annual general assembly meeting of EPF. The first day was dedicated to lectures about AI.

Barcelona - Spain • April 19th - 20th

IMPAHCT

Hall participated in the 6th edition of the international meeting organised by Ferrer, gathering more than 140 HCPs from all over the world.

Barcelona - Spain • June 26th - July 1st
WPHS
Several representatives from the board and staff participated in the large world PH symposium. PHA Europe had a stand and Hall presented as part of task force 1.

Indianapolis - USA • August 14th - 18th
INTERNATIONAL PHA CONFERENCE
Hall represented PHA Europe's work at the international conference. In addition, he ran a presentation together with a HCP about PH and mens' health issues.

Amsterdam - The Netherlands• June 18th - 19th
IRC (INTERNATIONAL RESPIRATORY COALITION)
Eva participated in the IRC congress together with other self-help groups representing ILD and Sarcoidosis. The emphasis was on how multidisciplinary collaboration improves respiratory outcomes.

INTERNATIONAL RESPIRATORY COALITION

Vienna - Austria • September 7th - 11th
ELF NETWORK DAY, ERS CONGRESS
Several board and staff members participated during these two events. Eva ran a presentation titled: «Changing PAH Patient Lives: A Patient's Perspective

Barcelona - Spain • November 6th - 10th
APHEC (ANNUAL PH EUROPEAN CONFERENCE)
PHA Europe ran its annual conference in November with an Annual General Meeting + three more days of presentations and workshops.

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Virtual • December 11th, 13th
EMA
Hall participated in an EMA online training for patient associations associated with the EMA.

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APHEC 2024:

Uniting the PH Community in Castelldefels

PHA Europe proudly hosted the Annual PH European Conference (APHEC) 2024 in the beautiful city of Castelldefels, Barcelona, from November 6 to 10. This exceptional gathering brought together over 70 delegates from 42 national PH associations across 37 countries, along with healthcare professionals, industry leaders, and patient advocates. Since its inception in 2010, the APHEC has been organized by Gerry Fischer, the General Manager of PHA Europe, who presented both the financial report and the business plan for 2025 during this year's event. APHEC continues to be a beacon for the pulmonary hypertension (PH) community, fostering collaboration, sharing knowledge, and driving impactful change.

A NEW CHAPTER: INTRODUCING THE BOARD

The event began with PHA Europe's Annual General Assembly (AGM), which included the confirmation of the new interim board until the elections in November 2025:

- President: Zdenka Bradac (Croatia)
- Vice President: Dora Erdelyi (Hungary)
- Secretary: Natalia Maeva (Bulgaria)
- Vice Secretary: Nina Kobler (Slovenia)
- Treasurer: Tuulia Nikulainen (Finland)
- Vice Treasurer: Tadeja Ravnik (Slovenia)
- Auditor: Katica Mavracic
- Auditor: Bogdan Heinrich Burduja

We also welcomed new members, including Cyprus and Kosovo as a full member, and PHA USA and PHA Nigeria as associated members. While only European associations can become full members, the inclusion of these associated members highlights the global reach and collaborative spirit of our community.

EMPOWERING THROUGH EDUCATION AND COLLABORATION

The conference agenda featured a diverse mix of presentations, workshops, and networking sessions. Highlights from the event included:
Day 1: PHA Europe's annual activity and social media reports presented by Maleen Fischer and BC Hub, followed by presentations from patient advocates Hall Skaara and Eva Otter, who outlined plans for 2025.
Day 2: A keynote by Matt J. Granato, CEO of PHA USA, who shared insights on high-quality PH care through accreditation programs and the PHAR registry. Interactive workshops led by Neil Bertelsen and BOLDT BPI Partners equipped attendees with advocacy skills and insights into health technology assessment (HTA), including role-playing scenarios like TV interviews and mock political meetings.
Day 3: Clinical trial presentations and discussions with pharmaceutical leaders provided a deeper understanding of emerging therapies. The day ended on a celebratory note with a gala dinner, dancing, and networking.
Day 4: Educational sessions featured experts such as Prof. Mona Lichtblau (Pregnancy and PH), Prof. Polona Mlakar (CTEPH and its treatment options), and Prof. Ardeschir Ghofrani (current and future PH treatments). Their presentations underscored the advancements in personalized care and the transformative potential of new therapies like sotatercept.

TWO PATIENT SURVEYS

At APHEC 2024, the AOP Orphan survey provided valuable insights into the experiences and challenges of PH patients and their caregivers. Conducted in partnership with PHA Europe, the survey spanned nine European countries and gathered responses from 619 participants.

One of the most intriguing findings was the differing priorities and challenges faced by patients and caregivers. While patients often sought information to manage their disease, caregivers emphasized the need for psychological support. These findings underscore the importance of tailoring support programs to meet the distinct needs of both groups.

While not a central focus of the conference, the Pulmonary Vascular Research Institute (PVRI) Global Patient Survey from 2024 was also closely related to the themes discussed. This landmark survey engaged 3,770 participants across 88 countries and was translated into 24 languages. PHA Europe played a significant role in translating the survey and encouraging participation from member associations. The survey offers a wealth of data that will be analyzed in the coming years to shape clinical guidelines, research priorities, and health policies. Furthermore, PVRI plans to expand the survey to additional countries in 2025, ensuring even broader representation.

BEL AIR CENTER: A FOCUS OF APHEC

The Bel Air Center, PHA Europe’s virtual platform, was a central focus during APHEC 2024. All presentations (excluding those from pharmaceutical companies) were recorded and later uploaded to the platform, making them accessible to a global audience. Highlights include Professor Ghofrani’s talk, „PH Treatment Today and in the Future,” subtitled in nine major languages, as well as insightful sessions from Prof. Mlakar and Prof. Lichtblau.

Neil Bertelsen’s workshop on health technology assessment (HTA) and the other advocacy workshops from BOLDT BPI Partners are also available on the platform. These resources provide a wealth of knowledge for patients, caregivers, and stakeholders seeking the latest insights into pulmonary hypertension care and advocacy.

STRENGTHENING OUR COMMUNITY

APHEC continues to unite the PH community, empowering member associations through shared knowledge and fostering collaboration between patient leaders and medical experts. The event provides tools and resources for joint action, aligning us with our shared goals: early diagnosis, equitable access to treatments, comprehensive care, and ultimately, a cure for pulmonary hypertension.

PHA Europe extends heartfelt thanks to all participants, speakers, and sponsors for making APHEC 2024 a success. Together, we continue to empower one another, driving progress for the PH community.

PHA EUROPE AT THE 7TH WORLD PH SYMPOSIUM:

Advancing Global Collaboration in Pulmonary Hypertension

PHA Europe is honored to have been represented at the 7th World Symposium on Pulmonary Hypertension (WSPH), a landmark event held in Barcelona, Spain. This prestigious symposium serves as a pivotal forum for PH experts worldwide to share knowledge, foster collaboration, and develop strategies to improve outcomes for pulmonary hypertension patients globally. Our representative, Hall Skaara, participated as a member of one of the specialized task forces (task force one), contributing to the important discussions that have now culminated in the publication of the official proceedings.

THE 7TH WORLD PULMONARY HYPERTENSION SYMPOSIUM AND ITS TASK FORCES

The 7th WPHS established 15 task forces that focused on various critical areas of PH. Notably, this symposium marked only the second time that patients were directly involved in task forces, underscoring the importance of including patient voices in shaping clinical guidelines and research priorities.

Here is a list of the 15 task forces from the 7th WPHS:

TASK FORCE 1: Patient Perspective – Focused on integrating the patient's voice and experience into PH research and care guidelines.

TASK FORCE 2: Pathology and Pathobiology – Examined the underlying mechanisms of PH to better understand disease progression.

TASK FORCE 3: Genetic and Molecular Mechanisms – Investigated the genetic and molecular bases of PH, exploring how these factors contribute to disease development.

TASK FORCE 4: Imaging and Functional Evaluation – Studied advanced imaging techniques and functional assessments to improve PH diagnosis and monitoring.

TASK FORCE 5: Risk Assessment and Prognosis – Developed strategies for assessing patient risk and predicting disease outcomes.

TASK FORCE 6: Pharmacological Treatment – Reviewed current and emerging pharmacological therapies for PH.

TASK FORCE 7: Interventional and Surgical Treatment – Explored interventional and surgical options, including lung transplantation and pulmonary endarterectomy.

TASK FORCE 8: Pediatric PH – Addressed the unique challenges of diagnosing and treating PH in children.

TASK FORCE 9: Exercise and Rehabilitation – Focused on the role of exercise and rehabilitation in managing PH.

TASK FORCE 10: PH Associated with Left Heart Disease – Investigated PH when associated with left heart disease.

TASK FORCE 11: PH Associated with Lung Diseases – Examined the links between PH and various lung diseases, including COPD and interstitial lung disease.

TASK FORCE 12: PH Associated with Chronic Thromboembolic Pulmonary Hypertension (CTEPH) – Studied PH in the context of CTEPH and other thromboembolic conditions.

TASK FORCE 13: Biomarkers and Clinical Trials – Analyzed biomarkers for PH and discussed the design and conduct of clinical trials.

TASK FORCE 14: Epidemiology and Registries – Explored the epidemiology of PH and the role of patient registries in understanding the disease.

TASK FORCE 15: Future Directions and Innovations – Focused on emerging technologies and innovative approaches in PH care.

THE IMPACT OF TASK FORCE 1: AMPLIFYING THE PATIENT VOICE

Task Force 1, led by Dr. Jimmy Ford, was uniquely positioned as the first among the 15 task forces, underscoring the importance of the patient perspective. Our group included four doctors— Dr. Simon Gibbs, Dr. Adam Torbicki, Dr. Victor Moles, and Dr. Ford himself— alongside two PH patients: myself (Hall Skaara) and Colleen Brunetti. We were also joined by Pisana Ferrari, a former PH patient who has undergone a double lung transplant, and Gergely Meszaros, a dedicated patient advocate.

Our task force focused on exploring the global challenges that PH patients face in accessing care, as well as the critical need for multidimensional patient support and advocacy. We highlighted the role of patient associations in providing support and improving patient outcomes and emphasized the potential of patient-reported outcome measures (PROMs) in enhancing diagnosis and treatment plans. The inclusion of the patient perspective in our discussions and recommendations aims to ensure that the evolving needs and experiences of patients are at the heart of PH research and clinical practice. The proceedings of Task Force 1 not only discuss the state of PH care globally but also offer insights into the potential impacts of current global threats, such as pandemics, climate change, and armed conflict, on PH patients. Our report includes a summary of global surveys capturing patient and provider experiences and challenges regarding care access, alongside potential solutions for improving these outcomes worldwide.

The publication of these proceedings in the European Respiratory Journal is a testament to the hard work and dedication of everyone involved. I encourage you to explore the full findings and see how the patient perspective is helping to shape the future of pulmonary hypertension care.

For more details, you can read the full proceedings in the European Respiratory Journal. Links can be found in the news section of PHA Europe's website *(www.phaeurope.org)*.

Hall Skaara
Project Manager

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European pulmonary hypertension association

PHA EUROPE'S 2024 CONFERENCE HIGHLIGHTS:

Advancing Advocacy and Collaboration

2024 was a pivotal year for PHA Europe, marked by active participation and leadership in major international conferences, symposiums, and strategic meetings. These engagements provided us with opportunities to present, collaborate, and advocate for pulmonary hypertension (PH) patients. Below is an overview of our key activities and achievements this year.

PVRI CONGRESS IN LONDON, UNITED KINGDOM

The year began with PHA Europe's participation in the Pulmonary Vascular Research Institute (PVRI) Congress, held in London, United Kingdom. At this prestigious global meeting, we shared a stand with our associated member Pulmonary Hypertension Association (PHA) from the United States, which served as a focal point for engaging with many key players in the global PH community. Through our stand, we networked with clinicians, researchers, and patient advocates, fostering important connections and raising awareness of PHA Europe's mission. This event provided valuable opportunities to strengthen relationships and broaden our international network while staying informed about the latest developments in pulmonary vascular diseases.

SAPH2024: ADVANCING PH ADVOCACY IN RIYADH, SAUDI ARABIA

PHA Europe played an integral role at SAPH2024, held in Riyadh, Saudi Arabia, one of the leading global conferences on pulmonary hypertension. As presenters, we shared our perspectives on patient advocacy and engagement, focusing on improving quality of life and access to care for PH patients. The event also offered insights into the latest advancements in PH therapies, underscoring the importance of international collaboration in addressing the unmet needs of PH patients.

EPF'S ANNUAL GENERAL MEETING AND AI CONFERENCE IN BRUSSELS, BELGIUM

In April, PHA Europe participated in the European Patients' Forum (EPF) Annual General Meeting in Brussels, Belgium. This event brought together patient organizations from across Europe to discuss

In April, PHA Europe participated in the European Patients' Forum (EPF) Annual General Meeting in Brussels, Belgium. This event brought together patient organizations from across Europe to discuss healthcare policies and patient rights. Representing the PH community, we engaged in discussions on ensuring equitable access to care and the importance of amplifying patient voices in shaping healthcare policies. Prior to the AGM, we attended a dedicated conference day on Artificial Intelligence (AI) in healthcare. This event explored the transformative potential of AI in diagnostics, treatment, and patient care. The discussions highlighted how AI could revolutionize healthcare delivery, while also addressing the need for inclusivity and ethical considerations for rare disease communities like ours.

IMPAHCT 2024: REPRESENTING THE PATIENT VOICE IN BARCELONA, SPAIN

The IMPAHCT 2024 meeting, organized by Ferrer and held in Barcelona, Spain, was a global event bringing together key stakeholders to strategize on advancing respiratory health worldwide. PHA Europe contributed by representing the patient voice, presenting on the importance of patient-centered approaches in policy-making and advocating for improved care for pulmonary hypertension. The meeting emphasized the need for patient perspectives in global health strategies and policy development.

WORLD'S 7TH PH SYMPOSIUM IN BARCELONA, SPAIN

PHA Europe also participated in the World's 7th PH Symposium, held in Barcelona, Spain, a major global event dedicated to advancing research and clinical care in pulmonary hypertension. A separate article in this publication provides a detailed account of our involvement and the key takeaways from this landmark symposium.

INTERNATIONAL PHA CONFERENCE IN INDIANAPOLIS, USA

At the International Pulmonary Hypertension Association (PHA) Conference in Indianapolis, USA, PHA Europe ran a joint presentation with a leading PH specialist. Together, we addressed the important topic of PH and men's health, focusing on the gender-specific challenges faced by male patients in terms of diagnosis, treatment, and mental health. This session encouraged meaningful dialogue and emphasized the importance of addressing the unique needs of diverse patient groups. The conference also provided an excellent platform for fostering connections between patients, caregivers, and healthcare professionals while advancing advocacy on a global scale.

INTERNATIONAL RESPIRATORY CONGRESS (IRC) IN AMSTERDAM, NETHERLANDS

PHA Europe's participation in the International Respiratory Congress (IRC) was a notable highlight. During this event, a national working group, ARC, was established to advance respiratory care in the Netherlands. This group includes esteemed experts such as Prof. Dr. David Lang, Doz. Dr. Philipp Douschan, and Doz. Dr. Vasile Foris. Patient representatives from PH Austria, PHA Europe, and other self-help groups like ILD and Sarcoidosis contributed to meaningful discussions.

Additionally, the IRC featured a panel discussion titled „How Teams Advance Respiratory Healthcare Delivery," chaired by IRC President Guy Joos and Dr. Anita Simonds. This session emphasized the importance of multidisciplinary collaboration in improving respiratory healthcare outcomes.

ERS CONGRESS 2024 AND ELF NETWORKING DAY IN VIENNA, AUSTRIA

PHA Europe had a strong presence at the European Respiratory Society (ERS) Congress 2024 and the European Lung Foundation (ELF) Networking Day in Vienna, Austria. Here are some of the sessions where PHA Europe representatives spoke:

- **J&J-Sponsored Satellite Symposium:** A PHA Europe representative delivered a lecture titled «Changing PAH Patient Lives: A Patient's Perspective." This fully attended session underscored the critical importance of integrating patient experiences into the care of pulmonary arterial hypertension (PAH).
- **MSD Patient Voice Symposium:** Another impactful presentation, titled „Overview of the Impact of PAH: What Matters Most to Patients," highlighted the priorities and challenges faced by PAH patients, emphasizing their need for tailored support and innovative treatments.
- **AOP Health Poster Presentation:** The survey conducted by AOP Health/OrphaCare in collaboration with PH Austria and PHA Europe was showcased in a poster presentation titled „Reasons to Join PH Patient Associations: Do Not Forget the Caregivers." This study provided insights into the motivations behind joining patient associations and highlighted the crucial role caregivers play in supporting PH patients.
- **IRC panel discussion:** How teams advance respiratory healthcare delivery aims of this session were how to look at the role of teams contributing to the advancement of respiratory healthcare delivery. Chairs: IRC President Guy Joos and Dr. Anita Simonds
- **Interview with The American Journal of Managed Care - MH Life Sciences:** A PHA Europe representative participated in an interview to share insights into the evolving landscape of PAH care and the role of patient advocacy in shaping healthcare delivery.

STRATEGIC MEETINGS WITH EU AND EMA OFFICIALS IN BRUSSELS, BELGIUM

In collaboration with the European Lung Health Group, PHA Europe participated in high-level meetings with officials from the European Union (EU) and the European Medicines Agency (EMA) in Brussels, Belgium. These meetings, held under the Chatham House Rule, reflect our ongoing efforts to ensure PH patients are represented at the highest levels of decision-making. They demonstrate the importance of patient advocacy in shaping healthcare policies that prioritize patient-centric approaches and equitable access to care.

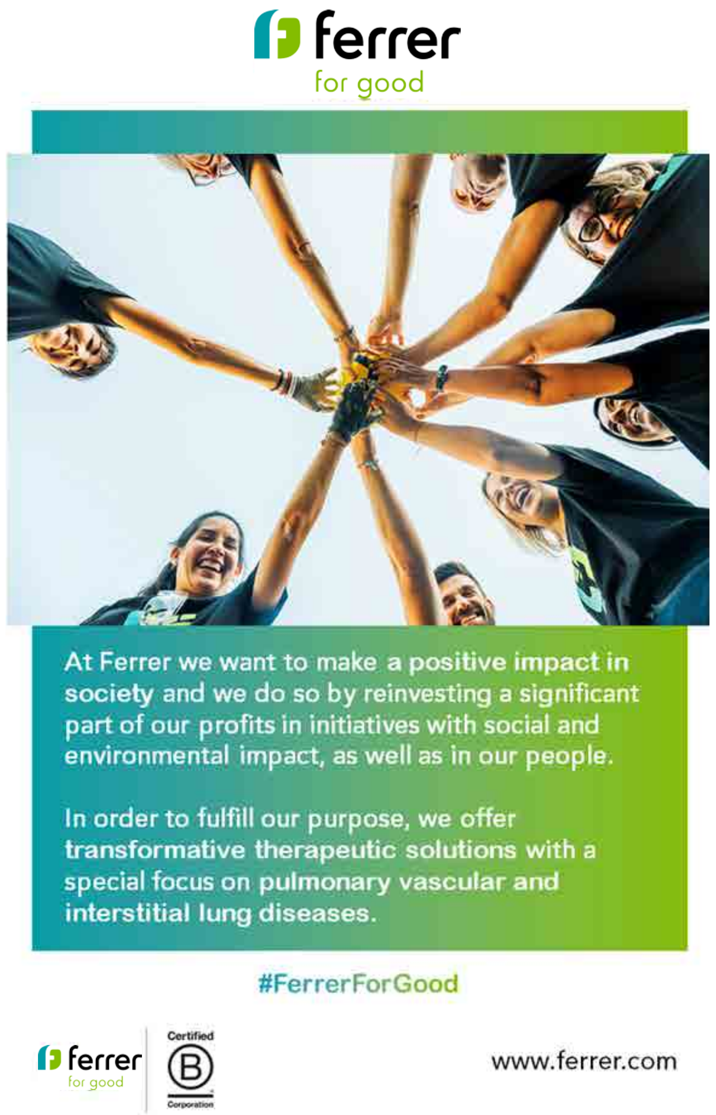
EUPATI PATIENT EXPERT TRAINING: STRENGTHENING PERSONAL EXPERTISE IN MADRID, SPAIN

On a personal note, I successfully completed the EUPATI Patient Expert Training Programme in 2024, which concluded with a final meeting in Madrid, Spain. This program provided in depth training on the medicines research and development process, equipping me to contribute more effectively to discussions on medical innovation and advocacy. This experience has been instrumental in enhancing our ability to advocate for patient-focused healthcare solutions.

LOOKING AHEAD: A UNIFIED VISION FOR PH ADVOCACY

PHA Europe's 2024 engagements have been instrumental in strengthening our advocacy efforts and expanding our network of collaborations. Through active participation, presentations, and discussions, we have worked to ensure that PH remains a priority in global healthcare. We are committed to building on these achievements as we continue to empower patients and advocate for improved care and treatment outcomes in Europe.

Hall Skaara
Project Manager



PHA EUROPE – SOCIAL MEDIA ACTIVITIES

Following WPHD 2024 in May, which was covered in the previous issue of Mariposa, PHA Europe maintained a strong and consistent presence on social media, addressing key topics of interest to the PH community across Europe and beyond.

In June, at the World Symposium on PH in Barcelona, our patient advocate Hall Skaara presented as a member of the task force on the patient perspective, joined by the PHA Europe board, led by our President. In September, at the ERS Congress in Vienna, PHA Europe continued to follow and reinforce its unwavering commitment to patient advocacy during the panels with speakers and presenters, fostering connections. Finally, in November, the Annual PH European Conference (APHEC) held in Barcelona, brought together the entire European PH patient community and those beyond, reuniting patients, esteemed PH healthcare professionals, and pharmaceutical representatives.

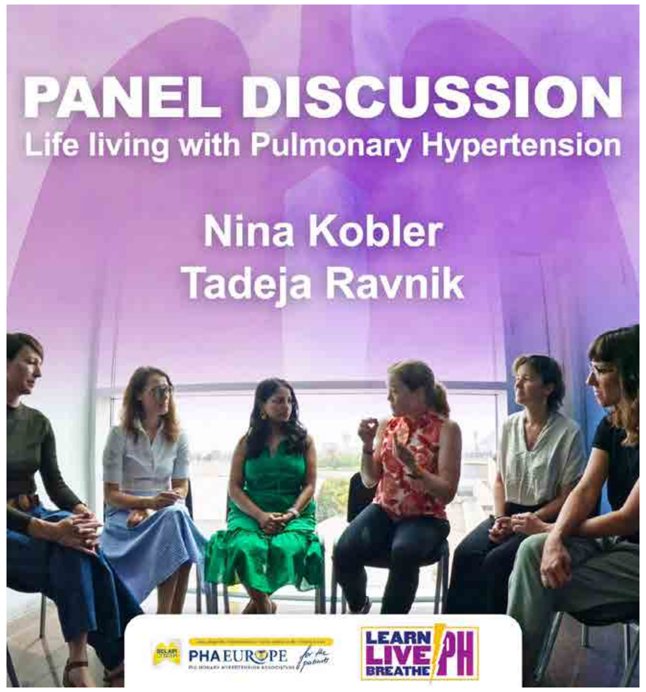
Each of these events, with PHA Europe's participation, was thoroughly covered through a series of posts, providing valuable information to our followers while actively advancing our advocacy efforts online, utilizing clear strategies of serving patients interest to be informed about the developments in the field of PH.

We ensured comprehensive coverage of each event, featuring a diverse range of posts and social media campaigns aimed at raising awareness of PH, advocating for patients' rights and access to care, and sharing vital information—while simultaneously strengthening our presence on social media.


ERS CONGRESS | 2024

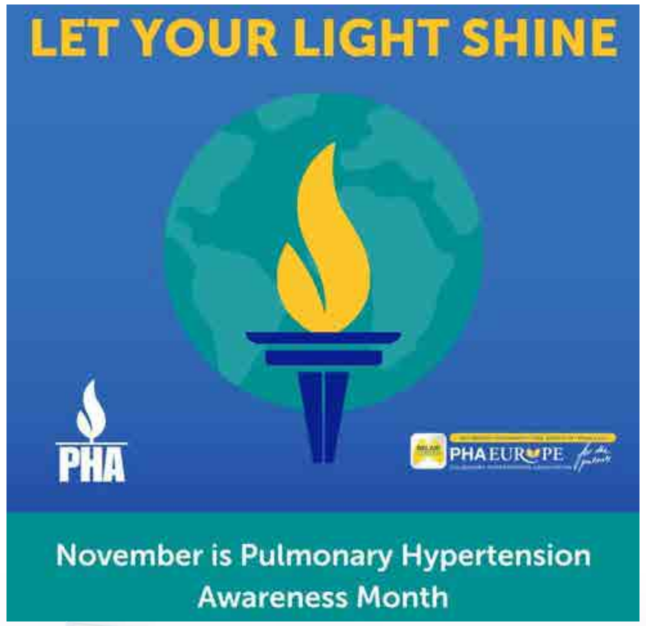
7-11 September | Vienna, Austria

ELF PAC member: Liliya Belenko Gentel (far left), Hall Skaara, ERS president Prof. Monika Gappa, and Oksana Kulish, Ukraine.



PHA Europe successfully closed 2024 by keeping the community informed about our umbrella association's activities while empowering our 40 member associations and PH patients worldwide, sharing their content, and providing them with a space to showcase their efforts. Our social media platforms featured a rich variety of content, including informational posts marking international health-related dates, the promotion of our Bel Air content showcasing insightful presentations by world-renowned PH experts and advocates freely available on our platform, and #goodPHnews highlighting positive developments across Europe withing our PH community. Additionally, our PHamily Photo Album posts series celebrated heartwarming moments within the PH community, captured on inspiring and heartwarming photos of our member associations, while a dedicated series highlighted the tireless work of our patient advocates and board members led by our President Zdenka Bradač and newly elected Vice President Dora Erdelyi.

Activities on our social media accounts also focused on collaboration, which was particularly evident throughout November. As part of our longstanding tradition, we joined forces with PHA US to mark PH Awareness Month by sharing their original posts and actively participating in the „Let Your Light Shine" campaign. This collaboration was further strengthened by the enthusiastic participation of our member associations.



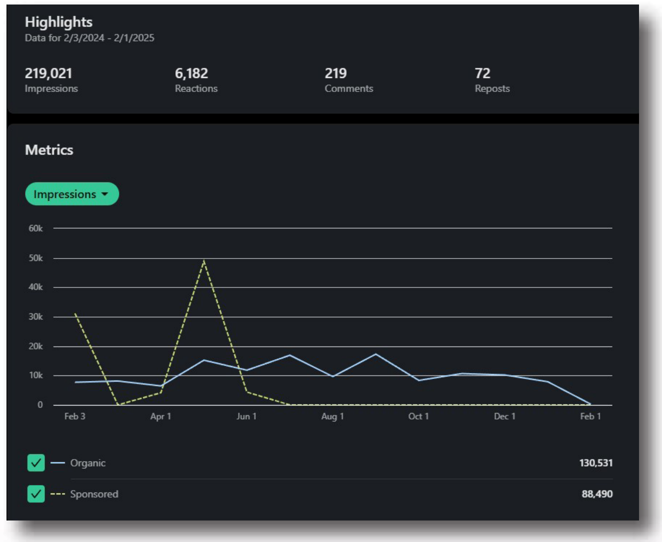

Views 141.2K
Reach 2.7M ↓ 1.2%
Content interactions 20.1K ↑ 134.7%
Link clicks 2.3K ↓ 15.3%
Visits 22.7K ↑ 47.9%
Follows 563 ↑ 77.6%

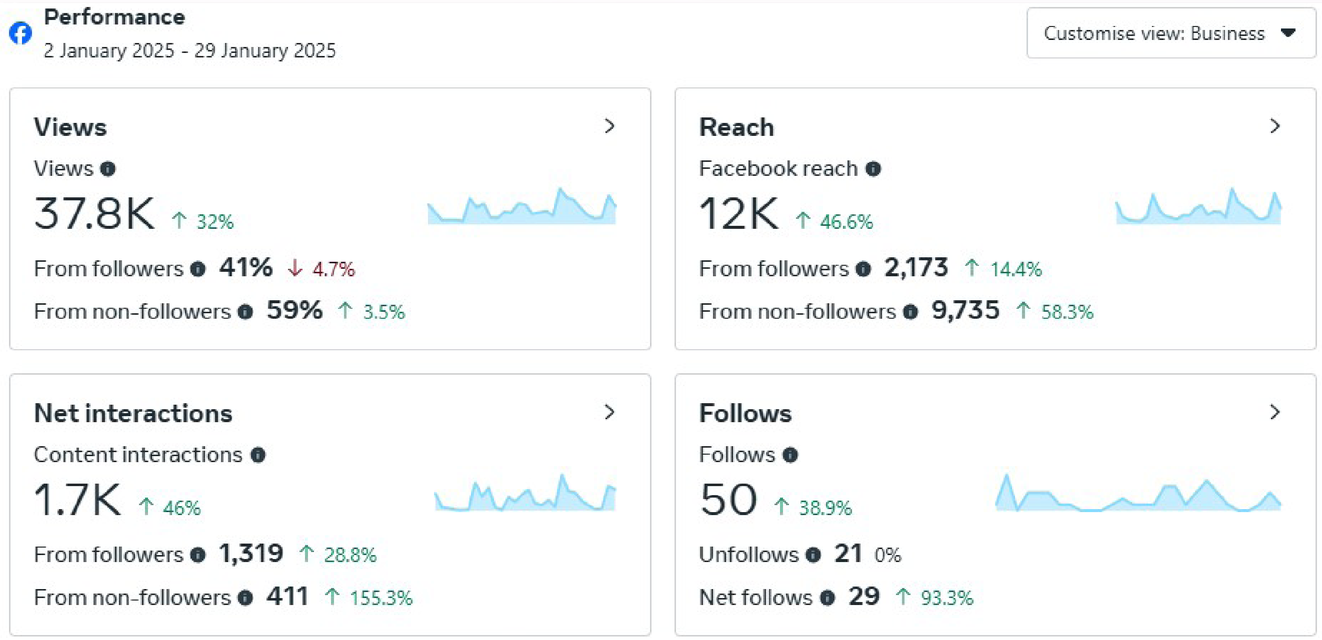
We are also proud of our ongoing collaboration with the PVRI and the European Lung Health Group, actively participating in their campaigns and sharing their content, such as the #KeepBreathing initiative, the PHGPS Survey, and the Lung Transplantation Webinar respectively. Additionally, a series of posts and social media activities were dedicated to maintaining and strengthening our partnerships with other associations. Though our social media platforms were bustling with activity, every post and our content served a meaningful purpose—fostering awareness, advocacy, and connectiona within the PH community. The numbers and analytics for the last quarter of 2024 showed that our consistent social media presence had a positive impact, as reflected in all key metrics. Compared to the same period in 2023, all social media accounts showed growth. Notably, we saw an increase in our follower base, organic reach, and engagement rate. With 300 new followers on Facebook, 175 on Instagram, and an impressive 650 on LinkedIn, we achieved positive growth across all our social media accounts. We are especially proud of the organic reach of some of our #goodPHnews entries, and the exceptional engagement during PHA Europe's presence at the WSPH 2024, ERS 2024, and APHEC. These results are a direct reflection of PHA Europe's commitment to patients and the unity of our PHamily and PH community.

With our new content and new campaign launched in January 2025 - „Without You, There Would Be No Us," we aim to encourage our member associations and all PH patients to reflect on the invaluable support they receive from caregivers, doctors, family members, nurses, pharmaceutical companies, and all people of goodwill—without whom many of the PH patients would not be here today. Our goal is to make our social media platforms a place of unity for the entire PH community, while also highlighting major breakthroughs in treatments, therapeutic options, procedures, improved policies, and better access to care. This content serves as a constant reminder that every small victory is a powerful source of hope for the entire community. With a clear vision and unwavering determination, we are excited to continue sharing content and stories that make a meaningful impact on both our followers and the PH community.

PHA Europe and the entire social media team, with Maleen Fischer at its helm, will build upon these achievements and bring a wave of improvements in how PHA Europe, our members, and PH patients are represented on our social media channels and online. With a series of new campaigns, polished post designs, fresh and engaging content, and the involvement of our entire community, we are excited to see the results unfold. PHA Europe's social media team always strives to break records, reflecting the spirit of PH patients, who never give up.

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


Highlights
Data for 2/3/2024 - 2/1/2025
219,021 Impressions
6,182 Reactions
219 Comments
72 Reposts
Metrics
☑ Organic 130,531
☑ Sponsored 88,490


Performance
2 January 2025 - 29 January 2025
Customise view: Business

Views
Views 37.8K ↑ 32%
From followers 41% ↓ 4.7%
From non-followers 59% ↑ 3.5%

Reach
Facebook reach 12K ↑ 46.6%
From followers 2,173 ↑ 14.4%
From non-followers 9,735 ↑ 58.3%

Net interactions
Content interactions 1.7K ↑ 46%
From followers 1,319 ↑ 28.8%
From non-followers 411 ↑ 155.3%

Follows
Follows 50 ↑ 38.9%
Unfollows 21 0%
Net follows 29 ↑ 93.3%

SUPPORTING PH MEMBER ASSOCIATIONS THROUGH THE MSP PROGRAM

The Member Support Program (MSP) remains a cornerstone of PHA Europe's commitment to empowering its member associations and fostering impactful advocacy initiatives. Since its inception, the program has provided vital resources to support projects aimed at improving the lives of pulmonary hypertension (PH) patients, raising awareness, empowering patient associations, and helping them mature.

2024 HIGHLIGHTS: EMPOWERING LOCAL INITIATIVES

This year, PHA Europe received numerous applications from its member associations, reflecting the creativity and determination of our network. After a careful review process, we are proud to announce that support was awarded to the following projects:

- **Bosnia & Herzegovina:** Funding was provided to establish a hotline, offering a vital communication channel for PH patients to access information, support, and guidance in managing their condition.
- **Hungary:** Support was granted for a rare disease event, fostering awareness and collaboration among stakeholders while highlighting the unique challenges faced by PH patients.

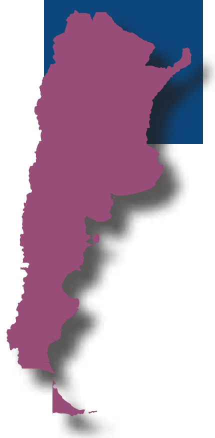
- **Sweden:** Assistance was given to organize a patient meeting with a special focus on children with PH, providing a platform for families to connect, share experiences, and learn from experts about the specific needs of pediatric PH patients.

EXPANDING RESOURCES AND VISIBILITY

In addition to these local initiatives, the MSP program has also helped member associations improve their digital presence and visibility. Several associations have received support to develop new websites using PHA Europe's customizable WordPress template. This ensures a cohesive and professional online presence that can better serve local communities.
The program has also provided assistance for creating and printing image folders based on the proven template used by PH Austria. Having an image folder that describes the association in simple terms, including its offerings, is crucial when meeting with PH stakeholders such as patients, healthcare professionals, and pharmaceutical companies. These tools help associations present themselves effectively and professionally, ensuring their messages resonate with key audiences.

LOOKING AHEAD

The MSP program continues to be a vital tool for enabling our members to make a tangible difference in their local PH communities. By supporting diverse projects—from patient support services to awareness campaigns and digital tools—PHA Europe ensures that its mission extends beyond borders, creating a lasting impact across Europe and beyond. We extend our heartfelt gratitude to all member associations for their dedication and the outstanding initiatives they bring forward each year. Together, we are driving progress and making a difference in the lives of PH patients worldwide.



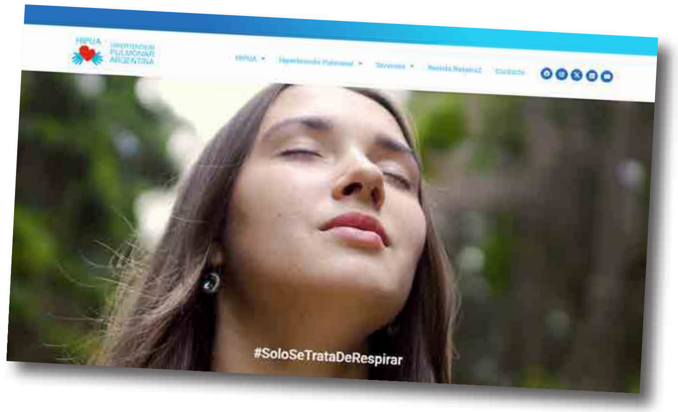
ARGENTINA

The past year 2024 was a busy one for HIPUA, filled with activities focused on training, dissemination, advocacy in public policies, and ongoing work with patients and their families to improve quality of life.

In the following section, we offer a detailed summary:

NEW WEBSITE FOR THE ARGENTINIAN PULMONARY HYPERTENSION CIVIL ASSOCIATION

HIPUA has launched its new website, specially designed for patients with pulmonary hypertension and their families. This fully professionalized platform features a more user-friendly and dynamic design, organized into sections with valuable content. It not only provides guidance and information for families after diagnosis and throughout the progression of the condition, but also showcases the extensive work carried out by the association. Additionally, it highlights activities, news, and resources of interest to those affected by this rare disease.




No estás solo...¡Unite a nosotros, unite a HIPUA!

RESPIRO2 MAGAZINE

Since 2019, HIPUA has continued to focus on the ongoing demand from patients and their families for up-to-date information about pulmonary hypertension (PH). To meet this need, we publish our biannual, digital, and free magazine, RESPIRO2. This publication features courageous testimonies from patients alongside insights from Argentina's leading medical experts, all presented in plain, accessible language.
Guided by the belief that "Being informed is a way of taking care of yourself", the magazine emphasizes that well-informed patients are more likely to adhere to their treatments, ultimately improving their quality of life. This year, we released editions 10 and 11.


EDICIÓN 10 Agosto 2024

RESPIRO2

#SoloSeTrataDeRespirar

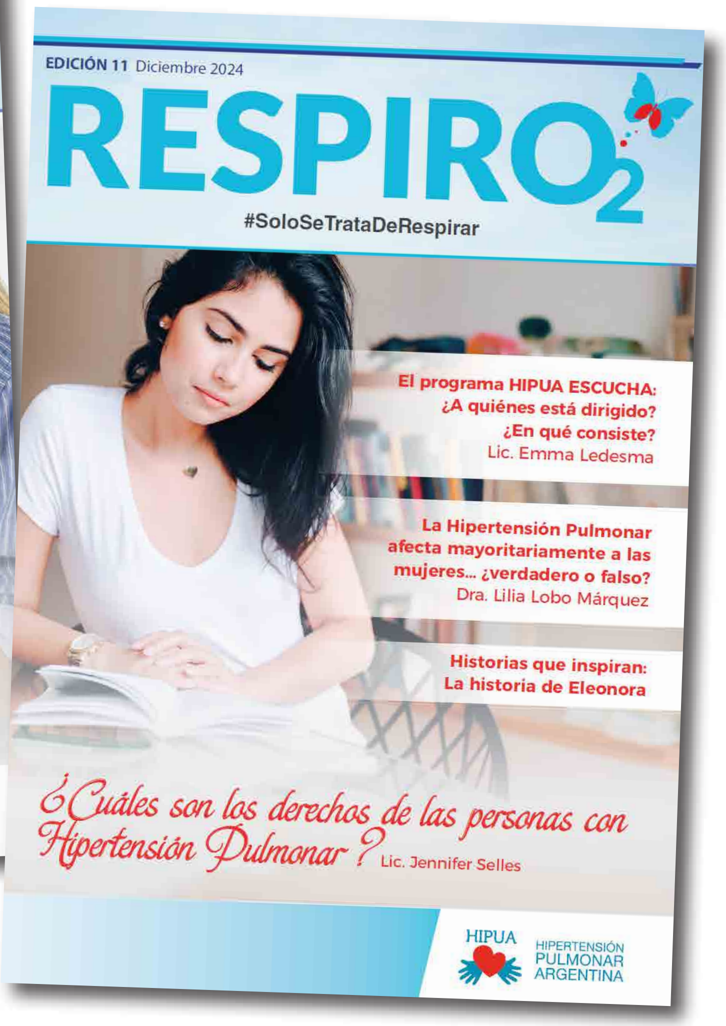
Cuando la Hipertensión Pulmonar se encuentra asociada al Virus de Inmunodeficiencia Humana (VIH)
Dr. Stewart Harris / Dra. Patricia Avellana

Oxigenoterapia: ¿De qué se trata? ¿Cuándo se indica? Sus beneficios
VitalAire Argentina

Historias que inspiran
La historia de Paola

HP y Nutrición: Mejorando nuestra calidad de vida
Lic. Claudia Fernández

HIPUA HIPERTENSIÓN PULMONAR ARGENTINA


EDICIÓN 11 Diciembre 2024

RESPIRO2

#SoloSeTrataDeRespirar

El programa HIPUA ESCUCHA: ¿A quiénes está dirigido? ¿En qué consiste?
Lic. Emma Ledesma

La Hipertensión Pulmonar afecta mayoritariamente a las mujeres... ¿verdadero o falso?
Dra. Lilia Lobo Márquez

Historias que inspiran: La historia de Eleonora

¿Cuáles son los derechos de las personas con Hipertensión Pulmonar? Lic. Jennifer Selles

HIPUA HIPERTENSIÓN PULMONAR ARGENTINA

HIPUA WAS INVITED TO THE NOVO NORDISK TRAINING

At the end of May, we had the honor of being invited to a new training session organized by Novo Nordisk. The event, called "Driving Change in the Approach to Serious Chronic Diseases" not only allowed us to explore the expectations of both the public and private sectors regarding a patient organization, but also addressed an essential topic: the right to health, and the state's obligations concerning non-communicable chronic diseases.

HIPUA AS A MEMBER OF THE HONORARY ADVISORY COMMITTEE OF COPIDIS

Once again, HIPUA has been selected as a full member of the Honorary Advisory Committee of COPIDIS, alongside the Asociación Argentina de Fribrosis Quística (FIFAN), as an alternate member, to represent individuals with visceral disabilities in the Autonomous City of Buenos Aires (CABA) until 2026.
COPIDIS is the Commission for the “Full Participation and Inclusion of People with Disabilities,” dedicated to advocating for the rights of people with disabilities within CABA. It promotes equal opportunities, access to employment, education, and independent living.

PATIENT ASSOCIATIONS IN THE LIFECYCLE OF MEDICATIONS

Between June and July, HIPUA was invited by the Institute of Policy, Economics, and Health Management (IPEGSA) to attend the training course “Patient Associations in the Lifecycle of Medications”, sponsored by the chamber of Medical Specialties of Argentina (CAEME). The objective of the training course was to provide education on topics such as ANMAT and international agencies, differences between regulatory and technology assessment agencies, safety, efficacy, and quality standards required for medication approval, pharmacovigilance, the importance of peripheral actors, phases of pharmaceutical research up to the approval and commercialization of a medication, as well as the ecosystem (Pharmaceutical Industry, Researches and independent Institutions, Regulators, Legislators, Patients, Ethics Committees, CROs).

Additionally, the course covered the interpretation, use and limitations of clinical research results, the social and economic contributions of clinical research (investment, knowledge economy, job creation, innovation and improved health standards), biological medicines, biosimilars, and multi-source medicines, as well as the role of patients and their participation in these processes.

HIPUA PARTICIPATES IN PROSERA RESEARCHERS MEETING

Gossamer Bio, a clinical-stage biopharmaceutical company, is focused on the development of Seralutinib, a novel molecule for the treatment of Pulmonary Arterial Hypertension (PAH).
In this context, Gossamer hosted a meeting in Buenos Aires with esteemed researchers from Latin America and the United States to launch the phase 3 clinical trial of Seralutinib under the PROSERA study.
Our gratitude goes to Gossamer Bio for giving HIPUA’s president, Lic. Nancy Campelo, the opportunity to share the various activities that our patient and family association has been carrying out for over 15 years in Argentina, driven by the hope of a cure.

We also thank this biopharmaceutical company for its commitment to continuing PAH research, and for developing a new molecule that we hope will soon be approved for use in treating this disease.

HIPUA AT THE LATAM PATIENT ORGANIZATIONS SUMMIT

HIPUA had the honor of being invited by MSD Argentina to participate in a meeting of patient and family organizations from our country as part of the Latin American Patient Organizations Summit.
The event provided a space for the exchange of ideas, concepts, and reflections, showcasing the best practices aimed at addressing common challenges.

We extend our heartfelt thanks to Merck Sharp & Dhome LATAM, and the authorities of MSD Argentina for allowing us to be part of this excellent initiative.

HIPUA AND THE EVOLUTION OF COPIDIS

HIPUA was invited as a member of the Honorary Advisory Council (CCH) of the Commission for the Full Participation and Inclusion of People with disabilities (COPIDIS) to a meeting held at the Government Headquarters of the Autonomous City of Buenos Aires. During the meeting, the start of a new phase in the implementation of public policies for disability was announced. The transformation of COPIDIS into a subsecretary marks a significant change, where the work of civil society organizations will take the prominent role it deserves for the benefit of our community. According to Law 447, Article 11, a key advisory space is created through the Honorary Advisory Council (CCH), bringing together public entities and NGOs to promote collaborative work in policies aimed at the disability community.
During the meeting, which was attended by the Deputy Head of Government, Clara Muzzio, the new authorities of COPIDIS and the Advisory Council were introduced. This is a great opportunity to build a new, higher-ranking space on the public agenda. It is a profound change where the work of organizations and civil society will have the prominent role it deserves to benefit our community.

HIPUA AT THE INTERNATIONAL HP SYMPOSIUM IN PORTO ALEGRE- BRAZIL

HIPUA's president, Lic. Nancy Campelo, had the honor of participating in the 6th International Pulmonary Hypertension Symposium held in Porto Alegre, Brazil. Her presentation addressed "What is the Pathway for a Pulmonary Hypertension Patient? Challenges and Obstacles."

We would like to express our deepest gratitude to the entire medical team that organized such a prestigious event, especially Dr. Gisela Meyer, and to the members of the Pulmonary Hypertension Patient Organization of Brazil – ABRAF (Hipertensão Pulmonar e Doenças Correlatas, particularly their incoming president, Lara Machado).

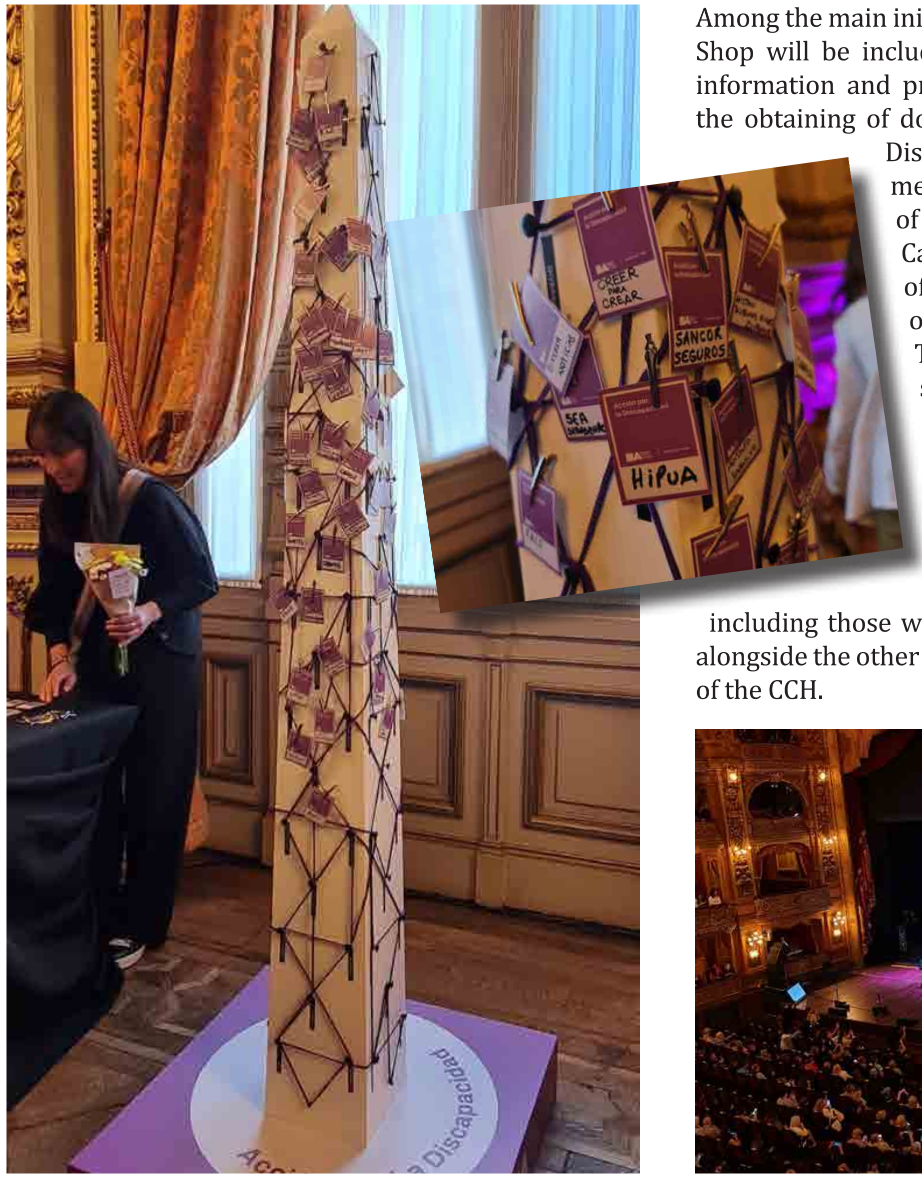
HIPUA AT THE XX WEEKEND OF HEART FAILURE AND PULMONARY HYPERTENSION- SALTA PROVINCE, 2024

The Heart Failure (HF) and Pulmonary Hypertension (PH) Committee, along with the Society of Cardiology of Salta, invited HIPUA to participate in the XX Weekend of HF and PH, held with great success on September 26-27, 2024, at the Alejandro I Hotel in Salta City. The Weekend is a scientific event aimed at promoting continuous education for physicians from various specialties across the country, featuring renowned global experts, such as Dr. Irene Lang from Austria and Dr. Tomás Pulido from México, who were invited to speak at this event.

"BREATHING BETTER" PROGRAM

Through this program, HIPUA promotes the donation of medications for coordinated distribution to patients facing difficulties in continuous access. This program often brings us face to face with very harsh realities, highlighting the generosity and immense solidarity of many. While the donation does not solve the underlying issue- the denial of access to medication or its discontinuation- it allows us to alleviate the situation in urgent cases. Therefore, we express our deepest gratitude to everyone who contributes with their donations to continue these efforts. In the meantime, HIPUA continues to work on solving these issues, either through administrative channels or by involving our legal team.

HIPUA AT THE COLÓN THEATER IN THE AUTONOMOUS CITY OF BUENOS AIRES

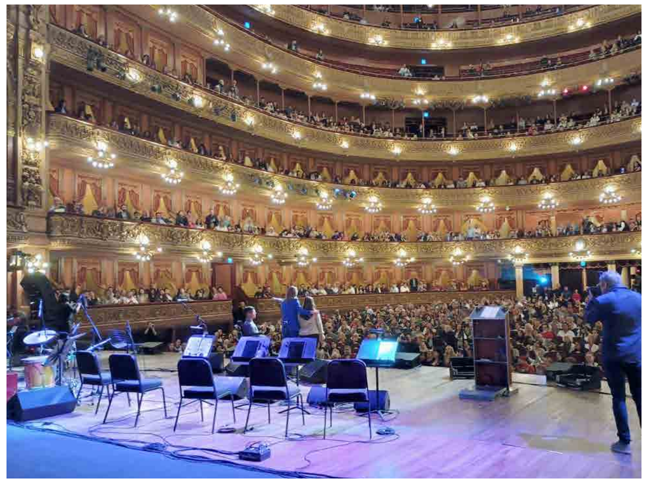


As part of inclusion Week, HIPUA – Pulmonary Hypertension Argentina, as a member of the Honorary Advisory Council (CCH) of the Commission for the Full Participation and Inclusion of People with Disabilities (COPIDIS), had the honor of being invited on international Day of People with Disabilities to participate in the wonderful event held at the Teatro Colón for the launch of the first Disability Plan, driven by the Deputy Head of Government of the Autonomous City of Buenos Aires, Lic. Clara Muzzio.

This plan includes 30 measures designed for the nearly 500,000 people with disabilities (PWD) living in or visiting the country's capital. These actions will be divided into three main areas: universal accessibility; training, well-being, and recreation; and employment and independent living, with the goal of addressing the comprehensive needs of this population by eliminating barriers to accessing procedures and services, among other issues.

Among the main initiatives, the creation of a One-Stop-Shop will be included to centralize and simplify all information and procedures. This tool will facilitate the obtaining of documentation, such as the Unique Disability Certificate (CUD). Other measures will include the construction of the first Comprehensive Disability Care Center in the southern part of the city, and the first public office staffed exclusively by PCD. Tax reduction for businesses and services that hire people with disabilities will also be considered.

From HIPUA, we reaffirm our commitment to continue working for the community of individuals with visceral disabilities, including those with pulmonary hypertension (PH), alongside the other partner organizations that are part of the CCH.



At the same time, as it has been doing since 2009, HIPUA continued to provide the following free services to the community of patients with pulmonary hypertension (PH) and their families.

INTERVIEWS WITH PATIENTS AND FAMILIES ACROSS THE COUNTRY:

Since its establishment, the Pulmonary Hypertension Argentina Association has been providing this service completely free of charge, both for individuals with a definitive diagnosis of pulmonary hypertension (PH), and for those who, upon noticing certain symptoms, suspect its presence. It is a space dedicated to support, counseling, guidance, and attentive listening to the concerns of those who approach us to share them, a service that has become more dynamic thanks to virtual platforms.

ACTIONS OF HIPUA'S LEGAL AREA

This area continued to address all issues related to the lack of access or discontinuation of treatments across the country, difficulties in obtaining the Unique Disability Certificate (CUD), disaffiliations, non-contributory pension applications, and more. These services were provided either for legal advice or for free legal representation in cases where it was deemed necessary.

NEW MEETINGS CALLED "I TAKE FIVE MINUTES… I TAKE A BREATH".

Since September 2022, the "I Take Five Minutes… I Take a Breath" meetings have resumed as a virtual initiative via the Zoom platform, aimed at patients and families across the country. These meetings provide an opportunity to receive support, build new connections, and share coping strategies in the face of uncertainty caused by pulmonary hypertension (PH).

AUSTRIA

PH AUSTRIA'S HIGHLIGHTS IN 2024

PH Austria looks back on a successful year 2024, filled with numerous activities and initiatives supporting patients and their families, while raising awareness of pulmonary hypertension.

PATIENT MEETINGS ACROSS AUSTRIA

Our regional patient meetings provided platforms for exchange, information, and support. Key events included meetings in **Graz on June 14th, 2024, Linz on November 18th, 2024, and Vienna on December 7th.** These gatherings strengthened the PH community and fostered solidarity among patients and their families.

MONTHLY OUTPATIENT CARE IN VIENNA AND UPPER AUSTRIA

In 2024, PH Austria introduced regular outpatient care services held monthly in Vienna, Upper Austria, and Styria. This offered patients direct support and opportunities to connect with healthcare professionals specialized in pulmonary hypertension.

THE 11TH VIENNA ZOO RUN ON JUNE 12, 2024

The annual Zoo Run was a true highlight of the year, bringing together over 2,000 participants for a day filled with energy and community spirit. The event not only encouraged physical activity, but also created a vibrant platform to raise awareness about pulmonary hypertension. Participants of all ages and fitness levels came together to support this important cause, showcasing the power of unity in tackling challenges. Additionally, the run successfully raised vital funds to advance research, leaving a lasting impact on the PH community.

FIRST YOUTH MEETING AT THE VIENNA COMIC CON 2024

A special highlight this year was our first-ever youth meeting. The Vienna Comic Con provided the perfect setting to bring together young PH patients. Alongside exploring the event, the focus was on exchange and networking. The overwhelmingly positive feedback has inspired us to continue this initiative in the coming years.

PUBLICATION OF THE „ATEMBERAUBEND" NEWSLETTER

PH Austria proudly released new editions of its „Atemberaubend" newsletter in 2024. This publication provides vital updates, inspiring patient stories, and the latest developments in the fight against pulmonary hypertension. It remains a key resource for the PH community in Austria.

PARTICIPATION IN INTERNATIONAL EVENTS

PH Austria was once again well-represented on the international stage. At the European Respiratory Society (ERS) Congress in Barcelona and APHEC, we exchanged knowledge and amplified the voice of Austrian PH patients worldwide. Such opportunities allow us to benefit from global developments and expand our expertise.


Atemberaubend

Ausgabe 50/2024

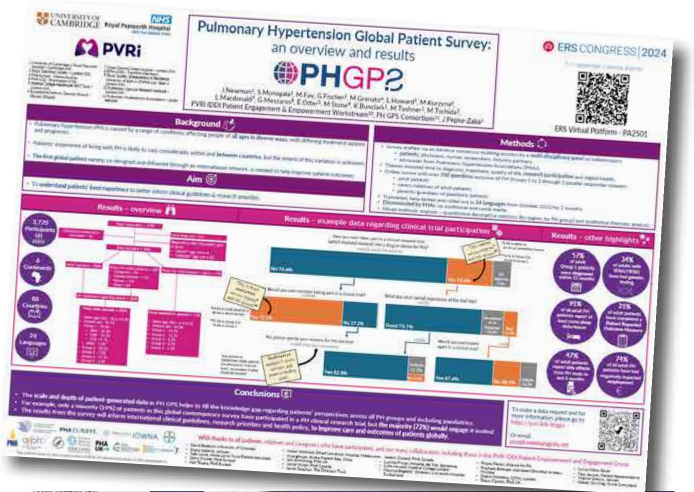
Das war 2024

PH AUSTRIA

www.phaustria.org

PARTICIPATION IN IMPORTANT SURVEYS

In 2024, PH Austria actively took part in the **survey on the importance of patient associations (sponsored by AOP Health)**, which collected insights from over 600 participants across Europe. This initiative aimed to better understand the critical role of patient associations in providing support, advocacy, and education for those affected by pulmonary hypertension. The survey results were presented at the ERS Congress in a dedicated poster, showcasing the profound impact of these organizations on improving care and raising awareness. In addition, PH Austria actively took part in the PHGS survey also conducted in 2024. PH Austria was happy to create and provide the PHGPS Logo.
You can find the poster at the following link in the Bel Air Center:
https://events.elevent.ly/pha/posters/wendys-nursing-room



CONTINUATION OF THE MILESTONES INITIATIVE

The Milestones Initiative continued successfully in 2024. At Oswald-Thomas-Platz in front of the Planetarium at Vienna's Prater, new milestones were laid, symbolizing both personal messages and a strong statement for progress in addressing pulmonary hypertension. Thanks to numerous donations, including support from prominent personalities, this initiative continues to grow.

CLOSING THOUGHTS

The year 2024, once again, demonstrated the importance of collaboration, engagement, and awareness for the PH community. We are proud to reflect on a strong network that supports patients and informs the public. We extend our gratitude to everyone who contributed and look forward to continuing our efforts for the PH community in 2025.

BELARUS

PULMONARY HYPERTENSION ACTIVITIES IN BELARUS

In 2024, significant progress was made in Belarus in diagnosing and treating pulmonary arterial hypertension (PAH), as well as strengthening international cooperation with leading specialists from other countries.

KEY EVENTS AND ACHIEVEMENTS

1. 2ND CONGRESS WITH INTERNATIONAL PARTICIPATION „INNOVATIVE CARDIOLOGY"

On October 24–25, 2024, a congress was held in Minsk, bringing together specialists from Belarus, Russia, Kazakhstan, and other countries. The event focused on new approaches to diagnosing and treating cardiovascular diseases, including pulmonary hypertension. Modern technologies in cardiac surgery and drug therapy were discussed, contributing to improved healthcare quality in the country.

2. SEMINAR „PULMONARY HYPERTENSION IN CHILDREN"

A significant educational initiative was a seminar aimed at increasing physicians' awareness of pulmonary hypertension in children. The event addressed modern diagnostic methods, treatment approaches, and prevention strategies, broadening specialists' knowledge of this complex condition.

3. INTERNATIONAL COOPERATION

Belarusian specialists participated in the European Conference on Pulmonary Hypertension in Spain, where they presented their developments and exchanged experiences with colleagues from other countries. This contributes to integration into the international medical community and the improvement of PAH treatment approaches.

4. SUCCESSFUL SURGERIES AND CLINICAL ACHIEVEMENTS

The Republican Scientific and Practical Center for Pediatric Surgery performed, for the first time in Belarus, a unique operation to correct a rare congenital heart defect in a child (the Nikaidoh procedure). This is a significant advancement in pediatric cardiac surgery, improving outcomes for patients with rare pathologies.

CURRENT STATUS AND CHALLENGES

Currently, around 40 patients in Belarus receive specific PAH therapy. Medications used include bosentan and sildenafil. Additionally, about 10 patients are enrolled in clinical trials involving selexipag. However, there is a shortage of prostacyclin analogs, limiting therapeutic options for some patients.

For newly diagnosed PAH patients, regular monitoring, treatment adjustments, and examinations, including the six-minute walk test (6MWT) and NT-proBNP measurements, are conducted.

CONCLUSIONS AND PROSPECTS

The events held in Belarus and abroad have enhanced the qualifications of specialists and fostered the development of innovative approaches to PAH treatment. Key advancements include implementing unique surgical techniques and active participation in international clinical trials. However, further progress requires expanding access to new medications, particularly prostacyclin analogs, to improve the effectiveness of treatments and patients' quality of life.

NEWS FROM PH ASSOCIATION

BELGIUM

Pulmonale Hypertensie vzw
samen op adem komen

This year, P.H. Belgium worked on four main pillars: education, advocacy, peer support, and support for scientific research. It was an exciting year, filled with interesting discussions, inspiring collaborations, and meaningful connections with peers!

EDUCATION

WORKING TOGETHER ON BETTER EDUCATION ABOUT PULMONARY HYPERTENSION (PH-PIP PROJECT)

Pulmonary Hypertension VZW, Hypertension Artérielle Pulmonaire ASBL, and the Patient Expert Center have launched a special project: developing clear and reliable information for people with pulmonary hypertension (PH). This is being done in collaboration with healthcare providers, patients, patient organizations, and the pharmaceutical industry.

The goal? To ensure that everyone can find understandable and accessible information about PH in one place.

▶ WHY IS THIS PROJECT IMPORTANT?

When faced with a diagnosis like pulmonary hypertension, you often have many questions: What does this mean exactly? What lies ahead? Unfortunately, not all information online is reliable or complete. By creating a central place with clear explanations, we aim to provide patients with more peace of mind and confidence.
Good education also helps patients better prepare for conversations with their healthcare providers. Patients can ask targeted questions and better understand what doctors explain. This makes a big difference, because well-informed patients often feel more engaged in their treatment and experience better outcomes. It also benefits healthcare providers, as they can focus on complex, personalized questions rather than repeating basic information.

▶ HOW DOES IT WORK?

This project begins with what patients need. In the first step, workshops are organized where patients, healthcare providers, and other stakeholders discuss important information. A list of priorities is then created, focusing initially on what patients need to know at the time of diagnosis. This information will be compiled into a handy "support kit."

This project is supported by the Prince Philippe Fund (KBS), MSD, Janssen-Cilag, and Gossamer Bio.

FRENCH-LANGUAGE WEBINARS: LEARN FROM THE COMFORT OF YOUR COUCH

As a patient, you encounter a lot of information, and it's not always easy to understand what your doctor is talking about. During consultations, there isn't always enough time for a detailed and illustrated explanation. That's why we organized a series of informative webinars this year, focusing on French-speaking patients, in collaboration with Professor Jean-Luc Vachiéry and his multidisciplinary team at the Erasme University Hospital in Brussels. From the comfort of their couches, patients and their families could learn more about pulmonary hypertension, standard treatment options, and how to support their treatment. Curious about the topics covered? You can rewatch the webinars on our website.

ADVOCACY AND AWARENESS

COLORFUL RARE DISEASE DAY

All the colors of the rainbow—these were everywhere on Rare Disease Day! It was impossible to miss. Across the country, buildings, houses, offices, and especially finger nails were adorned with color, as seen on social media.

We also got creative with color! Equipped with colorful wigs and clothing, and under the creative direction of team member Anne-Lies, we produced videos and photos that were shared on our social media during the week of February 29.

It was a success! On social media, we saw all the colors of the rainbow among patients and their families. Also politicians, including our Prime Minister Alexander De Croo and Minister of Social Affairs and Public Health Frank Vandenbroucke, took part in this campaign.

The iconic Port House in Antwerp even received a splash of color, thanks to the efforts of our vice-chairperson An.

In the press, notable supporters and people with rare diseases were also well-represented, including Professor M. Delcroix of UZ Leuven and some pulmonary hypertension patients.

SHARING STORIES ABOUT LIVING WITH PULMONARY HYPERTENSION

Over the past year, several patients and caregivers shared their personal stories as testimonials. These stories provide valuable insights into the experiences of people living with pulmonary hypertension. We thank all participants for their courage and openness. Sharing personal experiences can have a powerful impact and inspire others.

afph
ALLIANCE FOR PULMONARY HYPERTENSION

"Congenital heart disease and pulmonary hypertension"

Thursday May28, 2024 | 18.00 CET

LIVE WEBINAR

Speakers, from left:

Dr. Andreas Reimann
CEO admedicum, Germany, Moderator

•

Prof Maurice Beghetti
Head of Pediatric Cardiology Unit (HUG)
Co-Director Pulmonary Hypertension Program (HUG)
Children's University Hospital Geneva, Switzerland

•

Dr. Julie Wacker
Pediatric Cardiology Unit, Pulmonary Hypertension Program
Children's University Hospital Geneva, Switzerland

•

Katleen Verbergt
Mother of a young patient, Belgium

Learn more at ph-ksp.com

PULMONARY HYPERTENSION AND RARE DISEASES IN THE PRESS

ANNELIES (27):

‚I am not afraid of dying anymore. I've made peace with it''

Straf Verhaal

Annelies (27): 'Ik ben niet bang om te sterven. Ik heb daar ondertussen vrede mee.'

Annelies lijdt aan de zeldzame ziekte pulmonale hypertensie.

VIC HAS A RARE DISEASE:

PAH: VAGUE SYMPTOMS AND LACK OF AWARENESS DELAY TIMELY DIAGNOSIS

PAH: vage symptomen en gebrek aan bewustzijn bemoeilijken tijdige diagnose

Pulmonale arteriële hypertensie (PAH) is een zeldzame ziekte, wat betekent dat deze aandoening bij minder dan 1 op de 2.000 mensen voorkomt. Een vroege diagnose en behandeling kunnen het verloop van de ziekte aanzienlijk beïnvloeden en de kwaliteit van leven verbeteren. Meer bewustzijn over PAH is in dat kader cruciaal.

PAH is een ernstige, chronische aandoening waarbij de bloeddruk in de longslagaders – de bloedvaten die bloed van het hart naar de longen transporteren – abnormaal hoog is. Dat komt doordat de wanden van de longslagaders dikker en stijver worden, wat de bloeddoorstroming belemmert. Hierdoor moet het hart harder werken om bloed door de longen te pompen, wat uiteindelijk kan leiden tot hartfalen.

Vage symptomen bemoeilijken diagnose
De symptomen van PAH zijn vaak subtiel en kunnen variëren. Veelvoorkomende klachten zijn kortademigheid, vermoeidheid, duizeligheid, pijn op de borst en zwelling van de benen of enkels. Er zit vaak een aanzienlijke vertraging tussen het moment waarop de eerste symptomen optreden en de uiteindelijke diagnose. Deze vertraging kan variëren van enkele maanden tot jaren. Dat komt deels doordat de symptomen geleidelijk verergeren en vaak worden toegeschreven aan andere oorzaken, zoals astma of stress. Het is daarom van cruciaal belang om een specialist, zoals een cardioloog of longarts, te raadplegen zodra de symptomen optreden.

Patiënt getuigt over belang van bewustzijn
"Door de vage symptomen duurt het vaak te lang voordat de juiste diagnose wordt gesteld", zegt PAH-patiënt en ondervoorzitter van PH vzw An Damen. "Een snellere herkenning betekent een eerdere behandeling en betere vooruitzichten." Ze benadrukt ook het belang van begrip bij het grote publiek en roept beleidsmakers op tot actie: "Mensen zien ons soms als lui, terwijl we juist onze energie moeten managen. Erkenning en steun voor behandelingen zoals psychologische ondersteuning zijn essentieel voor onze kwaliteit van leven." ■

PAH is een chronische aandoening waarbij de bloeddruk in de longslagaders abnormaal hoog is.

WHEN A SERIOUS ILLNESS ISN'T TAKEN SERIOUSLY:

MSD

Wanneer een ernstige ziekte niet ernstig wordt genomen

Sensibilisering rond zeldzame aandoeningen blijft noodzakelijk. Dat blijkt ook uit de patiëntengetuigenis van Mevr. Wendy Vansteenkiste. Omdat haar klachten in dovemansoren vielen, duurde het twee jaar voordat ze de diagnose van pulmonale arteriële hypertensie kreeg. Ook vandaag, vijftien jaar later, blijft het vechten voor erkenning.

Newspaper for general practitioners, 08 October 2024

PEER SUPPORT

REGIONAL DAYS: A COZY GATHERING FOR PATIENTS AND SUPPORTERS

On Sunday, April 21 and 28, we came together for our Regional Days, an opportunity for patients, their families, and supporters to meet and share experiences. The gatherings took place at various locations in Flanders, where we enjoyed snacks and drinks in a relaxed atmosphere.

These meetups were the perfect chance to ask questions to the board, catch up with other patients, and meet new people. Nothing is more valuable than sharing your story with others who understand what you're going through. The gatherings fostered a sense of connection and support.

SUPPORTING SCIENTIFIC RESEARCH

CONTRIBUTION TO SCIENTIFIC RESEARCH: €7,500 FOR BASIC RESEARCH ON PULMONARY HYPERTENSION

We are pleased to announce that this year, thanks to your actions and donations, we are making a significant contribution to scientific research on pulmonary hypertension. With the support of our members and supporters, we have reserved €7,500 for the research of Professor M. Delcroix and her team at KULeuven.

This valuable sum will be used for basic research on pulmonary hypertension, aiming to expand knowledge about this rare and complex condition. The research conducted by Professor M. Delcroix and her team may hopefully contribute to new breakthroughs that improve the quality of life for patients worldwide.

Thanks to everyone who supports us, we are taking an important step toward more understanding and progress in the fight against pulmonary hypertension. Together, we hope to make a difference!

BOSNIA AND HERZEGOVINA

PRIORITY – MEDICATION FOR ALL PATIENTS

Throughout 2024, the Association of citizens suffering from Pulmonary Hypertension "Dah" in Bosnia and Herzegovina has continued its persistent efforts to raise awareness about the illness and improve the dire status of patients in our country. Once again, we emphasize that pulmonary hypertension (PH) patients in Bosnia and Herzegovina are in an extremely difficult position. There is no systemic solution for this vulnerable group of patients, forcing many to fend for themselves when it comes to acquiring medication, accessing treatment, and obtaining proper diagnostics.

Our Association strives, in every possible way, to change this situation, but the enormous and complex administrative system presents significant challenges, where PH patients are just one among many disenfranchised groups. Nevertheless, we remain undeterred, unshaken, and resolute in our mission!

This year, we achieved significant milestones and remain on track to accomplish our set goals, primarily ensuring access to medication for all patients.

ENHANCEMENT AND IMPROVEMENT FOR A BETTER PATIENT STATUS

This year, we concluded our participation in the project "Strengthening Integrity in the Process of Creating Drug Lists in Bosnia and Herzegovina," which focused on empowering patients to actively participate in the creation of drug lists and supporting healthcare institutions in achieving high standards of integrity for conducting credible, transparent, and inclusive processes. This project, implemented in Bosnia and Herzegovina by Net Consulting d.o.o. Sarajevo, in partnership with and supported by the Government of Switzerland, Roche d.o.o. – Roche Ltd., and the Association of Innovative Drug Manufacturers in BiH, spanned across the entire country.

Through this initiative, the patient advocacy network "Right to Medication" was established, which our Association joined three years ago, actively participating in all its activities. Numerous meetings have been held since, addressing various topics aimed at ensuring the right to medication for all disenfranchised patients in BiH. The efforts focused on connecting patients, planning their involvement in creating drug lists, and advocating for equal access to medication for everyone, not just a select few. This concept has provided us with invaluable insights and opportunities to pursue our primary goal: medication for all PH patients.

In addition to this important activity, we also participated in the 2nd Congress of Persons with Disabilities in Bosnia and Herzegovina, held in Neum under the theme "Inclusion is not illusion." Organized by the Union of Organizations of Persons with Disabilities in BiH, Caritas BiH, and MyRight, with financial support from the European Union, Catholic Relief Services, the Fund for Professional Rehabilitation and Employment of Persons with Disabilities, Slovene Caritas, the Municipality of Neum, the Federation of BiH Government, and Dr. Denis Bećirović, Member of the Presidency of BiH, the Congress aimed to offer new ideas and solutions for improving accessibility for persons with disabilities.

During the three-day Congress, which aimed to offer new ideas and solutions for improving accessibility for people with disabilities, nine panel sessions were organized dedicated to key topics, such as accessibility in healthcare, education, public and political life, sports, culture, transport and tourism. The Congress was also attended by Samir Hodžić, a member of our Association, this time as a representative of the Coalition of Organizations of Persons with Disabilities of the Zenica-Doboj Canton, who had the opportunity to meet with representatives of ministries of health at all levels, and to point out the position of PH patients in Bosnia and Herzegovina. Samir attended very interesting lectures and attended sessions dedicated to health, which provided us with a new basis for further work on improving the position of people with disabilities, especially invisible disabilities such as PH patients.

Our activities this year were also focused on attempts to provide a cure for all PH patients, and with that goal, an informational meeting was held with representatives of the pharmaceutical company MSD, which was attended by Azra Šerak Herceglić, product specialist Glossary, Ranko Bjelanović, public affairs manager MSD and Sabina Hodžić, activist of the Association of Citizens Suffering from Pulmonary Hypertension „Dah" - in Bosnia and Herzegovina. This was an opportunity to introduce the interlocutors to the difficult situation of PH patients in Bosnia and Herzegovina, but also to all the activities of the Association so far. With this meeting, we showed that we are ready and open for any form of cooperation with all serious partners who will strive together with us to improve the position of PH patients in BiH. We traditionally ended our annual activities by participating in the celebration of the International Day of Persons with Disabilities, which was organized in Tesanj by the Association of Disabled Persons of the Zenica-Doboj Canton. This event aimed to draw public attention to the rights of disabled persons, and to make invisible disabled persons, visible persons, who will be functional and respected in society. Pulmonary hypertension patients are invisible disabled persons and as such must be recognized in all spheres of life, therefore our presence at this event was a logical continuation of our activities aimed at recognizing PH patients as severely disabled.

RAISING AWARENESS THROUGH SPORTS

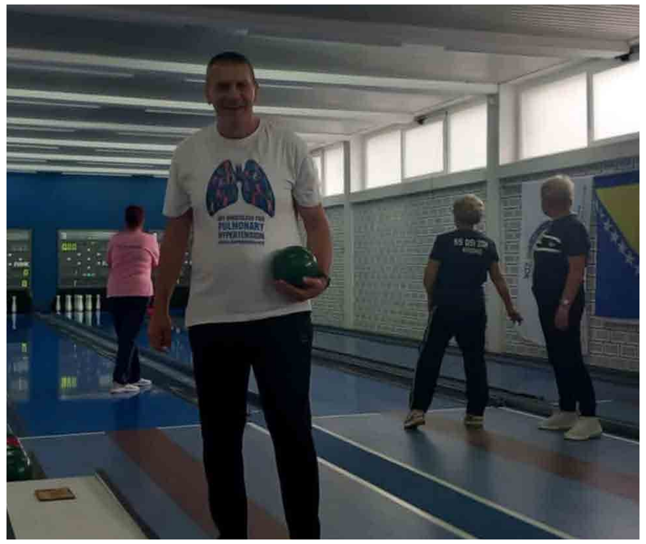
Sports activities were dedicated to raising awareness about pulmonary hypertension in 2024. Our exceptional athletes, both professionals and amateurs, have supported this cause. The year was marked by the participation of our runner, Enes Ibrahimagić, in ten marathons across Bosnia and Herzegovina and the region, running for PH patients, during which he ran out of breath for all those suffering from pulmonary hypertension. Sarajevo - We run for clean air (BiH), Slavonski Brod (Croatia) - Polonjska trka, Čazma (Croatia), Plitvički marathon (Croatia), Plješevička trail league (BiH), Šmajerski tek (Slovenia), Karlovac race (Croatia), Zagreb race marathon (Croatia), marathon Ljubljana (Slovenia) and Crikvenica (Croatia) were all races where Enes lost his breath for PH patients.

When all these routes are converted into kilometers, Enes was left breathless for those suffering from pulmonary hypertension for a length of about 300 km during 2024 alone, running through the streets of cities for those affected, which deserves great respect from the entire PH community. Along with Enes, who participated in all these races, we do not want to leave out the contribution of other runners from Bihać, who also ran for the symbols of the European PH community, but not in all the listed races: Emina Gradinović Čehajić, Amar Čehajić, Amir Muminović and Asmir Islamović. Thank you to everyone who remains breathless for PH, thus raising awareness about our disease. Bihac runners absolutely dominate the races in the region, and we are proud of all their participation regardless of the results. In addition to the runners, members of the mountaineering association „Tajan 1929." in Mašica - Mitrovići took advantage of the gathering of Zavidovići mountaineers to raise awareness about pulmonary hypertension among this group of athletes from the club, which holds the longest existence in this city. Alma, Ivana, Sena took advantage of the gathering of mountaineers from where they sent us a clear message: „We never forget you! Always with PH!" Further raising awareness for pulmonary

hypertension, we also went bowling. Under the auspices of the Sports Association of Persons with Disabilities of Zenica-Doboj Canton, a bowling championship for persons with disabilities was held in Kakanj. Participation in this championship had teams with about 70 competitors, including our Mihro Džaferović and Samir Hodžić, who achieved notable results in T-shirts with the logos of the European Association of Pulmonary Hypertension Patients and the Association of Citizens with Pulmonary Hypertension „Dah" - in Bosnia and Herzegovina. We used the participation of our members in order to continue raising awareness for pulmonary hypertension in this unique way as well.

OUR FIGHT CONTINUES!

Vera Hodžić,
president of the Association of Citizens Suffering from Pulmonary Hypertension „Dah" - in Bosnia and Herzegovina



BULGARIA BSPPH

SECOND EDITION OF NATIONAL SPORTS GAMES FOR TRANSPLANT RECIPIENTS

More than 40 participants took part in the second edition of the National Sports Games for Transplant Recipients, held on May 18 and 19, 2024. The event was initiated by the Executive Agency for Medical Supervision, with South-West University "Neofit Rilski" serving as the host. The university and the Municipality of Blagoevgrad co-organized the event.

Transplant recipients, medical professionals involved in donation and transplantation processes, representatives of NGOs, the Bulgarian Red Cross Youth, and supporters of the cause competed in sports such as swimming, mini football, tennis, table tennis, 60m running, mini golf, badminton, and darts. The event was officially opened by host Prof. Dr. Nikolay Marin and Mrs. Ivanka Dineva, the Executive Director of the Executive Agency for Medical Supervision.

At the end of the day, an emotional ceremony was held where all participants, demonstrating exceptional sportsmanship, were awarded medals. Students and faculty from South-West University who assisted in organizing the event, as well as other supporters, were also recognized. Rector Prof. Dr. Nikolay Marin surprised participants, who excelled in the competitions with special awards.

One of the honorees was Natalia Maeva, Chair of the Bulgarian Society for Patients with Pulmonary Hypertension. She earned one gold medal (mini golf) and two bronze medals (darts and badminton).

16 GOLD MEDALS FOR BULGARIA AT THE EUROPEAN CHAMPIONSHIP FOR TRANSPLANT RECIPIENTS

Bulgaria was represented by 11 athletes, who competed in seven different sports disciplines at the European Championship for Transplant and Dialysis Patients, held from July 21 to July 28, 2024, in Lisbon, Portugal.

The main goal of the participants was to promote the cause of organ donation and demonstrate that people with transplanted organs can lead active lives. This event is a true celebration of life itself, showing that life can continue in new and inspiring ways despite the incredible challenges these individuals have faced. All participants are winners at these games, showcasing the will to live and proving that life triumphs over any obstacles.

The most intense competition—badminton—took place on July 22, 2024, featuring seven Bulgarian athletes. Natalia Maeva won a gold medal and became the European champion in the 50-59 years of age category.

"I want to share the atmosphere—it's an incredible celebration of life's triumph! We are not here to win medals but to witness how people across Europe, who have undergone transplantation, express their joy and gratitude to the donors who made our lives possible," said Natalia Maeva, Chair of the Bulgarian Society for Patients with Pulmonary Hypertension.

She emphasized that transplant recipients must engage in sports, as it is one of the key factors for a better quality of life and maximizing the potential of their second chance at life. According to her, there should be specialized rehabilitation programs for those awaiting transplants and organized access to various sports for transplant recipients to help them live active and fulfilling lives.

"The medals we win represent another victory, but we are here to see friends, to feel the thrill that life continues, and to express our gratitude to the donors. Without them, we wouldn't be here," she said.

Natalia added: "I thought long and hard about whether to keep the gold medal I won almost jokingly at the European Championship for Transplant Recipients in Lisbon, or to give it to the person who crafted my new lungs to perfection! Of course, this honor belongs to Prof. Dr. Taghavi and his team, who nearly nine years ago spent nine hours making the impossible possible—allowing life to triumph over death."

ELF PATIENT ORGANISATION NETWORKING DAY 2024

Vienna hosted the 34th Congress of the European Respiratory Society (ERS) from September 7 to 11, 2024. On the opening day of the forum, an Information Day was held for patient organizations that are part of the European Lung Foundation (ELF). As is tradition, BSPPH participated in the event.
On September 9, 2024, in her capacity as a patient representative in the European Patient Advocacy Group for Rare Lung Diseases (ePAG-ERN-Lung), Natalia Maeva delivered a presentation on the opportunities offered by cross-border healthcare, particularly in the areas of lung transplantation and post-transplant follow-up, which often pose significant challenges. According to Maeva, raising awareness of communication problems between transplant centers in different countries, and the exchange of medical data from organ recipients' health records, is crucial.

She emphasized the need to develop an international electronic health record system that would be universally accessible to healthcare providers and ensure timely updates of patient information. "The quality of care for patients monitored abroad after transplantation must be ensured through close collaboration to facilitate scheduled follow-ups with access to updated medical information," said Natalia Maeva.

EXERCISE TO LIVE - TRUE CELEBRATION OF LIFE, SPIRIT AND FRIENDSHIPS

On October 5, 2024, the open spaces of the First English Language School and Zaimov Park in Sofia, Bulgaria welcomed participants in the initiative “Exercise to live.” The event was organized in partnership with the Sofia Municipality, “Oborishte” District, and with the support of the First English Language School. To the organizers’ delight, the date coincided with the European Day for organ, tissue, and cell donation, which has been celebrated for 30 years at the beginning of October.

The initiative relied on professional support from athletes representing lacrosse, baseball, cricket, softball, and ultimate frisbee clubs and federations. The diverse sports program also included clubs for pétanque, badminton, and pickleball.

The festive atmosphere was further enhanced by the cheerleading federation. The graceful cheerleaders from “The Stars of Bankya” at the 78th High School “Hristo Smirnenski” in Bankya and the Alma Rhythmic Stars Sports Club earned rounds of applause from all participants. Additional entertainment was provided by talented musicians from the orchestra of the First English Language School.

The event became a true celebration of life, spirit, and new friendships.

“Exercise to live” was aimed at people on dialysis, transplant recipients, individuals with mild physical and mental disabilities, and those with obesity, who have the desire and need to engage in sports. The project provided opportunities for participation in various sports activities that improve quality of life and support recovery.

Breathing exercises, diverse physical activities, and basic workouts demonstrated to everyone that sport equals health and can significantly enhance life quality.

The event also attracted social service users from Sofia, as well as many citizens in need of such motivation.

Greetings were extended to all participants by Mr. Tsvetomir Petrov, Chairman of the Sofia Municipal Council; Dr. Yordan Peev from the Executive Agency for Medical Supervision; Mrs. Milena Alexieva, Acting Mayor of the Oborishte District; and Mr. Alexander Chakmakov, Principal of the First English Language School.

“Thank you for dedicating your time today as we celebrate life’s triumph, because one ‘yes’ can save up to eight human lives. However, the unresolved issue of access for Bulgarian patients to lung transplant programs remains a burden on society’s agenda. The training of our medical professionals faces an uncertain future, and the situation for patients suffering from pulmonary hypertension continues to deteriorate,” said Natalia Maeva, president of BSPPH, in her address to participants at the sports event.

THE NATIONAL PICKLEBALL TEAM SUPPORTS THE CAUSE OF PH PATIENTS

We thank the Bulgairan national pickleball team for supporting the cause of pulmonary hypertension (PH) patients, not only in November - recognized globally as the awareness month for this rare disease - but throughout the year.

The team made its debut at the European Championship in Southampton, UK. On November 23, 2024, all matches in the mixed doubles discipline were played. Only the first and second teams from each group advanced to the championship finals.

OTHER ACTIVITIES

After nearly five years of advocacy, full reimbursement for home oxygen concentrators begins from November 1, 2024. The National Health Insurance Fund (NHIF) fully reimburses home oxygen concentrators for the following conditions: pulmonary arterial hypertension, cystic fibrosis, other specified chronic obstructive pulmonary diseases, other interstitial lung diseases with fibrosis, rheumatoid lung disease, and respiratory disorders associated with other diffuse connective tissue diseases.

The president of BSPPH Natalia Maeva became a member of the ELF Council. She has more than 12 years of experience in raising awareness about lung health in the NGO sector, both in Bulgaria, and in Europe. Her personal goals are to develop new initiatives to promote patient advocacy. Natalia’s personal point of view is that, as patients, we must fight against the existing health inequalities in the EU.

BULGARIA PHA

TODOR MANGAROV'S 50-DAY ODYSSEY FOR PH AWARENESS

Todor Mangarov embarked on an awe-inspiring 50-day expedition across Kenya, Tanzania, Uganda, and Rwanda to raise awareness for Pulmonary Hypertension. His journey covered an astonishing 5,198.6 kilometers through a variety of means:

- Cycling: 2,760 km
- Bus: 735 km
- Truck: 1,162 km
- Ferry: 32 km
- Jeep/Car: 348 km
- Walking: 82 km
- Motorcycle: 79.6 km

Todor's adventure featured some of Africa's most iconic landscapes, including the Great Lakes (Victoria, Naivasha, and Manyara) and the Indian Ocean. He tackled four volcanoes and summited the 5,895-meter Mount Kilimanjaro in just five days. His route included the Masai Mara, Serengeti, Ngorongoro, and Tarangire reserves, where he witnessed the region's stunning wildlife and natural beauty.

Through physical challenges and breathtaking encounters, Todor's journey became a powerful symbol of resilience, inspiring the global PH community. His story demonstrates how awareness campaigns can motivate action and bring visibility to this rare condition.

UNITING FOR RARE DISEASES: HIGHLIGHTS FROM TWO INSPIRING EVENTS

In the fight against rare diseases, collaboration, education, and advocacy are key. This November and December, two pivotal events brought together medical professionals, students, and patient organizations to raise awareness and enhance understanding of rare conditions. These gatherings aimed to foster partnerships and equip stakeholders with the tools needed to improve care for individuals facing these unique health challenges.

EMPOWERING FUTURE DOCTORS: SEMINAR ON RARE DISEASES

On November 23, under the auspices of the National Alliance for People with Rare Diseases, 120 medical students from universities across the country attended this seminar.

As the next generation of healthcare providers prepares to tackle the complexities of modern medicine, their exposure to rare diseases is crucial. This seminar offered a vital opportunity for medical students to engage with leading experts and delve into the nuances of diagnosing and treating these conditions.

The seminar featured nine educational sessions, with highlights including:

PULMONARY ARTERIAL HYPERTENSION (PAH): Experts presented cutting-edge treatments and patient management strategies for this rare, life-threatening condition.

CHRONIC THROMBOEMBOLIC PULMONARY HYPERTENSION (CTEPH): Attendees explored diagnostics and therapies for this complex pulmonary disorder.

ORGAN DONATION AND TRANSPLANTATION: A dynamic discussion featuring a donor coordinator and a transplant recipient, who provided firsthand insights into the transformative impact of organ donation on rare disease patients.

These sessions, alongside discussions on other rare conditions, aimed to instill a proactive approach among medical students, encouraging them to prioritize early detection, patient support, and interdisciplinary collaboration in their future careers.

BUILDING BRIDGES: ANNUAL MEETING OF PATIENT ORGANIZATIONS

On December 14 in Sofia, the annual meeting was held for the representatives of patient organizations for interstitial lung diseases and associated rheumatological conditions.

Patient organizations are often the backbone of advocacy for rare diseases, providing support, education, and a unified voice for those in need. This annual meeting, once again, brought together representatives from across the country to share experiences, coordinate efforts, and strengthen networks.

Two key presentations shaped the 2024 discussions:

PULMONARY ARTERIAL HYPERTENSION (PAH): A focus on the disease's impact on quality of life and advancements in therapeutic approaches.

CHRONIC THROMBOEMBOLIC PULMONARY HYPERTENSION (CTEPH): An exploration of diagnostic criteria, treatment breakthroughs, and ongoing research aimed at improving patient outcomes.
The event served as a platform for collaboration between patient organizations and healthcare professionals, fostering a stronger collective effort to advocate for and support individuals affected by these rare conditions.

A UNIFIED MISSION FOR RARE DISEASES

Both events underscored a shared goal: raising awareness and fostering collaboration within the rare disease community. By educating future healthcare providers and strengthening patient advocacy networks, these gatherings contributed to a brighter future for individuals living with rare conditions.

As the medical field continues to advance, the importance of understanding and addressing rare diseases cannot be overstated. These events stand as a testament to the power of collaboration, proving that together, we can make a difference.

CHINA

To further improve Chinese patients' overall quality of life and patients' understanding of treatment, we have launched several programs in 2024, including an education program, a survey program, as well as an advocacy program to promote patient-oriented clinical trials.
In our education program, we shared the latest advancement of the therapies in the U.S and Europe, as well as the insurance systems of Japan, which aroused patients' great interests and their aspirations for better and more diversified coverage for treatments and care.

In China, even with improved medical insurance coverage since 2019, our survey program still found out that Chinese patients, compared with U.S. patients with similar health conditions and physical functions, behaved much worse in mental health and social functioning. It warned us that most Chinese patients still heavily relied on the support of their family instead of social support.

Fortunately, China NMPA (National Medical Products Administration) has begun to pay more attention to rare disease patients' perspectives in clinical trials. Therefore, at the end of 2024, we were invited again by CDE (Center for Drug Evaluation) to share our perspective on PH drug development. With the knowledge we've learned from international communities, we introduced the best practices of the EMA and FDA, and highlighted the importance of early patient engagement in the design of clinical trials, which raised the officials' interests and attention.

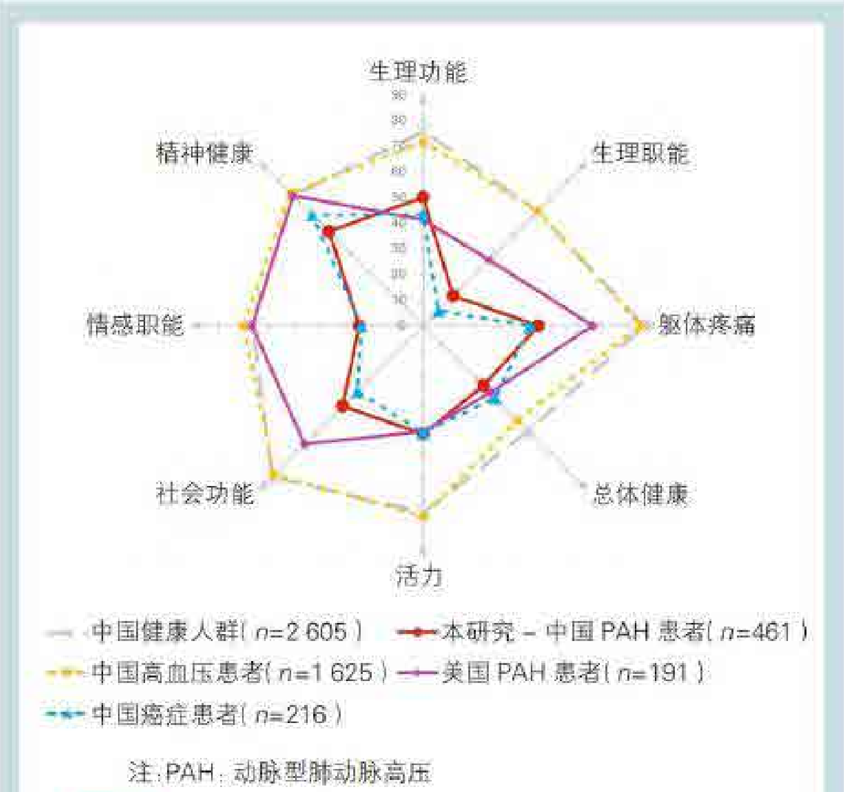


图 1 PAH 患者的 SF-36 生活质量评估和横向对比

CROATIA

Dear PH community,

The Croatian association "Plava Krila" has a lot of good news to share with you.

We participated in the Novartis Academy for Associations (Adriatic Region), which was held from November 22nd to 24th, 2024. The **Novartis Academy for Associations** took place in Osijek, gathering nearly 100 representatives from Croatia, Serbia, Bosnia and Herzegovina, and Montenegro. The aim of the Academy was to provide participants with education, support, and inspiration to enhance the work of their organizations.
The three-day program featured a wide range of relevant and practical topics, including:

- ▶ **Financial management** for associations, offering practical guidance on organizational leadership.
- ▶ **Artificial intelligence (AI)** and its potential applications in nonprofit work, which sparked great interest among participants.
- ▶ **Fundraising strategies,** addressing one of the most challenging aspects faced by all associations.
- ▶ **Motivational speeches,** including an inspiring talk by the well-known speaker Domagoj Jakopović Ribafish, who shared his personal story and infectious energy.

Beyond the lectures, the Academy provided ample opportunities for networking, sharing experiences, and forming new friendships. The atmosphere was filled with enthusiasm and positive energy, strengthening the sense of solidarity among association representatives.
In conclusion, participating in the Novartis Academy was an invaluable experience, offering new knowledge and fostering regional collaboration among associations. We sincerely thank the organizers for the opportunity to be part of such a meaningful event!

Thanks to the generous support from Orphacare Austria, we successfully translated and printed two new brochures designed to benefit patients living with pulmonary hypertension. These brochures focus on essential topics that address the everyday challenges of living with this rare disease:

1. Nutrition and Pulmonary Hypertension

This guide provides practical advice on a diet tailored to the specific needs of patients. It emphasizes the importance of balanced nutrition to help manage symptoms, maintain energy levels, and support overall health.

2. Travel Tips for People with Pulmonary Hypertension

The travel-focused brochure offers valuable tips for planning and staying safe while traveling. It includes recommendations on carrying medications, using oxygen during trips, and adapting to different conditions at the destination.

In addition to the printed versions, these brochures are also available in PDF format. They can be accessed on our **"Plava Krila"** website and on our profile at the **Bel Air Center.**

These resources mark a significant step forward in supporting patients and their families, providing them with essential information to navigate their daily lives more effectively. We extend our heartfelt thanks to Orphacare for their ongoing support, which enables us to realize such meaningful projects!

We were a big part of the 3rd National Meeting on Pulmonary Hypertension held in Zagreb.

In early December, Zagreb hosted the 3rd National Meeting on Pulmonary Hypertension, bringing together medical experts from various centers across Croatia, including Zagreb, Split, and Rijeka. The event gathered pulmonologists, cardiologists, internists, family medicine practitioners, and other professionals involved in the diagnosis and treatment of this rare and complex condition.

Discussions during the meeting focused on the challenges in treating pulmonary hypertension, the latest medical research and guidelines, and the importance of a multidisciplinary approach in providing high-quality care for patients.

Zdenka Bradač, as a representative of the "Plava Krila" association, had the opportunity to contribute with a short presentation and a panel discussion on the topic of "The Patient's Journey: From First Symptoms to the Diagnosis of Pulmonary Hypertension." Zdenka's contribution provided insight into the patient's perspective, highlighting key challenges such as:

- Delays in diagnosis,
- Lack of accessible information,
- The complexity of treatment and the need for long-term support.

The importance of collaboration among medical professionals and patient associations was emphasized to improve the situation in the country. Key priorities include accelerating diagnosis and ensuring accurate diagnoses, both of which are essential for timely treatment and improving patients' quality of life.

The meeting concluded with a strong acknowledgment of the value of such gatherings in advancing healthcare services and fostering collaboration among all stakeholders in the treatment of pulmonary hypertension. We extend our gratitude to the organizers for the opportunity to participate in this important event and hope that such initiatives will contribute to meaningful improvements in the future.

And last but not least, we had the honor of speaking with the esteemed Dr. Feđa Đubur, one of the leading experts in pulmonary hypertension. In this fascinating interview, we discussed the current situation regarding this condition in Croatia, the challenges faced by patients and healthcare professionals, and Dr. Đubur's vision for the future of pulmonary hypertension treatment.

One of the key topics we explored was the lung transplant program in Croatia—a subject that raises important questions for patients and their families.

We invite you to watch this inspiring and informative video on the Bel Air Center website! Learn more about the latest medical advancements, challenges, and hopes for a better future for all patients.

Don't miss the chance to hear insights from one of the top experts—visit our website and watch the video!

Link to the video:
https://mega.nz/file/I4gXiS6a#L_rkw3YvW_fBD2W7NuM9oq8IFu37fNQHfD5bZ0Y6srg

Katica Mavračić

CZECH REPUBLIC

ČAVO: ADVOCATING FOR PATIENTS WITH RARE DISEASES

The Czech Association for Rare Diseases (ČAVO) unites patient organizations representing individuals with rare diseases, advocating for their interests, and working to raise awareness about the unique challenges they face. ČAVO's mission is to improve the understanding of rare diseases among healthcare professionals, policymakers, and the public while striving to ensure that the healthcare system better addresses the needs of those affected. ČAVO actively contributes to the development and implementation of strategic documents, including the Strategy for Rare Diseases 2030 and National Action Plans for Rare Diseases. It participates in discussions within the Patient Council and working groups at the Ministry of Health and the Ministry of Labor and Social Affairs. The organization also collaborates with similarly focused groups both within the Czech Republic and across Europe. Founded in March 2012, ČAVO has been a vital part of the rare disease community for over a decade. Our association has been a proud member of ČAVO for many years, and we deeply value the support and opportunities it provides. Dr. Herčíková, one of our representatives, participates monthly in a dedicated working group that focuses on addressing the most pressing issues faced by patients with rare diseases. These regular meetings play a key role in ensuring that the voices of patients are heard and that meaningful solutions are sought for their challenges.

PATIENT FORUM 2024: PRIORITIES FOR A MODERN HEALTHCARE SYSTEM

The Patient Forum 2024, hosted by the National Association of Patient Organizations (NAPO), focused on key issues shaping the future of Czech healthcare. The event outlined actionable goals for improving patient care, transparency, and inclusion, aligned with the long-term **Patient Vision for Healthcare 2035.**

PATIENT JOURNEY: IDENTIFYING AND ELIMINATING INEFFICIENCIES

One key topic was the patient journey—tracking how patients navigate the healthcare system to identify inefficiencies and improve outcomes. While structured pathways exist for only a few diagnoses, analyzing care data can optimize processes, enhance therapeutic approaches, and improve reimbursement mechanisms. NAPO encouraged its member organizations to collaborate with healthcare professionals to define optimal patient journeys, assess the quality of care, and measure its impact on patients' lives.

TRANSPARENCY IN HEALTHCARE DATA

The forum also addressed the need for public access to data on the quality and availability of healthcare services. Currently, patients lack the ability to make informed choices about providers. NAPO aims to collaborate with stakeholders to ensure data on quality indicators is published in a user-friendly format. Access to such data would empower patients to choose care based on proximity or provider expertise and promote transparency and accountability in the healthcare system.

PATIENTS IN INSURANCE GOVERNANCE

The final discussion centered on including patient representatives in the governing boards of health insurance companies. Panelists emphasized that patients, as primary users of healthcare, should have a voice in decisions affecting care quality, accessibility, and funding. NAPO advocates for qualified patient representatives to join boards of both sector-specific and general insurers, including VZP, the largest Czech insurer. Their presence would ensure that long-term patient needs are prioritized over short-term financial goals, leading to more sustainable and patient-focused healthcare policies.

GOALS FOR 2024

1. OPTIMIZE PATIENT JOURNEYS

to improve care efficiency and outcomes.

2. ENSURE PUBLIC ACCESS TO HEALTHCARE QUALITY DATA

for informed patient decisions.

3. INCREASE PATIENT REPRESENTATION

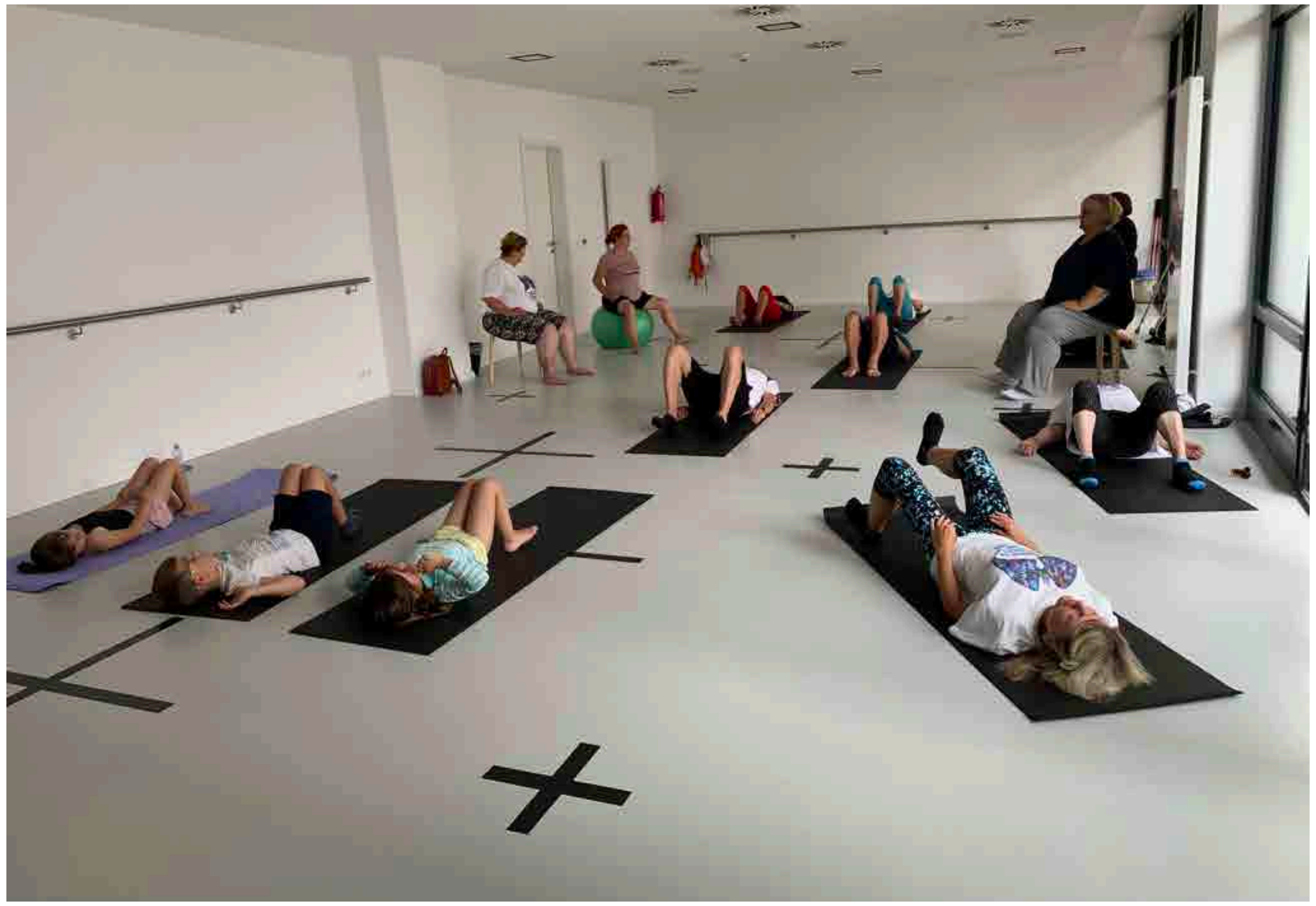
in health insurance governance to better reflect their needs and expectations.The Patient Forum 2024 reinforced that a patient-centered approach, transparency, and collaboration are vital to the evolution of healthcare in the Czech Republic.

STRENGTHENING COLLABORATION WITH THE MINISTRY OF HEALTH

The Vice President of our association continues to serve as a member of the advisory body for the reimbursement of drugs intended for rare diseases. This role highlights both the dedication and expertise of our organization and the growing recognition of the importance of incorporating patient perspectives into healthcare decision-making, particularly for rare diseases. Having a representative from a patient advocacy group in such a key position brings invaluable insights into the unique challenges and needs faced by individuals living with rare conditions. It ensures that the voices of patients are heard and considered when shaping policies and making decisions that directly impact their lives. This collaboration underscores the significance of fostering partnerships between patient organizations and healthcare authorities. Together, we can work toward a more inclusive and patient-centered healthcare system that better addresses the complexities of rare diseases.

ANNUAL REHABILITATION WEEK FOR PULMONARY HYPERTENSION PATIENTS IN PODĚBRADY

As in previous years, the second week of August was dedicated to the annual rehabilitation program for patients with pulmonary hypertension in Poděbrady. This event focuses on supporting the mental well-being of patients and their family members while also demonstrating that physical activity can be safely incorporated into their lives, even with a chronic condition.The program was conducted under the guidance of a physician from the Pulmonary Hypertension Center and physiotherapists. This year's activities centered on gentle breathing exercises, muscle stretching, and improving movement habits. New techniques were introduced to strengthen the core muscles, aiming to protect the spine and enhance overall physical stability. In addition to the physical aspects, patients had the opportunity to consult with a pulmonary hypertension specialist, addressing individual concerns, and receiving personalized advice. Building on the success of previous years, psychological relaxation sessions and one-on-one support were also included, providing a holistic approach to care. This weeklong program continues to be a vital resource for patients and their families, fostering a sense of empowerment, well-being, and community.



19TH WEEKEND MEETING OF THE PULMONARY HYPERTENSION PATIENTS ASSOCIATION

On September 21 and 22, 2024, the 19th weekend meeting of the Pulmonary Hypertension Patients Association (SPPH) took place. The event was held in a friendly atmosphere and offered a diverse program, including not only the general assembly but also a series of expert and practical lectures. One of the key highlights was a presentation by SPPH vice chairperson, Ing. Šulcová, who introduced the activities of the Advisory Body for the Reimbursement of Medicines for Rare Diseases. This body, established under the Ministry of Health of the Czech Republic, plays a crucial role in decision-making regarding the funding of treatments for rare diseases, and Ing. Šulcová has become one of its members. In her speech, she emphasized the importance of actively involving patients in decision-making processes and highlighted the significant role of their voices in healthcare policy. Another noteworthy moment was a lecture by Professor Jansa from the Center for Pulmonary Hypertension at the General University Hospital in Prague. Professor Jansa presented new treatment options for pulmonary arterial hypertension, focusing particularly on a newly approved medication that offers fresh hope for patients. His presentation captivated both medical professionals and patients, providing valuable insights into the progress being made in the treatment of this condition. The SPPH meeting, once again, provided an opportunity for participants to exchange information, share experiences, and strengthen the community of patients and their families. Attendees left not only enriched with new knowledge, but also with a sense of mutual support and reassurance that they are not alone in their fight.

GERMANY

Our self-help group PH Self-Help with Heart and IQ currently has 936 members, who are PH patients and caregivers. In 2024, we produced a brochure together with MSD Germany and with the collaboration of some patients from the PH association, which is tailored particularly to the newly diagnosed PAH patients. It gives a brief insight into what PAH is, advises you what things you should do, and what you should not do. It also informs about what disability compensations the patients are entitled to. Above all, it shows how serious this disease is, but also brings a lot of hope. With it, we are saying: „Hello you! You are no longer alone with the demon of Pulmonary Arterial Hypertension. We are here for you, you can contact us, and we will pick you up when you are down.

LEBEN MIT PAH

Entwickelt von Betroffenen

INFOS UND TIPPS FÜR BETROFFENE, ANGEHÖRIGE UND FREUNDE

Mit Unterstützung von MSD

HUNGARY

In May 2024, after many Saturdays that we have spent attending the lectures and workshops between November and May, we successfully graduated from the Patient Organization Academy organized by AIPM. We learned a lot of useful things, for example about communication and social media, but we also dealt with the legal environment and Health Technology Assessment.

EMLÉKLAP

Ezúton igazoljuk, hogy a

Tüdőér Egylet

betegszervezet képviselője elvégezte az Innovatív Gyógyszergyártók Egyesülete által szervezett Betegszervezeti Akadémiát a 2023/2024 évfolyam résztvevőjeként.

Szívből gratulálunk, sok sikert és örömet kívánunk a betegszervezeti munkához!

Budapest, 2024. május 4.

Dr. Szalóki Katalin
Igazgató

AIPM

Dr. Kocsis Janka
Főszervező

In 2024, we participated again in the event of RIROSZ (Hungarian Rare Disease Association), organized on the occasion of World Rare Disease Day. This year, it was held in the north-western part of the country on February 24th. The City of Sopron hosted it, which is in a region where there is not really a regional care/research network dealing with rare diseases, so it was important that the conference brought together health decision-makers, the region's professionals, and patient organizations. The enthusiastic association participants drew attention to the everyday problems of those suffering with PH, and the results achieved so far.

We had our General Assembly on April 25th, where our doctors talked about current issues with the participants, and those who joined could also receive a copy of a nutrition brochure.

During the year, we continuously monitored legislative changes, which require significant energy. We take advantage of every opportunity where a presentation is given.

We wrote grant applications and held discussions with several institutions on how we can ensure the financial background of the association's operation. We have published calls to offer 1% of the PIT, as well as the possibility of other forms of support. We also have a new method to collect donations: with the help of a QR code, people can donate money they received when they recycled packaging.

Egyedi azonosító

Kérjük, olvasd be az azonosító kódod, hogy közvetlenül a bankszámládra utalhassuk a visszaváltási díjat.

Tüdőér Egylet

We also took part in the general assembly of RIROSZ (Hungarian Rare Disease Association), the umbrella organization of which we are members.

We monitored the access to medicines for rare disease patients, as well as the innovations that promote a cure for PH. We also invited a representative of NEAK (National Health Insurance) to our National Conference to inform about the possibilities of state financing of drugs for PH patients.

We drew attention to the importance of patient organizations and the activities of our association at the HERA Info Days, META conference, and EESC conferences.

We also participated in the EgészségÉRTÉS - Women's Health Round Table events, where physicians and health decision-makers and representatives of patient organizations think together in the organization of the prestigious Semmelweis University (SOTE). We were also present at the AIPM meet-up event. These are good networking opportunities during which we can raise awareness for our association.

We introduced ourselves at the AIPM HEALTH. VALUE. MEDICINE event, where we informed those interested at our stand, and many took our materials with them.

In many cases, drug treatment of PH can slow the progression of the disease, but there is no cure yet. Fortunately, there are a variety of medicines available in our country, but there is a point where those no longer help. At that point, only lung transplantation can save patients' lives. That is why we cooperate with the MSZSZ and the Hungarian Heart and Lung Transplant Association. We took part in the Trapi days and the Lecsó festival in Szentes.

In October, we entered the SPAR Budapest Marathon. This time, it was not others that ran for us, but we signed up for the 2.3 km Gondosóra walk and the 500 meter FODISZ equal opportunities race together with fellow patients, family members, and friends. It doesn't seem like a long distance, but it was a great achievement for us to walk all the way. At our tent, we spoke to those interested about Pulmonary Hypertension and many people took our flyers and publications with them. The atmosphere captivated and inspired all participants. Out of breath, but happy, we reached the finish line. We also launched a fundraising campaign, as the association would need a portable oxygen concentrator, which the patients could receive for use as needed.

You can see our video at:
https://www.youtube.com/watch?v=8sJcjxwWOSo

In November, we represented the association at the APHEC, where we could hear useful presentations. We participated in workshops and spent a pleasant time with fellow patients from many European countries.

In November, we had our PH Awareness Month FB campaign as well, where we could use the visuals of the common campaign done by PHA USA and PHA Europe.

On November 29th, the high-level conference of our EU presidency and the EESC on rare diseases was held in Budapest, where we represented our association. At the conference, the exploratory opinion „Leaving no one behind: a European commitment to the fight against rare diseases" adopted at the October plenary session of the EESC was presented, which calls for the creation of an integrated European health framework program that sets specific goals for the improvement of the care of rare diseases by 2030.

CONFERENCE / KONFERENCIA #RareDiseases
For an EU commitment to tackling rare diseases
EU kötelezettségvállalás a ritka betegségek elleni küzdelem mellett
29.11.2024 | 9:00-16:00 | Budapest Congress Centre, Liszt room / terem | #RareDiseases

The year 2024 was eventful in the life of the association.

With our activity, we also satisfied basic needs of the society, in addition to keeping in mind the interests of the community of patients living with PH, such as:

▶ ***Increasing the population's health awareness*** *(education, awareness)*
▶ ***Improving the quality of life:*** *lifestyle advice, psychosocial support, community events*
▶ ***Advocacy:*** *participation in research, legislative opinions, innovative treatment options*
▶ ***Community building:*** *meetings, joint programs with other organizations*

We would like to continue this work in 2025 as well.

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

ITALY AMIP

The Pulmonary Hypertension Patient Association of Rome carried out many activities in 2025.
In addition to the daily action of offering psychological help 24 hours a day, for seven days a week, for those affected, we have also:

- launched our short movie "COL FIATO SUSPESO";
- participated in the annual meeting of the Pulmonary Hypertension Network;
- organized seven doctor/patient meetings in various Italian regions;
- participated in numerous meetings with pharmaceutical companies;
- participated in numerous art events (music festivals, theater performances);
- took part in scientific conferences organized by the National Research Centers;
- printed and distributed more than 4000 information leaflets,

...in short, our work to raise awareness in Italy takes place every day, and we don't lack the imagination to make ourselves noticed.

Città metropolitana
di Roma Capitale

amip

Associazione Malati di Ipertensione Polmonare

COL FIATO SOSPESO

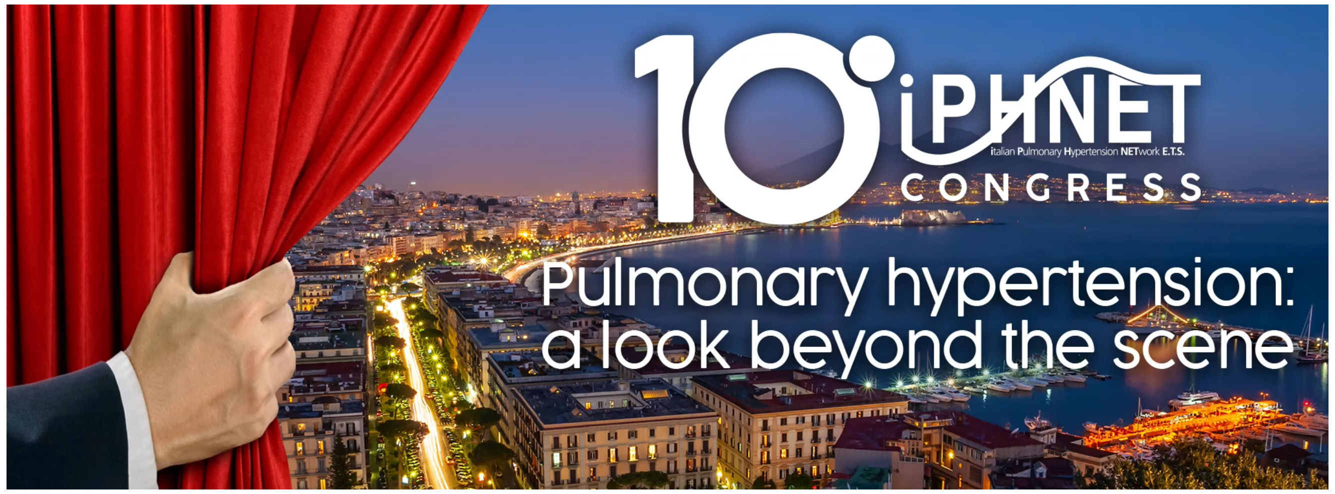
Giornata di sensibilizzazione sull'**IPERTENSIONE POLMONARE**, una malattia invisibile

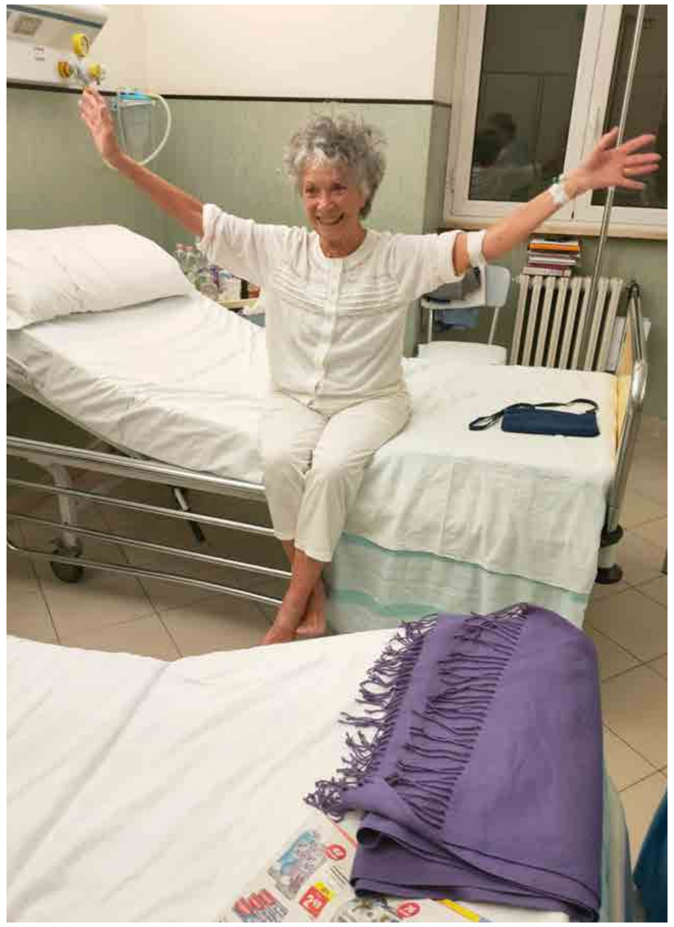
24 gennaio

Roma, Palazzo Valentini via IV Novembre 119/a
sala Di Liegro - ore 10:30 - registrazione ore 10:00

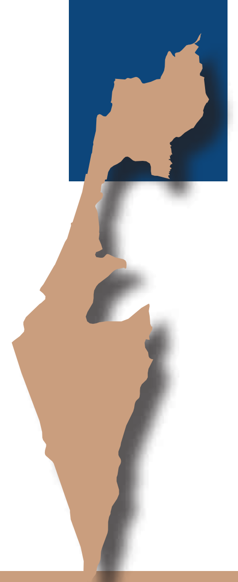
- Saluti istituzionali della Consigliera Delegata di Città metropolitana di Roma Capitale
  Tiziana Biolghini
- La patologia e l'associazione AMIP
  Presidente **Vittorio Vivenzio** e fondatrice **Maria Pia Proia**
- Proiezione del filmato AMIP
  Socia e ideatrice del filmato **Renata Zancanella**
- L'associazione europea dei malati di ipertensione polmonare
  Presidente PHA Europe **Eva Otter**
- "Cos'è l'Ipertensione Polmonare"
  dr. **Stefano Ghio**
- "Le difficoltà di gestione pazienti"
  dr. **Michele D'alto**
- "L'interconnessione tra centri specialisti e medici di medicina generale"
  dr. **Fabio Valente**
- "Le attuali terapie e cosa ci aspetta in futuro"
  prof. **Roberto Badagliacca**
- "Il trapianto cardio-polmonare o solo polmonare, ultima spiaggia"
  prof. **Patrizio Vitulo**

Modera l'evento ***Pino Insegno***





- Together we can! -



ISRAEL

PROJECT WITH PHA USA

The association from Israel translated a Guide to Intimacy and Pulmonary Hypertension. This guide is in final editing mode and will be made available for patients with PH and their partners and carers, to ensure an understanding of and improve intimacy and coping with its various challenges. Providing support and a greater understanding of intimacy contributes to a greater quality of life and relationship building among patients.

LAUNCH OF A NEW SUPPORT PROGRAM FOR PATIENTS IN NEED OF TRANSPLANTS

Much research was done, resources created and information provided to support patients. The program focuses on how to approach the process of application, guidelines and tools on how to cope with relevant bureaucracy, understanding the medical process and the timing for each stage of this journey, and when it is relevant to consider transplant overseas (not in your home country). This program is being worked on in partnership with the local lung transplant association in Israel.

ONLINE WEBINAR WITH DR. YOCHAI ADIR

There was a wide participation of many patients, including new patients, who joined a virtual conference of the association together with Yohai Adir, the director of the Carmel Lung Institute in Haifa. Although Haifa was under heavy rocket attack from Hezbollah terrorists, the doctor continued with a comprehensive and interesting lecture on new and groundbreaking drugs for the treatment of pulmonary blood pressure. The doctor explained at length about the need for existing drugs to work, and the new way in which new drugs work, as well as how they prevent the development of the disease. He also elaborated on the way of receiving the drug, its side effects, and the unique methods he found to help patients deal with these side effects. The members of the association prepared many intriguing questions before the lecture and Sharon Ronder, a member of the association's committee, raised questions for the doctor, who answered them at length and in a clear manner that clarified the full picture of the process of the new drugs for this serious disease. The doctor found a number of his patients in the audience who were on Sotatercept and brought them up to speak in front of the audience and tell them about the tremendous success they had with the drug. The patients listened attentively and were really captivated to hear firsthand about the success and coping of the patients, who have just received the drug as part of a research study and thus have been receiving it for a longer time. Many patients raised additional questions, which were answered very professionally by a great professor. The lecture ended on a high note, and the members expressed great satisfaction with the new and professional information presented to them.

news@israelhayom.co.il | חדשות היום | כ"ד בכסלו תשפ"ה | רביעי | 25.12.2024 | 15

התרופה שתציל חולות במחלת ריאות נדירה

כ־400 נשים בישראל חולות במחלה הפוגעת בעורקי הריאה וגורמת לכך שכל פעולה פשוטה, כמו פתיחת מקרר או סירוק השיער, כרוכה בסבל עצום ● כעת למחלה השקופה הזו יש טיפול חדש – התרופה סוטאטרספט שמפחיתה ב־84% את התקדמות המחלה והתמותה ממנה

מיטל יסעור בית-אור

"תחושה שאין אוויר". צילום: GettyImages

כלפי חוץ הן נראות בריאות, אבל החולות במחלת הריאות יתר לחץ דם ריאתי עורקי, מתקשות לעלות במדרגות, להוציא אוכל מהמקרר או אפילו להרים ידיים כדי לאסוף את השיער.

הנדירות של המחלה, שבה חולות כ־400 נשים בישראל (70% מהן צעירות בשנות ה־30–40 לחייהן), היא מאתגרת עבור הרופאים, ומשך האבחון הממוצע שלה הוא בין שנה לשלוש שנים. במהלך תקופה זו החולות נשלחות לפסיכולוגים ולפסיכיאטרים ומתויגות כסובלות מהשמנה או מדיכאון אחרי לידה, או כחלק מסימפטומים המקושרים להיריון.

כעת למחלת הריאות השקופה הזו יש טיפול חדש, שלראשונה לא מטפל רק בסימפטומים אלא במנגנון עצמו. התרופה, "סוטאטרספט", מפחיתה ב־84% את התקדמות המחלה והתמותה ממנה, והיא מועמדת להיכנס לסל התרופות הקרוב.

"יושבת בבית ובוכה"

ג'ודי לבדי (55) מרמת גן התלוננה בפני הרופאים שקשה לה לנשום בהליכה, שהיא צריכה לעצור לעיתים קרובות מרוב מאמץ, שכואב לה הגב במיוחד באזור הריאות, אבל אלה התייחסו אליה בביטול. "אמרו לי שאני שמנה ושכל התסמינים האלה הם בגלל המשקל שלי. חלקם הסבירו לי שאני צריכה להיכנס לכושר, ואחרים טענו שזה בכלל לחץ נפשי. למדתי לחיות עם המחלה מבלי שאני מבינה ויודעת מה יש לי. אחרי כל פעולה הכי פשוטה ושגרתית כמו לקום מהכיסא בעבודה לשירותים הייתי חוזרת מתנשפת עד שהגוף נרגע. הלכתי להמון רופאים, אמרתי להם שאני מרגישה כאילו 'משאית עוברת על כל הגוף שלי', והם אמרו שבסך הכל מדובר בלחץ.

"כשכולם אומרים לך שהכל אצלך בראש, כמעט השלמתי עם זה שכנראה משהו אצלי בראש לא תקין. שלחו אותי לפסיכיאטרים ולפסיכולוגים, והציעו לי טיפול בתרופות הרגעה. סירבתי משום שמשהו בתוכי אמר לי שזה לא נפשי", היא מוסיפה.

אחרי שהתחסנה נגד קורונה המחלה התפרצה במלוא עוצמתה, ואז גם הגיעה האבחנה הגואלת. "מאחר שאני עובדת בקופת חולים, עליתי לחדר האחיות ושם מדדו לי סטורציה (רוויון החמצן בדם) שעמדה על 84%, בעוד רמות תקינות נעות בין 96% ל־100%. מייד חיברו אותי לחמצן, ולמחרת קבעתי תור לרופא ריאות ששלח אותי לסדרת בדיקות בבית חולים", מספרת ג'ודי.

"מטפלת במנגנון עצמו". סוטאטרספט
צילום: Merck

"כבר ארבע שנים שאני 'תקועה' רוב היום בין ארבעה קירות. בתחילת המחלה עוד הייתי מסוגלת לבשל, אבל הטיפול ברמודולין פגע לי במפרקים, והידיים שלי לא מסוגלות לקלף ולחתוך. אני גם לא יכולה לעמוד יותר מדי. בבית יש לי מחולל חמצן, ובלון חמצן עם חוט באורך של 12 מטרים. נוסף על כך יש לי שלושה בלוני חמצן, שכל אחד מחזיק לפרק זמן של שעה ו־50 דקות. היות שחידוש הבלונים הוא אחת לשבוע, אני חייבת להיות מאוד מדודה ומחושבת ביציאות שלי מהבית. כל סוף שבוע וכל חג אני בבית. כולם יוצאים ומבלים, ואני יושבת לבד ובוכה. אני גם רוצה לבלות עם חברים ומשפחה, אבל אין לי חמצן".

ג'ודי היא אם חד־הורית ומתגוררת עם בנה בן ה־19 שמשרת בצה"ל. "בגלל המחלה שלי אני מחמיצה הרבה חוויות עם הבן. לגיוס ולסיום הקורס שלו בצבא לא יכולתי להגיע. החלום שלי הוא שנצא לחופשה שנינו. הנכות פוגשת אותי מדי יום", היא מספרת.

המחלה גורמת להיצרות של עורקי הריאה המובילים דם לריאות, וככל שהיא מתקדמת עורקי הריאה הקטנים נעשים צרים יותר ועלולים להיחסם. התקדמות ממושכת שלה עשויה לפגוע בתפקוד הלב, להביא למצב של אי־ספיקת לב ולהזדקקות להשתלה. מדובר במחלה כל כך קטלנית, שאחת מכל שתי נשים שמאובחנות בה הולכת לעולמה בתוך חמש שנים מרגע האבחון (שיעורי תמותה גבוהים מאוד שדומים למחלת הסרטן).

ד"ר יניב דותן, מנהל מכון ריאות רמב"ם – הקריה הרפואית לבריאות האדם, מסביר על התרופה: "התרופה החדשה סוטאטרספט היא היחידה שמטפלת במנגנון עצמו – מונעת את התהליך שגורם להתכווצות כלי הדם בריאות. זו תרופה שתיאורטית יכולה למנוע את התקדמות המחלה שהסיבה לה לא ברורה. היא ניתנת כזריקה תת־עורית פעם בשלושה שבועות.

"מחקר בתרופה שפורסם ב־2023 הראה שהיא חוללה המון שינויים לטובה – העלתה את יכולת המאמץ של החולים, את מרחק ההליכה שלהם, הפחיתה תמותה ותחלואה ב־84% והורידה את לחץ הדם בריאות. היא הוגשה השנה לסל התרופות ודורגה על ידי רופאי הריאות כתרופה החשובה ביותר. התרופה נראית מאוד מבטיחה, אך רק כשנתנסה בה נוכל לראות אם היא מועילה ברמה גבוהה".

לדבריו, הטיפול הנוכחי בחולות, בין היתר במשאבה שמזריקה את התרופות הקיימות, גורם לזיהומים חוזרים ולכאבים במקום ההזרקה ולאיכות חיים נמוכה מאוד.

"תחושה נוראית"

אחת החולות שהתנסו בטיפול החדש היא מעיין (שם בדוי), בת 43 מהוד השרון, שאובחנה לפני שלוש שנים עם יתר לחץ דם ריאתי־עורקי, נוסף על מחלת סקלרודרמה (טרשת רב־מערכתית שפוגעת ברקמות החיבור) שממנה היא סובלת זה כמה שנים.

"בתוך שבועיים מהאבחון הפכתי מבחורה צעירה ופעילה לכזו שלא יכולה לעשות כלום – אפילו להתלבש. אי אפשר להסביר את התחושה הנוראית הזאת שאין לך אוויר. כל פעולה קטנה כרוכה בסבל עצום. אין אוויר, אני לא יכולה ללכת יותר משני צעדים ופשוט נתקעים באמצע הכביש. זה מפחיד, וזה חוסר אונים משווע", היא מספרת.

מעיין מתאשפזת ומשתחררת מבתי חולים דרך קבע. "למרבה המזל, הטיפול החדש אפשר לי לעשות את זה ולשפר את איכות החיים באופן דרמטי".

אריה קופרמן, מנכ"ל העמותה הישראלית ליתר לחץ דם ריאתי, שגם אשתו אובחנה כחולה במחלה: "בגלל היעדר המודעות, אבחון המחלה מתבצע כמעט תמיד באיחור רב שיכול להגיע עד שנתיים, כאשר המחלה כבר בשלבים מתקדמים. לכן ישנה חשיבות רבה בהנגשת התרופה הביולוגית, שלראשונה מטפלת בגורם המחלה, ואף יכולה למנוע בצורה דרמטית את הצורך בהשתלת ריאה ובכך להציל את חייהם של חולים רבים".

"נראית מבטיחה". ד"ר דותן
צילום: באדיבות רמב"ם

"הרגשתי שזה לא נפשי". ג'ודי
צילום: באדיבות רמב"ם

"בתוך שבועיים מהאבחון הפכתי מבחורה צעירה ופעילה לכזו שלא יכולה לעשות כלום - אפילו להתלבש. אי אפשר להסביר את התחושה הזאת שאין לך אוויר. כל פעולה כרוכה בסבל עצום"

"מחקר הראה שהתרופה חוללה המון שינויים לטובה - העלתה את יכולת המאמץ של החולים, את מרחק ההליכה שלהם, הפחיתה תמותה והורידה את לחץ הדם בריאות"

JAPAN

PHA Japan was proud to celebrate 25 years of serving the Japanese PH patients. At the 17th National PH Conference held on the occasion, presentations were given about current and new treatments, and the possibilities of transplantation. Participants could also listen to information about the World PH Symposium, and the results of a survey-based study that explored treatment satisfaction between patients and doctors in PAH and CTEPH in Japan. The closing lecture was about genes.

17th National PH Conference
Oct. 13. 2024 (Sun) at Keio Univ. Hospital, Tokyo (124 attendees)

10:00～10:30	30	Resistration
10:30～10:40	10	Opening
10:40～11:00	20	**New drugs** Dr. Masaru Hatano (Tokyo University)
11:00～11:05	5	break
11:05～11:25	20	**Transplant** Dr. Masaaki Sato (Tokyo University)
11:25～11:35	10	break
11:35～11:55	20	**CTEPH** Dr.Tsuyoshi Ogo (National Cerebral and Cardiovascular Center)
11:55～12:00	5	break
12:00～12:30	30	**Pediatric** Dr.Hiroyuki Hukushima (Keio University) Dr.Shinichi Takatsuki (Toho University)
12:30～13:00	30	Break

13:00～13:20	20	**7thW SPH 2024/6/29-7/1(Barcelona)** Dr. Yuichi Tamura (Internatiional University of Health and Welfare)
13:20～13:25	5	break
13:25～13:40	15	**Exploring Treatment Satisfaction between Patients and Doctors in PAH and CTEPH in Japan:A Survey-Based Study** Jyuichi Omura (Janssen Pharma)
13:40～13:45	5	break
13:45～14:05	20	**Epoprostenol tratment** Dr. Noriaki Takama(Gumma University)
14:05～14:15	10	break
14:15～14:45	30	**Gene** Dr. Takahiro Hiraide (Keio University) Dr. Sarasa Isobe (International University of Health and Welfare)
14:45～		closing

17th National PH Conference
PHA Japan 25th anniversary
Oct.13,2024
At Keio University hospital in Tokyo

LATVIA

Making a Difference: PHA community of Latvia in 2024

PARTICIPATION 2024

From January to October 2024, the Pulmonary Hypertension Society of Latvia (PHB) implemented the project “Participation 2024,” financially supported by the Society Integration Fund from the Latvian state budget within the framework of the NGO Foundation 2024 program. Over the 10-month project, the association was able to meet its basic needs – hiring a part-time project expert, paying for an accounting service, ensuring the operation of a consultation hotline, purchasing necessary inventory and office equipment, and educating the public about the PAH diagnosis and actual health issues by creating social media content. The main project activities included PAH patient advocacy at the national level, an event for PHB members and their families, and a highly popular psycho-emotional health program consisting of a set of three social integration and educational events.

During the project, we gained valuable friends and potential partners for future events. The greatest added value was the suggestions for amendments about the Patient Rights Law, the development of a physiotherapy pilot program, new insights into creating more inclusive and interesting events, the involvement of 7 volunteers in organizing organizations’ events, and the willingness of volunteers to continue cooperating with PHB, as well as the involvement of members in generating ideas on how to better implement the psycho-emotional program and what activities are needed in the future.

The opinions expressed in the survey testify to the project’s success:

- There were many events, well-thought-out, interesting, thank you to the organizers.
- Very successful! You could feel the energy with which the PHB team is doing things!
- Qualitative and in accordance with the set objectives.
- I was with three children at the event at Anna’s Tree School. Magical! Calm, thoughtful, unhurried. The tour guide was very likeable. There was an opportunity to meet people I already knew, to talk calmly.
- This year’s events were very interesting and educational, they helped a lot to integrate into society and get to know your fellow association members and learn a lot of new things.
- I got acquainted with the association’s activities, which were very interesting. I enjoyed the colorful autumn in a place where I had never been before! Participants of different ages and with different special needs, but together there is harmony, support, warmth...

THE RESULTS OF THE PROJECT

As an advocacy activity, we realized the discussion “Is disability (in)ability?” with 22 participants in July 2024, provided 80 hot-line consultations of PAH patients and their family members, and PHB participated in 10 advocacy meetings with the Health Ministry, the National Health Service, and other stakeholders. We also realized the collaboration with four Latvian organizations, as well as international ones.

On August 25, 2024, PHB implemented the Membership Meeting and public event for our community members with 34 participants. On a beautiful day of late Summer, we gathered in a natural aroma workshop and a physiotherapy session, networked, and got acquainted with new members, while we talked about ideas for future events. During October of 2024, we held our organization’s popular psycho-emotional health program, during which we had 65 participants, 6 volunteers, and three additional engaging events took place – two of them in Riga, and one in Babite, near Riga. The events were attended by people with functional impairments and their relatives, children with developmental disabilities and their parents, foster parents, as well as PAH patients.

PARTICIPATION IN INTERNATIONAL CONFERENCES

PHB's international presence in 2024 was significant. By attending the World PH Symposia, Access to Care Event for Patient Advocates in CEE and PHA Europe's General Annual Meeting and Conference, PHB gained valuable insights into the latest research, treatment advancements, and patient advocacy strategies. These experiences will undoubtedly contribute to improving the lives of PAH patients in Latvia.

CHRISTMAS TASTE

On the 3rd Advent, the PH community event "Christmas Taste" took place in Riga, at the market of Agenskalns. PHB members, their family members, and volunteers of the organization participated in the vegetarian kitchen workshop. We whipped up some healthy treats and baked a batch of heartwarming gingerbread cookies. A comforting, sweet hot drink accompanied these treats. The freshly baked cookies were lovingly packed in gift boxes and sent via parcel service to our regional PHB members who, due to their health challenges, were unable to join us in person for our events.

A FESTIVAL, AN EXHIBITION, AND MORE: WHAT AWAITS THE PAH COMMUNITY IN 2025?

PHB continues its active work to improve the quality of life for individuals with pulmonary hypertension in Latvia. We are delighted to announce that PHB has won two prestigious projects – the Central Contract and Financial Agency's project „Support Program for People with Disabilities and Seniors" and the Society Integration Fund's project „Breathing as One!". In 2025, we will organize the Oxygen Festival 2025 and a photo exhibition featuring people with PAH – it will be a great way to show that PAH does not break our spirit. Several other public events are planned to inform the public about PAH, reduce stigma, and promote a supportive attitude towards people with this disease (such events as public walking, photo workshop). PHB representatives will also take part in the Rare Disease Forum 2025 with a presentation about patient engagement in clinical trials and will organize the discussion on reproductive health and rare diseases.

Ieva Plume,
President of PHA Latvia
www.phlatvia.lv

THE NETHERLANDS

Highlights from Our National Activities in the Netherlands

A detailed report of all our activities in 2024 will soon be available on our website: *www.stichtingpulmonalehypertensie.nl.*

In the meantime, you can already find a summary of our National Pulmonary Hypertension Information Day, the most important event for patients in the Netherlands. This event offers individuals living with PH an opportunity to gain valuable information, connect with others who share similar experiences, and engage in informal conversations with healthcare providers.

We believe events like these are vital in fostering community, empowering patients, and enhancing collaboration between all those involved in pulmonary hypertension care.

NATIONAL PULMONARY HYPERTENSION INFORMATION DAY: A BLEND OF EDUCATION, CONNECTION, AND HOPE

On Saturday, November 23, 2024, the National Pulmonary Hypertension (PH) Information Day brought together patients, caregivers, and medical professionals for an inspiring and informative symposium. This annual event, designed specifically for PH patients and their loved ones, offered a full day of learning, connection, and support.

The event was expertly chaired by Dr. Sanne Boerman, whose exceptional time management skills ensured that 160 attendees smoothly navigated the packed agenda and found their way to the right sessions.

A TAILORED PROGRAM FOR EVERY ATTENDEE

The day began with a shared plenary session, followed by two rounds of thematic workshops, a well-organized lunch that allowed ample time for catching up with peers, and a lighthearted cabaret performance to close the event. Attendees were also treated to snacks and drinks to wrap up the day.

This year's program introduced a "personalized education" approach, offering attendees the opportunity to choose from six thematic sessions led by leading experts:

- ▶ Chronic Thromboembolic Pulmonary Hypertension (CTEPH) – Prof. Dr. Marco Post, Cardiologist
- ▶ PH Basics – Dr. Thomas Koudstaal, Pulmonologist
- ▶ Systemic Sclerosis, SLE, & PAH – Dr. Madelon Vonk, Rheumatologist
- ▶ Navigating Social Care Regulations (WMO) – Petra Veen, Client Support Specialist
- ▶ Managing PH with Infusion Pumps – Miriam Kap MSc, Nurse Specialist
- ▶ Caregiving Support – Auckje Terwindt & Diane Goeree-Detz, Caregiver Support Advisors

LOOKING AHEAD: PROMISING TREATMENTS FOR PH

The plenary session featured an inspiring talk by Dr. Jurjan Aman, who presented the latest updates on current and future treatment strategies for PH. His presentation highlighted the tremendous progress being made in PH research, offering hope to attendees and their loved ones.

MORE THAN INFORMATION

The day was not just about education; it was also about connection. The informal atmosphere provided attendees with opportunities to interact with healthcare professionals and share experiences with fellow patients.

The National PH Information Day, once again, proved to be a valuable and uplifting event, leaving participants feeling informed, supported, and hopeful for the future.

NORTH MACEDONIA

One of the biggest events during which we participated this year was the “November Run Marathon,” which is based in Gevgelija, the hometown of our association. We, as always, had our ambassador marathon runners, who participated in honor of November’s PH Awareness Month and got breathless for patients, and thus helped us spread awareness for Pulmonary Hypertension. This year, for the fourth time, the marathon managed to garner a very solid number of participants, and it lasted for two days. The first day, there was a 1km run for kids, and also a 1km run for disabled people. On the second day, the big 10km run was held. On these two days, we marked November’s Awareness Month for Pulmonary Hypertension, and we will continue to repeat it in the coming years.

NORWAY

This autumn has been very busy for PH Norway.

On the agenda, we have the process to get PAH registered as a rare disease in Norway, and therefore have sent applications to the ministry of health with several reminders in 2024.
We have still not received any answer, but it will be followed up in 2025.
We are utilizing the help of the Norwegian Heart and Lung association in this matter, and we have also been in touch with Hall from PHA Europe, who will be helping us.

We decided early on to have a patient meeting in the autumn of 2024, since we had to postpone our spring patient meeting due to lack of funding.

Funding was still an issue this autumn, but we finally got a go-ahead with the help of LHL, MSD, and Nordic Infucare.

The meeting was held at Cathinka Guldberg Hospital at Gardermoen (Oslo Airport) from the 15th to the 17th of November.

It was very successful, and a report was published in the PH Europe Newsletter before Christmas.
In addition, we have team meetings every 4 weeks and finally had a Christmas lunch, where we met in person at the end of November.

We have a very active closed Facebook group where the members of the group can ask questions and get information about our agenda.

There has been a peer to peer course where 3 people from our group attended and were able to help our fellow patients.

We have also been at several meetings about advocacy and about how to influence and inform health workers and politicians about PAH.

MSD has been very active regarding PAH, and we have been to several meetings with them about their new PH medication, as well as about a new register to get more information about prevalence of PAH in Norway. MSD also has a project about the PAH patient journey.

In December, MSD organized a film and patient interview to advocate and make PAH more known to healthcare workers.

From the 6th to the 10th of November, the annual APHEC meeting was held in Casteldefells in Barcelona and Marit Nydal Nicholson and Ann-Kathrin Bruheim attended for PAH Norway.

It was a very interesting meeting with much good news about PH and how to live well with PH.

There are several new studies and medicines on the way, which makes the future for PH patients brighter.

We made a report on the conference in our Facebook group, so that our members can follow closely what is going on.

The resume on this report was also presented at our patient meeting in November.

POLAND

Polskie Stowarzyszenie Osób
z Nadciśnieniem Płucnym i Ich Przyjaciół

ACTIVITIES IN POLAND OF THE POLISH ASSOCIATION OF PEOPLE WITH PULMONARY HYPERTENSION

(Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół)

PUBLICATION OF GUIDES FOR NURSES: HOW TO CARE FOR A PATIENT WITH PULMONARY HYPERTENSION

PURCHASE OF PORTABLE OXYGEN CONCENTRATORS FOR PATIENTS

Rare Disease Day in Warsaw - conversation with the Minister of Health on the urgent reimbursement of medicines and the purchase of portable oxygen concentrators for patients

RARE DISEASE DAY - INVOLVEMENT OF DOCTORS, NURSES, AND PATIENTS, A LESSON AT SCHOOL ABOUT OUR DISEASE

RARE DISEASE DAY - PULMONARY HYPERTENSION NEWSPAPER INTERVIEW

Mogła spać tylko na siedząco, przy otwartym oknie. Prawdziwą diagnozę postawiono, gdy była w stanie krytycznym

EDUCATION OF THE PUBLIC - INTERVIEW ON TV

JOINING THE PATIENT ADVOCATE PROJECT „ŁĄCZY NAS PACJENT"

Our association has telephone shifts twice a month, during which you can call us and ask about your illness

EDUCATIONAL CAMPAIGN ORGANIZED BY THE PATIENT RIGHTS ADVOCATE

The program was created in cooperation with the Minister of Health. During the campaign, our association has telephone duty twice a week. Anyone who feels worse, or cannot be diagnosed, can call us, and we suggest where to seek help, how to recognize the disease, and what tests should be performed.

THE PROJECT „QUICK DIAGNOSIS OF PULMONARY HYPERTENSION" ADDRESSED TO FAMILY DOCTORS

We want to educate doctors on how to recognize PH - we have already distributed 6 thousand leaflets

The project „Rapid diagnostics of pulmonary hypertension" aimed at family doctors - we educate doctors on how to recognize pulmonary hypertension. We sent leaflets to our patients, acquaintances, friends, and families. We hand them out at various educational events. Each time, we ask them to pass the leaflets on to doctors to increase awareness of the disease. We have already distributed 6 thousand leaflets.

WORLD PULMONARY HYPERTENSION DAY

Many cities illuminated their facilities in blue in solidarity with us, information about the disease was broadcast on the radio, and our poster was displayed in the cinema before each film for a week

THREE LARGE EDUCATIONAL CAMPAIGNS, DURING WHICH THE ASSOCIATION EDUCATED PASSERS

by about the disease, took place. This year, we also promoted information about transplants

INFORMATOR DLA LEKARZY

PRZYCHODZI PACJENT Z ZADYSZKĄ DO LEKARZA... - SPRAWDŹ CZY TO NADCIŚNIENIE PŁUCNE!

Jeśli zachodzi podejrzenie nadciśnienia płucnego, należy pilnie skierować pacjenta do poradni kardiologicznej celem dalszej diagnostyki.

Co to jest nadciśnienie płucne?

Co to jest krążenie płucne?

Jakie jest prawidłowe ciśnienie w tętnicy płucnej?

Jakie są przyczyny nadciśnienia płucnego?

Jakie badania należy wykonać u pacjenta z podejrzeniem tętniczego nadciśnienia płucnego (TNP)?

Gdzie powinno się diagnozować i leczyć tętnicze nadciśnienie płucne?

A MAJOR EUROPEAN EVENT - AN ECONOMIC FORUM IN KARPACZ AND A CALL FOR URGENT REIMBURSEMENT OF THE DRUG WAS ORGANIZED

We also submitted comments to the „Rare Diseases Plan," which will be forwarded to the Minister of Health

TV INTERVIEW ON THE NEED TO EDUCATE SOCIETY ABOUT PH

THE VOICE OF A PATIENT FROM POLAND AT THE ERS CONFERENCE IN VIENNA

PARTICIPATION IN THE CONFERENCE FOR CARDIOLOGISTS „PULMONARY CIRCULATION SECTION” AND LEADING THE FIRST PANEL ON THE NEEDS OF PATIENTS WITH PH

MEETING FOR PATIENTS IN KRAKOW

We discussed topics such as: what’s new in PH, how to take care of yourself, how to eat properly, what prostacyclins are, as well as why patients shouldn’t be afraid of a pump

PARTICIPATION OF AN ASSOCIATION MEMBER AT A CONFERENCE IN BARCELONA

PARTICIPATION IN THE „RODZINNA” CONFERENCE, WHERE WE HANDED OUT LEAFLETS TO DOCTORS ABOUT OUR DISEASE. WE TRAINED ABOUT 2 THOUSAND DOCTORS OVER THE WEEKEND

PARTICIPATION IN A CONFERENCE FOR LEADERS OF PATIENT ORGANIZATIONS - WE LED A PANEL ON PATIENT RIGHTS

CONFERENCE FOR PH PATIENTS IN ZABRZE

we discussed the following topics: what’s new in treatment, Sotatercept and our expectations, how to take care of yourself, how to live with a Hickman catheter pump, and furthermore, we also showed films about the rehabilitation of our patients

PORTUGAL

Celebrating 20 Years of Advocacy

2024 marked our association's 20th anniversary! An online challenge had been launched (end of the year 2023), inviting participants to share motivating and inspiring slogans/phrases. The three best entries were awarded prizes and shared widely throughout the first half of the year on our social media, engaging our community of patients, families, and caregivers. This initiative celebrated two decades of dedication, unity, and progress, while inspiring hope for the future.

SHINING A LIGHT ON RARE DISEASES

Rare Disease Day shone brighter than ever, as many landmarks across the country lit up in vibrant colors to honor the 300 million people worldwide living with rare diseases. These striking displays symbolized solidarity, awareness, and a collective call for action. Locally, efforts went beyond the illumination, with campaigns and events sharing personal stories and understanding about rare diseases. The day served as a powerful reminder of the need to continue advocating for inclusivity, research, and improved healthcare access.

GRAND OPENING OF THE BEL AIR CENTER – PHA EUROPE'S VIRTUAL PLATFORM FOR KNOWLEDGE

A groundbreaking initiative this year was the launch of the Bel Air Center, PHA Europe's virtual knowledge sharing platform. This innovative platform was designed to unite the Pulmonary Hypertension (PH) community, offering a digital space for connection, learning, and engagement. The opening of the Bel Air Center was largely publicized on all our social media, including the production of leaflets to hand out at all events.

EDUCATIONAL WEBINARS

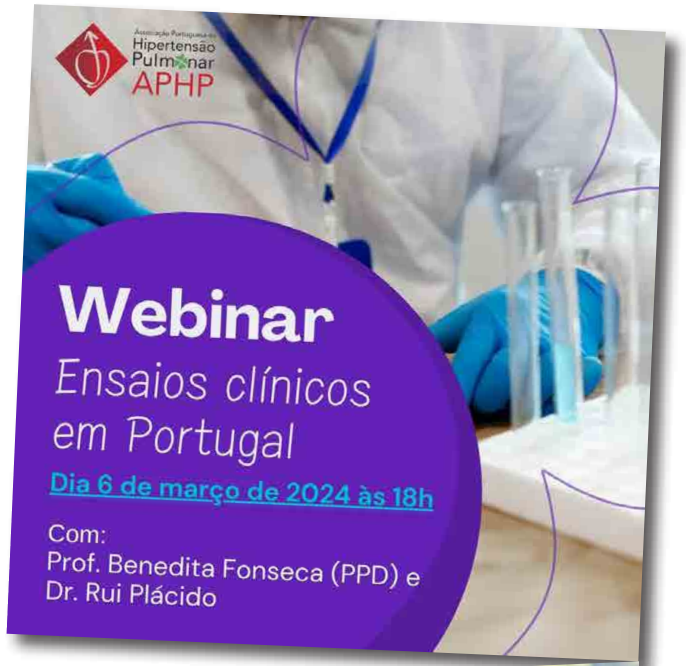
This year, a series of four webinars were hosted, generously sponsored by pharmaceutical companies, each addressing critical topics for the PH community:

▶ **6th of March – Clinical Trials in Portugal:**
Prof. Benedita Fonseca and Dr. Rui Plácido delivered an informative session aimed at demystifying doubts and misconceptions about clinical trials. Their expert insights helped participants understand the importance of trials and how they contribute to advancing treatments.

▶ **2nd of October – Cardio-Respiratory Rehabilitation:**
Dr. Pedro Saraiva, a renowned physiatrist, answered key questions on exercise, effort management, and strategies to improve quality of life. The session emphasized how structured rehabilitation can make a significant difference in the daily lives of PH patients.

▶ **23rd of October – Patient Rights and Social Support:**
Dr. Palmira Martins, a social assistant from Rare Disease Portugal, led a compelling discussion on the rights of chronic disease patients. She expertly highlighted the support systems available to PH patients in Portugal, empowering them and their families with knowledge.

▶ **27th of November – Understanding CTEPH:**
Cardiologist Dr. Mário Santos and nurse Andreia Bernardo provided an in-depth exploration of Chronic Thromboembolic Pulmonary Hypertension (CTEPH). Their expertise and interactive approach attracted excellent attendance, pointing out the importance of addressing this specific condition within the PH spectrum.



RAISING AWARENESS AT THE CARETO AIRSHOW

We continued our awareness efforts at the Careto Airshow in Bragança. This vibrant event provided a unique manner to engage with the public about Pulmonary Hypertension. A heartfelt thank you goes out to Nuno Miguel Fernandes, Rui Alves, and Paulo Cunha for their invaluable support in making this initiative a success.

EUROPEAN TRANSPLANT SPORTS CHAMPIONSHIPS

Our association was proud to attend the opening ceremony of the European Transplant Sports Championships in Lisbon, an inspiring event organized by GDTP that celebrated the “Gift of Life.” Countries from across Europe came together to honor the importance of organ donation and transplantation, showcasing the resilience of the human spirit.

OPEN DAY FOR PH PATIENTS

2. Edição
Curso Pós Graduado em HP
AULA MAGNA - FACULDADE DE MEDICINA, UNIVERSIDADE DE LISBOA

3º DIA
28.09.2024

Associação Portuguesa de Hipertensão Pulmonar APHP

Dia aberto para doentes com hipertensão pulmonar e familiares, em parceria com a Associação Portuguesa de Hipertensão Pulmonar (APHP

11:30

LIDAR PSICOLOGICAMENTE COM A HIPERTENSÃO PULMONAR
Dra. Cátia Rodrigues

Chairman do Curso / Course Chairman:
Prof. Fausto Pinto
Diretor do Curso / Course Director:
Dr. Rui Plácido

Comissão Científica / Scientific Committee:
Prof. Fausto Pinto
Dr. Nuno Lousada
Dr. Rui Plácido
Prof.ª Sara Correia
Dr.ª Tatiana Guimarães

Event endorsed by

In September, the Portuguese Association was invited to participate in the Open Day for PH patients, families, and caregivers as part of the 2nd Edition Post-Graduate Course on PH at Santa Maria Hospital’s Medical Faculty. Our involvement played a fundamental role in engaging with both existing and newly diagnosed patients, along with their families. This event provided a valuable opportunity to inform attendees about the association’s mission, exchanging experiences and handing out our literature, strengthening our connection with the community.

3º DIA | DAY 3
28.09.2024

Associação Portuguesa de Hipertensão Pulmonar APHP

Dia aberto para doentes com hipertensão pulmonar e familiares, em parceria com a Associação Portuguesa de Hipertensão Pulmonar (APHP)
Open day for patients with pulmonary hypertension and family members, in partnership with the Portuguese Pulmonary Hypertension Association (APHP)

09:00
INTRODUÇÃO
INTRODUCTION
Dr. Rui Plácido, Dr.ª Tatiana Guimarães, Dr. Nuno Lousada, Prof.ª Sara Correia & Nursing Team *(Lisbon, ULS Santa Maria)*

09:15
ATIVIDADE FÍSICA NA HIPERTENSÃO PULMONAR: VAMOS EM FRENTE!
PHYSICAL ACTIVITY IN PULMONARY HYPERTENSION: LET'S MOVE FORWARD!
Prof.ª Rita Pinto (Lisbon, FML & CCUL)

09:45
ESTRATÉGIAS DE CONSERVAÇÃO DE ENERGIA
ENERGY CONSERVATION STRATEGIES
Enf.ª Laura Soares, Enf.ª Tânia Cardoso (Lisbon, ULS Santa Maria)

10:15
ALIMENTAÇÃO SAUDÁVEL NO DOENTE COM HIPERTENSÃO PULMONAR

10:45 – 11:00
COFFEE BREAK

11:00
GESTÃO DO REGIME TERAPÊUTICO NA HIPERTENSÃO PULMONAR
THERAPEUTIC REGIMEN MANAGEMENT IN PULMONARY HYPERTENSION
Enf.ª Elisabete Tomé, Enf.ª Carla Sá (Lisbon, ULS Santa Maria)

11:30
LIDAR PSICOLOGICAMENTE COM A HIPERTENSÃO PULMONAR
PSYCHOLOGICALLY COPING WITH PULMONARY HYPERTENSION
Dr.ª Cátia Rodrigues (Coimbra, Associação Portuguesa de Hipertensão Pulmonar)

12:00
ENSAIOS CLÍNICOS EM HIPERTENSÃO ARTERIAL PULMONAR
CLINICAL TRIALS IN PULMONARY ARTERIAL HYPERTENSION
Dr.ª Sónia Cândido (MSD)

12:30
EMPODERAMENTO DO DOENTE COM DIAGNÓSTICO DE HIPERTENSÃO PULMONAR
EMPOWERMENT OF PATIENTS DIAGNOSED WITH PULMONARY HYPERTENSION
Dr.ª Palmira Martins (Lisbon, RD-Portugal CUIDARaro)

13:00
NOTAS FINAIS

Many presentations were held by leading professionals on topics such as nutrition, clinical trials, and social benefits. Cátia Rodrigues, our Associations president, held an excellent talk on the critical topic of mental health, emphasizing the urgent need to address this often overlooked aspect of living with PH. The scientific committee, featuring Prof. Fausto Pinto, Dr. Nuno Lousada, Dr. Rui Plácido, Prof. Sara Correia, and Dr. Tatiana Guimarães, ensured the highest standards of learning and engagement.

SOCIAL MEDIA PUBLICITY SPOT

The association launched a new publicity spot, shared across our media platforms. This initiative aimed to inform and raise awareness within our community, regarding its mission, objectives, and the importance of early diagnosis. The spot has been instrumental in connecting with a broader audience and ensuring that no patient faces their journey alone.

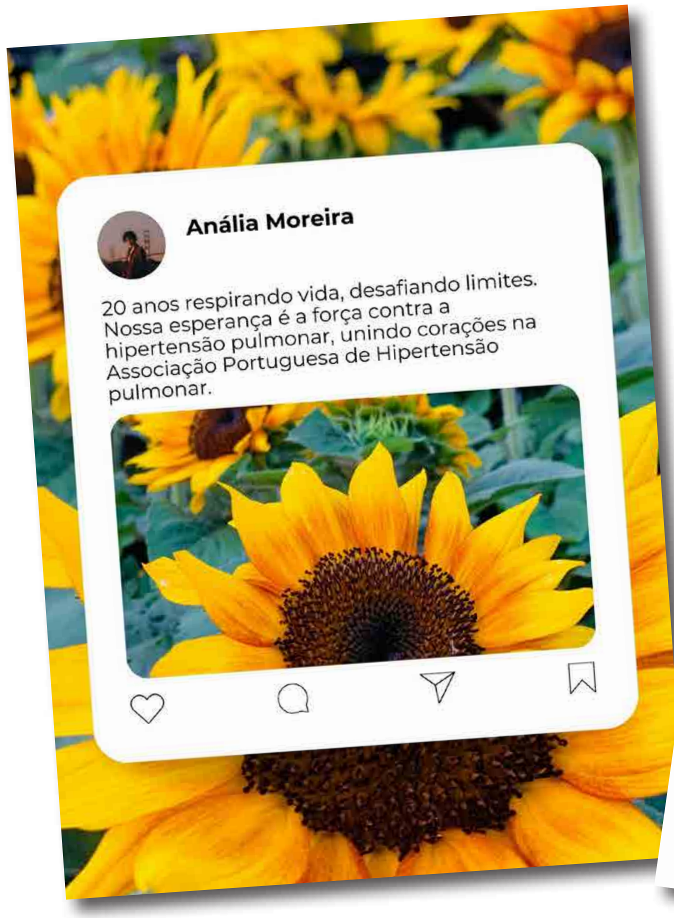
"Não nos podemos, simplesmente, render à HP (...) somos mais do que a doença."

MOVING FORWARD TOGETHER

As we reflect on this remarkable year, we remain steadfast in our mission to encourage healthy relationships between patients, health professionals, and PH reference centers. Together, we are building a brighter future for the PH community, grounded in hope, collaboration, and support.

No 20º aniversário da APHP o desafio é fazer história: devolver fôlego à vida e conseguir a cura para a Hipertensão Pulmonar

Luísa Pestana

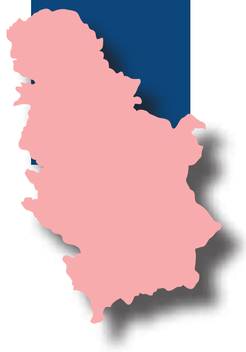


Anália Moreira

20 anos respirando vida, desafiando limites. Nossa esperança é a força contra a hipertensão pulmonar, unindo corações na Associação Portuguesa de Hipertensão pulmonar.

Vem dar um novo fôlego à tua hipertensão pulmonar, no 20º aniversário da APHP. Informar e sensibilizar a população é a nossa missão.

MÓNICA GONÇALVES



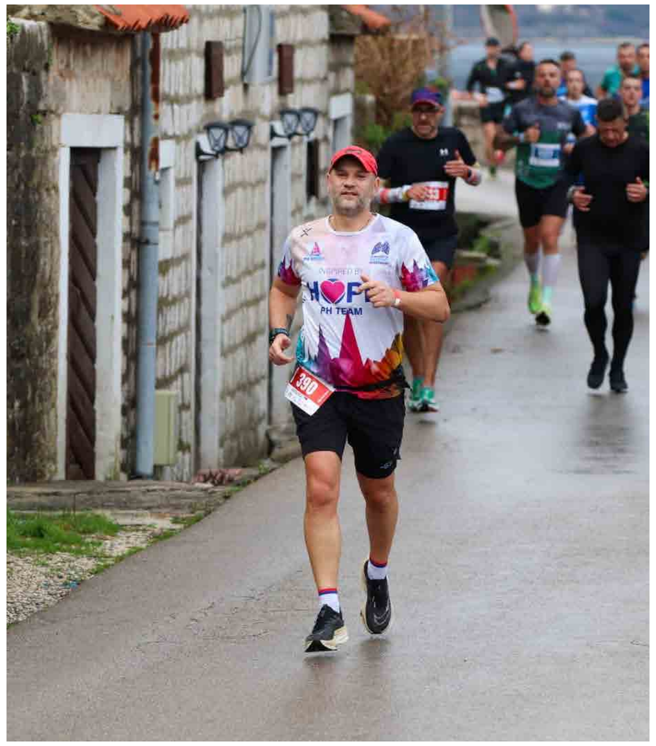
SERBIA

Recent Activities of the Serbian Pulmonary Hypertension Association: A Quarter Full of Advocacy and Awareness

Over the past three months, the Pulmonary Hypertension (PH) community in Serbia has raised awareness and advocated for improved care for those living with this challenging condition. These efforts have brought together patients, medical professionals, and dedicated ambassadors, who continue to shine a light on pulmonary hypertension through inspiring initiatives.

PH AMBASSADOR SLAVIŠA VESIĆ RUNS FOR AWARENESS

Slaviša Vesić, a renowned athlete and PH ambassador, has taken significant strides—both literally and figuratively—to spread awareness about pulmonary hypertension. Participating in numerous marathons across Serbia and internationally, Vesić has become a symbol of perseverance and advocacy. His involvement highlights the importance of physical activity and serves as a powerful reminder of the strength within the PH community. The impact of his efforts can be seen in the increasing recognition of PH among the general public and local communities.



EXPERT INSIGHTS ON NATIONAL TELEVISION

Another notable achievement was the recent appearance of Prof. Dr. Arsen Ristić, one of Serbia's leading PH specialists, on national television. Prof. Ristić provided valuable insights into the latest advancements in treating pulmonary arterial hypertension, shedding light on innovative therapies and their potential to improve patient outcomes. His participation underscores the commitment of Serbia's medical professionals to raising awareness and advocating for cutting-edge treatments for this life-threatening condition.

LOOKING AHEAD

The Serbian PH Association remains dedicated to its mission of improving the lives of PH patients through education, advocacy, and community engagement. The past three months have been a testament to the power of collaboration, with inspiring stories of athletic achievement and medical expertise bringing hope to the PH community.

As we continue to navigate the challenges of pulmonary hypertension, individuals like Slaviša Vesić and Prof. Dr. Arsen Ristić serve as a beacon of hope and determination. Together, we are making strides toward a brighter future for all those affected by PH.

We would like to highlight the tireless efforts of the Serbian PH Association and its members to raise awareness and bring attention to the needs of the PH community.

SLOVAKIA

We kicked off 2024 with a social media campaign for Rare Disease Day. We participated in the campaign „Magazín zriedkavých ochorení" (Rare Disease Magazine), launched as an attachment to the daily newspaper Plus 1 deň (Plus 1 Day) with the article „Včasná diagnostika je kľúčová" (Early Diagnosis is Key). On Rare Disease Day, February 29, we actively participated in the launch of a unique children's book about rare diseases, **Štikrafa a iné zriedkatká,** where attendees also heard a short testimony from our chairwoman, Iveta Makovníková, about the challenges of living with PH. On February 26, a teaser for this exceptional project aired on Radio Regina, which included a contribution from our chairwoman. We shared information about the opening of a unique virtual conference center, Bel Air Center, where we updated our virtual information booth.

On April 18, we commemorated European Patients' Rights Day in a unique way. The Association for Patient Rights Protection received an invitation to **Patient Day in Parliament**, held under the patronage of the Chair of the Parliamentary Committee for Health. Four members represented PHA at the meeting. In addition to the "Charter of Patients' Rights in Slovakia", we presented our "Call to Action" program, focusing on improving care for PH patients. At the start of the event, we had the opportunity to observe a parliamentary vote, followed by discussions between healthcare committee representatives and patients.

Through the project **"Keď dochádza dych" (When Breath Runs Out)**, we reached out to students at the Secondary Medical School in Lučenec to educate them about the real challenges PH patients face, including organ transplantation. This was conducted in the format of a live library, complemented with short patient stories and video clips. The two-hour seminar was structured as a discussion forum, concluding with group work by the students.

On April 10, Chairwoman of PHA Slovakia, Iveta Makovníková, was invited by MSD to present her story and activities of PHA Slovakia at an **employee conference.** The evening before, she attended a working dinner with MSD representatives. Her presentation received excellent feedback, gratitude from the company's leadership, and further support and collaboration opportunities.

On June 13, Dana Cziborová, a pharmacist, PHA Slovakia board member, and PAH patient, **presented on PAH** during regular educational meetings of the Komárno Pharmaceutical Chamber. The audience included pharmacists, pharmaceutical technicians, and doctors from the internal medicine department of the local hospital.

On September 26, in cooperation with Grape PR and with the support of MSD, we held a **press conference** on PAH for World Heart Day. Cardiologist Milan Luknár shared information about PAH and its treatment. Iveta Makovníková, Chairwoman of PHA Slovakia, discussed the importance of patient associations and shared her story, along with testimonies from two other patients.

In the last week of August, we organized a traditional six-day educational and rehabilitation retreat for members of PHA Slovakia at the Spa Sliač. One morning was dedicated to a group discussion on PAH, where patients exchanged experiences not only about PAH but also about recovery after lung transplantation. The chairwoman gave a presentation on the organizational and technical aspects of PHA Slovakia. We were also visited by Júlia, who collected information for her bachelor's thesis on the care of PH patients. The program also included cultural activities, such as a tour of the nearby water castle in Hronsek, and a theatrical performance. During the retreat, we were visited by a journalist from STVR in Banská Bystrica, who filmed a **report for Radio Regina Stred**, a broadcast in four segments, during the autumn.

We also worked on a unique film project, **"Dych pre môj život" (Breath for My Life)**, featuring real patients with PH. The video was promoted on YouTube and social media throughout November for PH Awareness Month. The film won third place in the Portrait category at the nationwide *Filmfest Nižná 2024.*

https://www.youtube.com/watch?v=z58HpcT-Hyc

In the autumn, we registered with NIHO (National institute for value and technology in healthcare), to advocate for the adoption of a new PAH drug, currently approved by the EMA, aiming to make it accessible to Slovak patients.

In November, we successfully lobbied the Ministry of Health to remove the co-payment for the medication Prograf 1 mg after the reduction of VAT on medicines.

We deepened our collaboration with the O Z *Zriedkavé choroby* (Rare Diseases Association) and worked on a joint awareness project, *"Dýchajme spolu"* (Let's Breathe Together). The first phase involved creating a wall calendar featuring patient portraits and stories, which will be distributed to hospitals and medical offices in January. Next year, the project will continue with a traveling exhibition across Slovakia, and a website featuring patient stories.

Throughout the year, we held four PHA Slovakia Council meetings, a general assembly, and seven working meetings, as well as provided 14 consultations. At the end of the year, we hosted a working dinner with partners and members of the Professional Advisory Team to evaluate our annual activities and present the work plan for the upcoming year.

Our runners promoted PH awareness throughout the year, participating in four two-day relay runs and over 15 individual races.

SLOVENIA

CIRCLE OF GRATITUDE

On the occasion of the European Day for Organ and Tissue Donation, the Slovenian Pulmonary Hypertension Association organized the event „Circle of Gratitude." The event was prepared in collaboration with various organizations and institutions that strive to improve the lives of patients in need of organ transplants. Among the participants were the Slovenian Transplant Society, the Cystic Fibrosis Association of Slovenia, the Federation of Kidney Patients Associations of Slovenia, the Slovenia-Transplant Institute, and the University Medical Centre Ljubljana.

THE MEANING OF THE CIRCLE OF GRATITUDE

The Circle of Gratitude symbolizes the comprehensive process of saving the life of a patient who needs an organ transplant. For a transplant to be successful, the circle must be complete – every individual and institution involved plays a vital role in this life-saving journey. The initiative for this event came from grateful organ recipients who, with their transplants, can continue living. Through their example and gratitude, they aim to raise awareness about the importance of organ donation.

KEY MESSAGES OF THE EVENT

THE EVENT SERVED AS AN OPPORTUNITY TO HIGHLIGHT IMPORTANT ASPECTS OF ORGAN DONATION AND TRANSPLANTATION:

- **Personal stories and gratitude from organ recipients:** These inspiring individuals shared their experiences, showcasing the immeasurable value of organ donation.

- **A living library with organ sculptures:** Exceptional artworks created by renowned artists visually conveyed the significance of organ donation.

- **Presentation of the expert team:** Gratitude was extended to everyone involved when an organ becomes available – from medical staff to support services working together to save lives.

GRATITUDE FROM "FIRSTHAND EXPERIENCE"

TADEJA RAVNIK, HEART TRANSPLANT (DIAGNOSIS: PH DUE TO HEART FAILURE)

„Life after a heart transplant means a lot to me because getting the chance to start anew is truly a privilege. I'm still active, living the life I envisioned. I can still be a mother, supporting my daughter as she grows. I laugh with her, encourage her, and enjoy time with my family and everyone I love. We do things together that I couldn't do before the surgery. It's something I am truly, deeply grateful for," says Tadeja Ravnik, sharing her story.

„The word ‚gratitude' still feels too modest to describe everything I feel," says Tadeja, adding, „When I think about how many people are involved in this process, it moves me every time." She also expresses her gratitude to the donor and their family, who chose to donate organs. „With my story, I want to encourage people to talk about this. We never know who will need an organ next—it might be us or our loved ones," she explains.

ALJAŽ PREVOLŠEK, LUNG AND KIDNEY TRANSPLANT (DIAGNOSIS PAH)

„A person chooses transplantation because such a surgery can significantly improve their quality of life," emphasizes Aljaž Prevolšek, who underwent two transplants: a lung transplant in 2013, and a kidney transplant five years later. „My life has improved considerably thanks to both transplants. For example, I went from having to stop every time I wanted to climb two flights of stairs to being able to engage in virtually any sport. I can even play two hours of very intense tennis without any issues," says Aljaž. „I am immensely grateful to the donors and their families. I wish every one of us could look up to them, as their selflessness helped nine different people gain a new chance at life, including me," emphasizes Aljaž Prevolšek.

THE ROLE OF THE SLOVENIJA-TRANSPLANT AND EUROTRANSPLANT INSTITUTE

The event emphasized the mission of the Slovenia-Transplant Institute, and the importance of Slovenia's membership in the Eurotransplant network. Through this collaboration, Slovenia has access to a broader pool of donors and recipients, enabling faster and more efficient life-saving efforts.

PROMOTING REFLECTION AND AWARENESS

The goal of the event was to inspire reflection on organ donation, break taboos surrounding the topic, and raise public awareness that organ transplantation is often the only way to save lives and improve quality of life. Special thanks were given to organ donors and their families, whose selfless decisions have enabled the continuation of life for others. Appreciation was also extended to the professionals who ensure successful transplants every day.

PRESENTATION OF OUR WORK TO THE MSD TEAM

Tadeja Ravnik attended the cyclical meeting of the Slovenian and Croatian MSD teams, which took place in Postojna at the end of September. The meeting also discussed pulmonary hypertension and new treatments.

Tadeja took the opportunity to thank the large MSD team for all their dedication on behalf of all patients with pulmonary hypertension. She told them what we stand for, how well we cooperate with other societies, and that, without their support, we would not be so visible and heard.

AUTUMN TRIP FOR MEMBERS

As in previous years, we organized an autumn trip for our members, this time visiting the beautiful Volčji Potok Arboretum. During a guided train tour, we admired the vibrant autumn colors and learned many interesting facts about the park. Over a delicious meal, members exchanged experiences, relaxed, and enjoyed each other's company. The trip provided a wonderful opportunity for connection, leaving everyone energized and motivated.

PULMONARY HYPERTENSION AWARENESS MONTH

In November, we marked Pulmonary Hypertension Awareness Month. One of the key activities was participating in the podcast "poslusam.se", where the association's vice president, Nina, shared her personal story. She emphasized the importance of early diagnosis, which can significantly improve the quality of life for pulmonary hypertension patients.

Through our activities at the Slovenian Pulmonary Hypertension Association, we build bridges between patients, experts, and the public. Together, we create a world where organ donation is not just an option but a profound gift of life.

SPAIN ANHP

2024 stands as a year of hope for the global pulmonary hypertension community. The approval of a highly effective drug marks a significant breakthrough in treating this condition, bringing new opportunities to thousands of people worldwide. In this setting, the National Pulmonary Hypertension Association (ANHP) emphasizes its crucial role as a key supporter for patients and their families. By partnering with public administrations and prioritizing enhanced comprehensive care, ANHP has diligently worked to assist those confronting the most challenging phases of the disease. Among the year's most notable initiatives, the joint work with the Heart Disease Association of the Hospital Universitario 12 de Octubre (ASECOR) has marked a turning point. Thanks to this alliance, the "Advancing Together in Pulmonary Hypertension" seminars were held, providing a space where patients and specialists discussed the active role of the patient and advancements in the treatment of chronic thromboembolic hypertension. This Exchange has strengthened the understanding of the disease and the importance of a multidisciplinary approach.

Looking ahead to 2025, we will continue working daily to achieve comprehensive care for people with pulmonary hypertension at a leading Spanish center, the Hospital Universitario 12 de Octubre. We will also persist in our efforts to ensure that this care is available wherever a person with pulmonary hypertension resides, thus achieving equity in care.

Networking is a pillar for us, which is why, during this year, we have participated in numerous meetings, conferences, and congresses with the aim of addressing the current needs of patients with pulmonary hypertension.

In this regard, the ANHP held a very productive meeting with Celia García Menendez, the General Director of Humanization of the Community of Madrid. During the meeting, we were able to address the current situation of patients and discuss improvements to achieve patient-centered care from a holistic perspective, considering their personal preferences, beliefs, and values.

Dissemination and education have been key for us this year. We conducted campaigns that transcended borders, such as Rare Disease Day (February 29) and World Pulmonary Hypertension Day (May 5th). Additionally, for Awareness Month, we ran a campaign under the slogan "Pulmonary Hypertension: Your life doesn't stop… live it". These efforts have served as platforms to raise awareness about the disease and the daily challenges of living with it.

From informational booths in public spaces to participation in radio programs, these actions have not only helped increase the visibility of pulmonary hypertension but also allowed us to strengthen a support network among organizations, patients, and families. In November, we launched a social media campaign titled "Challenges in Pulmonary Hypertension". Throughout the month, we issued challenges to the public to foster empathy for the symptoms of the disease and set challenges for those already living with the condition to promote self-care habits.

Mutual support is a key pillar of ANHP's activities. Throughout this year, we have continued offering spaces where patients from all over Spain could meet and exchange experiences and strategies, strengthening the bond and reinforcing the support network among association members.

Throughout the year, we have continued holding our mutual support group sessions. Currently, we have two groups:

- Mutual support for patients on subcutaneous treprostinil treatment. This year, we held bimonthly meetings, and in one of the sessions, we had the presence of a nurse from the FERRER patient support program, who provided advice and guidance on the daily life with this treatment.
- Mutual support for patients on the transplant list or post-transplant. These sessions are coordinated by the association's psychologist, where, in addition to fostering support and exchanging experiences, coping strategies are addressed. We have organized four virtual meetings for patients and families, called "Breakfasts that Hyperconnect." These spaces bring together the many patients who are part of the organization, association staff, and Board members. These moments help build a stronger community and allow us to better understand the needs related to pulmonary hypertension in the different autonomous communities of Spain. ANHP is deeply dedicated to educating and empowering patients, helping them better understand the disease, and building confidence in managing their condition, which is crucial for enhancing their quality of life. The online seminars the organization has been offering since 2020 are a vital resource for patients and caregivers, providing them with up-to-date information of the disease, treatments, and self-care.
- On February 28th, under the title "Hipertension Pulmonar en sus tipologías menos frecuentes " in English, "Pulmonary Hypertension in its Less Common Types," Dr. Isabel Blanco, head of the Pulmonary Hypertension Unit at Hospital Clinic in Barcelona, discussed this type of pulmonary hypertension and its approach. We also heard from a patient with chronic thromboembolic pulmonary hypertension, who shared her experience with diagnosis, treatments, and how her life is today.
- On November 20th, a seminar was held called "Living with Pulmonary Hypertension," where we discussed the essential aspects that every patient should know about the disease, the importance of the patient-doctor relationship, the patient's role in the decision-making process, and the current role of the patient. We concluded the seminar with the experience of a patient diagnosed with pulmonary hypertension 20 years ago, and how her quality of life has evolved over time.

The sessions were recorded and are available in Spanish on our YouTube channel:
https://www.youtube.com/@hipertensiopulmonar

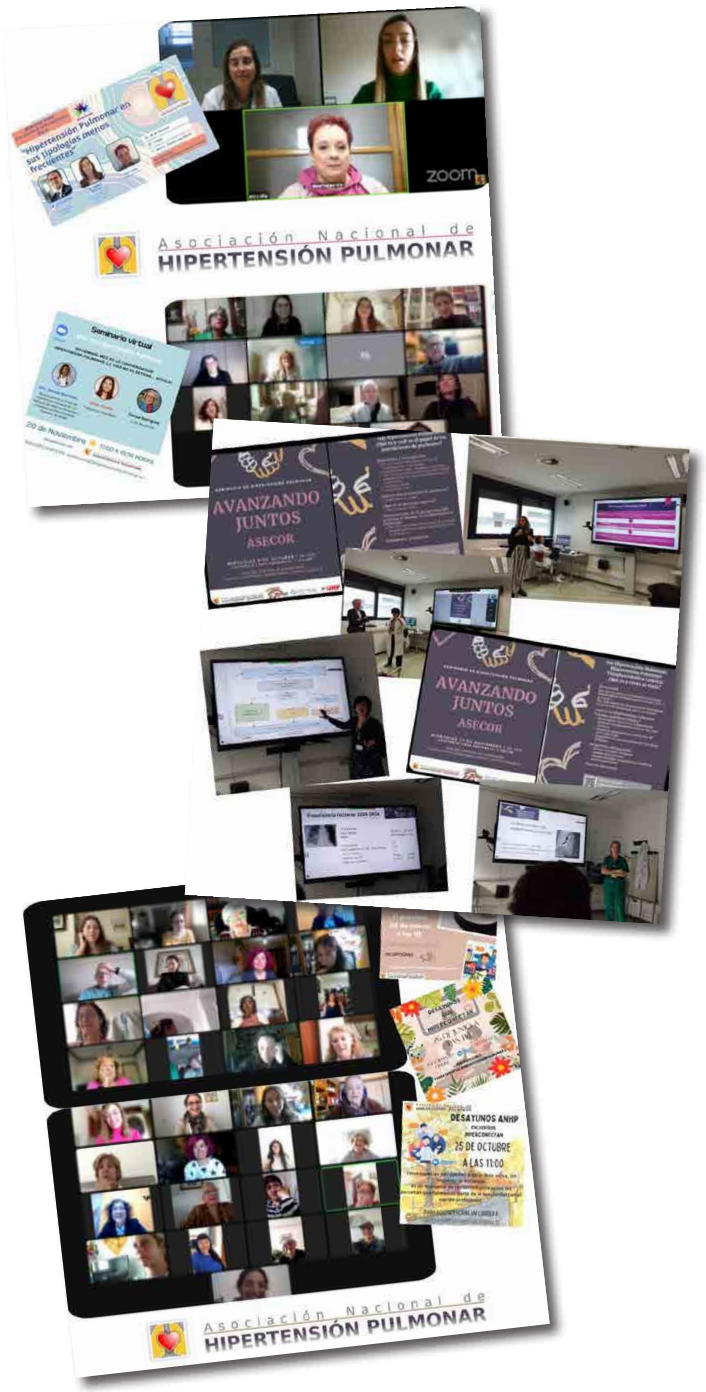
The most educational aspect of our work has been carried out through the organization of specialized workshops, led by the psychological support service, with the aim of providing tools for people with pulmonary hypertension and their caregivers to cope with the challenges of living with this condition.

FEBRUARY: "Coping Strategies for Difficult News" was held on February 19th, where individual and family strategies were discussed for dealing with difficult moments of the disease (diagnosis, transitions to invasive treatments, the transplant process, and posttransplant life).

SEPTEMBER: "Living with Pulmonary Hypertension" was a collaborative workshop with a patient who has suffered from pulmonary hypertension and underwent a transplant, where we addressed the challenges and experiences from the patient's perspective.

OCTOBER 22ND: "Managing Stress and Anxiety and Mindfulness Techniques." Stress and anxiety are two psychological aspects commonly present in people with pulmonary hypertension, so this workshop was organized to offer techniques for managing these situations that negatively impact our quality of life.

NOVEMBER 26TH: We held the workshop "Let's Talk About Sexuality," a topic that remains a taboo until today, but is of great importance in our daily lives. The workshop explored sexuality from a broader perspective, focusing on how we see ourselves, how others see us, and how our condition affects our ability to have a full and satisfying life.



Additionally, the ANHP continues to offer its online school for patients with pulmonary hypertension. Through an online platform, ANHP has been providing the Hyperexpert course since 2022. This course consists of 11 modules covering the disease, treatments, research advances, self-care strategies, healthy habits, and access to available social resources. The course is coordinated by the organization's social workers.

Alongside all the work carried out by the association's dedicated team, fundraising continues to be both a challenge and a priority. Events such as the 11th TRIAL SERRA CODÉS RACE, Dance Festival, solidarity gifts for weddings, communions, or baptisms, and the Christmas Lottery Campaign, not only help sustain the work we have been doing for 20 years, but also enable us to generate funds to donate to research projects.

SPAIN FCHP

MEETING WITH THE DIRECTOR OF THE CARLOS III HEALTH INSTITUTE

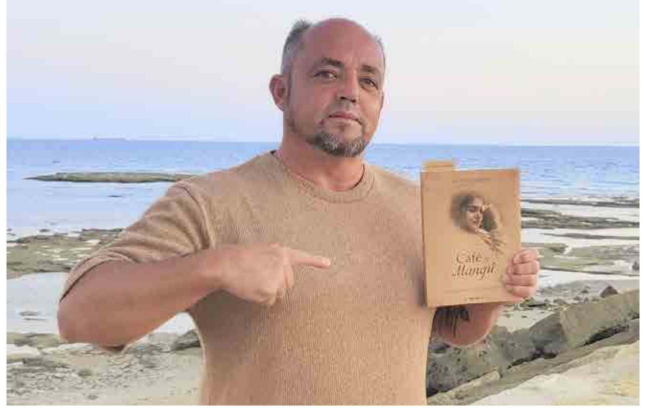
The President of the Pulmonary Hypertension Foundation (FCHP), Enrique Carazo, and trustee Gonzalo Gómez-Acebo met with Marina Pollán, Director of the Carlos III Health Institute, and Dr. Rosario Perona, a distinguished research professor. This meeting strengthened collaborative ties in pulmonary hypertension research, advancing our mission to deepen knowledge and treatment of this rare disease alongside leading public health and medical research institutions.

7TH SEPAR RESPIRA FORUM

We took part in the 7th SEPAR RESPIRA Forum for Patients with Respiratory Diseases, held as part of the 57th SEPAR Congress in Valencia. Our psychologist, Claudia Bohórquez, moderated the workshop "My Role as a Patient in Research," while Laura Ranz shone in the symposium "Answer in 60 Seconds: Caring for Caregivers," offering key perspectives and valuable contributions. It was an insightful forum for learning and collaboration in service of patients.

LAUNCH OF THE BOOK *"CAFÉ Y MANGÚ"*

"Café y Mangú" is a compelling novel that blends love and hate, with pulmonary hypertension as its backdrop. This is Salvador's fourth book dedicated to pulmonary hypertension patients, with funds raised supporting research and aid projects led by the FCHP – an inspiring work of art that brings hope while supporting a vital cause.



15TH INTERNATIONAL PULMONARY HYPERTENSION CONFERENCE IN INDIANAPOLIS

Our board member, Gonzalo Gómez-Acebo, and geneticist Jair Tenorio, represented the FCHP at this conference, addressing challenges and innovations in the treatment and support of pulmonary hypertension patients. We extend our gratitude to the Pulmonary Hypertension Association (PHA) and its president, Matt Granato, for their warm welcome at this key event for international knowledge exchange.

ANDREA MIGUÉLEZ RANZ: AMBASSADOR AT THE PARIS 2024 PARALYMPIC GAMES

Andrea Miguélez, ambassador for rare diseases and pulmonary hypertension, shone at the Paris 2024 Paralympic Games, competing in the triathlon event.

Her effort and dedication brought global visibility to pulmonary hypertension and rare diseases on an international global stage.

MEETING WITH SPAIN´S MINISTER OF HEALTH

In a productive meeting with the Minister of Health Mónica García, we introduced our proposal for a ”National Strategic Plan for HAP Patients.” We discussed the key points of the plan, which aim to improve the quality of life and care for pulmonary hypertension patients. This is an essential step toward state-level recognition and support.

1ST PATIENT CONFERENCE IN SEVILLE

In collaboration with the Virgen Macarena University Hospital, we organized the 1st Patient Conference on Pulmonary Hypertension. We congratulate Dr. Alejandro Recio and his team for an exceptional event that promoted awareness and enhanced care for this condition.

MEETING AT HOSPITAL UNIVERSITARIO VIRGEN DEL ROCÍO (SEVILLA)

We met with Medical Director Ignacio Jiménez López and his team to address challenges faced by HAP patients due to the lack of devices for Iloprost nebulization. This situation severely impacts therapeutic adherence, and we continue working toward concrete solutions.

WEBINAR: ADVANCES IN CLINICAL TRIALS

We organized a webinar on advances in clinical trials for pulmonary hypertension, featuring Dr. Isabel Blanco (pulmonologist) and Ana Mª Ramírez (nurse) from the Hospital Universitario Clínic of Barcelona. This event provided a valuable opportunity to learn about the latest innovations in treatment.

2024 ANNUAL EUROPEAN PULMONARY HYPERTENSION CONFERENCE

The Annual European Conference was a space for learning and connection, where advances and challenges in pulmonary hypertension management were analyzed at a European level. We shared enriching experiences that motivate us to continue consolidating ties with international associations.

16TH ANNIVERSARY OF THE PULMONARY HYPERTENSION FOUNDATION

Under the theme ”16 Years of Commitment, Hope, and Progress,” we celebrated a landmark event that brought together international experts, public institutions, and patients to strengthen support networks, analyze challenges, and share the latest research advances. This anniversary reaffirmed our commitment to the global community, marking a milestone in our fight against this rare disease.

6TH TRAINING AND INFORMATION SESSIONS

During these sessions, we highlighted contributions from Dr. Alejandro Cruz (Hospital Universitario 12 de Octubre-Madrid) on genetic advances, Matt Granato (PHA International) with his global perspective, and Oximesa Nippon Gases with a respiratory physiotherapy workshop. Additionally, our psychologists moderated a key discussion on patient and family perspectives. This event left a lasting impact on our community.

FUND ALLOCATION EVENT FOR THE PASION HP GENÉTICA PROJECT

The University Hospital La Paz hosted this event, which was led by Dr. Jair Tenorio. The allocation of funds represents a commitment to genetic research in pulmonary hypertension. We thank the experts and board members who supported this significant achievement.

APPROVAL OF THE NPL ON PULMONARY HYPERTENSION

This is a major milestone! The Non-Legislative Proposal on the diagnosis and treatment of pulmonary hypertension was approved by an absolute majority in the Health Committee of the Congress of Deputies. This historic achievement is the result of years of effort by the FCHP, and we will continue working passionately until its definitive implementation.

SPAIN HPE-ORG

Review of a very successful year

As every year, in 2024, the activities we have carried out at Hipertensión Pulmonar España Organización de Pacientes have focused on fulfilling our social objective: to offer specialized care and services to people with pulmonary hypertension and their families.

This year, we have continued to offer our members our "Learning to Breathe" program, which runs throughout the year and includes various activities: activities aimed at improving psychological health among which are the psychological care workshops Tardes de encuentro and workshops on Emotional Management, activities aimed at improving physical health, including physical activity workshops such as Yoga workshops and "Postural Training" and Nutrition workshops, and activities aimed at improving social health, such as our mutual help groups, including "Shall we have a coffee?" and the different groups of our WhatsApp Community for more specialized care, among which the Lung Transplant Group has had special relevance.

As a reinforcement of our "Learning to Breathe" program, we have continued with our Intervention Program: Welcoming the new member, which we began to outline at the end of last year, with which we aim to respond to newcomers to our association and offer them support throughout their Patient Journey, considering the social determinants of health.

Our activities also included participation in Conferences and Congresses, where we attended as spokespersons and speakers, offering our vision as expert patients, and as an association of patients with pulmonary hypertension. We have participated in conferences and congresses such as: the Pulmonary Hypertension Conference at the Hospital Clínic in Barcelona; the 17th WORLD DAY OF MINORITARY DISEASES Conference at the Art Nouveau Site of the Hospital de Sant Pau in Barcelona organised by the Plataforma de Malalties Minoritàries; the II Forum on Rare and Undiagnosed Diseases organised by FEDER in Castilla y León; the talk for the World Day for Rare Diseases in Sant Feliu de Llobregat; the recording of the Podcast "Nursing and Health 2x7: Pulmonary Hypertension (PAH)"; the I Convention of respiratory patients of FENAER. Furthermore, we participated as speakers at the conference "The patient's right to choose where to be treated by a specialist - Proceso de derivaciones intra e inter comunitarias en España: SIFCO y CSUR" organised by ICAM, and we also participated in the II JORNADA PARTICIPACIÓ CIUTADANA VALL HEBRÓN, as well as in the 57th SEPAR Congress, where our project "Intervention Programme: Welcoming the new member" was awarded the second prize among those presented in the competition. Additionally, we have attended the Conference on research in EERR in Barcelona, and the GAM and APHEC organised by PHA Europe, where we were able to share different experiences with our European counterparts and learn first-hand about the latest developments in pulmonary hypertension.

In order to be able to continue offering quality services to our partners, we continue to train ourselves as professionals. During this year, we have participated in several trainings offered by other entities such as EUPATI; the Spanish Patient Forum and COCEMFE, all of them related to patient participation in Clinical Trials, patient participation in the Health System and new technologies focused on patient care.

During this year, at HPE-ORG Patients, we have continued to participate in the Solid Organ Transplant Commission of the Vall d'Hebrón Hospital, which is part of the Participation Program of professionals and patient associations; at the same time, we have expanded our participation in two more work commissions: the Pneumology Commission and the ICU Commission, also at the Vall d'Hebron Hospital. We continue to be present in the collaborative resource Actius i Salut of the Agència de Salut Pública de Catalunya, disseminating and offering our activities to the population.

On the occasion of PH Awareness Month, we have collaborated with the awareness campaign launched by PHA through PHA Europe on social networks.

In terms of political advocacy, we have continued with our collaborative project on the unmet needs of patients with Pulmonary Hypertension and their families titled HAP NEEDS, endorsed by the scientific society SEPAR, which we carry out in the different Autonomous Communities. In May, we held the third meeting of this multidisciplinary working group in the Autonomous Community of Castilla y León, where we followed up on the proposals established in the first part and set new objectives for improvement at the care level. In October, we continued with the working group started last year in the Valencian Community, where we were able to verify that several of the proposals for improvement that came out of the 2023 working group have already been implemented

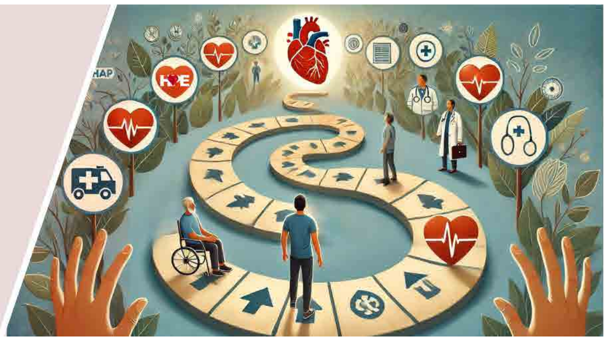
And to conclude the summary of our activities this 2024, we have also been very present in La Marató. La Marató de 3Cat is a solidarity project promoted by Televisió de Catalunya and the Fundació La Marató de 3Cat and focused on obtaining financial resources for scientific research into diseases for which there is no cure. However, the project goes beyond that, as it does important work to raise awareness. This year, two of our members have participated in the videos that have been broadcasted during the gala, telling their experience with Pulmonary Hypertension. With this, we have managed to give a lot of visibility to Pulmonary Hypertension in this television gala, which this year has managed to raise almost 6.5 million euros that will be destined to the research of respiratory diseases.

On the occasion of La Marató, we also attended a talk given by the City Council of Sant Feliu de Llobregat, where we were able to tell our experience with the disease. The digital newspaper Fet a Sant Feliu also published an interview with another one of our members during which he highlighted the importance of early diagnosis and what his day-to-day life with the disease looks like.

We ended the year with a good feeling of having done our homework and with many new ideas and projects for the coming year..

Fundació
La Marató de TV3

Programa de Intervención:
Acogida al nuevo socio



SWEDEN

During autumn, we have had two successful patient meetings together with the PH centers in Gothenburg and Linkoping.
We participated in a research conference that deals with the exchange of experience in PH between Sweden and Denmark, as well as a number of other meetings with various partners.

UKRAINE PHA

БЕЗКОШТОВНИЙ
NT-proBNP аналіз

GlobalGiving

АСОЦІАЦІЯ ХВОРИХ
НА ЛЕГЕНЕВУ ГІПЕРТЕНЗІЮ

The NGO „Association of Patients with Pulmonary Hypertension" remains dedicated to its essential mission of supporting patients living with pulmonary hypertension and enhancing their access to quality diagnostics and treatment.
The Association places special emphasis on providing psychological support to patients. Together with the Union „Rare Diseases of Ukraine," two two-day training sessions were organized for patients with rare diseases, including those with pulmonary hypertension. Participants learned to manage their emotions, cope with stress, and regain self-confidence. These events created a supportive environment where attendees could share their experiences, find understanding, and form new friendships. The training concluded with the creation of a symbolic artwork—a shared „place of happiness" that united all participants.

Another notable initiative was the launch of the Rare Disease Patient School, a unique space for knowledge and resources. This platform empowers patients to better understand their rights to medication access and to receive necessary support on various issues.
In September of this year, the Association actively participated in the XXV National Congress of Cardiologists of Ukraine, where it took part in a

dedicated session on pulmonary hypertension. Oksana Aleksandrova, the head of the Association, presented the organization's experience, achievements, and challenges. She also introduced the #BelAirCenter information platform, which has become a valuable resource for patients and doctors. The platform provides access to presentations by leading global experts and online conferences, ensuring continuous education and support.
One of the Association's significant projects is the „Free NT-proBNP Testing for Patients with Pulmonary Hypertension," implemented in collaboration with its partners. Currently, all patients undergoing evaluation at the Expert Advisory Center for Pulmonary Hypertension at the M.D. Strazhesko Institute of Cardiology can access this critical test free of charge, thanks to the program.
The activities of the Association aim to ensure that every patient with pulmonary hypertension receives not only quality medical care but also feels the support of a caring community. We firmly believe that these efforts will profoundly improve the lives of patients and bring hope for a better future!


Дата: 23 листопада 2024 Час: 14:00 Формат: онлайн

ЗАКОНОДАВСТВО У СФЕРІ ОХОРОНИ ЗДОРОВ'Я ПАЦІЄНТІВ З РІДКІСНИМИ ЗАХВОРЮВАННЯМИ: ПРАКТИЧНІ ПОРАДИ

Спікери: Тетяна Михайлова Модератор: Юлія Беребенець

UKRAINE PHURDA

Another year of challenges and achievements is behind us. We spent many hours with patients online, but there were also pleasant meetings. Thanks to joint efforts, we have implemented new projects that changed people's lives. Our achievements are your achievements.

THE RESPIRO VIGILANCE PROJECT

This is a new project that consists of fighting pulmonary hypertension and respiratory diseases through early detection, vaccination, and education. The aim is to improve the situation of patients with respiratory diseases and PH in particular. Important check-ups were done: ECG, ECHOCG, vaccination, blood sugar levels, express tests for hepatitis B and C, body mass index, saturation, and blood pressure. Doctors advised the participants on symptoms, life-threatening consequences of infectious diseases, and talked about healthy eating habits. The project is being implemented in cooperation with the Lviv Regional Center for Disease Control and Prevention and Nataliya Ivanchenko, with the support of the Global Allergy & Airways Patient Platform. We sincerely thank the Lviv City Council for its assistance in placing the street advertisement.

PH ACADEMY

We held a series of educational webinars for doctors on pulmonary hypertension diagnosis and treatment in the reality of Ukraine. We also held a series of online patient meetings on different topics: Anticoagulants and other medicines that need to be controlled due to side effects in PH patients, dental procedures in PH patients, vaccination in case of pulmonary hypertension, and smoking risks for PH patients. All these sessions are available online at *https://www.youtube.com/@poryatunok505.*

As part of the PH Academy, we have launched a new initiative for PH patients called "Patient Hearts". Every last Saturday of the month, we create a space for honest conversations without taboos. Patients can ask any questions, or share experiences with their doctor and with each other. We do not record these meetings, as they are dedicated to trust and openness. The format is called "Here and Now" - about the importance of every moment.

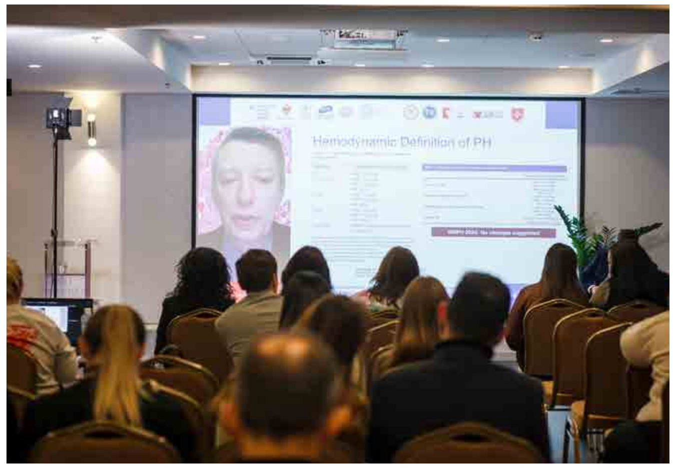
UKRAINIAN RESPIRATORY COALITION

We have initiated, and then, together with the Alergologists Association of Ukraine and the Pirogov Memorial National Medical University of Vinnytsia, officially created the Ukrainian Respiratory Coalition, which is a part of the International Respiratory Coalition. In September, URC had its first face to face meeting in Vienna. We have come together to implement a common mission - to support and protect patients with respiratory diseases in Ukraine, as well as to create effective solutions to improve access to diagnostics, treatment, and education. URC will work to solve urgent problems, particularly in the context of the challenges caused by the war. More about URC can be found here: *https://www.facebook.com/profile.php?id=61565344806286.*

INTERNATIONAL CONFERENCES

GAAPP ANNUAL GENERAL MEETING AND SAREAL 2024

The GAAPP Annual Meeting was held in Santiago, Chile. President Tonya Winders and Migdalia Denis presented the strategy and direction of the organization, which supports projects, including #respiratorycontrol from PHURDA. Two new GAAPP alliances were announced, and a SAREAL event was held to collaborate with organizations in Latin America. In addition to global challenges, PHURDA's President spoke about the difficulties in Ukraine caused by the war: the bombing of the National Children's Hospital, shortages of medicines and equipment, and the impact of constant stress on patients' mental health.



PHA CONFERENCE 2024

This conference is an excellent platform for sharing experiences, learning, and finding new solutions and partners. In Indianapolis, we had the opportunity to get acquainted with the latest achievements in the field of diagnostics and treatment of pulmonary hypertension. We ensured that the voice of Ukraine was heard, and together, we worked to ensure that every patient received proper support, regardless of geographical location. More information can be found here: *https://www.facebook.com/share/p/12FNKp1u8vi/.*

GAAPP SUMMIT

The summit was a great opportunity to bring together patient voices on pressing issues and share the best practices that we have brought to each country. The few days together with the rest of the world were full of opportunities to compare, grow, learn, and collaborate in the field of respiratory health. At the meeting, we discussed the future plans of the Eastern European Alliance.

ELF NETWORKING DAY & ERS CONGRESS

The ERS Congress provides an opportunity to draw the attention of the international community to the challenges faced by Ukrainian patients in wartime, to attract the support of international partners, to gain new knowledge from world experts, and to strengthen international cooperation. We had the opportunity to promote EPAP – the European Patient Ambassador Program *(https://elearning.epaponline.eu/)* in order to build and improve the medical literacy of patients with respiratory diseases.

APHEC

This is a special conference that feels like meeting with family, whom you haven't seen for a long time. We experienced a few days full of interesting presentations, new info from the pharma industry, and warm meetings. Thank you PHA Europe for this opportunity.

PH CONFERENCES IN LVIV, UKRAINE

In December, we organized two PH conferences in Lviv. The first one titled "Diagnosis and treatment of pulmonary hypertension in Ukraine and abroad: doctors and patients' experience" was for healthcare professionals. The keynote speaker was Marc Humbert. We also had speakers from Ukraine, Poland, the UK, and the USA.

The other day, we held a conference titled "Inspiring Change: Innovation and Support for Respiratory Patients," where we discussed modern approaches to the treatment of respiratory diseases, assessed the importance of vaccination in the prevention of respiratory infections, and the importance of catheterization. The conference became a unique platform for discussing the most important issues in the field of respiratory diseases, pulmonary hypertension, clinical trials, and organ transplantation.

A special moment at the conference was that we emphasized the power of partnership. On behalf of Gossamer Bio, we presented the Pulmonary Hypertension Center in Lviv with a certificate for the purchase of a defibrillator. We sincerely thank Gossamer Bio for supporting Ukrainian patients!

OTHER ACTIVITIES

We took part in the national contest „Charitable Ukraine" and received a diploma in the nomination „Charity in the social sphere".

This year has been difficult for all of us, but it has also been filled with moments that inspire us to move forward. We have seen the tears of joy of patients as they receive the care they need, and the strength of those who continue to fight for every breath, despite all the challenges.

We need your help. There are still many challenges ahead. Every day, we face a shortage of medications, equipment, and resources to support patients. The war only exacerbates these problems. We need your help to:

- provide patients with access to life-saving medicines,
- organize screenings for people at risk,
- support educational projects for patients and doctors,
- spread information about the challenges Ukrainians face.

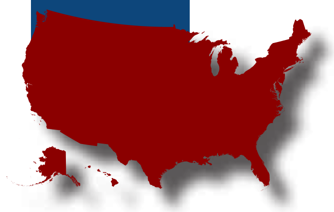
In summer, we held a special photo shoot with our patients. We spent several hours shooting pictures together, as well as engaging in conversations and enjoying a delicious dinner. This day became a real breath of oxygen during this gray everyday life in Ukraine.

For St. Nicholas Day, we have supported our little patients with special gifts, creating a festive atmosphere, which is very valuable in the difficult conditions of the war in Ukraine. This has become possible thanks to the Fujikura Automotive Ukraine company and other benefactors.

The PHURDA team works 24/7, providing patients with information, legal and psychological consultations, and a hotline, which is also working to support PH patients and their family members. Additionally, we continue to develop our long-term project „Cork for Life". During the year, the Humanitarian Nova Post helped us deliver important humanitarian parcels, medicines, and equipment to patients.

WE INVITE YOU TO COOPERATE.
If you want to be part of our mission, we are always open to new partners, ideas, and solutions. Together, we can change the lives of those in need. Write to us, join our projects, share your experience or resources. Together we can do more!
It was a year of struggle, but also a year of hope. Thank you to everyone who supported us.
We know that we are stronger together!

With best wishes from
Ukraine PHURDA team



USA

AWARENESS MONTH: LET YOUR LIGHT SHINE

Each November, the pulmonary hypertension community comes together for PH Awareness Month to raise awareness, advocate for better care and show support for people living with PH.

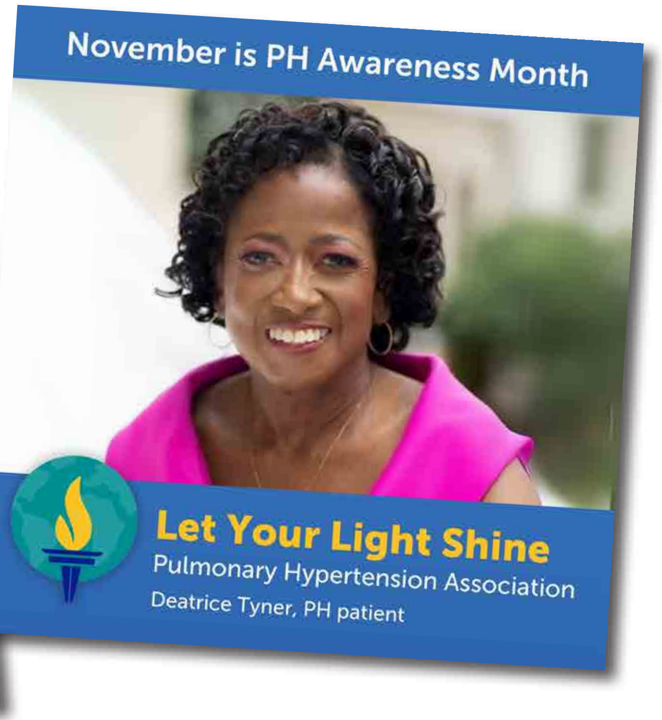
This year's theme, "Let Your Light Shine," emphasized the power of collective action and the strength of those living with this rare condition. From organizing fundraisers and leading support groups to sharing their personal stories, members of the PH community demonstrated what it means to let their light shine. This message of hope, strength and resilience extended across the PH community, serving as a reminder that every action—big or small—makes a difference.

Deatrice Tyner, who has lived with PH for over a decade, spoke about her commitment to raising awareness and fundraising to support PHA. "One day, we may have a cure," she said, reflecting the hope of many in the community.

For Jasmine Wells, living with pulmonary arterial hypertension means embracing a new version of herself while encouraging others to find strength in their journey. "It's okay to grieve the person you once were," Wells said. "You are enough. Be kind and allow yourself grace."

Ian Bartlett, a CTEPH patient, highlighted his commitment to staying active and inspiring others, while Petrice Moses, a support group leader in Virginia, emphasized the power of education and community in overcoming challenges. "We owe it to ourselves and every person with PH we encounter to share the torch of light," she shared.

Caregivers also play a huge role. Mitzi McIver-LaBarge's daughter, Ava, was diagnosed with PH as an infant. Motivated by their experience, she now mentors and supports parents of children with PH, reassuring them that they do not have to face PH alone. Similarly, McKenzie Adams honors her daughter's memory by sharing her story and working to raise awareness of PH and congenital heart defects.



DRIVING RESEARCH AND AWARENESS

PH Awareness Month also highlighted the critical role of research and advocacy in advancing treatment and improving outcomes for those with PH.

PHA hosted a PHA Live webinar, "PHA Research: Spotlight on Innovative Projects in PH," where researchers shared how PHA-funded studies are expanding scientific understanding of PH and uncovering potential breakthroughs. Scientists discussed their progress in areas such as immune system responses, early diagnostic markers and vascular changes in PH, paving the way for earlier detection, improved management and innovative therapies.

Beyond research, PHA mobilized advocates to push for legislative action. Advocates from across the U.S., sent over 2,000 messages to 338 legislators in 44 states and Washington, D.C., urging lawmakers to support the Supplemental Oxygen Access Reform Act and the Safe Step Act. The SOAR Act would improve access to supplemental oxygen for those who rely on it while the Safe Step Act seeks to remove insurance-imposed barriers to treatment. With growing support, the Safe Step Act advanced in Congress, gaining 47 Senate cosponsors and 234 House cosponsors, its strongest support to date.

COMMUNITY ENGAGEMENT AND FUNDRAISING

In addition to virtual education and advocacy efforts PHA's in-person events brought together patients, caregivers and supporters to strengthen connections and raise awareness and critical funds for research, patient support programs and more. Three major fundraising events were hosted in California and Texas:

- ▶ Monrovia O2breathe Walk in Monrovia, California.
- ▶ El Paso O2breathe Walk in El Paso, Texas (in partnership with Texas Tech University).
- ▶ Dallas Zebra PHest O2breathe Walk in Dallas.

By raising funds and awareness, these walks empower local communities to better understand PH and support those affected.

PH Awareness Month 2024 served as a reminder that everyone's light matters. Whether walking miles to raise awareness, advocating for policy changes or offering a listening ear, each contribution strengthens the PH community and brings hope for a brighter future. To read more inspiring stories and quotes, visit *www.phassociation.org/awarenessmonth.*

• Media clippings •

Austria

TOP STORY 2

Maleen Fischer über ihr Leben mit Lungenhochdru

ALS GÄBE E KEIN MORGE

Eine Pumpe, die ihr alle 40 Sekunden Prostacyclin ins Herz pumpt, ermöglicht **Maleen Fischer** seit 29 Jahren zu leben. MADONNA lernte sie als junges Mädchen kennen – und traf nun eine Powerfrau mit Message.

Lungenhochdruck – vor 20 Jahren noch für viele ein völliges Fremdwort. Erst Maleen Fischer, das damals kleine Mädchen mit der Bauchtasche, sorgte erstmals für Aufmerksamkeit auf die tückische Krankheit, die gefährlicherweise nur allzu oft mit Atem- oder Konditionslosigkeit verwechselt wird. Bleibt Pulmonale Hypertonie unbehandelt, kann sie innerhalb von nur 3 bis 5 Jahren zum Tod führen.

Die Schockdiagnose, dass seine Tochter Maleen wohl ihren 8. Geburtstag nicht erleben werde, wollte Gerry Fischer damals keineswegs akzeptieren. MADONNA berichtete damals über seinen Kampf für Forschung und Awareness – und unterstützte im Rahmen von „Make-A-Wish" die Verwirklichung von Maleens kleinen Träumen.

Heute ist Maleen 29 Jahre alt und arbeitet aktiv in dem von Fischer gegründeten Dachverband für Lungenhochdruck aktiv mit. Sie pendelt zwischen Wien und Florida – und lebt, soweit es ihre Krankheit erlaubt, ein normales Leben – als außergewöhnlich starke Frau.

Maleen, wir kennen uns schon viele Jahre. Sie haben uns schon als junges Mädchen mit Ihrer Geschichte beeindruckt. Inzwischen sind Sie 29 Jahre alt – wie geht es Ihnen heute?

MALEEN FISCHER: Es geht mir jetzt wieder besser. Lungenhochdruck ist ja eine fortschreitende Krankheit, für die man irgendwann die verschiedenen Therapiemöglichkeiten

Bei Ihnen ist die Krankheit sehr früh diagnostiziert worden – wie haben Sie das damals erlebt?

FISCHER: Meine Mutter hat früh bemerkt, dass etwas nicht stimmt – ich war schon beim Stillen außer Atem.

MADONNA

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TOP STORY 2

IHR BUCH „Als gäbe es kein Morgen", erschien 2014 und beeindruckte auch Stars wie Rainhard Fendrich. U.: An Maleens Zweitwohnsitz in Cape Coral in Florida tankt sie immer wieder Kraft für ihre wichtige Arbeit für PH Europe, den Dachverband für Lungenhochdruck. Infos & Hilfe unter phaaustria.org

„Die Angst ist ein ständiger Begleiter, mit dem man lernt zu leben."

FISCHER: In gewisser Weise ja, aber manchmal möchte ich auch einfach „normal" sein. Es ist wichtig, den Tag zu genießen, ohne dabei Kamikaze-mäßig zu leben. Ich denke, das ist ein Rat, den jeder beherzigen sollte.

Wie hat sich Ihr Leben im Erwachsenenalter verändert?

FISCHER: Ich habe mehr Erfahrung mit der Therapie und weiß, was ich mir zutrauen kann. Die Einschränkungen sind aber weiterhin da. Große Freude bereitet mir mein Hund, mit dem ich spazieren gehe. Zeit mit meiner Familie und das Lernen – und ich plane, nach meinem Master auch noch einen PhD in Public Health zu machen. Ich studiere sehr gerne, aber arbeite nun auch im Bereich Digital Media für PHA Europe, den Dachverband für Lungenhochdruck und engagiere mich ehrenamtlich für Make-A-Wish, wo ich schwerkranken Kindern Herzenswünsche erfülle. Diese Arbeit erfüllt mich sehr. Ich war ja selbst ein Make-A-Wish-Kind und weiß, wie wichtig diese erhebenden Erlebnisse sind, wenn es einem nicht so gut geht.

Erleichtert die digitale Welt Ihr Leben?

FISCHER: Sie hat mir viele Möglichkeiten eröffnet, wie etwa meinen Master an Harvard teilweise online abzuschließen. Die digitale Kommunikation ist schon gut, vor allem für Menschen wie mich, die nicht immer physisch präsent sein können.

Sie hatten auch Covid-19 – das muss für Sie ja ganz schrecklich gewesen sein...

FISCHER: Es war schwer, vor allem beim ersten Mal vor der Impfung. Ich lag zweieinhalb Monate flach, und es dauert für mich viel länger, mich davon zu erholen, als für viele andere. Grundsätzlich hat es uns, denke ich, allen gezeigt, wie fragil unsere Gesundheit ist. **Wie weit ist die Forschung in Bezug auf Lungenhochdruck?**

FISCHER: In den letzten Jahren hat sich durch Forschung und lautstarke Awareness-Arbeit gottseidank viel verbessert. Heute gibt es mehr Therapien und Hoffnung für Betroffene. Trotzdem bleibt es leider eine seltene und komplexe Krankheit.

Was wünschen Sie sich zu Weihnachten?

FISCHER: Dass Menschen auf Symptome wie Atemnot achten und sich untersuchen lassen. Frühdiagnosen können Leben retten! Deswegen mache ich diese Awareness-Arbeit seit meinem vierten Lebensjahr – wenn dadurch auch nur ein Mensch rechtzeitig Hilfe bekommt, hat es sich gelohnt.

DANIELA SCHIMKE ■

Erfülle Kinderwünsche, schenke Hoffnung:
SPENDEN & TRÄUME WAHR MACHEN
Online unter www.oe24.at/herzenswuensche
oe24 HERZENS WÜNSCHE
Make-A-Wish. ÖSTERREICH & oe24

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AUSTRIA PRESSE AGENTUR

SCIENCE

Chronischer Lungenhochdruck PAH wird oft spät erkannt

Durchschnittlich 2,3 Jahre dauert es laut einer neuen Publikation, bis die pulmonal-arterielle Hypertonie (PAH) erkannt und bei Betroffenen final diagnostiziert wird. In diesem Zeitraum wird im Schnitt sechs Mal ein Spezialist konsultiert und rund zwei Mal eine Hospitalisierung nötig. Betroffene leiden unter erhöhtem Blutdruck in den Arterien der Lunge, was zu einer Überlastung des Herzens und schließlich zum Tod führt, warnte der Mediziner Gabor Kovacs in Wien.

APA (dpa/Themenbild)

GESUNDHEITS TRENDS

DEINE NEUE WELL-BEING PLATTFORM

Leben mit PAH: Warum die Diagnose oft Jahre auf sich war lässt

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Der stille Kampf und der Wettlauf um die Zeit: Pulmonal arterielle Hypertonie

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WIRTSCHAFT POLITIK FINANZEN CHRONIK KULTUR MEDIEN KARRIERE

REMINDER: Einladung zum Pressegespräch: Awareness für pulmonale arterielle Hypertonie

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TOP NEWS

POLITIK WIRTSCHAFT CHRONIK FINANZEN MEDIEN KULTUR KARRIERE

REMINDER: Einladung zum Pressegespräch: Awareness für pulmonale arterielle Hypertonie

SCHLAGWÖRTER

Der Kardiopulmonale Arbeitskreis der ÖKG stellt sich vor

ÖKG-Arbeitsgruppen-- Der Schwerpunkt des kardiopulmonalen Arbeitskreises (KP-AG) liegt in der Erfassung von Epidemiologie, Pathogenese, Früherkennung, Diagnose und Therapie von kardio-pulmonalen Erkrankungen, mit speziellem Interesse für Lungengefäßerkrankungen.

ASSOC. PROF. PRIV. DOZ. NIKA SKORO-SAJER (AG-LEITERIN), AP. PROF. PRIV.-DOZ. DR. CHRISTIAN GERGES (AG-LEITER-STV.)

Die KP-AG möchte mehr Awareness für pulmonale Hypertension schaffen.

Der kardiopulmonale Arbeitskreis der ÖKG

Die Amyloidose-Gruppe des kardiopulmonalen Arbeitskreises rund um Prof. Johannes Kastner.

Top Publikationen

In den letzten Jahren haben AG Mit der mehr als 100 Papers in Top Jour wie European Heart Journal, JACC Circulation publiziert.

HYPERTONIE

Ein stiller KAMPF

Die pulmonal arterielle Hypertonie ist eine schwere und fortschreitende Erkrankung. Viele Betroffene sind nicht mehr in der Lage, alltägliche Aufgaben zu meistern. Doch neue Forschungsansätze machen Hoffnung.

Maleen Fischer ist drei Jahre alt, als die pulmonal arterielle Hypertonie bei ihr diagnostiziert wird. Ihre Kindheit ist geprägt von vielen Einschränkungen, was oft zu Ausgrenzung bei Geburtstagsfeiern oder auf Spielplätzen führte: „Es war schwer, zu verstehen, warum ich nicht alles tun konnte, was andere Kinder machten. Ich war beispielsweise noch nie in meinem Leben schwimmen." Mit der Zeit veränderten sich die Herausforderungen im Leben der Frau: Heute gehe es um Themen wie Reisen, Familienplanung und die Unheilbarkeit der Krankheit, erklärt sie. Bei der pulmonal arteriellen Hypertonie (PAH) leiden Betroffene unter einem erhöhten Blutdruck in den Arterien der Lunge und an der Verengung kleiner Lungenarterien, was zu einer Überlastung des Herzens und schließlich über das Versagen des rechten Herzventrikels zum Tod führen kann. In der EU leben zirka 30.000 Menschen mit der Erkrankung, die schnell voranschreitet. Trotz Therapie bleibt die Sterblichkeitsrate hoch, da die Behandlungen zwar die Symptome lindern, aber nicht die Ursache der Erkrankung bekämpfen. PAH betrifft ältere Menschen genauso wie jüngere Personen, vor allem Frauen und sogar Kinder.

bei denen die Krankheit nach der Geburt des Kindes ausbricht. Leidet man als Frau bereits an der Hypertonie und hat einen Kinderwunsch, ist auch hier Vorsicht geboten: Die Sterblichkeit während der Schwangerschaft ist durch die Erkrankung stark erhöht. Viele Patientinnen und Patienten sind nicht mehr in der Lage, alltägliche Aufgaben zu erledigen oder sich zu bewegen. In den schwersten Fällen ist sogar jegliche körperliche Betätigung im Ruhezustand unmöglich. Ähnlich beschreibt es auch Eva Otter, Betroffene und Kontaktstelle für Betroffene bei der Patientenvereinigung PH Austria: „Selbst einfache Treffen mit Freunden wurden unmöglich, weil der Weg ins Café zu anstrengend war. In dieser Zeit fühlte ich mich oft ‚wertlos'. Irgendwann verbringt man die meiste Zeit nur noch auf der Couch und konzent-

„Das Fehlen äußerlicher Anzeichen führt oft zu falschen Einschätzungen, was einerseits den Weg zur Diagnose verlangsamt und andererseits den einfachen Zugang zu notwendiger Unterstützung erheblich erschwert."

© APA-Fotoservice/PH Austria

Lungenhochdruck Experten fordern faire Leistungen bei seltenen Erkrankungen. 74

KONGRESS

RHEUMA TRIFFT HERZ – HERZ TRIFFT RHEUMA

T. M. Hofbauer, Wien
I. Lang, Wien

Rheuma trifft Herz – Herz trifft Rheuma
23.–24. Februar 2024, Wien

Pulmonal-arterielle Hypertension (PAH)

Einsatz von Vasodilatatoren: PAH assoziiert mit Bindegewebserkrankung

Die pulmonal-arterielle Hypertension (PAH) ist eine seltene Erkrankung, die gemeinsam mit Bindegewebserkrankungen wie der systemischen Sklerose auftreten kann. Die zeitnahe PAH-Diagnose bei diesen Patient:innen ist entscheidend, da sie mit einer erheblichen Prognoseverschlechterung einhergeht. Nach Diagnosestellung mittels invasiver Rechtsherzkatheteruntersuchung werden lungengefäßspezifische, gefäßerweiternde (vasodilatative) Pharmaka eingesetzt.

Lungenhochdruck (pulmonale Hypertension, PH) ist definiert als eine Erhöhung des invasiv gemessenen mittleren Pulmonalarteriendrucks (mPAP) > 20 mmHg. Die PH ist eine kardiovaskuläre Erkrankung, die auf die gesamte Weltbevölkerung bezogen sehr häufig ist. Rund 1 % der Menschen sind von einer Form der PH betroffen. Es besteht ein eindeutiger Zusammenhang zwischen Höhe des mPAP, Rechtsherzinsuffizienz und -versagen sowie Mortalität.[1]

Eine pulmonal-arterielle Hypertension (pulmonal-arterielle Hypertonie, PAH) liegt dann vor, wenn neben der Erhöhung

Kurze Diagnosewege, eine optimale Behandlung und gute Kommunikation sieht die Expertenrunde im PRAEVENIRE-Gipfelgespräch als Schlüsselpunkte um Lungenhochdruck erfolgreich zu bekämpfen

Neue Chancen bei Lungenhochdruck

PRAEVENIRE Gesundheitstage. Expertinnen und Experten diskutierten Strategien im Kampf gegen Lungenhochdruck

Thomas Holzgruber
Andreas Huss
Wilhelm Marhold
Eva Otter
Erwin Rebhandl
Regina Steringer-Mascherbauer
Gudrun Wolner-Strohmeyer

GESUNDHEITSTAGE IN EISENSTADT
KURIER-Serie

Pulmonale Hypertonie bei HFpEF – Differenzialdiagnose und Therapie

Lungenhockdruck-- Patienten mit HFpEF leiden oft an pulmonaler Hypertonie und rechtsventrikulärer Dysfunktion, was ihre Prognose verschlechtert und im klinischen Alltag häufig übersehen wird. Wie soll eine differenzialdiagnostische Abklärung erfolgen und welche Therapiemöglichkeiten gibt es?

PROF. DR. STEPHAN ROSENKRANZ

Kontakt-- Prof. Dr. Stephan Rosenkranz, Herzzentrum der Universität zu Köln, stephan.rosenkranz@uk-koeln.de

Pulmonale Hypertonie bei HFpEF

Untergliederung der PH

Bei Patienten mit HFpEF kommt es pathophysiologisch primär zu einer Erhöhung der Füllungsdrücke im linken Herzen und Rückübertragung in die Lungenstrombahn (postkapilläre PH). Ein Großteil der Patienten weist jedoch eine übermäßige PH auf, die durch einen erhöhten pulmonal-vaskulären Widerstand (PVR) gekennzeichnet ist.

PROF. DR. JOHANN BAUERSACHS

HFpEF – oft verkannt und unterdiagnostiziert

Kommentar--

Prof. Dr. Johann Bauersachs-- Medizinische Hochschule Hannover

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PULMONAL-ARTERIELLE HYPERTONIE

CHANCEN DURCH FRÜHZEITIGE DIAGNOSE UND INNOVATIVE THERAPIEN

36

Pulmonal-arterielle Hypertonie (PAH) ist eine schwere Erkrankung, bei der der Blutdruck in den Lungenarterien erhöht ist. Dies führt zu einer erheblichen Belastung des Herzens, da es gegen den erhöhten Druck ankämpfen muss. Unbehandelt kann die Krankheit zu Herzversagen und letztlich zum Tod führen. PAH betrifft Menschen jeden Alters, wobei auch jüngere Erwachsene, insbesondere Frauen, und sogar Kinder betroffen sein können.

Die Diagnose der PAH erfolgt häufig erst nach längerer Zeit. Im Durchschnitt vergehen zwei bis drei Jahre, bis die Krankheit erkannt und endgültig diagnostiziert wird. In dieser Zeit suchen Betroffene etwa sechs Mal Expert*innen auf und müssen rund zwei Mal ins Krankenhaus. Gabor Kovacs, Experte für pulmonale Hypertonie an der Klinischen Abteilung für Pulmologie der Medizinischen Universität Graz, erklärt, dass die verzögerte Diagnose oft dazu führt, dass sich die Erkrankung dann bereits in einem fortgeschrittenen Stadium befindet.

Behandlungsansätze zielen aktuell hauptsächlich darauf ab, die Symptome zu lindern, indem beispielsweise die Lungengefäße erweitert werden, um das Atmen zu erleichtern. Diese Maßnahmen können die Lebensqualität der Patient*innen verbessern, jedoch bekämpfen sie nicht die eigentliche Ursache der Krankheit.

„Es ist wichtig, das Bewusstsein für diese seltene und lebensbedrohliche Krankheit zu schärfen, um den langen Diagnoseweg zu verkürzen. In der EU leben rund 30.000 Menschen mit PAH."

GABOR KOVACS

Alarmsignal Atemnot ernst nehmen

Rund ein Prozent der Bevölkerung leidet an Lungenhochdruck: woran man diese gefährliche Erkrankung erkennt und welche Therapien es gibt.

Von Sonja Krause

Treppensteigen fühlt sich an wie Hochleistungssport, beim Spaziergang in der Ebene komme ich außer Atem, an Wandern ist nicht mehr zu denken: So kann die Atemnot das Leben einschränken. Atemnot, die sich über Jahre hindurch entwickelt und immer massiver wird, kann ein Alarmsignal für eine Vielzahl von Erkrankungen sein, erklärt Gabor Kovacs von der Abteilung für Pneumologie an der LKH-Universitätsklinik Graz bei der heurigen Jahrestagung der Österreichischen Gesellschaft für Pneumologie.

„Typisch ist, dass eine beginnende Atemnot in vielen Fällen bagatellisiert und nicht ernst genommen wird. So kann sie sich über die Jahre hinweg schleichend entwickeln. Irgendwann merken die Patienten: Ich kann meinen Freizeitbeschäftigungen nicht mehr nachgehen", erklärt Kovacs. In diesen Fällen seien sehr häufig Herz- und Lungenkrankheiten die Ursache. Zu den infrage kommenden Lungenkrankheiten zählen Atemwegs- oder Lungengewebekrankheiten, aber langfristige Atemnot kann auch auf Erkrankungen der Lungengefäße, wie Lungenhochdruck hinweisen. Neuesten Schätzungen zufolge leidet zumindest ein Prozent der Bevölkerung an Lungenhochdruck. Spürt man eine solche Atemnot bei Belastung, sollte der erste Weg zum Hausarzt, zur Hausärztin führen, denn dahinter kann sich eine Vielzahl von Erkrankungen verbergen. Es gilt, die Ursache zu finden.

Der Experte erklärt, wie es zum Lungenhochdruck kommt: Durch krankhafte Prozesse kann es zu Umbauten in der Wand der Lungengefäße kommen, mit der Folge, dass das Blut nicht mehr ungehindert fließen kann. Dadurch muss das Herz mehr arbeiten und der Blutdruck erhöht sich. Wenn der Blutdruck in den Lungenarterien dauerhaft erhöht ist, spricht man von Lungenhochdruck. „Dieser Zustand kann den rechten Teil des Herzens, der das Blut in die Lunge pumpt, schädigen und zu einem rechtsseitigen Herzversagen führen, das tödlich enden kann", erklärt Kovacs weiter. Lungenhochdruck ist oft mit einer bestehenden Herz- oder Lungenkrankheit verbunden, kann aber auch als Spätfolge einer Lungenembolie oder als eigene Erkrankung der Lungen-

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Patientenvereinigung möchte Bewusstsein schärfen

PAH wird oft spät erkannt

Durchschnittlich 2,3 Jahre dauert es, bis die pulmonalarterielle Hypertonie (PAH) erkannt und bei Betroffenen final diagnostiziert wird. In diesem Zeitraum wird im Schnitt sechsmal ein Spezialist konsultiert und rund zweimal eine Hospitalisierung nötig, so die Patientenvereinigung PH Austria. „Diese Krankheit betrifft nicht nur ältere Menschen, sondern auch viele jüngere Personen, insbesondere Frauen, und sogar Kinder", erklärt Ass. Prof. Dr. Gabor Kovacs, Leiter der PAH-Ambulanz an der Medizinischen Universität Graz. Wichtig wäre, das generelle Bewusstsein für die seltene Krankheit innerhalb der Bevölkerung zu schärfen, um so den noch (zu) langen Diagnoseweg zu verkürzen. In Hinblick auf Sozialleistungen gibt es laut PH Austria zudem enorme Ungleichheiten innerhalb unterschiedlicher Regionen. Die Bewilligung dieser Sozialleistungen – beispielsweise die Ausstellung von Behindertenausweisen – sowie die medizinische Versorgung sollten auf Basis der Befunde der spezialisierten Kompetenzzentren erfolgen. Ein zentrales Anliegen von PH Austria ist daher, dass Patientenvertreter:innen in Gremien, wie das neu eingerichtete Bewertungsboard, mit einbezogen werden, um für mehr Transparenz und Ausgewogenheit zu sorgen. *(red)*

Quelle:
Pressemitteilung der PH Austria vom 25.9.2024

Belgium

MEDIAPLANET

PAH: vage symptomen en gebrek aan bewustzijn bemoeilijken tijdige diagnose

Pulmonale arteriële hypertensie (PAH) is een zeldzame ziekte, wat betekent dat deze aandoening bij minder dan 1 op de 2.000 mensen voorkomt. Een vroege diagnose en behandeling kunnen het verloop van de ziekte aanzienlijk beïnvloeden en de kwaliteit van leven verbeteren. Meer bewustzijn over PAH is in dat kader cruciaal.

Vage symptomen bemoeilijken diagnose

Patiënt getuigt over belang van bewustzijn

Straf Verhaal

Annelies (27): 'Ik ben niet bang om te sterven. Ik heb daar ondertussen vrede mee.'

Annelies lijdt aan de zeldzame ziekte pulmonale hypertensie.

Wanneer een ernstige ziekte niet ernstig wordt genomen

Sensibilisering rond zeldzame aandoeningen blijft noodzakelijk. Dat blijkt ook uit de patiëntengetuigenis van Mevr. Wendy Vansteenkiste. Omdat haar klachten in dovemansoren vielen, duurde het twee jaar voordat ze de diagnose van pulmonale arteriële hypertensie kreeg. Ook vandaag, vijftien jaar later, blijft het vechten voor erkenning.

"Mijn leven is anders gelopen dan verwacht, maar het is goed zoals het is", aldus Wendy Vansteenkiste.

Bosnia and Herzegovina

"Znamo da u Kantonu Sarajevo pacijenti imaju 100 posto refundacije za lijek, u Tuzlanskom kantonu zahvaljujući radu našeg udruženja također imaju 100 posto refundacije, kao i u Srednjobosanskom. U Zeničko-Dobojskom kantonu imaju 50 posto refundacije, isto zahvaljujući radu udruženja, u Hercegovačko-Neretvanskom kantonu isto, samo 50 posto refundacije. Za ostale kantone nemamo informacije, a ni pacijente koji bi nam mogli prenijeti informacije koje zvanično ne dobijamo", rekla je.

Ona je pozvala sve oboljele da se jave udruženju DAH, na web stranicu ili putem društvenih mreža kako bi mogli doprinijeti zajedničkoj borbi i kako bi mogli dostaviti informacije iz ostalih kantona.

Sportisti i mediji uključeni u aktivnosti Udruženja „Dah“

DEŠAVANJA

"Plućna hipertenzija je rijetko i neizlječivo oboljenje krvnih sudova pluća. Radi se o otvrdnjavanju krvih sudova pluća gdje se smanjuje protok krvi kroz krvne sudove i samim tim dotok kisika u pluća", rekla je ona.

U svijetu postoji 13 lijekova kojima se bolest tretira kako ne bi progresirala, a u BiH pacijentima su na raspolaganju samo dva i ta dva lijeka su nedostupna svima. Upravo zbog toga je Vera Hodžić osnovala udruženje koje se bori za prava pacijenata i podiže svijest o plućnoj hipertenziji.

"Naš osnovni zadatak i cilj je lijek za sve pacijente. Smatramo da je nedopustivo da pacijenti oboljeli od plućne hipertenzije žive u jednoj državi, boluju od iste bolesti, a nemaju svi lijek", rekla je.

Također, među udruženjima koja se aktivno bore za prava oboljelih od rijetkih bolesti su Udruženje Udruženje roditelja djece oboljele od cistične fibroze, Savez za rijetke bolesti, kao i Udruženje DAH.

Predsjednica Udruženja DAH Vera Hodžić, koja i sama boluje od rijetke neizlječive bolesti plućne hipertenzije, za Klix.ba govorila je o tome šta je zapravo ta bolest i sa kakvim se problemima suočavaju pacijenti s tom dijagnozom u Federaciji BiH.

Sportisti i mediji uključeni u aktivnosti Udruženja „Dah“

DEŠAVANJA

25.09.2024. u 08:47

Udruženje građana oboljelih od plućne hipertenzije „Dah“ – u Bosni i Hercegovini čije sjedište je u

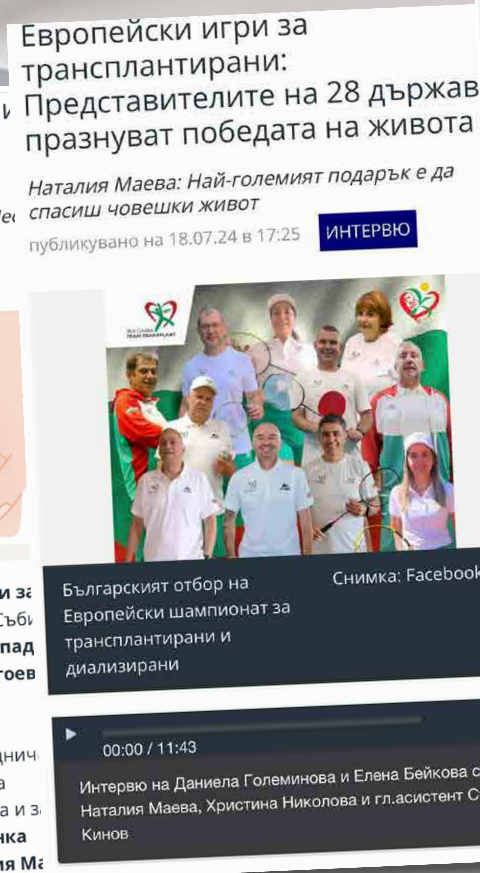
Bulgaria BSPPH

"Да! За живот!" – Национални спортни игри за трансплантирани започват

Домакин е Югозападният университет "Не Рилски" – Благоевград (18 и 19 май)

публикувано на 17.05.24 в 10:03

Започват **Националните спортни игри за трансплантирани – "Да! За живот!"**. Съби ще се проведе **на 18 и 19 май в Югозапад университет "Неофит Рилски" – Благоев** Спортният празник се организира по инициатива на Изпълнителна агенция "Медицински надзор" (ИАМН), в сътрудни с висшето учебно заведение и Община Благоевград. За силата, за мотивацията и з успехите в "Нашият ден" говорят **Иванка Динева**, директор на ИАМН, и **Наталия Ма** участник в игрите.



Европейски игри за трансплантирани: Представителите на 28 държав празнуват победата на живота

Наталия Маева: Най-големият подарък е да спасиш човешки живот

публикувано на 18.07.24 в 17:25

ИНТЕРВЮ

Българският отбор на Европейски шампионат за трансплантирани и диализирани

Снимка: Facebook -

00:00 / 11:43

Интервю на Даниела Големинова и Елена Бойкова с Наталия Маева, Христина Николова и гл.асистент Стеф Кинов

Какви са възможностите за спортна изява на трансплантирани хора

Наталия Маева спечели златен медал по бадминтон във възрастова група 50-59 г. на Европейските игри за трансплантирани в Лисабон

публикувано на 22.07.24 в 17:30 | обновено на 22.07.24 в 18:28

Наталия Маева е Европейски шампион по бадминтон в категория 50-59 години!

В Лисабон бяха открити Европейските игри за трансплантирани и диализирани. Спортистите се състезават в различни видове спорт – лека атлетика, тенис, тенис на маса, бадминтон, плуване… над 10 вида спорт. За първи път България участва със свой отбор.

Запознаваме слушателите на Lege Artis с акцентите в **34-тия конгрес на Европейскот респираторно общество**. На телефонната линия на предаването директно от Виена се включва кореспондентът **Наталия Маева** – журналист, трансплантиран пациент, член на Европейската асоциация по пулмонална хипертония.

Българското общество на пациентите с пулмонална хипертония участва със собст щанд в изложбения център.

На 5 октомври стартира инициативата "Спортувам, за да живея" за трансплантирани

публикувано на 04.10.24 в 11:35 | Автор: Гергана Хрисчева

Снимка: Българско общество на пациентите с пу

На 5 октомври 2024 г. ви каним да се присъедините към инициативата "Спортувам, за да живея", която ще се проведе на откритите пространства на Първа английска езикова гимназия и парка "Заимов", в партньорство със СО-район "Оборище".

публикувано на 07.10.24 в 15:06 | Автор: Мария Мира Христова

Инициативата "Спортувам, за да живея" събра в Европейския ден на донорството почитатели на спорта сред хора на диализа, трансплантирани пациенти, както и всички, които искат да поддържат добра физическа форма. Българското общество на пациентите с пулмонална хипертония получи подкрепа за събитието в лицето на програмата "София спортува" и подпрограмата "В играта съм" на Столична община.

В инициативата се включиха 5 федерации, 6 спортни клуба, както и доброволци – спортни и здравни специалисти, които запознаха участниците с различни спортни дисциплини и демонстрираха как спортът помага безопасно и според индивидуалните потребности за възстановяване и качествен живот.

Czech Republic

Uvízlá krevní sraženina se z plic odstraní i chirurgicky. Snadné to n

Od zdravezpravy · 6. 12. 2024

Sdílet

Kardiochirurgové Centra pro plicní hypertenzi II. Interní kliniky – kliniky kardiologie a a 1. LF UK a VFN při chirurgickém odstraňování krevní sraženiny z plicní tepny. Zákrok se nazývá plicní endarterektomie [PEA]. / Foto: VFN

Při akutní plicní embolii se ne vždy podaří krevní sraženinu v plicní tepn rozpustit například léky, a tak se kvůli ní uzavírá část plicního oběhu. A t problém, který, pokud se neodstraní, končí smrtí.

Na závažnou chorobu Evu upozornily oteklé a modr prsty: Sklerodermie měn vzhled a bolí

ZDROJ: CNN

Je to stav, který způsobuje zúžení a zesílení cév v plicích. Plicní hypertenze je progresivní onemocnění – jedna z těžkých forem postihující plicní tepny, která může vést až k selhání srdce a smrti.

CNN Prima NEWS

Jaké jsou příznaky nebezpečné plicní hypertenze?

9 Zobrazit galerii

Plicní hypertenze. Nebezpečné onemocnění, které může vést až ke smrti pacienta. Když se ale včas zachytí, lze ho léčit. Problém ale je, že lidé příznaky často buď ignorují, nebo je lékaři mylně přisoudí něčemu jinému, říká pro stanici CNN doktor Tim Lahm

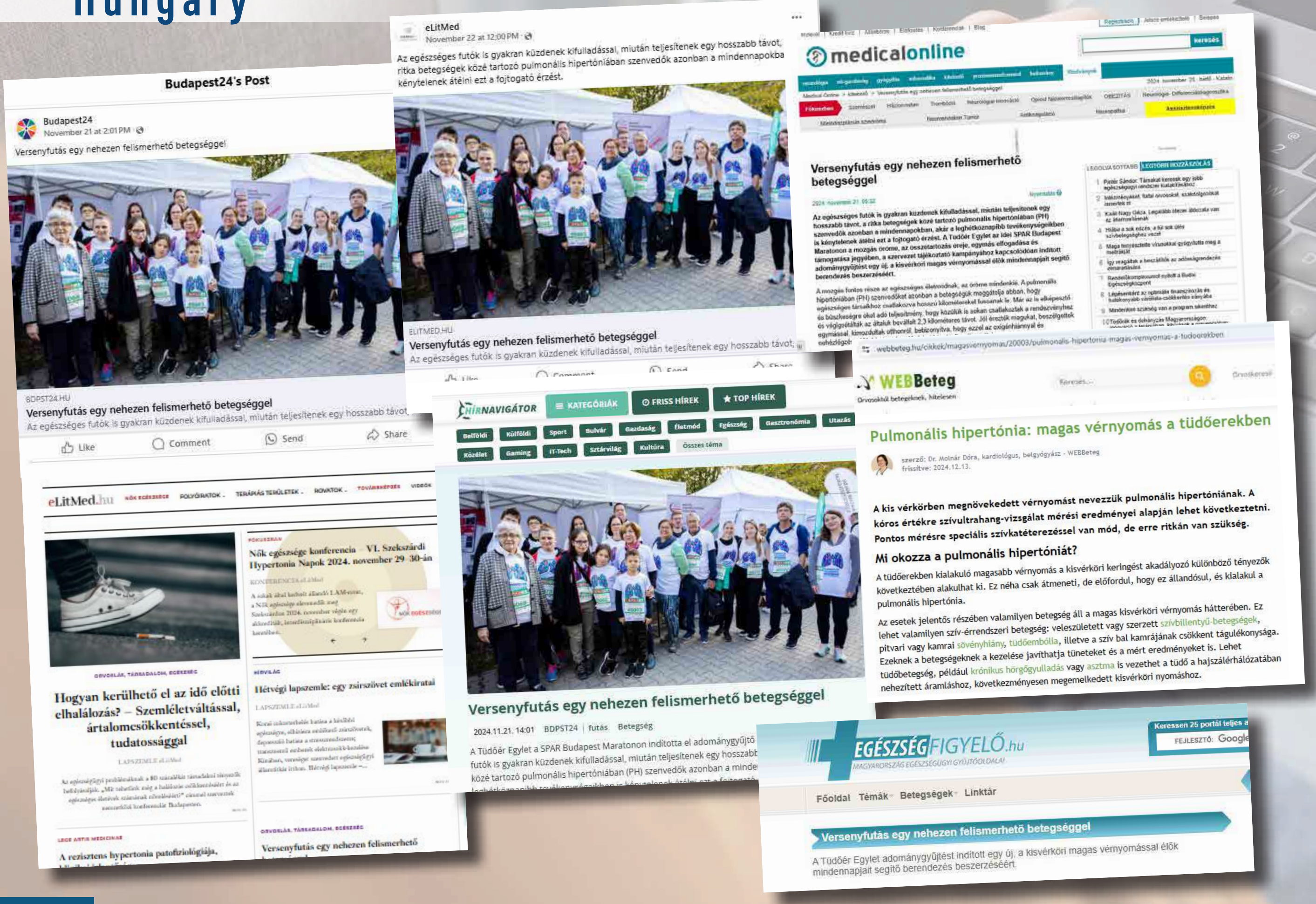
Český zázrak. V Motole provedli u dítěte transplantaci srdce i plic najednou

13. června 2024 15:34

Tým lékařů v motolské nemocnici provedl jako první v ČR transplantaci srdce a plic u dětského pacienta. Patnáctiletému pacientovi by nestačila jednotlivá transplantace plic či srdce a tak doktoři přistoupili k této kombinované metodě. Ta se v Česku používá od roku 2014, dodnes byla provedena na osmi dospělých pacientech.

Tým lékařů v motolské nemocnici provedl unikátní zákrok. Dětskému pacientovi zároveň transplantovali plíce i srdce. | foto: FN Motol

Hungary



Budapest24's Post

Budapest24
November 21 at 2:01 PM

Versenyfutás egy nehezen felismerhető betegséggel

BDPST24.HU
Versenyfutás egy nehezen felismerhető betegséggel
Az egészséges futók is gyakran küzdenek kifulladással, miután teljesítenek egy hosszabb távot

Like Comment Send Share

eLitMed
November 22 at 12:00 PM

Az egészséges futók is gyakran küzdenek kifulladással, miután teljesítenek egy hosszabb távot, ritka betegségek közé tartozó pulmonális hipertóniában szenvedők azonban a mindennapokba kénytelenek átélni ezt a fojtogató érzést.

ELITMED.HU
Versenyfutás egy nehezen felismerhető betegséggel
Az egészséges futók is gyakran küzdenek kifulladással, miután teljesítenek egy hosszabb távot,

eLitMed.hu

Nők egészsége konferencia – VI. Szekszárdi Hypertonia Napok 2024. november 29–30-án

Hogyan kerülhető el az idő előtti elhalálozás? – Szemléletváltással, ártalomcsökkentéssel, tudatossággal

Hétvégi lapszemle: egy zsírszövet emlékiratai

A rezisztens hypertonia patofiziológiája,

Versenyfutás egy nehezen felismerhető

medicalonline

Versenyfutás egy nehezen felismerhető betegséggel

2024. november 21. 05:32

Az egészséges futók is gyakran küzdenek kifulladással, miután teljesítenek egy hosszabb távot, a ritka betegségek közé tartozó pulmonális hipertóniában (PH) szenvedők azonban a mindennapokban, akár a leghétköznapibb tevékenységeikben is kénytelenek átélni ezt a fojtogató érzést. A Tüdőér Egylet az idei SPAR Budapest Maratonon a mozgás öröme, az összetartozás ereje, egymás elfogadása és támogatása jegyében, a szervezet tájékoztató kampányához kapcsolódóan indított adománygyűjtést egy új, a kisvérköri magas vérnyomással élők mindennapjait segítő berendezés beszerzéséért.

HÍRNAVIGÁTOR

KATEGÓRIÁK · FRISS HÍREK · TOP HÍREK

Versenyfutás egy nehezen felismerhető betegséggel

2024.11.21. 14:01 | BDPST24 | futás | Betegség

A Tüdőér Egylet a SPAR Budapest Maratonon indította el adománygyűjtő futók is gyakran küzdenek kifulladással, miután teljesítenek egy hosszabb közé tartozó pulmonális hipertóniában (PH) szenvedők azonban a minde

webbeteg.hu/cikkek/magasvernyomas/20003/pulmonalis-hipertonia-magas-vernyomas-a-tudoerekben

WEBBeteg
Orvosoktól betegeknek, hitelesen

Pulmonális hipertónia: magas vérnyomás a tüdőerekben

szerző: Dr. Molnár Dóra, kardiológus, belgyógyász - WEBBeteg
frissítve: 2024.12.13.

A kis vérkörben megnövekedett vérnyomást nevezzük pulmonális hipertóniának. A kóros értékre szívultrahang-vizsgálat mérési eredményei alapján lehet következtetni. Pontos mérésre speciális szívkatéterezéssel van mód, de erre ritkán van szükség.

Mi okozza a pulmonális hipertóniát?

A tüdőerekben kialakuló magasabb vérnyomás a kisvérköri keringést akadályozó különböző tényezők következtében alakulhat ki. Ez néha csak átmeneti, de előfordul, hogy ez állandósul, és kialakul a pulmonális hipertónia.

Az esetek jelentős részében valamilyen betegség áll a magas kisvérköri vérnyomás hátterében. Ez lehet valamilyen szív-érrendszeri betegség: veleszületett vagy szerzett szívbillentyű-betegségek, pitvari vagy kamrai sövényhiány, tüdőembólia, illetve a szív bal kamrájának csökkent tágulékonysága. Ezeknek a betegségeknek a kezelése javíthatja tüneteket és a mért eredményeket is. Lehet tüdőbetegség, például krónikus hörgőgyulladás vagy asztma is vezethet a tüdő a hajszálérhálózatában nehezített áramláshoz, következményesen megemelkedett kisvérköri nyomáshoz.

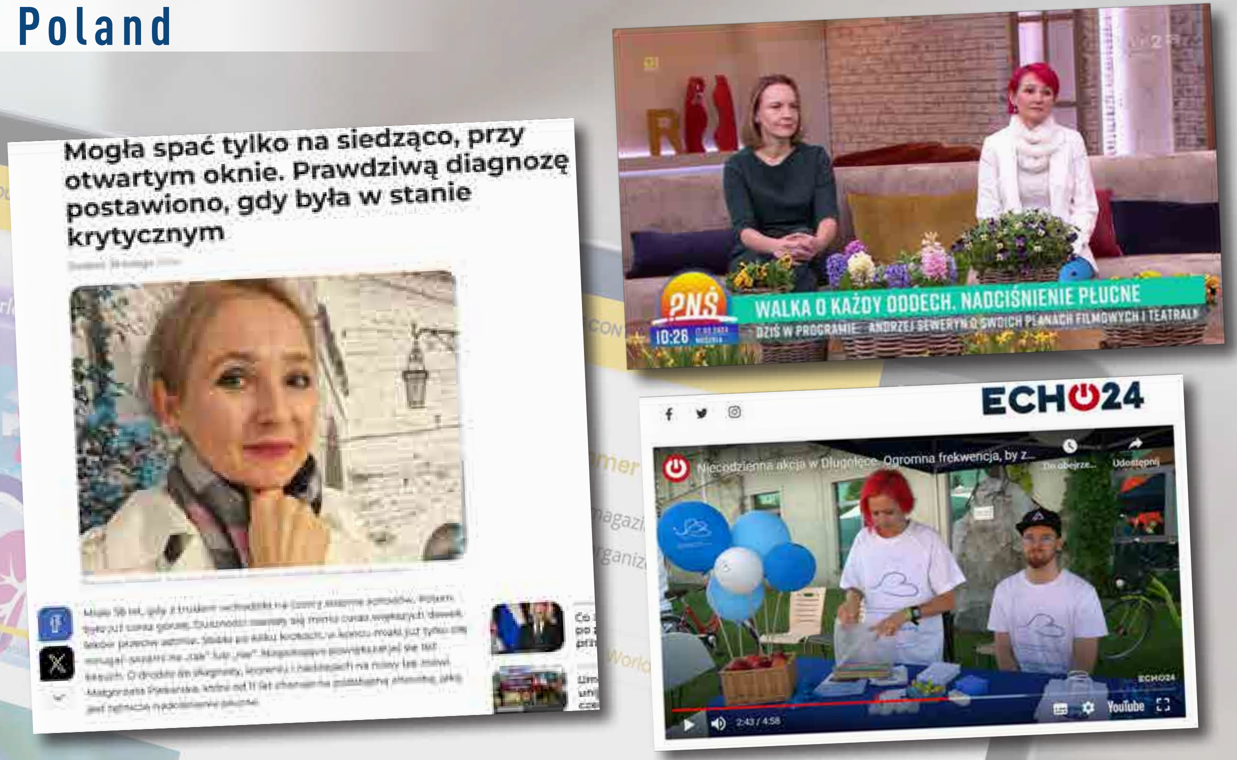
EGÉSZSÉGFIGYELŐ.hu
MAGYARORSZÁG EGÉSZSÉGÜGYI GYŰJTŐOLDALA!

Főoldal Témák Betegségek Linktár

Versenyfutás egy nehezen felismerhető betegséggel

A Tüdőér Egylet adománygyűjtést indított egy új, a kisvérköri magas vérnyomással élők mindennapjait segítő berendezés beszerzéséért.

Poland



Mogła spać tylko na siedząco, przy otwartym oknie. Prawdziwą diagnozę postawiono, gdy była w stanie krytycznym

2NŚ
WALKA O KAŻDY ODDECH. NADCIŚNIENIE PŁUCNE
DZIŚ W PROGRAMIE: ANDRZEJ SEWERYN O SWOICH PLANACH FILMOWYCH I TEATRALN

ECHO24

Niecodzienna akcja w Długołęce. Ogromna frekwencja, by z...

Slovakia

aktuality.sk

Kardiologička: Za dýchavičnosťou a únavou sa m skrývať aj nevyliečiteľné ochorenie

Normal Heart · Pulmonary Hy

Pľúcna artériová hypertenzia (PAH) je zriedkavé ochorenie, ktor pľúca aj srdce. Diagnostika býva oneskorená, keďže prejavy PAH dýchavica pri bežných činnostiach či únava, často pripomínajú ochorenia. Kedy už treba vyhľadať lekára a aké možnosti liečby slovenskí pacienti?

Aj o tom sme hovorili s kardiologičkou Bibiánou Kafkovou z Východoslovensk srdcových a cievnych chorôb v Košiciach.

Ochorenie pľúcna artériová hypertenzia má pomerne komplikovaný názov. O ide?

Na začiatok niečo z fyziológie: odkysličená krv sa z celého tela vracia do prav úlohou je prečerpávať krv do pľúc, kde sa okysličuje a vracia do ľavej komory, krvný obeh. Zvýšenie tlaku krvi v tomto obehu sa nazýva pľúcna hypertenzia. pľúcnom riečisku má asi percento dospelých ľudí a sprevádza najčastejšie ochorenie ľavého srdca alebo ochorenie pľúc. Vzácne ide o samostatné ochorenie – pľúcnu artériovú hypertenziu (PAH). Je to zriedkavé ochorenie, kde je toto zvýšenie tlaku v malom obehu (pľúcna hypertenzia) spôsobené postupným zužovaním malých pľúcnych tepien (artérií).

Vďaka novým pľúcam žije, aj na lanovke sa znova vracia do života

19.11.2024

Koliba a lesy pod Kamzíkom sú jeho domácí rajón. TOMÁŠ FALB tam vyrástol, pozna lesnú cestičku. Potom ho zdravotné problémy od tejto oblasti na pár rokov odstrihli. transplantácii pľúc ho môžete stretnúť opäť tam, kde to má najradšej. Napríklad aj v lanovky na Kamzík.

Happy end ako z amerického filmu. Ešte zaujímavejšie sú však okolnosti, ktoré mu predchádzali.

info-zdravie.sk

ADVERTORIAL

VČASNÁ DIAGNOSTIKA JE KĽÚČOVÁ

Zdroj: archív ZPPH

Mgr. Iveta Makovníková pôvodne pôsobila ako učiteľka. V roku 2004 jej diagnostikovali idiopatickú pľúcnu artériovú hypertenziu (PAH). Stala sa prvou pacientkou na Slovensku, ktorá po špecifickej liečbe PAH v roku 2011 úspešne podstúpila obojstrannú transplantáciu pľúc vo Viedni.

Mgr. Iveta Makovníková (62)
predsedníčka ZPPH

V marci 2010 založila Združenie pacientov s pľúcnou hypertenziou, občianske združenie s celoslovenským pôsobením, a dodnes sa venuje pacientom s týmto ochorením.

Štikrafa a iné zriedkatká

26. 02. 2024 14:13 | Kultúra a hudba

Voľakedy mali pomenovanie – vzácne choroby. Lenže, čo je vzácne na tom, ak má niekto závažnú diagnózu, ktorá ho sprevádza celý život. Prívlastkom „zriedkavé" dnes označujeme ochorenie, ktoré nemá viac ako jeden človek z dvoch tisíc ľudí. Polovicu pacientov so zriedkavými chorobami, ktorých môže byť na Slovensku až okolo 300-tisíc, tvoria deti. Vo štvrtok 29. februára si pripomenieme Medzinárodný deň zriedkavých chorôb. A práve v tento deň „Občianske združenie Zriedkavých chorôb" vypraví do života unikátnu ilustrovanú knihu pre deti „Štikrafa a iné zriedkatká". Na projekte je úžasná najmä myšlienka – vysvetliť jednotlivé zriedkavé diagnózy deťom i dospelým prístupnou a zrozumiteľnou formou. Janku Bleyovú však najskôr zaujímalo, ako sa predsedníčka spomínaného združenia Tatiana Kubíková – ocitla v úlohe spoluvatejky, teda autorky „Štikrafy".

Štikrafa a iné zriedkatká I.

Na Slovensku už 7 rokov úspešne funguje Občianske združenie Zriedkavé choroby. Pacientov s komplikovanými zriedkavými diagnózami formou poradenstva a podpory – združenie sprevádza nielen v čase hľadania samotnej diagnózy, ale aj terapie. Odborníci pritom odhadujú, že niektorou zo zriedkavých chorôb môže počas svojho života trpieť až 6 % populácie. Je to vysoké číslo, ale pritom, medzi ľuďmi, nízka informovanosť. Zmeniť tento nepomer je želaním autorov publikácie „Štikrafa a iné zriedkatká". Verím, že nadherne ilustrovaná kniha

a o zriedkavých diagnózach môže byť svetová

Už sedem rokov sa OZ Zriedkavé choroby venuje ľuďom, ktorí potrebujú pomoc počas diagnostickej odysey. Takisto združuje pacientky a pacientov do komunít a na svojom portáli prináša rozhovory s odborníkmi, príbehy pacientov i videoseriál o pracoviskách pre zriedkavé choroby.

KOMERČNÁ PRÍLOHA SPOLOČNOSTI MEDIAPLANET

Viac na www.info-zdravie.sk

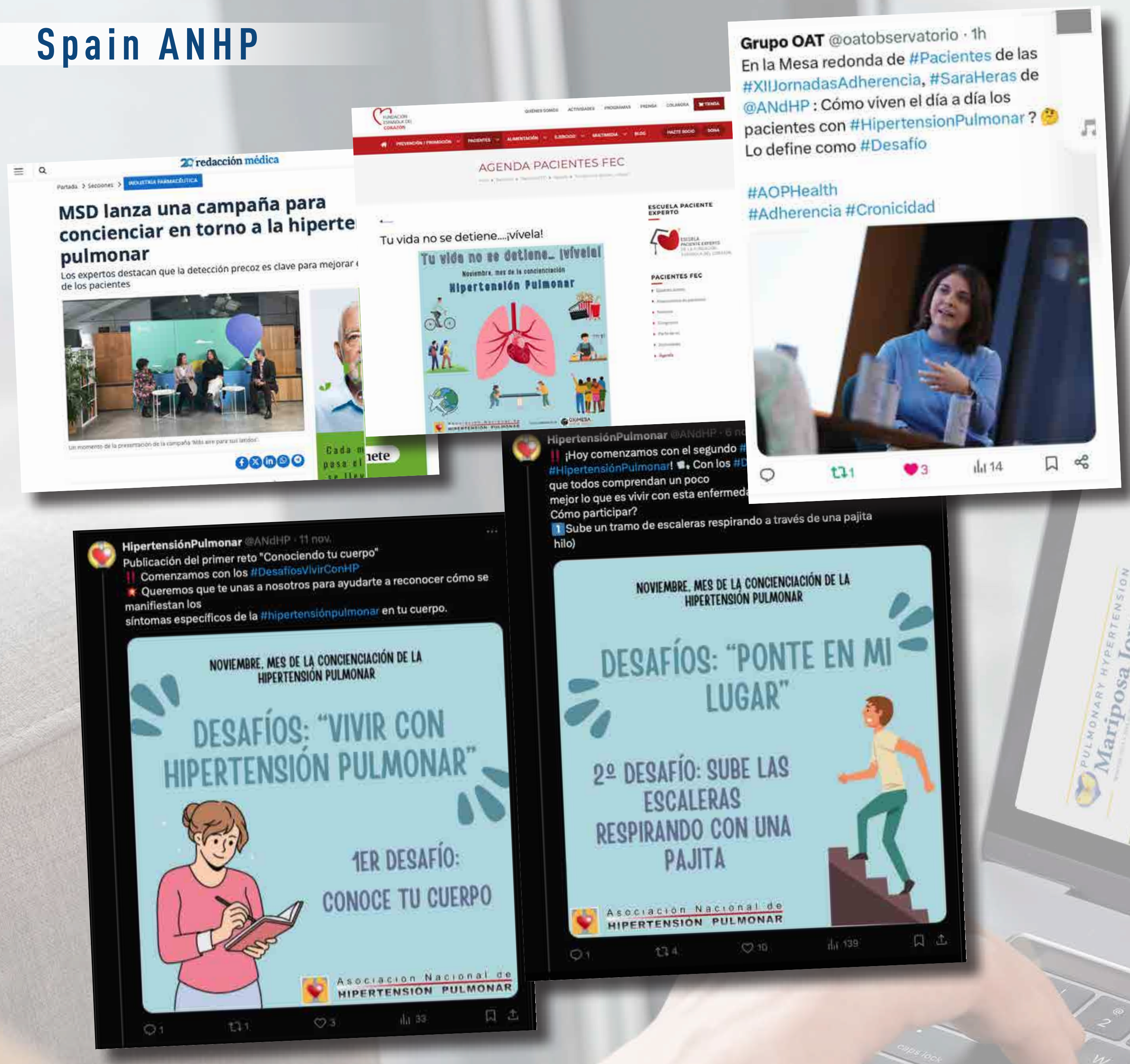
Magazín zriedkavých ochorení

03 Črevné zlyhanie a syndróm krátkeho čreva

06 Fabryho choroba: Upozornilo na ňu zväčšené srdce

08 Čo je generalizovaná pustulózna psoriáza?

Spain ANHP



Portada > Secciones > INDUSTRIA FARMACÉUTICA

MSD lanza una campaña para concienciar en torno a la hipertensión pulmonar

Los expertos destacan que la detección precoz es clave para mejorar de los pacientes

Un momento de la presentación de la campaña 'Más aire para sus latidos'

AGENDA PACIENTES FEC

Tu vida no se detiene....¡vívela!

Grupo OAT @oatobservatorio · 1h

En la Mesa redonda de #Pacientes de las #XIIJornadasAdherencia, #SaraHeras de @ANdHP : Cómo viven el día a día los pacientes con #HipertensionPulmonar ? 🤔 Lo define como #Desafío

#AOPHealth
#Adherencia #Cronicidad

1 · 3 · 14

HipertensiónPulmonar @ANdHP · 11 nov.

Publicación del primer reto "Conociendo tu cuerpo"
‼️ Comenzamos con los #DesafiosVivirConHP
Queremos que te unas a nosotros para ayudarte a reconocer cómo se manifiestan los síntomas específicos de la #hipertensiónpulmonar en tu cuerpo.

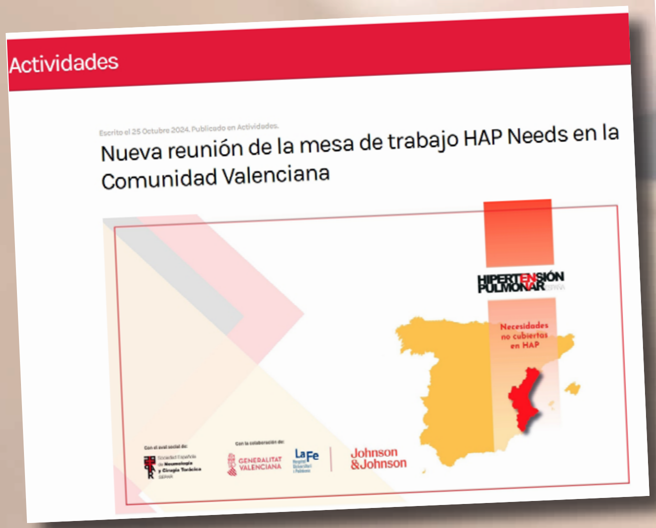
1 · 1 · 3 · 33

HipertensiónPulmonar @ANdHP · 6 nov.

‼️ ¡Hoy comenzamos con el segundo # #HipertensiónPulmonar! Con los #D que todos comprendan un poco mejor lo que es vivir con esta enfermeda Cómo participar?
1️⃣ Sube un tramo de escaleras respirando a través de una pajita hilo)

1 · 4 · 10 · 139

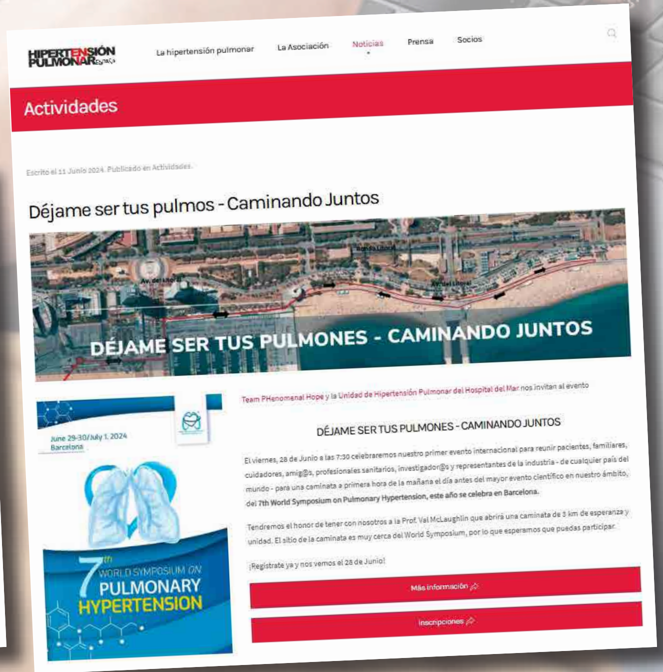
Spain HPE-ORG



Actividades

Escrito el 25 Octubre 2024. Publicado en Actividades.

Nueva reunión de la mesa de trabajo HAP Needs en la Comunidad Valenciana



La hipertensión pulmonar · La Asociación · Noticias · Prensa · Socios

Actividades

Escrito el 11 Junio 2024. Publicado en Actividades.

Déjame ser tus pulmos - Caminando Juntos

Team PHenomenal Hope y la Unidad de Hipertensión Pulmonar del Hospital del Mar nos invitan al evento

DÉJAME SER TUS PULMONES - CAMINANDO JUNTOS

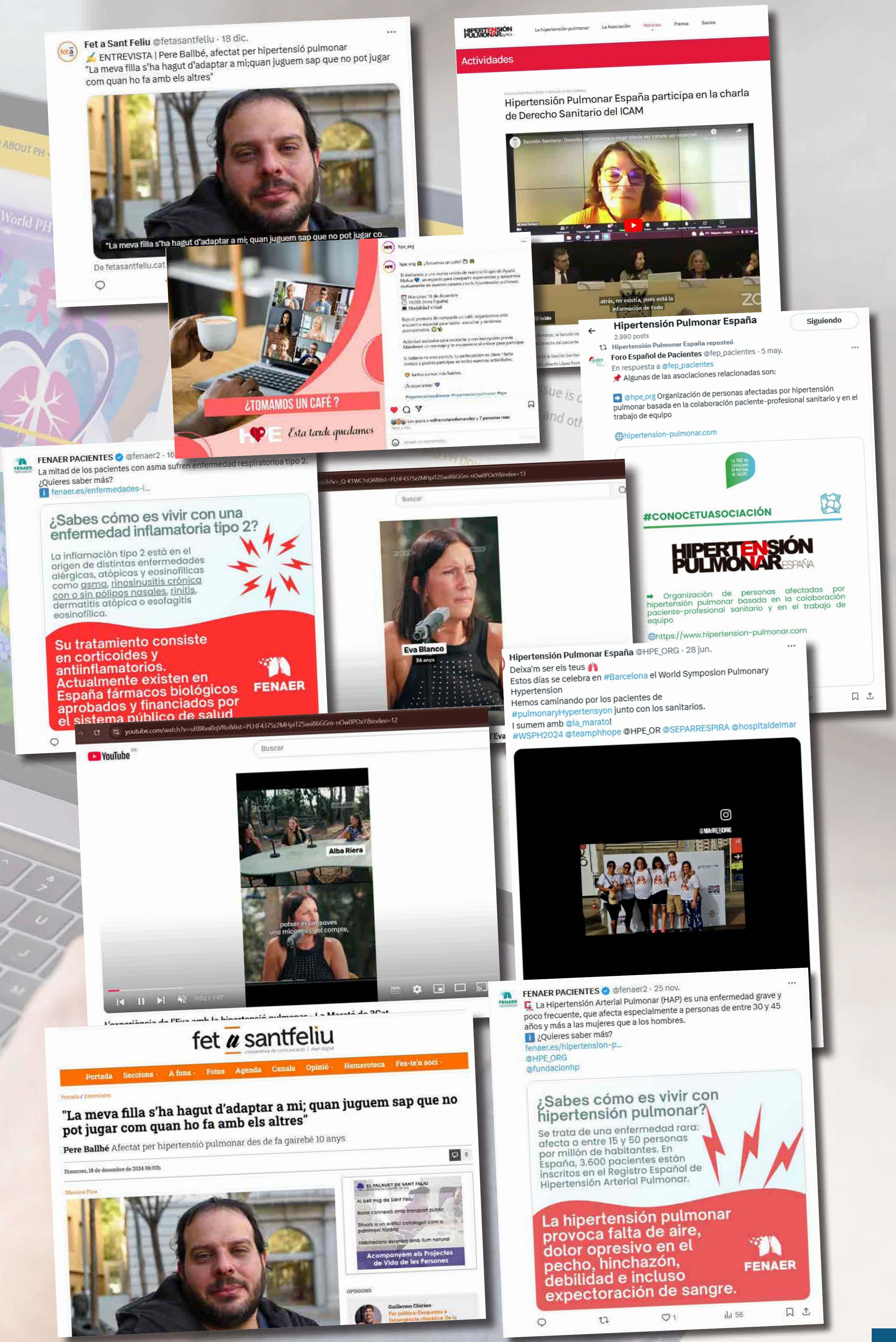
El viernes, 28 de Junio a las 7:30 celebraremos nuestro primer evento internacional para reunir pacientes, familiares, cuidadores, amig@s, profesionales sanitarios, investigador@s y representantes de la industria - de cualquier país del mundo - para una caminata a primera hora de la mañana el día antes del mayor evento científico en nuestro ámbito, del 7th World Symposium on Pulmonary Hypertension, este año se celebra en Barcelona.

Tendremos el honor de tener con nosotros a la Prof. Val McLaughlin que abrirá una caminata de 3 km de esperanza y unidad. El sitio de la caminata es muy cerca del World Symposium, por lo que esperamos que puedas participar.

¡Regístrate ya y nos vemos el 28 de Junio!

Más información

Inscripciones



Fet a Sant Feliu @fetasantfeliu · 18 dic.

✍️ ENTREVISTA | Pere Ballbé, afectat per hipertensió pulmonar
"La meva filla s'ha hagut d'adaptar a mi;quan juguem sap que no pot jugar com quan ho fa amb els altres"

"La meva filla s'ha hagut d'adaptar a mi; quan juguem sap que no pot jugar co...

De fetasantfeliu.cat

La hipertensión pulmonar · La Asociación · Noticias · Prensa · Socios

Actividades

Hipertensión Pulmonar España participa en la charla de Derecho Sanitario del ICAM

hpe_org

hpe.org 🍀 ¿Tomamos un café? 🍀

Te invitamos a una nueva sesión de nuestro Grupo de Ayuda Mutua 💙, un espacio para compartir experiencias y apoyarnos mutuamente en nuestro camino con la hipertensión pulmonar.

📅 Miércoles 18 de diciembre
🕒 18:00h (hora España)
💻 Modalidad virtual

Bajo el pretexto de compartir un café, organizamos este encuentro especial para hablar, escuchar y sentirnos acompañados.

Actividad exclusiva para socios/as y con inscripción previa. Mándanos un mensaje y te enviaremos el enlace para participar.

Si todavía no eres socio/a, tu participación es clave. Hazte socio/a y podrás participar en todas nuestras actividades.

Juntos somos más fuertes.

¡Te esperamos! 💜

Les gusta a estherootanofernandez y 7 personas más

Hipertensión Pulmonar España
2.990 posts
Siguiendo

Hipertensión Pulmonar España reposteó

Foro Español de Pacientes @fep_pacientes · 5 may.
En respuesta a @fep_pacientes
📌 Algunas de las asociaciones relacionadas son:

➡️ @hpe_org Organización de personas afectadas por hipertensión pulmonar basada en la colaboración paciente-profesional sanitario y en el trabajo de equipo

🌐hipertension-pulmonar.com

➡️ Organización de personas afectadas por hipertensión pulmonar basada en la colaboración paciente-profesional sanitario y en el trabajo de equipo

🌐https://www.hipertension-pulmonar.com

FENAER PACIENTES @fenaer2 · 16

La mitad de los pacientes con asma sufren enfermedad respiratorioa tipo 2.
¿Quieres saber más?
ℹ️ fenaer.es/enfermedades-i...

¿Sabes cómo es vivir con una enfermedad inflamatoria tipo 2?

La inflamación tipo 2 está en el origen de distintas enfermedades alérgicas, atópicas y eosinofílicas como asma, rinosinusitis crónica con o sin pólipos nasales, rinitis, dermatitis atópica o esofagitis eosinofílica.

Su tratamiento consiste en corticoides y antiinflamatorios. Actualmente existen en España fármacos biológicos aprobados y financiados por el sistema público de salud

FENAER

youtube.com/watch?v=uRBKva0qVRo&list=PLHF437Sz2MHpiTZSasi86GGm-nOw0POxY&index=12

YouTube

Buscar

L'experiència de l'Eva amb la hipertensió pulmonar - La Marató de 3Cat

Hipertensión Pulmonar España @HPE_ORG · 28 jun.

Deixa'm ser els teus 🫁
Estos días se celebra en #Barcelona el World Symposion Pulmonary Hypertension
Hemos caminando por los pacientes de #pulmonaryHypertensyon junto con los sanitarios.
I sumem amb @la_marato!
#WSPH2024 @teamphhope @HPE_OR @SEPARRESPIRA @hospitaldelmar

fet a santfeliu
cooperativa de comunicació | diari digital

Portada · Seccions · A fons · Fotos · Agenda · Canals · Opinió · Hemeroteca · Fes-te'n soci

Portada / Entrevistes

"La meva filla s'ha hagut d'adaptar a mi; quan juguem sap que no pot jugar com quan ho fa amb els altres"

Pere Ballbé Afectat per hipertensió pulmonar des de fa gairebé 10 anys

Dimecres, 18 de desembre de 2024 06:00h

OPINIONS
Guillermo Chirino

FENAER PACIENTES @fenaer2 · 25 nov.

La Hipertensión Arterial Pulmonar (HAP) es una enfermedad grave y poco frecuente, que afecta especialmente a personas de entre 30 y 45 años y más a las mujeres que a los hombres.
ℹ️ ¿Quieres saber más?
fenaer.es/hipertension-p...
@HPE_ORG
@fundacionhp

¿Sabes cómo es vivir con hipertensión pulmonar?

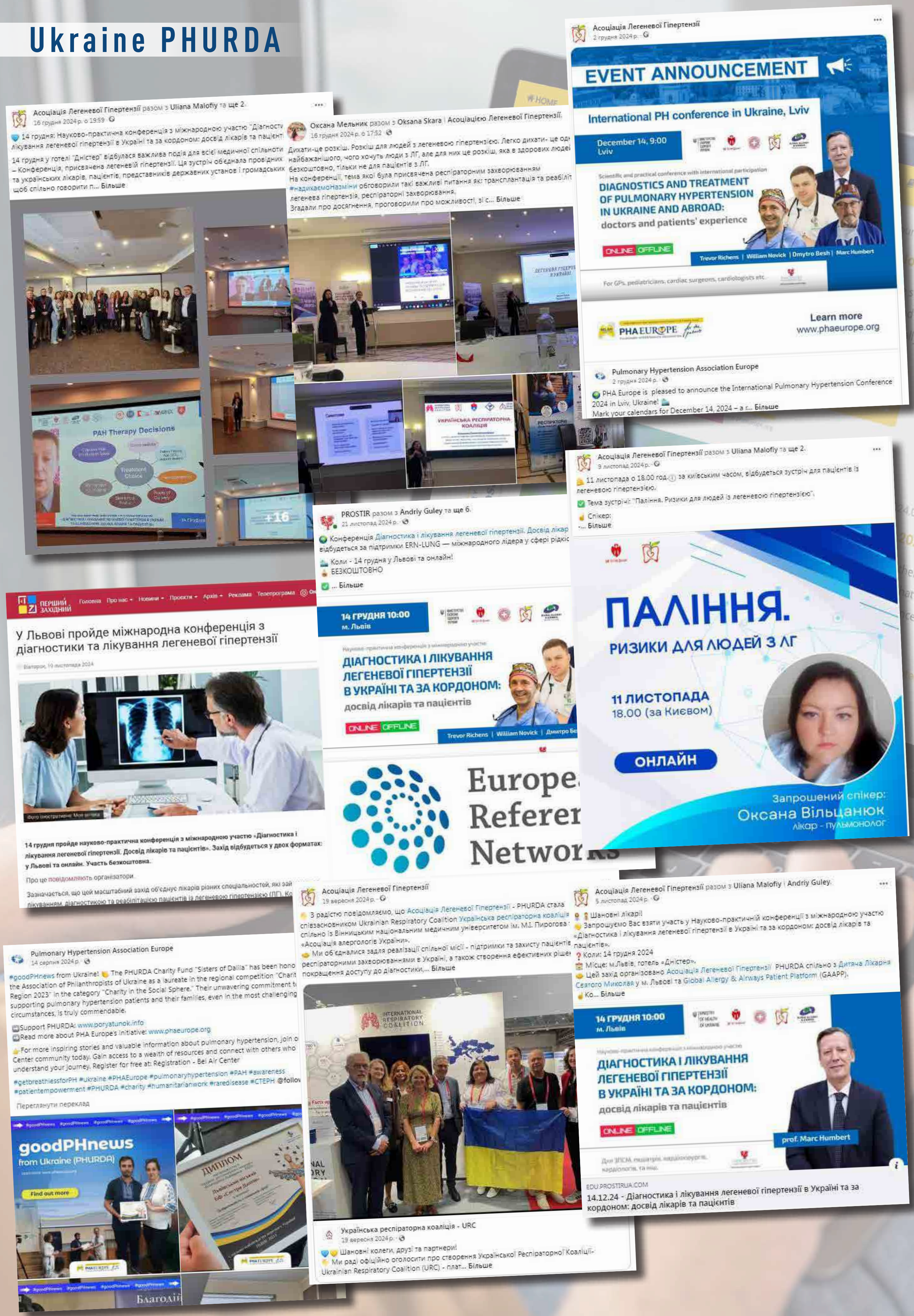
Se trata de una enfermedad rara: afecta a entre 15 y 50 personas por millón de habitantes. En España, 3.600 pacientes están inscritos en el Registro Español de Hipertensión Arterial Pulmonar.

La hipertensión pulmonar provoca falta de aire, dolor opresivo en el pecho, hinchazón, debilidad e incluso expectoración de sangre.

FENAER

1 · 56

Ukraine PHURDA



Асоціація Легеневої Гіпертензії разом з **Uliana Malofiy** та ще 2.
16 грудня 2024 р. о 19:59

14 грудня: Науково-практична конференція з міжнародною участю "Діагности
лікування легеневої гіпертензії в Україні та за кордоном: досвід лікарів та пацієнт

14 грудня у готелі "Дністер" відбулася важлива подія для всієї медичної спільноти
– Конференція, присвячена легеневій гіпертензії. Ця зустріч об'єднала провідних
та українських лікарів, пацієнтів, представників державних установ і громадських
щоб спільно говорити п... **Більше**

Оксана Мельник разом з **Oksana Skara** і **Асоціацією Легеневої Гіпертензії.**
16 грудня 2024 р. о 17:52

Дихати-це розкіш. Розкіш для людей з легеневою гіпертензією. Легко дихати- це од
найбажанішого, чого хочуть люди з ЛГ, але для них це розкіш, яка в здорових людей
безкоштовно, тільки не для пацієнтів з ЛГ.
На конференції, тема якої була присвячена респіраторним захворюванням
#надихаємоНазміни обговорили такі важливі питання як: трансплантація та реабіліт
легенева гіпертензія, респіраторні захворювання.
Згадали про досягнення, проговорили про можливості, зі с... **Більше**

Асоціація Легеневої Гіпертензії
2 грудня 2024 р.

EVENT ANNOUNCEMENT
International PH conference in Ukraine, Lviv
December 14, 9:00
Lviv
Scientific and practical conference with international participation
DIAGNOSTICS AND TREATMENT OF PULMONARY HYPERTENSION IN UKRAINE AND ABROAD:
doctors and patients' experience
ONLINE OFFLINE
Trevor Richens | William Novick | Dmytro Besh | Marc Humbert
For GPs, pediatricians, cardiac surgeons, cardiologists etc.
PHA EUROPE
Learn more
www.phaeurope.org

Pulmonary Hypertension Association Europe
2 грудня 2024 р.

PHA Europe is pleased to announce the International Pulmonary Hypertension Conference 2024 in Lviv, Ukraine!
Mark your calendars for December 14, 2024 – a r... **Більше**

Асоціація Легеневої Гіпертензії разом з **Uliana Malofiy** та ще 2.
9 листопад 2024 р.

11 листопада о 18.00 год. за київським часом, відбудеться зустріч для пацієнтів із легеневою гіпертензією.
Тема зустрічі: "Паління. Ризики для людей із легеневою гіпертензією".
Спікер:
-... **Більше**

ПАЛІННЯ.
РИЗИКИ ДЛЯ ЛЮДЕЙ З ЛГ
11 ЛИСТОПАДА
18.00 (за Києвом)
ОНЛАЙН
Запрошений спікер:
Оксана Вільцанюк
Лікар - пульмонолог

PROSTIR разом з **Andriy Guley** та ще 6.
21 листопад 2024 р.

Конференція Діагностика і лікування легеневої гіпертензії. Досвід лікар
відбудеться за підтримки ERN-LUNG — міжнародного лідера у сфері рідкіс
Коли - 14 грудня у Львові та онлайн!
БЕЗКОШТОВНО
... **Більше**

14 ГРУДНЯ 10:00
м. Львів
ДІАГНОСТИКА І ЛІКУВАННЯ ЛЕГЕНЕВОЇ ГІПЕРТЕНЗІЇ В УКРАЇНІ ТА ЗА КОРДОНОМ:
досвід лікарів та пацієнтів
ONLINE OFFLINE
Trevor Richens | William Novick | Дмитро Бе

Europe
Referen
Networks

ПЕРШИЙ ЗАХІДНИЙ
Головна Про нас Новини Проєкти Архів Реклама Телепрограма

У Львові пройде міжнародна конференція з діагностики та лікування легеневої гіпертензії

Вівторок, 19 листопада 2024

Фото ілюстративне: Моя аптека

14 грудня пройде науково-практична конференція з міжнародною участю «Діагностика і лікування легеневої гіпертензії. Досвід лікарів та пацієнтів». Захід відбудеться у двох форматах: у Львові та онлайн. Участь безкоштовна.

Про це повідомляють організатори

Зазначається, що цей масштабний захід об'єднує лікарів різних спеціальностей, які зай
лікуванням, діагностикою та реабілітацією пацієнтів із легеневою гіпертензією (ЛГ). Ко

Pulmonary Hypertension Association Europe
14 серпня 2024 р.

#goodPHnews from Ukraine! The PHURDA Charity Fund "Sisters of Dalila" has been hono
the Association of Philanthropists of Ukraine as a laureate in the regional competition "Charit
Region 2023" in the category "Charity in the Social Sphere." Their unwavering commitment t
supporting pulmonary hypertension patients and their families, even in the most challenging
circumstances, is truly commendable.

Support PHURDA: www.poryatunok.info
Read more about PHA Europe's initiative: www.phaeurope.org

For more inspiring stories and valuable information about pulmonary hypertension, join o
Center community today. Gain access to a wealth of resources and connect with others who
understand your journey. Register for free at: Registration - Bel Air Center
#getbreathlessforPH #ukraine #PHAEurope #pulmonaryhypertension #PAH #awareness
#raredisease #CTEPH @follow #patientempowerment #PHURDA #charity #humanitarianwork

Переглянути переклад

goodPHnews
from Ukraine (PHURDA)
Find out more
ДИПЛОМ

Асоціація Легеневої Гіпертензії
19 вересня 2024 р.

З радістю повідомляємо, що Асоціація Легеневої Гіпертензії - PHURDA стала
співзасновником Ukrainian Respiratory Coalition Українська респіраторна коаліція
спільно із Вінницьким національним медичним університетом ім. М.І. Пирогова
«Асоціація алергологів України».
Ми об'єдналися задля реалізації спільної місії - підтримки та захисту пацієнтів
респіраторними захворюваннями в Україні, а також створення ефективних рішен
покращення доступу до діагностики,... **Більше**

INTERNATIONAL RESPIRATORY COALITION

Українська респіраторна коаліція - URC
19 вересня 2024 р.

Шановні колеги, друзі та партнери!
Ми раді офіційно оголосити про створення Української Респіраторної Коаліції-
Ukrainian Respiratory Coalition (URC) - плат... **Більше**

Асоціація Легеневої Гіпертензії разом з **Uliana Malofiy** і **Andriy Guley**.
5 листопад 2024 р.

Шановні лікарі!
Запрошуємо Вас взяти участь у Науково-практичній конференції з міжнародною участю «Діагностика і лікування легеневої гіпертензії в Україні та за кордоном: досвід лікарів та пацієнтів».
Коли: 14 грудня 2024
Місце: м.Львів, готель «Дністер».
Цей захід організовано Асоціація Легеневої Гіпертензії PHURDA спільно з Дитяча Лікарня Святого Миколая у м. Львові та Global Allergy & Airways Patient Platform (GAAPP).
Ко... **Більше**

14 ГРУДНЯ 10:00
м. Львів
ДІАГНОСТИКА І ЛІКУВАННЯ ЛЕГЕНЕВОЇ ГІПЕРТЕНЗІЇ В УКРАЇНІ ТА ЗА КОРДОНОМ:
досвід лікарів та пацієнтів
ONLINE OFFLINE
prof. Marc Humbert

EDU.PROSTIR.UA.COM
14.12.24 - Діагностика і лікування легеневої гіпертензії в Україні та за кордоном: досвід лікарів та пацієнтів

• Sponsors •

early diagnosis • best treatment • better quality of life • finding a cure
PHA EUROPE for the patients
European pulmonary hypertension association

aerovate therapeutics

AOP HEALTH OrphaCare

electronRx

ferrer for good

gossamerbio

Johnson&Johnson

Liquidia™

MSD

BEL AIR CENTER

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

PHA EUROPE *for the patients*

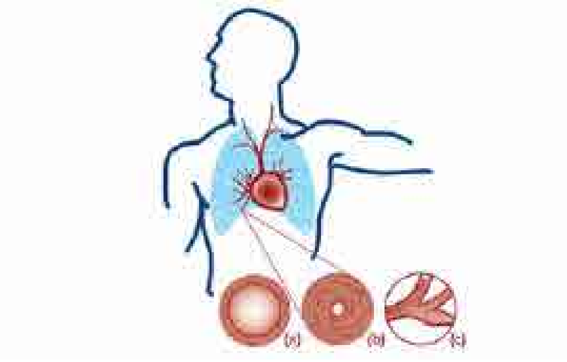
PULMONARY HYPERTENSION ASSOCIATION

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.

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