

PULMONARY HYPERTENSION

Mariposa Journal

WINTER 2023 • PHA EUROPE'S OFFICIAL JOURNAL • N. 31



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

PHA EUROPE
PULMONARY HYPERTENSION ASSOCIATION

*for the
patients*

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Editor's memo

WINTER EDITION • 2023

REFLECTING ON 2023 AND WELCOMING NEW MEMBERS

Dear Friends, Colleagues and Supporters,

As we turn the page on another remarkable year, it's with immense pride and gratitude that I reflect on the journey that was 2023. This year has been a testament to the unwavering dedication, resilience, and collaborative spirit that define our organization and community.

Advocacy and Engagement

Advocacy remains at the core of our mission, and 2023 saw us lead the way in several pivotal initiatives. At the forefront was our leadership in World PH Day, a project that we proudly championed. Our efforts in this global campaign have helped raise awareness about pulmonary hypertension on an unprecedented scale, bringing together communities and organizations from around the world.

In addition, our proactive engagement in national advocacy activities, together with the relentless effort of our member associations, continued to bear fruit. Our members all received our Call to Action document including an executive summary in their native language. This document serves as a compass, guiding our advocacy efforts and emphasizing the importance of patients in policy making, drug regulatory processes, and clinical guideline development.

The month of November marked another significant milestone as we collaborated with PHA on the November Awareness Month, further amplifying our impact and reach.

Workshops and Conferences

Our commitment to education and awareness took center stage at major congresses throughout the year. The European Respiratory Society (ERS), the European Society of Cardiology (ESC), and the European Society for Organ Transplantation (ESOT) provided vital platforms for us to engage with the global healthcare community. At these events, we not only showcased our expertise in pulmonary hypertension but also forged meaningful collaborations and shared our vision for the future of PH care.

Beyond these major conferences, we actively participated in various other workshops, symposia, and events, expanding our network and deepening our knowledge base.

Information and Education

In our quest to provide reliable information, our Mariposa journal continued to be a beacon of knowledge, with special editions dedicated to World PH Day projects and comprehensive coverage of our activities. Meanwhile, our online presence, including our website and social media platforms, allowed us to reach a broader audience and provide updates on conferences, learning opportunities, and new publications.

New Members and the Bel Air Center

In 2023, we celebrated five new members, a testament to our growing influence that now extends beyond Europe. We welcomed Germany

and in addition to our long time associated member Israel, our global reach now includes new associated members from Argentina, China, Japan and the US, underscoring the International scope of our mission.

As we look forward to 2024, we are excited to introduce the Bel Air Center, a dynamic platform for learning, collaboration, innovation, and social interaction that will further elevate our efforts to improve the lives of PH patients worldwide.

In closing, I would like to extend my heartfelt thanks to our members, partners, and supporters who have made the progress of 2023 possible. Together, we will continue to advocate, educate, and innovate, ensuring a brighter and healthier future for pulmonary hypertension patients across the globe.

With deep appreciation and optimism,

Eva Otter

President PHA Europe

CONTENTS

In 2023 PHA Europe was present at...	p. 5	SLOVAKIA	p. 83
Annual PH European Conference 2023	p. 16	SLOVENIA	p. 86
Reports On Congresses & Conferences	p. 20	SPAIN ANHP	p. 89
PHA Europe – Social Media Activities	p. 23	SPAIN FCHP	p. 93
Member Support Program (MSP)	p. 26	SPAIN HPE	p. 99
ARGENTINA	p. 27	UKRAINE PHA	p. 103
AUSTRIA	p. 30	UKRAINE PHURDA	p. 105
BELARUS	p. 33	SWEDEN	p. 109
BELGIUM	p. 34	Upcoming PH events	p. 110
BOSNIA AND HERZEGOVINA	p. 38	Media clippings	p. 112
BULGARIA BSPPH	p. 41	Austria	p. 112
BULGARIA PHA	p. 45	Belgium	p. 114
CHINA	p. 48	Bulgaria BSPPH	p. 116
CROATIA	p. 51	Croatia	p. 116
CZECH REPUBLIC	p. 54	Czech Republic	p. 117
HUNGARY	p. 57	Hungary	p. 118
ISRAEL	p. 62	North Macedonia	p. 118
ITALY AMIP	p. 63	Slovenia	p. 119
LATVIA	p. 65	Spain HPE	p. 119
THE NETHERLANDS	p. 70	Ukraine PHA	p. 121
NORTH MACEDONIA	p. 72	Sponsors	p. 123
NORWAY	p. 73	Aims of PHA	p. 124
PORTUGAL	p. 74	Members of PHA Europe and contact details	p. 125
SERBIA	p. 79	Associated members of PHA Europe and contact details	p. 127

BEL AIR CENTER



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In 2023 PHA Europe was present at...

Virtual (online) • January 12

PREPARATORY CALL WITH AOP ABOUT SURVEY

Staff members attended this call with AOP to refine the survey questions AOP will use when talking to association leaders and patients.



Virtual (online) • January 17

PREPARATORY CALL WITH EXPERT REGARDING EU APPLICATION

Staff members attended this call with an expert helping us with an EU application for a grant covering some 2023 projects.

Virtual (online) • January 18

WPHD PREPARATION MEETING

Staff members ran a meeting with international PH community to discuss the upcoming WPHD activities. Plans for templates, WPHD landing page, WPHD webinar, etc were presented and discussed.



Virtual (online) • January 30

KICKOFF MEETING FOR AOP SURVEY

Hall and Monika attended this kickoff meeting with AOP for their patient and carer survey.

Virtual (online) • February 8

EU PARLIAMENT RARE DISEASE EVENT

Hall attended this EU webinar about rare diseases.



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Vienna, Austria • February 14-15

PHA EUROPE CORPORATE MEETING

The board and staff ran a yearly meeting followed by a corporate meeting with industry partners highlighting plans for 2023.

Virtual (online) • March 1

PREPARATORY CALL WITH AOP ABOUT SURVEY

Hall attended this call with AOP to refine the survey questions AOP will use when talking to association leaders and patients.



Virtual (online) • March 2
TALK WITH FERRER

Staff members attended this call with Ferrer to plan collaboration activities for 2023.



Virtual (online) • April 13
WPHD PREPARATION MEETING

Hall and Maleen ran a meeting with international PH community to discuss the upcoming WPHD activities.



Virtual (online) • March 8
JANSSEN PHEN - GLOBAL STEERING COMMITTEE
Hall, Eva and Tadeja had a Pulmonary Hypertension Empowerment Network (PHEN) global steering committee meeting with Janssen.



Virtual (online) • April 14
EUPDHA - CALL FOR APPLICATIONS
Hall had a meeting with the group that will be judges for the MSD's EUPDHA.

Virtual (online) • March 10
WPHD PREPARATION MEETING

Hall and Maleen ran a meeting with international PH community to discuss the upcoming WPHD activities.



Virtual (online) • April 19
ELHG MEETING

Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.



Virtual (online) • March 21
MIMI PROPOSAL MEETING
Hall and Monika participated in a meeting with the MIMI team to prepare the application for grant from EU.



Riga, Latvia • April 21-22
4TH BALTIC CONFERENCE

Hall attended the 4th Baltic conference in Riga, Latvia learning about PH health care in the Baltic region and meeting with the Latvian PH association.

Virtual (online) • March 27
MIMI PROPOSAL MEETING

Hall and Monika participated in a meeting with the MIMI team to prepare the application for grant from EU.



Brussels, Belgium • April 28-29
20TH ANNIVERSARY EVENT - EPF

Hall attended European Patient Forum's 20th anniversary event in Brussels, Belgium.



Virtual (online) • April 3
MIMI PROPOSAL MEETING
Hall and Monika participated in a meeting with the MIMI team to prepare the application for grant from EU.



Virtual (online) • May 12
EHDS INTEREST GROUP
Hall attended a meeting with an interest group discussing EHDS opt-in/opt-out issues.

Virtual (online) • April 6
MEETING WITH PH SPECIALISTS

Hall had a meeting with Prof. Marion Delcroix and Prof. Marc Humber to discuss future collaboration between PHA Europe and PH scientific community.



Virtual (online) • May 16
FERRER PH-ILD VOP

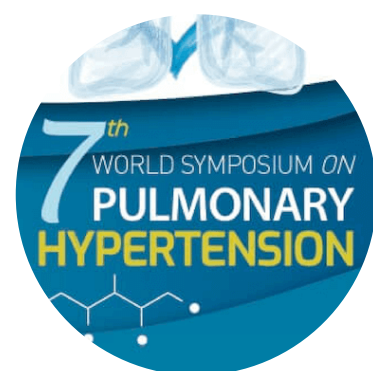
Hall attended a meeting with Ferrer discussing the draft Voice of the Patient (VOP) patient related to PH-ILD patients and cares.





Virtual (online) • May 16
FERRER IMPACT CONFERENCE PREPARATION MEETING
 Hall attended a meeting with Ferrer preparing for the upcoming Ferrer Impact conference.

Virtual (online) • May 17
ELHG MEETING
 Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.



Virtual (online) • May 17
TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM
 Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.



Stockholm, Sweden • May 25-26
EURORDIS MEMBERSHIP MEETING
 Hall attended a EURORDIS membership meeting in Stockholm, Sweden focusing on mental health for people suffering from a rare chronic disease.



Virtual (online) • May 26
FERRER IMPACT CONFERENCE PREPARATION MEETING
 Hall attended a meeting with Ferrer preparing for the upcoming Ferrer Impact conference.



Virtual (online) • May 30
FERRER IMPACT CONFERENCE PREPARATION MEETING
 Hall attended a meeting with Ferrer preparing for the upcoming Ferrer Impact conference.

Virtual (online) • May 31
EPF MEETING DISCUSSING NEW PHARMA EU LEGISLATION
 Hall attended a meeting with the European Patient Forum discussing the revised EU pharmaceutical legislation.



Virtual (online) • June 14
ELF MEETING
 Hall had a meeting with the European Lung Foundation discussing PHA Europe's participation in the World Village display at the upcoming ERS Congress.

Virtual (online) • June 14
MEETING WITH WORDLY
 Hall had a meeting with Wordly to discuss options for AI supported simultaneous translation at meetings and AI subtitling of presentations.



Virtual (online) • June 21
JANSSEN PHEN - GLOBAL STEERING COMMITTEE
 Hall, Eva and Tadeja took part in a Pulmonary Hypertension Empowerment Network (PHEN) alumni event meeting with Janssen.

Lisbon, Portugal • June 26-27
IRC SUMMIT
 Hall attended the International Respiratory Coalition summit in Lisbon, Portugal where world respiratory diseases were discussed.



Barcelona, Spain • June 30, July 1
FERRER'S IMPACT CONFERENCE
 Hall attended Ferrer's Impact conference, gave a presentation and took part in a round table discussion focusing on the patient voice.

Virtual (online) • May 12
EHDS INTEREST GROUP
 Hall attended a meeting with an interest group discussing EHDS opt-in/opt-out issues.





Virtual (online) • May 16
FERRER PH-ILD VOP

Hall attended a meeting with Ferrer discussing the draft Voice of the Patient (VOP) patient related to PH-ILD patients and cares.

Virtual (online) • July 4
ELF PAC MEETING

Hall had a meeting with the European Lung Foundation Patient's Advisory Committee.



Virtual (online) • July 5
MEETING WITH EPF

Hall had a meeting with the European Patient Forum about the draft revision of the pharmaceutical legislation.

Virtual (online) • July 6
ELHG MEETING

Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.



Virtual (online) • July 10
MEETING WITH THE SAUDI ARABIA PH ORGANIZATION

Gerry, Hall and Monika had a meeting with representatives for the Saudi Arabia PH organization to discuss participation in PHA Europe's APHEC and other collaborations.

Virtual (online) • July 12
MEETING WITH EPF

Hall had a meeting with the European Patient Forum to discuss issues related to paediatric medication.



Virtual (online) • July 18
EHDS INTEREST GROUP

Hall attended a meeting with an interest group discussing EHDS opt-in/opt-out issues.

Virtual (online) • July 20
MEETING WITH ELF PH PAG

Hall, Monika and Eva had a meeting with the newly established PH Patient Advisory Group (PAG) of ELF.



Virtual (online) • July 27
MEETING WITH PVRI

Hall and Monika had a meeting with PVRI discussing the GPS survey. PHA Europe offered to help translate the elaborate survey to numerous languages and ask our members to participate.



Virtual (online) • August 22
MEETING WITH PVRI

Hall and Monika had a meeting with PVRI discussing the GPS survey. PHA Europe offered to help translate the elaborate survey to numerous languages and ask our members to participate.

Virtual (online) • August 23
TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM

Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.



Amsterdam, Holland • August 25-28
ECS CONGRESS

Hall attended the yearly congress of the European Cardiology Society in Amsterdam, Holland.

Virtual (online) • August 30
ELF NETWORKING DAY PREPARATION MEETING

Hall attended a meeting with ELF preparing for the patient networking day during the upcoming ERS conference.



Virtual (online) • September 4
ELF NETWORKING DAY PREPARATION MEETING

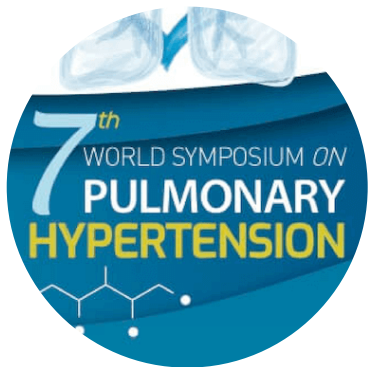
Hall attended the second meeting with ELF preparing for the patient networking day during the upcoming ERS conference.

Milan, Italy • September 8-17
ERS CONGRESS

Several PHA Europe board and staff members participated in the annual congress to the European Respiratory Society. PHA Europe had a stand in the World Village.



Athens, Greece • September 17-19
ESOT CONGRESS
Tadeja and Natalia participated in the annual ESOT Congress in Athens, Greece.



Virtual (online) • October 3
TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM
Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.

Virtual (online) • October 5
ELHG MEETING
Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.



Vienna, Austria • October 5
MEETING WITH PHA
Gerry, Hall, Eva and Monika had a face-to-face meeting with Matt Granato discussing possible areas for collaboration between PHA Europe and PHA.

Vienna, Austria • October 18
ELF ANNUAL STAKEHOLDER MEETING
Hall and Monika participated in ELF's online annual stakeholder meeting.



Virtual (online) • October 23
ELF ANNUAL STAKEHOLDER MEETING
Hall and Monika participated in ELF's online annual stakeholder meeting.

Virtual (online) • October 25
MEETING WITH PVRI
Hall and Monika had a meeting with PVRI discussing the GPS survey. PHA Europe provided, among others, translated surveys.



Virtual (online) • October 26
MEETING WITH SUBLY
Hall had a meeting with Subly discussing possibility to use AI technology to subtitle presentations that will be available in the Bel Air Center.



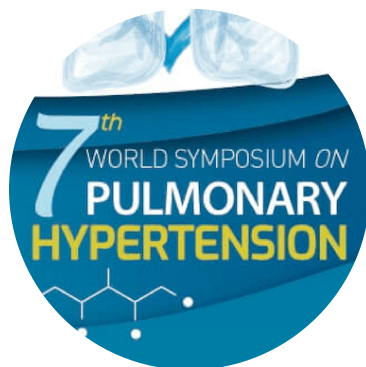
Virtual (online) • October 27
MEETING WITH ELF PH PAG
Hall, Monika and Eva had a meeting with the newly established PH Patient Advisory Group (PAG) of ELF.

Virtual (online) • October 27
MEETING WITH PHAWARE
Hall had a meeting with Steve in PHAWARE to discuss the possibility to include their podcasts into Bel Air Center.



Wordly
AI-Powered Translation

Virtual (online) • October 31
MEETING WITH WORDLY
Hall had a meeting with Wordly to discuss options for AI supported simultaneous translation at meetings and AI subtitling of presentations.



Virtual (online) • November 6
TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM
Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024.



Barcelona, Spain • November 8-12
PHA EUROPE - ANNUAL PH EUROPEAN CONFERENCE (APHEC)
Staff and members ran the annual PH conference in Barcelona together with their members. See a separate report.

Virtual (online) • November 13
EHDS INTEREST GROUP
Hall attended a meeting with an interest group discussing EHDS opt-in/opt-out issues.



Virtual (online) • November 22

ERN-LUNG EPAG

Hall attended a meeting with the ERN-LUNG ePAG group and was accepted as a member. ePAG members will ensure that the patient voice is heard throughout the ERN development process.



Neuromuscular Diseases
(ERN EURO-NMD)

BREATHE
IN
2030
VISION



Virtual (online) • November 30

ELHG MEETING

Hall and Monika participated in a meeting with the European Lung Health Group in which PHA Europe is one of the nine members.

Madrid, Spain • December 1

FCHP ANNIVERSARY EVENT

Hall attended FCHP's anniversary event and gave a speech thanking congratulating them on their day and thanking them for the work they do as a member of PHA Europe.



Madrid, Spain • December 5

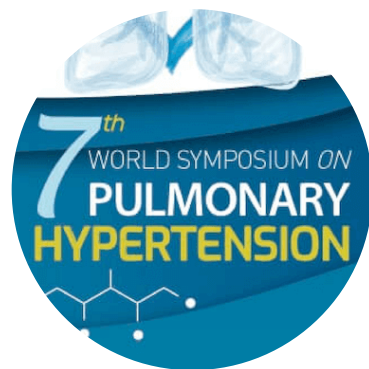
ELF PH PAG MEETING

Hall, Monika and Eva had a meeting with the the ELF PH Patient Advisory Group (PAG). Plans for 2024 were discussed.

Virtual (online) • December 7, 11 and 14

TASK FORCE 1 MEETING - WORLD PH SYMPOSIUM

Hall attended a meeting in the task force 1 group preparing for the proceedings for the World PH Symposium in 2024



Virtual (online) • December 18

FERRER IMPACT CONFERENCE PREPARATION MEETING

Hall had a first preliminary meeting with Ferrer preparing for the 2024 Ferrer Impact conference.



Virtual (online) • December 29

PREPARATORY CALL WITH EXPERT REGARDING EU APPLICATION

Hall and Monika attended this call with an expert helping us with an EU application for a grant covering some 2024 projects.

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

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

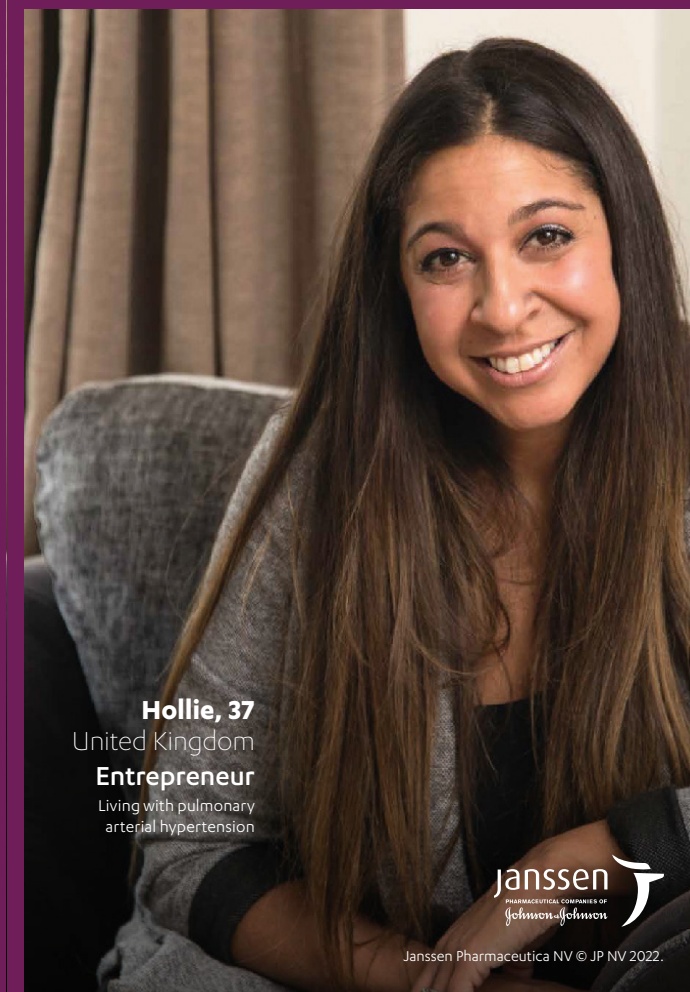
Whether you are looking for tools to support productive conversations with your healthcare team like our **Breathe In, Speak Out Conversation Kit**, interested in understanding the standards of care you should expect to receive through our **PAH Patient Charter**, or you are simply searching for tips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

Find out more on

PHuman[™]



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We are MSD

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



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ANNUAL PH EUROPEAN CONFERENCE 2023



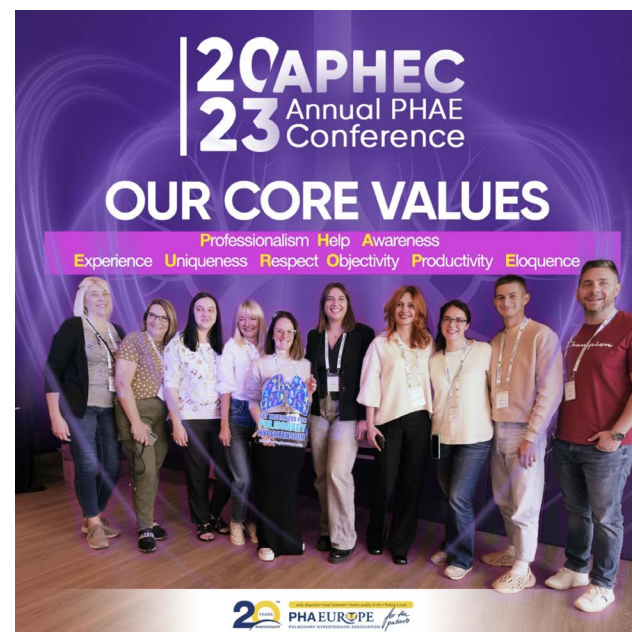
In November 2023, the PH community once again convened in the beautiful city of Barcelona for the Annual PH European Conference (APHEC). This event brought together not only the PHA Europe staff and board, but also around 90 PH association leaders and leading PH experts from 35 countries. It was a heartwarming family reunion set against the backdrop of the stunning Barcelona surroundings.

Before the official conference proceedings, we held a meeting with the association's fellows. These dedicated individuals act as intermediaries between PHA Europe and our member associations, providing invaluable translation and facilitating smoother communication. Additionally, they assist the associations with various tasks, such as organizing events for World PH Day. The fellow meeting was a resounding success, leading us to consider making it a regular feature during future APHEC gatherings.

During the first official day of the conference, we conducted our General Assembly Meeting (GAM). This important session featured presentations of the financial figures from the previous year and the upcoming budget. Our staff members presented an activity report, and board elections took place. We are delighted to welcome two new board members: Nina Kobler as Vice Secretary and Katica Mavračić as our newly elected auditor, succeeding Danijela Pesic and Monika Tschida, respectively. Furthermore, during the GAM, PHA Europe unanimously approved the inclusion of four new associated members: Argentina, China, Germany, and Japan. With their addition, our PHA Europe family has now grown to 37 member associations.

The subsequent two days were dedicated to our industry partners and PH specialists. The industry partners shared insights into their programs and clinical trials. This was of particular interest to PH leaders, given the exciting prospect of several new and potentially effective PH medications entering the market in the near future.

Our conference boasted an impressive lineup of renowned PH specialists, providing attendees with valuable insights and knowledge.



Professor Jean-Luc Vachieri's insightful session shed light on the dynamic evolution of PH treatments (2004-2022), focusing on improving quality of life, managing symptoms, and notably enhancing survival rates.

Delving into the clinical trial landscape, Prof. Vachieri intricately detailed the process, emphasizing ethical considerations, distinct trial types, and complex endpoints.

Prof. Jimmy Ford illuminated the patient perspective in PH. Decades of progress in diagnosing and treating PH have extended lifespans, improved health parameters, yet there's more to do!

Prof. Ford echoed Sir William Osler's timeless words, 'The good physician treats the disease; the great physician treats the patient who has the disease', emphasizing the essence of patient-centered care and the crucial integration of doctors into the patient's perspective, further underlining that supportive care should always be multidisciplinary!

Dr. Joanna Pepke-Zaba presented the groundbreaking idea of the Pulmonary Hypertension Global Patient Survey. Collaborating with PVRI, this survey, based on the 2012 model from PHA Europe, is reshaping PH research and care globally. During her presentation, Dr. Pepke-Zaba explained the elaborate construction process, featuring a structured design in three parallel streams for patients, carers, and young patients' caretakers.

With 2400+ responses from 74 countries, and being available in 17 languages, this survey empowers the PH community. The numbers are expected to improve even more in the months to come.

Prof. Torbicki highlighted disparities in PAH and CTEPH care between Eastern and Western Europe at the 2023 APHEC. While there's been progress in drug accessibility, disparities persist, notably in Eastern Europe, due to limited coverage and diagnostic challenges.

Ukraine's case underscored issues like limited reference centers and reliance on echocardiography for diagnoses, highlighting the need for comprehensive improvements.

Addressing these disparities requires improved drug access, increased awareness, and comprehensive diagnostic approaches for all patients across Europe.



Prof. Ahmed M. Krimly shed light on Pulmonary Hypertension (PH) care in **Saudi Arabia** and the Middle East at #APHEC2023. Treatment advancements offer hope. Saudi Arabia boasts accessible therapies, including double and triple therapies, which are a standard. Ongoing research focuses on novel pathways, promising improved outcomes for patients. Notably, the majority of available and approved treatments are available in the Middle Eastern countries.

We were also thrilled to welcome the Pulmonary Hypertension Association **CEO Matt Granato** at APHEC in Barcelona! Matt shared PHA's incredible initiatives, driving change for pulmonary hypertension. Their workshops, collaborations with experts, and impactful publications **empower PH patients**. Granato highlighted PHA's advocacy, ensuring patient voices influence policymaking in USA. PHA's journey from humble beginnings inspires unity, showing that together, we can overcome challenges posed by PH.

After the APHEC, PHA applied to become a new associated member of PHA Europe.

Lastly, Dr Gergely Meszaros from ERN-LUNG gave the audience an introduction to the organization he represents. ERN-LUNG, the European Reference Network for Rare Respiratory Diseases, is a collaborative network of healthcare professionals and centers of excellence across Europe. It focuses on improving the diagnosis, treatment, and care for patients with rare respiratory diseases, such as pulmonary hypertension and interstitial lung diseases. By fostering cooperation and knowledge

sharing, ERN-LUNG aims to enhance patient outcomes and raise awareness about these conditions across Europe.

The APHEC was a great success, as always. With its impressive program and the opportunity for PH leaders to meet face to face, the conference provided a significant boost of inspiration and energy to all attendees. This renewed vigor will undoubtedly invigorate the work carried out by PHA Europe's 37 member countries in 2024.

*Hall Skaara
Staff member PHA Europe*

2023 APHEC Annual PHAE Conference

We would like to extend heartfelt gratitude to everyone who participated in the APHEC 2023 conference.



Aerovate Therapeutics is proud to support PHA Europe

We are committed to developing new therapies to improve the lives of people living with rare cardiopulmonary diseases. We are currently developing an investigational therapy to address pulmonary arterial hypertension (PAH).

Learn more at www.aerovatetx.com

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Vision • Connection • Innovation

Gossamer Bio was named in symbolism of the gossamer thread, the connection that binds all relationships in life.

The goal of Gossamer Bio is to improve the lives of patients through meaningful advances in scientific development and an unwavering commitment to supporting patient communities across the globe.

Gossamer Bio is proud to support meaningful and engaging awareness and education programmes that are created and led by PAH patient advocacy groups.

Please follow this thread to learn more about us: www.gossamerbio.com

 @GossamerBio

REPORTS ON CONGRESSES & CONFERENCES

In 2023, PHA Europe took an active role in numerous significant congresses and conferences. This engagement not only served as a platform to amplify the voice of the pulmonary hypertension (PH) community, but also provided invaluable opportunities for learning about the latest advancements in the field of PH and fostering essential networking connections.

In spring, PHA Europe actively participated in the 4th Baltic PH Conference in Riga, Latvia, focusing on CTEPH and the latest PH guidelines. Professor Kurzyňa highlighted collaborative efforts with Latvia, including the country's first PEA operation.



A key discussion centered on the potential establishment of a unified PEA center among the Baltic countries, emphasizing the importance of a high-volume facility. BPA was also highlighted as an alternative to PEA when surgery isn't feasible. The conference facilitated in-depth discussions on patient cases, showcasing the region's high expertise and reassuring standards of care for pulmonary hypertension patients.

Next, PHA Europe participated in EPF's 20th anniversary event in Brussels with the theme „The Path of Patient Advocacy: Past, Present, and Future.“ Key moments included discussions on drug accessibility, the role of Artificial Intelligence in healthcare, and reflections on patient advocacy's journey. Workshops tackled issues such as conflicts of interest, youth involvement, and healthcare collaboration. EPF also endorsed a patient organization manifesto and shared its future goals, emphasizing a new European patient agenda. Lastly, a substantial pharmaceutical legislation revision was discussed, with PHA Europe's engagement in the process highlighted.

PHA Europe actively participated in the EU Commission's stakeholder dialogue in May on the extensive revision of EU pharmaceutical legislation, a process spanning four years. This revision, the most significant in two decades, aims to enhance patient access to treatments across EU member states, promote global competitiveness for the EU pharmaceutical industry, and stimulate innovation to address unmet medical needs. It also introduces

measures to strengthen supply chains, reduce environmental impact, and streamline regulatory processes, notably through incentives for the pharmaceutical industry. The legislation is not expected to be adopted before 2025 due to the MEP election next year, with the EU Commission forwarding the revision to the EU Parliament and Council for approval.



Later in May, PHA Europe actively participated in a EURORDIS membership meeting in Stockholm, focusing on rare diseases and holistic care. Workshops covered digital safety and mental well-being, including EU legislation for the European Health Data Space (EHDS), aiming to provide citizens with digital access to health data. Discussions emphasized the importance of minimizing personal data collection and the need for holistic care. Mental health challenges in the rare disease community were highlighted. The diverse nature of rare diseases and the importance of networks and shared experiences were underscored in workshops. PHA Europe had a strong presence, fostering knowledge exchange and networking opportunities.

In the summer, the International Respiratory Coalition (IRC), established in 2021, gathered in Lisbon for a summit to advocate for lung health and advance respiratory care. Comprising a diverse group of partners, including professionals, patients, and industry players, the IRC aims to promote national respiratory strategies and collaborate with policymakers globally. With approximately 550 million people living with chronic respiratory diseases globally, resulting in four million premature

deaths annually, the IRC's mission is crucial. Discussions at the summit addressed tobacco use, air quality, access to care, and vaccine skepticism. The summit culminated in the IRC's manifesto for better respiratory health, highlighting prevention, timely treatment, reducing health inequalities, and prioritizing research as key focus areas. PHA Europe's participation in the event aligns with its representation of the lung health community and shared goals with the IRC Manifesto.

Ferrer's IMPACHT conference, attracting 150+ healthcare professionals from 30+ countries for its fifth edition, introduced the „patient's voice“ this year. PHA Europe and EU-PFF leaders joined Dr. Gabor Covacs in a session on „Patient Support in PH.“ Topics included holistic PH patient care and PHA Europe's pillars: awareness, capacity building, advocacy, and information. The session's success could lead to future patient involvement. The conference delved into technical discussions on improving PH diagnosis, phenotyping, new guidelines, and medication for Group 3 PH ILD patients. Networking opportunities were plentiful, making it a valuable experience.

In August, PHA Europe actively participated in the European Society of Cardiology (ESC) annual congress in Amsterdam, featuring a record-breaking attendance of 30,000 participants. This provided an excellent opportunity to engage in pulmonary hypertension (PH) research and treatment discussions while expanding our network among medical professionals and industry representatives. Notable presentations included a groundbreaking study proposing urine biomarkers for PH diagnosis and a retrospective examination of the toxic oil scandal in Spain, shedding light on the potential causes of PH. A session on risk assessment and treatment perspectives in France and Ukraine highlighted the importance of guidelines in patient care and underscored the challenges faced by healthcare providers in conflict zones. Our presence at such events is essential to strengthen connections, raise awareness of our initiatives, and enhance our expertise for the benefit of the European PH community and patients.

In the subsequent month, PHA Europe actively engaged in the second major European congress hosted by the European Respiratory Society (ERS) in Milan, Italy. Similar to the ESC congress, this event featured numerous captivating sessions focused on Pulmonary Hypertension (PH) and showcased a wealth of research through a multitude of posters.

The ERS Congress not only serves as a valuable platform for exchanging ideas within the PH community, but also fosters collaboration with other organizations, including the European Lung Health Group (ELHG). ELHG comprises representatives from eight different respiratory patient associations, and this congress provides a unique opportunity for in-person interactions, a departure from our usual online meetings. Additionally, our participation in various groups under the European Lung Foundation (ELF), including the Patient Advisory Committee, is further enriched by this congress. Furthermore, PHA Europe had the privilege of engaging in the Clinical Research Collaboration PHAROS at the congress, which plays a pivotal role in coordinating future collaborative PH research efforts.

The ESOT Congress, the largest gathering of the transplant community in Europe, focused primarily on liver and kidney transplantation, with some attention given to heart transplantation and significant progress in anti-rejection drugs. Recommendations for patient organizations



included emphasizing healthy eating, regular exercise, and mental strength—all crucial aspects of post-transplant life that require more guidance and support. Raising awareness about organ donation was also highlighted, with impactful projects showcasing the value of scars and the strength of transplant recipients. The Patient Engagement

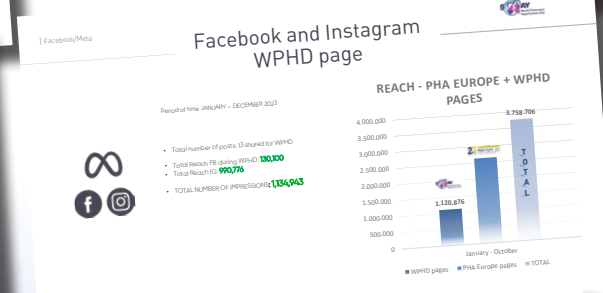
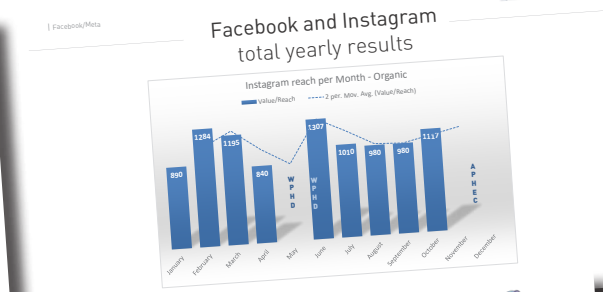
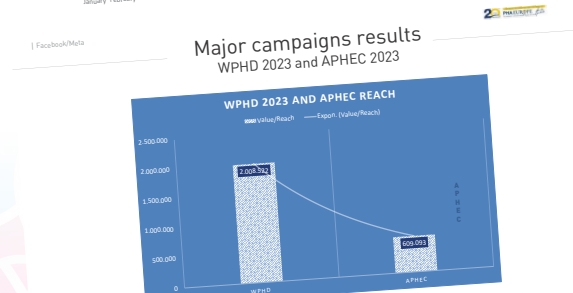
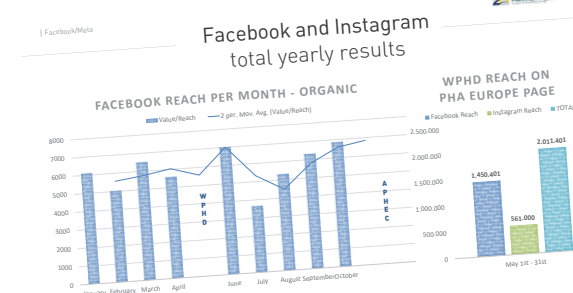
Room at the congress provided a dedicated space for transplant recipients and their families. PHA Europe sees an opportunity to integrate organ donation awareness into its campaigns, recognizing the importance of this topic for some potential transplant candidates within the PH community.

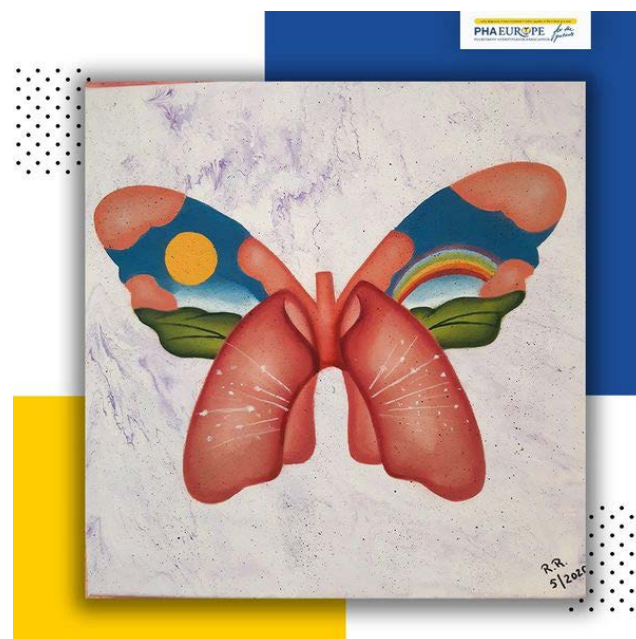
PHA EUROPE – SOCIAL MEDIA ACTIVITIES

In 2023, we witnessed significant successes in our social media campaigns, notably during Rare Disease Day in February and the World Pulmonary Hypertension Day (WPHD 2023) campaign throughout May, which boasted global reach. Since those two campaigns, we've increasingly focused on integrating the vibrant events of our annual PH European Conference (APHEC) into our social media presence, showcasing our lively community comprising participants from our member national associations, pharmaceutical partners, and expert speakers. Through a series of posts under the hashtag #APHEC2023, combined with content for November Awareness Month, we engaged with over half a million individuals across our social media channels. From introducing new board members and welcoming four new associated members to hosting a myriad of expert speakers shedding light on crucial PH topics, the APHEC campaign proved to be a valuable addition to our traditional social media content. Parallel to our APHEC campaign, PHA Europe

collaborated closely with the USA's Pulmonary Hypertension Association during November Awareness Month, transforming their original „Live PHearelessly” campaign into editable templates for all PHA Europe member associations to share, thus reaching a much broader audience.

Reflecting on 2023, we cannot overlook the success of our two original campaigns, „Bigger Than PH” and „PHeenomenal Art.” With „Bigger Than PH,” we aimed to spotlight our champions and PH fighters, whose life stories exemplify how individuals transcend their diagnoses, especially with the support of others, making all PH warriors „Bigger Than PH.” Similarly, „PHeenomenal Art” celebrated the vitality of each patient through their original artworks, created as a means of coping and healing through creativity. Countless pieces of art by PH patients radiate with their energy, resilience, and vitality evident in every brushstroke.





In addition to our endeavors, the promotion of PVRI's PHGPS, the first global survey for PH patients, stands as a testament to our commitment. Through the creation and dissemination of original content across our networks, we proudly report that our series of posts have successfully garnered the attention of the PH community, encouraging participation in the survey crafted by PVRI. Across Facebook, Instagram, Twitter, and LinkedIn, with more diversified content compared to the previous year, we attracted new followers from various demographics, thereby promoting our pages and PHA Europe's mission to a wider audience. This expanded reach underscores the resonating impact and widespread influence of our global initiative. Our practice of disseminating major campaigns in different languages through editable templates

has proven to be a powerful asset, and we extend immense gratitude to all members who utilize them to share content. A 23 percent increase in numbers during the last quarter of 2023 compared to the previous year, coupled with a steady organic growth of followers on Twitter and LinkedIn, indicates that our original and new content consistently engages our audience and piques interest. We remain committed to generating even more original content to further expand our pages and elevate pulmonary hypertension as a pertinent topic in everyday discourse among decision-makers and stakeholders. Through our robust social media networks and collaborative efforts with major PH associations and member associations, we are closer than ever to realizing this objective.



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

In addition, OrphaCare is acting as a manufacturer of a software medical product risk class I according to MDR*.

At OrphaCare,
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AOP
HEALTH

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

Needs.
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At Ferrer we want to make a positive impact in society and we do so by reinvesting a significant part of our profits in initiatives with social and environmental impact, as well as in our people.

In order to fulfill our purpose, we offer transformative therapeutic solutions with a special focus on pulmonary vascular and interstitial lung diseases.

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respira
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Do you know
someone with PAH?

Become a part of the clinical trial for people living with pulmonary arterial hypertension (PAH)*

For more information on the trial, visit:
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vipah prn^{2B}

*The treatment that Respira is researching in the VIPAH-PRN2B trial is investigational and has not yet been approved for doctors to prescribe. The VIPAH-PRN2B trial is sponsored by Respira Therapeutics, Inc.

ClinicalTrials.gov Identifier: NCT04266197; RT234-PAH-CL202

MEMBER SUPPORT PROGRAM (MSP)

The Member Support Program (MSP), formerly known as the CBP, builds upon the foundation laid by our White Spot Program (WSP). While the WSP focuses on establishing associations in new territories, the MSP is geared towards nurturing and advancing existing associations.

In 2023, we undertook a series of noteworthy initiatives under our MSP:

- 1. Website Development:** Leveraging the WordPress template utilized for PHA Europe's website, we assisted several member associations in designing their own websites. The resultant webpages boast an appealing aesthetic and share a consistent visual identity, enhancing their recognizability.
- 2. Image Brochure Creation:** Member associations seized the opportunity to create and print new image brochures, benefitting from a meticulously crafted template originally employed by the Austrian association. These brochures, though appearing simple, are the product of careful deliberation, encompassing elements ranging from color schemes to paper quality. Such brochures serve as vital tools for member recruitment and partnership outreach within the pharmaceutical industry. Almost all of PHA Europe's member associations now boast their own image brochures.
- 3. Cross-National Collaboration:** The Hungarian PH association translated and printed 500 copies of a nutrition brochure initially developed by their Austrian counterparts. This collaboration exemplifies the spirit of mutual support among PHA Europe's member associations, as successful materials are shared for adaptation and dissemination across different national contexts.
- 4. Patient Meeting Support:** In May 2023, the Swedish PH association organized a multi-day patient meeting with a special focus on pediatric pulmonary hypertension (PH) cases. PHA Europe extended financial support through the MSP program to facilitate the successful execution of this event.
- 5. Support Line Provision:** PHA Europe utilized MSP funds to fulfill requests from associations seeking assistance in establishing dedicated support lines. Recipients were provided with a basic mobile phone along with a one-year subscription, enabling them to offer enhanced support services to their communities.

PH AUSTRIA
 PULMONARY HYPERTENSION
 www.phaustria.org
 Tel: +43 1 402 37 25

Make use of your right to our free services!

- advise you in all social matters (handicapped pass, parking permit, care allowance)
- support you and have an open ear for all concerns / hotline
- organise patient meetings for you
- organise chat meetings to strengthen the feeling of togetherness
- promote communication between doctors and patients
- conduct intense public relations work and fundraising
- support national and international research projects
- advice you on everyday topics, like for example your travel planning

Our experience is your advantage!

ARGENTINA

THROUGHOUT THE SECOND HALF OF 2023, HIPUA CONTINUED TO DEVELOP THE FOLLOWING ACTIVITIES:

INTERVIEWS WITH PATIENTS AND RELATIVES AT THE NATIONAL LEVEL

Since its inception, the Argentine Pulmonary Hypertension Association has been providing this service completely free of charge both for those people who have a definitive diagnosis of PH and for those others who are faced with the perception of some symptoms, making them suspect its presence. It is a space intended for containment, advice, guidance, and attentive listening to the concerns of those who come to share them with us and who have been energized thanks to virtuality.



ACTIONS OF THE LEGAL AREA OF HIPUA

This area continued to address all problems related to the lack of access or discontinuation of treatments at the national level, difficulties in granting the Single Disability Certificate - CUD, disaffiliations, processing of non-contributory pensions, etc. either for advice or for free legal sponsorship in those cases that warrant it.



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

Since September 2022, the "I take five minutes... I take a breath" meetings returned as a virtual proposal through the Zoom platform aimed at patients and families throughout the country, who have the opportunity to receive support, build new ties, and share coping strategies in the face of the uncertainty generated by PH.



AFA AWARENESS CAMPAIGN

The fight of patients with Pulmonary Hypertension is represented by this hashtag: #It'sJustAboutBreathing. That is why the AFA Professional Football League carried out an impressive campaign with this hashtag on all fields with its 28 teams seeking to raise awareness about PH.



RESPIRO2 MAGAZINE

Since 2019, HIPUA continues to focus on the continuous demand, from patients and families, for updated information about PH. For this reason, every six months, we publish our digital magazine RESPIRO2 in which both patients as well as the greatest medical experts in Argentina intervene with their brave testimonies, in plain and accessible language, based on the premise that GETTING INFORMED IS A WAY TO TAKE CARE OF YOURSELF, and that a patient who takes care of himself is a patient who will undoubtedly experience better adherence to treatment.

HIPUA AT THE DEBATE DAY ON HIGH PRICE MEDICATIONS

We participated in this Debate Day organized by IOSFA. Reference was made to the enormous fragmentation of the Argentine health system, and the economic impact that these medications generate on it.



HIPUA FULL MEMBER OF ALIBER

At the last Ordinary Assembly of Partners of the Ibero-American Alliance for Rare, Orphan or Rare Diseases (ALIBER), the incorporation of HIPUA as a full member was approved.

FROM PATIENTS TO HEALTHCARE CITIZENS

HIPUA had the honor of being awarded a scholarship by the Health Observatory of the Faculty of Law of the University of Buenos Aires, to participate in this training that was called "From patients to healthcare citizens" whose objective was to train patient organizations to participate, influence, and transform health care processes, in terms of access, equity, and guarantee of rights.

HIPUA AT THE PHARMACOVIGILANCE DAY

Organized by the Argentine Chamber of Medicinal Specialties, it was developed within the framework of World Patient Safety Day, in recognition of the key role they play in the safety of health care, together with family members and caregivers.

"BREATHING BETTER" PROGRAM (DONATION OF MEDICATIONS)

Continuous access to treatments must be guaranteed for anyone affected. For this reason, HIPUA has a donation mechanism from individuals, pharmacies, health establishments, or the industry itself. Although these donations are not a definitive solution, they contribute to reducing the risks of non-access or discontinuation.



HIPUA IN THE INTERNATIONAL PULMONARY CIRCULATION COURSE YESTERDAY

The Pulmonary Circulation Section of the Argentine Association of Respiratory Medicine (AAMR) invited HIPUA to participate in the National Academy of Medicine, of the 8th International Pulmonary Circulation Course "Dr. Abel Ayerza". The scientific program dealt with topics related to PH that were presented by renowned foreign and local professionals, creating a unique space for the exchange of opinions and experiences.

HIPUA IN THE XIX WEEKEND OF HEART FAILURE AND PULMONARY HYPERTENSION MENDOZA

The Heart Failure and Pulmonary Hypertension Committee of the Argentine Federation of Cardiology, together with the Society of Cardiology of Mendoza, invited HIPUA to participate in this weekend held in the province of Mendoza. At the same time, taking advantage of the occasion, from HIPUA we had the joy of being able to meet with several patients from the province under the modality of our well-known meetings "I'll take five minutes... I'll take a break."



NOVEMBER, PH AWARENESS MONTH

On November 21 and 30, HIPUA developed two webinars with prestigious cardiologists and pulmonologists, who made reference to PH associated with respiratory diseases, current and future treatments, and the guidelines that must be followed for good adhesion.

NOVIEMBRE, MES DE
CONCIENTIZACIÓN DE LA
HIPERTENSIÓN PULMONAR

AGENDA DE ACTIVIDADES

**Martes 21 de
Noviembre | 18:00 hs.**

La Hipertensión Pulmonar asociada a
Enfermedades Respiratorias.

- Dr. Martin Bosio (Neumólogo)
- Dra. Gabriela Tabaj (Neumóloga)

NO REQUIERE INSCRIPCIÓN PREVIA

**Jueves 30 de
Noviembre | 18:00 hs.**

Tratamientos actuales y futuros para la
Hipertensión Pulmonar.
Pautas para una buena adherencia.

- Dr. Luis Lema (Cardiólogo)

NO REQUIERE INSCRIPCIÓN PREVIA

Sponsor

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www.hipertensionpulmonarargentina.org

AUSTRIA

PH AUSTRIA'S HIGHLIGHTS IN 2023

In 2023, PH Austria has organized a lot of activities to raise awareness and provide support to patients with pulmonary hypertension and elevate the levels of awareness surrounding this often-misunderstood condition.

PATIENT INFORMATION DAYS ACROSS AUSTRIA

PH Austria organized impressive events throughout 2023, bringing together patients, families, and interested individuals. From the Linzer Kellertheater in February to the Salzburg Information Day in November, each event provided an opportunity to share knowledge, ask questions, and connect with others facing similar challenges. PH Austria also hosted patient information days in Vienna, St. Pölten, Klagenfurt, Innsbruck, and Graz. These events contributed to raising awareness, providing resources, and creating a supportive community for those dealing with the challenges.



VERGISSMEINNICHT DANK EVENT ON APRIL 12TH

Another highlight was in April, where PH Austria expressed gratitude to the donors of the Vergissmeinnicht initiative. As a symbolic gesture of appreciation, participants planted a Forget-Me-Not flower in the beautiful setting of the Schönbrunner Park. The initiative Vergissmeinnicht currently unites nearly 100 Austrian non-profit organizations from the fields of social services, health, human rights, development cooperation, animal welfare and environmental protection, arts and culture, as well as science and education. The Forget-Me-Not initiative aims to give clear and neutral information about leaving money to charity and making a will for a good cause.



THE 10TH VIENNA ZOO RUN ON JUNE 12TH

Running shoes were laced up to make a statement at the 10th Vienna Zoo Run. Participation in this run was not only a physical challenge but also an opportunity to draw attention to pulmonary hypertension and raise funds for research. At the 10th Vienna Zoo Run 2023, 2000 ambitious runners participated in our charity run.



MSD PH NURSE FORUM ON SEPTEMBER 22ND-23RD

The MSD PH Nurse Forum provided a platform for the exchange of knowledge and experiences in the care of patients with pulmonary hypertension. PH Austria actively participated to ensure continuous improvement in patient care.



PARTICIPATION IN INTERNATIONAL EVENTS

PH Austria had a strong presence at the APHEC&GAM 2023 in November, a significant conference providing crucial insights and developments in the field of pulmonary hypertension. Additionally, PH Austria

participated in the European patient survey by AOP and the global patient survey by PVRI, amplifying the voice of patients worldwide.



CONTINUATION OF THE MILESTONES INITIATIVE

The Milestones Initiative, aiming to mark progress in understanding and treating pulmonary hypertension, was successfully continued. This shows PH Austria's commitment to bring positive change into the community. The Milestones Square is located at Oswald-Thomas-Platz in front of the Planetarium in Vienna's Prater. For a donation of at least €29, a milestone with a personal engraving can be acquired and will be laid in the square. In 2023, the renowned soccer player Toni Polster supported our campaign, helping raise awareness for our project.



CLOSING THOUGHTS

In 2023, PH Austria has once again demonstrated that the community in the fight against pulmonary hypertension is resilient and united. Through informational events, sports activities, international participation, and the continuation of initiatives, PH Austria is making a significant impact. We are proud to have 450 active members, which is 50 per Million of the total population of Austria.



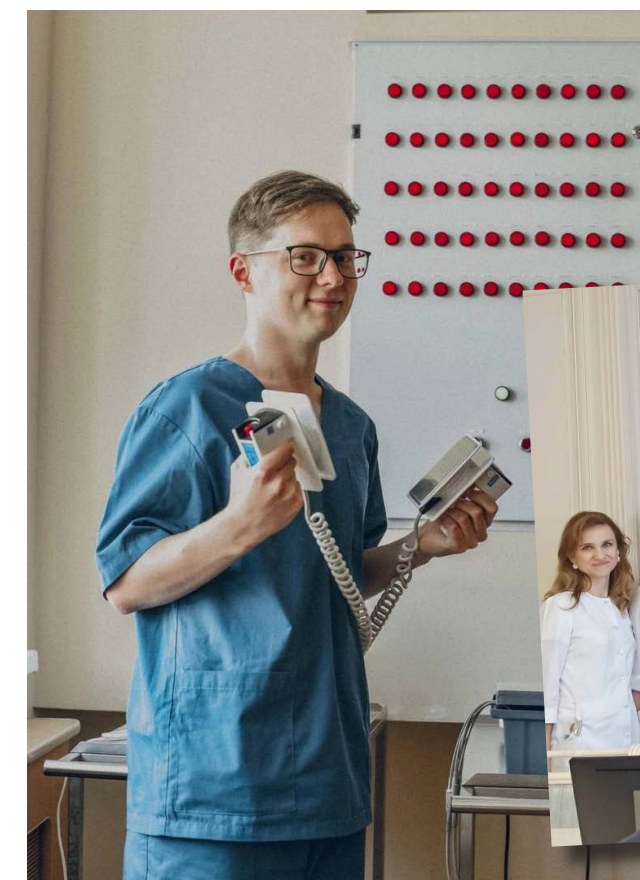
BELARUS

The Belarusian Congress of Pediatric Cardiac surgeons and specialists in congenital heart diseases was held in Minsk. Experts discussed new techniques and achievements in cardiac surgery, sharing forecasts for the future of treatment and surgery in children with congenital heart defects. Cooperation with pharmaceutical companies has become an important step in providing patients. Despite the delays, generic drugs of bosentan and sildenafil, produced in India, are now available on the Belarusian market.

The Center actively maintains its social networks – Instagram, VKontakte, and Facebook, providing patients and their parents with up-to-date information and support. The Telegram channel chat creates an additional space for communication and exchange of experience.

Not only medical care is provided, but also legal and psychological support is provided to patients, which is important for full-fledged care of their well-being. These measures, together with our medical successes, underline our dedication to providing a high level of care and treatment for children with congenital heart defects in Belarus.

The RNPC „Cardiology” successfully performed a lung transplant operation. A 58-year-old resident of Osipovichi, suffering from pulmonary fibrosis, received a new organ. It was her only chance to survive, so the doctors performed the operation.





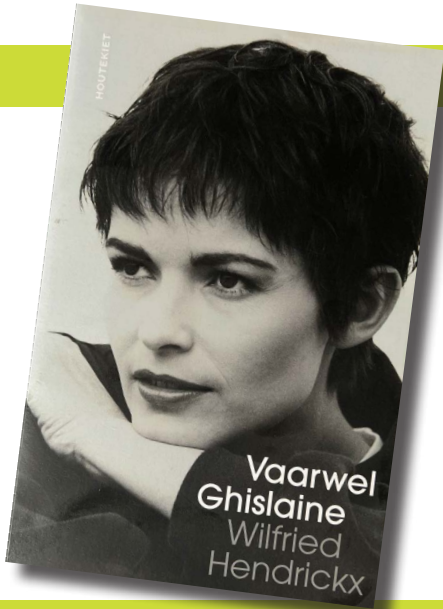
BELGIUM



2023 was a pretty busy year for our association, it was all about getting together, informing our members and learning a lot ourselves. Here is an overview of our activities this year:

FAREWELL GHISLAINE

Belgian top model and fashion icon Ghislaine Nuytten died in January 2022 from the effects of pulmonary hypertension. Her husband, Wilfried Hendrickx, wrote a book about her last years with the disease and spoke about it in Humo, a popular magazine in Flanders, early this year. This resulted in an honest and recognizable story about living with an advanced stage of the disease.



RARE DISEASE DAY

This year's RDD campaign, pulled by the Belgian umbrella patient association RaDiOrg, focused on the connection between all rare diseases, because alone we may be rare, but together we make up a large group of some half a million Belgians. We can look back on a successful campaign, with a lot of media attention, including for pulmonary hypertension! Professor M. Delcroix was featured in a national newspaper, President Wendy made an appeal on a local newspaper and television, and finally, Vice-President An ensured that Antwerp's skyline was dominated by Rare Diseases Day, by changing the lighting of the famous Port House from white to the colors of 'Rare Diseases Day'.



WEBINARS

As is our annual custom, we organized a webinar series during the winter. These webinars aim to inform patients without having to leave their house. They are also recorded and put on our website and YouTube-channel, so that they remain accessible at all times. This year's agenda included the following topics: Informal care, self-management: recognizing the symptoms of right heart failure, and social rights.



ADVOCACY IN PRACTICE

Many events took place this year where we made the patient's voice heard through testimonials and workshops. President Wendy and treasurer Erik testified at a Johnson & Johnson workshop, vice-

president An gave a testimony for physicians in an MSD webinar and, together with experience expert Wim, at a Johnson & Johnson event for physicians.



TRAINING PATIENT EXPERTS

The patient's voice is becoming increasingly important in the decision-making processes of government departments, hospitals, health insurance funds, healthcare providers, pharma companies, ... When developing and improving services or products, the patient's opinion is increasingly sought. However, this is only possible if this patient is also aware of the processes and procedures being followed and the objectives being pursued. This is why the Patient Expert Centre organizes training and ensures cooperation between those different players, so that the patient's voice is heard.

The training consists of a general part and a disease-specific part with weekly online classes. In 2023, 8 patients from our association took up the challenge, they may call themselves 'patient experts' from now on!

„Thanks to the patient expert training, I gained more insights about my disease, but also about general issues such as the social map of Belgium. This knowledge helps me to help my fellow patients and to volunteer for projects of my patient association such as reading up on Janssen-Cilag's PAH starter kit.”
Lore, patient expert



INFO MOMENT ON PH FOR NEW PATIENTS

On the 21st of October, we organized an info moment for new patients. Professor C. Belge gave a presentation on what PH is. Among other things, the different types of PH, possible causes and also treatment options were discussed. Besides basic information, the day also covered financial and practical support and tips on how best to deal with pump medication and oxygen use, among other things, and the impact on your daily life.

„I have learned that sometimes I have to hand my work over to someone else and that it won't always be the way I want it, but then I have more time to do nicer things myself.” (patient)



THEME AFTERNOON 'LIVING LOSS'

Grief is often associated with a death, but saying goodbye to your life as it was, such as due to a chronic illness, can also involve a grieving process. As patients, we all experience that there is a life before and a life after the diagnosis of PH. On Saturday October 21st, we had Psychologist and Professor Emeritus Manu Keirse as our guest with a lecture on 'living loss', followed by a panel discussion with Sven Van Lommel (PH psychologist UZ Leuven hospital), Tess Wynants (PH nurse UZ Leuven hospital), Wim Schauvliege (PH patient), Katleen Verbergt (mum of) and her son Vic Moens (PH patient). Some interesting quotes from this afternoon were:

„Grieving is normal behavior, of normal balanced people.”
Manu Keirse

„I have always been very honest and open with Vic. A lot of people commented on that. I'm happy to hear that I've done that well anyway.”

Katleen, mum of a PH-patient

„The disease turns your whole life upside down. Whether it's depression or not, at least you don't feel good.”

Wim, patient

„When diagnosed, people sympathize, but after a while they don't, while each time there is a confrontation with what is no longer possible or because something changes in treatment.”

Anja, patient

„The nurses are ready to give additional explanations because there is a real need for that. I take as a tip that proactively addressing the patient, even if it's just five minutes, can make a big difference”

Tess, PH nurse



SCIENTIFIC RESEARCH FUNDING

Several actions were done during the year, both by us and by third parties. For example, we received a nice cheque from the Mercier-Van Lanschot bank. We also sold sweets for PH. All together, this enabled us to raise 12,000€ for scientific research on pulmonary



hypertension! This money was transferred to the KU Leuven University for the 'pulmonary hypertension' research chair led by Prof. Dr. M. Delcroix.

BOSNIA AND HERZEGOVINA

Bosnia and Herzegovina – Mariposa journal winter 2023.

TOGETHER TO THE GOAL

Since the founding of the Association of Citizens Suffering from Pulmonary Hypertension „Dah” in Bosnia and Herzegovina, one of our main goals has been a cure for all pulmonary hypertension patients in our country. To achieve this goal, we have expanded our mission by teaming up with other associations that bring together people suffering from other diseases who, like us, do not have an available cure.



ACTIVITIES WITH OTHER ORGANIZATIONS AND ASSOCIATIONS

One of the non-governmental organizations that deals with the protection of basic human rights in Bosnia and Herzegovina is the Centers of Civil Initiatives. We recognized them as a possible collaborator, who could help us in our fight for a better position of PH patients in Bosnia and Herzegovina, and during 2023, we participated in several activities together. First of all, we held direct and online meetings in order to present the problems faced by patients with pulmonary hypertension in our country, and among them, we especially pointed out that all PH patients do not have the same right to medicine, and that it primarily depends on where we live. This startling fact that leaves no one indifferent provided us with a sure comrade in the fight for our rights. With the Centers of Civil Initiatives, we participated in the realization of a round table on the subject of the Solidarity Fund in the Federation of Bosnia and Herzegovina, which aimed to point out the perennial problem of ignoring legal obligations by the authorities regarding the financing of the Solidarity Fund of the Federation of Bosnia and Herzegovina. We were part of this story because we thought that it is a very important topic for us, since people suffering from rare, severe and incurable pulmonary hypertension were referred to the funds of this Fund in terms of providing expensive therapies and possible interventions outside the country, which, among other things, relate to heart, lung, or both heart and lung transplants. On this occasion, the Centers

of Civil Initiatives also recorded a video confession of a PH patient from Bosnia and Herzegovina, Vera Hodžić, who spoke about her illness, but also about all the problems faced by patients with pulmonary hypertension in Bosnia and Herzegovina. The video attracted a lot of attention from the public, and over 31,000 views were recorded on the FB platform of the Centers of Civil Initiatives in six days alone.



ACTIVITIES WITH OTHER ORGANIZATIONS AND ASSOCIATIONS

In addition, during this year, we continued our work in the network of patient association „Right to medicine”, which aims to have a possible influence on the creation of a unique list of medicines in Bosnia and Herzegovina. As part of these activities, we attended a training session on the topic „Public appearance in the media”, as well as a meeting where it was emphasized once again that the network will insist that representatives of the network, i.e. member associations of the network’s „Right to drug”.

In order to unite as much as possible with other seriously ill patients, we participated in the first

founding meetings of the Alliance for Rare Diseases in FBiH, as well as in the final Conference on Rare Diseases within the project „Contribution of networks of civil society organizations to improving the daily life of people suffering from rare diseases”. Our regular activities during 2023 included the celebration of the International Day of Rare Diseases, as well as the World Day of Pulmonary Hypertension, and with these activities we attracted a lot of attention on social networks, highlighting the problems we face, raising awareness of pulmonary hypertension, and presenting our creativity with the same goal.



WE RAISE AWARENESS WITH SPORT ACTIVITIES

However, a cure for all patients is not our only task. Together with the media and athletes, we continuously raised awareness about our disease.

So, in addition to the series of sports events that we realized during the celebration of WPHD 2023, our recreational athletes showed their willingness to help us in raising awareness about pulmonary hypertension during their regular annual activities. This time, we would like to highlight the members of the cycling club „Tajan” from Zavidovići, mountaineers from two towns: Zavidovići and Žepče, and tireless runners from SD Ultra Bihać.

Cyclists led by Nedin Maličbegović breathed for those suffering from pulmonary hypertension during their trip to Velež (915 m), while mountaineers Arminka Memišević, Nerma Sinanović, Marko Brkić, Mustafa Memišević and Dino Sinanović did the same, but at much higher altitudes, on Mt. Bjelašnica, by conquering the peak of Obalj (1,896 masl) as a sign of solidarity with all those suffering from pulmonary hypertension.

Our tireless runners from Bihać Enes Ibrahimagic, Emina Čehajić Gradinović, Amar Čehajić, Amir Muminović, Armin Alagić, Haris Mašić, Asmir Islamović, Dženana Mušić, Elza Ljubijankić, and Sanel Kurtagić participated in half marathons and marathons not only in Bosnia and Herzegovina, but in the entire region, breathing for patients with pulmonary hypertension. During this year, these ten runners from Bihac covered a total of about 2,000 km on the trails in Bihac, Mostar and Bosanska Krupa in Bosnia and Herzegovina, and Koper, Kranj, Ljubljana and Novi Mesto in Slovenia, as well as Šibenik, Slavonski Brod, Zadar, Karlovac , Plitvice, Pula, Čazma and Zagreb in Croatia, thereby raising

awareness of pulmonary hypertension together with us. What makes us particularly happy are their successes, because they often returned from those races with well-deserved medals.

We will continue at this pace in the years ahead because we have no intention of giving up our lives and our fight for equal rights for all patients with pulmonary hypertension in Bosnia and Herzegovina.

Vera Hodžić, president

Association of citizens suffering from pulmonary hypertension „Dah” - in Bosnia and Herzegovina



NEWS FROM EUROPEAN PH ASSOCIATIONS

BULGARIA BSPPH

CELEBRATING THE RARE

A „Walk of Hope” was held on February 26th, 2023 in Sofia. The initiative aims to draw public attention to the problems of people with rare diseases. The campaign is organized by the Rare Diseases and Transplantation Section of the National Patients’ Organization (NGO) and is dedicated to Rare Diseases Day. ‘When you suffer from a rare disease, you need to be at least two steps ahead of the disease to save your life. These patients are usually

„invisible” to the public. I would liken the suffering in every family where there is a patient with a rare disease to a daily battle for survival - starting from the very beginning to seeking and making the right diagnosis and access to treatment”, said Natalia Maeva, president of the BSPPH. On February 28th at 19:00, emblematic buildings in five Bulgarian cities were illuminated in the colors of the rare - blue, green, pink, and purple.



MOTOFEST SUPPORT OF DONATION AND TRANSPLANTS

People with big hearts kicked off the first motorcycle festival of its kind in support of donation and transplants, organized by the Sofia motorcycle clubs. It was held from the 23rd to the 25th of June, 2023, in the park area next to Terminal 2 of Sofia Airport and aimed to promote the cause of donation.

National Assembly President Rosen Zhelyazkov attended the opening ceremony of the three-day charity motor fest.

With the collected funds, the organizers of the moto-fest purchased and donated medical equipment related to the donation and transplantation process, as well as the post-transplantation period. The Bulgarian society of patients with pulmonary

hypertension was also an active organizer and participant in the meeting. Even one human life is worth saving thanks to our efforts!



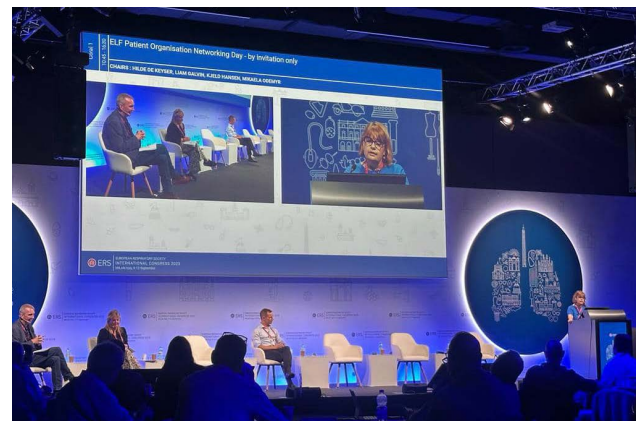


ELF PATIENT ORGANISATION NETWORKING DAY 2023

At the European Respiratory Society (ERS) Congress, the annual ELF Patient Organisation Networking Day brought together numerous organizations dedicated to respiratory health. Among the esteemed speakers and panelists, Natalia Maeva, member of the board of PHA Europe and a respected figure in the field, delivered a presentation titled „Living with Pulmonary Arterial Hypertension: Navigating Challenges and Promoting Adjustments.”

Her presentation took us on a journey, starting with the foundational understanding of PAH and the complexities of this disease. It then emphasized the crucial significance of early diagnosis, symptom awareness, and managing the emotional impact. Moving forward, Natalia explored the challenging diagnostic process, highlighting the importance of ultimately accepting one's condition. Her insights extended to practical coping strategies and the role of PHA Europe and other associations in empowering patients to actively participate in their care and find support through patient networks.

She is a Founding Member and current President of the Bulgarian Society of Patients with Pulmonary Hypertension. She has fought a relentless battle against Pulmonary Hypertension (PH) for over 14 years. Her remarkable journey includes a double lung transplant in 2016, enabling her to lead a vibrant, active life for the past seven years. Her profound expertise in PH made her presentation a pivotal moment of the event.



THE STORY OF CASPAR, WHO WANTS TO OVERCOME ISOLATION

The story of „Casper - the bear with blue lips” has finally been officially presented in the Bulgarian language on the 30th of September 2023, in the „Peroto” literary club at the National Place of Culture in Sofia.

Clowns Kuku and Pippi presented the tale of the brave bear Caspar, who, despite everything, manages to overcome the illness with the help of his parents. Traveling and exploring the world of this rare condition, the little one learns to live in a new and different way, successfully defeating the disease. Caspar has just one simple dream—to play longer with the other children. When the bear plays with his friends, his lips turn blue, and he gets tired very quickly because he suffers from a rare condition

that is challenging to diagnose. Concerned parents do everything, but Caspar misses his friends and the endless games. After much searching, far through several mountains, the brave bear, along with his family, finds Dr. Panda, who will change the bear's life.

Natalia Maeva, Chair of BSPPH, shares, „For me, it was a great goal to write and publish such a book to educate about the importance and impact of a rare condition affecting both children and adults.”

The story of Casper the bear has been translated into English, Croatian, and Bosnian. Next year, the book will be available on the book market in Slovenia and China.



TRANSPLANT RECIPIENTS TOOK PART IN THE WIZZ AIR SOFIA MARATHON

On the 8th of October 2023, more than 60 transplant recipients, doctors, as well as representatives of the Executive Agency Medical Supervision participated in the Wizz air Sofia marathon 2023.

On the occasion of the European Day of organ donation and transplantation, and in support of the National Campaign for popularizing the meaning of donation and transplantation “Yes! For life!”, the participants ran the symbolic distance of 42.19 m - by analogy with the entire length of the route - 42.195 km. Lung transplant patients were among the participants.

“This way, we not only showed that transplantation allows a person to lead a completely normal, healthy life, but also that we can be of benefit to the society and our country. It is therefore important to have more transplantations in Bulgaria and fewer people waiting for their second chance for life. Organ donation is the most humane and supreme act of a modern society which helps people with disabilities and their loved ones. A society without morality and without human values is doomed to die. I believe that we Bulgarians are capable of empathy, compassion and humanity! All of us who participated in the marathon together showed this!”, said the Natalia Maeva chairman of the BSPPH.





EXHIBITION TELLS STORIES ABOUT DIVERSITY

The exhibition „Mirrors of love! About love from first sight” is organized in collaboration with the Foundation „Movement of Bulgarian Mothers,” the Association „Down Syndrome-Bulgaria,” and the „Bulgarian Society for Pulmonary Hypertension Patients.” It’s a photo project to Rositsa Bukova, an active advocate for the rights of people from vulnerable groups in our society. The project aims to show that individuals with Down Syndrome can lead dignified lives when supported by their families and embraced by the community with a full awareness of normalcy. It symbolizes respect and attention to parents and loved ones, who have devoted care and love, enabling individuals with Down Syndrome to reach an age that is challenging if spent in institutions. Each hero in the exhibition has one extra chromosome, making them always smiling, sunny, and loving. They carry incredible energy and vitality for life, emotions, and genuine feelings that they don’t hide. They demonstrate that their lives are worthy and serve as an example of the respect we owe them. Some of them also suffer from pulmonary hypertension. The exhibition is traveling and has been presented on the 1st of December 2023 at the Ombudsman’s Club and on the 6th of December 2023 at the Ministry of Labor and Social Policy.



NEWS FROM EUROPEAN PH ASSOCIATIONS

BULGARIA PHA

INFORMATION SEMINAR

On November 4, 2023, an information seminar on the topic of “Rare Diseases Challenge” was held at the Kaylaka Hotel in Pleven. The event was organized by PHA Bulgaria and the National Alliance of People with Rare Diseases. A total of 124 students from all medical universities in the country participated in the event. The moderator was Todor Mangarov, the chairman of PHA Bulgaria. The seminar aimed to raise awareness about rare diseases, and their impact on patients and their families. The event covered a range of topics related to rare diseases, including challenges in diagnosis and treatment, patient experiences, and the need for increased research and funding. Dr. Simona Markova, a physician at one of the three PH treatment centers in Bulgaria, gave a presentation on the topic of pulmonary hypertension - challenges and diagnosis. She discussed the difficulties in diagnosing pulmonary hypertension and the importance of early detection and treatment. She also highlighted the need for increased awareness and education among healthcare professionals and the public. Mr. Anton Mujdrakov shared his life story before and after lung transplantation. He spoke about the lack of opportunity for lung transplantation for Bulgarians for several years, which represents a peculiar form of genocide against patients in an advanced stage of lung disease. His story emphasized the importance of organ donation and the need for increased support for patients with rare diseases. The seminar was

an important step in raising awareness about rare diseases and the challenges faced by patients and their families. It highlighted the need for increased research, funding, and support for patients with rare diseases in Bulgaria.

Todor Mangarov, a lecturer on pulmonary hypertension, inspired the audience at the Tarlov cysts congress with his motto:

„Make your dream come true! Start with I can.”



HONORARY SIGN OF THE PRESIDENT

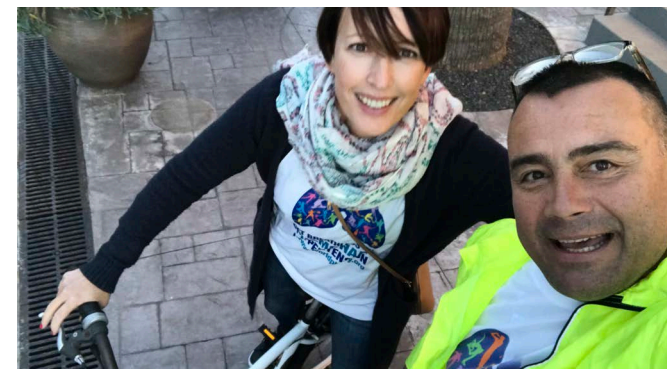
On September 29, 2023, President Rumen Radev of the Republic of Bulgaria personally awarded the “Honorary Sign of the President” to Professor Dr. Rumen Stefanov, Vladimir Tomov, Assoc. Prof. Polina Milusheva, Todor Mangarov, Yordanka Petkova, and Iliana Tnova (posthumously). They were recognized for their pioneering work 15 years ago that paved the way for the cause of people with rare diseases in Bulgaria. The “Honorary Sign of the President” is a prestigious award given to individuals who have made significant contributions to the development of Bulgaria in various fields, including science, culture, and social activities. The award recognizes the outstanding achievements of individuals who have dedicated their lives to serving the country and its people. Professor Dr. Rumen Stefanov is the director of one of the three treatment centers for pulmonary hypertension in Bulgaria. Vladimir Tomov is the founder and chairman of the National Alliance of People with Rare Diseases. Assoc. Prof. Polina Milusheva is the founder and chairman of the National Association of Patients with Growth Hormone Deficiency. Todor Mangarov is the chairman of the Pulmonary Hypertension Association. Yordanka Petkova is the founder and chairman of the Hereditary Angioedema Association. Iliana Tnova was posthumously awarded for her contributions to the National Sarcoidosis Association



TODOR'S BIKE TOUR 2023

Inspired by the idea of giving hope to all PH patients, Todor Mangarov, chairman of the Bulgarian PHA association, took his traditional bike tour.

At the end of 2022, after the long-awaited live patient's association meeting in Barcelona, Todor started from Barcelona to reach the city of Sofia. Passing Girona, Perpignan, Narbonne, Montpellier, Marseille Cannes, and reaching Nice, where he was forced to quit and postpone his bike tour, due to illness and extreme weather conditions.



Nevertheless, He gave us an example that diagnoses on time, correct treatment, and adequate follow up of PHA can, in some cases, lead to a normal, active life.

He looks forward to finishing the planned tour.



CHALLENGES FACED BY PEOPLE WITH RARE DISEASES

On September 28, 2023, the Commission on Health, and the Commission on Labor, Social, and Demographic Policy held a meeting to discuss changes to the regulation for people with rare diseases. The meeting was attended by representatives from the Ministry of Health, the Bulgarian Medical Association, the Commission for Protection against Discrimination, the National Health Insurance

Fund, the Ombudsman of the Republic of Bulgaria, the Ministry of Labor and Social Policy, and non-governmental organizations advocating for the rights of people with rare diseases and disabilities. The purpose of the meeting was to discuss the challenges faced by people with rare diseases and to propose changes to the existing regulations to better support their needs.



CHINA

TWO BREAKTHROUGHS

This year, we have made two breakthroughs, one is our engagement in clinical trial, the other is our membership in PHA Europe.

On 29th Nov, we were invited to attend a conference, held by the Center for Drug Evaluation, NMPA (National Medical Products Administration), on how to improve Chinese patients' engagement in clinical trial and drug development. Nearly 40 attendees were present, including government officials, medical professionals, domestic and international pharmaceutical enterprises, and

patient organizations. They eagerly shared their experiences and thoughts on "patient-centered" research. This is the first time for iSEEK to express patients' perspective in a face-to-face meeting with government officials, so we highlighted the importance of patients' involvement in pre-clinical phases, and the design of questionnaires, called for the revisions of quality of life based on the patients' concerns and emotions, as well as strengthened the regulation of informed consent. Although people from different backgrounds may have different perspectives, all the participants believed "patient-centered" research will become a trend in the future and were very happy to collaborate in this field.



During 8th~12th Nov, We attended the 2023 APHEC held by PHA Europe in Barcelona and luckily became an associate member of PHA Europe. This is our first conference with European PH leaders face-to-face, and we are not only impressed by their warmth and generosity, but also astonished by their efforts in collaborating and helping each other. Despite many disparities in languages, cultures, and social systems, PH leaders in European countries are working constantly to help each other even during the war. We benefited from speeches, private talks, and were always deeply moved and inspired by patient's stories. These valuable insights and experiences will help us to call for more Chinese patients in pursuit of better quality of life.



VIRTUAL BLUE LIPS CLASSROOM

Due to the pandemic, our education program "Blue Lips Classroom" has moved on-line since 2019, and drew a lot of attention all over the country unexpectedly. So this year, we decide to sustain our on-line program in more diversified contents, not only inviting PH patients and doctors, but also sociologists, lawyers, psychologist, pharmacists, dietitians, social workers, and patients of other diseases. Therefore, patients are able to hear

different perspectives that may inspire or empower them to make their own decisions. As most of the PH medications are largely covered by the national insurance systems, patients start paying more attention to live better rather than live longer. In the long term, we hope this virtual classroom will improve patient's health literacy and their awareness for policy-making.



GUIDELINES FOR INSURANCE COVERAGE

Starting from 2019, the cost for PH medications are covered by the national insurance system and patients are expecting a better life. However, the implementation varies widely. Some provinces offered higher coverage, while others only reimburse a little. In some cities, patients can buy their medications through local pharmacies, but others are only allowed to buy it through professional PH centers, which may be far away from their home.

As a result, we asked patients to submit their claims to the healthcare administration at their local levels. Through endless calls and constant consultation, most of the problems are solved. By sharing information among different provinces and cities, patients are more acquainted with each other and united. Some local support groups issued their guidelines for applying reimbursement, which is useful and easy to read.



NEWS FROM EUROPEAN PH ASSOCIATIONS

CROATIA

When we look back, we can happily say that the last year was very dynamic and successful for the Blue Wings Association!

We managed to implement 2 projects co-founded with ESF (European Social Fund) funds in the amount of 85%, and the State Budget of the Republic of Croatia in the amount of 15%.

We have already written about the projects „Do more breathe together” and „Full lungs forward” during the duration of projects, but we will once again boast about that. Despite being a small association and a small country, we completed both projects with very demanding and detailed paperwork, so we hope that maybe some other PHAE member

countries will be encouraged and decide to take that step, try to write a project, and apply for an open call in the future. We plan to apply for similar calls and are already talking to our colleagues from Slovenia about it, because the call for applications for cross-border cooperation projects, in this case between the countries of Slovenia and Croatia, has opened.



One of the projects was aimed at strengthening the capacity of the association itself. In contrast, the other project, which we just finished on the 24th of November 2023 from the call for the promotion of health and disease prevention, was aimed at raising awareness of PAH and working with school-age children through sports activities, with an emphasis on the importance of playing sports, because unfortunately in the Republic of Croatia, we have a large number of obese children. The project aimed to encourage children to play sports, but also to introduce them to rare diseases like ours. The children accepted our visits to their schools surprisingly well. They were ready to cooperate



and asked interesting questions. We visited 6 less developed cities in Croatia; Karlovac, Obrovac, Bjelovar; Vukovar, Sisak, and Đakovo. External collaborators in this project were well-known rowers Tomislav Smrček Čonč and Nikica Ljubek, who were crowned with a silver Olympic medal.

Thanks to PHAE funds from the CBP program, we also held the first art colony called "Art from the Heart," which consisted of two parts. The first was when we spent the day with the fine artists in the picturesque Botanical Garden of the city of Zagreb, where they found inspiration for their works, which we then equipped with frames and exhibited in the Loža gallery in Zagreb in November, also known as an awareness month for respiratory diseases. The exhibition was for sale, and the collected funds will be used to further the work of the association and new projects, and the visitors took home a new work of art, painted from the heart.

So that not everything stays on land, we dived into the depths from where divers sent us support with wonderful pictures that we will use in our projects related to raising awareness about PAHs. Photos were taken by the famous Croatian photographer Damir Zurub (photographs for National Geographics).



Throughout the year, many runners defended our colors in various races across the country, and one of the interesting ones was the last one of the year, the only costumed race in Zagreb, the Zagreb Advent Run 2023, where we had the Blue Wings team, which, despite the cold weather, was left breathless for PH (Get Breathless for PH). We have been featured on television and radio stations, and our activities have been covered by many portals across the country, a lot of work for a small association, but we are continuing to do the same because there is still a lot of work to do.

Katica Mavračić and Zdenka Bradač



CZECH REPUBLIC

COOPERATION WITH THE MINISTRY OF HEALTH AND THE STATE INSTITUTE FOR DRUG CONTROL DURING DRUG APPROVAL

At the beginning of the year, the Ministry of Health approved the third medicine for rare diseases according to a new legislation in Czech Republic. It was a medicine for patients with chronic thromboembolic pulmonary hypertension (CTEPH) in III. and I. Functional class. Subsequently, the reimbursement was approved by the State Office for Drug Control. We are very proud that as a patient Organization we could participate in the approval process.

NAPO

We became a member of NAPO in February this year. The National Association of Patient Organizations brings together patient organizations focused on all types of illness and disability operating in the Czech Republic. Joining the National Association of Patient Organizations (NAPO) indicates our commitment to being a part of a collective effort to advocate for the interests of patients and support member organizations. Being a member of such an association

can provide valuable networking opportunities, resources, and a platform to contribute to the improvement of healthcare and patient experiences. The goal is to become a respected partner for the Ministry of Health, the State Office for Drug Control, the State Institute of Health, and other health promotion institutions that seek or consult the views of patients.

NAPO má 42 členských organizací



COOPERATION WITH THE MINISTRY OF HEALTH

This year, we have seen great success by appointing a colleague from the association of patients with pulmonary hypertension to the position of advisory organ for reimbursement of drugs intended for rare diseases. This reflects not only the dedication and expertise within our organization but also the recognition of the importance of patient perspectives in decision-making processes related to healthcare, particularly for rare diseases. Having a representative from a patient organization in such a role can contribute valuable insights into the unique needs and challenges faced by individuals with rare diseases. It also emphasizes the importance of collaboration between patient advocacy groups and healthcare decision-makers.



RECONDITION STAY IN PODĚBRADY

As every year, the second week in August is devoted to a recondition for patients with pulmonary hypertension in Poděbrady. Its program supports the mental health of patients and those of their family members, and we have the opportunity to show patients that they can also take care of their physical condition, even with this chronic disease. The whole stay is supported by a physician from the PH centre, psychologist, and physiotherapists. Like in past years, the program focused on light breathing exercises, muscle stretching work, and the improvement of movement habits. We also introduced some new techniques to strengthen the middle part of the body to protect the spine. Our patients also had the opportunity to discuss their problems with a PH specialist. Like last year, we also prepared psychological relaxations and individual support for our patients.



ANNUAL MEETING IN OLOMOUC

Organizing meetings of patients with the General Meeting in Olomouc, one of the three centers for the treatment of lung hypertension, is an excellent opportunity for members of the association from more distant locations. The program included not only law for the association, but also lectures on specialists on various topics of progress of treatment and social support, as well as lectures on the members of the Board of the Association. The budget choices and approval are key parts of the general meeting where members can influence the direction and decision-making of the organization. Overall, these events contribute to the strengthening of patients' community, sharing experience and

gaining important knowledge. Professional lectures from specialists in the treatment of pulmonary hypertension (PH) are valuable because they provide participants with up-to-date information on therapeutic options, research, and care



MEETING WITH PATIENTS FROM IKEM

We have wonderful news this year! Being invited to the meeting for patients with pulmonary hypertension at IKEM in September 2023 was a great opportunity. Such gatherings provide a platform for patients to connect with each other, share experiences, and gain valuable insights into pulmonary hypertension and its treatment. Meetings like these often feature

discussions with experts, allowing attendees to ask questions, learn about the latest developments in treatment and research, and receive support from both healthcare professionals and fellow patients. It's a chance to build a sense of community and find encouragement in facing the challenges associated with pulmonary hypertension.

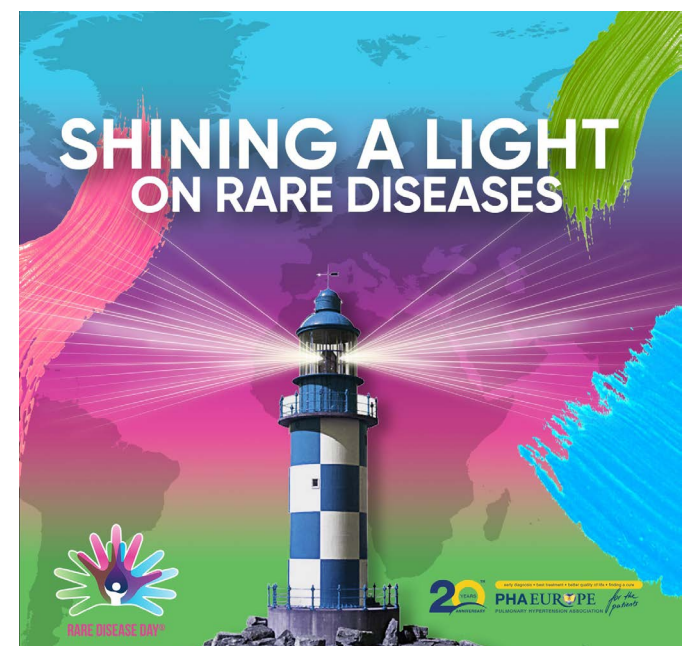


HUNGARY

We have many colours and we have manifested them many times and in numerous places throughout the year.

Among the representatives of several types of rare diseases, our association also participated in the World Day of Rare Diseases organized by RIROSZ (the Hungarian Federation of Rare Diseases).

We also raised awareness on social media that pulmonary hypertension is one of those rare diseases. The fabulous, colourful visual materials of PHA Europe attracted the attention of the audience.



On the **PHA Europe - PHenomenal Art Exhibition** – we already have two presenters. This is the campaign that aims to show how creative activities help in the management of PH.



In the special form of PH, in chronic thromboembolic pulmonary hypertension (CTEPH), a surgical solution is recommended, rather than drug treatment. We are happy that balloon pulmonary angioplasty procedures have been successfully performed in Debrecen already for 6 years.

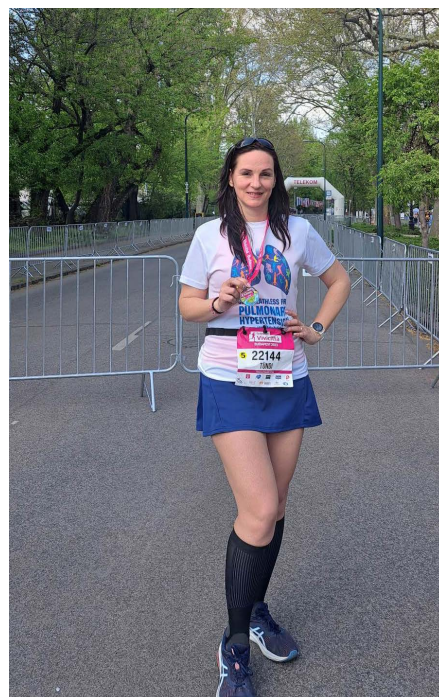
We consider it very important to improve the quality of life of those suffering from pulmonary hypertension by making as many dietary recommendations as possible available. For this reason, we have translated and made available the Nutrition brochure of PH Austria- Initiative Lungenhochdruck.

We were very pleased that a study was completed under the auspices of Semmelweis University on precisely which vitamins, minerals, and antioxidants can be taken to slow down chronic obstructive pulmonary disease (COPD), but this diet can also be useful for other lung diseases. One of the main problems is inflammation, and the recommended Mediterranean type diet is rich in antioxidants and vitamins. One of the authors of the study, Dr. János Varga, appeared in several places in the media and emphasized the importance of an appropriate diet and lifestyle.

You can see further details here:

https://semmelweis.hu/pulmonologia/2023/11/09/a-helyes-etrend-javithat-a-copd-betegseggel-elok-allapotat/?fbclid=IwAR14JwbtpsHg8_37aQdQAAS8UV7WoAM16spq4YhAz4AWwf4MmlPdKEqsfuU

Our sports ambassadors were also active during the year. Tündi performed at the Vivicitta running race, then unfortunately got injured, but we hope she will completely recover soon. Gyuri also joined in, who gets breathless every day by running 10 kms for people suffering from pulmonary hypertension. Nóri also pushed her limits many times and in various places - Aldi Women's Running Gala, UltraBalaton, Spar Marathon, even during her vacation in Portugal – feeling similar struggle for oxygen as the PH patients can experience during their daily activities.



Dóra also completed a 2.3 kms walk at the Spar Marathon. It's not a long distance, but for someone with PH, it's a big achievement to walk all the way. She was a member of the team of the Hungarian Transplant Federation, it cannot be said enough times that 'Organ transplantation' saves lives. At the race, we also raised awareness for Pulmonary Hypertension with the RIROSZ team.



The FitKondi Running Club is a charity running club. In addition to participating in regular training sessions, its members always collect donations for a good cause. With the recommendation and support of our sports ambassador Nóri, this collection was carried out for our association for 9 months in 2023. We are very grateful that, on the occasion of World



PH Day, a whole team agreed to fulfill an unusual challenge for us, to raise awareness to pulmonary hypertension and our association. Posts about the team and the race were very popular on our FB page, drawing attention to ways of making donations and offering 1% of PIT. The collected donation has been handed over to our association recently.



Our other fundraising activity was the collection of plastic caps. Usually, we deliver the caps once a year, this year was no exception.



We are proud of our doctors, who continuously educate themselves and perform excellent scientific activities.

Our doctor Péter Andrea has defended her PhD.



This year, Dr. Csóza Györgyi received state recognition for her devoted work and professional commitment after Dr. Kristóf Karlócai's earlier award.



Dr. Karlócai Kristóf cooperates in the project of ERN-Lung (European Reference Network for rare respiratory diseases) called „Go East”. The main aim of this initiative is to include healthcare providers from Eastern-European countries. So far, there is no center for pulmonary hypertension, which is a member of ERN-Lung, so our Hungarian PH association is happy that initial talks started between ERN-Lung and one of the biggest PH Centers, with the cooperation of Dr.Mészáros Gergely. Luckily, the Pulmonology Clinic is already a member of ERN-Lung, together with other rare lung diseases, so we hope that the process will go smoothly. The continuous education and the participation in projects is not only important for our doctors, but also for our association.

In November we participated on the annual PH conference of PHA Europe. We came home with a lot of useful information and it was nice to meet the fellow associations.

There is always some knowledge acquire of patient organizations. We try to take advantage of every opportunity where we can listen to experiences, where others share good practices with us that are maybe worth adopting, and where we can have



discussions with our peers about the difficulties we are facing.

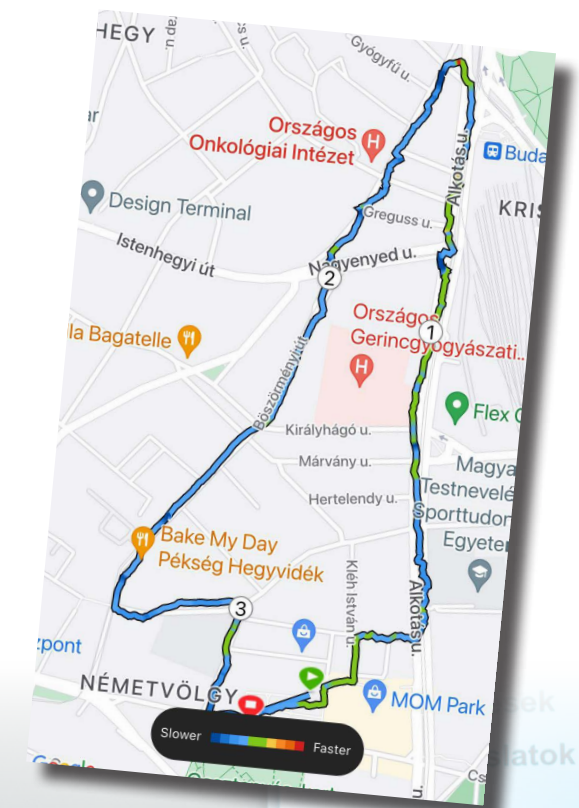
For this reason, the Patient Organization Meetup event organized by the Association of Innovative Pharmaceutical Manufacturers is very much appreciated. On this event, we had the opportunity to listen to useful presentations and participate in workshops, where we went through the problems the associations are facing, and the possible solutions.

To continue this education, we became students of the Patient Organization Academy and continue to study.

One of our association's members, István, has drawn a Christmas tree by walking. Let us wish Happy Holidays to everyone with this!

Eszter Csabuda -Tüdőér Egylet
www.tudoer.hu

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



ISRAEL

difficult. Our association spends hours on calls with patients and their carers providing over-the-phone support and understanding.

Also, there are many patients, who have been forced to leave their homes for many weeks due to repeated bombings of their city or their homes not being safe. They need assistance in creating a space in their temporary dwelling that is suitable to their medical limitations, they need oxygen in their new place, but they could not take the oxygen concentrators with them because of its weight. Patients need help with ensuring they have access to their medication and treatment or follow up with doctors or PH Centers. We have managed to secure subsidized taxi fares for these patients, and we are working on assisting them with their set up and making sure their temporary homes are suitable. The association is also continuing our efforts to raise funds to purchase portable oxygen concentrators that will allow them to move around in their new homes with attached oxygen. We have thus far succeeded in finding a donation for 2 such portable oxygen concentrators from one of our pharma partners, who maintain constant contact with our association. We hope to report on an end of the war, with life returning to some level of normal. We know there will be much work to do after the war with support for both physical and mental needs of the patients.

The members of the Israeli Association for Pulmonary Hypertension are currently facing a very difficult and complex situation due to the war that is taking place in Israel. All activities for the year which were planned, and any other forms of engagement, have been put on hold, and we find ourselves focused only on ensuring that our patients are supported. The struggles exist on many levels - Our patients with pulmonary hypertension find it very difficult to breathe with every slight effort they make, so that when the sirens indicating the bombs coming are heard and they have between 60 seconds to 2 minutes to run to a protected room, they cannot do so, so as not to pass out from the respiratory effort. Patients who are on the way to the hospital when a siren goes off, have to get out of their vehicle and lie on the ground, but this is simply not practical for them, because they are unable to bend down due to the respiratory effort involved. This has caused great anxiety in many patients who experienced it first hand, when on the one hand they cannot do what is required according to the emergency guidelines, and on the other hand they cannot protect themselves. Anxieties for these seriously ill patients make their already difficult cardiac condition even more



ITALY AMIP

In the last 4 months, the activity of the Pulmonary Hypertension Patients Association has been truly constant. There were no weeks during which there were no events or institutional meetings.

On the 6th and 7th of October, we participated in the national conference titled "Knowing and treating embolism and pulmonary hypertension". This was very interesting. It has opened our eyes to future lines for screening that also concern pulmonary hypertension patients.



On October 14th, in a beautiful farmhouse in Pavia, Lombardy, we held a meeting between Lombard doctors and patients being treated. The absolutely informal atmosphere allowed us to discover new horizons for defeating the disease or improving the quality of life. Doctors and patients discussed constructivelyin short, it brought forth a fantastic emotion.



On October 21st, we held the doctor/patient meeting in Rome....incredible joy.



On the 27th and 28th of October, we were present at the conference of the Italian Pulmonary Hypertension Network (IPHnet) in Bari. We made our voices heard there too.



From the 8th to the 12th of November we met again with our European friends in Barcelona. What to say! We were able to see that the spirit of collaboration, the intent to unite, the fun of being together, the extension to our friends from Argentina, China, and Japan, and the very interesting presentations we experienced for four full days. Thank very much for the commitment made by our friends on the board and the staff....they are a security point for all of us.

On November 18th, we held the doctor/patient meeting in Palermo....in this case too, incredible joy.

We participated in numerous events organized by the institutions (The country of rfarity – Naples), Janssen Patient Association Lab – Milan – MSD Global Patient Voice Group Meeting - Milan – Laboratory of the patients – AOP...and others scheduled in the coming months.

In this article, we want to write only a flash.... but the photos are very interesting.

*Togheter we can
Vittorio*



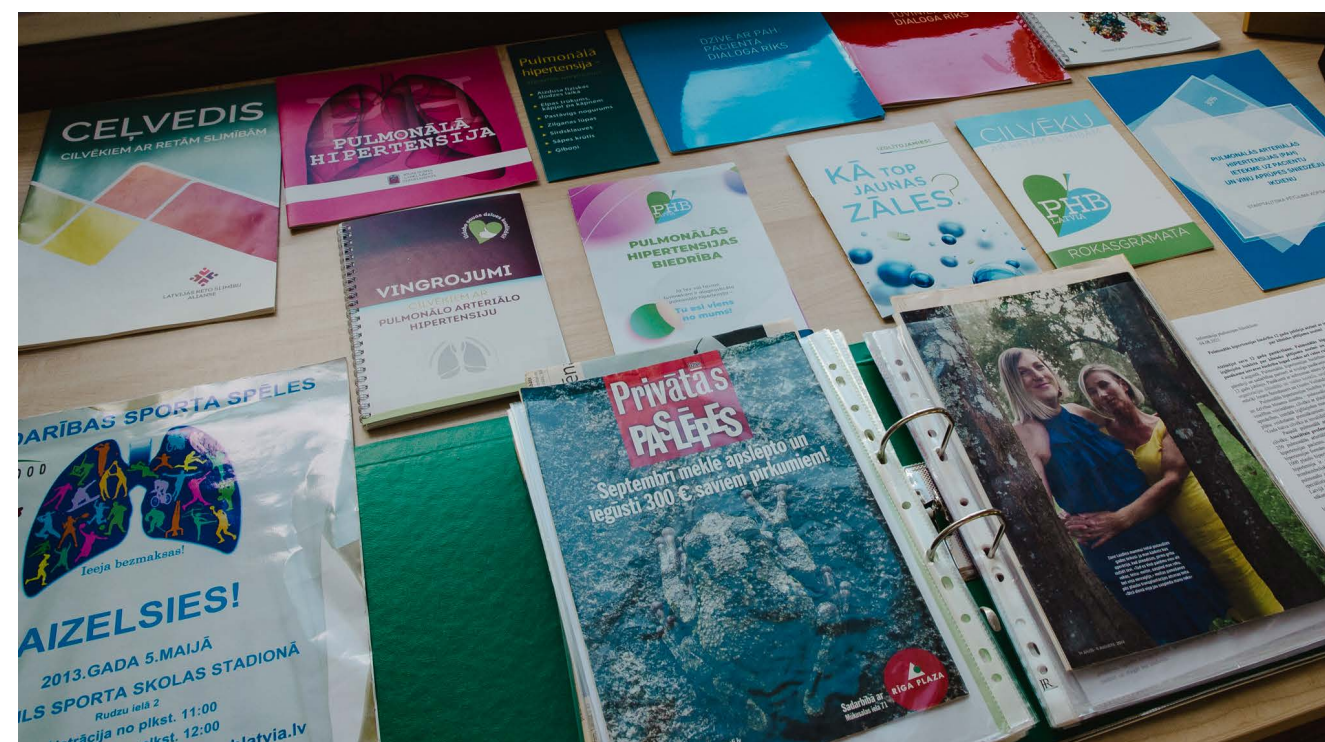
LATVIA

PHA Latvia's Dynamic Journey and Impact in 2023

NGO FOUNDATION PROJECT "STRENGTH IS US!"

The year 2023 unfolded a mosaic of impactful endeavors within Latvia's pulmonary hypertension community. One significant initiative, the project „Strength is Us!” received support from the Society Integration Foundation. Spanning over ten months, it aimed to fortify the association's resources, expand its membership, commemorate its 12th anniversary, champion patient interests, provide a mobile phone help-line, and psychological support, and amplify public awareness about the association's endeavours and Latvia's healthcare landscape.

Throughout this journey, milestones were achieved, including the creation of an informative flyer, targeting potential new PHA Latvia members, the addition of 8 new members and 6 volunteers, provision of 64 consultations, sharing 138 posts on social networks, hosting a jubilant anniversary event, initiating a discussion on the Patient Rights Law amendments, delivering 2 expert opinions, and collaborating with the Latvian Physiotherapists Association to develop a pilot project for a PH physiotherapy program in Latvia.



12TH ANNIVERSARY CELEBRATION

One significant milestone for the association was its 12th-anniversary celebration held on August 4th, 2023. The celebration, hosted at the NGO House in Riga, featured a heartfelt concert by Joran Steinhauer and Guntis Veilands. The event, moderated by PHA Latvia's Chairperson Ieva Plume, alongside TV personality Kaspars Berzins, welcomed 53 attendees to explore the association's history, engage in informative material exhibition, and relish in networking.

Moreover, the association also created an informative material focusing on clinical research. This material aimed to educate the public, particularly individuals affected by pulmonary arterial hypertension, about regulatory norms in clinical research, various research phases, their practical goals, and crucial considerations for those contemplating participation in such studies. Ieva Plume, the association's leader and the author of the material, emphasized the significance of informed consent when patients agree to participate in clinical research.



During celebration, participants engaged in an interactive game called "Patients' Rights and Responsibilities", organized by the Latvian Alliance of Rare Diseases. Through discussions and role-play scenarios, attendees explored and pondered upon aspects of patients' rights and actions in specific situations.

The jubilee celebration was live-streamed on the PHA Latvia's YouTube channel, enabling those unable to attend physically, especially individuals with health limitations, to partake in and experience the warmth and joy of the celebration from their homes.



PARTICIPATION IN CONFERENCES AND SCIENTIFIC EVENTS

On January 20th, 2023, physiotherapist Lina Puga defended a pioneering dissertation on integrated physiotherapy for PAH patients „Integrated and Remote-Monitored Physiotherapy Program in an Interdisciplinary Treatment Approach for Patients with Pulmonary Arterial Hypertension”. It is an outstanding event in the context of Latvia's rehabilitation and physiotherapy development. Ieva Plume and Dr. med. Andris Skride joined the dissertation defense, adding their voices and insights to the discussion.



One of the highlights this year was the 4th Baltic Pulmonary Hypertension Conference, which was held in Riga Stradins University on the 21st of April, representing the research work in PAH field to achieve new therapeutic targets and better quality of life goals for patients living with PAH. The representatives of the association Ieva Plume, Gunita Skaldere-Darmudasa, Zane Lazdina, Inita Lazdina, Linda Romanovska, Arina Bazarbajeva participated in the conference, and the Chair of PHA Latvia Ieva Plume gave a short opening speech at the conference.

Ieva Plume also participated in the EURORDIS conference, working together with delegates



from the USA, Latin America, Croatia, UK, and the Netherlands at the Mental Health workshop in Stockholm in May 2023.

The Congress organized by the European Respiratory Society and the European Lung Foundation in Milan in September 2023 was both exciting and beneficial. Two delegates from PHA Latvia, Ieva Plume and Mark Plume, participated in this congress.

At the Annual PH European Conference – APHEC 2023, which took place in Castelldefels, Spain, from November 8th to 12th, the Board member of PHA Latvia, Gunita Skaldere-Darmudasa, and active member of the community, Ieva Araja, participated.



INFORMATION IS POWER

PHA Latvia represents 250 PAH and 50 CTEPH patients in Latvia. The continuous work to raise awareness in society about PAH is never ending. Social media plays a major role, where we have been active this year posting and publishing all the information about our events, activities, news, and articles. In this way, we have also raised publicity of our association, gained new followers, and members.

In collaboration with the Latvian Alliance of Rare Diseases, we disseminated Rare Disease Day 2024 campaign materials and participated in the photo session for people living with rare diseases. We also took part in the informative campaign initiated by PHA Europe during the Pulmonary Hypertension Day celebration.

PHA Latvia's actuality of this year have been focused on participating in clinical trials and information spreading on importance of clinical research in the field of PAH. As all of us know, that work in research and development of new medication and technologies to treat PAH is ongoing all over the world. PHA Latvia has released an educational brochure detailing the process of creating new medication and emphasizing the significant role that each patient's participation in clinical trials plays. In line with this concept, we've also developed video content to underscore the aspects of participation in clinical trials through real-life patient stories.

All informational materials released this year are available in both printed and digital formats, including the association's flyer and the brochure on clinical research.

Additionally, an informational video reel on this topic has been uploaded to the association's YouTube channel and social media platforms.

Spēks esam mēs! Mūsu sasniegumi

Cilvēki un atbalsts:

- 8 jauni biedri
- 6 brīvprātīgie
- 64 konsultācijas cilvēkiem ar PH

Sabiedrības informēšana:

- 138 ieraksti sociālajos tīklos
- 7 raksti tīmekļa vietnē

PHB 12 gadu jubileja:

- Līdzdalības pasākums ar 53 dalībniekiem
- Iedvesma un izglītošanās
- Dokumentēta PHB vēsture

Resursi:

- Tehniski uzlabota vietne www.phlatvia.lv
- Nodrošināts biedrības ikdienas darbs

Interesu pārstāvība:

- Sarīkota diskusija par Pacientu tiesību likuma grozījumiem
- 2 atzinumi, 1 priekšlikums ārstēšanās pieejamībai
- Sadarbībā ar partneriem izstrādāts pilotprojekts PH fizioterapijas programmai
- Tīkšanās ar LR Prezidentu, LR Veselības ministru, dalība sēdēs un darba grupās

Kultūras ministrija, Sabiedrības integrācijas fonds, PULMONĀLĀS HIPERTENSIJAS BIEDRĪBA



ADVOCACY AND RIGHTS OF PATIENTS

Throughout 2023, Ieva Plume contributed to the National Rare Disease Plan monitoring working group at the Ministry of Health and engaged in significant discussions, including meetings with the President of Latvia, the Minister of Health, and sessions within



the Parliament's Social Committee, and the Rare Disease Coordination Centre. PHA Latvia proactively submitted two proposals aimed at enhancing health services for PAH patients in Latvia. On September 19th, 2023 Ieva Plume and Gunita Skaldere-Darmudasa organized a crucial discussion regarding changes in patient rights legislation concerning the expression of patient will in potential future situations. This important discussion on patient rights legislation engaged a diverse panel and garnered rich insights from anesthesiologists, legal experts, representatives of the Ministry of Health, PAH patients, and patients' advocates.

Consistently active throughout the year, PHA Latvia remained a committed member of both the Network of Patient Organizations in Latvia and the Latvian Alliance of Rare Diseases. Ieva Plume was elected as a board member in the latter. Presently, the PHA Latvia eagerly awaits the results of the state pilot projects' competition for the establishment of a PH physiotherapy program in Latvia. PHA Latvia stands as a project partner with Riga Stradins University and the Latvian Association of Physiotherapy in this endeavour.

THE AWARD OF THE OMBUDSMAN



This year has unfolded with a tapestry of delightful surprises. In a grand ceremony on December 5th, 2023, Ieva Plume, the Chairperson of PHA Latvia, was bestowed with the Annual Award for Support People with Disabilities by the Ombudsman of the Republic of Latvia in the category "Courage". This accolade heralded her fervent dedication, actively championing the cause of individuals with disabilities, staunchly advocating for their rights and interests.

*Article by
Ieva Plume
Gunita Skaldere-Darmudasa*

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[@phlatvia](https://www.instagram.com/phlatvia/)

THE NETHERLANDS

FULL AND FESTIVE PULMONARY HYPERTENSION INFORMATION DAY

The room is full, chairs even have to be added. "It's incredibly nice that all of you have come today," says Louise Bouman. The theme of this day is "20 years moving forward together," referring to the association's twenty-year anniversary. Established at the urging of Dr. Anco Boonstra, she explains. "He was a strong advocate for an independent patient association and 'recruited' Wim Patist as chairman." She takes a brief look at the history. It goes from the first information day in 2001 (even before the foundation existed and still without social media and with hardly any internet) to the first change in

leadership in 2009. She talks about the extensive lobbying with insurers, led by the late chairman Ferdinand Bolsius. And she thanks the founders and former board members for all their work. Louise herself took over in 2018. She invested heavily in social media and in collaboration with PH nurses, PH doctors, pharmaceutical companies, and medical wholesalers. "The lines of communication are short, and that's incredibly nice!" In the past twenty years, the importance of the association has become evident, Louise concludes. "With great thanks for your input," she tells everyone

MEDICINE RESEARCH

The first speaker on the agenda is Thomas Koudstaal, a pulmonologist at Erasmus MC. He talks about non-clinical research (learning more about a disease to identify a target for treatment) and explains that there are different types of drug research. "Research for a new drug when there is nothing yet; research for a better treatment than what already exists, or research to see if an existing drug can also be used for another disease." Clinical research, he assumes, is familiar to many of you. "Many of you are or have been involved in phase 3 research." After phase 1 (is the drug safe) and phase 2 (does it work and what dosage), he explains that phase 3 is the most crucial. "Then we assess whether the new drug works better than the existing treatment. Often, we conduct this in multiple countries and in a double-blind manner, meaning that both the patient and the doctor do not know who receives the drug and who receives a placebo." After completing the research and publishing in medical journals, phase 4 follows. "Then we observe in the real world, among all patients, whether it works and is the best option." Only then, he says, is there a new drug. It gets registered with the European Medicines

Agency (EMA), the Medicines Evaluation Board (CBG) evaluates whether it can be marketed in the Netherlands, and the Dutch Healthcare Institute determines whether it will be covered by basic health insurance. "On average, it takes about fifteen years from a brilliant idea in the laboratory to an approved drug that can be prescribed." That may sound long, he acknowledges, "but it is crucial to always prioritize safety."



NEW DEVELOPMENTS

The next speaker is Prof. Dr. Anton Vonk Noordegraaf, he tells about new developments and focuses particularly on the promising drug sotatercept, which is currently in a phase 3 study. In PAH, the pulmonary vessels become increasingly narrow due to an imbalance in the growth of the vessels, he explains first. How this mechanism – "the seesaw" – works has been known since 2013. However, several studies to restore the balance in the seesaw were halted in earlier phases because such a drug

caused too many side effects. With sotatercept, things seem to be going well. "This drug is going to make it," says Vonk Noordegraaf. "Although there are still many questions." For now, sotatercept is only administered in a study, and it seems that it should be used when existing medication yields insufficient results. "Exactly who qualifies is yet to be determined in the study." Approval is discussed in 2024, but unforeseen circumstances could arise. "So, the details may still change."

AFTERNOON WORKSHOPS

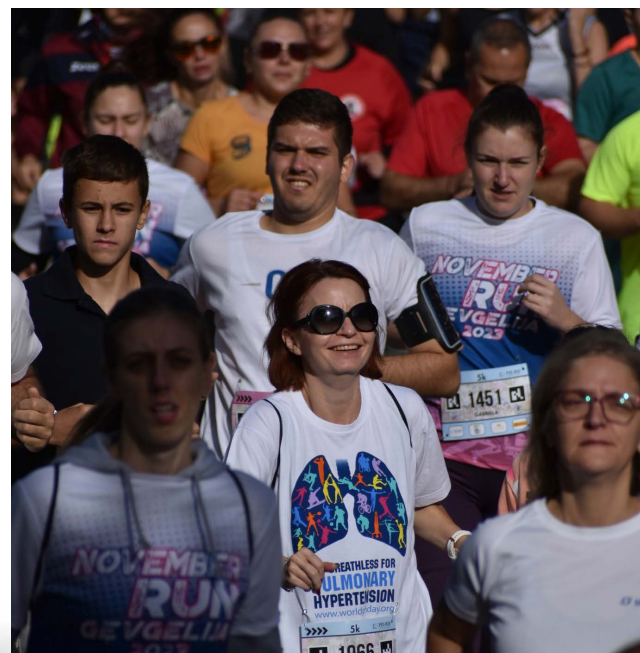
After the informative morning program, there's chair-yoga for a bit of relaxation. Some exercises elicit laughter or a chat with neighbours, but when it comes to stretching arms, almost everyone participates. After an extensive lunch and time to catch up with everyone and explore the informative booths, the group splits. Dr. Sanne Boerman and Nurse Specialist Ingrid Verheul from St. Antonius Hospital in Nieuwegein provide basic explanations about pulmonary hypertension in one room. In the other room, Margot Bos from the advocacy group Per Saldo discusses the personal budget (PGB). She

talks about the advantages of "personal control and determining where and when you receive care and from whom." But, she emphasizes, it also demands something. "With a PGB, you become the employer, you have to keep records, and you are personally responsible for the quality of care." For those considering a PGB, she offers some tips. "Prepare yourself well, use an independent client supporter when applying for a PGB, check www.pgb-test.nl to see if you are able to manage a PGB, and consider taking courses offered by Per Saldo."



NORTH MACEDONIA

This year was a long year fulfilled with a lot activities in which we participated and events during which we were hosts. We were part of a Marathon that happened for the third time in Gevgelija, a small city in Macedonia. People with "Get Breathless" shirts were all over the town, supporting PH patients to be stronger and letting them know that they are not alone, and that there is someone by their side. There were also runners which ran with "Get Breathless" shirts. We had flags all around the city and the running path, as well as flyers, banners, and many different types of promoting material with which we let people know what Pulmonary Hypertension actually is, that PH is here, that it exists, and that it is dangerous.



Also, we had our biggest supporters Valentina Uzunova, Nikola Nanchev, and Darko Prosev running through the country and in other countries supporting PH patients and spreading the awareness for Pulmonary Hypertension, taking the flag, shirts, banners, and flyers with the "Get Breathless" logo all around with them. They support us from the beginning and everywhere we go.



NORWAY

We started our first meeting after the summer holiday on Aug 28th.

We are planning a larger patient meeting for PH Norway with a weekend on the 19-21 April 2024.

As this is very costly, since Norway is a country with large distances, people have to fly from far away to attend our meeting, which we have planned at a hotel near Oslo airport.

Because of this, we have applied for a grant from a foundation called the DAM foundation.

The application involves a very elaborate application and follow-up to give us a chance to get the grant.

Most of our time this year has been devoted to this work, and we are waiting in suspense for the answer to the application.

We have made all the plans for the meeting with lecturers and ordered the hotel. If we do not get this grant, the meeting has to be cancelled and we have to start work with a much less elaborate meeting at a later date.

We will have lecturers from cardiologists with PH as a speciality and nurses and physiotherapists working with treatment and rehabilitation of PH.

On the last day, we will have an inspirational lecture from a well-known lecturer on the topic of "how to live a good life with a serious disease."

In addition to the work with the patient meeting we have attended meetings on how medicines are financed by the government and another meeting on how new methods are used when new medicines are applied for in Norway.

There has also been a meeting on the adult vaccination program, which we attended, and the significance of this for us with PH.

We have also had several meetings with MSD, Janssen, and Nordic Infucare about their work for PH and hopefully they will give us a small grant to enable us to hold our patient meeting in April.

I, Ann-Kathrin Bruheim, and Marit Nydahl Nicholsson attended the excellent GAM meeting in Barcelona in November for PHA Europe.

There are many new medicines on the way for PH and it was nice to learn about all the good work being done around the world.

*From
Ann-Kathrin Bruheim
board member PAH Norway*



PORTUGAL

Our main objectives this year has been to increase visibility and recognition as a Patient organization, improve patient engagement, strengthen and improve ties with Health professionals, recognizing their role as the initial point of contact with patients, and the focus on the importance and need for early diagnosis.

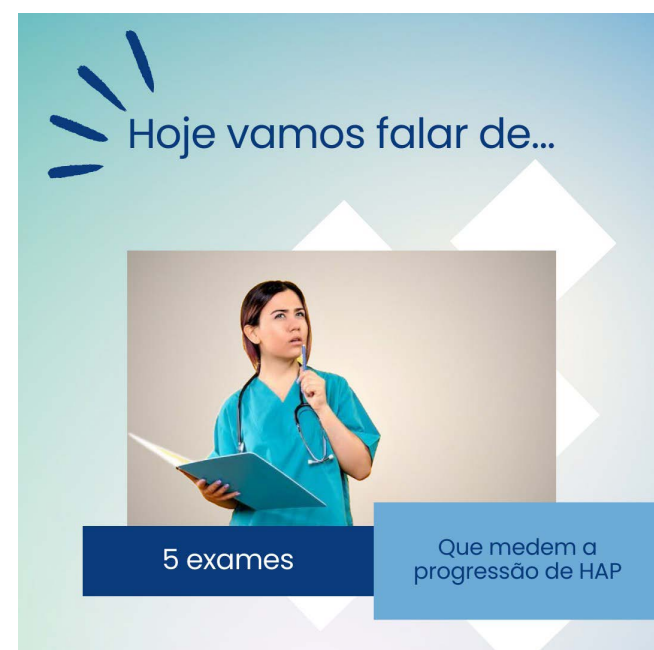
SOCIAL MEDIA

Initiatives were implemented to increase patient awareness regarding all of the association's services. This involved regular and diversified social media presence across platforms like Facebook, Instagram, and YouTube.

THREE NEW AND REGULAR TOPICS WERE INTRODUCED TO ENGAGE COMMUNITY:

- **Patient Testimonials:** sharing personal stories and experiences proved highly effective in creating a sense of unity and support within the community.
- **Health Literacy:** A new topic aimed at improving and understanding health knowledge.
- **Phenomenal News:** posting updates on articles related to Pulmonary Hypertension, keeping the community informed about the most recent developments and research.

A new informational brochure was produced, detailing the Patient Association's mission, as well as information regarding Pulmonary Hypertension, focusing on the importance of an early diagnosis to improve patients' outcomes with this condition. We are currently reconstructing our website, updating all information, regarding services, resources, and future events.



Laura Edelma's dedication to raising awareness for Pulmonary Hypertension through her passion for makeup artistry is truly inspiring. Her use of various channels to spread awareness demonstrates the power of individual advocacy, and the impact it can have on others facing similar health conditions. By sharing her personal journey with PH on national TV, Laura not only truly inspires many by highlighting the importance of resilience and determination, but serves as a reminder that dreams indeed come true in the face of adversity.



WEBINARS

The additional online webinars held by the PH association further demonstrate our commitment to education and support. The webinars are an excellent way of our patients getting involved by asking questions and getting an immediate response directly from the health professionals.

The webinar held in July, featuring cardiologist, and PH specialist Dr. Rui Plácido along with two patients, focused on the daily management of Pulmonary Hypertension, providing valuable insights into the crucial role patients play in their own process of treatment.



During the Awareness Month of November, a webinar was organized to specifically address Chronic Thromboembolic Pulmonary Hypertension (CTEPH). This webinar aimed to raise awareness, provide information, and discuss treatment options related to CTEPH, and was conducted by both Dra. Catia Ferreira, Nurse Sandra Mendes, and Dr. António Marinho. Both webinars were moderated by our PH patient Dulce Barbosa.



COMMUNITY EVENTS

In June, our PH patient association was present at the “Careto Air show”, promoted by the Aeroclube de Bragança, who celebrated their 60th anniversary. An event that attracted thousands of spectators to appreciate the aerobatics performed by national and international pilots, the Portuguese Airforce F16 fighter jets, and the traditional Careto skydivers (boys wearing masks and colourful fringe costumes with rattles attached to their waists) provided



chilling moments as they descended with our “Get Breathless for PH” flag.

Our presence at the event was fruitful, as we were able to raise awareness and sell our PH merchandise. Dulce Barbosa, a PH patient, was interviewed by the local radio, and we had the opportunity to interact with public figures. It was an excellent day enjoyed by all!



During a Petanca tournament in August, a team wearing the “Get breathless for Pulmonary Hypertension” t-shirts during a hot day not only supported the cause visually, but also showcased solidarity for all dealing with Pulmonary Hypertension. This kind of involvement in sporting events not only spreads awareness, but also fosters a sense of unity within the community.



APHP ENGAGEMENT

One of our members, Rita Rodrigues, participated in a scientific commission held on-line by the pharmaceutical company Janssen with several health professionals specializing in Pulmonary Hypertension from various reference centers in Portugal. Many issues were discussed, mainly the primordial need to increase PH literacy, not only in patients, but also health professionals. It was an excellent opportunity to share ongoing projects and engage in discussions on how best to overcome unmet needs within the health system.

Patricia Miranda’s representation of the association at the Gossamer Bio workshop titled „Understanding the patient perspective” in Vienna is a significant achievement. The opportunity to contribute to the patient’s viewpoint in such a workshop highlights the importance of collaboration between patient associations and pharmaceutical companies. Our Vice President Patricia Miranda also participated in a series of short videos for the health channel S+ (saúde +) facilitated by Janssen pharmaceutical. This was an excellent opportunity, and a credible platform to reach a broader audience, ensuring that accurate information was shared by knowledgeable professionals, thus clarifying existing myths surrounding PH.

Catia Rodrigues, the President of APHP, was invited by the esteemed HT - Health Team to participate in an exclusive Educational program - tailored to health professionals. Cátia presented the fundamental aspects of the organization since 2004, elucidating its mission and objectives within the PH community. This interaction between the association,

pharmaceutical companies, and health professionals demonstrates a positive synergy, emphasizing the benefits of mutual understanding, collaboration, and the potential for improving patient care and treatment outcomes. It’s a testament to the organization’s commitment to advocating for patients and ensuring that their voices are heard and considered in the development of therapies and treatments.

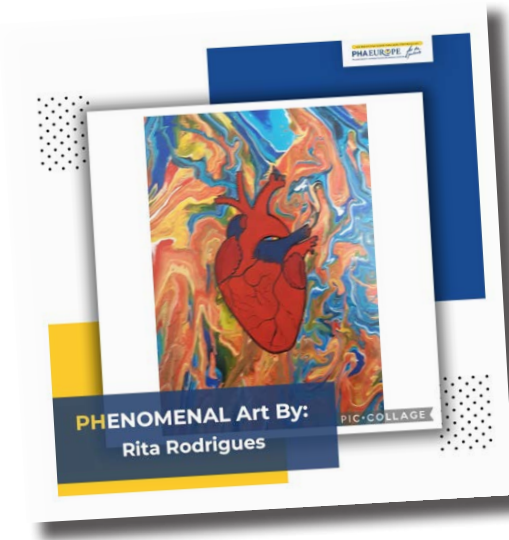


O [#cansaço](#) é o principal sintoma da Hipertensão Pulmonar? Foi uma das perguntas em destaque no "Fact-Check da Saúde" de ontem. Descubra a resposta dos nossos especialistas.
[Johnson & Johnson Associação Portuguesa de Hipertensão Pulmonar - APHP](#) [#hipertensãopulmonar](#) [#factcheck](#) [Serviço Nacional de Saúde](#)



PHENOMENAL ART

The „PHENOMENAL ART” campaign initiated by PHA Europe, inviting patients passionate about arts to share their creative works, within the concept of “art cures”, enhancing therapeutic and transformative power, had a very positive impact on Rita Rodrigues (PH patient), who participated with various works. Rita’s involvement not only highlights the positive impact art can have on a patient’s well-being and healing, but also having artwork displayed in medical settings has the ability to uplift spirits, and provide a sense of accomplishment, especially when dealing with health challenges like Pulmonary Hypertension.



FUNDRAISING

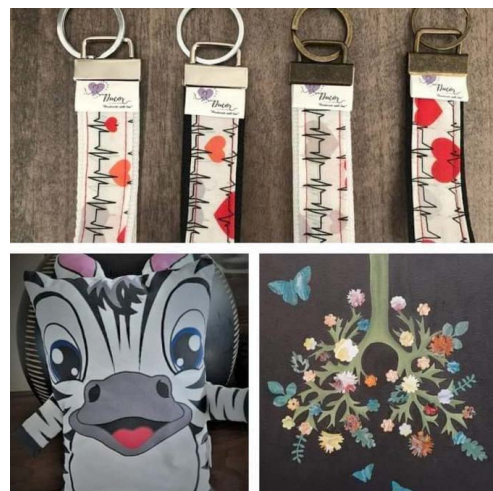
Our merchandise has been sold throughout the year, and it is now featured on our website and can be purchased at any time.

An on-line raffle was organized, in which 75€ was raised. This raffle was very special, as all the prizes were crafted by members, adding a personal touch and creating a sense of involvement among supporting participants.

These fundraising efforts serve multiple purposes: raising essential funds for the association’s activities, community engagement, and continuous spreading of Pulmonary Hypertension awareness.

As we embark on our 20th year as a dedicated patient organization for Pulmonary Hypertension, we are launching a challenge that puts the power of creativity in our patients’ hands. The top three

slogans selected, will not only win exciting prizes, but will represent our campaigns for PH awareness throughout the year.



Happy New Year 2024

SERBIA

STRATEGIC ENGAGEMENTS WITH INSTITUTIONAL REPRESENTATIVES

Throughout September and October, January, and February 2023-2024, PH Serbia, in collaboration with the National Organization for Rare Diseases of Serbia (NORBS), engaged in a series of pivotal meetings with representatives from key institutions, including the Ministry of Health and the Republic Fund for Health Insurance of Serbia. These discussions focused on enhancing the treatment and overall position of individuals suffering from rare diseases. Our continuous and proactive engagement with decision-makers has been instrumental in shaping an inclusive healthcare framework. A noteworthy session was dedicated to the Action Plan and developing a new Program for Rare Diseases for 2023-2025. Our collaboration with the Office at the

Ministry of the Republic of Serbia remains vigorous, with PH Serbia actively contributing data on patient challenges, membership demographics, medication needs, and medical equipment shortages. Our ongoing work is a testament to our dedication to bridging gaps between patients’ needs and healthcare provisions. Administrative Advocacy and Awareness Campaigns PH Serbia has been at the forefront of addressing administrative hurdles, particularly in mitigating medication shortages for PH patients. Our consistent correspondence and dialogue with healthcare institutions, pharmacies, and policymakers have yielded positive outcomes, ensuring that patient crises are promptly addressed.

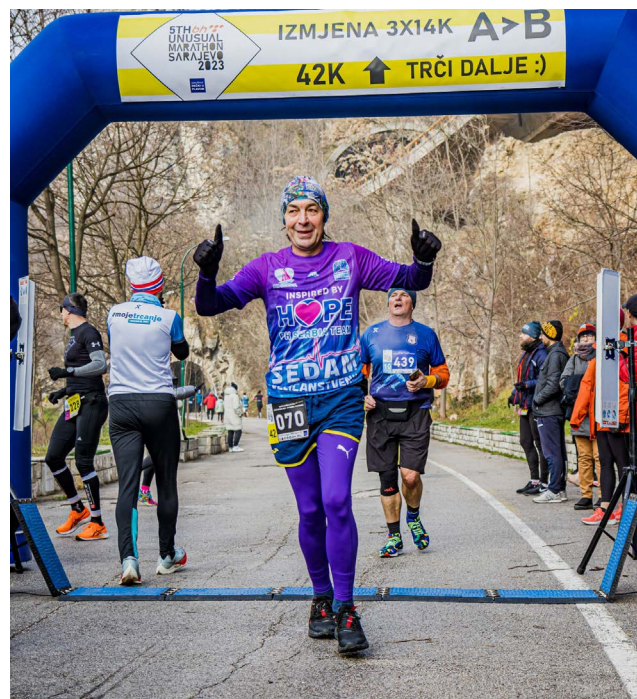
PSYCHOLOGICAL WORKSHOPS:

In 2023, PH Serbia organized a series of psychological workshops that covered various topics related to chronic diseases and accepting them, as well as solving multiple situations as a challenge that accompanies all people and families with chronic diseases. These workshops take time, especially in the winter season.



INSPIRED BY HOPE TEAM

During the winter and autumn periods, which host the majority of marathons, our campaign has proudly participated in over ten marathons, five ultramarathons, and several international ultra races across Europe. The images we send will speak louder than words, capturing the essence of our involvement and the spirit of these events. We are confident that these visual and narrative highlights will enrich Mariposa's winter edition, offering readers an inspiring look at our campaign's efforts and achievements during these bustling seasons.



INTERNATIONAL COLLABORATION AND MEDICAL INNOVATION

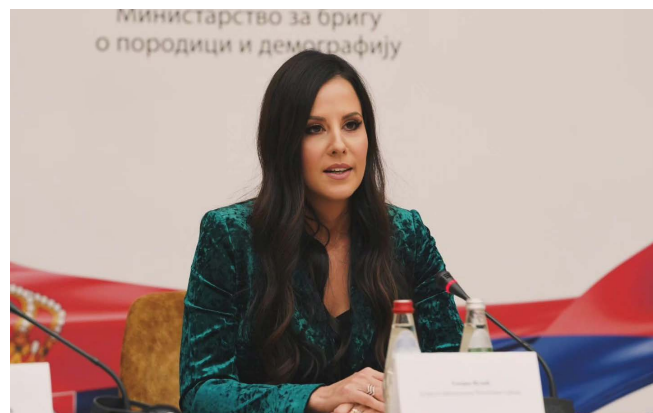
1. PH SERBIA HONORED AS GUEST OF A SPANISH ORGANIZATION

PH Serbia was honored as a guest at the 25th-anniversary celebration of a Spanish organization. Bilateral relations were strengthened, paving the way for mutual support and cooperation.

2. SPECIAL GUEST AT THE SERBIAN ACADEMY OF SCIENCES - PROF. DR. THOMAS LUSCHER, A PROMINENT CARDIOLOGY EXPERT AND DIRECTOR OF THE CENTER FOR MOLECULAR CARDIOLOGY AT THE UNIVERSITY OF ZURICH

We had an incredible afternoon at the Serbian Academy of Sciences and Arts with Prof. Dr. Thomas Luscher. Prof. Dr. Thomas Luscher, a prominent cardiology expert and director of the Center for Molecular Cardiology at the University of Zurich, was a special guest at the Serbian Academy of Sciences. Discussions on cutting-edge treatment methodologies and diagnostic approaches have ignited hope for a new era in medicine, particularly benefiting those afflicted by rare diseases with the promise of advanced molecular and AI-driven medical solutions, Patient Support, and Outreach. Prof. Luscher's broad spectrum of interests covers the entire field of cardiovascular medicine. His work includes everything, from disease prevention to treating coronary artery diseases and heart failure. He is recognized as one of the most cited scientists in the world and has received numerous research awards.





STARTING A GLOBAL PROJECT

Last but not least, PH Serbia launched the GLOBAL ImPHAct worldwide project in 2023. to bring pulmonary arterial hypertension and other lung diseases closer to as many people as possible, with a different approach, both to the audience, from the youngest to more mature patients. Through the multilingual content of all video clips dealing with other issues, and with the help of AI patient friends of the global online platform, it is unique in that it can experience significant expansion every day and provide a new way of information.



SLOVAKIA

ACTIVITIES OF PHA SLOVAKIA IN 2023

This year, we again commemorated Rare Disease Day with a campaign on our social networks. On this occasion, we conducted a webinar on PAH and organ transplantation in two classes of third-year students of the Secondary Medical School in Lučenec. Within this project called „When you run out of breath,” we also addressed another health school in Bratislava, where we prepared a discussion forum for post-matriculation students of the third year of physiotherapy. It was also attended by a member of the National Council. The school requested a yoga class for the students with a therapist who guides patients with PH.

At the end of May, during our activity for World PH Day, the general meeting of ZPPH took place. The goal was to evaluate activities for the year 2023, solve fundraising problems, and approve the work plan for the next year.

Since 2015, we regularly visit the Spa Sliač as part of a 6-day educational and rehabilitation stay. This stay is intended not only for patients with PH, but also for their caregivers. This year, 20 members attended

the stay, including 5 new ones, to whom we devoted ourselves intensively and during joint informal evening meetings, we exchanged our experience. The program consisted of two parts: in the morning, we devoted ourselves to education, and in the afternoon, to yoga exercises and meditations with Tibetan bowls. During the educational part, the members were addressed by a mental coach, the director of the Bielik Institute of Psychological Assistance from Zvolen, with his lecture „How to say YES to life despite the circumstances“. At the same time, we established a partnership with the institute, which solved the problem of free psychological counseling for patients and their caregivers. The advantage is that patients can contact each other for support, not only in person, but also in the form of a video call, by e-mail, or by phone. There was also a workshop aimed to acquire skills in decorating honeypots, and even men were interested in this activity. We devoted a part of our stay to culture. We visited a theater and a ballet performance in nearby Banská Štiavnica. We completed the spa procedures, used a natural swimming pool with healing water, went for walks in nature, and shared sittings.



One of the main priorities is to help PH patients. We are trying to implement points conclusions of the Call to action program into practice. On the occasion of the 7th All-Slovak Patient Conference of the Association for the Protection of Patients' Rights, the chairperson Iveta Makovníková gave a presentation on the priorities and needs of the patient association. The conference was held with the participation of policymakers in the field of healthcare in Slovakia.

Throughout the year, we are dedicated to spreading awareness about PH. Runners especially support us in this matter. This year, they completed 19 running competitions, including 3 relay runs from the Tatras to the Danube, Vltava run and Hory Bory. Relay runs are physically demanding, as they take place over two days in all weather conditions and the runs average at around 350km. The number of runners is increasing, and this year, they even formed an Ultra



team in the relay-race „From Tatras to Danube“. They carried photos of patients with the inscription „I run for you“ on their backs. This attracts the attention of the public, and the runners successfully helped us in spreading awareness about PH.

Our member Zuzka is certainly not lacking in empathy, as she tried as much as possible to help the patients and the association. Zuzka is a member of our cross-country team, which in September climbed the highest peak in the High Tatras, Gerlachovský štít at 2655m. In addition, she actively participated in the PH awareness month campaign. In her private hairdressing salon, she dedicated two days of her work to PH patients, and the association received €805 for the purpose of improving the quality of life of PH patients.



We participated in a global patient survey and other surveys related to PH. We intensively support the transplant program and organ donation. On November 22nd 2023, a meeting of the transplant team of the MOTOL hospital in Prague (Czech Republic) took place with the President of the Slovak Republic Zuzana Čapútová and representatives of transplanted patients. One of them was a member of our association, Tomáš. The expert team presented the lung transplant program to the President of the Slovak Republic, which has already included patients from Slovakia since 2018, and presented calls for better and in-time lung transplantation. Transplant patients spoke about their experiences with the president and the media. During the first and second Sundays of Advent, holy masses were held in 3 cities

in Slovakia for the dead who became organ donors. It's a nice opportunity to say thank you for saving a life.

A council meeting was held in early December, together with an expert advisory team of doctors and industry representatives. We evaluated the activity for the year 2023 and presented them with the work plan for the year 2024, including the financial budget. Together, we have solved the problems we are struggling with. The session was very pleasant and constructive. The conversations continued during the joint dinner. Great news include that we were able to re-establish contact with the MSD representative.



SLOVENIA

The second half of the year was dedicated to raising awareness about the symptoms of pulmonary hypertension, the importance of organ donation, and socialising with members.

YOU ARE MORE THAN ONE LIFE

Our President Tadeja Ravnik has made a wonderful link with the Slovenia Transplant Organisation and the Slovenian Transplant Association, where she has also highlighted pulmonary hypertension patients and transplantation as a last possibility for the disease itself.

Tadeja was an important part of the „You are more than one life” project and also of the October awareness on the importance of organ donation on the occasion of the European Day for Organ Donation and Transplantation.

Tadeja was a guest on the Good Morning show on Planet TV, where she shared her personal story, including pulmonary hypertension and heart transplantation.


SLOVENIJA
Slovenka s srcem iz Nemčije: 'To se dogaja v filmih, ne more se zgoditi meni'
 Ljubljana, 15.10.2023, 9:14 | Posodobljeno pred enim mesecem

PREDVIDEN ČAS BRANJA: 8 min

AVTOR
 Urška Železnik

Tadeja Ravnik je Slovenka s srcem iz Nemčije. Prejela ga je pred petimi leti, ko njeno zaradi redke oblike srčnega popuščanja ni moglo več učinkovito prečrpavati krvi. In zanj je neizmerno hvaležna. Da bo kdaj potrebovala obliko zdravljenja s presaditvijo, ni nikoli niti pomislila, saj v njeni družini ni bilo nobenih srčno-žilnih obolenj. "Spominim se, da sem že od vedno rada gledala zdravniške nadaljevanke. A ko sem jaz dobila tako diagnozo, sploh nisem mogla verjeti. To se meni ne more zgoditi. To se dogaja le v filmih," opisuje občutke, ko je izvedela, da bo njeno srce prenehalo biti, ona pa bo lahko živela naprej.

POP Hotel Transilvanija 3
 nedelja 16.50



▲ Article:
<https://www.24ur.com/novice/slovenija/slovenka-s-srcem-iz-nemcije-to-se-dogaja-v-filmih-ne-more-se-zgoditi-meni.html>

Ponudba srca velja le 30-minut

Akcija se je začela, ker je zvočni signal na sedežu Eurotransplanta naznanil novega darovalca. Koordinacijski center na Nizozemskem je povezava med darovalci in prejemniki. Deluje 24 ur na dan, sedem dni v tednu. Združuje 8 držav in 79 transplantacijskih centrov. Okoli 13.200 bolnikov trenutno čaka na skupnem seznamu. Direktor Slovenija transplanta **Andrej Gadžijev** pojasni, kako poteka postopek ujemanja in iskanja najprimernejšega prejemnika: "Vsi pacienti, ki potrebujejo zdravljenje s presaditvijo organov, so vodeni centralno v posebnem računalniku računalniku v Leidnu."

FOTO: Živa Salobir



▲ Article:
24 ur: <https://www.24ur.com/novice/slovenija/z-letalom-po-srce.html>

Jutro na Planetu je v kraju Planet TV.

18. oktober · Ljubljana ·

Ali ste vedeli, da en človek lahko z darovanjem organov po smrti reši do devet življenj? Slovenija je po presaditvah srca na prvem mestu, saj opravimo skoraj 14 presaditev na milijon prebivalcev. Danes smo spoznali eno takšno zgodbo. Govorili smo s prejemnico podarjenega srca Tadejo Ravnik.

Planet TV



▲ Article:
Good morning show: <https://www.facebook.com/JutroNaPlanetu/videos/1012472896748734>

TRIP FOR MEMBERS AND GREETINGS TO ALL NEW PH FIGHTERS

We organised a day trip for the members of the association to the Sečovlje Saltpans Natural Park, which are one of the few salt pans in the world that produce salt in the traditional way, which makes our Slovenian salt even better. The sunny weather brought us into the real summer. We enjoyed a perfectly guided tour, chatted, laughed, exchanged experiences, made new friends, and breathed in the sea air, which is good for patients. Lunch was provided by Master Chef Darko, and it was a tasty end to another wonderful gathering of like-minded people.



A NEW GREAT ACHIEVEMENT FOR SLOVENIAN HEALTHCARE

Zdravje

Ksenja Tratnik

23. november 2023 ob 9:58

Ljubljana - MMC RTV SLO

Ko telo podhladijo in odstranijo vso kri iz telesa, imajo 20 minut za odstranitev strdkov

Za ljubljanskimi kirurzi je že deset operacij, do konca leta načrtujejo prvo samostojno

Kirurzi UKC Ljubljana so ob pomoči tujih strokovnjakov v letu dni izvedli deset operacij, pri kateri odstranijo strdke iz najgloblji plasti pljučnih žil, medtem ko pacientu odstranijo vso kri iz telesa in ga globoko podhladijo.

Do konca leta načrtujejo tudi prvo samostojno izvedbo posega.

Piljučna tromboembolizacija je poseg, ki ga zdravniki lahko izvedejo pri bolnikih z redko boleznijo: kronično tromboembolično pljučno hipertenzijo. Ki se pojavi pri 2-4 odstotkih bolnikov po preboleli pljučni emboliji, pri katerih telo strdke ni raztopilo z ustreznimi antikoagulačnimi zdravili (zdravili za redčenje krvi), zato jih je treba odstraniti mehansko. Prve tovrstne operacije so opravili v 60. letih prejšnjega stoletja, vendar je bila takrat umrljivost zelo visoka, v zadnjem desetletju oz. dvehi pa so postale rutinske in varne operacije, sta v pogovoru za MMC pojasnila gonilna sila izvajanja novega posega v Sloveniji, kardiologični kirurg Juš Kleša in internistka Polona Mlakar.

Slovenske bolnike, ki so bili primerni za to operacijo, so zadnjih 15 let pošiljali na Dunaj, letno so jih tam operirali približno pet. Med epidemijo covid se je sodelovanje okrmilo, na drugi strani pa so se okrepile ambicije ljubljanskih kirurgov, da bi operacije opravljali sami. S kolegom Slovencem, ki je v bolnišnici Royal Papworth v Cambridgeu – ta je za San Diegom v ZDA drugi največji center za tovrstne posege na svetu – leto dni preživel na subspécializaciji, so navezali stik s tamkajšnjimi kirurzi s Choo Yen Ngom na čelu. Ti so jih usmerjali pri operacijah, Yen Ng je bil tudi proktor pri izvedenih operacijah lanskega decembra ter aprila in oktobra letos, zdaj pa načrtujejo, da bodo do konca leta izvedli prvo samostojno operacijo, še naprej pa ohranjajo skupne konzilije z britanskim centrom.

Najmlajša operirana bolnica pri nas je bila stara 22 let, med desetimi operiranimi bolniki je bil tudi 30-letni športnik.

Zadnje iz sekcije



Operacijo izvajajo pri bolnikih, pri katerih zdravila ne raztopijo strdkov. Foto: UKC Ljubljana

DRUŠTVO
 PROSIMO, PODARITE NAM
 1% DOHODNINE

PREPROSTO IZPOLNITE
 V PRAVNOSTI VARNOSTI

▲ Article:
<https://www.rtvsl.si/zdravje/ko-telo-podhladijo-in-odstranijo-vso-kri-iz-telesa-imajo-20-minut-za-odstranitev-strdkov/689213>

Article: ▶
https://www.24ur.com/novice/slovenija/filmska-operacija-na-ukc-bolnika-podhladijo-in-mu-odstranijo-kri.html?utm_medium=Social&utm_source=Facebook&fbclid=IwAR2APjPYbR-Pe4dGbnGiKJUwdLyaiZpBSzUlhnIQXXxRh_5fH9Ljji0_ic#Echo-box=1698176306-1

Filmska operacija: bolnika podhladijo in mu odstranijo kri

Ljubljana, 24.10.2023, 18:11 | Posodobljeno pred enim mesecem

PREDVIDEN ČAS BRANJA: 2 min

AVTOR
 Tjaša Dugulin


KOMENTARJI
 20

Kljub vsem težavam v slovenskem zdravstvu naši strokovnjaki dosegajo nove mejnike in pišejo zelo uspešne zgodbe. Ekipa ljubljanskega kliničnega centra se je s pomočjo kolegov iz Cambridgea izurila v operaciji kot iz znanstvenofantastičnih filmov. Da bi iz najgloblji kotičkov pljučnega žilja odstranili strdke, ki se pri zdravljenju pljučne embolije niso raztopili, bolniku iz telesa odstranijo kri in ga globoko podhladijo, da bi ohranili možganske in ostale telesne funkcije. To je velika pridobitev za Slovenijo in širšo regijo, pravijo UKC Ljubljana, saj so morali takšne bolnike doslej pošiljati na Dunaj.

KANALA
PET - NED
 20.00

VIKEND ROBERTA DE NIRA

Iz 24UR: Filmska operacija



V največji bolnišnici v Sloveniji po novem operirajo bolnike s kronično tromboembolično pljučno hipertenzijo, ki bi jim sicer oslabilo srce. Ta se po navadi pojavi v nizkem odstotku pri bolnikih s prebolelo akutno pljučno embolijo, razlaga **Polona Mlakar** iz kliničnega oddelka za pljučne bolezni in alergije UKCL. "In pri teh bolnikih se strdki v bistvu ne raztopijo na ta način zdravljenja, ko dajemo zdravila za redčenje krvi in se na neki način organizirajo v pljučne arterije, tam zabrazgotinijo," še pove.

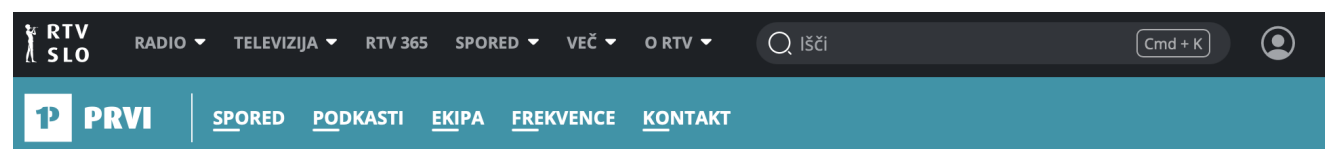
Great news for our patients and for the region itself - the South-Eastern Balkans, where these operations are not performed: a team from the Ljubljana Clinical Centre (led by associate prof. Juš Kšela, specialist in cardiovascular surgery, and assistant dr. Polona Mlakar, spec. internist), with the help of colleagues from Cambridge, has been trained to operate on patients with chronic thromboembolic pulmonary hypertension, which would otherwise

weaken their hearts. To remove clots from the deepest recesses of the pulmonary veins that have not dissolved with pulmonary embolism treatment, the patient's blood is removed from the body and deeply hypothermicised to preserve brain and other bodily functions. This is a great asset for Slovenia and the wider region, as such patients have had to be sent to Vienna until now.

RADIO TALK SHOW "MED ŠTIRIMI STENAMI"

In addition to our social media activities, November's awareness-raising-month for pulmonary hypertension was enriched by the radio show "Med štirimi stenami" on RTV Slovenia. We talked about Pulmonary Hypertension, with a focus on the thromboembolic form, which usually occurs after a pulmonary embolism. We presented the

remarkable achievements of Slovenian medicine, which impresses with its progress, and we added 2 personal stories of Tadeja and Tone, featuring how it all started for them, what symptoms they had, and how advanced medicine in Slovenia helped them to achieve an almost complete recovery.



20. 11. 2023 42 min

November - mesec ozaveščanja o pljučni hipertenziji

November je mesec ozaveščanja o pljučni hipertenziji. Gre za stanje z zvišanim krvnim tlakom v pljučnem krvnem obtoku, katerega posledica so lahko resni zapleti. Pomembno je, da je diagnoza postavljena čimbolj zgodaj. Gre sicer za redko bolezen, lahko pa se pojavi v vseh starostnih obdobjih. O soočenju, zdravljenju in življenju s pljučno hipertenzijo bomo govorili v tokratni oddaji. Goste je v studio Prvega povabila Lucija Fatur.

Med štirimi stenami

Lucija Fatur

We are glad that our activities and also our new website reached patients and their relatives and achieved a greater response and, as the doctors also pointed out, an earlier diagnosis, because pulmonary hypertension is talked about a lot and is thought of earlier!

*We wish you all the best of health, laughter,
and carefree breathing in 2024!*



SPAIN ANHP

ASOCIACIÓN NACIONAL DE HIPERTENSIÓN PULMONAR (ANHP) ESPAÑA.

During this year, 2023, The National Association of Pulmonary Hypertension (ANHP) has kept working to offer care and support to patients with Pulmonary Hypertension and their families.

Our aim is to spread and raise awareness about Pulmonary Hypertension, for which, in addition to World Pulmonary Hypertension Day, we have carried out actions for World Rare Disease Day in February, with the dissemination of the disease in the lottery tickets of the National lottery of Spain.



In the concert of the ONCE Foundation Choir, together with others of the associations located in Vicálvaro, Madrid, Spain, we were able to disclose

what the disease is, the importance of knowing the signs and symptoms to achieve an early diagnosis, and a better prognosis of the disease.



One of the most important campaigns in the last four months of the year has been the awareness campaign in November that the ANHP has carried out under our slogan/motto "Pulmonary Hypertension: Invisible but real". During this month we have organized different actions to make visible the invisibility of the disease.

November the 17th, we organised the "invisible but real" conference that took place at Hospital Universitario Ramón y Cajal in Madrid, in which we have great pulmonary Hypertension professionals, such as Dr. María Jesús del Cerro, who addressed the challenges for early diagnosis, and Dr. Pilar Escribano that addressed the reality in Pulmonary Hypertension research studies. We made use of GossamerBio to make the documentary INVISIBLES. Please feel free to access our Youtube Channel : https://www.youtube.com/watch?v=S406Bd9_Vmo, and in the meeting, we took the opportunity to hold a debate forum with the main characters of the documentary.



With the delivery from Ramón y Cajal Foundation of the collaborative check for the Oncolytic Viruses in Pulmonary Hypertension project, our commitment to research in HP became a reality



We retook the face-to-face meetings that we were holding once a year with our associates at the Annual Meeting of the Member's Assembly. This current year, we held it from the 2nd until the 4th of June. In the Assembly we had the participation of Dr. Domingo, a pulmonologist specialized in



Pulmonary Hypertension at Miguel Servet Hospital in Zaragoza- Spain, with whom we were able to learn about the latest developments in the approach of Pulmonary Hypertension. That weekend, HP patients and their caregivers had the chance to exchange and share moments between them



Fundraising is one of the pillars of the association, not only to achieve funds for the services and activities of the entity, but also for the research fund that we have created in 2021. For this, we have relied on the collaboration of individuals associated

with the organization. The activities that have been carried out are:

-April, the 1st, XI SIERRA CODES TRIAL RACE organized by the Cofradía Nuestra Señora la Virgen de Codés, Navarra- Spain.

-Book sale "El Espinar su Iglesia" by the autor María Victoria Gutiérrez Rodríguez. Part of the money raised from the sale of the book went to the purposes of the association.

-11th November, a Charity Concert "Orquesta de Pulso y púa Lorenzo Moya"

-16th and 17th November, Solidarity market in Segovia.

-30th December, Villacastin Racing charity match in Segovia.

-Christmas Lottery Campaign.



We have also continued with the organization of our psychoeducational workshops and online seminars on topics about Pulmonary Hypertension. These actions have been carried out with an online format to reach a larger number of people, not only within a national level, but also abroad. During this year, we have continued with the mutual aid groups, starting two groups in online format with two meetings a month. One of the groups is aimed to patients with subcutaneous Treprostinil, and another for those who have already received a transplant, or may be on the transplant list.



This year, we have been finalists in the VI OAT Group Adherence Awards with our respiratory rehabilitation project for patients with PH, and we have also participated in webinars, conferences, and congresses throughout this year, carried out by entities to which we belong.

Hospital Universitario 12 de Octubre

FISIORESPI

i+12

Eficacia de un Programa de Rehabilitación Respiratoria domiciliaria en pacientes con hipertensión pulmonar. PROYECTO RESPIRA.

Juan Izquierdo García^{1,2}, Mar Esteban Lombarte³, Teresa García-Barredo Restegui⁴, Sara Heras Mathies⁴, M^{ra} Paz Sanz Ayán^{1,2,3} y Adrián Arranz Encuentra^{1,2,3}
¹Servicio de Rehabilitación del Hospital Universitario 12 de Octubre, ²Departamento de Radiología, Rehabilitación y Fisioterapia de la Universidad Complutense de Madrid, ³Fisiorespi, ⁴Asociación Nacional de Hipertensión Pulmonar, ⁵Instituto de Investigación 12 de Octubre

INTRODUCCIÓN

Los Programas de Rehabilitación Respiratoria (PRR) de 3-6 meses de duración han demostrado beneficios en pacientes con Hipertensión Pulmonar (HP). Pero existe falta de continuidad del PRR por falta de recursos domiciliarios y supervisión directa. Este proyecto refuerza los conocimientos adquiridos y estimula la continuación del PRR en domicilio con los recursos disponibles y bajo la supervisión de un fisioterapeuta especializado.

OBJETIVO

Se pretende mejorar y/o mantener la función respiratoria, capacidad funcional y tolerancia al ejercicio en PH.

Variable	Capacidad Funcional	Capacidad Respiratoria	Fuerza Muscular	Nivel Actividad Física	Calidad de vida
Método de evaluación	Test 6 minutos	Espirometría y PIM (Foto 1)	Hand Grip	Cuestionario IPAQ	Cuestionario SF-12

Foto 1

Foto 2

MATERIAL Y MÉTODOS

Estudio cuasiexperimental con 6 pacientes con HP. Se recogieron variables sociodemográficas (edad y sexo) y clínicas al inicio y 6 meses tras el PRR. Variables clínicas (Tabla 1): Capacidad funcional (Test de 6 minutos marcha (T6MM)), función respiratoria (espirometría y presión respiratoria), fuerza muscular (Hand Grip y SMM en brazos) y fragilidad (Short physical performance battery (SPPB)). El PRR consistió en ventilación dirigida, entrenamiento de la musculatura inspiratoria y periférica, y ejercicio de resistencia (Tabla 2). Se realizó una sesión de fisioterapia domiciliaria semanal el 1^{er} mes, y durante los 5 meses siguientes se realizó una consulta telefónica semanal y una sesión domiciliar mensual de recordatorio. Para estudiar los cambios en las variables se empleó la prueba t Student y el tamaño del efecto con el Cohen, con un nivel de significación de 5% (alfa 0.05).

RESULTADOS

De los pacientes reclutados, 4 pacientes terminaron el PRR domiciliario y 2 no: uno por comorbilidad no cardíaca (dolor depresivo) y otro por comorbilidad cardíaca (apicalización de la enfermedad). La edad media fue de 58,33 años (± 15,5 años) y 5 eran mujeres. Se introdujeron las variables índice de masa corporal (IMC) y frecuencia cardíaca (FC), y aumentaron los resultados en la espirometría, la fuerza de bíceps, la presión manual y los minutos recorridos en el T6MM. La fuerza de bíceps mejoró significativamente (p<0.05), volaron en el T6MM al 1^{er} segundo (FEV1), presión manual y SPPB tuvieron un tamaño del efecto mediano. El peso de flujo respiratorio (PFR), saturación de O₂, PIM, fuerza de bíceps y T6MM tuvieron un tamaño del efecto grande.

CONCLUSIONES

La supervisión y seguimiento de un PRR domiciliario a medio-largo plazo tras el PRR hospitalario tiene un impacto clínico moderado sobre función respiratoria, capacidad funcional y tolerancia al esfuerzo. Hay que seguir buscando modelos de PRR similares, que se adapten a la vida social, familiar y laboral de los pacientes.

Jornada concienciación de la Hipertensión Pulmonar

Viernes 17 de noviembre de 15:30 h a 18:00 h

Hospital Universitario Ramón y Cajal - Comunidad de Madrid
AULA JOAQUIN ORDUÑA

- Detección precoz en Hipertensión Pulmonar
- Visibilidad de la Hipertensión Pulmonar

LANZAMIENTO DOCUMENTAL INVISIBLES

Hipertensión Pulmonar. Invisible pero Real

Noviembre, mes de la concienciación

Para más información: www.hipertensionpulmonar.es/

Asociación Nacional de HIPERTENSIÓN PULMONAR

NEWS FROM EUROPEAN PH ASSOCIATIONS

SPAIN FCHP

1. SOLIDARITY SPORTING EVENTS

Improvised street dances by the Alma Calí Flamenco Dance Association of Barcelona, and Marea Rosa solidarity races, the proceeds of which went entirely to research into pulmonary hypertension.



2. MEETINGS IN HOSPITALS: PATIENT COUNCILS

Meetings in hospitals in the Community of Madrid within the Patients' Council were held, giving patients a voice in hospital decisions.



3. CONGRESS OF THE PLATFORM OF PATIENT ORGANIZATIONS

We participated in the VII POP Congress with the slogan „Protagonists in the construction of healthcare in Europe”.



4. MEETINGS WITH PUBLIC BODIES

Meetings with public bodies were held, in order to voice the needs in terms of disability and to find solutions to the problems of patients with Pulmonary Hypertension.



5. SOLIDARITY EVENTS

Solidarity weddings filled us with emotion, in which we have demonstrated the true meaning of a gift for the research of pulmonary hypertension. As well as a solidarity paella in a small town in Salamanca.



6. GOSSAMER WORK MEETING

We were part of a very productive working meeting on Pulmonary Hypertension with the Gossamer laboratory. This time with a different approach, where the patient is an integral part of the decision-making process.



Hope Through Research in Pulmonary Hypertension Webinar Series PHA LIVE

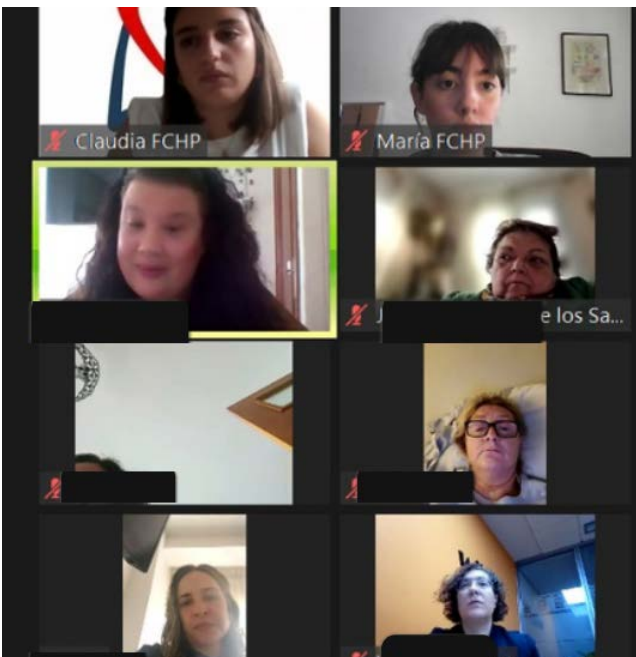
Hope Through Research in Pulmonary Hypertension: Emerging Developments Nov. 30, 2 p.m. EST

Hope Through Research in Pulmonary Hypertension: Clinical Trials Dec. 14, 2 p.m. EST



Register Now

Hosted by the Pulmonary Hypertension Association and Fundación Contra la Hipertensión Pulmonar



7. WINNERS OF THE PATIENT DIGITAL EMPOWERMENT AWARD

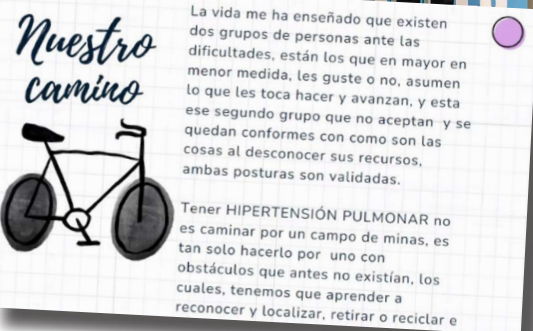
We received the Ennova Health Award as Digital Patient Empowerment Winners. We are proud to collaborate to improve the quality of life for patients with #PulmonaryHypertension with the PH Human app from The Janssen Pharmaceutical Companies of Johnson & Johnson.

8. PHA AND FCHP WEBINARS

The Pulmonary Hypertension Association, in collaboration with the Foundation Against Pulmonary Hypertension, is hosting two webinars, Hope Through Research in Pulmonary Hypertension series, featuring promising studies, and clinical trials and their process in both adults and children.

9. SUPERCAREGIVER AWARD WINNERS

The award went to Salvador Calderón for his story „En busca de aliento” (In Search of Breath), a book that explains the life of a person affected by pulmonary hypertension.



10. V TRAINING AND INFORMATION DAYS FOR PEOPLE AFFECTED BY PULMONARY HYPERTENSION, FAMILIES, AND TRANSPLANT RECIPIENTS

This year, we have the presence of **Dr. Alejandro Cruz** **cardiólogo del HU 12 de Octubre** and with geneticists **Jair Tenorio Tenorio y Natalia Natalia Gallego del INGEMM (HU La Paz)**. In addition, we will have a **taller de psicología con dinámicas** with our partners **María, Claudia and Laura García**. These are going to be very interesting.

11. XV ANNIVERSARY OF THE FOUNDATION AGAINST PULMONARY HYPERTENSION

Last Friday, December 1st, the Foundation Against Pulmonary Hypertension (FCHP) commemorated its fifteenth anniversary, marking a significant return to face-to-face events. The Hotel AC FERIA de Madrid was the setting for this emotional meeting, which was attended by prominent personalities in the field of health.



During the celebration led by our dear **Carlos García Hirschfeld**, who gave way to the emotional welcome of **Mr. Enrique Carazo**, president of the FCHP.



The grand opening was in charge of **Mrs. María Luz de los Mártires**, Director of Research and Teaching, **Mrs. Mónica Rodríguez** of the Spanish Federation of Rare Diseases, **Dr. Cristóbal Belda** Director of the Carlos III Health Institute, and **Mr. Juan Manuel Moreno Bonilla** President of the Junta de Andalucía, extended a warm welcome to the XV Anniversary of the FOUNDATION AGAINST PULMONARY HYPERTENSION. The event was divided into two round tables:

- CLINICAL SCIENTIFIC TABLE:**
- **Dr. Pilar Escribano** as moderator of the table (Cardiologist of the HU 12 de Octubre-Madrid).
 - **Dr. Sergio Alcolea** (Pneumologist HU La Paz-Madrid).
 - **Dr. Alejandro Cruz** (Cardiologist HU 12 Octubre-Madrid)
 - **Dr. Andrés Quezada** (Pneumologist HU 12 Octubre-Madrid)
 - **Dr. Natalia Gallego** (Researcher INGEMM HU La Paz-Madrid)
 - **Dr. María Álvarez** (Pediatric Cardiologist HU Ramón y Cajal-Madrid)
 - **Dr. Rafael Bravo** (HU Costa del Sol-Malaga)

We had a special guest, **Dr. Roham Zamanian**, who did not want to miss an important day such as the anniversary, and he also sent us a very encouraging video about Pulmonary Hypertension.



- MULTIDISCIPLINARY TABLE:**
- **Ms. Mirta Vázquez** (Nurse Pediatrics HU Ramón y Cajal-Madrid).
 - **Ms. Laura García** (Social Worker FCHP)
 - **Mrs. María Jiménez** (Psychologist FCHP)
 - **Ms. Celia Vargas** (Caregiver of a person affected with PH)
 - **Mrs. Paz Sanz** (Rehabilitation Physician of the HU 12 Octubre-Madrid)
 - **Dr. Joan Albert Barberá** (Pneumologist HU Clinic-Barcelona)
 - **Mrs. Mónica Rodríguez** (Board of Directors of the Spanish Federation of Rare Diseases).



The appointment of Honorary Patron 2023 was entrusted to **Dr. Juan José Ríos**, who gave the new title to **Dr. Juan Abarca Cidón**, President of HM Hospitals. And the Scientific Committee of the FCHP was enriched with the incorporation of **Dr. Alejandro Cruz**, cardiologist of HU 12 de Octubre, and **Dr. Jair Tenorio**, geneticist of HU 12 Octubre. It is an honor to have them on the team.



Dr. Maria Sancho gave us a detailed overview on the progress of the FCHP General Grant, awarded last year with a funding of 12,000 Euros. Also, **Dr. Jair Tenorio** shared the latest news related to the **PASIONHP GENETICS Project**, and **Dr. Joan Albert Barberá** updated us on the **EMPATHY Project**. Both projects are officially supported by the FCHP, which has earmarked 517,000 Euros for Pulmonary Hypertension research. As for the central cause, research, substantial funds were earmarked, including a check given by **D. Emilio Butragueño**, Patron of Honor of the FCHP, for 6,000 Euros for the **EMPATHY PROJECT**, and another of equal value for the **PASION HP GENETICS PROJECT**, led by **Dr. Barberá** and **Dr. Jair Tenorio**, respectively.



One of the most awaited moments was the Patient's Voice, where we were able to hear the stories of Dario, a young man helped by the FCHP to undergo a treatment that has allowed him to continue living, and that of Marina, a 15 year old girl who spoke about how she lives with Pulmonary Hypertension, a story of complete overcoming, and that managed to move all the attendees.

The international entities had their space as a mutual commitment to continue working together and aligned to seek projects that help with Pulmonary Hypertension in any of its fields. From the Pulmonary Association, it was Matt Granato, president and CEO of the entity, who spoke about the excellent relationship of both entities and the webinars that



are being conducted jointly on research and new clinical trials. In addition, Matt presented a check for \$13,200 to be used for research. Hall Skaara, on behalf of the European Pulmonary Hypertension Association, highlighted the great work carried out by the Pulmonary Hypertension Foundation in terms of dissemination, and the dedication of part of its funds to research. Hall left a phrase that touched our hearts: Together we make a difference and together we will win.



It is worth mentioning the presentation of awards to those who have significantly supported the Foundation's outreach and awareness-raising work. Special recognition was given to Mr. Fernando Díaz de la Guardia (Cuatro al Día, Mediaset), the Enrique Flores Foundation, Dr. Federico Larraya, and Dr. Inmaculada Guillén, Mr. Antón Morkin (TBX4 life), Dr. Sergio Cadenas, Dr. Gregorio Pérez Peñate, and the musical group Efecto Pasillo. Gregorio Pérez Peñate, and the musical group Efecto Pasillo, who wanted to share with us some of their songs live, and the transfer of the downloads of the song SIMILARES, whose funds raised will go to the research of Pulmonary Hypertension.



The closing of the celebration was in charge of the musical group Efecto Pasillo, marking a vibrant end. With the farewell words of Enrique Carazo, president of the Pulmonary Hypertension Foundation, we once again experienced a deep sense of pride for all the valuable support received in one of the most significant events dedicated to the fight against Pulmonary Hypertension. We thank everyone for being a part of this special day.



SPAIN HPE-ORG



ACTIVITIES MARIPOSA'S WINTER EDITION

In this current year, 2023, the activities we have carried out at **Hipertensión Pulmonar España Organización de Pacientes** have focused on fulfilling our social objective: delivering specialized care and services to patients with pulmonary hypertension and their families. To ensure the smooth operation of our activities and the organization, we have the need to continue our process of professionalization. This includes attending several training sessions, highlighting the most relevant training: **The Patient Organizations Leadership and Management Program at Deusto University.**

This year, following our main aim, we have continued offering our program "**Learning to Breathe**" to our members throughout 2023. This program includes several activities aimed at improving different aspects: Activities focused on enhancing psychological health such as psychological care workshops, **Meeting evenings**, and emotional management workshops. Activities aimed at improving physical health, such as **Yoga workshops** and "**Postural training**", as well as **nutrition workshops**. Also, we have activities directed towards enhancing social health, such as our mutual support groups, including "**Shall we have a coffee?**" and several specialized WhatsApp groups for more targeted support.

To reinforce our „Learning to Breathe” program, we have launched a new „**First Welcome**” program at the end of the year, with which we aim to respond to newcomers to our association and offer them accompaniment throughout their **Patient Journey**.



Tele –EPOC: Telemonitorización domiciliar de pacientes con EPOC (D GOLD). Inicio en I. cardíaca.

Mi viaje como paciente: semejante a Sacyl conecta.

Centro de Salud digital: educación para la salud.

Telepsiquiatría: video consulta, video conferencias.

Telerehabilitación: programa de entrenamientos adaptados por fisioterapia, avance del entrenamiento, chat entre pacientes.

Geri-Tool box: enfermeras visitan a domicilio a pacientes pluripatológicos con maletín digital. Consulta por teléfono con MFYC/hospital.

www.jadecare.eu

Our activities also include participation in **Conferences and Congresses**, where we attend as spokesperson and speakers, offering our viewpoint as expert patients and as an association dedicated to patients with pulmonary hypertension. We have taken part in events such as: **“La Acción Conjunta (JA) of JADECARE; the Rare Diseases Day at Vall d’Hebron Hospital; the 6th Forum of Patients with Respiratory Diseases (SEPAR patients), the SEPAR Committee Forum on Winter and Respiratory Infections in Adults: How do we get started?; the session on Experiences and Best Practices of Patient and Family Associations of Castilla and León; the annual HAP 360º meeting held in Madrid at the Hospital 12 de Octubre, and**

we could not miss one more year, **our attendance to the GAM and APHEC** organised by **PHA Europe**, where we could share different experiences with our European counterparts and get first-hand insights into the latest developments in pulmonary hypertension.

We also participated as speakers in the patient workshop and in the scientific conference of the 5th International Conference on Pulmonary Hypertension organised by the Hospital 12 de Octubre in Madrid on the 30th November and 1st of December, in which we highlighted our perspective as patients in the organisation of care in Pulmonary Hypertension.

Fem Vall d’Hebron amb tu

Vall d’Hebron
Barcelona Hospital Campus

Over the course of the year, at HPE-ORG Patients, we have succeeded in participating in the Solid Organ Transplant Commission at Vall d’Hebron Hospital, as part of the Participation program involving professionals and patient associations. Additionally, we are engaged in the collaborative resource “Actiu i Salut” by the Catalanian Public Health, promoting and sharing our activities with the residents. As part of this initiative and in observance of Pulmonary Hypertension Awareness Month, besides supporting PHA Europe’s awareness campaign on social media, we have conducted an in-person meeting in Sant Feliu de Llobregat, where the Clinical psychologist Alicia Navarro led a session focused on perception and health.



To finish our activities in 2023, we have had the honour of holding the first presidency of **National Coordinator of Minority Respiratory Diseases of FENAER**. In terms of political advocacy, we have participated in the joint document drawn up by **COCEMFE proposing 35 measures to the political parties for the inclusion of people with disabilities**, making visible the organic disability of having pulmonary hypertension, as well as continuing our collaborative project addressing unmet needs of patients with Pulmonary Hypertension and their families, **HAP NEEDS**, endorsed by the **scientific society SEPAR**, conducted across several Autonomous Communities. In June, we conducted the second part of this multidisciplinary workshop in the **Autonomous Community of Castilla y León**. This session involved following up on the proposals established in the initial phase and setting new improvement objectives in healthcare. Then in November, we went to **Valencian Community**, where we were assessing the situation of patients with pulmonary hypertension and outlined proposals for improvement.



PRIMERA ACOGIDA TRAS EL DIAGNÓSTICO

- SERVICIO SIO 1er CONTACTO
- FASE DE ACOGIDA
- ATENCIÓN PSICOLÓGICA

COLABORA: janssen

WWW.HIPERTENSIONPULMONAR.COM.LA.ASOCIACION.SERVICIOS

Propuestas electorales

4 de desembre
18:00
Centre Cívic Les Tòvalloles

DILLUNS SALUT
Percepció i salut: Veiem les coses, no com SON, sinó com SOM

Alicia Navarro Psicòloga
Ajuntament de Sant Feliu de Llobregat
Centre Cívic Les Tòvalloles
HIPERTENSION PULMONAR



Español English

EL INVIERNO Y LAS INFECCIONES RESPIRATORIAS EN EL ADULTO ¿CÓMO NOS PONEMOS EN MARCHA?



Si quieren hacer alguna pregunta, pueden enviarla a: pacientes@separ.es

ORGANIZADO POR
Sociedad Española
de Neumología
y Cirugía Torácica
SEPAR
COMITÉ ASIA
CON LA COLABORACIÓN
Pfizer



NEWS FROM EUROPEAN PH ASSOCIATIONS

UKRAINE PHA

During this year, the Ukrainian community of patients with pulmonary hypertension continued fighting for its life. It was a fight with both illness and military aggression. Many patients are still abroad and are not able to come back home.

However, we do believe in our victory and future of our patients in Ukraine!

Many families of our patients needed help with medicines, in covering transportation expenses, and assistance with visiting hospitals in Ukraine and abroad. We are extremely happy that we were able to help our wards.

Also, we have managed to help the PH Expert Center with handing over necessary medical products. During the year, we have also launched and are now implementing the program of NT-proBNP tests, which are currently not being paid by the state. With the help of our partners, we were able to make these tests free of charge for our patients.

We continue the program of providing patients with stationary and portable oxygen concentrators.

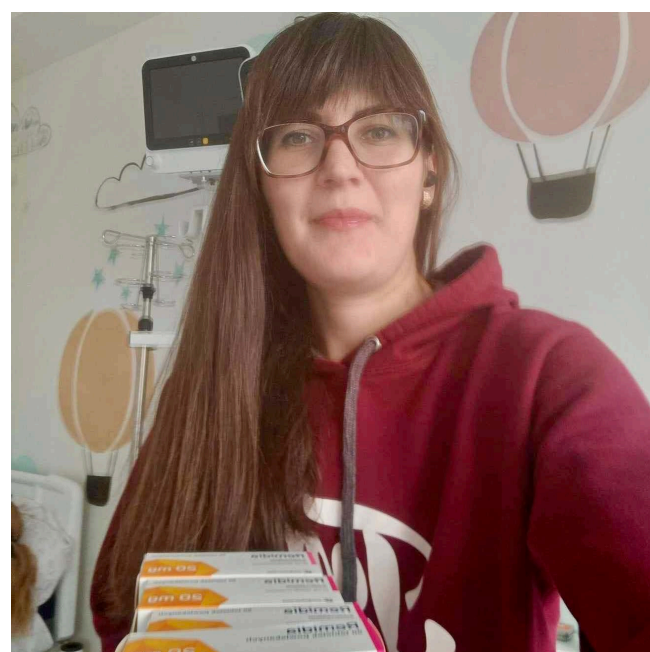
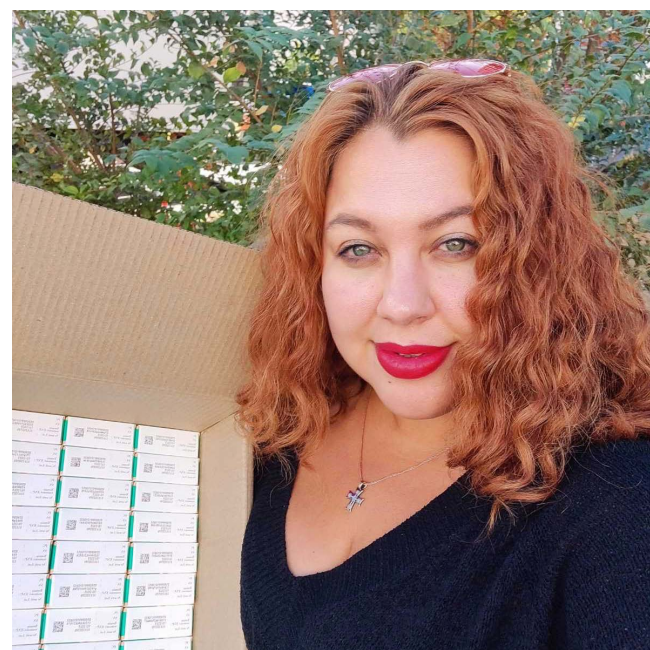
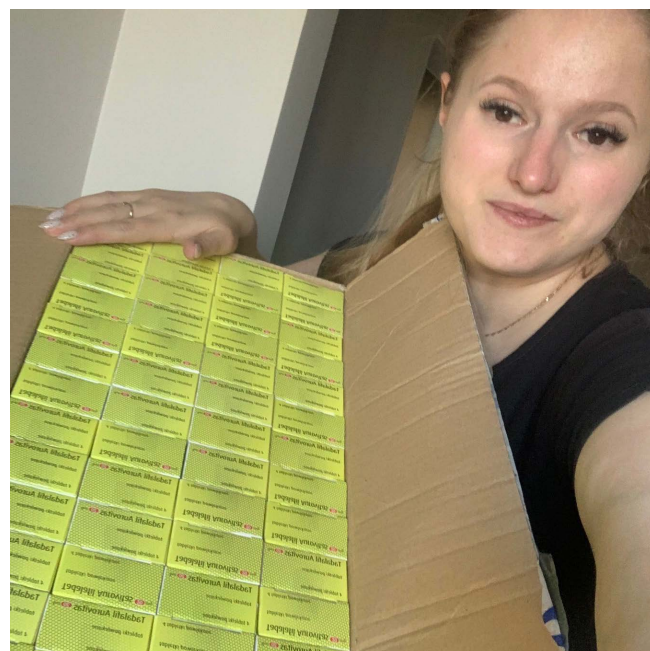
Despite all the difficulties we keep on facing, we always feel the supportive hand of one another. We all dream about times when we will be able to live in our houses peacefully.

We are sending the warmest hugs to all our friends, who have joined to help Ukrainian patients!



Easy breathing to everyone!





UKRAINE PHURDA

Another difficult year for Ukraine, Ukrainian patients, and our Association is passing. We stood up to the challenges, tasks, and our patients' needs. We achieved a lot and met wonderful people, as well as new partners. So, we share our successes with you.

PARTICIPATION IN MEETINGS, ROUND TABLES, CONFERENCES ETC.

• UKRAINE

On rare disease day, we participated as a speaker in a webinar titled "Rare disease in the practice of family doctors: What to pay attention to". There were presentations about PH and pulmonary fibrosis. Representatives of PHURDA talked about prevalence, frequency of detection, and mortality rates of rare diseases in Ukraine.

We took part in a round table on the topic: „Pre-hospital care in Lviv region: interaction of emergency medical service and primary care". We shared our experiences, and together with the participants, we looked for opportunities to solve failures.

Also, we attended the Scientific and Practical Conference titled „Transplantation in Ukraine: functioning of the system in conditions of war". The leading specialists in the field of transplantology of Ukraine gathered to discuss the possibility of transferring transplantation from the „pilot project" of the Ministry of Health of Ukraine to the „service package" of the National Health Service of Ukraine, and to share the results of postmortem transplants carried out in the conditions of war in Ukraine.

Another significant event we attended was the National Congress on Multidisciplinary

Rehabilitation called „Forming the Strategy of Work in Wartime". The event brought together more than 300 of the best specialists and national as well as international experts in the field of rehabilitation. The interaction of specialists with the patient, psychological assistance, and human-centered communication are the first steps necessary for a person to want to recover, to believe in themselves, and to establish trust in the rehabilitation team.



• EURORDIS

Throughout the year, we regularly participate in EURORDIS meetings with Ukrainian NGOs, where we discuss the action plan for the development of the system of rare diseases in Ukraine. Thanks to our cooperation, PH patients have received portable and stationary oxygen concentrators, which they badly need since the beginning of the war. With the support of Eurordis, a program of psychological and legal assistance is implemented. Also, we participated in a number of trainings from Eurordis: „Digitalization of healthcare in the EU”, „Participation of patients in clinical research: what is worth knowing” and a meeting on patient access to innovative treatment through the implementation of the „compassionate use of medicine” program.

• ELF

In September, we attended the ERS Congress and participated in the ELF Patient Networking Day. We talked about the difficulties with research in Ukraine, substantiated that today it was not only research, it would be a chance for treatment, and for some patients it was a reason or opportunity to return home. The first meeting of the PH Patient advisory group took place within the framework of the ERS. As an active member of the ELF Council and PAG EPAP, we regularly participate in working meetings where we discuss current activities, future plans, and events important to the respiratory community. Together with ELF, we are working on the translation of EPAP into Ukrainian, so that Ukrainian patients can have access to such an excellent educational tool. We are also involved in work regarding the IRC Manifesto. This year, the IRC summit was held in Lisbon. We support this Manifesto and analyze the potential of Ukraine. It is available in Ukrainian, and we are happy about that fact.

• PHA EUROPE

The annual meeting in Barcelona during APHEC always inspires and gives confidence in the future for PH patients. Along with the fact that we represented the Ukrainian PH community, we also tried to learn more about the situation of rare and respiratory diseases in European countries. We talked about the excellent patient education platform, the European Patient Ambassador Program, which could serve as a kind of „elevator” through which you would become a member of the ELF Council. And we also talked about the newly created PH PAG at the European Lung Foundation. During the conference, we also discussed the importance of the PVRI survey, and how we recruited PH patients and achieved excellent results.



HUMANITARIAN SUPPORT FOR PATIENTS AND HOSPITALS

With the support of international partners, PHURDA was able to both receive humanitarian aid, as well as purchase medicines for PH patients due to delays in government procurement, because of the war. Also, we purchased oxygen concentrators, pulse oximeters, and other first aid necessities.

Thanks to benefactors from Norway: Egersund kommune, Ukrainians of Egersund, and Oksana Dikhnych, we provided hospitals with protective medical gowns, consumables, medicines, and other medical products.

A big thank you to Nova Poshta Humanitarian for your constant support. Thanks to you, we can deliver humanitarian parcels throughout Ukraine for free.

• TRAININGS FOR FAMILY DOCTORS

Every month starting from January, we held educational webinars about pulmonary hypertension for family doctors. We invited different specialists to cover various topics related to PH. The aim of this project was to increase the understanding of pulmonary hypertension for the purpose of early diagnosis among family doctors.

• PATIENT MEETINGS

In this trying time, Ukrainian PH patients need to improve medical literacy and better understanding and realize how to live with PH. Therefore, through online meetings we teach, explain, and help them maintain their interests; sharing the latest news in the field of pulmonary hypertension.

• AWARENESS CAMPAIGNS

Information campaigns on social networks, flash mobs, photo shoots, social advertising on billboards, city lights, and the involvement of various categories of the population - we implemented all this in the pulmonary hypertension awareness project during 2023. As part of the project, we held a number of activities aimed at increasing awareness, early diagnosis, and prevention of pulmonary hypertension. Together with the Lviv Regional Center for Disease Control and Prevention, the Department of Health Care, and the „Veselka” Children’s Polyclinic, we held an informational campaign titled „City of Health”, where a team of doctors did free examinations and vaccinations for all those willing.

In November, with the support of the Lviv City Council, we placed billboards and city lights on the streets of Lviv city. Patients and famous people are depicted on each of the social advertising pieces, as well as the hot line telephone number for PH patients. We thank the staff of the Lviv Regional Center for Disease Control and Prevention, especially Nataliya Ivanchenko Timko for supporting this informational campaign and cooperation in the direction of early diagnosis of PH.

During PH Awareness Month, we created regular posts about PH on our social networks. For this purpose, we have created special information leaflets with photos of our patients and information about PH. We involved family doctors, hospitals, and health care departments of all regions of

Ukraine in the dissemination of information, who in turn disseminated information about PH on their websites or in social networks.

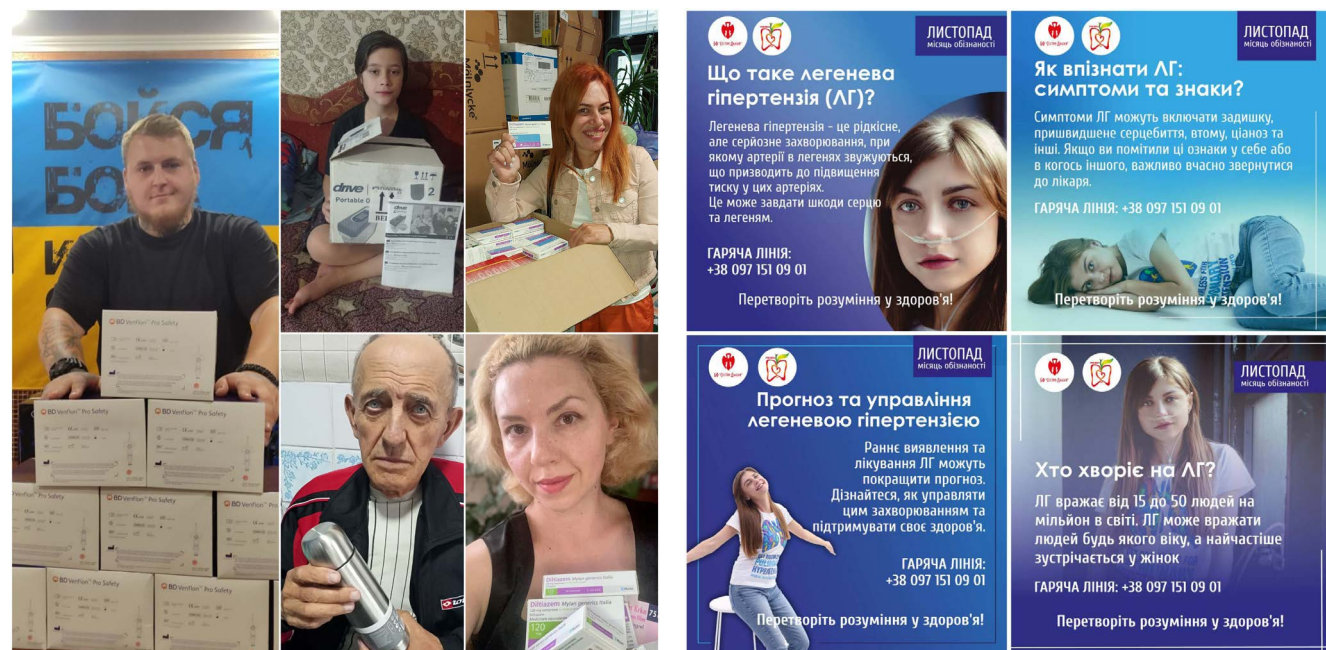


Thanks to our „Cork of Life” project, we were able to provide PH patients with oxygen concentrators, raise awareness of PH, and build a community of volunteers. The hotline is working to support PH patients and their family members under the following number: 097 1510901.

A key event for the PH community of Ukraine this year was the invitation of the PH Center for Adults to join ERN Lung as a referent PH center in Ukraine. We started talks about the importance of creating a children’s pulmonary hypertension unit, because children are our future.

We are proud to share that the CF „Sister Dalila” received a 3rd place diploma at the National Competition „Charity Ukraine 2022” for last year’s activities.

Thank you PHA Europe and everyone who makes us stronger and stands with us for peace. Together, we bring the victory of Ukraine closer. Glory to Ukraine! Glory to heroes!



SWEDEN

We arranged and held patient meetings together with PH-teams from the PH-centers at Uppsala University Hospital in the spring, as well as with Norrlands University Hospital in the fall.

In May, we held a three-day camp with younger patients with PH in Gotland (picture). We mixed lectures with excursions and social activities. All together, we were about 25 people.

We organized a presentation at the cardiovascular spring meeting that gathered about 1,500 doctors, nurses, and physiotherapists. The theme for the presentation was “The role of the PH-nurse” and

was held together with a PH-nurse from Karolinska University hospital.

We have opened a web shop with t-shirts, cups, hats, and other things, featuring our logo: <https://www.netshirt.se/foreningsklader/pah-sverige>

We also held a round table meeting together with PH-professionals and industry partners to discuss what we can do together to develop the PH-care in Sweden. The main topic for the meeting was early diagnosis in PH, and what we can do to.

We’ve also finally had our first patient meeting for parents with children with PH!



PVRI CONGRESS 2024 • 31.01.2024

<https://pvrinstitute.org/en/professionals/events/2024/1/31/pvri2024-london/>



SAPH CONFERENCE • 15.02-17.02.2024

<http://saphconference.com/>



ERN-LUNG BOARD MEETING • 19.02-20.02.2024

<https://ern-lung.eu/news/events-2/>



EURORDIS BLACK PEARL AWARDS • 20.02.2024

<https://www.eurordis.org/de/category/veranstaltungen/>



RARE DISEASE DAY • 29.02.2024



ISHLT 2024 • 10.04-13.04.2024

<https://www.isHLT.org/annual-meeting>



EPF AGM 2024 • 14.04.2024

<https://www.eu-patient.eu/Events/upcoming-events/agm-2024/>



WORLD PULMONARY HYPERTENSION DAY • 05.05.2024



INTERNATIONAL NURSES DAY • 12.5.2024



ECRD 2024 • 15.05-16.05.2024

<https://www.rare-diseases.eu/>



ATS 2024 • 17.05.-22.05.2024

<https://conference.thoracic.org/>



WORLD SYMPOSIUM ON PULMONARY HYPERTENSION • 2024 29.06-01.07.2024

<https://www.wsphassociation.org/>



PHA INTERNATIONAL PH CONFERENCE AND SCIENTIFIC SESSIONS • 15.08-18.08.2024

<https://phassociation.org/pha-conference/>



ESC CONGRESS 2024 • 30.08-02.09.2024

<https://www.escardio.org/Congresses-Events/ESC-Congress>



ERS INTERNATIONAL CONGRESS 2024 • 07.09-11.09.2024

<https://www.ersnet.org/congress-and-events/congress/>



ESPEN CONGRESS • 07.09-10.09.2024

<https://espencongress.com/>



WORLD LUNG DAY • 25.09.2024



ESOT CONGRESS 2024 • 03.10-06.10.2024

<https://esot.org/esot-events/elpat-congress-2024/>



EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION • 09.10.2024



WORLD MENTAL HEALTH DAY • 10.10.2024



PULMONARY HYPERTENSION MONTH • 11/2024



PHA EUROPE APHEC • 06.11-10.11. 2024



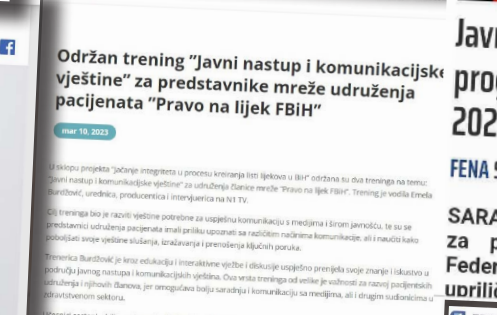
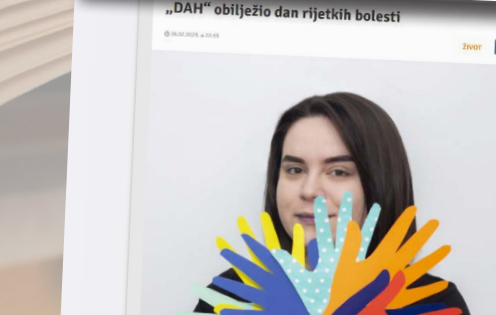
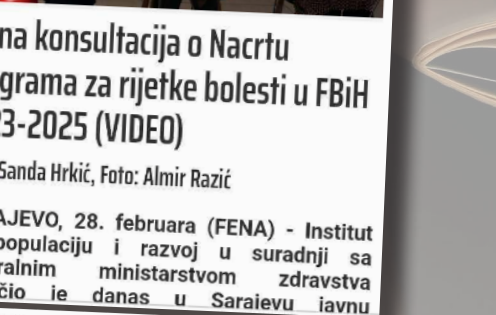
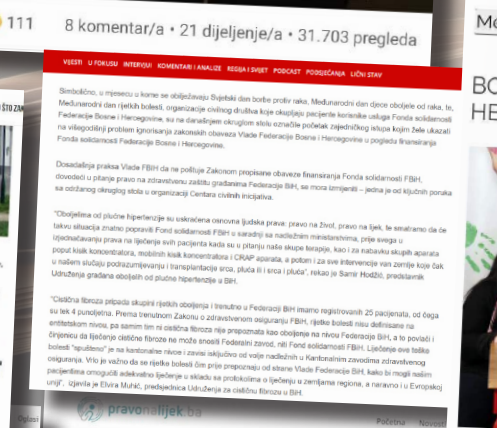
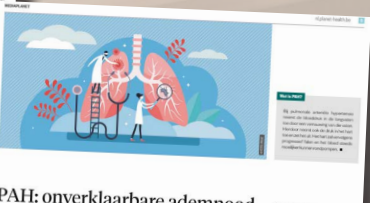
SCIENTIFIC SESSIONS 2024 • 16.11-18.11.2024

<https://professional.heart.org/en/meetings/scientific-sessions/>



INTERNATIONAL VOLUNTEER DAY • 05.12.2024







Bulgaria BSPPH

Наталия Маева: Пред чакащите трансплантации у нас няма светлина

За трансплантациите трябва отново да отговаря самостоятелно звено, категорична е тя

11.10.2023 | 16:22 Редактор: Калина Донкова

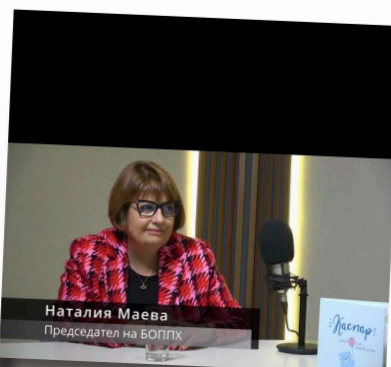


Държавата трябва да върне Изпълнителната агенция, която отговаряше за трансплантациите и беше закрита преди години. Това ще изисква законодателни промени, но нуждата от отделно звено, което да движи процеса, е изключително голяма. Такова мнение изрази в ефира на предаването "Директно" Наталия Маева, председател на Българското общество на пациентите с пулмонална хипертония.

OFFNews
OFFNEWS > ЗДРАВЕ

Кой помага на хората с дихателна недостатъчност
„Истории за доброто“ се осъществява с финансовата подкрепа на Исландия, Лихтенщайн и Норвегия по Фонд Активни граждани България в рамките на Финансовия механизъм на Европейското икономическо пространство. - www.activecitizensfund.bg

Янка Петкова 3055 0
24 октомври 2023 в 15:17



Наталия Маева
Председател на БОПХ



ШАНС ЗА ВТОРИ ЖИВОТ
Наталия Маева за пътя прегу и след трансплантацията

Nova News

Какво е да живееш с трансплантиран бял гроб?

Croatia



Klikni.hr

Kroz projekt "Punim plućima" klinici diljem Hrvatske učili o plućnoj hipertenziji

KLINICI HR
20. studenoga 2023.

PODIJELI S PRIJATELJIMA

Plućna hipertenzija složena je, rijetka i progresivna bolest o kojoj javnosti malo znaju. Prema zadnjem popisu iz 2019. godine u

inPORTAL

S 'Punim plućima' i osmijehom na licu proširimo svijest o plućnoj hipertenziji

Objavljeno prije 2 tjedna / 22. studenoga, 2023
By IN-PORTAL

U sklopu projekta izdan je i priručnik 'Vodič za život s

inPORTAL

ART FROM THE HEART Održana prva izložba i humanitarna aukcija Udruga Plava Krila

Objavljeno prije 11 sati / 29. studenoga, 2023
By Anita Blažinović

Zahvaljujemo se svima koji su došli i podržali nas, posebno mladim i perspektivnim umjetnicima koji su odvojili svoje vrijeme i stvorili divna umjetnička djela od srca, kako i sam naziv likovne kolonije i čitavog projekta glasi.

PUNIM PLUĆIMA!

Zahvaljujemo se svima koji su došli i podržali nas, posebno mladim i perspektivnim umjetnicima koji su odvojili svoje vrijeme i stvorili divna umjetnička djela od srca, kako i sam naziv likovne kolonije i čitavog projekta glasi.

U Hrvatskoj preko 250 osoba boluje od plućne arterijske hipertenzije, rijetke bolesti o kojoj se premalo zna i premalo priča o javnosti. Bojimo se da još toliko osoba boluje od iste dijagnoze a toga još nisu svjesni, što nas potiče da kroz razne aktivnosti progovaramo o bolesti i pokušavamo podići svijest o njoj.

Promo

Uspješno završen projekt 'Punim plućima'

20. studenoga 2023. — DOGAĐANJA — Píše Branka Sobotić

Plućna hipertenzija složena je, rijetka i progresivna bolest o kojoj javnosti malo znaju. Prema zadnjem popisu iz 2019. godine u Hrvatskoj ima tek nešto više od 200 oboljelih osoba, no pretpostavka je, da ih barem toliko živi s bolešću ne znajući da ju imaju.

Iz toga razloga, nužno je o tome pričati. Kroz projekt „Punim plućima“ progovara Udruga „Plava Krila“.

Održana izložba i humanitarna aukcija Udruga Plava Krila

Posted by: Obitelj hr
in Događanja, Promo, Vijesti

Izložba i humanitarna aukcija pod nazivom Art from the Heart održala se 24. 11. u Loži (Vinogradska 4, Zagreb) od 18h – 21 h.

Czech Republic

PLIČNÍ HYPERTENZE SE PROJEVUJE DUŠNOS I NAMODRALOU KŮŽÍ. PODLE PŘÍČINY ROZLIŠUJEME PĚT TYPŮ OBTÍŽÍ

Pavla Široká 2. 11. 2023 7:30

Příčiny hypertenze označují stav projevující se vysokým krevním tlakem v plicích tepnách, které přenášejí krev ze srdce do plic. Příznaky často bývají nespecifické a diagnostika může být zdlouhavá. Typickým symptomem však bývá dušnost, která se zpočátku objevuje pouze při sportu, později i v klidu. Mezi nejčastější příčiny této abnormality se pak řadí onemocnění srdce, plic a nedostatek kyslíku v krvi.

Trpím sklerodermií. Na diagnózu jsem čekala přes dvacet let

21. září 2023

Hned po porodu v devětatleté letech se mi začaly nedokřvovat prsty u rukou, flakovaly mi ačž bály. Diagnózu sklerodermie jsem se ale od lékaře dozvěděla až po dvaceti letech. Čtenářka Hanka napsala další díl naší seriálu MŮJ boj s nemocí.

Ilustrační fotografie | Foto: Profimedia.cz

Obtíž, tedy žádné zvláštní, jsem neměla, možná jsem se občas zadýchávala při procházce a někdy se mi také rozdušilo srdce, ale nešlo o nic, co by mě nějak znepokojovalo. Z toho mě však vyvedla běžná preventivní prohlídka u praktika. Lékař odhalil selhání na srdci a radši mě poslal na kardiologii do Všeobecné fakultní nemocnice v Praze.

I s vážnou nemocí jsem se stala mámou. Trpím plicní hypertenzí

27. září 2023

Až do svých pětadvaceti let jsem se cítila úplně zdravě. Jen jsem se občas při procházce zadýchávala. Až preventivní vyšetření u mě odhalilo plicní hypertenzi. Čtenářka Hermína napsala další díl seriálu MŮJ boj s nemocí.

Ilustrační snímek | Foto: Profimedia.cz

Obtíž, tedy žádné zvláštní, jsem neměla, možná jsem se občas zadýchávala při procházce a někdy se mi také rozdušilo srdce, ale nešlo o nic, co by mě nějak znepokojovalo. Z toho mě však vyvedla běžná preventivní prohlídka u praktika. Lékař odhalil selhání na srdci a radši mě poslal na kardiologii do Všeobecné fakultní nemocnice v Praze.

MEDICAL TRIBUNE

MEICINA ZDRAVOTNICTVÍ KOMENTÁŘE VZDĚLÁVÁNÍ SPECIÁLY

Tipy a triky v léčbě hypertenze

14 minut čtení 13. 6. 2023 300 Vydáno v titulu Medical Tribune

Svoučasně Vyročního sjezdu ČKS byl i zcela praktický zaměřený blok s názvem Tipy a triky v léčbě hypertenze. Diskutovalo se zde o strategických, které vedou ke kontrole krevního tlaku u specifických, vidělek počítaných populací nemocných – až už jde o obezní pacienty, jedince s fibrilací síní, nebo o ty s rezistentní hypertenzí. Tuto část programu podpořila společnost PRO.MED.CS Praha a. s.

Když při chůzi do kopce lapáte po dechu, nemusí jít o špatnou kondičku

31. 10. 2023, 6:03
Dana Školová

Pokud při chůzi do lehkého kopce lapáte po dechu a cítíte mírnou bolest na hrudi, nemusí se jednat o špatnou kondici. Na vině může být i plicní hypertenze, tedy zvýšený krevní tlak v plicích.

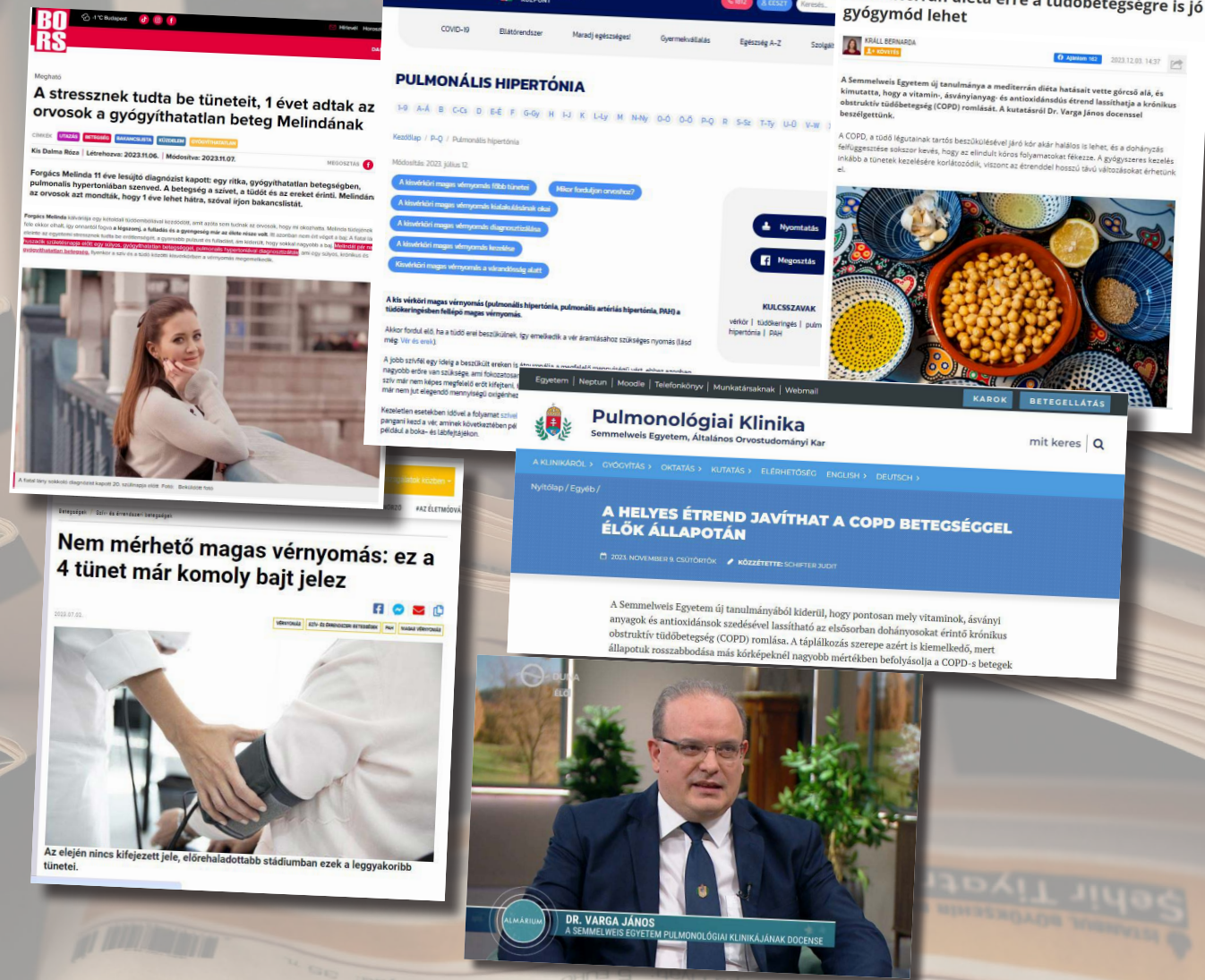
Plicní hypertenze může být snadno zaměněna s jiným onemocněním.

Těhotenství u žen s plicní hypertenzí? Dřív nemožné, dneska už to díky lékům jde

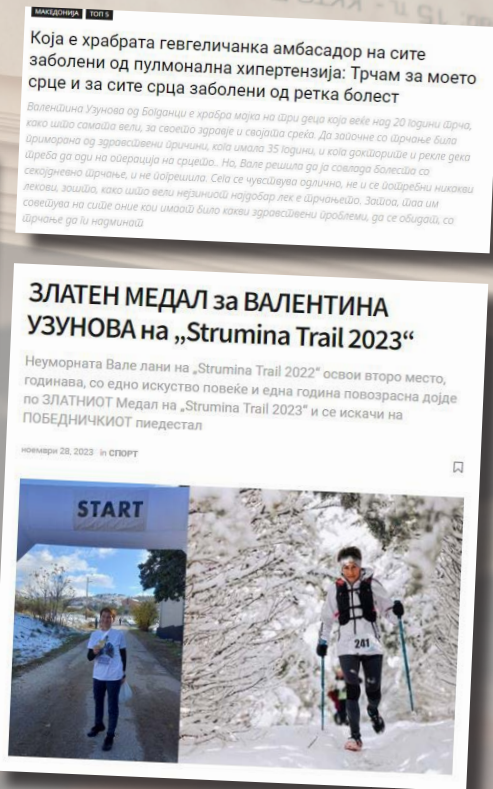
ANNA DVOŘÁKOVÁ | 9. 6. 2023

Promodralé rty, lapání po dechu už po krátké procházce, bolest na hrudi, není úplně jednoduché, přitom včasná léčba je zásadní, aby se zabránilo závažným následkům. Naštěstí jde i léčba stále kupředu, a nemoc tak nemusí být překážkou například ani v těhotenství.

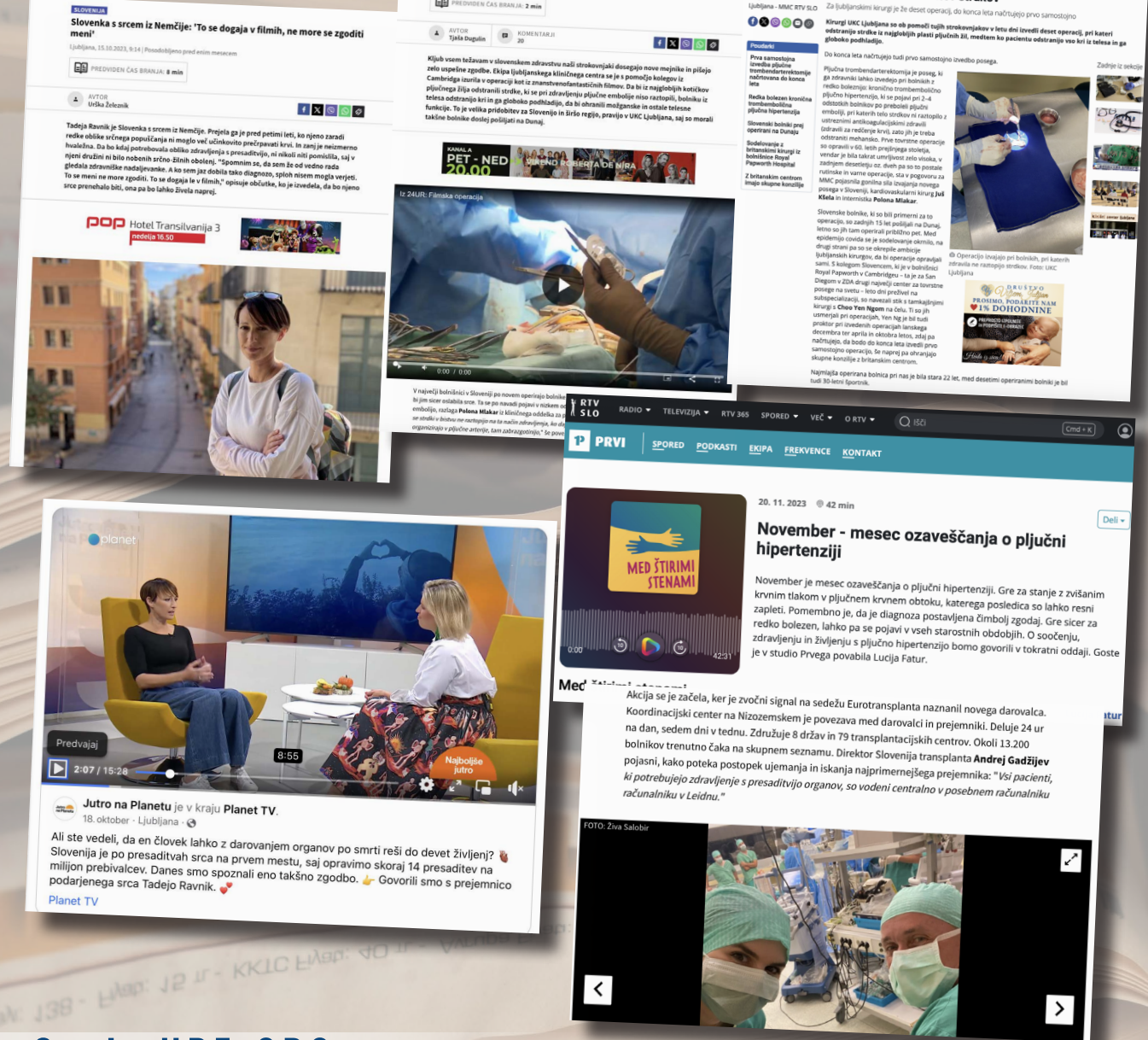
Hungary



North Macedonia

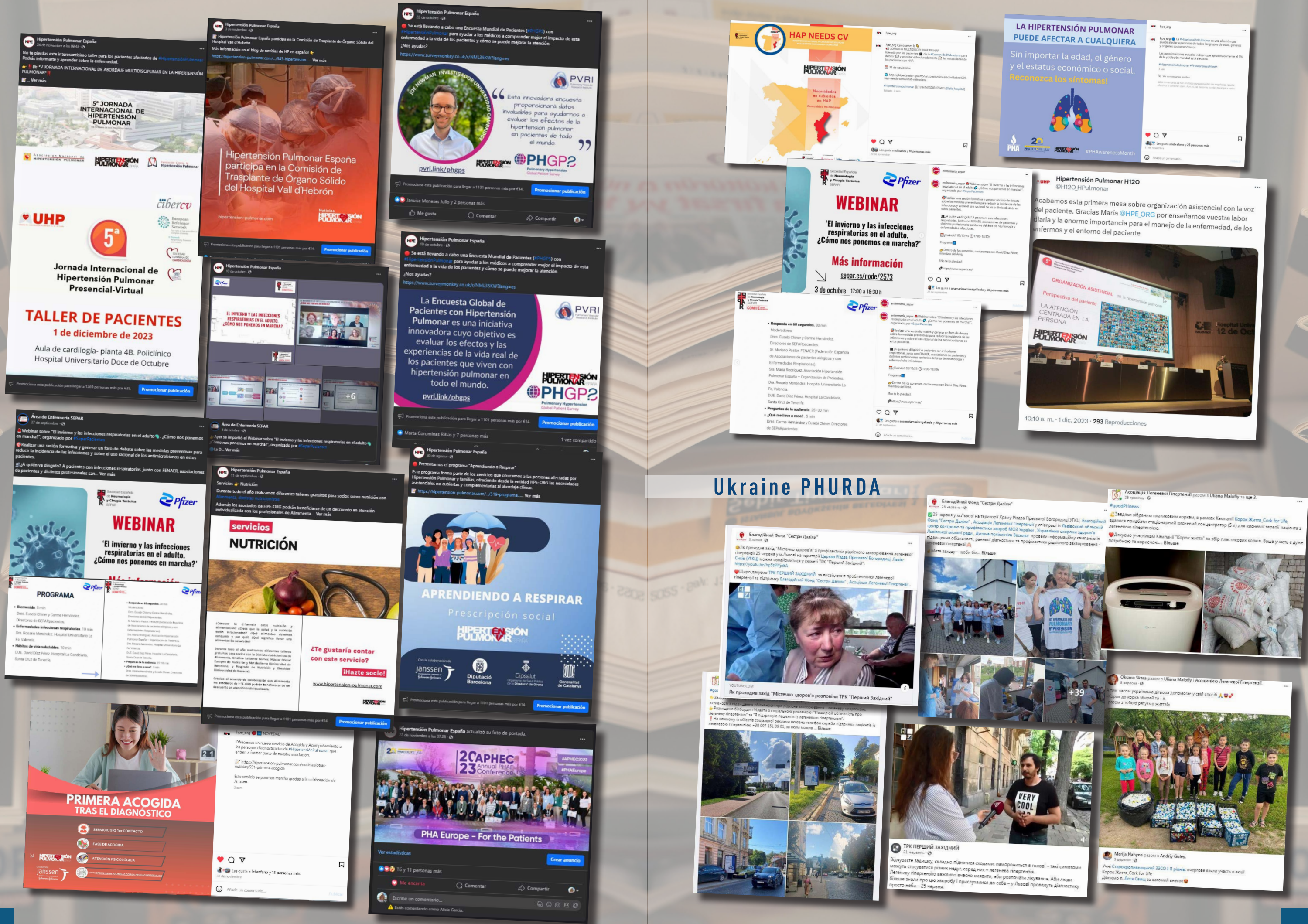


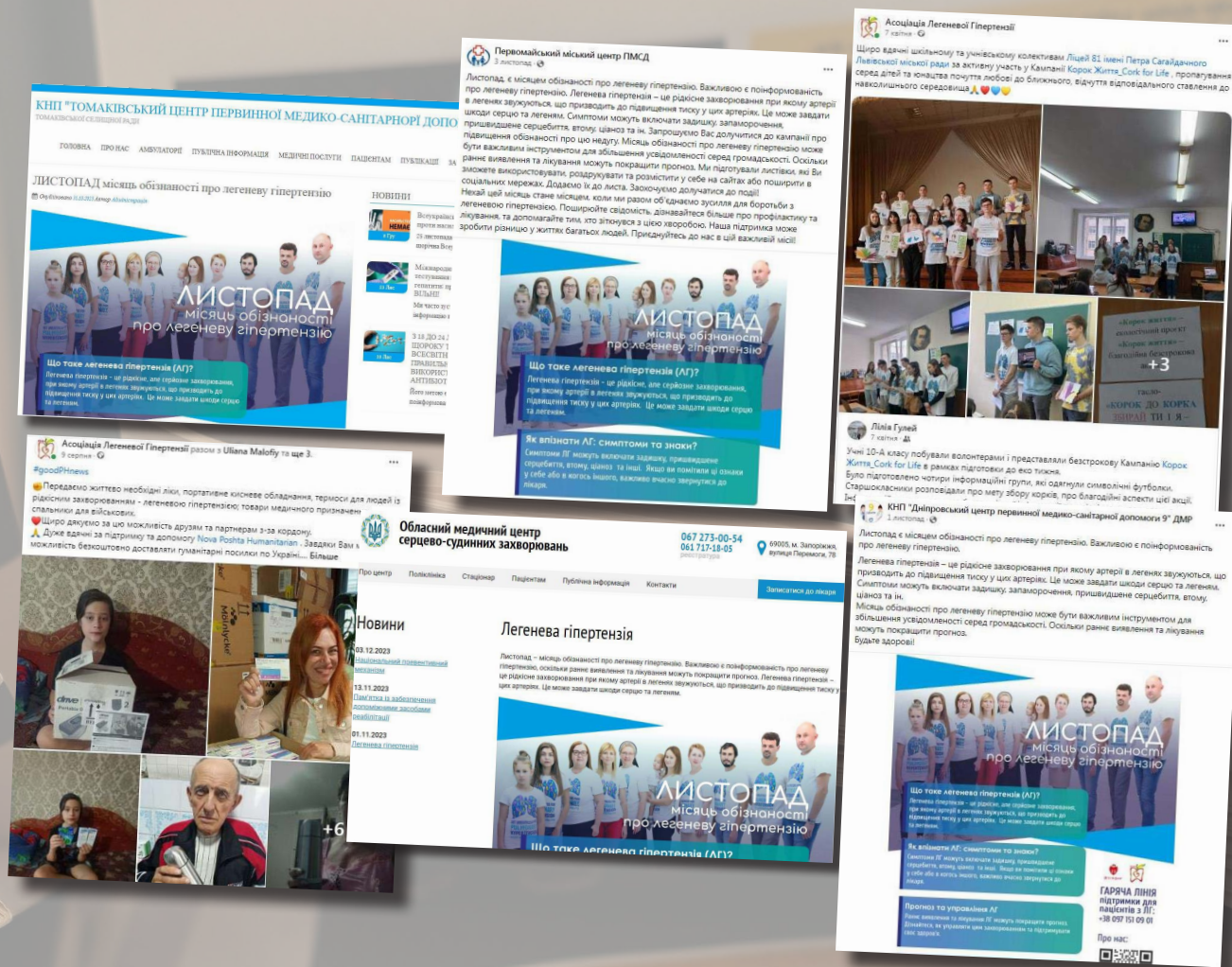
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European pulmonary hypertension association

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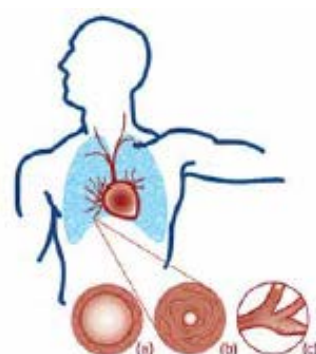
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AIMS OF PHA EUROPE

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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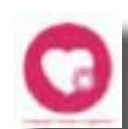


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