

PULMONARY HYPERTENSION

# Mariposa Journal

WINTER 2022 • PHA EUROPE'S OFFICIAL JOURNAL • N. 29



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

**PHA EUROPE** *for the patients*  
European pulmonary hypertension association

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# Editor's memo

WINTER EDITION • 2022

*Dear Friends, Colleagues and Supporters,*

It is always a great pleasure to look back and see the ample accomplishments of the past year.

From the previous, summer edition of Mariposa, you could learn about our efforts and success to celebrate the 10th anniversary of World Pulmonary Hypertension Day. You got insight how a single, but very prestigious conference organized in Madrid evolved to a real global event with more than 80 participants. We celebrated the anniversary with a webinar which had a scientific lecture part with those key opinion leaders who participated in the very first conference and the memories of the Spanish PH organization, ANHP - which had a key role in kicking-off WPHD - were also presented. The webinar was the premiere of our anniversary video which highlighted the most eye-catching pictures and original ideas of the previous WPHD celebrations, the cooperation with Ironman triathlon and many more.

The third pillar of this anniversary celebration, on top of the capacity building and awareness raising potential of WPHD, was advocacy: a special event in the European Parliament (Brussels, Belgium) was organized on the 26th of April to launch the revised Call to Action on the unmet needs of patients with pulmonary hypertension position paper. Patient representatives from all over the world, key opinion leaders from the field, and last, but not least politicians (members of the European Parliament – MEP) and decision makers from European institutions attended the event. The result and the messages on access, research, screening, psychosocial support and patient empowerment, however, have effect well beyond Europe and applicable to other parts of the world. The follow-up campaign was a great success also with millions of reaches on various social media channels.

The other major result of the year of 2022 was the release of the revised guidelines on the diagnosis and treatment of pulmonary hypertension. It was the very first time that patient representatives were invited and involved in the task force from the beginning. It is a big honor

that one delegate out of two was the representative of PHA Europe. You can learn more details about the work within the task force and the presentation of the new guidelines in this edition of Mariposa.

We have been involved in many initiatives within the field of pulmonary hypertension and in the broader respiratory and rare disease field.

During the years we become an integral part of the scientific societies: we participate and report on our yearly activity in the meetings of the ERS Assembly 13 (pulmonary vascular diseases), furthermore attend as speakers in the annual congresses of ESC and ERS. We are one of the key drivers of the patient empowerment working group in PVRI and patient representative as well as steering committee member of the ERS Clinical Research Collaboration (CRC) on PHAROS – severe Pulmonary Hypertension mAnagement acROSS Europe and participants of the patient forum to ESC. When it comes to rare diseases, European Reference Network on rare lung diseases (ERN-Lung) is one of the most significant institutions. The first 5-year period of ERN-Lung came to an end and a report to European institutions became due, which generates extra workload on our end as being the co-chair of the patient group to the network. In the previous years we worked tirelessly on this very important project and were active partners not only in PH specific matters, but also in cross-disease topics in the so-called functional committees.

EURORDIS is an important partner in ERN-Lung, but we have other fruitful collaborations as well: Rare 2030 is one of these projects which re-started in 2022 and provides excellent opportunity to connect to other rare disease patient representatives and build up a vision for the coming decade for the healthcare of rare disease.

European Lung Health Group (ELHG) and European Lung Foundation (ELF) are another excellent example how patient organizations including rare lung diseases such as pulmonary hypertension and more prevalent ones as asthma can work together. The political launch

event of the International Respiratory Coalition (IRC) during the summer in Paris, the presentation of Lung Facts in September by IRC, political statements as well as advocacy events with the involvement of European Union politicians and decision makers under the umbrella of ELHG were the landmark achievements of 2022.

Hot topics of the year were artificial intelligence (AI) and the European Health Data Space (EHDS) which provided an opportunity to collaborate with European Patients' Forum (EPF) and other umbrella organizations.

PHA Europe applied to be registered as an eligible association at the European Medicines Agency (EMA) –we are extremely happy that in the last days of December our submission was approved!

The partnership with our sponsors has further strengthened. We were participating in educational projects (eg. PHEmpowerment network), joining forces in awareness raising activities (eg. PHantasticals), contributing to patient boards of trials and providing the patient perspective in various events (eg. symposia, team building events, internal informative sessions) in 2022. We expect even closer collaboration especially in the field of access and awareness raising.

The year of 2022 was very special as we had two general assemblies (GAM) and Annual Pulmonary Hypertension European Conferences (APHEC). In the beginning of the year, we held the 2021 GAM and APHEC virtually – postponed due to aggravated COVID situation at the end of 2021. We finally managed to organize our most important event of the year, the Annual Pulmonary Hypertension European Conference (APHEC) 2022 in person in Barcelona during November. You can read more about these events and check the best moments in the following pages.

It is not possible to conclude an editorial without mentioning the sad situation in Ukraine. It was PHA Europe who gave the first aid to the member associations to help their patients and we participated in workstreams and make efforts to facilitate the continuous medication supply. We truly hope that the situation will be stabilized soon.

Let me close this editorial with a big applause to our members, patients, family members, caregivers, volunteers, friends and also to our medical partners, physicians, surgeons and researchers, who are with us on this long journey. We re looking forward to an even brighter year of 2023!

*Gergely Meszaros*  
Project manager • PHA Europe

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**Virtual (online) • January 4**

PREPARATORY CALL TO PVRI MEETING

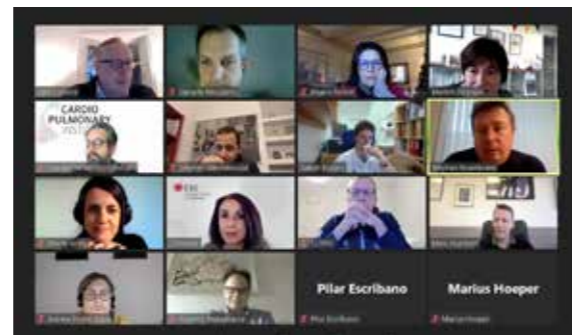
Gergely attended this call with Prof. Joanna-Pepke Zaba to discuss next steps in the PVRI-IDDI – patient empowerment working group.



**Virtual (online) • January 10**

PREPARATORY CALL TO PVRI MEETING

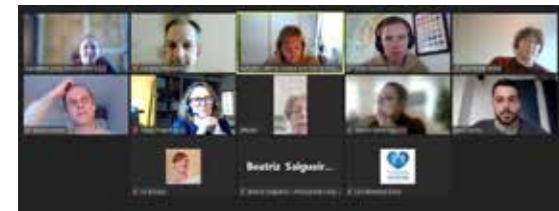
Gergely attended this call with Prof. Joanna-Pepke Zaba, Prof. Paul Corris and the representatives of PHA US and PHA UK to discuss next steps in the PVRI-IDDI – patient empowerment working group.



**Virtual (online) • January 11**

TASK FORCE MEETING ON THE NEW GUIDELINES ON PULMONARY HYPERTENSION

Gergely attended this virtual meeting.



**Virtual (online) • January 12**

EUROPEAN LUNG FOUNDATION (ELF) PATIENT ADVISORY COMMITTEE (PAC) MEETING

Gergely attended this meeting.

**Virtual (online) • January 16**

GENERAL ANNUAL MEETING (GAM) OF PHA EUROPE

Gergely attended this regular meeting on behalf of PHA Europe.



**Virtual (online) • January 18**

EUROPEAN SOCIETY OF CARDIOLOGY

Gergely attended this regular call about patient involvement in guidelines task force.



**Virtual (online) • January 20**

EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING

Gergely represented PHA Europe participated in this regular call.

**Virtual (online) • January 25**

VIRTUAL SCHOOL ON PULMONARY HYPERTENSION (ORGANIZED BY ERS)

Gergely attended this webinar of series of lectures on the new developments in PH.



**Virtual (online) • January 26**

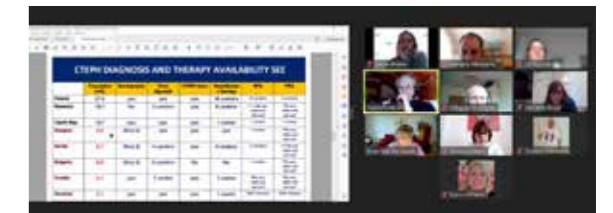
PVRI IDDI REGULAR MEETING

Gergely co-chaired this meeting

**Virtual (online) • February 4**

EUROPEAN REFERENCE NETWORK ON RARE RESPIRATORY DISEASES (ERN-LUNG) PATIENT ADVISORY GROUP (EPAG) MEETING

Gergely chaired this regular meeting.



**Virtual (online) • February 8**

MEP LUNG HEALTH GROUP – IMPROVING LUNG HEALTH THROUGH THE FUTURE EUROPEAN HEALTH DATA SPACE

Gergely attended this important political event.

**Virtual (online) • February 8**

EURORDIS BLACK PEARL AWARDS EVENT

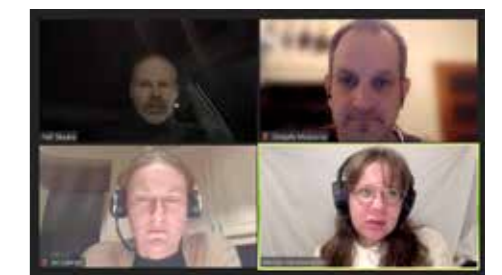
Gergely participated in this virtual gala.



**Virtual (online) • February 9**

ERN-LUNG PRO (PATIENT REPORTED OUTCOME) FUNCTIONAL COMMITTEE (FC) MEETING

Gergely participated in this call as patient lead.

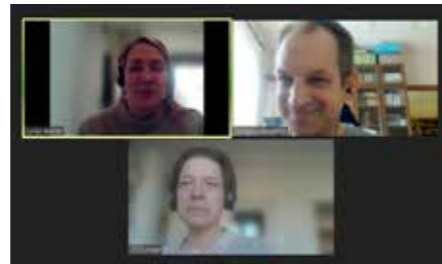


**Virtual (online) • February 10**

MEETING WITH THE BELGIAN PH ASSOCIATION

Hall and Gergely participated in this meeting about future cooperation.

**Virtual (online) • February 15**  
 ERN-LUNG EPAG CO-CHAIR MEETING  
 Gergely attended this meeting as one of the co-chairs.



**Virtual (online) • March 11**  
 IOWNA MEETING  
 Gergely met with this IT company to discuss the survey's technical background.

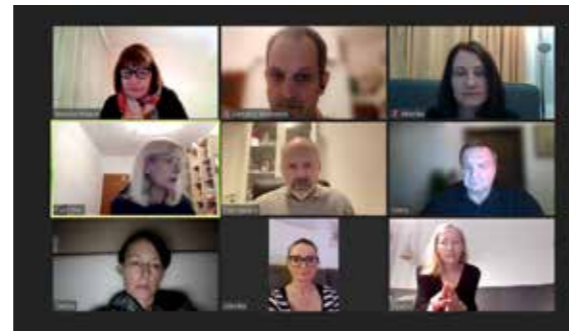


**Virtual (online) • February 16**  
 ERN-LUNG PH CORE NETWORK MEETING  
 Gergely represented PHA Europe in this meeting.

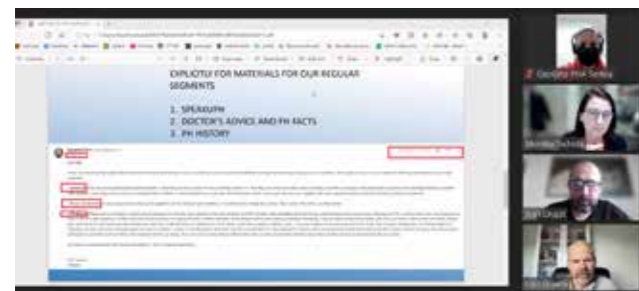
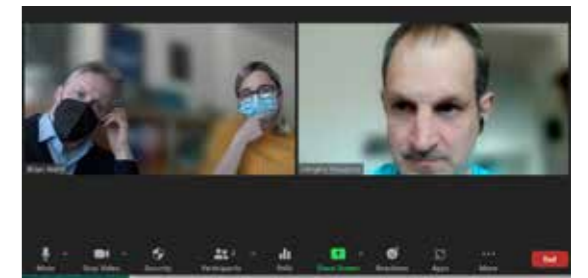


**Virtual (online) • March 1-2**  
 PHA EUROPE'S ANNUAL PULMONARY HYPERTENSION EUROPEAN CONFERENCE  
 Biggest gathering of European PH associations' leaders.

**Virtual (online) • February 16**  
 PHA EUROPE BOARD&STAFF MEETING  
 The complete board and staff attended this meeting.



**Virtual (online) • March 3**  
 CALL TO ACTION PREPARATORY WORK WITH ERS  
 Gergely attended this meeting.



**Virtual (online) • February 17**  
 MEETING WITH SOCIAL MEDIA COMPANY, BC HUB  
 Danijela, Monika, Hall and Gergely attended this meeting.

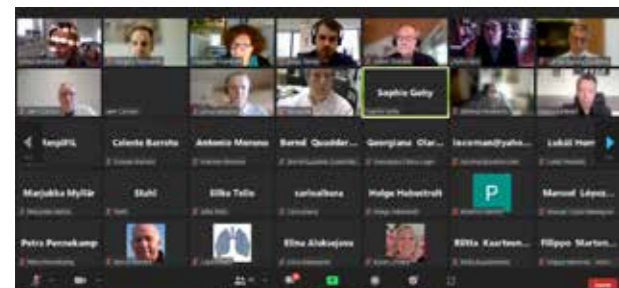
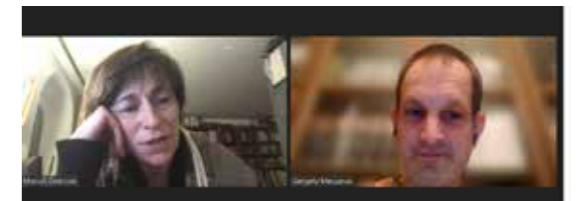


**Virtual (online) • March 3**  
 ELF PREPARATORY MEETING ON PATIENT ORGANIZATIONS' DAY  
 Gergely attended this meeting as one who is responsible for the program

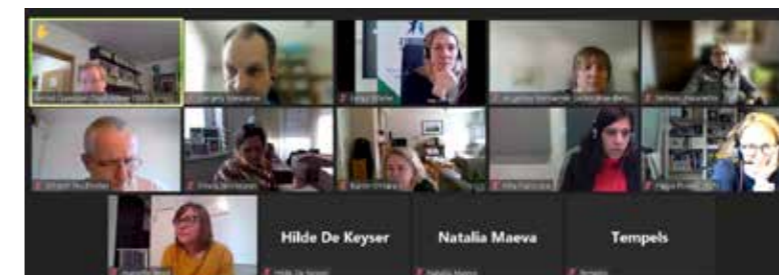
**Virtual (online) • February 17**  
 EUROPEAN MEDICINES AGENCY (EMA) 'WALK IN' CLINIC WEBINAR ON REPURPOSING  
 Gergely attended this webinar.



**Virtual (online) • March 3**  
 MEETING WITH PROF. MARION DELCROIX  
 Gergely attended this event on recent developments and projects.



**Virtual (online) • February 23**  
 ERN-LUNG BOARD MEETING  
 Gergely represented PHA Europe in this meeting.



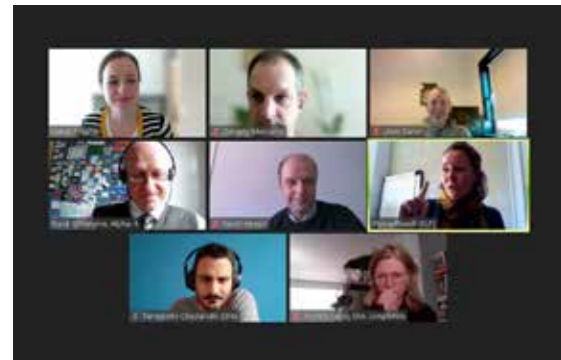
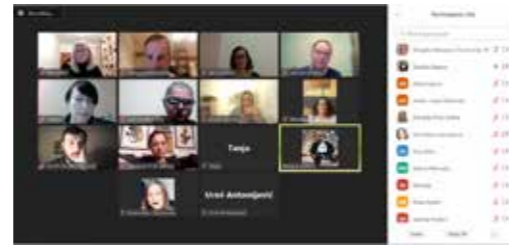
**Virtual (online) • March 4**  
 ERN-LUNG EPAG MEETING  
 Gergely chaired this regular meeting.

**Virtual (online) • February 28**  
 RARE DISEASE DAY ORGANIZED BY EURORDIS  
 Gergely attended this political event.



**Virtual (online) • March 9**  
 MULTIDISCIPLINARY TEAM MEETING  
 Hall participated in a team consisting of patients, HCPs and Industry. They met to focus on improving patient support in a changing landscape. Hosted by Janssen.

**Virtual (online) • March 11**  
 INFORMATIONAL WEBINAR ON WORLD PH DAY 2022  
 Gergely chaired this event.



**Virtual (online) • March 17**  
 EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING  
 Gergely represented PHA Europe on this meeting.

**Virtual (online) • March 18**  
 CALL TO ACTION PREPARATORY WORK WITH ERS  
 Gergely attended this meeting.



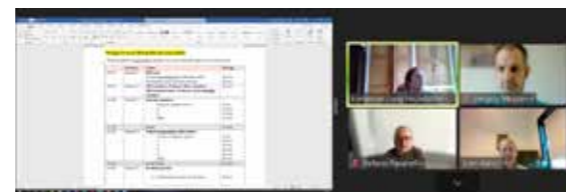
**Virtual (online) • March 22**  
 PATIENT ACCESS PARTNERSHIP (PACT): ACCESS TO QUALITY HEALTH & CARE  
 Gergely represented PHA Europe in this political event.

**Virtual (online) • March 23**  
 PVRI IDDI REGULAR MEETING  
 Gergely co-chaired this meeting.

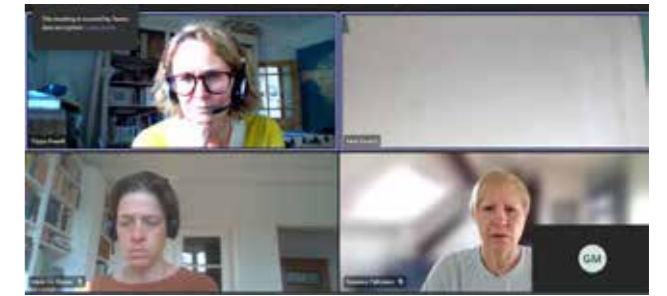


**Brussels, Belgium • March 23-24**  
 HEART FAILURE ASSOCIATION CONFERENCE  
 Hall participated as a patient representative in the workshop entitled «A roadmap for therapeutic discovery in pulmonary hypertension due to heart failure». Hosted by HFAfailure». Hosted by HFA.

**Virtual (online) • March 24**  
 ELF PREPARATORY MEETING ON PATIENT  
 Gergely attended this meeting as one who is responsible for the program.

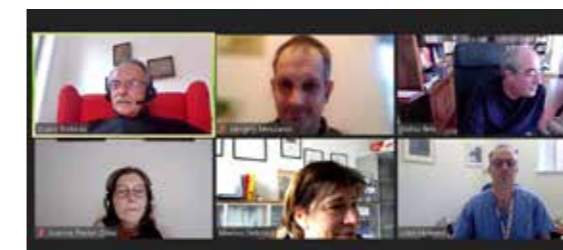


**Virtual (online) • March 25**  
 EUROPEAN LUNG HEALTH GROUP MEETING ON HELPING UKRAINE  
 Gergely represented PHA Europe in this meeting.



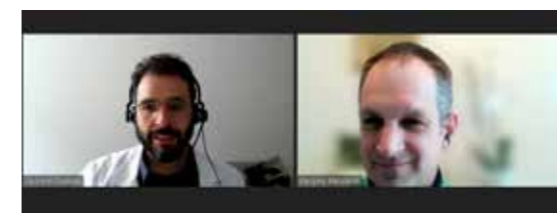
**Virtual (online) • March 29**  
 CALL TO ACTION PREPARATORY WORK WITH ERS AND MEMBER OF THE EUROPEAN PARLIAMENT (MEP) OFFICE

**Virtual (online) • March 29**  
 CALL TO ACTION PREPARATORY WORK WITH THE TASK FORCE  
 Gergely chaired this meeting.



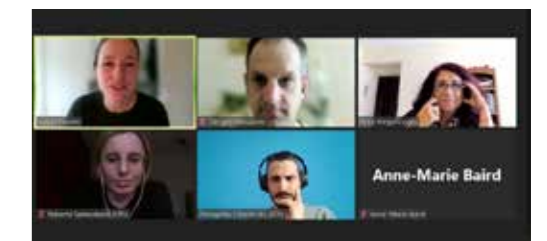
**Virtual (online) • March 31**  
 ERS CLINICAL RESEARCH COLLABORATION (CRC) – PHAROS MEETING  
 Gergely participated in the steering committee meeting.

**Virtual (online) • April 4**  
 GO CTPEH TRIAL STEERING COMMITTEE MEETING  
 Gergely represents PHA Europe in these meetings.



**Virtual (online) • April 5**  
 MEETING ON EJP-RD NSS APPLICATION  
 Gergely attended this online meeting.

**Virtual (online) • April 6**  
 EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING  
 Gergely represented PHA Europe on this meeting.



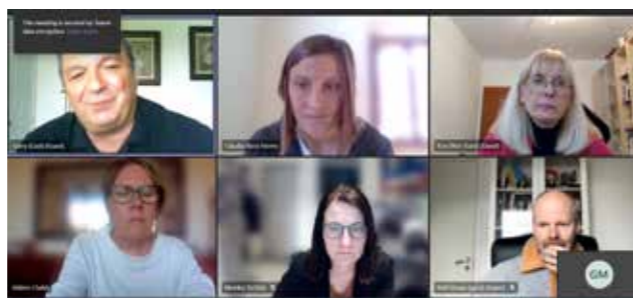
**Virtual (online) • April 6**

PVRI WORKING GROUP MEETING ON AIDS TO UKRIANE  
Gergely represented the patient voice in this discussion.



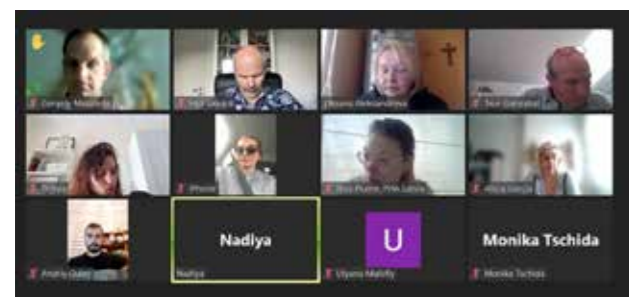
**Virtual (online) • April 6**

ADVISORY BOARD MEETING  
Hall participated in an advisory board meeting with a handful of other patients to give advice to a new company running trial for a potential new PH drug. Hosted by Aerovate.



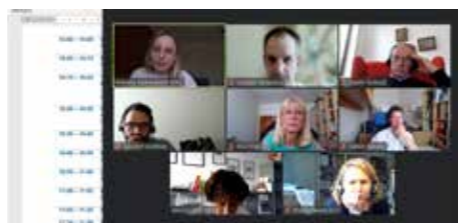
**Virtual (online) • April 7**

MEETING WITH FERRER  
Eva and staff members attended this call.



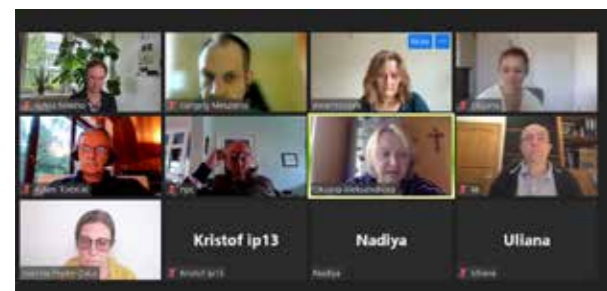
**Virtual (online) • April 11**

PHA EUROPE'S MEETING ON UKRAINE  
PHA Europe staff members and member associations attended this call.



**Virtual (online) • April 12**

REHEARSAL MEETING ON THE CALL TO ACTION  
LAUNCH EVENT  
Gergely chaired this event.



**Virtual (online) • April 20**

PVRI WORKING GROUP MEETING  
ON AIDS TO UKRIANE  
Gergely attended this call from PHA Europe.



**Brussels, Belgium • April 26**

LAUNCH EVENT OF PHA EUROPE'S CALL TO ACTION IN  
THE EUROPEAN PARLIAMENT  
Board and staff members attended this high-profile political event.

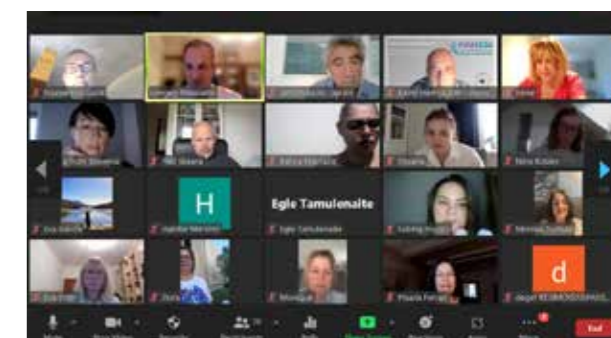
**Virtual (online) • April 27**

ESC WORKING GROUP ON QUALITY INDICATORS  
Gergely attended this series of meetings



**Virtual (online) • April 28**

EURORDIS IMI C4C WEBINAR  
Gergely represented PHA Europe on this meeting



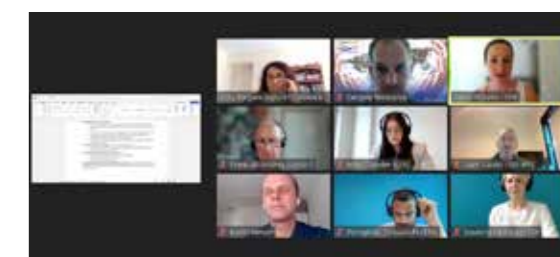
**Virtual (online) • May 5**

ANNIVERSARY WORLD PH DAY WEBINAR  
Participants all over the world joined this event -  
the event was chaired by Gergely



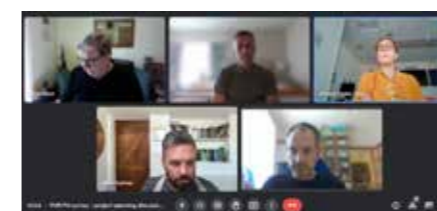
**Virtual (online) • May 12**

EPF 360° HTA PATIENT INVOLVEMENT WEBINAR  
Gergely attended this webinar



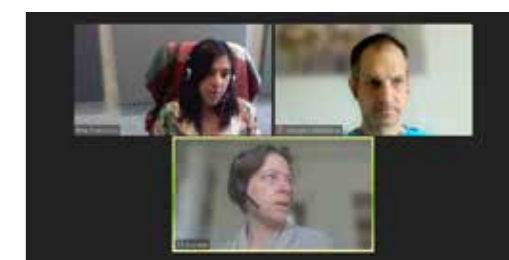
**Virtual (online) • May 19**

EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING  
Gergely represented PHA Europe on this meeting



**Virtual (online) • May 27**

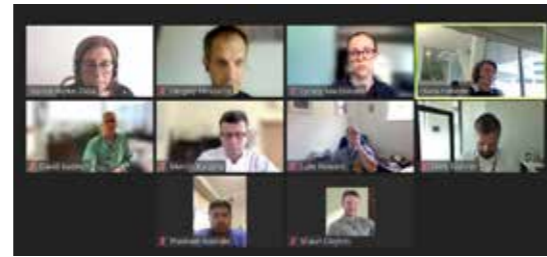
IOWNA MEETING  
Gergely met with this IT company to discuss the survey's technical background



**Virtual (online) • June 1**

ERN-LUNG EPAG GAP ANALYSIS  
Gergely attended this meeting

**Virtual (online) • June 8**  
 PVRI IDDI REGULAR MEETING  
 Gergely co-chaired this meeting.



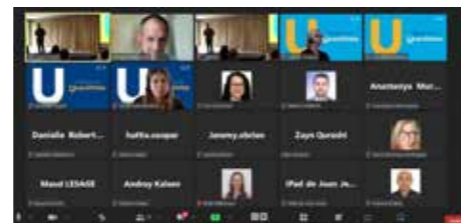
**Atlanta, Georgia, USA • June 8-12**  
 INTERNATIONAL PHA US CONFERENCE  
 Hall participated in the international PH conference joining sessions and talking to industry partners.

**Virtual (online) • June 21**  
 ERN-LUNG VIRTUAL SCHOOL  
 Natalia ran a presentation about patient perspective.



**Virtual (online) • June 21**  
 PATIENT FOCUS GROUP  
 Hall participated in a meeting together with PH-ILD patients focusing on an early access treatment program. Hosted by Ferrer.

**Virtual (online) • June 28**  
 PRESENTATION OF THE CALL TO ACTION AT J&J'S REGIONAL/COUNTRY MEETING  
 Gergely ran this presentation.

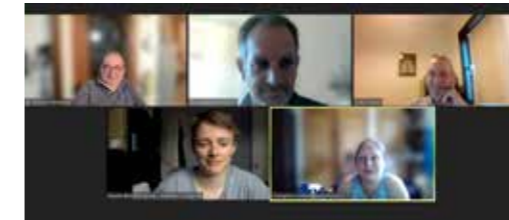


**Paris, France • June 28-29**  
 ERS'S LAUNCH EVENT OF INTERNATIONAL RESPIRATORY COALITION (IRC)  
 Gergely represented PHA Europe on this political event.

**Virtual (online) • June 30**  
 PULMONARY VASCULAR DISEASE UNIT (ROYAL PAPWORTH HOSPITAL, UK) - RESULT OF THE STRATOSPHERE SURVEY  
 Gergely attended this webinar.



**Virtual (online) • July 13**  
 ERS BPA TASK FORCE KICK-OFF MEETING  
 Gergely represented PHA Europe on this event.



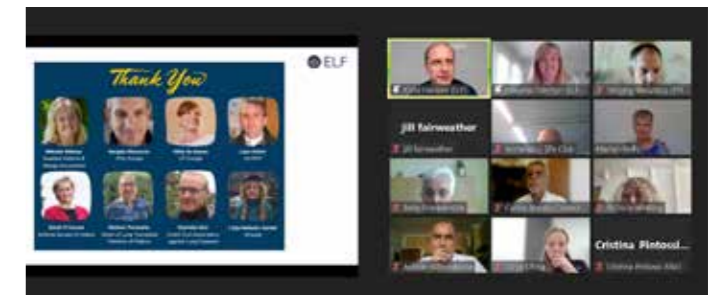
**Virtual (online) • August 17**  
 ELF PATIENT ORGANISATIONS' DAY BREAKOUT FACILITATOR BRIEFING  
 Gergely attended this meeting.

**Virtual (online) • August 23**  
 ERS CRC PHAROS STEERING COMMITTEE MEETING  
 Gergely represented PHA Europe on this meeting.



**Barcelona, Spain, August 26-28**  
 EUROPEAN SOCIETY OF CARDIOLOGY (ESC) ANNUAL CONGRESS  
 Gergely attended this important conference.

**Virtual (online) • August 31**  
 ELF PATIENT ORGANISATIONS' DAY  
 Gergely attended this meeting as facilitator.



**Barcelona, Spain • September 2**  
 PATIENT STORY  
 Hall gave a presentation about his PH journey to MSD/Merck employees. Hosted by MSD/Merck.

**Barcelona, Spain, September 3-6**  
 EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS  
 Eva, Monika, Hall and Gergely participated in this conference on behalf of PHA Europe.





**Barcelona, Spain • September 3**  
GOSSAMER PATIENT ADVISORY BOARD MEETING  
Eva, Monika, Hall and Gergely participated in this meeting.



**Virtual (online) • September 14**  
PULMONARY HYPERTENSION EMPOWERMENT NETWORK  
Eva, Tadeja, Zdenka and Hall represented PHA Europe on this meeting.

**Prague, Czech Republic • September 20-22**

JANSSEN PATIENT PANEL  
Hall participated as one of four participants in a patient panel at an internal Janssen meeting for employees around the world. Hosted by Janssen.

**Virtual (online) • September 21**

ADVISORY BOARD MEETING  
Hall participated in an advisory board meeting with a handful of other patients to give advice to a new company running trial for a potential new PH drug. Hosted by Aerovate.

**Virtual (online) • September 21**

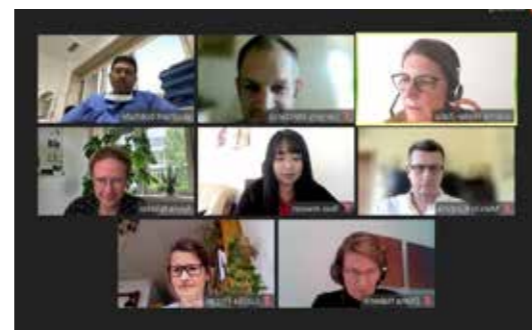
PULMONARY HYPERTENSION EMPOWERMENT NETWORK  
Hall participated in a conference with a handful of participants from various patient associations around the globe. Theme: Exercise and Nutrition. Hosted by Janssen.

**Virtual (online) • September 22**

EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING  
Gergely represented PHA Europe on this meeting.



**Virtual (online) • September 27**  
FERRER BOOTCAMP PREPARATORY CALL  
Gergely attended this meeting.



**Barcelona, Spain • October 3**  
FERRER TEAM-BUILDING BOOTCAMP  
Gergely was invited to participate in a roundtable discussion.

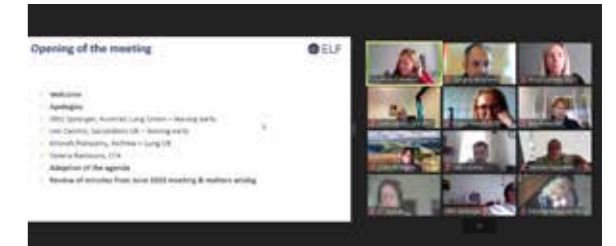


**Virtual (online) • September 28**

PVRI IDDI REGULAR MEETING  
Gergely co-chaired this meeting.



**Virtual (online) • October 4**  
EUROPEAN LUNG FOUNDATION (ELF) PATIENT ADVISORY COMMITTEE (PAC) MEETING  
Gergely attended this meeting.



**Virtual (online) • October 5**  
ERN LUNG MEDICAL STEERING COMMITTEE (MSC) MEETING  
Gergely attended this meeting as the member of the MSC.

**Virtual (online) • October 5**

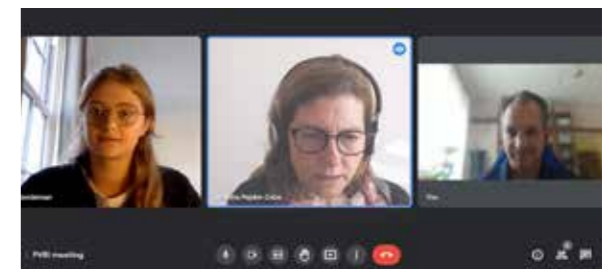
PULMONARY HYPERTENSION EMPOWERMENT NETWORK  
Theme: Managing mental health. Hall attended this meeting.



**Virtual (online) • October 7**  
EURODIS: KICK-OFF MEETING FOR EUROPEAN STAKEHOLDER NETWORK FOR RARE DISEASES  
Gergely participated in this webinar.

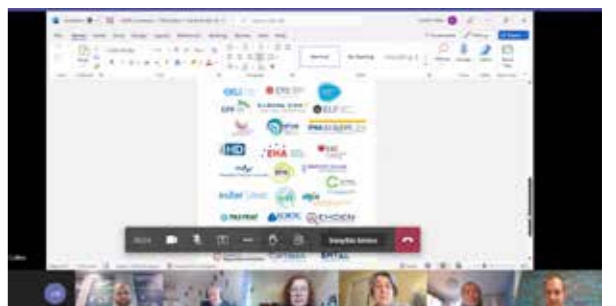
**Virtual (online) • October 11**

IOWNA MEETING  
Gergely met with this IT company to discuss the survey content.



**Virtual (online) • October 11**  
EUROPEAN WORKSHOP FOR HEALTHY DATA  
Gergely attended this political event.

**Virtual (online) • October 18**  
EHDS (EUROPEAN HEALTH DATA SPACE) COMMUNICATION PLAN DISCUSSION  
Gergely attended this meeting.





**Virtual (online) • October 26**

**PULMONARY HYPERTENSION EMPOWERMENT NETWORK**

Theme: Crafting disease education campaigns that address patient needs company running trial for a potential new PH drug. Hosted by Aerovate. Eva, Tadeja, Zdenka and Hall represented PHA Europe on this meeting

**Barcelona, Spain • November 3-6**

**APHEC – ANNUAL PULMONARY HYPERTENSION EUROPEAN CONFERENCE**



**Virtual (online) • November 11**

**PDHA AWARD CEREMONY**

Hall participated in the PDHA award ceremony after being one of the judges for entries submitted for digital innovation in the disease prevention and treatment journey. Hosted by MSD.

**Virtual (online) • November 16**

**PULMONARY HYPERTENSION EMPOWERMENT NETWORK**

Theme: Growing patient group audiences through online/offline campaigns. Eva, Tadeja, Zdenka and Hall represented PHA Europe on this meeting.



**Virtual (online) • November 17**

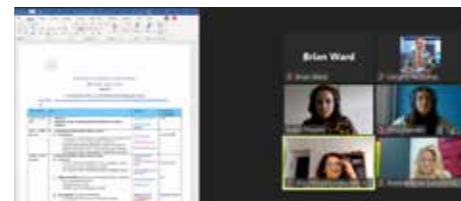
**EURORDIS ALL ePAG MEETING**

Gergely represented PHA Europe on this meeting.

**Virtual (online) • November 17**

**EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING**

Gergely represented PHA Europe on this meeting.



**Vienna, Austria • November 25**

**2ND PAH 360° WEBINAR: "PAH – EVIDENCE AND GAPS IN EVIDENCE"**

Gergely attended this live-streamed webinar as presenter and round table participant.

**Madrid, Spain • November 24**

**GALA OF THE 14TH ANNIVERSARY OF THE FUNDACIÓN CONTRA LA HIPERTENSIÓN PULMONAR**

Danijela represented PHA Europe in this gala.



**Upcoming events**

**2023**

*Brussels, Belgium • February 21*

**EURORDIS BLACK PEARL AWARDS**

Annual fundraising gala meeting of EURORDIS around Rare Disease Day.

*Frankfurt, Germany • March 22-23*

**ERN-LUNG BOARD MEETING**

Annual meeting of health care providers, which are members of ERN-Lung and patient representatives.

*Brussels, Belgium • April 28-29*

**EUROPEAN PATIENT FORUM ANNUAL GENERAL MEETING AND 20TH ANNIVERSARY POLICY EVENT**

*Stockholm, Sweden • May 25-27*

**EURORDIS MEMBERSHIP MEETING**

*Amsterdam, The Netherlands • August 25-28*

**EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS**

*Milan, Italy • September 9-13*

**EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS**

*Athens, Greece • September 17-20*

**EUROPEAN SOCIETY FOR ORGAN TRANSPLANTATION CONGRESS**

*San Diego, USA • September 29-30*

**INTERNATIONAL CTEPH CONFERENCE**

*Date&Venue TBC*

**ANNUAL PULMONARY HYPERTENSION EUROPEAN CONFERENCE (APHEC)**

The biggest annual gathering of European PH associations' leaders.

**2024 AT A GLANCE**

*London, United Kingdom • January 31 to February 3*  
**PVRI CONGRESS**

*Barcelona, Spain • June 29-30/July 1*  
**7TH WORLD SYMPOSIUM ON PULMONARY HYPERTENSION**

*London, United Kingdom • August 30 to September 2*  
**ESC CONGRESS**

*DATE&VENUE TBC*  
**ERS CONGRESS**

Gergely Meszaros

## UPDATED GUIDELINES FOR THE DIAGNOSIS AND TREATMENT OF PULMONARY HYPERTENSION



Last Friday in August 2022, as part of the annual ESC (European Society of Cardiologist) congress, the new ESC/ERS (European Respiratory Society) guidelines on pulmonary hypertension was presented.

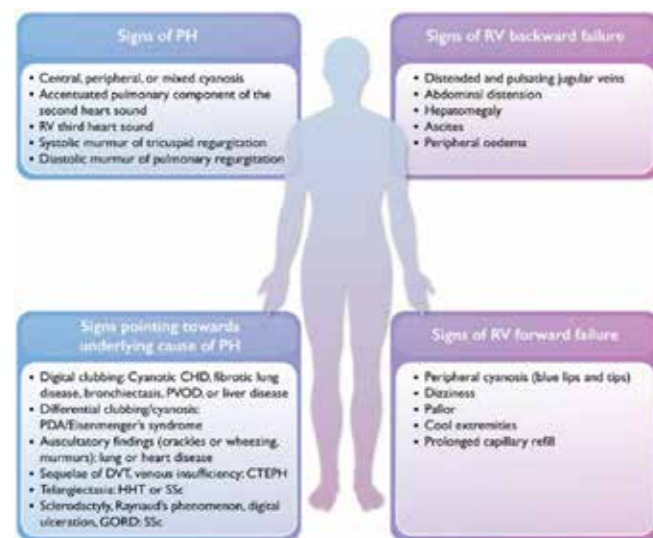
The Task Force (TF) on the new guidelines made an enormous effort in the last two years to update the previous guidelines which was published in 2015. This was the very first time that two patient representatives were involved in such a review and it is a great honor that PHA Europe was part of this work and was co-author of the new guidelines! It was possible to work closely together with key opinion leaders of the field and patient representatives were truly handled as partners in this whole process: participation was

ensured in countless Zoom meetings; we were part of hundreds of email exchanges. We were even asked to run a presentation about the importance of patient empowerment to the TF members. Moreover, we contributed to the wording as well: commented on the draft paper and provided the draft text for the "patient associations and patient empowerment" section.

Special attention was paid to visuals in the new guidelines which makes the more than 100 pages more understandable and digestible.

The new guidelines provides many novelties as follows:

- New hemodynamic definition of PH: the 6th World Symposium on Pulmonary Hypertension already introduced the proposal on the new definition which was implemented by the TF.
- Updated PH classification: the various sub-groups of pulmonary hypertension were finetuned and some of the groups were re-named to better reflect the conditions covered.
- New diagnosis algorithm: a more detailed and comprehensive diagnosis and treatment algorithm was outlined with one of the aims of fast-tracking those cases which require special attention.
- Expanded and fine-tuned risk-stratification table (four-strata risk assessment for follow-ups): the previous three strata (low-intermediate-high) model was expanded and the group of intermediate was divided to intermediate-low



and intermediate-high – data suggests that such further stratification is justified and contribute to a better treatment of the patients.

- Recommendation for the management of PH-LHD group: primary the underlying lung condition(s) to be treated.
- Updated CTEPH therapeutic algorithm: more detailed guidance was elaborated with the inclusion of fast-track referral.
- Patient-reported outcome (PRO) measures: such health-related quality of life questionnaires (HR-QoL) became more important and this role was honored by devoting a separate section on general and PH-specific HR-QoL questionnaires.
- New section on patient associations and patient empowerment: this new part of the guidelines underlines the important role of patient associations in the holistic care of the patients and emphasize that patients can also do a lot on an individual level to live better by taking more control on the decision which has impact on their life.

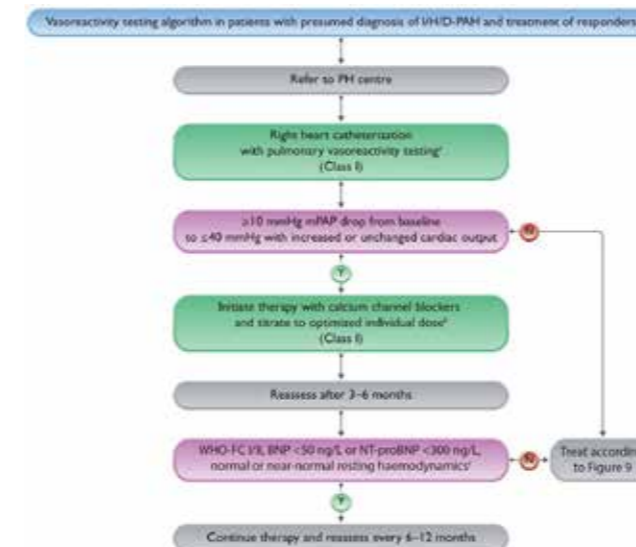
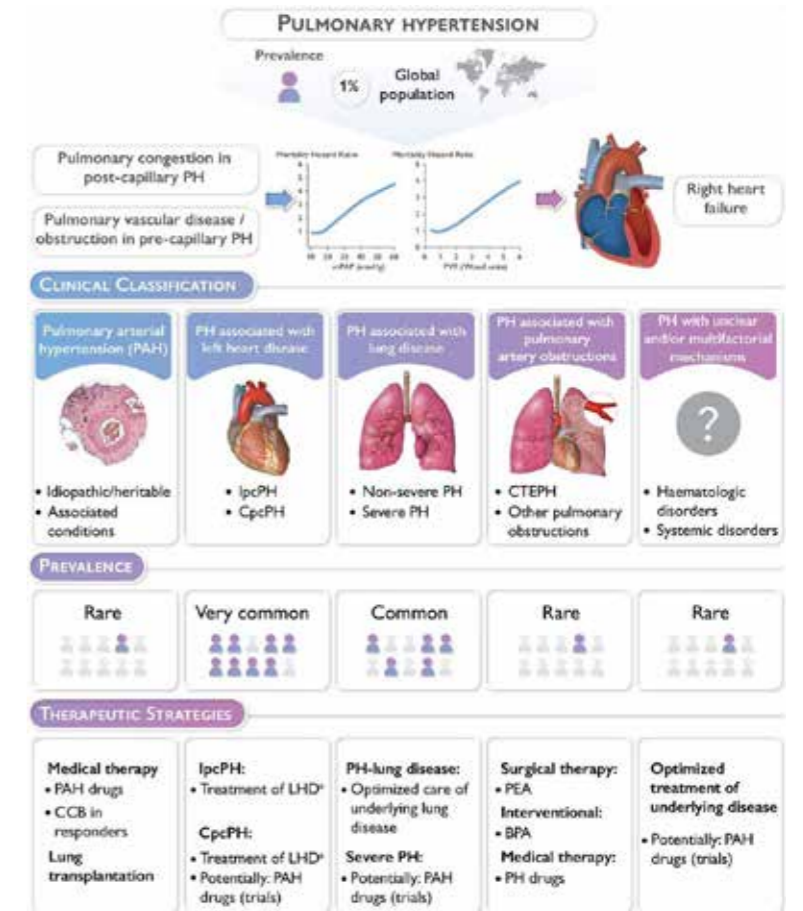
It was also the first time that a lay summary was prepared to facilitate the better understanding and dissemination of the guidelines. The new lay summary was officially launched during the annual congress of ERS in Barcelona on the 5th of September.

This lay summary is the transcription of the professional guidelines in simple terms – the correctness and accuracy of this paper is ensured by the revision of the writing committee of the guidelines. When this edition goes to printing the lay summary is translated to many languages, however PHA Europe would like to make sure that all of

its member can read the lay summary in their local language. Naturally, the work has not stopped with the presentation and publication of the new guidelines as it is our mission to make sure that the whole patient community is aware of this important paper.

To facilitate this goal, PHA Europe

- invited key opinion leaders from the TF to attend our APHEC 2022 in Barcelona to provide us with lectures on the new guidelines
- launched series of posts with big success on our social media channels to highlight these changes, and
- many more activities are planned on local levels.



**DIAGNOSING AND TREATING PULMONARY HYPERTENSION**  
*Understanding the professional guidelines*

## ANNUAL PH EUROPEAN CONFERENCE 2021

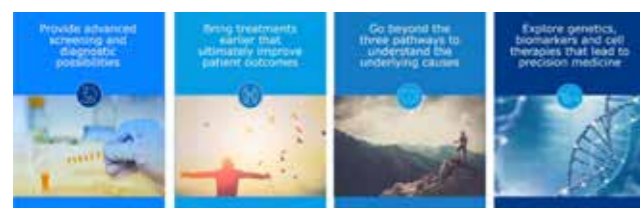


WPHD - Bel Air hotel floor plan

PHA Europe has run an annual conference for many years in a row. We usually meet in a hotel by the beach just south of Barcelona. We call it APHEC (Annual PH European Conference). The participants are leaders of the European national associations.

They are invited to bring an extra person – often a translator, if English is a challenge for the national presidents. The conference has always been a source of inspiration and opportunity for the participants to bond. We often use the term «our PH family», because our meetings have united us and made us a closely connected PH community, where no country borders exist. In this type of atmosphere, sharing and supporting each other comes naturally. So, our APHECs are very important to us.

Due to the pandemic, it was impossible for us to meet in Barcelona in 2020. It unfortunately also proves impossible to meet in 2021. By the end of the year, we understood that we needed to implement an alternative solution like in 2020. So, we contacted a Dutch company, who specializes in virtual events. They had a strong graphic department, and helped us recreate our Barcelona hotel. The two-story building, with alleys on both sides, was easily recognizable to all with the pool in the front and the beach in the back of the hotel. With this we managed to “open the doors” of our virtual hotel and held our conference on the 1st and 2nd of March, 2022.



Building our future legacy, two decades on  
Pulmonary Hypertension - Our focus to achieve our vision

### Hall Skaara

The participants entered the hotel through the virtual lobby. Here they got their badge and were greeted by one of the staff members. In addition, a welcome address from our president was played at the tv screen behind the desk counter. From the reception, one could go to any of the other areas in the hotel.

During our face-to-face meetings, the national associations often bring brochures and other materials to the conference room. Here it is all displayed and representatives from other associations can get inspiration and exchange samples with each other.

We wanted to create something similar in our virtual conference center and made an exhibition area, where all national associations were given a booth. Here they could write a description about their association, upload videos and documents that could be downloaded by all participants.



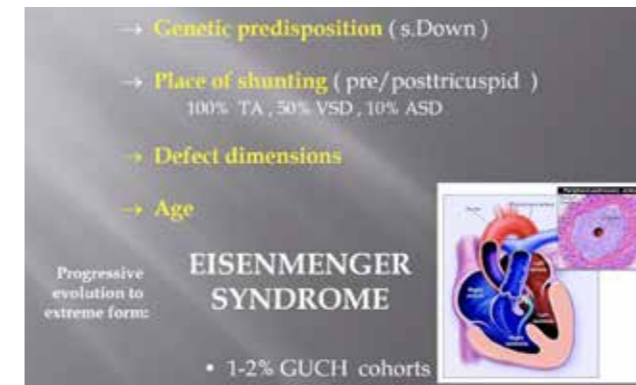
Aerovate Therapeutics - Impahct Clinical Trial

We also created a second exhibition hall. Here pharmaceutical companies, that we collaborate with, had a booth each. Likewise, the speakers of the conference also had a booth, where the participants could read their micro biography.

The social aspect of the APHEC is very important and we tried to recreate the nice social atmosphere by creating a meeting area by the pool. Here participants could chat with other online participants by clicking on their icons. In addition, they could run video meetings with each other one to one or even group meetings.

One important part of our APHEC is the presentations. We often attract top of the line PH specialists to speak for us, and our virtual APHEC was no exception. We prerecorded their presentation and made it available for our participants in the presentation room. The participants could watch them when it suited them, and they would write down questions they wanted to ask the presenters. The participants had obviously watched

the presentations carefully, because they submitted a total of 289 questions! We set aside two days where each of the eleven presenters would participate in an hour-long Q&A (Questions & Answers) session. A PHA Europe staff member was the moderator and asked the questions that were previously sent to him by the participants. The video session was streamed live to the theater room in the virtual conference area and the participants could ask additional questions to the presenter via the moderator. A large portion of the PHA Europe's national associations took part in the very interesting Q&A sessions and seemed to enjoy the state-of-the-art virtual setup.



PHT development Factors of influence

We covered a lot of interesting topics during the presentations. In addition to European presenters, three professors from USA ran presentations



## PH therapies in the United States, Today and Tomorrow

Franck Rahaghi, MD,  
MHS, FCCP

Chairman, Dept. of Pulmonary  
and Critical Care  
Director, Pulmonary HTN Clinic



for us. The Rahaghi brothers, ran presentations about CTEPH and PH treatment in the US. And Professor Preston ran an interesting presentation about exercise, sex and contraception. Prof. Hansmann talked about children and PH, while professor Torbicki talked about challenges and answers to access to treatment in Eastern Europe. Prof. Vonk Noordegraaf talked about future PH drugs, while Prof. D'Alto presented the concept of initial combination therapy in PAH. We also had sessions on peer-to-peer mentoring, nutrition and a presentation about Ayurveda. All in all, a diverse and interesting set of presentations very well perceived by the participants.

Of course, nothing beats a face-to-face meeting, but 2021 was another year where alternative solutions had to be made. We think we managed to portray the friendly and great atmosphere of our APHEC and provide our participants with a memorable and informative very professional online event. Now that the pandemic seems to be fading away, we hope that we can eventually meet face-to-face again in Barcelona. Our APHEC for 2022 is planned for the first week of November.

Our virtual APHEC was, once again, a great success. We will keep the conference area open which enables the participant to revisit/rewatch the materials and presentations.

## ANNUAL PH EUROPEAN CONFERENCE 2022

Hall Skaara



Due to the COVID pandemic, the Annual PH European Conference (APHEC) had to be run virtually. This has worked very well as we utilised an excellent online platform where we rebuild our conference hotel in Barcelona.



However, there is nothing like the real thing. Nothing beats meeting face-to-face and finally we were able to meet in Barcelona for our APHEC 2022 conference. It was a great joy to see each other again and many participants expressed the feeling of participating in a family reunion.

We had an excellent program: the first day we ran our General Assembly Meeting (GAM). Activity report

was presented for the previous year, the financial status was presented and a budget for the next year was approved. Two new member associations were accepted: PH associations from the Netherlands and Belgium. We also had two representatives from Luxembourg present. We will help them to establish an association in their country and they expressed an interest to join PHA Europe at the GAM in 2023. So PHA Europe now consists of 34 national PH associations from 29 different countries.

Social media is an important area for us, and we have outsourced it to a Serbian company called BC Hub. During our first day of the APHEC, they made a presentation about what has been achieved during the past year and the social media plans for the coming year.



Staff member, Hall Skåra, also made a presentation about the fellow program and our CBP program. We ended the past year with 15 fellows. They work part-time for given national associations with miscellaneous task and also act as liaises between PHA Europe and the associations translating material from English to the local language and vice versa. We plan to expand the fellowship program and in 2023 we will, for instance, have a new fellow in Spain. Hall also presented the Capacity Building Program which aim is to help the associations to mature. He pointed out which projects that had been supported in 2021 and encouraged associations also to apply for fund for appropriate projects in the coming year. Prior to the APHEC, most associations had completed a questionnaire highlighting the offerings of their national associations. Hall presented the results and pointed out areas in which the associations do well and areas that have room for improvements. We plan to use the CBP to help mature the associations where needed as pointed out in the questionnaire report. PHA Europe's general manager, Gerald Fischer, also presented an organigram. The delegates learned about the tasks that PHA Europe performs and who are responsible for them.

The next day was dedicated to our industry partners. It was exciting to meet both new and old friends from the pharmaceutical industry. Here the delegates learned about the companies, their priorities, programs and trials. The activity level within the field is very high and it is reassuring to the delegates to see that many new programs and medications are planned for the upcoming years.

The third day was mostly dedicated to our health care professionals (HCP). However, the staff member, Gergely Meszaros, started the day by presenting one of PHA Europe's most important activities in the recent year: our renewed Call to Action. PHA Europe's

position paper was originally launched in 2012 and it was high time to revisit our calls whether they are still relevant, need more attention and resources. Gergely in his speech covered the revision process, the main changes implemented, the launch event of the new paper in the European Parliament and future plans, including national activities.

During the day, we also had two excellent presentations about news in the new ERS/ESC guideline on pulmonary hypertension. Presentations were made by Prof. Marion Delcroix and Prof Stephan Rosenkranz. Among the changes that was highlighted, was that the patient voice was also taken into account. PHA Europe, represented by Gergely Meszaros, was part of this task force and made important contribution to the guidelines. This is proof of the acknowledgement by the medication community of the importance of a patient centric approach to the treatment of Pulmonary Hypertension.

We also had a very interesting session by Chermaine Kwant about nutrition and PH. She is currently working on a PhD in the field. Her background is very relevant to the topic, as she used to suffer from PAH before she was transplanted a few years ago. Chermaine is planning to run a large international study on the topic, and PHA Europe is endorsing her and her project.

Prof. Regina Steringer-Mascherbauer also talked about the experience they have at her Austrian hospital with implantable pump. One of the delegates commented on her experience with the pumps and how it had influenced her Quality of Life (QoL).

APHEC 2022 was unquestionably a great success. The 52 delegates enjoyed a very interesting and educational program, but most of all they enjoyed to meet each other again face-to-face. It was a great «family reunion», and we cannot wait until meeting again in Barcelona for the APHEC 2023 meeting.



## O2KIDS CAMPAIGN

*Hall Skaara*

Unfortunately, even children are affected by PH. In 2022, we ran a continuation of the 2021 O2Kids campaign. Based on the experience from the previous year, we made sure to focus on real children with PH in the videos, and no actors.

The aim of the campaign is two-fold. First of all, we would like to do fundraising and to fulfil the wishes of some unfortunate PH children. We received a wish-list from 13 children all over Europe. Their gift wishes were very modest: some wanted a special tricycle or an electric scooter. This is because they often have problems with physical activity since their lungs say «no» even if their mind says «yes» to physical activity. So they might need help in getting to school or to play with other children in the playground. Another examples of wishes were a watch to measure the heart rate and blood oxygen level. And another child's biggest wish was a portable oxygen concentrator that would help him to breath more easy. Fortunately, the O2Kids campaign enabled us to fulfil all the wishes of the children. It made them very happy and their lives easier.

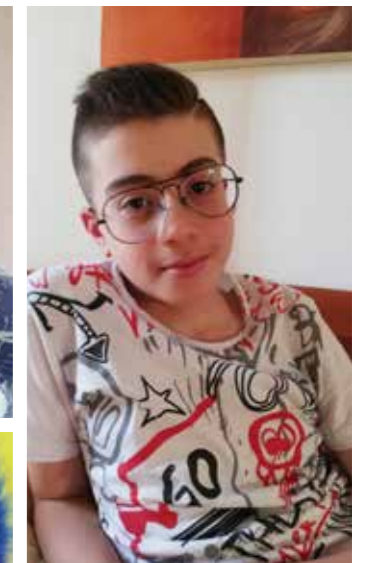
The second aim of the project is to create awareness for PH. It can, unfortunately, affect anyone. It does not discriminate between age groups, sexes or countries. And the initial symptoms of the disease are very diffuse. PH is therefore often misdiagnosed and confused with other less serious conditions. PHA Europe wants to make sure that people are diagnosed at an earlier stage in their disease. This will help both with the quality of life and life expectancy of the patients since they will get access to appropriate medication earlier. In this respect, the O2Kids campaign is a great success! People are curious and have a lot of empathy with the



PH sick children, and they watch the videos and learn about PH and its symptoms. The reach on social media has been fantastic and many have clicked on the links and seen the landing page that gives more information about the disease and also a chance to donate money. Here is some of the key information about the O2Kids campaign of 2022:

Key info:

- The O2Kids campaign generated more than 3.3 million impressions on social media creating a tremendous amount of awareness for PH
- Almost 900 000 users were reached
- More than 5400 clicked on the O2Kids link that took them to our landing web page
- The O2Kids video generated more than 400 post reactions, 43 post comments and 40 post shares.
- 13 children's wishes were fulfilled. The children represented 12 different European countries: Austria, Belarus, Bosnia & Herzegovina, Bulgaria, Croatia, Hungary, Israel, Italy, Serbia, Slovakia, Slovenia and Ukraine.



## MEMBER SUPPORT PROGRAM

Hall Skaara



The Member Support Program (MSP), previously known as the CBP, is a continuation of our White Spot Program (WSP). In the WSP, we help to establish an association in a country. In the MSP, we help associations to mature.

During 2022 we had several interesting activities related to our MSP:

- Based on the Wordpress template used for PHA Europe's own website, we helped design websites for eleven of our member associations. Their webpages look great! Furthermore, they all have the same look and feel which makes them easily recognisable.
- Member associations took advantage of our offer to create and print new image brochures. We use a template that was used when developing an image brochure for the Austrian association. The image brochure looks simple, but there is a lot of thought process behind it. Everything from the colour/illustrations to the paper thickness is well planned. An image brochure is important when recruiting new members and when approaching the pharmaceutical industry for partnership.

Almost all of PHA Europe's member associations now have an image brochure.

- The children's book about Casper, originally created by the Bulgarian (BSPPH) association, is now also available in Bosnia & Herzegovina thanks to the support from the MSP. The book has proven very successful and more translations might follow in 2023.
- Croatia got financial support for a program they called «21 Art from Heart». It involves 21 academic painters from Croatia. They will gather for a one-day art colony where each of them will paint two works of arts. Doctors from the PH center in Zagreb, as well as the media, will be invited to the colony also. With this project, the Croatian association would like to emphasise that in the 21st century, there is still no cure for PAH even though the disease was first mentioned 130 years ago.
- PHA Europe has used MSP funds to help associations that have requested it to provide a support line. A basic mobile phone + a year's subscription were awarded.

## REPORT ON CONGRESSES AND CONFERENCES

Gergely Meszaros

### REPORT ON EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS

Following the online annual congresses due to COVID everybody was very much looking forward to this hybrid event of (European Society of Cardiology) ESC end of August in the sunny, but a bit too warm Barcelona. This year was special for the PH community as the new guidelines on the diagnosis and treatment of pulmonary hypertension was presented on the first day of the conference.

It was Prof. Marion Delcroix (Belgium) the Prof. Stephan Rosenkranz (Germany), co-chairs of task force of the guidelines who presented the new guidelines on the very first day. In their presentation they outlined the main novelties and underlined that it was the first time that patient representatives participated in the task force. The most eye-catching visual, which was presented throughout the conference, was the one which was built-up as a puzzle and the patients were in the centre.

technology add value, what are the patients' expectation on artificial intelligence, and Pisana Ferrari (Italian patient association, AIPI) provided her experiences on working in the PH guidelines task force.



Thanks to the participation in the Task Force of the guidelines we became the member of the Patient Forum of ESC – we hope that it will position us to represent the patient perspective in this scientific society as well.

### REPORT ON EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS

Some days after the ESC congress, almost in the same place the European Respiratory Society (ERS) held its annual congress.

The congress was very well attended and some of the presentations could be only followed on a screen outside the rooms as the rooms were full.

One of these sessions covered the novelties of pulmonary hypertension management. An interesting data was shown from Germany about the impact of PH on employment, work productivity and quality of life. The main takeaways were as follows:

- re-education strategies are needed for patients in manual labour are needed, if a patient is eligible to work
- physicians should empower and help patients getting back being employed considering employment as a treatment goal
- employment can provide patients with more independence and thus a more favourable quality of life (QoL) and social participation

A complete symposium was devoted to the new guidelines and special cases were also discussed to highlight the differences. The session was kicked-off by the patient presentation on thoughts about the involvement in the guidelines task force Prof. Sean



The following days more sessions followed the inaugural presentation and the members of the task force went into more details on the different group of pulmonary hypertension, the new risk assessment model, the diagnostic pathway with fast tracking possibilities. Prof. Irene Lang (Austria) put the new guidelines into perspective in a separate presentation and outlined the long journey and looked back to the last twenty years. Despite pulmonary arterial hypertension (PAH) is a rare disease it attracts more and more attention: it was even in the ESC TV - The Day in Focus program together with more prevalent diseases. You can learn more about the novelties of the new guidelines from another article of this Mariposa. Patient involvement was not solely an empty slogan, but patients actively contributed to the program as speakers: we tried to answer the questions where does

Gaine played the devil's advocate role in one of the lectures and listed some challenges to be addressed by the practice aligned with the new guidelines.

### 1/ASSEMBLY 13 MEETING

The ERS Assembly 13 (pulmonary vascular diseases) links its annual meeting related to the ERS yearly congress. This year it was an online meeting, but followed previous years' agenda:

- presentation of awards, including mid-career awardees as well
- funding programs with upcoming deadlines
- preparation for the next ERS Congress in Milan (2013)
- educational activities and learning resources
- ERS in numbers (number of abstracts, congress participants, clinical cases – slight decrease can be identified, membership)

We are honored to be part of this meeting and have had the chance to present the main achievements of this year – our report was welcomed by the healthcare professionals.

### 2/POSTERS

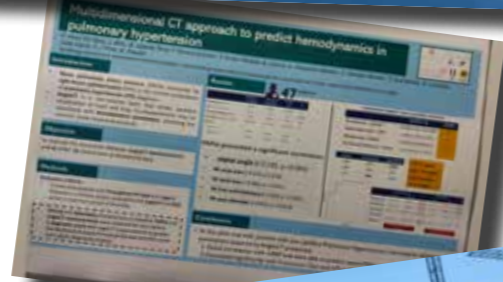
The poster area is always worth visiting with their eye-catching visuals, concise information and topics which are of great interest. This year the best abstract of ERS Assembly 13 was related to the PEX-NET CRC (clinical research collaboration). Another poster was dealing with childhood trauma in PAH patients resulted from maltreatment. Right heart catheterization is the cornerstone of the diagnosis: one of the papers revealed that these procedures are frequently incomplete if they are not performed in expert centres. An interesting paper was exploring AngioCT which is a non-invasive diagnostic tool: they found good correlation in mPAP (mean pulmonary artery pressure) and significantly associated with functional class and NTproBNP.

### 3/AWARDS

Key opinion leaders of PH were appreciated by ERS: Prof. Gerald Simonneau received the ERS presidential award and Prof. Paul A. Corris received the ERS lifetime achievement Award in thoracic surgery and transplantation.

### 4/TASK FORCE ON TECHNICAL STANDARDS

Balloon pulmonary angioplasty (BPA) is a relatively new technique in CTEPH patients. A new task force under the umbrella of ERS was officially kicked-off with the aim of standardization, which can contribute to daily practice and increase access of patients to this curative treatment, help to design further studies. Finally, it can be a source of information for patients and increase the knowledge of both the medical community and the general public of BPA.



Gergely with Prof. Joanna Pepke-Zaba and Prof. Paul A. Corris

The Task Force consists of 8 working packages about decision making processes, BPA procedure, comorbidities, prerequisites of CTEPH centres to name a few.

We were invited to participate in this work and represent the patient perspective during these discussions.

### 5/PHAROS

After lots of preparatory work and meetings (in the early phase with the involvement of ERN-Lung) PHAROS (severe Pulmonary Hypertension

mManagement acROs Europe), the newest clinical research collaboration (CRC) of ERS was officially launched during the congress with following working packages (WP):

- WP1: establishment of an inventory of existing registries
- WP2: evaluation of patient access to care in Europe
- WP3: characterization of PH patients with failing right ventricle
- WP4: phenotyping and treatment of patient with PH associated with lung diseases (group 3)

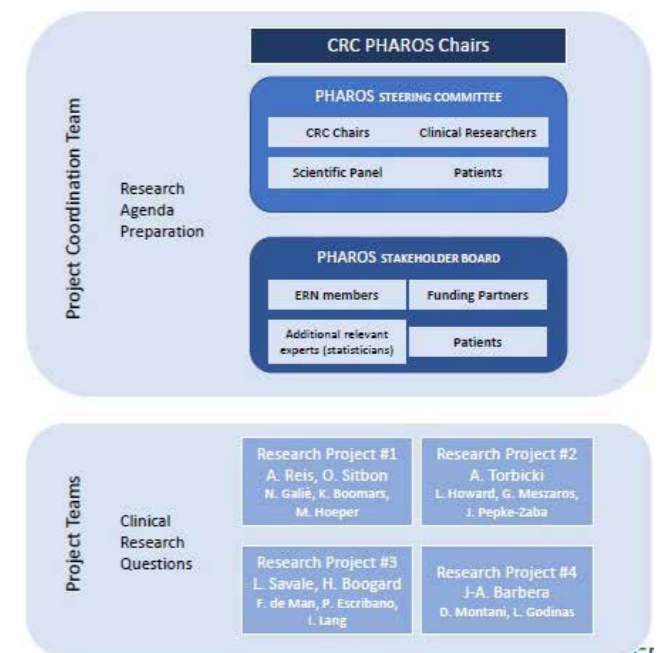
In WP2 surveys to map the current situation is planned to be sent out and based on the responses action items will be outlined.

We are part of WP2 and WP4 and very much looking forward to the work ahead of us.

### 6/ELF PATIENT ORGANIZATIONS' NETWORKING DAY

The gathering of patient associations linked to and active on the respiratory field was always integral part of the ERS yearly congresses: usually it was organized by the European Lung Foundation (ELF) on the day before of the congress. Luckily, this information day was not stopped, but went online during the pandemic. As respiratory patients are at higher risk, the patient organizations' day remained online for an additional year, however there was a possibility to meet in person with some of the representatives during the congress. ERS president Prof. Marc Humbert and ERS president elect Prof. Carlos Cordeiro greeted the more than 70 attendees and highlighted

- the launch of the International Respiratory



- Coalition (IRC) and the Lung Facts website
- the importance of self-management, patient and caregiver empowerment as well as the integration of the multidisciplinary team

The whole day was built around self-management – man could learn from theory to implementation, development of digital screening tools and online physiotherapy programs. The plenary was followed by interactive break-out sessions and the main takeaways were to invest more in education, to support mental health services and to raise awareness of respiratory diseases.

We played an active role in this event: we were not only one of the group facilitators, but member of the working group responsible for the program.



## SOCIAL MEDIA ACTIVITY 2022

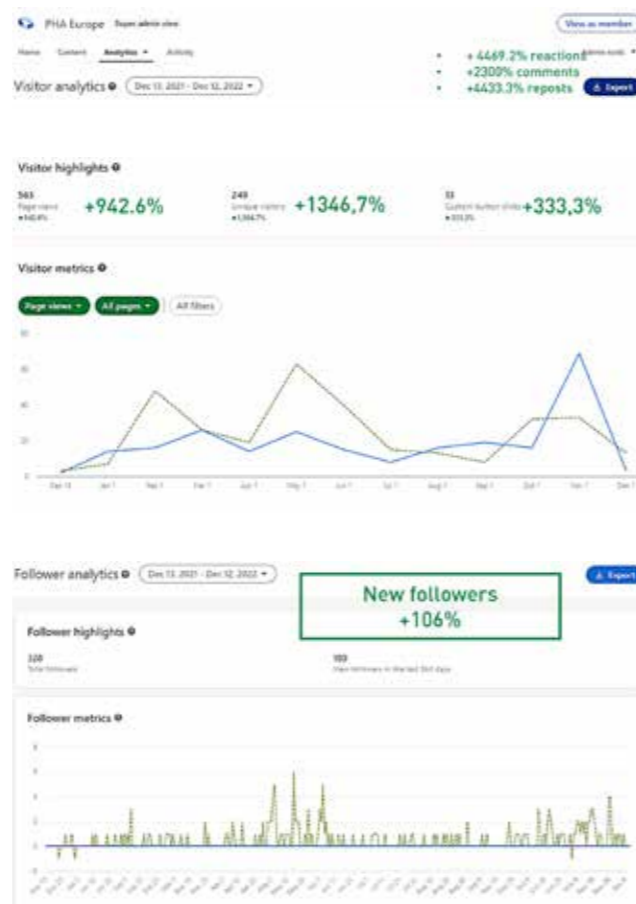
Gergely Meszaros

In 2022, we saw a steady increase in organic parameters across all social media platforms. This included an increase in our fanbase, total organic reach, number of interactions, and engagement. Despite spending less financial resources on campaigns and content boosting, we were able to achieve better results than the previous year.



### LINKEDIN

On LinkedIn, the number of followers on our page increased from 190 in January 2021 to 333 in December 2022, a 143 follower increase without any boosting or paid content. Additionally, we saw a 333% increase in custom clicks and a major increase in unique visitors. This demonstrates a consistent growth of our page without the use of boosting or paid content. Custom clicks refer to the number of clicks on a LinkedIn ad that leads to a specific destination, such as a website or landing page. A 333% increase in custom clicks indicates that our ads are effectively capturing the attention of our target audience and encouraging them to take action. It is important results as the targeted audience on LinkedIn are mainly healthcare professionals, experts, key opinion leaders, pharma companies representatives etc. A major increase in unique visitors suggests that our LinkedIn page is attracting a larger audience and potentially reaching new users. A significant growth of LinkedIn page is evident from the provided date. This is a positive sign that our content and strategies are resonating with our target audience and effectively driving engagement. We will continue to monitor and analyze the performance of LinkedIn page to identify opportunities for further growth and improvement.



### TWITTER

We also saw similar results on Twitter. In 2022, our Twitter page saw a total of 66,905 tweet impressions, representing a 22.4% increase from the previous year. We also saw a significant increase in the number of tweets we posted, with a total of 340 original and reshared tweets, representing a 45% increase compared to the benchmarked period. These efforts were successful in driving traffic to our page, with a total of 7,400 unique page visits. We also gained 117 new page followers and an average of 5,000 post impressions per month. Our May WPHD 2022 Twitter campaign demonstrated strong performance, surpassing the success of the previous year. By producing 45% more content, we were able to achieve a 64% increase in overall campaign performance.

### FACEBOOK AND INSTAGRAM

On Facebook and Instagram, we saw an impressive increase of 54% in total reach compared to the previous year. The total reach on Instagram even increased by 90% compared to the previous year. While there were periods where the numbers dipped, such as after our regular campaigns like WPHD and Awareness Month, we are focusing on developing new and engaging content to maintain a consistent growth on these platforms. Unlike the previous year, when we saw a total decline in traffic on our social media channels after May and a lack of engagement, our new approach and strategies have led to a change in this trend. Our efforts are starting to pay off, resulting in increased traffic and engagement on our social media channels. We will continue to refine and improve our approach to ensure that we are able to maintain this positive momentum and drive even better results in the future. To present the results of our social media efforts during 2022, please refer to the diagrams and analytics provided by the relevant social media platforms. These figures accurately depict the progress and success of our social media strategy on both Facebook and Instagram.



It is noteworthy to mention that the PHA Europe Facebook page has amassed a total of 547 likes, representing a 90% increase compared to the previous year.

### EMERGING PLATFORMS

It is important to recognize the importance of new and emerging social media platforms, such as TikTok. We recommend considering opening a TikTok profile and allocating resources towards building a fanbase on that platform.

### CAMPAIGNS OVERVIEW

During February PHA Europe has once again supported Rare Disease Day. We have created and shared visually appealing content on PHA Europe's social media pages featuring the slogan "We are rare and it's great that people care." The message resonated well with people and we even shared a powerful video with an impactful and informative message. Similar to the previous year PHA Europe conducted a series of campaigns to raise awareness about pulmonary hypertension among the general public but also among healthcare professionals, key opinion leaders, and pharmaceutical partners. These campaigns were designed to educate and inform individuals about the signs, symptoms, and treatment options for pulmonary hypertension, as well as the importance of early diagnosis and management. The campaigns were successful in raising awareness about pulmonary hypertension and reaching a wider audience. In 2022, PHA Europe conducted a total of 10 different social media campaigns with strong results. These campaigns demonstrate PHA Europe's dedication to raising awareness about pulmonary hypertension (PH) and working with key opinion leaders to address a variety of topics related to this condition. Some of the key campaigns we conducted include: A call to action in the European Parliament, World Pulmonary Hypertension Day (WPHD) 2022, O2Kids handover campaign, Annual PH conference (APHEC), Presentation of the new guidelines for diagnosis and treatment of PH from the European Respiratory Society (ERS) and the European Society of Cardiology (ECS), "Speak Up About PH" (speakuPH) where the main campaigns utilized a variety of tactics, with tailored made and appealing visuals and straight to the point descriptions we have managed to reach a wide audience and educate them about PH.

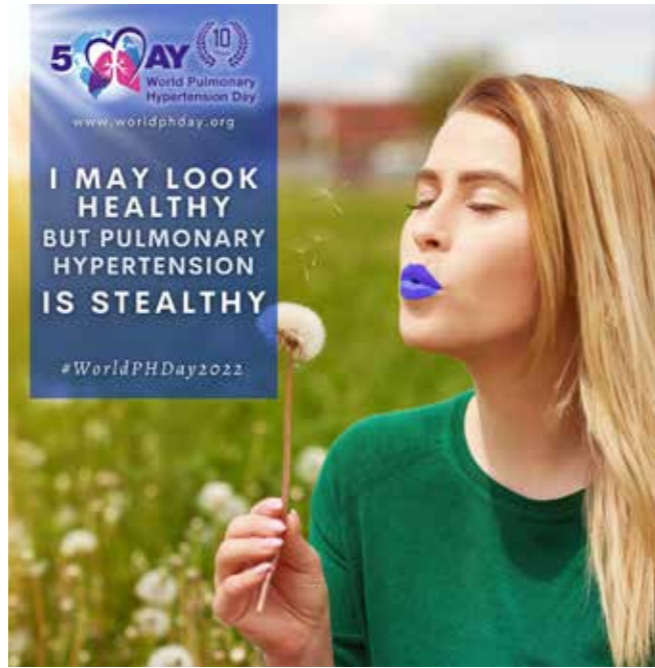
### FLAGSHIP CAMPAIGN • WPHD 2022

For World Pulmonary Hypertension Day (WPHD) 2022, PHA Europe prepared a total of 19 posts and a 5-minute video. These materials were translated into a variety of European languages and distributed across PHA Europe's member association social media pages.





# AUSTRIA



Thanks to the coordinated efforts of PHA Europe and member associations, the WPHD campaign made a strong impact, reaching over 5 million people worldwide. A single post that we are most proud of collected more than 700 likes which speaks volumes about the overall success of this particular campaign.

"Speak Up About PH" (speakuPH) is a well-designed content campaign for PHA Europe's social media pages that brings attention to the realities of living with pulmonary hypertension (PH). By featuring real people suffering from the disease and sharing their stories, we are able to connect with the general audience and create a sense of relatability. This helps to raise awareness about PH and the importance of early diagnosis and management.

We believe that the success of the speakuPH campaign is due to its ability to engage and inform the public about PH on a more personal level. These types of campaigns are effective at raising awareness and engaging the public, and we believe that they will be an important part of our strategy going forward. We strongly propose making a one or two similar campaigns in the 2023.

The "Awareness Month" campaign, which took place in November, was focused on raising awareness about pulmonary hypertension (PH). By resharing posts from the Pulmonary Hypertension Association, we made a coordinated effort to amplify the voices of PH patients and demonstrate our unity in raising awareness about PH.



INFORMATION DAY KLAGENFURT - Presenter and Ayurvedic Expert Anna Vamos

Linz, Graz and Vienna, as well as workshops in Salzburg and Graz. We were joined by many doctors and specialists in the field, who presented and discussed various topics. The new ERS/ESC guidelines, the connection between one's skin and the heart, healthy eating habits and a new device for the diagnosis of lung diseases, are only some examples. We were especially happy to see everyone in person again, of course while strictly adhering to all advised Covid-19 safety measures. On average, more than 50 attendees utilized our information meetings and workshops this year to not only network and connect with other patients, but to receive valuable insight from doctors and specialists, as well as tips, tricks, and even trainings for a healthier way of life. We also welcomed our 450th member of our Association!

## SUCCESSFUL INFORMATION DAYS - NOW FINALLY IN PERSON AGAIN!

This year, we were able to plan and execute the first ever recurring information day in Klagenfurt, Carinthia. Patients, their relatives, and friends described the event on the 14th of October as an "entertaining, funny and really informative training for those affected!"

Lectures by Anna Vamos, certified Ayurvedic practitioner, and a respiratory muscle training by physiotherapist Tim Kogal, were able to inform participants about various ways to stay fit, while the lecture by senior physician Dr. Buchacher also fully focused on our affected attendees and relatives. There was a subsequent quiz and even prizes! The idyllic conference room adjoined a cute garden at the Seepark Wörthersee Resort – this ensured pure relaxation. We also held our usual information meetings in Innsbruck,



Univ.-Prof. Dr. Irene Lang talking about the new ERS/ESC guidelines



INFORMATION DAY VIENNA - Gerry Fischer, Univ.-Prof. Dr. Irene Lang, and current president Eva Otter





### OUR 9TH VIENNA ZOORUN AND 8TH GHOSTRUN

After a two year break due to Covid-19, we were especially ecstatic to finally organize the 9th Vienna ZooRun, which is held in the traditional Vienna Schönbrunner Zoo, in person again. An incredible 1.800 passionate runners from all over the world joined us for this unique event on June 22nd. Under the motto „Get breathless for PH”, the charity run drew attention to Pulmonary Hypertension. The idea behind it of course: to run for those who cannot do it themselves due to the breathlessness-causing disease. Many companies, such as Octapharma, Asphalt Felsing, HDI, the Austrian Lotteries, and KPMG, were at the start with large running groups and used the run for team building.



Our 8th GhostRun, which was also finally held locally in the Vienna amusement park Prater again, was a roaring success this year! We were able to hit a participants record for this event with over 1.000 costumed runners of all ages, who ran in solidarity for Pulmonary Hypertension patients under the motto “We run away from the Grim Reaper.” The proceeds from the entry fees, as well as merchandise and mask sales, will be used to give patients access to information, therapy, and support options, in order to improve their quality of life and to advance research projects.

Gerald Fischer, PH Austria - Initiative Lungenhochdruck  
[www.phaustria.org](http://www.phaustria.org)  
[www.facebook.com/lungenkinder](https://www.facebook.com/lungenkinder)



## BELARUS



Our work in the association is extremely diverse. We always have a lot of vitally important conferences. For instance, on 25 03 2022, a training course (seminar) „Early diagnosis and therapy of PAH diseases” was held on the basis of the educational center of the RNPC “Cardiology”, which was attended by specialist doctors from various regions of the Republic of Belarus. Besides, on the 28th of November was held the conference that was named „Asymptomatic progression of LAG is a myth or a reason for caution”. The leading professors of cardiology centers were answering questions and giving more useful knowledge about that field of medicine. Moreover, from the 3th of November till the 6th of the same month we had another conference in Barcelona. It was held literally in the beach hotel, which was so nice and pretty. Also, our work concerns translating the news on different social media, such as Telegram, VKontakte, Instagram. On the 22th of October there was a lawyer’s consultation on how to get LAG drugs for free. Later we had the conference „Children Pulmonary Hypertension. What do parents need to know?” During the whole conference Irina Mikhailovna Miklashevich was telling and answering different questions about the program, children’s dosages of lag drugs and all the parents’ concerns.

We are also trying to find an interesting information about people, whose life more or less concerns our issue. For example, a 31-year-old resident of the Far East Tatyana Kiryanova was the first woman, who gave birth after a lung transplant. Deep down Tatyana had already taken risks when she went for the operation. Pregnancy has become a new test - with an unpredictable outcome, because after a transplant there is a high risk of rejection. „I don’t regret at all, that I gave birth to a daughter. She is my miracle girl! I do not impose anything on anyone, this is a personal matter for everyone. But if you are confident in doctors, if you have moral support from loved ones, then you don’t need to be afraid” - said that incredible Earth hero. On the 22th of December, 2022, an advanced training course „Minimally invasive approaches in cardiac surgery” was held. There were highly qualified student specialists from the Republic of Uzbekistan. The purpose of the educational program for advanced training was the professional development of cardiac surgeons in the use of innovative surgical methods for the treatment of cardiovascular diseases.

Alina Katsubinskaya  
 PH Belarus

## BOSNIA AND HERZEGOVINA



### A YEAR WITH MANY ACTIVITIES

During the year 2022, we realized a lot of activities that we focused on two goals that are equally important for us in Bosnia and Herzegovina - a better position of patients with pulmonary hypertension and raising awareness about pulmonary hypertension. It is really difficult to list everything we have done in one text, but we will try to put focus on the most prominent and important ones:

### IMPERATIVE BETTER POSITION OF PATIENTS

As a rule, public activities during a year begin with the celebration of Rare Disease Day - RDD. Pulmonary hypertension in our country must be recognized as a rare disease and everything that this term implies must also apply to people suffering from this disease, which is why we organized two events during the last day of February. One was the street performance "Lungs of the city - a healthy lung" in the very center of the capital, Sarajevo, and the second was the holding of an informative lesson on pulmonary hypertension, where students and employees of the Gymnasium "Rizah Odžević" from Zavidovići joined us. Both activities were realized by our activists Sabina Hodzic and Vedrana Kupusovic.

During the year we continued to participate in activities organized by European organizations dealing with the health of people suffering from respiratory diseases. Among them, we highlight the participation in the online webinar organized by the ERS (European Respiratory Society), the topic of which was "Health of the respiratory system in women - should we focus

especially on the female respiratory system?", as well as the participation in the summer school organized by the European Forum of patients (EPF), i.e. training for young patient advocates, Summer Training Course for Young Patients Advocates (STYPA). Our Sabina Hodzic and Amina Berbic participated in these activities as members of the Association of Citizens Suffering from Pulmonary Hypertension "Dah" - in Bosnia and Herzegovina.

We did not give up this year either and continued with the implementation of the project "Strengthening integrity in the process of creating a list of medicines in Bosnia and Herzegovina" as part of the patient network "Right to medicine of the Federation of Bosnia and Herzegovina", which is implemented in parallel in the Republic of Srpska and in the Brčko District, and which were attended by Jasmin Jukan and Samir Hodzic with the aim of the participation of patient representatives in drug commissions, which can only be achieved through the joint action and partnership of all those involved in the process of creating the list of drugs.

We finished the end of the year with another commemoration, on December 3 - the International Day of Persons with Disabilities together with all other disenfranchised patients in our country, but also by printing a wonderful picture book with the help of PAH Europe "Kasper - the blue-lipped bear", intended for the youngest.

All these activities were aimed at a better position of PH patients, more adequate medical protection and mandatory continuous therapies, which are, as a rule, extremely expensive for all PH patients in our country.

### SPORTS TO RAISE AWARENESS OF PULMONARY HYPERTENSION

As in previous years, this year our best partners in raising awareness of pulmonary hypertension in Bosnia and Herzegovina are athletes. We regularly write about the incredible successes of our famous alpinist and speleologist Zdenko Veljacic Veki and recreational cyclist Ismet Skulj. This year, too, we recorded new heights that Veki won for us, as well as new thousands of kilometers that Skulj rode us on a bicycle.

During 2022, Zdenko Veljacic Veki won three new peaks for PH patients: Breithorn (Switzerland), Musala (Bulgaria) and Vosac (Croatia), and in addition to the peaks he was on in previous years, Veki ended this year with a total of 32,989 conquered meters above sea level for patients with pulmonary hypertension in order to draw the public's attention to the plight of PH patients in Bosnia and Herzegovina.

Unlike Veki, who conquers heights for PH patients, Ismet Skulj drove us on European roads again this year for patients with pulmonary hypertension. In addition to his drive to Austria and back, he also drove to Turkey and back at the beginning of 2022. When we add those two rides together with all the previous ones that Skulj rode with the signs of the European PH community, his total is 9,310 km that he traveled riding his bicycle on the roads of Europe to raise awareness about pulmonary hypertension together with us.

These two sportsmen deserve great respect from the whole PH community of Europe and the world.

Apart from them, of course, we must not forget our own Samir Okic, mountaineers and runners Enes Ibrahimagic, Sanel Kurtagic, as well as girls Dzenana Music and Elza Ljubijankic.

The symbols of the European PH community were worn by our runners at national and international races, even at the 100 km world championship, while former PH patient Samir Okic is now a mountaineer who has had a heart transplant and lives a completely normal and active life. Veki's successes are far from this brave PH fighter, but who knows, nothing is impossible with a new heart and without pulmonary hypertension.

All these endeavors of vital, healthy, brave and tireless athletes realized with in order to raise awareness and improve the situation of patients with pulmonary hypertension in Bosnia and Herzegovina, and that is why they must not go unnoticed, and they give us in Bosnia and Herzegovina the strength to endure without adequate medical care and therapy.

*Vera Hodzic, President of the Assembly Association of Citizens Suffering from Pulmonary Hypertension „Dah” - in Bosnia and Herzegovina*



## BULGARIA BSPPH



### CELEBRATING THE RARE

A "Walk of Hope" was held on February 27 in three Bulgarian cities - Sofia, Pleven and Varna. 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 like 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 28 at 19:00, emblematic buildings in ten Bulgarian cities were illuminated in the colors of the rare - blue, green, pink and purple.

### TRANSPLANT RECIPIENTS TOOK PART IN THE WIZZ AIR SOFIA MARATHON

On 20 June 2021, more than 40 transplant recipients and their doctors, as well as representatives of the Executive Agency Medical Supervision participated in the Wizz air Sofia marathon.



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.



### BULGARIAN HELSINKI COMMITTEE GAVE OUT ITS ANNUAL HUMAN OF THE YEAR AWARDS

For the 14 consecutive year, the human rights organization Bulgarian Helsinki Committee gave out its annual Human of the Year awards. Traditionally, this takes place on December 9th – the International Day of Human Rights. The awards are given to promote bold and tenacious people and organizations in their efforts to advance human rights. Ten statuettes with a crystal



flower – the symbol of light, truth and justice went to volunteers, activists and organizations helping the Ukrainian people.

Among the nominees was Natalia Maeva, president of the Bulgarian Association of Patients with Pulmonary Hypertension, which has been working for the benefit of patients with rare lung diseases for nearly 10 years. Together with three other lady patient advocates and part of the European Reference Networks, Petya Stratieva, Boryana Stoyanova and Nataliya Grigorova conducted an intensive campaign with the Ministry of Health in connection with the nomination of a coordinating institution in Bulgaria for the implementation of the European joint action for integration into the European Reference Networks for rare diseases (ERN) of Bulgarian healthcare.

Natalia Maeva, Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH

[www.bspph.net](http://www.bspph.net)

[www.facebook.com/BSPPH.Bulgaria?ref=h](https://www.facebook.com/BSPPH.Bulgaria?ref=h)





## BULGARIA PHA

### TODOR BIKE TOUR 2022

Inspired by the idea of giving hope to all PH patients Todor Mangarov chairman of the Bulgarian PHA association take 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 city of Sofia. Passing Girona, Perpignan, Narbonne, Montpellier, Marseille, Cannes and reaching Nice where he was forced to quit and postpone his bike tour, caused by illness and extreme weather conditions.

Nevertheless, he gave us example that diagnoses on time, correct treatment and adequate follow up of PHA can lead to normal, active live. Looking forward finishing the planned tour.

Todor Mangarov, PHA Bulgaria  
<http://www.phabulgaria.eu/>  
[www.facebook.com/aph.bulgaria](http://www.facebook.com/aph.bulgaria)



## CROATIA



We all need support to face difficult situations, especially the smallest ones. That's why there is Kasper the bear, a bear whose lips turn blue due to pulmonary hypertension and who is now playing with his friends again!

Recently, a stack of freshly printed, fragrant stories by the Bulgarian author Natalia Maeva, who herself suffers from pulmonary hypertension and who decided to write a story about a slightly different teddy bear, came to our table. When playing with his peers, Kasper the bear's lips suddenly turn blue because he suffers from pulmonary hypertension. Concerned parents take care of him as best they can, but the bear misses friends and play. But far behind the mountains, Doctor Panda is waiting for this brave family, who will help Kasper and his friends to finally be able to play together!

When we are together, everything is easier, and that is why we are very proud of this picture book! Translation and printing funds were provided by PHA Europe

As part of the project "Let's do more - breathe together", on the 4th of December in Bjelovar we conducted and filmed a rescue operation in crisis situations for people with disabilities. Apart from the project holder, the Blue Wings association, the partner association of people with intellectual disabilities Osit, and the sports association Argo from Bjelovar, none other than a wonderful HGSS team participated in the action! Their cutest member of the team - A Border Collie, search dog quickly found the injured so now we know that in crisis situations we are not only in safe hands but also in safe paws.

The goal of our rescue demonstration is to strengthen the capacities of CSOs, provide support to marginalized groups in society and show them that the community stands behind them.

The video recording of the rescue operation (yes! We have that too!) will be available to all users of the associations as well as to the Croatian Mountain Rescue Service for the education of future members, and we believe that it will help everyone to find their way in crisis situations. This project was financed by the European Social Fund.

On the 16th of November, a round table and conference took place, where we presented our new Guide to Life with PAH! The authors of the guide will participate in the round table. Prim. dr. sc. Latinka Basara, Ana Hećimović, MD. specialist internist-pulmonologist and academician Miroslav Samaržija.

On the occasion of the conference, we would like to share with you a few sentences from the Guide, which we hope will help all the patients and their families:

*"Because PAH is a rare and complex disease, good care for PAH patients includes good communication with the PAH specialist, as well as support from family and friends. If you have PAH, your life can change a lot."*

Knowing that we suffer from a disease, which is chronic and incurable, will cause a certain psychological or emotional reaction in most people. Although unpleasant, such reactions are quite normal; they usually don't last long and actually serve to help the person, (in this case, you), better face the situation in which they found themselves. It is important to know that none



of these emotions are harmful in themselves, but they can cause some behaviors that are harmful (e.g. giving up treatment, irregular check-ups, not taking therapy, abuse of psychoactive substances for relaxation, etc.) We're talking about PAH and we're here for each other - come get your copy of the guide and find out more! Dr. Latinka Basara, one of the authors of "Guide to Life with PAH", was recently a guest on a tv network

"Mreža TV". She presented our guide and specifically addressed the psychological and emotional aspects of living with Pulmonary Arterial Hypertension. Watch the show and learn more about how to take care of your mental health when faced with a life-changing diagnosis!

*Katica Mavračić and Zdenka Bradač*



## CZECH REPUBLIC



### CELEBRATION OF RARE DISEASE DAY 2022

As every year, we participated in the World Rare Disease Day celebrations. This year there was an online campaign with colorful photos of everyone who wanted to get involved in the colors of rare diseases. All over the Czech Republic, buildings were lit up in the colors of a rare disease in a chain of lights.

### MEETING OF PATIENT ORGANIZATIONS WITH RARE DISEASES

We attend meetings of all representatives of patient organizations for rare diseases. In recent years, the Czech Association for Rare Diseases, of which we are members, has been organizing two meetings. At this meetings, there were lectures mainly in the field of legislation, research and palliative care.

### STATE OFFICE FOR DRUG CONTROL

This year we are participating in the administrative procedure for approving the reimbursement of the drug for pulmonary hypertension, Trepulmix at the state institute for drug control. 13 drugs for rare diseases have entered the proceedings, for the time being only one would be approved. Unfortunately, there is no deadline in the law by which the procedure must take place.

### RECONDITION STAY IN PODĚBRADY

The second Sunday in August marks the starting day of our reconditioning stay in Poděbrady. One week long stay in this spatown near Prague for PH patients with their families. As in past years, the program was focused on light breathing exercises, muscle stretching work and 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. As last year we prepared also psychological relaxations and individual support for our patients.





### ANNUAL MEETING IN PRAGUE

On 17-18 September a meeting of patients and their family members took place at the ILF Hotel in Prague. We needed to take some basic important steps that the law dictates, then we could educate and discuss about patient's needs. Specialists in the field of pulmonary hypertension, physiotherapy and our patron Sabina Laurinová accepted the invitation. In the afternoon we went to the Alphonse Mucha exhibition and the National Museum.

### NATIONAL ASSOCIATION OF PATIENT ORGANIZATIONS

NAPO was founded on November 17, 2021, with 11 founding members at its birth. On September 19, 2022, we became members of this organization. It currently brings together 35 patient organizations.

The National Association of Patient Organizations brings together patient organizations focused on all types of diseases and disabilities operating in the Czech Republic. NAPO's mission is to promote the collective interests of patients and provide support to its member organizations. The goal is for NAPO to become a respected partner for the Ministry of Health, the State Drug Control Office, the State Health Institute and other institutions in the field of health promotion that seek or consult patients' opinions.

We are currently participating in a workshop organized by NAPO focused on strategic planning.

*Milena Kaftanová*

[Sdružení pacientů s Plicní Hypertenzí www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)



## HUNGARY

At the beginning of 2022 we have still lived COVID times, so we have celebrated Rare disease day in the frame of a FB campaign, utilising the materials prepared by PHAE.

As at the progression of PH illness transplantation is the solution and several of our fellow patients have undergone this lifesaving procedure we are trying to maintain a good relationship with the Hungarian Association of Transplanted people. We are volunteering on programs. Also, we have participated on Trapi days, which is a conference for transplant recipients. We had the opportunity to listen to useful presentations among others about viruses, the beginning and future of the heart transplantation in Hungary, situation of the organ donation in Hungary.

Our association represents those living with PH from the whole Hungary, but our seat is in Budapest.



In recent years, the leadership of Budapest has created several means of participation and opportunities for inclusion in the spirit of open city governance. Our association also participated in the meeting held to deepen and celebrate the relationships developed at various civil-government forums, so that we could personally meet and get acquainted with other civil organizations. Despite the heavy rain that day, nearly ninety of us gathered in the Crystal Theater of Margitsziget, and we learned personal stories and professional experiences with the help of playful tasks. Mayor Gergely Karácsony and Deputy Mayor Gábor Kerpel-Fronius also joined the crowd, so we had the opportunity to talk directly with them.

## ISRAEL



Our sport ambassadors, Nóri, Tündi and Antal have continued their activity this year as well, they raised awareness of this rare disease on several races.



As a result of our educational and awareness raising work more and more people are aware of the symptoms of PH and we can help those who are contacting us on our hotline to get a timely diagnosis.

Eszter Csabuda • Tüdőér Egylet  
[www.tudoer.hu](http://www.tudoer.hu)  
[www.facebook.com/pages/Tüdőér-Egylet/151123348280359](https://www.facebook.com/pages/Tüdőér-Egylet/151123348280359)



As we watch 2022 come to an end we reflect back on the progress we have all made post corona, on the adaptations back to “normal” functioning and on the exciting progress we learnt of during our annual PAH conference. Our highlight of the year was without a doubt the gift of meeting in person with our fellow associations and connecting, learning and strengthening one another. APHEC this year allowed us all to be reinvigorated and we learnt so much. Coming back to Israel and reporting on all the exciting developments, the potential for new treatments and the power we have as an association when we all work together was wonderful. PH Israel would like to thank everyone involved.

For some local updates we hosted some wonderful small support sessions for visitors, continued our meetings with individual patients, maintained and grew our Portable Oxygen rental program and have focused on local corporate sponsorships. Our CEO Aryeh Coperman met with representatives from Bayer medical company. In these meetings a collaboration for PH awareness was confirmed and we look forward to raising more awareness in Israel together! This awareness will be created at a medical conference planned to take place in Haifa. Doctors specializing in pulmonary hypertension and those with a subspecialty in CTEPH will meet to discuss all the innovations in this field. The topics planned for the conference are the diagnosis of the disease and innovations in the world in the field of CTEPH by Ader Adir, director of the Haifa Lung Institute, Carmel Medical Center. The second lecture is by Der Segal, Director of Pulmonary Blood Pressure at Shiva Ramat Gan on the subject of the treatment of CTeph -multiple modalities and another lecture by Professor Segev Amit on the subject of CTeph case studies. We are honored as

an association to be invited to participate and work together! We are also very excited, after being introduced to MSD representatives at APHEC to be meeting with them to discuss their new trials in Israel. In summary we welcome two new board members this week and look forward to their invigorated energy giving us more power! We have many ideas in the pipeline and are excited to watch them come to fruition this year!

Maayan Steele  
 Pulmonary Hypertension Association Israel  
[www.phisrael.org.il](http://www.phisrael.org.il)  
<http://on.fb.me/1bPDL5v>





## ITALY-AMIP



*Hello Everybody!*

After these intense months we rewrite. The recovery after the COVID, the heat, the crisis and so on, but the AMIP has managed to keep the straight bar dictated by the tracks of the statute. In this period we managed to participate in many events, for example:

- webinars with the Rare Disease Observatory at Health Ministry
- interentions for updating the new website, which I ask you to visit [www.assoamip.net](http://www.assoamip.net)
- donation an electrocardiograph to the ospital in Catania (Sicily) for the needs of the local center PHA
- meetings with the global planet of pulmonary hypertension patient associations
- help to a patient member for the purchase of a very important help for oxygen
- we joined other associations to help our Ukrainian brothers and we write to our government

But want to focus on the events that are closest to our hearts:

- Meetings doctor/patient in Naples, Rome, Pavia and Palermo. We managed, in total, to bring together about 200 patients and to involve a



lot of doctors from first-level centers PHA who collaborate with expert centers.

- We have created a help line for young people with PAH. Yes, the young people we often don't consider, but they need to unite, form a group, fine answers. From this point of view we have a help line managed by a young patient, who is giving unexpected results (they will soon be a meeting of them). So now we have two help lines: one for all and one for young.

But we didn't just deal with that. During these months we have had numerous meetings with national and regional institutions to resolve problems, mostly bureaucratic, connected to the supply of drugs and aids, to define diagnostic therapeutic assistant pathways that would allow easy access to diagnosis and tratment, to sensibilizate the medical profession on the need for „early diagnosis”.

Allow me to sincerely thank all those who have met, listened and supported us. Our volunteers who, with their determination, their time, their inventiveness, have made it possible to carry out the initiatives.... initiatives unanimously appreciated by other patients and supporters.

*Vittorio Vivenzio*



# NORTH MACEDONIA

Our marathoners ambassadors get breathless for PH every weekend on sunny, rainy and windy days raising the awareness for Pulmonary Hypertension. We also had kids who ran and got breathless for Pulmonary Hypertension. With all that we show that the patients aren't alone and that we are stronger together. More than 8500 participants took part in the Wizz Air Skopje Marathon, TCS Amsterdam Nederland,

November Run Gevgelija Macedonia, Tsipouro Race Greece, Thessaloniki Marathon Greece, Strumina Trail. Half Marathons, Marathons, Trails, short races and much more sport activities all over the world.

Ratko Kjaev - APH Macedonia „Moment plus”  
<http://www.phmomentplus.com.mk/>



## NORWAY



The last weekend in October we arranged a patient meeting at the LHL hospital at Gardermoen. This included lectures with our medical experts, info on Oxygen Therapy and on sexual health and severe diseases among other topics. Saturday night we had a dinner at the Hotel across the road.

The first weekend in November was spent in Barcelona with you on a very special and interesting APHEC meeting with PHA Europe.

*Ann-Kathrin Bruheim*



In Norway we have had one board meeting in each month. Mostly on teams due to Covid, but we had the last one before the summer holidays and before Christmas in person.

We also had a round table conference with Janssen and the best specialists on PAH Norway on the 10th of May to create awareness and go through new guidelines in treatment of PAH.

We had stand in the Heart an Lung hospital on the 5th of May on the PH day to raise awareness on PH which the whole board participated in.

## PORTUGAL

### FUNDRAISING FOR UKRAINIAN HP ASSOCIATIONS

The Portuguese Association for PH (APHP) carried out several initiatives to collect goods and money to send to Ukrainian PH Associations.

For goods collection, the Association mobilized three work groups that operated in the north, center and south of the country. Dozens of boxes of clothing, food, medicines and utensils were collected.

To raise funds, the Association organized an auction of paintings by Rita Rodrigues, an artist with PH who uses art as a form of healing. Almost 400 euros were raised!



## FACEBOOK WEBINARS

The first webinar took place on Rare Disease Day and, given the proximity to the beginning of the war in Ukraine, was entitled “Living with a Rare Disease in Times of War”. The initiative essentially served to mobilize efforts and people to raise funds and goods for the Ukrainian associations.



The second webinar took place a few months later and had the theme “Subcutaneous/Intravenous Treatment of PH”. A lecture was given by a cardiopulmonologist from a PH reference center in Portugal. The audience, made up mostly of patients, clarified many doubts and shared experiences and tips on how to alleviate the drug-related adverse effects. The third webinar was about implantable IV treprostnil therapy. For this conversation, Patricia Miranda, a nurse who lives with PH since childhood and who had recently received the implant, shared her experience.

The fourth and final webinar was about “Sexuality at PH” and had a clinical psychologist as the main speaker. Patrícia Miranda also gave her testimony about her participation in the Summer Training Course for Young Patient Advocates (STYPA) 2022 which theme was “The Sexual Health and Well-Being of Young People With Chronic Condition”. The chat was joined by several patients with a number of questions about sexuality, pregnancy, and contraception.



## CTEPH AWARENESS MONTH

In CTEPH awareness month, the APHP launched a fundraising raffle to help ensure the sustainability of its services. The items that were drawn were handcrafted by PH patients, their families and friends. A total of 75 numbers were raffled, worth one euro each. Those interested were able to buy one or more numbers.

As part of CTEPH Awareness Month, APHP also organized a Photo Contest, with the aim of highlighting and publicizing the disease. It was highlighted, in which 5 of the group members had to wear the “Breath for LiPHe” shirt designed by APHP for this campaign. The winner will be awarded with a flight in a ultralight aircraft!

*Teresa Carvalho  
project manager and responsible for patient support  
at PH Portugal*



## SERBIA



We are proud of our racing team INSPIRED BY HOPE who is continuously raising awareness of PH despite every challenge that they may face. It's their dedication and resilience that really bring hope to us making us feel accepted, and alive. Their participation at more than 10 different races in the past couple of months is a lesson for others. That's how much they fight for us. Our ambassadors remain true to our cause. With the help of PH Serbia association, ultramarathon racer Jovica Spajić went to Salt Lake City, USA to participate at the world largest ultramarathon races. It's our great privilege and delight to have Jovica wear our shirt with PH symbols and colors. After extremely long race through hundreds of kilometers of wild forests and treacherous terrains, Jovica managed to arrive at the final destination first leaving other participants far behind. He dedicated his accomplishment to all suffering from pulmonary hypertension. He is currently the world champion in ultramarathon races. We continue to raise awareness of PH not only among the general audiences but at the expert congresses and symposiums, only during last 4 months we were represented at the four different congresses. From ECHOS congress about echocardiography to Synergy congress where prof. Stephan Rosenkranz presented the new guidelines for diagnosis and treatment of PH shortly after their publishing.

Despite our other activities which include the expansion of our statute that now includes other lung and heart conditions related to PH, and our cooperation with pharmaceutical companies, we managed to organize a small international gathering of Serbian patients suffering from PH who were treated at Tiršova Clinics during their childhood with the president of Macedonian Outreach organization

that provided a tremendous help to many of our patients and allowed them to travel to USA for various treatments and surgeries.

Its our mission to continue raising awareness of PH through various different channels and using social media and website is our current priority. We have launched a brand-new website and intend to expand our content significantly. In November we have marked a Month of PH on our Facebook and Instagram pages.

Our president, Danijela Pesic was invited to represent PAH patients at the Symposium in Madrid, and she provided many experts present with patient's perspective, giving them an invaluable wealth of resources which they can use when treating any PH patients.

PH Serbia is also grateful to PHA Europe for giving us the opportunity to learn a lot of new things and to share many ideas, experiences and invaluable resources with other European PH associations at the Annual PH Conference that took place in Barcelona in November of 2022.

We remain optimistic and eager to continue our mission now more determined than ever, especially in the light of current affairs in the field of developing new therapies for PH, where we have 6 different drugs in clinical trials. All our struggles now seem small and insignificant, because we can clearly see the light at the end of a long tunnel called PH. We will never stop!

*Danijela Pesic and Uros Antonijevic  
PH Serbia*



## SLOVAKIA



We commemorated the Rare Disease Day with a campaign on social networks. On this occasion we have organized a webinar on PAH and organ transplants for two classes of 3rd year of the Secondary Medical School students in Lučenec.

PHA Slovakia general assembly was held at the beginning of May. In addition to evaluating the activities and approving the work plan, the members' meeting elected new council members. The president and vice-president were reelected for next period.

Our community does not mean only a group of people with the same interests, but also kindness, goodness, mutual trust and help. At least that's how we see it in our association. That's why we like to meet on any occasion. One of them is the annual 6-day stay in the Spa Sliač. The program consisted of two parts. We dedicated our mornings to education and the afternoons to yoga and light pilates exercises. The participants expanded their knowledge about organ transplantation. To make our ladies happy, we have dedicated two hours with Mary Kay to the topic of the eye area liftin. We devoted part of our stay to culture and a trip to historical monuments in the nearby area. Spa treatments, nature walks, shared sessions and mutual exchange of experiences couldn't be missed during the stay.

Throughout the year, we were dedicated to spreading awareness about PH. Especially our runners helped us support this cause. They have completed more than 30 cross-country competitions across whole Slovakia. We value the two-day relay race from the Tatras to the Danube (346 km) the most. On their backs, the runners carried photographs of patients with the inscription „I



run for you". This also attracted the attention of the commercial TV JOJ, which invited the representative of the cross-country team and the president of the association to broadcast the news.

We participated in the 6th National Slovak Patients Conference, which was organized by the Slovak Association for the Protection of Patients' Rights in November. The conference was called Patient management - the patient's journey. In addition to the speeches of health policy makers, representatives of patient organizations were also given space. Iveta Makovnikova presented Call To Action paper and addressed the participants with the needs to improve diagnostics and treatment in Slovakia. We have also distributed brochures. In the evening, a gala evening was held with the presentation of the "My Doctor, My Nurse" awards. For the "My doctor" award, our association nominated cardiologist from the PH Center, MD. Milan Luknár, who has supported our association since its foundation and helps us whenever possible. This prestigious award was presented to him by a member of the parliament.

A council meeting was held in early December, together with an expert advisory team of doctors and industry representatives. We evaluated the activity for 2022 and presented them with the work plan for 2023, including the financial budget. The meeting was very pleasant and constructive, and at the end we received a promise of financial support.

Iveta Makovniková

Združenie pacientov s pľúcnou hypertenziou, o.z.

<http://phaslovakia.org/>



## SLOVENIA

This part of the year we were participating in the GAM and APHEC meeting in beautiful Barcelona. As you all know, this was a long-awaited meeting, as COVID-19 kept us online for 2 years. Many new people have joined us and that's really exciting. We are trying to bring all this fresh energy into our national association.

That's why we organized a Zoom meeting soon after we came back from Barcelona. We invited all of our members, caregivers and of course our healthcare professionals Dr. Salobir, dr. Mlakar. This time we were also joined by Dr. Ilovár, who takes special care in treating paediatric pulmonary hypertension patients. The theme of the meeting were the new guidelines that were presented to us by our doctors. We could feel the enthusiasm and satisfaction with how things are moving forward through our doctor's presentation

and subsequent Q&A session. We all felt very thankful to everyone who has contributed to the progress that has been made in the last 10 years when it comes to care of pulmonary hypertension patients.

We have a strong connection with our members and we're discussing their situation among other things every now and then. We identified that some of them are still going through difficult times even now after covid. That being said, we are delighted that one of our patients successfully went through a lung transplantation.

Our community is strong and we want to grow it further - that is still and always will be our goal.

Tadeja Ravnik

Društvo Za Pljučno Hipertenzijo Slovenije

[www.pljucna-hipertenzija.si](http://www.pljucna-hipertenzija.si)



## SPAIN ANHP



During this 2022 from the National Association of Pulmonary Hypertension (ANHP) we have gradually resumed face-to-face events, but without neglecting the online format that allows us to reach many more people, even outside of Spain. During this year we have carried out three awareness campaigns:

- February, for World Rare Disease Day, we joined forces with three other rare disease associations, based in the Vicálvaro district (Madrid, Spain). Under the motto „Be unique like us. Vicálvaro with Rare Diseases”.
- We make publications in the different social networks.
- We participated in the Radio program “Escucha Vicálvaro”.
- We recorded a video among the 4 associations to raise awareness about Rare Diseases.
- Eva García, president of the ANHP, participated in a virtual meeting organized by the School of Patients of Andalusia and Granada Digital, where we were able to learn about the realities of various minor diseases.
- From April 30 to June 1, 2022, Campaign for World Pulmonary Hypertension Day under the slogan "HIPERsensitize, we are Pulmonary Hypertension" The activities were published in Mariposa summer edition.
- During the month of November, we carried out a campaign to raise awareness about the disease under the slogan "When breathing is a challenge". During this month we have published information related to the disease on social networks and we carried out the following activities:
  - Webinar „When the treatments are not effective... the transplant". We have the participation of Dr. Víctor Becerra, cardiologist specializing

in Pulmonary Hypertension at Hospital Virgen de la Victoria in Malaga (Spain) and Dr. Carlos Andrés Quezada, pulmonologist at the Pulmonary Transplant Unit of Hospital 12 de Octubre in Madrid, and we have the experience of the patient, Nieves Encinas.

- Psycho-emotional support workshop “our values, a self-care strategy” given by one of the two ANHP psychologists.
- Information table to publicize the disease in the Hall of the Ramón y Cajal University Hospital (Madrid, Spain).

In addition to awareness campaigns, we have continued to provide support and guidance to all people with pulmonary hypertension, family members, and health professionals through the entity's Psychosocial Support Service, which currently has two social workers, two psychologists, and an attorney. We maintain mutual aid between patients with pulmonary hypertension through two whatsapp groups and one, of parents with children with the disease, having bi-monthly meetings with the latter through zoom. Every three months we have held associative meetings in an online format and on the weekend of September 30 to October 2 we organized a Meeting of partners in the town of Alcalá de Henares (Madrid), where we were able to meet again with our associates after two years of pandemic, it was a meeting that was very well received and valued by the people who attended.

From March to July we launched a mindfulness group for people with pulmonary hypertension to help and support them in managing negative emotions, with biweekly sessions via zoom.

We continue to carry out emotional support workshops, “The emotional impact of the disease. How to deal with it” taught by Jennifer Moreno, ANHP psychologist.

One of the objectives of the Psychosocial Support Service is to empower and train the patients about the disease, for which we have carried out an informative webinar on "sexuality, maternity and family planning in Pulmonary Hypertension".

And we continue to offer the HiperexPertos online course, for patients with pulmonary hypertension in which information on the disease, care, etc. is offered. and for people who can be expert patients, they receive specific training to carry out this task, and thus be able to be a reference for other patients.

We have participated in webinars, conferences and congresses throughout this year carried out by entities to which we belong: FEDER, EURORDIS, ELF, etc. and/or with which we collaborate:

- Hospital Clínic de Barcelona organized the XIII Conference for patients with pulmonary hypertension and their families.
- We have attended the events, conferences and webinar organized by the Spanish Federation of Rare Diseases throughout 2022.
- We attended the 6th Meeting of patient associations organized by the Spanish Patient Forum.
- We participated as speakers in the 6th Congress of the Patient Platform
- We attended the APHEC of 2022 in Casteldefells
- We attended the 6th Pulmonary Hypertension Research Meeting organized by CIBERES (Center for Biomedical Research in Respiratory Diseases

network) coordinated by Dr. Joan Barberà.

- V Congress SEPAR patients "Breathing the air of Vitoria-Gasteiz together" where our lawyer, Mr. Álvaro Lavandeira participated as a speaker. And we present the previous results of the cardiorespiratory rehabilitation study that the ANHP carried out in collaboration with the Hospital 12 de Octubre in Madrid.
- Karina Lozano, a patient with pulmonary hypertension and member of the ANHP, participated in the II Conference for patients, families and health professionals organized by the Pulmonary Hypertension Unit of the Ramón y Cajal Hospital. Karina shared her experience with treprostenol subcutaneous treatment

Throughout this year, various fundraising events have been carried out to continue with our social goals and allocate, to the extent of our possibilities, resources for research in pulmonary hypertension.

- X-trail Sierra Codes race in Navarra (Spain)
- I Solidarity Padel Tournament "When breathing is a challenge" in the town of Olot, Girona (Spain)
- Solidarity play "Mamá" performed by the theater group La Sabika in Granada (Spain)
- Dance Festival of the Real Soul Dance, in Alcalá de Henares (Madrid, Spain)

From the ANHP, we will continue working during 2023 to continue offering support, accompaniment and training to patients with pulmonary hypertension and their environment to improve their quality of life.



Eva García

Asociación Nacional de Hipertensión Pulmonar

[www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)

<http://www.facebook.com/hipertensionpulmonar>



# SPAIN FCHP

His Excellency Mr. Enrique Ruiz Escudero, Minister of Health of the Community of Madrid, Her Excellency Ms. Catalina García, Minister of Health of the Regional Government of Andalusia, and Mr. Cristóbal Belda, Director of the Carlos III Health Institute, welcomed the 14th Anniversary of the FOUNDATION AGAINST PULMONARY HYPERTENSION.



Last Thursday 24th November, the Foundation Against Pulmonary Hypertension (FCHP) celebrated its fourteenth anniversary with the return to face-to-face attendance and, on the occasion of this event, different awards were presented to personalities, entities and institutions that have supported the Foundation in the work of dissemination and awareness during this year.



The anniversary was held at the Hotel AC Feria in Madrid, and the first part of the event included two round tables, one clinical and the other on research, with the best specialists in this rare disease in Spain, such as Dr. Pilar Escribano, Dr. Del Cerro, Dr. Inmaculada Guillén, and Dr. Antonio Moreno, together with the FCHP psychologist Claudia Bohórquez. And prestigious researchers from Stanford University, Dr. Vinicio de Jesús Pérez and Dr. Roham Zamanian, together with Dr. Pablo Lapunzina, Dr. María Sanch and Dr. Jesús Ruiz Cabello.



On this anniversary two awards were presented, the first ones were for the people who, during the pandemic, supported us giving visibility to our collective, such as Dr. Olga Mediano, Dr. Andrés Quezada and Dr. Javier Sayas from HU 12 de Octubre, the virologist Mr. Alfredo Corell, the Director of HM Hospitals, Mr. Juan Abarca, the Sexta Noche, the City Council of Parla and the ONCE Foundation, the European entities PHA Europe with Danijela Pesic, and the PHA United States with its president Matt Granato.



And the 2022 awardees went to Her Excellency Diana Morant, Minister of Science and Innovation, Dr. Elena Mantilla, General Director of Inspection, Organisation and Health Strategy, the Hospital Pharmacy team of the HU Virgen del Rocío in Seville, the journalist Marta Solano, Dr. Alejandro Cruz, the nurse of the HU Clinic in Barcelona, Ana M<sup>a</sup> Ramírez Gallardo, Encarna Valero, Director of the Clínica de fisioterapia Óseo, and the researchers Natalia Gallego and Mauro Lago.



In addition, Dr. Pilar Escribano, cardiologist of the HU 12 de Octubre, and Dr. Juan José Ríos, Medical Director of the HU La Paz as Honorary Patron of the FCHP, were incorporated as members of the Scientific Committee of the FCHP. We are proud!



Pulmonary Hypertension is a rare, fatal and incurable disease that affects both adults and children. In Spain there are 15 cases per million inhabitants. It affects the arteries of the lungs, causing a narrowing that makes it difficult for the patient to breathe, weakens their heart and reduces their quality of life. And that all-important voice of the patient was in the hands of Salvador Calderón, an PH sufferer and father of two daughters with the same pathology.



All hope is placed in research, which is one of the central axes of our Foundation, led by our President, Mr. Enrique Carazo Mínguez, father of a child with Pulmonary Hypertension. And all this is achieved by raising funds throughout the year through a multitude of activities (sports, charity flea markets...).



This year, Emilio Butragueño, patron of the Foundation against Pulmonary Hypertension, handed over a cheque for 12,500 euros for the EMPATHY PROJECT, and 12,500 euros for the PASION HP GENETICS PROJECT, led by Dr. Barberá and Dr. Jair Tenorio. These cheques were presented by Mr. Emilio Butragueño, patron of the Foundation against Pulmonary Hypertension. In addition to a cheque for 17,000 euros with the funds donated by the Enrique Flores Foundation, now defunct, which will go to the project of Dr. Del Cerro, of the Ramón y Cajal Hospital (Madrid) "Biomarkers and response to exercise in Pulmonary Hypertension", which will be projected through the purchase of a cycloergometer for catheterisation in paediatrics. With these amounts, the FCHP has endowed Pulmonary Hypertension research with a total of 500,000 euros. This year we were accompanied by a young actress, but not for that reason, Luna Fulgencio. She is very involved with patients suffering from Pulmonary Hypertension, thank you for joining us.





This anniversary has once again been a great success, and each time we add more and more support to find a cure for Pulmonary Hypertension.



Award of the FCHP GENERAL RESEARCH GRANT in Pulmonary Hypertension. Awarded to Dr. María Sancho, researcher at the Complutense University of Madrid. With the project "ATP-sensitive potassium channels (KATP) as a possible therapeutic target against pulmonary hypertension". We continue to pursue our objectives with 489,000 euros donated to Pulmonary Hypertension research. Our sincere thanks to Mr. Emilio Butragueño, Honorary Patron of the FCHP, to Ms. Margarita San Andrés, Vice Chancellor of Research and Transfer of the Complutense University of Madrid for their support on this important day.



The "Marea Rosa Solidaria" popular race organised by the Torrenueva Costa Town Hall (Granada). We would like to thank the town council for this beautiful initiative, and above all, all the participants who left their mark on all the health associations to

which the funds raised went. The Foundation against Pulmonary Hypertension will donate these funds to research into the disease.



Around 400 people gathered at the VIII Solidarity Walking Route, organised by the association Anda Ya Cúllar, in which all the funds will go to the research of Pulmonary Hypertension. Little Laia, affected by Pulmonary Hypertension, and her family did not want to miss the event. We would like to thank the organisers for all their efforts and the participants for creating a unique atmosphere.



Important meeting with the Director of the Instituto de Salud Carlos III, Dr. Cristóbal Belda, where possible lines of collaboration for #research in #PulmonaryHypertension were discussed.



Mutual support groups for those affected and relatives with our professionals. These groups serve to share personal experiences and feelings, in addition to facing situations or experiences about our disease.



Synergies Forum meeting organised by the pharmaceutical company Janssen.



Our colleague and psychologist María Jimenez represented the FCHP at the V SEPAR PACIENTES RESPIRATORIOS Congress held in Vitoria at the round table "Responde en 60 segundos".



European Congress on Pulmonary Hypertension, organised by the European Pulmonary Hypertension Association. A wonderful few days getting to know the stories of many friends and learning about new developments in Pulmonary Hypertension.



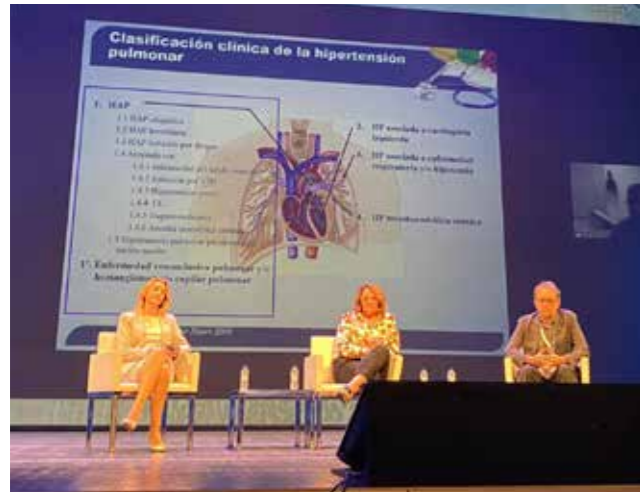
We participated in the Clinical Trials and Regulatory Processes course organised by the European Patients' Academy on Therapeutic Innovation (EUPATI).



IV TRAINING AND INFORMATION DAYS FOR THOSE AFFECTED BY PULMONARY HYPERTENSION, RELATIVES AND TRANSPLANT RECIPIENTS. This year we had the presence of Dr. María Jesús del Cerro, paediatric cardiologist of the HU Ramón y Cajal and Dr. Alejandro Cruz, cardiologist of the HU 12 de Octubre (both in Madrid). In addition, we did a dynamic workshop with our two psychologists, to get to know each other better with the rest of the affected and family members, and to share our story.

Enrique Carazo Minguez

# SPAIN HPE



The activities we set ourselves during this year have been defined by our corporate purpose, which is no other than to provide specialised services and care to people with PH and their families. This attention demands an extra effort from those responsible for the management of HPE-ORG patients, not only when it comes to maintaining certain levels of quality in the provision of services, but also at a management and planning level that allows us to face the future from a more stable perspective, and it is for all these reasons that we strive to increase the level of professionalism, not only of the organisation, but also in the training

of the volunteers themselves. It is because of this that an important part of the work carried out has been aimed at increasing the education of the members of the organisation such as, Leadership and Management of Patient Organisations Programme (University of DEUSTO), Clinical Trials and regulatory processes (EUPATI), labour reform, the Mezzanine Law, public subsidies, etc...

On the other hand, within our activities included in Congresses and Conferences, our presence is increasingly required as spokespersons and vision from associations of patients with PAH and patient support programmes in congresses of scientific societies such as the Spanish Society for Quality Care (SECA).

The 5th SEPAR Congress of Respiratory Patients in which we received the first prize for our project HAP NEEDS SACyL (Unmet Needs in HP SACYL) from SEPAR. Providing our voice and experience as patients with pulmonary hypertension experts together with healthcare professionals at conferences such as the 2nd "PAYPR" Conference (Patients and Professionals aimed at hospitalisation nurses) at the Ramón y Cajal Hospital in Madrid; 6th National Nursing Course: Care for patients with Pulmonary Hypertension at the Hospital Clínic in Barcelona, Aula Clínic.

The services we offer to those affected, aimed at accompanying those affected and their families, are focused on the three basic pillars of health: biological-psychological and social, and of special relevance is our "Learning to breathe" programme, in which we offer people various activities to work on their health, taking responsibility for their own self-care, promoting a more active and empowered patient hand in hand with professionals. This programme continues to reap awards and this year has once again received the "Ayudas al Paciente VitalAire" award for our Postural Training programme, in the category of education, training and health promotion programmes, which encourages us to continue improving every day in our projects to improve quality of life due to the recognition obtained.

This year we have resumed our project of continuity, of political-collaborative advocacy HAP NEEDS SACyL endorsed by SEPAR (Scientific Society of Pneumology and Thoracic Surgery) Day of reflection on the needs of patients with Pulmonary Arterial Hypertension (PAH) in Castilla y León.

A multidisciplinary working day in PH led by patients to discuss and prioritise in a structured way the needs of patients with pulmonary hypertension in this Autonomous Community. In our eagerness to adapt to the new social and health reality that we are living, HPE-ORG patients never cease in our efforts to meet the needs of patients and families with Pulmonary Hypertension. The geographical dispersion of the members of HPE-ORG and the complexity of our National Health System have led us to detect the needs of patients regarding the quality of care and the unequal treatment of patients depending on whether they live in one Autonomous Community or another. This project gives us the opportunity to solve this problem or at least to put it on the table to visualise it to work together and look for solutions.

María Rodríguez, Hipertensión Pulmonar España  
[www.hipertension-pulmonar.com](http://www.hipertension-pulmonar.com)  
[www.facebook.com/pg/HPSpain.org](https://www.facebook.com/pg/HPSpain.org)

## HAP NEEDS SACyL

Necesidades no cubiertas en HAP SACyL

### INTRODUCCIÓN

Reunión multidisciplinaria en Castilla y León con representación de especialistas en Cardiología, Neumología, Farmacia, Enfermería, profesionales de los servicios centrales de Sacyl, representación de HPE-ORG y liderada por los pacientes de CyL, para debatir y priorizar de forma estructurada las necesidades de los pacientes con HAP, con el propósito de conseguir la voluntad y el compromiso de los implicados y trabajar en aquellas áreas susceptibles de optimizar y/o que sean más eficaces.

### OBJETIVO GENERAL:

Establecer un plan de acción para mejorar la atención de los pacientes por CCAA.

OBJETIVOS ESPECÍFICOS:

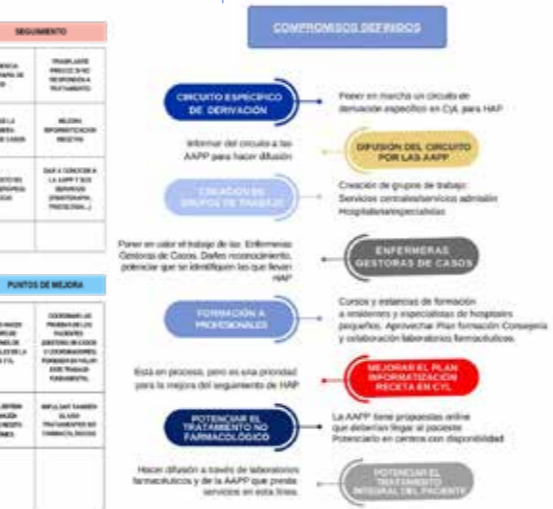


DIAGNÓSTICO	SEGUIMIENTO																		
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**RESULTADOS:**  
 Para poder establecer un plan de acción se establecieron diferentes puntos de discusión, enfocados en mejorar la atención integral de la enfermedad.



**METODOLOGÍA:** Metaplan, método de moderación grupal  
**TIPO DE TRABAJO:** Desarrollado  
**AUTORES:** Alicia García Jiménez. Directiva HPE-ORG  
 María Rodríguez Reyes. Directiva HPE-ORG.  
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Con la colaboración de: Janssen, 5º CONGRESO SEPAR DE PACIENTES RESPIRATORIOS, and SEPAR COMITÉ.



## SWEDEN

Unlike the pandemic years, 2022 has meant that we have once again been able to meet for "real" which feels very good! At the same time, the digital meetings have lived on and I think it is positive that we as an association can offer different ways to meet! Our members (finally +200 members) will by now probably recognize the activities we usually carry out and participate in every year. This is because our annual wheel (what we do for a year) has many fixed elements. Personally, I think it provides a safe and stable foundation for the organization. Some examples: For almost 10 years, a spring and an autumn meeting with the Swedish Association for Pulmonary Hypertension (association for those who work with PAH and CTEPH in healthcare). These meetings are about consolidating the close relationship we have and to talk about concrete cooperation plans.

For the seventh year in a row, we headlined the

WPHD-meeting (organized by Janssen) for talks about how PAH care can be developed in Sweden.

We continue with our appreciated patient meetings that we arrange together with the PAH centers in Sweden. In May we were in Stockholm and in November in Lund.

There are a few other activities that are more or less standing features. Our Fårö meetings can probably be counted among these by now. This summer, for the fourth time, we arranged a camp on the island of Fårö, which is located north of Gotland. This year was the first time that we targeted people who were over 50 years old.

We have also had time for some digital events and we have FINALLY got out our new folder. It took us two years but we are very proud of it (picture)!

*Patrik Hassel*



## UKRAINE PHA



2022 for Ukrainian patients, - is the year of opposition to Russian aggression. For each patient, along with the daily struggle with pulmonary hypertension, there was literally a struggle for life added. Bombing, occupation of territories, life in basements - are the realities of many Ukrainian patients. As a result, many were forced to leave their homes and move to safer regions. About 20% emigrated to other countries.

For the Ukrainian Association of Patients with Pulmonary Hypertension, this year has become a real challenge, because almost everyone needed help. Interrupted drug supplies, closed hospitals in the first months of the war, disrupted transport links - these are the realities in which we looked for an opportunity to help our patients.

During this period, we managed to organize the delivery of medicines for the humanitarian program and transfer them to more than 300 patients, we helped the pulmonary hypertension expert centers with medicines. They also handed over the necessary equipment to PH centers: sensors for the equipment, an ultrasound examination device, and a non-invasive lung ventilation (BiPAP) device. For patients, we purchased and donated 2 oxygen concentrators and 20 nebulizers for taking the Ventavis. During the blackout period, we also donated a battery system to a family in dire need. We want to express our deep gratitude to the European Association of Pulmonary Hypertension, which donated for our patients 3 portable oxygen concentrators with a battery that allows up to 6 hours of uninterrupted operation. All of these portable concentrators were also



## UKRAINE PHURDA



given to those patients for whom the lack of oxygen therapy became critical.

Throughout the year, we were in touch 24/7 with our patients, providing psychological and financial support, helping with moving to a new place of residence and finding the nearest pulmonary hypertension centers where they could receive medical care.

In 2022, our cooperation with international organizations has strengthened. Cooperation with the European Organization for Rare Diseases (EURORDIS) has become especially close. With their support, together with the Ministry of Health of Ukraine, we continued to implement the strategy on rare diseases in Ukraine. Great steps were taken to introduce the Orphanet registry in Ukraine, register expert centers for rare diseases, and develop neonatal screening centers. We are also proud to announce that the organization "Orphan Diseases of Ukraine", one of the members of which is the head of our Association, was awarded the prestigious EURORDIS "Black Pearl" award.

We thank the entire PHA Europe and each of its members for the help and support of Ukrainian patients in this difficult year for us.

Together we are a huge force! We are convinced of this!

Oksana Aleksandrova  
Ukraine Association of Patients with PH  
[www.pha.org.ua](http://www.pha.org.ua)  
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This year has become the most difficult for us, our patients and our country. In January we were planning our work for the year ahead. But February 24th came... We have changed our plans, activities and have got new areas of work. We started working 24/7. PHURDA and CF „Sister Dalila” started active work to support PH patients in the times of war. We provided patients with needed medicines as government purchase and delivery was stopped. We made contacts with foreign organizations to help PH patients to go abroad and get medical care there. We managed to organize logistics for patients fleeing the war. Poland, Italy, Norway, France and some other countries accepted our patients.

Thanks to the cooperation between PHURDA and Italian organization AVIS Nazionale (Associazione Volontari Italiani Sangue OdV) we managed to settle several PH patients in Italy to get proper medical care and treatment. Also, AVIS Nazionale sent PHURDA humanitarian aid with medicines and medical equipment for PH patients who stayed in Ukraine. With the support of PHA Europe and EURORDIS we organized lines for legal and psychological support for PH patients. We organized temporary shelter. Since May we have been holding online meetings with PH patients where we discuss different topics that are interesting for them, e.g. „Problems and opportunities for PH patients during the war in Ukraine”, „Question and answer session for PH patients”, „Current information from the latest world conferences 2022. Opportunities for patients during the war”, „Psychological support sessions”, „Motherhood and PAH”, „New European recommendations on PH: what to pay attention to”, „How to survive during the war...”. We have already handed over humanitarian aid kits with medicines,

medical equipment (pulseoximeters, tonometers, oxygen concentrators, nebulizers, thermometers etc.), food sets and hygiene products, everything that is necessary for a person to survive in wartime. It has become possible due to humanitarian aid from PVRI, AVIS Nazionale, Adam Torbicki, Adrian Goretzki, Polish doctors Ewa Lewicka and Ewa Mroczek together with Lions Club Poland and Lions Danmark, the Netherlands for Ukraine Foundation, the „Anna-Maria” Foundation, the Help Center „Social Pantry”, St. Jude Thaddeus Foundation, Knights of Columbus, Kamelchuk Family Foundation, CF „ZDOROVY”, CF „Patients of Ukraine”, Morten Aakre and shopping mall „Amfi” in Egersund, Norway. We thank Colombian and Greek PH associations for the humanitarian aid with medicines. We managed to provide also financial support to PH patients and to doctors. We as well provide humanitarian aid to Ukrainian soldiers. They are dying for the sake of peaceful sky for all of us.

## PARTICIPATION IN CONFERENCES AND MEETINGS

Though PHURDA had very intensive year we found time to participate in quantity of events to spread information about situation in Ukraine, the problems and needs which PH patients face now and of course we have got valuable knowledge:

- Our collaboration with EURORDIS seemed very important and fruitful. We are extremely pleased to be part of this working group to support PH patients in critical situations. We participated in EURORDIS zoom meeting on “How to best help people living with rare diseases in the Ukraine or seeking refuge, to coordinate efforts and be most effective” and ECRD 2022 where one of the sessions was dedicated to Ukraine.
- President of PHURDA Oksana Kulish participated in PHA Conference in Atlanta. We made invaluable contacts and global support there.
- On June 2-3 in Lviv, Ukraine PHURDA and CF „Sister Dalila” took part in a meeting with EURORDIS representatives and other Ukrainian patient organizations and the Ministry of Health of Ukraine.
- At ELF Networking Day 2022 we shared our experience in physical and psychological rehab.
- During ERS Congress we participated in the

session that was dedicated to Ukraine. We got the honor to talk about the challenges that our PH patients face and ways of solutions. Dr. Joanna Chorostowska-Wynimko made extraordinary efforts to highlight the issue of Ukraine. We are very thankful for her fruitful work.

PHURDA was awarded with a diploma of the „Charity Ukraine” Contest for the implementation of the „O2Kids” Project.

We say THANK YOU to PHA Europe, every friend, benefactor and partner who supported Ukrainian PH patients and our association during this challenging time.

Oksana Kulish  
Sister Dalila-PHURDA-Ukraine  
<http://poryatunok.info/uk/>

In spite of new challenges we continue our projects such as the fundraising campaign „Cork for Life”, Help line, Legal assistance services etc. Traditionally, in December on St Nicolas Day children get presents. And this year children asked about power banks, flashlights and other non-children’s items; children asked about peace.



## Media clippings Austria



Bosnia and Herzegovina

BSPPH Bulgária

07info "DAH" OBILJEŽIO DAN RIJETKIH BOLESTI

FENA FEDERALNA NOVINARSKA AGENCIJA

Oboljeli od rijetkih bolesti moraju imati sistematiziran i humaniji pristup lijekovima i terapijama

UKRATKO O PLUČNOJ HIPERTENZIJU

PREPORODINFO

Medunarodni dan rijetkih bolesti: Rijetke bolesti su teške i progresivne, a jednina zajednička tačka im je rijetkost

OSOBNE S INVALIDITETOM NAJAVILE PROTEST...

3. DECEMBAR

Zdenko Veljačić Vuki - nakon novog poduhvata

Ismet Škalj nakon još jedne humane misije posvećene oboljelima od plućne hipertenzije

BICIKLOM NA EKSPEDICIJI U TURSKOJ: Još jedna vožnja za oboljele od plućne hipertenzije

Klagenfurt am Wörthersee

Ismet Škalj na biciklističkoj ekspediciji

Belibolu 48 Eceabat 90 Çanakkale 100

ДЕЦАТА И РЕДКИТЕ БОЛЕСТИ: Мечето Каспър учи на приемане и толерантност

Мелена Яневска

ПЪРВИЧНАТА БЕЛОДРОБНА ХИПЕРТЕНЗИЈА Е КАТО АЙСБЕРГ

Д-р Любомир Димитров - началник на Отделението по детска кардиология в Националната кардиологична болница

На 5 май за 10-и път се отбелязва Световният

ПАЦИЕНТИТЕ ЗАСЪПНАТИ В ЕРМ НАСТАВНИК ЗА СРЕЩА С МИНИСТЪРА НА ЗДРАВООПАЗВАНЕТО

ИЗТИЧА СРОКЪТ ЗА УЧАСТИЕТО НИ ЗА ИНТЕГРИРАНЕ НА ЕВРОПЕЙСКИТЕ РЕФЕРЕНТНИ МРЕЖИ ПО РЕДКИ БОЛЕСТИ В НАЦИОНАЛНИТЕ ЗДРАВНИ СИСТЕМИ

4 ПАЦИЕНТИ ЗАСТЪПНИЦИ В ЕВРОПЕЙСКИТЕ РЕФЕРЕНТНИ МРЕЖИ СА ГОСТИ В ПОДКАСТА "ЦЕНТЪРА НА СИСТЕМА"

НАТАЛИЯ МАЕВА НАПИСА ПРИКАЗКА ЗА ДЕЦА С ПУЛМОНАЛНАТА ХИПЕРТЕНЗИЈА

Книжката на Наталия Маева за мечето Каспър вече е преведена и е достъпна и за малчуганите в Босна и Хърватска

ПОНЕЖИ ПОСЛЕДНИ СМЕ ПО ТРАНСПЛАНТАЦИИ В ЕС

БЪЛГАРИЯ Е ПОЧТИ ПОСЛЕДНА В ЕС ПО ТРАНСПЛАНТАЦИИ

НАТАЛИЯ МАЕВА

За тънката нишка животът да продължи и след смъртта

Защото донорството е най-безценният дар?

публикувано на 12.10.22 в 11:38

ПАЦИЕНТИТЕ НЯМА КАК ДА ЗНАЯТ ТЕРАПИЯТА СИ

Няма как една 80-годишна пациентка да помни в детайли сложните медицински изследвания, които са й правени при последното постъпване в болница, казва Наталия Маева

ИСТОРИЯТА НА МЕЧЕТО КАСПЪР УЧИ ДЕЦАТА ДА ПРИЕМАТ ХОРАТА С РЕДКИ БОЛЕСТИ

публикувано на 26.07.22 в 18:31

ДЕЦАТА И РЕДКИТЕ БОЛЕСТИ

Историята на мечето Каспър учи на приемане и толерантност

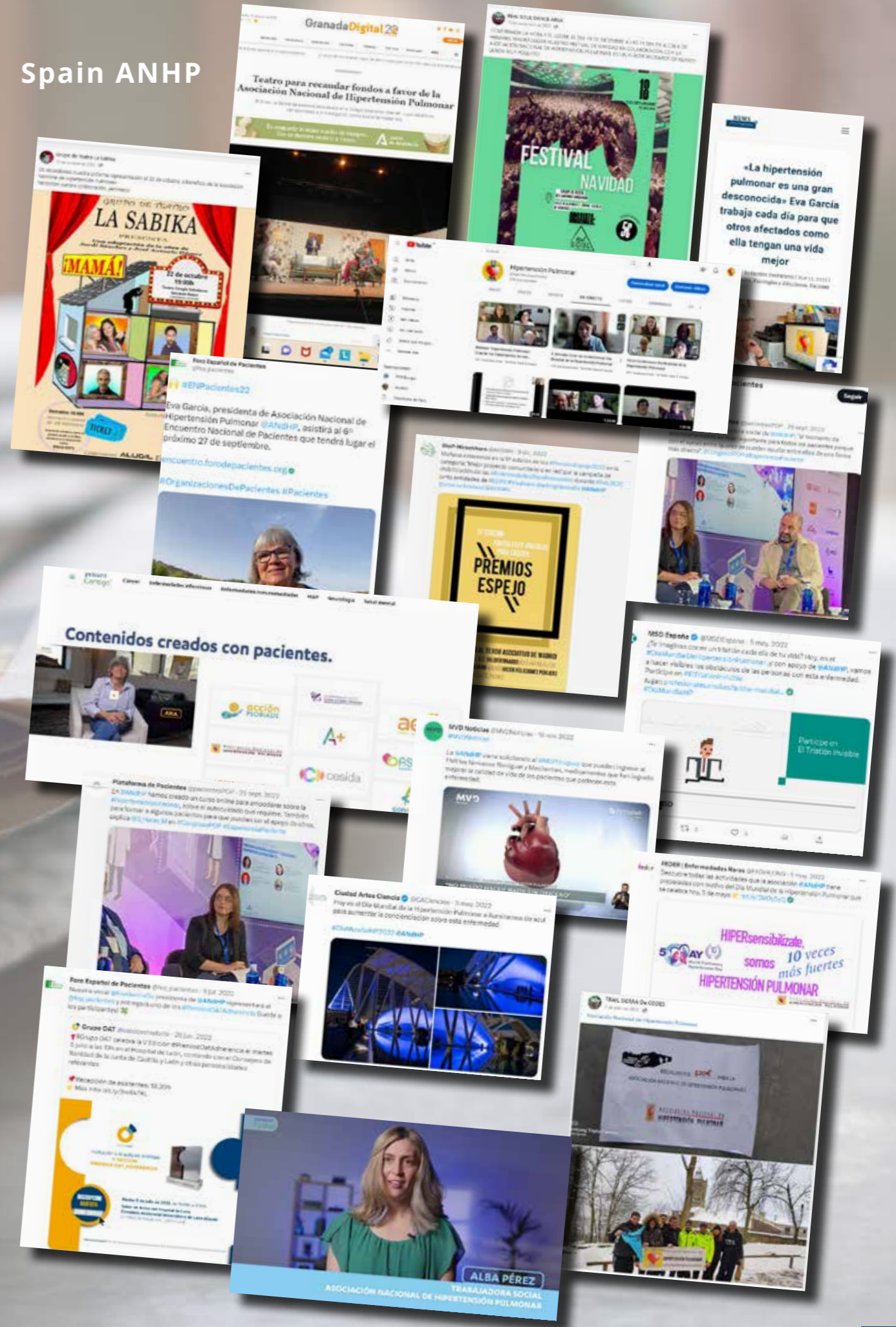
# Czech Republic



# Hungary

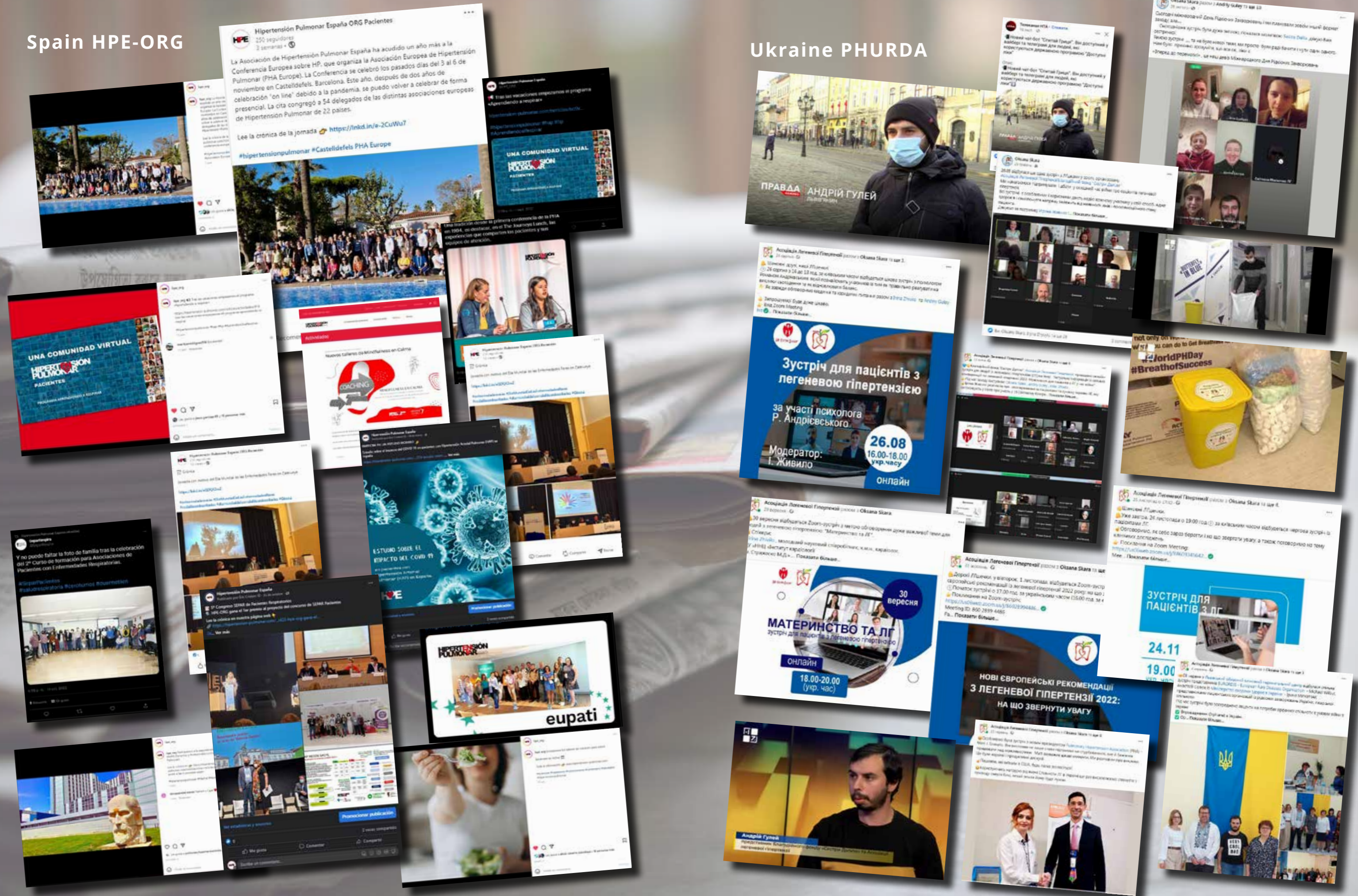


# Spain ANHP



# Spain HPE-ORG

# Ukraine PHURDA





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For more than a century, we've been at the forefront of research, bringing forward medicines, vaccines and innovative health solutions for some of the world's most challenging diseases.

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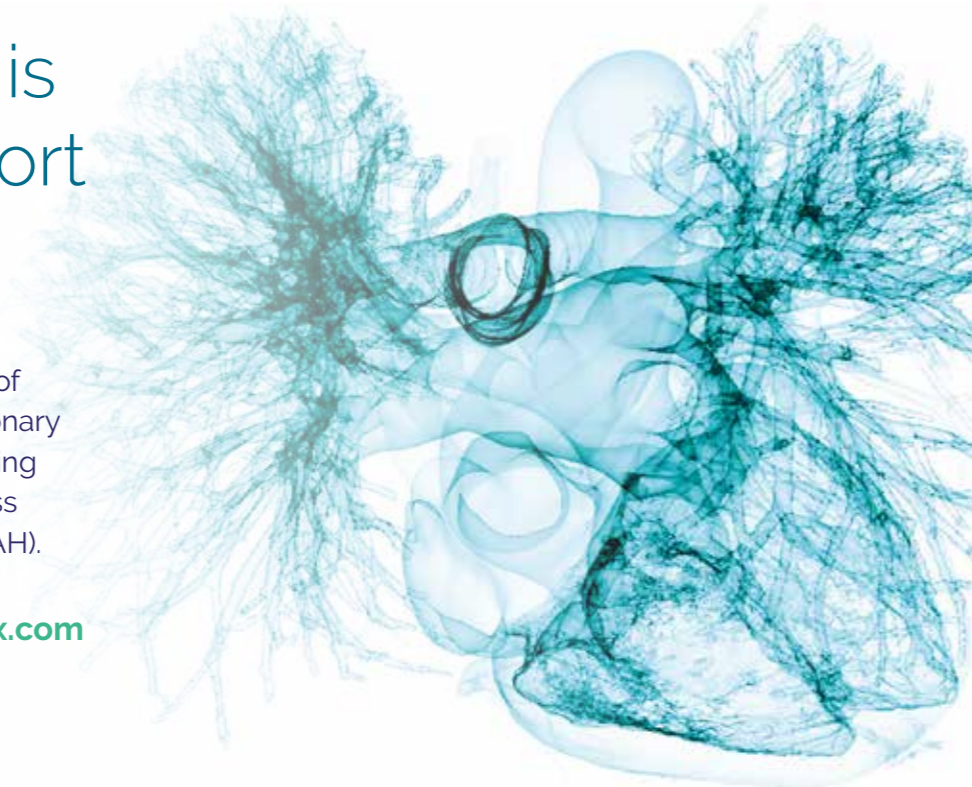


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# Aerovate Therapeutics is proud to support PHA Europe

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](http://www.aerovatetx.com)



## Vision • Connection • Innovation

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

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

Gossamer Bio is proud to support PAH awareness and education programmes for the community across Europe.

Please follow this thread to learn more about us: [www.gossamerbio.com](http://www.gossamerbio.com)

 @GossamerBio

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**<sup>™</sup>



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



AOP Health is the European pioneer for integrated therapies for rare diseases such as

**PAH**



PULMONARY ARTERIAL HYPERTENSION

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TREP\_10\_122022\_INT



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Altavant and Enzyvant have combined, creating a biopharmaceutical company focused on advancing life-altering therapies in immunology and cardiopulmonology.

Operating as Enzyvant, the company is proud to continue the development of rodatristat ethyl, an investigational treatment option for pulmonary arterial hypertension (PAH).



[www.enzyvant.com](http://www.enzyvant.com)



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**We make a positive impact.**



At Ferrer we make a positive impact in society. Our aim is to provide significant differential value to people suffering from Pulmonary Hypertension (both PAH and PH-ILD).



**Meet the PHantasticals**

Because we know they exist, we can identify them, we care about them and we put all our effort in helping them. Because the more we know, the stronger we are!

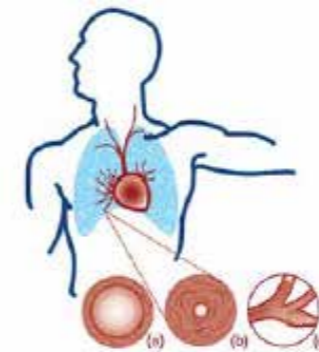


**AIMS OF PHA EUROPE**

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 non profit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hyper-tension 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 for pulmonary arterial hyper-tension, 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.



CLINICAL TRIAL

**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: [www.vipah-prntrials.com](http://www.vipah-prntrials.com)



\*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

\* EU Medical Device Regulation (MDR) 2017/745  
Map: © dflabrazly / iStockphoto.com, Foto: © alvarez / iStockphoto.com, Montage: Leitner, Layout: design.enateliteiner.com

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### BOSNIA AND HERZEGOVINA



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[www.plavakrila.hr](http://www.plavakrila.hr)

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