

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



**2022**

## INTRODUCTION

PHA Europe is the European umbrella association for pulmonary hypertension (PH) in Europe. It was founded in 2003 in Vienna, Austria, and brings together 34 PH patient associations from 29 countries. PHA Europe's activities are coordinated by the Board of Directors, elected by the General Assembly every two years, and run by the Staff members. Board and Staff Members are multinational and multilingual and have long standing competences and experience in different areas including patient advocacy, business, political, legal, accounting, IT, project management. Most members of the Board and Staff are related to PH, either directly or through family members or friends.

PHA Europe has over the years become a recognized stakeholder in Europe for PH. It has close working relationships with:

- EU institutions (EU Parliament, EU Commission, European Medicines Agency)
- European Reference Networks (ERN-Lung, ERN-Transplant-Child)
- Main EU level public health organizations (EPF, ESOT, EURORDIS, ELF)
- European federations for diseases of the lungs, heart, liver, kidney (EFA, ELPA, EKHA, EFKP, EHN, CCE, CCE...)
- Public health multi-stakeholder platforms dedicated to access issues (PACT)
- European professional societies for cardiology and pulmonology (ESC, ERS)
- Research organisations (PVRI)
- Individual members of the European PH scientific community
- Main companies in the pharmaceutical field involved in the development/distribution of PH drugs
- Other PH associations around the world

The 4 “pillars” on which PHA Europe's activity rests are: awareness, advocacy, capacity building and information.



- ✓ **AWARENESS** - to raise the profile of PH, still a little known condition which is diagnosed and treated very late, with dramatic consequences for patients
- ✓ **CAPACITY BUILDING** - to empower our member associations to reach the level of skills, knowledge, activity and services to effectively support PH patients and family members
- ✓ **ADVOCACY** - to strive for best standards of care and access to approved treatments and surgery as well as medical intervention at an affordable cost for all PH patients in Europe
- ✓ **INFORMATION** - to disseminate up-to-date and easy to understand news about PHA Europe and PH generally with its member associations, other NGOs, HCPs, industry and all other relevant stakeholders through various communication channels, including own webpage and social media channels.

## **PHA EUROPE'S MAIN ACTIVITIES**

### **Awareness**

PH is a little known disease. It takes on average 2-3 years from the first symptoms until the patient finally is diagnosed with the disease. One of PHA Europe's main activities is to raise awareness for PH. In 2022, we performed two main awareness related activities: World PH Day & Awareness month November and the O2Kids campaign.

### **World PH Day**

Despite progress in the PH field in recent years, it can still take up to 3 years or more and 3 doctors or more to get a correct diagnosis, and the condition is still little known, not only in the general population, but also in the medical profession. World PH Day (WPHD) is an annual campaign, the aim of which is to achieve greater visibility for the condition. The first World PH Day (WPHD) was held in Madrid in 2012, on the initiative of the Spanish PH association ANHP. So 2022 was the 10 year anniversary of WPHD which has gained increasing consensus over the years. In 2021, PHA Europe took over the coordination role of WPHD on a global basis. This was a great honour, but at the same time also a great responsibility which we believe was handled well. The reach of more than 5 million total impressions on Facebook and Instagram gave proof to a very well coordinated global campaign. Almost all of our European PH associations held awareness-raising events and WPHD activities were also organised by PH associations in the USA, Canada, Latin America, Australia, Asia and South Africa. Furthermore, we coordinated successful awareness campaigns on social media in November providing our associations with entries to post at given dates during the month.

Taking over the global coordination of World PH Day events, which is a big honor, other hand is a great responsibility and a lot of work.

- WPHD in Europe and all over the worlds is coordinated by PHA Europe staff. As of 2021 PHA Europe has taken over the coordination globally: new webpage (WorldPHDay.org) has been launched and managed by us both in English and Spanish, ready-to-use materials were delivered in both of these languages. More specifically, in Europe our member associations apply to take part and submit projects for approval and funding. The campaign has a common theme and a professionally developed toolkit, including common artwork for T-shirts, banners, sea flags, merchandising and other materials, as well as templates for press conferences, flash mobs and other events being held for the occasion.
- WPHD started out as a campaign targeted at the general population, but has increasingly seen the involvement of national political and health authorities, academia, health care professionals and celebrities. To foster these activities an online petition has been launched for immediate actions to ensure access to treatments.
- WPHD has contributed to the empowerment of the member associations by providing them with the opportunity to hold national awareness raising, educational, advocacy and fundraising activities.
- WPHD was celebrated with a very successful webinar on Accelerating EU research for rare diseases – the case of pulmonary hypertension, which was hosted by members of the European Parliament (MEPs) and endorsed by ERS, ELF, ERN-Lung and MEP Lung Health Group.
- We organized an anniversary webinar. We had a record high attendance and we were happy to see many medical students and physicians among the participants. Irene Delgado, a patient from the Spanish PH association (ANHP), Prof. Nazzareno Galie from Bologna, Italy and Prof. Gerald Simonneau from Paris, France were the speakers of the event.

- The staff members of PHA Europe have also shown their dedication to World PH Day and marked this very day in different ways: some of them got breathless for PH in trail running and triathlon races, others turned into our color of blue or wore our branded T-shirt and had fun.
- The World PH Day events always have the same message: we are a big family!

## **O2Kids**

Unfortunately, and as you know, children are also affected by PH. We have run special campaigns to raise funds for them so that we can offer these unfortunate children electric scooters and bicycles, oxygen equipment, etc. This was 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. In addition to helping the children, the O2Kids campaign is also a great awareness campaign as people are always affected by seeing seriously ill children. And the fact that we focus on the positive in the campaign, that sick children are helped, makes the campaign very effective and memorable.

- 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.

## **Capacity Building**

Capacity building is another very important part of PHA Europe's activities. Our organisation's ultimate goal is to put in place a strong European PH community consisting of empowered national associations, working together for the PH cause.

### **White Spots & Capacity Building Program/Member Support Program**

The White Spot Program is a program where we help to establish a PH association in a country where no association exists. The White Spot Program has been very successful as we have helped establish more than 20 national PH associations in Europe. Once established, the Member Support Program (MSP) takes over. In the MSP, we help associations to mature. The need for The White Spot program is greatly reduced the recent years, as there are almost no countries in Europe left without an association. The MSP is, hence, the most active program of these two at the moment. 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 many 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 and Croatia thanks to the support from the MSP. The book has proven very successful and more translations will 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.
- The outbreak of the war in Ukraine had a highly adverse impact on PH patients in the country. It generated an urgent need for support, and PHA Europe donated funds to both of our Ukrainian PH associations. This support enabled them to assist PH patients who were in dire need as they fled their homes, requiring everything from shelter to medication. Additionally, we provided several portable oxygen concentrators that could be used even during electricity shortages.

## **Fellowship**

PHA Europe's official working language is English and, as the organisation expanded over the years to include more and more countries, communication started to become a critical issue with those associations where neither Board members nor volunteers had a good command of this language. Thanks to our "Fellowship" program, PHA Europe has been able to provide these associations with a part time English speaking assistant. The program started in 2013 with nine Fellows; in 2022 we were able to support 18 patient associations with a Fellow. The program has been very successful in ensuring a smooth flow of communication and actively engaging our member associations in common activities. The fellows help with translations and support the associations on the basis of 8-10 hours per week.

## **APHEC (Annual PH European Conference)**

The Annual PH European Conference (APHEC) serves as a pivotal driver for activity and engagement, playing a crucial role in inspiring, supporting, educating, and motivating its members. Traditionally held in Barcelona, the pandemic forced us to conduct virtual APHEC events in 2020 and 2021. However, in 2022, we joyfully reunited in person in Barcelona, bringing together 52 delegates who expressed the sentiment of a family reunion. Notably, we welcomed two new member associations: PH associations from the Netherlands and Belgium, with two representatives from Luxembourg also in attendance. We are committed to assisting them in establishing an association in their country, and they have expressed interest in joining PHA Europe at the

GAM in 2023. Consequently, PHA Europe now comprises 34 national PH associations spanning 29 different countries.

In addition to our General Assembly Meeting (GAM), one day was dedicated to our industry partners, while an additional day featured specialists who delivered outstanding presentations. Some presentations delved into the new ERS/ESC guidelines on pulmonary hypertension, while a nutritionist discussed a study related to PH and nutrition.

### **Bel Air Club**

Throughout the two years of the pandemic, we conducted virtual meetings, utilizing a virtual conference center we created for this purpose. In this virtual environment, we hosted presentations and explored booths of industry partners and associations. In addition, participants had the option to engage in chats or partake in informal video conferences with one another. These virtual conferences proved highly successful, prompting us to extend the benefits of our virtual conference center even after the pandemic had subsided.

As a result, we are now actively evolving this virtual center into a PH hub accessible to patients, caregivers, healthcare professionals (HCPs), and other PH stakeholders worldwide, and we've named it our Bel Air Club. Recognizing that the club will be frequented by individuals of diverse nationalities, we've incorporated translation features. Additionally, we are diligently working on subtitling presentations, enhancing the social gathering space, establishing an area dedicated to artworks created by PH patients and HCPs, and more. Our grand opening for the club is scheduled for January 2024.

### **Information materials and resources**

Providing up-to-date information materials is an important part of capacity building. Read more about this in the «Information & Education» section.

## **Advocacy activities**

PHA Europe's mission is to achieve best standards of care, equal and affordable access to treatment/surgery and better quality of life for all PH patients in Europe, including the very important and largely unmet psychosocial support needs. Despite enormous progress in past years, there are still very wide disparities and inequalities in Europe: not all approved drugs are available in all countries across Europe and there are countries where no drugs at all are accessible and where expert centers/surgical facilities do not exist.

- PHA Europe is active in its support to national advocacy activities by providing guidance and strategic advice, by writing letters and participating in meetings with national health authorities and other relevant stakeholders and by engaging in one to one talks with representatives of the pharma industry
- Since 2017 PHA Europe has organised and supported the training of physicians from countries with serious drug access problems, the rationale being that these physicians can transfer the knowledge gained to colleagues in their own countries and can become future PH “champions” at national level. Unfortunately, this project has been put on hold due to the pandemic, but we hope in restarting it.
- At European level PHA Europe has been active, within larger and very influential organisations (EURORDIS, EPF, PACT, ESOT) and within the main professional societies (ERS, ELF, ESC, PVRI) in contributing to the discussions on policies to reduce waste/improve investment in healthcare, in



involving the patients in policy making, including the patients in the drug regulatory processes, including the patients in definition of clinical guidelines, including patients' goals in scientific agendas. PHA Europe also plays an important role in ERN-Lung and was elected in the Medical Steering Committee.

- For the future, there is an absolute need to define what is really relevant in terms of outcomes from the patient's point of view. The different degrees of access to therapies leads to an adaptation of what is to be expected in real life at country level. This will also be conducive to evaluate the impact of the disease and of the available therapies, which is an extremely powerful tool in the advocacy field.
- Likewise, PHA Europe intends to collect the expertise and experience of its members in order to contribute to the definition of clinical endpoints and composite endpoints that are as relevant for patients as for HTA agencies and physicians.
- PHA Europe has also been very active in organ donation and transplant issues. Its 2015 Call to Action was endorsed by 90+ national and European organisations and a PHA Europe initiated European Parliament (EP) event was held in 2016, whose media reach was over 70M. The EP event in 2016 was followed up with meetings in 2017 with the federations for heart, lung, liver and kidney diseases; a social awareness event was organized at the European Parliament in February, 2019 with the presence of members of the European Parliament and other stakeholders. Despite previous efforts organ donation and transplantation is still problematic in many countries. In order to identify the critical points to be improved we plan to launch a survey within our members.
- In 2022, we revisited our Call to Action white paper originally published in 2012. A special event took place at the European Parliament in Brussels, Belgium, on April 26th. The event drew patient representatives from around the world, key opinion leaders in the field, and notably, politicians including Members of the European Parliament (MEPs) and decision-makers from European institutions. We compiled an executive summary of the paper, which we translated into 27 different languages. This comprehensive resource, along with the original white paper, was distributed to our members. We firmly believe that this initiative will prove to be of significant importance to our association and its members in the years ahead.

## **Information & Education**

The dissemination of up-to-date information about pulmonary hypertension is another important part of PHA Europe's activities. It is instrumental both in raising greater awareness of the disease and in the empowerment of the national associations.

### **Journals**

The journal of Mariposa is our flagship "product". We have two issues yearly: the complete summer edition is devoted to World PH Day and from these summer editions the reader can learn more about the specific World PH Day projects both on European and global as well as country level – please visit the World PH Day section for more information.

The winter edition covers all other activities conducted by PHA Europe or member associations.

We disseminate the journals both electronically via our webpage, social media channels and by email and printed copies are also handed over to physicians, decision makers, representative of pharmaceutical companies and other stakeholders. The graphic design, the printing and shipping of the copies are centralized.

## **Website, social media and online platforms**

One of PHA Europe's main goals is to provide up-to-date and reliable information. Nothing can be better resource for this than a continuously managed and maintained webpage.

We put special emphasis on reliability: our entries on pulmonary hypertension were validated by a PH expert. Our news section contained heads-up about conferences and congresses, learning opportunities, new publications.

While we consider our webpage as one of the most important sources of information, we needed to realize the importance of communicating through the social media, thus we started paying more attention and invested more energy on the management of these platforms. The numbers related to our activities are growing on all social media networks. Luckily, this is also the trend of the national associations' activities and the success is measurable and very visible. We primarily observe this from the number of posts published on social networks. The associations have realized the great potential that social networks provide and, in cooperation with PHA Europe, achieve significant results.

Social media activities were also important pillars of our two main projects: World PH Day and Awareness month.

## **Workshops and conferences**

PHA Europe representatives are increasingly invited to participate in significant congresses, symposia, workshops, and other essential events. They are also actively engaged in the work of advisory committees, task forces, and working groups within prominent scientific societies, EU regulatory agencies, and European NGOs.

- Attending these scientific events offers PHA Europe valuable opportunities to both raise awareness of the disease and stay up-to-date with the latest developments in pulmonary hypertension (PH) and public health-related issues.
- Involvement in advisory committees, task forces, or working groups of prestigious organizations empowers us to advocate effectively and contribute to the formulation of health policies.
- Our training workshops play a pivotal role in education, equipping attendees to become more effective advocates at both the European and national levels.
- As members of larger organizations such as EURORDIS, the EUROPEAN PATIENT'S FORUM, and the EUROPEAN PUBLIC HEALTH ALLIANCE, we enjoy numerous benefits, including the ability to shed light on PH issues to broader audiences.
- Ultimately, all these meetings offer excellent networking opportunities, a vital element in our efforts to raise awareness and advocate for change.

In the following pages, you will find a listing of events that PHA Europe was present at in 2022:



**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-IDD1 – 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-IDD1 – 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) • February 16****ERN-LUNG PH CORE NETWORK MEETING**

Gergely represented PHA Europe in this meeting.

**Virtual (online) • February 16****PHA EUROPE BOARD & STAFF MEETING**

The complete board and staff attended this meeting.

**Virtual (online) • February 17****MEETING WITH SOCIAL MEDIA COMPANY, BC HUB**

Danijela, Monika, Hall and Gergely attended this meeting.

**Virtual (online) • February 17****EUROPEAN MEDICINES AGENCY (EMA) 'WALK IN' CLINIC WEBINAR ON REPURPOSING**

Gergely attended this webinar.

**Virtual (online) • February 23****ERN-LUNG BOARD MEETING**

Gergely represented PHA Europe in this meeting.

**Virtual (online) • February 28****RARE DISEASE DAY ORGANIZED BY EURORDIS**

Gergely attended this political event.



### **Virtual (online) • March 11**

#### **IOWNA MEETING**

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



### **Virtual (online) • March 1-2**

#### **PHA EUROPE'S ANNUAL PULMONARY HYPERTENSION EUROPEAN CONFERENCE**

Biggest gathering of European PH associations' leaders.



### **Virtual (online) • March 3**

#### **CALL TO ACTION PREPARATORY WORK WITH ERS**

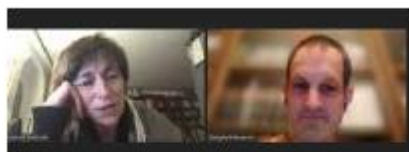
Gergely attended this meeting.



### **Virtual (online) • March 3**

#### **ELF PREPARATORY MEETING ON PATIENT ORGANIZATIONS' DAY**

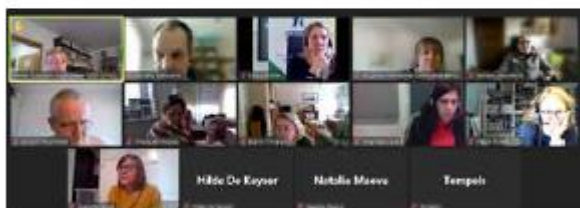
Gergely attended this meeting as one who is responsible for the program



### **Virtual (online) • March 3**

#### **MEETING WITH PROF. MARION DELCROIX**

Gergely attended this event on recent developments and projects.



### **Virtual (online) • March 4**

#### **ERN-LUNG EPAG MEETING**

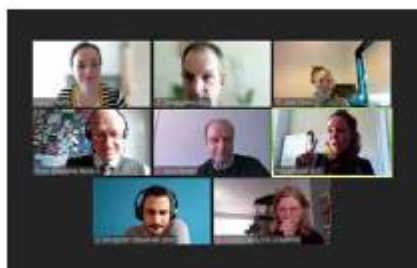
Gergely chaired this regular meeting.

### **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.

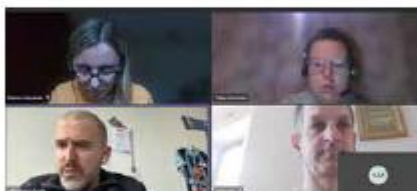
**Virtual (online) • March 24**  
ELF PREPARATORY MEETING ON PATIENT  
Gergely attended this meeting as one who is responsible for the program.





**Virtual (online) • March 25**  
EUROPEAN LUNG HEALTH GROUP  
MEETING ON HELPING UKRAINE

Gergely represented PHA Europe in this meeting.



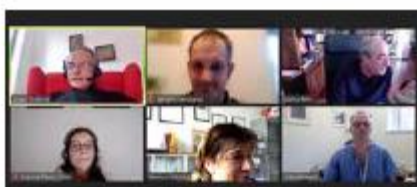
**Virtual (online) • March 29**

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 CTEPH TRIAL STEERING COMMITTEE MEETING

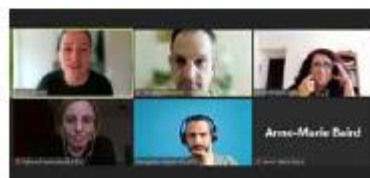
Gergely represents PHA Europe in these meetings.



**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

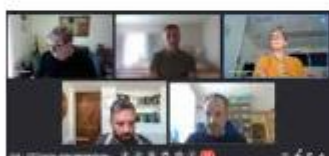


**Virtual (online) • May 5**  
 ANNIVERSARY WORLD PH DAY WEBINAR  
 Participants all over the world joined this event –  
 the event was chaired by Gergely



**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.



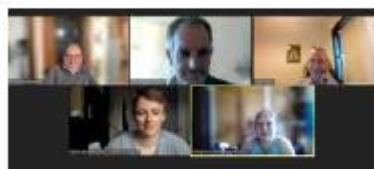
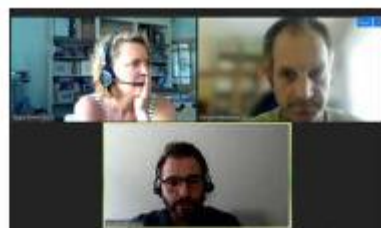
**Paris, France • June 28-29**  
ERS'S LAUNCH EVENT OF INTERNATIONAL  
RESPIRATORY COALITION (IRC)  
Gergely represented PHA Europe on this  
political event.

**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 a 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.



**Virtual (online) • September 28**

**PVRI IDDI REGULAR MEETING**

Gergely co-chaired this meeting.



**Barcelona, Spain • October 3**

**FERRER TEAM-BUILDING BOOTCAMP**

Gergely was invited to participate in a roundtable discussion.



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



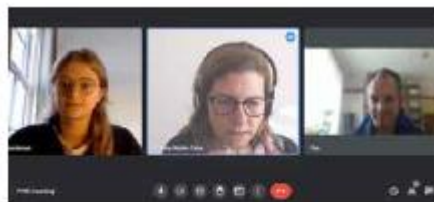
**Virtual (online) • October 5**  
**ERN LUNG MEDICAL STEERING**  
**COMMITTEE (MSC) MEETING**  
 Gergely attended this meeting as the member of the MSC.

**Virtual (online) • October 5**  
**PULMONARY HYPERTENSION EMPOWERMENT NETWORK**  
 Theme: Managing mental health. Hall attended this meeting.



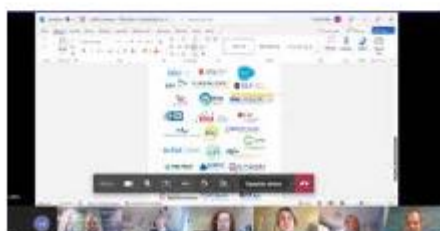
**Virtual (online) • October 7**  
**EURODIS: KICK-OFF MEETING FOR**  
**EUROPEAN STAKEHOLDER NETWORK**  
**FOR RARE DISEASES**  
 Gergely participated in this webinar.

**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**

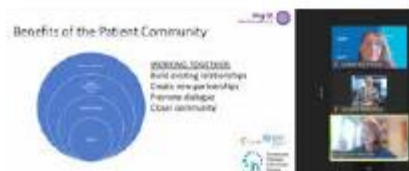
Theme: Crafting disease education campaigns that address patient needs company running trial for a potential new PH drug. Hosted by Aerovate. Eva, Tadeja, Zdenka and Hall represented PHA Europe on this meeting

**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**

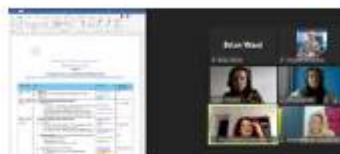
Theme: Growing patient group audiences through online/offline campaigns. Eva, Tadeja, Zdenka and Hall represented PHA Europe on this meeting.

**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.

