

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



2021

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 33 PH patient associations from 27 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 2021, we performed two main awareness related activities: World PH Day and the O2Kids campaign.

World PH Day

The year of 2021 was challenging again due to the COVID pandemic and made the proper planning difficult, but we learnt from the previous year and were prepared for a plan "B" if needed.

There was a great variety of events organized by member associations: in some countries it was possible to run in-person events, however in other countries the activities were limited to the online world. We were also witness to a nice combination of both types of initiatives.

As of this year PHA Europe has taken over the global coordination of World PH Day events, which is a big honor, but on the other hand a great responsibility and a lot of work.

- As part of this work, we have re-launched the WorldPHDay.org website which is a hub with ready-to-use materials in English and Spanish. The site contains an interactive calendar about events (with login details) organized all over the world, and information about pulmonary hypertension, the participating partners and also our sponsors, who made World PH Day celebrations possible.
- We prepared and made available many visuals to the PH community which attracted great interest on the social media platforms.
- On top of raising awareness of pulmonary hypertension we were busy with advocacy activities: we launched an important initiative of an online petition some days before World PH Day: we called upon the decision and policy makers to take immediate steps and address unmet needs of patients living with pulmonary hypertension. The call covers, among others, action on access, transplantation and holistic care.
- But the online petition was not the only advocacy activity we planned and organized this year: we co-organized a very high-profile online event with the European Respiratory Society. With the participation of members of the European Parliament, a representative from the European Commission and key opinion leaders from the medical field of PH an online webinar was held by the MEP Lung Health Group on Accelerating EU research for rare diseases – the case of pulmonary hypertension. We were happy and very optimistic that we have had the chance to include the patient perspective in this event by providing a patient journey. The webinar was recorded and made available on our social media channels.
- Some years ago, we started to include patient empowerment elements into World PH Day events. This year we were extremely successful and organized and co-organized five webinars in various languages such as English, Spanish and Portuguese on different topics. We put emphasis during these webinars on health-related quality of life measures and everyday life's problems, but also touched upon the effects of COVID and congenital heart disease on PH patients. All the webinars were recorded and made available on our youtube channel. We hope that they will be important and valuable resources for the PH community.
- 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! To facilitate interactions between the patient associations from all over the world, we re-opened our virtual centre previously used for the Annual Pulmonary Hypertension European Conference and made fine-tunes, provided new materials and resources and held a meeting at our famous virtual pool!

O2Kids

Unfortunately, even children are affected by PH. In 2021, PHA Europe ran a special campaign to raise funds for them so that we can offer these unfortunate children electric scooters and bicycles, oxygen equipment, etc. The basis for the campaign is a professional looking fundraising video. 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. We will adjust and improve the 2021 campaign to make it even more effective in 2022.

Key info:

- The O2Kids campaign generated more than 12.3 million impressions on social media creating a tremendous amount of awareness for PH
- More than 32.000 clicked on the O2Kids link that took them to our landing web page
- The O2Kids video generated more than 3000 comments on Facebook and was shared more than 10.000 times
- The number of donations were unfortunately lower than expected. One reason is probably that the video was too professional looking making it less believable than if we had used real PH children and not actors. We will adjust the campaign for 2022

NGOs in general seem to struggle to scale private fundraising initiative like O2Kids. We need to make sure that donations for children are made in given countries in 2022. This will probably increase the will to donate money.

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

Under PHA Europe's "White Spots" program, started in 2013, PHA Europe has reached out to patients/caregivers/medical professionals in European countries where no PH association previously existed and provided start up funds, guidance and training in order to establish a local association and support it during its first years of establishment. The White Spot Program has been a great success and there are almost no white spots left in Europe. Our focus has therefore now shifted to a new program called the Capacity Building Program. The aim is to help the association in the first difficult years after they have been established. Often they need both guidance and financial support in order to survive. We help them with both. The financial support is given to support projects that will help them to mature and to become financial independent. We are therefore especially eager to help support fundraising projects that can help the association to improve their financial situation.

During 2021 we had several interesting activities related to our CBP:

- New association web pages: PHA Europe recently renewed their webpages using Wordpress. We offered the template to our members and several wanted to replace their pages with our new design. This is very positive since numerous PH pages across Europe then will have the same look and feel. Five associations have so far had their home pages redesigned or built up from scratch: Finland, Hungary, Italy (AIPi), Moldova and Austria. Many more will follow in 2022.
- Infographics: Two different PH infographics were produced in 2020. Some associations decided to take advantage of the CBP and make printed versions of the infographics in 2021. The infographics seemed

well suited as handouts as they were printed in A5 size with the informational infographic on one side, and association information on the opposite side.

- Many associations already offer hotline services. Through the CBP program, several additional associations offered this important service to their members in 2021 as PHA Europe supported the national associations financially in order to purchase phones and pay for subscriptions.
- Image brochure: PHA Europe has a template for an image brochure that was developed by PH Austria. We offer to share this with other member associations. Several have accepted the offer and will make adjustments to it so that it will fit their association before printing it. Some have already done so in 2021, and many more plan to follow in 2022.
- Lawyer support: The Ukrainian association in Lviv was awarded CBP funds for lawyer cost. The lawyer will fight for PH patients' right to access to diagnosis and medication, their right to rehabilitation and the right for lung transplantation. The lawyer will discuss these issues locally in Lviv and nationally with the ministry of health in Kiev.
- Booklet about PH and children. The Bulgarian association (BSPPH) used CBP funds in order to develop a booklet related to PH and children. The booklet is produced both in local language and English. It will be made available to other associations that might also produce it if requested.
- PH booklet. The Ukrainian association in Kiev will rework an older PH booklet by means of CBP funds. The 50 pages long booklet will be made up to date and printed in 500 copies intended for Ukrainian PH patients and health personal. As part of our share policy, the association will offer the booklet to other European association that might adjust it to their needs and reprint it.
- PH video. The Belarusian association will produce a video lead by a cardiologist. The video is intended for Belarusian PH patients and various PH related topics will be featured like PH rehabilitation, nutrition, training program after voiced, etc.

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 2021 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.

Annual PH European Conference

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 exists. In this type of atmosphere, sharing and supporting each other comes natural. So our APHECs are very important to us.

Due to the pandemic, it was impossible for us to meet in Barcelona in 2021, like in the previous years. By the end of the year, we understood that we needed to find an alternative solution. So we contacted a Dutch company, who specialises 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 recognisable to all with the pool in the front and the beach in the back of the hotel.

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 centre 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. 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. For a couple of weeks, we ran informal chat meetings by the pool every evening at 7 o'clock. 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. Then we set aside two days where each of the ten 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 theatre 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.

We covered a lot of interesting topics during the presentations. An Austrian PH specialist talked about PH and covid-19. A British nurse talked about patient followups and diagnostics during the pandemic. In addition, we had an interesting session about PH and yoga, plus a related session on PH and breathing exercises. In addition, Prof. Grünig, a leading PH specialist, talked about PH and rehabilitation. Mental health for people living with a chronic disease was also covered by a physiologist, who has worked with PH patients for more than a decade. Prof. Humbert talked about PH research and Prof. Lang presented future PH treatments. Prof. Klepetko talked about advances made in lung transplantation for PH patients. In addition, a long term survivor of PH presented his personal survival guide. 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 a year where alternative solutions had to be made. We think we managed to portrait the friendly and great atmosphere of our APHEC and provide our participants with a memorable and informative very professional online event.

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 psycho-social 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 centres/surgical facilities do not exist.

Advocacy at European level

Despite the COVID measures were re-introduced in many countries, we had a very fruitful year in 2021.

PHA Europe – Pulmonary Hypertension Association Europe, Wilhelmstr. 21, 1120 Vienna, Austria

www.phaeurope.org, email: info@phaeurope.org, registration number: ZVR-Zahl: 070826881

PHA Europe represented the interest of patients living with pulmonary hypertension in more than 80 events. In this section you can get more insight in the most important ones.

We kicked-off the year of 2021 with the launch event of a very important position paper “Towards a European Health Union – BREATHE Vision for the future”. We were a presenter and a panelist in the online event hosted by members of the European Parliament (MEP) and organized by MEP Lung Health Group.

We launched the renewal of our position paper, Call to action early in the year of 2021 and progressed nicely with the review. We were lucky to have all the key opinion leaders from the medical teams, our partners from the pharmaceutical companies, and representatives from the wider PH community and beyond. We planned to relaunch it 2022 spring – and we managed to do it with great success!

Rare Disease Day was celebrated online in February and many activities were conducted also by our members to mark this event.

In March we were invited as a panelist in the ERS Live Vision, which is the respiratory channel of European Respiratory Society. The main theme was how to cope with the challenges COVID brought to the rare lung disease patients.

Still in March we participated in the board meeting of ERN-Lung. We are one of the most active patient representative members of this network and fulfilling a cross-disease coordinating and representative role as well.

A nice gift was presented for World PH Day: the result of our PH care COVID survey - which was truly an international project and collaboration with ERN-Lung, ESC, ERS and ELF and which collected more than 1000(!) responses – was published mid-May in the Orphanet Journal of Rare Diseases.

We collaborated with EU-IPFF (European umbrella organization of pulmonary fibrosis) and participated in their virtual European patient summit, as panelists, in April.

We attended many online conferences and webinars and shared the information we gained with the PH community:

- The EURORDIS membership meeting was again an important source of best practices from other rare diseases,
- ERS Digital Health Summit provided interesting insight into new technical developments and
- EPF (European Patient Forum) organized a series of webinars on artificial intelligence.

Last, but not least, we attended the ERS and ESC annual conferences and the CTEPH conference organized by ICA (International CTEPH Association) which are must-visit events where state-of-art management of PH is provided by the key opinion leaders.

We continued our close collaboration with many – both scientific and patient led – stakeholders, throughout the year and we even managed to enlarge our collaboration with other non-governmental organizations. We became members of and are co-leading a patient-empowerment initiative within Pulmonary Vascular Research Institute (PVRI). Most recently we joined the ESOT-ETPO (European Transplant Patient Organizations) alliance.

We celebrated PHAwareness month in November with the participation as panelist in the First Forum of the Latin-American PH coalition, with ready-to-use and easy-to-share materials and with very touching videos: you can get to know three incredible people from our community in the ‘PH no limit’ footage.

Due to confidentiality requirements, we could not announce it earlier, but only with the publishment of the new guidelines on the diagnosis and treatment of pulmonary hypertension, that PHA Europe was represented in the task force working throughout in 2021 and 2022: it was the very first time that patient representatives participated in such a work.

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. Due to COVID we experienced a slight drop of printed copies orders from our membership though the total number of orders is still almost 250 copies. 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.

During 2021, PHA Europe conducted a series of campaigns aimed at raising awareness of pulmonary hypertension (PH). Through these campaigns, we aimed at further educating the general public about PH. We hoped to increase the effectiveness of the campaign by providing a personal touch to them. With this we managed to provide a more peculiar aspect of the disease which generated more interest and interactions around our posts.

Among others, we conducted a new project #PHALeaderStory, which aimed to present all those brave people who dared and decided to establish and lead patient associations across Europe. The project fulfilled its goal and presented the leaders' desire to help the patients in their country, despite the fact that most leaders suffered from the serious illness themselves. Wonderful and brave people shared their touching, emotional stories with everyone.

We also supported the Rare Diseases Day's message of "DARE TO BE RARE" with a large, colorful and joint campaign. It was heartwarming to see that almost all our members participated in this initiative.

The campaign "DO YOU KNOW THIS FACT ABOUT PH" was met with a great response. The primary objective was to bring PH closer to everyone interested through easily understandable text and eye-catching graphics.

#BlueMonday is a campaign that aims to share positive thoughts with everyone on Mondays, and was one of the favorite posts among our members.

These periodic campaigns were nicely underpinned with our standard campaign, the #GoodPHNews. It is an informative campaign and presents some of the activities of our member associations across Europe in a positive manner. This year almost 20 member associations participated and provided materials to make posts!

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

World PH Day in 2021 was unquestionable a breakthrough in terms of numbers. We managed to create enormous interest towards our messages and the online reach of 9,4 million (!) and almost 9 million (!) on Facebook and Instagram, respectively, was far better than our expectation. These results are even more impressive if we take into account how the social networks were overloaded with contents due to COVID.

The "Awareness month" social media campaign supplemented our series of videos of "PH no limit" and was aimed at raising awareness of PH. It once again showed the great strength of PHA Europe as the member national associations worked together as a unity. Through our materials, which were translated into English, Spanish and German, we provided accurate and exact facts about PH and could reach many people through the social media.

Annual PH European Conference

The 2020 Annual PH European Conference (APHEC) was held as a virtual event from March 1st to March 13th 2021 due to the pandemic. As previous years, the event gave a good opportunity for the member national association to meet, promote the material they had made and learn news from leading PH specialists. In the presentation room they could watch 13 different presentations. These had been pre-recorded and the members had two weeks to study them. Then live Q&A sessions were held with the presenters. Each presenter was present for one hour and answered questions that the member associations had accumulated during the two weeks of viewing. There were also an opportunity to ask additional questions during the two live Q&A days.

The Q&A sessions used states of the art technological solutions as the sessions were streamed to a theatre room in the virtual conference area where the members had gathered.

The presentations covered topics like future PH medication, transplant advancements, yoga and breathing techniques, how to handle the mental challenges of living with a chronic and serious disease, etc.

Workshops and conferences

PHA Europe representatives are increasingly invited to take part in important congresses, symposia, workshops and other events. They also take part in the work of advisory committees, task forces and working groups of important scientific societies, EU regulatory agencies and European NGOs. In the course of 2021 the events were primarily virtual due to the pandemic.

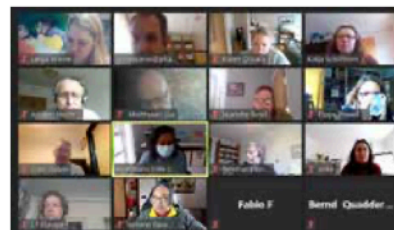
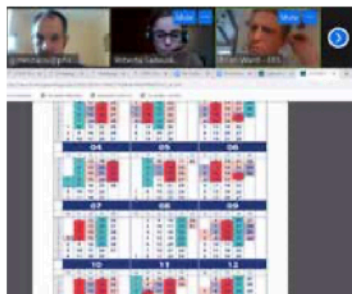
- Attending scientific events gives PHA Europe great opportunities to raise awareness of the disease as well as to be in the loop of the most recent developments in PH and public health related issues;

- Being part of advisory committees, task forces or working groups of prestigious organisations provides opportunities for advocacy and input into health policies
- Training workshops have a key educational role and give those attending the possibility of becoming better advocates, both at European and national level;
- Being members of larger organisations (EURORDIS, the EUROPEAN PATIENT'S FORUM, the EUROPEAN PUBLIC HEALTH ALLIANCE) has many advantages, such as raising awareness of PH issues in wider audiences.
- Finally, all meetings have great networking potential, a key ingredient of awareness raising and advocacy

In the following pages, you will find a listing of events that PHA Europe was present at in 2021.

Virtual (online) • January 12 RESPIRATORY VISION COLLABORATION

Gergely attended this webinar hosted by European Federation of Allergy and Airways Diseases Patients' Associations (EFA)



Virtual (online) • January 14

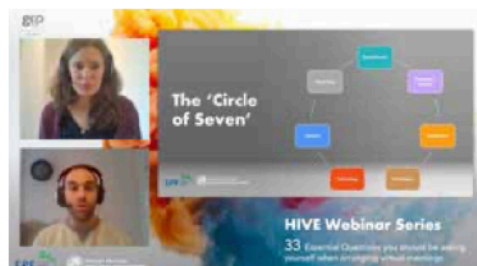
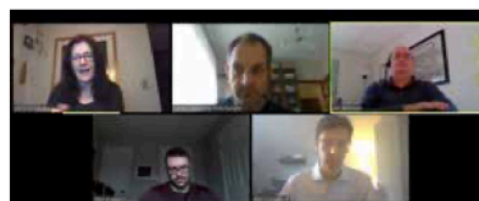
MEP LUNG HEALTH GROUP CALL

Gergely attended this call to discuss the details of the coming MEP Lung Health Group event on EU research – the case of pulmonary hypertension

Virtual (online) • January 14

WORLDPHDAY.ORG WEBPAGE TAKEOVER STEPS

Gergely attended this call to agree upon the steps of taking over the webpage of WorldPHDay.org



Virtual (online) • January 15

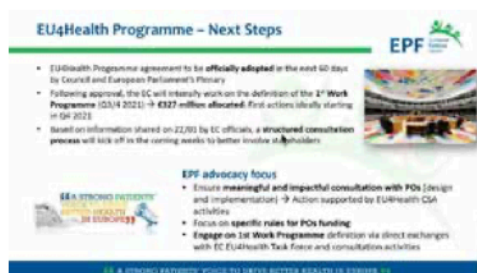
VIRTUAL (ONLINE), JANUARY 15

HIGH IMPACT VIRTUAL ENGAGEMENTS WEBINAR

Gergely attended this webinar about how to organize meaningful and impactful virtual meetings. The webinar was hosted by the European Patients' Forum (EPF)

Virtual (online) • January 20 EUROPEAN LUNG FOUNDATION (ELF) PATIENT ADVISORY COMMITTEE

Gergely attended this regular meeting on behalf of PHA Europe



Virtual (online) • January 23

EUROPEAN PATIENTS' FORUM (EPF)

EXTRAORDINARY GENERAL MEETING

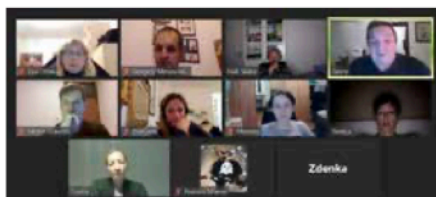
Gergely represented PHA Europe on this event



Virtual (online) • January 27

MEP (MEMBERS OF THE EUROPEAN PARLIAMENT) LAUNCH EVENT OF THE BREATHE VISION

Gergely represented PHA Europe and was a speaker on this event



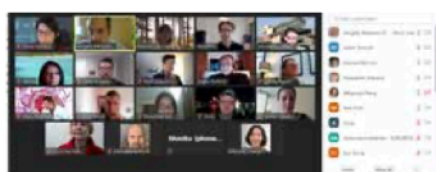
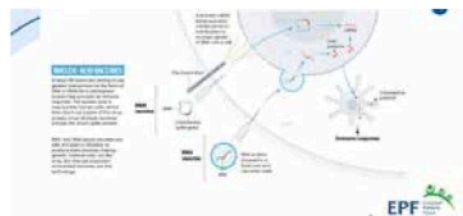
Virtual (online) • January 27

PHA EUROPE BOARD AND STAFF MEETING HIGH IMPACT VIRTUAL ENGAGEMENTS WEBINAR

Virtual (online) • January 28

SHOT CALLERS WEBINAR ON COVID 19

Gergely attended this webinar organized by EPF



Virtual (online) • February 11

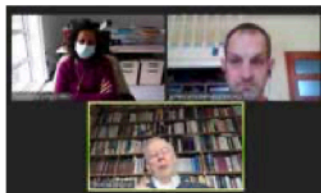
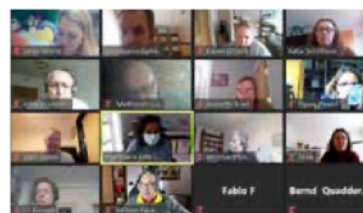
KICK OFF CALL OF THE REVISION OF PHA EUROPE'S CALL TO ACTION

Gergely hosted this call with the participation of representatives of non-governmental organizations, medical partners and pharmaceutical companies

Virtual (online) • February 12

ERN-LUNG EPAG MEETING

Gergely represented PHA Europe on this meeting



Virtual (online) • February 19

CALL ON THE EJP-RD SUBMISSION

Gergely participated in this call with the representatives of ERN-Lung

Virtual (online) • February 19

EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING WITH DG SANTE

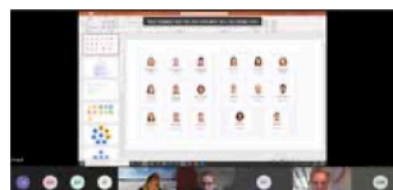
Gergely attended this event as the member of the ELHG. The Commission was represented by Mr. Delsaux



Virtual (online) • February 23

RARE 2030 FINAL POLICY CONFERENCE

Gergely participated in this event as the member of the Rare 2030 expert panel



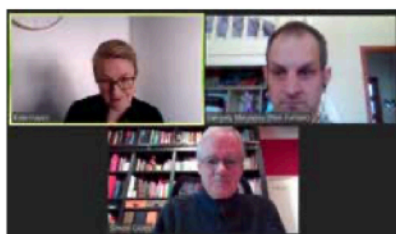
Virtual (online) • February 23

EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING

Gergely represented PHA Europe on this meeting

Virtual (online) • February 24

EURORDIS ROUNDTABLE DISCUSSION
AND BLACK PEARL GALA DINNER
Gergely attended these events as Rare 2030 expert
panel member

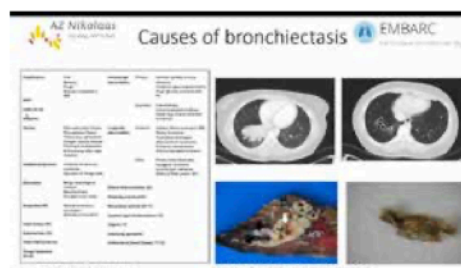


Virtual (online) • February 25

ERN-LUNG PATIENT REPORTED OUTCOME (PRO)
FUNCTIONAL COMMITTEE MEETING
Gergely hosted this event

Virtual (online) • February 27

BRONCHIECTASIS PATIENT CONFERENCE
Gergely attended this virtual event



Virtual (online) • March 1-13

ANNUAL PULMONARY HYPERTENSION
EUROPEAN CONFERENCE (APHEC)

The biggest European PH conference organized for
patient associations

Virtual (online) • March 3

ERN-LUNG BOARD MEETING

Gergely attended this meeting as the member of the Medical
Steering Committee



Virtual (online) • March 8

CHRONIC RESPIRATORY DISEASE IN THE COVID ERA
Gergely attended this webinar organized by GARD
(Global Alliance against Chronic Respiratory Diseases)

Virtual (online) • March 12

PREPARATORY CALL FOR THE ERS LIVE VISION

Gergely attended this call as the speaker of the subject event

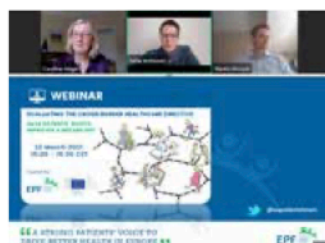
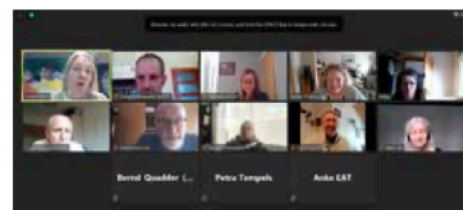


Virtual (online) • March 18

ERS WEBINAR ON CTEPH

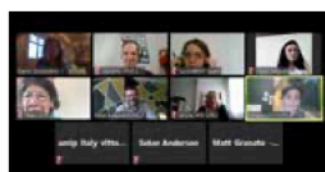
Gergely attended this webinar as previous task force
member of the ERS Statement on CTEPH

Virtual (online) • March 19
ERN-LUNG EPAG MEETING
Gergely represented PHA Europe on this meeting



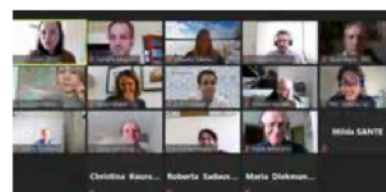
Virtual (online) • March 23
EVALUATING THE CROSS-BORDER HEALTHCARE DIRECTIVE
Gergely attended this webinar organized by EPF

Virtual (online) • March 23
ERS LIVE VISION: LIVING WITH RARE RESPIRATORY DISEASES THROUGH THE COVID-19 PANDEMIC
Gergely attended this session as a speaker



Virtual (online) • March 29
WEBINAR OF THE INTERNATIONAL PH COMMUNITY
Gergely represented PHA Europe on this event hosted by PHA USA

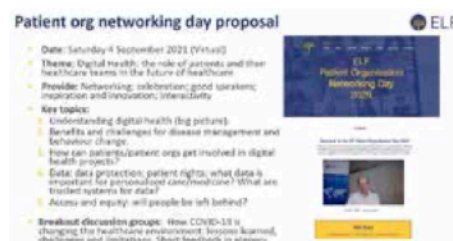
Virtual (online) • April 13
WEBINAR ON BEST PRACTICES BY DG SANTE
Gergely attended this event hosted by EFA and the ELHG



Virtual (online) • April 19
MEP IG EVENT – TURNING PRINCIPLES INTO A REALITY OF MORE EQUITABLE HEALTHCARE
Gergely attended this event organized by PACT



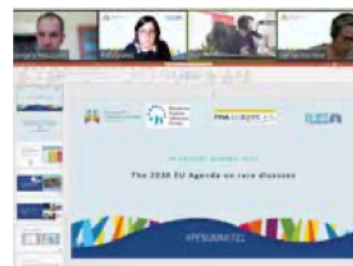
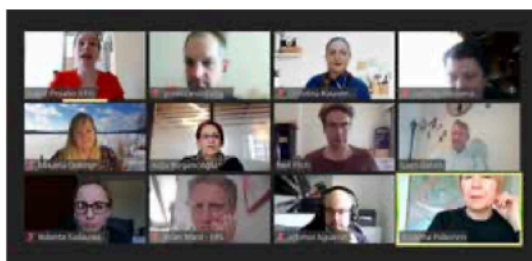
Virtual (online) • April 20
ELF PATIENT ADVISORY COMMITTEE (PAC) MEETING
Gergely represented PHA Europe on this meeting



Virtual (online) • April 21
ACCELERATING EU RESEARCH FOR RARE DISEASES – THE CASE OF PULMONARY HYPERTENSION
Important political event co-organized by MEP Lung Health Group, ERS and PHA Europe

Virtual (online) • April 25

EUROPEAN PF (PULMONARY FIBROSIS) PATIENT SUMMIT
Gergely participated in this event as a speaker

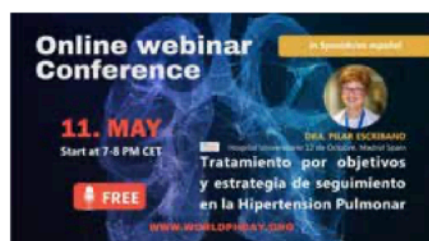
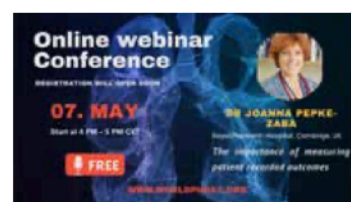


Virtual (online) • April 27

EUROPEAN LUNG HEALTH GROUP MEETING
Gergely represented PHA Europe on this webinar

Virtual (online) • May 7

WORLD PH DAY (WPHD) WEBINAR SERIES:
PROF. JOANNA PEPKE-ZABA
Gergely hosted this English language webinar on patient reported outcome

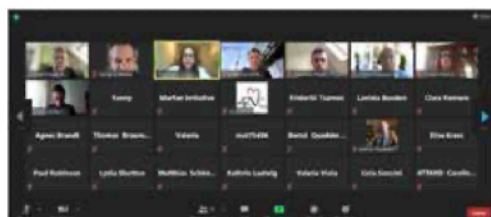
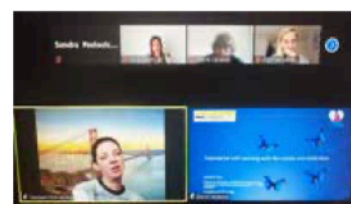


Virtual (online) • May 11

WORLD PH DAY (WPHD) WEBINAR SERIES:
PROF. PILAR ESCRIBANO
Gergely co-hosted this Spanish language webinar on treatment strategies

Virtual (online) • May 12-14

EURORDIS MEMBERSHIP MEETING (EMM)
Danijela and Gergely represented PHA Europe on this event.
Danijela ran a presentation about experience with working with the media and celebrities

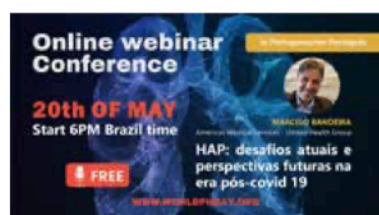


Virtual (online) • May 20

INCISIVE HEALTH MORNING CLUB
Gergely attended this online webinar

Virtual (online) • May 20

WORLD PH DAY (WPHD) WEBINAR SERIES:
PROF. SANDEEP SAHAY AND PRASHANT BOBHATE
Gergely co-hosted this English language webinar on everyday tips on PH



Virtual (online) • May 20

WORLD PH DAY (WPHD) WEBINAR SERIES:
PROF. MARCELO BANDEIRA
Gergely co-hosted this Portuguese language webinar on management of PH in light of the COVID era

Virtual (online) • May 21

SHAPING EUROPEAN HEALTH DATA SPACE FOR PATIENTS
AND WITH PATIENTS

Gergely attended this webinar organized by EPF



Virtual (online) • May 26

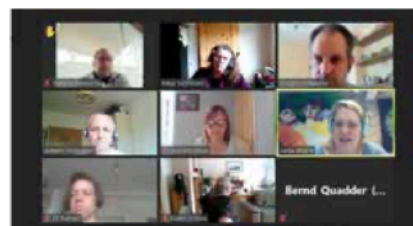
WORLD PH DAY (WPHD) WEBINAR SERIES:
PROF. FLAVIA NAVARRO

Gergely co-hosted this Portuguese language webinar on congenital heart disease and PH

Virtual (online) • May 28

ERN-LUNG EPAG MEETING

Gergely represented PHA Europe on this meeting



Virtual (online) • June 3-4

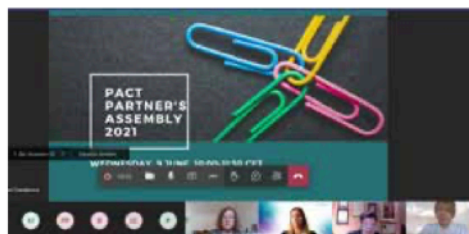
ERS DIGITAL HEALTH SUMMIT

Gergely attended this conference on behalf of PHA Europe

Virtual (online) • June 7

EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING

Gergely represented PHA Europe on this meeting



Virtual (online) • June 9

PACT PARTNER'S ASSEMBLY

Gergely attended this assembly of Patient Access Partnership (PACT)

Virtual (online) • June 14

EFA MEET AND GREAT THE EU TRAINING:
THE EUROPEAN MEDICINES AGENCY

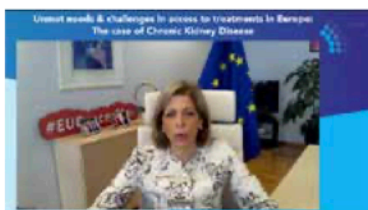
Gergely attended this webinar about EMA



Virtual (online) • June 15

PVRI PATIENT ENGAGEMENT & EMPOWERMENT
WORKSTREAM MEETING

Gergely is co-chairing this initiative of Pulmonary Vascular Research Institute (PVRI)

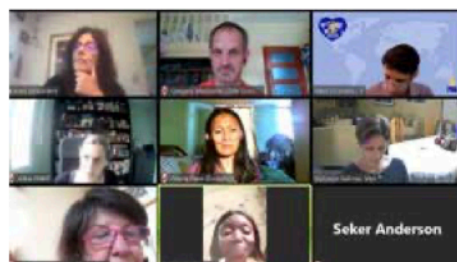


Virtual (online) • June 18

UNMEET NEEDS & CHALLENGES IN ACCESS TO TREATMENT IN EUROPE: THE CASE OF CHRONIC KIDNEY DISEASE
Gergely attended this political event

Virtual (online) • June 21

WEBINAR OF THE INTERNATIONAL PH COMMUNITY
Gergely represented PHA Europe on this event hosted by PHA USA



Virtual (online) • June 22

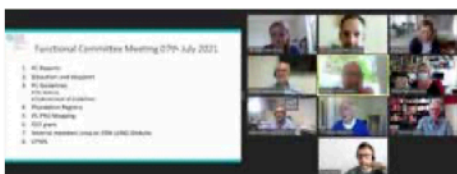
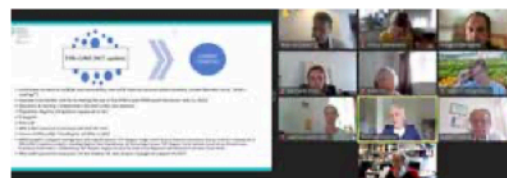
ERS VIRTUAL CONGRESS UPDATE

Gergely attended this briefing to have better understanding of the upcoming congress

Virtual (online) • June 30

ERN-LUNG CORE NETWORKS MEETING

Gergely represented PHA Europe on this event



Virtual (online) • July 7

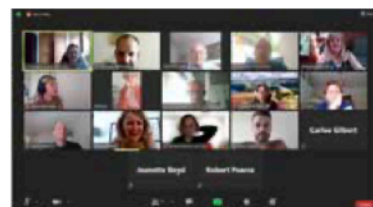
ERN-LUNG FUNCTIONAL COMMITTEES MEETING

Gergely represented PHA Europe on this event

Virtual (online) • July 8

ELF PATIENT ADVISORY COMMITTEE (PAC) MEETING

Gergely represented PHA Europe on this meeting



Virtual (online) • August 23

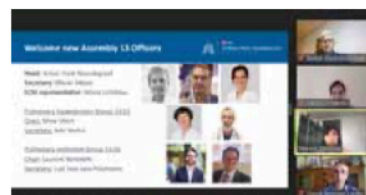
ELF FACILITATORS BRIEFING

Gergely attended this briefing to prepare for the patient associations' day

Virtual (online) • August 27

ASSEMBLY MEMBERS' MEETING (AMM)
(PULMONARY VASCULAR DISEASES)

Gergely attended this meeting as patient representative



Virtual (online) • August 27-30

EUROPEAN SOCIETY OF CARDIOLOGY (ESC)
ANNUAL CONGRESS

Gergely attended this important conference



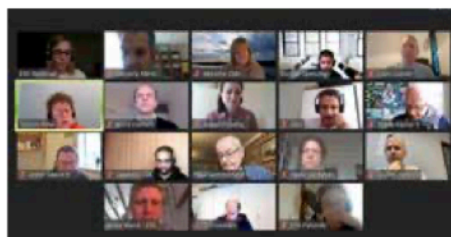
Virtual (online) • September 22
LAUNCH EVENT OF THE WHO 2021 AIR QUALITY GUIDELINES
 Gergely participated in this political event

Virtual (online) • September 27
PACT-EPF WEBINAR: MODEL ACCESS SOLUTIONS
 Gergely attended this meeting



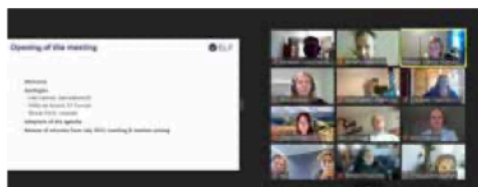
Virtual (online) • September 29
BEYOND DNA: THE UNSEEN GENOME AND NOVEL OMICS APPROACHES TO PH
 Gergely attended this webinar organized by PVRI

Virtual (online) • October 6
PH EMPOWERMENT NETWORK (PHEN) WORKSHOP
 Danijela, Tadeja and Hall participated in this workshop coordinated by Janssen



Virtual (online) • October 18
EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING ON BREATHE VISION 2030
 Gergely participated in this event

Virtual (online) • October 27
PH EMPOWERMENT NETWORK (PHEN) WORKSHOP
 Danijela, Tadeja and Hall participated in this workshop coordinated by Janssen



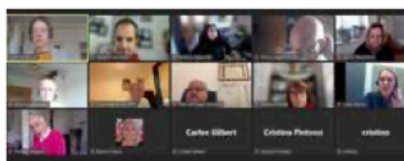
Virtual (online) • October 28
ELF PATIENT ADVISORY COMMITTEE (PAC) MEETING
 Gergely represented PHA Europe on this meeting

Virtual (online) • November 9
PHA EUROPE BOARD AND STAFF MEETING



Virtual (online) • November 17**PH EMPOWERMENT NETWORK (PHEN) WORKSHOP**

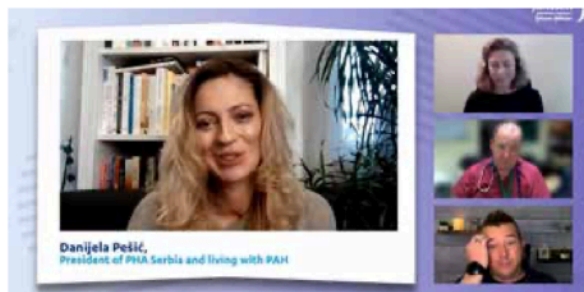
Danijela, Tadeja and Hall participated in this workshop coordinated by Janssen

**Virtual (online) • November 18****ERN-LUNG EPAG MEETING**

Natalia and Gergely represented PHA Europe on this meeting

Virtual (online) • November 19**LIVING WITH PAH PANEL DISCUSSION****ORGANIZED BY JANSSEN**

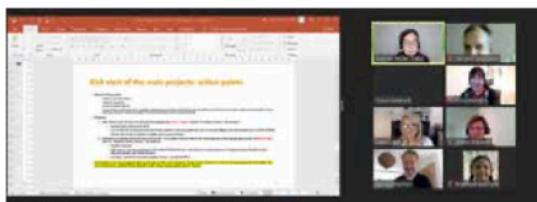
Danijela attended this meeting on behalf of PHA Europe

**Virtual (online) • November 19****FIRST VIRTUAL FORUM OF THE LATIN-AMERICAN PH COALITION**

Gergely attended this meeting as a panelist

**Virtual (online) • November 23****MEETING ON THE EUROPEAN HEALTH DATA SPACE**

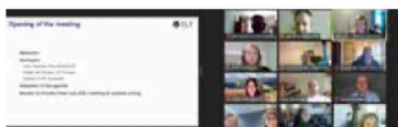
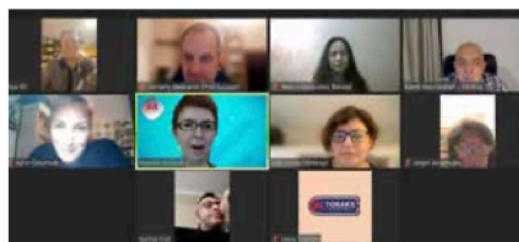
Gergely participated in this event with some of the members of the ELHG

**Virtual (online) • November 24****PVRI PATIENT ENGAGEMENT & EMPOWERMENT WORKSTREAM MEETING**

Gergely is co-chairing this initiative of Pulmonary Vascular Research Institute (PVRI)

Virtual (online) • December 7**MEETING WITH THE TURKISH THORACIC SOCIETY**

Gergely attended this meeting

**Virtual (online) • December 8****PH EMPOWERMENT NETWORK (PHEN) WORKSHOP**

Danijela, Tadeja and Hall participated in this workshop coordinated by Janssen

Hybrid • December 10-11**INTERNATIONAL CTEPH CONFERENCE**

Gergely attended virtually this congress organized by the International CTEPH Association (ICA)

