

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



# ACTIVITY REPORT 2020 & WORK PLAN 2021

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# 1. FOREWORD

Dear Friends,  
I am delighted to present our 2020 activity report. On the 10th of March, the World Health Organization declared the COVID-19 outbreak a pandemic. Everybody's life changed dramatically and established plans were demolished in minutes. Sooner or later, however, we learnt to live together with this new situation: we became experts of online tools and successfully ran meetings, webinars and conferences on various virtual platforms. Despite the pandemic, we can be proud of the lots of activities and achievements of this year and how well pulmonary hypertension (PH) is positioned amongst the rare diseases. We launched our new webpage with new contents and regular updates. All of the scientific articles were either reviewed or a completely new text was drafted. We made our materials more visible and accessible. A fabulous World Pulmonary Hypertension Day (WPHD) was organized: more than 200 articles, TV and radio interviews were issued and half-thousand views were collected with our webinar on access. We introduced to the "Cure for PH" slogan with the lips and the O2kids video (collecting more than 1 million (!) views) about Thomas, who would like to play with his friends, but due to his PH, his lungs say: "NO". Later, in autumn we launched a crowd-funding project using the O2Kids concept with same success. We participated in various questionnaires and were one of the key drivers of the PHCare COVID questionnaire, which collected more than 1000(!) responses from PH patients and carers all over the world: The result was an interesting and very informative paper about COVID and PH. In collaboration with EURORDIS and ERN-Lung and in cooperation with our valued partners from the medical field, we

compiled a patient journey which outline the whole patient path from the first symptoms to the follow-ups. The leaflet also contains what we think is ideal at each stage and the patient needs. The leaflet was translated into 22 (!) different languages by our fellows.

It was very important for us to help our member associations in these challenging times: we sent branded masks to our members and health care providers. November was also a very busy month: on the occasion of PH awareness month, a number of events were organized from Spain to Ukraine, from Bosnia-Herzegovina to Portugal. There were, among others, scientific lectures, a virtual gala "dinner", a solitary and solidary walk, a breath-taking rowing tour and messages/quotes and videos about COVID and the importance of responsible behavior. We devoted lots of energy and time to advocacy work as well. We are working closely with big umbrella organizations such as EURORDIS and European Patients' Forum (EPF) and are pleased to have a good working relationship with European Lung Foundation (ELF) and European Federation of Allergy and Airways Diseases Patients' Associations. We are members of the steering committee of the newly (re)launched MEP (Members of the European Parliament) Lung Health Group, whose primary aim is to keep airways diseases on the EU agenda.

Back in 2012, PHA Europe created a Call to Action on the Unmet needs of Patients with Pulmonary Hypertension. It was presented at the EU Parliament. We have done considerable work to revise and renew the paper in 2020 and we are very excited about the possibility to run another event at the EU Parliament hopefully in 2021.

Finally, we warmly thank our industry partners, who make our work possible and tirelessly support our projects.

Gerald Fischer

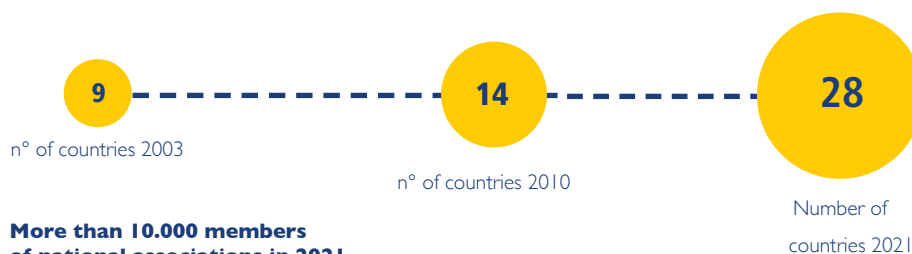
## 2. PHA EUROPE IN BRIEF

### BACKGROUND AND MISSION

PHA Europe is the umbrella organization for national associations of patients living with pulmonary hypertension (PH) in Europe. It was founded in Vienna, Austria, in 2003 and is registered as an international non profit organization. PHA Europe works together with its 33 members across 28 countries to enhance awareness of PH across Europe,

promote optimal standards of care for people living with the disease, ensure the availability of all approved treatments and encourage research for new medicines and therapies. PHA Europe strives to achieve its objectives through activities in four main areas: awareness raising, advocacy, capacity building, information and education.

### KEY FIGURES



### MEMBERSHIP

PHA Europe was founded in 2003 in Vienna by eleven pulmonary hypertension patient associations, coming from nine countries. Membership has grown steadily over the years and currently stands at 33 patient organizations, from 28 countries: Austria, Belarus, Bosnia & Herzegovina,

Czech Republic, Croatia, Denmark, Estonia, Finland, Hungary, Israel, Ireland, Italy (2), Latvia, Lithuania, Norway, Moldova, Poland, Portugal, North Macedonia, Romania, Russia (2), Serbia, Slovakia, Slovenia, Spain (3), Sweden, Ukraine (2).





## 3. GOVERNANCE

### BOARD AND AUDITORS



**Danijela Pešić**  
President



**Zdenka Bradac**  
Vice President



**Tuulia Nikulainen**  
Treasurer



**Tadeja Ravnik**  
Vice Treasurer



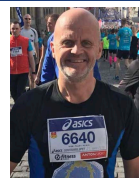
**Natalia Maeva**  
Secretary



**Eva Otter**  
Vice Secretary



**Bodgan Heinrich Burduja**  
1st Auditor



**Odd Erling Børstad**  
2nd Auditor

2019; it's mandate ends in November 2021. The current members of the Board and the Auditors represent patient associations from eight European countries: Austria (Eva Otter), Bulgaria (Natalia Maeva), Croatia

(Zdenka Bradac), Finland (Tuulia Nikulainen), Norway (Odd Erling Børstad), Romania (Bodgan Heinrich Burduja), Serbia (Danijela Pesic), Slovenia (Tadeja Ravnik).

Due to the Covid-19 pandemic, face-to-face meetings were impossible. Instead, the board ran several

recorded Zoom conference calls in 2020. The Board is instrumental for the implementation of decisions taken at the GAM. They supervise the work performed by the staff and plays a key role in strategic planning.

The PHA Europe Board is elected every two years at the Annual General Assembly (AGA) and consists of President, Vice President, Secretary, Vice Secretary, Treasurer and Vice Treasurer. There are also two Auditors. Elections for the renewal of the Board took place at the PHA Europe AGA in November

### STAFF & CONSULTANTS

PHA Europe has one staff member: Gerald Fischer (Austria). In addition, they work with three consultant companies run by: Hall Skaara (Norway), Gergely Meszaros (Hungary) and Mirko Glavinic (Serbia). Day to day management of PHA Europe typically includes programming and implementing PHA Europe activities, in coordination with the national member associations, correspondence and contact programmes, monitoring and information gathering, financial and administrative tasks. In previous years, the staff/consultants performed a considerable amount of travelling

in order to be involved in collaborative work with our partner organisations, participate in conferences, workshops and other events. However, due to the pandemic, the staff/consultants have mostly worked from their home office participating in virtual events. They have communicated with their members primarily by means of webinars.



**Gerald Fischer**



**Hall Skaara**



**Gergely Meszaros**



**Mirko Glavinic**

## 4. MAIN AREAS OF ACTIVITY

### AWARENESS



PHA Europe has conducted annual global awareness campaigns for many years. From 2010 to 2012 these were organized around International Rare Disease Day (last day of February). In 2012 the Spanish PH association ANHP launched the idea of establishing a World Pulmonary Hypertension Day (WPHD): this initiative was embraced by PHA Europe and PH associations around the world and is now celebrated annually on May 5. In 2020 WPHD events were held in over 80 countries, across all continents despite the pandemic.

### ADVOCACY

Advocacy is one of PHA Europe's key activities and vital to drive change in health policies both at national and EU level. PHA Europe is active in providing input into EU policy through position papers and submissions to public consultations as well as contact programmes with key EU COMMISSION officials and MEPs. Its main area of interest is access to treatment, including organ transplantation. PHA Europe also provides support to national advocacy initiatives.



### INFORMATION



PHA Europe's information channels include a website with a geo-locator, which enables patients to find PH experts in Europe, the Mariposa Journal, which is issued twice a year; regular updates and other resources, all of which are available online. Information about relevant issues is posted regularly on PHA Europe's social media platforms, Facebook and Twitter. Information and educational opportunities are also provided at the Annual PH European Conference (see below). PHA Europe and its members interact on a regular basis by means of an internal Google Group.

### CAPACITY BUILDING

Capacity building activities are important in order to increase the skills and knowledge of the national associations. The "White Spots" program provides start-up funds and support to new and "young" patient associations. The "Fellowship" programme provides the national associations with a paid part-time English-speaking assistant. Lectures and medical updates from top international PH physicians, training sessions and workshops on PH related issues are regularly held at the Annual PH European Conference.



# 5. AWARENESS RAISING

## World Pulmonary Hypertension Day

Ever since the very first World Pulmonary Hypertension Day (WPHD) took place on 5 May 2012, our important annual milestone has been used to combine and highlight our international efforts to raise awareness of, and support for, patients with

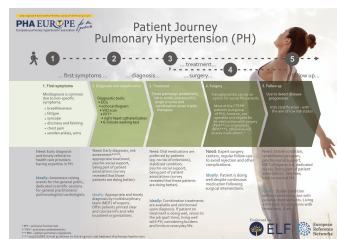


Despite the pandemic, a fabulous World Pulmonary Hypertension Day (WPHD) was organized: More than 200 articles, TV and radio interviews were issued and half-thousand views were collected with our webinar on access. We introduced to the “Cure for PH” slogan with the lips and the O2kids video (collecting more than 1 million (!) views) about Thomas, who would like to play with his friends, but due to his PH, his lungs say: “NO”. Later, in autumn we launched a crowd-funding project using the O2Kids concept with same success.

## Infographics

The original idea of building-up patient journeys for various rare lung diseases came up as a result of the collaboration between EURORDIS and ERN-Lung. We have not developed such a material previously and thought that the strategic and analytical approach this initiative provides is beneficial for the whole PH patient community. The patient journey nicely demonstrates the – sometimes difficult – stages the PH patients are facing following the identification of their very first symptoms.

The main objective of this infographic was to provide a comprehensive summary of each step, ie. what are the symptoms, how the disease is diagnosed, what type of treatments and medications are available and what to expect from the follow-ups?



The patient journey at the same time, however, sheds light on the – often unmet – needs of the patients and outline the ideal situations. By doing this, it may also serve as an excellent advocacy tool for discussion with other stakeholders. It may help in the identification of the obstacles and hurdles in each stage – providing solutions how to overcome them. The patient journey was developed in collaboration with our PH expert colleagues. Special thanks go to Prof. Marion Delcroix, Prof. Marc Humbert and Prof. Olivier Sitbon for their valuable input. The infographics was translated into 22 (!) different languages by our fellows.

## O2Kids

O2Kids was originally a campaign developed by PHAustria and also later made available to PHA Europe. The campaign was based around a short movie describing a young boy (Thomas) suffering from PH. In the film, we see Thomas secluded from his playing friends. When they ask him to play with them, he says «no». But really it is his lungs that say «no». The video of Thomas has touched many hearts. The reach on social media has been fantastic. In this way, we have accomplished one of the main goals with the campaign: To create awareness for PH and especially for children suffering from PH. Cristina Makarchuk from Ukraine was the first child to receive a scooter by money raised by the campaign. This will make it easier for her to go to school as PH made it hard for her to walk far.



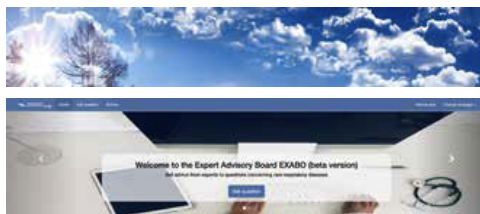
## 6. ADVOCACY

Advocacy is one of our key activities and is vital to driving change in health policies, both at the national and EU levels. The main focus of our advocacy activities is on access to treatment and surgery (including organ transplant), as these are critical issues for many of our patients across Europe. Not all approved PH drugs are available in all countries across Europe and there are countries where patients do not have access to any drugs at all or to expert centres/surgical facilities. We are also active in advocacy activities aimed at improving the quality of life, specifically emotional wellbeing.

### Advocacy at European level

We are working closely with big umbrella organizations such as EURORDIS and European Patients' Forum (EPF) and are pleased to have a good working relationship with European Lung Foundation (ELF) and European Federation of Allergy and Airways Diseases Patients' Associations. We are members of the steering committee of the newly (re)launched MEP (Members of the European Parliament) Lung Health Group, whose primary aim is to keep airways diseases on the EU agenda.

The European Reference Networks (ERNs) continue to be a very important factor in the European level advocacy work and becoming a real bridge towards the European Commission in health-related matters on rare diseases. Unfortunately, the COVID-19 pandemic made the respiratory medical professionals extremely busy, which resulted in the postponement of some of the initiatives, however, there are still some achievements which we can be proud of. Only one face-to-face meeting was possible this year, just before the COVID lockdowns: the board meeting was held in Frankfurt on 26-27th of February. ERN-Lung has the following two important IT modules: CPMS, the platform for online tool for discussing patient cases under the umbrella of ERN-Lung, still has its difficulties. Luckily in the PH core network informal discussions are held amongst the physicians regarding complicated cases.



EXABO, the Expert Advisory Board, the online tool which links the questions from patients to an expert on the field - preferably on the respective language -, still has not reached its full potential.

Registries are one of the hot topics in ERN-Lung: there are various solutions all over Europe (HCP-based, one or more registries per country, etc.) and a common dataset has not been achieved yet, which is a pre-condition of future harmonization and ultimately the interoperability.

The network of ERN Lung is growing: it was good to hear that as a result of the European Commission's call in 2019 autumn more than 40 health-care providers (HCP) applied for standard membership - 12 applications were submitted to join the PH core network. A detailed, multi-step decision making process was completed and most of the applicants were approved.

Despite, and parallel with, the above call, lots of HCPs apply for supporting membership - mainly those, which cannot fulfil the quantitative requirements of becoming a standard member. Together with standard members the white spots on the map decreased radically. There is an important collaboration between ERN-Lung and ERS (eg. common symposium) and ERN-Lung plays an active role in various calls (eg. eSupport, EJP).

### Support to national advocacy activities

Some countries unfortunately still struggle with access to medication. PHA Europe has played an important role in supporting associations in some of these countries in order to influence the authorities to cover basic PH medication for its patients.

## 7. 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.

### Fellowship

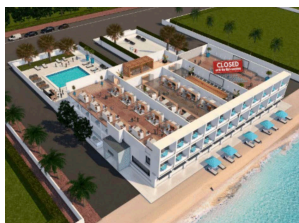
PHA Europe's official working language is English and, as the organisation expanded over the years to include more and more countries, communication started to become a critical issue with those associations where neither Board members nor volunteers had a good command of this language. Thanks to our "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 2020 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

The Annual PH European Conference (APHEC) also provides member associations with opportunities for education and skills development. Due to the pandemic, it was impossible to meet in Barcelona like we've done in the previous years. Our conference was postponed until it was clear that an alternative platform had to be found. So in March 2021, we ran our



conference as a virtual conference. Great efforts



were made in order to give the conference the same look and feel as when we met annually at the

hotel by the beach in Castelldefels outside Barcelona. We collaborated with a deutch company and created a virtual version of the hotel. By using photoes from Google Map, even the surrouding rounds and beach area were realistically depicted in the virtual conference area. We included exhibition areas where each association could highlight their work by uploading brochure, video clips, etc. We also had a presentation room with 13 presentations available - some of them by leading PH specialists in Europe. In addition, we had a pool area (accuratly located in the front of the hotel) where people could meet for an informal chat or even do conference calls with each other. Read more about the APHEC on page 8.

### Information materials and resources

Providing up-to-date information materials is an important part of capacity building. Read more about this on page 8.



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 and newsletters

The Mariposa Journal ([www.phaeurope.org/news-events/mariposa-journal/](http://www.phaeurope.org/news-events/mariposa-journal/)) is produced twice a year; it is targeted mainly at PHA Europe's member associations but is also distributed to other patient associations worldwide as well as to a mailing list of selected PH physicians, researchers, nurses, health care professionals, representatives of NGOs, policy makers at local, regional, national and EU levels, regulatory authorities and pharmaceutical industry partners. The journal is also posted on the PHA Europe website and distributed at major European and international scientific and industry events such as the European Society of Cardiology's (ESC) and European Respiratory Society's (ERS) annual congresses and the Board meeting of ERN-Lung.

## Website, social media and online platforms

We rebuilt our webpage in 2020. The old one was more than 5 years old, and needed a facelift. Some of the leading PH specialists reviewed and rewrote the medical part. We think the new webpage is visually attractive, but new elements like sliders and different boxes have an additional function: they help the visitors to better navigate amongst our materials and projects and the most recent initiatives are easily accessible by one click. Behind the scene we made finetunes to enhance the search engine functionality (SEO). We've also been very active in social media in 2020. We launched a major



campaign called #goodPHnews where associations across Europe has contributed with countless positive PH small news articles.

## 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



*Prof. Marc Humbert during the Q&A session. In his presentation, Prof. Humbert talked about the latest news from PH research.*

theater 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.

## Other

All across Europe, PHA Europe representatives are also continually active in the dissemination of PH information, through scientific symposia, panel discussions, roundtables, workshops, and academic courses. (see pages 9-12).

## 9. 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 2020 the events were primarily virtual due to the pandemic. The activities cut across all of the four main areas of PHA Europe's work: awareness, advocacy, capacity building and information:

- 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 organizations 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 organizations (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.

### **Vienna (AUSTRIA), February 15-16 BOARD AND STAFF MEETING**



The members of the Board and staff of PHA Europe held a face-to-face meeting to evaluate last year's achievements, discuss the plans and meet with the industry partners.

### **Frankfurt (GERMANY), February 26-27 ERN-LUNG BOARD MEETING**



Gergely, who is a member of the ERN-LUNG Medical Steering Committee, attended the ERN-LUNG Board meeting on behalf of PHA Europe and ran various presentations.

### **Virtual (ONLINE), March 11**

European Kidney Forum 2020



A SHARED VISION FOR  
**IMPROVING ORGAN  
DONATION &  
TRANSPLANTATION IN  
THE EU BEYOND 2020**



European Kidney Forum  
Co-chaired Presidency of the  
Council of the European Union



Gergely attended this webinar hosted by the Croatia Presidency of the Council of the EU originally scheduled in the European Parliament. The event is built on the Joint Statement on Improving Organ Donation and Transplantation, the paper which PHA Europe contributed to and endorsed.

### **Virtual (ONLINE), April 14 BOARD AND STAFF MEETING**

The members of the Board and staff of PHA Europe gathered on Zoom to discuss the concept of World PH Day



### **Virtual (ONLINE), April 25 EUROPEAN PATIENT FORUM (EPF) - ANNUAL GENERAL MEETING (AGM)**

Gergely represented PHA Europe on the first ever online AGM of EPF. New ethics committee was elected and various decisions were made about the strategic plan.



### **Virtual (ONLINE), April 27 ESOT - WEBINAR**



European Society for Organ Transplantation ran a seminar about how to cope with

uncertainty during the Covid-19 pandemic. The challenges the pandemic brought for transplantations and for transplanted patients were presented by surgeons and patients.

## Virtual (ONLINE), May 21 PHA EUROPE - WEBINAR ON ACCESS



PHA Europe organized a webinar, as part of the World PH day celebration, to talk around the

challenges of access to treatment.

## Virtual (ONLINE), May 23 BRIDGING THE COMMUNICATION GAPS IN PAH PATIENT CARE

Danijela, Hall and Gergely attended a patient association representatives webinar meeting and discussed the possible ways of overcoming the communication difficulties.



## Virtual (ONLINE), May 26 EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES PATIENTS' ASSOCIATIONS (EFA) - EUROPEAN RESPIRATORY HEALTH COALITION MEETING

Gergely attended the kick-off meeting with the aim of forming a European Respiratory Vision Paper



## Virtual (ONLINE), June 25 RELAUNCH OF MEP INTEREST GROUP ON EQUITABLE ACCESS

Following the introductory speeches of the MEPs, a lecture was held by DG Sante about health-related recommendations in the framework of the European Semester. The meeting was concluded with a stakeholders' debate. Gergely attended the meeting.



## Virtual (ONLINE), July 7 NORD WEBINAR - BUILDING A VILLAGE: HOW TO RE-ENGAGE YOUR BOARD MEMBERS, LEADERS AND VOLUNTEERS

The guest speaker was Joan Garry, who is an interationally recognized champion



for the nonprofit sector. Gergely dialed-in to this webinar.

## Virtual (ONLINE), July 20-22 EURORDIS - RAR 2030 PANEL OF EXPERTS

Gergely attended these meetings (Subgroup 6 - integrated, Social & Holistic Care - and subgroup 7 -



Patient Partnerships - and represented PHA Europe.



## Virtual (ONLINE), September 7-9 EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS

The congress was originally scheduled to be held in Vienna, but due to the pandemic, it went online. Gergely represented PHA Europe at the congress.

## Virtual (ONLINE), September 16 ERN LUNG EPAG AND MEDICAL STEERING VIRTUAL MEETING

Natalia and Gergely represented PHA Europe. Gergely ran a presentation about the patient journey in

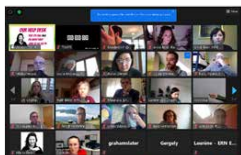


the ePAG meeting and provided update on the work of the PRO committee in the Medical Steering Committee meeting.



## Virtual (ONLINE), September 28 EURORDIS - ERN FOCUSED POLICY RECOMMENDATIONS SESSION 2: INTEGRATING ERNs TO NATIONAL SYSTEM AND FRAMEWORKS

Gergely commented on the paper on ERN's integration and participated in this discussion.



## Virtual (ONLINE), October 3 EUROPEAN PATIENT FORUM (EPF) EXTRAORDINARY GENERAL MEETING (EGM)

The strategic plan (we commented on previously) of EPF for 2021-2026 was approved and proposed



changed to constitution (possibility to hold online general meetings) was presented during this meeting. Gergely represented PHA Europe.

## Virtual (ONLINE), October 12 ERN-FOCUSED POLICY RECOMMENDATIONS SESSION 4 ERNs, RESEARCH, AND THE DATA ECOSYSTEM OF THE FUTURE



Gergely represented PHA Europe in this interactive meeting.

## Virtual (ONLINE), October 13 MEP LUNG HEALTH GROUP LAUNCH "EVERY BREATH COUNTS - RESPIRATORY HEALTH IN COVID-19 TIMES"



Gergely represented PHA Europe in the official launch of MEP Lung Health Group. Presentation were run by Commissioner for Health and Food Safety, ERS president and ELF.

## Virtual (ONLINE), October 19 EUROPEAN MEDICINES AGENCY (EMA) WORKSHOP ON GUIDELINE ON REGISTRY-BASED STUDIES

Gergely dialed in to this workshop, which gave an overview of core recommendations of the draft guideline.



## Virtual (ONLINE), October 20 EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES PATIENTS' ASSOCIATIONS (EFA)

The 2nd meeting was held to further discuss the Vision Paper. Gergely attended this meeting on behalf of PHA Europe.



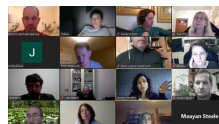
## Virtual (ONLINE), October 26 CLOSING PRENARY OF THE RARE 2030 ERN EVENT



Gergely attended this plenary session, which was the conclusion of the previous workshops and sessions of Rare2030.

## Virtual (ONLINE), November 2 PHA EUROPE - COVID-19 (INFORMAL ROUND-UP)

It was a gathering of PHA Europe's members to discuss the impact of the second wave of Covid-19 in their respective countries.



## Virtual (ONLINE), November 4 HEART AND STROKE MANAGEMENT



Hall attended this seminar which was hosted by the alliance of

BMS and Pfizer. The webinar highlighted how stroke is serious health issue in Europe and the globe today. A call for action was presented. PH patients are at risk since irregular heartbeat (Afib) might lead to stroke.

## Virtual (ONLINE), November 15-17 EUROPEAN SOCIETY FOR ORGAN TRANSPLANTATION (ESOT)



ESOT held two day special sessions on Transplantation Learning Journey (TLJ 2.0)

focused on some of the hot topics in specific areas of transplantation. Natalia represented PHA Europe in this event.

## Virtual (ONLINE), November 30 EUROPEAN MEDICINES AGENCY (EMA) WORKSHOP ON SUPPORT FOR DEVELOPMENT OF ORPHAN MEDICINES



Gergely attended this workshop which was broadcasted on the YouTube channel of EMA.

## Virtual (ONLINE), December 1 BRIDGING THE COMMUNICATION GAPS IN PH PATIENT CARE

Empowering patients to improve HCP dialogues and raising awareness of PH patient association &



healthcare professional webinar. Danijela, Hall and Gergely attended this meeting and discussed the possible ways how the communication between patients and health care professional can be improved.

## Virtual (ONLINE), December 2 MEP LUNG HEALTH GROUP AIR POLLUTION AND COVID-19

Gergely attended this meeting which mapped the possible correlation of air pollution and the spread of Covid-19



## Virtual (ONLINE), December 2 PHA (US) INTERNATIONAL LEADERS MEETING

Hall and Gergely attended this meeting with the main focus on next year's World PH Day



## Virtual (ONLINE), December 4 EURORDIS HTX TRANSFERABILITY WEBINAR



## Virtual (ONLINE), December 14 EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES PATIENTS' ASSOCIATIONS (EFA)

The 3rd meeting was held to discuss the different aspects of the launch of the Vision Paper and outline the frame of further



collaboration. Gergely attended this meeting.

## Virtual (ONLINE), December 14 PHA EUROPE - YEAR CLOSING MEETING

It was a gathering of PHA Europe's members to share local traditions and meet with each other - virtually.



## UPCOMING EVENTS 2021

Online, January 23  
EPF EXTRAORDINARY GENERAL MEETING

Online, February 23  
EURORDIS RARE 2030 FINAL CONFERENCE

Online, February 24  
EURORDIS BLACK PEARL AWARDS

Online, March 1st - 13th  
PHA EUROPE ANNUAL CONFERENCE

Online, mid March  
ERN-LUNG BOARD MEETING

London, 28 August to 1 September  
ESC ANNUAL CONGRESS

London, 28 August to 1 September  
ESC ANNUAL CONGRESS

Barcelona, September 4 - 8  
ESC ANNUAL CONGRESS

## 2022/23 AT A GLANCE

ERS annual congress 10-14 Sep (Munich, Germany)

ESC congress

7 World Symposium on PH Feb/Mar Orlando, FL, USA

# 10. WORK PLAN 2021

## AWARENESS

Over 80 countries across five continents took part in the 2020 global awareness campaign for World Pulmonary Hypertension Day (WPHD) with incredible results in terms of reach and media coverage. In 2021 PHA Europe has taken over the global coordination and lead of the WPHD events, but we are still working together with PHA USA and the PH Latin Society, as we did last years. In Europe the financing procedure has not changed: it is PHA Europe who will finance the national events. On a global level (including Europe), we have re-launched the [worldphday.org](http://worldphday.org) website, refreshed and promote the social media platform of World PH Day and provide assistant and coordination support to local initiatives. We prepared new ready-to-use posters, banners and stories for social media sharing with a detailed and comprehensive timetable, but previous toolkit is also available which includes briefings on how to best promote the initiative, how to organize press conferences, merchandising activities, etc.

We fine-tuned the theme to mental health due to COVID, but in those countries where events can be organized the slogan "Get breathless for PH" remained.

We will also continue to raise awareness of PH through other channels, including the participation of PHA Europe representatives in international scientific congresses, symposia, round tables, academic courses and industry events, but we have launched new initiatives as well: we organized a high-profile virtual event on research with the involvement of members of the European Parliament and the representative of the European Commission, organize online webinars in various languages with Key-opinion leaders and kicked-off an online petition on better access.

## ADVOCACY

### EU level

Our main focus for 2021 will continue to be access to treatment and surgery (including organ transplant), as access is still a critical issue for many of our patients. We will continue to be actively involved at European level in the task forces and working groups of public health NGOs dedicated to access to treatment and will collaborate with the PH professionals in the context of the EUROPEAN REFERENCE NETWORKS for rare lung diseases ERN-Lung, European Respiratory Society (ERS), European Lung Foundation (ELF) and European Society of Cardiologists (ESC). In 2021 we will be collaborating closely with our member associations, as in past years, in order to

provide guidance on possible strategies to adopt at national level to advocate for access to treatment and surgery and patient rights in general. Early this year as a result of cooperation of NGOs, Breathe Vision 2030 position paper was launched and we are planning to organize more events around it.

The revision of our paper "Call to action on the Unmet Needs of PH Patients" was postponed from last year due to COVID, but we have re-started it this year.

## CAPACITY BUILDING

Building on the achievements of past years, we plan to continue our support programs for the member associations.

Through our “White Spots” program we will provide support to the new associations who joined PHA Europe in 2020 as well as to recently founded associations that are just starting out. Our ultimate aim is to put in place a European PH community of empowered and strong patient associations.

Through our CBP (Capacity Building Program) we aim at maturing the associations. We support projects that can strengthen the associations - in particular fundraising projects. We also try to learn from each other and use best of practice methods. Here we look at what services the most mature associations offer, and try to make others copy them.

Through the “Fellowship” programme, which is currently in place in 20 countries, we plan to continue to provide the national associations with a part-time English speaking assistant and we hope to be able to extend the programme to any new member associations which have significant language barriers. Capacity building is also a crucial part of the program of the Annual PH European Conference, which consistently provides opportunities for sharing and learning from each other as well as training sessions on different topics which are important in the running of a patient association.

## INFORMATION AND EDUCATION

PHA Europe's traditional information channels are the Mariposa Journal, which is issued twice a year, its website and social media platforms. Whilst we do not expect to make major changes to our journal during 2021 we do plan to continue to make improvements to our website which was re-launched in 2020..

Our social media platforms saw a great increase in the number of followers last year and we plan to build on this in the coming year. We will also continue to work on search engine optimization, in order to improve the website's traffic.



# 11. PARTNERSHIPS

## EU INSTITUTIONS, NGOS, PROFESSIONAL SOCIETIES...

PHA Europe is a member of the EUROPEAN ORGANIZATION FOR RARE DISEASES (EURORDIS) and participates in the work of several of its task forces: Rare2030, PAG of European Lung Foundation (ELF), ePAG of ERN-Lung. PHA Europe representatives have taken part in in past years in consultations as experts at the European Medicines Agency (EMA). PHA Europe also interacts through many different channels with the EU institutions (MEPs and EU COMMISSION officials), other European patient associations/federations and NGOs as well as professional scientific societies.



## SPONSORS

The collaboration with the pharmaceutical industry is very important to PHA Europe. We have a partnership on many important projects, such as our WPHD celebration, our annual conference, renewed Call to Action, our fellow program, etc. In addition, the pharmaceutical industry provides us with much needed financial support. This can take form of unrestricted grants or can be related to specific projects. We look forward to continuing this fruitful cooperation also in future years.

Gold



Silver



Platinum



# 12. MEMBERS OF PHA EUROPE



**AUSTRIA**  
**PH Austria**  
 Initiative Lungenhochdruck  
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**FINLAND**  
 Suomen PAH-potilasyhdistys ry.  
 PHA Finland



**BELARUS**  
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**BOSNIA & HERZEGOVINA**  
 Udruženje građana oboljelih od plućne  
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**The Bulgarian Society of Patients  
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**ITALY**  
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**CROATIA**  
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**LITUANIA**  
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**MOLDOVA**  
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## PORTUGAL

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## REPUBLIC OF MACEDONIA

**APH Moment**  
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## ROMANIA

**Association of pulmonary  
hypertension patients**  
[www.phader.eu](http://www.phader.eu)



## RUSSIA

**Natasha Charity Fund**  
[www.community.livejournal.com/fond\\_natasha](http://www.community.livejournal.com/fond_natasha)  
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## Save and Protect

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## SERBIA

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## SLOVENIA

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## SPAIN

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## FCHP Fundación Contra la Hipertensión Pulmonar

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**Hipertensión Pulmonar  
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## UKRAINE

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## Ukraine Association of Patients with Pulmonary Hypertension

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