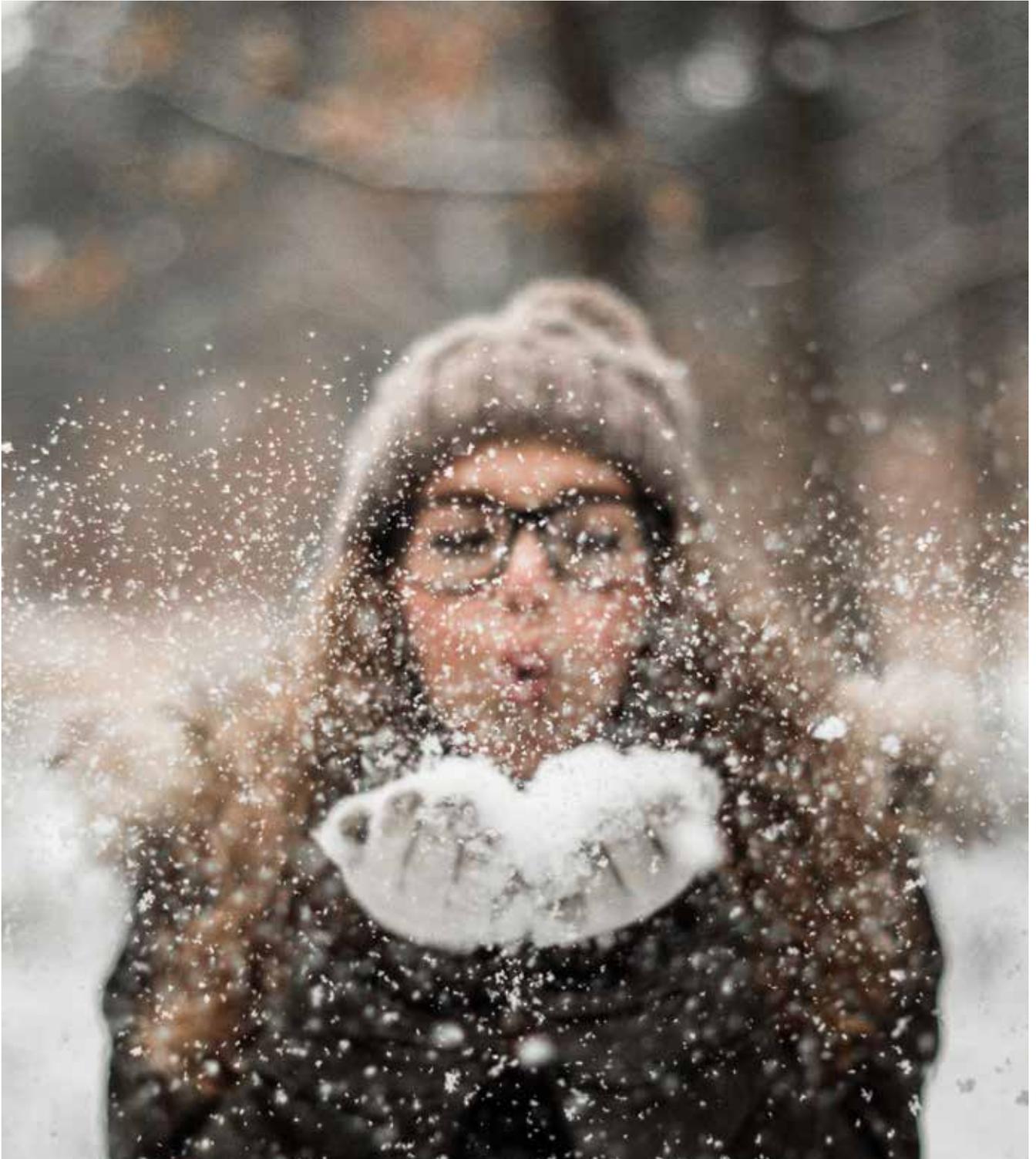




PULMONARY HYPERTENSION  
**Mariposa Journal**

WINTER 2021 • PHA EUROPE'S OFFICIAL JOURNAL • N. 27.



• early diagnosis • best treatment • better quality of life • funding & care

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

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# Editor's memo

*Dear Friends, Colleagues and Supporters,*

It is with mixed feelings that I started writing this editorial. We had hoped that thanks to various precautionary measures we would be in the position to organize our long-awaited Annual PH European Conference again in person this fall. Unfortunately, COVID statistics became unfavorable and also a new variant was revealed: most of the countries started closing down their borders which resulted in the postponement of our event. It seems uncertainty will stay with us for a longer period of time and we need to cope with and prepare for this unprecedented situation.

On the other hand I am delighted to let you know that we have never closed such an active and successful year as 2021.

We kicked-off the year 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 this year and are progressing nicely with the review. We are 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 plan to relaunch it next spring and hopefully it will be an in person event hosted by MEPs in the European Parliament.

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

We managed to organize our first-ever virtual Annual PH European Conference 2020 in the early days of March. You can learn more about it in this journal.

Also, in March we participated as panelists in the ERS Live Vision, which is the respiratory channel of ERS. 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.

Tremendous effort and work were invested into this year's World PH Day celebration during April and May. A separate edition of Mariposa is dedicated to this series of events, but the main activities included the building of a new dedicated webpage, co-organizing high profile policy event on research with MEPs (Members of the European Parliament), launching an online petition,

organizing five webinars in various languages and delivering a toolkit with detailed social media timeline in English and Spanish, are worth being mentioned here again.

We received a nice gift for WPHD: 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.

Despite the challenging spring we managed to collaborate with EU-IPFF (European umbrella organization of pulmonary fibrosis) and participated in their virtual European patient summit, as panelists, in April.

We participated in 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. EPF (European Patient Forum) organized a series of webinars on artificial intelligence.

Last, but not least, ERS and ESC annual conferences and the CTEPH conference organized by ICA (International CTEPH Association) 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 conducted a lot of very successful communication campaigns. O2Kids campaign was relaunched, the main target is raising money to make the dreams of children living with PH come true. We have already helped many kids and made them smile: this campaign gave us the idea and dedication to give a helping hand to many more. We ran many social media campaigns to raise awareness of PH: #PHLeadersStory to introduce the leaders of our member associations, #goodPHNews to collect and share all the achievements of our members which we can be proud of.

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 a very touching video: you can get to know three incredible people from the 'PH no limit' footage.

We must not forget the support we provide to our member associations under the umbrella of the Capacity Building Program. Last year we re-built our homepage which gave the idea to make it happen to our members as well. The template was ready, the capacity was available and many member associations were keen to start working on their own new webpage. Thanks to this program we managed to deliver new webpages to Hungary, Finland, Moldova, Italy (AIPI) and Austria and more to come!

Let me conclude this editorial with a big thanks to our members, patients, family members, carers, friends and also to our medical partners, physicians, surgeons and researchers, who are with us on this long journey. Without their assistance we would not be where we are now. We are very grateful to our industry partners, who continue to support our work.

*Gergely Meszaros*  
Project manager  
PHA Europe

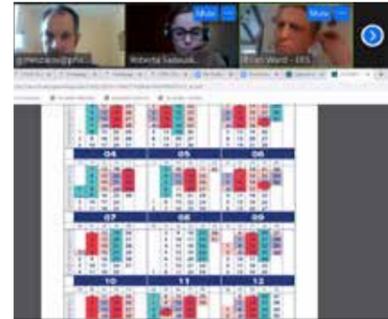
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**Virtual (online) • January 12**

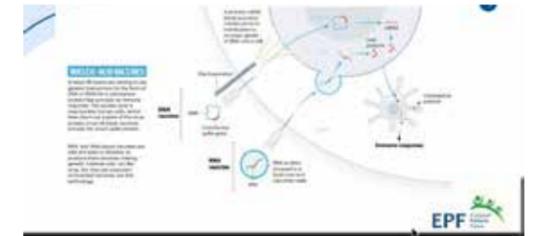
**RESPIRATORY VISION COLLABORATION**

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



**Virtual (online) • January 27**

**PHA EUROPE BOARD AND STAFF MEETING HIGH IMPACT VIRTUAL ENGAGEMENTS WEBINAR**



**Virtual (online) • January 28**

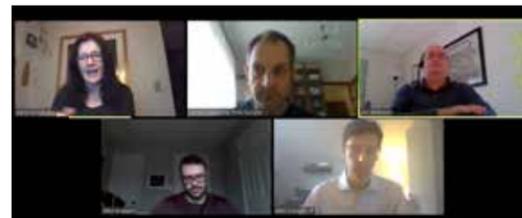
**SHOT CALLERS WEBINAR ON COVID 19**

Gergely attended this webinar organized by EPF

**Virtual (online) • 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) • 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) • 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) • 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) • 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) • February 19**

**EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING WITH DG SANTE**

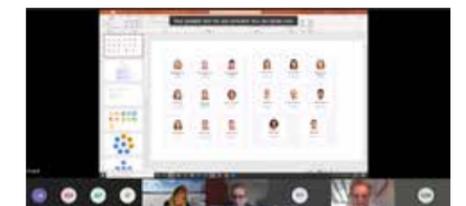
Gergely attended this event as the member of the ELHG. The Commission was represented by Mr. Delsaux



**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) • January 27**

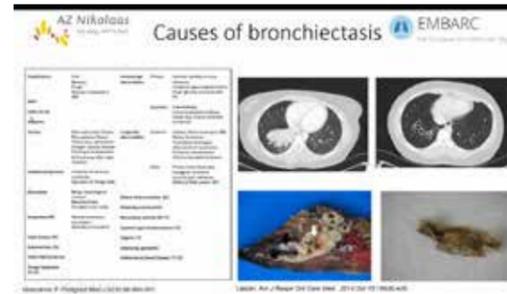
**MEP (MEMBERS OF THE EUROPEAN PARLIAMENT) LAUNCH EVENT OF THE BREATHE VISION**

Gergely represented PHA Europe and was a speaker on this event

**Virtual (online) • 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)

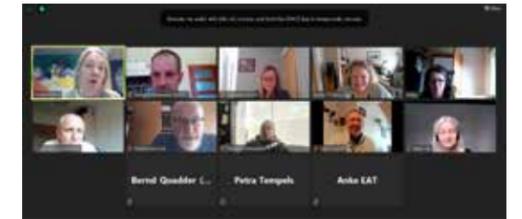
**Virtual (online) • March 12**  
 PREPARATORY CALL FOR THE ERS LIVE VISION  
 Gergely attended this call as the speaker of the subject event



**Virtual (online) • March 18**  
 ERS WEBINAR ON CTEPH  
 Gergely attended this webinar as previous task force  
 member of the ERS Statement on CTEPH

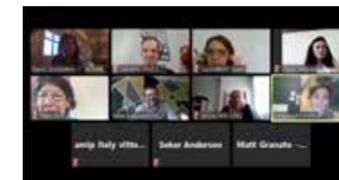


**Virtual (online) • March 19**  
 ERN-LUNG EPAG MEETING  
 Gergely represented PHA Europe on this meeting



**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



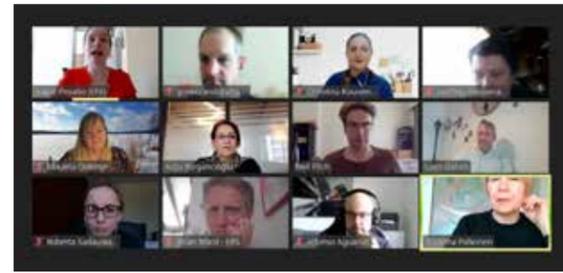
**Virtual (online) • April 20**  
 ELF PATIENT ADVISORY  
 COMMITTEE (PAC) MEETING  
 Gergely represented PHA Europe  
 on this meeting



**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

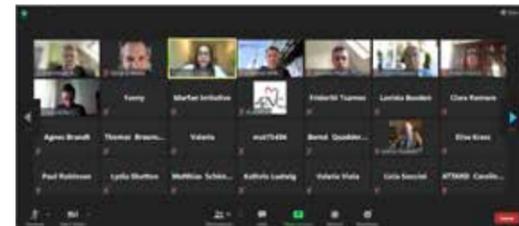
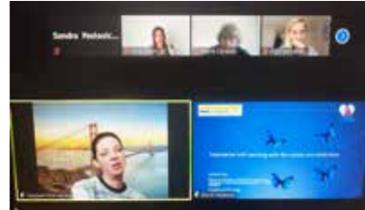


**Virtual (online) • May 11**

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

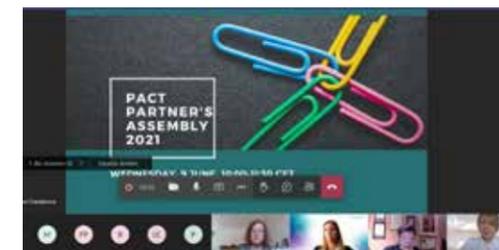


**Virtual (online) • June 3-4**

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)



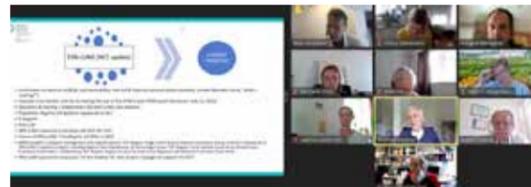
**Virtual (online) • June 18**  
 UNMEET NEEDS & CHALLENGES IN ACCESS TO TREATMENT IN EUROPE: THE CASE OF CHRONIC KIDNEY DISEASE  
 Gergely attended this political event

**Virtual (online) • June 21**  
 WEBINAR OF THE INTERNATIONAL PH COMMUNITY  
 Gergely represented PHA Europe on this event hosted by PHA USA



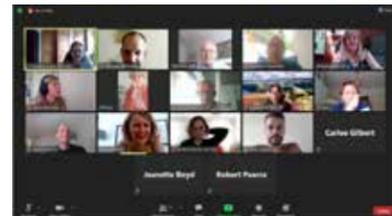
**Virtual (online) • June 22**  
 ERS VIRTUAL CONGRESS UPDATE  
 Gergely attended this briefing to have better understanding of the upcoming congress

**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



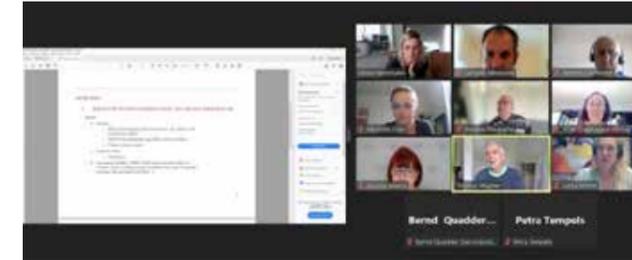
**Virtual (online) • August 23**  
 ELF FACILITATORS BRIEFING  
 Gergely attended this briefing to prepare for the patient associations' day

**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) • August 29 - September 1**  
 EUROPEAN SOCIETY FOR ORGAN TRANSPLANTATION (ESOT) CONGRESS  
 Natalia and Gergely represented PHA Europe on this congress



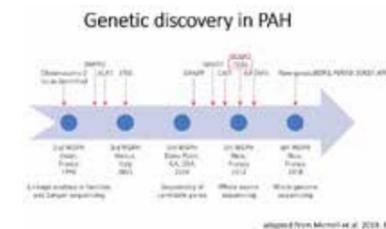
**Virtual (online) • August 30**  
 ERN-LUNG EPAG MEETING  
 Natalia and Gergely represented PHA Europe on this meeting

**Virtual (online) • September 2**  
 ELF PATIENT ORGANIZATIONS' DAY  
 Gergely attended this meeting and also helped as facilitator



**Virtual (online) • September 3**  
 PHA EUROPE BOARD AND STAFF MEETING

**Virtual (online) • September 5-8**  
 EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS  
 Gergely participated in this conference on behalf of PHA Europe



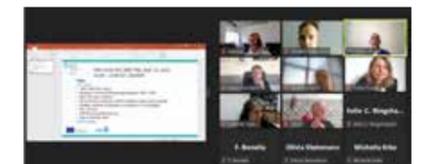
**Virtual (online) • September 13**  
 PVRI WEBINAR: TBX4, DEVELOPMENTAL LUNG DISEASE, AND PULMONARY HYPERTENSION  
 Gergely attended this webinar

**Virtual (online) • September 13-16**  
 71ST SESSION OF THE WHO REGIONAL COMMITTEE FOR EUROPE  
 Gergely attended this political event as part of the EFA delegation



**Virtual (online) • September 15**  
 PVRI PATIENT ENGAGEMENT & EMPOWERMENT WORKSTREAM MEETING  
 Gergely is co-chairing this initiative of Pulmonary Vascular Research Institute (PVRI)

**Virtual (online) • September 22**  
 ERN LUNG MEDICAL STEERING COMMITTEE (MSC) MEETING  
 Gergely attended this meeting as the member of the MSC

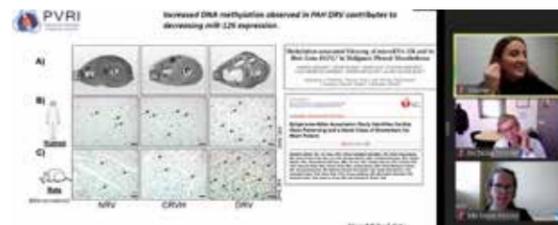




**Virtual (online) • September 22**  
 LAUNCH EVENT OF THE WHO 2021 AIR QUALITY GUIDELINES  
 Gergely participated in this political event

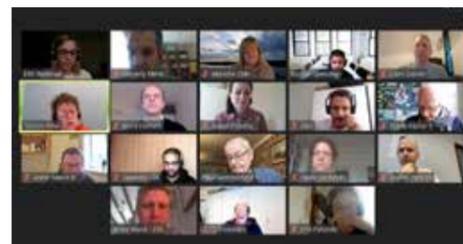


**Virtual (online) • September 27**  
 PACT-EPF WEBINAR: MODEL ACCESS SOLUTIONS  
 Gergely attended this meeting



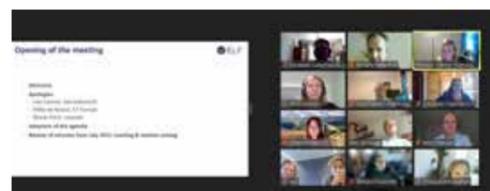
**Virtual (online) • September 29**  
 BEYOND DNA: THE UNSEEN GENOME AND NOVEL OMICS APPROACHES TO PH  
 Gergely attended this webinar organized by PVRI

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

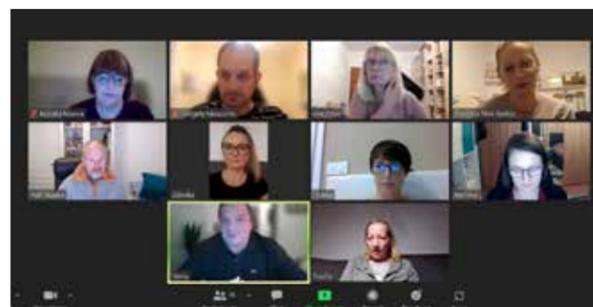


**Virtual (online) • October 18**  
 EUROPEAN LUNG HEALTH GROUP (ELHG) MEETING ON BREATHE VISION 2030  
 Gergely participated in this event

**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



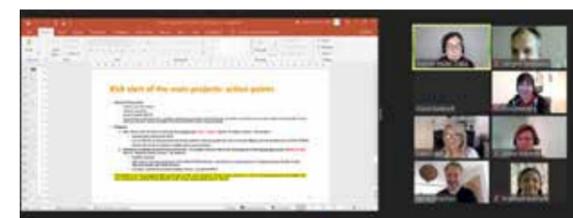
**Virtual (online) • November 18**  
 ERN-LUNG EPAG MEETING  
 Natalia and Gergely represented PHA Europe on this meeting

**Virtual (online) • November 19**  
 LIVING WITH PAH PANEL DISCUSSION ORGANIZED BY JANSSEN  
 Danijela attended this meeting on behalf of PHA Europe



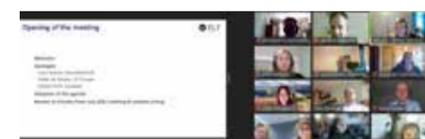
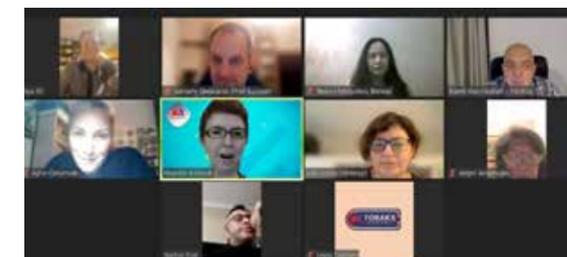
**Virtual (online) • November 19**  
 FIRST VIRTUAL FORUM OF THE LATIN-AMERICAN PH COALITION  
 Gergely attended this meeting as a panelist

**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)



## UPCOMING EVENTS 2022

Online • 8 February

### EURORDIS BLACK PEARL AWARDS

Annual fundraising gala meeting of EURORDIS around Rare Disease Day.

Frankfurt, Germany • 23 February

### ERN-LUNG BOARD MEETING

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

Online • 1- 2 March

### ANNUAL PULMONARY HYPERTENSION EUROPEAN CONFERENCE /APHEC/

The biggest annual gathering of European PH associations' leaders.

Brussels, Belgium • 23 April

### EUROPEAN PATIENT FORUM ANNUAL GENERAL MEETING

Berlin, Germany • 15 -18 May

### ESOT INTERNATIONAL TRANSPLANT SCIENCE (ITS) MEETING

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

Online • June

### EURORDIS GENERAL ASSEMBLY

Athens, Greece • 22 - 26 June

### 15TH PVRI ANNUAL WORLD CONGRESS ON PULMONARY HYPERTENSION

Online • 27 June - 1 July

### EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS

Barcelona, Spain • 26 - 29 August

### EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS

Barcelona, Spain • 4 - 6 September

### EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS CONGRESS 2022

Amsterdam, Netherlands • 25 - 28 August, 2023

### ESC CONGRESS

Stockholm, Sweden • 2023

### EURORDIS MEMBERSHIP MEETING

Milan, Italy • 9-13 September, 2023

### ERS CONGRESS

Athens, Greece • 17-20 September, 2023

### ESOT CONGRESS

2023

### ICC (INTERNATIONAL CTEPH CONFERENCE)

London, United Kingdom • 30 August - 2 September, 2024

### ESC CONGRESS

2024 February

### 7TH WORLD SYMPOSIUM ON PULMONARY HYPERTENSION

## ANNUAL PH EUROPEAN CONFERENCE

Hall Skaara



was easily recognizable 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 center and made an exhibition area, where all national associations were given a booth. Here they could write a description about their association, upload videos and documents that could be downloaded by all participants.

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

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.



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 theater room in the virtual conference area and the participants could ask additional questions to the presenter via the moderator. A large portion of the PHA Europe's national associations took part in the very interesting Q&A sessions and seemed to enjoy the state of the art virtual setup.

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 2020 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. It will be interesting to see if we can finally meet again in Barcelona in 2021 or if we need to copy the virtual event also this year. We hope to be able to meet, but if not, we know we have a good alternative in store. Our virtual APHEC 2020 was a solid proof of that!



## REPORT ON THE VIRTUAL ERS PRESIDENTIAL SUMMIT

Gergely Meszaros



The ERS Presidential Summit was held virtually in the first week of June and covered the topic of digital health.

Prof. Anita Simonds, ERS president outlined:

*"I chose digital respiratory medicine as it affects all team members and patients across the whole range of respiratory medicine. It can improve care, but in other areas it has been introduced with little formal evaluation – a situation which would never apply with any other medical interventions. During the COVID-19 pandemic, there has been a rapid increase in digital care delivery, to a large extent out of necessity. Patients have been seen by virtual consultations and there has been a marked increase in telemonitoring to reduce infection risks. There has also been an increase in use of big data and artificial intelligence to improve diagnostics and improve management algorithms. Our aim in the Summit is to assess what works, what is realistic for current practice, and what is futuristic and requires further evaluation."*

Prof. Thierry Throosters, past ERS president pointed out the aspects of patient care and provided a nice idea that healthcare systems should work as Lego blocks, ie. interoperability is a must and the only way which might bring in real changes in the healthcare systems.

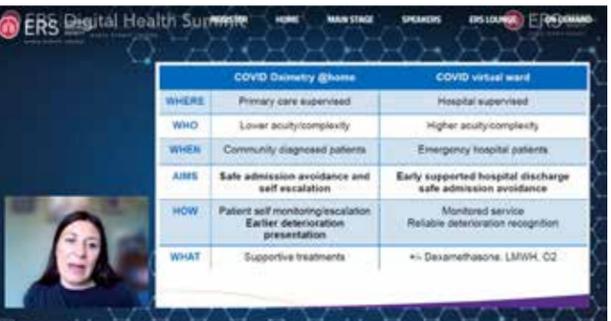
The program continued with a session held by the representative of ESC and a lot could be learnt about best practices. It is also good news that FDA (US Food

and Drug Administration) has cleared a huge amount of machine learning products for cardiology most recently. More and more wearables are used in the general public and also by patients, however a clear distinction needs to be made between medical devices and such publicly available "gadgets". Sport related research and such "gadgets" are important factors and contribute to digitalization, but to generate reliable, comparable and medically assessable data, requirements of the EU medical devices directive are to be met. Naturally, there are challenges to be addressed regarding these wearable products, but the first steps are definitely made to pave the way for e-health.

Couple of sessions with country-specific examples were devoted to tele medication, how patients were tracked and treated remotely (data show that adherence to medication and treatments were better) during COVID-19. However, the most interesting and promising lectures were about artificial intelligence (AI). AI is still challenged by having an "in the box" view, which means that decisions are made in a black box

and you can only see the input and the result. There are some ways how these challenges can be mitigated, but would you rely on the decision of a black box. ... or would you rather trust in the decision of a pigeon? – a survey revealed that pigeons can identify some types of tumors from X-ray images.

A lot to do on this field, but it became clear that acceleration to digitalization, more reliance on AI is the undisputable proceeds of the COVID pandemic.



## REPORT ON THE VIRTUAL ESC ANNUAL CONGRESS

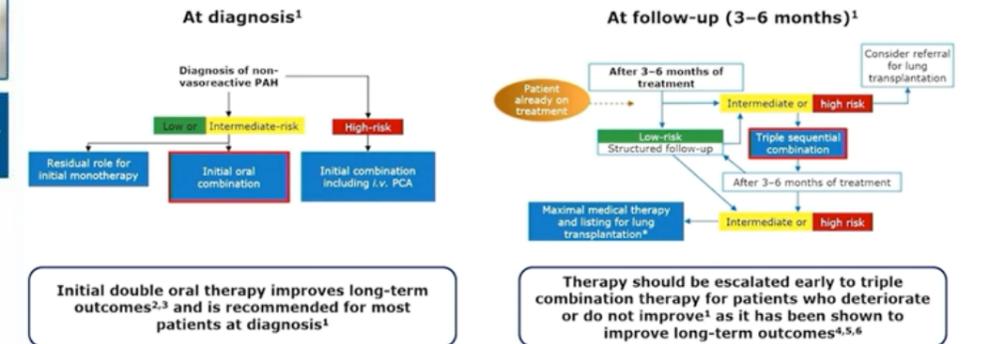
Gergely Meszaros

### Improving long-term outcomes in PAH: Time matters!

CO-CHAIRS | Olivier Sitbon | Paris-Saclay University, Le Kremlin-Bicêtre, France  
Jean-Luc Vachiéry | Erasme University Hospital, Brussels, Belgium



#### A timely treatment plan is recommended to optimise long-term outcomes for PAH patients



PHH: endothelin receptor antagonist; i.v.: intravenous; PAH: pulmonary arterial hypertension; PCA: prostacyclin analogue; PDE-5: phosphodiesterase type 5 inhibitor.  
1. Figure adapted from Galie N, et al. Eur Respir J 2015; 53:1801889; 2. Sitbon O, et al. Eur Respir J 2016; 54:2006673; 3. Galie N, et al. Presented at ESC 2016; 4. Coghlan JG, et al. Am J Cardiol 2016; 118:121-123; 5. Sitbon O, et al. Eur Respir J 2017; 50:1700740; 6. Sitbon O, et al. Eur Respir J 2017; 50:1700689.



With the last days of the summer and the commence of the autumn many congresses and meetings took place. The ESC congress overlapped with the hybrid bi-annual congress of ESOT (The European Society for Organ Donation), where one the most important topics was the ways of collaboration between the patient community and the medical professionals.

### Improving long-term outcomes in PAH: Time matters!



The annual congress of the European Society of Cardiologists (ESC) was organized between 27th and 30 of August and held virtually. Luckily, PHA Europe became part of the ESC patient forum, which provided us with the opportunity to attend some of the sessions. Many sessions were running simultaneously on the robust virtual platform, thus this article is not intended to fully cover all the lectures, but only highlight some of them which might be interesting from patient perspective.

Prof. Olivier Sitbon (France) and Prof. Jean-Luc Vachiery (Belgium) chaired an interesting session of "Improving long-term outcomes in PAH: Time matters!" sponsored by Janssen. We learned that there has been a clear shift in the focus of the clinical trials: previously short-term functional improvements (eg. 6MWT) were the primary endpoints, however in the Grifphon, Ambition, Seraphin studies long term morbidity and mortality became the clinically meaningful endpoints.

In another session comparison was made and the effect and benefits of the initial and sequential (double/triple) combination (oral vs. intravenous) therapies were presented; however, it was pointed out by Prof. Galie that in real life we are very far from the optimal situation. Despite the recommendation (underpinned by strong data and many trials with high number of patients) which proposes 60-70% of the patients to be on double oral therapy, the real-life data shows that only 10-20% of the patients receive this combination of medications.

On the very same day a mixed session was organized which has some relations to pulmonary hypertension. The most interesting was about pregnancy and heart: there is an ESC guideline on the management of cardiovascular diseases during pregnancy and the ESC/ERS PH guidelines is also dealing with this delicate and very important topic. It has never been challenged that pregnancy means a high risk for cardiovascular disease patients, however the question nowadays is whether a safe pregnancy and delivery is possible for a low-risk patient.

A complicated case study was provided in another session co-chaired by Stephan Rosenkranz (Germany). Michele D'Alto (Italy) emphasized the importance of risk stratification, achieving a low risk profile and referred to studies about combination therapies.

The early risers were witness of an unusual poster session from 7.15 AM (!) on Monday morning. A special committee selected the most relevant posters and the authors had the chance to introduce the background and the main findings.

Two posters were dealing with non-invasive prediction and stratification methods, another poster was covering data analysis of 20 years of pediatric care and the last one presented the Treprostinil inhalation powder study. Many materials were accessible and available online for the participants which supplemented the live sessions.

"Guidelines in Practice: management of atrial septal defect with pulmonary hypertension"

**History**

- A 62-year-old hypertensive female
- Presented with dyspnea, palpitations and fatigue for the past 6 months.
- Examination
  - Overweight (BMI 33)
  - BP 155/90
  - AF 300/min
  - Mildly accentuated P2, S2 with murmur lower left sternal border

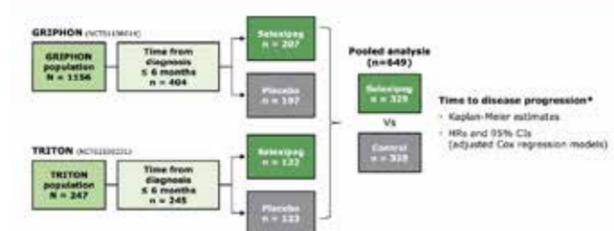
Treatment effect of selexipag on time to disease progression when initiated early in pulmonary arterial hypertension patients: GRIPHON and TRITON pooled analysis

Griffiths RP, Galie S, Chessa R, Chin KM, de Souza C, Gibbs JB, Hoeper MJ, Long SM, Richter H, Sitomirski W, Sitomirski L, Sitomirski G, Sitomirski J, Sitomirski K, Sitomirski L, Sitomirski M, Sitomirski N, Sitomirski O, Sitomirski P, Sitomirski Q, Sitomirski R, Sitomirski S, Sitomirski T, Sitomirski U, Sitomirski V, Sitomirski W, Sitomirski X, Sitomirski Y, Sitomirski Z, Sitomirski AA, Sitomirski AB, Sitomirski AC, Sitomirski AD, Sitomirski AE, Sitomirski AF, Sitomirski AG, Sitomirski AH, Sitomirski AI, Sitomirski AJ, Sitomirski AK, Sitomirski AL, Sitomirski AM, Sitomirski AN, Sitomirski AO, Sitomirski AP, Sitomirski AQ, Sitomirski AR, Sitomirski AS, Sitomirski AT, Sitomirski AU, Sitomirski AV, Sitomirski AW, Sitomirski AX, Sitomirski AY, Sitomirski AZ, Sitomirski BA, Sitomirski BB, Sitomirski BC, Sitomirski BD, Sitomirski BE, Sitomirski BF, Sitomirski BG, Sitomirski BH, Sitomirski BI, Sitomirski BJ, Sitomirski BK, Sitomirski BL, Sitomirski BM, Sitomirski BN, Sitomirski BO, Sitomirski 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Background and purpose

- In PAH clinical practice, drugs targeting the prostacyclin pathway, including the oral prostacyclin receptor agonist selexipag, are often initiated years after diagnosis<sup>1,2</sup>
- In a post-hoc analysis from GRIPHON (N=404), selexipag treatment within 6 months of diagnosis reduced the risk of disease progression by 55% compared with placebo<sup>3</sup>
- In TRITON (N=247), triple therapy (selexipag, macitentan, tadalafil) in newly diagnosed patients reduced the risk of disease progression by 41% compared with double therapy (placebo, macitentan, tadalafil) (exploratory analysis)<sup>4</sup>
- Here we investigate the impact of initiating selexipag within 6 months of diagnosis on disease progression in a large PAH population of pooled GRIPHON and TRITON patients

Methods: Post-hoc analysis of pooled TRITON and GRIPHON data



Baseline patient characteristics

	Selexipag (N = 329)	Control (N = 320)	Selexipag (N = 329)	Control (N = 320)
Female sex - n (%)	256 (77.8)	249 (77.8)	84 (25.5)	82 (25.6)
Time since PAH diagnosis - median (Q1, Q3) months	0.8 (0.4, 2.7)	0.8 (0.3, 2.2)	245 (74.5)	238 (74.4)
Age - median (Q1, Q3) years	48.0 (35.0, 59.0)	48.0 (34.0, 60.0)	141 (42.9)	123 (38.4)
PAH aetiology - n (%)			188 (57.1)	197 (61.6)
Idiopathic PAH	158 (48.0)	174 (54.4)	365.0 (281.0, 409.0)	360.0 (273.0, 408.0)
Connective tissue disease	109 (33.1)	102 (31.9)	254 (77.2)	238 (74.4)
Congenital heart disease	26 (7.9)	24 (7.5)	23 (6.4)	21 (6.6)
HIV infection	5 (1.5)	5 (1.6)	88 (26.7)	77 (24.1)
Drug- or toxin-induced	18 (5.5)	7 (2.2)	145 (44.1)	140 (43.8)
Other	13 (4.0)	8 (2.5)		
Geographical region - n (%)				
North America			84 (25.5)	82 (25.6)
Rest of the world			245 (74.5)	238 (74.4)
WHO FC - n (%)				
I - II			141 (42.9)	123 (38.4)
III - IV			188 (57.1)	197 (61.6)
6MWD - median (Q3, Q3) m			365.0 (281.0, 409.0)	360.0 (273.0, 408.0)
Other PAH therapy <sup>a</sup> - n (%)			254 (77.2)	238 (74.4)
ERA			23 (6.4)	21 (6.6)
PHCS			88 (26.7)	77 (24.1)
ERA+PHCS			145 (44.1)	140 (43.8)

Conclusions

- Initiation of selexipag within 6 months of diagnosis as part of triple or double combination therapy or as monotherapy reduced the risk of disease progression by 52% (HR 0.48; 95% CI 0.35, 0.66) in a large cohort of PAH patients from GRIPHON and TRITON
- This highlights the benefits of early use of selexipag in delaying disease progression in PAH and supports the principle of early escalation of therapy targeting the PGI<sub>2</sub> pathway, consistent with current treatment recommendations<sup>1</sup>

Guidelines in Practice: management of atrial septal defect with pulmonary hypertension

REPORT ON THE ESOT CONGRESS

Natalia Maeva

**Physical activity**  
Any bodily movement produced by skeletal muscles that results in energy expenditure.  
Including: movement performed during leisure time, at work, day to day activities, ...

Intensity Frequency Time/duration Type

WHO 2020 physical activity recommendations in adults with chronic conditions

**Aerobic activities**

- ≥ 2.5 h/week @ moderate intensity, or
- ≥ 75 min/week @ high intensity, or
- Equivalent combination of both

**Muscle-strengthening activities**

- ≥ 2x per week

**Multicomponent activities:**  
= Aerobic/strength activities which include balance training

- ≥ 3x per week

Exercise training after transplantation

**Increases:**

- Cardiorespiratory fitness (VO<sub>2peak</sub>)
- Muscle strength
- Health-related quality of life

More data required on optimal mode of implementation

- Growing direct evidence in Tx recipients
- Overwhelming indirect evidence in other populations
- Undisputable, pleiotropic health benefits from physical activity & exercise
- It is one thing to know about its benefits, another to implement it in daily life
- Prehabilitation and rehabilitation to increase ability for activity → standard treatment of care
- Physical activity interventions aiming for long term behavior change:
  - Intervention development with input from all stakeholders
  - Individualized
  - Identification of barriers and facilitators
  - Co-development of intervention (patient and health care professionals)
  - Behavior change techniques (i.e., motivational interviewing)
  - SMART goal setting
  - Self-monitoring of physical activity behavior (i.e., physical activity trackers)
  - Follow-up prompts (gradually decreasing over time)

The ESOT (*The European Society for Organ Transplantation*) Congress took place in Milano from the 29th of August to 1st of September, 2021 and the organizers made available the online access to the sessions.

The hybrid event really provided world-class science, from revolutionary abstract presentations to Think Tank sessions full of debate and discussion in various areas of transplantology.

The most interesting part of the congress for the patient was the ESOT-ETPO alliance Online Symposium. It was held on the 28th with the title of „When every small step is a step forward. Being physically active after solid organ transplantation.“ This session was very well attended by patients and patient representatives.

The main message was that physical activity is a crucial lifestyle component of long-term health management for people with organ transplants.

The following questions were discussed during the event: „What do we know about the physical activity after solid organ transplantation? What is the patient experience with physical activities?“ The symposium addressed these questions with an expert panel of speakers, including physical therapists and recipients of transplants while providing accessible information and practical advice. Every transplanted patient knows very well that exercise not only changes your body, but it changes your mind, your attitude and your mood.

We were also witness of extraordinary sport achievement of transplanted patients: among others the Billion Steps Challenge project of the World Transplant Games Federation was promoted.

The results of two surveys were presented during the symposium and the action points derived therefrom. One of the surveys was dealing with the main concerns of the patients (330 responses were collected from 27 countries) and a Transplantation Learning Journey (TLJ) 2.0 was launched with the aim of establishing a platform for learning and collaboration.

Other promising initiatives were also presented as the Ambassador program, the Patient Inclusion Initiative (Hesperis course) and the EPITA Symposium. PHA Europe was represented by Natalia Maeva, Board member and Gergely Meszaros, staff member.

The mission of the ESOT-ETPO alliance is to promote realistic medicine in organ donation and transplantation. The alliance aims to achieve this by empowering people with transplants, encouraging and facilitating a meaningful dialogue between patients, organ donors and their families, caregivers and transplant professionals to ensure that their views and experiences are represented.

During the previous meeting of the ESOT-ETPO Alliance Advisory Board, which took place in 2019 in Copenhagen, 17 patient organizations / societies from 13 countries were represented. This time in Milan the number of participants increased to 24 patient organizations / societies from 19 countries participating in 3 ESOT Sections and Committees.

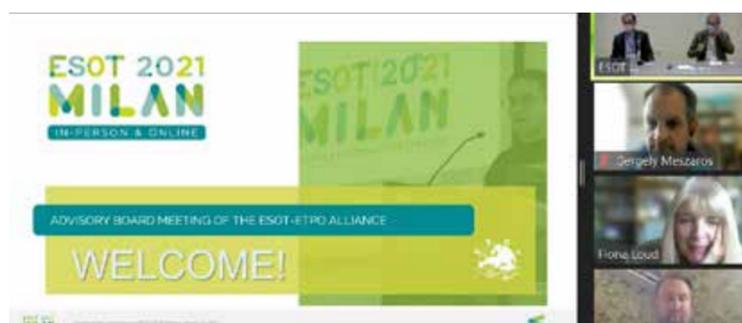
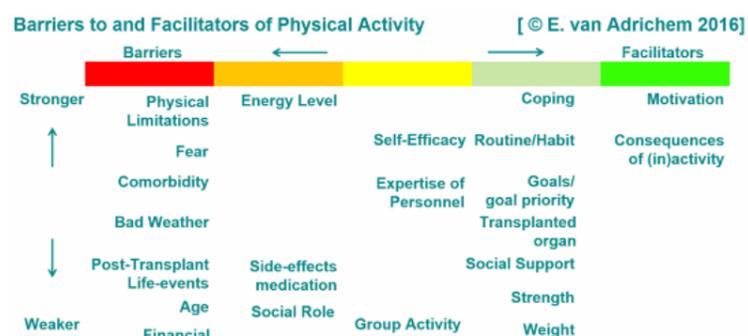
The journey in organ donation world does not stop because saying one "yes" 8 people can receive second chance for a new life.

**Proposal**

1. Establishing European Transplant Patient Organization (ETPO) Alliance
2. An online platform that will function as an online hub of the European patient organizations
3. Partnership with patient organizations promoting sport in transplant patients
4. Organization of workshops on communication with patients
5. Inclusion of patients and patient perspectives in all future ESOT events
6. Organization of the meeting of the European Transplant Patient Organization (ETPO) Alliance, to be held at the ESOT 2021 congress
7. Travel grants to support patient participation in ESOT events

**Take home message**

1. **Exercise training after transplantation**
  - Promote recovery in physical fitness: aerobic capacity, strength, balance
  - Promote self-efficacy
  - Prevent chronic comorbidities
  - Promote quality of life: physical and mental well-being + social connectedness
2. **Active living after transplantation**
  - Maintain health benefits of previous exercise training
  - Integrated in daily life
  - Adapted to personal needs, capacity, and preferences
3. **Every small improvement in physical activity counts**
4. **It is never too late to (re-) initiate physical activity in your life; start today!**



**fit for life**  
BILLION STEPS CHALLENGE

Proudly supported by **NOVARTIS**

**What: 2 Billion Steps**  
**When: 20th Sept – 28th Nov 2021**  
**Who: Everyone**  
**Why: To STEP your way 2 better health**  
Celebrate the Gift of Life  
Show your support for organ donation

**How: Download the MoveSpring App**  
Select WTGF21 as the Org Code  
Create or Join a team  
Sync device or add steps manually

**STEP your way 2 better health**  
10 weeks to reach 2 billion steps  
20th September – 28th November 2021

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**REPORT ON THE VIRTUAL ERS ANNUAL CONGRESS**

Gergely Meszaros

**ERS**

**Assembly Members' Meeting 2021**  
**Assembly 13: Pulmonary Vascular Diseases**  
Friday 27 Augustus 2021  
15:30 – 16:30 CET

**INTERNATIONAL CONGRESS 2020 virtual**

Due to the uncertainties of COVID, the biggest gathering of respiratory physicians, the annual congress of the European Respiratory Society (ERS) (Sept 5-8) was organized this year again virtually.

**1**

On one hand it is very practical, because ample of pre-congress materials were shared online and it was not a must to squeeze all the meetings into 3-4 days, however everybody is missing the face-to-face meetings and informal discussions.

Solely on the field of PH 27 pre-recorded presentations were available in different topics: we could learn about artificial intelligence (AI), a new app which might be used for home 6MWT, the link between pulmonary fibrosis and PH and many more. Two presentations were dedicated to the delicate issue of pregnancy and the recommendation of the guidelines – that PH patients should avoid becoming pregnant – was echoed, however reassuring



data was provided from Hannover covering 12 years.

**2**

More than one week prior to the Congress the ERS Assembly 13 (Pulmonary Vascular Diseases) held its annual meeting virtually - it is usually part of the ERS Congress. Prof. Marion Delcroix introduced the new chair Prof. Anton Vonk Noordegraaf from Amsterdam, NL and informed the audience about the slight decrease of the number of the members, abstracts and clinical cases. Awards were handed over virtually to Prof. Joanna Pepke-Zaba (Great Britian) and Prof. Gabor Kovacs (Austria).

Overview was given about upcoming funding and educational opportunities, ongoing clinical research collaborations (PEX-NET and PHAROS) and first preparatory steps were made to the next ERS Congress (2022 - Barcelona).

**3**

It became a routine that for patient advocates the ERS Congress

started with the patient organizations day organized by the European Lung Foundation.

The main theme was digital health: Prof. Anita Simonds, ERS president, summarized the main findings of the ERS Presidential Summit on digital health solutions. It was followed by the presentation of Pascal Lardier about the new and active roles of patient associations in the new digital world.

Before the lunch break patient organizations provided insight into some of their most recent initiatives like home spirometry, assistance provided during the COVID-19 pandemic.

The afternoon continued with break-out sessions, where PHA Europe was one of the facilitators and the day was closed by Prof. Marc Humbert, ERS President elect and Hans Kjeld, ELF president.

It was good to see that 3 e-posters were submitted from our community: one from BSPPH, Bulgaria, one from PHURDA, Ukraine and PHA Europe also submitted one – about PH Care Covid survey.

#### 4 • ERS Congress - Main part

Various lectures were presented about pulmonary embolism (PE) (which can be turned to CTEPH). One of the co-authors, Prof. Erik Klok (NL) presented the soon-available new PE guidelines.

Prof. Frances S. De Man (NL) tried to find the answer in her presentation whether right ventricle imaging can improve risk stratification. She compared various registries, assessment methods, including Reveal and the French approach, and they ran a survey with more than 400 patients involved. Unfortunately, the results

need validation from a bigger cohort of patients, so currently there is no answer.

Based on an original idea a session was held about the current classification of PH. Prof. David Montani (F) introduced those scientific criteria that the guidelines need to meet in general (eg. evidence based, widely disseminated, adaptive) and the ESC/ERS guidelines on PH meet these ones. The opposite part represented by Prof. Harm Jan Boogard (NL) challenged these statements: why initial triple combination therapy is given to cca. 5% of the patients, problematic phenotypes (elder and/or obese patients) within the same class, 60 (!) subgroups of PH and only 3 pathways.

On the last day various lectures were held: Prof. Laurent Savale highlighted that liver transplantation might be a possible treatment of portopulmonary hypertension (PoPH) patients, but more data is needed.

Prof. Harm Jan Boogard (NL) in his presentation outlined the clinical distinction between pre- and post capillary PH. Prof. Karen Olsson (Germany) talked about the lungs' diffusing capacity (DLCO) which is mildly reduced in iPAH.

Prof. David Kiely (GB) made one of the last presentations which covered the role of imaging in the diagnosis and follow-ups of PH - with special attention to the Fleischner Society position statement.

Attending the Congress was a great experience, but everybody hopes that next time the Congress will be held in a hybrid format, thus there will be a possibility of face-to-face meetings and discussions.



## REPORT ON INTERNATIONAL CTEPH CONFERENCE

Gergely Meszaros



The International CTEPH Association usually runs their congresses on a biannual basis, however due to the COVID pandemic it was postponed for couple of times.

Finally, there was a possibility of organizing a hybrid event from 10 to 11, December in Germany, however, due to compliance issues, we could not attend the event personally, but followed the event online.



All the key opinion leaders from the field of CTEPH were invited as speakers from Europe and beyond.

Following the opening remarks of Prof. Mayer, Prof. Simonneau helped the audience navigate amongst the various abbreviations, which earlier cleared by the ERS Statement: the general term is chronic thromboembolic pulmonary disease (CTEPD) which covers both CTEPH and chronic thromboembolic disease (CTED) – the later one is for patients without PH.

Prof. Klok from the Netherlands briefed the audience about the pulmonary embolism guidelines and outline the possible correlation between COVID and higher CTEPH incidence.

Prof. Toshner provided an overview on genetics: based on the results of recent studies CTEPH genetic architecture significantly shared with pulmonary embolism, but not with idiopathic PAH. As per the common understanding whole genome sequencing can define disease causing genes, but it is not the case in CTEPH.

Prof. Vonk Nordegraaf's presentation about right ventricular failure in CTEPH was followed by an overviewed of imaging techniques by an UK radiologist, Dr. Nick Screatton.

The rest of the first day was devoted to various treatment modalities: BPA (balloon pulmonary angioplasty) and PEA (pulmonary endarterectomy). An interesting question was raised by Prof. Madani in his presentation: *what constitutes distal disease?* However, it is thumb rule between BPA and PEA, it varies between clinicians and patients and there are also grey zone situations. Prof. Jenkins provided an insight into perioperative complications, while we could learn conclusions from French BPA data and the international CTEPH registry. The program was made diversified with symposia

### Flagship EU initiatives

- European Green Deal – aimed at making EU economy sustainable, restoring biodiversity and cutting pollution.
- Digital Health - the creation of a European Health Data Space to promote health-data exchange and support research
- ECDC and EMA – in relation to COVID-19 pandemic, reinforced mandates will be proposed
- Cross border health threats legislation will be revised
- New €95.5 billion Horizon Europe programme for research and innovation
- New €5.3 billion EU4Health EU health programme
- New Innovative Health Initiative (IHI) - a new public-private partnership (PPP) for health under Horizon Europe

### Remote consultations for acute care: Prof Pinnock

**Primary care**

- Fewer problems / consultations
- Less data gathering
- Less education/learning
- Less partnership building
- Less education going

**ACE centers**

These studies found the assessment of patient priorities and outcomes

### Comprehensive Approach to Wellbeing

- Four-Part Meditation Series
  - Introduction to mindfulness & meditation practice
- Four-Part Qi-Gong Series
  - Introduction to Qi-Gong practice
- Emotional and Mental Wellness Series
  - Monthly webinars led by experts
- SecSocials
  - Monthly virtual networking events

sponsored by pharmaceutical companies and with a day-closing the poster session chaired by Prof. Pepke-Zaba: altogether 54 posters were submitted and 4 of them were awarded.

The second day was kicked off by Prof. Ghofrani with a short overview of the CTEPH statement and possible medical therapies. Prof. Xais presented the RACE study in details focusing on medical therapy vs. BPA in case of non-operable patients. The main findings were that sequential combination of BPA and Riociguat was very effective; also once patients were treated with Riociguat prior to BPA – by optimizing the pulmonary haemodynamics – the safety of BPA also improved.

Prof. Wiedenroth covered multimodal interventions in

his presentation: BPA/PEA + medical therapy, medical combination therapy, hybrid PEA +BPA, BPA+PEA.

Prof. Lang ran a very interesting lecture about neutrophil extracellular traps (NET). Research is still in early phase, however these NETs promote fibrous vascular occlusions.

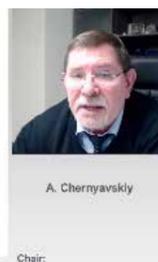
Prof. Hoepfer talked about the use of various types of anticoagulations and mapped the the potential pros and contras of their usage.

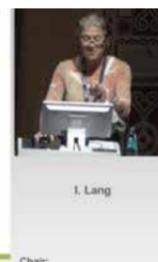
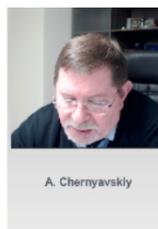
CTPEH is probably to mostly changing territory of PH. We cannot only see novelties on various interventions, but more and more data become available on medical therapies, imaging and genetics.




Pros	Cons
Safety and efficacy well established for the recurrence of DVT and VTE.	Uncertain efficacy and safety data in CTEPH
Available studies indicate reasonable safety in CTEPH	Insufficient efficacy in high-risk conditions, e.g., antiphospholipid syndrome
Convenience of use, no need for monitoring	Some studies indicate a higher risk of recurrent VTE with NOACs in patients with CTEPH
Few drug-drug interactions, no dietary restrictions	Uncertainties in patients with renal or hepatic impairment
Easy to handle during invasive procedures (BPA)	Lacks long-term experience in CTEPH than with VKA





## PROJECTS AND INITIATIVES 2021

Gergely Meszaros

The virtual roundtable consists of representatives from the health care professionals, non-governmental organizations and pharmaceutical companies. Our main idea was to make available the document on a shared drive which allows simultaneous work.

We organized a successful virtual kick-off meeting on the 11th of February and since than many email exchanges, drafting and editorial work was invested to make an up-to-date position paper.

The paper is almost ready for the final comments and we plan to launch the revised Call to Action in the European Parliament around World PH Day.

### ERN-Lung

ERN-Lung continues to be an important imitative PHA Europe is part of and plays an active role.

### Call to action

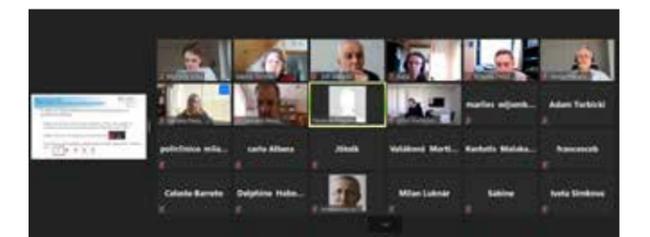
Back in 2011 PHA Europe initiated a roundtable discussion with the involvement of all of the stakeholders from the globe on the field of pulmonary hypertension, which resulted in the Call to Action on the unmet needs of Patients with Pulmonary Hypertension in 2012.

Nine years has elapsed since the launch of this paper in the European Parliament, so it was high time to:

- Look back and assess the achievements and revisit the call to action to map what is still ahead of us.
- Discuss which parts of the paper needs to be re-drafted in light of the political and scientific developments and.
- Agree which topics are in need of attention and so the allocation of effort and resources.

PHA Europe invited many stakeholders from various field to take part in the working group/virtual roundtable. The plan was to run two or three online meetings, with the opportunity to comment on and develop the updates to the document between times. This working group aimed at discussing the main ideas and to facilitate the drafting of the update to this Call to Action.

Early preparatory work has been made and some discussions conducted in 2020, but these were suspended due to COVID-19. Fortunately, in the meantime MEP Lung Health Group has been established <https://www.ersnet.org/advocacy/mep-lung-health-group> which can facilitate the organization of the launch event of the new paper in the European Parliament.



Welcome to the ERN-LUNG Annual Board Meeting 2021

- To make our Videoconference a success we kindly ask you to consider the following:
  - Make sure you don't have acoustic feedback (howl) in your system by avoiding microphone and speakers close or opposite to each other
  - Always mute your microphone, when just listening
  - If you want to ask a question: please use the function "raise hand" or the the chat

The board meeting of ERN-Lung was held on the 4th of March. It is usually a two-day event, but being not able to organize the face to face talks due to the COVID pandemic, it was squeezed to a one day tiring virtual meeting. As always it had a very busy agenda: the network coordination team, all the disease areas (core networks) and the functional committees presented their annual report. The report of the Network Coordination team was very detailed:

- Thanks to the new call by the European Commission a lot of new health care providers (HCP) joined the network and managed to cover almost the full



- We have tried BASECAMP
  - We have tried CN calls and FC calls
  - We have tried our Newsletter
- NOTHING compared to the motivation we all got from our board meetings
- We will offer a Membership area within our homepage
  - We will offer „What’s cooking?“
  - We will invite you to „Coffee rounds“
  - Your ideas welcome

European Union. The number of participants has grown despite the effect of BREXIT (UK service providers have been transformed to supporting partners). 12 new HCPs applied for membership to PH and 8 of them were approved.

- The advantages, challenges and current status of the various online platforms (CPMS, EXABO) were discussed - highlighting the ways how they could be better promoted.
- Considerable time was spent on registries: the ERN-Lung, the disease specific ones and the newly launched population registry. It also correlates with the PH related PHAROS project, which a Clinical Research Collaboration under the umbrella of ERS.
- There are lots of European-level calls which are open for ERNs and ERN-Lung was and is being active on this field: IT-Helpdesk and eSupport project was previously awarded and a European Joint Programme applications were submitted relating to cystic fibrosis and another one on behalf of PHA Europe.

The program continued with the PCD, nCF-BE and AATD (rare lung diseases) core networks' presentation. There was a big lesson-learned from the presentation of PCD: they mentioned their plan in their ERN-Lung report to apply for funding under a specific program, but they were excluded due to this because they breached secrecy rules. The nCF- bronchiectasis network presented their EMBARC project: the European Multicentre Bronchiectasis Audit and Research Collaboration, which might serve as an excellent example for PH. They were followed by Prof. Marc Humbert, who - this time - spoke as the president elect of ERS. He emphasized the importance of building a strong relationship between ERN-Lung and ERS and mentioned the common ERS-ERN-Lung symposia of last years. There is a plan to organize a common program this year again during the annual ERS congress.

Before the lunch break other rare lung diseases also reported on their yearly activity. It is always very interesting to listen and learn from cystic fibrosis, which is one of the best structured rare diseases. CF has more than 70 quality of life questionnaires and they have recently launched a multilanguage application to measure and record health-related quality of life. The application of „Q-life“ is available from the different app stores - it

is worth looking into it! The presentation of PH core network run by Prof. Marion Delcroix was persuasive. She talked about:

- the increasing number of health care providers in the PH core network
- the ERS CTEPH statement and task force we were part of
- the ESC/ERS Task Force was launched to revise the PH guidelines
- the two ongoing CRCs: the PEX-NET and the PHAROS
- COVID 19 in PH patients: a reference center survey. The results was published in the ERJ and the summary thereof was translated by PHA Europe member associations to various languages
- the PH-CARE-COVID patient survey, which was translated and disseminated by PHA Europe member associations. The manuscript of the survey was accepted for publication by <https://ojrd.biomedcentral.com>
- the survey initiated by Prof. Adam Torbicki about the impact of the new PH definition
- the MEP Lung Health Group event about PH organized by ERS and PHA Europe

After the lunch the functional committees ran their presentation and PHA Europe was a co-presenter with Prof. Simon Gibbs of the patient reported outcome (PRO) functional committee and had the chance to talk about the importance of recording the quantitative measures (QoL questionnaires) and the result of the mini survey PHA Europe ran last autumn about the PH related application - the later one was very well accepted. The communication and outreach committee was happy to report on the many updates of the webpage and the launch of the newsletter, but they also mentioned the challenges of promoting ERN-Lung.

**LETTER** Networking ERN-LUNG

**FUTURE OF ERN-LUNG : STRATEGY TASK FORCE TO BEGIN WORK**

We are now in Year 4 of the first five-year funding period of ERN-LUNG. We expect to see another call for the next funding period sometime next year and we should prepare for this. I would like to gather a small group of enthusiastic supporters of the idea of ERN-LUNG to build a strategic group (not a writing group). I have thought of involving some new people with a somewhat outside view and for sure, we should involve some young clinicians as well. We will certainly invite all Core Networks and all Functional Committees to be part of this group. So, if you would like to contribute actively to this process, please, get in touch with the Network Coordination Team. The group will mainly be working via videoconferences, but that has become our default anyway these days.

**Map of ERN-LUNG representation**

A time slot was ensured for providing the patient perspective. The Terms of Reference (the rules applicable to patient representatives) was introduced and PHA Europe was asked to present the patient journey project with special focus on how it has been used in PH. We called for further and stronger collaboration with our physician partners and emphasized the advantages of PRO questionnaires.

The meeting was closed with a nice outlook to the future and full of plans for the next 5 year period of ERN-Lung. A lot of meetings, including ones with the sole participation of patient representatives and others with the involvement of healthcare professionals were held during the year and aimed to make rare lung disease patients' life better.

### ERS Vision Live: Living with rare respiratory diseases through the COVID-19 pandemic

The European Respiratory Society (ERS) works with leaders in respiratory education to assess training and development needs and identify appropriate teaching and learning methods. As a result of this work "ERS Vision Live" series have been launched with the aim of covering the latest advances in respiratory medicine and support health professionals to continually improve their practice.



The second event of these live panel discussions was broadcasted on the 23rd of March, 2021 and focused on the experiences and learnings of specialists and patients in the fields of IPF, pulmonary hypertension, cystic fibrosis and bronchiectasis since the emergence of COVID-19. PHA Europe as a patient organization was invited to this panel.

- The discussion areas include the following topics:
- How the pandemic has affected follow-up and highly specialised care; a patient's perspective.
  - The results of a survey on French cystic fibrosis patients with COVID-19.
  - Recent events in non-cystic fibrosis bronchiectasis.
  - The severity and outcomes of COVID-19 in patients with IPF.
  - The impact of COVID-19 infection in patients with rare forms of pulmonary hypertension.

*„The COVID-19 has changed everyone's life and surveys with the involvement of PHA Europe aimed to map how the pandemic has affected a vulnerable group of patients, those who are living with pulmonary hypertension. It is a privilege to represent the patients' voice in this interesting talk and to give insight how the healthcare systems coped with and patients handled these unprecedented times.“*

Gergely Meszaros

### COVID /PHCARE-COVID/ patient survey

Extensive work was invested to launch and manage this project in 2020, which was a real collaboration with many stakeholders: we worked closely together with many patient organization in translating and disseminating the questionnaire, with our physician partners in structuring the questions and validating

**PH Care COVID Survey: An International Patient Survey on the Care for Pulmonary Hypertension Patients during the Early Phase of the COVID-19 Pandemic**

Laurent Godina<sup>1,2</sup>, Keerthana Iyer<sup>3,4,5</sup>, Gergely Meszaros<sup>6</sup>, Marion Delcroix<sup>1,2</sup>

1. Clinical Department of Respiratory Diseases, University of Medicine and Pharmacy of Bucharest, Bucharest, Romania; 2. Department of Clinical Strategy & Innovation (CDS&I), All-Source, University of Groningen, Groningen, The Netherlands; 3. ERS Task Force for Rare Lung Diseases, 4. ERS Task Force on COVID-19, 5. ERS Task Force on Pulmonary Hypertension, 6. PHA Europe

Acknowledgments: This survey was supported by PHA Europe, the European Reference Network for rare lung diseases (ERN-LUNG), the European Respiratory Society (ERS) Assembly, the ERS Clinical Research Collaboration PHAROS, the European Lung Foundation (ELF) and the European Society of Cardiology (ESC) Working Group on Pulmonary Circulation & Right Ventricular Function.

**Background and Patient survey**

SARS-CoV-2 may be particularly dangerous for PH patients due to risk of pulmonary embolism and pulmonary vasculitis. Cancellation of non-urgent care for patients with chronic diseases was frequent during the pandemic.

We designed an international patient survey in the early phase of the COVID-19 pandemic to evaluate:

- How PH patients were affected by the COVID-19,
- How was the evolution of PH during lockdown
- What was the impact of COVID-19 on PH patients care\*

by using an online questionnaire open from 22/5/2020 to 28/6/2020 translated in 16 languages.

We received 1073 answers from 52 countries (mainly in Europe), 96% were adult patients and 4% paediatric patients). 92% of the patients reported a diagnosis of PAH or CTEPH. Most of the patients (87%) received oral therapy and 21% received parenteral therapy.

**Figure 1. Geographical distribution of the participants.**

**Main results**

Only 13 patients (1%) reported hospitalization for COVID-19, of which 2 patients reported hospitalization in intensive care units. No death was reported. 4% were hospitalized due to their PH condition (from whom 14% hospitalized in ICU).

14% of the patients experienced deterioration of their health status.

**Figure 2. Health status evolution of PH patients during the early phase of the pandemic.**

**Figure 3. Reported causes of health deterioration. Health problems related to PH were far more frequent than due to COVID.**

**Figure 4. Feelings of the patients concerning evolution of their health status**

**Main results**

**Continuity of care assessment by patients**

Difficulty to join the PH treating team	11%
Difficulty to join other health professionals	9%
Difficulty to receive PH specific medications	16%
Cancellation of medical appointments	49%
Cancellation of appointments without rescheduling or other instructions	13%
Treatment interruption due to shortage of medications	3%
Interruption of IV medication due to shortage	0.2%

Remote consultations were frequent during the early phase of the pandemic. Only 12% reported face-to-face contact with their PH team and 81% remotely. Main sources of information for patients was the internet and PH patient associations.

**Figure 5. Consultation methods during the early phase of the pandemic.**

**Figure 6. Main sources of information concerning PH health status and COVID-19.**

**Conclusions**

During the early phase of the pandemic, PH related problems were 4 time more common than COVID-19 related problems. PH patients experienced health deterioration, mood disorders, difficulties to join their PH team, interruption of care and shortage of vital medications. Remote consultations were used to maintain contact with patients. Patients associations could play an important role to spread reliable medical information. These data could be of interest for further planning of strategies and organization of PH centres to ensure continuity of care and adequate communications with patients.

the translations and ERN-Lung provided useful administrative and data- assessment support.

Thanks to this collaboration more than 1000 responses were collected from all over the world and based on the results a manuscript was submitted.

Following several rounds of discussion, the article was published in Orphanet Journal of Rare Diseases and available at: <http://lnnk.in/hfc8>

The work has not been stopped with the publication as a poster was made <http://lnnk.in/hhc4> about the main findings and promoted during the Patient Organization Networking Day organized by the European Lung Foundation.

**RESEARCH** **Open Access**

### PH CARE COVID survey: an international patient survey on the care for pulmonary hypertension patients during the early phase of the COVID-19 pandemic

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**Abstract**  
**Background:** During the COVID-19 pandemic, most of the health care systems suspended their non-urgent activities. This included the cancellation of consultations for patients with rare diseases, such as severe pulmonary hypertension (PH), resulting in potential medication shortage and loss of follow-up. Thus, the aim of the study was to evaluate PH patient health status evolution, access to health care and mental health experience during the early phase of the pandemic.  
**Methods:** We conducted an online patient survey, available in 16 languages, between 22/05/2020 and 28/06/2020. The survey included questions corresponding to demographic, COVID-19 and PH related information.  
**Results:** 1073 patients (or relatives, 27%) from 52 countries all over the world participated in the survey. Seventy-seven percent (77%) of responders reported a diagnosis of pulmonary arterial hypertension and 15% of chronic thromboembolic PH. The COVID-19 related events were few: only 1% of all responders reported a diagnosis of COVID-19. However, 8% of patients reported health deterioration possibly related to PH, and 4% hospitalization for PH. Besides, 11% of the patients reported difficulties to access their PH expert centre, and 3% interruption of treatment due to shortage of medication. Anxiety or depression was reported by 67% of the participants.  
**Conclusion:** Although COVID-19 incidence in PH patients was low, PH related problems occurred frequently as the pandemic progressed, including difficulties to have access to specialized care. The importance of primary health care was emphasized. Further studies are needed to evaluate the long-term consequences of COVID-related PH care disruption.  
**Keywords:** Pulmonary hypertension, COVID-19, Patient survey, Pulmonary arterial hypertension, Chronic thromboembolic pulmonary hypertension

**Introduction**  
 SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) emerged in China at the end of 2019 causing coronavirus disease 2019 (COVID-19). The outbreak rapidly spread around the world and on the 11th of

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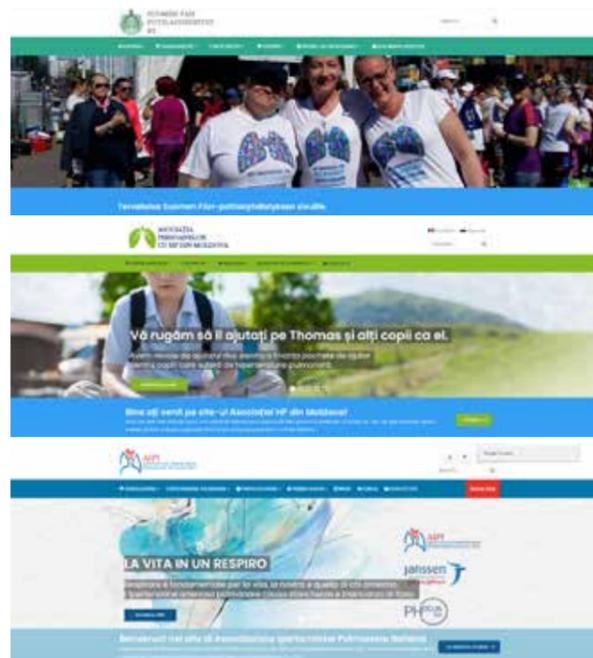
### Capacity Building Program (CBP) *Hall Skaara*

The Capacity Building Program (CBP) is a continuation of our White Spot Program (WSP). In the WSP, we help to establish an association in a country. In the CBP, we help associations to mature.

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 made 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 covid, etc.

### Breathe Vision

The Breathe Vision position paper was the result of a very fruitful collaboration of respiratory patient groups and health care professionals. However, the paper was finalized in 2020, the official MEP Lung Health Group event 'Towards a European Health Union – BREATHE Vision for the future', took place virtually on 27 January, 2021.

The paper aimed to increase awareness of respiratory health, improve lung health care and research, and tackle COVID-19 and its long-term impacts in Europe.

MEPs István Ujhelyi and Željana Zovko; European Commission DG Sante Deputy Director-General, Pierre Delsaux; and Coordinator of the WHO European Office for Noncommunicable Diseases, Jill Farrington opened the meeting and introduced general presentations from European Federation of Allergy and Airways Diseases Patients' Associations (EFA) President, Mikaela Odemyr and ERS Past President, Thierry Troosters.

These sessions were followed by an interactive virtual roundtable with discussion by patient groups focusing on the key aims of the paper, and a Q&A session with the audience.

PHA Europe was asked to present the importance of raising awareness of respiratory diseases, more specifically of rare diseases. We were happy to introduce World PH Day and the results we managed to achieve in the past 9 years.

The meeting was closed by European Lung Foundation (ELF) Chair, Kjeld Hansen and MEP Željana Zovko.

You can learn more about this initiative at: <https://www.breathevision.eu/vision-2030>



### Awareness month

PHA Europe has been participating in the awareness raising campaign: November – PH awareness month for the second year in row. Despite challenging COVID situation in 2020 many activities were conducted to mark this month. In 2021 we focused on online activities

Three people with PH tell us how the condition hasn't stopped them achieving great things...



Todor: bicycle tours



Patrick: open water swimming



Danijela: running

and made available ready-to-use materials to be shared on various social media platforms. In order to ensure unified appearance and coordinated timing with our members, a social media timetable was elaborated and made available.

We would like to address and help the Spanish language PH community both in Europe and beyond, thus the materials were made both in English and Spanish. Naturally, upon request, we helped editing the visuals and provided local language versions. The main theme of the visuals was "Get the fact on PH". Our main audience target was the general public: with our informational cards we tried to navigate them between the terms and provided information about - among others - symptoms and treatment options which helps them to better understand this rare disease.

### O2Kids Campaign

Hall Skaara

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.



## SOCIAL MEDIA ACTIVITY 2021

Gergely Meszaros

### Many activities and great response on all social networks of PHA Europe

Since we have realized the importance of communicating through the social media, we pay more attention and invest 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.

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.

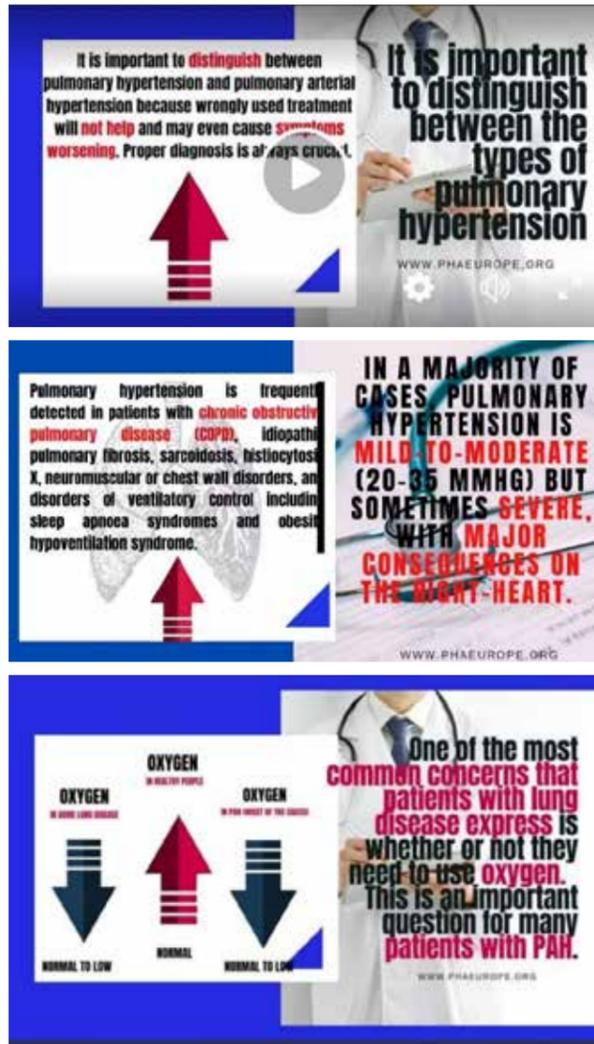
We also supported the Rare Diseases Day's message of "DARE TO BE RARE" with a large, colorful and joint campaign. It was heartwarming to see that almost all our members participated in this initiative.



During 2022, 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 more 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



# AUSTRIA



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!



We will keep up the momentum and build on what worked in the past. We also promise that you will meet new ideas and campaigns on our social networks in 2022!

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 is one of the favorite posts among our members.

Social media activities were important pillars of our two main projects: World PH Day and Awareness month. You could learn more about our World PH Day bi-lingual ready-to-use materials from the previous edition of the Mariposa journal.

The "Awareness month" campaign, run in November, 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.

These periodic campaigns were nicely underpinned with our standard campaign, the #GoodPHNews. It is an

## Initiative Lungenhochdruck

In 2021 we were able to implement numerous events and projects.

### Events for Members 2021

- 01/30 Virtual vaccination information event
- 06/30 Internal member meeting Vienna
- 07/07-09 PH information event Innsbruck
- 07/12 Internal member meeting Linz
- 08/27 PH information event Graz
- 09/09 PH information event Klagenfurt
- 09/16 PH information event Linz
- 11/20 Virtual PH information event Vienna

## COVID-19 vaccination information event

On January 30th, a virtual patient meeting took place with Prof. Löffler-Ragg about the COVID-19 vaccination. Many questions were answered and published in our newsletter. "The group of vulnerable people is better protected through testing and vaccination. Thus, the burden of disease can be reduced."



## Internal member meeting Vienna

The first small meeting after almost a year took place in Vienna on June 30th. The requirements were that only vaccinated people are allowed to join. In the wonderful garden of Cafe Diglas we enjoyed being together and of course our breakfast.



## PH information event Innsbruck

There was an interesting lecture about oxygen by Mr. Täubl, DGKP from the LKH Hochzirl – Natters and Prof. Dr. Löffler-Ragg from Innsbruck University Hospital told us news on the treatment goals for PH, but also went into the latest developments in diagnostics and therapy for PH. While eating, talking to each other, but also getting to know new members we recognized again how important meetings in person are.



## Internal member meeting Linz

During a good lunch there was a lot of interesting news to report. Eva brought up to date brochures and the latest information to our participants.



### Information event in Graz

The information event took place in Graz on August 27th, 2021. We welcomed 38 participants. Univ.-Prof. Dr. Horst Olschewski and Ass. -Prof. PD Dr. Gabor Kovacs, both MUG Graz, guided the meeting. In a question-and-answer session with the two PH specialists, the latest developments in diagnostics and therapy for PH were discussed, and participants also asked whether studies are planned for those affected in Austria. For our members it was extremely informative. One participant summed it up with these words: „It was an honour to be there, we went home richer than we came.”



### Information event Klagenfurt

The personal meeting on September 9th in Klagenfurt was important to us, as it had to be postponed several times. Mrs. OÄ Dr. Tamara Buchacher, cardiologist and PH specialist at the LKH Klagenfurt, patiently answered all questions and reported on the latest developments in diagnostics and therapy for PH.



### Information event Linz

A separate room had been rented in advance for the numerous guests who had appeared, so that they could comfortably exchange ideas among themselves. Mrs. OÄ Dr. Steringer – Mascherbauer reported on news regarding diagnosis and therapy for pulmonary hypertension.



### Information event Vienna: a virtual experience

Actually, we all wanted to meet again on the information day, chat with each other, see each other again. But for security reasons we decided to hold the meeting virtually. And it was a complete success! All the preparatory work had been worth it. Over 50 participants eagerly awaited the many presentations. Gerry Fischer reported on the activities and projects that PH Austria tackled and successfully carried out even in stormy times. We opened the meeting with a panel discussion. Members talked about how they are coping with life with PH. Sandra, Franziska, Ursula and Najat reported on life after the diagnosis. Sandra talked about how her everyday life with 2 children is like. Franziska reported on the positive change that the implantation of the pump brought with it, Ursula told how life in the family changes when a child has pulmonary hypertension and Najat spoke very impressively about the changes in her life her husband was diagnosed with PH <https://lnnk.in/aPfr>.

After a short break, everyone was waiting eagerly for Mrs. Univ. - Prof. Dr. Irene Lang's lecture, which was about the new approaches in diagnostics and therapy and about the current study situation. First, she reminded us of the risk score from the European guidelines, which provide information about how a PH patient is classified. The diagnostic importance of the right heart ventricle and BMPR2, the gene that triggers pulmonary hypertension and the importance of genetic testing, was also the subject of the lecture. She encouraged us by reporting that several new promising studies are available. For example Sotatercept and Seralutinib. <https://lnnk.in/d7c4> Ms. Assoc. Prof. Univ. Doz. Skoro - Sajer dedicated herself to the comorbidities that can be found in addition to pulmonary hypertension, such as diabetes or kidney diseases. <https://lnnk.in/d9c1> Next up was nutrition and psyche. Here we learned about the influence of both parameters. <https://lnnk.in/aRfo> It continued with an introduction to the world of Ayurveda. <https://lnnk.in/aTfh> At the end there was a workshop with the Feldenkrais trainer Mag. Theresia Paal.



### Education / Awareness

02/29	Rare Disease Day
04/21	MEP Lung Health Event
05/05	World PH Day as shown in the summer Mariposa 2021
09/26	Day of Self Help
10/02	National Nurse Forum
10/31	GhostRun

### Industry discussion on Rare Disease Day

To be left alone is the worst: For people with rare diseases, the corona pandemic has exacerbated an already difficult situation. That is why an industry discussion was held on this highly explosive topic on February 19th at the invitation of "Die Presse". Among the participants were Univ. - Prof. Irene Lang, who unfortunately could only participate virtually, patient advocate Dr. Gerald Bachinger, AOP Orphan founder, Dr. Rudolf Widmann and PH Austria, represented by Eva Otter. The occasion for the panel discussion was the Rare Disease Day, which takes place annually on February 28th. The consensus was: rare diseases need a stronger voice!



### Maleen Fischer Speaker at the European meeting

In addition to Marc Humbert, Marion Delcroix, to name just a few, Maleen Fischer was also invited as a speaker at the MEP Lung Health Event, i.e., the European Meeting for Lung Health. Her talk was about the benefits patients experience from research. <https://lnnk.in/hycc>

### Day of Self Help

On the Day of Self Help the Vienna City Hall had the motto "We have air to breathe", a predestined topic for PH



Austria. The event of the Wiener Gesundheitsförderung (WiG) took place for the seventh time. The event was held outdoors for the first time in the newly designed covered arcade courtyard in the Vienna City Hall. Many interested visitors were enthusiastic about what the 50 exhibiting self-help groups and organizations had to offer. Peter Hacker, the Vienna Health Council, emphasized the importance of non-profit institutions. The lectures were streamed from separate rooms onto large screens, so that all visitors could attend lectures by well-known doctors such as Univ. - Prof. Dr. Marco Idzko, about lungs. There was also the opportunity to take part in workshops on breathing techniques, yoga, or Nordic walking, which also met with great interest. Of course, there was also an oxygen barrel for refuelling. In addition to all of this, organizations such as the Lungenunion and PH Austria were able to introduce themselves with a presentation. With the participation of numerous non-profit organizations, Self Help Day promotes public awareness of what these groups have to offer.

### National Nurse Forum

At this year's National PH Nurse Forum, PH Austria was represented by Eva with a lecture on the subject of „Advising and caring for patients with PH - what has changed due to Corona". For the fourth time, the participants had the opportunity, including PH specialists, nursing staff, study nurses and physiotherapists, to continue their education and training.





### 7<sup>th</sup> Viennese GhostRun

On Sunday, October 31st, 2021, the time had finally come again: Our charity run, the “GhostRun” on Halloween took place again in Vienna’s Prater. Around 800 runners, including many children and adults in scary disguises, ran for a good cause in beautiful autumn weather and generated more attention for the rare but incurable disease of pulmonary hypertension. „We run away from the Grim Reaper” - this is the motto of the annual running event, in which large and small ghosts, zombies and witches, alone or in a group, run 1.5 or 6 kilometers through the Vienna Prater. After the GhostRun took place only virtual last year because of Corona, it was particularly great to host a live event again this year, in which not only the idea of competition, but also happy togetherness was in the foreground again. In times of Corona, we all learned what isolation means. This is a sad everyday life, especially for the children, and that is why we are so happy that so many participants took part. In addition to the well-known sports event moderator Martin Patak, who led through the GhostRun 2021 with humor, charm and sovereignty, other prominent supporters such as Hademar „Hadschi” Bankhofer and his family were there in the Prater to cheer up the little and big runners! Between the family and friends run, the main run and the award ceremony, the drummers from the Austrian percussion band Batala Boom created a lively atmosphere. The prizes, snow globes from the Original Viennese Snowglobe museum, were presented by district chairman Alexander Nikolai.

He emphasized on stage that his participation in the GhostRun was a matter close to his heart. Our Gerry on the GhostRun 2021: “My thanks go to all those involved: the many volunteers, the participants and the spectators! They all made a huge contribution to make the 7th GhostRun something real and special. PH Austria uses the income from the entry fees as well as merchandise and mask sales, to give patients access to information, therapy, and support options, to improve their quality of life and research projects to push ahead to defeat the disease, which is still incurable today.

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



## BELARUS

Hi PHamily!

In Belarus, we do not really have any major updates or events due to the ongoing political regime and the COVID pandemic. However, we still have something to share! What seems to be major in our realities is that we opened a private telegram channel with PAH news, which is also used for communication and support between patients.

In addition, we’re planning to launch online sessions with a cardiologist from Belarus who is also going to create video manuals on rehabilitation for patients with PAH.

Besides there were numerous online events and here are some of them:

- On August 12, there was an online conference held by professor Zateyshchikov - Living with PE - where the issues of therapy for pulmonary embolism, dosage of drugs, and diet were discussed in detail
- September 8 there was a conference of the peritoneal center where the following topics were covered:

- Hereditary heart defects in children.
- Intrauterine diagnosis and treatment
- Disability
- Operations
- Peculiarities of a child's life with heart defects, sports, discussion: is home-based education necessary
- November 13 School for parents "Child with a rare disease" was held, organized by National Medical Research Center. VA Almazov ONLINE.
- The meeting was dedicated to the treatment and rehabilitation of children with cardiovascular diseases. Informational and organizational aspects of medical care and psychological issues of a family with a child with a rare disease were considered.
- September 28 there was a Broadcast "Legal and medical issues of improving the quality of life of patients with PAH, CTEPH and other rare diseases"

That is all the news from us for now. Hoping to see you all at APHEC!

Alina Katsubinskaya  
 PH Belarus

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- Сочетание с приобретенной патологией сердца
- Сочетание с другими факторами риска

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## BOSNIA AND HERZEGOVINA

**Active despite the pandemic**

Despite the fact that the pandemic does not pass and that we have been working for two years in conditions that are not recommended for the activities of PH patients as a high-risk group, during 2021 we managed to realize a lot.

**Medicine for all patients**

The year began with meetings and seminars, among which we highlight the beginning of our participation in the implementation of the project, which focuses on the right to medicine for all patients in our country. The project "Strengthening Integrity in the Process of Creating Drug Lists in Bosnia and Herzegovina" is focused on supporting patients in their desire to be actively involved in the process of creating drug lists, supporting health institutions to achieve high standards of integrity for credible, transparent and inclusive the process of creating drug lists. This project in Bosnia and Herzegovina is implemented by Net Consulting d.o.o. Sarajevo in partnership and with the support of the Government of Switzerland, the company Roche d.o.o. - Roche Ltd. and the Association of Innovative Drug Manufacturers in B&H and is implemented throughout Bosnia and Herzegovina.

Considering that we are vitally interested in this topic, the Association of Citizens Suffering from Pulmonary Hypertension "Dah" in Bosnia and Herzegovina participates in its implementation. Sabina Hodzic signed a memorandum of cooperation on behalf of our association and has been an active participant in activities dedicated to this project since the beginning. In order to be as involved as possible in the process and in achieving one



of the goals of our Association - a cure for all PH patients, Ernard Mujanovic, MD, joined the realization of these activities on behalf of our Association. We hope that the implementation of this project will help patients with pulmonary hypertension in Bosnia and Herzegovina to finally make medicines available to everyone. There is still a lot of work ahead of the network of associations gathered around this project, but we are optimistic and expect positive changes.

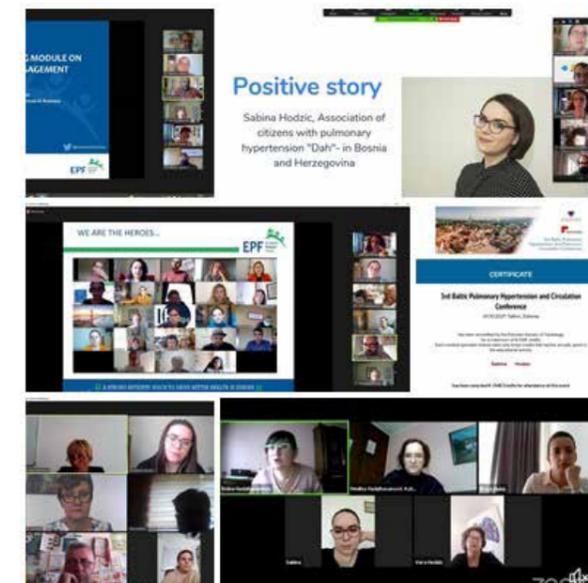
In addition to participating in the implementation of this project, we are part of the project "Contribution of



CSO networks to improving the daily lives of people with rare diseases", funded by the European Union and implemented by the Institute for Population and Development in partnership with the RS Rare Diseases Alliance. In trainings on various topics organized for associations that bring together patients with rare diseases, and indirectly participate in the establishment of the Association for Rare Diseases in our country.

**Online activities**

Our activities were also related to the online activities and work of many European organizations. First of all, we continued work on the Capacity Building Module project organized by the EPF (European Patients Forum), following and actively participating in webinars organized throughout 2021. Among others, at one of the webinars, our Sabina Hodžić presented a presentation "Positive story" which presented the problems faced by the Association "Dah", but also positive examples of our engagement with the media, other associations, patients and celebrities and sports clubs in our country. This is for



Sabina another successfully completed module organized by EPF. We hope that the acquired knowledge will contribute to the improvement of the position of patients in our country.

By the way, Sabina Hodzic received a certificate of this organization for 2020 for successfully completed participation in the work of the module during the last year. After all, that was the reason why it was chosen for this year's module, which is another confirmation that we are doing well at the European level. We saw Sabina's certificate as another confirmation that our efforts and commitment to a better position for all patients with pulmonary hypertension in Bosnia and Herzegovina are not in vain, and that we have young and healthy staff who are recognized as quality and will help us in our future activities. In order for them to be at the European level.

During the pandemic, our Association continues the practice of regular online activities with other European and domestic organizations and associations that focus on the better position of the patients. We attended an online discussion organized by ERS, one of the leading European medical organizations in the field of respiratory health on "Living with rare respiratory diseases through the COVID-19 pandemic", and APHEC and GAM organized by PH Europe, as well as the Third Baltic Conference on Lung hypertension organized by the North Estonia Medical Center and the Estonian Society of Cardiology.

**Marking important dates and participation in projects**

In addition to regular participation in the celebration of WPHD, during this year we marked a number of activities with the International Day of Rare Diseases, as well as November - the month of raising awareness about pulmonary hypertension.

Association of Citizens Suffering from Pulmonary Hypertension "Dah" - in Bosnia and Herzegovina this year on the occasion of the International Day of Rare Diseases gathered a large electronic and media support of associations, organizations and individuals for all rarely

ill patients in our country, all under the motto "Rare are many, rare are strong, rare are proud" which is the motto of this year's EURORDIS - European Rare Diseases Organization campaign.

We were also participants in the First Conference on Rare Diseases organized by the Association of Rare Diseases in Bosnia and Herzegovina, as well as webinars organized by Pharmion - student section for pharmacology and immunology. At both online events, we talked about our Association and the situation of patients with pulmonary hypertension in B&H.

During the month of November, we raised awareness of pulmonary hypertension through a series of posts on social networks, pointing to symptoms, diagnostics,

therapies, but also to people and organizations that have helped us to raise awareness of pulmonary hypertension all these years, not just during a day or month.

Of course, we did not miss the participation in the realization of the project "O2 kids" organized by PH Europe, thanks to which we fulfilled the wish of our young PH patient Nejra Imamovic and donated a wheelchair with accompanying equipment. Participation in this project has touched our hearts and we hope that there will be such and similar projects in the future.

*Vera Hodzic, President  
Association of Citizens Suffering from Pulmonary  
Hypertension "Dah" - in Bosnia and Herzegovina*



## BULGARIA BSPPH

### Celebrating the rare

On February 28, 2021 in front of the National Palace of Culture in Sofia, Bulgaria, patients with rare diseases symbolically painted their hands in different colors, which represent their difference and struggle. "The world of people with rare diseases remains invisible to the general society. If we get to know them and hear their stories, and if we learn more about their disease, which makes them different, we will actually realize how strong and determine they are. We will understand that they have a place among us on the labor market" added Natalia Maeva president of BSPPH.



guide is now available for Bulgarian patients in the three PH expert centers.

### Transplant recipients took part in the „Vitoshka 100“ ultra mountain marathon



On 20 June 2021, more than 40 transplant recipients and their doctors, as well as representatives of the Executive Agency Medical Supervision participated in the "Vitoshka 100" ultra marathon in support of donation and transplants in Bulgaria. "This way, we not only showed that transplantation allows a person to lead a completely normal, healthy life, but also that we can be of benefit to the society and our country. It is therefore important to have more transplantations in Bulgaria and fewer people waiting for their second chance for life. Organ donation is the most humane and supreme act of a modern society which helps people with disabilities and their loved ones. A society without morality and without human values is doomed to die. I believe that we Bulgarians are capable of empathy,

### Nutrition and pulmonary hypertension

Food is the main source of satisfaction and positive emotions in our lives, and also a source of physical and spiritual health. The main focus of nutrition, especially when pulmonary hypertension has led to heart failure, is to control the volume of fluids in the body.

Patients with pulmonary hypertension often need to make an extra effort to understand what they need to eat. Some foods and vitamins can interact with medications and contribute to the accumulation of excess fluids in the body or cause nausea or diarrhea. You need to remember three things:

- Control salt and sodium intake
- Do not overdo fluids and avoid foods which may cause discomfort in combination with your individual therapy
- It is important to avoid foods rich in vitamin K, as they further reduce the effect of your daily therapy

The guide of the Austrian nutritionist Claudia English contains handy recipes that will help you eat well. Thanks to our cooperation with PHA AUSTIRA, the



compassion and humanity! All of us who participated in the marathon together showed this!", said Natalia Maeva chairman of the BSPPH.

### ELF Patient Organisation Networking Day 2021

The BSPPH was part of the ELF Patient Organisation Networking Day 2021. It took place online on September, 2nd. This year event was focused on digital health and the role of patient organisations explore how they can take an active role in this changing environment.

This year BSPPH present e-poster named: "Access to healthcare for PH patients through the COVID-19 pandemic". The access to healthcare in COVID-19 conditions as a whole is assessed as worsened by the patients with PH, on top of that, this is the case for almost

every aspect with the exception of access to medication. 82% from patients report that the Bulgarian healthcare system was focused exclusively on COVID-19 treatment at the expense of other chronic diseases. Access to oxygen therapy for home use was difficult due the period October to December 2020. There was overstocking with O2 concentrators from non-risk groups.

### A donor's park was opened in Plovdiv

On 5th November was opened a special area for donors has been set up in the "2019 park" in the Trakia district, Plovdiv. The event was attended by Government Spokesman Anton Kutev, Deputy Executive Director of the Medical Supervision Executive Agency Miroslav Mutafchiyski and representatives of patient organizations.

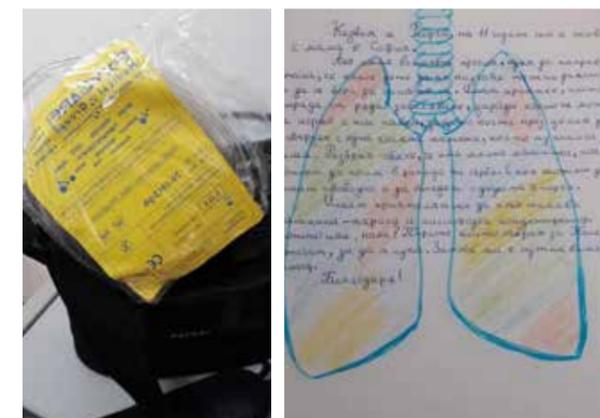


The donation park is an expression of gratitude to the people who gave someone else the opportunity to continue their life. The campaign "Because we are alive" is twining project of BSPPH and the Association of Patients with Respiratory Failure and Lung Transplantation. The donor park includes the construction of a fountain and 12 benches in memory of donors. The members of the BSPPH donated money for two benches.

### O2 kids project helps small PH patients

BSPPH is one of the beneficiaries of the O2kids project, organized by PHAE this year. Thanks to this fact we managed to make the biggest dream of 11-year-old Georgi from Sofia a reality.

"My name is Georgi, I'm 11 years old and I live with my mother in Sofia. If I had a magic wand, like the fairies, I would make that no child learns difficult diagnoses and fights for his life. I have a rare disease PH that prevents me from playing with other children. All day I am connected to a large machine that helps me breathe. I have learn there is a small machine that I can carry in a backpack and I can breathe freely and I will able to go with other children to the park. I want to have such a machine - it's called a portable oxygen concentrator. Complicated name, isn't it? The money I collected for last Christmas is not enough to buy it. That's why I asking for your help." - wrote in Georgi in his touchable letter. It is wonderful when we can see the joy in the eyes of our small PH patients.



### Other activities

The president of BSPPH Natalia Maeva as ePAG in ERN-Lung was among the 23 patient advocates, from 15 countries, representing more than 23 rare diseases who successfully completing the EURORDIS Leadership School. It aims of this training is empowering European Patient Advocacy Groups (ePAGs) advocates and other rare disease patient advocates to be valued partners in European Reference Networks (ERNs) and when engaging with healthcare providers and other rare disease stakeholders. The participants were trained on the following topics "360° self-awareness" and "Emotional leadership".



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

[www.bspph.net](http://www.bspph.net)  
[www.facebook.com/BSPPH.Bulgaria?ref=hl](https://www.facebook.com/BSPPH.Bulgaria?ref=hl)

**ACCESS TO HEALTHCARE FOR PH PATIENTS THROUGH THE COVID-19 PANDEMIC**

**TREATMENT AND PH CENTRES DURING COVID-19 PANDEMIC:**

**82%** from patients report that the Bulgarian healthcare system was focused exclusively on COVID-19 treatment at the expense of other chronic diseases.

Access to oxygen therapy for home use was difficult due the period October to December 2020. There was overstocking with O2 concentrators from non-risk groups.

**QUALITY OF LIFE**

**45%** of responses said PH has a "major impact" on their overall quality of life during COVID-19 pandemic.

**55%** Life expectancy has a big impact on quality of life, along with emotional and mental wellbeing and relationship and family.

**FINANCIAL IMPACT:**

**38%** said it had a "major impact"

The patients that have contracted COVID-19 have experienced a financial burden in relation to the illness.

**62%** said PH affects their ability to attend work or education.

**CONCLUSIONS:**

- The access to healthcare in COVID-19 conditions as a whole is assessed as worsened by the patients with PH, on top of that, this is the case for almost every aspect with the exception of access to medication.
- The practice where general practitioners give consultations on the phone to patients with PH is assessed as inadequate regarding the treatment of COVID-19 and the vaccination campaign.
- The patients with PH have received adequate information from the specialized centers.
- The use of digital media for improving the access to healthcare for patients with PH is unpopular and too unknown.

\*The research is part of project "Patient response against COVID-19", conducted in March 2021.

Bulgarian society of the patients with **PULMONARY HYPERTENSION**

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

#BSPPH.Bulgaria @bspph bspph\_bulgaria @bspph bspph@gmail.com





## BULGARIA PHA

In the difficult times of insolation and uncertainty for all the society, but even more for people with chronic disease PHA Bulgaria is constantly trying to encourage patients suffering from the PH.

PHA Bulgaria traditionally participated in the annual "Vitosha 100" run and cycling race in Sofia with small team. Our social and awareness videos were re promoted and have reached new auditory.

Todor Mangarov participated with his cycling achievements to European Lung Foundation video called "No limits" showing sport achievements from people suffering PH.

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



Todor, from Bulgaria, began international bike tours after having surgery for PH.



## CROATIA

*Dear Friends,*

Despite these challenging times and measures in which we have been living for almost 2 years, we are pleased to say that we managed to carry out some very successful and interesting activities in the second half of 2021. We have shared most of it through the good news announcements, but we are also happy to remind you once again of everything we did.

At the end of June, for the second time as partners of the Maksimir Athletic Club, we participated in the race in Maksimir Park, otherwise known as the most beautiful race in the city of Zagreb, at least that's what the journalists called it. The Maksimir Minus Zwei Cener race has been held traditionally for years and each time deals with a health topic or issue, and this year, just like last year, it was dedicated to patients with pulmonary hypertension and raising awareness about this serious disease. We were also supported by the Croatian Breathing House Foundation, as well as doctors from our PH center, ie. KBC Zagreb, some of whom ran and even won medals in their categories, while others gave statements to journalists. In any case, it was a wonderful gathering and an opportunity to see our doctors outside the hospital

and to get to know each other better. We hope to do so in the future. Representatives of the city authorities were also present and we all spent a wonderful, sunny day in the beautiful Maksimir Park, under the motto Get breathless for PH. Despite the covid measures, the race gathered over 150 runners, plus children's races, and everything was broadcasted on various portals.

At the end of July in cooperation with the Koprivnica-Križevci Tourist Board, on Lake Šoderica near the Aquaterra lake resort in Podravina, a boating duel called "Waves of Energy" was organized. This was an event in which we brought rowing closer to the public as an interesting sports activity through an interesting program. There were several disciplines, and over 200 competitors have shown their skills in rowing. The forces were measured by 8 teams, including the sports association Argo, who wore our T-shirts to raise awareness about PH and they said that during the race with every stroke they made, they were breathing for us.

On the occasion of World Lung Day, we supported the project implemented by the friendly association Jedra from Zagreb, and in the center of Zagreb, we socialized



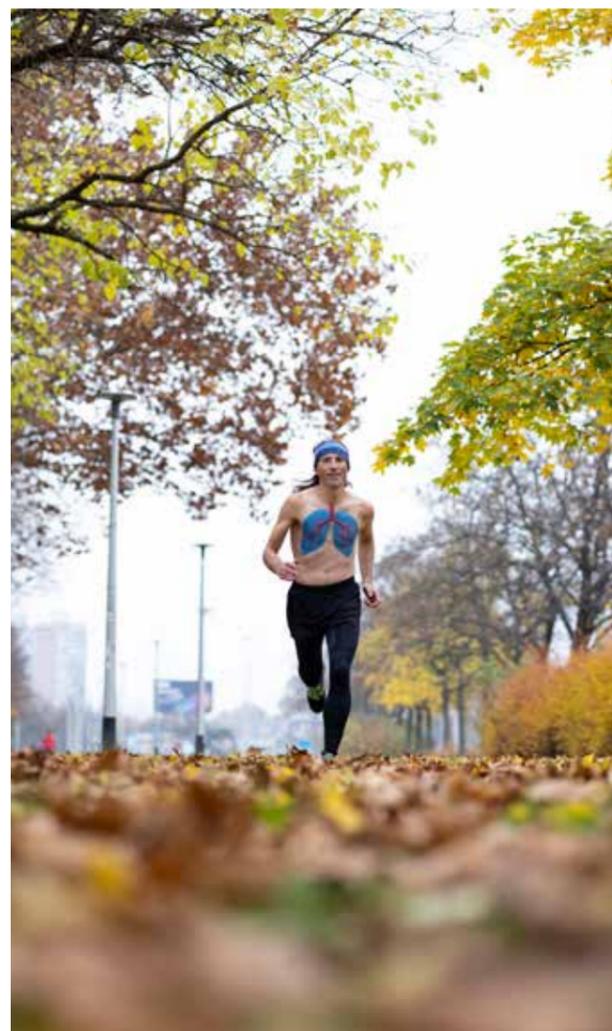
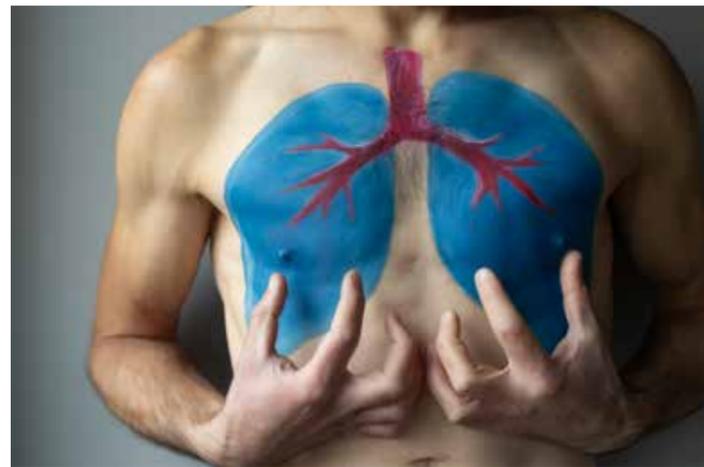


with citizens, and passed through the maze in two ways, once without instructions and the other time with instructions. This project wanted to draw attention to how difficult it is to go through the health system once you get a diagnosis, and how much easier it is when you have instructions, in this case, the medical staff who steered us in the right direction. Support is extremely important to all of us.

In October, thanks to PHAE and the O2kids campaign, we made Lovro very happy. Lovro is a boy who suffers from PH, lives modestly in a large family, with parents, 2 brothers, and 3 sisters. Lovro wanted an electric bike, the O2 kid's campaign made it possible. We have never experienced such happiness and anticipation on the face

of a nine-year-old and would like to thank everyone who is helping to continue this campaign and to cheer up many more children.

Children are not the only ones who need to be cheered up, adults like to get attention to, so the association "Blue Wings" prepared a surprise for our members. In cooperation with the company "LUSH Croatia", we managed to provide a nice, useful and fragrant gift box donation for our members. As we all know November is a month dedicated to raising awareness about all respiratory diseases, including raising awareness about pulmonary hypertension. For us, it was an ideal opportunity to distribute this valuable donation to members.



Since most of our members are women, the products are as created for them, a handful of scented bath balls, shampoos, and conditioners for hair and body. We didn't forget about our male members, so there were some products for shaving and facial care, soap as well. A little bit of everything.

In November, which is dedicated to raising awareness about respiratory diseases, we conducted a small but very successful campaign on pulmonary hypertension. Marathoner Juro Buljan, who often wears our T-shirts with the logo of the lungs and the inscription get breathless for PH at many races throughout the year, this time agreed to run through the city of Zagreb without a T-shirt.

On his chest, a picture of lungs was painted, by makeup artist Tena Bašić in two variants, with "rich" blood vessels, and with those that symbolize PH. Jura's pictures and our text were transmitted by various portals and FB pages.

And the last news without which we did not want to write a text for Mariposa, happened just yesterday 2nd of December at the International Hotel in Zagreb. We signed a grant agreement for a project funded by the European Social Fund - Operational Program Effective Human Resources to strengthen the capacity of CSOs to respond to the needs of the local community. With the project called "Do more - breathe together", we networked and connected with the Association "OSIT"





from Bjelovar, which cares for people with intellectual disabilities, and with Argonauts and sports association "ARGO". With this project, we have designed various and innovative educational workshops and the preparation and development of an educational manual.

The project holder is a Blue Wings Association and the president of the association Zdenka Bradač signed the valuable project, and at this solemn moment, was supported by colleague Smrček Tomislav - ČONČ from Argo as a partner organization and secretary of Osit - Mario Blaha. The ceremony was also attended by Minister Marko Pavić, a Member of the Croatian Parliament, and representatives of the Office for Non-Governmental Organizations and the National Foundation.

A big Thank you to everyone who supported us in this joint project, the implementation of which we look forward to in the next 18 months. We hope that this news will encourage other PHAE member associations to try to apply for open calls from EU funds in their countries. It is not easy, but it is possible, and we know that PH patients are fighters and do not lose sight of their goals even in the worst moments!

At the end of this year, we wish you all a peaceful holiday, to stay healthy and keep yourself to the maximum. Covid pandemic will pass, and we will continue with full lungs in new victories!

*Zdenka Bradač  
president of PH Blue Wings, vice president of PHAE  
Katica Mavračić  
secretary of the association*



## CZECH REPUBLIC



### Celebration of Rare Disease Day 2021

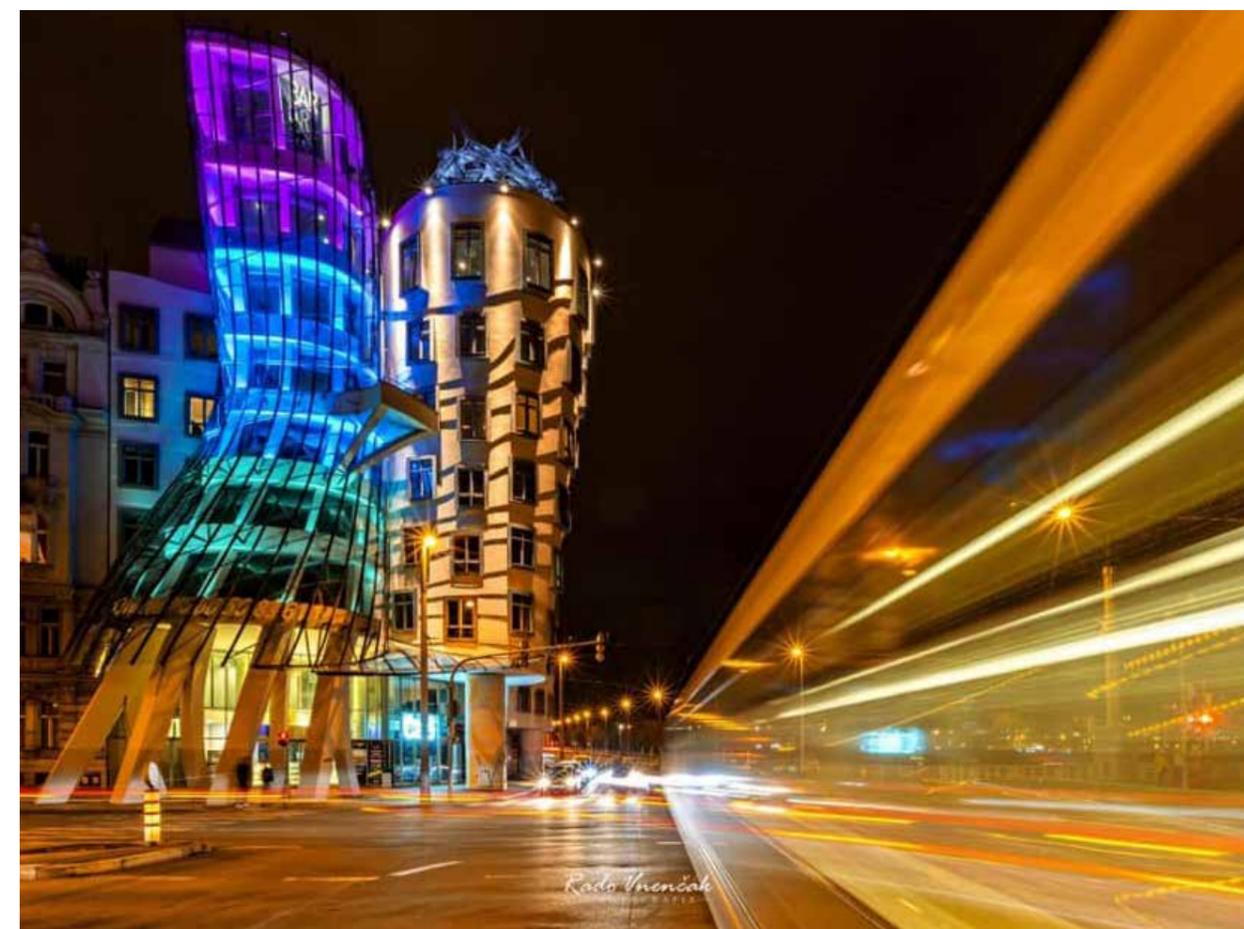
Every year we participate on the celebration of Rare Disease Day. broadcasted famous buildings in Czech Republic.

### Meeting of patient organizations with rare diseases

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

### SUKL conference

An online conference organized by the State Office for Drug Control took place on June 15. The most important content of the program was the topic of vaccinating Covid, the introduction of a new website and a new electronic voucher for compensatory aids.





### Patient Council of the Ministry of Health

Each year, the Ministry of Health organizes 4 meetings with the board of patient organizations in which we participate, where it presents new projects and consults on current topics. This year, all took place online like most events and the biggest topic was Covid-19, vaccination and treatment of specific patients.

### Recondition stay in Poděbrady

The second Sunday in August marks the starting day of our Reconditioning stay in Poděbrady. One week long stay in spatown near Prague for PH patients with their families. As in past years, the program was focused on light breathing exercises, muscle stretching work and light workout in the pool. We also introduced some new techniques to strengthen the middle part of the body to protect the spine. Our patients also had the opportunity to discuss their problems with a PH specialist. As last year we prepared also psychological relaxations and individual support for our patients.

### Webinars

This year, our organization started organizing webinars with leading doctors of pulmonary hypertension. So far, two have taken place and we hope that this activity will be useful for our patients, and in the future we will invite experts from other fields, whose advice patients could use in practical life.

### Annual meeting in Olomouc

This year's meeting of members of our patient organization took place in mid-September. It took place in a beautiful guest house in the center of the historic city of Olomouc. The election of board members was followed by lectures by pulmonary hypertension specialists from Prague and Olomouc.

*Milena Kaftanová*

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



## FINLAND



### A Rare Good Life

The Finnish Network for Rare Diseases ordered/organized A Rare Good Life - photo exhibition in November. Network for Rare Diseases advocates rare diseases associations in Finland. PHA Finland belongs to it. The photo exhibition consisted of 12 pictures and stories. Pictures were taken by a Finnish photographer Valtteri Nevalainen. The purpose of the photo exhibition was to showcase the diversity of rarity. It aims to raise awareness of rare diseases and their effects on everyday life. Three members of our association attended it with their photos and stories. The photo exhibition goes around in Finland at least in 10 cities.

The opening was in Helsinki on the 23th November. Sonja Koski and Maarit Mäkinen were present there.



## Annual meeting in person

PHA Finland organized, after a long wait, a peer support meeting in Helsinki. Due to covid restrictions, the event had to be postponed several times, until we finally were able to get together to meet face to face on 12.-13. 11. 2021.

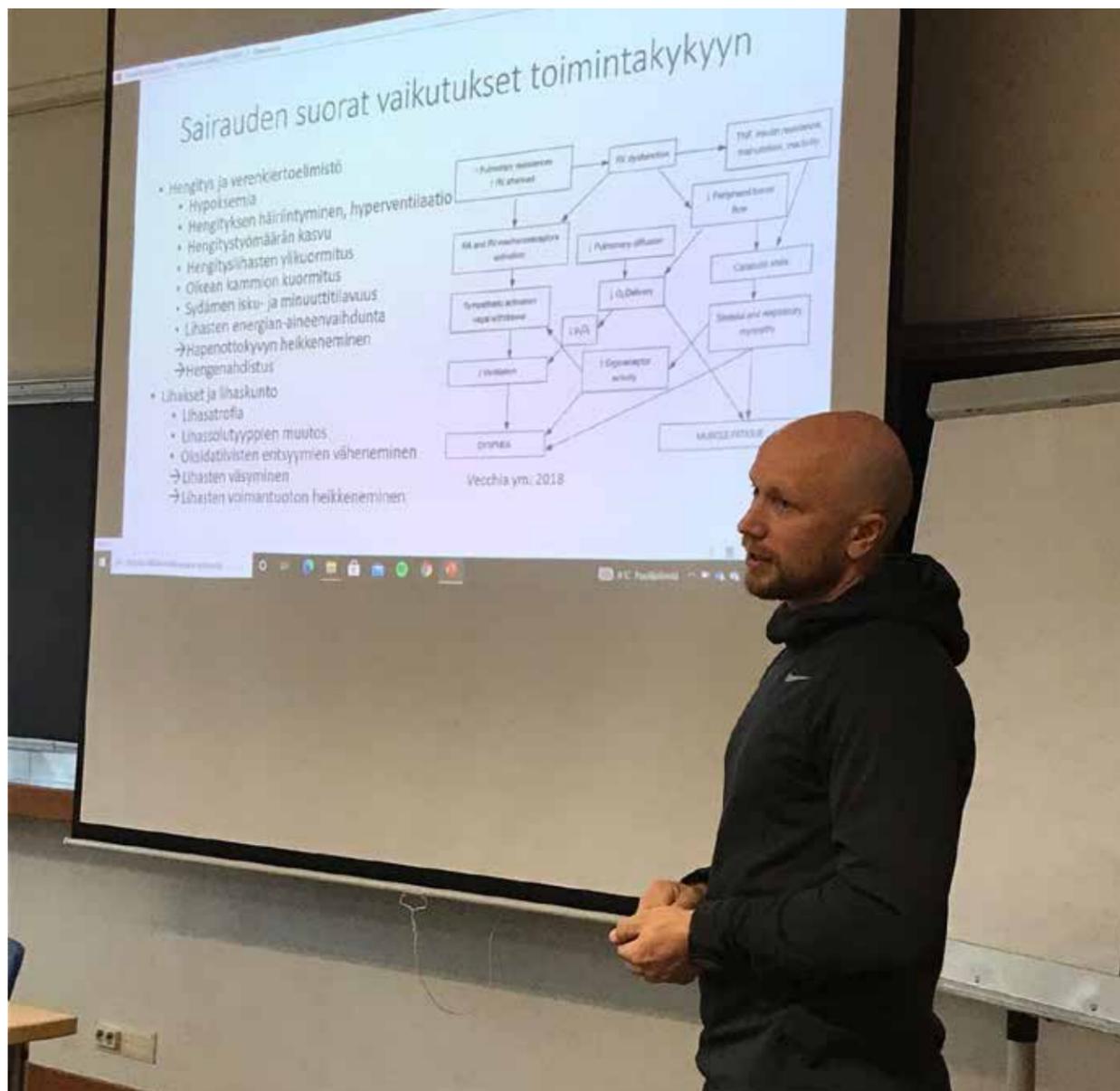
For the first time, we joined forces with the Organisation for Respiratory Health, Finland. They have years of experience as being the leading national-level organization that invites PH-patients for peer support meetings. As we share, broadly speaking, the goals of action, we decided it would benefit us both to act together. In addition, we received generous financial sponsorship from Johnsson-Cilag Oy of Johnsson & Johnsson.

The meeting was a two-day event that took place in a beautiful seashore conference center & hotel, Hotelli

Rantapuisto. On the first evening, we attended a lecture by the representative physician of Janssen informing us of the latest plans of action regarding care management of PH patients. This was followed by dinner and long-awaited chats and merriments with some bubbly!

Day two was all about self-care. First in the program was a brilliant talk and discussion with MD, psychotherapist Päivi Hietanen about the importance of psychological welfare. This was followed by an equally fabulous delivery of Herkko Ryyänen, physiotherapist specialized in respiratory illnesses. We were informed of the latest research on the importance of exercise, after which we got to put it in action. Doing push-ups and squats in fresh outdoors was sure to wake us all up and put a smile on our faces! After a lunch we bid goodbyes, hoping to see each other soon again!

Tanja Sointu



## HUNGARY

Year 2021 did not turn out to be any easier than the previous year. Strict closure measures lasted until the end of April and the pandemic was easing slowly. Our healthcare workers had a few months to breathe easier a little and then sadly in September the number of COVID cases was rising again.

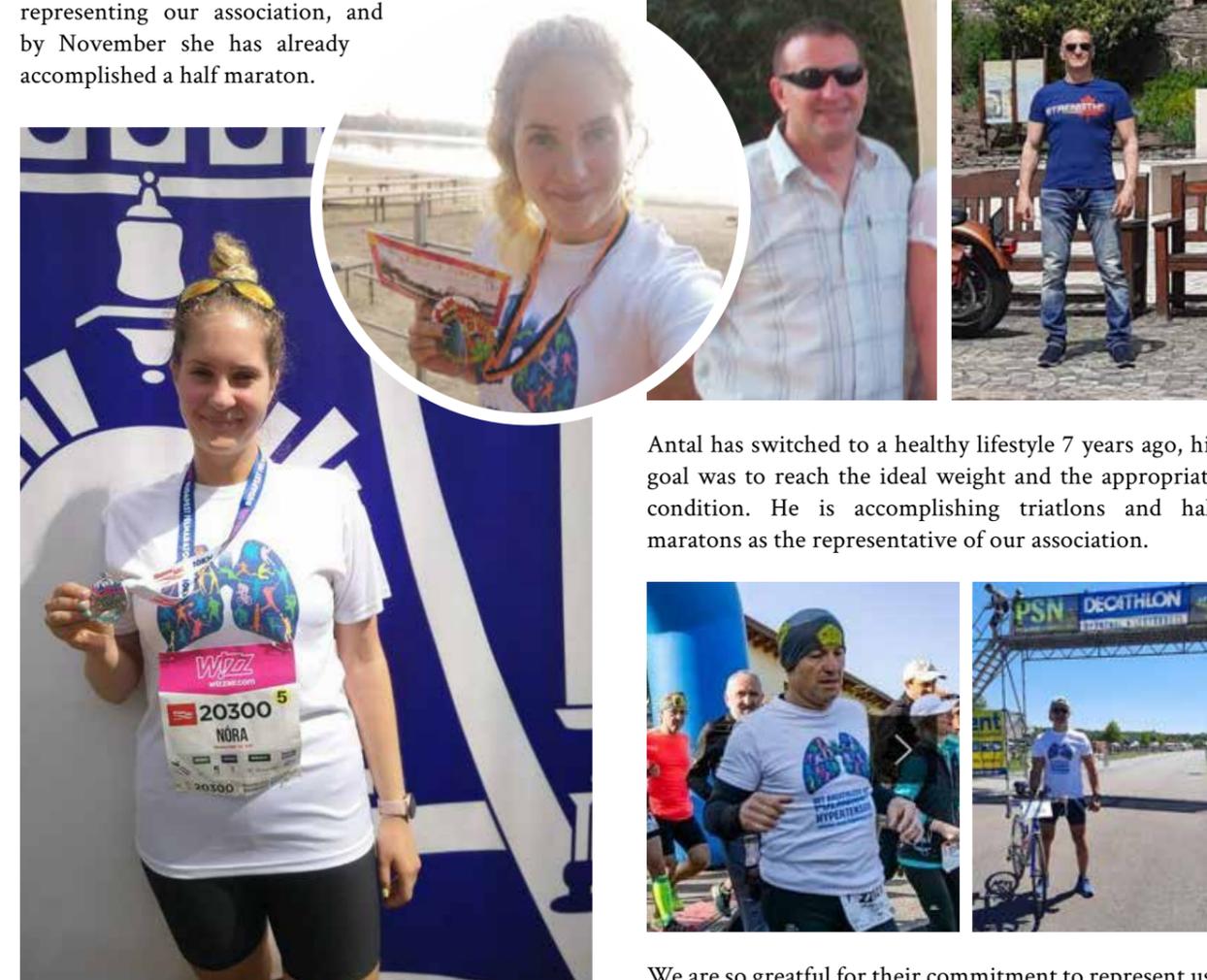
Our fellow patients have been disciplined, endured that social distancing is still needed unfortunately. Therefore our only personal meeting was the World PH day event. Even our General Assembly meeting was online. With a heavy heart we had no choice but to postpone our usual annual autumn meeting again.

To raise awareness to PH our new sport ambassadors have agreed to run in the T-shirt of our association, to represent our fellow patients, to get breathless for us. Let us introduce them briefly.

Nóri started running seriously a year ago and first completed a 10 kilometer competition representing our association, and by November she has already accomplished a half marathon.



Tündi has also started the representation of our association with a 10 kilometer run, then she became bolder and already completing distances over 20 kilometers.



Antal has switched to a healthy lifestyle 7 years ago, his goal was to reach the ideal weight and the appropriate condition. He is accomplishing triatlons and half marathons as the representative of our association.



We are so grateful for their commitment to represent us!

In August Dr. Kristóf András Karlócai, the head physician of the Pulmonology Clinic of Semmelweis University, who is also the Vice President of our Association, has been awarded the Knight's Cross of the Order of Merit of the Republic of Hungary to recognise his work and dedication. We are hoping that he will be with us for many years in health.



In October our association was represented on the Annual Congress of the Transplantees. We had the opportunity to listen to the sessions and we were networking with the Hungarian Association of the Transplanted people. We would like to have a closer cooperation, because after exhausting the drug therapy possibilities, the ultimate step is lung transplant. Several members of our association has already undergone this life saving operation. We hope to acquire useful knowledge that will enable us to help our fellow patients.



Previous autumn Petra, a young lady preparing to start secondary school needed a mobile oxygen concentrator. We managed to collect the donation needed and Petra has received an opportunity to lead a more mobile life that she is still enjoying enormously.



This year thanks to the O2Kids campaign we could help Dani with an e-bike, so that he could go on trips with his family, keep up the pace with his friends, he would be able to get around with greater independence.

It was emotional to see the joy and greatfulness, this makes us wish we would be able to help more children. Already in October we have launched our awareness raising campaign. We have started with an article in Egészségkalauz (Health guide) which is a website dealing with health issues. In November in addition to joining the PHEurope Facebook campaign, we have organized other media appearances. As part of this we had the opportunity to appear in the morning show of the two highly rated commercial TV channels to tell about the symptoms of PH, the difficulties of those living with PH and we drew attention to the importance of early detection and diagnosis and the importance of the timely treatment.

In addition to that articles were written about PH in two online media with good ratings. In these besides the PH specialists fellow patients were telling about life with PH.

We hope that our fellow patients and PH physicians will take care of themselves and we can enjoy the Holidays in health and peace even in these times of pandemic.

*Eszter Csabuda*  
Tüdőér Egylet  
[www.tudoer.hu](http://www.tudoer.hu)

<https://www.facebook.com/pages/Tüdőér-Egylet/151123348280359>



## IRELAND



2021 saw another Covid disrupted year for the patients and team at PHA Ireland.

While the annual patient conference was deferred due to restrictions, patients and medics alike got used to living with Covid and the high vaccine uptake in Ireland meant that people were able to get out, exercise and mingle more than the previous year. To this end, a large focus was put on exercise and the patient, with two big initiatives.

Ciara McCormack, an expert clinical exercise physiologist working with PHA Ireland devised a bespoke Pulmonary Hypertension (exercise) rehabilitation programme. It aims to provide PH patients with an opportunity to engage in some light exercises within their own home to help maintain their aerobic fitness and muscular strength. PH Patients are encouraged to try the exercises but to work at a level that feels comfortable for them. Ciara undertook some classes directly with patients, where possible and also produced an exercise video, introduced by Professor Sean Gaine, allowing others to follow along with the video at home.

The exercise video is available for patients to access free on the PHA Ireland website, here:

<https://www.pulmonaryhypertension.ie/ph-rehabilitation-programme>

The 2nd new initiative from PHA Ireland was the PHull Bull Tri, an inclusive triathlon aimed at PH patients themselves and their family and friends. The idea is for participants to do whatever distance and discipline (swim, bike, run) they feel comfortable with, either as a solo or a team effort. The headline event, which was also a fundraiser, involved a team of patients, medics and supporters doing the PHull Bull Tri around Bull Island in Dublin Bay, comprising a 10 km open water swim, a 30 km cycle and a 10 km run.

The inspiration for the PHull Bull Tri came from Patrick Corkery, a former patient with PH, who swam the English Channel, just 20 months after pulmonary endarterectomy surgery. As someone who suffered with PH, Patrick knew what it was like to be the spectator, watching on as others took part in events and races, living vicariously, but wanting to be involved more. His aim, with the PHull Bull Tri, was to allow patients to partake in a triathlon, rather than just looking on from the sidelines, as usual. He says "for some patients, it will involve a 10 min walk, or perhaps the exercise bike...and they can even put their feet in the sea to complete the triathlon. It really is up to you how challenging you want your PHull Bull Tri to be - it's not for nothing the word 'Bull' is in there,



## ISRAEL



*it doesn't have to be too serious! Some may partner up with friends and family to complete a relay, with one team member swimming, perhaps 1.5 km and another cycling maybe 20 km, As this is mainly a virtual event, you can take part wherever you wish. In fact, we even had some competitors from abroad. The PHull Bull Tri really is an event where everyone can enjoy taking part".*

With an eye-catching logo showing a Bull bursting through the chambers of the heart in the PHA Ireland logo, the event was advertised with postcards sent to patients announcing the event and t-shirts for all participants. A video, shot with some spectacular drone footage highlights the fun and inclusive nature

of the event and should prove a great tool to get even more involvement next year. Bull Island itself is a nature reserve, right beside Dublin city and the beach and seafront lent itself well to the bike and run parts, while the sea proved a challenge for the swim. With approximately 200 PH patients in Ireland, we are looking forward to even more patients and their families taking part in 2022.

To see the PHull Bull Tri in action, click here: <https://www.pulmonaryhypertension.ie/phull-bull-tri-in-action>

Patrick Corkery



Another year shadowed by Corona has passed and as we all adjust to our new life reality we are that much more appreciative of the everyday normal functioning. Corona restrictions may have limited our interactions and changed the way we engage with one another or meet, but the activities and responsibility of the Israel Pulmonary Hypertension association and its team have continued. We have shifted our focus and realigned our goals and made sure to push forward with full force working to improve awareness and create greater opportunities for better healthcare for our patients.

Our association was very pleased to have been invited to share the patients perspective and speak on a webinar geared towards over 100 participating medical practitioners about PH. The webinar panel included lung specialists, a cardiologist and a rheumatologist who spoke about how PH and its symptoms affect people. Post webinar we received fantastic feedback that all 100 participants (whom almost never stay for the full duration) were spellbound and found the material and information shared so crucial that they all participated in the full session. This has furthered our association's belief that educating medical staff, doctors, nurses and specialists who are the first step in diagnosis is crucial and has a much further reach and impact on creating PH awareness. A link to the webinar can be found here: <https://vimeo.com/641927668/db2e7cca92>

We managed to arrange for several articles exploring PH and explaining its effects to the average man. We worked very hard at engaging with medical companies, promoting the advancement of medications being included in the government medical basket, ensuring that our patients' needs were met and that they were all coping with the corona related restrictions. We pushed our „subsidy” for transport to medical appointments and ensured our patients had a safe and affordable way to get to and from their medical treatments. Our ongoing efforts for patient support included online classes and lectures, working with doctors and staff to assist in better understanding of the mental health affects for patients' limited movement, Education about the vaccine program and the options for patients who struggled to decide regarding vaccination, Online social meetings - ensuring that our members have human contact, do not become despondent or lonely because of isolation. We ensured continued distribution of oxygen saturation devices for the low cost of \$5 (sponsored to patient) and support for corona and PH death related family bereavement. Debriefing with other members who were affected by this loss.

Another fantastic opportunity for us this year was an interview creating greater social awareness on Arutz 13, one of the most prominent national broadcasters. The opportunity to promote awareness to this wide audience and highlight the symptoms for women to be on the lookout will surely help with early diagnosis.

And finally we ended off 2021 with our first in person event (of course with an option for zoom log in for those who needed remote access) - A conference for all patients of our association. The afternoon started with a guided tour of the Biblical Museum of Natural History which allowed for some social interaction, education and laughter! All participants were encouraged to learn about nature from new perspectives and some of the braver guests even handled some of the animals! We then returned to the auditorium for a lecture by Professor Neville Berkman, specialist Director of Hadassah's Institute of





Pulmonology. Dr Berkman explained about the different treatment options, the new research being conducted and the potential shifts in treatment. It was very interesting for us all to be informed and kept up to speed with this information and as always our patients enjoyed their questions and answer time. Following this talk, Aryeh Copperman once again shared updates and information regarding the bureaucracy and any relevant information for grant application, assistance for patients how to navigate the relevant departments in social services etc. This is always crucial information especially for our new members who are often completely lost without the association guidance. Our evening ended with a healthy, corona regulation compliant dinner! We were thrilled

with the opportunity to dine together, reconnect and once again create a sense of support and family!

**Links for awareness material this year**

- <https://tinyurl.hu/kzL7/>
- <https://tinyurl.hu/7Nuq/>
- <https://tinyurl.hu/gGMp/>
- <https://tinyurl.hu/cr5I/>

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



ITALY-AIPI



2021 was a very important year for our Association. We have reached the important milestone of 20 years. These 20 years have been a long time indeed, during which we have built up a lot in terms of services, opportunities, contacts and support for pulmonary hypertension patients and their families.

We have embarked on a journey of great dedication in disseminating information about our disease on a micro and macro level. We started by sharing information through our telephone service and ended up with the information campaign entitled "Life in a Breath", with Carolina Kostner as testimonial. Throughout 2021, we were the protagonists of a great deal of media exposure to spread information about our disease and the importance of early diagnosis. Here's a brief report on the first quarter of the "Life in a Breath" campaign: 9 million impressions and 46,000 clicks on our web content; 5 million readers in major magazines; almost 500 times our video was shown on Sky, half of which in prime time; 516 media and magazine shots for a total of 23 million views.

On 24 October 2021, we held our first General Assembly online, a very interesting way of getting in touch and sharing information from a distance. In my speech, I wanted to report in chronological order on the many activities carried out during 2021, among the most important of which were: Fattore J project (in partnership with Janssen Italia and Fondazione Mondo Digitale) which sees us as the protagonists of numerous meetings with high school students, addressing the issues of "trust in science" and "fake news and correct information" (January/December 2021); we are the signatories of several letters sent to the Minister of Health on the vaccination priority of rare diseases (February/March 2021); AIPI OdV celebrates its 20th anniversary with a video, a gadget and a graphic dedicated to this occasion (15 March 2021); in the AIPI news we insert 2 highly protective FFP2 masks, to defend all our supporters more strongly from variants (March 2021); we participate in a training course for teachers dedicated to rare diseases, organised by the University of Messina, finding great attention towards the inclusion of patients in school curricula (March 2021); we took part in a meeting organised by the LUMSA University dedicated to the job placement of rare diseases starting from the concept of inclusion and collaboration between school and the world of work

(April 2021); for the World PH Day we took part in a meeting of Fattore Jentitled: "If the disease is rare, how do we recognise it?" with 600 students, Dr. Bergamini of J&J, Prof. Galiè, Dr. Michilli of Fondazione Mondo Digitale, Leonardo Radicchi and Carolina Kostner (May 2021); after 5 months we use up a voucher of 3.000 € made available to our patients and relatives for overnight stays in a hotel adjacent to the Policlinico S'Orsola in Bologna (May 2021), we participate in two Webinars dedicated to rare diseases opening a discussion on the management of rare diseases at regional level (July/September 2021); after months of work and thanks to the contribution of PHA Europe we launch a brand new version of our website [www.aipiitalia.it](http://www.aipiitalia.it) (October 2021).

This was followed by a very interesting talk by Professor Nazzareno Galiè, who took part in our online General Assembly and allowed us not to interrupt this traditional space for sharing with him. As usual, the Professor described the most recent aspects of the treatment of pulmonary hypertension. Following numerous questions that arose during his talk, the Professor also devoted considerable space and attention to an in-depth examination of the subject of vaccines and vaccinations. Following this, Giulia Tropea gave us an in-depth analysis of the Testo Unico on Rare Diseases: this was a great achievement for those working in the field of rare diseases. On 27 November, the "Law 10 November 2021, n. 175" on provisions for the treatment of rare diseases and support for research and production of orphan drugs was published in the Official Journal! After that Giulia also spoke about the issue of frail workers.

Finally, our dear Vice-President Claudia Bertini announced, with great regret, that she will not be standing for the next elections for personal reasons.

Summary 2021: it has been an incredible year, the pandemic has not made life easy for us, but we have achieved many important goals for AIPI OdV and we have found, despite the distance, many ways to be close to our entire community.

I would like to thank the AIPIOdV Board, our editorial staff and Giulia Tropea, who has worked alongside me with great professionalism in many decisions, for all the support and trust they have given me over the years.

*Leonardo Radicchi*

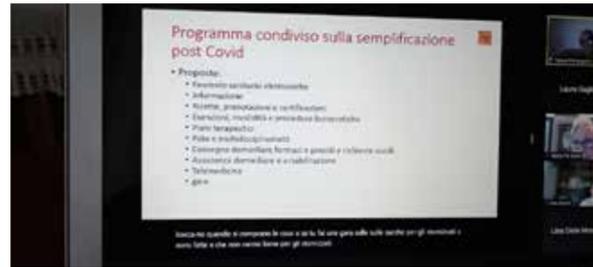


# ITALY-AMIP

*Hello at all!*

In these difficult months we have managed to always stay close to the patients, organizing calls together with them and the doctors of our scientific committee. We have identified counselling to help less resilient patients.

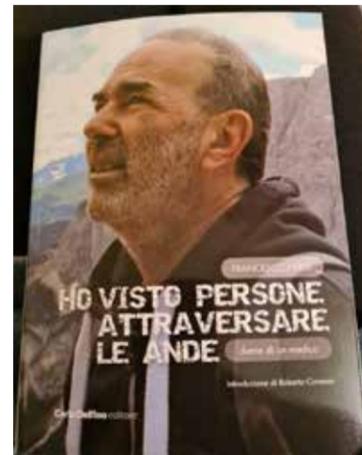
In October we had the opportunity to open, in attendance, the conference "NATIONAL CONGRESSI ITALIAN PULMONARY HYPERTENSION NETWORK 2021" which took place in Rome and saw the participation of international specialists. The meeting made us understand even more that networking is essential to help the patients.



In recent months we have also been busy participating in numerous meetings with the Italian institutions, in order to allow, during the covid era, to have a preferential path for the diagnosis and treatment of pulmonary hypertension patients. We have achieved results that go beyond our expectations.

We have been involved in various courses, also organized thanks to PHA Europe, concerning the empowerment of patients, the communication to them, the organization of a patient association.

In December, a space for AMIP was reserved at the GIFFONI JAZZ FESTIVAL to talk about pulmonary hypertension and the new book by our Prof. Parisi Francesco who treats children. Exciting as in such a broad and cultural context, AMIP has managed to make its voice heard and give greater visibility to the patients. Our work continues unabated.



*Together it's possible!*  
Laura



# LITHUANIA

The pandemic which is still holding the world in its tight grip has taken a toll on everyone. We all are waiting to finally be able to live without fear. People with chronic diseases are especially looking forward to that time. We must work to protect ourselves by avoiding unnecessary contacts to reduce the risk of becoming infected with the Covid-19 virus. Our PH patient organization is still avoiding live meetings to protect our patients. We very much hope that this situation will not last long.

Having previously become acquainted with mindfulness practices, this fall, we were able to offer PH patients weekly appointments with a psychologist and a mindfulness teacher. Participants met on the Zoom video chat platform every Wednesday at the same time and meditated together. It helped to escape from everyday worries, at least for a while, to relax and be together, even though at a distance. Such meetings, our unity, and togetherness make us stronger, bring us closer, and improve our emotional and psychological well-being.

Thanks to them, we can achieve our goals. Just before the holiday season of the year, the pharmaceutical company Norameda has helped us to fill the gift baskets to the ŽSPHA members by providing food supplements, pens, and ointment for pain relief. Bookstores „Niekio rimto” and „Knygos”. It donated books to children in our association. Our organization pleased the members of the association with honey treats and beeswax candles. Girls got stone bead sets for making bracelets, and the boy was given art supplies.



Užsiėmimus ves psichologas, atidos (mindfulness) mokytojas, o taip pat knygos apie sąmoningumo ugdymą „Staižmena gyventi” autorius bei meditacijų programėlės PAUZE kūrėjas Paulius Rakštikas.

**Kassavaitiniai atidos (mindfulness) užsiėmimai (meditacijos)**

Asmenis, sergančius plautine hipertenzija (PH) ir jų šeimos narius kviečiame kiekvieną trečiadienį, 13<sup>00</sup> valandą, susijungti nuotoliniu ir medituoti drauge. Tai bus 45 minučių sesijos, kurių metu 30-35 minutes skirsime meditacijai, o likusį laiką - susipažinimui su praktika ir aptarimui. Praplėsimė supratimą apie meditaciją ir patirsime įvairių būdų lavinti savo atidą, dėmesingumą, sąmoningumą. Visa tai padės susikaupti, nurinti, lavinti psichologinį atsparumą bei didins bendrystę.

**UŽSIĖMIMAI NEMOKAMI!**

**Visus norinčius dalyvauti atidos užsiėmimuose kviečiame susisiekti:**

Telefonu: +37064723450  
El. paštu: info@zspaha.lt

**UŽSIĖMIMAI VYKS:**

**DATA**  
Nuo 2021.10.20 iki 2021.12.29

**Susitikime**  
ZOOM vaizdo pokalbių platformoje, 13<sup>00</sup> val. (prisijungimo nuorodą atsiųsime iki spalio 20d.)

**Organizatoriai:**  
Žmonių sergančių plautine hipertenzija asociacija

**Rėmėjai:**  
MEDIS

Asmenis, sergančius plautine hipertenzija (PH), kviečiame į nuotolinius susitikimus su psichologu, atidos (mindfulness) mokytoju, o taip pat knygos apie sąmoningumo ugdymą „Staižmena gyventi” autoriumi bei meditacijų programėlės „Pauze” kūrėju Pauliumi Rakštiku. Susitikimai vyks Zoom vaizdo pokalbių platformoje.

**Birželio 7d. 19.00-20.00val.**  
Tema: **STRESO REAKCIJOS**  
Aptarsime įprastas streso reakcijas, bei tas, kurių išmokimas leistų išgyventi patiriamą stresą lengviau. Skirsime laiko atviro stebėjimo meditacijai ir jos aptarimui.

**Birželio 14d. 19.00-20.00val.**  
Tema: **NUOVARGIS-PERDEGIMAS-KAROSHI**  
Aptarsime sąlygas perdegimui ir prevencines priemones padedančias neprarasti pusiausvyros, taip pat įsivertinsime savo esamą būseną. Skirsime laiko atviro stebėjimo meditacijai ir jos aptarimui.

**Birželio 21d. 19.00-20.00val.**  
Tema: **PSICHOLOGINIS ATSPARUMAS**  
Aptarsime atsparumo temą ir strategijas padedančias išlikti sudėtingesnėse aplinkybėse. Skirsime laiko vizualizacinei meditacijai ir jos aptarimui.

**RENGINYS NEMOKAMAS!**

Norėdami gauti prisijungimo nuorodą kreipkitės:  
Telefonu: +37064723450  
El. Paštu: info@zspaha.lt

We are also pleased that some of our activities are willingly supported by pharmaceutical companies.



Another pharmaceutical company, AccordHealthcare, has donated our patients three meetings with a psychologist mindfulness teacher. During the meetings, topics relating to stress reactions, fatigue - burnout - karoshi, and psychological resistance were discussed. Thanks to the pharmaceutical company Medis, we were able to publish PH patient diaries. The compiling and designing of these diaries required a considerable amount of time because we wanted and sought to make it helpful not only for the patients but also for doctors. These diaries will be handed out to every Lithuanian PH patient.

We would also like to express our gratitude to the pharmaceutical company Janssen because thanks to their support, we were able to purchase a lecture prepared specifically for Lithuanian PH patients by a specialist dietician, a former PH patient, Chermaine Kwant. During the lecture, the dietician answered our patients' questions about nutrition. Special thanks go to the doctors of Kaunas PH Center, thanks to whom we had the opportunity to get acquainted with this special person. We can only be pleased that the common goal unites so many people.



Our organization is still working hard to raise the issue of lung and heart-pulmonary complex transplantations. The quantity and quality of these transplantations are still a source of concern. Our organization contributes to the spreading of information on this topic by publishing the stories of patients waiting for lung transplantation. Increasing public awareness on these subjects is particularly important, as the miracle of donation can only happen through peoples' benevolence and compassion. We communicate intensively with the National Transplantation Bureau, which is also trying to find ways to encourage transplantations in Lithuania. Together with other patient organizations, we signed a memorandum on changing the donation model in Lithuania. We currently have an informed consent model in our country. Based on the experience

← Nacionalinis transplantacijos biu... 🔍

nepagydoma liga, kuri naikina jos plaučius ir silpnina širdį. Dviejų vaikų mama laukia plaučių transplantacijos ir tikisi, kad iki to laiko, kai atsiras tinkamas donoras, jos širdelė nenusilps 🙏

🌱 Jautraus interviu autorė - žurnalistė **Laura Auksutytė**. Už šį straipsnį žurnalistų kūrybiniame konkurse „Organų donorystei – taip!“ ji buvo apdovanota pirmąja vieta 🏆

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Gyvenimas su liga praplėtė galimybių ribas



of other countries, we believe that changing the model of donation to implicit consent (where all residents of the country who haven't expressed their objection in writing are considered as donors) would increase the number of transplantations carried out in our country and save even more lives. At the same time, the number of currently rare transplantations would likely increase. The message on PH is being spread, although in small steps. At sports events, for example, our ambassadors, to whom we are always infinitely grateful, are wearing t-shirts with the logos of our organization.



One of our patients has participated in the TV show "Ask the doctor" on national television. In the part called "Doctors or the Internet" of this show, doctors compete with ordinary people who are trying to find out the diagnosis on the Internet. Both teams are trying to guess the disease the hero of the show is talking about introducing the symptoms. Despite the current situation, let us find the desire, strength, and ways to be happy.

Rima Gruodienė, Žmonių sergančių plautine hipertenzija asociacija (ŽSPHA), Lithuania  
[www.zspha.lt](http://www.zspha.lt)  
<https://www.facebook.com/zspha>  
[info@zspha.lt](mailto:info@zspha.lt)



## NORTH MACEDONIA

November, month of Pulmonary Hypertension, this year we celebrated with participation with more than 50 runners on Gevgelija run in a small city, Gevgelija, in honor of patients with PH. City in which from initiative from Gjurgica Kjaeva in the past years for raising the awareness for PH under the moto "Get Breathles" in 2014, "Breathe for Pulmonary Hypertension" in 2018 and "Dum Spiro Spero" in 2019, more than 70 runners humanitarian run 42km and 56km on regional road connecting more little cities an idea was born for a city run in Gevgelija realized from young enthusiasts who made the club

"7mi Noemvri Gevgelija". On this first run, there were more than 600 runners from all around our country and also from other countries. Except for this run, runners are running with PH shirts all across our country as in the big Marathon in Thessaloniki, Greece. Also there is support and they continue to raise the awareness of PH, Mountain Club Kozuv which are organizing mountain top climbings.

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



## MOLDOVA



The 2021 year stands out by administrative and developing activities mainly. Among these activities, three important topics can be named:

- Launch of the Association's website
- Participation in events organized by PHA Europe and
- Dissemination of information on Pulmonary Hypertension in Moldova

The rest of the activities, while not less important, are more related to daily activities and strengthening of the Association as an authoritative organization in the field of Pulmonary Hypertension.

#### Launch of the Association's website

According to the White Spot Programme, that is actively promoted by PHA Europe, the Association received required resources to develop its own website and successfully launched it in January 2021. The whole content was adapted and translated according to the information from the PHA Europe web site.

#### Participation in events organized by PHA Europe

This year the Association had an opportunity to participate at many events organized by PHA Europe,

such as APHEC 2021 with its thrilling Butterfly Hunt, WPHD 2021, containing a lot of new information, PH Awareness Month 2021, where patients throughout the world could share their life experience and many other smaller events.

#### Dissemination of information on Pulmonary Hypertension in Moldova

As the Association has only one active member – its founder – the dissemination of information about PH, related events and activities is rather limited. All that can be done is publishing news on Facebook, LinkedIn and distributing printed materials in specialized medical organizations. So, were distributed two sets of brochures and flyers, as well as the Image Brochure.

Other activities where the Association successfully participated are:

1. Registered the Association bank and fiscal information at state agencies;
2. Joined the Fellowship Programme by PHA Europe;
3. Established partnership with e-Homcare fund by UNDP that helps obtaining free oxygen concentrators and specialized help for PH patients;



4. Received the electronic signature for the Association;
5. Wrote and published articles for Mariposa journal;
6. Contacted new PH patients to invite them to the Association;
7. Organized Viber video meeting on latest PH news in Moldova and the rest of world, for three members of the Association, present in the country.
8. Established contact with Alliance of Organizations for People with Disabilities of the Republic of Moldova (AOPD);
9. Developed a small guide on how to diminish the discrimination of PH patients and other people with disabilities in different situations, etc.

The most time consuming, hard and interesting activities for the Association were:

#### Receiving the electronic signature for the association

As there is only one active member of the Association in Moldova, the founder, the processing of all required state documents is a very complicated procedure. Fortunately, the government is constantly expanding the range of digital government services it provides. In order to take full advantage of these services, you only need to have a digital signature. Thus, after spending two days on paperwork and a month for their delivery to the Certification Center, a digital signature was obtained. This allows, at the moment, to sign all the necessary documents requested by government organizations, including letters, reports, requests, etc.

#### Organizing Viber video meeting on latest PH news in Moldova and the rest of world, for three members of the Association, present in the country

There are a very small number of PH patients in Moldova (5 persons) and the majority of them refuses to join the Association. This is related to one of the former Soviet Union stereotypes "All non-profit organizations are created to steal people's money and you should never trust one" and many similar. From the other hand, the patients are dispersed throughout the Moldova, have a medium age of 57 years, don't like any electronical means of communications and don't want to be bothered with

anything that doesn't concern the instant improvement of their quality of life.

So, to keep them in touch with the PH news and get them to know each other better, a small video conference on Viber was organized. The summary of APHEC 2021 and WPHD 2021, along with other news, were presented, as well as the content of the printed materials on PH. Unfortunately, there were almost no questions and a strong feeling of rejection of new events.

#### Establishing contact with Alliance of Organizations for People with Disabilities of the Republic of Moldova (AOPD)

In summer 2021 was found information about the AOPD and were made some attempts of contacting their representatives. But, due to the serious condition of the founder (more than three weeks), the connection was lost and scheduled for December 2021 - January 2022. The AOPD aims to improve the quality of life of people with disabilities in the Republic of Moldova by collaborating with state public authorities in order to create an environment with equal opportunities to realize the potential for people with disabilities;

#### Developing a small guide on how to diminish the discrimination of PH patients and other people with disabilities in different situations

People with disabilities, and PH affected ones in special, are often discriminated in different common situations like: lack of access to institutions; receiving acts from organizations via their representatives; restricted possibility of receiving all kind of services; lack of understanding from the rest of the population, etc. To facilitate the solution of such issues, a small guide describing the possible steps of their resolving for both affected people and organizations. These steps were tested and approved some state, medical and financial organizations already. A more detailed description is given in "Mariposa", "Discrimination of rare disease patients in Moldova" article.

Roman Balmus



## POLAND



#### Mariposa PHA Poland Conference of the pulmonary circulation section

This year, as in previous years, PHA Poland took part in the 11th National Conference of the Pulmonary Circulation Section of the Polish Society of Cardiology, which was held on 21-23 October in Łódź.

The scientific programme of the conference included a number of issues related to various aspects of pulmonary hypertension: "A new look at PAH", "Don't slow down in virtual time", "Doctor, nurse and patient in a journey through the disease", "How can we shorten the time to diagnosis of PAH", "Why should the goal of treatment in PAH be low risk status?" - are just a few of the lectures that took place in the fifteen sessions of the conference.

The guest speaker at the session on COVID-19 and pulmonary hypertension was the leader and founder of the „Łzy” band - Adam Konkol. He talked about his experience with the disease and the problems he faces after Covid-19 infection. He also appealed to all the sceptics to get vaccinated against Covid-19 for their own safety and for the safety of their loved ones. Marta Mrozek, PHA POLAND Vice President talked about what had been done for patients during the pandemic. She also mentioned how our patients coped during this difficult period and the Association's plans for the coming year. Throughout the Conference, there was a stand of our Association in the open zone, which was willingly visited by doctors and nurses, who took guides and leaflets about pulmonary hypertension for their patients.

#### Football match PHA Poland Cup

On 21 October 2021, the Reds, captained by Professor Jarosław Kasprzak, and the Blue Team, captained by Professor Marcin Kurzyna, played against each other. From the beginning of the match, the teams made every effort to put the ball in the opponent's goal. Not surprisingly, minor injuries were reported, but they did not discourage the players from continuing the game. The second half ended with a score of 6:6 and



penalty kicks were needed to determine the winner of the Cup. In the end, the winner of the PHA POLAND Cup was the navy blue team, which defeated the Red team 4:3 in the penalty kicks. At the end of the match, Marta Mrozek, PHA Poland Vice President handed the winners the PHA POLAND CUP, and all the fans small gifts. Despite the unfavourable weather, the atmosphere in the hall was very warm.

### Nutrition guides for people with pulmonary hypertension

Thanks to the kindness of AOP Orphan Pharmaceuticals, we were able to obtain guides to proper nutrition for people with pulmonary hypertension. They include advice on how to maintain a balanced diet, a list of recommended and contraindicated products, and examples of recipes that can be used in the event of bothersome side effects associated with the therapy. The guides were sent to patients and a PDF is also available for download on the association's website.



### Boston Marathon – get breathless for patients with pulmonary hypertension

Once again, Krzysztof Sabisz dedicated his participation in the marathon to patients suffering from pulmonary hypertension. This time the goal was the Boston Marathon. „It is like Everest - exceptional and unique” says Krzysztof. „Many people dream about it, but only a few are able to fulfil this dream” – he adds. This year,

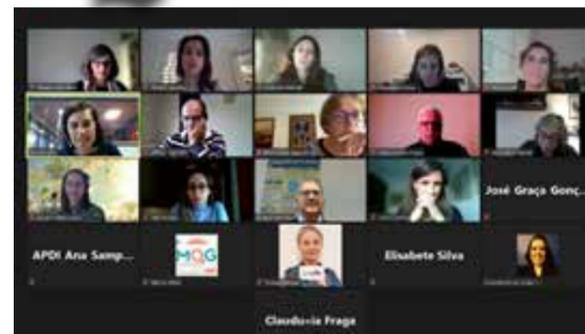
only 28 Poles qualified, and only 7 people from Poland reached the finish line. Get breathless for patients with pulmonary hypertension!

Agnieszka Bartosiewicz

[www.phapolska.org](http://www.phapolska.org) - [on.fb.me/1ORE2WJ](https://on.fb.me/1ORE2WJ)



## PORTUGAL



### PH Portugal attended workshops promoted by Bayer

BAYER Portugal has promoted constructive discussions on important themes, such as the involvement of patient associations in access to treatments and pharmacovigilance for the patients.

Sessions were dynamic and delivered in online format, given the limitations we are facing and the number of people involved. The initiative intended to capture the participants' perception and vision of new models of involvement of patient associations in accessing treatments and their role in reporting adverse reactions related to those therapies.

Workshops were divided into three main parts: the first parts were mainly introductory, followed by a zoom quiz wherein the alignment of perceptions and attitudes among all stakeholders on current models of participation were presented and discussed; finally, at the end of each workshop, groups were separate in parallel rooms to go deeper into possible ways to intervene in the models through new approaches focused on patient empowerment.

### PH Portugal invited to collaborate in a research study

PH Portugal was invited to collaborate in a research study entitled “Resilience and Family/Individual Adaptation in a Rare Disease Population: A Qualitative Study”.

The main objective of this study is to explore how resilience, strengths and coping strategies can contribute to individual and family adaptation to the rare disease. Six patients from PH Portugal will join this project that will be further detailed in the next edition.

### New questionnaire on PH is coming out

Patients from PH Portugal were invited to participate in the elaboration of a questionnaire that will be used in clinical practice, particularly in patients with pulmonary hypertension. PH Portugal played a crucial role in collecting a significant number of patients and thus contributing to the greater success of the project.

Este questionário foi concebido para determinar de que forma a hipertensão pulmonar (HP) afeta a sua vida. Responda a cada pergunta colocando um visto sobre O NÚMERO que melhor descreve a sua experiência recente de viver com HP. Para cada item abaixo, coloque um visto ( ) na caixa que melhor descreve a sua experiência.

Não sinto frustração por causa da minha falta de ar	0 1 2 3 4 5	Sinto uma grande frustração por causa da minha falta de ar
Ter falta de ar nunca interrompe as minhas conversas	0 1 2 3 4 5	Ter falta de ar interrompe sempre as minhas conversas
Não sinto necessidade de descansar durante o dia	0 1 2 3 4 5	Sinto sempre necessidade de descansar durante o dia

### Rita Rodrigues, from PH Portugal, is joining PH empowerment network's workshops

Rita Rodrigues, from PH Portugal was selected to attend the workshops promoted by PHEN (PH Empowerment Network), a new initiative from Janssen. The main purpose of the project is to help empower some selected PH patients around the world. PHA Europe was looking for four candidates and we are proud as Rita is one of them.

Rita is learning how to craft disease empowerment campaigns for patients, how to gain the most out of these campaigns, how to highlight the importance of physical exercise and mental health and how to maximize online and offline platforms. Rita will hopefully be able to use the knowledge she gained in order to help our association in this type of work.

### More about Rita...

She was born in South Africa in 1968, with a congenital heart disease, which went undetected until the age of 10. After a doctor's appointment, due to constant colds and flu, she was referred to a heart clinic. A catheterism was performed, as well as a lung biopsy, and she was diagnosed with Pulmonary Arterial Hypertension.



No correction surgery was possible, and no medication available, as this was an incurable disease. The disease made her stronger and helped her overcome imposed limitations. Because of this disease she fought harder, never created obstacles, and always accepted challenges. She has learned to push herself everyday a little more beyond her limits. She has achieved the possible by doing the impossible.

According to Rita, *“the first important thing to do when confronted with an incurable disease, is to not feel self-pity, rage or bitterness, all these negative feelings prevent us from moving forward and living our lives. I believe that physical activity and a positive mental attitude, contributed largely to my wellbeing, having outlived by far all my doctors’ expectations. The will and desire to live amongst PH patients is so great, that many times it overcomes the doctors’ expectations, and the ongoing, continuous research for a cure fills us with hope, faith and courage to fight every day”.*

**Patricia Miranda, from PH Portugal, is joining a project about uptravi**

PH Portugal was invited to join a set of workshops promoted by the company Merakoi which is a social impact company that, among other things, works with patient experts as consultants to bridge the gap between patients and healthcare companies, with the aim of improving the patient experience in various disease areas. Merakoi is currently working on a PAH specific project and was looking for a patient expert from Europe who has experience with (is currently taking or may have stopped taking) the treatment Uptravi.



Patricia is a nurse and was diagnosed with PH during childhood. She had a bad experience with Uptravi and was invited by PH Portugal to be a patient expert in this project. She is able to share a wide range of experiences as she is very well connected in her disease community and can bring the patient voice to the project, so she can also integrate multiple sources of research data and derive insights from other experiences.

**November is time to walk/run for PH**

PH Portugal organized a walk/run on the 21st of November aimed at raise awareness pulmonary hypertension and mark the PH awareness month (November). Leiria was the city chosen for the event, which was recently elected European Capital of Sport 2022.



Before the pandemic, we used to organize a 15 km trail / 5 km Walk which had an average of 200 to 300 people.

This year, due to the enormous unpredictability of the rules imposed by the Portuguese health authorities, it was not possible for us to obtain the necessary anticipation to organize an event of this dimension. In this sense, we organized something simpler, but still symbolic.



To warm-up, a set of exercises were proposed to our participants.



We had the support of Monica Rosa, a famous Portuguese athlete, who sponsored the event.

Despite all COVID-related restrictions, we brought together about 70 people of all ages, including patients. For the first time we had young children walking for PH, some of them PH kids.



And because this was all about Zebras, we also had a special support from Nestlé that send us KitKat Zebras to offer our participants!



A t-shirt was created especially for the event: Breath for LiPHe!

To educate our participants about the cause that led us to launch this event, a brochure was distributed:

**Hipertensão Pulmonar (HP): o que é?**

Doença pulmonar grave, progressiva e potencialmente fatal. Causa um aumento da pressão nos pulmões devido à inflamação ou formação de cicatrizes nas artérias pulmonares. Se não for tratada, pode levar ao enfraquecimento do lado direito do coração, um tipo de insuficiência cardíaca.

**Porque a HP é considerada uma zebra?**



A HP é frequentemente esquecida pelos profissionais de saúde.

Como muitos dos sintomas ocorrem noutras doenças menos graves, a HP às vezes não é considerada ou os sintomas são atribuídos a outras doenças.

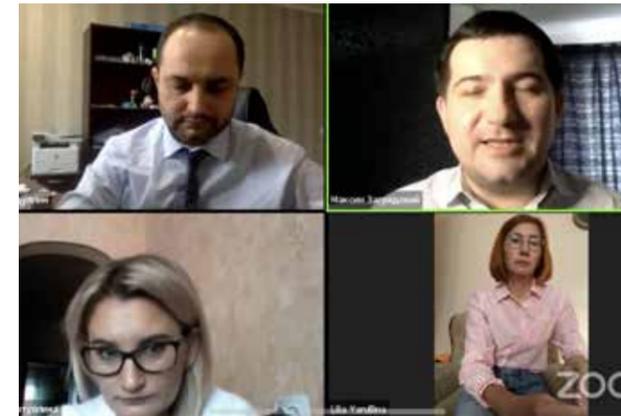
**Esta situação é o que os especialistas descrevem como uma doença zebra.**

A charity market took place at the end of the event, where several products hand-crafted by our patients were sold. The event's official t-shirt was also sold either online or at the event's place. A total 520 euros was reached!

Teresa Carvalho  
 Associação Portuguesa de Hipertensão Pulmonar  
<https://aphp.pt/>  
<https://www.facebook.com/hipertensaopulmonarportugal>



NEWS FROM EUROPEAN PH ASSOCIATIONS  
**RUSSIA**



On December 26, 2021, the long-awaited offline conference in zoom format on the topic of pulmonary hypertension and covid took place. The speakers of the conference were the doctor of pulmonary hypertension Rakhmatullina Ruziya, lawyer Akhmadullin Farit and Yarullina Lilia.

The doctor prepared an informative lecture on the topical topic "covid". She informed the assembled patients with pulmonary hypertension about the possible difficulties in patients with pulmonary hypertension with covid, spoke about the available statistics of the incidence of covid among patients with pulmonary hypertension. The doctor urged people to be more actively vaccinated and be attentive to their health, follow a diet, take medications on time, lead an active life and try to live an image, not give in to panic and despondency.

A large block of legal information is presented by a lawyer, Ahmadullin Farit. This was a lecture on the rights of the patient: to download even unregistered drugs under the state guarantee procedures.



Unfortunately, patients are often discriminated and receive life-saving medications, which can only be obtained by going to the courts. Farit spoke in detail about the stages of the judicial system, what difficulties one has to face in pre-trial proceedings. The conference was attended by participants - these are patients, their relatives, friends - in a word, a friendly family of pulmonary hypertension. During the active conversation, they shared news, asked questions to the speakers, and of course everyone was very happy to meet, albeit in an offline format, but very long-awaited, productive and interesting.

The recording of the broadcast was saved on the YouTube channel, you can see it at the link <https://youtu.be/fLP5Nnq9oaw>. Many thanks to the European Association of Pulmonary Hypertension for the support, the protective masks that are intended for patients and the very bright summer issue of the magazine Mariposa, which was very interesting for our patients.



Lilya Yarullina  
 PHA Russia "Save and Protect"  
[lilya-belle@yandex.ru](mailto:lilya-belle@yandex.ru)



# SERBIA

Despite all the obstacles that we have faced, 2021 was a fruitful year for PH Serbia, and the whole PH family. We live with PAH and PH, and all the difficulties that the world is facing now are our everyday normal. PH Serbia has carried out and successfully implemented numerous important and significant events and major projects. Our constant and consistent struggle and battle for every single PH patient is now even more vigorous than before, especially now when the COVID epidemics has shaken the whole world. People now came to realize that to be healthy and to remain as healthier as possible is a challenge, and they came to understand the difficulties that persons with PH are constantly battling

with greater depth. This very grim situation in the world was also an opportunity to promote the importance of public health, vaccination and to raise awareness of this serious rare disease through many events and projects.

Only during this year, we have successfully organized and carried out eight separate educational workshops together with PH experts, doctors, and patients. All the materials were recorded and later published on YouTube, all in an attempt to reach a greater audience and every single PH patient, so that they can all remain informed about the newest discoveries about PH and the following therapies and therapeutic methods.



Udruženje pacijenata PH Srbija organizuje on-line PH RADIONICU

Petak 05.03. u 18h

Gost: Prof dr. Arsen Ristić Radionicu vodi: Danijela Pešić



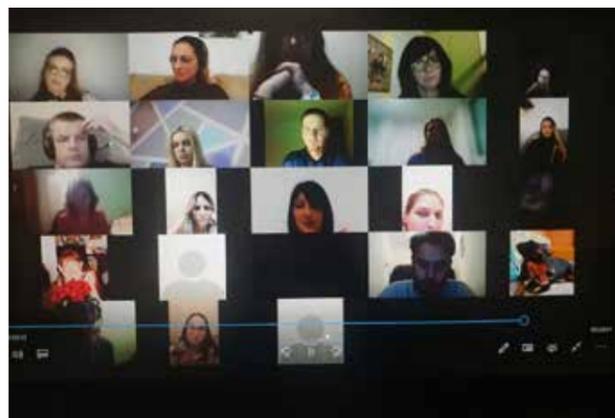
Udruženje pacijenata PH Srbija organizuje on-line PH RADIONICU

Sreda 07.04. u 18h

Gost: Dr Senka Milutinović Institut za Plućne bolesti Vojvodine Radionicu vodi: Danijela Pešić



We are really proud of our achievements during this year, but one of the most significant achievements was of course organizing a large scale expert congress about Pulmonary hypertension at the Serbian Academy of Science with more than 80 attendees, and 10 eminent professors from our country and abroad among which were Irene Lang from Austria, Olivier Sitbon from



France, prof Samardžija from Croatia. The main patron of the whole event was the First Lady of the Republic of Serbia, Mrs. Tamara Vučić. When the event of this magnitude takes place it was only natural that everything around it has been followed and monitored by various media from our country. The importance of this expert congress for the whole PH community cannot be stressed enough. It was a major step in bringing experts and patients closer than anytime before.



Organizing more than 10 different races, marathons and ultra-marathons is our norm nowadays, and it was no different during this year. Our Inspired by HOPE team was motivated and fit to run and to get breathless for PH across our country and abroad through various treacherous terrains and "exotic" locations. Spreading of awareness is easier when people experience what it means to be really breathless and that's why each and every race is a truly unique experience for everyone involved. It's both the promotion of a healthy lifestyle and at the same time a great opportunity to spread awareness of PH.

Our usual activities involve the acquisition of various medical equipment and supplies and that's what remains the same every year, pulse oximeters, oxygen concentrators, and other medical tools that can help our members and is something we need to take care and its one of the most important tasks of every association.




DRAGI PACIJENTI, OBAVESTITE NAS DA LI IMATE PROBLEMA U SNABDEVANJU PAH TERAPIJOM!!!

WWW.PHSERBIA.RS



Here in Serbia, our patients sometimes have to wait for some vital medications for PH, and that's where we step in, primarily to communicate with the Ministry of Health and with the Republic fund for health insurance of Serbia to ensure the regular distribution and availability of these vital medications. In that way, our patients avoid waiting for their medication for prolonged periods of time. It's a regular task for our association and we always continue our battle for a normal life by keeping our members and patients constantly informed and updated about every news in the field of therapeutic upgrades and innovations, and in the field of patient rights.

To mark the WPHD we have prepared several major manifestations but one of the most memorable events was certainly a rowing session in Dragon boats. That event on Ada Lake in the heart of Belgrade was something to be remembered. We will let the photos to the tale of the greatness of human heart and of true dedication to the cause.



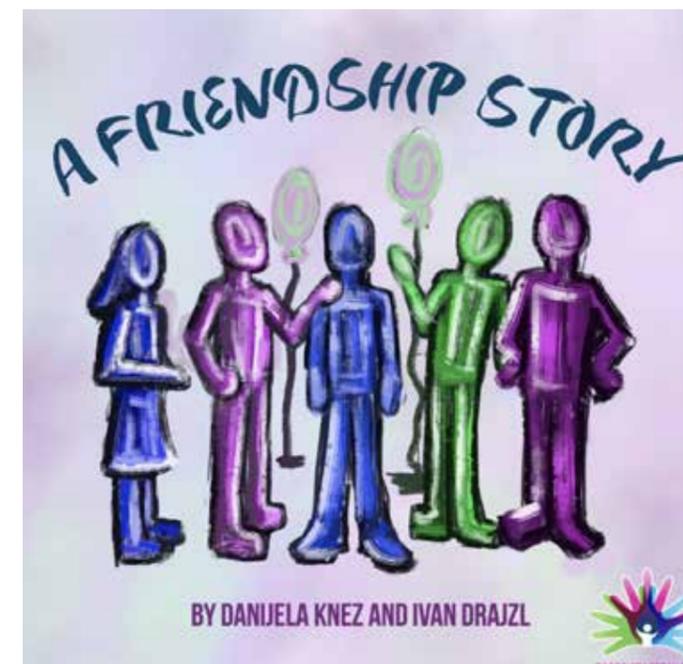
Danijela Pešić, as the president of Pulmonary hypertension Serbia was a guest on many TV stations and special programs dedicated to Pulmonary hypertension throughout the year, and her guest appearances were always oriented toward spreading awareness but also to presenting real human stories behind PH and the needs of those individuals that happen to suffer from this disease. Media and social networks proved to be a great aid in the moment of social and physical distancing. We are still learning how to employ those mediums to our advantage, but the past year and a half was a big learning curve. Participation in the realization of O2 Kids campaign



organized by PH Europe is surely something not to be missed. We have fulfilled the wish of a young girl from Kosovo suffering from PH by buying her an electric bike. This human and profound act will certainly help her to be stronger and to continue her fight. We hope that similar projects will continue in the future.



One of the most important campaigns by EURORDIS is the School toolkit: explaining living with a rare disease to young children for Rare Disease Day global platform will use a book authored by none other than Danijela Pešić. Her book A Friendship Story was translated to more than 25 different world languages and plays a vital part in this significant campaign. Read



more about this project here:

<https://tinyurl.hu/pmV6/>

Our association was also involved together with "Heliant" company in the creation of one of the most comprehensive databases for pulmonary hypertension in Serbia, and that's something we are especially proud of. That kind of database will be of great use, primarily when we speak about the diagnosis and about the general approach to treating PH. It will also include all the data about every single diagnosed PH patient.

More about it here: <https://heliant.rs/2021/05/05/nacionalni-registar-za-plucnu-hipertenziju/>

We will continue with the same vigor next year, all this was just a preparation for the next chapter of the great battle to cure PH. We will conclude by saying that every year is a tremendous teacher and we gain a lot of experience as time goes by, but the past two years were a great opportunity to really test what we have learned, to improve our weaknesses, and to reflect on our progress. As hardships grow larger, especially now with the COVID pandemics, we come out of it stronger, more resilient, and resolved to succeed in our attempts and ideas to make a better future for all of us!

Danijela Pešić  
PH SERBIA



## SLOVAKIA



Despite various anti-pandemic measures, we managed to carry out almost all the planned activities this year. In addition to the rich activity campaign on World PH Day, we focused not only on informing about PH, but also on patients and improving their conditions.

We have been regularly addressing students of the Secondary Medical School in Lučenec for several years in the form of a discussion forum entitled "When the breath runs out". This year, for the first time, we spread the information about PH online, via a webinar. The program consisted of two 40-minute blocks in which we talked not only about PH, but also about lung transplants and organ donation. The form of living libraries is always interesting and students had the opportunity to talk about problems with patients with various types of PAH directly.

We ran an online social media campaign on Rare Disease Day. We focused our contributions mainly on PAH. This day was also noticed by the top representative of our country, the president. On February 28th, the presidential palace was illuminated by the colors of the campaign.

In March, we actively participated in the Annual PHA Europe conference and the General Assembly Meeting

(APHEC and GAM). The online meeting was kind of exhausting, but it brought a lot more information.

At the end of July, after two years, we were again able to hold the long-awaited meeting of patients in Sliac Spa. Eleven patients participated in the 6-day educational-reconditioning stay. We focused on yoga exercises with adaptation to improve the functioning of the respiratory system and blood circulation. We ended the exercise hours with pleasant relaxation. Very pleasant morning for women with a beauty consultant who taught them how to take care of their skin was also part of the program. During each day we underwent spa procedures, we regularly visited an open-air swimming pool with healing mineral water for cardiac diseases. Those who were more able-bodied also used Nordic walking intensively.

At the end of the stay we held the General Assembly Meeting. The main point of the program was the evaluation of the association's activities over the last two years, as we were unable to hold our GAM last year. The General Assembly Meeting included the election of members of the Audit Committee for the years 2021-2023.

In October, we participated in the Rare Diseases campaign with the story of a patient with IPAH. During the year, we provided counseling to 18 patients. On the occasion of the Pulmonary Hypertension Month, November, we joined the united PHA Europe and worldwide campaign through social networks with unified graphics.

Runners in Get breathless for PH T-shirts raise awareness excellently. Through their participation in sporting events, they help us spread awareness of PH throughout the year. It's not only runners, but also tourists, that hike in undemanding terrains, often the patients themselves with PH. This form is very popular in Slovakia. In 2021 we were represented in 13 individual running competitions. Our runners, in addition, took part in two relay races - From the Tatras to the Danube (345 km) with a 12-member team and The Run Slovakia (524 km) with a 16-member team. They carried photos of patients on their backs to highlight real PH patients.

This year, as part of the O2Kids campaign, our association managed to obtain a grant from the PHA Europe for the purchase of a children tricycle for the handicapped 6-year-old boy Rayan.



Rayan was very pleased with the gift. The parents were also extremely happy. And of course we are with them. We have fulfilled one wish, but we will do what it takes to fulfill similar wishes for other children in order to make their lives easier.

<https://www.youtube.com/watch?v=OsYDBiqGzwo>

In November, we participated in a two-day Slovak Patient Conference, where we presented the activities of our association and had the opportunity to submit our proposals to representatives of legislative processes in the field of health and social affairs.

At the end of the year, we have prepared a new issue of PH magazine Fialka and we will also please the members of the association with Christmas packages.

*Iveta Makovníková*

*Združenie pacientov s pľúcnou hypertenziou, o.z.*

<http://phaslovakia.org/>



## SLOVENIA



extremely moved by our gift, as you can imagine a helping hand in difficult situations like theirs can give you a push when you need it most. In addition to the watch, we also gave Nermin an oximeter and protective masks.

For Društvo za pljučno hipertenzijo Slovenije the most discussed topic of the last few months has been the social life of our patients during the pandemic but also experience sharing between us and simply how to support each other even more. Due to the high burden of the pandemic on all of our social lives we have agreed to devote time to talk to each other more often, either online or in nature taking of course into regard the necessary pandemic measures.

We're happy to announce that we have moved from words to action and have organized a meeting for our members in our traditional spot, the nature resort called Mostec. It was great seeing each other in person again after quite some time. We were also joined by Mr. Kramar from the pharmaceutical company Medis who is very keen and proactive on supporting us in our future endeavors.

One of the fondest moments of 2021 for us is definitely the O2Kids campaign that was organized by our umbrella organization PHA Europe. With the help of Slovenian pediatric doctors, we were able to find and consequently bring a smile on the face of a sweet 7-year-old boy named Nermin.

Nermin suffers from a number of diseases, one of them being pulmonary hypertension. Due to this life is very challenging for him and his parents, especially because the boy is extremely lively and wants to live life to the fullest just like his peers.

Nermin's wish was a multifunctional watch, which can measure his heart rate and thus enables him to have more control during his daily activities. His parents were



We are very glad to see runners on the streets of Ljubljana this year as well. Among them were some of our amazing athletes who traditionally "get breathless" during the event in support of all our patients with pulmonary hypertension.

The event is a good example of neighborly cooperation. We were delighted to see the team from Serbia participate in the marathon this year as well. We also cannot forget to mention our superb doctor. Polona Mlakar, who participated in the event and helped patients by doing her best on the track just like she always does in the clinic.

The highest Slovenian peak - Triglav has been outdone many times in the name of the patients with pulmonary hypertension. Many athletes have already taken our blue lungs white T-shirt to the top. This time, however, it was done by a very special 9-year-old boy who proudly explains what the lungs on the T-shirt mean. Many thanks to his father who motivated him to tackle this impressive challenge.

After the meeting in Mostec we organized another online meeting with our members. We shared extremely moving stories from individual patients who have just recently joined our association. We talked about our wishes and needs, came up with quite a few ideas that we will advocate for in the coming year.

*We wish all Mariposa readers a wonderful year 2022!*

Tadeja Ravnik  
Društvo Za Pljučno Hipertenzijo Slovenije  
[www.pljucna-hipertenzija.si](http://www.pljucna-hipertenzija.si)





## SPAIN ANHP

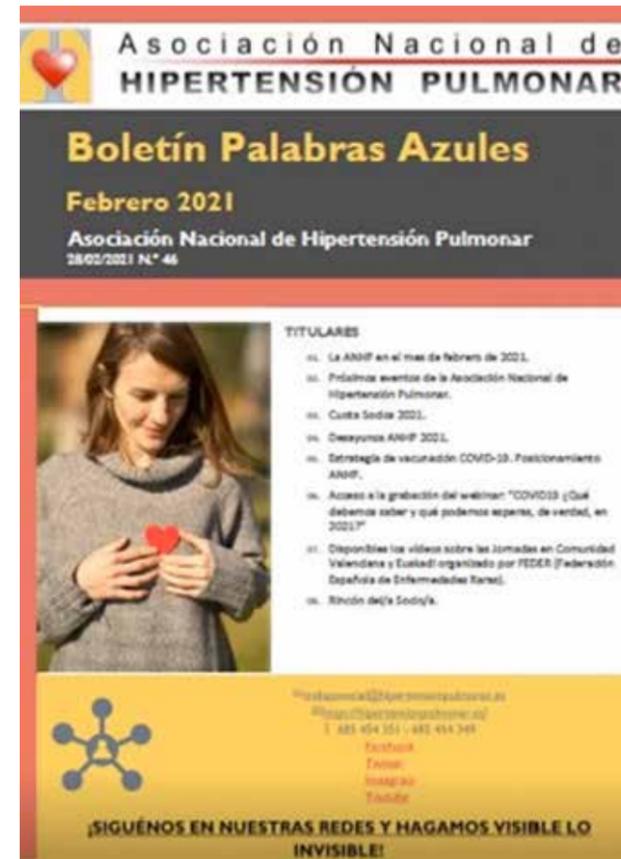
This 2021, marked by COVID and Vaccines, has been a year full of challenges, changes, and adaptations, which have made us even stronger. Both, the boards of directors and the staff members (social workers, psychologist and lawyer) have collaborated hard for another year, to give the best possible care to people with pulmonary hypertension, their families and caregivers. The pandemic has made us rethink our objectives and how to achieve them, but without losing our essence: to improve the quality of life of pulmonary hypertension patients.

- This year we have run all our activities online, which has allowed us to reach more members. We are very glad about the result, and although we will organize face to face activities when the healthy situation allows us it, we will not leave activities through platforms such as Zoom because it gives us the possibility of increasing participation. Our activities have been organized based on the member's demands and reflected in our 2021 strategic plan:
- Monthly Newsletter "Palabras Azules" (Blue Word): in 2021 we have baptized our newsletter, of which we have published 10 with information about our activities and information related to Pulmonary Hypertension such as stated aids. These bulletins are posted on our web: <https://www.hipertensionpulmonar.es/taxonomy/term/1>
- From 30th of April to 1st of June to celebrate our World PH Day Campaign with the slogan "Hypersensitize yourself we are Pulmonary Hypertension", the ANHP carried out different online activities like an awareness campaign in our networks, workshops such as Pulmonary Hypertension Conference Cicles: Social and Clinical Perspective of PH, I workshop for families of children with pulmonary hypertension, - Hiperactívate: Physical exercise in Pulmonary Hypertension in collaboration with the Siel Bleu Foundation, webinar „Emotional support: Working negative thoughts”, the lighting of fountains and monuments in different cities and municipalities in our country, Short videos "Questions and Answers about Pulmonary Hypertension" by patients, family members and caregivers, and the first virtual race "Deja tu huella por la HP" (leave



your footprint for PH).

- To celebrate the World Rare Disease Day, we run from February 15 to March 14 a campaign with the slogan "Educate, React, Do, Participate: HIPER unite". During this month several very interesting activities took place, such as the workshop "Techniques of relax" given by our psychologist Jennifer Moreno or the webinar "What does it mean to live with a rare disease?"
- In the month of November, the month of pulmonary hypertension awareness, we have organized a campaign from the 2nd to the 30th of November under the slogan "Words that give breath". Throughout this month the following activities have taken place: dissemination of aspects related to the pathology through infographics that have been published on our social networks, online awareness campaign through images of people with pulmonary hypertension, relatives, sympathizers, social and health professionals with a word or phrase of encouragement and videos prepared by people with pulmonary hypertension where they highlight what it has meant for them to belong to the National Association of Pulmonary Hypertension. Furthermore, we run psychosocial support workshop on the importance of assertiveness to take care of ourselves. Also, we offered our members with pulmonary hypertension 4 online sessions on the physical exercise.
- The XVII Annual General Assembly was held online June 5.
- In mid-September we started the Christmas Lottery campaign, which is one of the most important sources of funding for our association.
- During the year we have consolidated the online



meeting with families with sons and daughters with pulmonary hypertension. Every 2 months we have had a meeting with an average of 4 families. We have also organized 4 ANHP breakfast, one for each station for all members and a youth meeting.

- We started a Cardiorespiratory rehabilitation research in collaboration with the 12 de Octubre Hospital in Madrid, reference center in Pulmonary Hypertension in Spain.
- Our "Hiperexpertos" project ends the year with a pilot group that is testing the platform and validating the content like expert patients.
- In addition, this year we organized several online meetings and workshops with important information for our collective such as the webinar "Vaccines COVID-19; Pulmonary hypertension" in which a doctor specialist in pulmonary hypertension and a representative of the Spanish Medicines Agency answered the doubts and ask of our members. We also run the webinar on "Disability and Labor Handicap" where our lawyer gives us advice for the appraisal process and answered the doubts of the attendees. In the "Invasive treatments in Pulmonary Hypertension; the bomb, and now what?" webinar by D. Raúl Rodríguez, PH reference nurse at FERRER, and Ms. Mercedes Rodríguez and Vanesa Novoa,

nurses from PH unit of the Marqués de Valdecilla Hospital in Santander (Cantabria) were speaking about this type of treatment.

Participating in workshops, webinars and congresses such as moderators or speakers is very important to increase the visibility of Pulmonary Hypertension patients, their families and caregivers. In the 2021 we have participated in:

- We took part in the XII Conference on Pulmonary Hypertension patients and families" at the Hospital Clínic of Barcelona. This conference is part of the project called "Respira" Classrooms.
- We were speakers in the IV Congress of SEPAR in the table of "Answer in 60 seconds" and our lawyer D. Álvaro Lavandeira was speaker in the Organic illness symposium.
- Our social workers participated in the IV Association of Patients Meeting of FEP (Spanish Patients Foro) as moderator and speaker at the round table about the patient experience.
- Ms. Eva García García, president of the association attended the Webinar "In rare voice. Today and tomorrow of rare diseases" organized by MEHUER (Orphan Drugs and Rare Diseases Foundation of Seville) where, among other topics, the future of orphan drugs was addressed and Mr. Álvaro Lavandeira, lawyer of our entity, participated as a speaker.





We have attended conferences, workshops, and webinars related to our pathology, with the aim of expanding information and offering it to our members and sensitize the population about pulmonary hypertension, its causes, and consequences. We can highlight the following ones:

- Webinar “What should we know and what can we (really) expect in 2021?”. Organized by ProPatients (a non-profit organization).
- We attended the 5th Pulmonary Hypertension Research Meeting in organized by the PH research line of the Center for Biomedical Research in Respiratory Diseases Network (CIBERES).
- Webinar “The COVID-19 vaccine, respiratory patients” Organized by FENAER (Spanish Federation of Associations of Allergic Patients and Patients with Respiratory Diseases).
- VII Interdisciplinary conference on advances in Rare Diseases organized by IBIMA-RARE (Biomedical Research Institute of Malaga- Rare Diseases area).
- VII edition of the AE Awards Forum (affective-effective) Albert Jovell. This year our project has not been awarded.
- First part of the IV SeparPacientes Congress 2021. SEPAR is the Spanish Society of Pulmonology and Thoracic Surgery.
- At the XIV annual meeting of the CIBERER (Biomedical Research Center Network for Rare Diseases) we attended the round table “Challenges and Future of Research on Rare Diseases”.
- I Training Conference on Clinical Trials for patient associations organized by Janssen.

This year we have worked more than ever in collaboration with the entities to which we belong, such as the FEP (Spanish Patients Foro), the POP (Patient Organization Platform) or FEDER (Spanish Federation of Rare Diseases) to claim our inclusion in the vaccination strategy of Spain, improve care in health centers and

hospitals, provide our point of view to develop adequate telemedicine etc. Among the activities we have carried out with these entities we can highlight the following:

- As member of FEP (Spanish Patients Foro),
- Annual Assembly
  - Workshop HALIGH
- As members of POP (Patient Organization Platform),
- Online presentation of the 2020 Patient Care Laboratory Report.
  - Focus Group in which we talked about the participation of patient associations in relation to the state.
  - Meeting on the vaccination strategy of the Spanish government.
  - Focus group on Emotional Impact of Chronic Illness.
  - Focus Group on telematic attention.
  - Presentation of the report „Model of attention centered on the person with disease and chronic pain”.
  - POP breakfasts “The healthcare professional-patient relationship, opportunities and challenges after the pandemic”.
  - Annual Assembly.
  - POP breakfast where the importance of vaccination in the population with chronic diseases was discussed.
  - Annual Congress under the title „Health needs from the patient’s experience”.
  - Webinar „Model of early care centered on the person”
  - POP breakfasts „The role of patients in health technology assessments”.
  - Presentation of the „Consensus Document on the Promotion of Patients in the Hospital Environment” of the POP (Patient Organization Platform) and SEDISA (Spanish Society of Health Directors).

- As members of FEDER (Spanish Federation of Rare Diseases)
- Webinar „Experts in being united: Get the most out of awareness campaigns”.
  - Presentation of the World Rare Diseases Day Campaign and the open days of the Madrid associations.
  - Webinar „Experts in being united: Unique Helps”.
  - Official Act for the World Day of Rare Diseases.
  - Webinar „Experts in being united: How to prepare an assembly?”.
  - Webinar “Annual member survey results.



- Annual Assembly.
- Our partners from Valencia, Jesús García and Milagros Fernández, attended the event organized by FEDER (Spanish Federation of Rare Diseases) and the Valencia Football Club as representatives of the Association to present the Collaboration Agreement between the two entities to make the rare diseases and the importance of their research.
- Techsoup presentation. where we were able to learn about a platform designed for non-profit entities, like ours, to help us digitize and how they can help us optimize our resources.
- Webinar “ExpERTS in being united”: Delve into the concepts of the labor framework and discover the keys to improve the economic justification of aid”.
- Course „advancing together towards a 2.0 future” where we were able to learn and exchange collaboration and networking tools.
- Webinar „Experts in being united: fundraising”.
- Webinar „Experts in being united: Disability” in which we address, among other topics, the new disability assessment scale that will be approved in 2022.
- Online FEDER Training School.
- Sociosanitary-Educational Forum on Rare Diseases

in Euskadi. In which Dr. Javier Mazo, specialist in pulmonary hypertension from Hospital de Cruces (Bilbao) participated.

- I Madrid Forum on Rare Diseases.
- Conference „Determinants of diagnostic delay”.

In addition, during 2021, we have wanted to reinforce the collaboration with the European and American entities common aims since, together, we achieve more.

In the 2021 we can highlight the following:

- Participated as a full member in the Assembly of Eurordis, Rare Disease Europe.
- We have attended the meetings organized by the American PHA throughout the year with all the PH entities in the world to discuss different topics such as the organization of the awareness month or meeting with the new CEO of PHA US.
- We have participated in the meetings organized by PHA Europe and the PHA US to organize the World Pulmonary Hypertension Day and learn about the results.
- We have been present at the PHA Europe assembly where our psychologist Aldo Aguirre made a presentation.
- We participated in the presentation of the BREATHE Vision for the future 2030 campaign organized by different European patient organizations such as PHA Europe.
- We participated in the Webinar „Treatments by objectives and follow-up strategies in pulmonary hypertension” that PHA Europe organized around the World PH Day.

We are very proud of what we have done this year, and we plan to continue improving for 2022.

Eva García

Asociación Nacional de Hipertensión Pulmonar

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

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



## SPAIN FCHP

**The Pulmonary Hypertension Foundation**

The Pulmonary Hypertension Foundation presents a donation from the Pulmonary Hypertension Fund. The Foundation against Pulmonary Hypertension has made a donation of funds of 24,000 euros to the PASION HP genetics project. This project, led by Dr. Jair Tenorio and Dr. Pablo Lapunzina, both researchers at INGEMM, has as its main objective of the genetic diagnosis of all patients identified in Spain with this rare disease.

The donation was made at a ceremony held at the Hospital Universitario La Paz, which was attended by the Deputy Minister of Health Care, Juan González Armengol, and the medical director of the Hospital La Paz, Juan José Ríos Blanco. Also present were Emilio Butragueño, Director of Institutional Relations of Real Madrid C.F.; Dr. José María Villalón, doctor of Atlético de Madrid, both Honorary Patrons of the FCHP, and the President of the Foundation Against Pulmonary Hypertension (FCHP), Enrique Carazo Mínguez, who directed the event.

This project involves the Pulmonary Hypertension group of the Hospital La Paz (GRUHPAZ), the Institute of Medical and Molecular Genetics (INGEMM), the 12 de Octubre and Ramón y Cajal Hospitals, among others at national level, and the Biomedical Research Centre for Rare Diseases Network CIBERER.

**Pasion HP genetics project**

The work of this project is based on the identification and characterisation of variants and genes associated with the pathogenicity of the different aetiologies of Pulmonary Hypertension, through the application of massive sequencing, such as exome (WES) and whole genome

(WGS). Thanks to the genetic diagnosis of patients through the application of new generation genomic techniques, the PASION HP project will be able to stratify them according to the molecular defect they suffer from, which will help to identify personalised therapeutic targets for each of them.

It will also help to find new genes responsible for this disease in patients who currently have no alterations in known genes. An additional objective of this project is the identification of biomarkers of response to drugs, in order to predict possible adverse effects or the efficacy of a treatment.

**Grant for the Pulmonary Hypertension**

Grant for the Pulmonary Hypertension Project of Dr. Diana Valverde (University of Vigo), and General FCHP Grant for Dr. Cogolludo of the Complutense University (Madrid).

To contribute to the development of research, the Spanish Foundation against Pulmonary Hypertension has allocated 12,000 euros to support this work in the framework of a virtual event in which its president, Enrique Carazo, as well as Belén Rubio, Vice Chancellor of the University of Vigo and Miguel Ángel Correa, Director of CINBIO, participated.

Dr. Diana Valverde is responsible for the winning project, which addresses this rare, serious, progressive, chronic and complicated disease that affects individuals of different ages, mostly adult women.

The work is being carried out at the Rare Diseases Laboratory of the Biomedical Research Centre of the University of Vigo (CINBIO) with the aim of advancing towards early detection of the disease through genetic analysis. In this way, the aim is to delve deeper into its causes and improve the quality of life of patients.

And another award of 12,000 euros was for the FCHP 2019 General Scholarship for RESEARCH in Pulmonary Hypertension, to Dr. Ángel Cogolludo.

The FCHP Scientific Committee awarded the €12,000 to the project entitled "Functional consequences of mutations in the KCNA5 gene found in Spanish patients with Pulmonary Hypertension" led by Dr. Cogolludo from the Complutense University of Madrid. The aim of this new study is to find new therapeutic targets to which



to direct drugs that preserve and improve the activity of potassium channels of which alteration is crucial in the progression of the disease.

**Educating**

Educating those affected and their families with Pulmonary Hypertension. And Bereavement webinar How do we cope with change and loss in life?

The FCHP gives continuous training to those affected and their families, in this case with two webinars given by our professionals. "Caring for the caregiver": the importance of caring for ourselves in order to know how to care for others. An undervalued role with a high social and psychological burden.

In the Bereavement webinar, we faced not only the loss of a family member, but also the loss of quality of life. The guest speaker was Erno Parra, a psychologist specialising in bereavement.

**PASIONHP Project**

Accompaniment, care and psychosocial intervention with people affected by pulmonary hypertension, transplant recipients and their families in times of COVID.

This project is an initiative of the Foundation Against Pulmonary Hypertension that aims to offer comprehensive care to those affected by Pulmonary Hypertension and their families, focusing on their needs.

Providing them with accompaniment, psychosocial care and intervention, connection with health and care professionals who are experts in PH and meeting with people who live and coexist with the same disease, in order to reduce the level of uncertainty after a first diagnosis and normalise PH, and its treatment, in their lives, supported by the knowledge and experience of those of us who make up this Foundation.

**XIII Anniversary of the FCHP**

XIII Anniversary of the FCHP again in online format, with the Inauguration of the President of Andalusia

The Foundation Against Pulmonary Hypertension (FCHP) celebrates again the XIII Anniversary of the FCHP in online format. With inauguration by the President of Andalusia Juanma Moreno, the General Director of Research, Teaching and Documentation, Mrs. Teresa Chavarría, Mr. Juan Carrión President of FEDER and Enrique Carazo, President of the Foundation Against Pulmonary Hypertension.

The event was presented by our dear Carlos García-Hirschfeld, presenter and Patron of the FCHP.

**Donation for Empathy, Pasionhp and ACCELERON- FCHP 2021 research grant**

The Foundation Against Pulmonary Hypertension (FCHP) has presented a cheque for 35,000 euros to the heads of the EMPATHY Project for research into pulmonary hypertension, led by Dr. Barberá, and a cheque for 35,000 euros to the PASIONHP PROJECT led by Dr. Jair Tenorio.

This year the ACCELERON-FCHP RESEARCH SCHOLARSHIP worth 12,000 euros will be awarded. The grant is open to physicians and researchers working in the field of Pulmonary Hypertension.

Lisa Lea, Director, Global Patient Engagement and Advocacy Acceleron and Enrique Carazo were in charge of convening this grant for the year 2021-2020. With this amount, the Pulmonary Hypertension Foundation has allocated more than 478,000 euros to Pulmonary Hypertension research. One of the key objectives of our organisation.

**Clinical and scientific round tables on pulmonary hypertension**

Two tables were the centre of the colloquium of doctors of clinical medicine and another table of doctors of scientific medicine. They explained the latest developments in Pulmonary Hypertension.

Dr. del Cerro, cardiologist of the Paediatric Pulmonary Hypertension Unit of the HU Ramón y Cajal, and Dr.

Inmaculada Guillén, paediatric cardiologist of the HU Virgen del Rocío (Seville) participated in the clinical round table. In adults, Dr. Escribano, cardiologist and Dr. Andrés Quezada, pulmonologist, both from the Pulmonary Hypertension Unit of the HU 12 de Octubre, participated. Ana Ramírez, nurse from the HU Clínic (Barcelona) provided the nursing experience. Ana Benloch Charro, social worker, and María Jiménez, psychologist, both from the FHP team. This round table dealt with the latest developments in Pulmonary Hypertension.

The Scientific/Genetics Round Table was composed of Dr. Pablo Lapunzina, Director of the Genetics Service and researcher at La Paz University Hospital, Dr. Diana Valverde, Professor of Biochemistry and Molecular Biology. CINBIO. University of Vigo. Rare Diseases Group. Dr. Vinicio de Jesús and Roham Zamanian ambod Pulmonary Hypertension Researcher at Stanford University. Dr. Ángel Cogolludo Pulmonary Hypertension Researcher, Department of Pharmacology, Complutense University of Madrid. And as keynote speaker Dr. Christina Eichstaedt Geneticist Columbia University.

### Two new round tables Empathy Project and Pasionhp Genetics Project

Dr. Barberá, pneumologist at the HU Clínic Hp Unit and leader of the EMPATHY Project. Dr. Jair Tenorio, researcher at the INGEMM of the HU La Paz, and leader of the PASIONHP genetics project. These round tables dealt with the importance of genetic studies in people affected by PH, and the evolution of the research projects in which the FCHP participates as official collaborators.

### Appointment as Patron of Honour 2021

This year Dr. Olga Mediano, pulmonologist and collaborator of the Sexta Noche, has been named Patron of Honour of the Foundation against Pulmonary Hypertension for her support to those affected by Pulmonary Hypertension during the COVID19 pandemic. The nomination was made by our Patron of Honour Dr. Raquel Yotti, Secretary General for Research at the Ministry of Science and Innovation.

### FCHP 2021 Solidarity Award winners

The FCHP 2021 Solidarity Awards were presented for outstanding work both in dissemination and in support of the fight against Pulmonary Hypertension, respiratory diseases and our organisation:

- Award to the ONCE Foundation in recognition of its support and outreach work through the ONCE coupon launched on 5 May, World Pulmonary Hypertension Day. The award was collected by Ms. Patricia Sanz, vice-president of the ONCE General Council.
- Award to the City Council of Parla for the recognition



of the support given to the Foundation and for the cession of the flat in Parla to the Foundation. The award was collected by Ramón Jurado, Mayor of Parla City Council.

- Award for the recognition of the support and dissemination work through inclusive sporting activity. Andrea Miguélez, winner of the 2021 Paratriathlon World Championship, receives the award.
- Award for leading the action protocol to articulate and guarantee the supply of pharmaceutical products in their homes to people especially vulnerable to the disease, as well as to reduce the risk of contagion. The award was collected by Mr. Enrique Ruiz Escudero, Minister of Health of the Community of Madrid.
- Award to HM Hospitals for the role played in the care of COVID-19 patients and their collaboration in the control of the pandemic. Receives the award Dr. Juan Abarca, President of HM Hospitals.
- Award to the Ramón y Cajal University Hospital for having taken into account the risk groups in the COVID vaccination. Specifically, speeding up vaccination for people under 40 years with pulmonary hypertension. The award was collected by Agustín Utrilla, Medical Director of the Ramón y Cajal University Hospital (Madrid).
- Award for having explained the immunology and functioning of the COVID to the general population, for calming precautions and encouraging research especially with people with respiratory diseases. The award was collected by Alfredo Corell, Immunologist, University professor, Spanish science communicator and collaborator in Sexta Noche.
- Award to the UCRI UNIT of the Hospital Universitario 12 de Octubre, for its good coordination in the care of serious patients since the beginning of

the pandemic. The award was collected by Dr. Javier Sayas, pneumologist at the Hospital Universitario 12 de Octubre (Madrid), on behalf of the UCRI of the 12 DE OCTOBER HOSPITAL.

- Award to the Hospital Universitario La Paz, for its contribution at the care and scientific level in the management of Covid-19 infection. The award was collected by Juan José Ríos, Medical Director of the Hospital Universitario La Paz (Madrid).
- Award to the Transplant Unit of the Hospital 12 de Octubre, for their work with people affected by pulmonary hypertension. The award was collected by Dr. Pablo Gámez, Head of the Transplant Unit at the Hospital 12 de Octubre (Madrid).

### The Voice of the Affected

One of the most emotional moments was learning about the life of Laia, a little girl with Pulmonary Hypertension. Her mother, Patricia, tells us about the news that Laia had pulmonary hypertension, and how they live their daily lives.

### Activity Report 2019-2020

This is the moment in which we take stock of all the activities carried out from October 2020 to November 2021. It has again been a complicated year, but with a lot of imagination, with the help of many friends, we have managed to reach our objectives.

Enrique Carazo wanted to end the event with a message that sums up the work of the entity "from the Foundation we will continue to give all the support, training, information and accompaniment to each of those affected and their families, in each of their needs... and supporting research as hope for a cure".

### Colloquium Europa Press World Pulmonary Hypertension Awareness Month

Our president Enrique Carazo, participated in the Europa Press colloquium together with Dr. Sergio Alcolea and nurse Ana Ramirez. In the World Month of #PulmonaryHypertension Awareness, we join to give the maximum disclosure of the disease. "The first filter is you".

### COVID-19 Online Webinar

Experience in pulmonary hypertension one year after covid. After a year of Coronavirus, the team of the Foundation against Pulmonary Hypertension, pulmonologists, cardiologists and doctors from different hospitals in Spain and those affected and their families. will meet to talk about different topics of interest and to resolve doubts and questions. The following will participate as speakers:

- Dr. Olga Mediano pneumologist and collaborator in La Sexta noche.
- Dr. Isabel Blanco



pneumologist at HU Clínic de Barcelona.

- Dr. Andrés Quezada cardiologist at HU 12 de Octubre.
- Dr. Javier Sayas pneumologist at HU 12 de Octubre.
- Dr. Remedios Otero cardiologist at HU Virgen del Rocío.
- Dr. Elvira Garrido-Lestache Ramón y Cajal Hospital



### The Gales Consultancy

The Gales Consultancy gives us a wheelchair and a walker through the Renta Solidaria (Solidarity Income).

The company Asesoría Gales, located in Parla, gave us a wheelchair and a walking frame in their offices.

They will be destined for the reception flat we have in the town, so that those affected by #HipertensiónPulmonar who come from other Autonomous Communities for lung transplants can make use of them during their stay.

### The foundation against pulmonary hypertension in the Andalusian Parliament

Salvador Calderón, representing the Foundation Against Pulmonary Hypertension, has raised our concerns in the Andalusian Parliament.

Thanks to the Deputy and Health spokesperson M<sup>a</sup> Beatriz Jurado for welcoming us and dealing with such important and necessary proposals as our medicines:

"We are not complaining about generics, we are complaining about guaranteeing that pulmonary hypertensive patients are kept on the medicine that starts their illness and not constantly changing from original or brand to generic or vice versa... that they leave us with the medication that works for us", said Salvador Calderón.

Another proposal has been the aid for rent and maintenance for people who undergo a lung or cardio-pulmonary transplant outside the Andalusian community for people without economic resources. "There are Andalusians who cannot afford a room or a flat when waiting for the organ to be transplanted or for long-term treatment outside their autonomous community".

We are aware of the update being carried out for the PAPER (Care Plan for People with Rare Diseases) "it is high time that they listen to our Andalusian partners/affected people and include our proposals," Salvador pointed out.

The third point is the need for a financial injection in the budget for the creation of a CSUR in one of Andalusia's first level hospitals, as is the case in Madrid and Barcelona. This would be the way to have access and equity in the disease for all Andalusians with Pulmonary Hypertension.

<https://tinyurl.hu/NM7P/>  
<https://tinyurl.hu/VZ2u/>

Enrique Carazo Minguéz  
 FCHP Fundación Contra la Hipertensión Pulmonar  
<https://www.fchp.es/>  
[www.facebook.com/fundacionhpe](https://www.facebook.com/fundacionhpe)



SPAIN HPE

Presentación nueva Junta Directiva



Elecciones al Órgano de Representación de HPE-ORG 2021

Empowering people with PAH

During this year 2021, our associative social work has been focused on promote an active and empowered patient. For this reason, our work has continued along the same lines, our "mission". In addition, at Pulmonary Hypertension Spain we have participated in different activities organized by related entities and with which we collaborate on a regular basis, creating collaborative links and synergy.

Once again, this year, with the aim of raising awareness of rare diseases and placing them as a priority on the social and health agenda, World Rare Disease Day was celebrated on 28 February. The Pulmonary Hypertension Spain Patients' Organization has actively participated in the different campaigns organized by the Spanish Federation of Rare Diseases (FEDER), the European Organization for Rare Diseases (EURORDIS), the Pulmonary Hypertension Association (PHA), the Plataforma de Malalties Minoritàries and the Federació catalana de Malalties Minoritàries (FECAMM), among others.

In February, HPE-ORG participated in APHEC 2021. Due to the current health crisis, the conference was held virtually and although we missed the contact with the people and leaders of the European associations, it was a great success, very rewarding and innovative to create our own virtual stand,



where we shared information about our organization and the services we offer. We were also able to discuss issues of interest to pulmonary hypertension patients with the other European associations.

Among the collaborations with other entities, the collaboration in the field of dissemination at the X-Patients Barcelona Congress is noteworthy for its importance. And the participation in the seminar of the patients' day on the Patient's Perspective in the Health System, organised by Dr. Escarrabill and the Hospital Clínic.



As well as the participation with FENAER (Spanish Federation of Associations of Allergic



Patients and Respiratory Diseases) in the Podcast series "Date un Respiro" in which María Rodríguez, president of HPE-ORG, Dr. Manuel López Messeguer, specialist in Pneumology at the Vall de Hebrón Hospital in Barcelona, Ana María Ramírez, nurse specialist in pulmonary hypertension at the Hospital Clínic in Barcelona and several people affected by pulmonary hypertension, among others, took part.

In the same way, we also collaborate with public institutions in activities organised by them related to the associative world. Through the "Girona Voluntaria" programme, Marta Corominas, representative of our organisation in the city of Girona, took part in an event to raise the profile of volunteering in this city.

### Active and experienced patients

The main objective of Hipertensión Pulmonar España Organización de Pacientes is to work with an active, expert and empowered patient model. This is the reason why different workshops are carried out by professionals. Due to the geographical dispersion of PAH patients, the workshops are held online to reach all of them.



We run support groups to manage the critical situations that arise during the illness, and emotional management workshops where topics such as grief, stress, acceptance, emotional care, the importance of tools for self-knowledge and self-care are dealt with. Both workshops are led by expert psychologists in a group environment, in which the participants show satisfaction and gratitude at the end of the sessions.

In relation to the maintenance of physical activity, we organise yoga sessions with the collaboration of the teacher Lluïsa Lozano, who prepares breathing exercises adapted for PAH participants, helping to improve and

optimise breathing and the perception of stress. Along the same lines, Postural Training sessions are carried out with an expert physiotherapist in synchronous e-learning sessions, dealing with physical and respiratory rehabilitation in a supervised and controlled way. These sessions have been a success, as all participants agree that thanks to attending these classes, they have adopted techniques to control the body and mind.

We have also held workshops on dietetics and nutrition with nutritionist Cristina Lafuente, who has provided the keys to healthy eating and weight maintenance, as well as learning how to read food labels. Participants had the opportunity to ask questions and improve their knowledge on the different topics covered in the sessions, which have an impact on our daily lives.

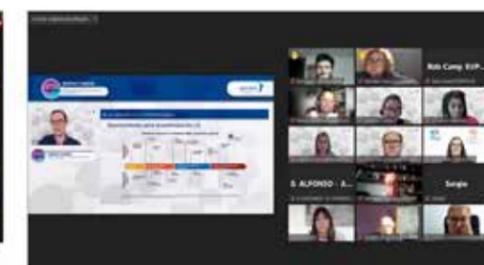


Thanks to the implementation of these activities aimed at improving the quality of life of patients and families affected by PAH, the organisation has been awarded twice; on the one hand, its work has been recognised in the VitalAire #AyudasPacienteVitalAire awards with the project "Respiraremos juntos: Acompañamiento psicosocial y emocional de las personas afectadas por Hipertensión Arterial Pulmonar" and on the other hand, we were awarded the second prize with the "Postural Training" project at the SEPAR Congress for patients, where we participated as speakers and where we addressed the issues of organic and invisible disability of minority diseases and patients as agents of change in health policies.

As every year, this year 2021 we have celebrated our V General Assembly of Members, in which we share with all our members all the activities, collaborations and trainings carried out in the previous year, we render accounts so that the members can evaluate the management of the entity that the Board of Directors has carried out and this year as a final touch of our assembly, we have renewed the positions of the Board of Directors to which two new members have joined. Due to the special circumstances caused by the Covid-19 pandemic, we have held the Assembly online.

To close this year 2021, we have prepared a final project consisting of an informative talk on adherence to treatment and legal aspects of PAH, two topics of great importance for all pulmonary hypertension patients.

### SESIONES INFORMATIVA Y FORMATIVAS



### Training and briefing sessions

In line with our work as an active and expert patient, we have taken part in various training courses throughout the year. Among others: Course on basic tools for strengthening associative work organised by COCEMFE (Spanish Confederation of People with Physical and Organic Disabilities). Training course on skills for the efficient management of rare disease patient associations (VII Edition) led by FEDER (Spanish Federation for Rare Diseases). Entity support with the Sant Feliu de Llobrega City Council.

We have also participated in activities organised by European entities such as the webinars „Living with rare respiratory diseases through the Covid-19 pandemic" organised by the ERS (European Respiratory Society) and „Towards a European Health Union", organised by MEP Lung Health Group to name but a few.

To bid farewell to the year, during the month of November, we have carried out an awareness campaign on Pulmonary Hypertension on the occasion of the month



of awareness of Pulmonary Hypertension worldwide, in addition to collaborating with the campaigns that have been carried out by PHA and PHA Europe, with great satisfaction for the results obtained.

In conclusion, we can say that 2021 has been a year of very intense but rewarding work and at the same time full of opportunities and we hope that the coming year will continue to provide us with opportunities to continue supporting pulmonary hypertension patients.

María Rodríguez, Hipertensión Pulmonar España

[www.hipertension-pulmonar.com](http://www.hipertension-pulmonar.com)  
[www.facebook.com/pg/HPSpain.org](https://www.facebook.com/pg/HPSpain.org)





## SWEDEN

For the third time since 2018 PAH Sweden arranged a camp for younger patients with PAH and CTEPH. It took place at the beautiful island Fårö in the Baltic sea in the beginning of September and we had three wonderful days together.

The arrangement was very appreciated and in November

we had a reunion party in Stockholm. In June 2022 we will for the first time arrange a corresponding camp for patients who is over 50 years old.

*Patrik Hassel*

<https://www.pah-sverige.se/>




## UKRAINE PHA



### February 11 • 2021

International Scientific Online Meeting: "How the COVID-19 Pandemic affects patients with rare diseases". The problems of patients with pulmonary hypertension were discussed in a separate block. The webinar is organized by Domenica Tarusio, Director of the National Center for Rare Diseases, Istituto Superiore di Sanità, Rome, Italy.

### In February 2021

PHA Ukraine, together with other public organizations, addressed the President of Ukraine and other government officials with a proposal to declare the penultimate day of February the annual Day of the Orphan Doctor. Doctors who specialize in orphan diseases (including PH) are as rare as their patients, because the qualifications of such doctors must be special, and they must have their own professional holiday.

### February 25 • 2021

Public Dialogue "State Support for Patients with Rare Diseases". A public dialogue between the authorities, the medical and patient communities on state support for patients with rare diseases was broadcast live. The event was timed to coincide with the Rare Disease Day 2021.

### February 26 • 2021

It was a very touching meeting in an atmosphere of kindness and compassion, which was accompanied by every word of His Beatitude Metropolitan Epiphanius. And our Julia Dmitrievskaya, a patient with pulmonary hypertension, together with the blessing received a gift from the bishop: an oxygen concentrator, and will now be able to receive the necessary oxygen therapy at home. "Today I had the opportunity to communicate and support those people who live with rare lung diseases.

Such moments make you think about every breath and its value. These people are respected, because despite the fact that diseases cause them a lot of difficulties, they choose not to give up: to fight for every day and with dignity accept the challenge of illness. They are teachers for each of us, how to love life, take care of our health, appreciate every moment spent with others... So let's ask ourselves: how can we help them? Only by joint efforts, united, can we become a support for these people, help them live", - wrote the Primate of the Orthodox Church of Ukraine His Beatitude Metropolitan Epiphanius after meeting. Thank you for these words and great support!

### 2021 year

This year on the eve of the Rare Disease Day, for the first time in Ukraine, the largest light initiative was held in support of orphan patients. 17 well-known locations in Kyiv, Odesa, Lviv, Dnipro, Mariupol, Mukachevo were illuminated for 10 days in orphan colors - green, pink and blue. On February 28, the culmination of the initiative took place on Mykhailivska Square in Kyiv - a light installation and an action of orphan patients. We are very glad that so many people held out their hands to orphan patients, and we have managed to draw attention to the problems of patients with rare diseases.

### March 12-14 • 2021

APHEC 2020. This year, through COVID-19 International Conference on Pulmonary Hypertension # APHEC2020 was held online. During the meeting, presentations of well-known doctors were presented, which covered important issues for patients with pulmonary hypertension. We thank the organizer of the conference PHA EUROPE and personally the moderator of the event for holding the summit and providing interesting and useful information.

### March 19 • 2021

Video meeting “Hearty conversations about pulmonary hypertension”, during which we discussed the following: What is pulmonary hypertension? What are the symptoms of this disease? Is this pathology related to heart defects? How do such patients live in Ukraine? Does the state help such patients? What should a mother pay attention to if her child is diagnosed with pulmonary hypertension? Is there a register of such patients in Ukraine?

### April 13 • 2021

A charity fair for Easter to support children and adults with orphan diseases that cause chronic oxygen deficiency: pulmonary hypertension, cystic fibrosis, spinal muscular atrophy.

### April 28 • 2021

The Cabinet of Ministers of Ukraine approved the Concept of providing assistance to orphan patients! This document provides for the identification of the exact number of orphan patients and the creation of registers, expanding methods of early diagnosis, development of industry standards, providing patients with special nutrition, providing psychosocial support. We have been fighting for this document for two years and now we are glad that Ukraine is gradually moving towards building a system that already operates in most European countries.

### May-August 2021

working meetings in the Departments of Health of Lviv, Kharkiv, Ivano-Frankivsk, Zhytomyr, Kramatorsk, Zaporizhzhia, Odesa to discuss the problems of providing patients with rare diseases (including patients with pulmonary hypertension) in regions of Ukraine in terms of COVID-19, as well as the purchase of medicines and medical devices in 2021.

### June-December 2021

The project of the PHA Ukraine “BREATHE = LIVE! Helping patients with pulmonary hypertension”. Children and adults with pulmonary hypertension, which causes chronic oxygen deficiency, need oxygen concentrators. After all, the possibility of round-the-clock access to outpatient oxygen therapy is improving the quality of life of our patients, facilitate the course of the disease and prevent possible complications. To help patients with pulmonary hypertension, it is necessary to buy oxygen concentrators for them, which allow them to remain mobile: children - to learn and play, and adults - to work, raise children and travel. This is especially important when you need to travel long distances. Due to the importance of the situation, PHA Ukraine has launched a project to raise funds for the purchase of stationary and portable oxygen concentrators to meet the needs of our patients. As part of the project “BREATHE = LIVE!” PHA Ukraine together with the Charitable



Foundation “Orphanni synytsi”, has already donated 8 oxygen concentrators to patients with pulmonary hypertension.

### August 29 • 2021

participation in the charity event “Move @ Smile” in support of patients with spinal muscular atrophy. This is the support of SMAs, who find it very difficult to go to their dream - to get the long-awaited treatment! This is a very serious rare disease that gradually deprives children of the opportunity to walk, eat and even breathe. There are now drugs that can stop the disease from progressing, but they are still not available to these children. We very much hope that this situation will change soon.



### September 22 • 2021

PHA Ukraine and PHA Europe were happy to fulfill the dream of our beautiful Alina Nikolenko, winner of the contest #O2kids - donated a scooter, which (we hope) will be a reliable helper during Alina’s travels short and long distances. We wish everyone easy breathing, good mood and new dreams!



### October 29 • 2021

Round table (online) for the Day of Acromegaly. In this way, we seek to draw the attention of officials in all regions to the problems of providing treatment for patients with acromegaly. The round table program includes issues such as a multidisciplinary approach to the treatment of patients with acromegaly, the situation with the provision of

medical care to patients with acromegaly and other orphan diseases in Ukraine, including pulmonary hypertension, the introduction of a register of patients with acromegaly and pituitary Ukraine, positive experience of implementing a regional program on acromegaly (steps that need to be taken by each patient) and more.

**November 16 • 2021**

A working meeting of the Committee on National Health, Medical Care and Health Insurance. The main topic of the meeting is financing the treatment of orphan patients in 2022. Representatives of the Committee, the Ministry of Health of Ukraine, the National Health Service of Ukraine, Medical Procurement of Ukraine, leading doctors and patient organizations took part in the discussion.

Oksana Aleksandrova  
Ukraine Association of Patients with PH  
[www.pha.org.ua](http://www.pha.org.ua)  
[info@pha.org.ua](mailto:info@pha.org.ua)



19 березня, 18:00

ДИТЯЧЕ СЕРЦЕ  
МІЖНАРОДНИЙ КЛАСТЕРНИЙ ФОНД

СЕРДЕЧНІ РОЗМОВИ  
про легеневу гіпертензію

ВАЛЕНТИНА ХАНЕНОВА,  
к.мед.н, дитячий кардіолог,  
старший науковий співробітник  
Центру дитячої кардіології та кардіохірургії

ОКСАНА АЛЕКСАНДРОВА,  
голова правління  
Всеукраїнської громадської організації  
«Асоціація хворих на легеневу гіпертензію»





# UKRAINE PHURDA



**28 лютого**  
ДЕНЬ РІДКІСНИХ ЗАХВОРЮВАНЬ



### Rare Disease Day 2021

PHURDA and Orphan Bell organised a round table meeting called „The Day of Orphan Diseases” February 26, 2021. Also participating in the meeting was the Lviv Regional Council with the leadership of the Lviv region representatives of the health and social protection of Lviv region.

The meeting consisted of discussions about the situation of orphan patients in Lviv region, their access to diagnosis, vital treatment, rehabilitation, including the following diseases: pulmonary hypertension, tuberous sclerosis, mucopolysaccharidosis, mucoviscidosis, VDDR2a, cystic fibrosis, Gaucher disease, SMA, cdk15, Acromegaly.

On February 26, 2021 the portrait exhibition "Invisible Heroes" was opened on the main square of Lviv. It was dedicated to Rare Disease Day. At the exhibition, portraits of patients were exposed with rare diseases. There was also a poster on the main wall above the entrance of Lviv City Council dedicated to Rare Disease Day.

### O2Kids

As a part of O2Kids project we filmed a video starring young PH patient called Artem, who had gotten an e-scooter for St. Nicolas Day last year. Later,



the video was translated to English. Also we launched -O2Kids- advertisement on radio. During August there were billboards placed together with city-lights in the streets of Lviv. In addition, we published flyers. Thus, we found one more child who needs e-scooter and tablet.

PHURDA received 2d place award from "Charitable Ukraine" contest for the O2Kids project.

### Participation in conferences

Despite the pandemic, PHURDA managed to participate in many events such as APHEC 2021, Eurordis Membership Meeting 2021, ERS Congress 2021, ELF Patient Networking Day 2021 etc. Oksana

Kulish Skaara has been an active member of

EPAP Patient advisory Group at ELF for a few years, and in September this year Oksana was elected to the ELF Council. This is a great honour to join the ELF team. But the most remarkable and memorable conference was APHEC. We were very excited to see the whole PH family which we are part of, and to see and to talk to friends at the pool.

### Participation in online trainings & meetings

We participated in a Zoom meeting with





“Patients of Ukraine” Charitable Foundation regarding advocacy to include new medicines into the Nomenclature 2022. Furthermore, we participated in online training programs like “Organization and communication: essential parts of successful vaccination campaign”, “Communication for NGO”, “Public expertise”, Eurordis Leadership School, “How to stop worrying and start living with PH”, “The importance of measuring patient recorded outcomes”, ERS Digital Summit, New approaches to mild asthma. GINA 2021 updating”, Long-Covid Patient Conference. The representatives from PHURDA continue their work in The Group of experts at the Ministry of Health of Ukraine on specialized support of procurement of medicines and medical devices in the field of “Pulmonary arterial hypertension”, Transplantation. This work is expanding the range of medicines for procurement, while maintaining funding of previous needs. All this is based on the real needs of patients gathered from all over Ukraine.

### Ongoing projects

We started a project called „Legal assistance services for PH patients” that started in May. During the year, our lawyer, Andrii Hulei, provided PH patients with legal consultations in order to increase the legal awareness among PH patients and their families (for instance, legal registration of the organization etc.) We also continue our helpline work. Every week we get calls from different people who suspect they suffer from PH or who has gotten diagnosed already. We provide informational and sometimes psychological support.

In Autumn we started a new fundraising project that consists of holding trainings on different topics. The training sessions are face-to-face and online. They are paid for by ordinary participants and free for PH patients. The first webinars were dedicated to Time management.

In October, with support of NGO “Inshyi pidhid”, we held online Blue IT Butterfly project. It was created for PH patients and others who suffer from any medical condition and that is unable to work off-line and full time. We held four webinars involving different speakers: HR, IT specialist, project managers. Participants got to know how and where it is possible to work in IT, how to start,

what soft and hard skills are necessary, etc.

We also run another activity through our collaboration with NGO “Inshyi pidhid”: “Give laptop to a child”. We collect used PCs, check, test them, repair if needed and then give to a PH child. Thanks to this project, one teenage girl has gotten a laptop already. This was very cool and helpful gift for her as she is in the senior class of school.

Christmas is approaching. Kids believe in miracle and wait for presents from St. Nicolas. We decided to help their dreams to come true. We gathered their letters to St. Nicolas and passed to the Church where all the letters would be distributed between benefactors and patrons.

And, of course, we continue “Cork for Life” fundraising campaign that helps us to cover some expanses.

PHURDA representative carried out the joint project from USAID and CF “Patients of Ukraine”, “The healthcare reform support”.

This year PHURDA signed a memorandum with Lviv regional organization of Red Cross Ukraine Community. As part of this collaboration, our PH patients got hygienically sets that are very helpful during pandemic.

In addition, we continue our active work related to the COVID-19 pandemic. We provided some oxygen-dependent patients that had suffered from COVID-19 with oxygen concentrators. Besides, we disseminate important information about COVID-19 and vaccination on social networks.

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



Media clippings Austria

Ihr wurde gehoffen, nun macht Maleen Kinderwünsche wahr

Vier Jahre haben wir die kleine Krissi Malen Fischer mit einem Wunsch Pop-Star Justin Bieberle teilhaftig. Der Traum wurde dank „Male A Wish“ wahr - nun erhebt sie sich für die Charity...

Yoga ausprobieren für den guten Zweck

Yoga-Trainerin Rani Gindl: „Ich biete am 6. und 13. September jeweils zwischen 17 und 18.15 Uhr eine Charity-Yoga-Einheit an.“



Ghostrun - Wiener Prater

21. OKTOBER 2021
Lauft (6km)
Die Walking (6km)
Hienlauf (1.5km)
...und dabei etwas Gutes tun!



ÖSTERREICH LÄUFT - AKTUALISIERTE TERMINE

Der österreichweit bekannte Platz der Meilensteine vor dem Planetarium in Wien Prater wurde vom „Lungenkinder Forschungsverein der PH Austria - Initiative Lungenhochdruck“ um einige neue Pflastersteine bereichert...



Wienerin startet mit dritter Lunge als Autorin durch

Mit 27 Jahren erhielt Rani Gindl die Diagnose Lungenhochdruck, zwei Lungentransplantationen folgten. In ihrem Buch berichtet sie über ihre Erfahrungen.



Frauenlauf, Night Run und mehr: Die Wettkämpfe starten wieder

Der Vienna City Marathon hat heuer auch symbolischen Charakter. Er ist der offizielle Startschuss für viele andere Laufveranstaltungen. Ein Überblick.



Alleingelassen zu werden, ist das Schlimmste

„Alleingelassen zu werden, ist das Schlimmste“, sagt eine Teilnehmerin beim Ghostrun. Die Veranstaltung wird von der Initiative Lungenhochdruck organisiert.



Schaurig-schönes Halloween

Halloween steht vor der Tür! Für alle, die den Gruselkick genießen und die schaurigsten (coronakonformen) Veranstaltungen. Am Sonntag ist Halloween-Damit Gruselaffen verbreitet, gib's in Wien Mitte eine coole Basestation heute (14 bis 19 Uhr) und morgen (11 bis 18 Uhr) werden Kürbisse gestekt und gebackt.



Planetarium Steine für den guten Zweck!

Der österreichweit bekannte Platz der Meilensteine vor dem Planetarium in Wien Prater wurde vom „Lungenkinder Forschungsverein der PH Austria - Initiative Lungenhochdruck“ um einige neue Pflastersteine bereichert...



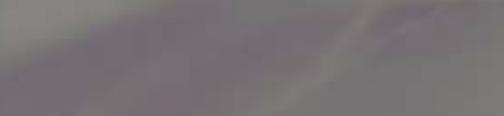
Yoga schnuppern für einen guten Zweck

Yoga-Trainerin Rani Gindl: „Ich biete am Montag, 13. September zwischen 17 und 18.15 Uhr Charity-Yoga an.“



Wienerin (43) startet mit dritter Lunge als Autorin durch

Mit 27 Jahren erhielt Rani Gindl die Diagnose Lungenhochdruck, zwei Lungentransplantationen folgten. In ihrem Buch berichtet sie über ihre Erfahrungen.



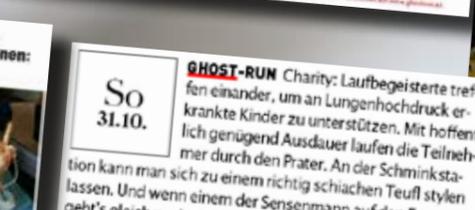
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Mitlaufen und Gutes tun!

Zu Halloween steigt Ghostrun im Prater. Im Rahmen gegen Lungenhochdruck klingen die Glocken gegen Lungenhochdruck.



So 31.10. GHOST-RUN Charity: Laufbegeisterte treffen einander, um an Lungenhochdruck erkrankte Kinder zu unterstützen.

Charity: Laufbegeisterte treffen einander, um an Lungenhochdruck erkrankte Kinder zu unterstützen. Mit hoffentlich genügend Ausdauer laufen die Teilnehmer durch den Prater.



Einzelnen rar, Rund eine halbe Million Österreicher sind von einer seltenen Erkrankung betroffen.

Einzelnen rar, Rund eine halbe Million Österreicher sind von einer seltenen Erkrankung betroffen. Die Erkrankung ist eine seltene Form der Arterienhypertonie.

Buch über Transplantationen: „Ich will Mut machen“

Buch über Transplantationen: „Ich will Mut machen“. Rani Gindl hat nach der Diagnose Lungenhochdruck zwei Lungentransplantationen erhalten.



Wien - Pressegespräch: Für mehr Versorgungssicherheit - AOP Orphan nimmt Betrieb einer Verpackungsanlage in Wien auf

Wien - Pressegespräch: Für mehr Versorgungssicherheit - AOP Orphan nimmt Betrieb einer Verpackungsanlage in Wien auf.



Weitere Events

Im Laufschrift für den guten Zweck

Im Laufschrift für den guten Zweck. Viele Veranstaltungen laden zum Mitlaufen und Mit Helfen ein.

Vienna Night Run. Sobald es dunkel wird, geht es fünf Kilometer rund um die Ringstraße.

Fit for Brain Run. Die Österreichische Schlaganfallgesellschaft veranstaltet im Prater eine Lauf- und Walk-Charity-Veranstaltung.

Wiener Herbstmarathon. Der LCC-Herbstmarathon startet zu Berdem Halbmarathon, Staffelmorathon, Stafhalbmarathon sowie die 10,32,5-Meter-Strecke.

Ghostrun. Der Wiener Kostümlauf zu Halloween wird zugunsten von Kindern mit Lungenhochdruck veranstaltet.

„Ich will anderen Mut machen“. Rani Gindl hat nach der Diagnose Lungenhochdruck zwei Lungentransplantationen erhalten.

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Croatia

**in PORTAL**  
 VESTI SPORT MODERNA VREMENA INKREŽA KUTAK ZA STRUČNJAKE IN POSAO

**STUĐENI - MJESEC PODIZANJA SVIJEŠTI O RESPIRATORNIM BOLESTIMA**

U DRUGA PLAVA KRILA Studeni - mjesec respiratornih bolesti

Kako je studeni mjesec podizanja svijesti o respiratornim bolestima, Zdenka Brađač, predsjednica Udruge Plava krila, poslala je poručio koje prerasimo u cijelosti

ZADNJE NOVOSTI

- Studeni - mjesec podizanja svijesti o respiratornim bolestima
- Javno-obavješćujuća kampanja - Govorimo o raku pluća „Ja znam“
- Osljeđen suzdržani dan kronične respiratorne bolesti pluća (CRB) u sklopu javno-obavješćujuće kampanje „Ja znam“
- Prešlih aktivnosti 2020/21

**Dr. Ana Hećimović o plućnoj hipertenziji, rijetkoj bolesti koja se javlja u mlađoj dobi**

128-slojni MSCT Vereos

OD SUNDAJE DO SUNDAJE U JEDNOM DANI

Kategorije

**portal ZDRAVLJE**

Studeni je mjesec afirmiranja svijesti o respiratornim bolestima pa tako i o plućnoj hipertenziji. Plućna arterijska hipertenzija je bolest koja karakteristično počinje slab u plućnom arterijskom ili sistolnom pritoku kroz leziju pluća.

Povijesnica toga je smjerna zasnoženosti koji kisikom što bolesnici osjećaju kao nedostatak zraka najčešće u većim naporima, a kako bolest napreduje očajnjeg nedostatka zraka javlja se već kod svakodnevnih aktivnosti i manjih napora. Upravo je to ograničavajući faktor za funkcioniranje bolesnika koji značajno narušava kvalitetu njihovog života. Kako je plućna hipertenzija rijetka bolest koja se javlja već u mlađoj životnoj dobi potrebna je potpora kako obitelji tako i okoline te je važno podizati svijest o rijetkim bolestima i problemima koje bolesnici imaju u svom svakodnevnom životu.

Podaci o učestalosti bolesti dobivani su iz različitih registara i međunarodno se razlikuju ovisno o registru, ali prema većini podataka bolest je češća u žena, a srednja dob prema novijim podacima je između 45 i 60 godina. U našem Registru za plućnu hipertenziju imamo nešto više od 450 bolesnika od kojih je njih oko 130 trenutno u aktivnom liječenju, do njih je u praksi, a jedan dio bolesnika je transplantiran.

Danas u Republici Hrvatskoj imamo dostupne lijekove za liječenje plućne arterijske hipertenzije kao prete smjernice za liječenje i naprosto dostupna lijekove, a kao krajnja opcija liječenja dostupna je i transplantacija pluća.

**Zarybapok**

OSIT Bjelovar

UDRUGA OSOBA SA INTELIGENCIJOM I TEŠKOĆAMA BIJELOVAR

**Osit Mario (Udruga Osit Bjelovar)**

UDRUGA OSOBA SA INTELIGENCIJOM I TEŠKOĆAMA BIJELOVAR

Czech Republic

**Smrtnou plućní hypertenzí můžete trpět, aniž byste o tom věděli. MUDr. Jansa vysvětluje, jak postupovat**

Zadýcháváte se při chůzi do schodů a bolí vás při fyzické námaze na hrudi? Můžete trpět plućní hypertenzí, tedy zvýšeným krevním tlakem v plućních cévách. Tuto nevléčitelnou chorobu mají v Česku desítky tisíc lidí, velké množství z nich ale svou diagnózu buď nezná, nebo se ji dozví pozdě. Právě včasné odhalení může zabránit vážným následkům, ale i smrti. Tito lidé jsou také mnohem více náchylní k nákaze nemocí covid-19.

03.09.2021 - 08:00  
 Autor: **Martin Chalupa** | chalupa@ctidoma.cz

**Lékaři mi ve 13 letech dávali dva roky života. Pomohla transplantace**

28. května 2021

Ve třinácti letech jsem si vylechla diagnózu plućní hypertenze – nevléčitelné onemocnění, které způsobuje zvýšený krevní tlak v plućních cévách. Lékaři mi tehdy předpovídali dva roky života. Čtenářka Bára napsala další díl našeho seriálu Můj boj s nemocí.

**Fotogalerie** +4

Bára po transplantaci | foto: Archiv Čtenářky

Protože jsem se narodila předčasně, už od malička můj stav hlídali kardiologové kvůli šelestu na srdci. Ve třinácti letech mi pak jedna z prohlídek změnila život: lékaři mi diagnostikovali plućní hypertenzi.

Při této nevléčitelné nemoci se nadměrně namáhá pravá strana srdce, která se postupně zvětšuje, a může dojít k srdečnímu selhání. Pacienti většinou kvůli špatnému oxyličování krve trpí únavou, dušností a mdlobami.

Mně tehdy dali lékaři dva roky života. Já ani moji rodiče jsme se s tím však nesmřili. Následující roky jsem brala léky, ale můj zdravotní stav se postupně zhoršoval. Zatímco ještě pár měsíců před stanovením diagnózy jsem chodila po Alpách, najednou jsem začala být často unavená, zadýchávala jsem se a promodrávala mi kůže, což je typický příznak plućní hypertenze.

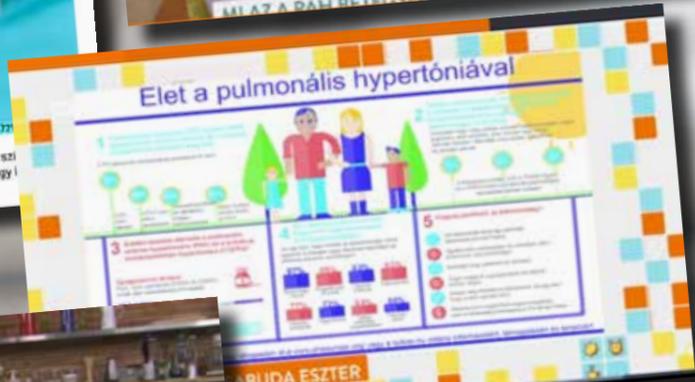
**blum**

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**Zjistit víc**

Hungary



Ireland



Portugal

**Leiria vai caminhar para sensibilizar para a hipertensão pulmonar**

Considerada uma "doença zebra" do ponto de vista médico, a Hipertensão Pulmonar é incurável e raramente diagnosticada precocemente.

Publicado há 5 meses em 11 de Novembro de 2021

**CORRIDA / CAMINHADA SOLIDÁRIA**  
20 NOV 2021 | 15H

**Hipertensão pulmonar lança apelo ao diagnóstico precoce através uma Caminhada solidária**

Caminhada/corrída solidárias para doentes, cuidadores e população em geral está marcada para o dia 20 de novembro, em Leiria. Inscreva-se.

Por ocasião do Mês da Sensibilização para a Hipertensão Pulmonar (novembro), a Associação Portuguesa de Hipertensão Pulmonar (APHIP) vai organizar uma caminhada/corrída solidária para doentes, cuidadores e população em geral, no dia 20 de novembro, em Leiria.

**Comunidade de hipertensão pulmonar lança apelo ao diagnóstico precoce através uma caminhada solidária**

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Por ocasião do mês de sensibilização para a Hipertensão Pulmonar (novembro), a Associação Portuguesa de Hipertensão Pulmonar (APHIP) vai organizar uma caminhada/corrída solidária para doentes, cuidadores e população em geral, no dia 20 de novembro, em Leiria.

Spain FCHP

**Investigan nuevas dianas terapéuticas para el tratamiento de la hipertensión pulmonar, una enfermedad rara y sin cura**

Grupo de Investigación del CIBERES liderado por Francisco Pérez Vizcaino (UCM) al que pertenece Ángel Cogolludo (primera fila izquierda) - CIBER Madrid, 14 May. (EUROPA PRESS) -

Investigadores del CIBER de Enfermedades Respiratorias (CIBERES) buscarán profundizar en el conocimiento de los mecanismos patogénicos implicados en el progreso de la hipertensión arterial pulmonar (HAP) que están asociados a distintas variantes del gen KCNAs, con el objetivo de encontrar nuevas dianas terapéuticas.

Este nuevo estudio, liderado por Ángel Cogolludo, investigador del CIBERES, de la Universidad Complutense de Madrid (UCM) y del Instituto de Investigación Sanitaria Gregorio Marañón (ISGM), pretende hallar nuevas dianas terapéuticas a las que dirigir fármacos que preserven y mejoren la actividad de canales de potasio cuya alteración es crucial en el avance de la enfermedad.

**La importancia de la detección precoz de la hipertensión arterial pulmonar**

Por Francisca Pérez

**La importancia de la detección precoz de la hipertensión arterial pulmonar**

Por Francisca Pérez

Noviembre es el mes de la Hipertensión Arterial Pulmonar. Una enfermedad rara, grave y progresiva que afecta a los vasos sanguíneos que transportan la sangre del corazón a los pulmones, lo que provoca un aumento de la presión arterial en el lado derecho del corazón. Las síntomas son muy inespecíficos al principio, lo que suele traducirse en el retraso en el diagnóstico, como han destacado los participantes en el encuentro digital El primer día que se organizó por Europa Press con la colaboración de Janssen.

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Slovakia

**Pandémia ľudí s chorými pľúcami neprekvapila**

Hoci sa vďaka zhrňutí pred nákazami, COVID sa nevyvíja ani inak

Podľa odborníkov sa na Slovensku, ako aj v ostatných krajinách, neprekvapila pandémia ľudí s chorými pľúcami. Hoci sa vďaka zhrňutí pred nákazami, COVID sa nevyvíja ani inak. Podľa odborníkov sa na Slovensku, ako aj v ostatných krajinách, neprekvapila pandémia ľudí s chorými pľúcami. Hoci sa vďaka zhrňutí pred nákazami, COVID sa nevyvíja ani inak.

**PLŮCNA ARTÉRIOVÁ HYPERTENZIA POSTIHUJE AJ MLADŠÍCH ĽUDÍ**

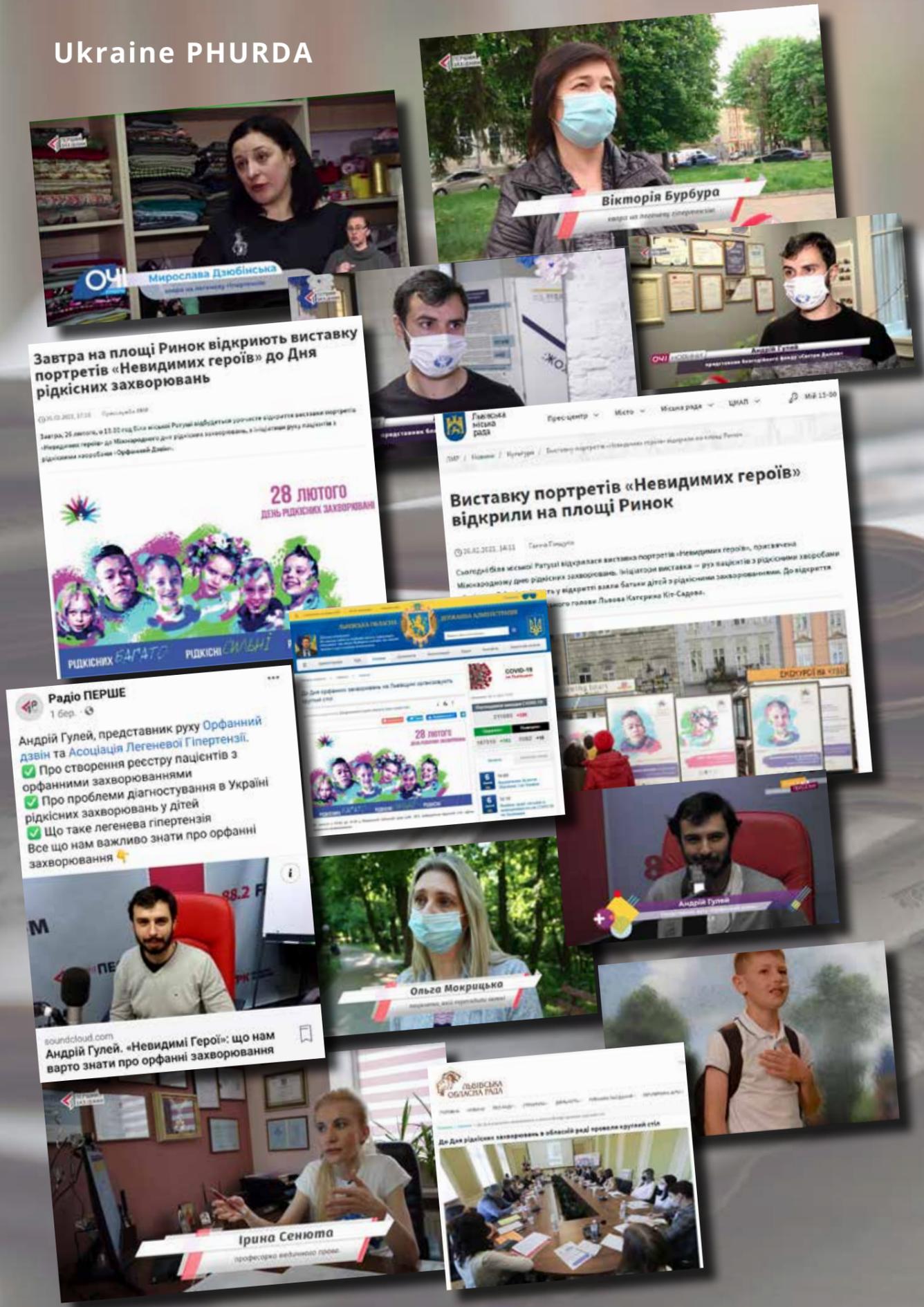
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**europa press**

**Enrique Carazo**  
Presidente de la Fundación contra la Hipertensión Pulmonar



# Ukraine PHURDA



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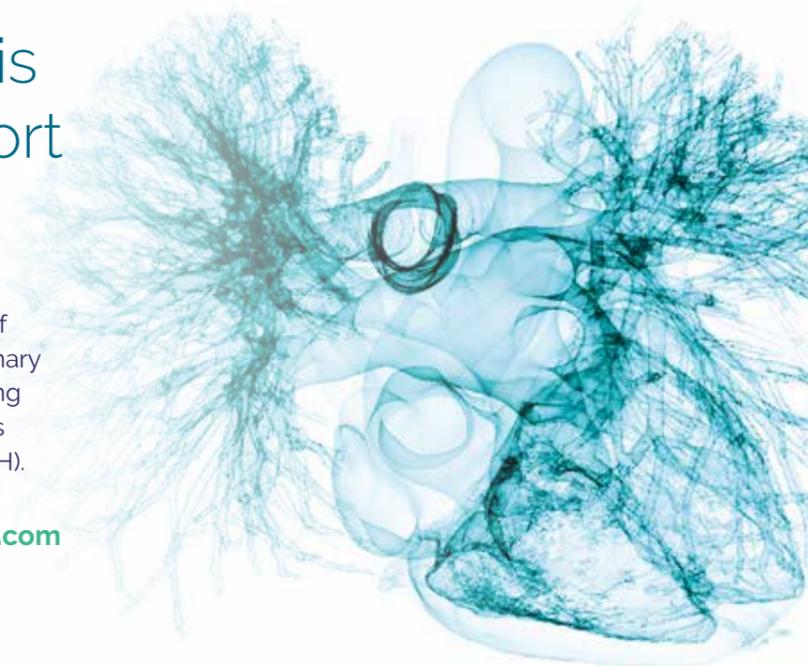
**Janssen**  
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## Aerovate Therapeutics is proud to support PHA Europe

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

Learn more at [www.aerovatetx.com](http://www.aerovatetx.com)



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## Collaboration with Bayer and MSD Making a difference, together



Throughout this issue of Mariposa, the positive impact of projects throughout PHA Europe – on patients, their carers and families – has never been clearer.

At Bayer and MSD, we are committed to supporting patients throughout their entire pulmonary hypertension (PH) journey, and to truly making a difference to patients' lives.

Collaborations between industry and patient organizations ensure our work continues to deliver what patients really need. In the past year alone, financial sponsorship from Bayer and MSD has helped PHA Europe to:

- Reach over **115,800 people on social media** to raise **disease awareness** in the PHA community<sup>1</sup>
- Facilitate **public, healthcare professional-led lectures and patient-focussed webinars** to help patients understand their disease
- Develop resources and fund over **50 local events** with over **276,600 attendees** to support those living with PH<sup>1</sup>
- Fostered collaboration with **non-PH groups** across Europe to increase the **impact of awareness activities**



**TRACEY HUDDY**  
 Head of Pulmonology and Established Products, Bayer

*"We won't rest until patients who suffer from pulmonary hypertension can forget their disease and return to a normal life"*



**ERIC COX**  
 Global Marketing Head for Heart Failure and Orphan Indications, MSD

*"Through the work of our local and global teams, we are committed to making a continued difference to the lives of people with pulmonary hypertension"*

<sup>1</sup> Bayer AG. Data on file: World PH Day 2019 evaluation report. 2019. PP-ADE-ALL-0197-1



## Vision • Connection • Innovation

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

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

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

Date of preparation: June 2021

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

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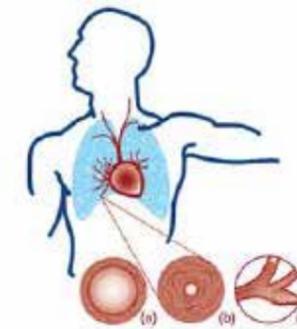


## AIMS OF PHA EUROPE

Pulmonary arterial hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria, as an international non profit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hyper-tension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations and public institutions worldwide and work towards achieving the best possible standards of care for all European pulmonary hypertension patients.

## WHAT IS PULMONARY ARTERIAL HYPERTENSION?

In patients with Pulmonary Arterial Hypertension characteristic changes occur within the pulmonary circulation, which include thickening of the linings and obstruction of the small pulmonary blood vessels. They are both structurally and functionally abnormal. In severe cases up to 80% of these very small blood vessels are rendered non-functional. As a result the pressure in the pulmonary circulation rises well above normal and this places strain on the right side of the heart. This strain can cause the heart to enlarge and the patient may develop heart failure. This is a disease that can affect all ages and is more commonly seen in females. Pulmonary arterial hypertension has an estimated prevalence of about 50 per million population.



a) Cross section of normal pulmonary artery

b) Reduced lumen of pulmonary vessels due to cell proliferation and remodelling in advanced pulmonary arterial hypertension

c) Longitudinal section with pathological changes within the vessels (proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs

## TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

Over the past decade a number of evolving therapies that either use complex delivery systems such as 24-hour intra-venous or subcutaneous drug infusion, drug inhalation and, more recently, oral medications, have transformed the outlook for PAH patients. PAH is a condition that can be rapidly progressive and needs careful, ongoing expert care and management. The disease can be insidious in its onset, with unexplained breathlessness and tiredness as its two main symptoms. If undiagnosed and/or inappropriately treated the average life expectancy for these patients is estimated to be around 2-3 years. For those patients who fail to respond to medical therapies double lung, or in some cases, heart and lung transplantation may be appropriate.

## THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

While a cure for this aggressive and life threatening disease is still some way off, there is much to be optimistic about. There are an ever increasing number of therapies available for the effective treatment for pulmonary arterial hyper-tension, which improve the quality and length of life. The aim for the present should be to ensure that all patients with pulmonary arterial hypertension have access to centres of excellence in the diagnosis, management and ongoing treatment of this disease.



At Ferrer we are dedicated to working for people with Pulmonary Hypertension to improve their physical and emotional wellbeing.

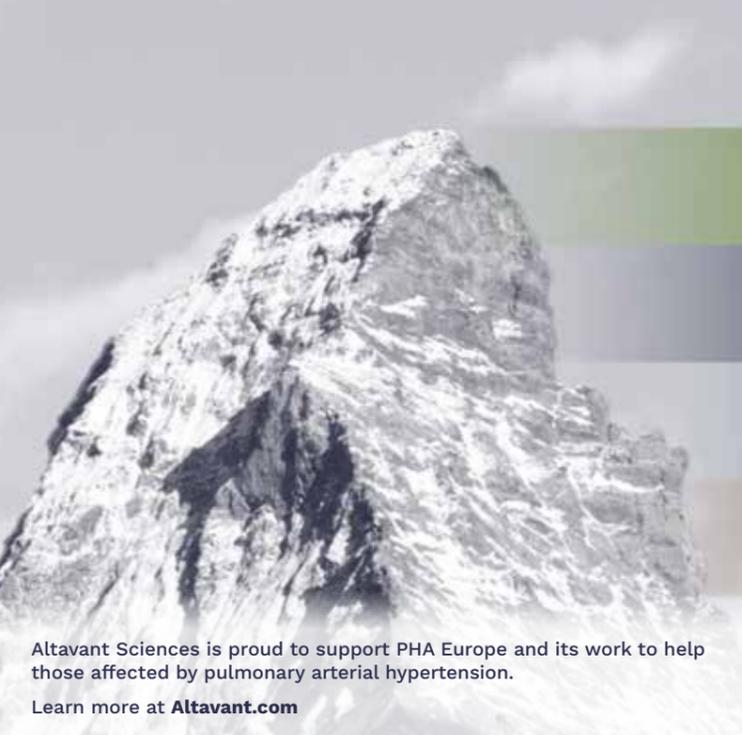
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Elevating patient-centric drug development in rare respiratory diseases



Altavant Sciences is proud to support PHA Europe and its work to help those affected by pulmonary arterial hypertension.

Learn more at [Altavant.com](http://Altavant.com)

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### FINLAND



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**Udruženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini**  
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[ugphbih@gmail.com](mailto:ugphbih@gmail.com)

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[csabuda.eszter@t-online.hu](mailto:csabuda.eszter@t-online.hu)

### BULGARIA



**Pulmonary Hypertension Association**  
37 Hadji Dimitar str, ent. B, fl. 2, ap. 3  
5800 Pleven  
[www.phabulgaria.eu](http://www.phabulgaria.eu)  
[todormangarov@abv.bg](mailto:todormangarov@abv.bg)  
[info@phabulgaria.eu](mailto:info@phabulgaria.eu)

### ISRAEL



**PHA Israel**  
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### BULGARIA



**The Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH**  
Pirinski prohod str., bl.24 A, entr. B, fl.3,  
ap.34 Sofia - 1680, Bulgaria  
[www.bspph.net](http://www.bspph.net)  
[bgspph@gmail.com](mailto:bgspph@gmail.com)

### ITALY



**Associazione Ipertensione Polmonare Italiana Onlus**  
Via della Spiga, 10 - 06135 Ponte S. Giovanni-PG  
[presidente@aipiitalia.it](mailto:presidente@aipiitalia.it)

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### ASSOCIAZIONE MALATI DI IPERTENSIONE POLMONARE ONLUS



**Associazione Malati di Ipertensione Polmonare Onlus**  
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[info@assoamip.net](mailto:info@assoamip.net)

### CZECH REPUBLIC



**Sdružení pacientů s plicní hypertenzí, z.s.**  
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