



PULMONARY HYPERTENSION

# Mariposa Journal

WINTER 2020 • PHA EUROPE'S OFFICIAL JOURNAL • N. 25.



*Warmest wishes for a Happy New Year*  
from PHA Europe



# editors memo

WINTER 2020 EDITION

*Dear Friends,*

I am delighted to present the Winter 2020 edition of Mariposa.

No one would have thought at the beginning of the year how special and challenging the coming days would be. On the 10th of March, the World Health Organization declared the COVID-19 outbreak a pandemic. Everybody's life changed dramatically and established plans were demolished in minutes. Probably the uncertainty was the most difficult to handle.

Sooner or later, however, we learnt to live together with this new situation: we became experts of online tools and successfully ran meetings, webinars and conferences on various virtual platforms. Life did not stop, despite all the strict measures the governments introduced to slow down the spread of the virus, or – as we learnt – “to flatten the curve”. Naturally, lots of things are missing from our life: the networking, visiting and being with our loved ones.

On the other, we can be proud of the lots of activities and achievements of this year and how well pulmonary hypertension (PH) is positioned amongst the rare diseases. We launched our new webpage with new contents and regular updates. All of the scientific articles were either reviewed or a completely new text was drafted. We made our materials more visible and accessible.

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

We participated in various questionnaires and were one of the key drivers of the PHCare COVID questionnaire, which collected more than 1000(!) responses from PH patients and carers all over the world: the publication of the results is expected soon.

In collaboration with EURORDIS and ERN-Lung and in cooperation with our valued partners from the medical field, we compiled a patient journey which outline the whole patient path from the first symptoms to the follow-ups. The leaflet also contains what we think is ideal at each stage and the patient needs. We hope that more and more translations of this awareness raising and advocacy tool will be finished in the coming days.

It was very important for us to help our member associations in these challenging times: we sent branded masks to our members and health care providers.

November was also a very busy month: on the occasion of PH awareness month a number of events were organized from Spain to Ukraine, from Bosnia-Herzegovina to Portugal. There were, among others, scientific lectures, a virtual gala “dinner”, a solitary and solidary walk, a breathtaking rowing tour and messages/quotes and videos about COVID and the importance of responsible behavior.

We devoted lots of energy and time to advocacy work as well. We are working closely with big umbrella organizations such as EURORDIS and European Patients' Forum (EPF) and are pleased to have a good working relationship with European Lung Foundation (ELF) and European Federation of Allergy and Airways Diseases Patients' Associations. We are members of the steering committee of the newly (re)launched MEP (Members of the European Parliament) Lung Health Group, whose primary aim is to keep airways diseases on the EU agenda. You might search for the detailed report and many photos in this edition of our Annual Pulmonary Hypertension European Conference (APHEC) usually organized in autumn. This conference provided lectures from PH experts and other professionals on various fields like patient empowerment and nutrition to name a few, presentations from the representatives of the pharmaceutical companies and opportunity for PH associations leaders to meet with each other and share experiences. The program usually covered small group discussions and the long awaited Gala dinner with lots of fun and laughter. We hoped that the pandemic will settle and there will be a chance to organize the APHEC and meet each other face to face. Instead, we decided, bearing in mind the safety of patients, carers and their relatives, to organize an online event early next year. I am sure it will be again a very interesting event with lectures about new information, updates on PH management and trials, “coffee rooms” to facilitate discussions amongst the members and many more.

Let me conclude with our appreciation to our medical partners, physicians, surgeons and researchers! Without their hard work and dedication, we would not be where we are now. We also warmly thank our industry partners, who make our work possible and tirelessly support our projects.

Looking forward to next years' challenges and initiatives!

**Gergely Mészáros**  
Project manager



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**Vienna /AUSTRIA/ • February 15-16  
BOARD AND STAFF MEETING**

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

**Frankfurt /GERMANY/ • February 26-27  
ERN-LUNG BOARD MEETING**

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



**Virtual /ONLINE/ • March 11  
PATIENT ACCESS PARTNERSHIP (PACT) – PARTNERS ASSEMBLY**

The originally scheduled face-to-face meeting on the annual report/budget and workplan for 2020/2021 was held online. Gergely represented PHA Europe on this meeting.



**Virtual /ONLINE/ • March 11  
SHARED VISION FOR IMPROVING  
ORGAN DONATION AND  
TRANSPLANTATION IN THE EU  
AND BEYOND 2020**

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



**Virtual /ONLINE/ • April 14  
BOARD AND STAFF MEETING**

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

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

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

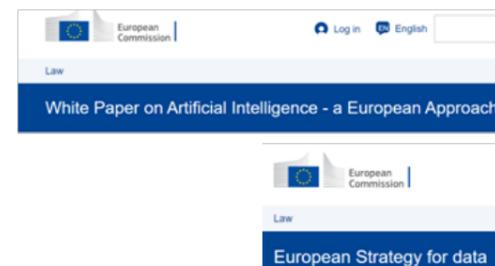


**Virtual /ONLINE/ • April 27  
EUROPEAN SOCIETY FOR ORGAN TRANSPLANTATION (ESOT)-WEBINAR:  
COPING WITH UNCERTAINTY DURING THE COVID-19 PANDEMIC**

The challenges the pandemic brought if for transplantations and for transplanted patients were presented by surgeons and patients. Gergely attended the webinar.

**Virtual /ONLINE/ • April 30  
ERN LUNG-ERS JOINT WEBINAR: COVID-19**

Various experts from the rare respiratory diseases held lectures about COVID-19 in the early phase of the pandemic. Gergely attended this webinar.



**Virtual /ONLINE/ • May 4  
EPF-CONSULTATION WEBINAR  
ON EU'S DATA STRATEGY AND  
AI PUBLIC CONSULTATIONS**

During the webinar the comments to the above two documents were discussed. Gergely reviewed the documents and participated in the webinar.

**Virtual /ONLINE/ • May 14-15  
EURORDIS – ECRD  
(EUROPEAN CONFERENCE OF RARE DISEASES)**

It is recognized globally as the largest, patient-led rare disease event with numerous lectures from policymakers, academia and patient representatives on the rare disease field. Gergely was awarded with a fellowship from EURORDIS to attend.



**Virtual /ONLINE/ • May 21  
PHA EUROPE  
WEBINAR ON ACCESS**

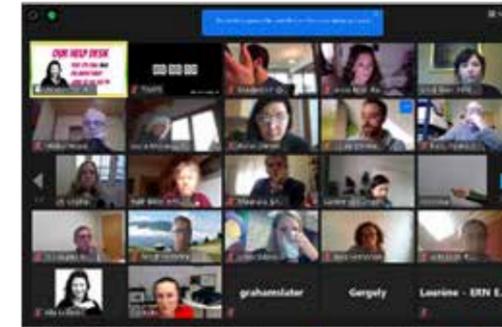
PHA Europe organized a webinar, as part of the World PH Day celebration, to walk around the challenges of access to treatment.

**Virtual /ONLINE/ • May 23  
PATIENT ASSOCIATION REPRESENTATIVES WEBINAR; BRIDGING  
THE COMMUNICATION GAPS IN PAH PATIENT CARE**

Danijela, Hall and Gergely attended this meeting and discussed the possible ways of overarching the communication difficulties.



**Virtual /ONLINE/ • May 26**  
**EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES PATIENTS' ASSOCIATIONS (EFA) - EUROPEAN RESPIRATORY HEALTH COALITION MEETING**  
 Gergely attended the kick-off meeting with the aim of forming a European Respiratory Vision Paper.



**Virtual /ONLINE/ • September 28**  
**EURORDIS - ERN-FOCUSED POLICY RECOMMENDATIONS SESSION 2: INTEGRATING ERNs TO NATIONAL SYSTEMS AND FRAMEWORKS**  
 Gergely commented on the paper on ERNs' integration and participated in this discussion.

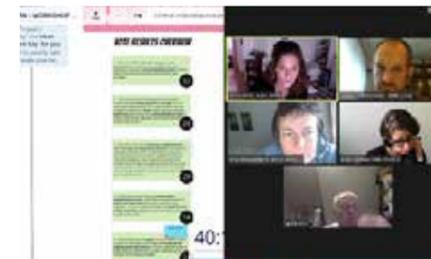


**Virtual /ONLINE/ • June 25**  
**RELAUNCH OF MEP INTEREST GROUP ON EQUITABLE ACCESS**  
 Following the introductory speeches of the MEPs, a lecture was held by DG Sante about health-related recommendations in the framework of the European Semester. The meeting was concluded with a stakeholders' debate. Gergely attended the meeting.



**Virtual /ONLINE/ • July 7**  
**NORD WEBINAR – BUILDING A VILLAGE: HOW TO RE-ENGAGE YOUR BOARD MEMBERS, LEADERS AND VOLUNTEERS**  
 The guest speaker was Joan Garry, who is an internationally recognized champion for the nonprofit sector. Gergely dialed-in this webinar.

**Virtual /ONLINE/ • October 3**  
**EUROPEAN PATIENT FORUM (EPF) EXTRAORDINARY GENERAL MEETING (EGM)**  
 The strategic plan (we commented on previously) of EPF for 2021-2026 was approved and proposed change to the constitution (possibility to hold online general meetings) was presented during this meeting. Gergely represented PHA Europe.



**Virtual /ONLINE/ • October 12**  
**ERN-FOCUSED POLICY RECOMMENDATIONS SESSION 4 ERNs, RESEARCH, AND THE DATA ECOSYSTEM OF THE FUTURE**  
 Gergely represented PHA Europe in this interactive meeting.



**Virtual /ONLINE/ • July 20-22**  
**EURORDIS – RARE 2030 PANEL OF EXPERTS**  
 Gergely attended these meetings (Subgroup 6 [Integrated, Social, & Holistic Care] and subgroup 7 [Patient Partnerships]) and represented PHA Europe.

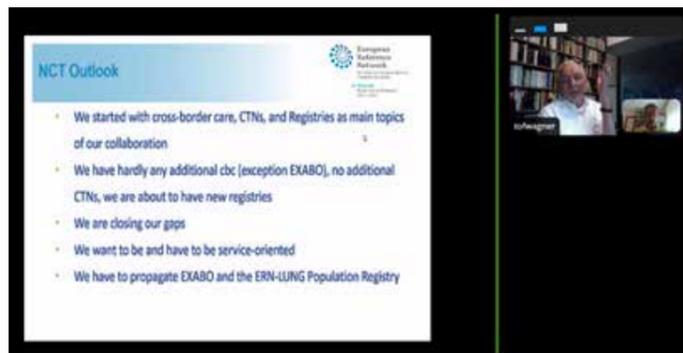
**Virtual /ONLINE/ • October 13**  
**MEP LUNG HEALTH GROUP LAUNCH “EVERY BREATH COUNTS – RESPIRATORY HEALTH IN COVID-19 TIMES”**  
 Gergely represented PHA Europe in the official launch of MEP Lung Health Group. Presentations were run by Commissioner for Health and Food Safety, ERS president and ELF.



**Virtual /ONLINE/ • September 7-9**  
**EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS**  
 The congress was originally scheduled to Vienna, but due to the pandemic went online. Gergely represented PHA Europe at the congress.



**Virtual /ONLINE/ • October 19**  
**EUROPEAN MEDICINES AGENCY (EMA) WORKSHOP ON GUIDELINE ON REGISTRY-BASED STUDIES**  
 Gergely dialed in this workshop, which gave an overview of core recommendations of the draft guideline.



**Virtual /ONLINE/ • September 16**  
**ERN LUNG EPAG AND MEDICAL STEERING VIRTUAL MEETING**  
 Natalia and Gergely represented PHA Europe. Gergely ran a presentation about the patient journey in the ePAG meeting and provided update on the work of the PRO committee in the Medical Steering Committee meeting.

**Virtual /ONLINE/ • October 20**  
**EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES PATIENTS' ASSOCIATIONS (EFA)**  
 The 2nd meeting was held to further discuss the Vision Paper. Gergely attended this meeting.





**Virtual /ONLINE/ • October 26  
CLOSING PLENARY OF THE RARE 2030 ERN EVENT**

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

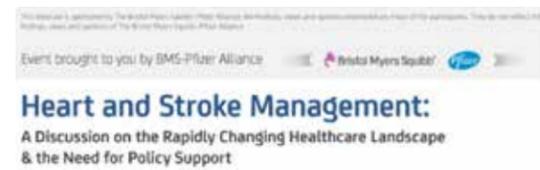


**Virtual /ONLINE/ • November 2  
PHA EUROPE – COVID-19  
(INFORMAL ROUND-UP)**

It was a gathering of PHA EUROPE’s members to discuss the impact of the second wave of COVID-19 in their respective countries.

**Virtual /ONLINE/ • November 4  
HEART AND STROKE MANAGEMENT**

Hall attended this seminar which was hosted by the alliance of BMS and Pfizer. The webinar highlighted how serious stroke is as a health issue in Europe and the globe today. A call for action was presented. PH patients are at risk since irregular heartbeat (Afib) might lead to stroke.



Welcome to Transplantation Learning Journey 2.0 Online Experience  
Featuring live streaming, content on-demand, real time networking. We wish you a fruitful journey.

**Virtual /ONLINE/ • November 15-17**

European Society for Organ Transplantation (ESOT) hold for two days the specialty sessions of Transplantation Learning Journey (TLJ 2.0) focused on some of the hot topics in specific areas of transplantation. Natalia represented PHA Europe in this event.



**Virtual /ONLINE/ • November 30  
EUROPEAN MEDICINES AGENCY (EMA) - WORKSHOP  
ON SUPPORT FOR DEVELOPMENT OF ORPHAN  
MEDICINES**

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

**Virtual /ONLINE/ • December 1  
BRIDGING THE COMMUNICATION GAPS IN  
PH PATIENT CARE: EMPOWERING PATIENTS  
TO IMPROVE HCP DIALOGUES AND RAISING  
AWARENESS OF PH PATIENT ASSOCIATION &  
HEALTHCARE PROFESSIONAL WEBINAR**

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



**Virtual /ONLINE/ • December 2  
MEP LUNG HEALTH GROUP  
AIR POLLUTION AND COVID-19**

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

**Virtual /ONLINE/ • December 2  
PHA (US) INTERNATIONAL LEADERS MEETING**

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



**Virtual /ONLINE/ • December 4  
EURORDIS  
HTX TRANSFERABILITY WEBINAR**

Gergely participated in this invitation-only webinar on ‘Next generation Health Technology Assessment’.

**Virtual /ONLINE/ • December 14  
EUROPEAN FEDERATION OF ALLERGY AND AIRWAYS DISEASES  
PATIENTS’ ASSOCIATIONS (EFA)**

The 3rd meeting was held to discuss the different aspects of the launch of the Vision Paper and outline the frame of further collaboration. Gergely attended this meeting.



**Virtual /ONLINE/ • December 14  
PHA EUROPE – YEAR CLOSING MEETING**

It was a gathering of PHA EUROPE’s members to share local traditions and meet with each other – virtually.

**UPCOMING EVENTS 2021**

*Date & Venue TBC*  
**ANNUAL PULMONARY HYPERTENSION EUROPEAN CONFERENCE /APHEC/**  
The biggest annual gathering of European PH associations’ leaders.

*Online, January 23*  
**EPF EXTRAORDINARY GENERAL MEETING**  
Online meeting with the aim of modifying the constitution of EPF to hold Annual General Meetings (AGMs) online.

*Online, February 23*  
**EURORDIS RARE 2030 FINAL CONFERENCE**  
Closing congress of the multi-year project, which PHA Europe also contributed to.

*Online, February 24*  
**EURORDIS BLACK PEARL AWARDS**  
Annual fundraising gala meeting of EURORDIS around Rare Disease Day.

*Frankfurt, mid-March*  
**ERN-LUNG BOARD MEETING**  
Annual meeting of health care providers, which are members of ERN-Lung and patient representatives.

*London, 28 August to 1 September*  
**EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS**

*Barcelona, September 4-8*  
**EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS**

**2022/23 AT A GLANCE**

- EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS 10-14 SEPTEMBER MUNICH (GERMANY) 2022
- ESC CONGRESS
- 7 WORLD SYMPOSIUM ON PULMONARY HYPERTENSION 27-28 FEBRUARY / 1 MARCH 2023 ORLANDO FL, (USA)

## REPORT ON THE ONLINE ECRD

Gergely Meszaros

The first ever online version of ECRD /European Conference on Rare Diseases/ took place on 14th and 15th. This event is organized every two years, this year it would have been held in Stockholm, but COVID-19 has re-written the plans.

In early March EURODIS, one of the main organizers made the decision to go online and a very nice online platform was built up for this occasion.

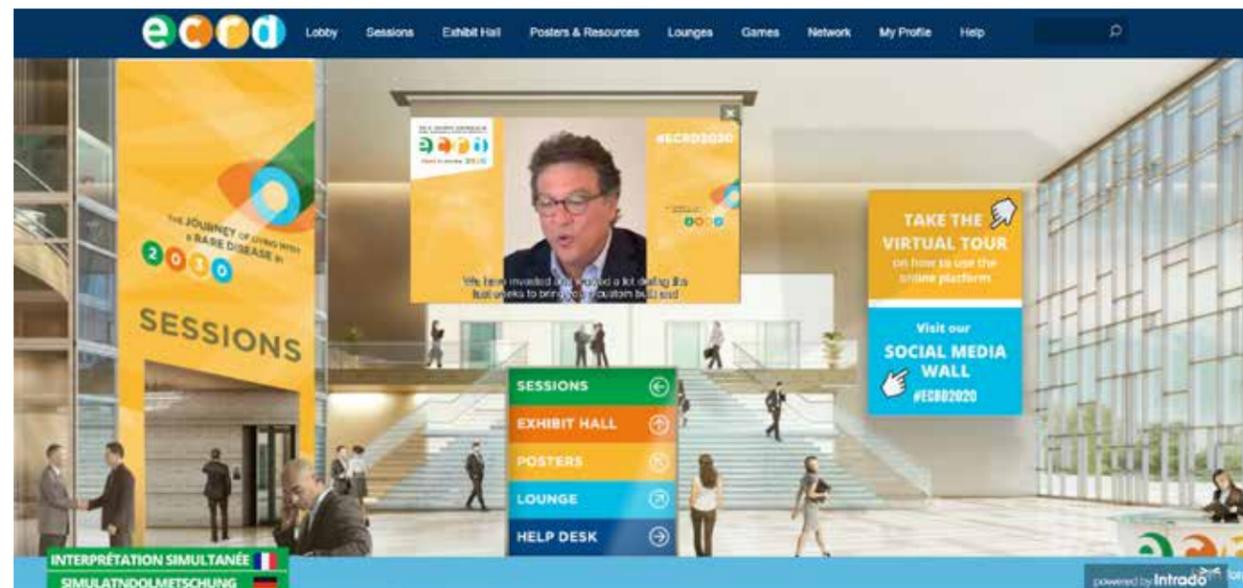
Once you logged in, the lobby welcomed you and it was easy to navigate between the different sessions. The non-official motto of the conference can be „no one left behind”. It was interesting to hear that since the possible orphan designation of medicine less than 200 drugs were approved in the EU in the last 20 years. It is shocking when you compare it to the number of rare diseases, which is over 6000.

The repartition of the diseases is very unbalanced: the 6% of the rare diseases cover more than 90% of the all of the rare diseases patients. However the program was shortened to 2 days from 4 days, the agenda almost followed the offline version.

The plenary session was kicked-off by the CEO, Yann LE Cam and the president of EURORDIS, Terkel Andersen (he talked about solidarity, helping each other, joining forces) and even Victoria, Crown Princess of Sweden greeted the audience in a video message.

A very nice introductory video was played about Sweden, which was followed by the following keynote speakers:

- **Lena Hallengren** - Minister for Health, Sweden - she talked about the long term strategy Sweden implemented for rare diseases: stronger patient perspective, funds for healthcare providers and coordination of the various regions.
- **Helena Dalli** - European Commissioner for Equality - in her video message she introduced the directive on prohibition of discrimination (eg. employment inequality based on disabilities) and underlined the COVID effects to generate inequalities on various fields.
- **Stella Kyriakides** - EC fo Health & Food Safety - she emphasized the important role of ERNs playing on the rare disease field.
- **Irene Norstedt** - DG Research&Innovation - she stressed the challenges of appropriate and timely diagnosis and the lack of medications for more than 90% of rare diseases. She outlined the main points of the European Joint Program
- **David Lega** - MEP-member of the European Parliament - in his inspirational speech he stressed the challenges COVID put on the table, however, at the same time, he said it is a great opportunity for rare disease advocacy: a very common feature of COVID and rare diseases is that anyone can be taken ill.



In the lunch break nice talks were held about COVID and its effects in various countries. The afternoon continued with the introduction of possible healthcare scenarios envisaged in 2030 - please see the diagram below.

The main part, however, of the afternoon consisted of different break-out sessions, with panel speakers. One could chose from the following themes:

- diagnosis
- human rights & inclusion
- care provision
- therapeutic development
- accessible, available and affordable treatments
- digital health

Within the digital health session a numerous considerations were provided of ethical and legal aspects of data - contribution to cross border data flow: is it only an options or must on the rare disease field, how we can build trust, so we are willing to share our sensitive data, who has access to such data (eg. insurance companies?).

There were a couple of presentations about the role of AI (artificial intelligence), the challenges AI is facing with (eg. consent, database, interoperability) and also the benefits AI can ossible role in diagnosis). The role of patient associations was discussed, namely patient organizations are the real driver of innovation as they know what they really need.

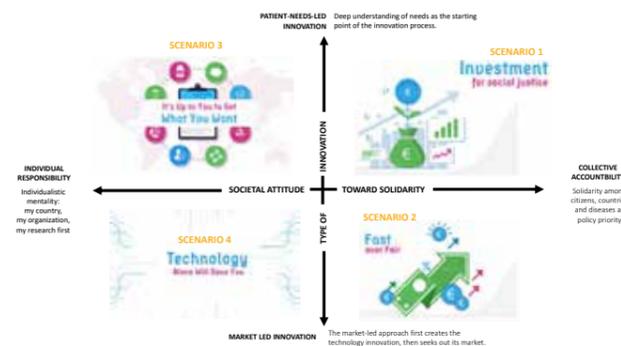
EURORDIS is a member of various organizations and initiatives. The first day was closed with a discussion about:

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

which EURORDIS plays an active role in.

During the breaks you could familiarize yourself with various posters. The most interesting ones are available from the following folder:

<https://Innk.in/egbo>



### Tremendous opportunities

- We are harvesting from historical discoveries

### Tremendous challenges

- Genome data needs to be put in context and used responsibly
- Multidisciplinary collaboration and data sharing absolutely critical!
- We still have a lot to learn...

The second day started with a presentation about the Nobel prize by Prof. Anna Weddel /member and formal chair of the Nobel Committee/. Nobel was a cosmopolitan, lonely Swedish man, but at the same time very passionate, who would have liked to make a better world. The Nobel prize is awarded since 1901 in science, literature and peace (physics, chemistry, physiology or medicine, literature and peace (The peace prize is awarded in Norway and the other prizes in Sweden). The main element has always been the „discovery”, the conceptional new thing, what has changed the status quo fundamentally. Nobel prize has become the most prestigious prize and nowadays the main focus is on genetics. She gave us a very brief insight into genome sequencing.

Dr. Gareth Bayman, clinical geneticist gave an excellent presentation about their work in Australia: how they discovered and identified a genetic rare disease in a family and what role the face analysis can play. The best posters were announced following these sessions: The winner was P.163, the second one is P.267 and the third one is P.268 (you can find them from the above link).

As in the first day, the afternoon again was dedicated to breakout sessions with the same main themes as outlined above.

Following the video message of Adam Vojtech, Minister of Health of the Czech Republic, the chairs of the breakout sessions summarized the discussions they had. Yann Le Cam (CEO) closed the two-day online conference with a big smile on his face: except for minor voice problems on the second day, they managed to organize a fully online conference with over 1,500 participants.

# REPORT ON THE VIRTUAL ERS CONGRESS

Gergely Meszaros

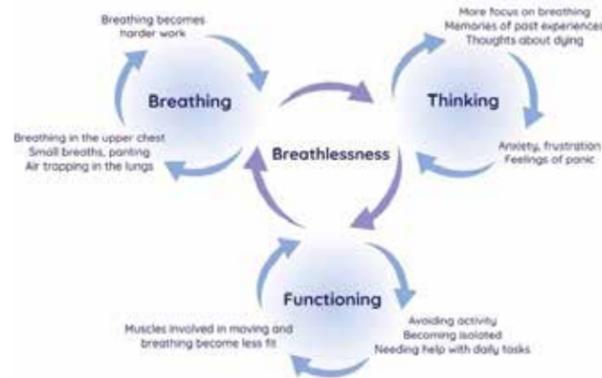
The first weekend and the following days of September were very busy with the online congress of ERS (European Respiratory Society).

Originally Vienna would have welcomed the 20.000+ visitors (including health care professionals, patients, patient advocates, reps. of the industry), but due to COVID-19 the 30th congress was held online with the record high of 33.000+ visitors.

The usual non-official kick-off program of the congress is the „patient org. day” held on Saturday. European Lung Foundation (ELF) provided again a very interesting program. A nice video offered us a virtual tour in Vienna and Austria.

We could learn about the breathing circle from Anna Spathis and I am sure that we will hear about it more in the coming years. In the breathing, thinking, functioning clinical model she emphasized that the breathlessness and disease severity are not closely related and there is always something (recovery breathing techniques, walking program), which may ease the breath. This lecture was very well supplemented by the presentation from Francesco Pagnini, who shed light on the importance of mindfulness and psychological aspects - not limiting his speech on yoga and other special exercises.

This day's presentations also touched on COVID, however the full day of Sunday was dedicated to the pandemic (pls. see summary at that day).



The newly elected ELF chair, Kjeld Hansen called the attendees for easy and fun exercises and in his following speech he underlined the importance of exercises both from physically and mentally. Anita Simonds, (ERS president-elect), Thierry Troosters (ERS president)

addressed the attendees and Isabel Saraiva (ELF chair) said her farewell speech.

It was very heart-warming to hear from Thierry the launch of the MEP interest group. Luckily we were promptly proposed to collaborate with this group. It is worth visiting the colorful virtual poster exhibition hall at:

**MEP Lung Health Group launch event** ERS ELF

- The launch event will be held 15:00 - 16:30 CEST on 13<sup>th</sup> October
- Hosted by MEP Pizarro (S&D, Portugal) and MEP Zovko (EPP, Croatia)
- Opened by the European Commissioner for Health and Food Safety Stella Kyriakides
- We invite all patient organisations to join this group
- For registration and other questions please contact [pippa.powell@europeanlung.org](mailto:pippa.powell@europeanlung.org) or [roberta.sadauskaitte@ersnet.org](mailto:roberta.sadauskaitte@ersnet.org)

[www.europeanlungpatientorgday2020.com/posters](http://www.europeanlungpatientorgday2020.com/posters)

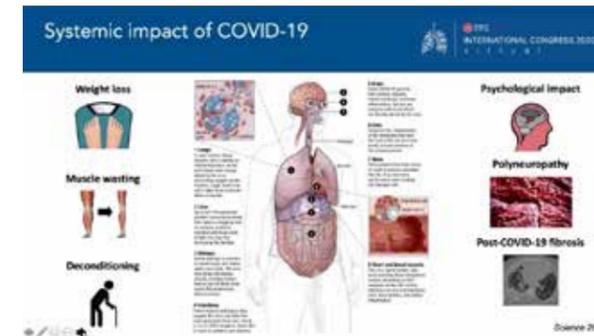
Let me thank to Natalia from BSPPH and Oskana from PHURDA Ukraine for submitting very nice posters. You can find them at the following link together with two useful materials from ELF:

<https://lnnk.in/bbc0>

Sunday was the COVID day. Previously the link to free access to these sessions was shared on our google group - hope many of you had the chance to at least join some of the sessions.

COVID is not a simple disease affecting solely the lungs, but has effects on other organs and functions of our body. Due to this complexity, currently it is unknown the residual harm it may cause. Nevertheless, some initial data is available which suggest that the mobility (climbing stairs, dressing, toilet use) is hardly hit after hospital discharge. Still we are facing lots of unanswered questions from remaining burdens, appropriate approach of rehabilitation to long term consequences.

I think one of the most interesting sessions was about COVID management. Paolo Navalesi, who was in charge with the organization of the healthcare system of the hardly-hit North-Italy outlined the protocol they followed in respiratory support (ventilation, ECMO).



John Beigel outlined the antivirals which are in the pipeline, but underlined in his conclusion that solely they will not likely be sufficient.

Remdesivir improved the outcome but the mortality only slightly decreased. Lopinavir and Hydroxychloroquine did not demonstrate benefit. Mono/polyclonal antibodies and interferons might be the future directions. Anti-inflammatory agents, as potential therapies on top of the background therapies might be the solution - suggested Richard Haynes in his presentation. Maxime Patout provided additional possible approaches: (i) convalescent plasma therapy (only for severe patients), (ii) anticoagulation (curative in ICU patients) and (iii) antibiotic - lack of data. A special session was dedicated to children and COVID. Alexander Möller shared the data with the audience: children are not at higher risk for COVID, and what is more children with asthma might be more resistant. Due to lack of data, however, the extra protection of children with respiratory conditions might be considered.

**Potential antivirals for SARS-CoV-2**  
In development

Clinical Phase in US	Pre-clinical Candidates
<ul style="list-style-type: none"> <li>• A522P</li> <li>• Abociclovir</li> <li>• CINA-001</li> <li>• DMS116 (Madrigal)</li> <li>• EIDD-2805</li> <li>• Galiravir (JCH&amp;CO)</li> <li>• GS-5734 (Merck)</li> <li>• Ibalizumab</li> <li>• Ibal-301</li> </ul>	<ul style="list-style-type: none"> <li>• Anti-SARS-CoV-2 mAb (multiple companies)</li> <li>• ACE2 and TMPRSS2 host modulation</li> <li>• CBP-101 (Novartis)</li> <li>• anti-TMPRSS2 mAb</li> <li>• AT-529</li> <li>• BQ-789</li> <li>• GSK-790</li> <li>• Nucleosides</li> <li>• Nucleotides</li> <li>• Soto-181</li> <li>• TQ-713 (Novartis)</li> </ul>

Monday and Tuesday were packed with PH related scientific sessions. As part of the ESC/ERS joint session Laurent Savale gave a presentation about the delicate balance between the lung and kidney health.

Nazzareno Galie spoke about interventional treatments focusing specifically on CTEPH interventions (BPA, PEA). The treatment algorithm is as follows: CTEPH expert team assesses whether the patient is operable or not: if yes, PEA is made. However, based on data from international registries, 37% of patients are non-operable. In such cases targeted medical therapy with or without BPA is followed.

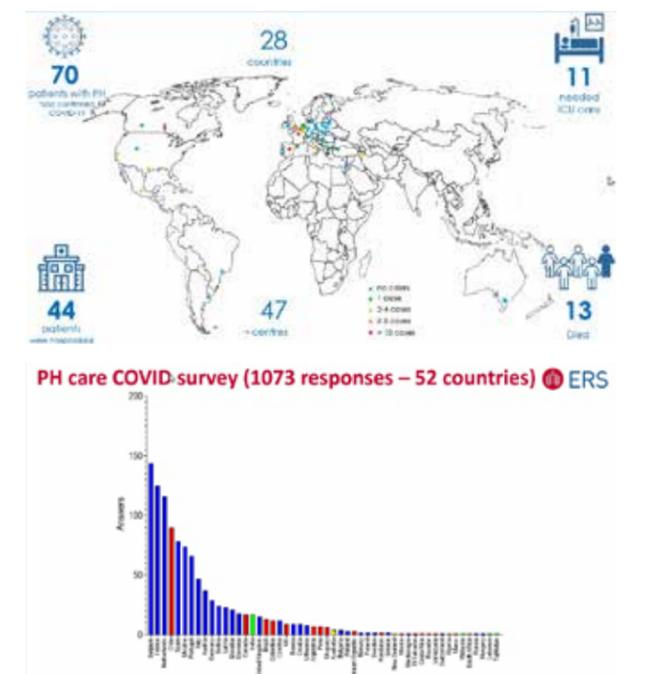
Konrad E. Bloch from Zurich gave a lecture about high altitude with PH. Proper acclimatization, gradual ascent, possibly low sleeping altitude and the use of acetazolamide were his basic recommendations.

The joint session was closed by Marion Delcroix. She

summarized the findings of the ERS CTEPH Task Force which PHA Europe was a co-author of. As a result of the work the ERS Statement on CTEPH was published online in the European Respiratory Journal (ERJ) as an early view and you can learn more about it in the Projects&initiatives part of this Mariposa.

This time there was no specific PH related session as part of the ERS-ERN Lung joint symposium. Gernot Rohde provided some statistical data about ERN-Lung and lectures were held about other rare lung diseases (PCD, CF, ILD) - Horst Olschewski touched on the correlation of IPF and PH a bit.

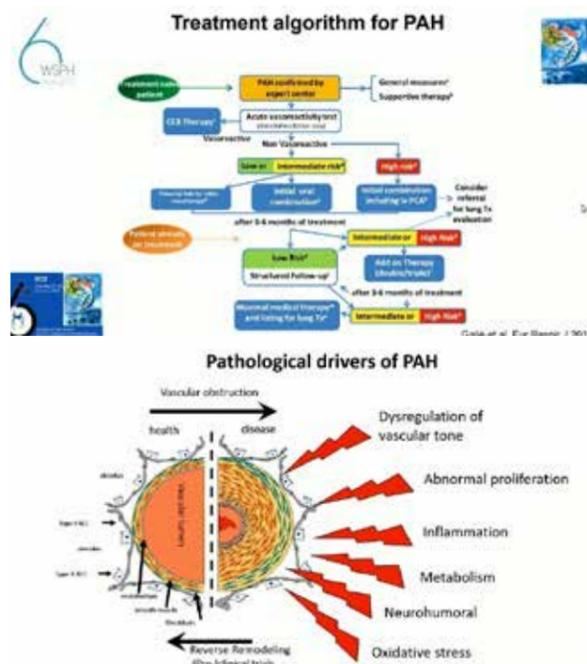
Assembly 13 (PH) of ERS chaired by Marion Delcroix had its regular meeting also on Monday. Marion briefed the audience about the coming assembly elections, deadlines for next year's ERS congress, the increasing number of the members and age/gender dissemination of the assembly and about the 'Lifetime achievement Award 2020' Gerald Simmoneau received (he is one of the world's highly cited researchers in the field of clinical medicine for 2017, 2018 and 2019). Currently there are two ongoing CRCs (clinical research collaboration): (i) PHAROS (aim is to build a cross-border register, but it is facing data protection issues at this stage - we are part of the working group) and (ii) PEX-NET (pulmonary hemodynamics during exercise - We have asked to join this working group). There are two ongoing task forces: CTEPH (previously mentioned) and about the future guidelines (we were invited to participate). Marion provided some details about the two questionnaires run recently. The main data of the centre based COVID questionnaire is shown on the infographics below:



Some initial data was presented about our COVID questionnaire - let us thank you again for your

translation and participation in that questionnaire. We hope that the results will be published soon. Tuesday offered a great variety of lectures mainly focusing on genetics and genomics. Pablo Otero-Nunez gave a presentation about RNA signaling which separated PAH patients from healthy volunteers. Emilia Swietlik informed the audience about the identification of rare sequence variations. They excluded from the study patients with eg. BMPR2, CAV1, to minimise the false-positive cases and realized that KDR is a new risk gene in terms of heritable PAH. In his lecture David Montani worked more on BMPR2. They realized a high incidence of PAH amongst asymptomatic BMPR2 carriers. Non-invasive diagnostic tools are useful and early PAH treatment of these patients kept them at low risk profile - naturally validation and evaluation is still needed. Benjamin Dunmore ran a lecture about a novel regulator of BMPR2: UBE2E2. Christina Eichstaedt reported on their study: they managed to identify previously undescribed pathogenic variants in one quarter of the patients. Still genetics: Ekaterina Legchenko introduced ATP13A3 as a new PAH-associated gene - the mutation of this gene can cause PAH due to disturbed polyamine homeostasis. Pierre Thore underlined in his presentation that MP9/BMPR2/ALK1 pathway appears to be a central player in PAH.

Anna R. Hemnes ran a more digestible presentation about PAH related data. Data from registries suggests that women are more likely affected by PAH (sex ration differs from 1.7-3.9:1 (female:male)), however men have worse outcomes (men more likely dead due to PAH). There are differences in how females and males are responding to therapies, but more investigations are needed on this field - potential treatments targeting sex hormones? Joanna Pepke-Zaba gave insight into different patient-recorded outcome questionnaires (CAMPHOR, emPHasis, PAH-SYMPACT). Joanna reminded us the clear position of the guidelines and the regulator. The World Symposium on Pulmonary

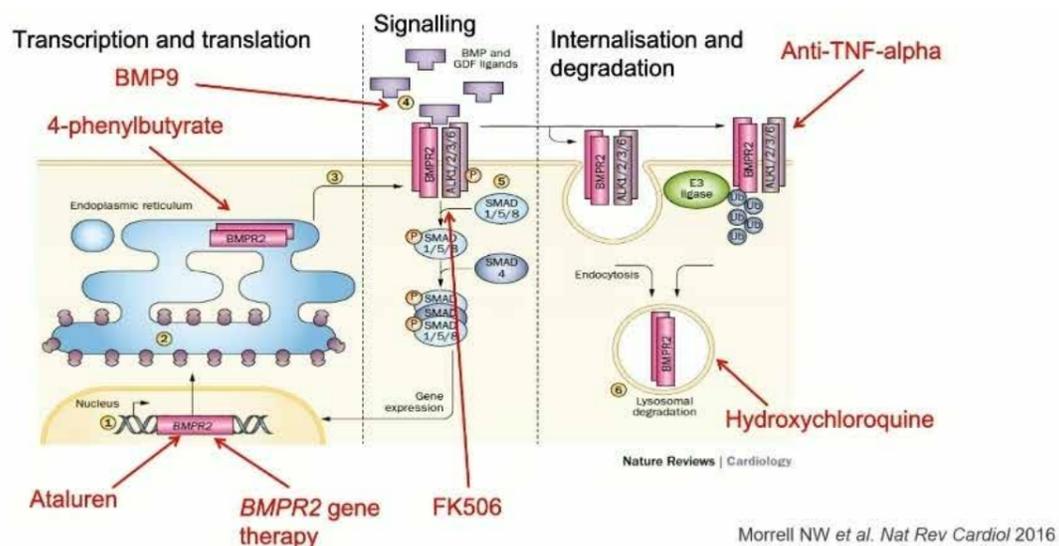


Hypertension (2008) confirmed a need for a multicultural disease-specific questionnaire approved by both EMA and FDA and the FDA report also stated PROs as valid and important endpoints to consider. In some of the countries, more recently PROs are playing an important role in the audit and assessment of health care providers.

The session was concluded by Marc Humbert, who gave a nice overview of the treatment algorithm and pathological drivers of PAH.

I have made plenty of screenshots, which are available from: <https://phaeurope.box.com/s/0ildieb21jy06fsg8po mpvcezbuxhhfl>

We had a virtual booth at the congress and if you watch the <https://www.youtube.com/watch?v=Npj3NbmW3eQ> video carefully you can get to know how we say 'Thank you' in Hungarian.



Morrell NW et al. Nat Rev Cardiol 2016

## PROJECTS & INITIATIVES 2020

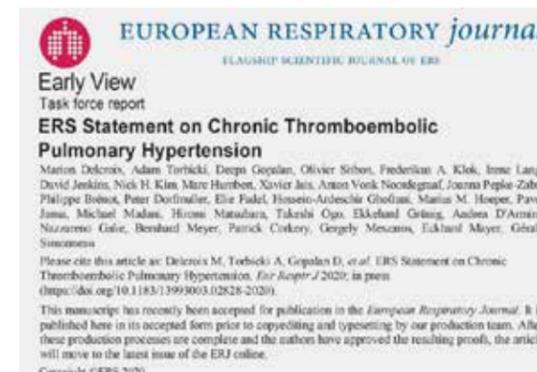
Gergely Meszaros

It would not be possible to list all of the activities conducted this year in terms of raising awareness and advocacy, but let us share with you a handful of initiatives we are proud of. PHA Europe was either the key driver of or contributor to these projects, which vary from social media campaign to being co-author to an ERS statement.

### ERS Statement on CTEPH

As a result of a multi-year project and many face-to-face and online meetings, the ERS Statement on Chronic Thromboembolic Pulmonary Hypertension (CTEPH) has now been published online in the European Respiratory Journal (ERJ) as an early view. PHA Europe was invited to provide the patient perspective and contribute to the discussion and to the statement. It was a great honor for us to work together with key-opinion leaders on this initiative.

This statement is a very important paper of the recent developments on the field of CTEPH, however, there is a main difference between the guidelines and the statements from methodological point of view: while the guidelines are consisting of recommendations with various classes and level of evidence, statements are the summary of relevant practices and common understandings without any proposals. By structure, the statements usually raise questions and provide answers which are given based on the literature and common practice. Orientation on future research and training is also drawn up.



The statement starts with the question whether CTEPH is the right abbreviation for these cohort of patients and continues with various diagnostic tools and possible replacements with each other - also providing the diagnostic algorithm.

Despite the great number of registries, data on CTEPH prevalence still show a great variety from 3,2 to 38 per million. Unfortunately, in daily practice, it may still take one or two years from the first symptoms to get the right diagnosis, which lead the deterioration of the patients' condition.

The statement describes in details the treatment methods: pulmonary endarterectomy (PEA), the balloon pulmonary angioplasty (BPA) and the medical treatment and raise the question whether the rehabilitation is safe and clinically relevant: a study shows that rehabilitation was safe and effective in inoperable patients. Moreover, home based rehabilitation might be also effective and safe option, but it should be adjusted to the patients and closely supervised.

The statement is concluded with a perspective on future research on biobanks and basic science. The early view of the statement is available at:

<https://www.phaeurope.org/wp-content/uploads/erj-early-view-ers-statement-cteph.pdf>

### COVID patient survey (PHCARE-COVID survey)

In order to better understand the COVID pandemic effects on the care of PH patients and to help prepare for future challenges, a patient-centric survey has been started in the last days of May.

The survey is the result of the collaboration of all of the stakeholders including our partners from the medical field. We received administrative help to setup all of the questionnaires from ERN-Lung. In order to ensure a great number of responses, with the effort of the fellow patients, the English version has been translated into 19 languages, which were validated by local physicians.

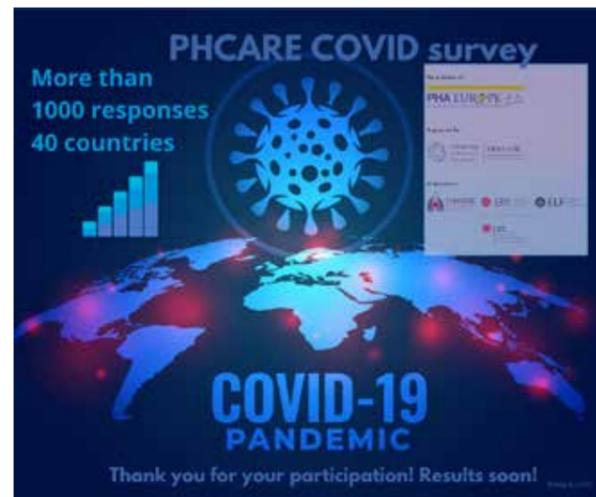
The questionnaire consisted of the following main parts:

- General information about the participant
- Coronavirus/COVID related questions
- PH related questions
- Previous vaccine related questions (eg. PREVENAR 13, BCG, seasonal flu)
- Personal experience
- Satisfaction questionnaire about the PHCARE-COVID survey

The number of responses we received was higher than we dare to imagine: more than 1000 patients and carers filled out the online questionnaire from all over the world.

Responses were sent from Chile to Russia, from India to Argentina and from Canada to Australia.

The manuscript has been submitted for publication, so we hope the main findings can be delineated soon.



### COVID center survey

In parallel with the PHCARE-Covid survey another questionnaire was disseminated throughout PH expert centers. 47 centers from 28 countries participated in this survey and provided valuable insight on how the pandemic effected the care of PH patients. We learnt from the survey that less than 10 % of the patients remained on normal (face-to-face) consultation and luckily online follow-ups were provided to the majority of patients. Symptoms lasted for an average of 6 days and the most typical one was pneumonia. The patients spent 3.4 days in average in the hospitals, received oxygen as supportive therapy (no ECMO) in addition to antibiotics which was the most common pharmacological treatment.

There is a big interest from our members to share these results in their respective network, so the translation of the summarizing slides has been started. The report is available from: <https://www.phaeurope.org/news-events/covid-19/ph-reference-center-survey-published/>

### COVID-19 in PH patients: a reference center survey<sup>1</sup>



### Breathe vision paper

"[The] (...) paper aims to create a Breathe Vision for 2030, reflecting the changes that lung patients want to see in their lives. The importance of these changes is reflected in the impact

that lung health has on our general health. Lung health, particularly in children, is such an important factor in our current health and in predicting our future health that attention for healthy lungs is crucial in improving the overall health of our population."

From the preamble of the Vision Paper

Nine lung patient groups, including PHA Europe and healthcare professionals across Europe started working on the position paper to outline their vision for the next decade. Each disease has its own and special aspects, however there are many common challenges which might be easier overcome with united advocacy work and efforts. As a result of number of online discussions and drafting the Breathe Vision paper was compiled.

This collaboration evolved to the formal launch of the European Lung Health Group and identified four main topics, which should be kept on the agenda (in addition the lessons learnt from COVID-19 were also included)

1. Raising awareness on respiratory disease
2. Greater prevention of lung disease
3. Getting the right care
4. Advancing research into lung health

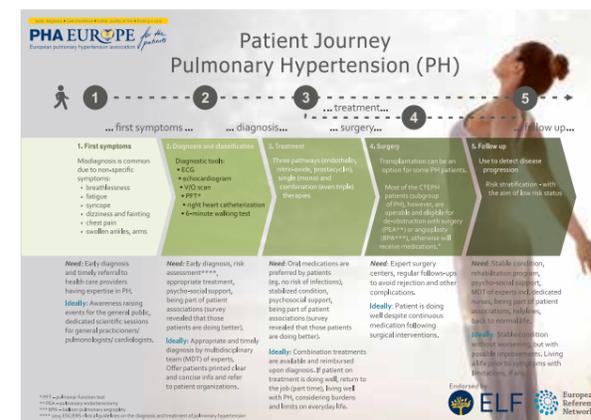
The Paper will be officially launched on the 27th of January with the help of the MEP (Members of the European Parliament) Lung Health Group. You can learn more about the Breathe Vision and the launch event from the next editions of the Mariposa.



### Patient journey

The original idea of building-up patient journeys for various rare lung diseases came up as a result of the collaboration between EURORDIS <https://www.eurordis.org/> and ERN-Lung <https://ern-lung.eu/>. We have not developed such a material previously and thought that the strategic and analytical approach

this initiative provides is beneficial for the whole PH patient community.



The patient journey nicely demonstrates the – sometimes difficult – stages the PH patients are facing following the identification of their very first symptoms.

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

The patient journey at the same time, however, sheds light on the – often unmet – needs of the patients and outline the ideal situations. By doing this, it may also serve as an excellent advocacy tool for discussion with other stakeholders. It may help in the identification of the obstacles and hurdles in each stage – providing solutions how to overcome them.

The patient journey was developed in collaboration with our PH expert colleagues. Special thanks go to Prof. Marion Delcroix, Prof. Marc Humbert and Prof. Olivier Sitbon for their valuable input.

The patient journey is endorsed by the European Lung Foundation <https://www.europeanlung.org/en/> and ERN-Lung.

The leaflet is available in various languages and can be downloaded from: <https://www.phaeurope.org/get-involved/advocacy-policy-work/patient-journey-for-ph-patients/>

### New webpage

Our webpage was built up more than 5 years ago and we thought that this time more is needed than a facelift. However, on the other hand, we were very much aware of the amount of work, which comes with such a big project.

From March the whole world was closed due to COVID, which provided us an excellent opportunity to focus on this “online” project.

Last year, during the APHEC the member associations

nominated a small working group which took care of this project and made the decisions on the very first steps (following the nomination of our vendor): they chose the template to be used and finalized the menu structure.

There was agreement on our side that not only a visually new webpage needs to be delivered but the critical review of the content is a must-to-do exercise. We contacted Prof. Simon J Gibbs, who was happy to contribute and review the medical part of our webpage to fully align it with the new developments. Prof. Irene Lang and Prof. Maurice Beghetti had completely re-written the CTEPH and pediatric articles on our webpage, respectively. We checked and updated information about the centers, self-help groups and oxygen supplies in various countries and a map helps in the navigation.



We think the new webpage is visually attractive, but new elements like sliders and different boxes have an additional function: they help the visitors to better navigate amongst our materials and projects and the most recent initiatives are easily accessible by one click.

Behind the scene we made finetunes to enhance the search engine functionality (SEO).

Last, but not least it is important to mention that the website serves as a template for member associations: the newly looking homepage of the Hungarian association went live in the very first days of 2021 and work has been commenced with the Finnish and Moldavian webpages based on the PHA Europe’s template. More webpages are expected under the umbrella of our Capacity Building Program (CBP).

### ERN-Lung

The European Reference Networks (ERNs) continue to be a very important factor in the European level advocacy work and becoming a real bridge towards the European Commission in health-related matters on rare diseases.

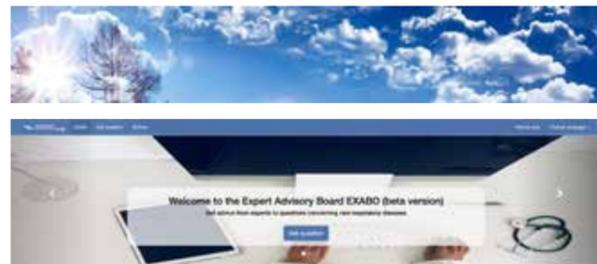
Unfortunately, the COVID-19 pandemic made the respiratory medical professionals extremely busy, which resulted in the postponement of some of the initiatives, however, there are still some achievements which we can be proud of.

Only one face-to-face meeting was possible this year, just before the COVID lockdowns: the board meeting was held in Frankfurt on 26-27th of February.

ERN-Lung has the following two important IT modules:

**CPMS**, the platform for online tool for discussing patient cases under the umbrella of ERN-Lung, still has its difficulties. Luckily in the PH core network informal discussions are held amongst the physicians regarding complicated cases.

**EXABO** (<https://ern-lung.eu/exabo-2/>), the Expert Advisory Board, the online tool which links the questions from patients to an expert on the field - preferably on the respective language -, still has not reached its full potential.



**Registries** are one of the hot topics in ERN-Lung: there are various solutions all over Europe (HCP-based, one or more registries per country, etc.) and a common dataset has not been achieved yet, which is a pre-condition of future harmonization and ultimately the interoperability. The network of ERN Lung is growing: it was good to hear that as a result of the European Commission's call in 2019 autumn more than **40 health-care providers (HCP) applied for standard membership** - 12 applications were submitted to join the PH core network. A detailed, multi-step decision making process was completed and most of the applicants were approved.

Despite, and parallel with, the above call, lots of HCPs apply for supporting membership - mainly those, which cannot fulfil the quantitative requirements of becoming a standard member. Together with standard members the white spots on the map decreased radically.

There is an important collaboration between ERN-Lung and ERS (eg. common symposium) and ERN-Lung plays an active role various calls (eg. eSupport, EJP).

PHA Europe had a possibility to run a presentation of the Functional Committees (FC) during the board meeting and could announce a multi-phase project on patient-reported outcome questionnaire (PROs). EmPHasis 10 (made by PHA UK more than 5 years ago) and CAMPHOR (privately used) are the commonly used in

PH. The main aim is to have a register of PROs, which can be widely used for

- research study endpoints
- monitor adverse events in clinical research
- monitor symptoms in clinical care, and more recently
- monitor health care quality (audit)

The second phase is, if support is received, the critical review of the existing PROs.

PHA Europe is an important partner of ERN-Lung since its launch and plays an active part in the projects. We are sure that ERN-Lung is/will be able to contribute to a better healthcare all over Europe.

## O2Kids

*Hall Skaara*

O2Kids was originally a campaign developed by PH Austria and also later made available to PHA Europe. The campaign was based around a short movie describing a young boy (Thomas) suffering from PH. In the film, we see Thomas secluded from his playing friends. When they ask him to play with them, he says «no». But really it is his lungs that say «no».



The video of Thomas has touched many hearts. The reach on social media has been fantastic. In this way, we have accomplished one of the main goals with the campaign: To create awareness for PH and especially for children suffering from PH. In addition, the campaign has managed to raise some money for PH children. The aim is to raise enough money to provide some needed children in Europe with oxygen concentrators and electric scooters. Although we have not reached our fundraising goals yet, we have been able to raise enough money to provide the first needed PH child with an electric scooter.

Cristina Makarchuk from Ukraine is a small girl suffering from PH. She has problems walking to and from school because of her illness. When she learned about the campaign, she wrote a letter that she put under the Christmas tree. She dreamed about a scooter for Christmas. PHA Europe fulfilled her dreams and Cristina

was presented with a scooter through the local Ukrainian association. We will soon publish video of Cristina on her scooter on social media.

The O2Kids campaign continues. We hope to go on raising funds for other children like Cristina and we hope to continue to raise awareness for the serious and chronic disease Pulmonary Hypertension. The campaign will hopefully create enough awareness that more people, both children and adults, get their correct diagnoses and are put on life saving medication early in their disease period. In this way, O2Kids campaign helps to greatly improve both survival and life quality of young and old affected by PH.

## CBP - capacity building program

*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 2020 we had several interesting activities related to our CBP:

In Belarus, they struggle with medication access. We supported the association with a lawyer that could negotiate on the association's behalf with the health authorities.



In Ukraine we supported two activities. The first activity supported was related to the association in Kiev. They established a beauty salon with special focus on service to the PH community. This is a great fundraising opportunity where all profit is channelized back to the association. In addition, it is a great awareness opportunity as all regular customers are told about PH. TV also made a story about the opening of the salon.

The Kiev-based association took advantage of a popular hobby in Ukraine: coloring. Art work was printed on big posters and sold all across the country with the support of the CBP. The profit will go to the association.

PHA Europe supported a collaborative initiative between the Bulgarian (BSPPH) association and the Latvian association. The aim of the collaboration was to educate women about PH issues through, among others, an online seminar.

Latvia also took advantage of PHA Europe's CBP to help finance some staff expenses, improve their home page and pay their support line subscription.

PHA Europe is in the process of updating the home pages for those associations that want to take advantage of the offering. Through the CBP, they will get a brand-new web page based on Wordpress. The template is PHA Europe's own new and modern web page.

Three different infographics have also been introduced in 2020. The associations have provided translations and PHA Europe has used them in order to produce the infographics in local languages. Most of the member associations have taken advantage of this offering, and posted the infographics on their social media and on their home pages. For those that requested it, PHA Europe has used CBP funds in order to produce printed infographic brochures and posters.

PHA Europe has used CBP funds to help associations that have requested it to provide a support line. A basic mobile phone and a year's subscription were awarded.

## PH cure masks

2020 was definitely an unprecedented year! Masks became part of our everyday life. We thought it is important to give a helping hand to our member associations to make them support the patients in their respective countries. ... but why not use the masks as an advertisement tool? We had 10.000 branded masks produced with our "CURE PH" image.

We disseminated the masks to 32 countries worldwide.



We sent packages to our member associations. However, our members preferred to deliver the masks to their local centers of expertise, we sent masks to about 30 PH centers and specialists directly.

Naturally, all our industry partners worldwide, including overseas, received a "gift" from us. You can find more photos of the masks at the editorial part of this Mariposa.

# #goodPHnews Amazing and positive stories on social media of PHA Europe

Mirko Glavinic

Following the launch of the project of #goodPHnews, we received a number of photos from our members to be published on our social media channels. It was delighted to see the beautiful and heartwarming side of each story. In these challenging times it was utmost important to

receive and post positive news and activities to strengthen the whole PH community. Everybody went through a difficult time during the presence of a virus COVID-19 and we felt the need of acting together and to try hard to make common projects

happen. Despite all the restrictions and rules of social distancing, 22 member associations shared good news from their countries. We collected and posted more than 520 posts on various social media channels. Huge success! Well done!



## AUSTRIA

## PH Austria - Initiative Lungenhochdruck

Our office is located in Wilhelmstr. 21, 1120 Vienna, where we are available on weekdays from 8:00 to 16:30.

Tel.: +43 (0) 1 / 402 37 25

E-Mail: [info@phaustria.org](mailto:info@phaustria.org)

Despite the difficult conditions this year, we were able to implement numerous projects.



## PH Austria and the challenging times

In 2020, the Corona Virus challenged the PH Austria team. In addition to routine work, we wanted to provide our members with the most up-to-date information as quickly as possible and to provide them with support and advice during these difficult times. Of course, we were and are, as usual, available around the clock via our service hotlines.

In order to prevent fear, uncertainty and sadness from arising at all, we have offered additional services. WhatsApp groups were founded, we wrote a letter of recommendation to the employer, counseling sessions were offered, and newsletters were sent out via Mailchimp. These mailings were always provided with our new label, the Lungis, which indicate that the article is particularly important.

These measures ensured that all of our members knew exactly about the opening times of the pulmonary hypertension specialist outpatient clinics and the availability of their pulmonary hypertension specialists in this difficult time, that the sense of community was promoted and strengthened, the isolation counteracted and many of the fear and insecurity relieved.

## Laughing is healthy

According to the motto of Ms. OÄ Dr. Regina Steringer - Mascherbauer we visited the Linz cellar theater on January 21st, before the virus changed our lives. The main aim of the Linz cellar theater is to offer the audience entertainment at the highest level, which has been demonstrated once again with the performance of the comedy classic „Boeing - Boeing restarted“. The focus is on Bernadette, for whom monogamy is an outdated model of life. Therefore, she maintains relationships with the three pilots Pierre, William and Alexej, who, however, do not know anything about each other. Because Bernadette chose them because of their different flight plans, two of them are always in the air. This well-coordinated system, however, starts to falter when unexpected weather conditions and spontaneous flight schedule changes occur. For the fast-paced comedy classic with lots of feminine charm and esprit, written by Marc Camoletti, a completely sold out house spoke!

## 1st Information Day Carinthia

For the first time, there was an information day for pulmonary hypertension patients and their relatives in Klagenfurt, Carinthia. Klagenfurt's pulmonary hypertension specialist Ms. OÄ Dr. Tamara Buchacher from the Klagenfurt Clinic on Lake Wörthersee spoke about the various forms of pulmonary hypertension and the therapies that are currently available. Eva Otter presented the wide range of activities at PH Austria. With this get-together, social issues, such as applying for a handicapped passport or filling out the forms for care allowance or parking permit will not be neglected. Eva did not miss the opportunity to stop by the Lindwurm, the symbol of Klagenfurt.



OÄ Dr. Steringer-Mascherbauer

## National Nurse Forum

The annual national nurse forum could not be held in the usual way. In order to give the participants, including doctors, nursing staff, physiotherapists and representatives of PH Austria, the opportunity to continue their education and training, the meeting was held virtually.

Under the scientific direction of OÄ Dr. Regina Steringer - Mascherbauer from the Ordensklinikum Linz Elisabethinen all about the care and support options for PH patients was presented. The speakers included Priv. Doz. Badr Eslam, Vienna General Hospital, Cardiology, OÄ Dr. Albinni, Vienna General Hospital, Pediatric Cardiology, Univ. Prof. Dr. Löffler - Ragg, University Hospital Innsbruck, and rehabilitation specialist Prim. Puchner from the Münster Rehabilitation Center. DGKP Karin Hahn and Verena Treml MSc, both of the Linz Elisabethinen Hospital, discussed the management of PH-specific care and diagnostics for right heart catheters from the nursing point of view in their workshops. Overall, this was an interesting and innovative virtual event.

## Most of our Information Days were also held virtually

Challenging times call for extraordinary measures. Since we always want to provide our members with the latest information and this was not possible as usual, the information days turned into virtual meetings. All meetings are also available on the PH-Austria YouTube page <https://www.youtube.com/channel/UCg7dV4mQkSNZW5VMSX6c2pQ>



We were happy to have many participants, including those affected, relatives and friends. The meeting in Vienna premiered on October 24th with Univ. - Prof. Dr. Irene Lang, Priv. - Doz. Nika Skoro-Sajer, both AKH Vienna Cardiology, and Dr. Lukasz Antoniewicz, Vienna General Hospital Pulmonology. Mrs. Univ. - Prof. Dr. Lang showed in her lecture which diseases belong to the risk groups, that also includes pulmonary hypertension. Mrs. Priv. - Doz. Skoro-Sajer explained in a very



Dr. Lukasz Antoniewicz



Priv. Doz. Dr. Nika Skoro-Sajer



Rani Gindl



Univ.-Prof. Irene Lang

understandable way how to recognize the presence of pulmonary hypertension in the ECG. She also described the current procedure in the PH outpatient department to protect patients due to the corona crisis. Dr. Antoniewicz gave a lecture on the process and the significance of the Pulmonary function tests. At the end there was yoga with Rani Gindl.

On November 7th, the virtual information days went on in Innsbruck with Mrs. Univ.-Prof. Dr. Judith Löffler - Ragg, Pneumologie Uniklinik Innsbruck, and Andreas Mühlbacher, MSc, head physiotherapist of the Rehabilitation Clinic Münster, Tyrol.



Prof. Löffler - Ragg heads the PH outpatient clinic at Innsbruck University Hospital, she is also a senior physician in the emergency room and a representative of the COVID infection service and gave an excellent lecture on the extent of the pandemic. „Looking back at the beginning of the COVID - 19 pandemic, we already know more about the behavior of the virus,“ says Löffler - Ragg. E.G. About the most common



Andreas Mühlbacher, MSc Univ.-Prof Judith Löffler-Ragg

symptoms: 80% have a mild course of infection cough, fever, difficulty breathing, loss of smell, loss of taste, headache, sore throat, diarrhea. The risk factors include age - older people with comorbidities are more at risk, cardiovascular diseases, diabetes, obesity.

The course of the COVID disease - it starts as an infection of the upper respiratory tract, continues into the alveoli, where the cells that are attacked by the virus are located. Here the T cells should be able to fight off the virus. If the immune response is good, the infection is over. One has an asymptomatic or mild course. If the T-cell response fails, the virus attacks the lungs, heart, or other organs. Fever, cough, breathing difficulties are the result. The pulmonary problem always occurs in the 2nd week from the onset of the disease, that's why you call it a mysterious lung disease.

The X-ray shows white spots as a result of the pulmonary involvement. If the patient is stable again, the disease can no longer be detected after 6 months. The New York Times published an article about the experiences of the team at the Innsbruck University Hospital.

The next information day took place on November 12th in Linz.



At the beginning Mrs. Senior Physician Dr. Steringer-Mascherbauer went into the currently applicable rules in the PH - Outpatient Clinic of the Ordensklinikum Linz Elisabethinen. "Due to the challenging situation, the care of PH patients is different than usual. Those affected who are stable get their prescription sent to their home and at the same time they receive a later appointment.

However, she emphasized that these measures only serve to protect patients and that the outpatient clinic is manned as usual. If problems arise, you get an



OÄ Dr. Regina Steringer Mascherbauer Claudia Englisch

appointment immediately. „The aim of this handling is to minimize the contacts,“ says Mrs. Senior Physician Dr. Steringer - Mascherbauer. She made an appeal to all PH patients: Stay at home, keep your distance, wear the mask when it is important, wash and disinfect your hands and reduce your contacts!! Let's look forward to the time to change when everything will be possible again! Find a job at home, such as reading or cooking. Please look forward to outdoor exercises in small groups, provided you have good rights and good body.

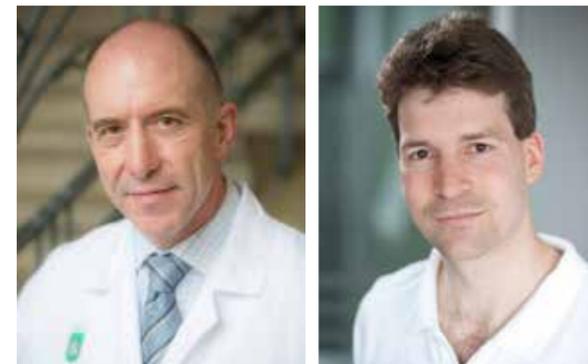
The dietician Ms. English spoke about nutritional measures that can affect the everyday life of patients with pulmonary hypertension because at the same time dealing with problems such as nausea, diarrhea, or loss of appetite.

Mrs. OÄ Dr. Steringer-Mascherbauer had the idea to put together a nutrition brochure. This brochure goes into details of the problems that PH patients have due to their medication. Text and tips were provided by Ms. English. The nutrition brochure will be provided to our members free of charge upon request.

The 4th virtual meeting took place in Graz on November 28th. Prof. Dr. Horst Olschewski and Mr. Priv.-Doz. Dr. Gabor Kovacs, both MUG Graz, and physiotherapist Petra Odelga were among the speakers. Prof. Dr. Olschewski, head of the clinical department for lung diseases and deputy director LBI / LVR Graz,



Petra Odelga



Univ. Prof. Dr. Horst Olschewski PD Dr. Gabor Kovacs

gave a case study of a patients who had a very severe course of COVID infection in his lecture. He discussed the measures that were taken in the course of the disease. He also pointed out that we are exposed to a flood of data. „It is important to know that not all information or data received can be implemented,“ says Olschewski. The COVID infection can be asymptomatic, there are mild - moderate courses and about 5% of all infections are severe. The incubation period is 5-6 days, after which the first symptoms appear. Before physiotherapist Petra Odelga waited for us in her workshop with good tips on breathing exercises for at home, the questions that were asked by the participants were answered.

### 9th Vienna ZooRun

The ZooRun had to be cancelled because of the pandemic, but a lot of starters decided to donate their participation fee and therefore we could generate about 10.000,- euros for PH Austria. The willingness to donate has never been as high as this year.

### GhostRun

More than 250 athletes took part in the first virtual GhostRun from October 30th to November 1st, showing their solidarity with people with pulmonary hypertension.

Every year, many sports enthusiasts take part at the GhostRun under the motto "We run away from the Grim Reaper". Due to Covid - 19, the charity run took place virtually for the first time this year - with complete success! We were delighted to see more than 250 participants who took part in the family run over a distance of 1.5 km or in the 6 km long main run from October 30th to November 1st, 2020. All the GhostRunners ran away from the Grim Reaper on their favorite route, some even in a scary,



beautiful costume. The personal running results were entered online by the participants. So they could take part in the virtual award ceremony. The fastest three received their prize per mail.

The switch to a virtual run presented the organizers with a major challenge. But the reward was inevitable, many ghosts sent us photos, whereupon proud and happy faces could be recognized.

Of course, Alexander Bichl was right at the front again. The family man and supporter of our charity runs said: "Of course it is important to me to win, but the GhostRun is primarily about creating awareness for the disease. Thus, all runners who participate are winners!,"

### Support for children's clinic at MedUni Vienna

For faster diagnosis and better therapy options – we supported Dr. Albinni and team at the children's clinic at MedUni Vienna. The aim of the project „Extended gene analysis and setting up a gene bank in children with PH“ is to set up a gene bank for the little patients and to be able to carry out an extended gene analysis using new genetic test methods. Above all, this is intended to record rare and previously unknown mutations and thus make it easier to assess the course of diseases. This is also intended to lay the foundation for a possibility of individualized therapy. However, genetic diagnosis is associated with high costs. With support of € 10,000, the Lungkids Research Association from PH Austria - Initiative Lung Hypertension guarantees the continuation of this important research work.

### Development of a website for a 6-minute walking test

PH Austria and Univ. Prof. Dr. Geiger worked on a website to enable the measurement of functional movement capacity in children suffering from pulmonary hypertension. This should help better monitor the effects of treatment and, like adults, can be used to predict morbidity and mortality in cardiopulmonary disease in children. The research team calculated Z scores that help to correlate the change in walking distance to growth. Now an app for clinical use is to be developed in which the reference values can be entered, and reference curves can be calculated. It could find worldwide use in pediatric, cardiac, and pulmonary centers. The Lung Children Research Association of PH Austria - Initiative Lung Hypertension provides an ongoing funding.

### Milestones

We were again able to get a lot of attention and donations through our place of milestones in the Vienna Prater.

Gerald Fischer, PH Austria - Initiative Lungenhochdruck  
[www.phaustria.org](http://www.phaustria.org)  
<http://on.fb.me/RzdEcb>



# BELARUS

The last year in Belarus was quite different from all the previous ones. As well as everyone we faced COVID pandemic. Some people were scared to simply go outside, others carelessly denied to just wear a mask to protect people around them.

Here's the latest COVID statistics in Belarus:

- Total number of the infected people: 208 601 (+1 805 per day)
- Recovered: 190 966 (+2 177)
- Died: 1 498 (+9)
- Tests made: 4 114 543 (+21 963)

But this was not the only obstacle to our usual activities and events.

The presidential elections took place this year. This changed the life of all the Belarusian people. For the moment all the public events are banned. The government doesn't pay attention to such "minor" things as troubles of a small group of people with Pulmonary Hypertension. The people are exhausted and everybody is waiting for the changes.

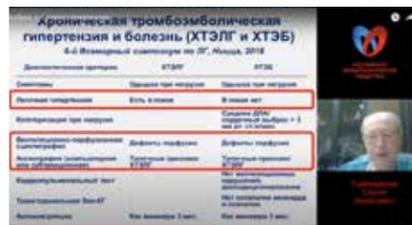
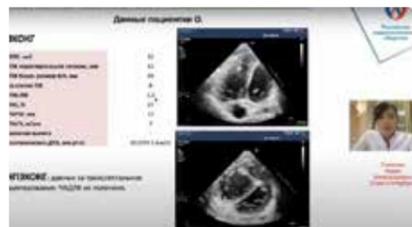
Yet our association tries to do our utmost to ease and improve the life of our patients. We keep translating interesting and informative articles, conduct online activities such as online webinars.

Here's a short list of some of the events:

- Online conference: COVID and respiratory disease - lecture given by the pulmonologist Tsareva. (They talked about therapy and safety methods during the epidemic.)
- Webinar June 23 - a review of domestic and foreign data on the management of patients with PAH.
- Psychological webinars (for those who need psychological support, we together with Republican charity public association for Hunter Syndrome, conducted an open psychological lesson)
- Webinar: Complex way of treatment for patients with Pulmonary Hypertension (Gorbachevkiy, Schmalz)
- Webinar: PH problem in pediatric cardiology (Miklashevich, Groznova)
- Webinar: Two sides of the same coin of PH

We all hope the new year brings us good news and nice and fruitful events. Thank you for being with us!

*Alina Katsubinskaya  
PHA Belarus*



# BOSNIA AND HERZEGOVINA



## Raising awareness about the disease is our continuous task

During the pandemic there was no adequate time for realisation of our planned activities, however, we managed to hold several significant events which caught public attention:

## New year's dive into the cold river

In early 2020, members of SNIK Atom, Zdenko Veljačić Veki and Emir Balić, plunged into the cold Gostović River. This dive was dedicated to patients with pulmonary hypertension. Their support left us breathless, not because of illness, but before the greatness of these selfless and humane people.



By the way, this is Zdenko Veljačić's 16th traditional New Year's dive into the cold river. The dive is organized directly below the waterfall in Kamenica, a tourist destination in Bosnia and Herzegovina. This year Zdenko was joined by young Emir Balić, who also dedicates his activities to SNIK Atom to patients with pulmonary hypertension.

Having their support is invaluable. Thank you from the heart and great respect for these fearless athletes.

## The symbol of the european PH community and on the surfaces of the highest top of the southern hemisphere

This year's expedition of BiH mountaineer and caveman Zdenko Veljačić Veki, the climb to the highest peak in South America, Aconcagua is over after just over three weeks. The Aconcagua Peak is the highest peak in both the Americas and the Southern Hemisphere. The height of the mountain is 6,962 m, and the peak belongs to the Andes mountain range and is located in Argentina. Zdenko Veljačić Veki was part of the international mountaineering team and the only member of SNIK „Atom” who participated in this expedition.

We learn that climbing to the top of Aconcagua has been hampered by extremely reduced atmospheric pressure and diluted air, low temperatures of up to - 30 degrees C and very strong winds over 100km/h. So conditions that are very difficult to survive. At the top of Aconcagua, it contains only 40% oxygen, and climbs without oxygen bottles, making it a very challenging peak and mountain. Zdenko Veljačić Veki interrupted his final ascent to 5,400 m for personal safety, at the top of Nido de



Cóndores, where a photo dedicated to patients with pulmonary hypertension was created. At these altitudes, alpinists feel a lack of oxygen and know best how they feel about their daily life with pulmonary hypertension. This was a very difficult expedition from the very beginning because of the hurricane winds and low temperatures it changed its plan and had to start earlier which reduced the time of acclimatization and made this expedition even more difficult. After Mont Blanc 4810m - France, Kilimanjaro 5895m - Tanzania and Muztagh Ata 7546m - China, and Matterhorn 4478 m - Switzerland, this is the fifth ascent of the famous climber Zdenko Veljačić Veki, dedicated to patients with pulmonary hypertension. Veki, big respect and thank you very much!



### For rare 2020

The Association of Citizens with Pulmonary Hypertension „Breath” - in Bosnia and Herzegovina, in cooperation with the „Secondary Technical School” from Zavidovići, organized an activity dedicated to marking the Rare Disease Day. In this way, a one whole class of sophomores at STS Zavidovići is included in this year’s activity Association „For the Rare 2020.” campaign by symbolically painting their fists in different colors representing various rare diseases in this campaign, which is in accordance with this year’s EURORDIS (European Rare Diseases Organization) photos dedicated to this day.



Selvera Mahić-Milinkić, a class teacher along with Vera Hodžić, founder and president of the Assembly of the Association of Citizens with Pulmonary Hypertension „Breath” - in Bosnia and Herzegovina dedicated one school class for informing the school youth about rare diseases, with a particular focus on pulmonary hypertension. The students took an active part in this marking, pleased that at least in some way they helped to draw the public’s attention to the plight of patients with rare diseases in Bosnia and Herzegovina.

### „Ladybird” with PAH patients

School sports for young children „Ladybird” led by prof. Amir Muminović is with patients with pulmonary hypertension this year as well.

Profesor Muminović and several students of the School of Sports supported small sports performances. In this way, together with us, they raised the world about pulmonary hypertension during these months pandemic. In addition to the participants showing their gymnastic abilities, the School of Sports published information about pulmonary hypertension and our Association on its website.

This sports society has remained consistent with the principle on which it was founded even in these difficult times - sports and health, educating the followers of their site and about pulmonary hypertension.

### Supporting the children with cancer

Under the slogan „Be golden” in Sarajevo is marked Golden September - the month of raising awareness about childhood cancer.

The information desks of the „Heart for Children with Cancer” association were set up on the plateau in front of the SCC and inside the SCC, where citizens had the opportunity to find out about children’s cancer, the problems they face, but also to by purchasing a gold ribbon and a specially designed gold mask they provide support to children with cancer.

On that occasion, Sabina Hodžić, a representative of the Association of Citizens Suffering from Pulmonary Hypertension „Breath” - in Bosnia and Herzegovina attended this event. In this way, Sabina expressed the

support of our Association for children with cancer, and with information about their activities we try to help make their voices heard as far as possible.

Activities like this point, among other things, to the poor state of health, to patients who are left to fend for themselves and who suffer from pulmonary hypertension in Bosnia and Herzegovina on a daily basis.

### Activities expand to European Patients Forum

A large number of activities she organized, as well as those in which our Association member Sabina Hodžić from Zavidovići participated, undoubtedly allowed her to be selected from 126 applications submitted to the European Patients Forum (EPF), Brussels for participation in Capacity Building Module on Empowering Leadership and Positive Organizational Governance for six months.

At the Association of Citizens with Pulmonary Hypertension „Breath” - in Bosnia and Herzegovina we are proud and happy because we believe that this opportunity will be well used in terms of strengthening leadership characteristics that are extremely important in our struggle, all with the aim of improving the position of patients with pulmonary hypertension in our country.

Sabina has been a very active member of our Association so far, and in addition to administrative work, she has been a participant and activist in a number of activities raising awareness of pulmonary hypertension and pointing to the very bad position of PH patients in Bosnia and Herzegovina, reaching into all spheres of social life, working with children and young people, and participating in several simposion and congresses.

From September to November this year, webinars where members had opportunity to present experiences they acquired during six-month programme were held. Even tough the whole programme was supposed to be done differently, and the ending of the programme should have happened in Brussels with meeting of all the members, work on the project didn’t stop despite the pandemic of coronavirus.

Thanks to the modern technologies and effort of all the participants, during six-month long period, all the training sessions were held online.

### Improving position of the PH patients

Leadership of the Coalition of Organizations of Persons with Disabilities of Zenica-Doboj Canton held a meeting in Zenica of all members, associations and unions at which the Information on the adopted Local Action Plan in the field of disability was presented.



The meeting was held in strict compliance with hygienic and epidemiological measures, in order to prevent the spread of the pandemic.

The meeting was also attended by a member of the Association of Citizens Suffering from Pulmonary Hypertension „Breath” - in Bosnia and Herzegovina, who spoke on behalf of all disabled people, drawing attention to the need to equalize the rights of all persons with disabilities. It was emphasized that most of the existing laws are not fully harmonized with the UN Convention

on Human Rights, and that in the coming period we should act in this direction - to harmonize and amend the laws with the UN Convention.

By the way, Zenica-Doboj Canton is the second canton in the Federation of Bosnia and Herzegovina to adopt this document. The Local Action Plan in the field of disability arose from the Strategy for the Promotion of the Rights of Persons with Disabilities in Bosnia and Herzegovina. Participation in such and similar activities, as well as monitoring such activities and news is for the purpose of one of the basic goals of our Association, to improve the situation of patients with pulmonary hypertension.

### Caring for rare

Regional online conference on rare diseases „Caring for Rare” was organized by NORBS (National Organization for Rare Diseases of Serbia).

The two days of the online conference were followed by over 60 participants from various countries of Central and Eastern Europe. The conference was free for everyone, so the association of citizens suffering from pulmonary hypertension „Breath” - in Bosnia and





Herzegovina took part in this interesting event. The Regional Conference on Rare Diseases, „Caring for Rare” is a unique event that brought together representatives of National Associations and Patient Organizations from Central and Eastern Europe, but also other relevant participants - health professionals, researchers, representatives of academia and the health industry. This two-day conference was extremely useful for our association due to a series of information we learned about rare diseases, approaches to treating rare diseases, the roles of patients in the complete system, as well as the role of umbrella organizations that bring together patients with rare diseases.

### November in Bosnia and Herzegovina

A month of raising awareness about pulmonary hypertension was also marked in Bosnia and Herzegovina.



The Association of Citizens with Pulmonary Hypertension „Breath” - in Bosnia and Herzegovina recorded a short video with the message: „Patients with pulmonary hypertension represent a risk group of the population. I'm wearing a mask! Let's be responsible! Let's save ourselves, but also them.” In addition to the video, photos were taken for photo messages with clear content, which drew attention to the need to protect patients with pulmonary hypertension with the basic appeal: „We are endangered if you do not wear a mask!” The video and photos were taken in Sarajevo in November in order to point out the importance of respecting WHO measures during the Covid-19 pandemic, but also the obligation to protect patients with pulmonary hypertension, as well as all other chronic patients.

During the month of raising awareness about pulmonary hypertension, patients also received PHA Europe protective masks. Despite the pandemic, Association of citizens suffering from Pulmonary hypertension „Breath” in Bosnia and Herzegovina is satisfied with everything that has been done under very difficult circumstances for raising awareness about Pulmonary hypertension.

*Vera Hodžić  
President of Assembly of Association of citizens suffering from Pulmonary Hypertension „Breath” in Bosnia and Herzegovina*



## NEWS FROM EUROPEAN PH ASSOCIATIONS

# BULGARIA BSPPH



Do you know that more than 80% of the patients with pulmonary hypertension are women?

For the first time BSPPH worked in cooperation with PHB Latvia in realization of a twining project “Women and PH”. This is result of the opportunities gives the Capacity Building Program of PHAE. Even the pandemic of COVID-19 did not prevent us from implementing our project. The next idea is a joint future workshop in Bulgaria.

Last year BSPPH created a handbook with real life experiences of women who tell about their journey in life with pulmonary hypertension, this year BSPPH runs the first twining project “Women and PH” with Latvian association.

The aim of the project “Women and PH” is to provide theoretical information and to achieve practical results enhancing the quality of life and emotional health of patients with PH by helping them to continue living effectively and to remain mentally stable. Every woman with PH experiences fear, guilt, anxiety, loss of libido, a sense of inferiority, and even worthlessness, worry and frustration. PH is a complex disease and the emotional support is vital to strengthen patients to continue fighting the disease.

Do you know that more than 80% of the patients with pulmonary hypertension are women? For that reason,



Bulgarian society of the patients with PH created the handbook to help patients, their families and friends, as well as the valuable information source for medical and other experts.

“Life is difficult with this diagnosis and it has significant impact on the quality of life. Therefore, patients shall be well informed about the effects of the disease spreading beyond the clinically defined symptoms and affecting the practical, the emotional and the financial aspect of life. You know that therapy with prostacyclin analogues is not available in Bulgaria. Only this therapy may maintain you but it may not heal you and then you stand up despite of the weakness of your body and you say “I have to win this battle!”, said Natalia Maeva, Chairperson of the Bulgarian Society of Patients with Pulmonary Hypertension.

Pulmonary Hypertension is commonly seen in women of childbearing age. For a woman whose body already have to contend with serious illness, pregnancy can have catastrophic consequences.

Usually women affected by PAH feel decline in their sexual desire. Usually they avoid intimacy because of concerns for too much load of their body. It is recommended that you talk openly with your partner in order to explain your concerns and how you feel during sexual intercourse.

Another important thing with great impact on women with PAH is the strong desire to become mothers. However, pregnancy is a great risk for women with PAH because this will put additional load on their hearts and lungs. Therefore, it is recommended that women with PAH use reliable contraceptive methods to avoid pregnancy.

Ieva Plume, President of PHA Latvia, says: “Many women dream to be a mother one day. Unfortunately, PH puts strong frames on these dreams. The handbook talks about these limits and our chances to look on life from a brighter side. BSPPH did all the organizational and practical part of the project. PHA Latvia was a consultant and we had the possibility to translate the brochure from English to Latvian”

### A donor's garden was opened in downtown Sofia



A garden of 202 roses – as many as the donors in Bulgaria from 2005 until now, was opened in the park of the National Palace of Culture. The event was attended by the Deputy Minister of Health Dr. Boyko Penkov, Acting Executive Director of the Executive Agency “Medical Supervision” Miroslav Mutafchiyski and representatives of patient organizations.

The rose garden is an expression of gratitude to the people who gave someone else the opportunity to continue their life.

The initiative for planting roses in memory of donors is at the suggestion of the Association “Bulgarian Society of Patients with Pulmonary Hypertension” and the Association of Patients with Respiratory Failure and Lung Transplantation.

The garden was established with the assistance of Executive Agency “Medical Supervision”, Sofia Municipality and the Municipal Enterprise “Parks and City Gardens” on the occasion of the European Day of Donation and Transplantation.

### Patients with PH and COVID-19

COVID-19 turned our daily lives upside down in a way that hardly anyone imagined. Many clinics have ceased operations, trips have been canceled.

Pulmonary hypertension causes many complications, especially in cases of secondary pulmonary hypertension along with other serious diseases such as lupus, scleroderma, COPD, idiopathic pulmonary fibrosis, congenital heart malformations. Patients with pulmonary hypertension fall into the most endangered group of chronically ill patients with pulmonary suffering with a high degree of hypoxia and severe heart failure.

The majority of patients with pulmonary hypertension have a disability of more than 80%. In the third and fourth functional classes, these patients are cared for by their relatives because, given the development of the disease, they are unable to cope with their daily duties, such as cleaning, shopping and cooking as they are confined to oxygen concentrators for more than 17 hours a day. In most cases, such patients are cared for by their parents, who are also elderly patients with chronic disabilities, and currently also have recommendations for home isolation.

Unfortunately, the Bulgarian health system is not adapted to the implementation of such measures. There are no conditions for remote monitoring, the legislation does



not allow the dispensing of prescription drugs online, and there is a lack of systematically organized home care, etc. So far, there is no algorithm for how to react if there are patients with pulmonary hypertension infected with COVID-19 and in which medical institutions such patients shall be referred for hospitalization.

The Association “Bulgarian Society of Patients with Pulmonary Hypertension” has created and maintains an information page about COVID-19, where you can find practical advice and recommendations for dealing with patients with pulmonary hypertension under COVID-19 conditions. With the help of specialist doctors we have also developed a flyer in which you can find useful information.

Together we will go through this hardship and it will make us even stronger. Take care of yourself, act prudently, support people around you who may need help. Be optimistic. And let's not forget: TOGETHER, WE CAN DO MORE!

Information line to help patients with pulmonary hypertension. From 18/11/2020, an information line was launched to help patients with chronic diseases 0800 14 515. This will reduce the burden on doctors

and consumers at a time when the health system is under severe pressure due to the continuous growth of COVID-19 patients.

The line is a joint project of the National Patient Organization and the Bulgarian Society of Patients with Pulmonary Hypertension, in partnership with VIVACOM, and allows for timely and adequate consultation with specialists, as well as helps to avoid unnecessary visits to health facilities. It provides patients with pulmonary hypertension with additional information and time with physicians to discuss their disease and COVID-19-related issues.

Every working day from 9 am to 6 pm, doctors from the COVID sectors, endocrinologists, oncologists, pulmonologists, cardiologists and psychologists consult patients on various issues related to the control of their chronic diseases. In case of symptoms of COVID-19, callers will also receive information about the steps that need to be taken to receive adequate treatment.

- Since July 2020, Natalia Maeva is a patient representative (ePAG) in the European Lung Reference Network (ERN-LUNG), which covers nine groups of rare lung diseases.
- President BSPPH President Natalia Maeva participated in the European Health Forum „Gastein 2020: Dancing with an Elephant” which took place online from September 30 to October 2. This forum is the most important event in the field of health policy and a meeting place for experts from various fields in the health system.

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

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

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

## BULGARIA PHA

The big success of PHA Bulgaria was the participation of Todor Mangarov in the prime time of the most watched Bulgarian TV in the health show "The Spirit of Health" for one hour together with Prof. Nina Gocheva on the topic of pulmonary hypertension and World Pulmonary Hypertension Day.

The future reporter Deyan, 10, also joined this year's campaign and supported patients with PAH. His photo traveled around the world and received 6,000 likes, winning first place in the PHA Europe competition.

In the beginning of the year PHA Bulgaria participated for 3 days with information stand and lecture in National Cardiological congress on the 26th to 28th of February, and later in the National Neurological congress on the 1st of March.

In the tie of first wave of COVID we PHA Bulgaria organized a presentation in the First Baptist Church Sofia in about 250 audience.

During the pandemic, we made an official note to the

employer to support home office for patients and to their family members. We also made a note to be used for traveling (to the hospital if needed) to be used in front of police as in Bulgaria was not allowed to travel outside city of residence. 14 PAH patients benefited from a note to the employer and another 11 to travel note. We also helped with the purchase of disinfectants and masks. Over 20 patients received them for free.

On June 11, after the cancellation of the quarantine, we had the first patient meeting of the year.

Participating in "Vitosha 100" an annual bike marathon in the Vitosha mountain near Sofia with a small PH team was a big success.

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



## CROATIA



Dear friends and PH family,

Like every year at this time, we would like to share our joy with you after the successful projects we ventured into. Those are Maksimir MZ cener (8 km race) and Breathless Adriatic adventure.

We all know how difficult and challenging this 2020 was, and how many planned projects we had to postpone and even cancel permanently.

To our satisfaction, Breathless Adriatic adventure was not one of those projects. It was, dare we say, the most successful project in 2020 in terms of raising awareness about pulmonary hypertension not only in Croatia but also beyond.

12 brave rowers decided to cross the Adriatic Sea in a 14-meter kayak from south to north, from Prevlaka to Savudrija. Their goal, apart from a sports venture (no one in Croatia has done it in this way), was to raise awareness about pulmonary hypertension.

The rowers were followed by the RTL television team from beginning to the end on their adventure, which we symbolically called Breathless Adriatic adventure.

From island to island, they docked in certain locations every night, appeared live on RTL TV, but also in the local media who welcomed them and took statements about their venture, and were even more surprised that bearded and muscular men gave statements with their lips painted blue.

Halfway through the project, they were greeted by

the famous Croatian photographer and film director Šime Strikoman, known for the project he has been implementing in the Republic of Croatia for 20 years, (taking millennial photos - were mostly from a large number of people forms some symbol or message which it then captures from the air).

Delighted by our idea to take a new form of millennial photography, since large gatherings were not allowed, we painted big blue lips 12x15 meters about the message of CURE PH, and the rowers were arranged around them. These are the biggest PH lips so far, and the message is more than clear, CURE PH!

The welcome of the rowers who crossed the 650 km of the Adriatic coast was not what they deserved, but we simply had to respect Covid's measures.

They were greeted by a limited number of people, but also we prepared for them gold medals as a small thank you for doing such a project for the PH community. There were tears in the eyes of these strong men because they did not expect such attention and even less gold. Their favorite medal ever, as they say ...

Captain Tomislav Smrček and Zdenka Bradač as president of the Blue Wings appeared live on national television and had the opportunity to talk about this unusual project that has caused a great deal of attention throughout the country and neighboring states and of course PAH community and how the cooperation started.

A large number of TV houses and portals carried the

news about Breathless Adriatic adventure, and it created a wonderful collaboration that we plan to continue. I hope some of you have already seen the short video we have prepared and translated into English. Also, we are very proud of Maksimirski MZ cener - 8 km race. For the sixth consecutive year, AK Maksimir has been organizing the Minus Zwei Cener race on World Health Day, (which was supposed to be in March but was postponed due to the Covid 19 situation).

The main topic of this year's race was to raise awareness of pulmonary hypertension. We run out of our breath for those who can't, under the motto "Get breathless

for Pulmonary hypertension" This year, somewhere between 200-500 runners decided to dedicate the race to raising awareness of pulmonary hypertension, as they recognized our struggle for every breath and selected Blue Wing's association as a race partner together with the Croatian Breathing House Foundation and the Croatian Thoracic Society. The race had a variety of media coverage and was successful in raising awareness about pulmonary hypertension.

*Katica Mavračić*  
[infoplavakrila@gmail.com](mailto:infoplavakrila@gmail.com)  
[www.plavakrila.hr](http://www.plavakrila.hr)



## CZECH REPUBLIC

### Celebration of Rare Disease Day 2020

Every year we participate in the celebration of Rare Disease Day. This year was organized the press conference on Ministry of Health for supporting us and a big social event as a thank for all those who help patients with rare diseases. We were supported by celebrities and Minister of Health Adam Vojtěch.

Meeting of patient organizations with rare diseases. As every spring, 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 meetings in a café at Prague's Thomayer Hospital. At this meeting, there are lectures mainly in the field of legislation, research and palliative care.

### Mentoring program

Last two years our association is participating in a very interesting project to support non-profit organizations. The aim of the mentoring program is to analyze the needs of our target group, find new sources of funding and launch new projects.

### New website

Thanks to the mentoring program, we were given the opportunity to have the patient association's website updated. Our website is now modern, simple and intuitive. Patient online counseling and telephone hotline. Thanks to the excellent cooperation with the General university hospital, we launched an online

counseling for patients with pulmonary hypertension. The doctor, who can be contacted by patients via the association's email, deals individually with each patient and their specific problems, or consults other treatment options directly at the centers. After a slight transformation, we also continue in the hotline, which is redirected 24 hours a day to doc. Jansa, the most experienced specialist in pulmonary hypertension in the Czech Republic. We really appreciate the support of these doctors, who are also available in their free time at any time of the day or night.

### Exercise online

Due to this year's coronavirus crisis, we had to cancel the annual reconditioning stay in Poděbrady for our patients. As a replacement, we started shooting videos with exercises and short greetings to make up for at least the impossibility of meeting in person, and we hope to meet again in person next year. Currently, there are 3 videos with breathing exercises, exercises for stretching the neck and exercises for stretching the thoracic spine. Our concept will include videos with a maximum length of 10 minutes and will be shared on FB, instagram and youtube. Our plans for next year Our biggest plan for next year is to see our patients again in person and hold meetings.

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





# HUNGARY



## Media tsunami

We have enjoyed the summer after the first wave, trying to spend as much time as possible outdoors to be recharged with fun, fresh air and sunlight. Our sport ambassadors were also active.



In order to participate in classes, it became necessary to provide oxygen. Our association immediately lent our concentrator, but we knew she would need her own device in the long run. Therefore, with a local collaboration fundraising was started to help. (Since Petra's birth, she's been ill and one of her treating doctors has undertaken her upbringing, as there are plenty of things to pay attention to in her case so that she could live a good quality of life.) Fortunately many people were touched by her story and several events has been held on which donations were collected. Local television and several newspapers reported on these events, and an interview broadcasted on the Kossuth national radio station encouraged everyone to donate. For example, participants in a go-kart race has offered their entry fees, but dance groups also supported the initiative and the line-up of events is not over yet.

And we were enthusiastically organizing the General Assembly of the association. We hoped this would be an opportunity to catch up with the meetings we could not have in May.

We have scheduled the General Assembly for September, and as a consequence of last-minute measures, we were unfortunately only able to attend in a small circle. In addition to the usual agenda, Dr. Karlócai, PH specialist gave us a summary of international experiences of how PH patients were affected by COVID-19 and what estimates are available for the second wave. He gave us advice on how we could best take care of ourselves. At that time, we were still hoping that we would be able to meet in person at the occasion of our usual national doctor-patient meeting.

When starting school in September, it became clear that Petra (who grew up in front of our eyes and colored our annual doctor-patient meetings with reading poetry every year) urgently needed help.



PATAKI PETRA

Besides the concentrator it is also an aim to ease the financial difficulties of this girls who is living a life with hardships. The Linde company also offered a huge help, so Petra ran happily at these events using her brand new concentrator and expressed her gratitude with her violin playing and poem reading. Huge thanks to everyone who has donated!

We planned our 10th national doctor-patient meeting to be held in early December. We would have come up with several surprises, but unfortunately, given the worsening situation, we had to give it up and so we had to draw media attention to PH in other ways to get the message to everyone, that early diagnosis is very important, can be life saving.

On TV, one of the most watched morning shows and a very popular weekly show both featured a report on PH, with patients and treating physicians talking about symptoms, diagnoses, treatments, and about how our association is trying to help patients with the physical and mental distress. Several reputable online health portals and online magazines read by many have also covered PH in long articles even containing embedded videos.

Based on the statistics, the results of the awareness raising work seems to bring the result

as the time until the diagnosis is becoming shorter in Hungary.

We did not forget about our fellow patients either. We made gift packages for them, in which we put useful things. We hope they will be able to use these with health for a long time.

Fortunately, we can also report that several of our fellow patients appear to have undergone COVID-19-induced disease without more serious complications.

We do hope everyone gets through these difficult times safely and we can see each other again in the spring.

*Eszter Csabuda, Tüdőér Egylet*

[www.tudoer.hu](http://www.tudoer.hu)

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



HETI NAPLÓ CSABUDA ESZTER  
A TÜDŐÉR EGYLET ELNÖKE, PAH-BETEG



DR. KARLÓCAI KRISTÓF  
FŐORVOS, SEMMELWEIS EGYETEM PULMONOLÓGIAI KLINIKA



FORGÁCS MELINDA  
A TÜDŐÉR EGYLET TAGJA, PAH-BETEG



DR. BÁLINT OLGA HAJNALKA  
FŐORVOS, GOTTSEGEN GYÖRGY KARDIOLÓGIAI INTÉZET

## ISRAEL



2020 has been a very challenging year for all, yet despite the challenges we have all learnt much about changing lifestyle, understanding physical limitations and the strain of restricted breathing.

We have adjusted our usual annual plan to include online programming, online interaction and a social support system of a different kind. Our members have had to face the struggles of not seeing their families, not being able to step outside their homes for fear of infection and also ensure that their mental health is not affected.

As an association our focus was on ensuring support and education for all PH patients. We have set up regular feedback and reporting from all PH specialists in the country as they became more versed in Corona and PH, with guidelines of how our patients should behave.

We are gathering information from specialists about the vaccine, preparing an online zoom lecture where a panel of doctors will share their opinions, the benefits and possible concerns.

We arranged social zoom sessions for participants to speak, see a friendly face and touch base sharing their struggles or just having a laugh. Our association whatsapp group has proved to be a vital tool. Participants are educating, questioning, engaging and supporting one another daily and keeping social via the group.

Another topic which we were able to share was nutrition and the balance of healthy eating and exercise during lockdown and limited mobility.

In addition, we have been working with medical companies for support, and have continued working on our main patient database which will create one central space for patient information and access for all doctors to learn about the disease, monitor their patients progress and ensure that they are able to cross reference medical information.

Our association has continued to work closely with the health department to ensure medication is available and covered for our patients and we are very grateful for the ongoing relationship we have with them. In working towards a greater awareness and more powerful stance we have often combined forces with other lung disease associations and have found these combined efforts very beneficial.

We look forward to a Covid19 free reality and to getting all our patients together, socializing, supporting and working together for PH awareness and cures!

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

## ITALY-AIPI



### „LIFE IN A BREATH“ Awareness campaign on pulmonary arterial hypertension

In Italy about 3 thousand people are affected by pulmonary arterial hypertension, a rare disease that is difficult to diagnose. Recognising this disease at an early stage and acting immediately is essential to prevent complications, which is why, on 15 December 2020, AIPI OdV presented the campaign „Life in a Breath“ at a press conference, promoted in partnership with Janssen Italia. Exceptional testimonial of this campaign is Carolina Kostner, multi-champion figure skater on ice.

The campaign aims to raise awareness of pulmonary arterial hypertension, a little-known and unfortunately underestimated cardio-pulmonary disease which, if not diagnosed in time, can have significant consequences on the quality of life of patients and their families.

„Pulmonary arterial hypertension is poorly understood by doctors and the general public. The fact that it

does not present specific symptoms often leads to underestimation of the alarm bells that appear in the form of exhaustion, breathlessness and fainting, with significant delays in diagnosis,” quote from Prof. Nazzareno Galiè, Director of Cardiology at the Policlinico S. Orsola, University of Bologna, and Coordinator of the Cardiology Department at the University of Bologna. Orsola, University of Bologna, Coordinator of the International Guidelines on Pulmonary Hypertension and head of the AIPI OdV Scientific Committee, who also explained during the press conference that „Pulmonary arterial hypertension increases blood pressure in the pulmonary circulation, with a progressive overload of work for the right ventricle of the heart and can culminate in heart failure and premature death in the absence of adequate treatment. Early diagnosis is essential for proper management and improved prognosis, so it is important to inform and raise awareness among the population.”

The „Life in a Breath“ campaign will continue in 2021 and aims to focus on the importance of breathing, which is fundamental to life, but at the same time not all taken for granted for patients with pulmonary arterial hypertension.

The campaign involves multi-channel planning: a video spot, advertising pages and digital content. Carolina Kostner, the multiple ice-skating champion, will be the protagonist of an intimate and emotional story, which aims to attract the public's attention in order to involve them and raise their awareness of the disease. The videos, materials and illustrations created for the campaign will also be available on the websites and social pages of „AIPI OdV“ and „PHocus360“.

„I am thrilled to have joined this initiative“ says Carolina Kostner „It is essential to turn the spotlight on this little-known disease and raise awareness among the widest possible public. Information, which is the basis of knowledge and prevention in the field of health, is a necessary element to stop the advance of the disease in time and intervene early.”

Patients with pulmonary arterial hypertension are confronted with a number of complications, both in their private lives and medically: regular check-ups and the assistance of specialists are necessary, as well as specific drug therapies. „Not knowing about



pulmonary arterial hypertension leads patients to go to the doctor when it is in an advanced stage and with complications already in place. The objective of AIPI is not only to promote the dissemination of scientific information on the disease, but also to encourage early diagnosis and timely intervention," these are the words of Leonardo Radicchi, President of AIPI, who reiterates how „important it is to create partnerships and campaigns like this one to promote research and information, and to organise initiatives dedicated to the direct involvement of patients and their families, for psychological and social support”.

„Janssen Italia is at the forefront in seeking innovative therapeutic solutions that can meet the treatment needs of people suffering from a rare disease, such as pulmonary arterial hypertension, and in raising public awareness of this disease,” said Loredana Bergamini, Medical Director of Janssen Italia. „Our goal is to

improve the quality of life and life expectancy of patients, making the disease increasingly manageable,” she added.

Stressing the need for a strong commitment not only on pulmonary arterial hypertension, but in general on rare diseases is Senator Paola Binetti, Member of the XII Commission for Hygiene and Health, Senate of the Republic and President of the Parliamentary Intergroup on Rare Diseases.

We would like to invite you to visit the websites [aiipiitalia.it](http://aiipiitalia.it) and [phocus360.it](http://phocus360.it) and the social pages of „AIPI ITALIA” and „PHocus360” to see and share the contents of our campaign.

Leonardo Radicchi  
[www.aiipiitalia.it](http://www.aiipiitalia.it)



## ITALY-AMIP



### Living with COVID

Well yes, we of the Association of Pulmonary Hypertension Patients - onlus have written, for 15 years now, a book entitled "LIVING WITH PULMONARY HYPERTENSION", with clinical-scientific analyzes and advice on daily needs by various patients.

In these six months we have had to readjust and we are trying to launch certain and verified messages from the scientific committee regarding the needs of pulmonary hypertension patients during COVID.

We have carried out an immense action to raise awareness of the institutions, so that the needs of the rare patients are not overlooked even in these times of emergency. This action made it possible to launch a heartfelt appeal also by the President of the Italian Republic.

Our help line is always in operation and we were also able to organize a doctor/patient meeting via the web. We have participated in national and international conferences, always via the web. We have participated in discussions with other world associations.

Even if our action did not have a striking "social" prominence, we can affirm, without a shadow of a doubt, that our closeness to the sick everywhere was not lacking. The attestations of esteem that we receive from them every day (either because we have solved a bureaucratic problem, or because we have been close to them psychologically at a particular moment, or just because we exist) have convinced us that the "on the road" action we are conducting is the one that comes closest to the patient.

Nonetheless, one of our members had the audacity and the stubbornness to carry out a project that combines music with solidarity: JAZZ is good for the lungs - SET ASIDE the triple album to support pulmonary hypertension patients.

The album is enjoying great success and has united famous musical artists with our world.

Vittorio Vivencio, AMIP Italy  
<https://www.assoamip.net/en/>

## LATVIA

## 2020 • Year of Challenges

Time of remote meetings: work doesn't stop.

As we all know, the 2020 was particularly challenging and PH patients spent much of the time at home as a risk group due to epidemic of Covid-19. For PHA Latvia it was time of remote meetings on the online platforms and chats in Whatsapp group. We launched #Tee Talks in the Spring and Summer of 2020 as our members initiative on Skype. #Tee Talks themes were healthy food recipes, meditation, hobbies, mindfulness, individual resources, and experience exchanging. This Autumn we organized trainings in using Zoom platform. Senior members of Association were glad to learn new tool for everyday communication.

PHA Latvia could not realize General Annual Meeting face to face regarding epidemiological situation in the country. So, we held our GAM 2020 virtually at Zoom in November. Now we have new Board members – Linda Romanovska and Gunita Skaldere-Darmudasa. Ms. Linda Romanovska is Honour Member of PHA Latvia with excellent knowledge in health administration. Ms. Gunita Skaldere-Darmudasa is carer of PH patient with professional interest in psychology. Ieva Plume, Founder of PHA Latvia, was elected as President of PHA Latvia.

On remote basis PHA Latvia supported Bulgarian PH patient's organization "BSPPH" in their project "Women & Pulmonary Hypertension". Thanks to the dedication of Natalia Maeva, President of "BSPPH", we have received 50 booklets about health of women with PH and we have possibility to translate the booklet in national language.

PHA Latvia participated in two PHA Europe programs – the Fellowship program and the Capacity Building program. Withing CBP we improved a home page, supported our patients and their family members by consultancy phone line, made new database of potential supporters, attract funding from municipality to organize diseases prevention campaigns 2020 - 2022.

## Committees and working groups

This year PHA Latvia was represented in several working groups and Committees. Ieva Plume worked in the Advisory Board of Technical Aids lobbying state-paid oxygen concentrators for PH patients. As expert in the field of rare diseases and representative of adults with



cardio diseases Ieva Plume participates on volunteer basis in the Advisory Board of Social enterprise "Medica Strengē" specialized in health care of congenital heart diseases. PHA Latvia also collaborates with the State Agency of Medicines of Latvia regarding communication for patients and wide public about Covid-19 vaccines. We are engaged in communication working group as the member of Patients Organization Network of Latvia. It is acknowledgment of PHA

Latvia dedication and experience because only 3 patient's organizations are involved in this expertise.

## Collaboration with Latvian Alliance of Rare Diseases

During year of 2020 PHA Latvia expert Ieva Plume participated in the project "Rare Diseases in Latvia 2020" of Latvian Alliance of Rare Diseases. There was a lot of activities for rare disease's patients' community in Latvia, including patients with pulmonary hypertension: advocacy work, expertise in social and health legislation, extensive work in monitoring of Rare Diseases Plan 2017-2019, organizing of Rare Diseases Day conference 2020, research and data collection about life people with rare diseases (social, financial, disease management).

In co-creation with Alliance of Rare Diseases we wrote and published the Rare Diseases Guide for wide public – doctors, social workers, patients, their family members. This informative material was developed based on PHA Latvia's Manual for People with Rare Diseases (was published in 2016). In the new Guide we gathered up-to-date information about Rare Diseases coordination centres, Medicines program for Rare diseases, rights people with disabilities, Rare Diseases registry in Latvia, state system of reimbursement of medicines, ABC about clinical trials, social support tools in Latvia, ERN's and other useful information.

In December 2020 together with Alliance of Rare Diseases we organized webinar about social support system of 2021 for people with disabilities and seniors. Elina Celmina, the Head of Social Inclusion Department of Ministry of Welfare presented brief lecture on theme and answered on participators questions.



Ieva Plume  
[www.phlatvia.lv](http://www.phlatvia.lv)  
[phbbiedriba@gmail.com](mailto:phbbiedriba@gmail.com)

## LITHUANIA

This year has been a challenge for everyone. The changed situation opened the door to new opportunities. The life of a common man has moved into the online space, many things have had to be learned to do without leaving home.

The life and activities of our association are no exception. This year, we released brochures for patients about pulmonary hypertension. We can be glad that the information provided in the publication was coordinated with the doctors of both Lithuanian PH centers. These publications are needed by patients to learn more about the diagnosis of pulmonary hypertension.



Another event in the life of our organization is that we have created our own t-shirt design. By wearing them, the ambassadors (athletes) of our association contributed to raising public awareness through sporting events. We welcome the goodwill of the ambassadors to contribute to this noble goal.



We would also like to be pleased that this year PH patients have managed to organize several group sessions with psychotherapists and psychologists. During them, the topic of anxiety management was discussed. We also had meetings with a psychologist, a mindfulness practitioner. Patients also had the opportunity to become familiar with this technique. Our patients had the opportunity to interact with the



nutritionist during two meetings. During the meetings, patients with PH learned how to choose a healthy oil and which ones are better to avoid. Another lecture was on the principles of a healthy diet. The nutritionist spoke about the importance of a healthy diet for human health. The dietary habits of the Lithuanian population were also reviewed.

One of the most important events of this year was a conference on pulmonary hypertension treatment options in Lithuania. The conference focused on treprostinil treatment. Treatment with this drug raises many fears and questions for patients, so not everyone decides to take treprostinil. Doctors from both Lithuanian PH

centers participated in the conference. A lecture on the treatment options for pulmonary hypertension in our country was given by a cardiologist. A dedicated nurse presented a report on Remodulin pumps. She shared her experiences and challenges working with patients of all ages. Several patients also shared their experiences with this medicine. The conference was also attended by a psychologist who shared tips on how to help calm down for yourself. At the end of the conference, time was devoted to patient issues and discussions took place.



Members of our organization received gifts from the association. Given today's situation, we sent members disposable medical masks, a disinfectant, and a publication on Pulmonary Hypertension. Also, members received a book "Dance with Elephants" recommended by a psychologist. We also included reusable face masks with blue lips donated by PHA Europe to the gift set. Our PH treatment centers also received such face masks.



The new pharmaceutical company Medis, which has entered the Lithuanian market, contributed financially to the implementation of this year's ideas. We would also like to be glad that the medical history of one patient has received a lot of attention this year. It was described by two online dailies and one article was published in a weekly magazine. This attention of journalists has helped to reach a larger part of the society by giving it knowledge about this rare disease (PAH) and living with it.



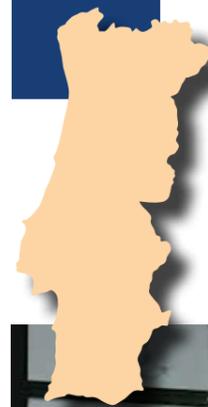
To bring more light and color into a gloomy routine, we created a mini-project, Jerusalem Dance, that aims to send a message of good mood and support to PH patients and others around the world. Despite the weather conditions and the rampant virus, the creative process and result brought a lot of joy to the whole creative team. We are happy that in this way we have at least briefly broke away from the panic these days and given this opportunity to others.



We are also pleased to have had the opportunity to contribute to projects carried out by other PHA Europe members. It's amazing, PH patients cooperate and help each other regardless of pandemic, political situation, or time of year.

We hope that next year will be rich in new opportunities for our organization.

ŽSPHA, Lithuania



## PORTUGAL



### Application for funding

Bayer's Award "Ideas that change the world" "Ideas that Change the World" aimed to finance original and innovative projects to support the community developed by public associations. Applications that support innovation in the areas of health, science and education and that benefit the community were privileged. A first place worth € 25 000, a second place worth € 20 000 and there is a complementary prize of € 5 000. We applied to this award, however the results have not yet been published.

### Connecting Healthcare Awards 2020

PH Portugal applied to Connecting Healthcare Awards 2020 that aim to reward projects involving multi-stakeholder collaborations, on national and EU level, that include patient organisations and industry partners. Applicants could apply to one of three categories: Prevention & Awareness Awards, Service Delivery Awards and Fight against Covid-19. PH Portugal applied for the Prevention & Awareness Awards with the project that have involved our collaboration with MSD Portugal, from which an awareness video has raised.

The prizes consist of a grant of €10 000 to the overall "Connecting Healthcare" winner and €5 000 to the other categories. The results have not yet been published.

### FUNDRAISING

#### Awareness Video'PH: the story of Maria

A video that tells the story of Maria, president of PH Portugal. The video is available both in English and Portuguese. It was shared on Facebook, Instagram and

LinkedIn and has reached thousands of views, some of them from newly diagnosed patients.

### Charity Market

An online event aimed at raising funds to help maintain all the services of PH Portugal during pandemic, such as the distribution of protection material or the maintenance of the help line. Most of the items sold in this market are made by patients, their family members and friends.

### PATIENT SUPPORT Newly diagnosed patients

PH Portugal is frequently contacted by newly diagnosed patients seeking for orientation. Our Association makes the bridge between them and medical community and promotes the access to doctors and treatments. The communication between newly diagnosed patients and the other ones is also promoted through discussion forums.

### Social support

PH Portugal has given social support to patients by providing protection material or establishing the contact with health professionals to identify the patients with special needs. Once identified, the patients are contacted so the Association can address those needs.

Some patients had some problems in their jobs because they were not isolated from other people and felt insecure due to a potential COVID-19 infection. Our Association contacted a social worker and several PH specialists in order to implement a possible medical discharge assignment for these patients.

## Psychological support

We identified patients who are at need of psychological support and forward them to our psychologist for further support.

The support is given by phone or e-mail and the follow up is also ensured by our psychologist. This support is also available for patients' families.

We have helped dozens of patients so far who have demonstrated a very satisfactory evolution in terms of dealing/coping with PH.

## Nutritional support

Some patients were told by their doctors to lose some weight. Therefore, they contact our Association asking for nutritional support. Each case is evaluated by phone and a nutritional plan is elaborated for those patients. Their follow up is also being ensured.

## Help line

The help line is available every day, 24h/day (by phone and e-mail). Questions about treatments, advice on vacation, food, travels and COVID-related issues are frequently asked.

## PATIENT ADVOCACY Access to treatments

PH Portugal ensured medicines were home delivered so patients could avoid going to the hospital to take it. We established the contact between the hospitals, pharmacies and patients.

## Legal protection for PH patients

Together with other chronic patients' associations, our Association contacted health authorities and the Portuguese government to keep fighting for a legal protection of PH patients. Doctors only can give patients a sick leave as a precautionary measure because there are no other legal actions they can take. Since having the sick leave is the only option to stay at home, patients are monetarily penalized. We have been spreading this situation through health polices and media channels.

Call for a strategy to keep health care after post-lockdown  
Together with other chronic patients' associations, we ask the health authorities to develop a security strategy for the resumption of hospital healthcare. This measure was taken to uniformize the access to medication avoiding territorial or social inequalities and promoting free access to medicines after the deadline of COVID-19 special



measures. Those measures should be renewed in order to ensure the maintenance of treatments, as well as to prevent the progression or worsening of many diseases.

## EVENTS

### Webinar: 'How to Live with Pulmonary Hypertension During Pandemic'

The webinar included the participation of a cardiologist, Dr Filipa Ferreira, a cardio pneumologist, Dr Debora Repolho (both from treatment centres for PH, a clinical psychologist, Dr Catia Rodrigues, a patient (Dulce Barbosa) and a member of PH Portugal, Teresa Carvalho.

Healthcare professionals explained how PH treatment centres have adapted to the COVID-19 pandemic, how they have kept in touch with PH patients, how the access to treatments and medication was guaranteed and what advice they could give to patients in this phase. The issue related with the post-lockdown phase implemented in our country was also discussed. The clinical psychologist addressed the impact of COVID-19 on mental health of PH patients and talk about the support provided to these patients during this phase. We could not fail to hear the patient's perspective, how they adapted, what were the biggest difficulties he faced, if there was worsening of the symptoms or if the treatment was compromised.

Finally, PH Portugal provided feedback on all the support provided during this phase: logistical support in providing protection material, permanent information sharing via social networks and website, support in accessing medication at home, intervention with the media and health authorities to denounce the lack of legal protection for PH patients, etc.

This was an open webinar and was held in a Facebook Live mode. The spoken language was Portuguese and everyone could participate by sending questions (by instant messages) that were answered during the webinar. This event had a huge success. We achieved thousands of people and dozens of unknown patients. We received a great feedback from them which made our work

### S+S Walking for Hope

Due to the current situation caused by the COVID-19 pandemic, all of our face-to-face events scheduled for this year (meetings, fundraising markets, solidarity trail, etc.) had to be canceled.

However, to celebrate the Awareness Month for Pulmonary Hypertension, PH Portugal joined an

Awareness Group for Cardiac Diseases and organized a "S+S Walking for Hope" on November 27, 28 and 29.

S+S Walking? What does it mean?

It was a SOLITARY walk (to avoid crowds), where people walked alone or with a maximum of 2 people. It also was a SOLIDARY walk, because for each kilometer traveled people donated 1 euro to PH Portugal.

## PH on media

Two patients were invited to give their testimony in the two talk shows with the highest ratings in Portugal. Dulce, a 39-year-old woman, talked about the life before and after the diagnosis, the challenges she faces on a daily basis and the strategies she found to deal with the disease. A PH specialist was also invited to join this patient to help spread the awareness around PH.

The other patient, Patrícia Miranda, shared the story of a little girl who was diagnosed with PH and the way she accepted the disease. Almost 30 years later, Patrícia created a blog (Blue Butterfly) and an Instagram page

(bluebutterflyhtp) to help other children/teenagers to deal with PH.

After the participation of those patients on TV shows, our visibility had a great increase. This was seen through the number of Facebook likes, Instagram followers and website hits. Additionally, we were invited to some interviews and to participate in research projects in 2021.

## OTHER - PH Guide 2020

Our Association was invited by Janssen Portugal to write some contents to the PH Guide 2020. An article about the role of patients' associations in PH community and some testimonies from PH patients were some of the contents included in the Guide.

Teresa Carvalho  
Associação Portuguesa de Hipertensão Pulmonar

<https://aphp.pt/>  
<https://www.facebook.com/hipertensaopulmonarportugal>



## RUSSIA



In 2020 the situation with Covid-19 was extremely difficult. In most parts of the world, as well as in Russia, public events were forbidden. The risk group citizens were not allowed to leave their homes, because they had a heavy penalty threat. All patients suffering from chronic diseases were included in the risk groups. That is why

the decision to change the event format was made and to organize meetings exclusively with non-commercial charity organization heads in order to improve their patient right protection skills.

In Moscow 10-11 July 2020 Association «Save and protect» along with Non-commercial organization «Live way» organized live trainings and masterclasses for 10 public organizations dealing with patient rights protection in Russia.

During the event, the public organization heads acquired the basis of the Russian Federation citizen civil rights over medicine provision, medical assistance, labor rights



of disabled people. There was also a practical part, where the participants could try themselves as medical law experts, were solving problems connected with patient routing.

Despite the bans connected with pandemics, the law representative of the Association «Save and protect» continued to stand for the medicine provision patient rights over Russia.

In 2020 over 30 court sessions were held with the result of justice restoration and patients getting their target therapy in more than 13 regions of Russia.

In order to increase the pressure on the authorities, media



representatives were invited to court sessions. Owing to the medicine provision media coverage, approximately 20 patients started to get their vital life-saving treatment for life with no more legal process.

Nevertheless, despite the court decisions, some regions continued to refuse medical provision to the patients.

That is why some radical measures were taken, like government bodies pickets. The patients' parents along with Association «Save and protect» representatives went out, ignoring the pandemic bans, to make their outrage posters seen.

In the majority of cases these actions gave positive results and patients could get their long-awaited medications.

The parents as well as the patients were only afraid of threatening complications as a result of the right therapy absence. They were not scared away by big penalties and police who went out to the picket participants first.



For our patients in Russia the year 2020 was more complicated than the previous years, when the government hadn't paid attention to disabled people problems, left their citizens in difficult situations and ignored their cries for help. That is why Association «Save and protect» is one of the most important destination for patients to get their quality life, and the year 2021 is not going to be an exception.

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

## SERBIA



Patient Association from Serbia - PH Serbia, continued with their activities during fall. We are aware that only with incredible activity of association, changes could happen for the better for all people who are diagnosed with Pulmonary Hypertension in Serbia.

Due to virus COVID19, we were prevented from organizing the conference, as well as whole series of education that we prepared for our PH patients. Because of that, we were forced to switch to "virtual conferences and meetings" with the patients. We were also participants in conferences organized by one of the most important pharmaceutical companies in Serbia, like MSD, Sandoz and Janssen.

Inspired by HOPE team participated in almost all the races that were organized during this difficult time. Great gate of HOPE has become our trademark on practically every race, through which runners in the race pass and who are happy to be photographed.

Thanks to the great efforts of PH Serbia Association and its members and dear friends from the Inspired by HOPE team, a significant and very big project was successfully realized. This project involved making a huge sign, start-finish gate that will be decorating almost all race tracks in Serbia in the future.

Almost all sport personalities in the country recognized our work and desire to help those who need it most, even more than that, they supported us. Organizers of large scale and important races will from now on place our gate on most noticeable places.



First among them, who did that, are the organizers of West trail Serbia, on their 30 km, 15 km and 7 km family race organized in nature. Photos that splashed across all social networks these days, only prove that we are not alone in this battle. Thank you all.

Members of Inspired by HOPE team participated in regional races (Bosnia and Herzegovina) in sep/october. Dedicated humanists and great human beings, were running in Mostar and Banovici races, in our recognizable shirts. Vesko, Ivan and Aleksandar literally got breathless during abovementioned races that they have dedicated to all suffering from Pulmonary hypertension.

Weekend in the october. Great number of racers gathered around Inspired by HOPE team, which was formed with the idea of raising awareness of Pulmonary hypertension, participated in the longest and perhaps hardest race in the region. Twelve members of the team successfully finished the 5,5 km long race with 1000 meters of height difference. Neither heat, and the temperature reached 36 degrees, didn't disrupt our team's eagerness to reach the top of the mountain and to dedicate their victory to all suffering from Pulmonary hypertension.

Nice companionship, great people led by PH Serbia association founder Danijela Peišić, once again showed that no matter how difficult the path before us is, we can cross it easier if we are surrounded by friends.

We are proud of these people.

## Large scale action of PAH community in Serbia

During October, in association with all PAH centres in Serbia and with all PAH doctors, a large scale initiative and action was launched by association of patients PH Serbia, inviting all PAH patients to do regular health check-up examinations during October without any delays, prolonged waiting and with reduced procedure of making appointments for detailed examination conducted by specialists.



and the whole amount of money from donation will be used for acquiring pulse oximeters that we plan to give to members of our association as a present.

More than 30 racers dressed in special PH shirts and shirts of our Inspired by HOPE team, have run half marathon and were left without breath for all persons suffering from Pulmonary hypertension.

We would like to wholeheartedly thank the organizers and all who participated in this big race in the city of Cacak.

Considering current situation in the world, caused by coronavirus, where many hospitals were turned into COVID centres and many doctors turned their focus on treating COVID patients, many persons suffering from chronic diseases, including persons suffering from PAH, that require constant control of specialists, unfortunately were left without that aspect of their care. Many before mentioned patients were forced to cancel their regularly scheduled health follow up.

Because of all that we started an action of preventive check-ups in Serbia with a special and reduced procedure of making appointments. Response of our members is terrific, and we are very glad because of that fact.

## Great and humane people in the biggest race this year in Serbia

Big race that took place in the city of Cacak had a humanitarian character. The race was dedicated to Pulmonary hypertension, in order to additionally draw people's attention to the existence of that rare and severe disease. Great start gate in the colours of our association and with the huge PH sign, was a real attraction of the racing track. A certain amount of money from registration fee was redirected to the account of PH Serbia. Our association accepted and received this donation,

Another part of our Inspired by HOPE team participated in a race in the city of Kragujevac, where they had a chance to spend some time with association members. Terrific atmosphere before, during and after the race marked beautifully spent time in the city of Kragujevac in central Serbia.

During the race in the city of Kragujevac-Serbia, we had a chance to be guests of honorary member of our association, Slaviša Vesić. Slavis is a great person, huge sportsman, Ironman, ultramarathon racer, cyclist and swimmer who for almost three years regularly helps our association, be it in the form of regular monthly donation that he makes, or by making himself at disposal of our association. Slavis is a great humanist, husband, father and he didn't forget about us even during pandemics of coronavirus. Even though he himself was affected by COVID pandemics because he lost his job, he continued to send us his donations regularly. This kind of person should serve as an example to all of us, our children and everyone else, as an example of great upbringing, an example of great humanism, and life.

Slavis, in the name of PH Serbia association, we once again thank you for everything. We are well aware that



you don't need our word of gratitude, because you are doing everything from your heart, and because you were not thought otherwise.

We happily await your future races, projects and Ironman races. We will be with you everywhere.

Thanks to the donation of „Cacak half marathon“ organizers and their decision to send a certain amount of money that they have earned from race registration fees to the account of PH Serbia, today we managed to buy pulse oximeters for members of our association. Pulse oximeter is one of the most important „instruments“, that everybody who is suffering from pulmonary



hypertension needs to have. We want to express our gratitude to the humane organizers who gave up their earnings for the higher cause. We thank all the racers who responded to this action and thanks to whom this money was gathered. Company Engel doo, like always before, met our needs, and they gave their best to service the needs of our association and to make its work much easier.

## Divčibare, 11.10.2020 • Divca trail

For the second time this year, organizers of this large scale manifestation - West Serbia Trails, that for the first time took place on Divčibare, have dedicated this race to all suffering from Pulmonary hypertension. After Vidra, we were guest-hosts on Divčibare too. That was the wish of organizers, and that's what terrific Vlada Panić and Đorđe Petrović wanted.

Great and humane young people, sportsmen full of energy and life, they wanted to use this race to additionally raise awareness of this rare disease.

Crew of the Inspired by HOPE team was welcomed by all participants, as always before, with great understanding and respect, because of everything they do for all gravely ill persons suffering from this disease. On two trails, one 15 km long and another 26 km long, they all got breathless for PH.



Vlada and Danijela were there to wish a successful race to Danijela J., Milica, Vesko, Vitaminka, Aleksandar, Ivan, Vladimir, Veljko, Nikola and Mirko.

Several people arrived at the destination after two hours, and some were running through the whole night, but we all managed to cross this difficult trail, literally getting breathless in order to reach the destination.

In the October, association PH Serbia, its members and all the activities regarding Pulmonary hypertension were on the highest level

New drug, Adempas, was officially presented to the expert community in Serbia. MSD Serbia Company has organized a large online experts meeting, which gathered around the most eminent experts in Serbia in the field of cardiology and pulmonology. Lectures were held by experts and professors from 3 of our PH centres. Along with that, a speech that Danijela Pešić, a founder of association PH Serbia, gave about the life of person suffering from PH, the problems that they face during their lives, from the diagnosis, to the use of therapies and the overall care that they need was one of the highlights of the event. She also spoke about how all that affects the life of the patients.



For November, we have prepared video answers to 50 questions about PH, which were picked by patients during our large-scale action, who later asked PH doctors to give their replies on them. All answers will be posted on our YouTube channel.

Great organization of Sandoz Patient Day. It was a privilege to be a part of such an event where we had the opportunity to, in addition to great representatives and presentations of LIPA and UKUKUS, talk about Pulmonary Hypertension from the expert point of view of Dr. Senka Milutinović from the Institute for Lung Diseases in Kamenica, which is extremely concise and great. presented PH, as well as what the profession faces when establishing the diagnosis and determining therapies, but also the importance of the next steps that must be taken for these seriously ill people to receive adequate care. In a great, emotional presentation, Danijela Pešić presented the life of a patient with PH, but also her struggle and everything that the association PH Serbia does in Serbia to raise the position of patients to an even higher level ...

Danijela and Mirko  
PH Serbia  
[www.phserbia.rs](http://www.phserbia.rs)

## SLOVAKIA



## Association activities

Despite current pandemic situation this year, we tried to make our planned activities happen. However not all of them successfully.

For the fourth time, we discussed with students of the third year of the Secondary Medical School in Lučenec not only the problems of filtered arterial hypertension, but also of organ transplants.

The project „When the breath runs out” is an interesting form of live libraries and students had the opportunity to talk about problems directly with patients with various types of PAH. Professional presentations, video spots and group work of students were not missing.

In February, Vice-President Jana Guráňová prepared a presentation entitled „The Role of Patient Organizations in Organ Donation and Transplantation” as part of a patient webinar organized by the DTI Community.



At the same time, she presented the joint activities of patient associations in Slovakia, which led to the launch of a nationwide campaign under the auspices of the Slovak Transplant Society. She also attended the Summer School on Organ Donation and Transplantation as a speaker.

Throughout the year, we informed the public about the issue of PAH through various sports activities, which involved doctors, health professionals, our supporters, as well as families of patients. In total, we have published 20 running and hiking activities on social networks. The most important was the two-day relay race From the Tatras to the Danube, attended by our runners wearing Get Breathless for PH T-shirts on a 345 km long track across Slovakia. They gained the attention mainly due to having photos of patients on their backs.

This year we commemorated the 10th anniversary of the founding of the association. COVID-19 measures

thwarted our plans. We were unable to carry out the planned gala conference with international participation. Nevertheless, at least we reminded our patients this occasion. We have published a video with patient testimonials <https://www.youtube.com/watch?v=7ABoig5VeLo>, we have helped them with packages of face masks, gels, herbal teas and a special issue of our magazine Fialka, dedicated to our anniversary.

We have also prepared new T-shirts with beautiful lung graphics designed by children's fairy tale illustrator Filip Horník. On this occasion, with the participation of doctors from the largest center for PAH, we planted a tree as part of the „Plant Your Lungs” campaign at the National Institute of Cardiovascular Diseases in Bratislava, which is a symbol of life and also a thanks for their PAH patients care.

A joint meeting of the association board with PH center healthcare specialists took place in September, where we addressed the possibilities of cooperation. We have drawn up an alternative plan for next year.

At the nationwide patient conference, the significant award „My Nurse” was awarded to the PH Center head nurse Gabriela Šuttová for dedication, professional care, support, cooperation as well as kidney donation. PHA Slovakia nominated her for this award.

## Support and help

- In May, we purchased a portable oxygen breathing device. With help of the Community Foundation Liptov, which contributed the money raised by the project „For those powerless”. Patients can it borrow if needed.
- Pharmaceutical company Actelion has prepared a print version of the PAH Patients' Charter brochure.
- The company Cetelem obtained and donated € 800 to our association for its activities, raised by plogging project in the capital city Bratislava.
- Patients had free psychological counseling available from a clinical psychologist.
- Legal and social assistance was offered to us by the Association for the Protection of Patients' Rights through an online counseling center
- Protective face masks were provided by AOP Orphan, the Association for the Protection of Patients' Rights and PHA Europe.
- Online training at national and European level has helped to raise awareness among members.

Iveta Makovníková  
Združenie pacientov s pľúcnou hypertenziou  
<http://www.phaslovakia.org/>





# SLOVENIA

## Raising awareness to protect younger patients from Covid-19

In October our association planned and organized an awareness campaign: „COVID-19 can be lethal for young patients as well!”. We believed that it was our responsibility to raise awareness that COVID-19 has a strong impact on the health and lives of both the young and the elderly living with a chronic disease. But there's only so much that a single association can accomplish, so we decided to ask our PHA Europe family members to join us in spreading the key message of the campaign. The response was overwhelming, and we quickly realized that we have stumbled upon a problem that causes concern to most pulmonary hypertension patients.

## Covid-19 - a global problem also for younger patients

At the start of the campaign, several European countries have recorded their highest daily number of COVID-19 infections. It didn't come as a surprise that the COVID-19 pandemic has indeed worsened since then. Various measures and restrictions were being adopted to limit the spread of the virus. Several calls of action to protect the vulnerable group of the elderly have been established. Unfortunately, there was very little information in the media, on how devastating COVID-19 could be for younger people such as we that have been struggling with a chronic illness even before the pandemic has started.

## The aim of our campaign

The aim of the campaign was to raise awareness that COVID-19 can severely impact both the everyday life of people with associated chronic diseases and, that in case of infection, there is an increased likelihood that their medical condition would deteriorate faster and

could even result in premature death. With the help of our PH family members, we collected different opinions, experiences, thoughts, and fears from our patients in the form of videos or profile pictures.

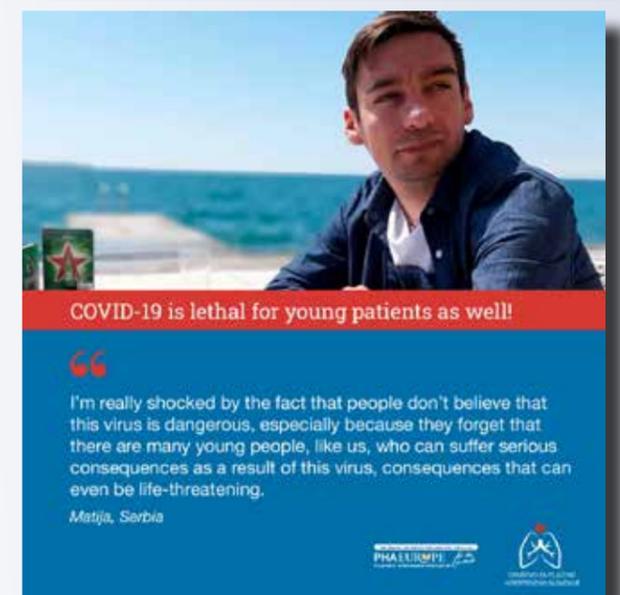
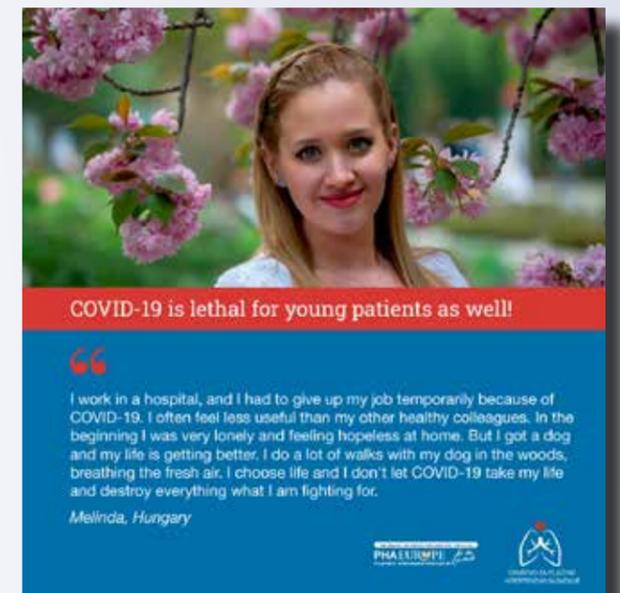
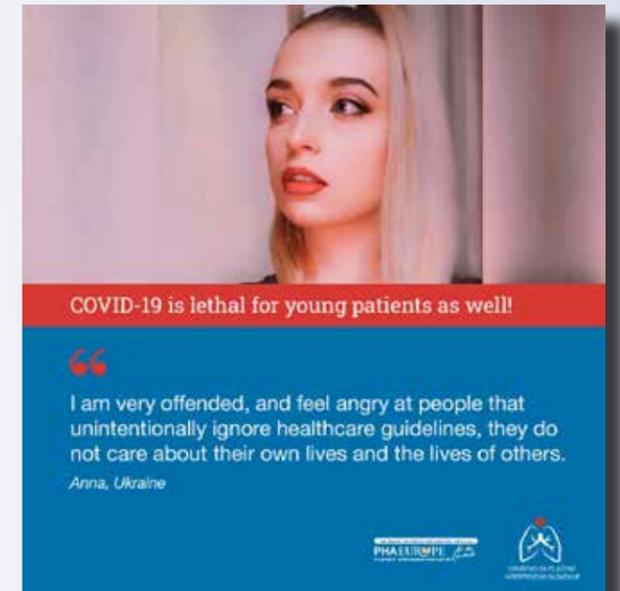
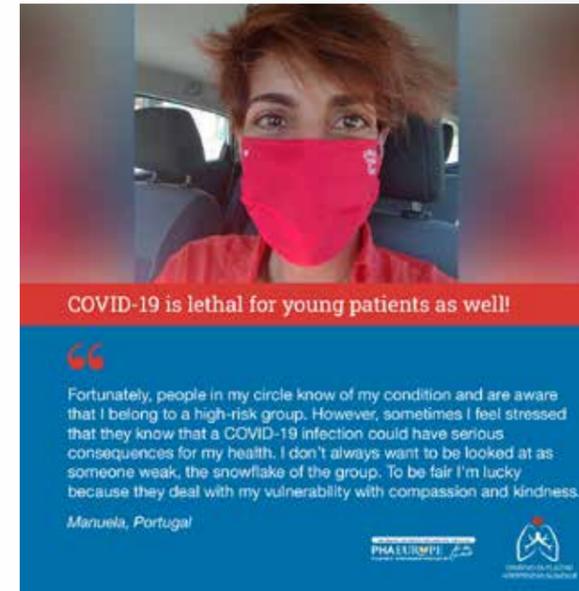
## Thanks 23 times

23 patients stepped forward and provided us with a rainbow of opinions that included thoughts of how they have protected themselves to their biggest fears.

The materials we received were both inspiring and a reason for concern. It gave us the final push we needed to really pull our efforts together and produce 4 videos and many pictures that have captured the opinions of our amazing campaign participants. The final products have then been shared with PHA Europe association members. A social media awareness campaign was structured and executed on our association's Facebook profile. 17 posts were published, and our message has reached more than 26.000 people. That's more than 1 % of the entire Slovenian population. We also reached out to the Slovenian media and our article has been published on two online news websites one of them being the biggest Slovenian online media website. We were also invited to a regional radio studio where our key messages were broadcasted to the public.

We admit, we expected more. We expected higher interest from people. Unfortunately, we can see also here, many people who do not believe in virus, ignored our messages and sometimes wrote to us not very polite words.

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



## SPAIN ANHP



2020 has been a year with many challenges. The COVID-19 made us to adapt our activities, to adapt our goals and change our means without losing our essence: help pulmonary hypertension patients. The members of the board and the workers have worked very hard. With a lot of effort, they follow, once more, the activities of the National Association of Pulmonary Hypertension (ANHP). This year had been very bad, we loss some friends, but being together has helped us to continue day by day.

The activities that our Association running are very important because they answer the member's demands and expectative. With the COVID-19 we increase the psychological and social work consultations. All these activities are inside the strategic projects of the year. In 2020 we can highlight the following ones:

- We send our members each month a newsletter with information about our activities and information related to Pulmonary Hypertension such us stated aids.
- To celebrate the World Day of Pulmonary Hypertension, in May 5th, the ANHP carried out different online activities like an awareness campaign in our networks, workshops, the lighting of fountains, and a fundraising campaign. With the fundraising of the World PH Day, we donated masks, gloves, and several materials to the pediatric of pulmonary hypertension hospitals.
- To celebrate the Rare Disease Day, we held an information day at the University Hospital "12 de Octubre" in Madrid, a reference center in Pulmonary Hypertension.
- We started a monthly online meeting with families with sons and daughters with pulmonary hypertension.
- The XVII Annual General Assembly was held online June 27. A few days before we run an online meeting to teach members to use the tool ZOOM.

- In September we run an online workshop about feeding in Pulmonary Hypertension with the collaboration of Alicia Foundation.
- The month of November is the month of awareness of pulmonary hypertension, for this reason we run a campaign in our social networks with different frames on Facebook, testimonials from patients of pulmonary hypertension and a fundraising campaign organized by Oximesa Nippong Gasses. Furthermore, our psychologist run the workshop "Emotional well-being in times of COVID-19" addressed to all patients in the world.
- In mid-September we started the Christmas Lottery campaign, which is one of the most important sources of funding for our association.
- This year we organized several online meetings with our members because the COVID-19 forced us to stay and home and, but It allowed us to stay in touch thank you new technologies.
- We took part in the online meeting of the "Consejo de la Salud" of Getafe (Madrid). This group aims to organized health activities in this community.
- Next year we are going to carry out a home cardiorespiratory rehabilitation research project with the collaboration of University Hospital "12 de Octubre" in Madrid. This year we held a meeting with our members to explain them the project and to ask them about their interest.
- Next year we will star the "Patient Expert" project. This year we have prepared the content and chosen the access platform. The content of the modules has been supervised by our lawyer, our psychologist, the specialist in Pulmonary Hypertension, and the patients, all very important. In this project the patient will always take part because they will be a support for other patients during the training. Like every year, we have participated as a speaker in different meetings, and congress which are organized by other stakeholders to increase the awareness and

sensitize about Pulmonary Hipertension. We have also participated in other informative activities among which we can highlight the following ones:

- We took part in the IX Conference on Pulmonary Hypertension at the Hospital Clínic of Barcelona. This conference is part of the project called "Respira" Classrooms.
- Some of the members of our Association participated in a discuss group about the quality of life of patients with Pulmonary Hypertension organized by MSD.
- Our social worker participated in the IV Association of Patients Meeting of FEP (Spanish Patients Foro) to explain the good practices of patient empowerment.
- We took part in the documental "Esenciales" of the POP (Patient Organization Platform). Our social worker explains the importance of the associative movement in COVID-19 time. [https://www.youtube.com/watch?v=qX\\_ko8PBUiU](https://www.youtube.com/watch?v=qX_ko8PBUiU)

The collaboration with other related organizations is very important. Our goal is to reach commons objectives related with our pathology. We think "Be together we become stronger". For this reason, we are members of other organizations and we actively participate in their activities.

As members of FEDER we actively participate in campaigns, projects, activities, meetings, etc. they organize. This year FEDER has organized very interesting online workshops, scientific days, and meetings like aids groups to improve the partnerships situation related with COVID-19. We took part in the most of them.

In relation to International Rare Disease Day, we attended the official ceremony, attended by the Queen of Spain. We had a booth at the "X race for hope" at the Casa de Campo in Madrid.

Furthermore, we took part in the IV meeting for social transformation organized by FEDER.

As members of POP (Patient Organization Platform), we attended the IV Annual Congress, the General Assembly, the meeting of environmental commission,

in the meeting to organize the strategic plan 2021-2023 etc..

As member of FEP (Spanish Patients Foro) we participated in different meetings. Our president is vocal in this organization so she took part in the different meeting of the members of the board, assembly, etc...

We participated in different meetings with Pulmonary Hypertension Association of America to share information between the world association of pulmonary hypertension. We took part in the Eurordis online activities such as the meeting to know the Covid-19 situation around the world or their assembly. We attended the global meteg of RDI (Rare Diseases International) and the Patients Day of European Lung Foundation.

To reach two of our objectives, to give correct and updated information to people with pulmonary hypertension and their families and to give visibility to the disease we participate in congress, conference, meetings etc. running by other organizations but related with our aims.

Like the 4º Investigation Meeting of PH and the Conference on designation, development, and access to orphan drugs organized both by CIBERER (Center for Biomedical Research in Rare Diseases Network) and the Malalties Minoritaires Platform. We also participated in the Conference on Orphan Drugs and Rare Diseases organized by News medical economics, and our vicepresident attended IV Congress of the Expert Patient School of the Heart Foundation.

At the end of the year, the AEMPS organized a meeting to explain the vaccination processes to the associations. It was remarkably interesting because we could ask about our doubts.

Eva García

Asociación Nacional de Hipertensión Pulmonar

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

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



## SPAIN FCHP



### XII Anniversary of the FCHP in online format, with the Inauguration of the Minister of Health Mr. Salvador Illa

The Foundation Against Pulmonary Hypertension (FCHP) has not wanted, in such a different year marked by the pandemic, to stop celebrating the XII Anniversary of the FCHP in online format. The inauguration was in charge of the Minister of Health, Mr. Salvador Illa, where he explained that the Ministry of Health plans to increase funding for CSUR, promote personalized medicine and facilitate the development of innovative therapies.

Along with the Minister of Health, the Minister of the Community of Madrid, Mr. Enrique Ruiz Escudero, Mr. Juan Carrión, President of FEDER, and Mr. Enrique Carazo Mínguez, President of the Foundation against Pulmonary Hypertension (FCHP) The event was presented by Carlos García-Hirschfeld, member of the Board of Trustees of the FCHP.

### Research grant from Empathy, Pasionhp and FCHP General Scholarship

The Foundation Against Pulmonary Hypertension (FCHP) has given a check for 10,000 euros to those responsible for the Empathy Project for research on pulmonary hypertension, led by Dr. Barberá, and a check for 10,000 euros to the PASIONHP PROJECT led by Dr. Pablo Lapunzina.

And a RESEARCH SCHOLARSHIP of 12,000 euros to one of the projects presented in our call (we will communicate it in these days). Enrique Carazo wanted to emphasize that these funds have been delivered with the great effort of the whole entity, since this year due to the pandemic no fundraising events have been held. Even so we have not wanted to leave aside one of our main objectives: RESEARCH.



DELIVERY OF EMPATHY /DR. BARBERÁ/ AND PASIONHP / DR. JAIR TENORIO/ CHECKS

### More than 372,000 euros collected in 11 years

During the 12 years that FCHP has been in operation, the entity has managed to raise more than 372,000 euros that have been allocated to scientific projects and study grants for professionals working in fields related to pulmonary hypertension. According to Enrique Carazo, president of the entity, "since we started this Foundation in 2008, our main objective has always been to promote research and raise awareness about this disease. For this reason, the more than 360,000 euros raised so far has gone entirely to projects promoted by professionals, training grants, the Empathy Project and the new PASIONHP PROJECT of genetics, and eleven years of hard work.

### Clinical and scientific tables in pulmonary hypertension

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

Dr. del Cerro, cardiologist of the Pediatric Unit of Pulmonary Hypertension of the HU Ramón y Cajal, and Dr. Moreno, pediatric pulmonologist of the HU

Vall d'Hebrón participated in the clinical table. In adults, Dr. Escribano, cardiologist of the Pulmonary Hypertension Unit of the HU 12 de Octubre, and Dr. Recio, cardiologist of the Multidisciplinary Unit of Hp of the HU Virgen Macarena of Seville participated. And Ana Benlloch Charro social worker and Mamen Almazán psychologist, both from the FHP team. In this table they discussed the latest developments in Pulmonary Hypertension and the impact of COVID\_19 on patients, among other questions of great interest.

The Scientific Table was composed by Dr. Raquel Yotti, Director of the Carlos III Health Institute, Dr. Barberá, a pulmonologist from the HU Clínic's Hp Unit and Leader of the EMPATHY Project. Dr. Lapunzina, head of the research group of INGEMM-IdiPaz, and Scientific Director of CIBERER, Dr. Jair Tenorio, researcher of INGEMM at HU La Paz, and Leader of the Project PASIONHP genetics. The importance of genetic studies in people affected by HP was discussed, as well as the evolution of research projects in which FCHP is an official collaborator.

### Appointment of Honorary Patron 2020

This year, Dr. Raquel Yotti has been appointed as Patron of Honor of the Foundation against Pulmonary Hypertension, for her support to our entity and to the research activities carried out in the field of research. It was Mr. Emilio Butragueño, Patron of Honor of our entity, who made public the appointment of the doctor.



Raquel Yotti

### FCHP SOLIDARITY AWARDS

- The prizes were awarded for the solidarity work of each of them, among the outstanding ones:
- To the television programme LA SEXTA NOCHE: For its support to the dissemination of research. The IÑAKI LÓPEZ and VERÓNICA SANZ, presenters of LA SEXTA NOCHE
- Award to the international associations "For their trajectory, involvement and support to patients with Pulmonary Hypertension".
- To the PULMONARY HYPERTENSION ASSOCIATION of the United States. He received the MICHAEL KNAAPEN "Director of Programmes for People and Families with Pulmonary Hypertension" award.



Danijela Pesic, President of PHA EUROPE

- To the PH ASSOCIATION EUROPE. She received the award from DANIELLA PESIC, President of the PHA Europe.
- TO THE LATIN AMERICAN ASSOCIATION, BLUE TISSUE. She collected the DIEGO GIL CARDOZO award, President of Tejido Azul.
- Prize for the Creation of the Multidisciplinary Unit of Pulmonary Hypertension at the Virgen Macarena University Hospital (Seville). The award was collected by Dr. Recio, Coordinator of the Pulmonary Hypertension Unit, together with the rest of his team.
- Award for his doctoral thesis CUM LAUDEN "Regulation of potassium channels in the pulmonary vasculature. Involvement in Pulmonary Hypertension". The prize was collected by Dr. GEMMA MONDÉJAR, researcher at the UNIVERSIDAD COMPLUTENSE DE MADRID. Award for her doctoral thesis CUM LAUDEN "Management of Pulmonary Arterial Hypertension: prognostic stratification and therapeutic options" to Dr. CARLOS ANDRÉS QUEZADA, pneumologist in the Transplant Unit of the Hospital Universitario 12 de Octubre.
- AWARDS FOR THE DISSEMINATION OF RESEARCH AND PULMONARY HYPERTENSION - To Dr. Olga Mediano, Pneumologist from the Sleep Unit of the Hospital Universitario de Guadalajara. For supporting our work in the media.
- To Chef Sergi Arola, for his support over all these years, and his culinary preparation, dedicated to World Pulmonary Hypertension Day.
- To the Olympic paratriathlete EVA MORAL, for supporting the dissemination of Pulmonary Hypertension with her image and her sport.
- To the ex-footballer and world champion CARLOS MARCHENA, for supporting our organisation through the Andalusian Solidarity Team.
- To EVA MORA, journalist from Televisión Española, and Patron of Honour of the FCHP, for being our eyes in the midst of the COVID\_19 pandemic

- To the artist ANTONIO OROZCO, for the launch of his song "SIX SECONDS" in support of respiratory diseases, in collaboration with SEPAR.
- To the journalist PEDRO PIQUERAS, for his collaboration in the campaign "TAKE AIR, BLOW LIFE", organised by SEPAR, and for his support to the FUNDACIÓN CONTRA LA HIPERTENSIÓN PULMONAR.

### Testimony of a lung transplant: Enara "Little Great Experience".

One of the most moving moments was the video sent to us by Enara's family. A little girl who in the middle of a pandemic was successfully transplanted from her lungs. Not all cases are like this, and the medications work correctly in the majority of those affected, but in this case Enara's family wanted to show us, from the hands of their daughter, the whole process of the transplant Enara telling about her experience in lung transplantation

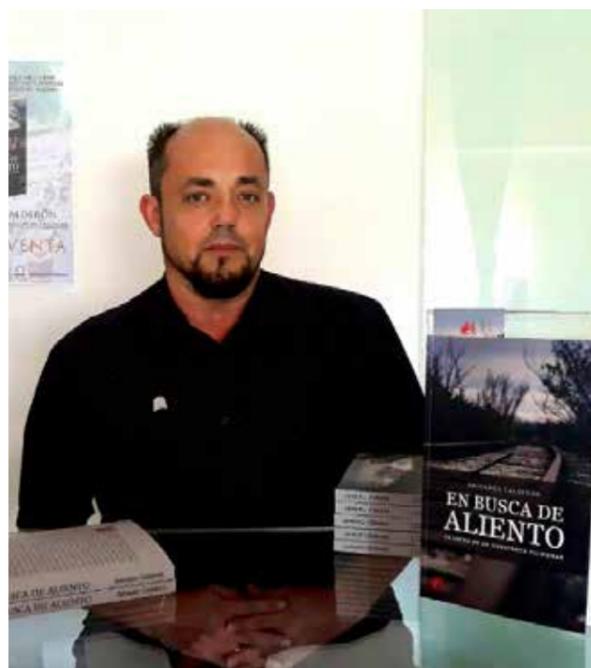
### A year marked by the COVID pandemic

The year 2020 has been marked by an unusual pandemic. During this year, we have had to reinvent ourselves, and from the first moment we wanted to be with each of the partners and friends of the FCHP. Numerous online activities have been organised to raise awareness of this disease, to care for the patient, to accompany him/her in all processes. We have put together a number of webinars on topics of primary interest to those affected by and families with Pulmonary Hypertension. We are sure that in a very short time, we will resume our face-to-face activities, but so far FCHP will continue to be part of the digital day-to-day life of each of our patients. Here is the video of the 2019-2020 activities report.

### REPORT OF ACTIVITIES 2019-2020

Enrique Carazo wanted to end the event with a message of hope and unity in such a complicated year for those affected by Pulmonary Hypertension "our entity will continue to accompany those affected by Pulmonary Hypertension and work very hard to ensure that the research reaches our homes as soon as possible with very positive results".

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



This year has been a complicated year due to the global pandemic that we have had to live with, but we have not stopped being by the side of our partners, listening to them, supporting them and giving them bio-psycho-emotional support, in these hard times more than ever.

As a result of the lockdown, we experienced in Spain from March to June, our psychological support and coaching workshops were extended and reinforced with meditation workshops to manage the stress this situation has caused for patients with Pulmonary Hypertension, and with "Flowing Health" workshops to combat the lack of mobility caused by being at home without being able to carry out any kind of activity outside. In addition to helping to keep up a routine of daily activity, we also provided and filtered information about Covid-19 which was a continuous and constant bombardment that generated more anxiety about not knowing which was truer.

At the same time, it has been a year of opportunities. The increase of online workshops and webinars has allowed us to participate in training activities that would otherwise not have been possible.

We have also participated in various campaigns that have been developed online: "Thank You Campaign



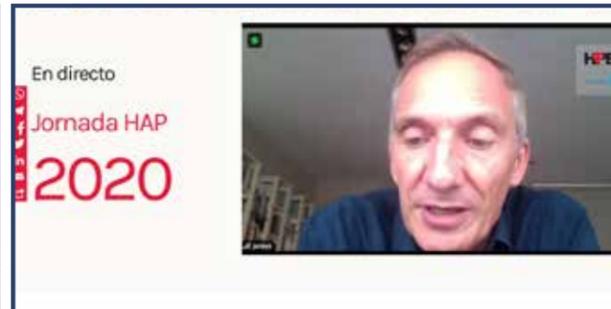
for Healthcare Workers, Breathe and Blow Campaign, Flu Vaccination Campaign and of course, our World PH Day Campaign".

This year, 2020, we had to hold our General Assembly online as well, because face-to-face meetings were not allowed, but we were eager to meet as soon as the situation allowed.

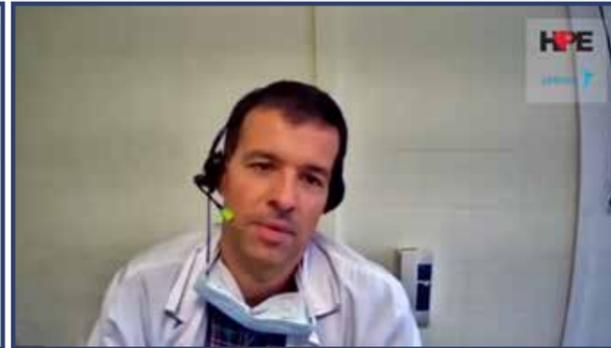
To close the year, on 30 November, on the occasion of Pulmonary Hypertension Awareness Month, we organized our "3rd Pulmonary Hypertension Conference for Patients, Families and Professionals,



## UKRAINE PHA



Dra. Pilar Escribano



Dr. Manuel López messeguer

NOVEDADES EN HIPERTENSIÓN PULMONAR  
DRA. PILAR ESCRIBANOSUBÍAS  
HOSPITAL DOCE DE OCTUBRE

TRASPLANTE PULMONAR EN HP  
¿CUÁNDO ES EL MOMENTO?  
DR. M. LÓPEZ MESSEGUER. NEUMÓLOGO  
HU VALL D'HEBRÓN.

30/11/2020

## MESA 1: ACTUALIDAD/ NOVEDADES EN HP

in virtual format", with the social support of the pneumology and thoracic surgery society SEPAR. It was a success in terms of participation, thanks to the format and to opening it up to health professionals.

Last but not least, in the month of December we have launched online Yoga workshops and workshops on emotion management, to continue to mitigate as much

as possible the side effects of this global situation that we hope will improve with the arrival of the long-awaited vaccines against Covid-19.

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)



## February 28, 2020

A Public dialogue was held in Kyiv on the establishment and implementation of a national strategy for rare diseases. For the first time in six years, representatives of all branches of government, business, the medical and patient communities, gathered at one site to discuss and find common solutions, important for patients with rare diseases. PHA Ukraine, which also participated in this event, expresses its deep gratitude for the PHA Europe, as well as personally Mirko Glavinic and Gergely Meszaros (Gergő Mészáros), who have magnanimously shared with us the experience of developing national strategies for Orphan diseases in their countries. We look forward to further fruitful cooperation with members of the PHA Europe!



## April 1-7, 2020

PHA Ukraine with the assistance and understanding of the doctors responsible for dispensing drugs, took on the function of delivering drugs to patients of Kyiv, since the quarantine regimen made it very difficult to obtain medications for patients with pulmonary hypertension.

The PHA Ukraine not only delivered the drugs, but was also able to communicate, found out about the condition and problems of our PH patients, who are almost all in quarantine at home.

Everyone understands the danger posed by COVID19 in pulmonary hypertension and is trying to protect their space as much as possible. And we hope that we will be able to survive this period without complications!

## February 20, 2020

Parliament of Ukraine, photo exhibition "Stars in support of orphans". In the Parliament building photo exhibition of famous Ukrainian took place - actors, singers, TV, radio presenters, who expressed support to patients with rare diseases and joined the charity photo session with our "rare" children. With this event, we sought to draw the attention of MPs to the problems of Ukrainians with rare diseases.

## February 29, 2020

To Rare Disease Day a photo exhibition which heroes became children with rare diseases (among them is our favorite little patient with PH Georgiy) and Ukrainian stars, who supported them, was held at the Kyiv Palace of Children and Youth. After the opening of the exhibition, an incredible show took place - a star charity concert "Belief in the Miracle" with the participation of the most famous Ukrainian artists. Seven hundred people gathered in the auditorium: orphan patients and their families, representatives of patient organizations, doctors and not indifferent who purchased tickets to support patients with rare diseases. All proceeds from ticket sales went to create a hotline to support Orphan patients. After all, none of those who have a rare disease should feel alone with their illness. We believe that the information wave about rare

## May 23, 2020

Online webinar "Current opportunities and current issues of pharmacotherapy of patients with PH" The webinar was conducted by the head of the expert group on pulmonary hypertension, a doctor of the PH Center at the Institute of Cardiology, Ph.D. Iryna Zhyvylo. She answered the questions that always interest our patients. The Chairman of the Association, Oksana Aleksandrova, also spoke about the situation with the supply of medicines for PH patients.

## June 12, 2020

Online meeting with representatives of the Permanent Working Group of the Ministry of Health of Ukraine, representatives of public organizations and European colleagues to study the experience of European countries in providing access to treatment of orphan patients.

## September - October, 2020

In cooperation with our partner, the O'Kroshka company <http://okroshka.ua/>, as well as with the financial support of PHA Europe, the PHA Ukraine has developed and released two huge colorings "Super School" and "Princesses".

In the modern world, it is simply necessary from time to time to plunge into some “anti-stress” activity. This is especially important for our patients, who are sometimes depressed due to physical or psychological conditions. And the extraordinary colorings produced by the O’Kroshka company is perfect for this.

By purchasing our colorings, each customer will receive not only pleasure from the fascinating process, but also information about such a rare disease as pulmonary hypertension, and most importantly-will provide financial assistance to the Ukrainian “Association of Patients of Pulmonary Hypertension”, as 25% of profit from the sales will be used on the implementation of projects of Association.

Many thanks again to the O’Kroshka company and PHA Europe for their help and collaboration!!!

### October 2, 2020

With the participation of the PHA Ukraine, the first orphan hotline in Ukraine was launched - a telephone number where people with rare diseases can get advice. From now on, Ukrainians with orphan diagnoses and their relatives or patients whose diagnosis cannot be determined by doctors for a long time have the opportunity to call the orphan hotline number and get advice on the algorithms of their actions regarding:

diagnostics, treatment, provision of medicines, medical devices or food.

The calls will be answered by specialists with many years of experience in community service in the field of rare diseases.

We also involve experienced lawyers and psychologists in the operation of the hotline - so patients will be able to receive psychological and legal support by number.

### November 19, 2020

The PHA Ukraine together with colleagues from the NGO “Rare Diseases of Ukraine” took part in an international webinar on advice and international joint ideas for the International Day of Rare Diseases, which will be held on February 28, 2021. Given that this year the preparation of the Day of Rare Diseases must take into account the realities of the COVID19 pandemic, we are working together on a bright and interesting format that will help highlight the problems of patients with rare diseases that need support from the state, society and each of us in this crisis time for all countries.

*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)



## UKRAINE PHURDA

#орфаннийдзвін

RAREDISEASEDAY.ORG

"РІДКІСНИЙ - не вирок!  
Ми маємо ПРАВО на ЖИТТЯ!"

29 ЛЮТОГО  
Міжнародний день  
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Львівська міська рада

соціальна реклама

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Here is an overview of the activities of the charitable foundation «Sister of Dalila», PHURDA in 2020:

- An organization called Orphan Bell for patients with rare diseases was created in order to improve the situation for patients with rare diseases in Ukraine.
- A photo session, organized by Orphan Bell, was held featuring patients with rare diseases and famous people. Photos from the photo shoot were used on billboard posters in the city of Lviv.
- Orphan Bell organized a Christmas Debate with participation of patients with rare diseases, their representatives, patient organizations officials, doctors, public activity and media representatives. During the meeting, it was decided to initiate changes that will improve the condition of patients with orphan diseases in Lviv and the Lviv region.
- Together with the Orphan Bell organization, we organized a round table discussion called «Day of Orphan Diseases». It was held at the Lviv Regional State Administration and it was attended by patients with rare disease, their representatives, the Ambassador of Orphan Patients, officials, doctors, politicians of various levels and media representatives. A roadmap was developed for further actions in the orphan communication, in the region, and in Ukraine. The aim is to improve the situation of orphan patients.

Active work has been done in order to overcome the negative consequences of the COVID-19 pandemic:

1. Funds were raised and protective gear was purchased and handed over to doctors in a hospital in the Lviv region.
2. PH patient Myroslava Dziubinska made protective masks together with ART workshop D&M. The masks were donated to doctors in a hospital in the Lviv region.
3. A video was made in order to raise funds for protective gears to be used by doctors.
4. We informed PH patients about COVID-19 and denounced incorrect information about COVID-19 that was spread on social media.
5. We provided oxygen concentrators and medicines for PH and COVID-19 patients that came to us for help.
6. We received protective masks from PHA Europe which were given to patients and physicians. In addition, a fundraising campaign was conducted based on some of the masks. The raised funds were used in the development of the Sisters Dalila Foundation in addition to an information campaign aimed at PH people interested in the blue lips symbol depicted on the masks.
7. An appeal was sent to the Department of Health of all regions of Ukraine with a request to provide patients with PH medication for three months in

advance in order to minimize the risk of disease while visiting the hospital.

8. Publication on social media of information from PHA Europe, ELF, ERS about the lives of patients with PH during the COVID-19 pandemic.
9. Participation in an online event about COVID-19 organized by the PH association of Slovenia, publications on social media about stories of young PH patients in Ukraine and their lives during the COVID-19 pandemic.

- A telephone hotline was made operational. We received a lot of calls from PH and COVID-19 patients.
- We were active in groups on Messenger (Facebook) where PH patients in Ukraine communicates. We quickly resolved patient issues.
- We launched and implemented the charitable project called «Beauty Studio: Butterfly in Blue». This is a fundraising and awareness initiative which offers stylistic and hairdressing services (haircut, hairstyle), manicure and pedicure. This propose of the project is:
  1. To do fundraising for the foundation Sisters of Dalila.
  2. To provide beauty salon services to PH patients.
  3. To give the opportunity for PH patients for beauty care training.
  4. To create awareness of PH for the beauty salon's customers.

Recently the Ukrainian singer of the band «DZIDZIO», Mykhailo Khoma, gave us a massage table for which we are very grateful. This made it possible to expand our services to also include massage services.

Together with the Orphan Bell organization, the First Western TV Channel organized the «June - month of good action». As part of the project, philanthropists realized the dreams of children with PH and other children with rare diseases. Tv and radio programs were featuring this project. This had a positive effect on the psycho-emotional state of children with a rare disease during the COVID-19. It was during this project that the head of the Lviv Regional State Administration, Maksym Kozytyskiy, presented the first electric scooter to a PH patient.

- We helped resolve transplant issues for PH patients in Ukraine. A patient was placed on a waiting list for a transplant at the Clinical Ambulance Hospital in Lviv. It was in this hospital in 2020 that organ transplants from a confirmed brain death donor were actively started. First of all, heart transplants were performed. Thanks to doctors, patients got a chance for a second life in Ukraine. We hope that a lung and heart-lung transplantation will be performed in 2021 at the Clinical Ambulance Hospital of Lviv.
- Thanks to the initiative of the Nova Poshta Company, a #marathon for all took place, where each runner chose a person who could not run due to some illness or other reason. One of the participants ran a marathon in support of the Sisters of Dalila Charitable Foundation Khrystynka Makarchuk, a child with LH. There were no winners. And the medals were won by those for whom the participants ran this marathon. Khrystynka also received a marathon medal. Thanks to #marathon for all the awareness that was raised about LH.

- A fundraising campaign was conducted for online raffles of handmade PH patents' products and charitable valuables. PH patients were invoiced in organizing the raffles.
- In December, children in Ukraine are traditionally given gifts by St. Nicholas. We initiated collection of gifts and philanthropist helped. Children with PH and children of patients with PH and children whose parents had died of PH were given Christmas gifts. Children's dreams do come true...
- We took part of the PHA Europe's O2Kids project. Khrystynka Makarchuk, who is a child with PH and who represent the face of the O2Kids project in Ukraine, received an electric scooter from PHA Europe. On St. Nicholas day, as part of this project and thanks to the nun Sister Delilah and the First Western TV Channel, two more children with PH were presented with electric scooters. The moment was full of emotions, happiness, childhood and faith in miracles. The information partner of the O2Kids campaign in Ukraine is the First Western TV Channel. A video about the boy Thomas has been repeatedly broadcasted on television. This is very good tool in overcoming the information barrier about PH and children. For us this is just the beginning of the O2Kids campaign.
- We did work in a group of experts at the Health Ministry of Ukraine on specialized support of procurement of medicines and medical devices in the areas of «Pulmonary Arterial Hypertension» and «Transplantation».
- We worked and were represented in the Commission of Health Care of the Public Council» at the Lviv Regional State Administration. We

helped monitoring the program in order to improve medical care for patients with pulmonary hypertension in the Lviv region and addressing issues related to orphan diseases.

We participated in the following events:

- Seminar named «New regulation of transplantation in Ukraine - new opportunities for patients and businesses»
- Training called «Increasing the capacity of patients organizations in Ukraine to implement budget advocacy measures at the local level.
- Conference named «Generous Tuesday: New Approaches to Charity»
- EURORDIS Summer School training 2020
- Training in charity management, project management, communication through social networks, media and fundraising through the project «ProCharity 2.0»
- OSCE training seminar on the development and application of good governance standards for NGOs and charities.

2020 was a difficult turning point in the life of every association. We express our condolences to all those who lost friends in the fight against PH or COVID-19. We sincerely wish every association in 2021 smiles without masks, strong hugs, the smell of coffee and the taste of chocolate and good health.

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





# CANADA



### November PH Awareness Month 2020

This November PH Awareness Month was all about connecting even if we couldn't be together physically.

The Canadian pulmonary hypertension community exceeded all our expectations with their involvement and support. Patients and caregivers shared their stories with us on Facebook Live, volunteer hosts supported the PH

community during virtual meet-ups, and fundraisers and donors helped us raise more than \$35,000!

Organizers from Ottawa, Ontario invited people affected by PH from across Canada to participate in a *Virtual 6-Minute Walk for Breath*. It was a big success! You can see Dr. Sanjay Mehta, Brooke Paulin, Joan Paulin, and Jodi Paulin from London, Ontario in the photo.



### Fall 2020 Webinar Series

PHA Canada was pleased to present an online education series in the Fall. The first webinar in the series—Facing Mental Health Issues—was a follow up to the Summer 2020 issue of *Connections* magazine. As people affected by PH are at an increased risk of *facing mental health* challenges, such as depression and anxiety, a panel discussed stories of families affected by PH. This panel of experts shared their thoughts, advice, and reflections for how people can approach these mental health issues in a healthy way and build resiliency.

For the second webinar, PHA Canada had Sylvia Rinaldi discuss her important research: “Nutritional Status of Patients with PH”. Sylvia is a Registered Dietitian, clinical researcher, and 2016 & 2017 *PHA Canada Paroian Family PH Research Scholarship* recipient! This webinar covered the nutritional concerns of people living with PH and more.

The third webinar—*Treatment 101: Introduction to PH Treatment*—was about understanding PH treatment options so that PH patients can be active participants in their own care. We had PHA Canada Executive Director Jamie Myrah, as well as Lyda Lesenko and Jessica Pinto, both PH Nurse Coordinators from Montréal, Québec, speak about different treatment pathways of PH, treatment side effects, and future PH therapies in Canada. Watch them here: [phacanada.ca/Webinars](http://phacanada.ca/Webinars).

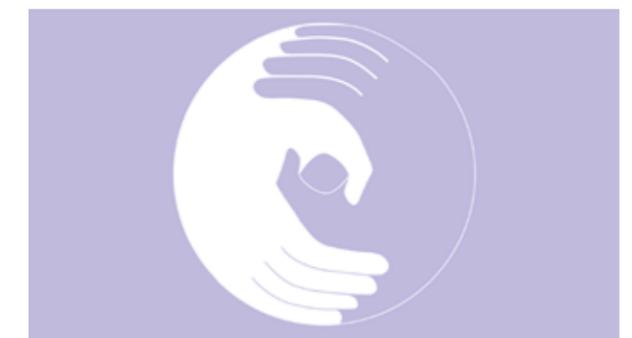
professionals, and more, *Connections* is a valuable resource that PHA Canada is committed to making widely available to the PH community.

The Summer 2020 issue of the magazine featured stories from patients and caregivers, as well as articles from experts, about PH and mental health. After the COVID-19 global pandemic arrived in Canada in March 2020, we quickly realized that it was important to share tips and resources with people affected by PH to help manage mental health challenges.

The Winter 2021 issue of *Connections* was about *PH & Family Planning*, a sensitive but important subject. Since it is recommended that pregnancy be avoided in PH patients, recognizing the harmful effects during pregnancy is of critical importance to understanding the reasons for this recommendation. However, the issue also puts forward diverse experiences of family life, including planned pregnancy, adoption, surrogacy, and having no children.

Subscribe to *Connections* magazine wherever you are in the world: [phacanada.ca/Connections](http://phacanada.ca/Connections)

PHA Canada  
[www.phacanada.com](http://www.phacanada.com)



### Connections Magazine

Published twice a year (Spring/Fall) in both English and French, *Connections* brings together the Canadian pulmonary hypertension community to inform, support, and celebrate one another.

Filled with community news and stories, research and treatment updates, interviews with PH medical



# USA PHA

## PHA Connects the PH Community Throughout the Pandemic

On March 11, 2020 the COVID-19 pandemic was declared and, within days, wheels began to turn at the Pulmonary Hypertension Association (PHA) to put in motion a response to this global phenomenon that would ensure patients and caregivers around the United States would remain informed and connected throughout the crisis.

The cornerstone of this response was a new program, PHA Connects: COVID-19 and Your Health, a series of informational resources, virtual events and support activities to keep the PH patients and caregivers of America not only informed but uplifted and united. Isolation threatened PH patients even before COVID-19, and this threat was compounded by the social distancing precautions necessary to patient safety. Many traditional PHA programs, such as its extensive network of support groups, "went virtual" to head off the looming prospect of serious and prolonged isolation.

Launched in April, PHA Connects spanned six months and produced 32 distinct activities including webinars, social media events and community engagement activities. PHA produced several informational flyers

and made these available online for digital download and mailed them to PHA constituents who may have been without internet access. Many live events were conducted in both English and Spanish, and publications appeared in both languages as well. PHA

developed and continuously updated a document answering frequently asked questions (FAQ) about COVID-19 and addressed topics including mental and emotional health, movement and exercise, handling emergencies and self-advocacy.

Patients and caregivers praised PHA Connects. Asked their opinion of the program, over 82% agreed that events met participants' expectations, were worth recommending to others and improved understanding of topics. With over 2,000 views of just one social media event, and over 5,000 recipients of mailed resources, PHA is proud of the reach and impact of this

initiative. One person who has not yet been diagnosed praised the program and presenters, saying, "since my diagnosis hasn't been confirmed yet, learning how well people can live with [PH] was good for me." That same feeling of hope and connection was echoed by a patient who said, "I'm not alone in feeling added stress because of COVID-19 but there are ways to try to control it."

Of course, PHA Connects was only one program of



As communities adapt to the COVID-19 pandemic, the Pulmonary Hypertension Association (PHA) continues to address questions and concerns from the pulmonary hypertension (PH) community. PHA provides the most recent Centers for Disease Control and Prevention (CDC) guidance to help the community make decisions about safety precautions and daily activities.

### Symptoms

- Q: What are symptoms of COVID-19?**  
A: COVID-19 symptoms can include fever or chills, cough, shortness of breath or difficulty breathing, muscle or body aches, headache, new loss of taste or smell, sore throat, congestion or runny nose, nausea or vomiting and/or diarrhea, according to CDC. Some may be a result of PH, but worsening symptoms might be warning signs. You don't have to be sick or have symptoms to spread the virus. Emergency warning signs include difficulty breathing, shortness of breath, severe chest pain and blue lips. This list isn't all-inclusive.
- Q: How do I know if my breathing issues are due to PH or COVID-19?**  
A: Symptoms of COVID-19 can be difficult to distinguish from your PH and from other viral infections, especially during cold and flu season. You know your symptoms and PH best. Significant worsening symptoms might be warning signs of COVID-19.
- Q: What should I do if I think I have COVID-19?**  
A: If you have these or other severe and worrisome symptoms, call your doctor or EMS immediately. Notify the 911 operator that you think you might have COVID-19. If possible, cover your mouth and nose with a mask before medical help arrives.  
If you have COVID-19 symptoms and want to be tested at a clinic, urgent care or emergency room, contact your PH health care team. In some places, COVID-19-specific testing sites and stand-alone respiratory clinics evaluate non-urgently ill people who might have the virus. Your health care team will work with you on how to proceed.



**PHA Connects:**  
COVID-19 and Your Health

PHA's health and wellness series educates and supports the PH community during the COVID-19 pandemic.

#PHACOV19 PHA

**PHA Connects:**  
COVID-19 y su Salud

¿Qué quiere saber sobre HP y COVID-19?

Preguntas y respuestas con expertos sobre hipertensión pulmonar y COVID-19

Dr. Gustavo Heresi

Facebook Live: 1.º de mayo de 6 a 6:30 p. m. EDT

#PHACOV19 PHA

**PHA Connects:**  
COVID-19 and Your Health

Join a Facebook Live Q&A

Dr. Ron Oudiz

Friday, April 17

7 p.m. EDT

PHA's created for these trying times. PHA's support group leaders, most of whom are patients, were grateful for PHA's rapid and robust assistance in transitioning to virtual platforms. One leader wrote, "The support from PHA to help set up virtual meetings has helped to keep our members informed and still part of our group. We need to be in contact with other patients in some way to keep our hopes up that eventually we will get through this." Although we long to connect again in person, we know that we must continue to meet virtually for the time being to remain safe. But we have also learned a great deal – for instance, that virtual meetings can unite people despite geographic or certain health limitations – and we hope to carry some of these learnings into our post-COVID programs.

2020 has indeed been a stormy year, but PHA is proud of the patients, caregivers and providers who have stepped up to make programs like PHA Connects possible, not to mention the countless acts of personal sacrifice or grit or self-care or instruction so many individuals have exerted for their own safety or for those in their care, so that we can navigate these troubled waters and make it at last to shore safely – and together.

Mike Knaapen, Pulmonary Hypertension Association USA  
<https://phassociation.org/>  
<https://Facebook.com/PulmonaryHypertensionAssociation>



# PHAWARE GLOBAL ASSOCIATION

## "The New Norm: Telehealth and Out of Clinic Testing"

As part of "Pulmonary Hypertension Week at the ATS" and in conjunction with PAR partner American Thoracic Society, ATS hosted a webinar entitled highlighting phaware's Walk.Talk.Track. 6MWT App, which was presented by Roham Zamanian, MD, FCCP and Vinicio de Jesus Perez, MD of Stanford University Medical Center.

Webinar Link: <https://www.thoracic.org/patients/lung-disease-week/2020/ph-week/webinar.php>

The phaware® podcast was selected as the #1 Pulmonary Hypertension Podcast You Must Follow in 2020!



**Lifestyle Strategies**

**Say no.** Don't feel guilty for saying no. If you tend to wear yourself out by helping other people, take a hard look at how you're doing before accepting requests, invitations or activities.

**Don't be afraid to cancel plans.** Some people with PH say it took a few years to understand that it was OK to cancel. That way, they didn't need multiple days of rest to make up for one day of overdoing things.

**Listen to your body:**  
Reduce your stress and anxiety.  
Take breaks or naps as often as you need.  
Ask other people to help you carry things, perform chores, or run errands. Many people feel good when they can help someone else.

**Maintain a healthy diet.** Ask your PH team about diet and fluid intake, and find more information about nutrition and fluid intake at PHAssociation.org/Diet.

**Break up large tasks** into smaller ones.

**Plan more taxing activities for when you have more energy.** For example, if you have most of your energy early in the day, plan most activities then.

**Home and Office**

**Elevate trash cans, garden boxes and furniture, especially your bed.**

**Keep a high stool** in the kitchen to use while cooking.

**Use a shower chair and movable shower head.**

**Use a robotic vacuum and a grabber.**

**Set a timer during activities** to remind yourself to take a break. For example, if you have to do physical work, set a timer for 10 to 15 minutes. When the timer goes off, stop working. Hydrate and rest at least one minute for every minute worked.

**Use a wagon, cart or wheelbarrow** to transport items.

**Keep anything you use often at hip level.** Avoid stooping, crouching or bending. If you have to bend, get up slowly.

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**Speakers:**  
• Linda Arden  
• Nancy Miller  
• Anna Popper  
• Rosemary Williams, MD

**Tips and Tricks to Maximize Your Energy**

Drawing on their professional and personal experiences, the speakers share strategies to find a balance that allows PH patients to enjoy life, engage in meaningful activities and prevent tiring themselves out.

"I'm Aware That I'm Rare: the phaware® podcast" was recently selected by Feedspot.com as one of the Top 10 PH Podcasts of 2020 based on relevancy, blog post frequency (freshness), social metrics, domain authority, traffic and many other parameters. phaware launched our 5th season leading into Pulmonary Hypertension Awareness Month 2020. With over 350+ episodes released to date, we are thrilled to be recognized for our collective commitment to raising global awareness for this rare disease. phaware is committed to sharing stories from all across PHA Europe with our engaged global audience. Whether you are a patient, caregiver, or medical professional, we are enlisting PH community members from across the globe. We can record anyone... from anywhere... anytime. Contact us to share YOUR story: <https://phawarepodcast.libsyn.com/contact>



## ASOCIACIÓN TEJIDO AZUL

Asociación Tejido Azul is a Colombian non-profit organization that was born in 2013 in Itagüí, Antioquia, as an initiative of Karen Narváz and Diego Gil, patients with pulmonary hypertension, and Milena Ruiz, mother of a pediatric patient with this pathology.

Its mission from the beginning until today has been to contribute to the well-being and improvement of the quality of life of patients, their families, and caregivers, for this, they raise awareness in the medical society, with a view to obtaining an early diagnosis and timely and adequate treatment. They carry out educational programs with which they help patients to know more about the pathology, they provide legal guidance in those areas where the patient, their relatives, or caregivers present difficulties, as long as they are related to pulmonary hypertension, they carry out awareness talks about the disease, hold meetings of support groups for patients in different cities of the country, create and promote communication campaigns for awareness of the disease and disseminate information of high academic level through their social networks.

Their work is carried out based on values such as respect, responsibility, commitment, collaboration,

and honesty, which has been essential to have solid foundations, which have allowed them to be a national and international reference in the defense of the interests of pulmonary hypertension patients. In addition, they have a mutual help and support approach which has been very important to the community.

Asociación Tejido Azul currently supports more than 400 patients and their families in Colombia, providing them with enough tools to be proactive, empowered, educated patients and can have an excellent quality of life and a positive vision of the pathology. Currently, the association is part of the Colombian Federation of Rare Diseases - FECOER, which works jointly with 28 other patient organizations in the formulation of public policies for the benefit of people who suffer from these types of conditions, they also work in an articulated way on projects of knowledge management and join forces in other common initiatives always with the premise of including all those who need support.

*Tejido Azul*  
[asociaciontejidoazul@gmail.com](mailto:asociaciontejidoazul@gmail.com)



## Sponsors



### Platinum

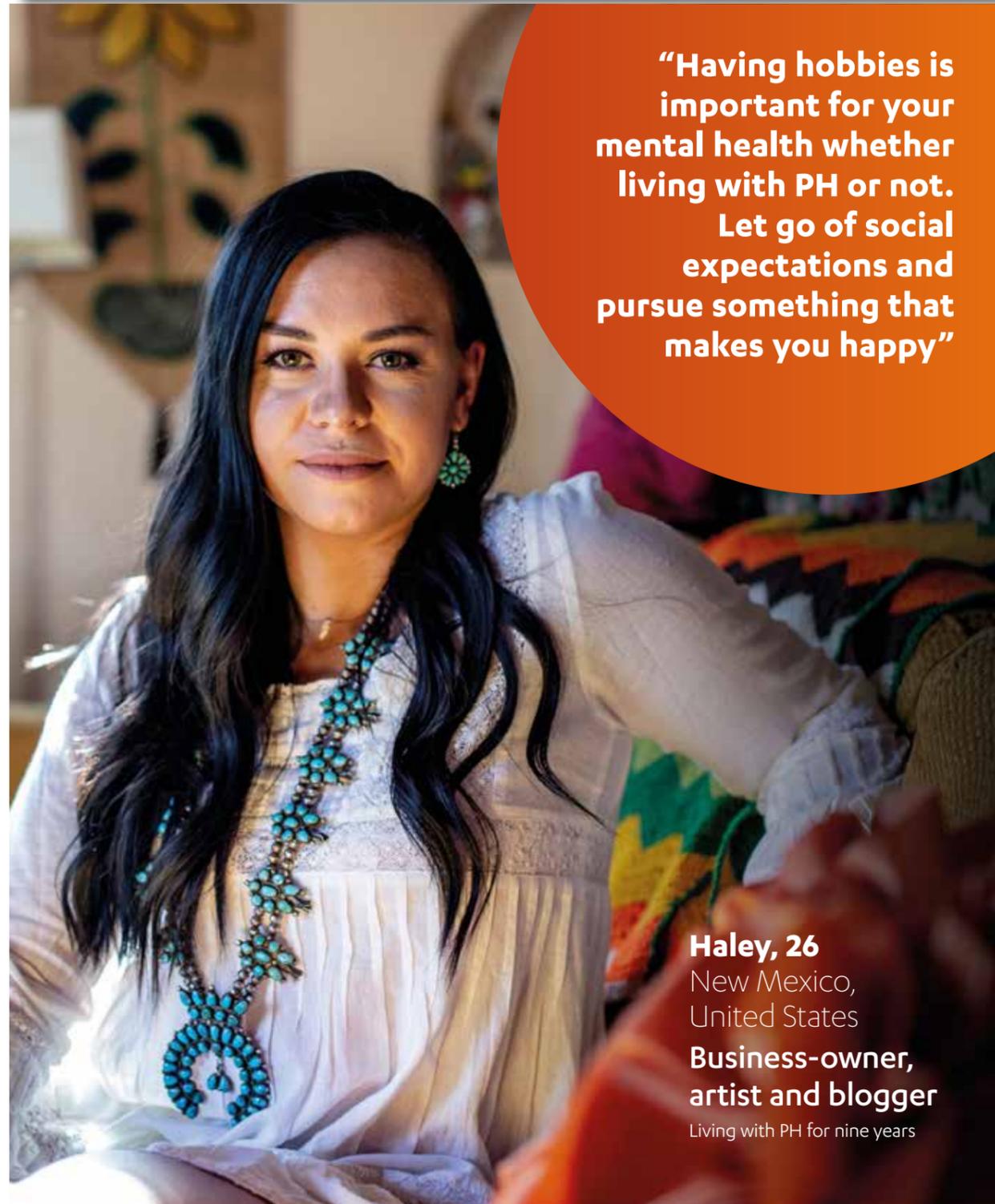


### Gold



### Silver





**“Having hobbies is important for your mental health whether living with PH or not. Let go of social expectations and pursue something that makes you happy”**

**Haley, 26**  
New Mexico,  
United States  
**Business-owner,  
artist and blogger**  
Living with PH for nine years

## 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

*Acceleron is dedicated to the discovery and development of innovative, life-changing medicines for patients with a wide range of serious and rare diseases*



### AOP Orphan: Integrated therapies for PAH patients

The AOP Orphan Group is the European pioneer in the field of rare and special diseases. Since 25 years the company focuses on developing integrated therapies for diseases like pulmonary arterial hypertension, that place patients' needs at the heart of the matter. In 2020 the company expanded its presence and has now more than 20 subsidiaries and representative offices all over Europe, as well as in the United Arab Emirates and Israel. This opens up new opportunities and chances for working together and improving the quality of life of patients with PAH.



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

#FerrerForGood



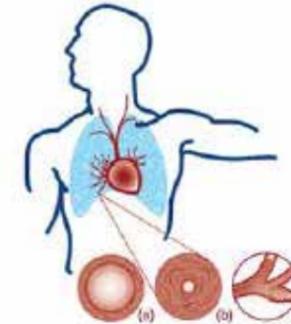
CADD®-Solis  
Ambulatory Infusion System

### 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.



## Members of PHA Europe and contact details

### AUSTRIA



**PH Austria**  
Initiative Lungenhochdruck  
Wilhelmstraße 21 - 1120 Wien  
[www.phaustria.org](http://www.phaustria.org)  
[info@phaustria.org](mailto:info@phaustria.org)

### BELARUS



**Aid to Patients with Pulmonary Hypertension**  
Zapadnaya str. 13 - 3  
Minsk, 220036  
[phbelarus@yandex.ru](mailto:phbelarus@yandex.ru)

### BOSNIA AND HERZEGOVINA



**Udruženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini**  
Zlatnih ljiljana 33, 72220 Zavidovići, BiH  
[ugphbih@gmail.com](mailto:ugphbih@gmail.com)

### 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)



**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)  
[bspph@gmail.com](mailto:bspph@gmail.com)

### CROATIA



**Plava krila - Udruga pacijenata oboljelih od plućne hipertenzije**  
Gorica Jamnička 23 - 10451 Pisarovina  
[infoplavakrila@gmail.com](mailto:infoplavakrila@gmail.com)  
[www.plavakrila.hr](http://www.plavakrila.hr)

### CZECH REPUBLIC



**Sdružení pacientů s plicní hypertenzí, z.s**  
Bělehradská 13/7 - 140 00 Praha 4  
[www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)  
[info@plicni-hypertenze.cz](mailto:info@plicni-hypertenze.cz)

### DENMARK



**PAH Patientforeningen**  
c/o Sofie M. Christensen  
Store Moelle vej 40, 1.tv  
DK- 2300 Copenhagen S  
<http://pah.dk>  
[pahforening@gmail.com](mailto:pahforening@gmail.com)

### ESTONIA



**Eesti Pulmonaalhüpertensiooni Ühing**  
[eessti.ph@gmail.com](mailto:eessti.ph@gmail.com)  
+37253004221

### FINLAND



**Suomen PAH-potilasyhdistys ry. PHA Finland**  
c/o Sonja Koski  
Kettutie 4 C, 00800 Helsinki, Finland  
[suomenpahry@gmail.com](mailto:suomenpahry@gmail.com)

### HUNGARY



**Tüdőér Egylet**  
19, Cházár András utca - 1146 Budapest  
[www.tudoer.hu](http://www.tudoer.hu)  
[csabuda.eszter@t-online.hu](mailto:csabuda.eszter@t-online.hu)

### ISRAEL



**PHA Israel**  
13 HaShoshan Street - Beit Shemesh  
9959013 Israel  
[www.phisrael.org.il](http://www.phisrael.org.il)  
[office@phisrael.org](mailto:office@phisrael.org)

### ITALY



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

### Associazione Malati di Ipertensione Polmonare Onlus



**Associazione Malati di Ipertensione Polmonare Onlus**  
Via Ardea 1/B - 00183 Rome  
[www.assoamip.net](http://www.assoamip.net)  
[info@assoamip.net](mailto:info@assoamip.net)

### LATVIA



**PHA Latvia**  
Str. Celnieku 6a - 35, Salaspils - LV - 2121  
[www.phlatvia.lv/en/](http://www.phlatvia.lv/en/)  
[phbbiedriba@gmail.com](mailto:phbbiedriba@gmail.com)

### LITHUANIA



**Žmonių sergančių plautine hipertenzija asociacija**  
Biržų g. 2, Papilys, LT-41221, Biržų raj., Lietuva  
[www.zspha.lt](http://www.zspha.lt)  
[info@zspha.lt](mailto:info@zspha.lt)  
[\(rima.gruodis@gmail.com\)](mailto:(rima.gruodis@gmail.com))

### MOLDOVA



**Asociația Obsteasca**  
"Asociația persoanelor cu hipertensiune pulmonară din Republica Moldova"  
Moldova, MD-2024, str. Andrei Doga 34, ap. 43  
[roman.balmush@gmail.com](mailto:roman.balmush@gmail.com)

### NORWAY



**PHA Norway**  
LHL PAH - Pulmonal hypertensjon  
Vitaminveien 1A  
0485 Oslo, Norway  
[www.lhl.no/trenger-du-hjelp/interessegrupper/lhl-pah](http://www.lhl.no/trenger-du-hjelp/interessegrupper/lhl-pah)  
[lhl.pah@lhl.no](mailto:lhl.pah@lhl.no)

### POLAND



**Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół**  
Władysława IV 34a m.15, 81-084 Gdynia  
[www.phapolska.org](http://www.phapolska.org)  
[Alicja.morze@phapolska.org](mailto:Alicja.morze@phapolska.org)  
[Agnieszka.bartosiewicz@phapolska.org](mailto:Agnieszka.bartosiewicz@phapolska.org)

### PORTUGAL



**Associação Portuguesa de Hipertensão Pulmonar**  
Rua Dr Costa Simões, 59. 3050-226 Mealhada  
[www.aphp.pt](http://www.aphp.pt)  
[associacaohipertensaopulmonar@gmail.com](mailto:associacaohipertensaopulmonar@gmail.com)

### ROMANIA



**Association of pulmonary hypertension patients**  
Sinaia/Prahova Carol I, nr 11 street  
<http://hipertensiunepulmonara.ro/>

### RUSSIAN FEDERATION



**Natasha Charity Fund**  
c/o Evgeniy Komarov - Kondratevsky prospect  
House 57, apartment 6 - St.-Petersburg  
[natasha.otzovitesnam@mail.ru](mailto:natasha.otzovitesnam@mail.ru)

### Save and Protect



**Save and Protect**  
Pobedi prospect 102 / office 45 - Kazan  
Republic of Tatarstan, 420140  
<http://www.ph-association.ru/>  
[lilya-belle@yandex.r](mailto:lilya-belle@yandex.r)

### SERBIA



**Plućna Hipertenzija Srbija**  
Bulevar Crvene Armije 11b/13  
11070 Beograd  
[www.phserbia.rs](http://www.phserbia.rs)  
[officephserbia@gmail.com](mailto:officephserbia@gmail.com)

### SLOVAKIA



**Zdruzenie pacientov s plucnou hypertenziou,**  
o.z. Lucenska, 31 - 990 01 Velky Krtis  
[www.phaslovakia.org](http://www.phaslovakia.org)  
[phaslovakia@gmail.com](mailto:phaslovakia@gmail.com)

### SLOVENIA



**Društvo za pljučno hipertenzijo Slovenije**  
Slovenska 29, 1000 Ljubljana  
[dbph.slovenije@gmail.com](mailto:dbph.slovenije@gmail.com)  
[www.facebook.com/PljucnaHipertenzija](http://www.facebook.com/PljucnaHipertenzija)

### SPAIN



**ANHP Asociación Nacional de Hipertensión Pulmonar**  
Calle Villajimena nº 85, 1º 4 C.P.  
28032 Madrid  
[www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)  
[informacion@hipertensionpulmonar.es](mailto:informacion@hipertensionpulmonar.es)



**FCHP Fundación Contra la Hipertensión Pulmonar**  
Calle Pablo Neruda, 39 28980 Parla - Madrid  
<http://www.fchp.es/es-info@fchp.es>  
<https://www.facebook.com/fundacionhp>  
<https://twitter.com/fundacionhp>



**Hipertensión Pulmonar España Organización de Pacientes (HPE-ORG)**  
Sant Feliu de Llobregat  
c/o Anselm Clavé no 33 3o 3a - CP 08980 Barcelona  
<http://www.hipertension-pulmonar.com>  
[presidencia@hpe-org.com](mailto:presidencia@hpe-org.com)

### SWEDEN



**PHA Sverige**  
c/o Patrik Hassel  
Kärntorpsvägen, 37  
121 55 Johanneshov  
[www.pah-sverige.se](http://www.pah-sverige.se)  
[patrik@pah-sverige.se](mailto:patrik@pah-sverige.se)

### UKRAINE



**Pulmonary Hypertension Ukrainian Rare Disease Association-PHURDA**  
Hlyboka street 12, Lviv 79013  
[fond.poryatunok@gmail.com](mailto:fond.poryatunok@gmail.com)



**PHA Ukraine**  
Panasa Myrnoho str., 14 (litera A) 01011, Kyiv  
[www.pha.org.ua](http://www.pha.org.ua)  
[info@pha.org.ua](mailto:info@pha.org.ua)





EDITOR & RESPONSIBLE FOR THE CONTENT:

**PHA EUROPE**  
Wilhelmstraße 21  
A-1120 Vienna  
Austria

**[info@phaeurope.org](mailto:info@phaeurope.org) - [www.phaeurope.org](http://www.phaeurope.org)**