

PULMONARY HYPERTENSION

# Mariposa Journal

WINTER 2019 • PHA EUROPE'S OFFICIAL JOURNAL • N. 23.



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



# editors memo

WINTER 2020 EDITION

*Dear Friends,*

I am delighted to present the Winter 2019 edition of Mariposa. When such a report is compiled at the yearend I am always surprised about the huge amount of projects we participated in. Following challenging times we successfully rebuilt our connections with the main stakeholders on the rare disease space, the European level umbrella organizations and more specifically on the PH field. We can be also proud that in 2019 we got back on growing track: we managed to increase the number of our members. At the Annual General Meeting the applications of Estonia and Moldova were accepted, which means they became our full members.

We kicked-off the year with an event in the European Parliament: multi-year, European Commission funded project, EUDONORGAN came to the end. To conclude previous years' achievements and activities, with the involvement of members of the European Parliament, a social awareness multidisciplinary meeting was held. But it was not the only activity, which related to the organ donation and transplantation! A thematic working group was launched some years ago and worked tirelessly to elaborate on a joint statement (call to action) underpinned by a comprehensive analysis of the current situation of organ donation and transplantation in the European Union. This call to action was presented in the European Parliament and you can learn more about it in the coming pages of the Mariposa.

Thanks to our sponsors, PH physicians mainly from Eastern-Europe could return to the training in Madrid to learn more about PH from top experts.

March was the busiest month: firstly a very important press conference was held in Paris: World Symposia of Pulmonary Hypertension Association presented the next steps and plans, which are needed to continue the work for the next World Symposium.

Also in March we attended the board meeting of ERN-Lung, a face-to-face meeting of ERS Task Force on CTEPH in Lausanne and a workshop in Berlin, which resulted in the Patient Charter.

Simultaneously with these efforts, preparations were made to celebrate World Pulmonary Hypertension Day on 5th of May. You can find details about our activities, the infographics we made and the events organized by our members in the previous edition of our Mariposa journal, however let me stress again how successful they were: almost 300 media pieces covered the event, more than 75,000 (organic) page reach, 50 events with more than 275,000 attendees. As usual, the awards for the best World PH Day events were only announced during our annual congress. If you are interested who organized the

best events, feel free to visit the following pages of this Mariposa to find it out.

We are also an active contributor and player of various projects on the rare disease field. In May we attended the EURORDIS membership meeting. This is a multiday event starting with the annual general meeting of EURORDIS followed by workshops. One of the main projects of EURORDIS is Rare 2030: a foresight study to map the challenges of the coming decade and outline possible scenarios to address them. It was a great honor to be chosen as the sole contributor to the project from the rare respiratory diseases.

September and October were packed with congresses. Delegates from PHA Europe attended the annual congress of ERS (European Respiratory Society) and met with physicians, representatives of the pharmaceutical companies, patients and patient representatives from lung diseases and other stakeholders. Regional congresses were organized in Pleven, Bulgaria and Novi Sad, Serbia with the involvement of PHA Europe. We are happy to see the growing number of PH specific conferences in the Eastern-European countries!

Our Annual PH European Conference closed off this year for us. We returned to Barcelona and spent four very productive days in a good atmosphere. The summary of the event together with ample photos can be found on the following pages.

A very big thanks and applause goes to our member associations, who have been working very hard to keep pulmonary hypertension on the agenda in their respective countries. We know it is sometimes difficult, we know sometimes doors close ahead of us, we know that sometimes a good idea is difficult to implement, but we are sure that the efforts we made are worthwhile...because we are working for better treatments, better quality of life and ultimately for a cure for people living with a devastating condition, pulmonary hypertension.

We are pleased that we can collaborate with a number of valuable partners. EURORDIS and European Patient Forum always give us a helicopter view and valuable insights into hot medical issues and happenings on a European level. Thanks to the work of European Reference Network on rare respiratory diseases and European Lung Foundation we got closer and know more about other rare lung disease communities. There are lots of things we can share with them and learn from each other.

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

Looking forward to next years' project and collaboration!

*Gergely Meszaros*



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## In 2019 PHA Europe was present at...



### *Vienna (Austria), February 9-10* **PHA EUROPE BOARD & STAFF MEETING**

Board and staff members gathered to a face to face meeting to evaluate the running programs and discuss future plans and projects.

### *Brussels (Belgium), February 18* **EUDONORGAN SOCIAL AWARENESS EVENT ON ORGAN DONATION, EUROPEAN PARLIAMENT**

A multi-stakeholder event with the participation of members of the European Parliament (MEPs) with special focus on how to expand the donor pool and the roles of patient associations. Gergely represented PHA Europe.



### *Madrid (Spain), February 25-26* **2ND PH MEDICAL TRAINING FOR DOCTORS**

A PHA Europe funded initiative, now in its second year, to provide PH training to physicians in countries with no or little access to medical/surgical facilities or targeted drugs.

### *Paris (France), March 8* **PRESS CONFERENCE WSPHA**

Hall participated on the press conference where the World Symposia of Pulmonary Hypertension Association was presented. The press conference was lead by prof. Simonneau, prof. Galié, prof. McLaughlin and prof. Rubin. The purpose of the association is to secure a continuation of the work performed by the world symposium every fifth year.



### *Frankfurt (Germany), March 13-14* **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.

### *Lausanne (Switzerland), March 19* **ERS TASK FORCE MEETING**

Gergely attended this face-to-face meeting. The aim of the Task Force is to elaborate statements for CTEPH.

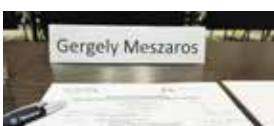


### *Berlin (Germany), March 28-29* **PATIENT CHARTER WORKSHOP**

Actelion had invited health care professionals, patients and representatives for patients association from all over the world to participate in a workshop (Hall participated). The purpose was to produce input to a patient charter. The charter is the first of its kind and will empower PH patients and carers. (It was published late 2019.)

### *Bucharest (Romania), May 17-18* **EURORDIS MEMBERSHIP MEETING (EMM)**

Each year, EURORDIS holds its General Assembly; every two years this is coupled with a 2 day capacity-building workshop specifically targeted to its members. Gergely attended this event from PHA Europe.



### *Amsterdam (The Netherlands), July 14* **IPF SUMMIT STEERING COMMITTEE MEETING**

Gergely attended this meeting, which was dealing with the organization of the first ever IPF (idiopathic pulmonary fibrosis) summit.



### *Madrid (Spain), September 27-29* **ERS CONFERENCE**

Hall, Danijela, Mirko and other national association representatives participated in the yearly ERS conference in Madrid. Most of them also participated in the day long ELF conference that was held in the same conference center during the first day of the ERS conference. The ERS conference provided a great opportunity to meet with PHAE's sponsors and potential sponsors.





*Pleven (Bulgaria), October 25-27*

### **INTERNATIONAL PATIENT ASSOCIATION MEETING**

Hall participated in the Bulgarian PHA International conference. He was a presenter at the conference that also included young Bulgarian medical students. This was a great opportunity to familiarise them with PH so that they can diagnose patients at an early stage in the future.

*Novi Sad (Serbia), October 24-26*

### **INTERNATIONAL REGIONAL PAH SUMMIT**

Gerry and Danijela attended this Summit and both ran presentations. It was a great honor that the event was attended by First Lady of Serbia, Mrs. Tamara Vučić.



*Brussels (Belgium), October 25*

### **EPF AND MEDICINES FOR EUROPE WORKSHOP**

Gergely attended this workshop and met with the representatives of EPF and different generic pharmaceutical companies and other patient representatives.

*Barcelona (Spain), November 30 – December 3*

### **PHA EUROPE'S ANNUAL PH EUROPEAN CONFERENCE (APHEC)**

Annual general meeting and conference with the participation of patient leaders of the member associations.



## **Upcoming events 2020**

*Brussels (Belgium), February 20*

### **EURORDIS BLACK PEARL DINNER**

A fund-raising event organised by EURORDIS within the context of celebrations for RARE DISEASE DAY.

*Frankfurt (Germany), February 26-27*

### **ERN-LUNG BOARD MEETING**

*Warsaw (Poland), April 24- 26*

### **EU-IPFF SUMMIT**

First European IPF (Idiopathic Pulmonary Fibrosis) Summit

*Brussels (Belgium), April 25-26*

### **EUROPEAN PATIENT FORUM**

Annual General Meeting and Leadership meeting

*Stockholm (Sweden), May 15-16*

### **EUROPEAN CONFERENCE FOR RARE DISEASES**

The largest, patient-led rare disease event with more than 800 participants from over 50 countries around the world.

*Anaheim (California, USA), June 12-14*

### **PHA'S INTERNATIONAL PH CONFERENCE AND SCIENTIFIC SESSIONS**

*Amsterdam (The Netherlands), August 29- September 2*

### **EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS**

The largest cardiovascular medicine meeting in the world and covers all disciplines from basic research to clinical practice.

*Vienna (Austria), September 5-9*

### **EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS**

This congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

*Lyon (France), September 19-22*

### **ESPEN (EUROPEAN SOCIETY FOR CLINICAL NUTRITION AND METABOLISM) CONGRESS**

### **ANNUAL PULMONARY HYPERTENSION EUROPEAN CONFERENCE (Date & venue TBC)**

## **2021 AT A GLANCE**

- EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS 4-8 SEPTEMBER 2021, BARCELONA (SPAIN)
- EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS 28 AUGUST TO 1 SEPTEMBER, LONDON (UNITED KINGDOM)

# ANNUAL PH EUROPEAN CONFERENCE

## APHEC

In 2018 we opted for a different location and held our Annual PH European Conference in Berlin, but this year we returned to the vicinity of Barcelona, to the lovely small village of Castelldefels the venue which provided excellent conditions to many previous conferences and meetings. Delegates from all over Europe arrived in the last days of November with big smiles on their faces. It was not only because of the nice weather, so patients could travel despite wintertime, but the happiness of seeing each other again.

## General annual meeting

Following the opening speech of Gerry Fischer, voting was made on different matters as part of the general annual meeting. The general meeting unanimously accepted Moldova and Estonia as new members. Voting was made on the financial report of 2018 and the forecast of 2019. The previous board was discharged and new board was elected: first time ever PHA Europe has a woman PH patient president—Danijela Pesic from Serbia. It is also interesting about the new board that it consists of only woman: Zdenka from Croatia, Natalia from Bulgaria, Eva from Austria, Tuulia from Finland, Tadeja from Slovenia. In contrast the auditors are men: Odd Erling from Norway and Bogdan from Romania. Let me congratulate them for their positions! The break between the annual meeting and the dinner provided excellent opportunity to freely chat with others and share ideas. Everybody had another new and new story, so the dinner ended late night, despite everybody was tired from the travelling and we all know that tomorrow's agenda is very tight.

## Industry day & Gala dinner

The second day of the congress was dedicated to the pharmaceutical companies. It is always interesting to learn how the industry sees the patient community, get insight into new studies and discuss common projects. The day was kicked-off by the common presentation of Bayer and MSD. Mikyung Chang and Chandra Rao outlined their patient engagement initiatives. It was heartwarming to see their clear message on the slides: "Place Patients First". They are thinking about a continuous learning curve: they invite patients to listen and learn from their experiences, get to know their needs, concerns and challenges they are facing. This information is used in solutions, which hopefully meet patient expectations.

The next phase, which close the circle, is the feedback: collecting information from the patients how the talks are built in. And the process restarts. The presentation was not theoretical it might look like, but covered lots

of practicalities. It outlined the partnerships Bayer/MSD relies on and their commitment from drug development to better care of patients. We could learn about special programs on the field of medical education and patient supporting. Acceleron, a relatively new player on the field of PH, gave a valuable insight into their company and the trials they are working on. We could welcome Jessica Barnes, Ameet Khara and Sujay Kango as presenters. It was interesting to see the potential repurposing of currently existing drug(s) the trend, which is currently followed on many areas of the rare disease field. The current treatments promote widening of blood vessels (dilation), however, as they understand, abnormal cell growth may also be a target for PAH treatments. Two animal models have already underpinned this approach, as they showed promising results in improving hemodynamics. Actelion closed the industry day. Despite Actelion went through a lot of changes in the past years as they became the part of the Johnson and Johnson Family of Companies, they remained one of our most important partners. Alessandro Maresta kicked-off the presentation and gave a patient advocacy update. More details about these projects were provided by Rajashree Dhamanaskar. The patient diary is undoubtedly a great success and used by hundreds of patients on a daily basis. To address the need of younger patients, Actelion developed the smart phone application version of the diary. It is easy to use and record different health-related and other relevant data and the reminder functions are one of the most liked features. PAHuman, the online booklet, gives a comprehensive guide and provide useful information for patients on their whole patient journey in a very eye-catching way. The PAH Patient Charter and the Careers and hobbies campaign are also the ones, which need to be mentioned. The day did not end with these presentations, because that evening was held the greatly expected Gala Dinner. But before everybody could enjoy the excellent foods, Prof. Nazzareno Galie made an excellent presentation about the advances in diagnosis and management of PH. In his very detailed lecture we could look back to decades and witness how the understanding, management and treatment strategies of the disease changed and evolved in light of the symposia and the guidelines from 2004, 2009 and 2015. The Gala Dinner is always about celebration: we celebrate the long journey which behind us and where we are now and the big accomplishments of the year. Colorful presentations reminded us of the great success of World PH Day and videos showed the pictures of the photo contest and the highlights of the best events. We handed over the photo award to Fundación Contra la Hipertensión Pulmonar, Spain. Big applause went to the awardees for the best



*(...) thank you to everyone who organized this year's APHEC. Everything was excellent. APHEC is extremely useful for all member countries of the Association. During APHEC, besides the work of the Association, we also find out many news in the field of medicine and pharmacy related to pulmonary hypertension, not only in Europe but also in the world. It also gives us the opportunity to exchange experiences with other European countries about the activities of the association, but also to present our work in the past through Mariposa Journal."*

Bosnia and Herzegovina



*The most valuable thing I can do for our organization is to compare the level of patient care with other European countries. This happens every year at the annual meeting of PHA Europe! The relationships and friendships that emerge during the forum are unique and remain over time. It's great to be a part of this family!"*

Bulgaria /PHA/



MIKJUNG CHANG

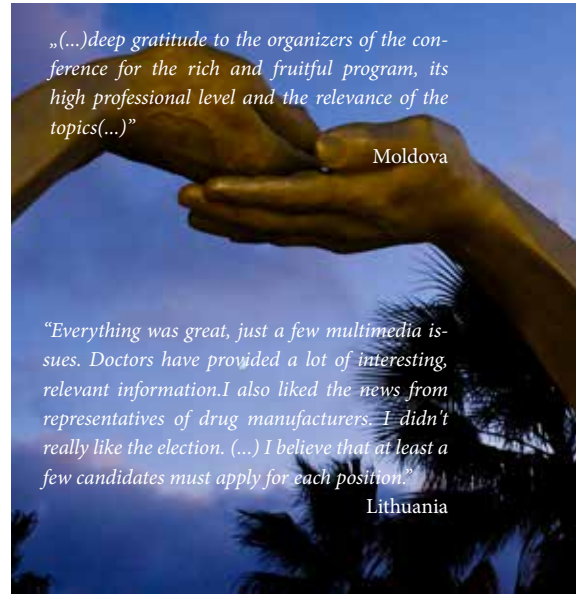








AMEET KHARA

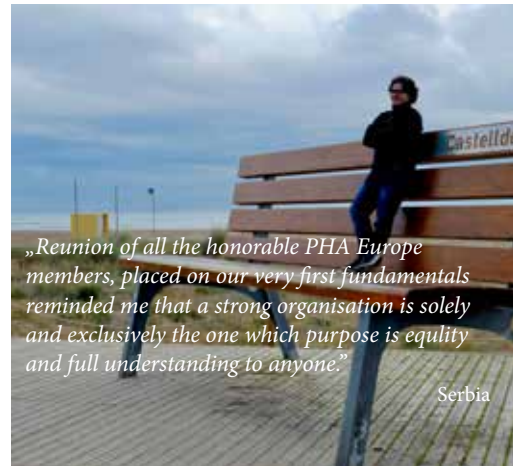


„(...)deep gratitude to the organizers of the conference for the rich and fruitful program, its high professional level and the relevance of the topics(...)”

Moldova

“Everything was great, just a few multimedia issues. Doctors have provided a lot of interesting, relevant information. I also liked the news from representatives of drug manufacturers. I didn't really like the election. (...) I believe that at least a few candidates must apply for each position.”

Lithuania



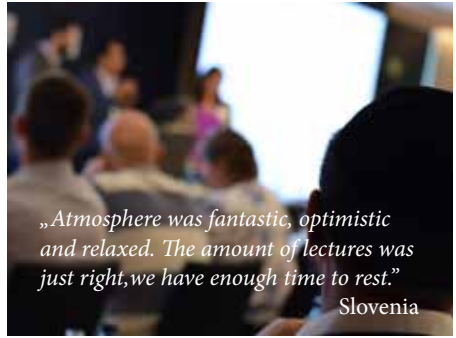
„Reunion of all the honorable PHA Europe members, placed on our very first fundamentals reminded me that a strong organisation is solely and exclusively the one which purpose is equity and full understanding to anyone.”

Serbia





*"APHEC was time to start again.  
The family reborn,  
a new cycle begins.  
It's not time to give up  
but bring strengths together."*  
Portugal



*„Atmosphere was fantastic, optimistic  
and relaxed. The amount of lectures was  
just right, we have enough time to rest.”*  
Slovenia



SUJAY KANGO



PROF.  
NAZZERENO  
GALIE





*"we have experienced this year's APHEC as a reunion (...) and together we stand stronger (...)"*  
Croatia



*"nothing starts from nothing"; it was wonderful: the annual meeting, guests and members of associations; every year we learn new things."*  
Romania



*"(...)it was wonderful to see the focus and motivation to move forward with the goal in mind -Pulmonary Hypertension awareness and improving the quality of life for its patients. The conference provided so much food for thought, exciting information from experts in the medical world, a different perspective from the pharma companies and the camaraderie that invigorates and motivates a person to do more!"*  
Israel



PROF. SIMON GIBBS





World PH Day events: Bosnia and Herzegovina (3rd place), Bulgaria BSPPH (2nd place) and Serbia (1st place). These moments were so touching that some of us could not resist crying. The event ended with dancing in a very good mood.

## Lectures

The Monday morning started early with the presentation of Prof. Simon Gibbs. Previous night-with the help of Prof. Galiewe looked back, this time we looked at the future, what is ahead of us, what we want to achieve in the future. We learned about the future of imaging biomarkers in the diagnosis, genetics, the planned use of artificial intelligence, digitalization, some potential new drugs (repurposing) and new devices and last, but not least the ways pediatrics can change in the future. The session of lectures was concluded by Prof. Arsen Ristic, who focused on access, especially in the East European countries and outlined possible ways of collaboration to improve the situation. Patients in these countries are facing difficulties: there are unmet needs regarding early (and differential) diagnosis, access to expert centers and equipments and the lack of dedicated rehabilitation programs also make the patients' life challenging. Before the lunch we had time for a short wrap-up of advocacy activities presented by Gergely Meszaros. He introduced the number of projects we are participating in and gave a report of this year's achievements.

The second part of the day continued with the presentation of Mirko Glavinic who unfolded the tips and hints of a successful social media campaign and gave valuable ideas how we can better use these channels. The day ended with the capacity building workshop: we could not only listen to different lectures, but the member associations were very active and presented their own projects, which worked well in the past. We discussed the importance of training and listed the learning possibilities available for patients. The last day was even more interesting, when it came to future projects. Gergely moderated this more than 2 hours long discussion and we agreed on launching different working groups, our involvement in projects driven by other umbrella non-governmental organizations and talked a lot about webpage update. Lots of questions and comments were raised and everybody could contribute to the discussion. The conference ended with a light lunch and the delegates left to the airport during early afternoon hopefully with lots of plans in their head. The general atmosphere of the congress was excellent, but please also visit the quote section with the feelings of the members! I am thrilled about and looking forward to our next conference.



*Gergely Meszaros*



# MOSAICS FROM ADVOCACY WORK

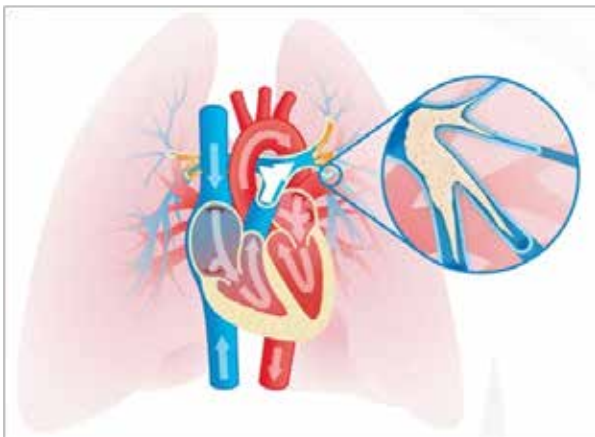


## CTEPH Task Force

Task Force of ERS (European Respiratory Society) and ERN-Lung (European Reference Network) on issuing a statement regarding CTEPH

*Gergely Meszaros*

We were witnessing considerable advances in the diagnosis and management of CTEPH. In order to establish common understanding a task force was launched with the aim of issuing a statement – by definition statements are different from guidelines and aiming to summarize best practices. The task force is consisting of key opinion leaders from the medical field and not only from Europe, but colleagues from the United States and Japan. PHA Europe has been invited to provide the patient perspective. The work of the task force is divided into subgroups



dealing with the followings:

- diagnosis (including diagnostical tools)
- different aspects of the treatment (medication, BPA, PEA, multimodality)
- rehabilitation
- future trends, possible trials

Face to face meetings were organized in Lausanne (19th of March) and at the ERS Congress in Madrid. These meetings are supplemented with intense email exchanges to finalize the statement paper until the next ERS Congress in Vienna.

## CRC-PHAROS project\*

ERS Clinical Research Collaboration (CRC) severe Pulmonary Hypertension management AcROsS Europe

*Gergely Meszaros*

In 2019 project PHAROS was initiated – in collaboration with ERN-Lung – with the following main objectives:

- Establish a platform for clinical research in PH
- Provide expert opinion on feasibility and priority for industry-sponsored RCTs (randomized controlled trial)
- Raise standards of research and harmonise standard operating procedures
- The project is divided into different work streams with well-defined goals:
- Establish an inventory of existing national and local PH registries and look at interoperability to exchange data
- Evaluation of patient access to care across Europe
- Characterisation of PH patients with failing right ventricle
- Phenotyping and treatment of patients with PH due to lung diseases

The main deliverables of the projects are the followings:

- Establishment of the PHAROS CRC and publication of its structure and aims
- Creation of a website that evolves as the CRC is developed, with appropriate information for clinicians, researchers and patients
- List of existing (national) registries and their interoperability to exchange/export a core of clinical data to a common repository, followed by additional details for the specific projects as agreed within the CRC
- Realisation of at least 2 collaborative projects funded by public or private (industry) sources, to be presented at the ERS International Congress and preferentially submitted for publication in the ERJ
- Development of a consensus statement on the research priorities for PH
- Elaboration of a comprehensive educational program on PH (with ERS and other organisations)

*\*Based on the slides from Olivier Sitbon and Ablio Reis*

## European Reference Network for rare or low prevalence complex diseases - Respiratory diseases (ERN-Lung)

*Gergely Meszaros*

On 13-14, March medical experts and patient representatives gathered at the registered seat of ERN-Lung in Frankfurt for the board meeting of ERN-Lung to discuss existing programs, evaluate the performance of the network in light of operational objectives and make future plans.

This two-day board meeting forms an important part of the life ERN-Lung as it provides an opportunity to a face to face meeting.

The first day started with the report of the Network Coordination team, which was followed by the report of the different functional committees. Gergely, as being the member of the Professional Training and Continued Medical Education, ran a presentation about the survey conducted with the aim of understanding the current educational needs in the network, about twinning fellowship (a program dedicated to extend the borders of the network by including Eastern-European countries) and CEF (Connecting Europe Facility) project.

The second day each core network (disease) had their own separate meetings. The PH core network discussion - this attracted other disease representatives as well, because PH is considered one of the golden standards - we covered, among others, the work of CTEPH Task force, the CRC-PHAROS project, how to strengthen the collaboration with ERS, possible launch of clinical trials network.

The leadership of ERS (European Respiratory Society) and ERN-Lung made a decision to closely collaborate. It means that for some EU calls a consortium is founded by these two parties, in other cases ERS provides the needed own sources. This collaboration makes possible to apply for more calls, ultimately generate more funds for the activities of ERN-Lung. The first sign of this cooperation was the ERS-ERN Lung common symposium in the ERS Congress 2018 in Paris co-chaired by Prof. Marc Humbert. As part of the symposium Prof. Tobias Welte, ERS president had a lecture and Gergely also had a speech about patient



expectations.

In autumn the European Commission issued two important statements on (1) cooperation with industry and (2) integration of ERNs in the national healthcare system. Both topics were heavily discussed in the past and the original concept was to completely exclude the industry from the work of ERNs, but the new approach aims to ensure a limited role for the industry with many restrictions.

The second statement was also very welcome as ERNs should be integral part of the national healthcare system by providing second opinions and expert support.

There are lots of ongoing projects under the umbrella of ERN-Lung and there are ones, which ERN-Lung applied for:

- ERN-Lung participates in the Task force of International Rare Diseases Research Consortium (IRDiRC).
- The above mentioned CEF grant “(...) will be used towards eLearning/eTeaching tools to disseminate knowledge relevant to rare respiratory diseases and at the same time these tools will be used to communicate SOPs and guidelines for cross-border services of giving advice, care and/or referral within the network and to an outside audience.” (Report ERN-Lung Board Meeting)
- The goal of the patient journeys initiative is to outline the patient pathways from the general practitioners to the ERN.

It is good to see that the network is growing: we could welcome new affiliated PH centers from Austria, Lithuania and Slovakia in 2019. The number of full members will radically increase in the coming months: new call for full membership was published in September, 2019 and as per the preliminary numbers from the European Commission 46 new applications were received. Following the validation of these applications we will have a clear picture, which currently “white spot” countries will be covered by the network.

We hope ERN-Lung will continue to be an engine in the integration of high level care to all patients living with rare lung diseases in Europe.

## Organ donation and transplantation in focus

Gergely Meszaros

However different types of treatments and pathways are available and luckily accessible in more and more European countries, in certain cases lung transplantation remains the only option for some of the patients.

The number of available organs and the level of access to transplantation depend on lots of factors, but everybody agrees that there is a lot to do on this field. As per the most up-to-date statistics, lung transplantations only represent cca. 5% of the transplantation, but they are usually life-saving and significantly improve the quality of life of the patients – the downside is the life-long need immunosuppressive therapy to prevent rejection.

Based on the initiative of PHA Europe work began back in 2015 and resulted in the CALL TO ACTION to improve Organ Donation and Transplantation across the EU (Call to Action). It addressed the EU Member States, among others, to support their national transplant programmes in collaboration with patient associations. PHA Europe called on the European Commission to launch awareness raising projects and continue with the implementation of its action plan and applicable directive. At the same other relevant stakeholders were also called upon to collaborate more closely.

A multi-stakeholder cross-condition meeting in the European Parliament on 18th of October, 2016 presented the Call to Action but the work did not stop with the launch of that important paper.

EUDONORGAN project was launched with multiple objectives. The ultimate goal of the European Commission supported initiative was to raise the organ donation rates in Europe. To help to achieve these objectives two basic tools were used: training and social awareness. ‘Train the trainers’ part of the project addressed healthcare professionals and other relevant actors in the field of organ donation – two patient representatives from our members were selected to attend the course and became the ambassador of the program. Under the umbrella of awareness raising different events were organized all over Europe to get in contact with relevant stakeholders.

The EUDONORGAN project ended on 18th of February, 2019 with a multi-stakeholder social awareness event



in the European Parliament with the participation of members of the European Parliament (MEPs) with special focus on how to expand the donor pool and the roles of patient associations.

Following the lectures and the panel discussions, we were witnesses of patient testimonies. We closed the project with a very nice and symbolic gesture: we released (environment-friendly) balloons to the sky with our very wishes.

### JOINT STATEMENT Thematic Network on Improving Organ Donation and Transplantation in the EU 2017

A Shared Vision for Improving Organ  
Donation and Transplantation in the EU



The road to the road is long. Beyond funding, legislation, changes, and data. The road to the road is long. Beyond funding, legislation, changes, and data. The road to the road is long. Beyond funding, legislation, changes, and data. The road to the road is long. Beyond funding, legislation, changes, and data.

In parallel with the EUDONORGAN initiative, the thematic working group continued the work and a more detailed paper was elaborated: A Shared Vision for Improving Organ Donation and Transplantation in the EU (Joint Statement). PHA Europe played an important role in this work and endorsed the paper, which was officially submitted to the European Commission on 3rd of October, 2019 and has been presented at the Commission’s annual Health Policy Platform event on 17th of October, 2019.

The Joint Statement broke down the general calls of the previous paper into the following well-defined, digestible action points:

- Mobilise political will: follow-up of EU Action Plan on Organ Donation and Transplantation (2009-2015) is utmost important to put back organ donation on the political agenda
- Boost benchmarking:
- Urgent need for data registry to support data and knowledge-sharing
- Leverage research: setup of common research priorities
- Improve legal and institutional framework: eg. promoting ‘expanded criteria donation’, facilitating international organ exchange, regulating and guiding transplantation from donation after circulatory death (DCD), applying an appropriate allocation strategy
- Streamline organization & invest in leadership: optimization is critical to ensure the organs reach the recipient as fast as possible
- Allocate appropriate funds: on both member states and EU level (ESF, ERDF, ESIF) calls and available funds are needed
- Promote education & training: continuous education on different levels, especially in ICU (intensive care unit) and raising awareness programs are important
- Eradicate inequities: special attention needed to address disparities due to ethnicity, education, socio-economic status
- “This stakeholder-led tool offers a unique opportunity to shape future policy on organ donation and transplantation in Europe, as it comprises actionable policy calls and recommendations to drive efforts at EU, Member State, and stakeholder level.”





## DOCTOR'S TRAINING

*Gergely Meszaros*

This was the second time we were in the position to fund and organize training for doctors dealing with pulmonary hypertension. Physicians were invited mainly from those countries, which have difficulties with access to PH treatments. We were happy that 8 doctors gathered on 25th and 26th of February in Hospital Universitario 12 de Octubre (Madrid), which ensured the venue of the training and the high level education.

The agenda of two day course was extremely tight and covered CTPEH, discussion of selected clinical cases, testing methods and different aspects of treatment of PH, including genetics and end of life crisis.

The training was well accepted by the physicians and we received lots of positive feedbacks. One point which can be made better is to “bring in more action” to the course. We are working on continuing this series of training and endeavor to deliver a more tailor-made and pragmatic course.

## PATIENT CHARTER

*Hall Skaara*

In late March 2019, Actelion invited patients, patient advocacy group representatives and healthcare professionals from the PAH global community for a two day workshop. (Hall Skaara participated as a patient and a representative of the Norwegian and European PH Associations.) The aim of the workshop was to give input to a patient charter. Following the workshop, Actelion developed the charter which was published in November 2019. The content was based entirely by the discussions where the participants reflected on their own views and perspectives on the best holistic care package for people with PAH.

The patient charter is the first of its kind. It is written in a non medical and easy to understand language and it is intended for the PAH patients and their carers. The aim with the charter is to enable and empower the patients and carers to communicate effectively with their healthcare professionals, to enable them to make decisions together and to agree on a care plan that is appropriate for the patient.

Although the charter is based on the input from the workshop participants, it is also based on the ESC/ERS international guidelines on the diagnosis and treatment of PAH.

The charter starts by describing the diagnosis of PAH. It is a difficult disease to diagnose as the symptoms often are mistaken with other more common and less serious diseases. However, the time to diagnose PAH today is too long. Early diagnosis is critical in order to improve life expectancy and Quality of Life. The charter there for states that «you should expect to receive a timely and accurate diagnosis». Furthermore, the charter lists which tests the patient should expect to undergo during the time

of diagnosis.

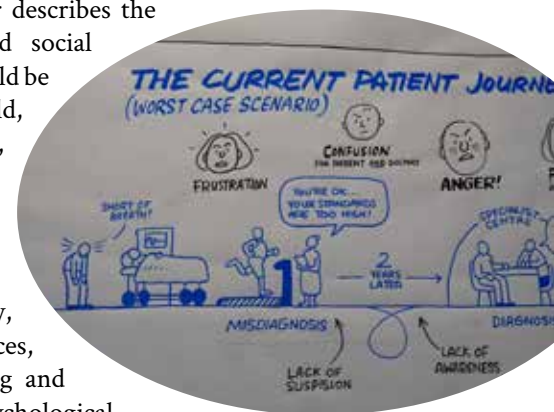
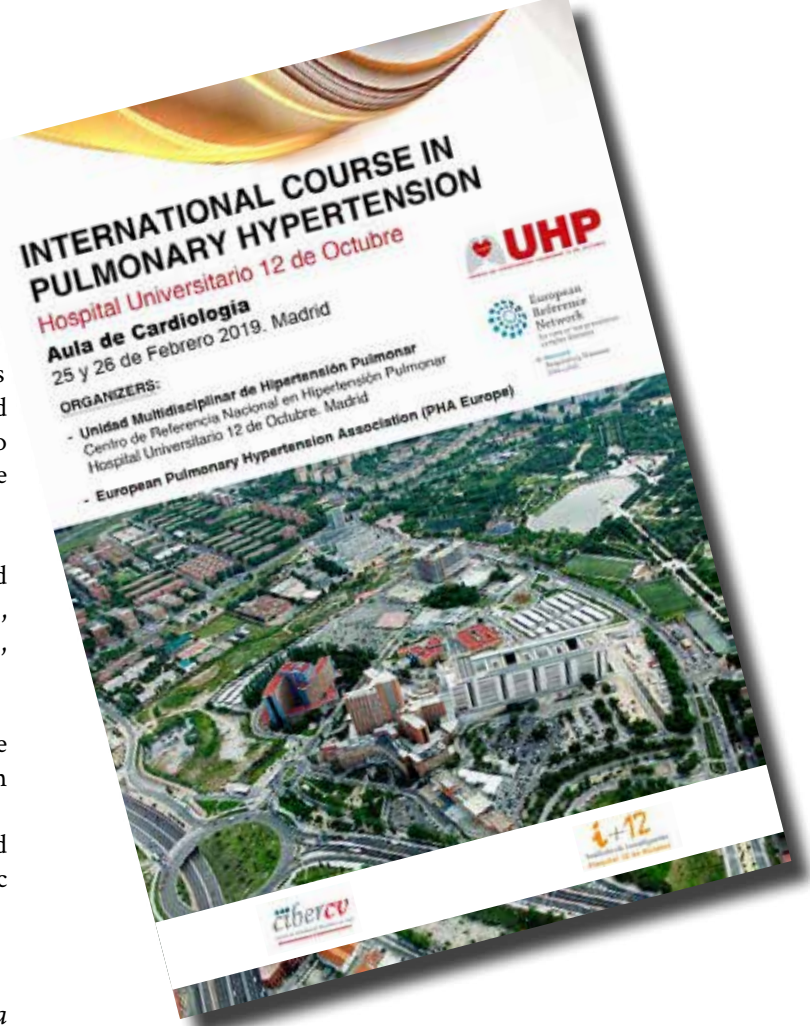
Secondly, the charter describes the treatment. The patient should expect the healthcare professionals to listen to the patient's preference and involve the patient in decisions about the care and treatment. The charter also describes expected followup frequencies and risk assessment that should be performed. Medical treatments are also listed.

Next, the charter describes the holistic care and social support that should be given. This could,

for instance, include advice on topics such as travel, nutrition, family planning, physical activity, career choices, financial planning and access to psychological support.

Finally, the twelve page long charter has a «call to action» section. The charter calls for PAH to be diagnosed earlier, to support people with PAH to access the care that is appropriate for them and support people to live as well as possible with PAH.

So the patient charter is the first of its kind, and it will hopefully be a great tool to empower the patients and carers in their dialogue with health care professionals.



## AUSTRIA



### Office PH Austria Patientservice 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)

### Information Days

We hold information days with scientific lectures across the country four times a year to keep our patients up to date. There are also chatting meetings several times a year, where our patients have the opportunity to exchange ideas at those peer to peer meetings.

### Service for patients

In addition to social care and personal consulting, we offer our patients counseling hours at the AKH and operate 3 24/7 patient hotlines. In 2019 we were also able to continue our projects to offer psychological and nutritional support to the PH patients.

### Awareness

In order to make PH known better, we organized the Vienna ZooRun for the 8th time this year, in addition there were major events such as the 5th Vienna GhostRun in the Vienna Prater, an interview with Reinhold Messner on World PH Day, the Silent Run as well as a diver in our t-shirt in the House of the Sea and much more.

### Information

We publish our newsletter four times a year for all of our patients and supporters. In addition, we operate an informative homepage and a Facebook account, which keeps our patients and members up to date.

### Kellertheater in Linz, January 17

Again, the evening was all about „laughing is healthy“! This also attracted many patients from Upper Austria and their relatives to the Kellertheater this year. For 65 years, the theater has been known for the best entertainment in the field of boulevard comedy. This year we saw the anniversary production „Reset-Everything at the Beginning“ by Michael Niavarani and Roman Frankl.

### Information Day Vienna, March 2

This time our info day took place on March 2nd. Around 100 patients and carers used the information day to get the latest information about PH and also exchange ideas among themselves. The speakers included Mrs. Univ. Prof. Dr. Irene Lang and Dr. Ioanna Campean, both from AKH Vienna, cardiology.

### Information Day Linz, April 12

On April 12, we met with patients and their relatives from Upper Austria for a joint information day. Eva and Monika from PH Austria were happy to welcome a big crowd of patients.

### Information Day Innsbruck, April 30

An exciting afternoon attracted many patients and carers on April 30th in Innsbruck. The participants in this meeting were the very first to be able to learn about our contribution to World PH Day. The speakers were Mrs. Univ. Prof. Dr. Löffler-Ragg and Dr. Sonnweber, both from University Hospital Innsbruck

### Chat Meeting Graz, June 7

On June 7th, for the first time, patients with pulmonary

hypertension had a chat meeting in Styria. The place to exchange ideas was Schlossberg restaurant, directly on the Schlossberg in Graz.

### Chat Meeting Innsbruck, September 26

Another chat meeting among patients took place in Innsbruck on September 26th with a highlight presented by a nurse of Univ.Prof. Dr. Löffler Ragg, presenting latin american dances and inviting people to dance with her.

### Infoday Graz, October 7

This annual Information Day was on October 7th. About 70 patients and carers attended. The lectures were held by Priv.-Doz. Dr. Kovacs, Dr. Douschan, Prof. Dr. Zirlik and Prof. Dr. Maier.

### Nurse Forum – PH in focus – the dialogue continues, 18-19. October 2019

„Doctor and nursing hand in hand“ was the motto of the national workshop from October 18-19 in Mondsee. For the second time, MSD organized a seminar that focused on the cooperation between doctor, nursing staff, study nurse and PH Austria. „In order to be able to optimally care for patients suffering from PH, the specialist knowledge of a wide range of professional groups is required“, said Dr. Steringer-Mascherbauer in her lecture.

### Service for patients - Info/ Image Brochure

We designed a new brochure to give patients, relatives and supporters an overview of our work. This brochure is available in all PH clinics across Austria.

### Clinic Day at AKH

Every 1st Tuesday of the month we offer counseling hours at the AKH PH clinic day. For this we have created new posters and service brochures.

### Patients' Helpline

We operate 3 patient helplines, through which our patients can reach us at any time 24/7. No problem is too small for us.

### Vienna ZooRun, June 13

Two thousand runners sprinted past tigers, trotted through Schönbrunn Zoo with zebras and competed with antelopes. The Schönbrunn Zoo and PH Austria inspired the participants for the eighth time to join a running event that is unique. The Viennese ZooRun has secured its in Austrian running calendar since 2012.

### Towerrun at the House of the Sea, October 3

The tower run is becoming increasingly popular worldwide, also in Vienna. For the fifth time the House of the Sea organized this run. 270 external steps had to be climbed as fast as possible. Despite the fresh temperatures and the wind, 34 stair runners accepted the challenge. Monika also climbed the 270 steps and reached the 10th palce.

### Viennese Ghost Run/Halloween, October 30

For the fifth time in a row, our charity run took place in the Vienna Prater. Our slogan is „We are running away from the grim reaper“ and the GhostRun has become an fixed part of Halloween events in Vienna. Ambitious ghost hunters were able to observe more than 700 sporty zombies, skeletons, witches and ghosts at the GhostRun.



## Milestones

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

## Information/Social folder

We have created a very detailed social folder for all of our members. The folder summarizes all social support options for PH patients in Austria. In addition, patients will find information on how and where to submit applications and what conditions are necessary. The folder is presented at every patient meeting and published on our website since 2016 and is updated continuously.

## Newsletter

In 2019 the newsletter appeared regularly every three

months. The content of 24 pages includes social tips, a patient story, preview and review of events, as well as guest contributions from specialists. The newsletter is sent to all patients and all clinics.

## Awareness

World PH Day:

- Interview Reinhold Messner, April 29
- Diver in the House of the Sea, May 5
- Silent Run, May 25

*Gerald Fischer, PH Austria - Initiative  
Lungenhochdruck*

[www.phaustria.org](http://www.phaustria.org) - <http://on.fb.me/RzdEcb>





## BELARUS



Hello PHfamily!

We're willing to share our success of 2019 with you. It may not seem so great, because we still have numerous troubles with treating PH in Belarus, but still we do have something to tell you.

What we find most important is the fact that we finally got several drugs legalized. It's only with the financial support of PH Europe that we were able to hire a lawyer who successfully worked for us for 3 months. Now kids in our country receive Bosentan and Sildenafil for free and this very drugs are partially reimbursed by the government for adults.

Moreover, the lawyer helped us organize collecting donations for buying oxygen concentrators. Now we have a short USSD request number to make it easy for people to donate some small sum of money.

Going further, we held the 4th official PHDay in Zhodino, which draw a lot of public attention. The city recreation park hospitably opened its doors to everybody eager to take part in the celebration. Favorable atmosphere of friendliness and sunshine, smiles and fun, perky laughter of tirelessly running and frolicking children filled this day with warmth in the soul and hope for mutual help. Among the organized activities there were a Volleyball competition, a photo-zone with colors of Holi of symbolic blue color, tug-of-war. Thanks to the joint work of children and adults, colorful drawings appeared on the asphalt, decorating the park and attracting the attention of

passers-by. Also volunteer activists informed people about the manifestations of this disease, the significance of this event, flyers were distributed to each visitor describing the possibility to help our patients.

Juniors from the Youth Center gave the audience a bright, colorful performance, and in the evening the guests of our holiday were in for a major surprise - a concert of the Post MC and Fresh Band groups. All the activities caused storm of positive emotions and there was no an indifferent person this day

Speaking about other events, we organized Belarussian seminar "PH In Pediatric Practice", where 178 new specialists gathered together to listen to 17 reports concerning PH in children. What's more, we're holding 2 more conferences for doctors, one - on January 20 and the other - on March 20, which is going to be a large scaled 2 days conference, comprising doctors from all regions of Belarus.

Thank you for being with us,

*Alina Katsubinskaya*

[www.phbelarus.by](http://www.phbelarus.by) - [phbelarus@yandex.ru](mailto:phbelarus@yandex.ru)



# BOSNIA AND HERZEGOVINA



## Together fight for patients

Many activities to raise awareness of pulmonary hypertension in Bosnia and Herzegovina are behind us. We are pleased with everything we have done in this 2019 year. Many athletes, doctors, sport professionals, professors and journalists are with us, because of our positive strength and energy, we believe that we will succeed in our efforts to improve the situation of patients with pulmonary hypertension in our country who do not yet have adequate medical care.

## Vice winner of the world in athletics is with us

After the 10th International Athletic Meeting held in Zenica, 12.06.2019., support for patients with pulmonary hypertension was also given by the best athlete in Bosnia and Herzegovina, our Amel Tuka. We are immensely proud of his countless successes around the world, athletic competitions, mitigates, and Olympic Games. Bravo! With the full respect of all the athletes who have participated with us in raising awareness of PH, we are joined by our best athlete Amela Tuka. Amel Tuka is the most successful athlete in Bosnia and Herzegovina. His disciplines are racing on shorter (400m) and medium (800m) tracks, and in these disciplines he has set national and European records. He is declared the best athlete of Bosnia and Herzegovina and the Balkans. We are proud!

Amel Tuka, world vice-champion in royal discipline, royal sport from Bosnia and Herzegovina, he won silver medal in running the 800 meters at the World Athletics Championships DOHA 2019th.

## 4th International Congress

As part of 4th International congress of Medical students "SaMED 2019" (SAMED - International Medical Students Congress Sarajevo) it was panel discussion on which our Association was invited because the theme was about registry

of rare disease in our country. Of course we are very interested in this topic because in Bosnia and Herzegovina there is no registry for pulmonary hypertension, so in front of our Association (Plućna hipertenzija BiH) as part of congress were Ernard Mujanovic, who was also a coordinator of plenary session, and Sabina Hodžić who was participant of congress. As part of panel discussion about registries of the hardest diseases there were guests from Slovenia, Macedonia, Croatia and representatives from the Public Health Institute and the Ministry of Health of FBiH, as well as doctors from the Clinical University Center in Sarajevo. On this congress there were about 400 participants from 34 different countries, and also a lot of guests.

## Workshop for PH

The „Heart full of smiles” association is always with us. We are very pleased with their support in disease awareness activities and the fight for better status of the sick. This time they organized a workshop where activities were dedicated to living with pulmonary hypertension. From the first symptoms to the daily activities, everything was applied among young people who are first introduced to the term pulmonary hypertension.

## We participated in the Vivicitta

We continue in the sports spirit. With the organizer of the race we have imagined a bit different participation in this year's Vivicitta International Race 2019, but weather conditions did not allow to realize it.

However, this did not prevent our two racers from participating in the race at 4km. Adin Mrkonjic and Talha Velagic ran with the marks of the European PH community. Adin has won the silver medal, second place in this race. Vivicitta is an international street race that has been running for many years in many cities of Europe and Bosnia and Herzegovina. Its main objective is popularization of recreation of the

population, and the race is recreationally up to 4 km and officially up to 12 km.

### All the beauty of Bosnia and Herzegovina for pulmonary hypertension

Association "Avantur" from Sarajevo is a mountaineering association that deals with the development of sports tourism and the promotion of the natural beauties of Bosnia and Herzegovina, and brings together the largest number of young mountaineers.

Its members, Segmedina Džaferović, Sumeja Muhić and Ena Hasković, their rise to the top of the mountain Vranica, Ločika, dedicated to patients of pulmonary hypertension. In this way, they became part of our team trying to raise awareness of the disease among all generations and at each step. From this visit, these three beautiful girls have said that the climb to 2.107 m / nm is dedicated to those who want but can't do it, and that we all need to breathe full lungs and enjoy the natural beauties because we may not be able to do it tomorrow.

From Fojnica to Prokoško Lake is 20 kilometers. The lake is 1.626 meters above sea level. From Prokoš Lake, there are mountain trails on the tops of the Vranica mountain, including the peak of Ločika - 2.107 m / nm, which is also the second highest mountain in this mountain range.

### The Bike Club "Tajan"

Members of the Cycling Club „Tajan“ participate in almost all of our pulmonary hypertension awareness activities during WPHD. However, now during the summer holidays in 2019, they participated in the „March of peace“ and have never forgotten us. Thanks to them, but also to Dr. Amira Hadzic, who supports and appreciates our work, they have carried out their activity in T-shirts with features of pulmonary hypertension and in this way have

raised awareness of this disease. The 350 km long route was driven in 16 hours by pedaling in the rain, but also by sunny weather.

### Picture from the underground

Thanks to the members of the Atom Research Club, the symbol of pulmonary hypertension was also underground. A three-member team of SNIK "Atom" is exploring the Odušak speleological object in Suha - Bosnia and Herzegovina these days. On the last day of August, more than 400 m of new canals were explored after eight hours of underground exploration. Now this object has a length of investigated 2,143 meters. This brave team hopes that favorable hydro-logical conditions will continue for some time and that more research will be carried out in Suha this year. Every activity of this club attracts public attention, and so does this one. It is this fact that Emir Balic, a member of SNIK Atom, used to show once again that they support the patients with pulmonary hypertension and that they are breathing for them in every action, drawing the public's attention to the plight of those suffering from this disease in Bosnia and Herzegovina.

### European Organ Donation Day

European Organ Donation Day is celebrated on 12 October. On this occasion, the Federation of Dialyzed and Transplanted FBiH and its Cantonal Members from Sarajevo, ZE-DO and SB Cantons, Sarajevo, Travnik, Kiseljak, Zenica, Kakanj, Tuzla and Visoko branches, as well as the Donor Network in BiH, during October organized the signing of donor card throughout the Federation of BiH. On the European Organ Donation Day, the signing took place at the frequency stations in Sarajevo and Travnik, and members of our Association were part of today's activity. In front of the SCC in Sarajevo, citizens





were able to inform themselves about the importance of organ donation and sign their donor cards. We thank Amela Siljevic, President of UDIT Sarajevo Canton for the opportunity she gave us to take an active part in this activity. Our association would like to thank these valuable and persistent people gathered in the dialysis and transplant associations in the cantons and the Federation of BiH who are continuously working to raise awareness of the im onation, transplantation and membership in Eurotransplant, for which we, as patients with pulmonary hypertension, are vitally interested.

### Together for life

The South-East Europe Transplant Network marked the European Organ Donation Day on 19.10.2019. in Tuzla (Bosnia and Herzegovina) under the slogan "Together for Life". With their presence, members of Association of Citizens Suffering from pulmonary hypertension "Breath" - in Bosnia and Herzegovina have joined associations from Slovenia, Croatia, Serbia, Macedonia, Romania and Bosnia and Herzegovina to support all persons who have been transplanted or are awaiting an organ transplant. A special message of gratitude was sent to all organ donors and their families, by releasing blue and white balloons, in honor of all living and deceased donors.

### Climb to Triglav in Slovenia

Climb to Triglav Members of club „Atom“ Huskic Senad and Huskic Sabahudin, together with Emin Huskic and guide Goran Golic on 10/26/2019. climbed to the Triglav. A very serious approach of the guides organization has resulted in a safe climb, enjoying unforgettable breathtaking Triglav images. The ascent went over the Plemenica, which is considered one of the most difficult marked routes in the Slovenian mountains, and the most difficult hiking route to Triglav. The path goes next to the monumental northern Triglav rock, right next to the

famous Sfingu, the steepest Triglav pillar marked by an overhang at the top. Across the west, the reached the last part of the ascent, secured by the very top of Triglav (2.864 m above sea level). The ascent and descent took about 13 hours and 50 minutes. This time, too, „Atomci“ contributed to raising awareness of pulmonary hypertension and improving the position of patients with the disease. We would like to emphasize that members of SNIK Atom use every opportunity to draw public attention to this disease.

### International Symposium

The 1st International Symposium on Pulmonary Arterial Hypertension was held in Sarajevo on 09.11.2019. organized by the Association of Cardiologists in Bosnia and Herzegovina. This is a big step for all PH patients in our country and we are immensely grateful to the Association of Cardiologists in BiH, and especially Prof. Sekib Sokolovic and Prof. Zumreta Kusljagic, who this time did not forget our Association, whose members were active participants. With our presentation on the current treatment options for PAH in BiH and our hopes, we tried to draw the attention of the profession to the position of patients with PAH and how much we need their understanding and support. The symposium brought together a large number of physicians from both Entities and other countries, and through a series of exceptional expert presentations, it provided quality comments on certain topics, which only confirmed that we have exceptional physicians who are involved in all PAH-related world events. In addition, this was an opportunity for us to make new contacts, get to know doctors and sponsors, and agree on the next steps in our fight for a better position for PH patients in Bosnia and Herzegovina.

Vera Hodžić, Udruženje građana oboljelih od plućne hipertenzije „Dah“ – u Bosni i Hercegovini  
<http://bit.ly/2aiEJgO>





## BULGARIA BSPPH



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

On 25th November 2019 at Social innovators club in Sofia the team of Bulgarian society of patients with pulmonary hypertension (BSPPH) presented the dialog tool "The Women and PH". This is the first brochure of this topic in Bulgarian.

The booklet target women affected by PAH in the active age group (20-50 years), as well as those at risk who may develop PH. Various studies show that pregnant women are particularly vulnerable. The project is also addressed to a wider audience of women because of a suspected link between the use of weight loss drugs and the likelihood of developing PAH.

The aim of the dialog tool is not only the theoretical provision of information, but also the achievement of practical results that enhance the quality of life and

emotional health of patients with PAH that will continue their lives effectively and remain mentally stable. Every woman with PAH has fear, guilt, anxiety, loss of libido, sense of inferiority and even uselessness, anxiety and frustration. It is well-known that PAH is a complex disease, in the fight against which is vital and emotional support that will give you the strength to continue.

The brochure is developed jointly with the help of patients, their families and friends, and the invaluable assistance of medical professionals working in the field of this rare disease. Many practical advices had been set aside that will be helpful to patents and their families, to all those who want to understand more about this invisible disease. It is important to know that for a woman whose body already has to deal with a serious illness, pregnancy can have catastrophic consequences. The risk of pregnancy-related deaths in women with pulmonary hypertension is much higher than 30 to 50%.

There is no exact data on the women affected in Bulgaria. This rare disease, PH, leads to severe complications requiring enormous financial resources, drastically worsens the quality of life, and disables people.

It is important for women suffering from PH to have a booklet detailing and presenting basic information about this disease. For the well-informed patients, it is always easier to control their condition which is the reason BSPPH had made this project.

The Women and PAH Booklet is now available to three referent centers in Bulgaria, specialized in PAH: the National Cardiac Hospital, University General Hospital for Active Treatments (UGHAT) "St. Anna"-Sofia, UGHAT "St. Marina"-Varna, as well as to the University Hospital "Lozenets", specialized hospitals "Nadezhda"-hospital for women's health, and the University Hospital of Gynecology and Obstetrics "Maychin Dom".

### "Yes!" for life

Since 2013 BSPPH has been actively involved in initiatives related to the implementation of the "Week of Organ Donation". Today, 13 October more than 30 transplanted patients attended the independent Start of the Wizz Air Sofia Marathon.

Special thank to the Minister of Youth and Sports, Mr. Krasen Kravev, the great Lyubo Ganev (former Bulgarian volleyball player) and Mr. Daniel Dukov, Director of the Sofia Marathon, for their full support and assistance in carrying out sports initiatives related to the European day of organ donation and transplantation in Bulgaria.

Everyone who has undergone double lung transplantation has his special history, one of them is Natalia Maeva (BSPPH). Today she run in her first marathon. Natalia hope



her story inspires others waiting for organ transplants- that they know that yes, it's a long and often dire road, but there are heroes all around us sharing the gift of life.

### To be an effective patient leader needs training

Patient organisations and patient organisations' leaders are becoming more and more visible actors in the healthcare arena. This is an important and positive change. Nevertheless, it also brings new and bigger challenges.

In 2019 the European Patient Forum (EPF) launched a new capacity building module on "Empowering Leadership and Positive Governance". The module aims at strengthening patient organisations by enhancing their leaders' leadership skills and consequently enabling positive governance in their organisation, with the final objective of supporting patient organisations in positioning themselves as legitimate

stakeholders, strong advocates and reliable partners on the national and European health policy environment. The programme targets patient organisations' leaders from across Europe, specifically Bulgaria, Hungary, Poland, Romania, Slovakia, Denmark, Malta, Portugal and the Western Balkan. The Chairperson of BSPPH Natalia Maeva passed the six-month training course successfully and received her certificate from the EPF.

The final module for 2019 took place in Sofia, Bulgaria. It was a 2-day event (6-7 September 2019). The initial number of participants planned was 24. Eventually, 23 representatives of patient organisations, participating in current training module, attended the event.

*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



## VIII. PH CONFERENCE

From 25 to 27 October 2019 in Pleven took place the VIII National Conference on Pulmonary Hypertension, organized by the Pulmonary Hypertension Association Bulgaria. Within the framework of the Conference it was organized and realized the Second National Patient meeting on Idiopathic Pulmonary Fibrosis-2019. The Forum was attended by patients from Romania as well.

A workshop for rare diseases flew parallel and was aimed at medical students from the five Medical Universities in the country.

The program of the conference included a variety of topics and interesting national and international speakers (Prof. Dr. Kosta Kostov, MD - Consultant for Pulmonary Diseases at INSPIRO MC, Chairman of the Board of INSPIRO Foundation; Dr. Piotr Radwan - Rorenschef of the National Institute of Tuberculosis and Pulmonary

Diseases, Warsaw; Hal Skaara - President of the European Pulmonary Hypertension Association; Dr. Georgi Ignatov - cardiac surgeon and coordinator of the program for surgical treatment of chronic thromboembolic pulmonary hypertension) who presented from the point of view of physicians and patients the contemporary perspectives for the diagnosis and treatment of chronic thromboembolic pulmonary hypertension, pulmonary arterial hypertension and idiopathic pulmonary fibrosis.

The group communication and collaboration help each and every one of the patients to find the answers to questions given solely by friends with similar fate. Reconnecting to a common goal teaches people to reveal their pain and problems, no matter what they are, and thus they become visible where with them can be handled.

*Todor Mangarov, PHA Bulgaria*

[www.apph-bg.org](http://www.apph-bg.org) - [www.facebook.com/aph.bulgaria](https://www.facebook.com/aph.bulgaria)



## CHRISTMAS PARTY

On 28th of December the Christmas party for the patients and leaders of PHA Bulgaria was held! The party was in Park Hotel Moskva Sofia. The PHA patients was able to communicate and celebrate with music and dances.

As usual it was organized together with the National Alliance of Rare disease.

*Todor Mangarov, PHA Bulgaria*

[www.apph-bg.org](http://www.apph-bg.org) - [www.facebook.com/aph.bulgaria](https://www.facebook.com/aph.bulgaria)





## CROATIA

### Dear friends,

We want to start by congratulating Happy New Year to everyone, in 2020 we wish you a healthy and successful work, both on the private and business plan.

Looking back, we can say that 2019 was a success and that we all went through a difficult period together, learned from it and moved on, looking forward to the future rather than back to the past. Because the past is something we cannot influence, but we can and need the future.

What we want to highlight in the second half of this year is a series of successful races attended by athletes who gladly wear T-shirts with our logo and are proudly breathless until the very end of the races, as they have recognized our struggle and efforts to raise awareness of pulmonary hypertension, so PH doesn't stay unrecognized, because the adversary has to be known in order to fight him more easily.

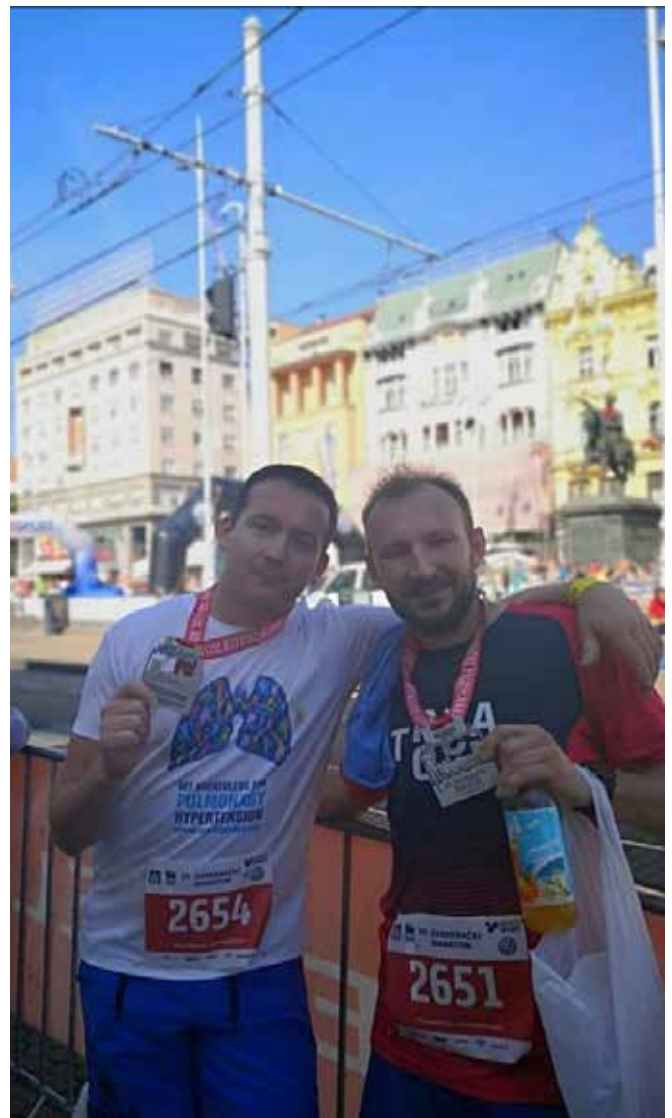
This way we would like to say thank you once again, to everyone, and we also hope for better cooperation in 2020 for which we already have plans.

Our association's website, [www.plavakrila.hr](http://www.plavakrila.hr) have a new graphic, which we have upgraded with a wealth of data and information, as well as a more professional approach. The creation and the cost of the site were made possible by the Croatian Breathing House Foundation, led by Academic Miroslav Samarzija, a leading expert in PH in Croatia.

In the end, we want to share with you photos from different parts of the country, various marathons, trail races and finally the most adventurous masked race Advent Run from Zagreb and thank all of those who leave us breathless with their nobility, and it is too much to list here!

*Katica Mavračić*

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## CZECH REPUBLIC



### Celebration of Rare Disease Day

Every year we participate on the celebration of Rare Disease Day. This year was organized the press conference on Ministry of Health for supporting us.

### Cafe

This year we decided to more support our patients from different regions and get closer to them. Every three months we organize meetings in Cafe with patients and physicians in different locations Czech and Moravian. We will work on better collaboration between patients and their families, establishing friendship and share experience with the daily lives of patients with the diagnosis.

### Mentoring program

This year, 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, and new sources of funding and launch new projects.

### Recondition stay in Poděbrady

As every year, the second Sunday in August marks the starting day of our Reconditioning stay in Poděbrady. One week long stay in spatown near Prague for PH patients with their families. As in past years, the program was focused on light breathing exercises, muscle stretching work and light workout in the pool. We also introduced

some new techniques to strengthen the middle part of the body to protect the spine. Our patients also had the opportunity to discuss their problems with a PH specialist. As last year we prepared also psychological relaxations and individual psychological support for our patients.

### Annual Assembly in Harrachov

On 21th September was held General Meeting of the Association of patients with pulmonary hypertension in Harrachov. We needed to make some basic important steps that law dictates, then we could educate and discuss about patient's needs. This year accepted an invitation our physiotherapist Katka Spilková and the main PH specialist in Czech Republic doc. MUDr. Pavel Jansa, Ph.D.

### SUKL Conference

In October we were invited for conference and discuss to Czech State Institute of Drug Control. Many patient organizations have participated. The biggest discussion was about the availability of drugs.

### New brochure

We have translated a new brochure for patients and carers about psychological care. The brochure translated from Slovakian association and is full of tips how to live with PH.

*Milena Kaftanová*

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





## HUNGARY



### Raising awareness Hungary-wide

In 2019 our Hungarian PH association, Tüdőér Egylet has done a lot to raise awareness. We have appeared several times in the television on occasion of the events of the Rare Disease Association and EUDONORGAN Awareness Raising. Also our specialist expert Dr. Kristóf Karlócai and one of our fellow patient in a live radio interview has talked about the symptoms of the illness, the importance of early diagnosis and about living with PH and after the transplant in the morning broadcast of the most popular, nation-wide radio channel.

Newspaper articles were written in national daily and weekly magazines in which our fellow patients have shared their personal journeys and also our leading specialist has talked about what can be known about PH.

Besides Rare Disease Day, EUDONORGAN Awareness Raising we have participated on the followings events as well.

Among others we have accepted the kind invitation of the mayor of Diósjenő (where our president lives) and represented the Hungarian PH Association, Tüdőér Egylet on the Village Day. Our booth has attracted many residents as our volunteers have been measuring blood pressure and

blood oxygen level. We have been raising awareness of PH by providing information about the disease and distributed leaflets. Fortunately, all people we have screened did not have extreme values, however some heart rates were slightly higher due to the excitement of the day.

We have a good relationship with the Hungarian IPF association, since IPF is also a rare disease effecting the lungs and often IPF patients develop secondary PH. On their awareness raising event „With exercise for Healthy Living” held on the picturesque Margaret Island we have drawn attention to PH. The day started with a walk then we did breathing exercises as it is very important to improve our lung capacity. The day has reached its peak when we have climbed the 152 steps to the top of the Water Tower and dedicated this climb to the PH patients.

In August, some of our members cycled around Lake Constance. They were getting breathless for PH in the picturesque countryside of 3 countries, pushing their boundaries and dedicated their effort to PH patients.

In September together with the Hungarian Transplant Association we have celebrated the wonderful achievement





of Anna, who has climbed to the highest peak of Hungary 3 years ago after her second lung transplant. (She was a cystic fibrosis patient) Unfortunately she has passed away but we will keep her in our hearts forever. A small team of our association got breathless together from the climb and dedicated it to her and to the CF, IPF, PH and all other patients with a condition that does not enable them to do such kind of activity.

Back in 2018 with the donation of Linde we have acquired a mobile concentrator that is available for our patients to use and many of them benefited from this opportunity this summer. Thanks to that we could reduce their isolation, since they could overcome their limitations and were able to have a holiday, to travel together with their family and friends.

To bring together PH patients to enjoy fellowship, in November we had our yearly Patient- Doctor meeting. 9th in the row. Where around hundred fellow patients and their relatives have listened enthusiastically to

beneficial presentations about fascinating subjects such as the different diagnosis methods (6 minute walk test, echocardiogram), PH and pregnancy and rehabilitation possibilities. We have been honored that the representant of the National Health Fund (NEAK) has accepted our invitation, who also gave us a very interesting presentation about the challenges of financing and she was glad that we have reached out to her because from now on, she will not only know the individual medication requests related to Pulmonary Hypertension but she saw the faces behind those as well. The usual exercise was not missed either, everybody has joined in, even those sitting in wheelchair and on oxygen. We have said goodbye to each other by saying „We will celebrate together next year on our 10th reunion!”

*Eszter Csabuda, Tüdőér Egylet*

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

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





# IRELAND

You might have heard about unbelievable swimming challenges in extreme water and weather conditions. I am sure, however, that you have never thought that for an Irish ex-CTEPH patient, Patrick swimming in the 6-7 °C water is not an unusual exercise.

Nothing great is easy – as Patrick says and he has lots of breathtaking swimming accomplishments: for instance, he swam the English Channel 20 months after PEA surgery in a time of 13hrs 12mins and he was the first person to do a 15km swim from Blacksod Lighthouse to Belmullet on Ireland’s Wild Atlantic Way coastline. Patrick is still keen to show what is possible post-surgery and continues to raise awareness of the disease – he had PEA surgery 4 years ago. He was even discovered by The Independent: on the front page of the Christmas edition he is jumping into the cold sea!

Keep going, Patrick, we are eager to hear your next plan!

Gergely Meszaros

[www.pulmonaryhypertension.ie/pha-ireland](http://www.pulmonaryhypertension.ie/pha-ireland)

[www.facebook.com/PulmonaryHypertensionIreland](https://www.facebook.com/PulmonaryHypertensionIreland)



## ISRAEL



In association with the Minister of Health, representatives from the Israel Association for Pulmonary Hypertension attended a meeting of the Association for Patient Rights in Israel. There were several goals for this meeting and points which were raised included the following:

- Promotion and development of computerised and innovative artificial intelligence to assist in patient care
- Protecting patients' rights
- The right to receive treatment and to refuse it
- The role of the doctor in front of the patient and vice versa

Aryeh Copperman, CEO of PH Israel attended a unique meeting focused on promoting Rare diseases in Israel. The meeting was a conference of all associations which represent rare diseases and discussed the importance of working together to promote equal interests. Ideas for raising awareness of rare diseases among medical and general staff, a database of all rare diseases, and the introductions of rare diseases onto the list of serious diseases for additional budgeting. In addition plans for lobbying Israeli parliament (Knesset) on behalf of all Rare diseases was discussed with the awareness that the larger numbers when combined would result in more effect. The last point was creating a more lenient approach to regulations so that we are able to promote more research into rare diseases.

Monthly drive to secure more Portable Oxygen Generators so that we can provide for lung disease patients around Israel - A collaborations was set up with overseas non profits to extend our mobile oxygen services to a patient in Swaziland.

Over the year meetings were held with several startups to promote innovative drugs / ways to treat pulmonary hypertension. These companies were given advice from

our association as to the important points for patients in promoting the study.

Much time and effort was spent this year working on a new design and plan for a more current, user friendly website. Several meetings were held with consulting firms to get advice as to best options and come to an understanding of how to create awareness with our website, be accessible for patients, carers, family members, doctors and anyone who stumbled upon the site. A final decision was reached and we hope to make great progress with the site in 2020.

Throughout the year several meetings and mini conferences were held with the different treatment centers around the country.

- Meetings and conferences with specific centers
- Patients from each of the centers received unique support from their center with the help of our association.
- Promote disease awareness activities among medical staff at the medical center.

#### Support Groups

- Support group meetings were set up based on the patient's location in Israel. We found that these meetings are better attended when scheduled closer to the patient's home and required less travel time.
- Meetings were held in the North and South of the country in order to accommodate patients and ensure their involvement
- These meetings included a cultural or social activity to increase motivation to attend meetings and raise morale.

*Maayan Steele*

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



## ITALY-AIPI

### “PH BY CLINICAL CASES”

As every year, as part of the University of Bologna Master in Pulmonary Vascular Diseases on June 14 and 15 there was the conference „Pulmonary Hypertension by clinical cases”.

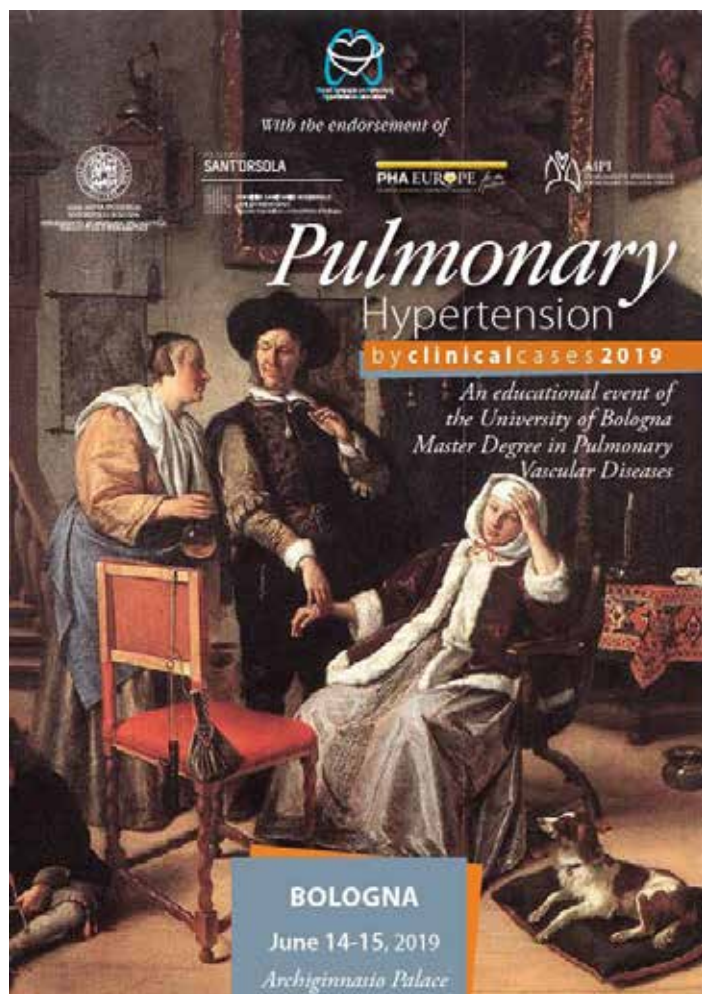
This year, AIPI ONLUS and the newly formed World Symposia on Pulmonary Hypertension Association had sponsored the initiative. AIPI ONLUS attended the event with its Vice President Claudia Bertini.

Over the two days there was the presentation of clinical cases, like they were „Episodes” of a television series with the sick as protagonists and a common thread: Pulmonary Arterial Hypertension and the challenges it has brought to the different teams.

A novelty aspect of this edition was the focus for risk assessment in the therapeutic algorithm. It was highlighted how should be analyzed the conditions of each patient taking into consideration multiple factors with a well-defined evaluation methodology and compelling: this is the only way to promptly highlight any alarm bells and indicators of improvement, consequently coming to manage better the route of therapeutic treatment.

However, ratings of this type, they are very complex and can be completed successfully only by centers that have sufficient knowledge and experience of the pathology.

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





# ITALY-AMIP



Dearest friends, as you know these past six months in Italy there have been many institutional changes for rare diseases, therefore AMIP non-profit organization had to do their utmost to represent the needs of the sick at the various institutional tables.

What have we been doing in these six months? Well we have collected in a book the poems and drawings of boys of 3 and 5 fifth grade to which our testimonial (Elena Drozina ... volleyball player also in the Italian national team) and Lello explained to him the pathology and the consequences on the quality of life of the children and adults with IP. We participated in 3 national conferences (Palermo, Rome, Chieti) and one international (Capri), or rather we opened the work by making doctors understand the needs of the sick. We had the solidarity of two theater companies who offered us their art for our cause, we also had the opportunity to be present at a running race and, read read, we were present at the day "INNO ALLA VITA - STOP ALLO SMOG" which took place in the central Via Caracciolo in Naples; on this occasion a volleyball team wore our shirts with the logo for "world IP day" created by Lello and Vittorio ... an idea to make it clear that for the sick it is always a world awareness day. But you have already noticed this in the previous Mariposa.

Furthermore, taking into account that our scientific committee has created a network for the IP (Italian Pulmonary Hypertension network - IPHNet), to which approximately 30 hospitals throughout the country have

joined today (from north to the islands), we have been called from the various hospitals to help the sick there. We are continuing to work on patient meeting and resilience projects.

In particular, from September to December 2019 we have:

- Opened the 1st European pediatric conference at the Bambino Gesù hospital in Rome;
- The IPHnet international conference in Catania is open;
- We received great solidarity from the football champion "Francesco TOTTI";
- We organized doctor / patient meetings in Sardinia, Pavia, Palermo and Naples;
- We have participated in numerous radio and television broadcasts;
- We are planning to launch the book on resilience;
- An evening of a GOSPEL choir was dedicated to us (Vitorchiano - Viterbo - Italy);
- An evening of BLUES artists was dedicated to us (Vietri - Salerno - Italy)

*Vittorio Vivenzio, AMIP Italy*

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

<http://www.facebook.com/AssociazioneMalatiDiIpertensionePolmonare?ref=ts&fref=ts>



## LATVIA



### The Award

The year of 2019 was very successful for PH community of Latvia. The Ombudsman of the Republic of Latvia grants PHA Latvia with the Award for Support People with Disabilities 2019. PHA Latvia was nominated in the category "The Best Educator". The Commission of the Award underlines our work spreading the information about PH diagnosis, medications, healthcare, physiotherapy, oxygen therapy. During 8 years of work PHA Latvia have published many information materials, exercises booklet, manual for people with rare diseases, established the Oxygen therapy lectures around country. The one of most popular analytical radio journalist in Latvia Aidis Tomsons presented the Award to the President of PHA Latvia Ieva Plume at the Honor Award Ceremony on 3th December, 2019.

### Advocacy and social work

Besides PH Day celebration with Oxygen festival PHA Latvia project team implemented two projects for PH patients in the previous year.

The important project was "Participation 2019" with financial support of NGO foundation of Latvia from 1st April to 31st October, 2019. Main aims of the project were promoting an active civic participation of people with pulmonary hypertension in decision-making process on the social and health sector in Latvia, developing community of PH in our country, strengthening the institutional and human resources of the Pulmonary Hypertension Society, and empowering people with PH and disabilities.

Project's results: the unique study on the social, emotional and daily life of PH patients on Latvia. Until now, there has not been such research study in Latvia analyzing the quality of life of people with rare diseases. We have statistical and

qualitative data from 60 PH patients (200 PH patients in our country). The study was designed on the approved research instruments and consists questionnaire about PH diagnosis, general health, emotional health, social life, economical aspects of households, demographical part.

Most worrying are the data about late diagnostic of PH, the emotional health of patients, and the inaccessibility of social and health services in Latvia. Approx. 25% of PH patients waited for an accurate diagnosis for 2 years, 13% PH patients waited for PH diagnosis for 3 years, but 25% PH patients waited it for more than 4 years. Therefore, in 63% of cases, people with pulmonary hypertension in Latvia did not receive appropriate treatment due to late diagnosis. More than half of the patients have third and fourth functional classes of NYHA. The burden of emotional problems is very high, as 48% of the patients with PH have moderate to severe depression, according to the PHQ-9 self-assessment questionnaire. Inaccessibility of services is another key factor in disease management. Medication reimbursement is inadequate for 38% of people with PH (all types of medication), rehabilitation and physiotherapy - 60%, medical devices - 20%, self-care assistant - 17%, lack of psychological support - 33% PH patients in Latvia.

We had a social worker during this project. PH patients and their relatives received the assistance of the social worker to organize their daily routine, to assist in socializing, to receive health and social care, to attend public events, psychological and emotional support. We provided social support to 61 people, provided service of oxygen therapy 29 times, and provided 93 consultations for patients and their families.

Advocacy and representing the interests of PH patients also was an important part of the project. During 2019 year PHA Latvia participated in 3 health and social workgroups

and commissions at Ministry of Health, Rare Disease Coordination Centre. We have submitted 3 letters with proposals for social and health service improvements for PH patients in Latvia (the establishment of a PH program in the country, supply of oxygen concentrators from the state). PHA Latvia were prepared 2 opinions to Ministry of Health about providing of reimbursable medicines and quality control of medicines. During all year PHA Latvia was active member of Network of Patient Organizations in Latvia and national Rare Disease Alliance. Ieva Plume was elected in the Board of the national RD Alliance.

We have achieved some result in the discussions with Pauls Stradins University Clinic about availability of PH specialists and from the Autumn of 2019 we have Dr. Viktorija Skuja – the 3rd cardiologist specializing in PH. The second project was performed by financial support of Riga Council excellent social inclusion event - an outdoor picnic near our biggest river Daugava on the island of Dole close to the capital of Latvia - Riga. On the hottest day of summer 33 PH patients and their relatives participated in team work, excursion about history of Daugava, meditation, psychical exercises, and slowly walking on the nice banks of river. The outdoor activity aim was to create the Bank of Ideas for PHA Latvia further work. 5 teams worked together to inspire each other in the fruitful discussions.

### Eurordis Digital School

Ieva Plume and Gunita Skaldere-Darmudasa, social worker of PHA Latvia, participated in the first Eurordis Digital School which took place from 8th to 9th October, 2019 in Agrenska Resource center near Goteborg (Sweden). During two days the professionals of digital and

social media showed how to deal with challenges of social networks, how engage the target audience, to understand better our clients – patients, specialists, relatives. We have learned useful tools of social and digital media and experience from other patient’s organizations in Europe. Our two delegates – Ilze Kikere and Anda Pudane participated in the PHA Europe General Annual meeting and PH conference from 30th November till 3rd December, 2019 in Spain, Castelldefels. Both delegates prepared useful report about conference for PHA Latvia Board and members. We have spread out it with PH community in Latvia.

### Looking to the future

The challenge for us will be an educational material about PH – a book in Latvian for patients, their families, general practitioners and specialists. The work on the book have started in the Autumn, 2019. We have a team of authors – cardiologists, physiotherapist, psychologist, PH patients, carers and two editors. The main task of the “PH book: more knowledge, more survive” will be financial and organizational issues.

Furthermore PHA Latvia is the author of an idea of Rare Diseases Day 2020 celebration in Latvia with an interdisciplinary conference about Rare Diseases healthcare. Of course, we are very interested not only in projects within our community, but also looking forward to start joint projects with friends of PH community across Europe.

*Ieva Plume*

<http://www.phlatvia.lv>

<https://www.facebook.com/phlatvia/@phlatvia>



## POLAND



On May 11, 2019 PHA Poland organized the meeting for PH patients in Wrocław. There were almost 100 patients and their relatives and caregivers. The meeting was a great occasion for patients to talk about their problems and benefit from the PH experts' presentations.

Agnieszka Bartosiewicz, PHA Poland vice president took part in a Patient's Heart Forum event that took place in Katowice at the end of September. This was the very first forum that was dedicated both to individual patients or to patients' organizations who gathered people with Circulatory System Diseases. There were experts' debates and very interesting educational workshops for patients like e.g., „Patient with heartfailure”, „Patient with heart arrhythmia”, „How to deal with stress” and also legal support and advise tips for patients' organizations.

PHA Poland supporters undertake sport challenges for PH patients in Poland. One of them is Krzysztof Sabisz - a businessman, an alpine climber who dedicated his runs for PH patients. This year he participated in three marathons: Virgin Money London Marathon one of Abbott World Marathon Majors, Chicago Marathon and Maratona do Rio – the biggest event in Latin America.

Next year he plans to start in Antarctic IceMarathon.

Alicja Morze – PHA Poland President participated in the 9th Conference of Pulmonary Circulation Section of the Polish Cardiac Society that took part on November in Katowice. PHA Poland organized an educational stand. Before the conference, there was a 2 800 run for doctors. A special award - PHA Poland Cristal Heart went to Ludwik Borecki. The second came to dr. Stanisław Jankiewicz and the third one to Katarzyna Kuliga-Skrobiś. All participants received PHA Poland medals.

One of the conference's honour guests was prof. Hiromi Matsubara - a very well-known world BPA (balloon pulmonary angioplasty) expert. During the conference prof. Matsubara was awarded with “Knight of the right heart” statuette. Thank to prof. Matsubara, Poland is the third country in the world, after Japan and Norway, where BPA has been conducted since 2013.

*Agnieszka Bartosiewicz*

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





## PORTUGAL



### A new life for Johanna

Johanna is a Venezuelan girl who came to Portugal in search of a better life. She suffers from PH and can not find a GP in the host country. A GP who would send her to a treatment center nearest her and give her access to the treatments she deserves.

Johanna's medication was about to come to an end, and the fatigue from her struggle took over her body. Johanna asked us for help and a phone call was enough to save her life. On the other side of the phone was Professor Abilio Reis, coordinator of the Unit of Pulmonary Vascular Disease of the Hospital Center of Porto. In less than 24 hours, Johanna was being welcomed by a medical team from one of the National Reference Centers in the treatment of pulmonary hypertension and one of the European Reference Network centers for pulmonary vascular disease.

Thanks to this amazing team, Johanna already has her medication and the oxygen that gives her the freedom she needed.

### Mental-health project with PH Patients

The role of psychological flexibility and self-compassion in quality of life and mental health in patients with pulmonary hypertension was the subject of the Master thesis developed by Dr. Cátia Rodrigues, psychologist and vice-president of PH Portugal. This project was conducted in the scope of MSc in Social and Cultural Psychiatry, at University of Coimbra. PH Portugal and PH Europe congratulate Dr. Cátia Rodrigues for another step in her professional success!

### Trail for CTEPH

On November 24th about 250 people attended 4th Trail for CTEPH promoted by PH Portugal! Neither rain nor cold discouraged the brave athletes. They ran for a cause, no matter what!

*Teresa Carvalho*  
 Associação Portuguesa de Hipertensão Pulmonar  
[www.aphp.pt](http://www.aphp.pt) - [www.facebook.com/associacaoportuguesa-sahipertensaopulmonar](https://www.facebook.com/associacaoportuguesa-sahipertensaopulmonar)



## RUSSIA

I am Liliya Yarullina. I have a rare, familiar to few of you, disease of the cardiovascular system - pulmonary arterial hypertension (PAH). I was diagnosed when I was 20 years old. Since then, my life has turned into a real fighting for survival. I had crossed the indifference of people who could help me, I met doctors who didn't know how to treat me, I had struggled with government people for a good treatment for me and other patients.

As a result, I achieved a proper attitude towards myself. I had a full medical research of my health condition by specialists who have a big professional treatment experience with patients like me. This is the only way I need expensive, vital medications.

Now nothing threatens me, my health condition is stable, all tests' results are normal, but I see people around me, in my country, who cannot overcome the difficulties on the way to a good and quality life, people with the same diagnosis - PAH. They are desperate to find the truth and help from doctors, government administration and officials.

The Pulmonary Arterial Hypertension Association „Help and Save” was founded in April 16th, 2011. This is a public organisation, which members are PAH patients and their relatives. The organisation was founded to combine our forces, ideas, activities and opportunities. We are all very vulnerable being alone, that is why we united. We support each other, together we seek the proper attitude to us and real help from doctors and officials.

All PAH patients in Russia faced with the problem of innovative medication's bad supplying. By my own example I have to say that disease is not a sentence! The people who don't want to deal with our treatment are sentencing us. But each of us has the right to a fully diagnosis's process and worthy therapy. If we defend our right to a full, comfortable life together, we will win!

In our country there are not many PAH specialised centres and specialists who can conduct a diagnostic research in time, talk about the disease and choose effective therapy. Even if one of these clinics exists in the city, patient, having heard his diagnosis for the very first time, most likely find himself in a situation that will forever change his life.

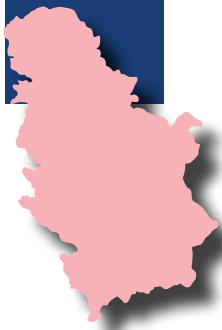
Our Association was founded with big efforts. Now everyone who was affected by PAH, can find answers to their questions, unite with other patients and fight together for their health, future and life. We are very proud that our work has been appreciated by Russian Federation Supreme Representative and Legislature, and we received the gratitude from the Chairman of the State

Duma Committee on Health Protection, Moscow, Russia. Russia - for social activities aimed at helping citizens suffering from rare (orphan) diseases.

PHA Russia „Help and Save” continue to implement plans for organising and conducting activities aimed to inform about prevention and patients with rare and life threatening diseases treatment, including Pulmonary Hypertension. We will do it with a big enthusiasm and inspiration!

*Lilya Yarullina, PHA Russia “Help and Save”*  
[lilya-belle@yandex.ru](mailto:lilya-belle@yandex.ru)





## SERBIA



We must only concur that many things have changed in Serbia. Even though people from medical branch often point out the significance of our association and claim that we are responsible for great improvements in the field of Pulmonary hypertension (we say otherwise, our contribution was modest from our point of view), we think and openly repeat otherwise. Medical branch and experts courageously met the challenge and faced with such a ferocious disease as PH is.

### Third PH International Regional Summit

At now concluded International regional Summit dedicated to Pulmonary hypertension in Novi Sad, organized by Institute for Pulmonary diseases of Vojvodina in Kamenica, Clinical Centre of Serbia and Croatian Thoracic Society, more than 40 most eminent lecturers in the field of pulmonary hypertension from all across Europe participated.

Great respect and honor during the opening ceremony was bestowed upon us by First Lady of Serbia Mrs. Tamara Vučić, great humanist and a recipient of this year award, granted to her by PH patients on a previous conference as a token of gratitude and for her immense contribution to the improvement of PH patient position and for her selfless efforts to save human lives. To them, patients fighting with this rare and extremely difficult disease in a very emotional speech during the opening ceremony of this year's Summit, Mrs. Vučić once again clearly said that she will continue to support PH patients in their fight, that she admires their courage and perseverance, saying that they are not alone in this fight for life and providing them

with additional support and paying her respect to all the experts dealing with this particular subject in Serbia.

Alongside Nazzereno Galie, certainly one of the greatest authorities in the field of pulmonary hypertension and congenital heart defects, others experts and lecturers from Austria, Germans, Great Britain, Italy, Slovenia, Serbia, Croatia attended this Summit.

One of the most visited and most noticed sessions was ours, where we talked about the perspective of PH patients, and Daniejla Pešić, president of PH Serbia in a very emotional speech talked about how it is to live with PH. Together with her, patients from Bosnia and Herzegovina, Dajana Marić and Amina Berić also attended this panel discussion, providing audience with an opportunity to hear their experiences in dealing with PAH, how they live with PH in Bosnia and Herzegovina and what kind of obstacles they face each day, considering the fact that they don't have access to adequate therapies.

The main idea of this Summit was fulfilled, because we once again proved that together we are stronger and more visible in society. Persons with PH together with their doctors sent a very strong message and expressed a hope that everyone in the region will have access to therapies and that life quality of persons with rare diseases will significantly improve in the period before us.

With great pride we must point out the fact that this meeting is one of the greatest meetings in Europe dedicated to Pulmonary hypertension.

Fourth Summit was also announced and it will take place in Serbia during the first half of October 2020.

## Inspired By Hope Team

At the races across Serbia, in Zrenjanin, Kula, Apatin, Belgrade, Kostolac, Požarevac, Kruševac, Kragujevac,... racers from Inspired by HOPE team, week after week lose their breath for all suffering from Pulmonary hypertension. In that way they provide invaluable contribution in raising awareness of Pulmonary hypertension. Many race organizers, primarily thanks to persistence of our racers, invite our team and members of association to be honorable guests on all those races, so that we could all together give contribution in increasing life quality of all suffering from this disease, and also to bring public attention stressing the significance and importance of making early diagnosis and starting with adequate therapies.

## GSK - PH Education

We had an excellent opportunity to actively participate on invitation of GSK Company (GlaxoSmithKline) in education of all employees of that company, especially on the subject of Pulmonary hypertension. Even though there are individuals with medical education among the company employees, but also those who are not knowledgeable in that field, inspired by our work and efforts, they all showed interest to hear something more about PAH.

“The point of this meeting was to get better understanding of biggest challenges that people with PAH face with, as well as learning about their life quality and talking about possible responses and solutions to those challenges, first and foremost for the benefit of patients and the doctors who are treating them.”

## Patients First Week – Pfizer and PH Serbia

The same as previous years, PFIZER organized “Patients’ First Week” in Falkensteiner Hotel Belgrade with an idea to bring together company employees and patients, allowing them to meet and talk to each other allowing better mutual understanding between the two. As organizers from Pfizer rightly put it, “It is important to know that we are there for each other and that we are working together to achieve the same goal”.

Aside from presentation by Danijela Pešić about the overall work of association and the difficulties that patients and association face with every day, we had an opportunity to show and demonstrate how persons with PH really breathe, every day, every hour, every moment 1.440 minutes in a day.

To recreate this feeling for company employees we used straws and clips, making them experience the same symptoms of this condition.

Much to our delight, ten members of our association had an opportunity to attend this important and significant event for all of us.

## Apatin Half Marathon

On Sunday, 20th of October, a race has been held in Apatin, Serbia. That Sunday was a day when all race participants lost their breaths for all suffering from Pulmonary hypertension. City of Apatin and Organizers of Apatin half marathon gifted that Sunday to all persons with PH in an attempt to additionally increase awareness of Pulmonary hypertension. On that Sunday, more than 30



members of Inspired by HOPE team, and all those racers who in any way helped and supported our association in the past to work better and to become more visible, also came to Apatin race dressed in HOPE and LUNG shirts which symbolize our fight and struggle for all suffering from PH. We would like to express our wholehearted gratitude for understanding, appreciation and humanity to city of Apatin, ASICS Apatin Danube Half-marathon, Ceger Goran, to all racers and whole racing community.

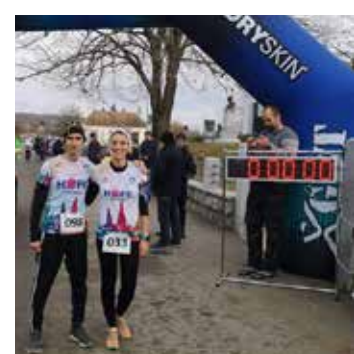
### True Team

Congrats and thank you all! Another very nice project has been realized. Traditionally, Pulmonary hypertension

Association from Slovenia and Pulmonary hypertension Association from Serbia, together with their racers have participated in the most significant and largest marathon in the region Ljubljana, Slovenia.

Dressed in recognizable shirts with PHA Europe logo, racers from Inspired by HOPE team and racers from Slovenia ran together at this race and once again lost their breaths for Pulmonary hypertension.

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



## SLOVAKIA



### Events focused on raising PH awareness

For International Rare Diseases Day we have created 10 short video recordings made by patients and their relatives. These were statements about the obstacles a patient must overcome and show unbelievable strength and courage. They were part of the campaign on social networks.

We have prepared a discussion forum for students of the Secondary Medical School called “When the breath runs out”. The aim of the seminar was to highlight the needs of early diagnosis. Part was devoted to organ donation and lung transplantation. Students also had the opportunity to discuss with patients.

For several years, we have been favored by athletes who represent our association in the T-shirt campaign Get breathless for PH at various cross-country competitions. They understood the need to disseminate information and made the PH visible through cross-country competitions not only in Slovakia but also abroad (Czech Republic, Austria, Australia). This year they represented PH in 16 competitions. The most important event was the 345 km long relay run “From the Tatras to the Danube”. The 12-member team ran wearing the Get Breathless for PH campaign t-shirts for the fifth year under the title „Patients with pulmonary hypertension“.

Two high school students decided to travel 764 km across Slovakia in 24 days to support PH patients in the project

“For the powerless”. The project provided the possibility of “adopting” kilometers. Those interested could buy them and join the tourists or just donate to the foundation fund, which was established for PHA Slovakia by the Community Foundation Liptov. The proceeds will be used to purchase a portable oxygen concentrator.

For several years we have been working to raise awareness of PAH among first contact physicians. We repeatedly attended the Annual Conference of General Practitioners in the High Tatras. We distributed dozens of leaflets and brochures. The information was supplemented with short information videos about PH on the TV screen.

### Activities for PHA members

In order to increase patient awareness and education, we prepared two full-day educational seminars focused on social care, first aid and medicine policy.

For the members of the association we have prepared a 6-day educational and reconditioning stay in Spa Sliach. The stay was focused on physiotherapy, relaxation, breathing exercises and education. A great reviviscence was the workshop, to develop creativity, to increase self-confidence, where patients painted different themes on canvas bags.

A 5-day rehabilitation stay was conducted for a group

of selected patients under the guidance of a specialized physiotherapist and clinical psychologist. The aim was to familiarize the participants with the basic principles of physical therapy and relaxation, which patients can realize independently in their home environment.

### Knowledgeability

We prepared posters about PH and activities of PHA Slovakia in A0-A2 formats, which we placed at specialized outpatients clinics in PAH Centers.

For new patients we have prepared information brochures "How to better understand PAH", which includes a USB stick with basic information and references. In cooperation with PHA Europe, we have prepared two new information leaflets "Few facts about PH" and "Living with PH".

The summary of activities will be published in the final issue of the PH magazine Fialka.

In May, treatment of prostacyclin via an integrated pump was introduced in Slovakia. A press conference was held at the Center for PAH in Bratislava to present the first patient receiving the treatment. The report was distributed in all media in Slovakia.

### Education

The president, Iveta Makovníková, continued with educational activities within Patient and drug project, which was introduced by Slovak Health University. The vice-president, Jana Guráňová, attended the meeting of project EUDONORGAN in Copenhagen and Brussels, where she gave her presentation.

### Cooperation

We are actively cooperating with other civic associations on activities that raise awareness of organ donation and transplantation. We took part in the competition "I AM HERE thanks to transplantation", which was intended for patients after organ transplants.

Mutual exchange of experience with the members of the Czech Association leads to closer cooperation, exchange of information, consultancy and mutual assistance.

*Iveta Makovníková*

*Zdruzenie pacientov s pľúcnou hypertenziou*

<http://www.phaslovakia.org/>





## SLOVENIA



In February, our association joined forces with a fitness center in the Slovenian city of Celje. Together we organized a spinning marathon event.

The purpose of the event was to spread awareness of pulmonary hypertension (PH) by teaching the participants about the basic PH facts, the importance of early diagnosis and symptom recognition while the disease is still in its early stage. Our marathon participants also performed a quick test which enabled them to experience the feeling of breathing in similar circumstances to those a PH patient experiences on a daily basis.

They were asked to plug their noses and then breathe through two straws they were provided with. Most of them had to stop cycling after 2-3 minutes as the exercise proved to be too difficult. The event was a big achievement for our association and we are looking forward to organizing similar events again in the near future.

In March, members of our association gathered for the general assembly. The steering committee presented the work that was completed by our association in 2018

and the plans for the year 2019. A constructive debate followed about what could be improved in the future. It was a pleasant evening that combined both, socializing with members and also planning the future goals of our association.

At the beginning of autumn, we organized a day trip for our medical team and association members in the beautiful region of Slovenia called Štajerska. We drove to a small village of Olimje, more precisely to Jelenov Greben, where we visited a monastery, had lunch at a nearby restaurant and observed deers that were casually walking only a few meters away from us. After lunch, we headed to the boardroom, where the medical team headed by two PH specialists presented useful ideas on how to live a more fulfilling life with PH. Patients and their loved ones also had the chance to talk freely about their disease, exchange useful advice and even ask follow up questions to the doctor's presentation. We concluded our trip with a tour of a nearby chocolate factory.

We were also invited to the Slovenian branch of one of the leading pharmaceutical companies, Pfizer, where



we introduced PH to the employees. Most of them never had any contact with PH patients before so this was a great opportunity for us to present the life of a PH patient to them which we didn't let go to waste.

Some of our members even shared their inspiring stories with the employees who were delighted to actually see that all of their hard work is producing results in real life. Throughout the year, our volunteers participated

and »got breathless« in a few running marathons that were organized in Slovenia while wearing our PH shirts. The biggest one among them was the Slovenian Istria 70.3 - Ironman.

*Tadeja Ravnik*  
*Društvo Za Pljučno Hipertenzijo Slovenije*  
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## SPAIN ANHP



2019 has been a year with many challenges. 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). The activities that our Association running are very important because they answer the member's demands and expectations. All these activities are inside the strategic projects of the year. In 2019 we can highlight the following ones:

To celebrate the World Day of Pulmonary Hypertension, in May 5th, The ANHP run different activities in Madrid like "The PH room" in the University Hospital 12 de October or the solidarity event of spinning in Humanes.

The XVII Annual General Assembly was held in Almagro, between May 24 and 26. Before the opening of the assembly we run a meeting about healthy respiratory.

We run a meeting about respiratory rehabilitation.

We have given continuity to the advertising campaign "Become a Hipercoach" thanks to the collaboration of Alberto Cendrero, a sportsman. The goal of this campaign is increasing the awareness in the population about the sport in PH patients.

In September we organized in Valencia with the slogan "Breathless for PH" the IV Solidarity race for Maria Moreno", patient of PH who died. There were 2.000 participants.

The board of directors meets in person at least one a

year to discuss all the issues related to the Association. This year it took place on October the 7th and 8th in Madrid. This year we have participated thanks to different sportsmen and women, in the II Ultraking in Siruela (Badajoz). There was participant from all over the world. The month of November is the month of awareness of pulmonary hypertension, for this reason we run a campaign in our social networks, which has consisted of taking photos with one of the most obvious symptoms of pulmonary hypertension: Lips blues.

In December we run a awareness activity in a school in Madrid. 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 have participated as a speaker in different meetings, and congresses 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.

The VIII Trail Sierra de Codés (Navarra) dedicated the collected to help Pulmonary Hypertension patients and

they gave information about this pathology to the runners. We were speakers in the 1st School of Patients of Pulmonary Hypertension organized by University Hospital 12 de Octubre in Madrid.

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 III Congres of Patients of SEPAR, the Spanish Society of Pneumology and Thoracic Surgery, in the discussions on “Ready to ask. Answer in 60 seconds.”

As a member of FEDER we actively participate in campaigns, projects, activities, meetings, etc. they organize. In relation to International Rare Disease Day we attended the official ceremony at the Prado Museum, 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 III meeting for social transformation organized by FEDER.

The collaboration with other related organizations is very important. Our goal is to reach common 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. We can highlight the following ones:

We attended the Annual Congress of POP (Patients Organization Platform).

We were in the presentation of the Institute ProPatients because we are members.

We took part in the III Organizations Meeting of FEP (Spanish Patients Foro).

We attended the International Congress of ELF (European Lung Foundation) in Madrid and were participated in the

meeting “Healthy Lungs for life”.

We took part in the association meeting organized by University Hospital Gregorio Marañón. 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. We can highlight the following ones:

III National Conference of Biosimilar.

Conference of Generic Drugs Cost-Effectiveness for the system and access of the patient.

Albert Jovell Agards V Edition.

Symposium “Health without Fakes” at the University Hospital of the Princess.

VII Conference of “Somos Pacientes (We are Patients)” under the slogan “New patients, new needs” in Madrid, The 3rd Health Fair of the HUCA race in Oviedo, giving information about the ANHP. The Minister of Health asked about pulmonary hypertension in our stand.

This year we created an awareness videos about PH:

[https://www.youtube.com/watch?v=Du9\\_Cvofp-A&feature=youtu.be&fbclid=IwAR2EdrI-hqi9YHRRv6S5yoL8Qxx\\_OQCT3BOTruYPBEJ2-24ww1TZhSGJasI](https://www.youtube.com/watch?v=Du9_Cvofp-A&feature=youtu.be&fbclid=IwAR2EdrI-hqi9YHRRv6S5yoL8Qxx_OQCT3BOTruYPBEJ2-24ww1TZhSGJasI)

*Eva García,*

*Asociación Nacional de Hipertensión Pulmonar*

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





## SPAIN FCHP

The Foundation Against Pulmonary Hypertension (FCHP) has given a cheque for 30,000 euros to those responsible for the Empathy Project for research into pulmonary hypertension, led by Dr Barberá, and a cheque for 20,000 euros to the Pasionhp Project led by Dr Pablo Lapunzina.

FCHP has donated more than 300,000 euros to the investigation of pulmonary hypertension in the last 10 years.

The event held on the occasion of its 11th Anniversary on Thursday night and directed by the presenters and honorary patrons of the FCHP Carlos García Hirschfeld and Eva Mora. With this amount, FCHP has already given more than 340,000 euros for research since the entity was born in 2008. Two tables were the centre of the colloquium for doctors of clinical medicine and another table for doctors of scientific medicine. They explained the latest developments in Pulmonary Hypertension.



Enrique Carazo Mínguez, president of the association, said that this amount has been achieved thanks to the work of hundreds of people who throughout the year have made many fundraising activities, such as charity markets, concerts, awareness activities, sports championships, exhibitions or the sale of merchandising, among many others that have been organized throughout the Spanish geography, thanks to all of them! The institutions and private companies that support the work of FCHP have also played an important role in this fundraising.



### Appointment of Patrons and Godmother of Honor

This year four Honorary Patrons of the Pulmonary Hypertension Foundation have been appointed:

- Mr. Emilio Butragueño Director of Institutional Relations of Real Madrid C.F. with his wife Sonia González, came this year to collect his Patronage of Honor.
- Mr. José María Villalón, Doctor of Atlético de Madrid was another of the recently appointed Patrons of Honour, who will take Pulmonary Hypertension to the highest level.
- Ms. Eva Mora, Presenter of Canal 24 horas was named this year's Godmother of Honor, recognizing the title as a surprise that fills her with joy.

Finally, Dr. Roham T. Zamanian, picked up the Honorary Board of Trustees as a symbol of the union between Stanford University and the Pulmonary Hypertension Foundation.



### Nine FCHP Solidarity Awards

Prices were awarded for the solidarity work of each of them, among the outstanding ones were:



- Canal 24 Horas de RTVE, received the Cristina Ónega Award, Director of Canal 24 Horas.
- "Amar es para siempre", collects the price of the solidarity fiction series Eduardo Casanova, director of the series.
- Ms. India Martínez, the most supportive singer with Pulmonary Hypertension.
- Solidarity Personality to Mr. Juan Carrión President of FEDER.
- AQUADEUS solidarity company was awarded the price, which went to the Commercial Director of Aquadeus Mr. Julián Garré.
- Solidarity television network of Publiespaña-Mediaset Mr. Antonio Gómez, Director of Coordination and Commercial Management of Mediaset.

- Solidarity athlete, Dani García Lara, former first division soccer player.
- Solidarity Award to the Nursing Service of the 12 de Octubre University Hospital (Madrid).
- Journalist solidarity Mr. Angel Acién, of Canal Sur TV.
- Solidarity Stars, collected the Mr. Javier Cazallas Crespo price, representing Rebel Legion Spanish Base, 501 st Legion Spanish Garrison and Mandalorian Mercs Spanish.

## Two new appointments to the Scientific Committee

Dr. Pablo Lapunzina of La Paz Hospital and Dr. Francisco Pérez Vizcaíno of the Faculty of Pharmacology of the Complutense University of Madrid, have been appointed as part of the new Scientific Committee of the Foundation against Pulmonary Hypertension. Together with Dr. María Jesús del Cerro, Dr. Joan Albert Barberá and Dr. Miguel Ángel Gómez Sánchez, they will be in charge of assessing the medical-scientific part of FCHP.

We would like to thank all of them for their assistance, as well as the support they have shown to our cause, for us it is a luxury to be able to count on their presence on such an important day for Pulmonary Hypertension. THANK YOU!!!

## Testimony of a lung transplant and former water polo player Mr. Pedro García Aguado

One of the most emotional moments was when Paola Corina, affected by Pulmonary Hypertension and recently transplanted, told of her experience amidst nerves, tears and thanks to FCHP, for the welcome she had among us, and because she was able to enjoy the flat that the Parla Town Hall has given to those affected by the foundation who come from other communities to undergo a transplant in the Community of Madrid. Mr. Pedro García Aguado told us about his experience in life and sports, an example of overcoming, with the newly released position of General Director of the Community of Madrid.

## More than 340,000 euros raised in 11 years

During the 11 years that the FCHP has been running, the entity has managed to raise more than € 340,000 that have been allocated to scientific projects and scholarships for professionals working in the fields related to pulmonary hypertension. According to Enrique Carazo, president of the entity, "since we launched 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 340,000 euros raised so far has gone entirely to projects promoted by professionals, to training grants, to the Empathy Project and to the new PASIONHP PROJECT in genetics, they are already eleven years of incessant work".

## A year of effort and sacrifice in the fight against pulmonary hypertension

During 2019, FCHP members and friends have organized numerous activities to raise awareness about this disease and raise funds that have been allocated to the Empathy Project and the PASIONHP Project. Enrique Carazo thanked the collaboration of all the people who have promoted or supported any of these actions: "Fortunately, we have more and more support from friends of the Foundation, who are devoted to the needs of those affected and their families. Without them, today we could not have delivered these 30,000 euros for the Empathy Project."

## ACTIVITY REPORT 2018-2019

Carazo added that "this year we have also continued working from an institutional point of view to make our Foundation a much stronger entity.

In this sense, I would like to thank the collaboration and continuous support of the Spanish Society of Pneumology and Thoracic Surgery (SEPAR), CIBERES, CIBERER, the Carlos III Health Institute, the Spanish Federation of Rare Diseases (FEDER), the Parla City Council, the Pulmonary Hypertension Association of the United States or the European Pulmonary Hypertension Association".

## II International Research Forum on Pulmonary Hypertension

On the 27th, the II International Research Forum, promoted by the FCHP, took place during the whole day. The inauguration was made by Dr. Raquel Yotti, Director of the ISCIII, and Mr. Enrique Carazo Mínguez, President of the FCHP.



Dr. Yotti emphasized the effort made by FCHP to bring together the best doctors and researchers to work together and go hand in hand with the hope of those affected by PH. The keynote conference was given by Dr. Richard Trembath. Guy and St. Tomás Biomedical Research Center London.

From here in Spain, there were the best doctors and researchers,

*Dr. Alberto Mendoza. HU 12 Octubre. Madrid*

*Dr. Alejandro Rodríguez Ogando. HU Gregorio Marañón. Madrid*

*Dr. Andrés Quezada. HU Ramón y Cajal. Madrid*

*Dr. Ángel Cogolludo. Facultad de Medicina. Univ. Complutense. Madrid*

*Dr. Antonio Moreno Galdó. HU Vall D'Hebrón. Barcelona*

*Dra. Carmen Pérez Olivares. HU 12 Octubre. Madrid*

Dra. Diana Valverde Pérez. Universidad de Vigo  
 Dra. Elvira Garrido Lestache. HU Ramón y Cajal. Madrid  
 Dr. Federico Gutiérrez Larraya. HU La Paz  
 Dr. Francisco Pérez Vizcaíno. Faculta de Medicina. UCM. CIBERES  
 Dr. Ignacio Hernández González. HF Jiménez Díaz. Madrid  
 Dr. Jair Tenorio. HU La Paz. IDIPAZ. Madrid  
 Dr. Jeisson Osorio. HU Clínic Barcelona  
 Dr. Jesús Ruiz Cabello. CIC biomaGUNE San Sebastián. CIBERES  
 Dr. Juan José Ríos Blanco. HU La Paz  
 Dr. Mauro Lago Docampo. Universidad de Vigo  
 Dra. María Jesús del Cerro. HU Ramón y Cajal. IRYCIS. Madrid  
 Dra. Pilar Escribano. HU 12 de Octubre. I+12. Madrid  
 Dr. Pablo Lapunzina. HU La Paz. IDIPAZ. Madrid  
 Dr. Sergio Alcolea Batres. HU La Paz. Madrid

A forum from which large projects on the investigation of Pulmonary Hypertension have emerged.

### III Informative conference for those affected and families with Pulmonary Hypertension

Throughout Friday, FCHP organized some training days at the same AC Hotel Madrid Feria. These workshops were attended free of charge by patients with this disease and their families.

Throughout this session, several Cardiopulmonary Rehabilitation workshops have been held by Dr. Paz Sanz from the 12 de Octubre University Hospital, a reference center in this therapy. From the hands of María José Serrano Esteban, a lawyer specialized in medical-labour law and the psychologist of FCHP, they dealt with the documentation that must be provided to apply for disability rights.



### Award to FCHP

FCHP has been awarded by Her Majesty the Queen of Spain Letizia with the EMPATHY Project Scientific Research Award, which seeks a cure for Pulmonary Hypertension.



### About Pulmonary Arterial Hypertension

Pulmonary Arterial Hypertension is a rare, disabling, progressive, deadly disease, with no cure and of unknown origin in most cases. It is considered one of the 7,000 rare diseases in the world, according to data from the World Health Organization, as it affects about 20 people per million inhabitants. However, many suffer from it without knowing it because of the large number of misdiagnoses. Therefore, according to specialists, this pathology could affect more than 1,000 people in Spain.

This disease is caused by a narrowing of the arteries in the lung, so the blood passes through them more difficult and does not oxygenate them properly. This is why the right side of the heart must make an extra effort to pump harder and generate higher blood pressure. Over time, because of this overwork, the heart becomes larger and less efficient. As a result, it becomes increasingly difficult for it to carry blood to the rest of the body.

Until not long ago, the person who was diagnosed with pulmonary hypertension had a life expectancy of 3 years. Today, a large percentage of those affected manage to live more than two decades with this disease. This has been achieved thanks to research and professionals who are dedicated to treating patients and seeking a better quality of life.

*Enrique Carazo Minguez*

*FCHP Fundación Contra la Hipertensión Pulmonar*

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

[www.facebook.com/fundacionhp](https://www.facebook.com/fundacionhp)



SPAIN HPE-ORG



This year the work of HPE-ORG has continued to be very intense and focused on our main objective of our project as an entity, promoting a holistic vision of care in PH, in addition to our informative and training objectives.

We have participated in different training courses such as the Area of Clinical and Molecular Genetics and the Rare Diseases Unit of the Vall d'Hebron Hospital, together with FEDER, organized the Advanced Workshop for Patients with Rare Diseases 2019, taught by Dr. Tizziano. The objective of this advanced workshop was to deepen the knowledge treated during the first edition of these



workshops with a more practical approach, both at the level of genetic studies and psychosocial aspects related to these pathologies.

Course on Rare Diseases for patient associations given by the University of Barcelona

X FEDER-CREER Training School in which the Queen of Spain was present and we were able to present our projects, in the 1st School for Patients with Pulmonary Hypertension at the 12 de Octubre Hospital, a state centre of clinical reference in PH, in which we took an active part in different work tables and workshops.

3rd course of nursing care for patients with complex pulmonary hypertension given by the Clínic Hospital of Barcelona, centre CSUR reference of PH.

We are proud to continue collecting recognition for our projects of patient empowerment, focusing on the psychosocial and emotional aspect, promoting a more active and involved patient in the management of PH, awarded by 'III Ayudas Paciente VitalAire' and in the '3rd SEPAR Pacientes congress of SEPAR'.

Finalists in the 'Albert Jovel' Awards, finalists in the 7th edition of the 'Somos Pacientes' de Farmaindustria Awards.

Attendance to different congresses of interest as an entity and as patients joining and learning about the changes that are taking place in the health care system in Spain with many working topics such as chronicity, sustainability of the Health System in Spain and the changes it requires, funding of treatments for rare diseases, environmental respiratory health. So every year we do not miss the appointment of the X-PATIENT BARCELONA CONGRESS, this congress is the paradigm of change in care, Third SEPAR Patients Congress participating in its organization with papers, presentation of posters, we also attended the ERS (European Respiratory Society) Congress.

We continue working on the PH day for patients and families in different PH reference hospitals in a collaborative way with professionals and patients, in an informative, formative and participative format in order to improve the management of PH and health care.

*María Rodríguez, Hipertensión Pulmonar España*  
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## UKRAINE PHA

### February 28, 2019, Kyiv

All-Ukrainian Forum “Orphan patients-a priority of the state”. Every year the PHA Ukraine together with NGO “Rare diseases of Ukraine” events by the International Day of Orphan Diseases. We spent this day with our patients, doctors, and Kyiv officials discussing providing orphan patients with the necessary treatment. A stunning photo exhibition of patients with rare diseases and their families was organized in the Kyiv City Hall where the event took place. Patients with pulmonary hypertension also became heroes of this exhibition.

### May 10-12, 2019, Toronto, Canada

International conference “1st International Rare Dialogue. PHA Ukraine represented by the Chairman of the Board Oksana Aleksandrova. It was three days of dialogue and deliberation on all things rare: from research and policy to action and better outcomes.

The conference brought together representatives from around the world, from Hong Kong to Colombia, who shared their problems, experiences and achievements in solving the problems of patients with rare diseases. At the same time, everyone noted the planned and constructive nature of the approach to treating patients with rare diseases in countries that have adopted relevant National Plans. And this is almost all European countries. This is the strategy that we, representatives of social organizations for rare diseases, are striving to develop in Ukraine.

During the Conference, we met the Head of the Association of Pulmonary Hypertension of Canada, Joan Linnett Paulin, who sent a huge hello to all Patients with pulmonary hypertension in Ukraine and expressed the hope that in Ukraine in the near future it will be possible to receive all types of modern treatment in expert centers of pulmonary hypertension.

### May 16-19, 2019, Bucharest, Romania

Annual Meeting of EURORDIS Members-European Alliance of Orphan Disease Organizations in Europe.

The Chairman of the Board of the PHA Ukraine Oksana Aleksandrova participated in the discussion of strategies for providing orphan patients (including patients with pulmonary hypertension), shared her experience, discussed and studied the experience of European countries.

### May, 2019

Great news for Ukrainian patients with pulmonary hypertension: for the first time, Ukraine received the drug Ambrisentan, which has a high efficacy for the treatment of pulmonary hypertension in combination therapy.

This drug will be available to Ukrainian patients for

the first time. Until now, it was impossible to buy it on the territory of Ukraine, since it was not registered in our state.

The path of the drug to Ukrainian patients with pulmonary hypertension was very difficult. But this is exactly the case when, by combining the efforts of the Ministry of Health, the procurement agency UNDP, the drug supplier GSK and the PHA Ukraine, we managed to overcome all obstacles! In the near future Ambrisentan will be in all regions of Ukraine!

### May 29, 2019, Kyiv

Meeting of the Committee of the Parliament of Ukraine on Health Care. We have made another important step in building a systematic approach in the treatment of orphan patients, including patients with pulmonary hypertension. The Chairman of the Board of PHA Ukraine Oksana Aleksandrova participated in this meeting, organized by the NGO “Rare Diseases of Ukraine” in association with PHA Ukraine.

Three important issues for Ukrainians with rare diseases were discussed:

1. Strategy for access to prevention, diagnosis, treatment and rehabilitation of patients with rare (orphan) diseases.
2. Problems and consequences of the absence of the Cabinet of Ministers of Ukraine approved by the Cabinet of Ministers Procedure for the establishment and maintenance of a state register of citizens suffering from rare (orphan) diseases.
3. Terms and mechanisms of financial provision of orphan patients with the necessary medical assistance and medicines from January 1, 2020.

Participation in the discussion was taken: People's Deputies of Ukraine, representatives of the Cabinet of Ministers of Ukraine, the Ministry of Health of Ukraine, other interested ministries and departments, the National Academy of Medical Sciences of Ukraine, scientific medical institutions, regional departments of public health, international and public organizations, leading domestic and European experts on orphan diseases, media representatives.

### May 30, 2019, Kyiv

President of the Association of Pulmonary Hypertension of Bulgaria Todor Mangarov, who independently overcomes the multi-day cycling route from Sofia to Lake Baikal, met in Kyiv with patients of the PHA Ukraine in order to support them and to jointly submit a petition to the Ministry of Health regarding the threat of cessation of



treatment in 2019 from patients with CTEPH. Attention to this problem of Ukrainian patients with PH is now very important - the drug “Riociguat”, which is a rescue for many patients with CTEPH, this year was not included in the public procurement list of the Ministry of Health of Ukraine. It’s life-threatening for those patients who started treatment with this drug in 2018.

Together with Ukrainian PH patients, Todor, who himself eight years ago suffered surgical treatment of CTEPH, handed over a letter to the Minister of Health Ulyana Suprun asking to resolve this problem urgently.

By his example Todor promotes hope for other patients - by means of early and timely diagnosis and appropriate therapy they can improve the quality of their lives and do all they dream of.

We were incredibly inspired by this meeting and the opportunity to travel by the bicycles to the paths of the Mariinsky Park. We sincerely wished Todor, our friend and colleague from Bulgaria, the passing wind and good luck!

### September 17, 2019 - Patient Safety Day, Kyiv

Ukraine celebrated Patient Safety Day for the first time. On this occasion, Ukrainians with rare diseases (including patients with pulmonary hypertension) from different regions of Ukraine arrived to Kyiv and came under the walls of the Office of the President of Ukraine and the Ministry of Health to tell the new government about the needs and problems of orphan patients. Patients demanded: “To turn on the green light for our uninterrupted treatment!”.

### September 28, 2019, Carpathians

This day transplant patients, their relatives, doctors, and

community organizations promoting the development of transplantation and upholding the rights of patients BEFORE and AFTER transplantation, have conquered the highest mountain in Ukraine - Hoverla. PHA Ukraine was represented by Oksana Aleksandrova and Iryna Zhuchenko, because the issue of lung transplantation is very topical for patients with pulmonary hypertension. Ascending to Hoverla, we:

- have demonstrated to society that transplantation for humans is a chance for a fulfilling life;
- stated the importance of rescuing mortally ill people through organ transplantation;
- asked the government to speed up the start of transplantation in Ukraine.

### December 18, 2019, Kyiv

This day the Minister of Health of Ukraine signed the Order “On Establishment and Approval of the Departments of Interdepartmental Multidisciplinary Working Groups”. According to this Order, the Chairman of the Board of PHA Ukraine Oksana Aleksandrova was a member of the working group on the development, improvement of the organization of prevention, diagnosis and treatment in the direction of “Orphan diseases”. This provides an additional opportunity to support patients with pulmonary hypertension at the legislative level. We are very excited about this news on New Year's Eve!

*Oksana Aleksandrova*  
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## UKRAINE PHURDA



Representatives of PHURDA became active participants in expert groups at the Ministry of Health of Ukraine on the Support of medicines procurement. The group of experts and specialists includes doctors and representatives of public organizations. In the expert group, we are fighting for the expansion of the nomenclature (the list of PH medication plus medication used before & after transplantation) in every meeting. This is a work responsibility that we do not take on lightly because lives depend on it. However, decisions must also take the economic aspects into account since the budget given is limited.

May 17-18, Bucharest (Romania) PHURDA representatives attended the EURORDIS Membership Meeting 2019 # EMM2019. In today's reality, Ukraine has many barriers. We value membership of EURORDIS because it is an opportunity not only to speak aloud about the problems of Ukraine's rare patients, but also to find leverage and new experiences.

Within the facilities of the Ukrainian Parliament, we took the opportunity to present a video (O2Kids) about PH, that was kindly provided to us by PHA Europe. Never before has a video like this been shown at the parliament. Our advocacy work has given results at the local level in the Lviv region as an official regional register of PH patients has been implemented. Furthermore, together with partners, we have managed to implement a medication and a rehabilitation program.

At the end of June, there was a work meeting held with

representatives of rare diseases at CF "Sister Dalila", PHURDA's office. We discussed the problems that patients with rare nosologies face today. The outcome of the meeting is that we now are developing a common strategy for Rare Disease Day. We initiate the Orphan Bell, to enhance the voice of the rare community.

The PHURDA team participated in a professional training aimed at those who work to help others every day. The goal of the training is to avoid that workers become burned out. The training was organized by the Ukrainian Philanthropic Forum.

We are proud of the special achievements of our PH patients who, despite their lung condition, were able to overcome the mountain peaks: Svetlana Malanchak – Medjugorje, Križevac hill, 520m (Bosnia&Herzegovina), Nadiya Nus - Hoverla, 2061 m (Ukraine).

From September 28th to October 2nd in Madrid (Spain), PHURDA representatives participated in the ERS Congress 2019, which was a major and significant event for anyone with a pulmonary condition. There were hundreds of speakers, thousands of participants. We became part of the event that inspired us. There were a number of meetings where we spoke about Ukrainian patients and the challenges we face every day. We have shared successful experiences of working with officials and doctors, successful "Butterfly in Blue" project. We had the opportunity to present a poster where thousands of participants got to know about our activities. We were heard, we were applauded! We also visited the Spanish Ministry of Health to talk about transplant issues and finding solutions for transplant development in Ukraine.

### Rehabilitation for PH patients

This fall, PH patients of Lviv region participated in the second stage of the rehabilitation program. The program includes: individual and group psychotherapy sessions, physical exercises, dance and movement therapy, as well as massage. We strive to convey that good nutrition, moderate exercise activity and a healthy psycho-emotional condition are the key to improving patients' quality of life. The program was implemented thanks to the financial support of the Lviv City Council and the partner support



of the Anna Mazurenko Children's Health Center. PHURDA Leader Oksana Kulish, together with the "Butterfly in Blue" fashion project, has been included in the list of Best Women Initiatives for Democratic Development of Local Communities-2019. The Butterfly in blue fashion project, which, through the prism of beauty, shows the PH problem, was a success at the Ukrainian Culture Festival in Toronto, Canada which was attended by one million visitors!

This year again CF "Sister Dalila" is on the Charity Map, which includes charities that have publicly disclosed their financial statements and confirmed the openness of their activity in the charity sector of Ukraine.

## APHEC

"So, I lost this year's board election, but it inspired me. Thank you those 4-6 votes that made it clear to me that I still have reasons for hope" says Oksana Kulish.

We very much hope that the newly elected president and board will structure and inform all associations about the country's eligibility criteria for holding APHEC and that

this information will be publicly available to all members.

Five years activity report

On December 13, CF "Sister Dalila" presented a report on its activity for five years. It was not just a report, it was a meeting with those who believed and were close to us in difficult times. The event contained everything - gifts and tasty treats from the PH community in combination with Ukrainian traditions. Also, during this event, "Charity Shop" was working and we managed to raise some funds to support the organization's future activities.

Last, but not least, we would like to thank all the good people and partners who have helped us to make our office comfortable and a friendly special place for our patients this year. In fact, it has been a great learning process, and the lawyer of CF "Sister Dalila" shared the experience "How to get a facility for rent from the local authorities?" in a presentation to NGOs of Ukraine.

*Oksana Kulish, Sister Dalila-PHURDA-Ukraine*

<http://poryatunok.info/uk/>





# CANADA



### New Resources - PH & Contraception

The Canadian PH Professionals Network (CPHPN) created a new resource addressing the importance of contraception for women living with PH that provides an overview of available contraception methods. We encourage the community to download this new resource for free in either English or French, along with our other tools, at [www.phacanada.ca/resources](http://www.phacanada.ca/resources).

### PH Parents Network

Dealing with the critical illness of a child is one of the most challenging things that a parent will ever face. The PH Parents Network is reaching out to a growing number of families who have children affected by PH in order to help them connect to share experiences and end feelings of isolation. Being part of the Network enables parents to access more resources and better adjust to life with PH. For more information, visit [www.phacanada.ca/pediatrics](http://www.phacanada.ca/pediatrics).

### Sometimes It's PH Video Series

In February, PHA Canada created fifteen educational videos in collaboration with PHAware. The series features four Canadian PH physician experts who explain PH and the importance of health care providers being on the look out for this uncommon condition. Check out the videos on PHA Canada's YouTube channel: [www.youtube.com/PHACanada](http://www.youtube.com/PHACanada).

### Atlantic Forum

In October, PHA Canada held its first-ever educational forum in Canada Atlantic region. This free event offered people affected by pulmonary hypertension the unique opportunity to learn about current research and treatment developments, acquire skills to successfully manage life with PH, and connect with members of the Canadian PHamily.

### Research Scholarships

In 2018-19 PHA Canada awarded five \$10,000 scholarships

to research trainees working to advance PH research in Canada. PHA Canada's Research Scholarship provides a financial stipend to an outstanding trainee in support of their research into pulmonary hypertension. To read more about these projects, visit [www.phacanada.ca/research](http://www.phacanada.ca/research).

### New Website

All of us at PHA Canada are incredibly excited to share the news of our new website! We've upgraded various sections of the site to include better and more interactive features designed to make the PH journey easier. We believe that patients and their families should be able to find the information and tools they need, and in a way that they understand, so they can feel both supported and informed. [www.PHACanada.ca](http://www.PHACanada.ca)

### Annual Events

November Awareness Month: Celebrating 'Life In Purple' Part of having an "invisible chronic illness" like pulmonary hypertension is that it can be difficult for people who aren't directly affected by PH to understand what it means to live with the illness.

During PH Awareness Month, we help people across the country to better understand the daily impacts of PH on patients and caregivers through a social media campaign highlighting what "Life in Purple" looks like everyday for those affected by PH.

### World PH Day: Paint Canada Purple

To raise awareness, the PH community successfully requested a record number of illuminations for this year's Paint Canada Purple on May 5th. Over 20 public buildings and monuments were lit up in periwinkle purple from coast to coast!

PHA Canada

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

<https://www.facebook.com/PHACanada/>



# USA PHA

## 2019: A Year of Progress

2019 was a year of progress for the Pulmonary Hypertension Association (PHA). The accreditation of expert centers grew to 70 nationwide, enrollment in the PHA Registry (PHAR) passed 1,000 registrants and new educational content and awareness campaigns empowered and engaged thousands of patients and their families.

Five years after the PH Care Centers (PHCC) initiative began, the Pulmonary Hypertension Association accredited its 70th PH center at the end of June 2019.



To be accredited, PH centers must demonstrate expertise in PH and a commitment to providing expert-level care, evaluating PH patients based on published evidence-based guidelines and assembling a team of health care professionals dedicated to PH. The concept for the PHCC program developed from discussions in 2011 between members of PHA's medical advisors, the Scientific Leadership

Council (SLC), and PHA leadership about the need to better assess and consequently improve the quality of care and treatment for patients. The accreditation process began after a pilot program for the PHCC initiative concluded in 2014.

What started as a quality improvement initiative utilizing accreditation as a tool to assess centers now includes a patient registry in which accredited programs can participate. The PHA Registry (PHAR) enrolled its 1,000th patient in August 2019. The PHAR continues to expand its important role in improving pulmonary hypertension (PH) research, the patient experience and quality of care for those with pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH). Data is collected at 43 participating adult and pediatric PH Care Centers (PHCC) throughout the country.

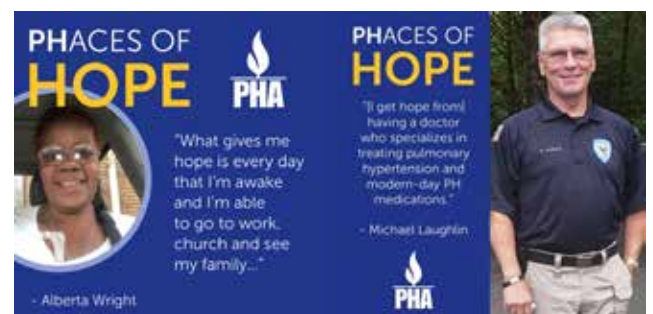
PHAR is a multi-center, observational patient registry that measures quality of care and the patient experience in newly evaluated patients with PAH or CTEPH, two forms of PH for which targeted treatments are available that can extend and improve patients' lives. PHAR centers collect information when a patient interested in participating is initially evaluated at the PHCC. They contribute

information approximately every six months, allowing the PH community to understand how the disease impacts patients over time. In addition to measuring quality of care – including assessing differences in centers' adherence to evidence-based guidelines – PHAR helps determine the relationship between expert-recommended care strategies and patient outcomes. PHAR gives participating centers a platform to perform their own research and quality improvement, including access to their data in real-time through a center dashboard. External scientists can participate in research through the PHAR Data Analysis Service, launched in December 2018.

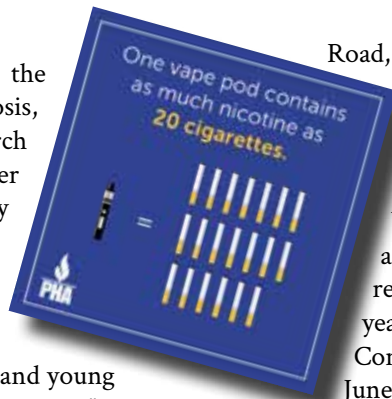
Beyond its quality care and research initiatives, PHA has developed new and expanded support services. While the in-person support groups of PHA, numbering over 200, remain the cornerstone of this support network, virtual support – online and by phone – is essential to ensure every patient, wherever they live and whatever their condition, can know that they are not alone. PHA grew its social media support groups from 4 to 8 and expanded its reach to over 2,500 individuals. PHA expanded its support to bereaved families by adding a bereavement telephone support group (the sixth such group) and creating a bereavement guide for families, *In Your Time of Sorrow*. Through publication of its *Roadmap to Hope: a guide for people who are newly diagnosed with pulmonary hypertension (PH)*, PHA has reached over 1,500 newly diagnosed patients.



PHA's celebrated the community in November during PH Awareness Month through a successful patient empowerment and storytelling campaign, PHaces of Hope. Patients and families told their own stories to raise



awareness about PH, explained the importance of early and accurate diagnosis, and expressed their desire for research to lead to a cure. Social media and other digital channels, as well as the quarterly PHA magazine Pathlight, drove this campaign to reach our widest audience ever. PHA also took on the vaping crisis which threatens many Americans as marketing has convinced many smokers and young people to switch to vaping as a “safe alternative,” despite grave warnings and recent scientific findings that vaping is quite dangerous.



Education remains central to PHA’s mission to empower patients to live their longest, best lives, and our online resource library, PHA Classroom, is stocked with incredible videos educating patients about disease management, diet and exercise, research and clinical trials – and much more. Patient voices often contribute, notably in 2019’s pediatric series, and physicians lend their expertise to primers on important topics as when a CTEPH expert discussed that rare form of PH from diagnosis to treatment. Two in-person regional forums, programs called PHA on the

Road, brought greater understanding of PH and its management to hundreds of patients and families in Kansas City, MO and San Francisco.

2020 will build on these successes as we build new resources, engage more patients and families and expand our quality care and research initiatives. 2020 is also a conference year. The PHA 2020 International PH Conference and Scientific Sessions takes place June 12-14 in Anaheim, CA – and you are invited. You can learn more about this one-of-a-kind event, which brings together 1,500 patients, caregivers and PH experts every two years, at [www.PHAssociation.org/PHA2020](http://www.PHAssociation.org/PHA2020).

To learn more about any of PHA’s activities, please contact [international@PHAssociation.org](mailto:international@PHAssociation.org). Thank you!

*Brad A. Wong, Pulmonary Hypertension Association USA*  
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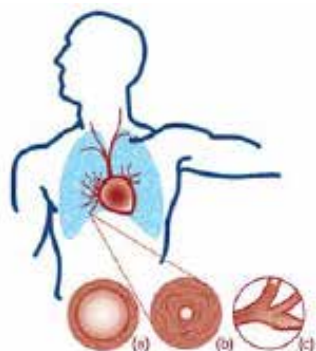
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## AIMS OF PHA EUROPE

**Pulmonary arterial hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria, as an international non profit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hypertension 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 hypertension, 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.**

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