



# PULMONARY HYPERTENSION Mariposa Journal

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THE EURORDIS  
Black Pearl  
AWARDS  
PROUD WINNER OF  
THE EURORDIS 2018 BLACK PEARL AWARD FOR  
BEST PATIENT ORGANIZATION

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







# Editors memo Winter 2017 edition

Austria
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Belgium
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Bulgaria
Croatia
Czech Republic
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Finland
France
Germany
Greece
Hungary
Ireland
Israel
Italy
Latvia
Lithuania
Netherlands
Norway
Poland
Portugal
Republic of Macedonia
Romania
Russia
Serbia
Slovakia
Slovenia
Spain
Sweden
Switzerland
Turkey
Ukraine

Dear members, friends and supporters, welcome to the Winter 2017 edition of the Mariposa Journal. We are proud to report on the numerous projects and activities that our organisation has successfully carried in the course of the year to advance the cause of pulmonary hypertension (PH) patients in Europe. We are also very proud of the accomplishments of our member associations, who have been incredibly active in their respective countries in raising the profile of the disease in many different ways: by organising public awareness and educational events; advocating for affordable access to treatment, life saving surgery and better standards of care; raising funds to finance PH research; developing support programs for patients and their families and, last but not least, in rallying politicians, health authorities, PH health care professionals, academia, sportsmen, celebrities and media to the cause. The reports from the individual member associations in this journal show how much determination, passion and dedication there is behind their work and how creative and innovative they have been in organising very interesting and engaging activities. All of them have provided invaluable support to patients and their families. Some have also been successful in paving the way for better access to treatment and increased patient support in their countries, others have given significant contributions to PH research. Solidarity is one of key values of our community and it is great to see that many associations have joined forces across borders in order to reach the critical mass that is necessary to have a louder voice. And, as, for different reasons, not all patients are able to travel to attend PH meetings or conferences, some associations have decided to go “on tour” through their countries to reach out to those less fortunate in a more advanced stage of the disease or more elderly.

At a global level, PHA Europe’s activities have revolved around four main themes: awareness raising, capacity buiding, advocacy and information provision. The main awareness raising event for 2017 was, as in past years, World Pulmonary Hypertension Day (WPHD), which takes place on and around May 5. WPHD was launched in 2012 in Spain and, in only five years, has gone truly global, with over 40 countries worldwide taking part in the 2017 edition. WPHD started as a campaign targeted at the general population but it has increasingly seen the involvement of national political and health authorities, academia, health care profes-

sionals and celebrities. The campaign has also gained increasing media interest over the years, with the 2017 edition generating over 400 media clips (print and online, TV and radio), in Europe alone, reaching millions of people (see also the Summer 2017 Mariposa Journal).

Capacity building is another very important part of PHA Europe’s activities. Our organisation’s ultimate goal is to put in place a strong European PH community consisting of empowered national associations, working together for the PH cause. Under PHA Europe’s “White Spots” program, started in 2013, PHA Europe has reached out to patients/care-givers/medical professionals in European countries where no PH association previously existed and provided start up funds, guidance and training in order to establish a local association and support it during its first years of establishment. Since the start of the program, thirteen patient associations have been set up (or are currently being set up) in Europe. Only two countries in Europe with a population of over 1 Mn still do not have a patient association. As we complete the White Spots program PHA Europe intends to implement the next stage of organisation development, which is to ensure that all PH associations reach a certain level of skills, knowledge, activity and services. We have identified 40 areas of services that define a “mature” and well organized association. Our aim is to work together with the associations and assist them in eventually providing the missing services. PHA Europe’s official working language is English and, as the organisation expanded over the years to include more and more countries, communication started to become a critical issue with those associations where neither Board members nor volunteers had a good command of this language. Thanks to our “Fellowship” program, PHA Europe has been able to provide these associations with a part time English speaking assistant. The program started in 2013 with nine Fellows; in 2017 we were able to support 22 patient associations with a Fellow. The program has been very successful in ensuring a smooth flow of communication and engaging our member associations in common activities. Our Annual European PH Conference also continues to provide excellent educational and training opportunities to our members, through the presence of some of the top international medical opinion leaders as speakers, as well as experts in different related areas from other prestigious European organ-

isations and high level representatives of the pharmaceutical and medical devices industry. The 2017 edition saw the participation of 63 PH Patient Leaders from 35 countries.

Advocacy is also one of our key activities and is vital to driving change in health policies, both at the national and EU levels. The main focus of our advocacy activities is on access to treatment and surgery (including organ transplant), as these are critical issues for many of our patients across Europe. Not all approved PH drugs are available in all countries across Europe and there are countries where patients do not have access to any drugs at all or to expert centres/surgical facilities. We are also active in advocacy activities aimed at improving the quality of life, specifically emotional well-being. PHA Europe cooperates actively with the main public health European NGOs: we are members of the Board of the European Patients’ Forum (EPF) and sit on the Drug Information Transparency and Access (DITA) task force of EURORDIS, the European Organisation for Rare Diseases. In the context of these organisations we work on issues such as the standardisation of Health Technology Assessment and the implementation of the Cross-Border Health Care Directive, which advances the empowerment of patients across Europe. A number of meetings with these organisations have taken place over the year. We also take part in activities organised by the main relevant scientific societies, i.e. the European Society of Cardiology (ESC) and the European Respiratory Society (ERS). PHA Europe is active in the European Lung Foundation (ELF) of the ERS and a member of our staff is sitting on the ELF Council. Since 2017 PHA Europe has also started to collaborate with the European Society for Organ Transplant (ESOT), as part of the follow-up activities to our 2016 European Parliament dedicated event. A very important development for 2017 was our official involvement in the European Reference Networks, ERNS, set up by the EU COMMISSION, as mandated by EU legislation on rare diseases and cross-border health. PHA Europe will be actively involved in the work of the ERN-LUNG with two officially designated members serving on the ERN-LUNG European Patient Advocacy Group (ePAG) and one serving on the Medical Steering Committee. We also have two officially designated members serving on the ERN-TransplantChild. ERNs will provide a unique opportunity for clinicians to work across borders in Europe to tackle the challenge of organising care for the scattered patient populations across Europe and we, as patient representatives, will play an important role in their work. We would like to mention two other initiatives from this year which we feel have made an important contribution to empowering our members (as well as physicians) to become better advocates for the disease in their own countries. Firstly, thanks to our collaborative work on organ donation and transplant with other European organisations, four of our members were able to take part in the EU-funded EUDONORGAN training program for organ transplant advocates (they were from Bulgaria, Bosnia & Herzegovina, Hungary and Slovakia). And we also funded a pulmonary hypertension medical training program in Madrid, at one of the top PH

expert centres in Europe, for ten physicians coming from countries where there are big issues in access to treatment and surgery. PHA Europe also provides strategic advice and support to national advocacy activities by writing letters and participating in meetings with national health authorities and other relevant stakeholders and by engaging in one-on-one talks with representatives of the pharma industry.

Finally, through its website, social media channels, bi-annual magazine and fortnightly newsletters, PHA Europe raises awareness of PH and empowers its national associations. All across Europe, PHA Europe representatives are also continually active in the dissemination of PH information, through scientific symposia, panel discussions, roundtables, workshops, and academic courses.

We believe that through our active engagement in all of the areas described above PHA Europe has made a significant contribution to the PH cause in Europe. At the same time we are conscious that we still have a long way to go before minimal standards of care are met in all countries across Europe, so our collective efforts must continue. Our warmest thanks go to our member associations for their active and enthusiastic participation in PHA Europe’s activities. We also thank all the other European and international stakeholders we work with as well as our industry partners, for their invaluable support, and look forward to another year of fruitful collaboration.

*Pisana Ferrari*

PS. As we go to print we have just received the news that PHA Europe has been given the EURORDIS Black Pearl 2018 award for “Best Patient Organisation”. What better way to start the new year, very auspicious indeed!

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JANUARY

*Lviv (Ukraine), January 14*

**PHURDA'S FIRST PATIENT MEETING**

Hall Skaara participated in the first patient meeting of the Ukrainian PH association PHURDA and ran a couple of presentations. He also participated in a TV interview with Lviv's local TV station about PH treatments on January the 16th.

*Brussels (Belgium), January 30*

**PATIENT ACCESS PARTNERSHIP (PACT) ASSEMBLY**

Face to face meeting attended by Juan Fuertes. The Patient Access Partnership is a multistakeholder group (MEP's, pharma industry, and physicians, chaired by an European Patients' Forum, EPF). The assembly reviewed the work of the previous year and discussed next course of action.

*Geneva (Switzerland), February 2*

**EUROPEAN LUNG FOUNDATION (ELF) COUNCIL MEETING**

Face to face meeting attended by Juan Fuertes. Coordination, budget and strategy. The members are patient representatives and the highest positions within the European Respiratory Society, ERS.

*Dubai (Emirates), February 4*

**SAUDI PH ASSOCIATION (SAPH) ANNUAL MEETING**

Juan Fuertes was invited by the SAPH to give a lecture on the role of patient organisations in fostering new patient organisations.

*Brussels (Belgium), February 21*

**EURORDIS GALA DINNER**

Pisana Ferrari was asked by EURORDIS to do the opening speech. The Gala Dinner was also attended by Luc Matthysen, President, and Juan Fuertes.



*Brussels (Belgium), February 27*

**LAUNCH OF THE UNIVERSAL HEALTH COVERAGE CAMPAIGN AT EU PARLIAMENT**

Juan Fuertes, in his capacity as European Patients' Forum (EPF) Board Member, made the launch speech for the EPF Universal Health Coverage Campaign.

*Brussels (Belgium), February 28*

**EUROPEAN PATIENTS' FORUM (EPF) WORKING GROUP ON ACCESS**

Face to face meeting attended by Juan Fuertes.

FEBRUARY

MARCH

*Vilnius (Lithuania), March 9-10*

**3RD CONFERENCE ON EUROPEAN REFERENCE NETWORKS (ERNS)**

Juan Fuertes and Gergely Meszaros attended the launch conference for the 24 ERNs set up by the EU Commission. Gergely, on behalf of the coordinator of ERN-Lung, attended the ceremonial dinner with the representatives of the Members States, the coordinators of ERNs, etc. and ran a short presentation about PHA Europe. Juan participated in the ERN-TransplantChild Board meeting.



*London (UK), March 17-18*

**12TH JOHN VANE MEMORIAL SYMPOSIUM ON PROSTACYCLIN SCIENCE**

Pisana Ferrari was invited to speak on the "Unmet needs of the pulmonary hypertension patient" at this meeting which had over 150 participants. It was the first time a patient representative was asked to speak at this prestigious annual event.

APRIL

*Athens (Greece), April 4*

**FUTURE OF HEALTH CARE IN GREECE CONFERENCE**

Juan Fuertes attended the meeting as lecturer. The annual Healthcare conference in Greece is an important event where authorities, patient organisations and pharma industry present their views about the healthcare system.

*Frankfurt (Germany), April 5-6*

**ERN-LUNG BOARD MEETING**

Gergely attended the ERN-Lung meeting which covered many interesting topics regarding the operation of ERN-Lung. A special session for all the patient representatives from different rare lung diseases was also organized.



*Sarajevo (Bosnia and Herzegovina), April 22*

**FIRST PATIENT MEETING**

Hall Skaara participated in this meeting and ran a couple of presentations.

*Barcelona (Spain), April 20*

**MEETING WITH ESOT AND EDTCO**

Juan Fuertes attended a meeting with the representatives of ESOT, the European Society for Organ Transplant and EDTCO, European Donation and Transplantation Coordination. The idea of creating a bridge organization to facilitate dialogue and cooperation between transplant specialists and the patient community was discussed.

*Limassol, Cyprus, April 28-30*

**EUROPEAN KIDNEY PATIENT ASSOCIATION AGA**

Pisana Ferrari was invited to give a talk on "Patient involvement in European Awareness Campaigns", during which she spoke of the PHA Europe Call to Action on Organ Donation and Transplant.



*Zurich (Switzerland), April 28*

**EUROPEAN LUNG FOUNDATION (ELF) COUNCIL MEETING**

Juan Fuertes attended the meeting. Preparation of the patients' work and activities at the ERS Congress.

*L'viv (Ukraine), May 5*

**ROUND TABLE ON TRANSPLANT**

Juan Fuertes attended the meeting as lecturer at the Round Table organised with authorities, physicians and health authorities by the Sister Dalila PH patient organization in L'viv, Ukraine.

*Budapest (Hungary), May 18-20*

**EURORDIS MEMBERSHIP MEETING**

Juan and Gergely attended the meeting, which included a special session for e-PAGs. Juan Fuertes was asked to be panelist in a session on the future of rare diseases.



*Brussels (Belgium), May 18*

**ORGAN TRANSPLANT MEETING**

Pisana Ferrari organised a meeting with EU Commission official Stefaan van der Spiegel, DG Sante, David Paredes, European Society for Organ Transplant, and representatives of the European federations for diseases of the liver, lung and kidney to discuss possible future collaboration and a joint EU platform.

*London (UK), June 12*

**EMA/FDA/HEALTH CANADA WORKSHOP ON PAEDIATRIC PULMONARY ARTERIAL HYPERTENSION (PAH)**

Gerry Fischer and Patrick Hassel, both parents of children with PH, attended the meeting on pediatric PH organised jointly by the EMA, FDA and Health Canada.

*Madrid (Spain), June 14*

**ROUND TABLE ON COOPERATION BETWEEN PHARMACEUTICAL INDUSTRY AND PATIENTS' ORGANIZATIONS**

Juan was invited as person of reference in Spain in patient engagement to moderate the panel on patient collaboration with pharma at the event in Madrid organized by CEFI (foundation whose mandate is on pharmaceutical law and ethics).

APRIL

MAY

JUNE



**Vilnius (Lithuania), June 15-16**  
**INTERNATIONAL SEMINAR EAST EUROPE**

Hall Skaara participated in a meeting in Vilnius together with the Russian speaking associations. Common challenges and strategies for the associations were discussed.



**Warsaw (Poland), June 30-July 1**  
**BAYER PH NURSE FORUM**

Pisana Ferrari and representatives of PHA Polska, including Agnieszka Bartosiewicz, were invited to this annual workshop which had 120 participants from 17 different countries. PHA Europe had an information booth.



**Barcelona (Spain), August 25-29**  
**CONGRESS OF OF THE EUROPEAN SOCIETY OF CARDIOLOGY (ESC)**

Juan Fuertes attended the PH scientific sessions and meetings with representatives of the pharma industry.

**Milan (Italy), September 9-13**  
**EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS**

Gergely participated in the ERN-Lung Medical Steering Committee meeting and an e-PAG meeting organized within the frame of ERS. Pisana Ferrari and Juan Fuertes attended several meetings with industry partners. Juan Fuertes took part in a meeting with industry (Bayer, Bellerophon), and PH specialists, organized by the Pulmonary Vascular Research Institute, PVRI, he facilitated the workshop on registries organised by the European Lung Foundation (ELF), and attended face to face meetings of the ELF Patients Advisory Committee, Advocacy Working Group and the International Patients Advisory Committee.



**Barcelona (Spain), September 18**  
**ROUND TABLE OF COMPANIES EURORDIS**

Juan Fuertes was asked to chair one of the breakout sessions about funding of ERNs.

**Madrid (Spain), September 21**  
**INSTITUTE OF HEALTH DATA INTERNATIONAL CONFERENCE**

Juan made a presentation on patients' perspectives on reuse of Health Data.

**Barcelona (Spain), September 18-21**  
**PHA EUROPE'S ANNUAL PH EUROPEAN CONFERENCE (APHEC)**

The PHAE meeting was attended by 63 PH Patient Leaders from 35 countries and featured KOL Dr. Pilar Escribano, 12 de Octubre Hospital, Madrid, as medical guest speaker.



**Barcelona (Spain), September 25**  
**EUROPEAN SOCIETY FOR ORGAN TRANSPLANT CONGRESS**

Juan Fuertes attended the ESOT annual congress and the first ever patient organizations' meeting organized within it.

**Brussels (Belgium), October 23**  
**MEETING WITH INDUSTRY ORGANIZED BY EPF**

Annual session on the work done by EPF and hot topics such as Intellectual Property.

**Brussels (Belgium), October 24**  
**PRO-STEP FINAL CONFERENCE**

Juan made the concluding remarks that closed a project on self-management funded by the European Commission.

**Madrid (Spain), November 20**  
**PH MEDICAL TRAINING FOR DOCTORS**

PHA Europe organised and financially supported a PH medical training program for ten physicians coming from countries where access to treatments and surgery are a critical issue. The training program took place at the 12 de Octubre Hospital in Madrid, one of the top PH expert centers in Europe.



**Madrid (Spain), November 23**  
**FCHP GALA DINNER**

Juan made a short presentation at the Gala Dinner organized by the Spanish Foundation against Pulmonary Hypertension.

**Brussels (Belgium), December 4**  
**WORKSHOP ON CROSS-BORDER HEALTHCARE DIRECTIVE**

The meeting was organized by the European Patients' Forum, EPF. Juan Fuertes made the opening speech and facilitated the workshop on actual implementation and ways to improve the users' experience.

**Brussels (Belgium), December 6**  
**PRESENTATION OF THE EPF ROADMAP ON UNIVERSAL HEALTHCARE (UHC)**

During this meeting the EPF Roadmap on universal health coverage (UHC), on which Juan Fuertes collaborated actively throughout the year, as Member of the Board of EPF, was presented, as well as a video in which he and other patient representatives were speaking. He could unfortunately not attend the meeting on account of overlapping engagements.



**Rome (Italy), December 6**  
**WORKSHOP ON CLINICAL GUIDELINES GENERATED BY ERNS**

Juan Fuertes participated at the workshop where the future of guidelines by Member States was discussed. Attended by ERNS e-PAGs, ERN-Coordinators, the European Commission.

**Frankfurt (Germany), December 10**  
**PHA EUROPE JOINT BOARD AND STAFF MEETING**

PHA Europe's Board and Staff members held a joint meeting in Frankfurt to discuss the 2018 budget, and future activities and strategies.



**Paris (France), December 18**  
**ERN EPAG FACE TO FACE MEETING**

Gergely attended this meeting organized by EURORDIS for those e-PAGs, who have positions in governing bodies of the different ERNs.



**Madrid (Spain), December 20**  
**CONFERENCE ON GENOMICS**

Juan Fuertes was asked to speak at this conference organized by the Institute of Genomics and attended by Regional Ministry of Health and patients' organizations.

**2018 AT A GLANCE**

- EURORDIS BLACK PEARL GALA DINNER, Bruxelles, Belgium, January 20
- 7TH WORLD SYMPOSIUM ON PULMONARY HYPERTENSION, Nice, France, February 27-March 1
- 9TH EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS, Vienna, Austria, May 10-12
- PHA INTERNATIONAL CONFERENCE AND SCIENTIFIC SESSIONS, Orlando, USA, June 29-July 1
- EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS, Munich, Germany, August 25-29
- EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS, Paris, France, September 15-19



# Annual PH European Conference

Barcelona, September 18-21, 2017

The Annual PH European Conference (APHEC) 2017 was held in Castelldefels, Barcelona (Spain) from 18-21 September. The APHEC represents one of PHA Europe's central activities: it is a key driver for activity and engagement and has in past years played a crucial role in inspiring, supporting, educating and motivating its members. The 2017 edition was no exception: we had a record turnout of 63 pulmonary hypertension representatives, from 35 countries, a leading Spanish KOL as medical guest speaker and best practice sharing sessions and workshops. PH representatives from the following countries attended the meeting: Albania, Belarus, Belgium, Bosnia & Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, France, Finland, Greece, Germany, Hungary, Iceland, Ireland, Israel, Italy, Kosovo, Latvia, Lithuania, Montenegro, Netherlands, Poland, Portugal, Republic of Macedonia, Romania, Russia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Ukraine. It was the first time that we had PH patients attending from Iceland and Montenegro (two young women); the Albanian PH community was represented by a young lady doctor from Tirana.

## Annual General Assembly

The APHEC was preceded, as always, by the Annual General Assembly (AGA). We had a very important topic on the agenda this year, the elections for the renewal of the PHA Europe Board, whose mandate will run from 19 September 2017 to 19 September 2019. There were eleven candidates from eleven different countries for the six positions of the Board and two for Auditors. Our new and very international Board members are: President Hans-Dieter Kulla (Germany), Vice President Ioanna Alissandratos (Greece), Treasurer Tuulia Nikulainen (Finland), Vice Treasurer Agnieszka Bartosiewicz (Poland), Secretary Danijela Pesic (Serbia) and Vice Secretary Tadeja Ravnik (Slovenia). Our two Auditors are Vittorio Vivencio (Italy) and Zdenka Bradac (Croatia). During the AGA we also voted on new membership applications and it was a pleasure to greet into our community a new PH association from Spain (HPE-Org) and from Russia (Help and Save), bringing our total number of members to 41 (*the Swiss association HTAP revive has since dissolved so the current number of members, as we go to print, is 40*).

During the AGA the financial report for 2016 was approved and the financial data for 2017 and projection for 2018 also discussed. PHA Europe has seen its overall budget reduced in the past two years so, in order to keep up our support programs and advocacy and awareness work at the current level, one of the key priorities for the future will be to diversify our sources of funding.

## Training workshops

After the AGA the conference itself got off to a start with four interactive workshops, each on different aspects that PHA

Europe considers vital for the empowerment of its member associations. The workshops were moderated by PHA Europe staff members, with different member associations sharing their experiences in the relevant fields. We were very happy to see that there was a high participation also from the audience, with lots of questions and lively discussions.

The first workshop was about patient training. In the current context, where patient representatives are increasingly called upon to take part in discussions on health care policy, it is essential that they have the knowledge and skills to be on a peer-to-peer level with health care professionals, payers, industry and other relevant stakeholders. In addition to training programs such as the EURORDIS Summer School for patient advocates and EUPATI, which are quite challenging in terms of time and energy and require travel for face-to-face meetings, a number of other, shorter, but very valuable online resources are now available, which also allow for - very useful - self testing. These include the European Patient Ambassador Program, the EUPATI "tool box" and the Eurordis e-learning program. It is also important that patient associations take part in any training programs which may be organised at national level: on this topic we had an interesting case study from Serbia and Croatia.

Our second workshop was on patient advocacy and here the underlying idea was to highlight the added value of taking part in the work of larger organisations in order to increase visibility and reach, eg. national patient organisations or rare disease alliances, and to collaborate more closely with professional societies and drug regulatory bodies. We had interesting examples from Bulgaria, Italy, Latvia, the Republic of Macedonia, Spain and the Ukraine.

The third workshop's focus was on cross-border collaboration and how it can prove very effective in achieving common objectives: examples included bilateral agreements, mentoring programs and regional groupings, with case studies from the Balcan region and Norway.

Our fourth and last workshop was about fundraising, a vital aspect for the sustainability of patient associations: about twenty different fundraising ideas were presented by our members from across Europe.

## Scientific session

This year, as a special tribute to the country which has been hosting our annual conference since 2010, we invited one of the leading Spanish PH experts in Europe, PH cardiologist Dr. Pilar Escribano, from the 12 de Octubre Hospital in Madrid. Her presentation opened on the genetic aspects of PH. She stated that the discovery of new genes related to PH has been one of the most important developments of past years and that all centers should all be able to offer genetic screening. She went on to speak of the multi-parameter risk assessment evaluation system introduced by the latest clinical guide-











lines and the importance of regular assessments to monitor disease progression: evidence shows that survival correlates with risk assessment. Unfortunately, patients are still being diagnosed very late. According to a Swedish registry, only 23% are diagnosed when they are in functional class II, whereas 67% are already at “medium” risk level and 10% at “high risk” level. There is a need to push for earlier diagnosis and the future is in more aggressive treatment strategies. The AMBITION study has shown that initial double combination treatment strategy can give better results than monotherapy. But, according to the COMPERA registry, currently in Europe 78.3% of patients are on monotherapy, 18.4% are on two drugs and only 3% are on three. The clinical guidelines suggest triple upfront with prostanoids for “high risk” patients and French researchers are already having very positive results in studies with this treatment strategy. It will be interesting to see the results of the TRITON study on triple oral therapy with prostanoids. In the second part of her presentation Dr Escubano talked about CTEPH, which she says is a highly undiagnosed disease. A certain percentage of patients who have survived pulmonary embolism can develop it (2-4%) and these patients should be screened if they develop symptoms. Pulmonary endarterectomy (PEA) is the elective surgery and there is great hope for pulmonary angioplasty (over 5.000 procedures carried out up to now in the world). Riociguat, an oral treatment, has been approved for CTEPH (non operable and residual post PEA, and studies are ongoing with other molecules.

#### News from our industry partners

At the PH annual conference it was a great pleasure to welcome representatives of Actelion, Arena, Bayer, Bellerephon, Ferrer, GlaxoSmithKline, MSD and Pfizer, and to hear some of the latest developments with regards to treatments and medical devices, research pipelines and, in general, changes in the pharma environment. These are some of the recent developments they shared with us:

- a study is currently ongoing on upfront triple vs double combination therapy called TRITON (Actelion)
- a new and potent oral prostacyclin will shortly be entering a phase III clinical trial (Arena)
- a portable nitric oxide device is the object of a study (Bellerephon) and a new inhalation device for iloprost called Breelib has recently been developed (Bayer)
- a new patient self management app is being developed by GSK.
- agreements have been made between Bayer and MSD for the marketing of riociguat, and between United Therapeutics and Ferrer for the distribution of treprostinil in Europe.

#### WPHD awards

One of the highlights of the conference was the WPHD 2017 Awards ceremony: this year the first prize went to PHA Ireland, for their amazing awareness and fundraising initiatives involving no less than the Irish Navy! Second and third prizes went to Austria and Serbia, respectively.

Pisana Ferrari





The European Reference Networks (ERNs) have been established to implement and facilitate the vision and objectives of Directive 2011/24/EU of the EUROPEAN PARLIAMENT and of the COUNCIL of 9 March 2011 on the application of patients' rights in cross-border healthcare. ERNs address the challenge of organising care for the thousands of heterogeneous rare conditions affecting scattered patient populations across Europe and provide for the first time a unique opportunity for clinicians to work across borders in Europe in healthcare. In order to make this possible, an appropriate technical background, standardized procedures, databases and operating systems had to be put in place. The ERNs were officially approved and registered as a legal entity in December 2016. The 24 approved ERNs bring together more than 300 hospitals and almost 1.000 healthcare units of expertise covering all major disease groups from 25 EU Member States plus Norway. All this could not have happened without the huge amount of work and collaboration of all the stakeholders in the rare disease field, including politicians, both at European and Member States' level, physicians and patient representatives. It is always interesting to witness when something new is coming into life. It is even more exciting when you can be an active part of this process and model it in a way which suits your needs and expectations in the best way: PHA Europe was honored to participate in the preparatory work of ERN-Lung, the European Reference Network for rare respiratory diseases. With the launch of the networks the work has not stopped, but continues at a different speed, as lots of materials, policies and procedures are to be delivered to the EUROPEAN COMMISSION. Each disease-specific ERN was free to decide its own structure, however it was a requirement that the patient perspective and interests had to be represented on a very

high level. PHA Europe contributed to the wording and drafting of the by-laws of ERN-Lung and in this way directly shaped the working structure for the coming years.

PHA Europe was privileged to have a delegate in the highest decision-making and operating body, the Medical Steering Committee (MSC). The MSC consists of the coordinator of the ERN, the coordinators of the core networks (see below), and two patient representatives - one of them is a PHA Europe delegate. The MSC takes the decisions in all the most

important questions: an intellectual property statement was finalized, upon our proposal; we submitted a position paper on the conflict of interest policy; and we gave our input in many other organizational questions such as the clarification of the supporting member status, overlapping issues with other ERNs, acceptance procedures for new patient representatives, new core networks, collaboration with the European Respiratory Society (ERS), applications to EU calls (eg. IT platform).

Each ERN has a Patient Advocacy Group (e-PAG), the aim of which is to integrate the patient view and feed it into the work of the MSC. It regularly hold both online and face to face meetings and in the beginning the work consisted mainly of deciding on the working method and the information flows. The main body of the ERN is structured as a matrix governance framework, which practically means that so called core networks are operating vertically by disease groups (eg. pulmonary hypertension, cystic fibrosis, PCD) and consist of health care providers (HCPs) accredited by the European Commission under a very strict and rigorous procedure. However, in order to cover cross-disease projects and issues some horizontal Functional Committees (FCs) have been established, which are the main point of interest of patient representatives. It is/was possible to nominate patient representatives to these committees and, thanks to this, PHA Europe is taking part in the work of the following FCs:

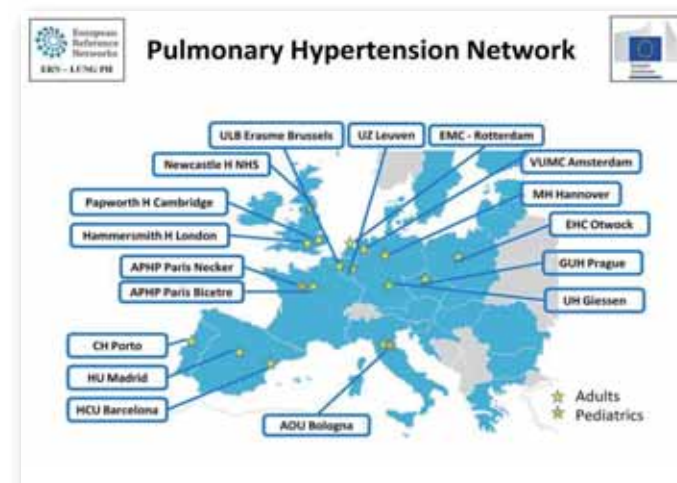
- Research and clinical trials.
- Ethical issues.
- Patient recorded outcomes (PRO) and quality of life (QoL).
- Communication and outreach.
- Professional training and continued medical education.

This year our main work was to be a co-author of the 5 year communication and dissemination plan, which is also deliverable to the EUROPEAN COMMISSION.

On top of the online meetings and work on different policies and deliverables, face to face meetings were also held:

## 1. ERN meeting in Vilnius

This was the third meeting, but it is considered the official kick-off meeting for the ERNs. All of the ERNs had had the possibility to provide a "who is who" introduction during the poster session. The main focus, however, was on the celebration of the launch of the ERNs. The ERN-Lung coordinator was not able to attend the ceremonial dinner with the representatives of the Member States and the Commission, and PHA Europe was asked to replace him and attend this important event. As part of the two-day meeting, we had the possibility to have a presentation on PHA Europe and generally about the activities of patient organizations, which was very well received by the MSC of ERN Lung.



## 2. Board Meeting in Frankfurt

This was also a two-day meeting, but specific to ERN-Lung. On the first day the representatives of the HCPs and other stakeholders were informed about the work of ERN-Lung. Other strategic questions and decisions were taken (eg. the nomination and decision on the invitation to the members of the e-PAG). On the second day disease specific consultations were held. The patient representatives had the possibility to meet in a separate session and share their opinions, views and expectations about ERN-Lung.

## 3. Medical Steering Committee and Patient Board meeting in Milan during the ERS congress

The yearly conference of the European Respiratory Society (ERS) is an excellent opportunity to meet as most of the key opinion leaders attend this congress. The MSC held its regular meeting and the most important topic was to discuss the collaboration between ERS and ERN-Lung. Thanks to Prof. Marc Humbert, vice-coordinator of ERN-Lung, a discussion has started between the parties. As a result, lectures on ERN-Lung related topics will be held during the next annual congress of the ERS in Paris, and, upon the proposal of PHA Europe, special patient-centric sessions will be also be organised. Communication and the involvement of patient representatives were the key questions of the e-PAG meeting, where we could welcome the delegates of the European Lung Foundation (ELF). We requested that all of the patient representatives should have access to the project management tool of ERN-Lung, Basecamp, and agreed that all of the information, which might be relevant to the patient representatives, but only shared on an MSC or FCs level, will be cascaded down. Prof. Thomas Wagner, coordinator of ERN-Lung, also attended the e-PAG meeting and was very satisfied with the work of the patient representatives.

## 4. Meeting in Rome on clinical guidelines

ERNs are primarily about care, which requires the development of clinical practice guidelines. The

Rome meeting focused on this particular aspect of ERNs and was organized by RD-ACTION and DG-SANTE on the 6th and 7th of December, at the Instituto Superiore di Sanità (ISS). The workshop united 63 participants representing 23 of the 24 ERNs. Although there are some examples of patient involvement in guidelines generation and dissemination, there are still gaps that need to be addressed through the promotion of increased patient engagement. Capacity building and replication of peers' success cases will be part of the reflection process within the networks. National impact will be challenging due to the different legislations (binding national legislation in Italy and France) and the disparity in access across EU countries. PHA Europe's goal as stated during the workshop is that not only knowledge will travel across countries, but also prescriptions must be recognized and provided by all Member States.

## 5. EURORDIS e-PAG face to face meeting in Paris

This meeting is an excellent example of peer-to-peer learning: patient representatives from 24 ERNs having important roles in their respective ERNs met in Paris for a one day workshop to share their experiences, views and best practices. The meeting had multiple goals: one of the most important was to learn how the patient representatives are involved in the work, what type of work and responsibility they have. The other was to look at the future and set strategy and goals, always bearing in mind that one of the most crucial objectives is to ensure that patient representatives are, and will always be, equal partners in any discussions with other stakeholders on the field.

We are looking forward to continuing our work in ERN-Lung and truly hope that patients will directly benefit from our efforts and will truly experience the value of ERN-Lung in the coming years.

Gergely Meszaros

### What are the ERNs?

ERNs are networks of centres of expertise and healthcare providers that are organised across borders so that clinicians and researchers can share expertise, knowledge and resources across the EU. ERN create a clear governance structure for knowledge sharing and care coordination across the EU to improve access to diagnosis and treatment, as well as the provision of high-quality healthcare for patients.

Source: EURORDIS

### Mission statement of ERN-Lung

The European reference network for rare diseases of the respiratory system (ERN-LUNG) has been established to develop innovative care models and improve cross border care for patients suffering from rare lung diseases. ERN-LUNG will develop and provide eHealth tools, will contribute to medical solutions and device development, and will offer services such as cross border health care for those affected by rare diseases of the Respiratory System. ERN-LUNG will boost research through large clinical studies and contribute to the development of new pharmaceuticals, and will lead to economies of scale and ensure a more efficient use of costly resources, which will have a positive impact on the sustainability of national healthcare systems, and for tens of thousands of patients in the EU suffering from rare and/or complex diseases and conditions





# CAPACITY BUILDING

## Eudonorgan and PH medical training

### Eudonorgan

EUDONORGAN is a 36 month service contract awarded by the European Commission from the European Union (EU) budget, on the initiative of the European Parliament, for “Training and Social Awareness to increase Organ Donation in the EU and Neighbouring Countries”. It is developed by an international consortium including universities and organizations from Spain, Slovenia, Croatia and Italy. The main objective of the course is to train health care professionals and other key actors who can in turn advocate for organ donation and train colleagues in their countries/regions/hospitals, with the overall objective to monitor and improve performance in the management of donated and transplanted organs. The program included 98 hours of training, of which 40 online and 58 face-to-face. The latter took part in Barcelona, Spain, from 18-22 September 2017.

Six representatives of PHA Europe’s member associations had the privilege of being accepted for the EUDONORGAN training program of which four actually attended: a young doctor from Bosnia & Herzegovina and three patients, respectively from Bulgaria, Hungary and Slovakia, two of which, from Hungary and Slovakia, had undergone lung transplant surgery. We have had great feedback from them and are extremely grateful to Melania Istrate for mentioning PHA Europe and thanking us in her article about EUDONORGAN which we are delighted to publish in this issue of our Mariposa Journal. Melanie Istrate is from the Donation and Transplantation Institute, DTI, Barcelona, Spain, which, together with the University of Barcelona, Bosch i Gimpera Foundation, led the first “package” of the program, “Train the Trainers”.

“The EUDONORGAN service contract (...) brings its first results! After dedicating the first 6 months of 2017 to the development of a unique and innovative training tool, EUDONORGAN implements its training program with exceptional results. Despite the summer holidays, we received 173

applications out of which 101 participants were selected, both health care professionals and other key players involved in the organ donation process. A total of 28 European countries were represented in the program (Austria, Belgium, Bulgaria, Bosnia & Herzegovina, Croatia, Cyprus, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Malta, Montenegro, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, The Netherlands, Turkey). Among them there were 51 medical doctors, 27 nurses, one medical student, eight patients and patient representatives (four of them transplant recipients), two journalists, eight communication experts mainly working for National Competent Authorities, two other representatives of national authorities or ministries, one manager of a health care establishment and one documentalist.

The challenging training program employed a blended learning methodology, by means of webinars, online (via WebApp) and face to face training, and amounted to a maximum of almost 100 study hours.

During the online training, a WebApp with different routes and scenarios was made available to our participants, according to their profile. Out of the total, 97 participants joined the face-to-face session, along with experts from six different countries: Croatia, France, Italy, Slovenia, Spain, The Netherlands. The program was highly evaluated and put the basis of a strong community of advocates in organ donation. In this regard, a EUDONORGAN Facebook group has been created where we continue to share common initiatives and future steps.

We want to acknowledge the EUROPEAN PARLIAMENT and the EUROPEAN COMMISSION for such a unique initiative, the project partners for the ongoing effort and last but not least the National Competent Authorities, PHA Europe (European Pulmonary Hypertension Association) and other collaborators for their valuable support during the selection pro-

cedure. Together we make a difference!”

We look forward to hearing news about the second package of the EUDONORGAN program, on “Social Awareness”, led by the Institute for Organ and Tissue Transplantation of the Republic of Slovenia, Slovenija-transplant, together with the Institute for Transplantation and Biomedicine, Ministry of Health of the Republic of Croatia, which aims at rising social awareness through six public events (e.g. awareness or information days, journalist workshops). These events will include information on deceased and living donation as well as on organ, tissue and cell donation. The 6 communication events will be promoted with the active support and contribution of the participants trained during the first work package. Each event will take place in different European Member State.

### PH medical training

PHA Europe has identified the training of physicians as a means to improve the situation of patients in countries with no or little access to medical/surgical facilities or targeted drugs. We are very proud to have been able to organise and secure

funding to support the training of ten physicians at the 12 de Octubre Hospital in Madrid in November 2017. The applicants came from Albania, Belarus, Bulgaria (2), Republic of Macedonia, Portugal, Serbia (2), Ukraine (2). The 12 de Octubre hospital is one of Europe’s top PH centres; it has a two-day training program on PH that has been successful in the capacity building of doctors from Latin America. It is particularly adapted to participants from countries where the conditions are not conducive for the proper management of PH patients. We had great feedback from the participants and hope to be able to support this program again in 2018.

Pisana Ferrari



# COLLABORATIVE EDUCATIONAL PROJECTS

## Time Matters, PAH Diary and Supporting young PAH adults

### Time Matters

“Time Matters when you have PH”. All PH patients and carers know this. PHA Europe ran a first Time Matters campaign (in 2011) and in 2017 we decided to run a second one. In the first campaign anyone could leave an entry on the web page answering some simple questions. This gave the campaign a nice personal touch. This time we tried to make it even more personal than before and our aim was also to use given themes to raise discussions and sharing of experience about the disease on social media. In this way, we hoped to both raise awareness about the disease and to support PH patients and carers in their struggle living with PH.

Four associations from the following countries were selected among several applicants to participate in the campaign: Portugal, Serbia, Austria and Israel. We decided that the most effective way to convey personal messages about living with PH was to have PH patients or carers to make short film clips about the given themes. The clips were made short (mostly around one minute) in order to make them suitable for sharing on social media. The four themes chosen were:

1. The time it takes for people to realize that you are ill.
2. How much more time is needed for daily tasks when you have PH?
3. How many times per day do you think of PH?
4. How long did it take to get the correct diagnosis?

#TIMEMATTERS - Subtitle overview								
	Theme 2		Theme 3		Theme 4		TOTAL	
	#	%	#	%	#	%	#	%
Subtitles English	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Portuguese	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Norwegian	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Czech	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Ukrainian	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Bosnian	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Spanish	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles German	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Croatian	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Macedonian	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Polish	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Hungarian	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Hebrew	10	100 %	9	100 %	9	100 %	28	100 %
Subtitles Serbian	10	100 %	8	89 %	9	100 %	27	96 %
Subtitles French	9	90 %	9	100 %	4	44 %	22	79 %
Subtitles Slovenia	10	100 %	9	100 %	0	0 %	19	68 %
Subtitle Swedish	10	100 %	0	0 %	0	0 %	10	36 %
Subtitles Latvian	3	30 %	2	22 %	4	44 %	9	32 %
Subtitles Danish	8	80 %	0	0 %	0	0 %	8	21 %
Subtitles Slovakian	8	80 %	0	0 %	0	0 %	8	21 %
Subtitles Italian	5	50 %	0	0 %	0	0 %	5	18 %
Subtitles Russian	0	0 %	0	0 %	0	0 %	0	0 %
Subtitles Dutch	0	0 %	0	0 %	0	0 %	0	0 %
Subtitles Bulgarian	0	0 %	0	0 %	0	0 %	0	0 %
Subtitles Finnish	0	0 %	0	0 %	0	0 %	0	0 %
Subtitles Greek	0	0 %	0	0 %	0	0 %	0	0 %
Subtitles Lithuanian	0	0 %	0	0 %	0	0 %	0	0 %
Subtitles Romanian	0	0 %	0	0 %	0	0 %	0	0 %
Subtitles Turkish	0	0 %	0	0 %	0	0 %	0	0 %
TOTAL	189	90 %	145	77 %	134	71 %	468	58 %







We also made sure to subtitle the videos in the language spoken. In this way we included hearing impaired viewers and viewers who, for whatever reason, could not view the video with sound (e.g. running the video in a work environment). In this way, the videos had a tremendous reach and were shared and commented an impressive amount of times.

Besides the subtitles, the main reason for the success of the videos was, of course, the content. The PH patients and carers talked about difficult subjects in a very open and honest way. This resulted in very touching stories and many viewers expressed that they were deeply touched by the videos. This created a lot of awareness for PH for those who were not familiar with the disease, and for patients and carers the videos reassured them that the experience of living with PH are very similar, even across country border. Here are some of the common experiences expressed by the patients and their carer. They all expressed how difficult it was to live with a chronic and serious disease when most of them looked healthy. This causes

friends and even family to underestimate the health situation of the patients. As a consequence, the patients expressed that they tended to isolate themselves. They also expressed that the disease was constantly on their mind. Rafi from Israel, for instance, said that even getting out of bed gets him breathless. So he is reminded of PH from the very moment that he wakes up. Carlo from Austria added in his video that he now needs at least twice as long to perform his everyday tasks. And Biljana from Serbia expressed that it was not possible for her to do many of the things she used to do before she got sick. Part of this is due to the fact that she is linked to an oxygen tank for 14 hours every day. The sad thing is that it seems like it took almost all the patients years to get their correct diagnosis. Graca from Portugal told the viewers that the doctors misdiagnosed her PH with depression. Unfortunately, this is not uncommon. After being treated for this for years, the doctors finally reached a correct diagnosis of PH after four years. This really shows the importance of creating awareness for the disease through campaigns like “Time Matters”. The end report showed that it was a very successful campaign. The videos had 22.284 views on PHA Europe’s Facebook page. Furthermore, they were shared 691 times! When including the views of the shared videos, the total view number was an impressive 336.776! The videos and blogs will be stored at PHA Europe’s home page so that they can be accessed by anyone interested also in the future. We believe that the themes chosen are timeless and they show that time really matters when you have PH.

Hall Skaara

*Time Matters is part of a collaborative educational project carried out with our industry partner Bayer.*



### Starting 2018 with the new PAHuman Diary!

- The diary is now spiral-bound, so that it can be laid flat and is easier to write in.
- The sharp edges of the pages have been rounded to help people living with scleroderma who may have digital ulcers.
- There is more free space for notes each day for people to write down their general thoughts and feelings.
- There is a new mood scale to make it easier for people to track and compare how they’re feeling each day.

### Supporting young adults living with pulmonary arterial hypertension (PAH)

Living with PAH can be tough when you’re just starting out in life and young adults living with the condition face a specific set of challenges. One PHA Europe member who is already leading the way in terms of successfully engaging young adults living with PAH, Danijela Pešić, President and founder of PHA Serbia, was heavily involved in advising on a recent report carried out by Actelion. Her foreword opens the report beautifully and a case study on PHA Serbia’s approach to attracting younger members showcases the importance of appealing to PH patients’ “fighting” spirit”. The report developed by Actelion explores the particular challenges of being a young adult living with PAH beyond the physical symptoms, and how clinicians and patient groups can better support them. Based on insights collated over the past 18 months from a number of young adults from Europe, the US and Canada, the report provides an explanation as to why young people are often more reluctant to join formal patient groups. It offers guidance on how to better embrace digital channels to provide tailored information on a wealth of issues affecting young people, such as choosing a career, achieving and maintaining independence and discussing more “embarrassing” topics like becoming sexually active. On Monday 27 November, PHA Europe and PH Serbia were excited to act as panellists in the first ever live Tweet Chat hosted by Actelion, to discuss issues affecting young adults living with PH and what could be done to better support them. The one hour live session provided a great opportunity to discuss issues affecting young adults living with PH and to engage social media users in a live dialogue with PH experts and young adults. The discussion was enriched by the presence of two other panellists: specialist clinician Luke Howard (UK) and patient representative, Serena Lawrence (Canada). The Tweet Chat gen-

- The timings of the day have been updated to AM/PM for a freer structure.
- The upfront section of the diary now includes the year-at-a-glance for all dates.
- There are two new bright front-cover colour options for 2018.
- Importantly, we have 53 new and inspiring quotes and tips from patients, family members, friends, carers, physicians and nurses

The diaries have been distributed to PHA Europe member associations. Four PH patients have shared their experience of using the diary; the videos have been uploaded on the PHA Europe YouTube channel at:

<https://www.youtube.com/user/PHAEUROPE>

*The PAHuman diary is part of a collaborative educational project to improve self management in PH patients carried out in collaboration with our industry partner Actelion and other relevant stakeholders.*

erated lots of valuable insights, with 26 active participants joining from 14 countries and regions across 4 continents. 100+ posts were shared, which had a potential audience reach of 45.645 and 119.300 impressions. A webinar organised on 14 December, provocatively entitled “Patient groups are only set up to support the over 30s”, the key speaker for which was Danijela Pesic, also provided interesting insights and useful ideas on how to better engage young adults with PAH in the future. Three young adults living with PAH, including Danijela Pesic, have also shared their thoughts, hopes and fears on video, see our YouTube channel at:

<https://www.youtube.com/user/PHAEUROPE>



*The Young Adults with PAH initiative is part of a collaborative educational project to improve self management in PH patients carried out in collaboration with our industry partner Actelion and other relevant stakeholders.*



## AUSTRIA

- Zoolauf (Zoo Run): 2.000 starters (max capacity) ran 6 km through the Vienna Zoo in the evening after the official closing time, with an after run party and an earning of € 28.000, -. It was the 6th time we held this event and we were sold out 2 months before the date.
- Mirnomore: one week sailing in Croatia together with 160 other sailing boats. Six young patients from Austria, Serbia and Bosnia and Herzegovina and our medical doctor Sulaima Albinni from the Vienna University Hospital (AKH) had the time of their life!
- Ghost Run: this was our 3rd Halloween Ghost Run in the Viennese amusement park Prater. We had a school class run, a family run and the main competition. We were happy to welcome many celebrities including former top model Carmen Kreuzer (Chanel), whose father passed away from PH.
- Direct Mind: with our fundraising agency Direct Mind we are planning to do a huge fundraising mailing for the Lung Kids project, which will be addressed to 20.000 households, as a test to see if we get donations. If we get a feedback of more than 3%, we will extend the fundraising mailing to 950.000 households. Please keep your fingers crossed
- Social Care Guide: we expanded and updated our social care guide, offering all necessary information about possible social care support for PH patients in Austria.



- Meetings: Info Day in Graz: 75 Patients attended very educational presentations under the medical lead of Prof. Horst Olschewski and many other PH specialists, as well as representatives from the Austrian authorities.
- Roundtable meetings for patients only! With no agenda, but with a nice lunch buffet - in Innsbruck and Vienna - with more than 20 patients attending each meeting.
- PH comedy theatre in Linz with more than 60 patients plus health care professionals. We had great fun!
- We celebrated 7 years of the Ludwig Boltzmann PH vascular research centre in Graz and Vienna.
- "Under Pressure" Science Lunch: over 100 medical students and health care professionals attended the session this year led by Prof. Horst Olschewski, during their lunch break. We offered them an organic lunch box and a free t-shirt. The health care professionals received CME points for their attendance. The session was broadcast live on Facebook and YouTube, watched by more than 160 live viewers. Even new patients joined our association because of it.
- Riesenrad Styling: for a whole day we turned one of the gondolas of the Vienna Riesenrad (Giant Ferris Wheel) into a hairdressing salon. A star coiffeur offered his art prior to the event on social media and on his website, as well as PH



- Austria's and the Vienna Prater website. For the press we invited well known celebrities including our Miss Austria and had a huge media attention. The earning was €3,700. --.
- Our donation of €15.000,- to the AKH Vienna enabled the

founding of the first pediatric gene database for PH patients.

Gerald Fischer, Selbsthilfegruppe Lungenhochdruck  
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## BELGIUM-VZW

**30.000 euros donation for PH research project**

VZW are proud to have been able to support this year an important PH research project; this is an extract from an article in a national Belgian newspaper:

*The Pulmonary Hypertension Belgium (Flanders) recently donated 30.000 euros to a research project by lung specialist Prof PhD. M. Delcroix, from the University of Leuven UZ. This amount was the result of various activities that were mainly organized within the framework of Music for Life (=an action of a Flemish radio program). The professor has been researching this condition for several decades.*

Earlier this year the members of the Board of VZW were together in a meeting. We had collected a piggy bank and wanted to use this money for the patients: all kinds of ideas came up, there are serious unmet needs among patients, for example, covering travel costs was one of the suggestions. At that time, Prof. M. Delcroix had serious problems: part of her research team was at risk of having to stop their research activities due to lack of financial resources. At our Board meeting the choice was made quickly and we decided to give the full budget to the professor and her team so that this research, which would

benefit all patients with pulmonary hypertension, could be continued.

Where did this money come from? Since the association was founded, in 2001, it has regularly received donations and funds from sporadic fundraising events. This revenue was necessary to keep the association running. Since 2013, some changes occurred in this respect. On the one hand, thanks to bigger sponsors who supported the association, we were able to save the "extra" amounts that came in through donations and promotions. On the other hand, this was also the first year that we registered as a charity for the "Warmest Week" of Studio Brussel. It all started with candy sales, which since then has been a regular feature of our yearly program of activities. Over the next few years, we saw an increase in activities, both during the Warmest week and beyond, with a constant income of around €10,000 per year since then!

Things are going well ... but we cannot rest! We must continue to keep the fire burning, so that people find us and are willing to commit to this good cause!

When Prof. Delcroix told us how difficult it is nowadays to raise funds for scientific work, we were amazed! It is outrageous that the pennies for this important scientific work, hopefully leading to the cure for this so far incurable disease, must





be collected by volunteers, patients, parents, family and friends. It is astounding that the optimization of research and the treatment of pulmonary hypertension to improve life expectancy and the quality of life of patients should depend on other parties, and on the proverbial pancake sales!

What about:

- The accreditation of the expert centers, which seems to be a joke due to the “two-track policy”, which seems to be specific to Belgium?
- The reimbursement of travel costs? The distance from the home to the best care center should not be a problem. Invoices for trips sometimes run sky-high. The Minister(s), the national health service ... they are silent.
- The reimbursement of medications and home care?
- The support and financing of the patient organization? Every player in healthcare recognizes its importance, but the pennies for support stay away.

We still have a lot to do as a patient association, not just for the money! In the meantime, we have saved the “small and big bits”, so that we could at least help to support this research project. Not only because it is related to Prof. Delcroix, who is close to our association, but because we, and all our patients, are convinced of the importance of scientific research. Every patient hopes that there will be a day that brings a cure for this disease, which has an immense impact on the daily life of the patient and his environment.

#### PH Belgium on tour with a “new” project

For a long time the association has become aware of the fact that it is difficult to “get people out of their seats”. Research shows that our members are getting older. The average age is about 65 years, a lot older than in 2001 (= the start of the association in Flanders). So we thought “If the people do not come to us, we go to the people”: we now go to all the Belgian provinces to reach out to them. The results are overwhelming. Halfway through our “PAH on tour” we have already reached more people than those who attend our classic annual meeting. Various speakers are present at the meetings. One of them was a pretty innovative one for our members ... Read what Lode

Claes, a physiotherapist from Leuven, has to say: Whereas in the past physical exercise was considered incompatible with pulmonary hypertension, new data from German clinical trials on exercise in PH has shown encouraging results. In order to break the vicious circle of lung, heart and muscle problems, according to recent insights, it is better to “maintain the movement” than “to stay put and keep very calm”. After all, shortness of breath reduces movement which in turn reduces muscle strength. The latter is also the cause of shortness of breath so the circle is round. The goal of rehabilitation is to increase exercise capacity, which in turn increases the quality of life and hopefully increases the long-term survival (this is yet to be proven).

A German clinical trial, started in 2006, showed that rehabilitation improves the exercise tolerance. In 2009 this was confirmed but nuanced by the knowledge that no efforts should be made that (could) trigger (disease) symptoms. In 2013, this concept was broadened with the knowledge that rehabilitation can be effective but also safe and, in 2016, a cautious study was initiated to prove that rehabilitation could actually reduce the disease. In 2017, it can be argued that specialist rehabilitation can be safe and efficient.

Currently, the rehabilitation test program in Belgium, which is part of the study, consists of: 1. screening with a test battery and 2. a four-week training program (of which two weeks hospitalized at the UZ in Leuven and two weeks of day hospital, three times a week). The tests consist of cycling, muscle strength exercises, guided walking and relaxation exercises, all held within an individual training program, according to each patient's specific capabilities. Ultimately there are 11 weeks of training at home with bicycles and an ergometer, keeping in close and regular contact with the hospital.

All this is quite new and the results of the study need to be confirmed. In addition, after positive confirmation, the aim is to extend the exercise program to all patients with PH. A big difference in any case with the advice that was given in the past!

Wim Colle,

President Patiëntenvereniging Pulmonale Hypertensie vzw  
[www.ph-vzw.be](http://www.ph-vzw.be) - <https://www.facebook.com/PHBelgium>



## BOSNIA AND HERZEGOVINA

#### Raising the profile of PH in Bosnia and Herzegovina

The condition of patients with PH in Bosnia and Herzegovina continues to be very serious and it is difficult to change anything. Patients are completely marginalized in our country. We do not have a patient registry or a specialized medical center or specialized doctors for pulmonary hypertension. There is no possibility for organ transplant either in our country or outside of our country because we are not a member of EUROTRANSPLANT. Most patients have no reimbursement for medications and therefore must buy them at very high prices. In such a situation, it is very difficult to work on improving the position of patients and our association is constantly faced with the lack of interest, the lack of understanding and the ignorance of those who could and should help us - the competent ministries. Despite these facts, the association is very active in raising awareness for the disease. A number of activities which we have carried out in the course of the year have succeeded in raising attention for pulmonary hypertension and have pointed out the difficult position of patients. We have worked in cooperation with the media and with other associations which are also struggling for a better position for their patients in the country as well as with sports clubs who are very happy to work together to raise awareness for pulmonary hypertension (eg. for World PH Day) and with artists. We have participated in EURORDIS projects, in the EUDONORGAN training program for organ donation advocates, organized under the supervision of the European Commission, as well as with PHA Europe and Lungenhochdruck Austria in the “Mimomore” project. We have also been working with the Bosnia and Herzegovina association for dialysis and transplantation to raise awareness about the importance of organ donation and signing donor cards. All these activities have contributed to increasing the number of new members. We thank all those who helped us in the course of the year to raise awareness of pulmonary hypertension, especially our sportsmen, climbers, disabled volleyball players and journalists.

Vera Hodžić, Udruženje građana oboljelih  
od plućne hipertenzije “DAH” - u Bosni i Hercegovini  
[ugphbih@gmail.com](mailto:ugphbih@gmail.com)







## BULGARIA-BSPPH

### Pongo, the rare purple elephant, on tour in Bulgaria

A message of love, courage and acceptance of diversity was delivered by “Pongo”, the rare purple elephant, in his first official introduction to the Bulgarian public. The Bulgarian version of the original Greek book with Pongo’s story was presented on the Bulgarian Day of Education and Culture - 24 May, this year, in the literary club “Peroto”, housed in the National Palace of Culture. The publication première was organized by the Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH). The “medical clowns” Dr. Kuku and Dr. Pipi performed a play of Pongo’s story and the children drew him as they imagined him. “Pongo” in the only children’s book in the world so far to be dedicated to the rare disease pulmonary arterial hypertension. It tells the story of little Eleni, who suffers from pulmonary arterial hypertension and is scared of the oxygen mask she constantly needs to live with. The story is intended for children between 4 and 12 years old. The book won’t be sold; it will be handed out for free by the BSPPH. The first copies were given to the Children’s Cardiology Clinic in the National Cardiology Hospital.

The creator of the unique purple character is Ioanna Alissandrato, the President of the Greek PH Association, who arrived in Bulgaria especially for the première. Pongo has only one nostril and has problems breathing as a result. “You might not meet Pongo the purple elephant in the jungle, or in the circus! This “different” elephant represents each patient with pulmonary arterial hypertension. For sure in your life you will meet at least one of them, who will transform their difference into an advantage,” said the author. The book was translated into Bulgarian by Natalia Maeva, President of BSPPH. Thus two patients with pulmonary arterial hypertension were united, across borders, in the name of the PH cause, to speak about pulmonary hypertension in newborns, which in most cases is treatable. “At all levels of education teachers speak to children about religious and cultural diversity, but no one speaks about the diversity in bodily differences. For this reason the BSPPH undertook this ambitious project,” said Natalia Maeva. She thanked the pharmaceutical company GSK for their support in publishing the book in Bulgaria. Among the guests at the book’s presentation was Dr. Pana-

giotis Kariofillis, interventional cardiologist and medical coordinator for pulmonary hypertension at the “Onassis” Cardiology center, Greece, one of the leading specialists in Europe in Balloon Pulmonary Angioplasty (BPA). Pongo’s tour will continue in 2018 in other Bulgarian cities Plovdiv, Varna, Pazardzhik and Burgas.

### “Together at school with the purple elephant Pongo”

Dozens of children and their parents celebrated the beginning of the school year in In Vitro Dimitrov Center on September 16th. The special event was for the children born and grown under the care of physicians and nurses from this medical center. The story of Pongo was presented during this event. The founder of the In vitro center, Dr. Josif Dimitrov, personally greeted the children and gave them many presents.

### The Sixth National Congress of Patients’ Organization in Bulgaria

The representative of the European Commission from the Directorate-General “Health and Safety of Food”, Mr. Philip Domansky was a special guest at the opening of the largest patient organisations’ forum - the Sixth National Congress of the National Patients’ Organization, which took place on 29-30 June 2017 in Sofia, Bulgaria. The congress was on “Universal Access to Health” in the context of the Health Campaign launched by the European Patient Forum and the UN Long-Term Sustainable Development Goals. On June 30, 2017, during the Annual General Meeting of National Patients’ Organization, Dr. Stanimir Hasardzhiev was confirmed as Chairman of the Management Board, and two new Board members were elected - Natalia Maeva, President of the BSPPH, and Bilyana Petkova, chairman of the Multiple Sclerosis Bulgaria Foundation.

Natalia Maeva, Bulgarian Society of Patients  
with Pulmonary Hypertension - BSPPH  
[www.bspph.net](http://www.bspph.net)  
[www.facebook.com/BSPPH.Bulgaria?ref=hl](https://www.facebook.com/BSPPH.Bulgaria?ref=hl)







## BULGARIA-PHA

### 6th National PH conference and 2nd second Balkan leaders meeting

The sixth National Conference on Pulmonary Hypertension and second Balkan PH leaders meeting was held in the town of Hissarya, Bulgaria, from the 6th to 8th of October, in the Augusta SPA Hotel. A rare diseases training course for medical students was held in parallel to the conference, as in past years. There were almost 150 participants, including 50 patients, 14 international guests and over 90 medical students.

For the second consecutive year, the conference, which was organized together with the National Alliance of People with Rare Diseases, included guests from nearby countries. More than 50 patients with pulmonary hypertension and their relatives, as well as representatives of PH-related organizations from Romania, Republic of Macedonia, Albania, Slovenia, Kosovo, Lithuania, Russia and Moldova, gathered at the Augusta Hotel in the town of Hissarya. The representatives of these organizations shared their experience in treating the disease in their countries and the level they each reached in these areas. This year the sessions for patients were mostly about psychological support. Patients and their loved ones had the opportunity



to participate in a workshop on art therapy, to help solve psychosomatic problems through finger painting, to learn useful yoga techniques for breathing and meditation, to talk about faith and what is happening to us, and to participate in discussion on PAH and nutrition. The attendees heard a lecture on one of the forms of PH - chronic thromboembolic pulmonary hypertension, days after the first patients with CTEPH were operated in a Bulgarian hospital. Great interest was raised by the discussion with a lawyer who presented the rights and obligations of patients. The conference ended with the release of china lights in the sky above the town of Hissarya with wishes for health and many other meetings with friends.

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

### Croatia, Slovenia and Serbia together for the PH cause

On the 17th of September, the Croatian PH association joined forces with other PH patient associations for a big event to raise awareness of pulmonary hypertension. The PH associations from Croatia, Serbia and Slovenia put together a unique international team of athletes to take part in the Pula Ironman 70.3. Ironman is considered to be one of the most challenging races in the world. The "70.3" refers to the total distance in miles (113.0 km) covered in the race, consisting of a 1.2-mile (1.9 km) swim, a 56-mile (90 km) bike ride, and a 13.1-mile (21.1 km) run. The "United Pulmonary Hypertension Team", was composed of 11 competitors/triathletes: three from Slovenia, seven from Croatia and one from Serbia. They took part in the race wearing specially PH branded triathlon suits to raise awareness of pulmonary hypertension and in particular of the importance of early diagnosis and initiation of treatment. This is a very big problem as many countries in Balkans do not have sufficient or adequate access to available therapies.

Branka Fresl and Zdenka Bradač,

Plava Krila, Udruga pacijenata oboljelih od plućne hipertenzije

<http://www.plavakrila.hr/> - <http://bit.ly/2hN2aQK>





## CZECH REPUBLIC

### Meeting of patient organizations with rare diseases

In May our association was invited to the meeting of Czech associations for patients with rare diseases. This year we discussed the European reference centers (ERN's), research, development and palliative care.

### SUKL conference

In June we were invited to the Czech Institute of Drug Control for a conference and discussion, where many other patient organizations participated as well. The biggest discussion was about the electronic prescription of medicines, which will be implemented in the Czech Republic from 1.1.2018.

### Cafe

This year we decided to give more support to our patients from different regions and get closer to them. Every three months we will organize meetings in a Cafe with patients and physicians in different locations in the Czech Republic-Bohemia and Moravia. We will work on a better collaboration between patients and their families, establishing friendships and sharing experiences about daily lives of patients with the diagnosis.

### How to talk to a doctor

This year, the first two members of our association joined the psychological training course to improve communication with doctors. If we get positive feedback from the course, we will try to organize the training for the other members as well.

### Recondition stay in Pod brady

As every year, the second Sunday in August marks the starting day of our Reconditioning stay in Poděbrady. This is a one-week long stay in a spa town 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. For next year we are planning to include psychological relaxation and individual psychological support for our patients.

### Patients meeting in IKEM

This year we started to cooperate more with the PH centers. We participated in a meeting for patients from the IKEM (the Institute for Clinical and Experimental Medicine) centre in Prague and made a presentation about our goals and work. Before the end of the year we would like to organize the same meeting in the third PH centre in the Czech Republic.

### Patient Council of the Ministry of Health

In September we supported a friend from the Czech Rare Disease Association to be nominated as member of the Patient Council of the Ministry of Health. On October 6, 2017, the Czech Rare Disease Association handed down the appointment decree to the new Patient Council of the Minister of Health. We are very pleased to be able to represent and defend our interests in this Council.

### Annual Assembly in Prague

The General Annual Meeting of our association was held in Prague on the 21th of October 2017. During the meeting we took some basic important steps that national law dictates, we had presentations to educate our members and discussions about patient needs. This year the invitation to participate in the Annual Assembly was accepted not only by our patron Sabina Laurinova, but by three main PH experts, Iveta Makovnikova (President of the Slovak PH association), with

their psychologist Pavla Notová, our physiotherapist Katka Spilková, and phytotherapist Landa, MD.

### New brochure and leaflets for patients and carer

This year we also prepared a new brochure and leaflets for patients, carers and physicians. The brochures contain information on pulmonary hypertension and its treatment. The

leaflets contain a brief description of the disease and contacts and an application form for new patients wishing to join the association.

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



### First year of the Estonian Pulmonary Hypertension Association (PHA)

The second meeting of PH patients in Estonia took place on the 11th of December 2016. The Estonian PHA was established on the same day, in Tallinn. There were ten founding members: seven patients, two doctors and one nurse. During the previous months the statute was drafted, discussed and accepted. The aims of the associations are formulated as follows:

- to raise awareness about PH,
- to improve access to modern PH treatment in Estonia (also to make PH drugs more readily available in Estonia),
- to provide psychosocial support to patients with PH and to their family and friends.

The association was officially registered on the 15th of March 2017. The Board consists of three members.

In following months the association logo was designed. Currently we are working on the web page for the association. Our first event took place at the "Kliinik 2017" conference which was held in Tartu (30.1-1.2.2017). This is the biggest annual meeting of healthcare specialists in Estonia. More



than 800 family physicians and specialists came together. There was a special section devoted to pulmonary hypertension. Elena Revyakina spoke very openly about how difficult it was to get to the right diagnosis. Jaak Nerut presented

the newly created Estonian patient association. Four doctors (Prof. Alan Altraja, Kaija Tammekivi, Ly Anton and Sulev Meriste) covered different aspects of PH. Four out of six speakers were members of the Estonian PHA.

In June Jaak Nerut participated the international workshop of Eastern European PH patient organisations (15.-18.06.17), in Vilnius, held by the Lithuanian PHA. He gave a presentation about the current state of PH treatments in Estonia and about the activities of the Estonian PHA.

Jaak Nerut  
Eesti Pulmonaalhüpertensiooni Ühing







## FRANCE

### HTaPFrance on the top of Europe

2017 has been a busy year for HTaPFrance, its volunteers and salaried staff.

After 20 years of existence, HTaPFrance took a very important step and has hired a social worker (8 hours/week). We have established a working group dedicated to social issues. This group consists of four members, two salaried and two volunteers, and is directed by Mélanie Gallant-Dewavrin (CEO). We held our General Assembly in March, in Paris. More than 100 members participated and had then the great opportunity to attend the presentations from our top experts (Prof.s Marc Humbert, Olivier Sitbon, David Montani, Dr.s Xavier Jaïs, Barbara Girerd, and Marie-Camille Chaumais) on varied topics like PH and pregnancy, treatment strategies, exercise and PH, genetics, ERNs, etc.

A regional meeting took place in the region of Champagne (East of France), where a cardiologist and an internist from the PH expert centre of Reims talked about PH and research and about the guidelines for general management.

A nurse and a cardiologist were involved in the WEEF (week-end for families with PH-kids) that was organised in the region of Dordogne (south-west of France) last autumn.

More than 15 Cafés HTaP have been organised by our volunteers, bringing together about 150 patients, family members,

carers and friends all over France. A Café HTaP is a simple meeting in a café where people can talk together about the disease, about their everyday life, far away from the doctors and the hospitals. Some of our volunteers and our salaried secretary took part in training programs provided by Alliance Maladies Rares in order to improve their competences in relations with patients.

This hard work has led HTaPFrance to the top, to the top of Europe! Hervé Davy and Pat Balard are lifeguards. After Hervé's mother passing away due to PH, they decided to raise awareness and set themselves an incredible challenge: climbing on the top of the Mont Blanc and coming down again, without even sleeping. And they did it! Our heroes needed 22 hours to accomplish their amazing feat. Congratulations and thank you! All the proceeds of this event will be donated to the INSERM research unit directed by Prof. Marc Humbert.



Laure Rosé, HTaPFrance

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

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



## GERMANY

### PH patient meeting 2017

The 20th meeting of the German PH association ph e.v. took place in Rheinstetten-Frankfurt am Main from October the 20th to 23rd. The association advises and supports patients and their families, promotes medical research and conducts public relations work in order to raise the profile of PH with the medical profession and the general public. More than 200 participants, including patients, relatives and other interested parties, arrived from all over Germany to learn about current developments in diagnostics and treatments as well as to exchange personal experiences and establish new contacts. Numerous lectures and workshops in the course of the meeting showed that research and treatment of PH are making steady progress.

### Annual PH Journalist Award

For 2017 a large number of applications of high quality were received, so that the decision was not easy for the jury. The prize, consisting of 3.000 euros, went to Pamela Dörhöfer for her article "When even the smallest step becomes torment", published in August this year in the Frankfurter Rundschau. In the paper, the freelance editor, who is responsible for the scientific side of the Frankfurter Rundschau, is dedicated to chronic thromboembolic pulmonary hypertension (CTEPH), one of the forms of severe PH. In a detailed and vivid style the author touches on clinical aspects and treatment options and describes her encounter with a person affected by PH. Hans-Dieter Kulla, Chairman of ph e.v., in his speech commended the high informative value of the article and its capacity to



reach a broad audience. Pamela Dörhöfer thanked her interlocutors, the PH patient for her openness and trust as well as the physicians Prof. Ardeschir Ghofrani and Dr. Christoph Wiedenroth, from the Kerckhoff Clinic in Bad the detailed and understandable explanations they had given her.

### Diagnosis and therapy - the sooner, the better

Education about pulmonary hypertension is vitally important as disease outcomes depend on early diagnosis and initiation of treatment. Pulmonary hypertension is progressive and can lead to death if left untreated. Often, however, the disease begins slowly with nonspecific symptoms such as tiredness, fatigue and shortness of breath during exercise. Pulmonary hypertension affects the lungs and the heart. The blood vessels of the lungs are narrowed, and the blood pressure in the pulmonary circulation - from the heart to the lungs and back again - is increased abnormally. This leads to a circulatory disorder of the lungs, to a deteriorated oxygen uptake and to an increasing overload of the right ventricle up to the heart failure. Pulmonary hypertension can have various causes.

The current clinical classification of pulmonary hypertension distinguishes five groups: 1. Pulmonary arterial hypertension (PAH); 2. Pulmonary hypertension due to left heart disease; 3. Pulmonary hypertension due to lung disease and/or hypoxia; 4. Chronic thromboembolic pulmonary hypertension (CTEPH) and other pulmonary artery obstructions; 5. Pulmonary hypertension with unclear and/or multifactorial mechanism. The first group includes, among others, idiopathic PAH, whose cause is by definition unknown, hereditary, ie hereditary PAH, and PAH caused by medications, such as certain appetite suppressants, or by toxins.

A total of eleven drugs are currently available in Germany for the treatment of PAH: the endothelin receptor antagonists ambrisentan, bosentan and macitentan, the phosphodiesterase 5 inhibitors sildenafil and tadalafil, the sGC (soluble guanylate cyclase) stimulator riociguat, the prostacyclin analogs epoprostenol, Iloprost and treprostinil, as well as the prostacyclin receptor agonist selexipag.





**Treatment according to individual risk stratification**

Prof. Ekkehard Grünig, Head of the Center for Pulmonary Hypertension in the Thorax Clinic of the Heidelberg University Hospital, reported the guidelines now also include a so-called risk stratification: after a detailed examination, patients are classified as having “low risk”, “intermediate risk” and “high risk”; this, too, is the focus of the treatment. In case of high risk, a lung transplantation should also be considered. Among other things, the researchers at the Center for Pulmonary Hypertension in Heidelberg are currently testing a prostacyclin receptor agonist that is inhalable and thus better tolerated. In his lecture, Prof. Grünig also emphasized the importance of doctor-patient communication. He called on patients to speak openly with their doctor about their concerns, for example about possible side effects of medication, as well as to doctors, to take their patients’ assessment seriously.

**Implantable pump for prostacyclin therapy**

Dr. Natascha Sommer, from the Medical Clinic II of the University Hospital in Giessenn, spoke about prostacyclin therapy by intravenous pump. Intravenous administration can lead to complications such as infection, pump failure, or catheter dislocation. Subcutaneous administration, ie administration under the skin, often results in pain at the site of application or other side effects. Fully implantable pumps exclude catheter infections and local side effects; their use is permitted if the patient is unable to cope with the subcutaneous application because, for example, the pain at the infusion site does not subside. In any case, since the implantation is expensive, the drug should first be administered subcutaneously.

**Anticoagulation: a plea for shared decision-making**

Prof. Horst Olschewski, Head of the Clinical Department of Pulmonology at the University Clinic for Internal Medicine Graz, discussed the complex topic of anticoagulation in PAH. The 2015 ESC/ERS guidelines recommends lifelong use of a drug for CTEPH patients to inhibit blood clotting. In PAH, however, the recommendation for anticoagulation is downgraded to “can be considered”. As Prof. Olschewski emphasized, however, the evidence is inadequate. The pathophysiological mechanisms in CTEPH and PAH are similar; studies show that anticoagulation also contributes to improved survival in PAH. “We absolutely must continue to research the topic in order to achieve a better data situation”, Prof. Olschewski demanded. He advocates shared decision making, meaning that the doctor and the patient decide together and on an equal footing. “That’s why it’s important that patients are well informed and able to have a say”.

**Oxygen therapy for better physical performance**

Dr. Mona Lichtblau, from the Clinic for Pulmonology of the University Hospital Zurich, in her lecture on oxygen therapy

said that oxygen promotes physical performance during exercise, during the day and at night. Particularly noteworthy are the improved breathing efficiency, the improved circulation of the brain and muscles as well as the reduction of sleep-related respiratory disorders.

**Donations to promote research**

A donation of €2000 was given by Actelion Pharmaceuticals Deutschland GmbH to ph e.v. at the patient meeting. The company had organized a quiz to draw attention to the topic of pulmonary hypertension and to collect donations. The action “Team PHenomenal Hope”, which was founded in the USA, also draws attention to the disease, shows its solidarity with those affected and recruits donations for research. Endurance athletes such as runners, cyclists and triathletes compete in this competition. Katrin Hetebrügge and Axel Schauf are involved as German ambassadors of the campaign. They know what it means to live with the disease - one of their two daughters suffers from PH. This year the “Team PHenomenal Hope Germany” organized a Germany bike tour from the hospital Neuwittelsbach in Munich to the University hospital in Hamburg-Eppendorf. In addition, the team took part again in the “Rad am Ring”, an extremely demanding 24-hour cycle race at the Nürburgring. At the patient meeting, Axel Schauf reported on both actions and handed over a total of €3.500 euros to ph e.v. as a donation, of which €1.000 euros from the Sisters of Charity of St. Vincent de Paul, bearer of the hospital Neuwittelsbach. Hans-Dieter Kulla, Chairman of ph e.v., warmly thanked the association for all donations and was impressed by the athletes’ extraordinary commitment.

**Workshops and information exchange**

In addition to the scientific lectures various workshops were organised: here are some of the topics: Feldenkrais, Tai-Chi and Qigong, mental training and singing, legal questions and topics related to partnership and family.

Ph e.v. would like to thank Actelion Pharmaceuticals Germany GmbH, Bayer Vital GmbH, GlaxoSmithKline GmbH & Co. KG and MSD Sharp & Dohme GmbH as well as Continentale Betriebskrankenkasse, OMT GmbH & Co. KG and Philips GmbH Respiration. For the partial oxygen supply the association thanks the companies Linde Gas Therapeutics GmbH, VitalAire GmbH, Vivisol Deutschland GmbH and air-be-c Medizintechnik GmbH. A special thank you goes to Professor Ekkehard Grünig, who supported the design of the program and took over the moderation.

Sibylle Orgeldinger

Hans-Dieter Kulla, pulmonale hypertonie e.v.

[www.phev.de](http://www.phev.de)

<https://www.facebook.com/pages/Lungenhochdruck-Deutschland/386143468153378>



This year, as in past years, the Hellenic PH association organized a number of activities to raise awareness of pulmonary hypertension in the country.

**5th Clinical Seminar of PH and CTEPH**

Our association attended the 5th Clinical Seminar on Pulmonary Hypertension and Chronic Thromboembolic PH in Thessaloniki, where we also had the chance to organize a meeting for the patients and the caregivers of Northern Greece. Together we discussed some major issues, such as “Living longer with Pulmonary Hypertension”, “New data to monitor and address PH for patients and caregivers” and “Recording problems in the provinces”.

**Time Matters when you have PH**

The Hellenic PH association created a new specialized clinical seminar on “Time Matters When You Have PH”, addressed to doctors in the fields of medicine, pathology, cardiology, pulmonology, intensive care, as well as to the nursing staff. It was the first cycle of many clinical seminars that will continue all over Greece, with specialized speakers. Our goal is for the disease to be managed more efficiently in first line hospitals, health centers and clinics, since that is where patients are initially examined, and often precious time is wasted with incorrect diagnoses of the illness.

**Balloon atrial septostomy (BPA)**

We are extremely proud to announce, that after the well-developed training program structured by our organization for the training on the BPA procedure of two of our Cardiologists by Prof. Hiromi Matsubara, from Japan, we are having great success with the BPA procedures and patients are already being treated, including from abroad. We collected all the footage, interviews from the doctors and the patient as well

as part of the BPA sessions and other material and we created a documentary for this pioneering method which was launched on YTV and media.

**PH Guesthouse**

Another great achievement of this year was to secure the funding to equip our guesthouse with the necessary technological equipment and special machines that cover the needs of patients with pulmonary hypertension. It has been operating for two years, is in the center of Athens and is well-designed to accommodate up to ten people at the same time, offering overnight accommodation and all that is needed for patients with pulmonary hypertension and their caregivers. Under our Board's decision we permanently accommodate a patient's family as well any other patient from all over Greece when there is the need.

**“Women in Action for PH”**

In 2017 we held our annual Women in Action for PH” event, which also provided the occasion to celebrate five years of our work with representatives from all the public bodies, PH doctors, PH patients, volunteers, friends. Together we became one to commemorate the large proportion of women who suffer from PH in our country. The leading star in all of our events was Pongo the Rare Purple Elephant who always manages to raise interest for PH from people of all ages, in his own unique way!

Ioanna Alisandrato, PHA Greece

[www.hellenicpulmonaryhypertension.gr](http://www.hellenicpulmonaryhypertension.gr)

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







# HUNGARY

## Rare Disease Day 2017

This year we celebrated the 10th anniversary of Rare Disease Day organized by RIROSZ, the Hungarian Rare Disease Organization, together with 45 other patient organizations. This year for the first time the Rare Disease Expert Centre of the University of Debrecen and the Genetic Disorder and Rare Disease Working Group of the Academic Committee of Debrecen contributed to the event. The main topic was: "The active role of the patients in the research." We arranged the travel and accommodation for the members of our association to enable the participation in this high level event. The meeting of patients living with rare diseases gave the opportunity to discuss the situation and plans of the rare disease patients and we could also meet with physicians and nurses.

## World PH Day 2017

PHA Hungary celebrated WPHD on May 6. We conquered the second highest hill of Hungary, so called Csóványos.

## Annual General Assembly

Our yearly general assembly was held on May 23rd of 2017.

We took the opportunity to discuss with the Vice President of our association, Kristóf Karlócai MD, cardiologist, how to deal with the psychological problems of the patients.

## TV talk show

One of the commercial TV channels in Hungary provided us with the possibility in June to highlight the importance of early diagnosis of PAH in course of a morning talk show. Eszter Csabuda, President of the Hungarian association, and Olga Hajnalka Bálint MD, cardiologist, talked about the causes, symptoms and treatment possibilities of PAH as well as the support provided by patient associations.

## Sporting events

In July we participated in a cycling tour for PAH patients. Eszter Csabuda, President of the association, together with her friends raised the awareness of PAH in the historical center of Hungary, in the town of Szarvas and vicinity during a 4 day trip. We also continue raising awareness of PH with sports through our sport "Ambassadors". We participated in a couple of different sports events (trail running in the hills of Börzsöny,

Hungary, half-Ironman) and our athletes wore the "Get Breathless for PH" T-shirt to spread the word.

## 7th National Patient meeting

On the 28th of October we organized the 7th national patient meeting in Palace Stefánia, Budapest. We could see a very picturesque presentation by Andrea Péter, MD, Cardiology Clinic of Debrecen. She was the member of the international team who made the first ever balloon pulmonary angioplasty (BPA) surgery in Hungary, in Debrecen. Recordings were presented of surgery on two post lung embolism patients. Kristóf Karlócai, MD presented the new treatment options for PAH, which have resulted in the increase in life expectancy from 2,7 years to 7,5 years. For the time being even in Hungary acceptable treatment options are available in the university clinics. Áron Zoltán Vincziczki informed us about the medical treatments options covered by the National Health Insurance Fund. We could see that in the last 5 years the number of PAH patients has doubled in Hungary. Currently 599 PAH patients are receiving treatments. Csaba Máthé, PhD, informed the audience about the rehabilitation possibilities available in Hungary.

A report was presented by Dóra Erdélyi, member of our association, who participated this September in the EuDonOrgan training course in Barcelona. As Dóra passed the exam, she became a "Transplant Ambassador" and can give a helping hand to her patient fellows. Dóra also made a presentation about a long term survival guide, which was provided by PHA US. The Hungarian translation of the material will shortly be available for the Hungarian patients.

Eszter Csabuda, Tüdőér Egylet

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

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







## IRELAND

On Monday, 6th November two school friends had the pleasure of meeting again. They hadn't been in touch for almost 30 years. Both have had very different lives. One girl, Sonia O' Sullivan, became a world champion and an Olympian. Her achievements include: Four times Irish Olympian - Barcelona 1992: 4th place in 3000m, Atlanta 1996: 5000m finalist, Sydney 2000: Silver Medalist 5000m, Athens 2004: 5000m finalist. Current World record holder over 2000m, 5:25.36, Edinburgh 1994, three times World Champion, 1995, 5000m, 1998 World Cross Country long & short course, three times European Champion, 1994, 3000m, 1998 5000m & 10,000m, Twelve times All-Ireland Champion, currently holds ten Irish records in every distance from 1000m to half marathon, Dublin City Marathon Winner 2000.

The other girl, Christine Coakley, remained in Co Cork, where she lived and worked for many years. In November 2014 Christine was diagnosed with pulmonary arterial hypertension. While PAH has created a change in Christine's life, it most certainly has not dampened her spirits nor enthusiasm and she has thrown herself into our PH awareness campaign. It was Christine who introduced us to the members of the Irish Navy who performed the very successful Row-a-Thon for PH in July 2017.

Not one to rest on her laurels, Christine decided that she would contact her class mate Sonia to ask if she would help with our PH awareness campaign. She sent an email and wasn't sure if Sonia would have the time to respond. Christine explained all

about PH and our Get Breathless campaign. She also mentioned that November was awareness month for PH. Within hours, a response was received from Melbourne, Australia (where Sonia lives). She told Christine that by coincidence, she would be home for a few days in November and was delighted to be part of the awareness event. Sonia had read all about pulmonary hypertension and was very explicit when speaking about it.

The PH Association issued Press Releases to journalists and to local politicians. We were astounded with the response we received. We were given both national and local coverage. Three politicians attended the event in the Coral Leisure Centre in Cobh, Co Cork. They had never heard of Pulmonary Hypertension before and were very concerned about certain issues which patients endure. They would like to learn more about the condition and have vowed to help to make the lives of patients easier if they can. Consequently, the Pulmonary Hypertension Association has been invited to meet politicians in Government Buildings on Tuesday 13th February. Prof. Sean Gaine will make a presentation to 20 Members of our Government. Our Pulmonary Hypertension Clinical Nurse Specialists and some patients have also been invited to attend this very prestigious occasion. We will be very happy to update Mariposa News with outcomes of this meeting.

Regina Prenderville, PHA Ireland

[on.fb.me/1KaUHeN](https://on.fb.me/1KaUHeN)

<http://www.pulmonaryhypertension.ie/pha-ireland/>



## ISRAEL

The Israel Pulmonary Hypertension Association was established in 2000 in order to assist and support people suffering from the disease. The organization's objectives include advocacy, support for patients and raising social awareness. Our association is made up of patients from across the spectrum of ethnic and religious groups.

### Drug access

PH patients in Israel have access to all medications which are by government funding. The treatment that is not currently included in the government funding is Adempas (riociguat). The association is working hard to incorporate this medication in the list of available treatments.

### Portable oxygen concentrators

Our association has 25 portable oxygen concentrators which we rent out on a long term basis to patients. The concentrators are meant for patients who require oxygen 24 hours and allows them the freedom of movement and the ability to leave their homes. These concentrators are battery operated and can be conveniently charged in the car or wall socket. The rental of the concentrators costs the patient \$90 per month. Post expenses this generates an additional income for our association while providing a crucial service to our patients. The Israeli PH association has also made an agreement with the Israeli Cystic Fibrosis association to provide their patients with this service as well.

### Patient mini conferences

This year we started a new project focused on running several mini conferences at each of the patient clinics around the country. This enabled patients and doctors from each clinic to come to a more intimate conference, interact, learn and connect with each other and the association. The conferences take place at the PH Clinic itself, which makes it easier for the patients of that specific clinic to participate, and raises the motivation of the patients to come to the clinic where they are treated. This also creates a stronger cooperation between the medical staff of the specific clinic with the association. The aim is for the medical team in that clinic to be allied to the association and thereby refer new patients and issues that need to be dealt with, to the association. This year we held two of these conferences, in the center and in the south of Israel. We found that participation was much higher than expected and that we were introduced to many new patients.

### CTEPH

Surgery options are now available for CTEPH patients. This includes regular surgery for the removal of clots as well as the endoscopic procedure using balloons to open the arteries in the lungs. These procedures/surgeries are performed at the Tel HaShomer PH clinic.

Maayan Steele, Pulmonary Hypertension Association Israel

[www.phisrael.org.il](http://www.phisrael.org.il) - [http://on.fb.me/1bPDL5v](https://on.fb.me/1bPDL5v)







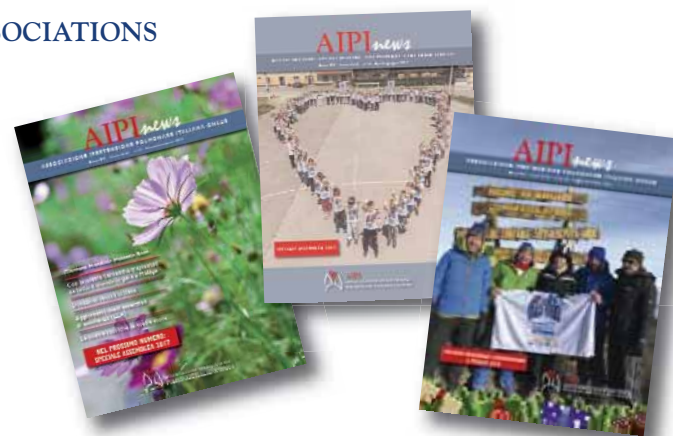
## ITALY-AIPI

**General Annual Assembly**

Over 100 patients, caregivers, family members and friends came from all over Italy for AIPI's annual general assembly which was held on the 26th of March in Bologna. In addition to the annual report of activities and approval of the budget, the meeting agenda featured a medical update by leading international PH specialist Prof. Nazzeno Galiè and on new Italian disability legislation by expert Mr. Adelmo Mattioli. The meeting was followed by nice lunch and lots of photos sessions, including one the participants doing the #GlobalWave4PH, and of all the lung transplant recipients with the official T shirt of the Italian Organ Donation campaign (see below). In the afternoon a very amusing performance by well-known Italian comedian Alessandro Serra and the annual lottery provided a nice ending to what a wonderful and happy day in the company of old and new friends.

**New services for patients**

Since last year AIPI is proud to be able to offer to its



members social support and legal counsel. Psychological support has been available for some years, care of a Bologna based psycho-therapist working pro bono for AIPI.

**Publications**

AIPI's quarterly magazine is the main showcase for AIPI activities and it always features reports of PHA Europe projects, check the cover with Croatia's lovely World PH Day photo with the children assembled in the shape of a heart.

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

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



## ITALY-AMIP

**How to reach as many PH patients as possible:  
a change of strategy**

AMIP's annual patients-doctor meeting has been a well established tradition since the first year of its foundation in the year 2000. We are aware that to be able to socialize among patients and exchange experiences is very important for everybody, even more so if the disease is rare! To have doctors that up-date you on PH research and developments and who are ready to answer all your questions is an invaluable gift. Yes, but how many patients can actually attend such meetings? We all know that to travel can be sometimes too difficult or impossible. We tried to help by offering one or two nights' stay in a hotel to those who came from far away but it wasn't enough. So we organized a streaming session during the doctors's conference. This was a success and we were able to reach many more patients, who were able to take an active part in the conference. But, not everybody has, or is able to use, a pc; moreover the "social" aspect of the gathering was lost. Patients would miss the "entertainment" and social part of

it: making new friends, laughing together, enjoying a good dinner in a pleasant place and the company of old and new friends: what a pity!

This year we tried out a new strategy: taking advantage of the fact that the Expert Centers represented by the doctors from our Scientific Committee are scattered along the entire Italian territory, we decided it would be AMIP to reach out to patients and not vice-versa. We organized a one-day meeting in each PH centre, with the precious help of the local PH doctors who invited the patients we did not know personally. Many patients were able to participate and we had dozens of new membership requests for the association. The cost was more or less the same: we had no hotels to pay and more meals to offer... We had to travel up and down the country to be there to welcome our friends but it was well worth it!

Vittorio Vivenzio, AMIP Italy  
[www.assoamip.net](http://www.assoamip.net)

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







## LATVIA

**NGO capacity building project**

In October PHA Latvia completed a Latvian government-funded NGO capacity building program. Thanks to this program we implemented 8 activities for 99 patients with PAH, their relatives, and specialists. During the seven months of the project the PHA Latvia team worked with professional NGO fundraising experts, with experts in advocacy, social work and PR. The fundraising expert wrote five projects for other grants, and PHA Latvia won three of them. The advocacy expert regularly monitored legislation changes in health and social sector, participated in the working group of the National Rare Diseases plan 2017-2020, analyzed data from sector, drew up 3 official PHA Latvia position papers about legislation changes. Our social work specialist gave patients support in PAH management and everyday life, organized an oxygen therapy program and worked as a consultant for patients' rights. There were 127 consultations and 45 patients got oxygen therapy support within the project framework. The PR specialist promoted awareness of PHA Latvia, wrote every day news and articles for the associations's web page, Twitter, and Facebook accounts and established a volunteer group of 13 medical students to help with PHA Latvia's activities. In July we had a Patient Education Workshop with 32 participants near lake Lilaste, 20 km from Riga. Patients and caregivers learned how to develop social service in an NGO framework and about everyday life with PH, patient rights, the Latvian Rare Disease Registry and with energy and joy also participated in the practical part of workshop-motivational event with a psychologist.

**Our delegates in conferences**

Ieva Plume, and Anda Pudane from PHA Latvia participated in an international seminar in Vilnius, Lithuania, which gathered the Presidents of the PH associations from Latvia, Lithuania, Estonia, Norway, Ukraine, Belarus, and Russia. Seminar delegates presented their association's activities in a very fruitful and active work atmosphere. Ieva Plume presented some ideas for collaboration between the Baltic countries and Ukraine with funding possibilities from the the Council of North Minister and the Latvian Ministry of Foreign affairs. Marta Augucevica, PHA Latvia fellow, attended the Annual PH European Conference 2017 in Castelldefels, Spain, where she represented our community and met people from all over Europe. This participation was very useful, Marta now has new connections with other PH communities and new inspiration for PR activities in Latvia.

**Booklet on physical exercise for PH patients**

PHA Latvia published a new educational resource with the financial support of the Riga Council, a 30 page booklet with quality photos and information about a home exercise program for PH patients, developed by PH physiotherapist Lina Butane. The booklet was launched at the end of November during a workshop and socializing event for patients.

Ieva Plume, PHA Latvia  
[www.phalatvia.lv/en/](http://www.phalatvia.lv/en/) - <https://www.facebook.com/phlatvia/>  
<https://twitter.com/phlatvia>



## LITHUANIA

**PH patient meeting**

The first patient meeting of the year was organised in February, in the context of International Rare Disease Day. We invited many organisations working in the field of disability: the Rare Disease Lithuanian foundation; the Center for the professional rehabilitation of disabled people; pharma company representatives and our dear doctors. It was warm friendly meeting, with useful and interesting discussions and much new information.

**World PH Day**

The next event was for World PH Day 2017. Our organisation's team created a big public action on the city centre's square. Citizens and guests enjoyed our free "oxygen bar" and received presents and brochures about the disease. Our team informed people about pulmonary hypertension while they were having oxygen cocktails. We took the opportunity of WPHD to also hold our annual assembly and patient meeting. It is a good tradition to celebrate WPHD with patients separately. This year it was not an ordinary celebration or meeting; we also held elections and elected new board members.

**International seminar**

Our second international meeting was organized in June in Vilnius, with representatives of the PH associations of Belarus, Estonia, Latvia, Lithuania, Russia and Ukraine. An observer from PHA Europe was invited: Hall Skaara, from Norway. All the participants shared the same language, periods of common history and the same disease. It was a great meeting!

**PH rehabilitation**

Many good things happened in the year for PH patients. The first one, and most important, is that rehabilitation for PH patients is now available. We did not have it until this year, it was reserved for people who had suffered from trauma or post surgery. It is thanks to our Board and our dear doctors that, together, we have achieved rehabilitation for patients. Now every patient can get three weeks of rehabilitation every year. The three weeks include sport classes, nutritional advice and medical consultation. It took two years but we finally made it!

**PHA Lithuania magazine**

PHA Lithuania edits a seasonal magazine for patients, which is called "Live and Breathe". The magazine has many good articles, which we translate from other languages to Lithuanian, for example from the PHA Europe website. Our team is very thankful to PHA Europe for the good information for patients. The magazine really helps not only patients who have had the disease a long time but also the newly diagnosed.

PHA Lithuania wishes good luck and a lot of health for all European patients for the new year!

Anastija Kovaliova,  
 Žmonių Sergančių Plautinė Hipertenzija Asociacija  
[www.phalithuania.eu](http://www.phalithuania.eu)







## THE NETHERLANDS

### Special day for Young Adults:

PHA Netherlands organised a special day for young adults in November 2017. We arranged a cooking workshop, guided by Chermaine Kwant. She is a dietician and a ex PH-patient (she had a lung transplant one year ago) and knows what kind of nutrients PH-patients need or which food they need to avoid.

Ten young people, between 17 and 35 years old, joined the workshop. They all learned a lot, not only about what kind of food is healthy, but also how to prepare it for the optimal taste. During breaks and lunch they also had time to talk to each other and share their experiences with PH. It was a very successful and day and more than worth repeating!

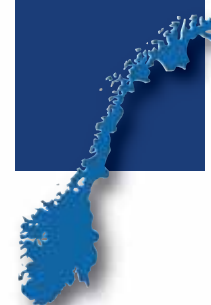
### November: Awareness Month for PH

November 2017 is the awareness month for pulmonary hypertension and therefore we planned an awareness campaign for

social media. We invited all patients to send a picture of themselves in the well known "Get breathless for PH" T-shirts and write a short story about the picture. We posted one picture and one story every day during the entire month of November. We managed to get a lot more followers and likes for our Facebook page. All the photos and stories have been shared by our followers, so a lot more people now know about PH. Mission accomplished!



Leny van der Steen, PHA-NL  
[www.pha-nl.nl](http://www.pha-nl.nl)



## NORWAY

### PAH forum

A PH conference called "PHA Forum" was held for the fifth year in a row in Oslo in November 2017. At the first conference, twelve health care professionals participated. The turnout this year was 80! PH doctors and nurses from all Scandinavia participated. Some great guest speakers were invited: Prof. Dr. Stephan Rosenkranz from Germany, Prof. Sean Gaine from Ireland and Dr. Konstantinos Dimopoulos from England. In addition to very informative and good lectures from these KOLs, patient cases were presented and discussed. PHA Norway had the honour of ending the conference by presenting the patient association and its offerings.

### PH rehabilitation

Feiringklinikken ran the PH rehabilitation program for the sixth year in a row in June at their clinic, beautifully situated by a lake which is one hour's drive north of Oslo. The rehab program has become very popular among the Norwegian PH patients, and many participate regularly every year.

There are several reasons why the rehab has proven to be a great success. First of all, PH patients learn what is considered safe exercise for them. Each patient is tested individually and receives an individually adapted training program. The key point seems to be that the physical training recommended is often much less vigorous than one should expect. Daily walks at a certain pace are often sufficient as excellent PH training.

Feiringklinikken offers much more than just physical training. During the 3-4 weeks stay, the participants are, for instance, trained in healthy cooking. They have a kitchen available and a chef helps them to prepare healthy food. They also have lectures by a psychologist. The topic is related to how to manage a chronic and serious disease.



Each participant fills out a questionnaire and, based on this, individual sessions with a therapist are offered. In addition, there are training and information sessions with doctors, social workers, lawyers, yoga instructors, etc. The offering at Feiringklinikken is, in other words, a complete psycho-social support offering. No wonder it is very popular among the PH patients! The entire stay is furthermore free of charge as it is covered by the residing counties of the patients.

A PH patient and a PH doctor from Ukraine (PH Urda) visited the rehab clinic for a few days as part of a memorandum between our two associations.

Hall Skåra, PHA Norway  
[www.pha-no.com](http://www.pha-no.com) - <http://on.fb.me/TDzyKI>







## POLAND

### International Rare Disease Day

On February 28 PHA Polska participated in the International Rare Diseases Day conference in Warsaw. Many patient organisations and Ministry of Health representatives took part in the event. PHA Polska was represented by Alicja Morze, PHA Polska's President, Agnieszka Bartosiewicz, Vice President and Iwonna Kamińska and Tomasz Kamiński, members of PHA Polska.

### PH Nurse Forum

On July 1 Agnieszka Bartosiewicz joined the 7th International PH Nurse Forum which took place in Warsaw. The meeting focused on three themes: collaboration within interdisciplinary teams; how to support patients with therapy and the challenges in treating different forms of PH. Real-world cases were presented by experts in the field of PH to provide insights on how situations encountered in daily clinical practice can be handled. The participants also discussed challenges arising in patient care such as contraception and pregnancy. The Forum was attended by 120 participants from 17 countries.

### Patient meetings

During 2017 PHA Poland organized three patient meetings in the cities of Gdansk (March), Lublin (April) and Poznan (September) with the cooperation of the local PH centers' experts. The meetings were a great occasion for both patients and their relatives and carers to talk about their problems and benefit from the presentations of the speakers, both doctors and patients.

### Ballon pulmonary angioplasty

On August 23 a Polish cardiologist team performed the world's first percutaneous balloon pulmonary angioplasty procedure using the HoloLens 3D imaging system and 3D digital printing. The surgery was performed by a team composed of Szymona Darocha, MD, PhD, Arkadiusz Pietrasik, MD, PhD, Marta Bataszkiewicz, MD, led by Prof. Marcin Kurzyna, from the Department of Pulmonary Circulation, Thromboembolic Diseases and Cardiology, Health Center Otwock, on a 67 year old patient with persistent chronic thromboembolic pulmonary hypertension after pulmonary endarterectomy.



### PHA Polska Cup

On October 12, one day before Conference of the Pulmonary Circulation Section of the Polish Cardiac Society, a third PHA Polska Cup football match took place in Wroclaw. The match was organized between two teams of doctors from the West and doctors from the East of Poland. The event attracted fans and supporters. Alicja Morze handed a beautiful PHA Polska Cup to the East Poland doctors' team who won the match with the result of 10:8.



### Polish Cardiac Society conference

7th Conference of Pulmonary Circulation Section of the Polish Cardiac Society took place on November 13 -14 in Wroclaw. The program of this year's conference was very interesting. During more than 40 lectures the participants discussed, among others, PAH treatment and CTEPH disease.

Alicja Morze, PHA Polska

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



## PORTUGAL

### Patient/caregiver meetings

On November 8th, the Janssen company invited our association to an educational session entitled "Clinical Research: decoding the process and the role of the patients". Several topics were covered, such as clinical trials (what they are and their importance for patients and society), patients' rights and responsibilities, the patient in the centre of clinical research and the testimony of EUPATI Portugal regarding their work in promoting patient involvement in research. Also, on



November 23rd, PH Portugal was represented at the workshop about the importance of literacy and the involvement of the citizens in the future of health, promoted by Janssen together





with the Portuguese Association for Hospital Development. We are establishing a close relation with Janssen and working together towards a development of a solid strategy envisioning the improvement of health literacy of PH patients. For this reason, it is becoming increasingly important for us to attend these meetings and workshops.

#### Awareness raising for CTEPH

Our association organised the second edition of a solidarity trail running that took place on November 19th. For those who couldn't run, there was a 7km walk! The event aimed not only to raise awareness of CTEPH but also to raise funds. About 400 participants were present at the event and 2.400 euros were raised! As last year, we had the presence of a Portuguese celebrity: Aurora Cunha, a retired long-distance runner. She represented our country in three consecutive Olympic Games. Cunha's greatest successes were in road running, at which she was a three-time World Champion. She also won several marathons during her career, including Paris, Tokyo, Chicago and Rotterdam. Beside the successful adhesion and the presence of a celebrity, we had the presence of several CTEPH patients, having one of them participated in the 7km walking. This made us proud! Several local authorities/entities were also present at the event: the Mayor, the Board of directors of a local Hospital, representatives of social solidarity institutions, schools, the International Red Cross and also a representative of Actelion Portugal. Regarding our involvement in CTEPH Day, a CTEPH patient was invited by a local radio station in order to give his testimony, to talk about his life as a patient and also to promote our CTEPH Day event. Also, the patient who participated in the Solidarity Walk for CTEPH was invited to do an interview for a TV channel. She will talk about the disease but mainly about the event.

Maria Joao Saraiva  
Associação Portuguesa de Hipertensão Pulmonar  
<https://www.facebook.com/associacaoportuguesaahiperten-saopulmonar/>



## REPUBLIC OF MACEDONIA



#### A busy year for our association

The PH association of the Republic of Macedonia is constantly at work thinking of ways to raise the awareness of the existence of rare diseases and pulmonary hypertension. A number of activities in different fields were organised in the course of the year, including the celebrations for World PH Day, which are summarised in the summer edition of Mariposa. We were fortunate to have the support of many different sports clubs, mountaineers, runners, media personalities who, each in their own way, gave us an important contribution.

#### Advocacy with health authorities

Our association, together with 30 other non-governmental associations working for rare disease patients and persons with special needs, participated in a working meeting at the invitation of the Minister of Health, in the premises of the Ministry of Health, where a discussion was opened on the inclusion of amendments to the Law on Health Care and the process of preparation of the regulations in the field of health care.

#### Unmet needs of patients

In this period, we developed a matrix "Building the Theory of Change", a letter highlighting the unmet needs of patients with PH, the problems and perceived causes of problems, what changes should be made to solve them and alleviating the patient's path from diagnosis to treatment and which activities to be undertaken. Together with the Alliance for Rare Diseases, initiatives and proposals for orphan drugs and orphan diseases are being made.

#### Mountaineering for PH

An expedition from the Republic of Macedonia brought our branded PH association flag to one of the highest peaks in the

country, "Mount Damavand" (5.609,2 m), in Iran. Mount Damavand is a stratovolcan, which is the highest peak in Iran and in the Middle East, and the highest volcano in Asia. All our admiration and respect goes to the young man who climbed, Risto, as well as to the young doctor and woman who managed to climb such a high peak.

We also had the support from our dear doctor, cardiologist Milev Ivan, who climbed almost every weekend the mountain peaks in Macedonia.

#### National PH Conference Bulgaria

We were invited and attended the PH conference organized by the President of PHA Bulgaria, Todor Mangarov. A special tribute was made to Todor and Gjurgica for their participation in the Skopje Marathon and for winning of the 5 km marathon (with Todor pushing Gjurgica's wheelchair the entire distance) in honor of the fight against this disease, a proof that everything is possible if you put your heart on it.

#### Special thanks

Ivica is a young man who supported our association for three years with various sporting feats, such as running marathons, climbing peaks, a really extreme sport, as well as the climbing of the Matka Canyon, in the Republic of Macedonia, where he very sadly lost his life. Below is a photo of Ivica three months before his death. Thank you, you will always remain in our hearts.

#### Visiting patients

We visited two patients with PH in Macedonia, Rosica, who has Scleroderma and PH and Mimi, who has Scleroderma, PH and Pulmonary Fibrosis. Experience and memories that remain.







### Challenges in access to drugs

Prof. Dr. Sofijanov, the initiator of the Center for Rare Diseases and an individual approach patients with a rare diseases, was a guest of the national Macedonian TV. Our association was at a meeting with government and there were interviews on national TVs aimed at raising awareness and taking concrete



steps to address the problem of drug shortages for Macedonian patients for more than 3 months. The struggle continues...

Gjurgica Kjaeva, President APH Moment Plus  
[www.phmomentplus.com.mk](http://www.phmomentplus.com.mk)  
<http://on.fb.me/1kUSn5x>



### Patient-doctor meetings

Russia is a very big country and in order to reach out to as many patients as possible it is necessary to organise conferences and patients meetings in different regions. Our first meeting was in Voronezh on the 8th of April. Doctors from the big regions of Russia were invited to join the patient meeting and they presented new and useful information about PH. Interesting discussions followed on treatment options, patient advocacy and plans for the future. The following meeting was organised in the Nizhnekamskaja region, the one with the biggest problems. Patients of this region remember the history of a little girl whose parents took legal action in 2014 against the government to get medicines for their daughter. The situation has not improved since then and eleven patients who are without treatment came to the meeting. Anton Shmalc, a surgeon from Moscow, attended and gave many individual consultations. The third event was organized in the Samarskaja region. Discussions centered on advocacy and treatment problems.

### European and national events

Our association participated in three European meetings and one local one: the Inter-



national seminar in Lithuania in June, the Annual PH Europe Conference in Spain in September and the Balkan conference in Bulgaria in October. The local one is the big Moscow Forum "Community" where rare diseases and new projects in Russia were discussed. We took part in many trainings and open discussion classes for all participants.

### Advocacy and new materials

Our organisation advocates and supports new patients to get medicines. In addition, we have created brochures and magazines about PH for patients and caregivers. PHA Russia "Help and Save" wishes good luck and a lot of health to all European patients!

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



## SERBIA

### Belgrade Ultra Marathon (12h running)

The Belgrade Ultramarathon lasted an incredible 12 hours, during which the racers were "inspired by hope" in supporting the struggle for the life of PH fighters. They all wore pulmonary hypertension T-shirts during the entire race. After 12 hours of running, the last one through the finish line was a woman who was 67 years old. She ran an amazing 69 km, while the first-placed runner ran an impressive 130 km. That night, all the ultramarathoners gathered around the Ultra Runner Serbia movement, "Inspired by Hope", which has run, in total, over 6.000 km and which has dedicated their race to pulmonary hypertension patients. Lots of love, emotion, hope and tears flooded that night's celebration in the Belgrade fortress.

### IRONMAN 70.3 Pula - United for PH

On the 17th of September we joined forces with other patient associations for a big event to raise awareness of pul-







monary hypertension. PH Serbia, together with the PH associations from Slovenia and Croatia, put together a unique international team of athletes to take part in the Pula Ironman 70.3. Ironman is considered to be one of the most challenging races in the world. The “70.3” refers to the total distance in miles (113.0 km) covered in the race, consisting of a 1.2-mile (1.9 km) swim, a 56-mile (90 km) bike ride, and a 13.1-mile (21.1 km) run. The “United Pulmonary Hypertension Team”, composed of 11 competitors/triathletes (three from Slovenia, seven from Croatia and one from Serbia), took part in the race, wearing specially PH branded triathlon suits, to raise awareness of pulmonary hypertension and in particular importance of early diagnosis and initiation of treatment. This is a very big problem as many countries in the Balkans do not have sufficient or adequate access to available therapies.

#### Position paper on PH treatment

We organized a major expert meeting attended by directors, professors and assistant professors from all six reference clinics where PAH patients are diagnosed and treated. The purpose of this kind of meeting was to prepare an official document, i.e. an expert opinion, on the need for earlier and more adequate treatment for patients with PAH and CTEPH, based on the official ESC/ERS clinical guidelines from 2015, allowing for use of combination therapy and for reimbursement from the state health service of organ transplant performed abroad, given that this surgery can not be performed in Serbia. After a very successful meeting, 15 of our best experts in the field of cardiology and pulmonology signed the document that thus became official and was submitted to the Republic of Serbia's Expert Commissions for Cardiology, Pulmology, to the Director of the Health Fund of the Republic of Serbia and the Minister of Health of the Republic of Serbia.

#### “Inspired by HOPE team” - A great victory, dedicated to all those suffering from PAH in the world

The team “Inspired by HOPE” has become popular and well-known not only in Serbia but also in rest of the world and has achieved, through its challenging physical feats, such as the three biggest ultramarathon races in the world in which it took part this year, in drawing attention to the existence of a rare and serious illness like PH. The third and last ultramarathon of the year 2017 took place October 8-14 in Brazil, in the heart of the Amazon forest, for the length of 254 km. Our runner and PH Ambassador Jovica Spajić (whom you had the opportunity to get to know and see on the front page of the Mariposa Journal summer edition), arrived first in the race after 36 hours of running and over 3 hours ahead of the second competitor. We had chosen this race, as all previous ones, very carefully. Namely, the race was held in the heart of the Amazon, in the last “lungs of the world”: in this way we wanted to highlight the problem of breathing and of the lack of oxygen with which PAH patients are faced. The race was being followed not only in Serbia but also in many parts of the world.

Also, the “Inspired by HOPE” team had an exceptional pro-

motion in Serbia. One of the biggest and most important chains of sports clothing stores in Serbia has become an official partner of our team. At the promotional event which was held in the newly opened GO Active store, our team was introduced and also its mission and plans for the future. More than 25 journalists from TV, newspapers and web portals were present at the event and over the next two days more than 50 articles about PH and the “Inspired by HOPE” team were published. We also received a very significant amount of space on national TV Central News during prime time.

#### Education for representatives of Rare Diseases Association

PH Serbia and Danijela Pešić, who is the Vice-President of the National Organization for Rare Diseases of Serbia, participated in the organization of the 3rd Regional education meeting for rare diseases and the second one being held in Serbia, which was also attended by associations from Slovenia, Croatia, Bosnia, Macedonia and Serbia.

The conference discussed very important and useful topics, such as :

1. Improvement of knowledge and understanding of rare diseases, orphan medicines, clinical trials, regulatory issues.
2. Strengthening the capacity of associations for rare diseases so that they become more powerful and more active
3. Sharing experiences and good practices with other countries
4. Improving cooperation among associations for rare diseases in the region

#### Project “Mimo more” (Calm Sea)

PH Serbia had the honor and the opportunity, thanks to PH Austria, to include in this really impressive and purposeful project two young patients who spent seven unforgettable days cruising on a sailboat on the Croatian coastline, with other young PH patients and top Austrian doctors and PAH experts. This exchange of experiences with people of similar age created unbreakable friendships, and is sure to have a positive influence on the further development and future of these young people. During the seven days with the doctors they also had the opportunity to find out everything they could about PAH and thus be far more prepared to continue their fight with this very powerful opponent.

#### Cocktail reception at the British Embassy

We had the honor of being invited by His Excellency, Mr. Denis Keefe, the British ambassador to Serbia. His Excellency showed interest in PH and in PH patients, he heard from us how difficult the situation with patients is in Serbia as well as in the rest of Europe. These are some of his words in the official press release: “Without a healthy society there is no development and improvement of economic potential.” What can we say, except that we are in complete agreement with his words.

Danijela Pešić, PHA Serbia

[www.facebook.com/plucnahipertenzija](https://www.facebook.com/plucnahipertenzija) - [danijela@pesic.rs](mailto:danijela@pesic.rs)







## SLOVAKIA

**PH raising awareness events**

In the course of 2017 our association decided to start PH awareness raising activities with primary care physicians. We were present at the Annual General Practitioners Conference in the High Tatras with an information stand this year and for next year the President of the General practitioners' association promised us an hour slot for a presentation about PAH. This is a very promising new development.

The Commercial TV Markiza made two reportages for the highly popular TV Show "Reflex". One of them was about the consequences and impact of PAH and featured our President,, Iveta Makovnikova PH medical expert Dr. Milan Luknar. The other one was about pediatric PAH.

With the support of our PH doctors we launched a new project called "Breath-taking", for university and high school medical students, which will consist in discussion forums with participation of patients.

We attended an important sporting event, called "From Tatras to the river Danube" during which we addressed the general public. Our 12 team members took part in this 345km long relay race for the 4th year in the row, wearing Get Breathless T-Shirts. Two cars followed them with PHA Slovakia branded materials with the names of the patients for whom they were running.

**Activities for the members**

A 6-day educational-rehabilitation stay in the spa Sliac was organised for our members. It was focused on physiotherapy,

relaxation, breathing exercises and PH education. A creativity development and self-confidence improvement workshop was also held, during which patients painted different motives on canvas bags.

In cooperation with the PAH center and the Physicia and rehabilitation department of the National Cardiology Institute, we developed the video "Physical training for patients with PH", which aims to help patients with their regular home exercises.

At the beginning of the year, we also launched a new website.

**Improving access to drugs**

Our association participated in a Ministry of Health workshop discussing an amendment of legislation on reimbursement of medicines, medical devices and dietetic foods by the public health insurance. We have supported the comments of the organisations SAZCH and AOPP against the planned changes to introduce supplementary charges for medicines and medical devices on patients.

We supported the protest of civic associations with cystic fibrosis against the planned relocation of the Pulmonary department of University Hospital in Ruzinov to a facility with significantly worse conditions.

We also participated in the creation of a protest letter to the Ministry of Health on the Facebook social network and introduced a paid advertisement for the article.

**Education**

Our member Jana Guranova participated in the training program for organ transplant advocates organised by EuDonOrgan, an EU-funded project, in Barcelona. Jana's role will now be to cooperate with National Transplant Organization and the Slovak Transplant Society to prepare and conduct activities directed on improvement of organ donation in Slovakia.

**Cooperation**

We are actively working with other civic associations on activities that increase the awareness of organ donation and transplantation. We have been involved in the "My Story" literary contest that was designated for patients after transplant. The stories will be published.

The Slovak Transplant Society organised an itinerant photo exhibition of patients after transplant for World Organ Transplant Day, in which our member's photo was published. Mutual exchange of experience with members of the Czech PH Association has lead us to closer cooperation, exchange of information, guidance and mutual help. In October three of our members attended their General Assembly in Prague and discussed further cooperation.

*Iveta Makovníková*

*Združenie pacientov s pľúcnou hypertenziou*

[www.phaslovakia.org](http://www.phaslovakia.org)

<https://www.facebook.com/Združenie-pacientov-s-plúcnou-hypertenziou-oz-236811429798179/>



## SLOVENIA

**Slovenia, Croatia and Serbia joined their forces for PH**

On Sunday 17th September everything was ready for the 3rd Ironman 70.3 Pula to begin. The Ironman race is an international competition of endurance where athletes swim 1.9 km in the ocean, bicycle for 90 km and run for 21.1 km. The maximum amount of entrants (1400) participated in the event.

The participants came from 53 different countries. Most were from Austria, Germany, Slovenia, Poland and Croatia. Sadly, there was a big storm the night before the event and the sea was rough. The organizers had to cancel the first part of the triathlon, because it would be dangerous to let the athletes swim in such conditions.

The weather on the morning of the event provided ideal



circumstances for the race. The sunny conditions transformed the astonishing Pula Arena into the most beautiful Ironman finish area.

It was the 3rd Ironman event we participated in, but this year was very special. This year it was all about collaboration. Associations from Croatia and Serbia joined forces with us, making sure our voice was heard more than ever before.







Together we assembled an amazing team: “United Pulmonary hypertension Team” - “United PH Team” with 11 athletes: 3 Slovenians, 7 Croatians and a Serb competing to represent pulmonary hypertension patients.

All did a great job of raising awareness for a disease which prevents patients to take part in any sport activity. The message we tried to spread was that “early diagnosis and access to all treatments are essential for a better life expectancy for patients of pulmonary hypertension!”

Members of the United PH Team:

SLOVENIJA: Luka Kobler, Grega Ilc, Rudi Smolej

SRBIJA: Marko Stanković

HRVAŠKA: Nino Strajher

We also had 2 Croatian teams who participated in the relay race:

Ivan Čurović, Vedran Jović, Lana Dragojević - 1. place  
Maja Šekoranja, Ranko Antolović, Berislav Sokač - 5. place  
A big hurrah goes to Ivan, Vedran and Lana who beat all other teams and finished in the 1st place!

*Tadeja Ravnik*

*Društvo Za Pljučno Hipertenzijo Slovenije*

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



habilitation, thanks to the collaboration of the Hospital 12 de Octubre in Madrid and the voluntary work of several members. They are currently available on our website.

- In March in Valencia the “III Solidarity Race Causa María Moreno” took place, with the slogan “Get breathless for PH”. María Moreno was a patient who passed away and the race is in her honour. This year we shared the money collected, a total of 12.198 euros, with the association for the xbp1 syndrome.
- We prepared guidelines for the key issues in pulmonary hypertension. The psychologist and the social worker of the

association have worked together on the content and format of these guidelines, which will be published in the near future. Several members participated in a discussion group in April whose purpose was to provide content to these guidelines. This project was selected in the “I Call for Aids to the Vitalaire Project”.

- To celebrate World PH Day the ANHP organized different activities in Madrid:
  - On April 27 we recorded the video “4 generations without breath because of PH”, which was broadcast on social networks on May 5.
  - On May 5 we were with the “PH Room” at the University Hospital of La Paz. The people who passed by the square did the activities that we indicated to them so that they felt how PH patients feel when they perform basic activities of daily life such as making the bed.
  - On May 6 we organized the III Solidarity Gala for Pulmonary Hypertension in Parla.
  - On May 27 we organized a Solidarity Concert in favor of the ANHP of Dones per la Pau with the collaboration of Lidia Pujol.
- The 15th Annual General Assembly was held in Ávila, between June 2 and 4. Before the opening of the assembly Dr. Alcolea, from the University Hospital of La Paz, gave a talk on the different types of treatment in pulmonary Hypertension. It was a meeting of fun and tourism in which the members could share experiences.
- This year we launched the campaign “Become a Hypercoach”, thanks to the collaboration of Alberto Cendrero Nieto, a sportsman. The main objective is to sensitize the population about the characteristics of physical activity in people with pulmonary hypertension. In addition, with the sale of the “headbands” we raised funds to finance other projects. On July 13, Eva García, our President, was interviewed by Radio Siberia de Siruela (Badajoz) in relation to the organization of the “I Triathlon Solidarity of Siruela, Convert ten Hipercoach” which took place on July 15.
- The Board of Directors meets in person at least once a year to discuss all the issues related to the association. This year it took place on October 6 and 7 in Madrid.
- In November we held the first meeting of families with children with pulmonary hypertension in Madrid, attended by 4 families. The goal of this year was to improve the communication between parents and children and to strengthen a support network for families who live many kilometers away. The day was a big success.
- In mid-September we started the Christmas Lottery campaign, which is one of the most important sources of funding for our association.

#### Participation in events organized by third parties.

Representatives of the association are often invited as speakers by other organisations.

- We took part in the VIII Conference on Pulmonary Hypertension at the Hospital Clínic of Barcelona. This con-



ference is part of the project called “Respira” Classrooms.

- Eva García gave a presentation about the contribution of cardio-respiratory physiotherapy in improving the quality of life of PH patients to the Physiotherapists Association of Madrid.
- The participation of our social worker in the First Congress of Patients of SEPAR, the Spanish Society of Pneumology and Thoracic Surgery, in the discussions on “Equity in care, access to medicines, rights and duties of patients”.
- We also actively participate in campaigns of related PH associations. Our member Anne was interviewed for the “I’m aware that I’m rare” campaign run by the Phaware Global Association.

#### Congresses in Hospitals

Making ourselves known among professionals in the medical field in general and especially in relation to pulmonary hypertension is part of the strategy of our association. Therefore, in 2017, we participated in different scientific activities, among which we can highlight:

- On March 21-22 we attended the Workshop “Rare Disease



In 2017 the Board of Directors of the National Association of Pulmonary Hypertension (ANHP) completed its first year of mandate with a positive balance for the period. These times are difficult for everyone, but even so great work has been done thanks to the efforts of the members of the Board of directors and their colleagues.

#### Activities organized by the association

The activities organized by the association are fundamental to respond to the demands and expectations of the members. All of them are included within the strategic projects that are developed each year. During the year 2017 we would like to highlight the following:

- Recording of different videos about cardio-respiratory re-



Registry” at the University Hospital of La Paz (Madrid).

- On September 20 we participated in the “Hot Topics in Pulmonary Hypertension” conference organized by the University Hospital of La Paz in Madrid.
- On 20 and 21 October, the Seminar on Pulmonary Hypertension in Autoimmune Diseases of Neumosur took place in Cádiz and the association participated in the congress by contributing materials.
- On November 3 the association participated in the IV International Day of Pulmonary Hypertension Hospital 12 de Octubre.
- On November 30 the association was present at the 1st Conference on the update of respiratory diseases at the Ramón y Cajal Hospital.

#### Spanish Federation of Rare Diseases (FEDER)

As members of FEDER we actively participate in campaigns, projects, activities, meetings, etc. they organize.

This year we were present at the meetings of the Madrid delegation which took place in February, May and November and at the June General Assembly.

In February we participated in the VIII International Congress for Orphan Medicines and Rare Diseases in Seville and we were present at the presentation of the Agreement between the Ministry of Social Policies and Family and FEDER in the field of social services of the Autonomous Community of Madrid.

In relation to International Rare Disease Day we attended the official ceremony at the Prado Museum, attended by the Queen of Spain, and the closing ceremony at the Assembly of Madrid. We had a booth at the “VIII race for hope” at the Casa de Campo in Madrid.

Contributing our point of view as social work professionals, we participated in the Discussion Group for the update of the ENSERIo study (study on the situation of the sociosanitary needs of people with rare diseases).

We also attended the I Breakfast (Gosari) in Bilbao in October, the Conference on Europlan and the presentation of the documentary film “Winning to the wind” where a girl with pulmonary hypertension appears in November, and at the III AEMPS-FEDER meeting and at the “Days of gratitude and solidarity with the Rare Diseases” in December.

#### Collaboration with other organisations

For us, collaboration with other related organisations is paramount because it gives us greater weight in many areas. For this reason we are members of other organisations and we actively participate in their activities.

- In February we attended a meeting of SEPAR, with the purpose of presenting the initiative of the “Year 2017 of the Respiratory Challenges” and the organization of the I Congress of patients. In April we attended the closing and opening ceremony of the year of SEPAR.
- In March we participated as a full member in the General Assembly of FEP (Spanish Forum of Patients). And in

November we attended the II Congress of Patient Experience through them.

- In June, we participated in the Assembly of the POP (Patient Organization Platform). In October, several members of the Board of Directors and the social worker participated in the First Congress for Patients of the POP.
- Our President and our social worker attended the Annual Conference of PHA Europe in Castelldefels (Barcelona).
- In September we attended the inauguration of the XXXIII “Heart Week” in Madrid and had an information stand at the fair.

#### Rising the profile of the disease

On the one hand one of our basic objectives is to give correct and updated information to people with pulmonary hypertension and their families and on the other hand to give visibility to the disease. For this we attend conferences, conferences, talks, etc. organized by other organisations that serve to fulfill these objectives. In the year 2017 we have been present in:

- The presentation of the “Women for the Heart” Campaign with the participation of the journalist Ana Rosa Quintana, the singer Mónica Naranjo and the athlete Ruth Beitia.
- The day for “Quality of Life in the Respiratory Patient”.
- The day for : “How to seek information on health on the Internet with rigor”.
- The First Protagonists Forum: “A clinical trial is an opportunity for everyone.”
- The presentation of the “National Study of Adherence to Treatment in Chronic Pathologies”.
- The day “The protection of the person with chronic illness or chronic symptoms”.
- The 2nd Health Fair of the HUCA race in Oviedo, giving information about the ANHP.
- The First International Conference on Social Responsibility in the Health Area.
- The V “We Are Patients” Conference entitled “The Patient’s participation in public life: politics, society, health system”.

#### Other activities

We would also like to mention that this year our psychologist Aldo Aguirre defended his thesis for the Doctorate on “Quality of life in people with PH”, whose results will be available in the near future.

- On July 4 we participated in the informative meeting about selexipag at Actelion’s headquarters
- On May 27 we attended the Presentation of Oximesa Solidario

Eva García

Asociación Nacional de Hipertensión Pulmonar

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

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



#### Gala anniversary FCHP

The Spanish PH association Fundación contra Hipertensión Pulmonar (FCHP) was proud to present a check for 50.000 euros to the Empathy Project for research on pulmonary hypertension. The presentation of the check was made during the Gala Dinner for the 8th anniversary of the association by journalists Carlos García-Hirschfeld and Eva Mora. Also, as a surprise this year, Mr. Emilio Butragueño, the Director of Institutional Relations of the Real Madrid Football Club, accepted to be Honorary Patron of the FCHP. With this amount, the total sum that the FCHP has given for research in the last five years is 200.000 euros. This incredible result has been achieved thanks to numerous activities such as charity markets, concerts, awareness activities and sports championships and has had the support of public institutions and private companies.

The Empathy Project, coordinated by the Center for Biomedical Research in Respiratory Diseases Network (CIBERES), seeks to improve the quality of life and find a cure for those affected by pulmonary hypertension.

“Since we started this Foundation, our main objective has always been to promote research and raise awareness about this disease, which is why the more than 200.000 euros collected so far has gone entirely to projects promoted by professionals, training scholarships and the Empathy Project”, said the president of FCHP, Enrique Carazo.

The Empathy Project is one of the great hopes for patients

worldwide, since, according to Carazo, researchers are working from complementary areas to identify the markers that will help in the early diagnosis of the disease and also in therapies that will improve the quality of life and life expectancy of those affected.

#### Training days for patients

The day after the Gala, the first training day for patients with PH by the FCHP was held, with the aim of educating them about medications, medical devices, and the management of each one of them. The doctors who were giving the workshops were Dr. Labrandero, pediatric cardiologist at the University Hospital of La Paz, Dr. Mendoza, pediatric cardiologist at the University Hospital 12 de Octubre, Dr. Elvira Garrido Lestache, pediatric cardiologist at the University Hospital Ramón y Cajal (all in Madrid) and the PH nurse specialists, Begoña Navarro, from the University Hospital 12 de Octubre and María Morillo del Vall d’Hebrón of Barcelona. In addition, two interesting workshops were given by the psychologist Mamen Almazán and Marta Fernández, Professor of Physical Education in Primary Education. Both the Anniversary Gala and the Training Days were a success.

Enrique Carazo Minguez

FCHP Fundación Contra la Hipertensión Pulmonar

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

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





## SPAIN HPE-ORG

### The need for networking: a reality for patients, professionals and public administration

The workshop on “Minority Respiratory Diseases”, which is part of the International Week of Idiopathic Pulmonary Fibrosis, was inaugurated by Dr. Cristina Nadal, Director of the Health Care Area of the Catalan Health Service, together with the Dr. Victoria Martorell, Head of Services Development at the Sant Pau Hospital, and member of the Minority Disease Advisory Commission (CAMM). Both emphasized the need for participatory workshops in clusters of pathologies to create a common space where patients and professionals can share news, experiences and needs.

During the inaugural lecture, Dr. Roser Francisco explained the criteria and requirements (established in the 12/2015 provisions for minority diseases in Catalonia) to be able to be part of the units of clinical experience (XUECS), in a multidisciplinary and interhospital day organized by the Platform of Rare Diseases, in conjunction with the Sant Pau hospital and the Association of Relatives and Persons Affected by Idiopathic Pulmonary Fibrosis (AFEPFI).

Andreu Clapés, President of the Aire association, called on associations and patients to join forces for the active participation of patients in networking. In the words of Dr. Molina: “Initiatives like this help inform the general population



and the institutions. They prove to be an essential requirement to publicize the existence of these diseases and serve as spaces for encounter between patients who share experiences among them and with health professionals”. Key aspects of the network work model are: collaboration and coordination among the members of XUEC and other healthcare professionals and the transfer of knowledge to guarantee quality.

We were invited to participate in the organization of a multidisciplinary workshop on pulmonary arterial hypertension where patients, together with PAH experts, were able to debate a number of issues that worry us about our condition.

### The first separate conference of respiratory patients

“The objective of the Congress was to give voice to the patients in a dynamic and participatory way, therefore, it has

worked together with the associations of patients selecting subjects such as the social-health rights of the patients, clinical trials, equity in care and access to medications, among others”, explains Dr. Carme Hernández.

Dr. Eusebi Chiner emphasized that “this Congress has been an excellent opportunity to listen and work together for better global patient attention”. And a participatory success. HPE-ORG Patients actively participated in proposing subjects and organizing the workshop on emotional health in conjunction with the Fundación contra Hipertensión Pulmonar (FCHP) and with psychologists Mamen Almazán Peña and Mr. José V. Pérez Bombero.

The different associations for respiratory diseases that participated in the congress were able to present our work and disseminate information about PH with a booth.

We also presented our project “Pulmonary Hypertension, Learning to breathe”, which received the 3rd Vital Air Prize, for €1.200. This was a project designed by the psychologists Pau Solano, Alma Aron and María Rodríguez, President of HPE-ORG Patients, with the collaboration of the a team from the Masters Degree in self-leadership and group leadership of the University of Barcelona.

### Patients in the evaluation of healthcare technologies

A meeting on this important topic was organised by EUPATI (European Patients Academy on Therapeutic Innovation) Spain and the Spanish Agency of Medicines and Health Products (AEMPS).

Before a drug or medical device reaches our homes, it must undergo a review process of its properties, effects and impact. This evaluation is also carried out in various dimensions:

medical, social, ethical, and economic. In all of them, patients have a lot to say.

The assessment of health technologies (HTA) is a multidisciplinary process that summarizes information on the medical, social, economic and ethical aspects related to the use of health technology in a systematic, transparent, non-biased and consistent manner. Its objective is to base the development of healthcare policies centered on the patient and achieve maximum value. Regardless of the objectives of the policies, the HTA process must be based primarily on research and the scientific method.

As patients we must be part of the development and evaluation processes of HTA from design to marketing and this requires the training of experienced patients. HPE-ORG Patients believe that we should get involved in all the courses focused on patient training, the participation of patients in these courses is very interesting and recommended to participate in the tables of experts where.

### 4ª Edición Behobia San Sebastián

Our participation in the 4th Behobia San Sebastián Edition was quite exciting. This is a 20km tour which starts at the border with France (Behobia) and ends at Donostia-San Sebastián. It had 34.000 registered runners. During the race we were able to give visibility to the PH by giving encouragement to the runners and shouting our message about PH and the importance of lungs ... a very emotional participation.

María Rodríguez, Hipertensión Pulmonar España  
[www.hipertension-pulmonar.com](http://www.hipertension-pulmonar.com)  
[www.facebook.com/pg/HPSpain.org](https://www.facebook.com/pg/HPSpain.org)



## SWEDEN

In September the Swedish association arranged a successful meeting together with the PAH center in Lund. The meeting is part of our strategy to collaborate with the PAH centers in Sweden in order to reach out to patients and carers.

Patrik Hassel, PHA Sweden  
<http://pah-sverige.se/> -  
<http://on.fb.me/WcaOWZ>







## SWITZERLAND-SPHV

### 2nd Meeting for PH Patients and Family in Olten January 21, 2017

Willi Oesch and Martin Nobs, who is a psychologist and discussion leader, welcomed the six members of the association who took part in the meeting. After a short introduction on “managing pulmonary hypertension with one’s partner” the participants had to shortly introduce themselves and were encouraged to talk about the main problems the patients or family members/partners were facing with this disease. It was quickly clear that the problems are very many and most of the time are due to lack of knowledge about the disease. Out of this an intensive discussion arose about all those little but also bigger problems and prejudices which a non-curable disease like PH can create between healthy people and PH patients. Martin Nobs, drawing on his experience as a psychologist, showed possible ways to better understand the situation and feelings of patients and also give tips and tricks for daily life. During lunch information and experiences were shared.

### 7th general Meeting March 18, 2017

President Bruno Bosshard welcomed 31 members to the general meeting. He reported on the last year’s activity,

which was characterized by various events and excursions: Word PH Day, a bus excursion to the “Glasi Hergiswil”, Family Meetings, Swiss PH Meeting in Olten and a lot more. There was certainly something interesting for everybody.

### 16th Annual Swiss PH Meeting in Olten May 20, 2017

President Bruno Bosshard welcomed more than 50 members, patients and representatives of our sponsors to the Annual Swiss PH Meeting. Our Board invited two speakers to this meeting. The first presentation was from Esther I. Schwarz, from the Unispital in Zurich. Mrs. Schwarz gave us insights on how the spiroergometry is used for diagnosis and treatment. It was very interesting also to hear how all the different parameter graphs can be evaluated. The next speaker was Dr. Angela Oxenius, from the Children Cardiac Centre in Zurich, who explained the problems in diagnosing and treating children with PH.

The participants used the time during lunch and until the end of the meeting to get to know each other better and exchange experiences.



### Bus excursion and meal of asparagus June 9, 2017

On Friday, 9th of June 2017 we made an excursion to Burkheim, in the Black Forest, where we were treated to a very nice asparagus meal. There were 30 participants and we were lucky with the weather. Our driver, Peter Hardegger, drove via the “Hauenstein” to the first stop in Birsfelden, where we had coffee and croissants, after which we drove further through the wonderful Alsace. Around lunchtime we arrived in the beautiful restaurant and hotel “Kreuz” in Burkheim. We enjoyed being together and ate so much asparagus that we all were stuffed at the end. Time flies while having fun and so it felt like we just arrived and we had already to return back home.

### 9th PH Family Meeting in the Bernese Oberland September 2-3, 2017

We met on Saturday morning at 10 o’clock in the event hall 6 in Thun. The rain was pouring but luckily the first part of the program was held in a restaurant. Adrian Tschanz “the kitchen rocker” welcomed us and made us cook, or rather, he gave aprons to the children and took care of them while we, the parents, took a walk into the historic city of Thun. We had to be back at 12 o’clock. Delicious flavours lead our way back to hall 6. Now it was time to sit back and get spoiled. In the afternoon it was not so cosy anymore. We tried to do a foxtrail in the pouring rain but it was a strange feeling walking through Thun in this grey and muddy weather trying to find the next stop of the foxtrail. At some point we all were drenched and one group found itself at the border of the city in the woods of Thun. Even the thick vegetation could not hold back the rain and after 1 ½ hours we stopped and went into a restaurant to warm up. In the afternoon we travelled to Brienz, where we stayed overnight in a youth hostel. The kids were in big rooms with space for 8 and were totally happy. At 7pm we had dinner and sat together having a good time and looking at photos from the last meetings. It was funny and also exciting to see what kind of trips we have made in the past years and how big our children are now and how old we are! Some went to sleep but some were talking until late in the night and wanted to enjoy every moment of the meeting. On Sunday,

after breakfast, we went to the shipping pier in Brienz. We took a ship trip travelling through Giessbach, Iseltwald and Boeningen. There, we took a walk along the lake to the restaurant “Elemant”. After having an apero outside on the terrace, we enjoyed a delicious lunch and desert.

### 17th PH patient meeting in Nottwil September 16-17, 2017

For the first time, our association organized a 2-day meeting for PH patients and their families. Our president Bruno Bosshard welcomed 30 members. In the afternoon we had a first presentation on breathing therapies. For about 2 hours breathing therapist Mrs. Eva Glatt, from Lucerne, showed us how our breathing operates and how small, daily, breathing exercises can improve oxygen intake. During the dinner together we exchanged experience and information. The second presentation took place the next day, on Sunday. Mrs. Stephanie Saxer, a physiotherapist from the Unispital in Zurich, explained to us, how in the rehabilitation centre “Wald” PH patients can improve their physical performance and general condition. The training programme which is used in the rehabilitation centre “Wald” has been developed by Prof. Ekkehart Grünig, from the University of Heidelberg. After having lunch together the members travelled back home.

### 20th PH patient meeting in Frankfurt, Germany

From October 20 to October 22 2017 a group of 21 members from the Swiss PH Association travelled to Frankfurt. With the numerous presentations and workshops we were happy to gather again a lot of new information on research and treatment of PH.

### Regional Patient Meetings during 2017

During the 5 different regional meetings in Bern, Chur, Meggen, Olten and Zurich, patients and family members exchange personal experience and information about problems with insurance, doctors and hospitals.

Therese Oesch, SPHV

[www.lungenhochdruck.ch](http://www.lungenhochdruck.ch) - <http://on.fb.me/1dfRZ2B>





## UKRAINE-SISTER DALILA-PHURDA

### Organ transplant in India

The President of PHUrda visited the Global Hospital network of clinics in India to visit the hospitals where transplants are being carried out for foreign citizens. This trip coincided with the presence in one of the clinics of the “Global Hospitals” network of a Ukrainian orphan child, Alina Didusenko, who had successfully undergone a heart-lung transplant. This surgery gives great hopes for all patients in Ukraine. One more child, Karina Ovcharenko, who is 13 years old, has also taken to this hospital and is waiting for a heart-lung transplant.

### Visit to Norwegian rehab center

An Ukrainian doctor and a PH patient from CF “Sister Dalila” visited the LHL-Klinikkene (Heart and Lung Diseases) Rehabilitation Center in Norway, within the framework of the PHUrda Memorandum with PH Norway. They participated in the rehabilitation program for PH patients, which includes physical activity, nutritional advice and communication. This was a very valuable experience. We hope to be able to set up a similar program in Ukraine for our patients, with the involvement of PH patients, doctors, rehabilitation specialists, psychologists, social workers.

### Ventacare

Thanks to our hard work Bayer restored the nursing program of PH patient support in Ukraine “VentaCare”. We extend

out warmest thanks to the company for this important support.

### Prizes and awards

- The “Cork for Life” campaign is one of this year’s winners of the Lviv Regional Environmental Projects Competition held by the Department of Ecology and Natural Resources of the Lviv Regional State Administration.
- LCCF “Sister Dalila” was awarded a Diploma from the Lviv Region Charity Competition for the “For Coffee” project, aimed at raising funds to save the life of Alina Didusenko.
- LCCF “Sister Dalila” once again was marked by the National Philanthropists Rating for reliability, accountability and transparency.
- The Lviv City Council decided to allocate premises for the activity of LCCF “Sister Dalila”

### Magazines and TV

- A social photo session for LCCF “Sister Dalila” member Oksana Melnyk was conducted on the initiative of the model magazine “M’VIVE”.
- Representatives of PHUrda participated in the TV program “Neodnakovo” (“Not indifferently”), where the reasons for the lack of post-mortem donation in Ukraine were discussed and what should those Ukrainians do who are already in need of transplantation.

### Fundraising

- A member of LCCF “Sister Dalila”, Tetyana Fedosyuk has started her own fundraising project. For several months she has been baking delicious “Shu” pastry and given the funds she raised to support the needs of PH patients.
- During the Lviv Fashion Week, funds were collected for another member of “LCCF “Sister Dalila”, Yuliya Kaviy, who needs a heart-lung transplant in India.
- There was also a series of cork sorting events, with the active participation of children. During these events we sorted out 600 kg of plastic corks (caps).

### Information campaign and materials

- The information campaign “Lack of air? This may be pulmonary hypertension” was carried out by the association with the support of the Lviv City Council who provided information billboards and citylights.
- PHUrda translated some information materials from the Norwegian PH association.

### International meetings and conferences

- Participation in the International meeting of PH associations in Vilnius, Lithuania
- Participation in the annual PH European Conference, Barcelona
- Participation in the Medical forum and the Eastern Regional Symposium on October 13-14, 2017 in Toronto, Canada. The PHUrda President visited the Toronto General Hospital, where transplants are performed, and networked with doctors, patients, their carers, representatives of pharmaceutical companies to discuss the prospects



for implementation of joint cross-border projects (Ukraine-Canada) in 2018. PHUrda had a booth at the conference and was able to give out information materials on diagnosis, treatment of PH, that made a step forward to overcome the information barrier between the physician and the patient.

- Participation in the Symposium “Orphan diseases in children and adults”.
- Participation in V Ukrainian Scientific and Practical Conference “Orphan Diseases in Cardiology”.

This eventful year ended with a patient meeting, where we presented the yearly financial report of LCCF “Sister Dalila”, a report on the experience in the rehabilitation program in Norway and where PH patient took part in a sessions on art-therapy and group psychotherapy. And at the end everyone got a present: the 2018 PAHuman Diary!

We take this opportunity to thank PHA Europe, thanks to whom the voice of PH patients is becoming stronger.

Oksana Kulish, Sister Dalila-PHURDA  
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# UKRAINE-PHA

## First National Conference on Pulmonary Hypertension May 18-19, 2017, Kyiv

The First National Conference on PH united specialists in pulmonary hypertension, for whom it was important to exchange experience and knowledge in the fight against this serious disease. The Conference was organized in collaboration with the Association of Cardiologists of Ukraine, the "M.D. Strazhesko Institute of Cardiology" and the "Center for Pediatric Cardiology and Cardiac Surgery". And, of course, the help of experts from the University Clinic of Giessen, Germany, Prof. Dietmar Schranz and Prof. Henning Gall, was invaluable. Thanks to their German colleagues, Ukrainian doctors have discovered many new things in the field of diagnostics and modern methods of treating pulmonary hypertension.

## Meeting of Eastern Europe PH associations June 16, 2017, Vilnius (Lithuania)

The meeting was organized by the Lithuanian Association of PH. It was very pleasant to meet and communicate with representatives of Lithuania, Latvia, Estonia, Belarus, Russia and Ukraine. During the meeting we discussed many topics - access to treatment, drugs used in each country, the work of PH, diagnosis, transplantation and rehabilitation of patients. It was important for us to learn that in Latvia, Lithuania, Estonia, Russia, patients with pulmonary hypertension can be treated and they can be prescribed drugs only in the specialized PH centers. The appointment of other doctors is not a basis for providing patients with the necessary drugs! This is what we in Ukraine are also striving for and what we are constantly talking about! Such meetings are very important for interaction and exchange of experience between PH associations from different countries.

## Press Briefing on "Decree N 180" August 15, 2017, Kyiv

Decree N. 180, adopted by the Cabinet of Ministers of Ukraine,

suspended budget purchases and prescription of medicines that are not included in the National List of Essential Medicines for free and reduced-price prescriptions. This list, which has about 300 items, does not include medications for patients with rare diseases, including those with Pulmonary Hypertension. As a consequence, a large number of patients today are left without treatment. In her speech, Oksana Aleksandrova stressed that it is important to develop legislation that will separate the orphan diseases from Decree N. 180.

## Ukraine-Europian 2 workshop October 20, 2017, Kyiv

The workshop was devoted to the problems of orphan disease patients and was attended by the representatives of the Ministry of Health of Ukraine, the Ukrainian Parliament Commissioner for Human Rights, representatives of EURORDIS and other patient organizations, doctors and scientists. It discussed the implementation of national measures to create registries of orphan patients, including patients with pulmonary hypertension, providing treatment for patients with rare diseases, as well as issues of genetic diagnosis and counseling. The guest of honour, the Director of the National Centre on Rare Diseases, Dr. Domenica Taruscio, shared her experience with the Ukrainian colleagues on working with the European patient registries. At the end of the workshop, many important decisions were taken, namely: to consider that the State Register of Orphan Patients should be an integral part of the development and implementation of the state policy on rare diseases and the basis for recording patients, planning and ensuing actions to provide timely, complete and uninterrupted assistance to such patients, calculating the costs of providing them with medications; to establish a working group to develop a methodology for the establishment of a state register of orphan patients, including patients with pulmonary hypertension; to create a unified system of giving specialized assistance to patients with

rare diseases at the state and regional levels; to provide modern diagnostic equipment for centers for rare diseases. We very much hope that the implementation of the decisions made at the Workshop will significantly improve the quality of life of our patients with Pulmonary Hypertension.

## Round Table on rare disease in the Southern Regions October 26, 2017, Odesa

The Round Table was attended by patients with rare diseases and patient organizations, heads of the Health Departments of the Odesa and Mykolayiv regions, experts of the State Institution "Institute of hereditary pathology of the Academy of Medical Sciences of Ukraine", representatives of the media. The leaders of the Odesa and Mykolaiv regions spoke frankly about the shortcomings in providing patients with rare diseases, about the allocated funding for many nosologies, including Pulmonary Hypertension, and about the open desire to cooperate with patient organizations. We still have a lot to do in the southern regions of Ukraine - to open Orphan centers in Odesa, Kherson and Mykolayiv, to create patient registers, to expand financing programs. But, as the saying goes, the road will be mastered by the going!

## Articles about PH

The Chairman of PHA Ukraine, Oksana Aleksandrova, took part in the writing of the article "Diagnosis and treatment of Pulmonary Hypertension in Ukraine: the ice broke?", which was published in the magazine "Health of Ukraine" in the spring of 2017. In the article Oksana wrote about the latest developments in the activities of the PHA Ukraine and about the importance of providing Ukrainian PH patients with affordable and easy-to-use drugs.

## Inhalation therapy with prostanoids

Our association, in collaboration with the Ukrainian representative office of Bayer, received as a charity 70 Omron NE-U22-E MicroAir nebulizers, for patients who need Ventavis inhalation, which will provide Ukrainian patients on this drug an essential device. A representative of Bayer wished our patients strength and a successful treatment! On behalf of all our patients, we thanked them for this valuable support!

## Advocacy with health authorities

During the year PHA Ukraine continued to take part in the working groups of the Ministry of Health to provide medicines for patients with pulmonary hypertension, on creating a patient register and putting into practice a system of reference centers for the diagnosis and treatment of PH patients and participated in the development of the Resolution of the Cabinet of Ministers on providing patients with rare diseases. To date, doctors in six regions of Ukraine have already been trained at the Center of Pulmonary Hypertension for adults.

Oksana Aleksandrova

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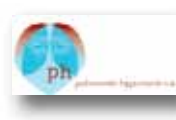
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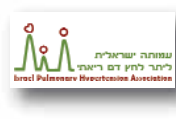
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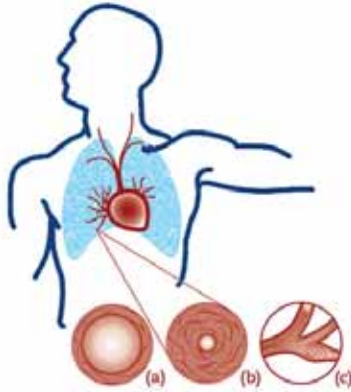


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## AIMS OF PHA EUROPE

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 39 Pulmonary Hypertension patient associations across 33 countries. 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.



- 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

## 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.

## TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

Over the past decade a number of evolving therapies that either use complex delivery systems such as 24-hour intravenous 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 is 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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