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# ACTIVITY REPORT 2017 & WORK PLAN 2018

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# 1. FOREWORD

Dear members, friends and supporters, welcome to PHA Europe's 2017 annual activity report and workplan for 2018. We are proud to look back on the year that has just ended and at all the projects and activities that our organisation has successfully carried out 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 for PH research; developing support programs for their members and, last but not least, in rallying politicians, health authorities, PH health care professionals, academia, sportsmen, celebrities and media to the PH cause. 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 help each other and to reach the critical mass that is necessary to have a louder voice and bigger impact. 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 older.

At a global level, PHA Europe's activities have revolved around four main themes: awareness raising, capacity building, advocacy and information provision. Our 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 and an unprecedented media reach. Capacity building is another very important part

of PHA Europe's activities. In 2017 we further expanded our "White Spots", "Fellowship" programs", designed to support new associations in their start up phase and providing English linguistic support for other associations, in order to enable them to take an active role in the community. Our Annual PH Conference, attended by 63 patient Leaders from 35 countries, also provided valuable educational and training opportunities.

It was a very busy year also for our advocacy activities, both in terms of providing strategic advice and support to our members at national level and, at European level, in our collaborative work with the main European public health NGOs, other patient federations, scientific societies and industry. 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. The 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. Information provision is another key activity for PHA Europe. We are active online through our web site and social media channels, our twice yearly magazine called "Mariposa" and twice-monthly newsletters. 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.

As we go to print we have just been notified that PHA Europe has won the 2018 EURORDIS BLACK PEARL award for Best Patient Organisation, what better way to start the year; very auspicious indeed!

*Pisana Ferrari*

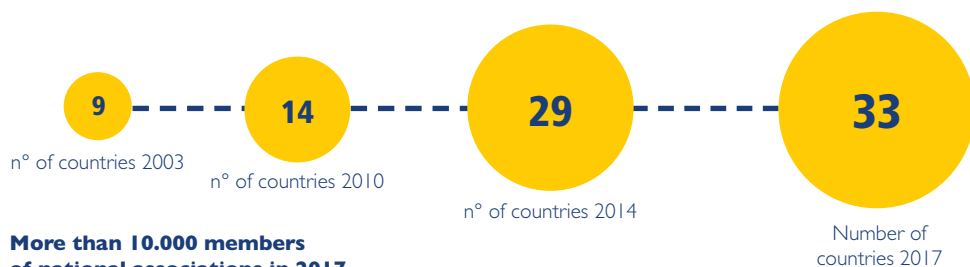
## 2. PHA EUROPE IN BRIEF

### BACKGROUND AND MISSION

PHA Europe is the umbrella organization for national associations of patients living with pulmonary hypertension (PH) in Europe. It was founded in Vienna, Austria, in 2003 and is registered as an international non profit organization. PHA Europe works together with its 40 members across 33 countries to enhance awareness of PH across Europe,

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

### KEY FIGURES



### MEMBERSHIP

PHA Europe was founded in 2003 in Vienna by eleven pulmonary hypertension patient associations, coming from nine countries. Membership has grown steadily over the years and currently stands at 40 patient organizations, from 33 countries: Austria, Belarus Belgium (2), Bosnia & Herzegovina,

Bulgaria (2), Czech Republic, Croatia, Denmark, Finland, France, Germany, Greece, Hungary, Israel, Ireland, Italy (2), Latvia, Lithuania, Netherlands, Norway, Poland, Portugal, Republic of Macedonia, Romania, Russia (2), Serbia, Slovakia, Slovenia, Spain (3), Sweden, Switzerland (1), Ukraine (2), Turkey.



## 3. GOVERNANCE

### BOARD AND AUDITORS



**Hans-Dieter Kulla**  
President



**Hans-Dieter Kulla**  
Vice President



**Tuulia Nikulainen**  
Treasurer



**Agnieszka Bartosiewicz**  
Vice Treasurer



**Danijela Pešić**  
Secretary



**Tadeja Ravnik**  
Vice Secretary



**Vittorio Vivenzio**  
1st Auditor



**Zdenka Bradac**  
2nd Auditor

mandate ends in September 2019.

The current members of the Board and the Auditors represent patient associations from eight European countries: Croatia (Zdenka Bradac), Finland (Tuulia Nikulainen), Germany (Hans-Dieter Kulla), Greece (Ioanna Alissandrato), Italy (Vittorio Vivenzio), Poland (Agnieszka Bartosiewicz), Serbia (Danijela Pesic), Slovenia (Tadeja Ravnik).

PHA Europe Board members are all volunteers, working pro bono, whereas the staff members receive financial remuneration. In 2017 the Board held regular meetings online through Skype

conference calls and had three face-to-face meetings, in Brussels in February, in Barcelona during the Annual PH European Conference (APHEC) and in December in Frankfurt. The Board is instrumental for the implementation of decisions taken at the AGA, and plays a key role in strategic planning.

### STAFF

PHA Europe has five staff members. Pisana Ferrari (Italy), Gerald Fischer (Austria), Juan Fuertes (Spain), Hall Skaara (Norway) and Gergely Meszaros (Hungary). PHA Europe collaborates with a Brussels-based Public Affairs consultant for advice on EU-level advocacy and external consultants are also supporting us for book keeping and tax advice.

Day to day management of PHA Europe typically includes programming and implementing PHA Europe activities, in coordination with the national member associations, correspondence

and contact programmes, monitoring and information gathering, financial and administrative tasks. A considerable amount of travel is involved to take part in collaborative work with our partner organisations, in conferences, workshops and other events. PHA Europe staff work closely with the Board and report regularly on all their activities.



**Pisana Ferrari**



**Gerald Fischer**



**Juan Fuertes**



**Hall Skaara**



**Gergely Meszaros**

## 4. MAIN AREAS OF ACTIVITY

### AWARENESS



PHA Europe has conducted annual global awareness campaigns for many years. From 2010 to 2012 these were organized around International Rare Disease Day (last day of February). In 2012 the Spanish PH association ANHP launched the idea of establishing a World Pulmonary Hypertension Day (WPHD); this initiative was embraced by PHA Europe and PH associations around the world and is now celebrated annually on May 5. In 2017 WPHD events were held in over 40 countries, across all continents.

### ADVOCACY

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



### INFORMATION



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

### CAPACITY BUILDING

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



## 5. AWARENESS RAISING

### World Pulmonary Hypertension Day

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



PH. This year it was clear that WPHD has grown into a spectacular celebration of our community's

work, and we reached more people with our campaigns than ever before. As in previous years, the PHA Europe WPHD 2017 theme was "Get breathless for PH". Healthy people were encouraged to take part in high-energy sports and activities to get breathless, demonstrating their solidarity with people with PH who struggle to breathe. Part of our mission is to continue to highlight that patients with PH often endure life-changing physical limitations every day. This year, 35 associations from 30 countries took part in WPHD across Europe, with many more worldwide. It is always amazing to see the creativity of the events organised by the different patient associations for WPHD, and 2017 was no different in this regard. As a result of the great work of our member associations, in Europe alone, over 1 million people attended a total of 58 events, which generated an impressive 425 pieces of media coverage: 16 press agencies, 61 print articles, 225 online media, 77 TV clips and 37 radio announcements, reaching millions of people across Europe. Read more about WPHD 2017 in the Mariposa Journal Summer 2017 edition.

### "Time Matters" online campaign

Time is, of course, precious to us all, but for PH patients even more so. Time to a correct diagnosis and initiation of treatment are vital in order to slow the progression of the disease. PHA Europe ran a first "Time Matters in PH" campaign (in

2011) and in 2017 we decided to run a second one. In the first campaign anyone could leave an entry on the dedicated web page, answering some simple questions. This gave the campaign a nice personal touch. This time round 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 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. A total of 38 videos were produced, with 468 subtitles in 21 different languages. 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 on 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. Read more about this in the Mariposa Journal Winter 2017 edition, p. 17-18.



### Other

PH awareness raising was achieved also through other channels including the participation of PHA Europe in international scientific congresses, symposia, and industry events (see pages 9-12).

## 6. ADVOCACY

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

### Advocacy at European level

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 EUORDIS, 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 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). PHA Europe 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.

### Support to national advocacy activities

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.

## 7. CAPACITY BUILDING

Capacity building is another very important part of PHA Europe's activities. Our organisation's ultimate goal is to put in place a strong European PH community consisting of empowered national associations, working together for the PH cause.

### White Spots

Under PHA Europe's "White Spots" program, started in 2013, PHA Europe has reached out to patients/caregivers/medical professionals in European countries where no PH association previously existed and provided start up funds, guidance and training in order to establish a local association and support it during its first years of establishment. 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.

### Fellowship

PHA Europe's official working language is English and, as the organisation expanded over the years to include more and more countries, communication started to become a critical issue with those associations where neither Board members nor volunteers had a good command of this language. Thanks to our "Fellowship" program, PHA Europe has been able to provide these associations with a part time English speaking assistant. The program started in 2013 with nine Fellows; in 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 actively engaging our member associations in common activities.

### Annual PH European Conference

The Annual PH European Conference (APHEC) also provides member associations with opportunities for education and skills development. For the 2017 APHEC four workshops had been organised, on different aspects that PHA Europe considers important for the empowerment of its member associations. The first workshop was about patient advocate training programs (eg EUPATI, the EURORDIS Summer School, etc) and the vital role they can play in enabling patient representatives to take part in



discussions on health care policy, on a peer-to-peer level, with all the relevant stakeholders. Our second workshop was on patient advocacy and here the underlying idea was to highlight the added value, for patient associations, in 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. 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. Our fourth and last workshop was about fundraising, a key factor in the sustainability of patient associations. Read more about the APHEC on page 8.

### Information materials and resources

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

## 8. INFORMATION & EDUCATION

The dissemination of up-to-date information about pulmonary hypertension is another important part of PHA Europe's activities. It is instrumental both in raising greater awareness of the disease and in the empowerment of the national associations.

### Journals and newsletters

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

### Website, social media and online platforms

Other information channels include the PHA Europe website and social media platforms. In the course of 2017 we have continued to update our website to include the most up to date information. and were also very active on social



media channels with a very big increase in number of followers in Facebook and Twitter. In 2017 we celebrated two years from the launch of the "PH Library", a comprehensive online platform, set up together with the PHA US, with over 200 resources (booklets, videos, etc.) from PH associations around the world, in 24 languages. In the past year the PH Library had about 1.000 visitors.

### Annual PH European Conference

The 2017 Annual PH European Conference (APHEC) 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. As in past years, we also invited our industry partners to the APHEC, who provided very interesting news of recent developments in treatments and medical devices as well as on future and ongoing research.



*Dr. Pilar Escribano, one of the leading PH experts in Europe, from the I2 de Octubre Hospital in Madrid, Spain*

### Other

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

## 9. WORKSHOPS AND CONFERENCES

PHA Europe representatives are increasingly invited to take part in important congresses, symposia, workshops and other events. They also take part in the work of advisory committees, task forces and working groups of important scientific societies, EU regulatory agencies and European NGOs. In the course of 2017 there were an average of three such events per month. This activity cuts across all of the four main areas of PHA Europe's work: awareness, advocacy, capacity building and information:

- Attending scientific events gives PHA Europe great opportunities to raise awareness of the disease as well as to be in the loop of the most recent developments in PH and public health related issues;
- Being part of advisory committees, task forces or working groups of prestigious organizations provides opportunities for advocacy and input into health policies;
- Training workshops have a key educational role and give those attending the possibility of becoming better advocates, both at European and national level;
- Being members of larger organizations (EURORDIS, the EUROPEAN PATIENT'S FORUM, the EUROPEAN PUBLIC HEALTH ALLIANCE) has many advantages, such as raising awareness of PH issues in wider audiences.
- Finally, all meetings have great networking potential, a key ingredient of awareness raising and advocacy.

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### **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.

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### **Brussels (Belgium), January 30** **PATIENT ACCESS PARTNERSHIP (PACT) ASSEMBLY**

Face to face meeting attended by Juan Fuentres. 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.

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### **Geneva (Switzerland), February 2** **EUROPEAN LUNG FOUNDATION (ELF) COUNCIL MEETING**

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

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### **Dubai (Emirates), February 4** **SAUDI PH ASSOCIATION (SAPH) ANNUAL MEETING**

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

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### **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 Fuentres.



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### **Brussels (Belgium), February 27** **LAUNCH OF THE UNIVERSAL HEALTH COVERAGE CAMPAIGN AT EU PARLIAMENT**

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

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### **Brussels (Belgium), February 28** **EUROPEAN PATIENTS' FORUM (EPF) WORKING GROUP ON ACCESS**

Face to face meeting attended by Juan Fuentres

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### **Vilnius (Lithuania), March 9-10** **3RD CONFERENCE ON EUROPEAN REFERENCE NETWORKS (ERNS)**

Juan Fuentres and Gergely Meszaros attended the launch conference for the 24 Erns set up by the EU Commission. Gergely, on behalf of the coor-



director of Ern-Lung, attended the ceremonial dinner with the representatives of the Member States, the coordinators of ERNs, etc. and ran a short presentation about PHA Europe. Juan participated in the Ern-TransplantChild Board meeting.

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### **London (UK), March 17-18** **12<sup>th</sup> 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.

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### **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.

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### **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.



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### **Sarajevo (Bosnia and Herzegovina), April 22** **FIRST PATIENT MEETING**

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



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### **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.

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### **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.



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### **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.

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### **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.

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### **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.

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### **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.

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**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.

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**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).

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**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.



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**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.



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**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.

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**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.

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

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

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

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

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**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.

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**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.

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**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.

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**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.

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**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.



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

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

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**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.

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**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.

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**Rome (Italy), December**  
**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.

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**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.



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**Paris (France), December 18**  
**ERN E-PAGs EURORDIS 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.

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**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.

# 10. WORK PLAN 2018

## AWARENESS

Over 40 countries across five continents took part in the 2017 global awareness campaign for World Pulmonary Hypertension Day (WPHD) with incredible results in terms of reach and media coverage. In 2018 we plan to conduct the campaign along the same lines: it will be coordinated centrally by PHA Europe, who will finance the national events and members will be provided with guidance and support and a very comprehensive media toolkit

which includes briefings on how to best promote the initiative, how to organize press conferences, merchandising activities, etc. The theme will be, as in past years, sports, and the slogan “Get breathless for PH”. We will again work together with the US

PH association, the PHA, and the PH Latin Society, as we did last year, to promote WPHD through the dedicated website and Facebook page, on social media generally and also through the online platform “Thunderclap” (see map with 2017 reach). Joining forces together has proven to be a key factor in the success of last year’s WPHD celebrations. We will also try to involve even more countries in the 2018 edition of WPHD.

We will also continue to raise awareness of PH through other channels, including the participation of PHA Europe representatives in international scientific congresses, symposia, round tables, academic courses and industry events.



## ADVOCACY

### EU level

Our main focus for 2018 will continue to be access to treatment and surgery (including organ transplant), as access is still a critical issue for many of our patients. We will continue to be actively involved at European level in the task forces and working groups of public health NGOs dedicated to access to treatment (see also pages 9-12) and will collaborate with the PH professionals in the context of the EUROPEAN REFERENCE NETWORKS for rare lung diseases ERN-Lung, European Respiratory Society (ERS) and European Lung Foundation (ELF). Very importantly, we will also be following up on the idea of setting up an informal dedicated working group, together with the European federations for diseases of the lung,

heart, kidney and liver; to improve organ donation and transplant in Europe.

### National level

In 2017 we will be collaborating closely with our member associations, as in past years, in order to provide guidance on possible strategies to adopt at national level to advocate for access to treatment and surgery and patient rights in general. PHA Europe will be following up, in 2018, on the idea of organising cluster groups of countries to work on access to treatment at regional level. We will also be fostering the setting up of bilateral agreements between member associations and working on a proposal for a PHA Europe mentoring program.

## CAPACITY BUILDING

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

Through our “White Spots” program we will provide support to the new associations who joined PHA Europe in 2017 as well as to recently founded associations that are just starting out. Our ultimate aim is to put in place a European PH community of empowered and strong patient associations. Much remains therefore to be done to ensure that all our member associations have a minimum structure in place which allows them to run efficiently and provide the necessary support to their patients as well as to engage in effective awareness and advocacy activities. Through the Organization Devel-

opment Program, we will help all associations “mature”.

Through the “Fellowship” programme, which is currently in place in 22 countries, we plan to continue to provide the national associations with a part-time English speaking assistant and we hope to be able to extend the programme to any new member associations which have significant language barriers.

Capacity building is also a crucial part of the program of the Annual PH European Conference, which consistently provides opportunities for sharing and learning from each other as well as training sessions on different topics which are important in the running of a patient association.

## INFORMATION AND EDUCATION

PHA Europe's traditional information channels are the Mariposa Journal, which is issued twice a year; its website and social media platforms.

Whilst we do not expect to make major changes to our journal in the course of 2018 we do plan to continue to make improvements to our website: and will work on a more direct connection with the social media feed. Our social media platforms saw a great increase in the number of followers in 2017 and we plan to build on this in the coming year. We will also continue to work on search engine optimization, in order to improve the website's traffic.

The “PH Library” was launched in 2015 and celebrated its second year in 2017. It is a comprehensive platform which contains 200 resources (booklets, videos, newsletters, etc.) from PH associations around the world, in 24 languages, indexed and readily available for all through an easy “search” function. We truly hope that it will become a key reference point for PH patients, caregivers and

health care professionals across the globe. We will continue to promote the PH Library through all our information channels and ensure that any new resources published are uploaded in a timely manner so that it is always up to date.

PHA Europe will of course also continue to provide information and educational opportunities on pulmonary hypertension through the Annual PH European Conference and by being part of key scientific congresses, work forces and advisory committees, as we have been in past years.



# 11. PARTNERSHIPS

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

PHA Europe is a member of the EUROPEAN ORGANIZATION FOR RARE DISEASES (EURORDIS) and participates in the work of several of its task forces: the DRUG INFORMATION, ACCESS & TRANSPARENCY (DITA), the "European Rare Disease Day 2019" and "Rare Best practices". Since 2013 PHA Europe is a member of the EUROPEAN PATIENTS' FORUM (EPF) where staff member Juan Fuertes is Member of the Board. PHA Europe was also accepted in 2014 as a member of the EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA).

Juan Fuertes works closely with the European Lung Foundation (ELF), where he was a Member of the Council up to end of 2017.

PHA Europe representatives have taken part in in past years, including 2017, in consultations as experts at the European Medicines Agency (EMA). PHA Europe also interacts through many different channels with the EU institutions (MEPs and EU COMMISSION officials), other European patient associations/federations and NGOs as well as professional scientific societies.



## PHARMACEUTICAL INDUSTRY

PHA Europe has partnered with the pharmaceutical industry on a number of important projects, such as the development and launch of the "Policy Brief and Call to Action on the Unmet Needs of PH Patients", the International Patient and Carer Survey, International Rare Disease Day, World Pulmonary Hypertension Day and IRONMAN global awareness campaigns, the

"Call to Action to improve Organ Donation and Transplant across Europe", as well as on the development of audiovisual materials and educational programs and IT. This partnership can take the form of unrestricted grants or can be related to specific projects. We look forward to continuing this fruitful cooperation also in future years.



# 12. MEMBERS OF PHA EUROPE



**AUSTRIA**  
**PH Austria**  
 Initiative Lungenhochdruck  
[www.phaustria.org](http://www.phaustria.org)  
[info@phaustria.org](mailto:info@phaustria.org)



**BELARUS**  
**Aid to Patients with Pulmonary Hypertension**  
[www.phbelarus.by](http://www.phbelarus.by) - [phbelarus@yandex.ru](mailto:phbelarus@yandex.ru)



**BELGIUM**  
**HTAP Belgique, Asbl**  
[htapbelgique@hotmail.com](mailto:htapbelgique@hotmail.com)  
[htapbelgique@hotmail.com](mailto:htapbelgique@hotmail.com)



**VZW Pulmonale Hypertensie (vzw PH België)**  
[www.ph-vzw.be](mailto:www.ph-vzw.be) - [colle.wim@gmail.com](mailto:colle.wim@gmail.com)



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



**BULGARIA**  
**Pulmonary Hypertension Association**  
[www.apph-bg.org](http://www.apph-bg.org)  
[todormangarov@abv.org](mailto:todormangarov@abv.org)



**The Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH**  
[www.bspph.net](http://www.bspph.net) - [bgspph@gmail.com](mailto:bgspph@gmail.com)



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



**CZECH REPUBLIC**  
 Sdružení Pařs Plicní Hypertenzi  
[www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)  
[info@plicni-hypertenze.cz](mailto:info@plicni-hypertenze.cz)



**DENMARK**  
**PAH Patientforeningen**  
<http://pah.dk> - [pahforening@gmail.com](mailto:pahforening@gmail.com)



**FINLAND**  
**Suomen PAH-potilasryhdistys ry. PHA Finland**  
[suomenpahry@gmail.com](mailto:suomenpahry@gmail.com)



**FRANCE**  
**HTaP France**  
[www.htapfrance.com](http://www.htapfrance.com)  
[administration@htapfrance.com](mailto:administration@htapfrance.com)



**GERMANY**  
**pulmonale hypertonie e.v.**  
[www.phev.de](http://www.phev.de) - [info@phev.de](mailto:info@phev.de)



**GREECE**  
 H.P.H. - Πνευμονική Υπέρταση Ελλάδας  
[info@hellenicpulmonaryhypertension.gr](mailto:info@hellenicpulmonaryhypertension.gr)  
[www.hellenicpulmonaryhypertension.gr](http://www.hellenicpulmonaryhypertension.gr)



**HUNGARY**  
**Tüdőér Egylet**  
[www.tudoer.hu](http://www.tudoer.hu) - [csabuda.eszter@t-online.hu](mailto:csabuda.eszter@t-online.hu)



**IRELAND**  
**PHA Ireland**  
<http://www.pulmonaryhypertension.ie/pha-ireland/> - [rprenderville@mater.ie](mailto:rprenderville@mater.ie)



**ISRAEL**  
**PHA Israel**  
[www.phisrael.org.il](http://www.phisrael.org.il) - [aryeh35@gmail.com](mailto:aryeh35@gmail.com)



**ITALY**  
**Associazione Ipertensione Polmonare Italiana Onlus**  
[www.aiipiitalia.it](http://www.aiipiitalia.it) - [presidente@aiipiitalia.it](mailto:presidente@aiipiitalia.it)



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



**LATVIA**  
**PHA Latvia**  
[www.phlatvia.lv/en/](http://www.phlatvia.lv/en/) - [info@phlatvia.lv](mailto:info@phlatvia.lv)



**LITHUANIA**  
 Žmonių Sergančių Plautine Hipertenzija Asociacija  
[www.phalithuania.eu](http://www.phalithuania.eu)  
[kovaliova.nastyia@gmail.com](mailto:kovaliova.nastyia@gmail.com)



**NETHERLANDS**  
**Stichting PHA Nederland**  
[www.pha-nl.nl](http://www.pha-nl.nl) - [info@pha-nl.nl](mailto:info@pha-nl.nl)



**NORWAY**  
**PHA Norway**  
[www.pha-no.com](http://www.pha-no.com) - [hall@pha-no.com](mailto:hall@pha-no.com)



**POLAND**  
 Polskie Stowarzyszenie Osób z  
 Nadciśnieniem Płucnym i Ich Przyjaciół  
[www.phapolska.org](http://www.phapolska.org)  
[bartosiewicz.agnieszka@phapolska.org](mailto:bartosiewicz.agnieszka@phapolska.org)  
[admin@phapolska.org](mailto:admin@phapolska.org)



**PORTUGAL**  
**Associação Portuguesa  
 de Hipertensão Pulmonar**  
[www.hp.sunlive.pt](http://www.hp.sunlive.pt)  
[mariajsaraiva@gmail.com](mailto:mariajsaraiva@gmail.com)



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**APH Moment**  
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[phmomentplus@gmail.com](mailto:phmomentplus@gmail.com)



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



**RUSSIA**  
**Natasha Charity Fund**  
[www.community.livejournal.com/fond\\_natasha](http://www.community.livejournal.com/fond_natasha)  
[otzovitesnam@mail.ru](mailto:otzovitesnam@mail.ru) - [www.nurm.ru](http://www.nurm.ru)



**Save and Protect**  
<http://www.ph-association.ru/>  
[lilya-belle@yandex.r](mailto:lilya-belle@yandex.r)



**SERBIA**  
**Plućna Hipertenzija Srbija**  
[daniijela@pesc.rs](mailto:daniijela@pesc.rs)



**SLOVAKIA**  
 Združenie pacientov s plúcnou  
 hypertenziou, o.z.  
<http://phaslovakia.org/>  
[hypertenzia.pluc@gmail.com](mailto:hypertenzia.pluc@gmail.com)



**SLOVENIA**  
**Društvo Za Pljučno Hipertenzijo  
 Slovenije**  
[dbph.slovenije@gmail.com](mailto:dbph.slovenije@gmail.com)  
[www.facebook.com/PljucnaHipertenzija](https://www.facebook.com/PljucnaHipertenzija)



**SPAIN**  
**Asociación Nacional de  
 Hipertensión Pulmonar**  
[www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)  
[informacion@hipertensionpulmonar.es](mailto:informacion@hipertensionpulmonar.es)



**FCHP Fundación Contra la  
 Hipertensión Pulmonar**  
<http://www.fchp.es/es> - [info@fchp.es](mailto:info@fchp.es)  
<https://www.facebook.com/fundacionhp> -  
<https://twitter.com/fundacionhp>



**Hipertensión Pulmonar  
 España Organización de  
 Pacientes (HPE-ORG)**  
<http://www.hipertension-pulmonar.com/>  
[presidencia@hpe-org.com](mailto:presidencia@hpe-org.com)



**SWEDEN**  
**Nätverket för PAH**  
[www.pah-sverige.se](http://www.pah-sverige.se) - [patrik@pah-sverige.se](mailto:patrik@pah-sverige.se)



**SWITZERLAND**  
**Schweizer PH-Verein (SPHV) für  
 Menschen mit pulmonaler  
 Hypertonie**  
[www.lungenhochdruck.ch](http://www.lungenhochdruck.ch) - [www.sphv.ch](http://www.sphv.ch)  
 President: [praesi@lungenhochdruck.ch](mailto:praesi@lungenhochdruck.ch)  
 Webmaster: [bosshard@lungenhochdruck.ch](mailto:bosshard@lungenhochdruck.ch)



**TURKEY**  
**Pulmoner Hipertansiyon Derneği**  
[uatli@hotmail.com](mailto:uatli@hotmail.com)  
[www.phderneği.org.tr/](http://www.phderneği.org.tr/)



**UKRAINE**  
**Pulmonary Hypertension  
 Ukrainian Rare Disease Asso-  
 ciation-PH URDA**  
[o\\_kulish@inbox.ru](mailto:o_kulish@inbox.ru)



**Ukraine Association of Patients  
 with Pulmonary Hypertension**  
[www.pha.org.ua](http://www.pha.org.ua)  
[nfo@pha.org.ua](mailto:nfo@pha.org.ua)



**Pisana Ferrari - Via Cortazzis, 5 - 33100 Udine**  
**mob. +39 329 9214217**  
**[p.ferrari@phaeurope.org](mailto:p.ferrari@phaeurope.org)**

**Gerald Fischer - Vienna Office - Wilhelmstrasse, 19 - 1120 Vienna**  
**ph +43 1 4023725 - mob +43 6642288888 - fax +43 14093528**  
**[g.fischer@phaeurope.org](mailto:g.fischer@phaeurope.org)**

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