

early diagnosis • best treatment • better quality of life • finding a cure

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

# ACTIVITY REPORT 2016 & WORK PLAN 2017

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# 1. FOREWORD

Dear members, friends and supporters, welcome to PHA Europe's 2016 annual activity report and workplan for 2017.

2016 was a very busy year for PHA Europe, during which the association organised a number of awareness and advocacy initiatives as well as educational and capacity building programs.

World Pulmonary Hypertension Day (May 5), our main yearly awareness raising initiative, has become a very impressive display of capacity to reach out to society, and is ready to start being used as leverage in the bilateral talks between patient organizations and health authorities on issues such as access to treatments and surgery. It was celebrated in 2016 in 47 countries worldwide, with the involvement locally of influential figures such as health authorities, politicians and celebrities, and achieved very good media coverage.

The European Annual PH Conference 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.

Advocacy is also in the rise with a more prominent role for our representatives in the biggest and most influential EU level patient organizations, which serves to reinforce our position and our public exposure. The European Parliament event on Organ Donation and Transplant in October 2016, initiated by PHA Europe, is a good example of how far we have succeeded in reaching out to the decision makers at EU level, and this thanks to a close collaboration with the European patient federations for diseases where organ transplant is relevant (lung, liver, kidney and heart).

The capacity building activities are also providing very good results. Our member associations are increasingly active at national level and are more demanding, because they are stronger, which is excellent news. We are contributing to this process via our member support programs.

We cannot speak of our activities without mentioning the financial crisis and its consequences. In

2016 there was a very significant drop in our income, compared to the previous year, which led to a negative end-of-year balance. This was luckily compensated by leftover funds from the previous accounting year, but we will need, in future, to diversify our source of funding and seek alternative means. The available project funds were distributed among our main areas of activity: Awareness: 29%, Educational: 24%, Capacity Building: 20%, Advocacy 15% and Fund Raising 13%. PHA Europe, under the present Board and Management, made enormous efforts to keep these five blocks up and running. It was no easy task, but the objective of having an umbrella organization is to serve its members who in turn serve the patients. As you will see in this activity report, we managed in 2016 to deliver a quantity and quality of services that is above expectations, considering the reduced budget.

With regard to the general environment, there are important elements in the healthcare field that play in our favour as well as very serious stumbling blocks. It is widely recognised that patient input has great value in clinical management, drug development and the legislative progress. We have a key role to play also in the good financial management of national healthcare systems as we are a source of savings and labour that contribute to the sustainability of healthcare. We have the experience and vision and the capacity to raise our skills and knowledge, so that we can intervene in all those fields to make significant changes. Our stumbling blocks are that there is lack of experience to include the patients in all those fields as equal partners. As far as we are seen as beneficiaries we will not reach the quality of care that PH patients need to live longer and have acceptable quality of life. Things are changing luckily and patients are increasingly being involved in a number of ways but there is still a long way to go. It is exciting and it fills us with hope to see the potential we have at individual level and all the things we can do collectively so let us behold a better future.

*Pisana Ferrari, CEO*

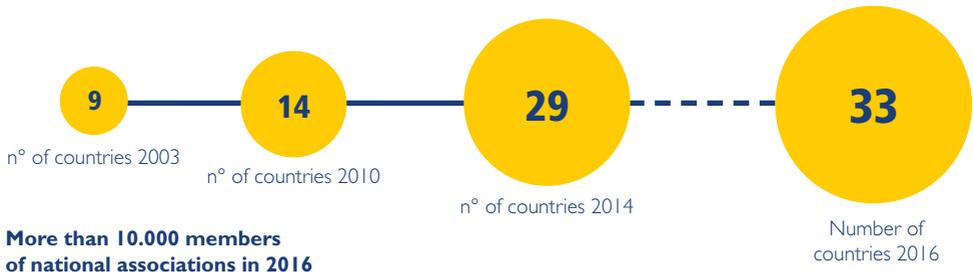
## 2. PHA EUROPE IN BRIEF

### 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 39 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 nine patient associations. Membership grew steadily up to 14 in 2010 and has more than doubled since. It currently stands at 39 patient organizations from 33 countries: Austria, 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, Serbia, Slovakia, Slovenia, Spain (2), Sweden, Switzerland (2), Ukraine (2), Turkey.



# 3. ORGANIZATION AND FUNDING

## BOARD AND AUDITORS 2015-2017



*Luc Matthysen*  
President



*Hans-Dieter Kulla*  
1st Vice President



*Mélanie Gallant Dewavrin*  
Treasurer



*Natalia Maeva*  
Vice Treasurer



*Ieva Plume*  
Secretary



*Laure Rosé*  
Vice Secretary



*Hendrik Ramaker*  
1st Auditor



*Vittorio Vivenzio*  
2nd Auditor

The PHA Europe Board is elected every two years at the Annual General Assembly (AGA) and consists of President, Vice Presidents, Secretary, Vice Secretary, Treasurer and Vice Treasurer. There are also two Auditors.

The current members of the Board and the Auditors represent patient associations from seven European countries: Belgium (Luc Matthysen and Hendrik Ramaker), France (Mélanie Gallant Dewavrin and Laure Rosé), Bulgaria (Natalia Maeva), Latvia (Ieva Plume) and Italy (Vittorio Vivenzio).

The current Board was elected at the AGA in September 2015 and its mandate ends in September 2017, when new elections will be held at the 2017 AGA.

PHA Europe Board members are all volunteers, working pro bono, whereas the staff members receive financial remuneration. In 2016 the Board held regular meetings online through Skype conference calls and had one face-to-face meeting in Barcelona during the Annual PH European Conference (APHEC). The Board is instrumental for the implementation of decisions taken at the AGA, as well as with regard to strategic planning.

## MANAGING THE ORGANIZATION

PHA Europe has five staff members. Pisana Ferrari (Italy) took over the position of CEO in July, the other members of the staff are Juan Fuertes (Spain), Advocacy and Access manager; Gerald Fischer (Austria), Financial Director; Hall Skaara (Norway), in charge of support programmes for the national associations and of IT, and Gergely Meszaros (Hungary), who collaborates actively in the advocacy field, in particular in the EUROPEAN REFERENCE NETWORK for rare Lung diseases, ERN-LUNG. We collaborate 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 and liaising with our A considerable amount of travel is involved to take part in scientific and other events.

PHA Europe is financed by means of membership fees as well as financial support from the pharmaceutical industry. This support may take the form of unrestricted grants or be related to specific projects.

## 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 2016 WPHD events were held in 47 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" programme 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 2016

## World Pulmonary Hypertension Day



For WORLD PULMONARY HYPERTENSION DAY (WPHD) 2016 once again people around the globe were encouraged to take part in sporting activities to "get breathless" for PH. This powerful way of highlighting the restrictions on physical activity provided an effective way to raise awareness of PH by bringing the challenges these patients face to the forefront. A record 30 European PH patient associations held "Get Breathless for PH" events. These ranged from a Viking Splash Bus tour around Dublin to an international backwards sporting event in Oslo. To help us raise awareness and fly the flag for PH patients around the world, our member associations enlisted the support of world famous figures from the participating countries. In Bulgaria alone, the local WPHD event had the support of the Minister of Health Petar Moskov and the Minister for Sports Krasen Kravlev.

For the first time ever, PHA Europe launched two Thunderclap social media online campaigns on the 5th of May: one sharing a message globally from PHA Europe and the second coming from the Latin America PH Society. An amazing 457 supporters signed up to send out a coordinated WPHD message in Europe, which read: "I am supporting #WPHD May 5 to show solidarity with pulmonary hypertension patients who struggle to breathe". This message achieved a social reach of 533,069 people. A further 500 people supported the WPHD Latin American PH Society Thunderclap, which reached an amazing 2,473,423 people. In total, these inspirational messages reached over 3 million people around the world, a fantastic result!

In Europe alone, thanks to the great work of our member associations, WPHD generated an impressive 218 press and online articles, 106 TV broadcasts and 20 radio broadcasts, across 23 countries, potentially reaching several million people.

In 2016 PHA Europe took its first step into digital communication, by speaking to the PH audience via Facebook. We were able to identify those who were already having conversations about PH and provide them with more information on how they could be part of WPHD. Over 4 million people saw our adverts, which encouraged over 35,000 people to visit the pages of local patient associations to learn more about our activities.

The PHA Europe website saw a high rise in engagement between April and July, including over 6,000 people visiting the website for more information and over 7,000 visits to the 'What is CTEPH' page after viewing the PHA Europe Facebook page on their mobile.

The PHA Europe Facebook page saw even better results, with the Facebook content reaching over half a million people and over 5,000 people liking, sharing or commenting on the WPHD posts. As a result, the PHA Europe Facebook page reached an impressive 8,809 likes.

WPHD activities also took place in Australia, Asia, North and South America, so that in total 47 patient associations across all continents contributed to spreading awareness!

### 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 2016

Despite progresses made in past years in the management of PH - new treatments, improved surgery techniques, the introduction of clinical guidelines and better management of the disease - we are still far from having achieved our objectives. Access to treatment and to surgery (including organ transplant) are still critical issues with wide disparities across Europe. Advocacy is therefore a very important part of PHA Europe's activities.

## Advocacy activities at EU level

### Access to treatment

PHA Europe was very active in 2016 in the field of access to treatment through our work at EU level in a number of important working groups such as the Drug information, Access and Transparency (DITA) task force of the EUROPEAN RARE DISEASE ORGANIZATION, EURORDIS, the EUROPEAN PATIENTS' FORUM (EPF) working group on access to treatment and the PATIENT ACCESS PARTNERSHIP (PACT).

### European Reference Networks

PHA Europe had planned to play an important role in the life of the European Reference Networks (network of rare diseases), set up by the EU on the basis of the cross border health directive, and officially approved in December 2016. Therefore it submitted applications to be part of the patient representative groups (ePAG) within the ERNs. Four representatives from PHA Europe were elected (Luc Matthysen and Gergely Meszaros for ERN-Lung and Juan Fuertes and Pisana Ferrari for ERN-TransChild). Pisana Ferrari is also part of the core network coordination team for ERN-Lung. The initial phase of such an important initiative is crucial, so we were happy to also to be elected in the Medical Steering Committee of ERN-Lung and contribute to several topics (eg. providing input in the draft by-laws)

### Organ Donation and transplant

PHA Europe's "Call to Action to improve organ donation and transplantation across the EU", was officially launched on European Organ Donation Day 2015 and has been endorsed by over 90 organizations, active at both EU and national levels.



Follow up activities include, in October 2016, a dedicated event in the European Parliament, hosted by three MEPs and attended

by leading European specialists in the field of organ donation and transplantation, as well as the main European public health NGOs and a number of European federations representing kidney, lung, heart and liver disease patients. The press materials issued for the event were picked up by almost 70 media outlets across the world and the estimated reach was over 70 million.

### Other advocacy opportunities

Taking part in international congresses, symposia and other events also provides interesting opportunities for advocacy. In 2016 PHA Europe representatives were invited to speak at and/or attend a number of prestigious such events (see page 9).

### National advocacy

PHA Europe is active in providing guidance and support to its member associations facing problems in the areas of access to treatment and organ donation and transplantation.

PHA Europe has written interventions for the Ministries of Health of Ukraine, Serbia, Republic of Macedonia, Portugal, Spain (Regional Ministry of Health). PHA Europe staff have participated at events with the local and national authorities in Ukraine (Round Table on Transplant in Lviv, Rare Disease Day in Kiev, Round Table on Access to Medicines in Kiev). These contributions have helped in the advances made by the national organizations obtaining the inclusion of new therapies in Serbia and Macedonia.

On a "solo" action, PHA Europe also started a dialogue with the pharma industry to improve access in Eastern Europe. As a result of this initiative, two countries (Serbia and Croatia) will benefit from a market access strategy to enlarge the number of available therapies, hopefully in 2017.

# 7. CAPACITY BUILDING 2016

Patient associations give invaluable support to patients and carers in a wide variety of areas, such as providing accessible and understandable information about the disease, practical advice for living with the condition and psycho-social support. They are therefore uniquely placed to advocate patient interests. PHA Europe's goal is to put in place a strong European PH community consisting of empowered national patient associations, working together to achieve common objectives. PHA Europe's capacity building activities include support programmes as well as educational and training opportunities.

## **“White Spots” program**

Countries in which there are no PH patient associations, are defined by PHA Europe as “White spots” on the map of Europe. Thanks to PHA Europe's support in past years through the White Spots program, there are now only very few countries left. Of the European countries with more than one million citizens, only two countries have no patient associations: Moldova and Albania. Contacts have been established there and we hope to soon get associations started in these two countries. Then PHA Europe will turn its attention to the four remaining countries with a population between half a million and a million citizens: Montenegro, Luxembourg, Malta and Iceland. We have made a booklet that describes the startup process and an easy to follow guide that new associations can follow. We will, for instance, provide them with sample statutes, set up a standard web page, etc. In this way, even only one dedicated person can manage to get a new association up and running.

## **Organization Development Program**

The next natural step after “colouring in” all the white spots, is to help the new associations to “mature”. The more efficient and self-reliant the associates get, the stronger PHA Europe, as an umbrella association, gets. Luckily, PHA Europe has some very advanced and strong associations under its umbrella. As a basis for the Organization

Development Program, PHA Europe has identified 40 areas of services that define a mature and well-organised association. Our aim is to work together with the member associations, to inform and educate them and assist them in providing the missing services. More mature associations will be used to help and guide less mature associations. In this way, we will use “best of practice” method to help make the associations as well as PHA Europe stronger.

## **“Fellowship” programme**

PHA Europe's “Fellowship” programme was launched in 2013 as a pilot project, with the aim of improving communications between the member associations. English has been the working language since PHA Europe was first set up in 2003. With its rapid expansion language barriers had become a major challenge, in particular for those associations where command of English was limited. Through the “Fellowship” programme PHA Europe provides the member associations with a part-time assistant with a good knowledge of English. The part-time assistant acts as a liaison person with PHA Europe and also helps the association in its day-to-day work. In 2016 PHA Europe was able to provide 20 member associations with a “Fellow”. The program has been very successful in improving communications as well as in increasing the level of engagement of the national associations in PHA Europe projects such as, for example, World Pulmonary Hypertension Day.

## **Annual PH European Conference**

The Annual PH European Conference also provides member associations with opportunities for sharing information and experiences, mutual learning, networking and education and skills development. Read more about this 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 2016

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 contains news of activities organized by the national patients associations, reports on PHA Europe meetings and initiatives, summaries of relevant scientific congresses, EU developments in the field of public health and research as well as the latest updates on PH treatments. The journal is targeted mainly at PHA Europe's member associations. However, it 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 2016 we have continued to update our

website to include the most up to date information. We were also very active on social media channels with a very big increase in number of followers in Facebook and Twitter.

In 2016 we celebrated one - very successful - year 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 this year the PH Library had over almost 40.000 website visits and 55.000 page views (see infographic below on left).

## Annual PH European Conference

The Annual PH European Conference (APHEC) gives member associations opportunities for capacity building as well as for information and education.

The 2016 APHEC featured three international PH medical opinion leaders as speakers, a cardiologist, a pulmonologist and a paediatrician, who provided the attendees with the latest information on treatment strategies, surgery and research. We also had a very interesting lecture on the European Reference networks and in particular ERN-Lung (1).



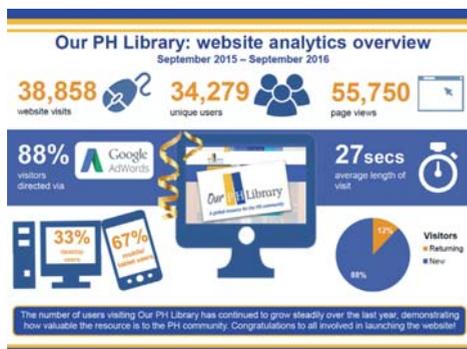
Prof. Marc Humbert, from France, speaks of ERN-LUNG at the APHEC

Sixty-three PH Patient Leaders from thirty European countries attended the 2016 APHEC.

## Other conferences

Attending European and international congresses, workshops etc. also provides opportunities for the dissemination of information at a very high level (see pages 9-12).

*Note 1. At the time of the APHEC the ERNs had not yet been approved officially by the EU, this happened in December 2016.*



## 9. WORKSHOPS AND CONFERENCES 2016

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 2016 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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### **Brussels (Belgium), January 19** **PATIENT ACCESS PARTNERSHIP (PACT)**

Participation at two meetings of PACT: ad hoc working group on "access package" and "mapping workstream" - *Juan Fuertes*

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### **Geneva (Switzerland), January 28** **EUROPEAN LUNG FOUNDATION (ELF)**

Participation at the meeting of the Patient Advisory Council (PAC) of the ELF - *Juan Fuertes*

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### **Amman (Jordan), February 3-7** **ANNUAL PH** **CONFERENCE** **OF THE SAUDI PHA**

"PH from the patient perspective" - *Pisana Ferrari*



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### **Brussels (Belgium), February 4** **EUROPEAN PATIENTS FORUM (EPF)** **LEADERSHIP MEETING**

Attended by *Luc Matthysen*

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### **Brussels (Belgium), February 24-25** **MULTI-STAKEHOLDER SYMPOSIUM**

Symposium on "Improving Patient Access to Rare Disease Therapies, organised by EURORDIS - *Juan Fuertes*

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### **Kiev (Ukraine), February 29** **RARE DISEASE DAY CONFERENCE**

Organized by the Ukrainian Rare Disease Alliance. Juan Fuertes was invited to give a lecture on legislative development in the EU about rare diseases - *Juan Fuertes*

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### **Brussels (Belgium), March 21-23** **EUROPEAN PATIENTS FORUM (EPF)** **GENERAL ASSEMBLY**

Attended by Luc Matthysen and Juan Fuertes. Juan was elected Board Member with a 2 year mandate.

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### **Brussels (Belgium), April 7** **EUROPEAN REFERENCE NETWORK** **(ERN) LUNG**

Core coordination meeting in Brussels - *Juan Fuertes*

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### **Dublin (Ireland), April 14-17** **PHA IRELAND ANNUAL PATIENT** **MEETING**

*Hall Skaara* participated and ran two presentations covering lifestyle and exercise in PH patients.



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**Zurich (Switzerland), April 21**  
**ELF COUNCIL MEETING**

European Lung Foundation (ELF) Council meeting  
- Juan Fuertes, Member of the Council.

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**Zurich (Switzerland), April 22**  
**EUROPEAN RESPIRATORY SOCIETY**  
**(ERS) SPRING MEETING AND**  
**EUROPEAN LUNG FOUNDATION**  
**(ELF) COUNCIL MEETING**

Juan Fuertes

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**Rome (Italy), April 22-23**  
**EUROPEAN SOCIETY FOR ORGAN**  
**TRANSPLANT (ESOT) ANNUAL**  
**CONGRESS**

Attendance at ESOT Annual Congress Transplant Congress - Juan Fuertes

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**Buenos Aires (Argentina), May 4-5**  
**CELEBRATIONS FOR WORLD PH DAY**

Attendance at the celebrations for WPHD of the Latin PH Society - Juan Fuertes

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**Düsseldorf (Germany), May 11**  
**WORKING GROUP ON ACCESS OF THE**  
**EUROPEAN PATIENTS FORUM (EPF)**

Attended by Juan Fuertes, Member of EPF Board

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**L'viv (Ukraine), May 12**  
**ROUND TABLE ON TRANSPLANT**

Organized by the Sister Dalila Foundation - Juan Fuertes gave a talk promoting the improvement of transplant legislation.

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**Namur (Belgium), May 20**  
**9ÈME JOURNÉE DU PARTENARIAT**

Pisana Ferrari was invited to speak at the Belgian National Lung Transplant Center; Mont-Godinne, Namur; about her experience of lung transplant.

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**Edinburg (UK), May 22**  
**EUROPEAN CONFERENCE ON RARE**  
**DISEASES (ECRD)**

Pisana Ferrari was invited to speak on "How to develop a successful advocacy campaign using surveys and getting members and policy makers involved".

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**Amsterdam (the Netherlands), May 27**  
**ROUND TABLE OF THE EUROPEAN**  
**SOCIETY OF CARDIOLOGY (ESC)**

Juan Fuertes attended the Round Table of the ESC where he was invited to make a presentation about the sustainability of healthcare.

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**Brussels (Belgium), May 30**  
**MEDICINES FOR EUROPE**

"Value Added Medicines: Rethink, Reinvent & Optimise Medicines, improving Patients Health & Access" - organized by "Medicines for Europe" - Attended by Juan Fuertes

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**Varna (Bulgaria), June 8-10**  
**ANNUAL CONGRESS OF THE**  
**BULGARIAN SOCIETY**  
**FOR RESPIRATORY MEDICINE**

Pisana Ferrari was invited to speak on "The role of patient associations and successful awareness and advocacy campaigns".

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**Vienna (Austria), June 9**  
**EUROPEAN PATIENTS FORUM (EPF)**  
**BOARD MEETING**

Attended by Juan Fuertes

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**Lisbon (Portugal), June 13-14**  
**EUROPEAN RESPIRATORY SOCIETY**  
**(ERS) PRESIDENTIAL SUMMIT**

Juan Fuertes was invited to make a presentation on patient empowerment at the ERS Summit for Chairpersons of ERS Councils.

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**Madrid (Spain), June 17**  
**FIRST CONGRESS ON PATIENTS**  
**EXPERIENCE**

Organized by the "Spanish Institute for Patients'

Experience". *Juan Fuertes* made a presentation on the role and need of empowerment of patients' organizations in advocacy.

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### **Dallas, June 17-19** **PHA INTERNATIONAL CONFERENCE**

*Gerald Fischer* attended the PHA International Conference in Dallas and was invited to make a presentation about fundraising. In this photo he is with the Immediate Past President of the PHA, *Rino Aldrighetti* (right), and the new President and CEO *Brad Wong* (left).



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### **Brussels (Belgium), June 22** **HIGH-LEVEL POLICY ROUNDTABLE -** **"MAKING EMPOWERMENT A REALITY:** **PATIENTS AS PARTNERS" AT THE** **EUROPEAN PARLIAMENT**

The event presented the main achievements of the campaign and offered a platform for exchange of good practices and patients testimonials - attended by *Juan Fuertes*

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### **Brussels (Belgium), June 29** **PATIENT ACCESS PARTNERSHIP** **(PACT) EVENT AT THE EU** **PARLIAMENT**

The theme of this meeting was "Better Access Better Outcomes" - *Juan Fuertes*

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### **Rome (Italy), August 27-30** **EUROPEAN SOCIETY OF CARDI-** **OLOGY (ESC) ANNUAL CONGRESS**

*Pisana Ferrari* attended the ESC Annual Congress sessions on pulmonary hypertension and CTEPH on behalf of PHA Europe.

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### **London (United Kingdom), September 3-6** **EUROPEAN RESPI-** **RATORY SOCIETY** **(ERS) ANNUAL** **CONGRESS**

*Pisana Ferrari* was invited to



speak at a joint PHA Europe-ERS Symposium on "Future challenges for PH patients" and speak at a session on physical exercise in PH. During the ERS Congress a European Lung Foundation (ELF) Council meeting was held which was attended by *Juan Fuertes*, Council Member.

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### **Barcelona (Spain), September 14-18** **PHA EUROPE'S ANNUAL PH** **EUROPEAN CONFERENCE (APHEC)**

Attended by 63 PH Patient Leaders from 30 countries and featuring leading KOLs *Marc Humbert* (France), *Irene Lang* (Austria) and *Maurice Beghetti* (Switzerland) as medical guest speakers.

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### **Madrid (Spain), September 30** **HEALTH TECHNOLOGY ASSESSMENT** **(HTA) MULTI-STAKEHOLDER** **WORKSHOP**

Organized by the Spanish Royal College of Pharmacy - *Juan Fuertes*

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### **Sofia (Bulgaria), October 7-9** **BULGARIAN PATIENT MEETING**

*Hall Skaara* participated in PHA Bulgaria's annual patient meeting. He ran two presentations covering lifestyle and exercise in PH.

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### **Sophia Antipolis (France), October 14-15** **EUROPEAN SOCIETY OF** **CARDIOLOGY (ESC) ANNUAL** **EDUCATIONAL COURSE ON PH**

*Pisana Ferrari* was invited to present the PH patient view of the current joint ESC/ERS clinical guidelines on PH.



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### **Brussels (Belgium), October 18** **EUROPEAN PARLIAMENT EVENT ON** **ORGAN DONATION AND TRANSPLANT** **(ODT)**

Meeting hosted by Members of European Par-

liament Jakovcic, Vautmans, Tomc and Peterle on the initiative of PHA Europe and as a follow up to the "Call to Action on ODT" launched in 2015 - Pisana Ferrari, Luc Matthysen and Juan Fuertes attended.

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**Brussels (Belgium), October 28**  
**PATIENT ACCESS PARTNERSHIP (PACT) FACE TO FACE MEETING**

Attended by *Juan Fuertes*

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**Paris (France), November 2-4**  
**EURORDIS COUNCIL OF EUROPEAN FEDERATIONS**

*Juan Fuertes* attended this annual training session organised by EURORDIS

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**Brussels (Belgium), November 7**  
**WORKING GROUP ON ACCESS OF THE EUROPEAN PATIENTS FORUM (EPF)**

Attended by *Juan Fuertes*

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**Brussels (Belgium), November 8-9**  
**PATIENT INVOLVEMENT IN PATIENT SAFETY**

Organized by European Patients Forum (EPF) - *Juan Fuertes*



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**Vienna (Austria), November 19-20**  
**ANNUAL CENTRAL EUROPEAN PH CONFERENCE**

Pisana Ferrari was invited to speak on "PAH and the patient perspective".

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**Lisbon (Portugal), November 23**  
**HEALTH CLUSTER CONFERENCE**

EU funded platform that aims to create the best conditions and induce the best healthcare practices in Portugal. *Juan Fuertes* made a presentation on Patient Involvement



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**Brussels (Belgium), November 25**  
**EUROPEAN PATIENTS FORUM (EPF) BOARD MEETING**

*Juan Fuertes* attended as Member of the Board.

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**Brussels (Belgium), November 28**  
**PATIENT ACCESS PARTNERSHIP (PACT) EVENT AT THE EU PARLIAMENT**

Presentation of "Health at a Glance", meeting attended by *Juan Fuertes*.

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**Zurich (Switzerland), November 29**  
**MULTISTAKEHOLDER WORKSHOP ON PATIENT SELF MANAGEMENT**

A number of patient representatives from PHA Europe and the PHA attended this workshop dedicated to self management in PH, together with members of the nursing and medical professions. The workshop was organised in collaboration with Actelion Pharmaceuticals, Switzerland.



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**Basel (Switzerland), November 29**  
**DRUG DISCOVERY DAY**

*Pisana Ferrari* was invited to speak about "Living and coping with PH" at the annual event dedicated to research organised by Actelion Pharmaceuticals, Switzerland.



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**Kiev (Ukraine), December 3**  
**ROUND TABLE ON ACCESS TO RARE DISEASES' TREATMENT**

Organized by the Ukrainian National Rare Disease Alliance - *Juan Fuertes*

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**Vienna (Austria), December 5**  
**17TH IASLC WORLD CONFERENCE (LUNG CANCER ANNUAL EVENT)**

*Juan Fuertes* made a presentation on Patient Advocacy.

# 10. WORK PLAN 2017

## AWARENESS

Over 47 countries across five continents took part in the 2016 global awareness campaign for World Pulmonary Hypertension Day (WPHD) with incredible results in terms of reach and media coverage. In 2017 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". WPHD will also be on social media through the online platform "Thunderclap". PHA Europe will also be running in 2017 an awareness campaign called #TimeMatters, which will end in the summer of 2017. 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. Time is important in many other ways as well. Four patient associations have been given the task to find patients or carers to make short videos about different themes related to time. Each participant also writes a short blog that accompanies the video. It is striking to see how similar the patients experience their problems even though they come from different corners of Europe. Each video is subtitled in more than 15 different languages and shared among PHA Europe's member associations through social media platforms. This gives the videos and blogs a bigger reach and helps to create both awareness for the disease and awareness of PH patients' life styles. Once finished, all the videos and blogs will be collected on PHA Europe's website, in the dedicated section, and the end-of-project report will be officially presented at the Annual PH Conference in Barcelona in September 2017.

## ADVOCACY

### EU level

Our current advocacy activity at the EU level includes careful monitoring of any public health or research developments potentially of interest to us, the submission of position papers on EU initiatives and actions on specific public health issues. Our main focus for 2017 will continue to be access to treatment as this is a critical issue for many of our patients. We will continue to be actively engaged at European level in the task forces and working groups dedicated to access to treatment (see also pages 9-12).

Very importantly, we will also be following up on the success of the launch of our "Call to Action to improve organ donation and transplantation across the EU" (see page 6) by creating an informal group

with the European federations for diseases of the lung, heart, kidney and liver; in order to work together towards improving organ donation and transplant in Europe.

### National level

In 2017 we will be collaborating closely with the members in order to provide guidance on possible strategies to adopt at national level to advocate for patient rights. We know that at national level advocacy is a long term investment, however; PHA Europe members feel that there is one more step to reinforce supranational efforts in the access field. Thus, PHA Europe is taking on 2017 the first steps in organizing cluster groups of countries to work on access at regional level.

## 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 Development

Program, we will help all associations “mature”.

Through the “Fellowship” programme, which is currently in place in 20 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 2017 we do plan to continue to make improvements to our website: new sections are in the pipeline, 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 2016 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 first year in 2016. 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. The results of the first year post launch were great (see page 8). This gives us great hopes

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, is also a Member of the Council of the EUROPEAN LUNG FOUNDATION (ELF), which is part of the European Respiratory Society.

PHA Europe representatives have taken part in in past years, including 2016, 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 2016



**AUSTRIA**  
Selbsthilfegruppe Lungenhochdruck  
[www.lungenhochdruck.at](http://www.lungenhochdruck.at)  
[info@lungenhochdruck.at](mailto:info@lungenhochdruck.at)



**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)



**Patiëntenvereniging Pulmonale Hypertensie vzw**  
[www.ph-vzw.be](http://www.ph-vzw.be)  
[hendrik.ramaker@skynet.be](mailto:hendrik.ramaker@skynet.be)



**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) - [bspph@gmail.com](mailto:bspph@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 Pačs Plicni 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-potilasyhdistys ry.  
PHA Finland  
[pha.fin@gmail.com](mailto:pha.fin@gmail.com)



**FRANCE**  
HTaP France  
[www.htapfrance.com](http://www.htapfrance.com)  
[secretariat@htapfrance.com](mailto:secretariat@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.aipiitalia.it](http://www.aipiitalia.it) - [presidente@aipiitalia.it](mailto:presidente@aipiitalia.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)



**LITUANIA**  
Žmonių Sergančių Plautine Hipertenzija Asociacija  
[www.phalithuania.eu](http://www.phalithuania.eu)  
[kovaliova.nastya@gmail.com](mailto:kovaliova.nastya@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 APHP**  
[www.aphp-hp.org](http://www.aphp-hp.org) -  
[mariajsaraiva@gmail.com](mailto:mariajsaraiva@gmail.com)



**REPUBLIC OF MACEDONIA**  
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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)



**SERBIA**  
**Plućna Hipertenzija Srbija**  
[danijela@petic.rs](mailto:danjela@petic.rs)



**SLOVAKIA**  
**Združenie pacientov s pľúcnou 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>



**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)



**Association HTAP Revivre**  
[www.saph.ch/SuisseRomande](http://www.saph.ch/SuisseRomande)  
 President: [lydia\\_mb@bluewin.ch](mailto:lydia_mb@bluewin.ch)  
 Coordinator: [monika.sorgemaitre@hcuge.ch](mailto:monika.sorgemaitre@hcuge.ch)



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



**UKRAINE**  
**Pulmonary Hypertension Ukrainian Rare Disease Association-PH URDA**  
[o\\_kulich@inbox.ru](mailto:o_kulich@inbox.ru)



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

**Gerald Fischer, GM - 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)**