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# ACTIVITY REPORT 2015 & WORK PLAN 2016

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Dear members, friends and supporters, welcome to PHA Europe's 2015 annual activity report and workplan for 2016. As in past years, PHA Europe has been active mainly in the areas of awareness raising, advocacy, capacity building and information and education.

To start with, we are very happy and proud of the results of our annual awareness campaign for WORLD PULMONARY HYPERTENSION DAY, May 5th. Over 40 PH patient associations across five continents took part in the campaign, of which twenty six in Europe alone. Importantly, a number of influential public figures, politicians and celebrities publicly pledged their support to the campaign. We had excellent media coverage, with over 500 articles in press and online media and almost 100 TV and radio clips, as well as about 500.000 reach through Facebook and Twitter.

Secondly, we had a busy year in the field of advocacy, with a very active and high level involvement in policy discussions on access to treatment - which is one of the really critical areas for our patients - in the context of a number of European working groups or task forces we are part of. These include the EUROPEAN ORGANIZATION FOR RARE DISEASES (EURORDIS), the EUROPEAN PATIENTS' FORUM (EPF), and the PARTNERSHIP ON ACCESS TO TREATMENT (PACT).

As part of our focus on access to treatment this year we decided to initiate a campaign to raise awareness specifically on the problems of organ donation and transplantation (ODT): shortage of donors, long waiting lists, high mortality on lists, lack of transplant centres, etc. We officially launched a cross-condition "Call to Action to improve ODT across the EU on October 10, EUROPEAN ORGAN DONATION DAY (EODD). The Call to Action has so far received the endorsement of over 90 organizations, active at EU and national level. Further activities are planned in this area for next year; see also the dedicated section of this report.

Despite our active engagement we are far from having achieved our objectives. PH is still a little-known disease, diagnosis can take up to three years, even in the most advanced countries and, as mentioned above, access to approved treatments or transplant is a critical issue in many

others. In addition, the whole area of psychosocial support, which is vital in a chronic, fatal and progressive disease such as PH, still needs to be addressed. Until minimal standards of care are met in all countries, our collective efforts must continue.

PHA Europe's ultimate goal is to put in place a strong European PH community consisting of empowered national patient associations working together to achieve common objectives. In the course of this year PHA Europe has provided support to its member associations through two programmes. The "White Spots" programme provides start up funds and guidance for new associations. The "Fellowship" programme, which provides member associations with a paid part-time English speaking assistant, is vital to ensure communications and overcome language barriers. Educational and training opportunities for PH patient leaders were also available through various channels, including the Annual PH European Conference, which featured, once again, a prestigious panel of internationally renowned specialists in PH and other areas of interest to PHA Europe.

Our community has further grown this year, with six new associations joining. It now includes 39 PH patient associations from 33 countries. PHA Europe is increasingly recognized as the key stakeholder in the field of PH in Europe. We have this year again been asked to endorse important scientific events and prestigious educational university programmes. We have been invited to speak at and/or attend numerous conferences and other events and are actively involved in health care policy through the participation not only in the working groups mentioned above but also in important scientific professional societies (EUROPEAN LUNG FOUNDATION, ELF) and regulatory agencies (EUROPEAN MEDICINES' AGENCY, EMA).

We thank our member associations and our valued partners for their continuing support, without whom none of this would have been possible and look forward to another year of close and successful collaboration.

Gerald Fischer

## 2. PHA EUROPE IN BRIEF

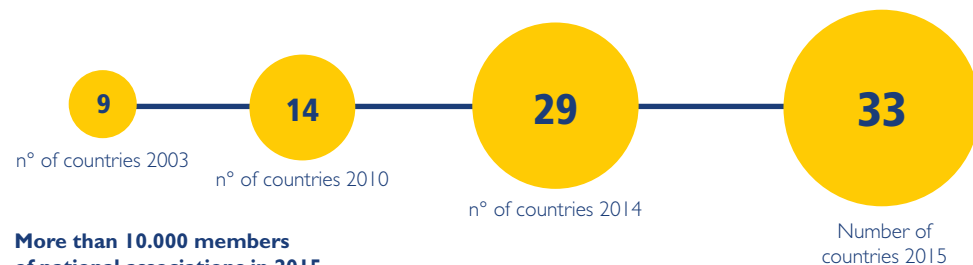
### BACKGROUND AND MISSION

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 members 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: raising awareness, advocacy, capacity building, information and education.

### KEY FIGURES



### MEMBERSHIP

PHA Europe was founded in 2003 in Vienna by nine patient associations. Over the years 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. ORGANISATION AND FUNDING

### BOARD AND AUDITORS 2014-2015



The PHA Europe Board is elected every two years at the Annual General Assembly (AGA) and consists of a President, two Vice Presidents, Secretary and Vice Secretary, Treasurer and Vice Treasurer. There are also two Auditors. The current members of the Board and the Auditors represent nine patient associations from seven European countries: Austria, Belgium, France, Hungary, Italy, Norway, Spain. The new Board, whose mandate will run from January 2016 to December 2017, was elected at the AGA in September 2015.

The Board meets twice a year, once in the summer in Barcelona during the Annual PH European Conference (APHEC) and again in Vienna in the winter. In the course of the year it also holds regular Skype conference calls. The Board is instrumental for the implementation of decisions taken at the AGA, as well as with regard to strategic planning.

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.

### MANAGING THE ORGANIZATION

PHA Europe's head office is in Vienna. The current President, Gerald Fischer, works out of the Vienna office with the support of a full time assistant. The head office works in close collaboration with the Vice President, Pisana Ferrari, in Milan and the Secretary, Juan Fuertes, in Madrid. Two task forces have been set up to manage the support programmes for the national associations and IT, coordinated by Hall Skaara, Vice Treasurer, in Oslo.

Day to day management typically includes programming and implementing PHA Europe activities and events, networking and coordinating with the national member associations, correspondence

and contact programmes, monitoring and information gathering, financial and administrative tasks and liaising with our Brussels based Public Affairs consultant, implementing EU-level advocacy work. External consultants are also used for legal counsel - Gergely Meszaros in Budapest - as well as book keeping and tax advice. A considerable amount of travel is involved in order to participate in scientific events and take part in the work of advisory committee meetings and task forces.

A reorganization of PHA Europe is planned for 2016, with separate functions for Board and Staff.

## 4. MAIN AREAS OF ACTIVITY

### AWARENESS RAISING 2015



PHA Europe has successfully conducted annual global awareness campaigns for the last five years. The first two campaigns were organized on International Rare Disease Day (February 28). More recently campaigns have revolved around World PH Day (May 5). The theme is sport, with the slogan “Get breathless for PH”. For the last three years WPHD celebrations have included the participation as “Official Charity Partner” in IRONMAN, one of the world's most challenging sport's events.

### ADVOCACY 2015

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.



### CAPACITY BUILDING 2015



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.

### INFORMATION 2015

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.



## 5. AWARENESS RAISING 2015

### World Pulmonary Hypertension Day

For WORLD PULMONARY HYPERTENSION DAY (WPHD) 2015 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, experienced by PH patients, provided an effective way

to raise awareness of PH by bringing the challenges these patients face to the forefront.

In 2015 twenty-six European countries held “Get Breathless for PH” events as part of WPHD. More and more celebrity endorsers and influential public figures are joining the PH cause every year; including, for 2015, political leaders and health ministers, sporting heroes such as The World's Strongest Man, Franz Müllner, Olympic Gold Medal swimmer Federica Pellegrini and World Champion free diver, Goran Čolak, as well as the world-known Riverdance group, rock bands “Beni and Non Stop” and “Neverland” and singing sensation Iván Gardesa.

Each country put its own unique twist on their WPHD events, ranging from Irish dancing from our Gaelic friends to the breathtaking feat of climbing the snowy peaks of Rysy Mountain by members and supporters of the Czech and Slovakian associations. WPHD activities also took place in 17 other countries across the globe including Australia, Canada, China, Latin America, the Middle East and the U.S.A, meaning PH awareness was spread across 43 countries in five continents. All the national events worldwide were showcased through a dedicated website set up in 2013 by the US PH association (PHA) and there is a detailed report in the Summer 2015 edition of the Mariposa Journal.

This year, in Europe, in addition to the activities conducted around the “Get breathless for PH” theme, we also introduced the #BreathofSuccess initiative to the campaign, an educational, story-

sharing activity that aimed to increase understanding of chronic thromboembolic pulmonary hypertension (CTEPH), the only type of PH to have potentially curative surgery without having to resort to lung transplant.

The media once again played a vital role in accelerating the reach of WPHD: it generated over 500 print/online articles and almost 100 TV/radio clips. Social media also proved to be a great platform to drive momentum and helped us to spread our messages. The PHA Europe Facebook and Twitter pages received a huge surge in page visits and “likes” indicating increased levels of engagement.

In 2015 PHA Europe launched for the second year running a World PH Day “Thunderclap”, an online social media “flashmob”: one hundred and fifty-eight people signed up to send out a coordinated World PH Day message from their social media channels on 5 May, with a social reach of almost 140,000 people. We estimate the total social media reach at about 500,000. Finally, there were over 2,000 uses of the hashtag #BreathofSuccess.

### Ironman Official Charity partnership

For the third year in a row we were proud to be the Official Charity Partner of the IRONMAN EUROPEAN TOUR. We were present at the European Championship which was held in Frankfurt on July 5, with 6 athletes running for PH. Through the race-newsletters alone we reached 100,000 people, hundreds of thousands more were reached



through attendance at the race and news posted on Ironman's website and social media.

### 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 2015

Despite the huge progresses made in past years, which include 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. Much remains to be done in a number of areas. Access to treatment, in particular, is a critical issue in many countries, with dramatic consequences for patients in terms of health outcomes and the important role of psycho-social support is still not fully recognized. Access to treatment in the broader sense of the word also includes organ transplantation. Here again in some countries this is major problem, with either no transplant centres available or very long waiting lists, with a high mortality while waiting for the call. Advocacy is therefore a very important part of PHA Europe's activities. Our advocacy actions are directed mainly at the EU Institutions but we also support national initiatives.

### Advocacy activities at EU level

In recent years the EU institutions have taken a number of interesting initiatives in the field of public health which are relevant to PH, for which PHA Europe has responded to calls for consultations or submitted position papers. In the course of 2015 PHA Europe submitted position papers on two key EU policy documents: the "Preliminary Opinion by the Expert Panel on Effective Ways of Investing in Health - Access to Health Services in the European Union" and the EU cross border directive.

We have been very active 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, which was chaired by one of our members this year and the PATIENT ACCESS PARTNERSHIP (PACT), set up in 2015. With regard to organ donation and transplantation PHA Europe this year has taken the lead in launching a cross-condition "Call to Action to improve organ donation and transplantation across

the EU". This Call to Action was officially launched on EUROPEAN ORGAN DONATION DAY (EODD) in Lisbon on October 10 and has so far been endorsed by over 90 organizations, active at both EU and national levels, including the main scientific professional societies in the area of cardiology and respiratory medicine (ESC and ERS), EURORDIS, and the two main public health stakeholders at EU level, the EUROPEAN PATIENTS' FORUM (EPF) and the EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA), as well as a number of disease-area related European associations representing kidney, lung, heart and liver patients. Additionally many important organizations at national level have endorsed the Call to Action including 12 organ donor or transplant societies. At EU institution level we are very honoured that MEP Karen Kadenbach publically supported the Call to Action on October 10 with an article and posts on her social media channels. Contacts with other MEPs and Commission officials have also been very very promising in terms of future support. We are continuing to collect endorsements throughout the year and have some interesting follow-up awareness and advocacy activities planned around the Call to Action for 2016 (see page 13).

Taking part in international congresses, symposia and other events also provides interesting opportunities for advocacy. Once again this year PHA Europe Board Members were invited to speak at and/or attend a number of prestigious such events (see pages 9-12).

### National advocacy

At national level PHA Europe is active in providing guidance and support to associations facing problems in the areas of access to treatment and organ transplantation.



## 7. CAPACITY BUILDING 2015

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 and 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" programme

Despite many new patient associations having been set up in recent years, there are still some countries without (see the light blue areas on the map below). Through its "White Spots" programme PHA Europe offers start-up funds and support for associations wishing to set up and to recently established ones.

In January 2015 PHA Europe held a workshop in Oslo, Norway, for PH patients interested in setting up a patient association in their countries



and for recently founded associations. The aim was to present PHA Europe and its activities and to provide guidance and support with registration and administrative issues, patient association management issues, IT and publications. Attendees included PH patient representatives from Belarus, Croatia, Russia, Serbia and the Ukraine. The workshop was followed up in the course of the year with Skype calls and conference calls with the new associations in order to help them apply for membership at the PHA Europe Annual General Assembly in September 2015.

Contacts have recently been established with patients in Estonia and Iceland with the aim of providing support to help them establish their own national associations in the coming year.

### "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 between 2010 and 2015 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 2015 PHA Europe was able to provide 15 national member associations with a "Fellow": these associations were from Bulgaria (BSPPH and PHA), the Czech Republic, Finland, Lithuania, Greece, Hungary, Italy, Israel, Latvia, Poland, Slovakia, Slovenia, Portugal, Switzerland and the Ukraine.

The Fellowship programme was very successful and considerably improved communications as well as the level of engagement of the national associations in PHA Europe projects such as WPHD and IRONMAN.

### 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 (see 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 2015

The dissemination of up-to-date information about PH 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 PHA Europe newsletters are issued periodically and consist of brief one page summaries of recent activities in fields which are relevant to PH. Three newsletters were issued in 2015.

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 and newsletters are 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 and EUROPEAN RESPIRATORY SOCIETY's annual congresses.

### Website, social media and online platforms

Other information channels include the PHA Europe website and social media platforms. In the course of 2015 we carried out a very comprehensive review of the website, with improvements to the geo-locator, which directs viewers to PH physicians and centres across Europe, with new sections, providing information on different topics, including links to new educational materials developed in 2015. We also created mobile and tablet versions of the website and focused on search engine optimization, in order to improve the website's traffic. We were also very active on

social media channels with a very big increase in number of followers in particular on Twitter, which we started only very recently (May 2015) and now has 650 followers (Facebook has over 7.000). The true highlight of the year in terms of information dissemination was the launch of "Our PH Library", a



comprehensive online platform where over 200 resources (booklets, videos, etc.) from PH asso-

ciations around the world, in 24 languages, have been indexed and are readily available for all through an easy "search" function.

### Educational & training sessions

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

This year's APHEC featured three international PH medical opinion leaders as speakers, who provided the attendees with the latest information on new drugs, treatment strategies, surgery and new developments in research. It also had lectures on advocacy & lobbying at national and EU level and fundraising and presentations from our industry partners. Seventy-one PH Leaders from thirty-one countries attended the 2015 meeting.



Prof. Nazzareno Galiè from the University of Bologna, Italy, at the APHEC 2015

### Conferences

Attending European and international congresses, workshops etc. also provides opportunities for the dissemination of information at a very high level.

## 9. WORKSHOPS AND CONFERENCES 2015

PHA Europe representatives are increasingly invited to take part in important congresses, symposia, workshops and other events. They 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 2015 there were an average of two 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 organisations (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.

### Brussels, January 14 DITA TASK FORCE CONSULTATION ON SUPPLEMENTS

DITA is the DRUG INFORMATION, TRANSPARENCY AND ACCESS task force of EURORDIS, the EUROPEAN ORGANIZATION FOR RARE DISEASES. Juan Fuertes and Luc Matthysen are both members and took part in this consultation on behalf of PHA Europe.

### Oslo, January 15 "WHITE SPOTS" TRAINING MEETING

This meeting was organized to present PHA Europe and provide guidance and support to PH patients setting up new PH associations in their countries and for recently founded groups. It was attended by PH patients from Belarus, Croatia, Russia, Serbia and the Ukraine. "White Spots" are the countries which have no patient associations.

### Brussels, February 23 EURORDIS RARE DISEASE DAY POLICY MEETING



Juan Fuertes, Luc Matthysen, Pisana Ferrari, Hans-Dieter Kulla and Gergely Meszaros attended the

EURORDIS policy meeting on behalf of PHA Europe. The policy meeting was followed by the traditional RARE DISEASE DAY "Black Pearl" Gala.

### London, March 6-7 SIR JOHN VANE SYMPOSIUM ON PROSTANOIDS (UT)

This annual international scientific conference on prostanoids in the treatment of PH was attended by over 200 medical professionals.

PHA Europe was represented by Pisana Ferrari, in the photo at right with Lady Jane Vane, wife of the late Sir John Vane, Nobel Prize winner for his work on prostacyclins.



### Riga, March 18 CHRONIC DISEASES SYMPOSIUM

Juan Fuertes represented PHA Europe at this international conference organized within the framework of the Latvian Presidency of the Council of the European Union. He gave a lecture entitled "Access to Care: Economic and Human Rights". The symposium resulted in a resolution from Latvia about involvement of chronic disease patients in health care processes and quality of treatment and care and their reintegration into an active economic and social life.

**Lisbon, March 22**  
**EUROPEAN PATIENTS FORUM (EPF) MEETING**

Juan Fuertes represented the EPF replacing Nicola Bedlington (EPF Executive Director) at a workshop for high profile international managers of Sanofi Pasteur.

**Barcelona, March 24-25-26**  
**EYE FOR PHARMA**

Juan Fuertes represented PHA Europe at this conference that is mainly addressed to the pharmaceutical industry. The main objective was to put the patient at the center of the pharmaceutical world.

**Copenhagen, March 27**  
**PULMONARY HYPERTENSION FORUM (ACTELION)**

Pisana Ferrari represented PHA Europe and was given the honour of opening the forum which featured a prestigious panel of speakers and was attended by over 1.000 persons.

**Brussels, March 30**  
**EUROPEAN PATIENTS FORUM (EPF) WORKING GROUP ON ACCESS**

Juan Fuertes from PHA Europe chaired this meeting. The outcome of this work was the definition of access in a way that can be measured and compared in order to evaluate the state of the art on access within the EU.

**Abu Dhabi, April 9-11**  
**SAPH 2015, SAUDI PH ASSOCIATION PAH CONFERENCE**



Pisana Ferrari, Juan Fuertes and Luc Matthysen represented PHA Europe at this important annual PH conference. Juan Fuertes

was part of the panel of speakers with a talk on the needs of PH patients.

**Paris, April 13**  
**DIA EUROMEETING**

Juan Fuertes represented PHA Europe at the DRUG INFORMATION ASSOCIATION annual meeting. He met there with Ieva Plume from Latvia and had contact with Ariane Weinman who works in the Governance and Public Affairs of EURORDIS where she is involved in the EUROPLAN project.

**Brussels, May 19-20-21**  
**EUROPEAN PATIENTS FORUM (EPF) GENERAL ASSEMBLY**

Luc Matthysen, Member of the Board, represented PHA Europe at the annual general assembly of the EPF.

**Madrid, May 28-29**  
**EURORDIS MEMBERSHIP MEETING**

Pisana Ferrari and Juan Fuertes took part in the annual membership meeting of EURORDIS.

**Madrid, May 30**  
**EURORDIS WORKING GROUP ON RARE BEST PRACTICES**

Pisana Ferrari is part of this working group which has as its aim to identify and share best practices on rare disease management across Europe.

**Luxembourg, June 3**  
**MEETING WITH EU COMMISSION**

PHA Europe was officially invited by Mr. Michael Huebel, Head of Unit, Health Programme and Diseases, DG SANTE, EUROPEAN COMMISSION, in Luxembourg, to present PHA Europe and its activities. Gerald Fischer and Pisana Ferrari attended on behalf of PHA Europe.

**Madrid, June 16-17**  
**ERS PRESIDENTIAL SUMMIT**

Juan Fuertes, represented PHA Europe at this Summit as member of the Council of the EUROPEAN LUNG FOUNDATION (ELF). The summit is organized yearly, the subject was personalized respiratory care. The highlight of the summit was the presi-

dential speech, which stressed the need to reduce inequalities in access to respiratory healthcare.

**Brussels, June 24**  
**INTEREST GROUP ON ACCESS TO HEALTHCARE AND PATIENT ACCESS PARTNERSHIP (PACT)**

Juan Fuertes represented PHA Europe at this event in the EUROPEAN PARLIAMENT. Representatives of Permanent Missions and health stakeholders gathered to follow the progress of the group in mapping barriers to access across the EU.

**Riga, July 4**  
**6TH INTERNATIONAL PH NURSE WORKSHOP (BAYER)**

Pisana Ferrari and Ieva Plume, representing PHA Europe, gave a joint presentation on the activities of patient associations, both at national level and at European level. This was followed by a talk by Pisana Ferrari on "Life after lung transplantation".

**Frankfurt, July 5**  
**IRONMAN EUROPEAN CHAMPIONSHIP**  
PHA Europe was present at the IRONMAN EUROPEAN CHAMPIONSHIP in Frankfurt with an information booth and six athletes who were running with our colours. Volunteers from the German PH association ph e.v. and Members of the PHA Europe Board were present to man the booth and take part in awareness raising activities about the partnership and PH (race briefings, press conference).

**London, September 1-3**  
**EUROPEAN SOCIETY OF CARDIOLOGY (ESC) ANNUAL CONGRESS**

Pisana Ferrari attended the ESC congress, which had over 30.000 participants. Many very interesting sessions at this congress were about PH. The high-

light of the congress for PHA Europe was the presentation of the new joint ESC/ERS clinical guidelines on pulmonary hypertension.

**Brussels September 3**  
**EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA) GENERAL ASSEMBLY**

Juan Fuertes represented PHA Europe, who has been a member of the since 2014, at its annual general assembly in Brussels.

**Barcelona, September 17-20**  
**ANNUAL PH EUROPEAN CONFERENCE (APHEC)**

This is PHA Europe's key annual event. Seventy-one PH Leaders from 31 countries attended the 2015 meeting which had a wide ranging program and medical KOLs as speakers (Profs Nazzareno Galie, Sean Gaine and Walter Klepetko) as well as nine other speakers (including representatives of EURORDIS and the EUROPEAN PARTNERSHIP ON ACCESS (PACT)).

**Amsterdam, September 26-30**  
**EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS**

PHA Europe had an information booth within the WorldVillage. PHA Europe was represented by Pisana Ferrari and Juan Fuertes. The congress' attendance was over 20.000 and many sessions were devoted to PH. Within the context of the ERS meetings of the EUROPEAN LUNG FOUNDATION (ELF) Council and Patient Advisory Committee were held, attended by Juan Fuertes, Member of the ELF Council.



**Lisbon, October 8**  
**ERN CONFERENCE**

Juan Fuertes represented PHA Europe at this event which was organized jointly by the EU Commission and EURORDIS. The objective of the con-



ference was to present the progress in the creation of European Reference Networks for rare conditions across the EU.

## **Lisbon, October 10 EUROPEAN ORGAN DONATION DAY**



Juan Fuertes with Rafael Matesanz, founder of the Spanish Organización Nacional de Trasplantes

The EODD is an annual event organized by the COUNCIL OF EUROPE on the first Saturday of October. Juan Fuertes, representing the PHA Europe Board and the Portuguese PH Patient association took part in the celebrations. The EODD was chosen by PHA Europe as the date to officially launch its "Call to Action to improve Organ Donation and Transplantation across the EU".

## **Brussels, October 16 EUROPEAN PATIENTS FORUM (EPF) STEERING COMMITTEE ON ACCESS**

Juan Fuertes represented PHA Europe and chaired this working session. The main outcomes were the drafting of questions about access for a future survey and the outlining of the Access Campaign that will be launched by EPF in 2017.

## **Brussels, October 27 CONFERENCE ON PRIORITIES FOR A EU POLICY ON MULTI-MORBIDITY**

Juan Fuertes represented PHA Europe at this event that was the first step in creating a multi-stakeholder working group that will provide the basis and the necessary inputs in creating a framework that will address the adequate provision of healthcare services for patients living with multiple conditions.

## **Brussels, October 28 EFPIA HEALTH COLLABORATION SUMMIT**

EFPIA is the EUROPEAN FEDERATION OF PHARMACEUTICAL INDUSTRIES. Luc Matthysen and Juan Fuertes repre-

sented PHA Europe at this event. For the first time the pharmaceutical industry a large number of patient representatives and centered the interest in patient participation and inclusion in the healthcare arena.

## **Brussels, October 28 EUROPEAN PATIENTS FORUM (EPF) WORKING GROUP ON ACCESS**

Juan Fuertes represented PHA Europe at this working group meeting.

## **Brussels, November 17 PATIENT ACCESS PARTNERSHIP (PACT) MEETING**

Juan Fuertes represented PHA Europe at this event held at the EUROPEAN PARLIAMENT and addressed a comment to the Commission as member of the steering committee of the EPF Working Group on Access. The session hosted by the lead MEPs, with active presence of the representative of Luxembourg as current President of the EU Council, aimed at addressing the suggestions and remarks to the Expert report on access to health services across Europe.

## **Brussels, November 24 DITA FACE TO FACE MEETING**

Luc Matthysen and Juan Fuertes attended this working session that focused on ethical aspects of health technology assessment and new methodologies to obtain more accurate and fair appraisals of the value of new drugs and technologies.

## **Brussels, November 27-28-29 PHA EUROPE BOARD MEETING**

The PHA Europe Board meets twice a year, once in September during the APHEC and once around the end of the year. It also holds regular Skype conference call. The end of year meeting is traditionally held in Vienna, head office of PHA Europe.



## AWARENESS

Over 40 countries across five continents took part in the 2015 global awareness campaign for World Pulmonary Hypertension Day (WPHD) with incredible results in terms of reach and media coverage: In 2016 we plan to conduct the campaign along the same lines: it will be coordinated centrally by PHA Europe, who will finance the national events upon submission of a detailed project and cost estimate. The members will be provided, as in past years, 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.

We hope to receive additional funding in 2016 in order to give the opportunity to a greater number of countries to participate. We have also encouraged the members to try to turn WPHD into an annual fundraising event as currently the funds provided by us only cover expenses.

We are also keen to continue with the Ironman "Official Charity partnership", which was part of WPHD also in 2015, with our participation in the Frankfurt Ironman European Championship on July 5th. We are working on new ways to optimise the awareness this event brings to the PH cause. As part of our 2016 awareness raising activities we will relaunch the online campaign called "Time matters", which aims to collect testimonies of patients who are suffering from PH, their families and friends and caregivers.



## ADVOCACY

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 2016 will continue to be access to treatment as this is a critical issue for many of our patients. Not all approved drugs for PAH are available in all countries across Europe and there are countries where no drugs at all are available or expert centers even exist. 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) as well as collaborating closely with the members in order to provide guidance on possible strategies to adopt

at national level to advocate for patient rights in this area.

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 associations/federations which have endorsed it in order to work together towards the possible organisation of an event in the EUROPEAN PARLIAMENT in Brussels, the aim of which would be to open up a cross-condition, transversal debate on the major issues at stake and what can steps can concretely be taken to tackle these. The EP event should ideally be held on or around the date of the EUROPEAN ORGAN DONATION DAY (EODD), which is held yearly by the COUNCIL OF EUROPE in October.



## CAPACITY BUILDING

Building on the achievements of past years, we plan to continue with our support programmes for members associations.

Through our "White Spots" programme we will provide support to the new associations who joined PHA Europe in 2015 as well as to recently founded associations who are just starting out.

Through the "Fellowship" programme, which is currently in place in 15 countries, we plan to continue to provide the national associations with a part-time English speaking assistant. We hope to be able to extend the programme to any new member associations which have significant language barriers.

The Annual PH European Conference also provides opportunities for sharing and learning from each

other as well as training sessions on different aspects which are important in the running of a patient association. For 2016 we plan to repeat what we did in 2015 which was to share successful case studies from the different countries in the fields of advocacy and fundraising.

Our ultimate aim is to put in place a European PH community of empowered and strong patient associations. Many associations are new or have only been founded recently; much remains therefore to be done to ensure that they 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.

## INFORMATION

PHA Europe's traditional information materials are the Mariposa Journal, which is published twice a year, the periodic newsletters, the website and social media channels.

Whilst we do not expect to make changes to our journal or newsletters in the course of 2016 we do plan to continue to make improvements to our website: new sections are in the pipeline, we will "liven up" our news section and will work on a more direct connection with the social media feed. Our social media channels saw a great increase in the number of followers in 2015 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.

In 2016 we will also continue to work on the project we launched last year, "Our PH Library", a comprehensive platform which contains 200 resources (booklets, videos, newsletters, etc.) from PH associations around the world, in 24 languages, indexed and are readily available for

all through an easy "search" function. The results of the first month post launch were amazing, the platform had 2,000 unique visitors and over 400 returning visitors. 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 promote it on all our info channels and ensure that any new resources

published are uploaded in a timely manner so that it is always up to date. We will of course also continue to provide information and educational opportunities through the Annual PH European Conference and by being part of key scientific congresses, work forces and advisory committees' work, as in past years.

## 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 it chaired in 2015 the working group on access to treatment. PHA Europe was also accepted in 2014 as a member of the EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA).

In 2014 one of the Members of the PHA Europe

Board was elected to the Council of the EUROPEAN LUNG FOUNDATION (ELF), which is part of the European Respiratory Society.

PHA Europe members have participated in past years, including 2015, in the EU new drug regulatory approval procedure 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, the International Patient and Carer Survey, the Rare Disease Day, World PH Day and IRONMAN global awareness campaigns, as well as on the development of audiovisual materials, IT solutions, social media and educational programmes. This partnership takes the form of unrestricted grants or is related to specific projects. It is our intention to continue this fruitful and welcome cooperation. The PHA Europe "Corporate Committee" (CC) was estab-

lished in 2014 as a means of partnering with the pharmaceutical companies sharing a common interest in pulmonary arterial hypertension in a structured manner. This was done much along the lines of the EURORDIS Roundtable of Companies and the PHA USA CC.

Two CC meetings were held in 2015, one in Barcelona in September and one in November in Vienna. These meetings provide Members with opportunities for an exchange of views on issues of common interest.

Actelion, Bayer Healthcare, GSK and United Therapeutics are current members of the CC.



# 12. MEMBERS OF PHA EUROPE 2015



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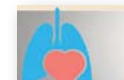
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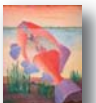
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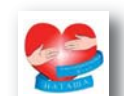
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