

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



ACTIVITY REPORT 2014 & WORK PLAN 2015

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1. FOREWORD BY THE PRESIDENT

Dear members, friends and supporters,

welcome to PHA Europe's 2014 annual activity report and workplan for 2015. This has been yet another very busy, eventful and exciting year.

I would like to start by saying that we are very happy with the huge progresses made in the last 15-20 years in the field of PH, in terms of new treatments, improved surgery techniques, introduction of clinical guidelines and better management of the disease. 2014 in particular was a very good year for the PH community. Two new treatments were approved by the EUROPEAN MEDICINES AGENCY and the preliminary results of a third treatment, which is currently being investigated, are very encouraging. Furthermore, the recent publication of a key clinical trial may lead to important changes in future treatment strategies.

However, 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 access to approved treatments is a critical issue in many others. In addition, the whole area of psycho-social 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.

Earlier diagnosis can only be achieved by increasing awareness of the disease, both in the general population and among medical professionals. In close collaboration with its members, PHA Europe conducts annual global awareness campaigns aimed at raising the public profile and spreading the knowledge of the disease. PHA Europe is also very active in advocacy at EU level and provides support to national advocacy activities. This activity is vital in order to drive change in health policies and ultimately improve access to treatment.

Building the community is another very important part of our work. Regular communication between

PHA Europe and its members are necessary to secure their interest and engagement and with PHA Europe's rapid expansion language barriers proved to be a challenge. Additionally although patient associations have been set up in most European countries, some are still "young" and have limited resources. PHA Europe has developed two programmes to support the member associations and tackle the linguistic problem. The "White Spots" programme provides start up funds and guidance to facilitate the setting up of new associations and help recently established ones. Through the "Fellowship" programme member associations can apply to have a paid part time English speaking assistant. Educational and training opportunities for PH patient leaders are also available through various channels, including the Annual PH European Conference. 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. Our community currently includes 33 patient associations from 29 countries. It is very rewarding to see the great work the member associations are increasingly doing at national level as well as their enthusiastic participation in PHA Europe projects.

PHA Europe is increasingly recognized as the main stakeholder in the field of Pulmonary Hypertension in Europe. We have been asked to endorse key scientific events and prestigious educational university programmes. We are invited to speak at numerous conferences and other events and are actively involved in health care policy through the participation in a number of advisory committees, task forces and working groups of important scientific societies, regulatory agencies and NGOs'.

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 a very fruitful future collaboration.

Gerald Fischer

2. PHA EUROPE IN BRIEF

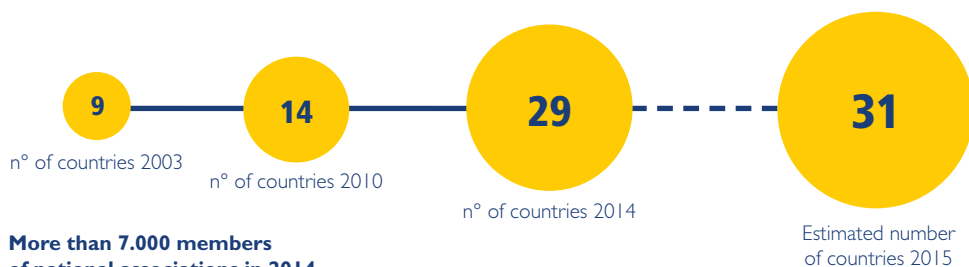
BACKGROUND AND MISSION

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 33 patient organizations from 29 countries: Austria, Belgium (2), Bosnia & Herzegovina, Bulgaria (2), Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Israel, Ireland, Italy (2), Latvia,

Lithuania, Netherlands, Norway, Poland, Portugal, Republic of Macedonia, Russia, Slovakia, Slovenia, Spain (ANHP), Sweden, Switzerland (2), Ukraine PHA, Turkey. Five new organizations have expressed an interest in joining PHA Europe in 2015. These associations come from the following countries: Croatia, Romania, Serbia, Spain (FCHP), Ukraine (Sister Dalila charity).



3. ORGANISATION AND FUNDING

BOARD AND AUDITORS 2014-2016



Gerald Fischer
President



Pisana Ferrari
1st Vice President



**Mélanie
Gallant-Dewawrin** 2nd VP



Luc Matthysen
Treasurer



Juan Fuertes
Secretary



Hall Skaara
Vice Treasurer



Gergely Meszaros
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 7 members: President, 2 Vice Presidents, Secretary & Vice Secretary, Treasurer & Vice Treasurer. There are also two Auditors. The members of the Board and the Auditors represent nine patient associations from seven European countries: Austria, Belgium, France, Hungary, Italy, Norway, Spain.

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 Milano 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. Both are 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 book keeping and tax advice. A considerable amount of travel is involved in order to participate in scientific and industry events and take part in the work of advisory committee meetings and task forces. A reorganization of PHA Europe is planned for 2015, with separate functions for Board and staff.

4. MAIN AREAS OF ACTIVITY

AWARENESS



PHA Europe has successfully conducted annual global awareness campaigns for the last four 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 two years WPHD celebrations have included the participation as “Charity Partner” in Ironman, one of the world’s most challenging sport’s events.

ADVOCACY

Advocacy is one of the main activities of PHA Europe’s as is 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 letters, position papers and submissions to public consultations as well as contact programmes with key Commission officials and MEPs. 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 2014



“World PH Day”

PHA Europe's campaign for World PH Day (WPHD) revolved around the theme of sport. People around the globe were encouraged to take part in sporting activities to “Get breathless” for PH. This was a powerful way of highlighting the restrictions on physical activity experienced by PH patients and provided an effective way to raise further awareness of PH, bringing the challenges these patients face to the forefront.

This year, 22 European countries joined forces to “Get Breathless for PH” as part of WPHD - from a balloon flashmob in Tel Aviv to a sporting event in the historical square of Prague, a marathon through the woods and hills of Tivoli and a blue-lip kissing chain of 295 persons in Dublin. WPHD activities also took place in 12 Latin American countries, in Australia, Canada, China, Ghana, Indonesia, Oman, South Africa and the USA - in other words a total of 42 countries rallied together to raise awareness for PH, building on the 30 that united together last year. All the national events worldwide were showcased through a dedicated website set up in 2013 by the US PH association (PHA).

The campaign was reported by the media worldwide with more than 150 press articles, 20 TV clips and 25 radio announcements and over 2.200 uses of the #WorldPHDay hashtag. This year PHA Europe also launched the first ever World PH Day “Thunderclap” - a social media “flashmob”: 314 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 124.000

people. This proved to be a fantastic way of creating awareness for the campaign on WPHD itself.

Ironman

Momentum of another kind was generated by the Ironman athletes who “got breathless” by participating in Europe's toughest triathlon in support of PH patients. The Ironman race starts with a 3.8 km swim, followed by a 180.25 km bike ride and ends with a 42.2 km marathon to the finish line.

For the second year in a row we were proud to be the official charity partner of the Ironman European Tour and had a strong presence at the races, with a total of 60 athletes running for PH in Mallorca, Kagenfurt, Nice, Frankfurt, Zurich, Copenhagen and Budapest. 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 platforms.

PHA Europe also actively promotes national awareness raising activities and a good example of this is recent #SelfieforPH campaign launched by the Greek PH association (see page 12).

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 section starting page 9).



6. ADVOCACY 2014

Despite the huge progresses made in past years - 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, and the important role of psycho-social support is still not recognized. We believe that only a multidisciplinary approach, to include psycho-social support, can lead to optimal treatment management in PH. Advocacy is therefore an important part of PHA Europe' activities.

Advocacy activities at EU level

These actions are directed mainly at the EU Institutions but we also support national initiatives.

In recent years the EU institutions have taken a number of interesting initiatives in the field of public health which are relevant to PH. These include a Recommendation on national action plans for rare

diseases, a Directive on organ donation and transplant and a Directive on cross-border health care. Other initiatives are being developed including ones on

chronic diseases, a new EU Health Programme, the Horizon2020 project etc.

In the course of 2014 PHA Europe submitted position papers on a number of EU policy documents including the following:

- EU Commission working document on "Investing in health";
- EU Commission progress report on health inequalities;
- Communication from the EU Commission on

effective, accessible and resilient health systems.

On occasion of the 2014 European Parliament Elections we endeavoured to initiate an activity aimed at engaging the national MEPs to our cause.

- A PHA Europe "EP Manifesto" was developed
- Template letters were provided for our members
- A briefing paper on how to use the Manifesto was circulated to members to encourage outreach to their MEPs.

Taking part in international congresses, symposia and other events also provides interesting opportunities for advocacy. In particular this year we presented a scientific poster on "The impact of PAH on the lives of patients and carers" at the European Conference on Rare Diseases. The poster summarizes the main findings of the International Patient and Carer Survey (IPCS) and highlights the main unmet needs of patients, in particular with regard to the need for psycho-social support.

Advocacy "tools"

Our advocacy activities are conducted using the key messages in the 2012 PH Policy Brief and Call to Action, presented at the European Parliament in 2012 (photo on left) and in the IPCS conducted in 2011 (photo above). The policy brief summary and IPCS materials are available in 16 languages. These documents are our main advocacy tools and we strongly encourage our members to use them also in their own activities at national level.

National advocacy

At national level PHA Europe has endorsed local advocacy campaigns, eg. campaign on organ donation and transplantation in Latvia.



7. CAPACITY BUILDING 2014

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, 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 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 the course of 2014 PHA Europe had contacts with and provided support with registration &



administration, IT, printing of publications and support to hold patient meetings to the national associations of Bosnia and Herzegovina, Denmark and Lithuania. The associations from

Finland and Slovenia were also provided with new websites as part of the “White Spots” programme. Contacts have recently been established with patients in Croatia, Romania and Serbia and support is being provided to help them establish their own national associations.

“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 2014 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 2014 PHA Europe provided fourteen national member associations with a “Fellow”: Bulgaria (BSPPH), Czech Republic, Finland, Greece, Hungary, Italy, Israel, Latvia,

Poland, Slovakia, Slovenia and Portugal, Switzerland and Ukraine. A training session for the new Fellows was held in Vienna early in the year. The Fellowship programme was very successful and considerably improved communications as well as the level of engagement of the national associations in common European projects such as World PH Day and Ironman.



From left: PHA Europe “Fellows” from Switzerland, Italy, Portugal, Finland and the Ukraine at the training session in Vienna in February 2014.

Annual PH European Conference

The Annual PH European Conference provides member associations with opportunities for sharing information and experience, mutual learning, networking and education and skills development (see next section).

Information materials and resources

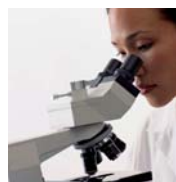
Providing up-to-date information materials is an important part of capacity building. Read more about this in the following section.

8. INFORMATION & EDUCATION 2014

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. Two editions were published in 2014.

The PHA Europe newsletters are issued periodically and

consist of brief one page summaries of recent activities in fields which are relevant to PH.

Both the journal and the newsletters are targeted mainly at PHA Europe's member associations. However, they are 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, like the European Society of Cardiology's and European Respiratory Society's annual congresses.

Website and social media

Other information channels include the PHA Europe website and social media platforms.

The PHA Europe website is comprehensive in terms of contents and links and contains a geo-locator to identify expert medical centres and oxygen suppliers in the different countries. It is regularly updated and through its links to the national associations also helps to direct traffic towards them.

The PHA Europe Facebook page has over 6.000 followers. In the course of the year about 70 entries were posted on our Facebook page, an average of just over one per week. Posts include updates on PHA Europe projects and activities, news from other PH associations around Europe, from the EU institutions and from other NGOs active in the field of health, such as EURORDIS, the EUROPEAN PATIENT'S FORUM, the EUROPEAN PUBLIC HEALTH ALLIANCE etc. In April we also opened a Twitter account; there have been 43 tweets since then, which is also just over one per week.

Educational & training sessions

The Annual PH European Conference (APHEC) gives member associations interesting opportunities for capacity building (see previous section) as well as for information and education. This year's meeting featured two of the key PH medical opinion leaders



Prof. Ekkehard Grüng from the Heidelberg University, at the GAM 2014

as speakers, who provided the attendees with the latest information on new treatments, treatment strategies, surgery, clinical trials currently being held, new developments in research. Other lectures related to life style issues such as exercise and nutrition. The APHEC also featured training sessions on fundraising, the role of the EU institutions, advocacy & lobbying at

national and EU level, and patient association management issues. Over 75 persons attended the 2014 APHEC including 60 PH Leaders from 27 countries and 15 speakers.

Workshops and conferences

Attending prestigious European and international congresses, workshops and training sessions provides opportunities for the dissemination of information and education (see section starting page 9).

9. WORKSHOPS AND CONFERENCES 2014

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 2014 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 16 **TRAINING MEETING FOR** **STAKEHOLDERS EUNETHTA**

Health technology assessment training organized by the European HTA association. Juan Fuertes represented PHA Europe.

Brussels, February 25 **EURORDIS SYMPOSIUM ON RD AND** **BLACK PEARL GALA DINNER**

EURORDIS (European Rare Disease organization) symposium and celebrations for Rare Disease Day. PHA Europe was represented by P. Ferrari, H. Skaara, HD. Kulla, L. Matthysen, H. Ramaker.



Copenhagen, March 4 **PH NURSE WORKSHOP (ACTELION)**



International scientific meeting for PH nurses, attended by 15 nurses from all Scandinavian countries. Pisana Ferrari, Vice President, represented PHA Europe and gave a talk on the role of patient associations.

Madrid, March 22 **MEDIA ADVISORY BOARD (BAYER)**

Juan Fuertes, Member of the Board, represented PHA Europe and gave a presentation about PH and its impact on the lives of patients at this training session for journalists.

London, March 28-29 **SIR JOHN VANE ANNUAL CONGRESS** **ON PROSTANOIDS (UT)**

International Scientific conference on prostanoids in the treatment of PH attended by 200 medical professionals from around the world. PHA Europe had an information booth. Pisana Ferrari, Vice President, represented PHA Europe.



Berlin, March 31 **BAYER ADEMPAS TOWNHALL** **MEETING**

Pisana Ferrari represented PHA Europe and addressed an audience of over 200 internal staff and management on the real life issues in PH and the role of PHA Europe.

Warsaw, April 2

**DRUG INFORMATION
TRANSPARENCY AND ACCESS (DITA)
TASK FORCE MEETING**

This is a task Force of EURORDIS, the European Rare Disease organization. Juan Fuertes and Luc Matthysen, Members of the Board, represented PHA Europe.

Warsaw, April 2

**EUROPEAN PATIENTS ACADEMY
OF THERAPEUTIC INNOVATION
(EUPATI) WORKSHOP**

Juan Fuertes and Luc Matthysen, Members of the Board, represented PHA Europe.

Brussels, April 3-4

**EUROPEAN COMMISSION SUMMIT
ON RARE DISEASES**



Hall Skaara, Member of the Board, represented PHA Europe as a member of the audience.

Basel, May 6

**“PAH HUMAN” CELEBRATIONS FOR
WPHD (ACTELION)**

Pisana Ferrari, Vice President, represented PHA Europe to this staff and top management meeting on her experience with PH and the role of patient associations.

Berlin, May 8-9

**EUROPEAN CONFERENCE ON RARE
DISEASES**

Presentation of a scientific poster on “The impact of PAH on the lives of patients and carers”. The event had almost 800 participants. Pisana Ferrari, Vice President, attended on behalf of PHA Europe.



Brussels, May 12-13

8TH EUROPEAN PATIENTS’ RIGHTS DAY

Luc Matthysen, Member of the Board, represented PHA Europe at this meeting which brought together 120 representatives of patient associations, federations and alliances.

Frankfurt, May 9-10

9TH INTERNATIONAL PH SYMPOSIUM

Scientific event on PH attended by over 300 medical professionals. PHA Europe had an information booth. Gerald Fischer, President, represented PHA Europe.



Brussels, May 12-13

**EUROPEAN PATIENTS’ FORUM (EPF)
ANNUAL ASSEMBLY**

Juan Fuertes, Member of the Board, represented PHA Europe and made a presentation about PHA Europe.

Brussels, May 14-15

**SUMMIT OF EUROPEAN ASSOCI-
ATION OF HOSPITAL PHARMACISTS**

Luc Matthysen, Member of the Board, represented PHA Europe. The EAHP represents 21,000 hospital pharmacists across Europe.

Madrid, May 21-22

3RD ORPHAN DRUG CONGRESS

Juan Fuertes, Member of the Board, represented PHA Europe and gave a presentation about the role of patient associations in drug approval process. The audience consisted of about 75 top level managers.

Barcelona, June 2-6

**EURORDIS SUMMER SCHOOL FOR
PATIENT ADVOCATES**

Gergely Meszaros, Member of the Board, attended this course on behalf of PHA Europe.

Paris, June 3 **INTERNATIONAL CTEPH** **CONFERENCE**



Juan Fuertes, Member of the Board, represented PHA Europe. The meeting was about chronic the thromboembolic form of PH known as CTEPH and was attended by over 1.000 medical professionals.

Vienna, June 25-26 **5TH BAYER NURSE WORKSHOP**

PHA Europe had an information booth. Pisana Ferrari, Vice President, represented PHA Europe and gave a presentation on PH in the life of patients and the role of PHA Europe to an audience of 180 PH nurses from 22 countries



Brussels, August 26-28 **EPF FUNDRAISING WORKSHOP**

Hall Skaara, Member of the Board, represented PHA Europe.

Barcelona, August 30-September 2 **EUROPEAN SOCIETY OF** **CARDIOLOGY (ESC) ANNUAL** **CONGRESS**



This congress had 30.000 participants. Many very interesting sessions at this congress were about PH. Pisana Ferrari, Vice

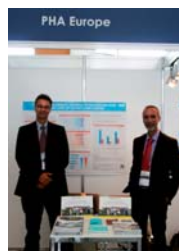
President, represented PHA Europe

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

Pisana Ferrari, Vice President, represented PHA Europe and presented PHA Europe, which had applied to become a Member (it was accepted).

Munich, September 7-11 **EUROPEAN RESPIRATORY SOCIETY** **(ERS) ANNUAL** **CONGRESS**

PHA Europe had an information booth. PHA Europe was represented by Pisana Ferrari, Vice President and Juan Fuertes. The congress' attendance was 22.000 and many sessions were devoted to PH.



Munich, September 7 **EUROPEAN LUNG FOUNDATION** **PATIENT ADVISORY COMMITTEE**

Juan Fuertes, Member of the Board, represented PHA Europe and gave a presentation about PHA Europe and it's activities.

Paris, November 20 **ROUNDTABLE OF INTERNATIONAL** **PATIENT LEADERS (ACTELION)**

PHA Europe was represented by Pisana Ferrari, Vice President, Juan Fuertes, Gergely Meszaros, Hall Skaara and Mélanie Gallant Dewavrin, Members of the Board and Hans-Dieter Kulla from the German PH association.

Wuppertal, December 1 **"BEHIND THE SCIENCE" MEDIA DAY** **(BAYER)**

Pisana Ferrari, Vice President, represented PHA Europe at this event and spoke of her experience of PH of the main challenges in PH care today. The event was attended by 80 journalists.

10. WORK PLAN 2015

AWARENESS

World Pulmonary Hypertension Day (WPHD), was initiated by the Spanish association ANHP in 2012 and has since then gained increasing consensus from PH patient associations around the world. Over 40 took part in the 2014 campaign.

The European campaign was coordinated centrally by PHA Europe who also financed the national events. The members were provided with guidance and support and a very comprehensive media toolkit which included briefings on how to best

promote the initiative, how to organize press conferences, merchandising activities, etc. We plan to run the campaign again in 2015 and hope to receive additional funding in order to give the opportunity to a greater number of countries to participate (this



#SelfieforPH: "Hold your breath and take a selfie for PH", a Facebook awareness campaign

year 22 took part out of our 33 members). We have also encouraged the members to try to turn WPHD into an annual fundraising event: currently the funds provided only cover expenses. We are

also keen to continue with the Ironman "charity partnership", which was part of WPHD. We hope to increase its impact in terms of awareness raising by bringing more resources to a smaller number of events.

As part of our awareness raising activities we will relaunch the online campaign called "Time matters" and generally improve our website and its online visibility (see also below). We also plan to improve and expand our activity on social media platforms.



Finally, we intend to continue supporting #SelfieforPH, an awareness raising initiative launched by the Greek PH association. The idea is to hold your breath (see photo on left), take a selfie and post it on the Facebook page of the campaign. #SelfieforPH is rapidly gaining ground and going viral.

ADVOCACY

Our current advocacy activity at the EU level includes careful monitoring of any developments potentially of interest to us, submission of position papers and other policy initiatives. In 2015 we will organize follow up activities with the new Members of the European Parliament and, at the beginning of the year, a contact programme with MEPs and EU officials in Brussels. Our main focus for 2015 will be access to treatment, which is increasingly becoming a critical issue in many of our affiliate's countries. We hope to involve some MEPs, as well as other patient associations or NGOs, in a future

campaign advocating EU wide recommendations on an "opt-out" donor registration system, which would improve access to organ donation and transplantation, another very critical issue for PH patients.

In 2015 we will also be promoting the use of our advocacy tools, the Call to Action and the International Patient and Carer Survey (IPCS) materials, by supporting new language versions and local initiatives and activities to advocate for the PH cause, and the need for a multidisciplinary approach in PH care to include psycho-social support. As part

of the follow up to the IPCS, a new project was launched in November 2014 with patient leaders from Europe, US and the UK (see photo on right) aimed at improving communications between patients and healthcare professionals. This is a vital step in the direction of the recognition of the important role of patient associations as a part of integrated,

multidisciplinary PH healthcare. PHA Europe will also continue to support national advocacy initiatives.



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 funds and assistance to four new associations in 2015, who are currently in the process of setting up (Croatia, Serbia, Romania and the Ukraine). In January 2015 we are organizing a meeting with these associations to facilitate their integration into PHA Europe later in the year.

Through the "Fellowship" programme, which is currently in place in 14 countries, we plan to continue to provide the national associations with a part time assistant. We would like to extend the programme any to new member associations which have significant language barriers. At the moment we have two new applications and more will follow. We will organize a training session for the Fellows in the early months of 2015 in Vienna, as we did last year.



At the 2015 Annual PH European Conference we plan to increase the number of training sessions on patient man-

agement issues (eg. how to write a business plan, management of volunteers, governance and funding,

etc.) and provide training on advocacy, with concrete examples eg. patient involvement in clinical trials and drug process approval.

An internal survey, conducted in August 2014, showed wide differences in the level of organization and services provided by the member associations across Europe, thus highlighting the need for further support from PHA Europe. We have had responses from 31 of our 33 members and below are some of the findings:

- 10 associations have neither an office nor staff nor a PHA Europe "Fellow" (part time assistant);
- 7 associations do not yet have a website (4 are planning to set them up soon);
- all but one association have Facebook but the use of other social media (YouTube, Instagram...) is not common;
- 10 associations have no information newsletter;
- 6 associations have no publications at all;
- 13 associations have no telephone patient helplines (two are planning to set them up);
- 5 associations have no psychological counselling for patients.

Therefore, much remains therefore to be done to ensure that the member associations have a minimum structure 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.

10. WORK PLAN 2015

INFORMATION

Whilst we do not foresee any major changes in 2015 with regards to our traditional information materials - we will continue with the Mariposa Journal and periodic newsletters - we have a few interesting developments planned in the IT area.

We will be shortly proceeding to a full review of our website, with new sections and more information



on different topics, including links to new materials. We will focus on search engine optimization, in order to improve the website's visibility and traffic, which are currently not

optimal. More work will be done in order to make better use of our social media platforms.

We plan to promote the exchange of information

between the member associations through an internal online platform called the BOX, where we will be able to share newsletters, files, photos, slide presentations, articles etc., in a structured and user-friendly way.

On a global level we have started working on a new PH resource website, which will be called "Our PH Library", where all existing resources (booklets, videos etc.) from PH associations around the world will be indexed and readily available for all.



We will of course also continue to provide information and educational opportunities through the Annual PH European Conference (see also above) and by being part of key scientific congresses, work forces and advisory committees' work.

NEW PROJECTS

Two new projects were launched at the end of 2014 and will carry over to 2015 and future years. Both were initiated by the EUROPEAN ORGANIZATION FOR RARE DISEASES (EURORDIS).



PHA Europe was invited to become a member of a EURORDIS Task Team which will campaign in support of the nomination of 2019 as European Year for Rare Diseases. 2019 is an

important year for the European rare disease movement. It marks the twenty-year anniversary of the adoption of the EU Regulation on Orphan Medicinal Products as well as the ten-year anniversary of the Council Recommendation on rare diseases.

EURORDIS is a partner organisation in RARE-Best-practices, a four year project funded within the European Seventh Framework Programme to deliver a platform for sharing best practices in the management of rare diseases. PHA Europe has been invited in this context to be part of a EURORDIS volunteer working group on clinical guidelines.

11. PARTNERSHIPS 2010-2014

EUROPEAN NON GOVERNMENTAL ORGANIZATIONS

PHA Europe is a member of 4 important European non governmental organizations. Is a member of the EUROPEAN ORGANIZATION FOR RARE DISEASES (EURORDIS), and participates in the work of several task forces: DRUG INFORMATION, ACCESS & TRANSPARENCY (DITA), "European Rare Disease Day 2019" and "Rare Best practices". PHA Europe is a member of the EUROPEAN PATIENTS' FORUM (EPF)

since 2013 and joined the EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA) in 2014. Since 2014 one of the Members of the Board was elected to the Council of the EUROPEAN LUNG FOUNDATION (ELF).

PHA Europe also interacts through many different channels with other European patient associations, institutions, NGOs, professional scientific societies etc.



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 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 2014, 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 2014



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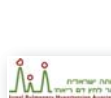
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