



PULMONARY HYPERTENSION  
**Mariposa Journal**

WINTER 2014 • PHA EUROPE'S OFFICIAL JOURNAL • N. 13



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



# Editor's memo Winter 2014 edition

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Dear members, friends and supporters,

welcome to the winter 2014 edition of Mariposa, the official journal of PHA Europe. This has been yet another very busy, eventful and exciting year and I take this opportunity to thank our member associations for their invaluable contribution as without their active participation none of this would have been possible.

We are delighted at the huge progresses which have been 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. This 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 promising. 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 improving awareness of the disease, both in the general population and in the medical class. This year our



Photo taken on the occasion of a CTEPH conference organized by PHA Netherlands at the Antonius Hospital in Nieuwegein

main activity in this area revolved around World Pulmonary Hypertension Day (May 5) where 22 European countries joined forces to "Get Breathless for PH" as part of the celebrations. Further activities took place in 12 Latin American countries, in Australia, Canada, China, Ghana, Indonesia, Oman, South Africa and the USA total of 42 countries rallied together to raise awareness for PH, building on the 30 that united together last year. 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.

Momentum of another kind was generated by the Ironman athletes, who "got breathless for PH" by participating in Europe's toughest triathlon in support of our patients: the Ironman race starts with a 3.8 km swim, followed by a 180.1 km bike ride and ends with a 42.2 km marathon to the finish line. For the second year running, we were proud to be the official charity partner of the Ironman European Tour and to have a strong presence at the races, with a total of 60 athletes running for PH in Mallorca, Klagenfurt, 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 races and news posted on the Ironman website and social media.

Advocacy is also a very important part of PHA Europe's activity and vital in order to drive change in health policies both at national and EU level. With the support of an EU public 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 officials and MEPs. On the occasion of the 2014 European Parliament elections, we also initiated an activity aimed at engaging the national MEPs to our cause. In the course of the year PHA Europe has also provided support to national advocacy initiatives undertaken by the member associations. Very promising results have been achieved in a number of countries.

Many of the PHA Europe member associations are still relatively "young" and have limited resources. In some cases language barriers hinder their effective participation in common projects. This issue has been addressed in recent years by setting up dedicated programs. Through its "White Spots" program PHA Europe offers start-up support for new associations. In the course of this year it helped several of these by providing materials, free websites, funds for registration and IT support. Through its "Fellowship" programme, launched in 2013, PHA Europe provides the member associations, with a part time assistant with a good knowledge of English to act as a liaison person with PHA Europe and to contribute to the association's day to day work. In 2014 PHA Europe provided fourteen national member associations with a "Fellow". The program considerably improved communications, as well as the level of engagement of the associations in common projects, eg. World PH Day and Ironman.

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. This is the second edition of the Mariposa Journal, which is produced twice a year. Mariposa includes news of activities organized by the national patients associations, reports of PHA Europe initiatives, summaries of relevant scientific congresses and updates on PH treatments. Mariposa is distributed to the member associations, other patient associations worldwide, as well as to 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. Other information channels include the PHA Europe website and very active social media platforms.

Our activity in the dissemination of information in 2014 notably includes the presentation of a scientific poster on "The impact of PAH on the lives of patients and carers" at the European Conference on Rare Diseases and joint authorship of an article for the European Respiratory Review on "Physicians' and patients' expectations of therapies for pulmonary arterial hypertension: where do they meet?" (see pages 14-15).

Taking part in PH and public health related European events and activities also contributes greatly to spreading knowledge of PH, awareness raising and advocacy: in the course of 2014 alone PHA Europe representatives attended around 30 scientific conferences, symposia, meetings of advisory committees, working groups & task forces, industry events, media briefings etc. (see pages 4-6).

Finally, our Annual PH European Conference (APHEC) gives member associations opportunities for capacity building, as well as information and education. This year's meeting featured two of the key international PH medical opinion leaders as speakers, who provided the attendees with the latest information on treatments, treatment strategies, surgery, clinical



Guinness world record attempt for longest kissing chain organized by PHA Ireland at the St Brigid's Gaelic Football Club in Dublin (see also pages 35-37)

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 (see pages 8-13). Even more are expected next year, as we have received a number of new membership applications for 2015!

We very much look forward to working together with our member associations in 2015 and again thank them and our valued partners for their support and participation.

Gerald Fischer, PHA Europe President

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JANUARY

**Brussels, January 16**

**TRAINING MEETING FOR STAKEHOLDERS EUNETHTA**

Health technology assessment training organized by the European HTA association. Juan Fuertes took part in this meeting on behalf of PHA Europe.

FEBRUARY



**Brussels, February 25**

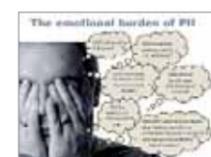
**EURORDIS SYMPOSIUM ON RD AND BLACK PEARL GALA DINNER**

EURORDIS (European Rare Disease organization) symposium and celebrations for Rare Disease Day. PHA Europe was represented by Pisana Ferrari, Hall Skaara, Hans-Dieter Kulla, Luc Matthysen, Hendrik 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 her experience of the disease and 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.

MARCH

**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 ADEMPASTOWNHALL MEETING**

Pisana Ferrari, Vice President, 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, are members of this task force and attended the meeting.

APRIL

**Warsaw, April 2**

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

Juan Fuertes and Luc Matthysen, Members of the Board, took part in this training session on behalf of PHA Europe.



**Brussels, April 3-4**

**EUROPEAN COMMISSION SUMMIT ON RARE DISEASES**

Hall Skaara, Member of the Board, attended this meeting on behalf of PHA Europe.

MAY

**Basel, May 6**

**"PAH HUMAN" (ACTELION)**

Pisana Ferrari, Vice President, represented PHA Europe and addressed 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**

PHA Europe presented a scientific poster on "The impact of PAH on the lives of patients and carers" at this conference which had almost 800 attendees. Pisana Ferrari, Vice President, attended on behalf of PHA Europe (photo with Ieva Plume, President of PHA Latvia).

**Frankfurt, May 9-10**

**9TH INTERNATIONAL PH SYMPOSIUM**

Scientific event on PH attended by over 300 medical professionals. PHA Europe had an information booth and was represented by Gerald Fischer, President (photo with Migdalia Denis, President of the Latin America PH Society).



**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.



**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 and its activities.

**Brussels, May 14-15**

**SUMMIT OF EUROPEAN ASSOCIATION 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 the drug approval process. The audience consisted of about 75 top level managers.



**Barcelona, June 2-6**

**EURORDIS SUMMER SCHOOL**

Gergely Meszaros, Member of the Board, attended this yearly training course for patient advocates on behalf of PHA Europe.

**Paris, June 3**

**INTERNATIONAL CTEPH CONFERENCE**

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



**Indianapolis, June 20-22**

**PHA INTERNATIONAL PH CONFERENCE AND SCIENTIFIC SESSIONS**

Gerald Fischer, President and Juan Fuertes, Member of the Board, represented PHA Europe at the bi-annual international conference organized by the PHA, the US PH patient association. The meeting was the largest to date, with over 1.500 attendees.



**Vienna, June 25-26**

**5TH BAYER NURSE WORKSHOP (SPEECH)**

PHA Europe had an information booth. Pisana Ferrari, Vice President, represented PHA Europe and gave a talk about PH and the role of PHA Europe to an audience of 180 PH nurses from 22 countries (photo with Andrea Clavel, Latin America Society).

MAY

SEPTEMBER



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

Hall Skaara, Member of the Board (first from left, with the other participants of the workshop), attended this workshop on behalf of PHA Europe.

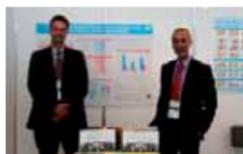
### Barcelona, August 30-September 2 EUROPEAN SOCIETY OF CARDIOLOGY (ESC) ANNUAL CONGRESS

This congress had 30.000 participants. A number of very interesting sessions at this congress were about PH. Pisana Ferrari, Vice President, represented PHA Europe.



### Brussels, September 3 EUROPEAN HEALTH ALLIANCE (EHA) GENERAL ASSEMBLY

Pisana Ferrari, Vice President, presented PHA Europe and its activities to the general assembly of the EHA who subsequently expressed a favourable vote on PHA Europe's membership application.



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

PHA Europe had an information booth at the ERS 2015 and was represented by Pisana Ferrari, Vice President and Juan Fuertes. The congress' attendance was 22.000 and many sessions were devoted to PH (photo with Juan Fuertes and Christian Richter from ph e.v., German PH association).

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

Juan Fuertes, Member of the Board and Member of the European Lung Foundation's Council, represented PHA Europe and gave a presentation about PHA Europe and its activities.

### Barcelona, September 17-21 **PHAE EVENT** ANNUAL PH EUROPEAN CONFERENCE (APHEC)

The APHEC provides PH patient leaders with opportunities for mutual learning, education and skills development. This year's meeting was attended by PH Leaders from 27 European countries.



### Paris, November 20 COMMUNICATION GAPS IN PAH PATIENT CARE WORKSHOP

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 participated in this event to raise awareness in the media about the reality of rare diseases together with the President of the US atrial fibrillation association.



### Vienna, December 12-14 **PHAE EVENT** PHA EUROPE BOARD MEETING

All but one of the PHAE Europe Board Members met in Vienna to review the year's activities and plan for 2015 (from left: Gergely Meszaros, Vittorio Vivencio, Hendrik Ramaker, Pisana Ferrari, Gerald Fischer, Juan Fuertes, Luc Matthysen and Hall Skaara).

### London, December 15 DEVELOPMENT PATHWAYS FOR ADVANCED THERAPY MEDICINAL PRODUCTS' WORKSHOP

Juan Fuertes represented PHA Europe at this regulatory workshop organised by European Biopharmaceutical Enterprises (EBE) in collaboration with the European Medicines Agency (EMA) and the Italian Embassy in London.



## New drugs and future treatment strategies in PH

The two largest congresses in the fields of Cardiology and Respiratory medicine, took place in August-September 2014. PHA Europe was present at both and it was again very encouraging to see that a large number of scientific sessions were dedicated to pulmonary arterial hypertension (PAH) and to chronic thrombo-embolic pulmonary hypertension (CTEPH) at both congresses, featuring some of world's leading experts as speakers or chairpersons. The results of recent clinical trials were presented at the congresses and it is likely that treatment strategies may change in future as new insights into the disease were revealed.

### EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS

Barcelona (Spain) was the venue for this year's ESC annual congress, which took place from August 30 to September 3 and was



Prof. S. Rosenkranz and Prof. M. Humbert both show a slide at ESC which lists the creation of patient associations as a factor in progress of PH in past years

attended by 30.000 participants from all over the world. PHA Europe was represented by Pisana Ferrari. As in past years, there was considerable interest on the part of the scientific community for the field of PH, as demonstrated by the six dedicated scientific sessions and around 200 posters. The sessions were extremely well attended and many had an audience of over 500, with people standing at the

back of the room for lack of seating space. Different aspects of the disease were analysed in the various sessions, including pathophysiology, genetics, screening of populations at risk (in particular scleroderma), diagnostic work up, new drugs and future treatment strategies. The clinical trials leading up to the recent approval by the European Medicines Agency of two new drugs were examined in great detail: the SERAPHIN study for Macintentan-Opsumit, a new endothelin receptor antagonist ("ERA"), and the CHEST-1 and PATENT-1 studies for Riociguat-Adempas, a soluble guanylate cyclase stimulator ("sGC") which acts



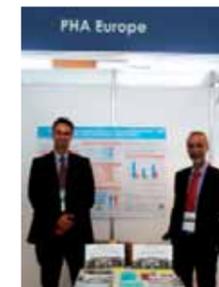
on the nitric oxide pathway. Macintentan-Opsumit has been approved for PAH, Riociguat-Adempas has been approved for both PAH and chronic CTEPH (for which it is the only drug currently approved). It was interesting to hear about the GRIPHON cli-



nical trial on selixipag, an oral prostacyclin receptor agonist which targets the prostacyclin pathway. The preliminary results of this study are extremely promising and may pave the way to a new era of oral prostanoids. At both congresses there was also much discussion of what the ESC and ERS clinical practice guidelines for PH, which are due out next year, will look like, in particular with regard to the treatment algorithm. There is much expectation for this and it is likely that there will be quite a number of changes. Importantly for us psycho-social support for patients has been given a higher grade of recommendation in the "general measures" section. It appears that lung transplant surgery has been moved slightly higher up in the algorithm to avoid patients being listed too late, which can seriously compromise their capacity to recuperate post surgery. Other changes discussed related to the use of "combination therapy", see below ERS report).

Prof. J-L Vachiéry at ESC speaks of PHA Europe and its "Call to action" during a PH session

numerous poster presentations which also covered quality of life and emotional (eg. depression) issues. The main highlight of the ERS congress for the PH community was the presentation of the results of AMBITION, a large, long term clinical trial investigating the benefits of "upfront" combination therapy with Ambrisentan-Volibris, an ERA, and Tadalafil-Adcirca, a PDE-5 inhibitor, which acts on the nitric oxide pathway. Previous studies had analysed only "sequential" combination therapy, where patients start with one drug and a second one is added at a later stage if treatment goals are not met. Three of these studies have proved substantial benefits sustained over time. The AMBITION study shows even more dramatic improvements with a 50 percent reduction in risk of clinical failure in the group having received both drugs right from the start as opposed to the ones on monotherapy. The rationale of this new approach is that the severity of the disease and its progressive nature may justify a more aggressive "hit early, hit hard" strategy. We now look forward to seeing how the new and exciting findings from these congresses will translate into future treatment management. Upfront combination therapy could potentially become the new standard of care for PAH.



C. Richter (left) and J. Fuertes at the PHAE booth - ERS

### EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS

Pisana Ferrari, Juan Fuertes and Christian Richter, from ph e.v., Germany, represented PHA Europe at the ERS annual congress, held in Munich from September 6 to 10. The congress was the largest to date, with 22.000 delegates. A number of scientific sessions were dedicated to pulmonary hypertension (these were also very well attended) and there were numerous poster presentations which also covered quality of life and emotional (eg. depression) issues.

The main highlight of the ERS congress for the PH community was the presentation of the results of AMBITION, a large, long term clinical trial investigating the benefits of "upfront" combination therapy with Ambrisentan-Volibris, an ERA, and Tadalafil-Adcirca, a PDE-5 inhibitor, which acts on the nitric oxide pathway. Previous studies had analysed only "sequential" combination therapy, where patients start with one drug and a second one is added at a later stage if treatment goals are not met. Three of these studies have proved substantial benefits sustained over time. The AMBITION study shows even more dramatic improvements with a 50 percent reduction in risk of clinical failure in the group having received both drugs right from the start as opposed to the ones on monotherapy. The rationale of this new approach is that the severity of the disease and its progressive nature may justify a more aggressive "hit early, hit hard" strategy. We now look forward to seeing how the new and exciting findings from these congresses will translate into future treatment management. Upfront combination therapy could potentially become the new standard of care for PAH.

Pisana Ferrari

# Annual PH European Conference

Barcelona, September 17-21, 2014



The Annual PH European Conference (APHEC) is one of PHA Europe's most important yearly events. It provides PH patient leaders with the opportunity for sharing information and experiences, mutual learning, networking, education and skills development. This year's five day meeting took place from September 17 to 21 in Castelldefels, near Barcelona (Spain). 27 countries were represented at the APHEC, of which four were newcomers: Austria, Belgium, Bosnia and Herzegovina, Bulgaria, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Latvia, Lithuania, Norway, Netherlands, Poland, Portugal, the Republic of Macedonia, Slovenia, Slovakia, Spain, Sweden, Turkey, the Ukraine. The meeting had a very busy and wide ranging agenda, with lectures on medical and life style issues, training sessions on fundraising, advocacy and patient association management issues and discussions on the main challenges facing the PH community and the future role of PHA Europe.

## New member associations and new Board member

After the opening speech by the President and the introductions of all the attendants we started our five day meeting with the annual general assembly, during which the yearly report and 2013 accounts were presented and approved. We also voted on the co-optation of the Secretary (Juan Fuertes) who filled a vacant position, and on the membership applications for 2014. It was great to welcome into the European PH family the newly set up associations of Bosnia Herzegovina, Denmark, Lithuania and the Republic of Macedonia. With these newcomers PHA Europe has reached a membership of 33 PH patient associations from 29 countries.

## Medical updates and lifestyle issues in PH

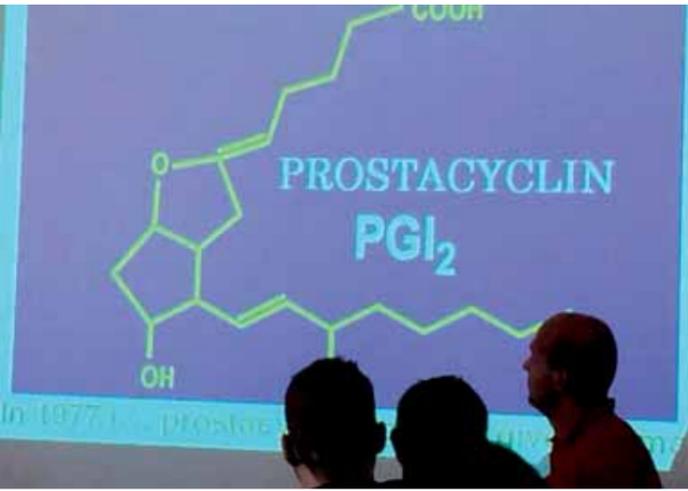
The remainder of the first day of our program was dedicated to medical and life style issues. It was a very big honour for PHA Europe to welcome as its guest medical speakers two key opinion leaders in the field, Prof. Werner Seeger, from the Medical University of Giessen (Germany), and Prof. Ekkehard Gruenig from the University of Heidelberg (Germany), accompanied by Nicola Ehlken, Study Coor-

ordinator and Biometrician from the same academic institute. Prof. Seeger gave a wonderful lecture in which he summarised twenty years of progresses in the areas of PH treatments and management strategies and looked at future developments with regard to research on new molecules and advanced treatments. Prof. Gruenig and Ms. Ehlken spoke about the importance of rehabilitation in PH and the results of their research in past years in this field which provide very substantial evidence that rehabilitation has a big role to play alongside drugs in the treatment of PH. Prof. Gruenig also told us about a PH rehab project he has presented recently - together with a consortium of researchers - responding to a call under the EU Horizon 2020 program. PHA Europe will of course endorse and support this project. Integrated and multidisciplinary care is something that PHA Europe has been advocating for over many years and rehabilitation is a very significant part of this, together with psycho-social support. Another area which is not often addressed is nutrition and a session was also devoted to this topic, with Nils-Paul Skaara, a professional nutritionist from Norway.



Front row, from left: Pisana Ferrari, Peter Bäärnheim, Joni Berg, Ljubica Timova, Sabina Hodžić, Marzia Predieri, Luc Matthyssen, Regina Prenderville, Gergely Meszaros, Vladimir Nikolaev Lazarov, Maria Joao Saraiva, Cátia Rodrigues, Uliana Fedyshyn, Juan Fuertes, Oksana Kullish, Teresa Carvalho. Back, from left: Umit Atli, Peter Makovnik, Yveta Makovniková, Annalena Bonelli, Gerald Fischer, Vittorio Vivenzio, Marta Corominas, Hall Skaara, Dominika Teplá, Vera Hodžić, Hendrik Ramaker, Gjurgica Kjaeva, Joanna Hryc, Agnieszka Bartosiewicz, Mélanie Gallant Dewavrin, Yosef Gotlieb, Christian Weber-Thomsen, Lotti Risbaek-Thomsen, Solvi Mones, Hans-Dieter Kulla, Laure Thevenot, Eszter Csabuda, Leny van der Steen, Nikolaos Ververas, Natalia Maeva, Magdalini Alysandratou, Ieva Plume, Nina Kobler, Ioanna Alysandratou, Nils-Paul Skaara, Liva Brizga, Tadeja Ravnik, Georgi Kostov, Anastasiia Stasiuk, Jaana Rajahlame, Tuulia Naeppi, Patrick Hassel, Oksana Alexandrova, Marius Januševskis, Mehmet Yanıkoğlu, Ellis Ribbens, Eva Otter, Barbara Kohlhas.







**2013 projects and activities**

The Annual PH European Conference as always provides the opportunity to present the year's projects and activities, such as:

- Our 2014 awareness raising activities, namely the World PH Day global campaign, which saw the participation of 22 European countries and the charity partnership with the IRONMAN EUROPEAN TOUR for six races (a full report of these events can be found in the summer 2014 edition of Mariposa).
- Our activities in the field of advocacy and lobbying
- Our capacity building programs (see below)
- The very numerous scientific events, congresses, meetings, training sessions that our Board members attended in the course of the year (around thirty, see also pages 4-6).

**Capacity building programs**

Capacity building is a very important part of PHA Europe's work as we strongly believe that only empowered patient associations can bring about change in health care policies. At the conference we reviewed PHA Europe's two main capacity building activities, the "Fellowship" and "White Spots" programs. Thanks to the Fellowship project, currently in its second year, fourteen national PH associations benefited in 2014 from having a paid part time assistant with a good command of English, to act as a liaison person with PHA Europe and assist the national association in its day to day work. The White Spots program provides start-up support for new associations: IT, legal advice, training, funds for websites, patient meetings and information brochures. It helped many countries this year, including but not exclusively, the new members.

**Training sessions**

Three training sessions were organized at this year's conference. The first one was about fundraising, with Carmen Netzel, a Spanish professional in this field. The focus of this session was to discuss how to make World PH Day a recurrent annual fundraising event for the national associations (who currently only receive reimbursement for costs of events). Another very interesting session was the one on advocacy at EU and national level, presented by Christine Marking, our Brussels-based EU affairs consultant. Advocacy is a very important activity for PHA Europe which we plan to increase in future years. We well know that despite the great progresses made in recent years, much remains to be done to ensure that patients are receiving the best possible care. Access to treatment, in particular, is a very dramatic issue in many of our new member countries. A session was also devoted to patient association management issues.

**Industry partners**

As in past years a session was set aside to meet with our industry partners and discuss common projects and new educational resources. We were delighted to welcome representatives of all the companies who develop drugs for PH: Actelion, Bayer, GlaxoSmithKline, Pfizer and United Therapeutics and take this opportunity to thank them warmly for their continued support throughout the years.

*Pisana Ferrari*



Thomas Ernst, Bayer

Sebastien Gagnon-Messier, Bayer



# Our commitment to raising awareness of the overall impact of PAH

## Introduction

As we look back on 2014, we are so pleased to see how widely the learnings from the International PAH Patient and Carer Survey have continued to be shared, raising awareness of the broader impact of the disease on the lives of patients and the people that care for them. As we know, the impact of PAH goes far beyond just the physical symptoms of the disease and we are committed to providing emotional and social support to those affected, as well as information and advice on the administrative and financial consequences of the condition.



Presentation of the scientific poster on "The impact of PAH on the lives of patients and carers" at the 7th European Conference on Rare Diseases and Orphan Products held in Berlin May 2014. From left: Ieva Plume, PHA Latvia and Pisana Ferrari, PHA Europe

Following the publication of the survey results in the peer-reviewed journal *European Respiratory Review* last December, we have since presented a scientific poster of the findings at the EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS (ECRD) in May this year and we are grateful to the national associations (Poland, Slovakia, Slovenia, Spain...) who also presented the findings of the survey at local meetings, all of which were very well received by the wider medical community.

## Article for the *European Respiratory Review*



Building on the survey results and examining the differences between physicians' and patients' expectations of their care, Dr Luke Howard, Dr Sanjay Mehta and I have published a second important paper in the *EUROPEAN RESPIRATORY REVIEW* this December. We are delighted to be able to share this with you all via the following link:

<http://err.ersjournals.com/content/23/134/458.full.pdf+html>

The paper calls for care to be tailored to the individual needs of each patient, including social and emotional support, as far as possible.

## Patient and Carer Dialogue Tools and best practice case studies

Thank you again to all who have helped to translate the Patient and Carer Dialogue Tools, which are now available in 19 European languages! In response to the survey findings, the Dialogue Tools were developed as a simple way of noting down thoughts and emotions to enable both patients and carers to get a clearer perspective of how they are feeling. These observations can also provide an important focus for discussion with family, friends or in consultations with healthcare professionals.

We appreciate the huge effort that many groups have made to raise awareness of both the survey findings and the importance of the Dialogue Tools in supporting more open conversations about the wider impact of PAH in their countries. We want to extend a special thank you to four groups that have shared their experiences with us around how they have achieved these goals:

- PHA Norway
- Bulgarian Society of Patients with Pulmonary Hypertension (BSPHH)
- HTAP France
- Hellenic Pulmonary Hypertension (HPH)

You can read about their successes and their top tips for other members by visiting the Patient and Carer survey section of our website and following the links to Member Resources and best practice case studies.



## Practical guides for PHA Europe member associations

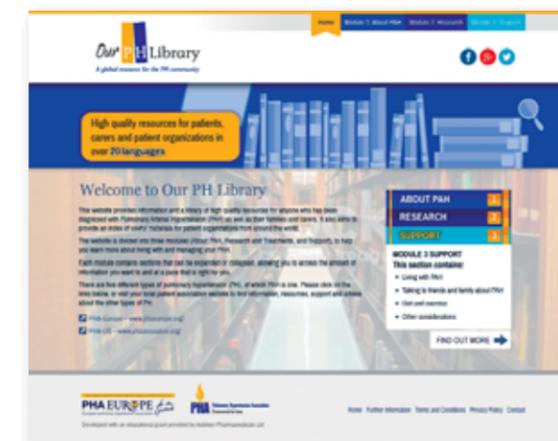
Here you will also find a suite of materials we have developed as part of our wider "Time to Talk" campaign, to support our members to communicate the survey findings and availability of the Dialogue Tools. Among the materials is a Member Guide that outlines ten different activities that you can coordinate yourselves or use for inspiration. These guides offer a step-by-step process for organizing meetings or speaking with the media, for example, as well as template materials which can be adapted locally.

Crucially, we have also developed "Time to Talk" materials for patients and carers, to offer guidance on how patients and carers can have better consultations and conversations with their healthcare teams around their emotional welfare. These provide a brief summary of the longer Dialogue Tools, to support patients and carers to write their answers to a short series of questions on a regular basis to track their feelings.

## Our PH Library

To continue to address the information needs of those affected by PAH, PHA Europe and PHA US are collaborating to

develop a website that provides easy access to a library of existing high quality resources for anyone who has been diagnosed with PAH, as well as their families and carers. It will provide an index of useful materials in English and non-English languages for patient organizations from around the world to encourage greater collaboration and sharing of the fantastic resources out there for patients and their families. The website will be a useful one-stop-shop for anyone searching for reliable patient information about PAH.



Thank you to those who have already shared their patient and carer materials with us for the index. We plan to launch the website, entitled "Our PH Library" in the first half of 2015 (see mock-up design of the PH Library above). Actelion Pharmaceuticals Ltd. is providing an educational grant to support the development of the website, which will be hosted jointly by PHA Europe and PHA US.

Pisana Ferrari

<http://www.phaeurope.org/projects-activities/pah-patient-and-carer-survey/pha-europe-member-resources/>

## EXPLORING THE COMMUNICATIONS GAPS IN PAH PATIENT CARE

In November, a select number of representatives from patient groups across Europe and the US attended a workshop in Paris, hosted by Actelion, to explore the communication gaps in PAH patient care.

Using the survey findings as a springboard for discussion, Actelion organized a series of three workshops for physicians, nurses and patient groups respectively, to gain insights into the relationships and communication between PAH patients and their healthcare providers. These insights will be developed into a report for distribution to key stakeholders and key messages will be communicated through a peer-reviewed article and appropriate media in 2015.

It is clear that more needs to be done to support a multi-disciplinary approach to patient care, as well as raise the profile of patient groups like ours to medical professionals.



# AUSTRIA

## “Plaudermeetings”

In Austria we organised several “Plaudermeetings” in the course of the year. These are patient-to-patient talks about their daily life with PH which are attended only by patients. There are no nurses, no doctors, no industry. In the last months we had “Plaudermeetings” in 5 different counties of Austria with an attendance of approx. 20-30 patients.



## Patient meeting in Graz

On September 12 we held a patient meeting in Graz which was very well attended (80 participants). Dr. H. Olschewski and Dr. G. Kovac from the University clinic of Graz informed our patients about the latest developments in pulmonary hypertension and their achievements in the Ludwig Botzmann Institute research centre. We had a very lively discussion. In addition Mag. M. Apfelbeck, from the Ministry of Social Affairs gave a very interesting speech about the recent changes and achievements in patient social support. We ended the day with a nice buffet and a warm get-together. It was a great day for all our patients and a big success for our association. Eva was happy to welcome 8 new members to our association after the meeting.

## Publications and info point

We have recently developed a new design for our newsletter, inspired by Regina’s newsletter (PHA Ireland) which gave us the first idea. Our newsletter is published every 4 months. We have also created a new patient info point in the cafeteria of the Vienna General Hospital (AKH), combined with a new service centre brochure. Eva and Barbara are available for

psycho-social support & information every Tuesday morning.

## 3RD Zoorun

On June 11th we held our 3rd Zoorun in Schönbrunn, the oldest Zoo in Europe. It was a great event, with over 1.800 starters. The Zoorun is a unique possibility to run through 5 continents in the Zoo with animals as spectators. We had a great media presence and an income of €15.000.



## “ENERGY FOR LIFE” concert

“ENERGY FOR LIFE” organized a classical music concert in Vienna for children with PH on the 6th July. “Energy for Life” is a social foundation, whose main concern is the integration of socially disadvantaged young people, including those with



special needs. We were selected as charity partner and the total income of €5.000 from the concert was donated to Prof. Michel-Behnke for her research to find a non invasive way of measuring the cardiac output in children.

## World record for PH

We were very happy to receive €3.000 from Knud Engelbrecht, who set up a new world record for 24 hours forging for the “Guinness Book of World Record”. He created little keyrings and gave the whole income to our association. There was a huge media coverage in Austria for PH.

## New info brochure

In cooperation with Actelion we have created a new information brochure for PH Patients. This brochure is about “How to live with PH” and provides useful advice on family planning, nutrition, work and in daily life.

## Donation guide

The Austrian Patient Association is part of a newly published “Donation Guide”. This guide includes information about 50 charity organisations in the country and will be sent to all major companies in Austria. The guide is an initiative of the Fundraising Association in cooperation with the initiative “Economy - helps!” from the Austrian Chamber of Commerce to make major companies aware of CSR possibilities.

## Christmas presents

This year we gave away self heating pads with our logo to all our patients. We took the idea from our friends from the Dutch PH association. They were very much appreciated!

Gerald Fischer,  
Selbsthilfegruppe Lungenhochdruck  
[www.lungenhochdruck.at](http://www.lungenhochdruck.at) - <http://on.fb.me/RzdEcb>





## BELGIUM-HTAP

### Patient association days in hospitals

In the course of the year HTAP Belgique continued its awareness campaign in the hospitals of the French-speaking part of the country. These hospitals are not specialized in PH. Organized by the LUSS (Belgium Patients' Platform), we have a one day presence in a hospital together with other associations. The hospitals are giving support and publicity to this event and we can have discussions with the medical teams in pulmonology and cardiology. These hospitals also have a nursing school, so we can inform also the future health caregivers about PH. We have all the contact details so we are



able to continue to provide further information to these hospital health care givers.

### Health technology assessment

The EUnetHTA training course in Rome was attended by 7 DITA member of the EURORDIS organization. We received a training about the what, why and how of HTA (Health Technology Assessment) I have added the link to presentations which are very clear: <http://www.slideshare.net/EUnetHTA>. This training session was followed by the HTA 2.0 Europe conference "Teaming up for value", attended by about 450 stakeholders (regulatory agencies, payers, providers, clinicians, patients, government health department officials, health care technology companies). The speakers were from the Directorate for Health Systems and Products, from DG Public Health and Consumers and the Executive Director of the European medicines Agency.

*Luc Matthysen, HTAP Belgique*



## BELGIUM-VZW



### Annual patient meeting, a highlight of the year's activities

On November 15 we held our annual patient meeting in Brussels. The meeting was well attended and had a very interesting program. There were three medical sessions on the agenda:

- Congenital heart diseases - Prof. W. Budts
- New developments in PH - Prof. M. Delcroix
- Chronic diseases - Ms S. Defloor, from the Flemish Patient platform

The agenda also included time for socializing and relaxation and a very nice musical program with singers from a gospel choir from Belgium. One of our board members is an active singer in this choir.

*Hendrik Ramaker,  
President Patiëntenvereniging Pulmonale Hypertensie vzw  
[www.ph-vzw.be](http://www.ph-vzw.be)  
<https://www.facebook.com/PHBelgium?fref=ts>*



## BOSNIA AND HERZEGOVINA

### Establishment of the BREATH association

Bosnia and Herzegovina is a country with 3.7 million inhabitants and is composed of two entities - the Federation of Bosnia and Herzegovina and the Republic of Srpska, each with its own government, ministers and laws. This is the geopolitical context in which, in the course of 2014, a non-partisan, non-governmental and non-profit citizens' association for pulmonary hypertension called "BREATH" was established. This association bases its work on voluntary and independent membership from both entities. The need for such an association arises from the fact that in Bosnia and Herzegovina, at the state level, there is no Ministry of Health, and from the knowledge that patients with pulmonary hypertension do not have the same rights in the two entities with respect to access to treatment. Specifically, in the Republic of Srpska the costs for sildenafil and bosentan for PH patients are covered by the State, whereas in the Federation of Bosnia and Herzegovina the patients themselves have to buy sildenafil at the full price (700 euros per month). Bosentan is listed as being available from a special "Solidarity Fund", but in practice this drug is not being prescribed because there is no state funding for it.

Patients in the Federation of Bosnia and Herzegovina could not come to terms with this fact and began to fight for their rights - they felt like prisoners on a "death row". They received expressions of support and solidarity from patients in the Republic of Srpska and this is how patients from both entities eventually decided to set up the BREATH association, which operates throughout Bosnia and Herzegovina.

### Advocacy initiatives with the local authorities

An official letter was sent to the Minister of Health by the association to highlight the problems of PH patients in the country. The response from the government was that they were very sorry but there were no funds to cover for this and that in any case they had not received any marketing authorization requests from the pharmaceutical companies. "Why are we denied the drugs, why we are denied the right to treatment and life", said Vera Hodzic, President of the BREATH association.

### Future initiatives

The members of the Association's will continue to advocate for





better access to treatment for people suffering from pulmonary hypertension in both entities of the country. They will try to increase membership and promote the setting up of a state wide patients' register. They will also contact cardiologists and pulmo-

nologists in Bosnia and Herzegovina, to get a real picture of the patients needs. These are not unrealistic tasks and goals. These are humane and civilized goals by patients which other patients in Europe have long since achieved.

**Transplant**

Bosnia and Herzegovina is not a member of Eurotransplant, as other countries in the region are, and has no agreements with any of the clinics for lung or heart-lung transplant surgery in the area. "We are simply left to die" says Jasmin Jukan, a leading member of the association.

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



**BULGARIA-BSPPH**

**Young Bulgarian yo-yo players support the Bulgarian PH patient association BSPPH**

Just a few weeks ago, on the 18th of October, the 6th Bulgarian National YoYo Contest was held. All the players supported BSPPH and got "BREATHLESS FOR PH" (see photo below). This year's National Champion in the Main 2

Division was Alexandar Bachvarov, from Varna. He defeated the previous 2-time Champion Konstantin Tudjarov to the top spot with a flawless performance in the 1A Freestyle and beat the 2011 Champ George Ganchev in the head to head battle! This was the first ever year for the contest to have a Beginner Division, where the "rising star" Evgeni



Radoslavov took top honors in it with a really good performance on stage! In the 4A Division, where the players sent the yoyo flying in the air, George Stoyanov won his 3rd title in a row with what he claims was his most fun and flawless freestyle ever on stage. The 5A Division was once again dominated by George Stoyanov, where he won the gold for the 5th consecutive year! The contest was really great fun! Not only for the yoyos but also because for the first time ever the participants had the opportunity to see two of the best K-pop dance groups in Bulgaria, M.O.D. and ADDICTED. These groups performed at the opening and closing of the contest. We also saw the new hip-hop group that our own High level competitor Biser Lukich formed with his friends, called SHIFTY GODZ ASSOTIATION. All of the groups had amazing performances and kept the crowd going! Finally all of the visitors and competitors at the event showed their support for PH by taking a collective "Selfie for PH" and posting it on the social networks to raise awareness for PH. All in all the event was really good and we hope next year to have more than one contest.

**Flash mob in Sofia - are we ready to be donors?**

For the second year in a row BSPPH participated in the events organized for the WEEK OF ORGAN DONATION AND TRANSPLANTATION (11 to 19 October 2014), together with the National Executive Agency for Transplantation and 20 other patient organizations, friends and partners. To mark



the EUROPEAN DAY OF ORGAN DONATION AND TRANSPLANTATION (12 October) BSPPH organized a flash mob in the area of the National Theatre "Ivan Vazov". The idea behind this event was to show how when a patient is declared dead (brain death) and with the consent of his relatives, his organs can save up to seven lives. A part of us can mean a whole world for someone else...

At the information booth situated in the public park in front of National Theatre in Sofia, volunteers and BSSPH representatives distributed information materials on organ donation and transplantation, as well as materials about pulmonary hypertension. Discussions with people who stopped by the booth were very interesting. We gathered quite disparate opinions on the issue of organ donation and transplantation. Young Bulgarians insisted that their wish to be organ donors should be indicated in their personal ID documents. For patients with PAH it is particularly important to gain access to the European clinics performing lung and combined lung and heart transplantations since this could give them back their normal life. The good news is that Bulgaria is already an associate member of EUROTRANSPLANT, but a lot of work lies ahead. One of the major priorities in BSPPH's work is to continue working for the National Donor Awareness Campaign.

**Psychological support**

BSPPH now offer to patients who are interested psychotherapy sessions in our office in Sofia. These sessions are conducted by a professional psychotherapist, Dr. Ivo Velichkov.

**Other projects**

- Mr. Lyubomir Naydenov from BSPPH attended the 26th Annual EuroMeeting of the DRUG INFORMATION ASSOCIATION (DIA) which took held in Vienna (25-27 March 2014).
- As members of the rare disease community BSPPH was present in Berlin, Germany, on 8-10 May 2014 for the EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS (ECRD 2014).
- BSPPH was part of the 4th NATIONAL CONGRESS OF PATIENT ORGANIZATIONS (13-15 June 2014).
- On 17th October Natalia Maeva, chairperson of BSPPH, successfully finished the ACADEMY OF PATIENT GROUPS, organized by Novartis.

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



**Week of Organ Donation and Transplantation**

For the second consecutive year PHA participated in the campaign dedicated to the WEEK OF ORGAN DONATION AND TRANS-

PLANTATION. PHA Bulgaria, together with students from medical universities, organized information booths in 8 major cities. PHA Bulgaria together with the NATIONAL AGENCY FOR TRANSPLANTS successfully organized and ran the first-ever multimedia conference seminar for "Organ donation". The Seminar was broadcast by MU Varna and also to five other medical universities in Bulgaria.

**3rd National PH Conference**

The Third National PH Conference was held from the 14th to the 16 November 2014 at the Hotel "Kamena" in Velingrad. The conference was attended by leading physicians of the three official PH centers in Bulgaria, other medical staff, volunteers and patients, which together had the opportunity to exchange experiences on treatments and living with PH and innovations in therapy - affordable and accessible to Bulgarian PH patients. There were also group sessions led by a psychologist, games and practical training sessions for team building of the community of PH patients. The conference was attended by about 60 PH patients and carers.



**Bulgarian celebrities support PH patients!**

During the month of November- the month dedicated to raising awareness about the disease, PHA Bulgaria organized a "Blue Lips" campaign aimed at giving informing about PH in an easy to understand way, so that more people are familiar with it and think of consulting a medical specialist if they present symptoms. The *Première* of the exhibition, with photos of the Bulgarian celebrities supporting the "Blue Lips" campaign, was held during the 3rd National PH Conference. For this campaign 12 Bulgarian stars had their photos taken with the symbols of PH (blue lips, blue lollipops...).

**Press conference for the PH Awareness Month**

On the 19th of November the NATIONAL AGENCY FOR TRANSPLANTATION held a press conference as part of the celebrations for the PH awareness month. During the press conference the "Blue Lips" project was presented as part of the broader campaign to raise awareness on the problems of PH patients. The press conference was attended by the Director of the NATIONAL AGENCY FOR TRANSPLANTATION Dr. Mariana Simeonova, Vladimir Tomov, Chairman of the NATIONAL ALLIANCE OF PEOPLE WITH RARE DISEASES, Todor Mangarov, Chairman of the PHA Bulgaria, PH patients and some of the Bulgarian celebrities who participated in the "Blue lips" project: rapper Ivan Dinev-The Mouth, actress Elen Koleva, singer Krassimir Avramov. The press conference was attended by TV, radio, press and i-media (more than 10 journalists). There were a lot of interviews with PH patients and the celebrities involved in the "Blue lips" project and agreements were made for future media events. The initiatives of PHA Bulgaria were widely covered by TV, radio and electronic media!

*Todor Mangarov, PHA Bulgaria*  
[www.apph-bg.org](http://www.apph-bg.org)  
[www.facebook.com/aph.bulgaria](https://www.facebook.com/aph.bulgaria)





## CZECH REPUBLIC

### Annual assembly in Seč June 21-22

Every year in June our members hold their annual meeting about 100 km from Prague, at a congress centre called Jezerkain, situated in a beautiful area with a view on the Iron Mountains. This year, the main topic of our general assembly was the elections of the new President and a new member of the Council of our association. We had to vote for a new President because our current president, Katka Nováková, had to resign on account of her deteriorating health condition. Dr. Regina Votavová, who is one of the few specialists in pulmonary hypertension here in the Czech Republic, was elected as the new President. The rest of the meeting was dedicated to presentations about new developments in PH and on day to day life issues such as traveling with this disease. Even though we were only a small group of 25 people we spent a really good two days and, most importantly, we could share information and experiences in a very pleasant atmosphere.



### Reconditioning stay in Poděbrady August 10-17

Despite the relatively low attendance at the annual assembly, there was great interest on the part of our members in participating in the week-long reconditioning stay which takes place every year in August in the spa town of Poděbrady. As in past years, the program was focused on light breathing exercises and muscle stretching work. We also introduced some new techniques to strengthen the middle part of the body to protect the spine (the basic and easy way, of course). Half way through our stay we were honored by an unexpected visit from the former Prague archbishop, Cardinal Miloslav Vlk, who attended one of our evening sessions and held a very lively discussion with members about various topics, not only about pulmonary hypertension.

*Regina Votavová*  
Sdružení Pacientů s Plicní Hypertenzí  
[www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)



## DENMARK

### The PH patient association of Denmark is now finally a reality!

The founding meeting of PHA Denmark was held with great success on the 7th of October 2014 in Copenhagen. It was the result of several information meetings arranged at two central locations in Denmark during the spring and summer of this year. These meetings indicated that PH patients in Denmark, like in all other countries, needed a forum where they could share and discuss their very different experiences of living with PH. Hall Skaara, from the Norwegian (and the European)



associations, attended the meeting and told us about the work being done both on national and on a European level and how a national association can benefit from being a part of a larger network of knowledge about PH. Hall Skaara also informed us about how a national association can help the European association becoming more influential in order to increase the awareness of PH.

The founding meeting was held in a very positive atmosphere and with great enthusiasm from all the participants. A lot of great ideas were launched during the meeting, encouraging the association to carry on with the future work. And of course a special thanks to the volunteers in Denmark, who with a huge effort have made the establishment of a national association possible in a very short time.

*Kristian Weber Thomsen, President, PHA Denmark*  
[pah.dk](http://pah.dk) - [pahforening@gmail.com](mailto:pahforening@gmail.com)



## FINLAND

*PHA Finland's Board, from left to right Sonja Koski, Jaana Rajahalme, Tuulia Näppi and Emma Pöyttäilä (all PH patients)*



### Board meeting

PHA Finland held a Board meeting on the 1st of November in Helsinki which was very productive and constructive. We were able to divide tasks amongst ourselves, which I'm extremely happy about. Now looking back on this year, I believe that delegating and dividing tasks plays a significant role in getting practical work done. At the moment we are focusing on recruiting new members and setting up the members' register. At the top of our list of priorities are also: contacts with all the central hospitals' lung and heart units - and also maybe visiting them - finishing our website, designing our brochures and having them printed, and planning and executing our official autumn meeting, plus plenty of minor practical tasks also have to be done.

### Meeting with nurses

On the 8th of December Emma, Tuulia and I had a meeting with 12 PH nurses at the Central Hospital of Helsinki. We talked to the nurses about the association, its meaning for patients, what we have done and our activities and plans for the future. The nurses showed a lot of interest and we left brochures with them. They promised to inform PH patients about the association. Also the physiotherapist dealing with PH patients promised to help us (she has visited the rehabilitation center in Heidelberg)!

*Jaana Rajahalme, Suomen PAH-potilasyhdistys ry, PHA Finland*  
<https://www.facebook.com/pages/Suomen-PAH-potilasyhdistys-ry-PHA-Finland/275701649277355?fref=ts>



# GERMANY

## Family meeting of the self help group Fulda, 25-26 April

It is difficult for patients and their families to meet with other families because of having to travel sometimes long distances. The Easter holidays take place simultaneously in almost all German states, so we chose this weekend to hold a family meeting. A full program had been organized for parents and children alike. Two PH experts attended: Dr. C. Apitz from the Children's Heart Center and Prof. G. Hansmann from the Centre for Pediatric Pulmonary Hypertension at the Hannover Medical School. The function of the heart was explained to the children in a simple way and using models. The next day all the families visited the children's Academy in Fulda, which has the biggest heart model in Europe (5 meters high, see below). Children and even adults can become blood cells and can glide through all four chambers of the heart! With a stethoscope everyone can hear their own heartbeat or that of their neighbours. Everyone enjoyed this visit very much. These family meetings are clearly very important and we realized this after the first one in 2013. It means a lot for parents of sick children to have contact with other parents in the same situation. It is also very valuable for the children and young people.



We plan to hold it again in 2015. Many thanks for their kind support to DAK, Vivisol Germany, the Rheinstetten Savings Loan Bank and the donors for the toys offered.

## PH awareness campaign in the railways

For World Pulmonary Hypertension Day our association launched a campaign in several IC and ICE trains of the German railway system, *Deutsche Bahn*. For six weeks, from May 1 to June 15, the campaign logo and message featured on the back cover of the travel guides that you can pick up on all seats of the trains and which provide information for travelers about stops and connections. The trains ran from Westerland to Stuttgart, Hamburg to Zurich, Dresden to Cologne, Berlin to Munich, Saarbrücken to Leipzig and Stuttgart to Greifswald. We thank Actelion Pharmaceuticals Germany GmbH and Bayer Vital GmbH for their support of the project.



## PHEV leaders meet in Rheinstetten

The association's President and regional coordinators meet at least once a year to exchange ideas and to plan joint projects for the future. These meetings feature presentations on medical, psychological or administrative issues as well as training sessions. This year, the ph e.v. leader's meeting was held in Rheinstetten, and it also provided the opportunity to visit the new office of the federation for the first time.



## General Annual Assembly Rheinstetten, 24 May

The general annual assembly of ph e.v. was opened by the 1st Chairman, Mr. Hans-Dieter Kulla, who presented the annual report of activities. Significant events and activities for the year include:

- the tenth anniversary of two regional associations - Hamburg and Berlin / Brandenburg / Meckl.-Vorp;
- the patient meeting in Frankfurt with the presentation of the annual Journalist Award;
- the participation in Ironman Berlin with the slogan "Breathless for PH", where the association provided information to the public and received a donation from PHA Europe for the work of its volunteers;
- the PH family meeting in Fulda;
- the awareness campaign for World PH Day in the German railways;
- the relocation of the office from Karlsruhe to Rheinstetten;
- the new newsletter format - DIN A-4;
- the restyling of the website.

Additionally, patient information sessions were conducted in every German Land (region) throughout the year. Countless requests via mail, e-mail and telephone were processed. Mr Kulla reported that the association currently has 1.340 members and 3 supporting staff. All the other helpers are volunteers.

Mr. Kulla thanked all those who made all these activities possible, stressing that only thanks to the cooperation of everybody the association can be such a vibrant and active community. At the meeting Board elections were also held. Mr Dieter Kulla was re-elected 1st Chairman, Mr Günther Thimm as Deputy. The Treasurer is Mr. Roman Kopp and the Secretary is Mr Manfred Weber. Other members of the board are Ms Helga Kühne and Ms Anne Kopp. The auditors are Mr. Henry Kowalski and Mr. Marco Bachmann.

## Donation to the René Baumgart Foundation of over €1,725.

Despite heavy rain, the regional group Ostalb organized a booth and a raffle and raised over €1.725 at the farm festival in Haisterhofen. Members and supporters of the self-help group were constantly on the move and did a great job. Most lots were sold in the halls because of the bad weather conditions. Very big thank you to all those involved!

## Marathon PH team Karlsruhe, 20-21 September

Over 7.000 participants participated in the Fiducia Baden marathon on the weekend of the 20th-21st of September 2014. Our PH team scored n.158, we were very proud! We would like to thank Christian Röttges, Roland Koch-Woehlte and Thomas Kleckers for their physical performance in the race and their involvement in fundraising. They raised 650 euros which will go towards funding the 2015 family meeting.





### 17<sup>TH</sup> Patient meeting Frankfurt am Main, 17-19 October

The 17th meeting of ph e.v. took place from the 17th to the 19th of October 2014 in Frankfurt/Main. The meeting was attended by approximately 250 patients, relatives and other interested parties. In addition to the lectures there were numerous workshops on the agenda. Topics ranged from weight loss and nutrition in PH, progressive muscle relaxation and autogenic training to parents with PH and the impact of chronic diseases on family and partnership. These provided ample opportunity for personal interactions and discussion.

During this meeting there was also the presentation of the 8th annual Journalist Award. The prize of €3 000 for 2014 went to Claudia Richter, an Austrian journalist. Ms Richter described the life of Maleen Fischer, a 19-year-old pulmonary hypertension patient, in an article for the newspaper "Die Presse". She explained how Maleen's daily life is marked by

limitations and not being able to do what other young people of her age do: swimming, dancing and partying. Via an external pump and an implanted tube in the chest, she is administered prostacyclin, a drug to help her breathe. Maleen is a brave young woman who has a great curiosity and zest for life. Her father, Gerald Fischer, is committed to the PH cause as President of the European PH association. Claudia Richter's article was published in August. "There is great need to raise awareness of pulmonary hypertension," Claudia said at the awards ceremony. "Your article discusses important issues for PH patients, such as misdiagnosis and lack of understanding of the disease," responded the chairman of ph e.v., Hans-Dieter Kulla.

One of the topics on the agenda was genetics and this topic was presented by Professor Ekkehard Gruenig, director of the Center for PH at the University Hospital of Heidelberg, Germany. He explained that scientists have now discovered several genes that regulate the growth of lung vessels and play a role in PAH. The most important gene is the BMPR2 gene. Mutations in this gene are an essential risk factor for the development of PAH. Professor Gruenig emphasized, however, that PAH is a multifactorial disease and further genetic and non-genetic factors are required for it to occur. Anyone who has inherited a genetic mutation, therefore, does not necessarily become ill. Through genetic testing non-mutation carriers and carriers of the mutation can be identified. Mutation carriers should be closely monitored to diagnose the disease early. This is important because BMPR2



mutation carriers often develop PAH earlier and are seriously ill than other patients with PAH. "Genetic testing is only useful when combined with genetic counseling," said Professor Gruenig. New discoveries in genetics may help to develop new therapies to treat pulmonary hypertension.

Prof. Ardeshir Ghofrani from the Lung Center of the University Hospital in Giessen and Marburg spoke about how important it is in rare diseases such as PAH to be treated in specialized centers. Only in specialized centers can doctors gather enough experience with the treatment of such diseases. "The quality comes with the quantity," said Prof. Ghofrani. In his view, a PH center should meet the following criteria:

- a high degree of specialization;
- an interdisciplinary team of pulmonologists, cardiologists, radiologists, surgeons and representatives of other disciplines;
- it should cover the entire therapeutic spectrum, possibly through cooperation;
- it should conduct research activity; experimental and translational;
- it should be integrated into international networks.



"Every patient should at least once visit one of the great PH centers to confirm the diagnosis", Prof. Ghofrani recommended.

Dr. Silvia Ulrich Somaini of the Department of Pulmonology at the University Hospital in Zurich spoke of quality of life issues in pulmonary hypertension. She presented various general and disease-specific instruments to assess quality of



life and recommended to combine both types. Studies have shown that the quality of life of PH patients immediately after diagnosis is at its worst whereas it improves over the course of time with therapy. Exercise training can positively affect the quality of life. PH patients often suffer from depression or anxiety; this

should be addressed in a personal conversation with the treating physician.

Dr. Leonhard Bruch, Director of the Department of Internal Medicine /Cardiology of the Unfallkrankenhaus Berlin spoke about arrhythmia in pulmonary hypertension. In PH the overload of the right heart can lead to arrhythmias. This, however, can also occur independently of PH and aggravate them. Therefore, early intervention is required. The common service centers for rehabilitation support patients who need advice for questions and requests concerning medical or vocational rehabilitation, reported Annett Grieser of the German Pension Insurance Hessen. The discussion which followed was mainly about standardization of rehab clinics and the choice of a suitable rehab clinic for PH-patients.

The PH patient meeting was held under the patronage of the Minister of Social Affairs Dr. Erwin Vetter. Ph e.v. warmly thanks its main sponsors, Actelion Pharmaceuticals Germany GmbH, Bayer Vital GmbH and Pfizer Pharma GmbH, the additional sponsor GlaxoSmithKline GmbH & Co. KG. Many thanks also to VIVISOL Germany GmbH for the oxygen supply.

### New ph e.v. website

The PH association now has a new website. Our aim was to make the website visually appealing and dynamic, to improve navigation and add new content. I think that we have done a good job.

In the main menu we have new sections with News & Info reports and a glossary. These pages are maintained by Mr. Schmiedel and constantly updated. In the forum there is now a general and a password-protected area. In the password-protected area discussions on sensitive issues can be held.

Currently, Mr. Schmiedel offers a moderated chatroom every Thursday at 8 pm. Registration is through the forum. We wish all visitors to our website an informative and enjoyable visit! Suggestions and comments are much appreciated.

Hans-Dieter Kulla, pulmonale Hypertonie e.v.

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

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





# GREECE

The Hellenic Pulmonary Hypertension association has been very creative and busy throughout the year. Especially at a time when Greece is going through a massive economic crisis, our mission is more challenging and valuable than ever. In spite of the harsh realities, our association has recorded some major accomplishments such as promoting and safeguarding patients' rights, ensuring standards of healthcare for the insured as well as uninsured patients, and achieving cooperation with pharmaceutical companies and courier services that improve the daily life of the patients. The strategy of our association has been to establish special "event days" that will be organized on an annual basis and put forward ideas and actions capable of reaching a wider audience. To fulfill our strategy we have concentrated our efforts in reaching three target groups: women, kids, and the world community.

### Reaching Women: "Women in Action for PH"

On the last Sunday of November a group of women came together in Athens to show their support for patients with PH. It is a sad fact that PH is more common in women. By organizing an annual charity day dedicated exclusively to women we seek to make this unfortunate situation known to all women, as well as to draw support from women. As our motto for the event says, this event is organized "by women for women". A woman is always there: whether as a mother, or a sister, or a daughter, or a caregiver, or a patient. She knows that she is not alone, but in most cases it feels like she is being left alone. We wanted to bring all this positive energy together and the result is an annual charity event dedicated exclusively to women. Women of any age can come, bringing together the enormous power of their soul, their experiences, and their positive energy. The event is held at a nice restaurant and accompanied by beautiful music and joyful activities. It was wonderful to see the warm atmosphere at this event.

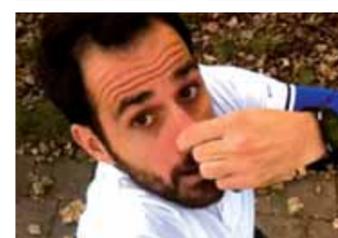
### Reaching Kids: "Learning and Living with Rarity"

The project "Learning and Living with Rarity" is an interactive educational program aimed at educating children about rarity, rare diseases, and PH in particular. The project is intended to

offer children of various ages information about PH, starting from nursery school up to high school. A class hour is devoted to inform children about rare diseases - the focus being PH, its symptoms and methods of treatment, and ways to achieve early diagnosis. An instructor explains to the children the concept of rarity, the meaning of rare diseases, and the symptoms of PH, in simple and playful ways, with drawings, games, fairytales, and funny words. Rarity is introduced through stories about rare flowers, rare animals, and rare words. In turn, the instructor distributes blue lip-shaped lollipops as a direct reference to the common symptom of PH, as well as blank drawing pages to the first age group, and composition pages to the second age group. The whole concept of rarity gave birth to our mascot: Pongo the rare purple elephant! Overall, the project raises awareness about PH in the most constructive and productive way possible: through the education system. We hope that if we reach early childhood we might achieve early diagnosis.

### Reaching out to the World: #SelfieforPH

The Hellenic Pulmonary Association has started a self photo-shooting (selfie) campaign that is already becoming viral! The concept is to take a picture of yourself while holding your breath to symbolize the shortness of breath that PH patients experience in their everyday life. Taking a picture while holding one's breath is easy and funny, but brings a very serious and direct message: it highlights the importance of breathing for PH patients. The idea behind our campaign is that PH patients can be often considered as "invisible" because their symptoms are not obvious. Our message is "Hold your Breath" for as long as you need to take a picture just to see how PH patients feel their whole life. Our selfie campaign has already become very popular with many of our friends and volunteers from all over the world are posting their pictures on our special Facebook page, on Instagram, and Twitter. Don't forget to post your own picture at #SelfieforPH!





# HUNGARY

## Charity Concert

PHA Hungary had a very busy year in 2014. We kicked off with a charity concert held at the Budapest Music Centre. Thanks to the coordination of Dr. Kristóf Karlocai, PH expert and Vice President of the Hungarian association, and the performance of the entire SEMMELWEIS PHYSICIAN ORCHESTRA, more than 100 persons attended the concert and PHA Hungary was able to raise funds during the event.

## General Annual meeting

The association held its General Annual Meeting on May 20th 2014. Under Hungarian law this event is important and central in the life of the association. Due to the rapidly changing legal environment the by-laws of the association needed to be changed, in order to ensure the non-profit status of the association.

## General annual meeting of the Hungarian Society of Pulmonology

This year the HUNGARIAN SOCIETY OF PULMONOLOGY held its 58th general meeting in Székesfehérvár on June 11th. Our association was invited to attend and was provided with an exhibition area. We were thus able to personally meet with the pulmonologists and raise the awareness of PH. We discussed our projects and talked about problems related to treatments. In the course of a cardio-pulmonology session of the meeting, Dr. Kristof Karlocai held a lecture about PH.

## Cycling trip in the west part of Hungary

The “cycling” department of the Hungarian Financial Regulatory agency organized a cycling tour to the west part of Hungary, called Órség. They wore the association’s “GET BREATHLESS FOR PH” T-shirts to raise the awareness of PH. During the trip Eszter Csabuda, President of PHA Hungary, was interviewed by a local TV and had the possibility to provide information about this rare disease.

## Ironman race in Budapest

Hungary successfully took part in the Ironman 2014 European Tour, one of the biggest awareness events organized by PHA Europe. The PHA Europe event included the races in Mallorca, Nice, Frankfurt, Klagenfurt, Zurich and Copenhagen. For the first time ever, Budapest, the capital of a Central-Eastern European and former socialist country, held an official Ironman 70.3 race, on August 23rd. It was a real milestone and, as a result of the dedication and work of Eszter Csabuda (President of PHA Hungary) and Gergely Meszaros, PHA Hungary had the possibility to be present at the race with a booth, information materials, beachflags, banners and a branded arch, in order to raise awareness of PH. Despite the short time available for the preparation and implementation of the cooperation agreement with the organizers, the event was a real success! The branded “GET BREATHLESS FOR PH” arch, which had also used at the other races, was set up on the most fantastic

location, resulting in the fact that it was almost permanently on the TV screen. Our booth was also in a very good location, next to the finish line. We were able to contact the athletes directly, because the organizers had inserted PH information materials into the starting packs of the athletes. We captured the attention of the attendees also with our stick-on tattoos.

It is important to have one of the athletes racing as a “PH ambassador”, who will compete in the race representing and in support of PH patients. This year we were very privileged to have as our “PH ambassador” Robert Szaniszló (Ironman Klagenfurt finisher), who completed the race with a good time, wearing a branded “Get Breathless for PH” suit. But even this visibility was not enough for PHA Hungary! Eszter managed to get a photo with Kovacs - “Koko” István - an Ironman Budapest finisher, former olympics athlete and World and European champion boxer (!) and Gergely and his family with Ironman Budapest finisher Hirling Zsolt, former World and European Rowing champion (!).

We have started negotiations for next year’s race with the organizer and hope to be able to have the lung function test, which was used at other races by PHA Europe, to hold a truly memorable event!

## National Patient meeting

The national PHA Hungary patient meeting took place in Budapest on the 9th of November. In her introductory speech, Eszter Csabuda, President of the association, said: “Since October of 2011 we have organized three national patient meetings and we are surprised and delighted to see how many attendees we have from all parts of the country! Thanks to



From left: Alma Rubio and Gerald Fischer

From left: Ester Csabuda and Dr. Kristof Karlocai



this we are made to feel that our work is important, that the patients and other members of the association are counting on us, and this gives us motivation to continue working and struggling [for our aims]”.

At the meeting we also welcomed as guest speakers PH experts, representatives of the pharmaceutical company and the President of PHA Europe.

Dr. Kristóf Karlócai, PH expert, held a lecture about new treatments and gave the audience insights into the different pathways. He emphasized that thanks to recent developments treatments have evolved considerably but nevertheless PH remains a severe, progressive disease. Some of the modern treatments are already available in Hungary, however there is still lot to do.

Dr. Tamas Forster, PH expert from the city of Szeged, explained in his lecture what functional classes in PH mean and which classification helps the PH expert to determine the most suitable treatment strategy. He mentioned the importance of the 6 minute walking test and underlined that the results of such tests should not be used as terms of comparison with other patients, but serve rather as the aim to follow-up on changes in a given patient’s condition.

Dr. Réka Falusi, from the city of Pécs, informed the attendees about how PH patients should incorporate sessions of physical exercise into their everyday life. She said that it is essential for PH patients to be on appropriate medications and that prior to doing any type of exercise they need to consult with their PH expert.

The PH experts confirmed that Hungary has a lucky situation, because we managed to decrease the average time for appropriate diagnosis from 3 years to 1-1,5 year.

Alma Rubio, PhD, the Global Patient Advocacy Director of Actelion Pharmaceuticals emphasized in her presentation the importance of patient associations. Actelion has partnerships with over 100 patient associations and they are trying to support our work in many different ways, including info materials. She presented the PAHuman e-book (which is available at: [www.pahuman.com](http://www.pahuman.com)), which is currently being translated.

Gerry Fischer, President of PHA Europe, informed the attendees about the work of PHA Europe. He talked about the results of the “White Spots Program” and other programs and events. The attendees had the chance to raise questions to Gerry, which resulted in two main action points: checking the possibilities of (1) setting up a telephone helpline and (2) obtaining handicapped status and parking permit to PH patients.

More than 100 attendees participated in the event and we closed our meeting with a late lunch in a very good atmosphere and in the hope of meeting with each other again next year.

*Eszter Csabuda, Tüdőér Egylet*  
[www.tudoer.hu](http://www.tudoer.hu)

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



## IRELAND

### GUINNESS WORLD RECORD ATTEMPT FOR LONGEST KISSING CHAIN 28 September 2014

*It was a wonderful day filled with fun and blue face paint  
It was a frustrating & disappointing day in many ways  
It was a day to raise awareness of PH  
It was a day we accomplished our most important mission*

On Sunday 28 September 2014 the Pulmonary Hypertension Association of Ireland attempted to break the Guinness World Record for the longest kissing chain. This was an interesting project where we made many friends, discovered wonderful new technology and learnt lots of lessons.

#### The Background

The current record for the longest kissing chain is held by Jiayuan.com in China. This record has been held since 30 January 2012. The number we were trying to break was 352. Guinness World Record guidelines are very strict and rigorous. The staff in the “Records” office are most helpful and

it was a pleasure to deal with all of them. Prior to the attempt we were given reams of guidelines.

#### Specific guidelines for longest kissing chain

These are just some of the many rules we needed to follow:

1. The line/chain must stay connected and in place until the record is completed.
2. All participants must be lined up one after the other.
3. All participants must kiss each other on the lips or cheeks, give and receive 2 kisses each.
4. The person at the beginning of the line must kiss the person next to him/her and so on.
5. If anyone refuses to continue the kissing chain, the record will be disqualified.

#### Mass participation - single venue guidelines

- The attempt must take place in a single location.
- All record attempts must take place in a restricted area with entrances and exits clearly marked.
- Attendance numbers must be accurately confirmed by a pre-approved method by Guinness World Records (because our numbers were less than 1.000 - we were







# ISRAEL



### PH Israel Annual Conference Tel Aviv, 5 November

This year's annual conference was held at the magnificent Sharon Hotel in Herzliya, north of Tel Aviv, overlooking the ocean and creating a sense of excitement from the moment the participants arrived. With over 24 rooms booked for the Israeli Pulmonary Hypertension Association, we opened the conference on Wednesday afternoon with an afternoon activity - two support groups.

The first group was presented by a child psychologist, Dr. Suzy Kagan, focusing on the challenges of bringing up children with PH, their experiences, treatment approaches and how the family copes at each stage of a child life. Dr. Kagan discussed what the families' responsibilities are towards the other children in the family, how to ease the process for the family as a whole and how to approach the child's illness productively within the family structure. The second group was chaired by Mr David Seal, a PH patient and life coach who is also board member of our Association. David ran a group focusing on the integrating of a family approach to living with PH.

While participants listened, shared and learned together in this intimate setting overlooking the sunset on Herzliya beach, a third and final group of participants made personalized jewelry under the guidance of two local jewelry designers who are patients a members of our Association, Orli Ben Zino and Inbar Romano.

After the evening workshops guests had time to enjoy the hotel and environments. Some chose to relax together in the lobby and socialize, some chose to rest and enjoy the quiet break. For dinner the PH Association Conference participants were transported by private bus to the nearby Herzliya Harbor where they enjoyed a special celebratory dinner at the fantastic harbor side restaurant. Added to our sense of celebration was the 19th birthday of one of our members who we managed to surprise with a small birthday extra!

Thursday morning saw the official opening of the conference with over 100 participants streaming into the hotel. A delicious spread of baked goods, fresh breads and spreads, hot drinks and fresh fruit platter was available in the two lecture halls.

Throughout the day participants were privileged to hear Israel's top lecturers speak on multiple topics. The topics covered included: first aid specific to PH patients, lung rehabilitation, right heart catheterization and the use of the different prostacyclin drugs. Before the final lecture a lavish lunch was served in the hotel dining room, providing not only nourishment but a wonderful opportunity to socialize and "digest" all that was heard throughout the morning. After lunch, all participants entered the large lecture hall for a panel discussion by some of Israel's leading PH professionals - Dr. Mike Segal, Prof. Neville Berkman, and Prof. Mordechai Kramer.

Joni Berg, Chairman of the Israel Association, wrapped up a most successful conference - highlighting the need for more interaction, the potential of our association to be a support and a leading force in the treatment of PH in Israel and patient conditions in our country! It was a wonderful feeling overhearing the pleasure expressed by participants as they walked out - sharing the sentiment that they felt truly supported, enlightened and not alone! From those who were only recently diagnosed, to those who have lived with PH for years - each participant was able to receive what he or she needed; each of their family members who attended was enriched, strengthened and supported! Aryeh Copperman, CEO of PH Israel set a very high standard and ensured that each and every person present at the conference was taken care of on every level.

*Yosef Gotlieb, PHA Israel*

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



# ITALY-AIPI

### Annual patient meeting

On the 6th of March 2014 AIPI held its 11th annual assembly which was attended by about 120 patients and family members from all over the country. The agenda included a lecture on the latest developments in PH by Prof. Nazzareno Galiè, Head of the PH Unit at the University of Bologna hospital, a presentation on legislation for the disabled in Italy and the annual report of activities. Lunch was followed by time for socializing and the traditional raffle. During the annual meeting six PH patients having had a lung transplant and myself wore the T-shirts of the official regional campaign for transplant and had a photo taken for the AIPI magazine. The motto of the campaign is: "Life is a gift, give this gift".



### AIPI at the "Alpini" annual gathering

The Alpini are an elite mountain warfare military corps of the Italian Army. The term derives from the word "Alps", the mountains on the Northern border of Italy. Established in 1872, the Alpini are the oldest active mountain infantry in the world. Their original mission was to protect Italy's northern mountain border against France and Austria. The Alpini hold annual



meetings which consistently draw many thousands of participants. This year they held their 78th annual meeting in Pordenone, a city in the North East of Italy and, thanks to one of our members, we were offered a free booth and the possibility to distribute information materials. Hundreds of Alpini walked past the booth and stopped to ask for information and showed great interest for the work the association is doing.

**Excursions**

This year AIPI organized a one-day excursion to Milan. The program included a visit to the exhibition of the famous Austrian painter Gustav Klimt, a tour of the old town and a nice lunch. Fifteen members of the association participated, most of whom were from Milan and surroundings. It was a very enjoyable day and it was nice to be able to spend some time together and share experiences.

**New publications**

Since the beginning of the year four issues of our quarterly magazine *AIPInews* have been issued. We are currently working on a booklet about CTEPH, chronic thromboem-



bolic PH, and on organ donation and transplantation. We expect these publications to go to print in the first quarter of 2015. All our existing resources can be downloaded directly from the AIPI website.

Pisana Ferrari, AIPI Italy  
[www.apiitalia.it](http://www.apiitalia.it)

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



**ITALY-AMIP**

**Raising awareness about PH: a new path**

As we all know increasing awareness about PH can really make the difference for patients and we at AMIP have always endeavoured to spread it in every

possible way. We are a small but very determined group of people, with big goals but scarce financial means, so we have tried to make the most out of what we have. But the message we are wishing to spread is appealing and powerful - PH patients could live longer if they were treated correctly. We have been very pleased to see how many people are generous and willing to be our "testimonials". Sport has proved to be a very fruitful area for awareness



Photos from the film "A tour of Rome" by Igor Gentili. From left: Karin Proia (director), Claudia Cardinale (actress), a scene from the set, Philippe Leroy (actor) and Claudia Cardinale. Photos below were taken during the shooting. Photo on far left: Vittorio Vivenzio with Giovanni Bordonì and Raffaele Buranelli (producer).

raising in the last few years. Today we have many friends among athletes: there are runners wearing our colours in Italy and abroad, we have a young karate champion testimonial, winning her medals all over the world and there is the entire volley ball team of Gricignano (now playing in A series) not only being visible on the media but also very much involved in many ways in our mission and also fundraising on our behalf.

**AMIP in a film!**

This year we found another encouraging way to give a voice to PH patients: we were able to penetrate the sparkling, fantastic, glamorous world of THE MOVIES! The adventure began last summer when we had the idea of asking the production of the film "A Tour to Rome" the permission to be on the background of a scene. We had read in the newspapers about a movie that was being cast and would tell a nice story about children wandering around Rome, a fantastic location. The screenplay had captured the interest of both Claudia Cardinale and Philippe Leroy, actors who are famous all over the world and who are also in it. Nicola Piovani (an Academy Award winner!) is writing the music. We knew we were in the good hands of top professionals. We talked about PH, and the message once more proved effective. Karin Proia (director) and Raffaele Buranelli (producer)

agreed to our request and gave us for free what you would usually pay a lot of money: the possibility to reach as many people as possible: an AMIP booth with our banners, our posters, our friends handing out the leaflets... it's all there. Our message will also be in the credits of the film, to be seen forever! During the 3 days during which the scene was being shot, we were able to make friends, to talk with the people we had around us, to make them understand how important their help was and how they could use their visibility for a good cause. And it is not over: the friends at the booth, myself and any of the patients that wish want to join us will be invited to the première of the film next spring. We are going to be able to speak about PH again! We wish the film "A Tour to Rome" every possible luck, naturally. We warmly thank Karin, Raffaele and the whole cast. One day we might be able to produce a movie ourselves, with their help... who knows? In these people we found lots of sensibility and understanding combined with great competence. Our heads are already full of wonderful ideas!

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

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



# LATVIA

## “Kitchen of Hope”

PHA Latvia, in association with the Rare Disease Society “Caladrius” launched “Kitchen of Hope”- a discussion forum and attractive cooking event with the Parliament and the local health authorities, to celebrate Rare Disease day 2014. This event took place in Riga on the 28th of February. Following the European Rare Disease Day’s main theme “Care” and the slogan “Join Together for Better Care” the rare disease NGOs underlined the lack of orphan products, surgery facilities, and technical equipment in Latvia for people with rare disorders. We called for real action to improve access to medicinal products and implement the National Rare Disease plan for Latvia with financial support from the state budget. So far, we have signed a protocol between the NGOs, the Health Ministry and the National Health Service of Latvia about rare disease patients’ data to be collected from all registries in the country. PHA Latvia with other rare disease

organizations will soon be attending a discussion on rare disease patients’ issues at the Commission of Social and Labour affairs in the Parliament of Latvia.

## Annual General Assembly

PHA Latvia organized its Annual General Meeting in Riga on March the 29th during which elections for the new Board were held. Our new Members of the Board are Liva Brizga (25, patient) and Ludmila Korlasa (59, family member of a patient). The general assembly elected Ieva Plume as Chairperson of PHA Latvia for a second mandate. Liva Brizga is also administrative secretary for the organization’s Board since August 2014.

## PHA Europe Annual Meeting

From September 17 to 21 PHA Latvia’s delegates Liva Brizga and Ieva Plume participated in the PHA Europe Annual



General Assembly in Castelldefels (Spain). New ideas, new contacts, meeting old friends, great memories, sharing of experiences - all these features characterize every year the PH family meeting. This year a special “Memory Award” of € 5.000 was given to the Chairperson of PHA Latvia for the project “Let’s Save Zane!” which raised 120 thousand euros to fund life-saving transplant surgery for a young woman from Latvia. Thanks to this project awareness of PH in Latvia has increased considerably both in the general public and in the health authorities’ circle. More than 124 articles, interviews, opinions and analytical comments were published and PHA Latvia gained a lot in terms of visibility and reputation.

Other patient organizations in our country had positive feedback after this big success of PHA Latvia with the lung transplant fundraiser. In October the Latvian Cystic Fibrosis society started a second, large, fundraising campaign for lung transplant abroad for Latvian citizens. Of course, PHA Latvia, together with its partners, continues to advocate for lung transplant to be included in the national health care basket. The problem is now how to have reimbursement of immunosuppressive therapy for Latvian patients having undergone lung transplant. For now there have been ad hoc solutions but we need to find a long-term solution of this issue.

## Latvian Alliance for Rare Diseases

The Latvian Alliance for Rare Diseases was established on October 3, as an umbrella organization, by five independent rare disease patient organizations. One of the founding members and the initiator of the idea is PHA Latvia. The Founding Members of the Alliance elected Ieva Plume from PHA Latvia as President of the new umbrella organization.

## Other projects

- PHA Latvia organized a “Thanksgiving lunch” for supporters in November and a “Christmas party” for patients and carers in December.
- We are part of the PHA Europe fellowship program.
- Our organization provides financial and organizational support to a CTEPH patient, Alexander, and his family, to undergo PEA surgery at the Vienna University Hospital.
- In November we started a project called “PHA Latvia team”: the first team-building event will take place near the Baltic Sea in Carnikava for PHA Latvia volunteers and employees under guidance of a professional HR expert. One of the team members will be Zane Lazdina (the first lung transplant patient in Latvia) who will work as project assistant for PHA Latvia.

Ieva Plume, PHA Latvia

[www.phal Latvia.lv/en/](http://www.phal Latvia.lv/en/)

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

<https://twitter.com/phlatvia>



## Health camp

PHA Latvia implemented the project “Health skills for people with rare dis-

# NORWAY



### Event by the Parliament

PHA Norway held their WPHD event a little late this year. We planned a six minute walk in front of the Parliament building in the centre of Oslo, and invited some leading politicians to a friendly walking competition together with pedestrians passing by. The politicians were unable to participate on the World PH day May 5th, and the event was therefore moved to mid June. Sadly, the politicians still didn't show up in June, but many spectators did. We handed out T-shirts and PH leaflets, and passers-by were eager to try to walk with nose clips and breathing through straws in order to simulate the lack of oxygen that a PH patient experiences every day. A video of the event was made and it was subtitled in English. It can be found and viewed at PHA Norway web page at [www.pha-no.com](http://www.pha-no.com)



### Contact with Scandinavian associations

The Scandinavian countries are closely connected and it was great to see the start-up of the Danish PH association this fall. The leader of the Norwegian association was invited as a guest speaker at the event. The associations of Norway, Denmark and Sweden are planning to meet in March 2015 to see how they can collaborate more closely in the future.

### Doctors' and nurses' meeting

The medical community is starting to include the Norwegian association at their PH meetings. Two representatives were recently invited to speak at a doctors' conference in Bergen (see picture of the meeting and Bergen by night). Later, the association was also invited to participate at a nurses' meeting. The medical community seems to welcome hearing about how the illness affects the lives of patients. They were also happy to hear about how a mature patient association can help and support newly diagnosed patients.

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



# POLAND



### World Rare Diseases Day seminar

On February 28, 2104 PHA Polska participated in the World Rare Diseases Day Seminar. This yearly meeting focused on issues related to patients' care. In most cases for both children and adults with rare diseases the families provide the biggest support. The Rare Disease day was seminar was important to underline role of the family and relatives in the patients life. PHA Polska was represented by Joanna Hryć.



### General Assembly of PHA Polska

The General Assembly of PHA Polska took place on May 9, 2014. 23 patients from all over the country joined the meeting on that day. Agnieszka Bartosiewicz talked about the activities organized in 2013 and presented PHA Polska's financial report for 2013. The meeting's guest speaker was Prof. Marcin Kurzyny, who made a presentation about current PH treatments in Poland. During the general assembly meeting a new Board was elected:

- Alicja Morze, President
- Agnieszka Bartosiewicz, Vice President
- Maria Golańska-Zabost, Treasurer

### Accreo Ekiden relay race

On May 10, 2014 Agnieszka Bartosiewicz met with the Bayer Life Team during Accreo Ekiden relay race. Twelve

people from Bayer dedicated their run to the Polish PH patients and supported PHA Polska with PLN 100 for each kilometer of their run (this made a total of 4220 zloties).

### Actelion Forum in Warsaw

On June 6, 2014 Alicja Morze, President of PHA Polska, was a guest at the PAH Forum organized by Actelion in Warsaw. Alicja shared her experience with PH and talked about PHA Polska's activities. The educational film "Class by class" was launched on that day.

### New website

In August 2014, PHA Polska launched a new website. Both the design and layout of the webpage were changed and all the content has been updated.



### Patients' meeting in Kraków

More than 90 people joined the patients' meeting in Kraków on September 27, 2014. This meeting was organized at the Centre for Rare Cardiovascular Diseases in the John Paul II Hospital in Krakow. The Centre was represented by Prof. Piotr Podolec and Dr Grzegorz Kopeć. The Polish Association's activities were presented by Alicja Morze - PHA





Polska's President. There was also a guest speaker from Warsaw - Prof. Marcin Kurzyna - who made a presentation on the Patient and Carer international survey results. All the participants had the opportunity to watch the film "Class by class" and to talk to Adam Konkol, musician and music producer who played in the film. During the meeting Adam talked about his life with the disease before and after his PH treatment. Both patients and their carers were very satisfied with the meeting's programme. They were glad that they could talk with the medical experts about their disease and meet other patients who experience similar issues and problems. The patient meeting and PH issues were covered by local and national TV stations.

**4<sup>TH</sup> Conference on Pulmonary Circulation**

PHA Polska participated in the 4th Conference of the Pulmonary Circulation Section of the Polish Cardiac Society. This year the conference took place on October 17-18, 2014 in Kraków. There were more than 260 persons attending, doctors, nurses and guests, who discussed the latest developments in pulmonary circulation. The special guest of this year's meeting was Prof. Nazzareno Galiè from the Institute of Cardiology of the University of Bologna, author of the European guidelines on pulmonary hypertension. At the beginning of the Con-



Prof. Marcin Kurzyna, Maria Golańska-Zabost, Prof. Adam Torbicki, Agnieszka Bartosiewicz, Alicja Morze sits



ference a short film that was made during PHA Polska patient's meeting in Kraków called "I hope - PH from patients' point of view" was presented. PHA Polska was represented by Alicja Morze, President, Agnieszka Bartosiewicz, Vice President and Maria Golańska-Zabost, Treasurer. The association had an



information booth. The conference provided a great opportunity to meet and talk with the medical experts and sponsors.

Alicja Morze, PHA Polska  
[www.tetniczenadciśnieieniaplucne.pl](http://www.tetniczenadciśnieieniaplucne.pl)  
<http://on.fb.me/Rzeo0U>



Alicja Morze, Agnieszka Bartosiewicz, Prof. Piotr Podolec, Prof. Nazzareno Galiè



**PORTUGAL**

**Solidarity walk on the Santiago de Compostela route**

Seven pilgrims, six days, 240 km! Between March 31 and April 5 a solidarity walk took place in the Portuguese part of the Santiago de Compostela route, which had, among its objectives, to show solidarity for the Portuguese Pulmonary Hypertension Association (APHP) and support the cause of PH. The group consisted of seven pilgrims (Jorge Rego, André Assumption, John Nunes, Henrique Oliveira, Domingos Morais, Leonardo Morales and Carlos Carvalho, the latter two having made the bike path), a photographer, Jose Antonio Moura, and three members of APHP, who, together with Sandra Azevedo, arranged logistics and the awareness campaign on PH.

These were the different steps in the walk:

- STEP 1 - Porto/São Pedro de Rates - 43,4KM
- STEP 2 - Saint Peter of Rates/Ponte de Lima - 43,5km
- STEP 3 - Ponte de Lima/Valenca do Minho - 39,9km
- STEP 4 - Valenca do Minho/Pontevedra - 47,0km
- STEP 5 - Pontevedra/Padrón - 41,0km
- STEP 6 - Padrón/Santiago - 24,3km

Along the route awareness raising events were organized and information materials about symptoms of PH were disseminated in schools in the municipalities of Póvoa de Varzim, Barcelos and Valencia, for about 400 children, local authorities and local media agencies. The arrival of the pilgrim group to schools caused great excitement and the participation was enthusiastic. The children actively participated in the activities which had been organized (drawing, making collages on the theme of PH) and replied to the questions and answers which were designed to highlight the limitations of PH and the implications of the disease in every day life. Thus, some students jumped rope and filled balloons to raise public awareness and many children painted their lips blue to symbolize one of the symptoms of the disease. The children were offered blue balloons and blue lollipops. For the participants in the walk this was a very enriching experience which demonstrated their capacity to overcome physical challenges, their resilience and their solidarity to the cause. It was about sharing of emotions, personal accomplishment and camaraderie. All the participants managed to finish the walk, despite the difficulties of the terrain, the weather, the long distance to go and health limitations.

**World PH day prize**

The Portuguese PH association won 1st prize for the best World PH Day campaign 2014. We were given the award at the APHEC in Barcelona.

Maria Joao Saraiva  
 Associação Portuguesa de Hipertensão Pulmonar  
<http://on.fb.me/13sawnu>





# REPUBLIC OF MACEDONIA

We are a very young association, founded in 2014, but were very active throughout the year in many different areas:

### European PH association

- In September at their Annual General Meeting APH Moment Plus was officially accepted as Member of PHA Europe, the European PH federation.
- At this same meeting it was a great honor to receive the



second prize for the best World PH Day campaign for May 5!

### Conferences

- APH Moment Plus was an active participant in Rare Disease Day and helped organize two events, one in the Medical faculty, with lectures for doctors and students, and an educational event in the medical faculty with an exhibition of posters from patients with different rare diseases.
- APH Moment Plus was a guest at the second national conference organized by PHA Bulgaria on November 16th.

### Rare Disease Alliance

APH Moment Plus took part and became a member in the conference to establish a national alliance for rare diseases in the Republic of Macedonia. It also signed a Manifesto for the adoption of the National Plan for Rare Diseases.

### Training sessions

In the course of the year we took part in a number of training sessions including:

- Training for non-governmental and non-profit organizations and journalists, on "how to spread awareness through media".
- Training about public health and budgets for civil society organizations in Macedonia.
- Training for special needs kids and how to help spread awareness.

### Collaboration with other associations

APH Plus Moment supported and helped organize activities by other associations, eg:

- March 21 - Day for children with Down syndrome, in support of one of our members with Down Syndrome and PH.



- April 2 - Day for Children with autism.
- April 23 - Day to raise awareness of the rare disease FOP- Fibro dysplasia ossificans progressiva.

### Sports events

- The K Kozuf Basketball Club Basketball from Premier League in the Republic of Macedonia dedicated their game to raise awareness of PH in Macedonia.
- At the Mountain Biking "XC Maraton Plackovica 2014" (29.7 km), the club "Tochak" for 02:58:31 raced with our GET BREATHLESS for PH T-shirts.

### Advocacy

APH Moment Plus has initiated an action to collect signatures and a petition to obtain medications for patients with PH, This petition will be given to the Ministry of Health.

### Media coverage

- APH Moment Plus took part in a live morning program for the Macedonian National Television.
- Gjurgica Kjaeva took part in CODE, a documentary movie

about the life of patients with rare diseases in the Republic of Macedonia, including Pulmonary Hypertension.

- APH Moment Plus was interviewed for a radio program for the Macedonian Radio. This news made the front page of a newspaper with the the story of Gjurgica the next day.
- APH Moment Plus featured in an article for a womans' magazine and in the Albanian magazine of the Albanian minority in Macedonia: this is important because we have two members who are Albanians.



Gjurgica Kjaeva, President APH Moment <http://on.fb.me/1kUSn5x>





# SLOVAKIA

Year 2014 was a very busy year for PHA Slovakia. The Board organized a lot of events for its members, which also helped to spread awareness about PH amongst medical professionals and the general public. We have worked hard, in particular, to change social conditions in legislation.

### Awareness raising activities

- On the 20th of February, we took part in a press conference dedicated to Rare Disease Day and we also participated in a traveling exhibition about rare diseases. Peter Makovník presented the results of the Patient and Carer Survey at the ANNUAL CONFERENCE OF NURSES IN CARDIOLOGY, which took place on the 25th of April in High Tatras. We were present with our own stand and with various information materials about PAH. We had many articles in daily newspapers, on National Slovak television, on Central TV and other local TVs.
- On the 5th of May our association, together with the GENERAL HEALTH INSURANCE COMPANY, prepared a “Day of Health” in the shopping center *Centro Nitra*.
- In addition to the sport activities we planned for World PH Day, we also attended another cross country running race from Tatras to the Danube river on the 17th and 18th of August. The route was 345 km long and runners ran 2 days

and 1 night without a break, representing us by wearing WPHD T-shirts. We plan to establish a partnership with the organizers of this race also for the future.

### Activities for ZPPH members

- We organized a 2-day meeting for our members on the occasion of the opening of the photo exhibition called “The beauty of the moment”. The first day was devoted to lectures and on the second day we held our Annual General Assembly. We prepared a cultural and social program with a visit of the National Theater and a concert of the Slovak National Orchestra, in support of the disabled.
- The last week of August we had a 7-day rehabilitation stay for 30 members of the association at the spa Vyné Ružbachy, with supervised rehabilitation of PH patients under the guidance of specialised nurses. Rehabilitation mainly consisted of breathing exercises, Nordic walking and relaxation exercises with a psychologist. At the end of the stay we organized rafting cruises on the Dunajec River in the Pieniny National Park.
- In October, we developed a project to give a financial contribution to patients undergoing rehab in 2015. We are registered with the national financial authorities to receive 2% of income taxes and the funds will go to this.



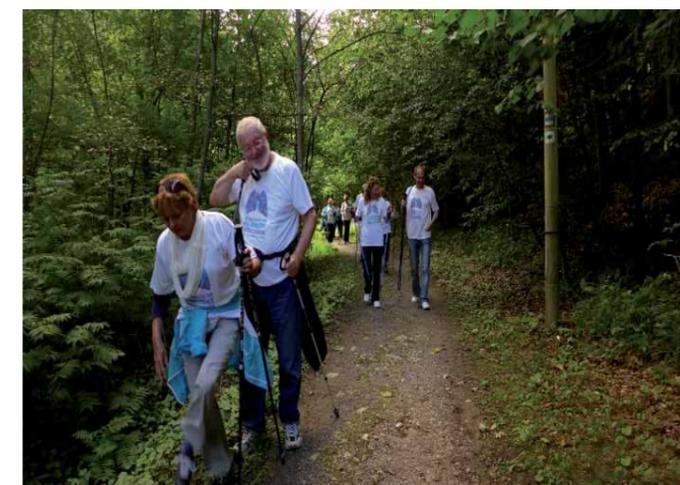
### Attracting new members

We have tried to increase the number of members of our association, mainly by creating and updating our own Bulletin Board in the PH Center. We posted photos and information about the association’s activities. We have also published some booklets, a general one about PH and a booklet called “Why join the PH association?” listing all the advantages and services we provide. This year seven new members joined us.

### Improving conditions for PH patients

In the first half of 2014, we sent reminders to the headquarters of the Social Insurance company, the Labour Office the Office for Social Affairs in order to change legislation and improve conditions for patients applying for disability status and benefits. Subsequently, with the support of the PH Center in Bratislava, we sent comments to the Ministry of Labour and Social Affairs. The aim is to secure the inclusion of PAH in evaluation tables for determining disability and compensatory allowances.

*Iveta Makovníková*  
Združenie pacientov s pľúcnou hypertenziou  
[www.phaslovakia.org](http://www.phaslovakia.org)  
<http://on.fb.me/Ud1DUf>



**Diplom**  
*Pacienti s pľúcnou hypertenziou o.z.*

Kategória: ALL 9 až 12-členné tímy  
Trať: 365 km - družstvá

Čas: 32 hod 09 min 00 sek  
6

Dátum podujatia: 17.8.2014

Tím:  
Martin Reguli  
Peter Baniš  
Júlia Adamičková  
Adrián Vaculín  
Ján Leško  
Jana Galabová  
Ingrída Koutová  
Ariánka Pinneš  
Michaela Lovrinčíková  
Michal Gajdovský  
Tamas Churavčí  
Simona Beškáková



# SLOVENIA

In the last few months our association was active in the following fields:

- We managed to secure a sponsor who will cover the costs for our psychologist, Darja. Every member of our association will be able to have professional psychological support just by picking up a phone.
- We are supporting the initiative to have a psychologist present at all times in the main pulmonology clinic in Slovenija at the UKC in Ljubljana.
- We contacted two Members of the European Parliament, Lojze Peterle and Tanja Fajon. Both agreed to support our activities. Whenever the need arises they will also represent us in the European Parliament.
- We have started a campaign to distribute our booklets to every family doctor (general practitioner) in Slovenia. We're currently in discussions with Pfizer to finalize the deal.
- The biggest Slovenian pulmonology clinic in UKC Ljubljana is being moved to a new and bigger location. The problem is that the UKC Ljubljana doesn't intend to fund the full sterilization of the new location. Many doctors think that the new location is currently not clean enough for patients with pulmonary diseases. Our association and the Slovenian association for Cystic Fibrosis are working together with the media to ensure that the sterilization of the new location does happen.
- A few days ago we started a Facebook campaign to raise awareness of PH. We have thought for a long time how best to spread the word about the disease. PH really is a very rare disease and most people will not be prepared to spend more than a few seconds in their busy lives to learn about it. With

that in mind we came to the conclusion that we needed to reach as many people as possible and to give them only a small amount of information. Those who are interested to learn more still need to have the option to do so of course. So we came up with the answer - Facebook advertising. It's very cheap and the targeted audience is huge. We can reach more than 700.000 people. That's more than a third of all Slovenians. The results until now have been amazing. Our ad was seen by 8.928 people in the first ten days. For this Facebook charged us 9.53\$. Our click-through rate is 6,4%. That means that 557 people at least have clicked on our ad on Facebook. 169 of them also clicked on our link and were redirected to our website where they could have read all about PH.

- We started discussions with our government and other associations for rare diseases to form an umbrella association for rare diseases. The discussions have only just started and we are looking forward to more.
- On the 9th of November we had a patient meeting which focused on the psychological aspects of the PH. We had a workshop with our psychologist and she also went through the patient and carers booklets together with us. Our members were briefed on the latest projects of our association. We finished the meeting with a Sunday lunch. The meeting lasted for 6 hours and it was a great chance to get to know each other even better.

Tadeja Ravnik

Društvo Za Pljučno Hipertenzijo Slovenije

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



Dr. Teruelj trying to get media attention to get sponsors for the new pulmonary clinic



Nina telling us about the meeting in Barcelona



Our psychologist reviewing our booklets and giving us a few tips on how to handle stress and depression



# SPAIN

The Spanish PH Association, Asociación Nacional de Hipertensión Pulmonar (ANHP), had a busy year, as usual. The number of members has increased and the efforts made to gain access to quality pharmacological treatments have leaped forward.

### Advocacy

- It is one of the achievements of the association in 2014 to have opened a lawsuit against a hospital in Andalusia (Southern region of Spain) where they were using an illegal generic to treat PH. The outcome of the lawsuit has been that the hospital has stopped using the illegal drug; however that hospital as well as many other hospitals in Spain is now using generics for erectile dysfunction which is a matter that has been taken up with the Spanish Agency of Medicinal Products because we have remarked clinical worsening of PH patients that do not receive the approved sildenafil for PH.



- There was a meeting with the Regional Ministry of Health in Madrid where the appraisal of quality of care for PH at Madrid Hospitals was discussed. At a higher level, the association was proud to help the process of getting the approval of PH Centers of Reference at national level.
- ANHP was requested by the Spanish Agency for Medicinal Products to give its advice on the added value of two new PH treatments for which marketing authorization had been requested.

### Quality of life issues

The association has kept up with the psychological support program which provides emotional support to patients and carers, by offering its experience to PHA Canada, who will adapt the project to its needs and specificities. Within the



CAMPAÑA DE SENSIBILIZACIÓN DE LA HIPERTENSIÓN ARTERIAL PULMONAR

LA HIPERTENSIÓN ARTERIAL PULMONAR

PARA LA ESCUELA PLACENTA LA SANGRE PULSA UNO MINUTO

psychological support program, ANHP is also supporting the academia in adapting the CAMPHOR to Spain so that patients can have a validated quality of life questionnaire specific for PH.

**Contribution to genetic research**

ANHP has helped the Vigo University (Northwest Spain) to collect blood samples for their genetic research on PH. The Vigo University staff has published three articles on genetic scientific reviews with the results of their ongoing research.

**European Parliament**

On the international arena, ANHP has acquired more knowledge and experience in European issues at Parliament level, having met with two Spanish MEPs, with whom the problems of PH patients in Europe were discussed. Special emphasis was placed on the issue of access to pharmacological treatment and reduction of inequalities between Member States.

**Cooperation with other NGOs**

Cooperation with other national and international organizations remains high on the agenda. On the scientific

level, ANHP attended, as it does every year, all the top gatherings of the pulmonology scientific association - SEPAR. - The first one was in Granada and the second event was the national congress that was held in Bilbao. In between these two events, ANHP attended the official opening of SEPAR's Year for Home Therapies for Chronic Respiratory Patients.

- Rare disease organizations such as the Spanish Rare Disease Federation and EURORDIS also received contributions from ANHP at different meetings and events. One of the most relevant contributions was advising the delegate of the Spanish Rare Disease Federation to help her write her speech for the Regional Government of Madrid on occasion of the Rare Disease Day celebration.
- EUPATI also features in the agenda of the association as we represented PHA Europe at the workshop in Warsaw and actively participated when we attended the official presentation of EUPATI's Spanish platform.

**World PH Day and Ironman**

- World PH Day got its share of sports in Spain, thanks to the close cooperation with PHA Europe and the partnership with Ironman.



- There was also the María Moreno Cause - this is the name of the sports activities of athletes from Valencia who participate wearing the ANHP logo. María Moreno was a member of ANHP who lived with PH and unfortunately did not survive the transplant. Her sister Rebeca honors her memory with fund raising activities related to sports and her strong commitment is stirring a huge movement in the Spanish social PH network.

**Other activities**

A string of activities would still have to be reported to cover all the work ANHP has done during the year, but it would be burdening to mention them all. Here are just a few:

- The ANHP Annual General Assembly in Toledo was a very special celebration (which was already mentioned in the previous Mariposa issue) as 50 PH patients got BREATHELESS FOR PH in the steep streets of the Imperial City.
- ANHP attended the PHA Europe General Annual Meeting in Castelldefels where we had the chance to learn and strengthen our bonds with other PH organizations in Europe.
- ANHP had a relevant role in the Third Annual Orphan Drug Congress in Barcelona where Juan Fuertes made a presentation and advised on patient centered approach during the preparation stages of the Congress, and made a presentation for an international webinar on patients and the world of orphan medicinal products.

**Support to the Latin American PH Society**



ANHP supports the LATIN PH SOCIETY. ANHP represented the Latin American Federation at the International Conference organized by the PHA in Indianapolis. The association also provided support by attending and facilitating a workshop for the PH leaders at the celebration of the Latin PH Day held in Santo Domingo, Dominican

Republic, during the month of November.

*Irene Delgado, Juan Fuertes*  
 Asociación Nacional de Hipertensión Pulmonar  
[www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)  
<http://www.facebook.com/hipertensionpulmonar>



*Princess Letizia at RDD at the Senate, Juan Fuertes is in the background*



*MEP Soledad Cabezón (socialist party), Juan Fuertes, Isabel Proaño (EFA), Dr Javier Contreras (FENAER)*



## SWITZERLAND-SPHV

### Rare Disease Day at the Inselspital Bern, 1 March



The slogan of the conference was "The priorities of patients". About 25 patient organizations were there and had the possibility to introduce themselves. We, the Swiss PH association,

had a booth and we presented a poster describing the disease itself as well as our association and its activities. We also provided some information materials for interested people. At the booth and at lunch time we had some very interesting discussions with other participants.

### 4th General Assembly of SPHV Olten, 29 March



On Saturday the 29th of March 2014 we held our 4th General Assembly at the Congress Hotel in Olten. 34 members were present. This year our association has grown considerably and we

now have 138 members. For the next year we will promote the following campaign: "Become a member and get the first year of membership for free" so that the people will have the possibility to get an idea of the association.

### 12th Regional Meeting of north-west Switzerland Olten, 12 April



On Saturday the 12th of April 2014 five PH patients and family members met at the Congress Hotel in Olten. There were three new members. Discussions were lively and interesting,

all spoke openly about their experiences and the newcomers asked many questions. The talks were not only about "serious" topics and there was also fun and laughter. SPHV invited all the participants for lunch. Everyone enjoyed the day very much and all came to the conclusion that such meetings are important and that it is important also to keep in touch.

### 5th Symposium for PAH St. Gallen, 12 April

On Thursday the 24th of April 2014 the 5th symposium for PAH took place in the Kantonsspital in St. Gallen. Our association was invited to this event for the first time. Our President

introduced our association and spoke of the disease and what it is like to live with it. We also had an information booth where we could distribute some information materials about our association. There were also other speakers who held very interesting speeches and we went home with much more knowledge. At the end of the day drinks and food were offered and everybody talked and exchanged experiences.



### 4th PH Regional Meeting Chur, 8 August

The 4th regional meeting took place in the restaurant Maron at the train station square in Chur. Sitting at a big table in a quiet part of the restaurant, we all talked about our wishes and concerns. Five people attended, including Therese Oesch who is the President of our association. Therese gave us some very valuable advice for our every day life. We talked about different topics such as nutrition, treatments and how to cope and accept living with the disease. It was a very nice, snug afternoon during which we shared a lot of tips and information to take back home.



Five people attended, including Therese Oesch who is the President of our association. Therese gave us some very valuable advice for our every day life. We talked about different topics such as nutrition, treatments and how to cope and accept living with the disease. It was a very nice, snug afternoon during which we shared a lot of tips and information to take back home.

### 13th PH Meeting of north-west Switzerland at MediService Zuchwil, 20 May

On Tuesday the 20th of May 2014 the specialized pharmacy "MediService" invited us to visit them in Zuchwil. This year Actelion was again so nice as to bear the costs for the speaker. The 19 participants were welcomed by Regula Palladino with



The 19 participants were welcomed by Regula Palladino with

coffee and croissants at 9:30 a.m. The event was guided by Otto Binggeli, who is one of the leading motivational trainers in Switzerland. The topic of the event was "The laws of life and how they take effect". Once more we spent a very informative and cozy day at MediService.

### 12th Annual Meeting of PH patients Olten, 14 June



On the 14th of June 2014 a patient meeting of our association took place in the Congress Hotel in Olten. 78 persons attended.

Dr. Séverine Müller-Mottet gave a lecture

on treatments for PAH/CTEPH before and after surgery. Here is a summary: before starting a PAH therapy a diagnosis of PH through right-heart catheterization is needed. There is effective medication for most forms of PAH. Regular controls, oxygen therapy, rehabilitation and training are of high importance. Dr. Müller-Mottet was answering all of our questions during and after her speech. In the name of all participants Therese Oesch thanked Dr. Müller-Mottet for the interesting speech and gave her a little present.

In the second part of the meeting Mr. Bruno Bosshard - who is a patient himself - made a presentation about "Lung transplantation as a last therapeutic option". Today, lung transplantation is a well-established therapy for advanced stages of lung diseases, especially for patients with cystic fibrosis (CF), pulmonary fibrosis (PF), chronic obstructive pulmonary diseases (COPD), pulmonary arterial hypertension (PAH) and other terminal pulmonary diseases. Lung transplantation is a "therapy" for all those patients who suffer from an advanced, serious disease which cannot be improved by drugs or other surgery. In these cases the disease is advanced in such a way that the quality of life as well as life expectation is very little. At the end of his speech Mr. Bosshard answered all the questions from the participants. Therese also thanked Mr. Bosshard for his speech and gave him a little present. After the two speeches all participants had the possibility to have lunch together, to get to know each other and to exchange experiences.

### 4th Regional PH Meeting Zurich, 16 August

One year has already passed since the last meeting on the Uetliberg. Unfortunately, this year the weather was not as sunny as last year. It felt a little bit like it was a meeting in the autumn and not in summer! However, this did not affect the good mood of our 14 attendees. Already at 12 o'clock 11 people arrived in order to have an excellent lunch in the cozy and old "Schützenstube" of the clubhouse in Zurich. Happy and with a full stomach we later welcomed all the other guests. Discussion groups on a lot of different topics were set



up immediately. After a while the seats were switched so that everybody got to talk about the problems and questions with all the other people there. Due to this there was a very relaxed atmosphere. Our hope is to bring the meaning and purpose of our association and our associations' activities closer to everybody. We also hope that some questions and problems were answered at this meeting. We are looking forward to having such a high participation again next year. Together we can surely solve a lot of problems as long as we have this exchange together.

### 6th PH childrens' meeting Luzern, 23-24 August

This year we met in one of the most beautiful cities of the world - Luzern! We welcomed 4 families to this meeting. Whilst having coffee and cake in a youth hostel, we were exchanging ideas and told each other about our every day situations. The kids were playing already within a short time and had a lot of fun. At the Swiss Museum of Transport we made an excursion into the world of movies. We were allowed to





look behind the scenes of the movie theatre and got some information on movies and photographs. While the adults got information on movies, the kids were watching the 3D-movie "Galapagos". After the movie was finished Mr. Wachter was making a how-to-make-movies tour with the kids. The special technique for recording these 3D-movies gives one the impression to be inside the movie itself. It was also very fascinating to see how complex it is to produce 3D movies. Even in the digital era of today, producers look for spectacular scenes and themes.

After a good night's sleep we all met for breakfast. Suddenly, there were a lot of people and we were surprised that there were so many guests in the youth hostel. At 11 o'clock we went to the "Chocolate Adventure" in the Swiss Museum of Transport. In a gondola which looked like half of a Lindt-kugel (Swiss Praliné), we were travelling through the world of chocolate and learned a lot about the history as well as about growing cocoa plants and producing chocolate. Of course we did not miss out on the opportunity to taste some chocolate!

#### **Bus Tour to Emmental 29 August**

On Friday the 29th of August 2014, at 9.10 o'clock in the morning, 16 participants were travelling by train to the restaurant Sternen in Trub. After a short ride we visited the company "Kambly" (cookie company) where we



bought a lot of different sorts of cookies. When travelling back we passed the beautiful region "Entlebuch".

#### **4th regional PH meeting Brunnen, 13 September**



On Saturday the 13th of September 2014 the 4th meeting of the region Innerschweiz in Küssnacht am Rigi took place. The restaurant where we met is located directly at the "Vierwaldstättersee" and the weather was very inviting for a short walk on the waterside. But first we had a very tasty lunch and talked a lot with each other. It would be nice if more people would join this meeting since this is a very good opportunity to meet other patients, exchange experiences, get new ideas on how to deal with the disease and - most importantly - to see that you are not alone! All those who attended were happy and went home with positive thoughts.

#### **3rd Regional PH meeting Bern, 27 September**



On Saturday the 27th of September 2014 the patients of the Bern region came together for the third time for their yearly social get-together at the restaurant "Altes Tramdepot", near the Bärengraben in Bern. Most of the participants already met at 12 o'clock to have lunch together. At half past one everyone was there. We had a very nice and warm autumnal weather and talked about our disease, the different kinds of therapy and also about our problems with doctors, insurance companies and other contact points for patients. After dessert all went home with the wish to come back next year to this cozy restaurant with its very nice and helpful employees.



#### **11th Oxygen patient meeting Olten, 11 October**

On Saturday the 11th of October our association took part in the annual Swiss Oxygen Patient Meeting at the Congress Hotel in Olten. Dr. Med. Clarenbach, senior physician at the Universitätsspital in Zurich, gave a talk about "From stopping to smoke to lung transplantation", which was fascinating. Afterwards the participants asked a lot of questions which were all answered by Dr. Clarenbach. At the different information booths several companies introduced their products and services which was interesting for a lot of participants. At lunch we all had the opportunity to have an exchange of opinions and experiences.

#### **17th PH patient meeting Frankfurt, 17-19 October**



On the 17th of October 2014, 22 patients were travelling to the patient meeting of the German PH association ph.e.v. in Frankfurt. This year 3 sponsors again took over the costs for the overland bus. Everybody could take a lot of interesting information back home. We strongly recommend this meeting to everyone!

Therese Oesch, SPHV

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

## UKRAINE

**Get breathless for PH event**

On the 29th of October we organized a GET BREATHLESS FOR PH event to support people affected by pulmonary hypertension. The goal of the event was to draw the attention of officials, doctors and the public to the problem of PH, especially with regard to children. That is why healthy children took an active part in the campaign. They raised their purple palms and held their breath supporting their peers, children with PH. These very young and bright faces gave confidence and faith

in the fact that in Ukraine the problem of PH and its treatment will be on the agenda at the Health Care Department and will be resolved. Of course, it has to be resolved because children are our bridge to future. It is important for this bridge not just to exist but to be strong.

*Oksana Alexandrova*

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



## USA

**Awareness Month USA 2014: Bigger and Better!**

Each year, in true American form, PHA tries to make PH Awareness Month even bigger than the last. This November, with a huge external awareness reach and a space on some of the biggest channels and biggest screens in the world, PHA might have succeeded!

One of PHA's Awareness Month traditions includes hosting a Congressional Luncheon, where members and supporters come to the nation's capital from around the country to lobby their Senators and Representatives to support PH-related legislation. This year, the bill of focus would create a committee of representatives from each of the nation's health-related agencies that would be charged with discussing and advocating on matters related to pulmonary hypertension. This Bill, which has a budget of \$0 attached to it, was very well-received. Lobbyists also focused on renewal of funding to the National Institutes of Health in the coming fiscal year.

One twist to the lobby day was that members who could not come to the capital took videos of themselves and their stories with the hashtag #StillFighting, and posted these videos to their representatives' social media pages with the request that they co-sponsor the Bill. These videos reached 50,000 views!

In Puerto Rico, a PH bill that proposed including PH in a special classification of illnesses under the territory's Medicaid plan passed the Senate. This Bill would greatly increase the ease in which people can be prescribed PH medication, gain access to medications they truly need, and stay on the medications that work well for them.

PHA also encourages media outreach during Awareness Month; people from across the country told their stories on TV, radio, and newspapers, creating 1,000 new pieces on PH in this month alone! Some of these pieces came from the many large-scale fundraising events, including several galas with high-profile attendees, walks and "6-Minute Marathons," and a repeat of the Belt family's incredibly successful "Color

for a Cure" color run in Louisiana. Some came from the inaugural "CTEPH Awareness Day" held this November 19th in an attempt to improve screening and treatment of Chronic Thromboembolic PH. Yet others came from the events surrounding the launch of PHA's new externally-focused awareness campaign, PHAware.

PHAware was born out of the success surrounding PHA's "PSA Media Blitz", which thanks to Board Member Steve Van Wormer's connections, led PSAs being played on contract for years from 11,500 TV and radio stations across the country - including some of the U.S.'s largest English - and Spanish language networks. PHA realized this was a good chance to push momentum towards reaching a larger audience that doesn't yet know about PH, and PHAware was born.

This Awareness Month, [www.PHAware.org](http://www.PHAware.org), the PHAware Twitter, Instagram, and Facebook pages, and a new PHAware app were all launched. Additionally, the PSAs were played throughout the month in taxi cabs across New York City and Philadelphia, and in print advertisements on top of New York City taxis - created moving advertisements with a giant audience! Lastly, PHA's pediatric research PSA was shown November 6th in the middle of Times Square on the NASDAQ building - the largest screen in the world and one of New York's most famous landmarks. NASDAQ held a special ceremony for the event, attended by some of PHA's biggest local movers and shakers.

The month ended with American talk show "The Queen Latifah Show" broadcasting their episode in which Queen Latifah (U.S.-based rapper, singer, TV actress, talk show host and movie star) talks to her mother about her battle with scleroderma and PH. Dr. Sean Studer, a doctor on PHA's Scientific Leadership Council, was also a guest on the show. 2014 surprised PHA in its large-scale success. Here's hoping for an even bigger Awareness Month next year!

*Julia Friederich, PHA*

[www.phassociation.org](http://www.phassociation.org) - <http://on.fb.me/RIFUOC>





## RIOCIGUAT EMA APPROVAL

On March 27, 2014, the European Medicines Agency (EMA) granted a marketing authorization valid throughout the European Union to Adempas (riociguat) to treat adults with two forms of pulmonary hypertension, pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH). Adempas belongs to a class of drugs called *soluble guanylate cyclase stimulators*. The active substance in Adempas, riociguat, stimulates an enzyme called “soluble guanylate cyclase” in the blood vessels of the lungs, which causes the blood vessels to relax and widen. This helps to lower the blood pressure in the lungs and improve symptoms of CTEPH and PAH.

Adempas is the first in this drug class approved to treat pulmonary arterial hypertension and the first drug of any class to be shown to be effective for patients with CTEPH.

Adempas is used to treat patients with CTEPH who cannot be operated on, or in whom CTEPH remains or returns after surgery.

Adempas is also used for patients with pulmonary arterial hypertension (PAH) of unknown causes, inherited or associated with connective tissue diseases. In PAH Adempas can be used on its own or in combination with other medicines for PAH called “endothelin receptor antagonists”.

The safety and effectiveness of Adempas to treat CTEPH were established in a clinical trial (CHEST-1) with 261 participants randomized to take Adempas, with the dose gradually increased up to 2.5 mg three times daily, or to receive a placebo three times daily. The study was designed to measure the change in the distance a patient could walk in six minutes (6-minute walk distance). After 16 weeks of treatment, the average improvement in a 6-minute walk distance in participants treated with Adempas was 46 meters (about 150 feet) more than in those treated with placebo. The clinical trial (PATENT-1) evaluating the safety and effec-

tiveness of Adempas to treat PAH included 443 participants randomly assigned to take Adempas 1.5 mg or 2.5 mg, or placebo, three times daily. After 12 weeks of treatment, the 6-minute walk distance in patients treated with Adempas improved by an average of 36 meters (about 118 feet) more than in patients treated with placebo.

Adempas is marketed by Bayer HealthCare Pharmaceuticals Inc.

Source:

[http://www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicines/002737/human\\_med\\_001733.jsp&mid=WC0b01ac058001d124](http://www.ema.europa.eu/ema/index.jsp?curl=pages/medicines/human/medicines/002737/human_med_001733.jsp&mid=WC0b01ac058001d124)

## TREATMENT STRATEGIES AMBITION TRIAL

The results of AMBITION, a large, long term clinical trial investigating the benefits of first line or “upfront” combination therapy with ambrisentan-Volibris, an endothelin receptor antagonist, and tadalafil-Adcirca, a “phosphodiesterase-V inhibitor” versus monotherapy on both these drugs were presented at the Annual Congress of the European Respiratory Society meeting in Munich on September 15.

AMBITION is a randomized, double-blind, multicenter study that included 500 treatment-naïve patients with New York Heart Association functional class 2 and 3 pulmonary arterial hypertension. Previous studies had analysed only “sequential” combination therapy, where patients start with one drug and a second one is added at a later stage if treatment goals are not met. Three of these studies have proven substantial benefits sustained over time. The AMBITION study shows even more dramatic improvements with a 50 percent reduction in risk of clinical failure in the group having received both drugs right from the start as opposed to the ones on monotherapy. The rationale of this new approach is that the severity of the disease and its progressive nature may justify a more aggressive “hit early, hit hard” strategy.

### Next PHAE newsletter

The next Mariposa Journal will be issued in June 2015 (Summer edition). The main focus will be the reports of the celebrations for World Pulmonary Hypertension Day (May 5) from the national associations around the world. It will also include news of activities in the member countries, updates on research and treatments and any other interesting and relevant developments at European level. We would be very grateful if the members could send their contributions by **the 15th of May at latest**. These may be sent in the national language and we will provide for translation. Any photos should have a minimum resolution of 1 MB. The newsletter will be available in PDF format and in a printed version. The PDF will be posted on the PHA Europe website. Printed copies will be sent by normal post to the national associations. *Many thanks in advance!*

2015



### February 24 - Brussels, Belgium EURORDIS GALA DINNER FOR RARE DISEASE DAY

The Black Pearl Gala Dinner is a fund raising event organised by EURORDIS within the context of celebrations for INTERNATIONAL RARE DISEASE DAY.

### May 5 - Worldwide 3rd WORLD PH DAY

PH associations around the world will be taking part in the annual World Pulmonary Hypertension Day 2015 (40 took part in 2014). PHA Europe and its affiliates will be running the “Get breathless for PH” awareness campaign developed last year, centred around sports to simulate the breathlessness that PH patients experience in their every day life and to show solidarity for those who are not able to physical activity.

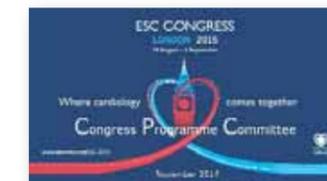


### May 29-31 - Madrid, Spain EURORDIS MEMBERSHIP MEETING (EMM)

Organised in a different European city each year, the EMM provides 200 attendees, made up of mainly patient organisation representatives, plus healthcare professionals and policymakers, with the opportunity to network, share best practices and take part in workshops.

### August 29-September 2 - London, UK EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS

PHA Europe will be present as an exhibitor at the EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS 2012. This Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines from basic research to clinical practice.



### September 26-30 - Amsterdam, Netherlands EUROPEAN RESPIRATORY SOCIETY'S ANNUAL CONGRESS

PHA Europe will also be present with a booth at the EUROPEAN SOCIETY FOR RESPIRATORY MEDICINE'S ANNUAL CONGRESS 2012. This Congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

### September 17-20 - Barcelona, Spain PHA EUROPE ANNUAL PH EUROPEAN CONFERENCE

PHA Europe will be holding its 2015 Annual PH European Conference in Castelldefels (Barcelona). PH Patient Leaders from 27 European countries represented the 2014 meeting.



### 2016 AT A GLANCE

- EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS, Edinburgh, Scotland, May 26-28
- PHA USA INTERNATIONAL CONFERENCE AND SCIENTIFIC SESSIONS, Dallas, USA, June 17-19
- EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS, Rome, Italy, August 27-31

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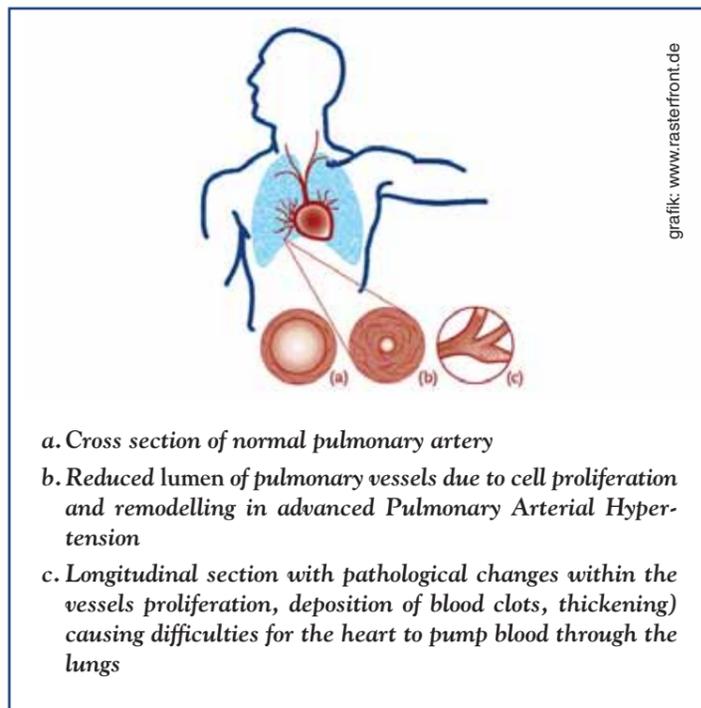
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### AIMS OF PHA EUROPE

Pulmonary Arterial Hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria, as an international non profit organisation. PHA EUROPE is an umbrella organization bringing together Pulmonary Hypertension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations and public institutions worldwide and work towards achieving the best possible standards of care for all European Pulmonary Hypertension patients.

### WHAT IS PULMONARY ARTERIAL HYPERTENSION?

In patients with Pulmonary Arterial Hypertension characteristic changes occur within the pulmonary circulation, which include thickening of the linings and obstruction of the small pulmonary blood vessels. They are both structurally and functionally abnormal. In severe cases up to 80% of these very small blood vessels are rendered non-functional. As a result the pressure in the pulmonary circulation rises well above normal and this places strain on the right side of the heart. This strain can cause the heart to enlarge and the patient may develop heart failure. This is a disease that can affect all ages and is more commonly seen in females. Pulmonary Arterial Hypertension has an estimated prevalence of about 50 per million population.



### TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

Over the past decade a number of evolving therapies that either use complex delivery systems such as 24-hour intravenous or subcutaneous drug infusion, drug inhalation and, more recently, oral medications, have transformed the outlook for PAH patients. PAH is a condition that can be rapidly progressive and needs careful, ongoing expert care and management. The disease can be insidious in its onset, with unexplained breathlessness and tiredness as its two main symptoms. If undiagnosed and/or inappropriately treated the average life expectancy for these patients is estimated to be around 2-3 years. For those patients who fail to respond to medical therapies double lung, or in some cases, heart and lung transplantation may be appropriate.

### THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

While a cure for this aggressive and life threatening disease is still some way off, there is much to be optimistic about. There are an ever increasing number of therapies available for the effective treatment for Pulmonary Arterial Hypertension, which improve the quality and length of life. The aim for the present should be to ensure that all patients with Pulmonary Arterial Hypertension have access to centres of excellence in the diagnosis, management and ongoing treatment of this disease.



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