



PULMONARY HYPERTENSION
Mariposa Journal

WINTER 2015 • PHA EUROPE'S OFFICIAL JOURNAL • N. 15

Warmest wishes for a Happy New Year from PHA Europe





Editor's memo Winter 2015 edition

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- Switzerland
- Turkey
- Ukraine

Dear members, friends and supporters,

welcome to the Winter 2015 edition of the Mariposa Journal. We are very proud of yet another busy and productive year for PHA Europe and its members, who have been active in a number of areas including awareness raising, advocacy, capacity building and information. After a brief summary of the year's overall activities this journal contains detailed reports from the individual national member associations.

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



Secondly, we had a busy year in the field of advocacy, with a very active and high level involvement in policy discussions on access to treatment - which is one of the really critical areas for our patients - in the context of a number of European working groups or task forces we are part of. These include the European Organization for Rare Diseases (EURORDIS), the European Patients' Forum (EPF), and the Partnership on Access to Treatment (PACT).

As part of our focus on access to treatment this year we decided to initiate a campaign to raise awareness specifically on the problems of organ donation and transplantation (ODT): shortage of donors, long waiting lists, high mortality on lists, lack of trans-

plant centres, etc. We officially launched a cross-condition "Call to Action to improve ODT across the EU on October 10, European Organ Donation Day (EODD). The EODD is a yearly event organized by the Council of Europe on the first Saturday of October. Our online "Thunderclap" campaign to promote the EODD had a social reach of over 150.000 and its link featured on the Council



Karin Kadenbach MEP supported the Call to Action on Organ Donation and Transplant with an article on European Organ Donation Day 2015

of Europe's official website. The Call to Action has so far received the endorsement of over 90 organizations, active at EU and national level. These include the main European scientific societies (ESC, ERS) and public health stakeholders in Brussels as well as patient associations active in the disease areas of kidney, lung and heart. Further activities are planned for next year.

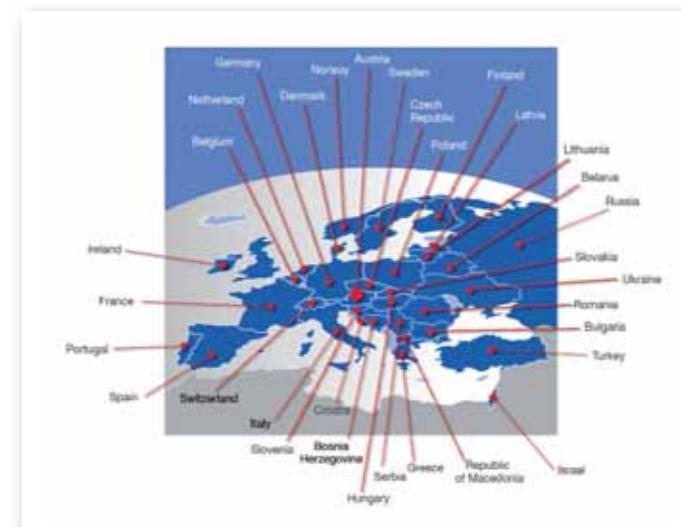
In the area of information and education, in addition to our journal, newsletters, lectures, training sessions at the Annual PH European Conference (APHEC) and participation at key scientific meetings, we are especially proud of the launch of a global PH Library. This project was developed in collaboration with PHA US.



Our "PH Library" officially launched on Friday 18th September 2015 at the APHEC in Barcelona and received a wonderful reception from all participants. The library hosts over 200 patient group resources from around the world and 23 different languages are represented on the website. The website provides three modules for visitors to gain an overview about PH, PAH, research, treatments and support that is currently available. More details are available in the articles on pages 16-17.

Despite our very active engagement in all these areas, we are far from having achieved our objectives. PH is still a little-known disease, diagnosis can take up to three years, even in the most advanced countries and, as mentioned above, access to approved treatments or transplant is a critical issue in many others. Until minimal standards of care are met in all countries, our collective efforts must continue.

We are pleased that some progress has been made this year with respect to the recognition of the need for psychosocial support, which as we well know, is vital in a chronic, fatal and progressive disease such as PH. In the new ESC/ERS Guidelines for pulmonary hypertension, presented at the ESC Annual Congress in September in London, psycho-social support has been upgraded with respect to the past and has been given the highest existing "grade of recommendation 1". To substantiate this higher grade the new guidelines make mention of an article which was co-authored by representatives of PHA Europe, PHA US and PHA UK and leading PH physicians and nurses, entitled "Understanding the impact of pulmonary arterial hypertension on patients' and carers' lives". The new guidelines also stress the need for PH to be treated within the context of multidisciplinary teams which, alone, can guarantee that all patient needs are met. The guidelines also recognize the important role of patient associations: "Encouraging patients and their family members to join patient support groups can have positive effects on coping, confidence and outlook" (6.3.1 General measures). These are all very important developments which give much hope for the future management of the disease.



As already stated in numerous other instances, PHA Europe's ultimate goal is to put in place a strong European PH community consisting of empowered national patient associations working together to achieve common objectives. In the course of this year PHA Europe has again provided support to its member associations through two programmes. The "White Spots" programme provides start up funds and guidance for new associations. The "Fellowship" programme, whereby member associations can apply to have a paid part time English speaking assistant, is vital to ensure communi-

cations and overcome language barriers with our affiliates. Educational and training opportunities for PH patient leaders were also available through various channels, including the APHEC in Barcelona, which featured once again this year a prestigious panel of internationally renowned specialists in PH and other areas of interest to PHA Europe.

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

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

Gerald Fischer, CEO PHA Europe

PS. Very big thank to PHA for nominating Bruno Kopp, Pisana Ferrari, Mélanie Gallant Dewavrin, Juan Fuertes and myself "Periwinkle Pioneers" for our dedication to the PH cause and for "helping to change the history of this disease".

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JANUARY

Brussels, January 14

DITA TASK FORCE CONSULTATION ON SUPPLEMENTS

DITA is the “Drug Information, Transparency and Access” task force of EURORDIS, the European organization for Rare Diseases. Juan Fuertes and Luc Matthysen are both members and took part in this consultation on behalf of PHA Europe.



Oslo, January 15 PHAE EVENT

“WHITE SPOTS” TRAINING MEETING

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

FEBRUARY

Brussels, February 23

EURORDIS RARE DISEASE DAY POLICY MEETING

Juan Fuertes, Luc Matthysen, Pisana Ferrari, Hans-Dieter Kulla and Gergely Meszaros attended the EURORDIS policy meeting on behalf of PHA Europe. The policy meeting was followed by the traditional Rare Disease Day “Black Pearl” Gala.



London, March 6-7

SIR JOHN VANE MEMORIAL SYMPOSIUM ON PROSTANOIDS (UT)



The John Vane Memorial Symposium on Prostacyclin Science and Pulmonary Vascular Disease is held annually at the Royal Society in London by the William Harvey Institute. The aim is to honour the memory of Sir John Vane, Nobel Prize winner for his discovery of prostacyclin and its analogues, including Remodulin. The 2015 meeting was attended by over 200 medical professionals. PHA Europe was represented by Pisana Ferrari, in the photo at right with Lady Jane Vane, wife of the late Sir John Vane.

MARCH

Riga, March 19-20

CHRONIC DISEASES SYMPOSIUM

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



Lisbon, March 22

EUROPEAN PATIENTS FORUM (EPF) MEETING

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



Barcelona, March 24-26

EYE FOR PHARMA

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

Copenhagen, March 27

PULMONARY HYPERTENSION FORUM (ACTELION)

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

MARCH

Brussels, March 30

EUROPEAN PATIENTS FORUM (EPF) WORKING GROUP ON ACCESS

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

APRIL



Abu Dhabi, April 9-11

SAPH 2015, SAUDI PH ASSOCIATION PAH CONFERENCE

Pisana Ferrari, Juan Fuertes and Luc Matthysen represented PHA Europe at this important annual PH conference. Juan Fuertes was part of the panel of speakers with a talk on the needs of PH patients.

Paris, April 13

DIA EUROMEETING

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

MAY

Brussels, May 19-21

EUROPEAN PATIENTS FORUM (EPF) GENERAL ASSEMBLY

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

Madrid, May 28-29

EURORDIS MEMBERSHIP MEETING

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



Madrid, May 30

EURORDIS WORKING GROUP ON RARE BEST PRACTICES

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

JUNE

Luxembourg, June 3 PHAE EVENT

MEETING WITH EU COMMISSION

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

Madrid, June 16-17

ERS PRESIDENTIAL SUMMIT

Juan Fuertes, represented PHA Europe at this Summit as member of the Council of the European Lung Foundation (ELF). The summit is organized yearly, the subject was personalized respiratory care. The highlight of the summit was the presidential speech, which stressed the need to reduce inequalities in access to respiratory healthcare.

Brussels, June 24

INTEREST GROUP ON ACCESS TO HEALTHCARE AND PATIENT ACCESS PARTNERSHIP (PACT)

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



Riga, July 4

6TH INTERNATIONAL PH NURSE WORKSHOP (BAYER)

Pisana Ferrari and Ieva Plume, representing PHA Europe, gave a joint presentation on the activities of patient associations and Pisana Ferrari also gave a talk on "Life after lung transplant" to an audience of 170 participants, including Bayer representatives, from 18 countries.

Frankfurt, July 5

PHAE EVENT

IRONMAN EUROPEAN CHAMPIONSHIP

PHA Europe was present at the Ironman European Championship in Frankfurt with an information booth and six athletes who were running with our colours. Volunteers from the German PH association and Members of the PHA Europe Board were present to man the booth and take part in awareness raising activities about the partnership and PH (race briefings, "pasta party", press conference).



London, September 1-3

EUROPEAN SOCIETY OF CARDIOLOGY (ESC) ANNUAL CONGRESS

Pisana Ferrari attended the ESC congress, which had over 30.000 participants. Many very interesting sessions at this congress were about PH. The highlight of the congress for PHA Europe was the presentation of the new joint ESC/ERS clinical guidelines on pulmonary hypertension.

Brussels, September 3

EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA) GENERAL ASSEMBLY

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

Barcelona, September 17-20

PHAE EVENT

ANNUAL PH EUROPEAN CONFERENCE (APHEC)

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



Amsterdam, September 26-30

EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS



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

Lisbon, October 8

EUROPEAN REFERENCE NETWORK CONFERENCE

Juan Fuertes represented PHA Europe at this conference which focused on the implementation of ERNs, under the Directive 2011/24/EU, with the goal to support interested highly specialised networks and centres of expertise across the EU which are already preparing for the call for ERNs in early 2016. Further the draft of the assessment manual and toolbox to be used for the technical assessment of the Network proposals was presented.



Lisbon, October 10

EUROPEAN ORGAN DONATION DAY (EODD)

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

Brussels, October 16

EUROPEAN PATIENTS FORUM (EPF) STEERING COMMITTEE ON ACCESS

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



Brussels, October 27

CONFERENCE ON PRIORITIES FOR A EU POLICY ON MULTI-MORBIDITY

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



Brussels, October 28

EFPIA HEALTH COLLABORATION SUMMIT

EFPIA is the European Federation of Pharmaceutical Industries. Luc Matthysen and Juan Fuertes represented PHA Europe at this event. For the first time the pharmaceutical industry invited a large number of patient representatives and centered the interest in patient participation and inclusion in the healthcare arena.

Brussels, October 28

EUROPEAN PATIENTS FORUM (EPF) WORKING GROUP ON ACCESS

Juan Fuertes represented PHA Europe at this working group meeting.

Brussels, November 17

PATIENT ACCESS PARTNERSHIP (PACT) MEETING

Juan Fuertes represented PHA Europe at this event held at the European Parliament and addressed a comment to the EU Commission, in his capacity as Member of the steering committee of the European Patients' Forum (EPF) Working Group on Access. The session hosted by the lead MEPs, with the active presence of the representative of Luxembourg as current President of the EU Council, aimed at addressing the suggestions and remarks to the Expert report on access to health services across Europe.

Brussels, November 24

DITA FACE TO FACE MEETING

The acronym "DITA" stands for "Drug Information, Transparency and Access" and it is one of the working groups of EURORDIS, the European Organization for Rare Diseases. Luc Matthysen and Juan Fuertes, who are both members, attended this working session in Brussels, which focused on ethical aspects of health technology assessment (HTA) and new methodologies to obtain more accurate and fair appraisals of the value of new drugs and technologies.

Brussels, November 27-29

PHA EUROPE BOARD MEETING

PHAE EVENT

The PHA Europe Board meets twice a year, once in September during the APHEC and once around the end of the year. It also holds regular Skype conference call. The end of year meeting is traditionally held in Vienna, head office of PHA Europe. This year the outgoing Members of the Board (2014-2015) met with the newly elected ones (2016-2017) in order to ensure a smooth transition of functions and planning of next year's activities.



New clinical guidelines for the diagnosis and treatment of PH

The new clinical guidelines on the diagnosis and the treatment of pulmonary hypertension (PH) were presented at the EUROPEAN SOCIETY OF CARDIOLOGY (ESC) Annual Congress in London in September 2015. (1) The new Guidelines are authored by the Joint Task Force of the ESC and of the EUROPEAN RESPIRATORY SOCIETY (ERS) and endorsed by the EUROPEAN PAEDIATRIC AND CONGENITAL CARDIOLOGY, the INTERNATIONAL SOCIETY FOR HEART AND LUNG TRANSPLANTATION, the EUROPEAN LEAGUE AGAINST RHEUMATISM, and the EUROPEAN SOCIETY OF RADIOLOGY. This latest edition follows the two previous ESC/ERS guidelines of 2004 and 2009 and is based on systematic literature review to identify new studies published since 2009.

The Joint Task Force was composed of 20 of the top international experts in different medical fields: cardiology, thoracic surgery, pulmonology, radiology and rheumatology. They were then edited by 70 experts in the course of a process which lasted three years.

Main changes since previous edition

What follows is a brief summary of the main changes with respect to the previous guidelines, courtesy of by Prof. Nazareno Galiè, University of Bologna.

- Updated clinical classification (more detailed conditions listing, new genes, new drugs and pediatric disorders included).
- Updated haemodynamic classifications (in particular post capillary PH with new wording) and inclusion of PVR in the diagnosis of pulmonary arterial hypertension (PAH).
- Diagnostic algorithm based initially on the echocardiographic probability of PH (low, intermediate and high) and followed by the identification of the most common causes of PH such as PH due to heart diseases, lung disease and chronic thromboembolic pulmonary hypertension (CTEPH). Indication for specific further work-up including right heart

catheterization. Specific imaging for CTEPH to better define the different treatment strategies. Final diagnosis including PAH and PVO genotype (wild type or different mutations). Pivotal role of expert centres starting with the diagnostic process.

- Assessment of individual patient risk profile based on the estimated 1-year mortality [low (<5%), intermediate (5-10%), high (>10%)] and including a panel of nine clinical, functional, exercise, biochemical, imaging and haemodynamic parameters. Definition of satisfactory/unsatisfactory clinical response to therapy based on the change or maintenance of the risk profile. Prospective follow-up assessment with specific suggested investigations.
- Novel treatment algorithm and treatment tables including recently approved new compounds. Strategies based on the patient risk profile. New evidence for efficacy of sequential and initial combination therapies. Early consideration for lung transplantation.
- Novel treatment algorithm including surgical, medical and interventional strategies.

The most important recommendations are related to multiple areas:

- Early referral of patients with established PH to expert centers.
- Confirmation of PAH diagnosis with right heart catheterization and performance of acute vasoreactivity test in the idiopathic, heritable and drug-induced forms.
- The assessment of the risk profile and the early indication for combination therapy in PAH patients.
- Priority for the surgical indication in patients with CTEPH and indications for medical and/or interventional therapies in not operable patients or patients with residual pul-



monary hypertension after surgery.

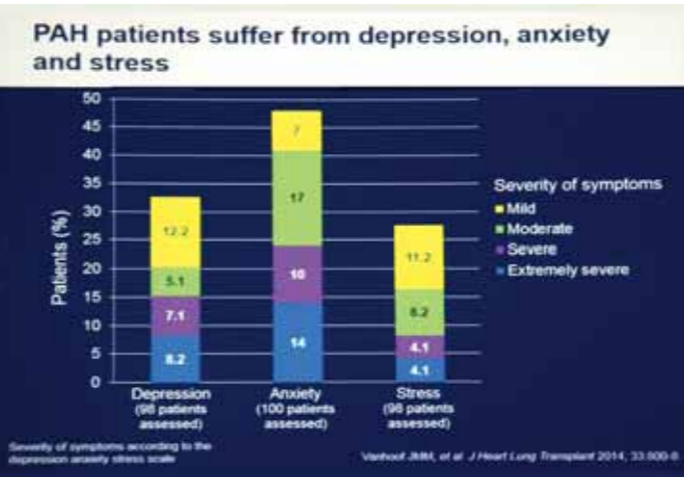
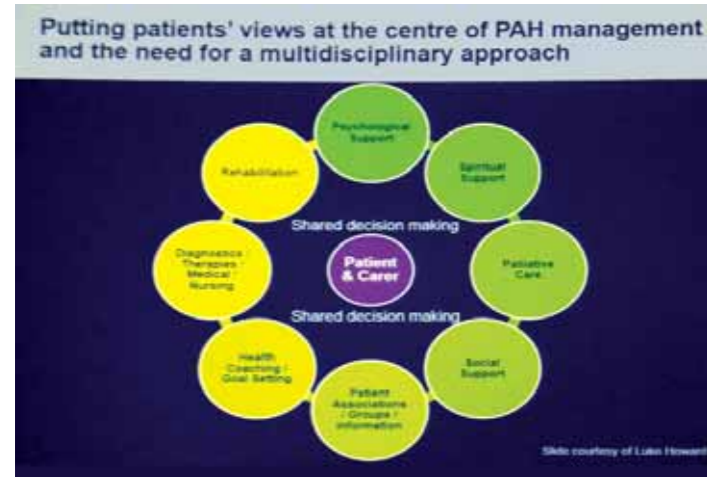
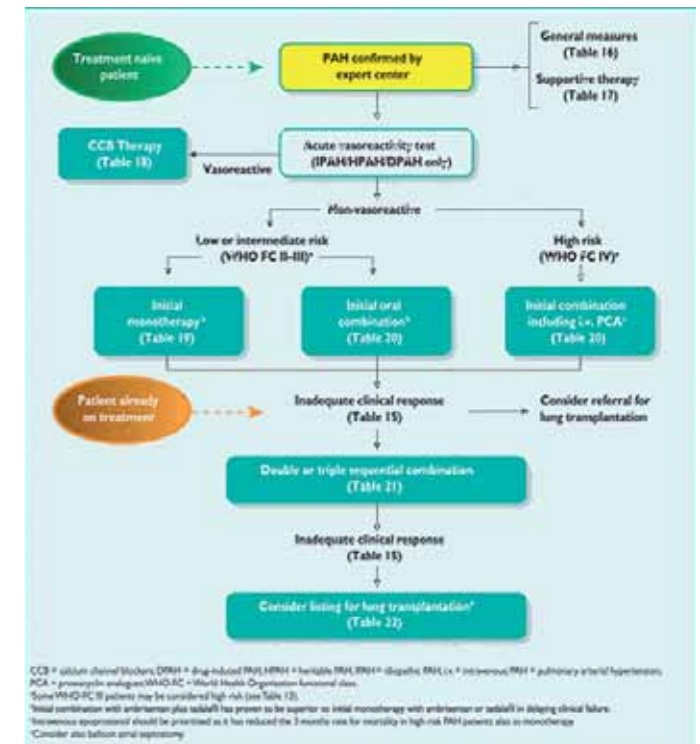
- No indication for drugs approved for PAH in patients with PH due to left heart diseases or lung disease.

The area with more evidence-based information is the pharmacological treatment of patients with PAH. All the available data needed to be reconciled in a comprehensive treatment algorithm (see table on right) and in multiple tables in order to include recommendations for different patients risk profiles. In addition, the information provided had to be inclusive enough to be applicable in different healthcare system with heterogeneous drugs availability. The new data and the new recommendations included in this updated version of the PH guidelines are intended to provide a practical approach to the management of these complex patients.

PHA Europe comments

The new guidelines provide clinicians worldwide with very valuable state of art recommendations for their daily practice. We are particularly pleased with progress in two areas: the recognition of the need for psychosocial support in the context of a multidisciplinary, holistic, patient-centered approach and the recommendation to physicians to encourage patients to join patient associations.

Psychosocial support is vital in a chronic, fatal and progressive disease such as PH. In the new guidelines psychosocial support has been given the highest existing “grade of recommendation”, which is I (see table below). To substantiate this higher grade the new guidelines refer (with the note number 168) to an article which was co-authored by representatives of PHA Europe, PHA US and PHA UK and leading PH physicians and nurses, entitled “Understanding the impact of pulmonary arterial hypertension on patients’ and carers’ lives” (2). This article follows up on the main findings of the International Patient and Carer Survey conducted in 2011 in five European countries (3).



Recommendations	Class ^a	Level ^b	Ref. ^c
It is recommended that PAH patients avoid pregnancy	I	C	160, 161
Immunization of PAH patients against influenza and pneumococcal infection is recommended	I	C	
Psychosocial support is recommended in PAH patients	I	C	168
Supervised exercise training should be considered in physically deconditioned PAH patients under medical therapy	IIa	B	153–157
In-flight O ₂ administration should be considered for patients in WHO-FC III and IV and those with arterial blood O ₂ pressure consistently <8 kPa (60 mmHg)	IIa	C	
In elective surgery, epidural rather than general anaesthesia should be preferred whenever possible	IIa	C	
Excessive physical activity that leads to distressing symptoms is not recommended in PAH patients	III	C	

Very importantly the new guidelines stress the need for PH to be treated within the context of multidisciplinary teams which, alone, can guarantee that all patient needs are met. A multidisciplinary approach will also enhance the level of collaboration between various specialists and centres with different levels of expertise and experience.

Last but not least the new guidelines acknowledge the important role that patient associations play, in two separate instances:

- “Encouraging patients and their family members to join patient support groups can have positive effects on coping, confidence and outlook” (6.3.1, General measures).
- “Patient support groups may also play an important role (in patient management) and patients should be advised to join such groups (6.3.1.5, Psychosocial support)

These are very important developments which give much hope to PH patients for the future management of the disease.

Pisana Ferrari

Notes

1. <http://eurheartj.oxfordjournals.org/content/37/1/67>
2. *European Respiratory Review*; 22:535–542, 1.12.2013, autori P. Ferrari, L. Guillevin, I. Armstrong, R. Aldrighetti, L. Howard, H. Ryttenius, A. Fischer, S. Lombardi, S. Studer, <http://err.ersjournals.com/content/22/130/535>
3. The survey was undertaken to provide new insights into the wider impact of PAH on patients and carers, with a focus on the practical, social and emotional impact on the patient and carer and their information needs: www.phaeurope.org/wp-content/uploads/PAH_Survey_FINAL.pdf

Annual PH European Conference

Barcelona, September 17-20, 2015

Annual report, election of new Board and approval of membership applications

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 meeting took place from September 17 to 20 in Castelldefels, near Barcelona (Spain). 27 countries were represented.

After the opening speech by the President and the introductions of all the attendants we started our three day meeting with the Annual General Assembly, during which the yearly report and 2014 accounts were presented and approved. We also voted on the new Board, whose mandate will run from January 1, 2016 to the 31st of December 2017 and on the membership applications for 2014. The new Board Members are: Luc Matthysen (Belgium), President; Hans-Dieter Kulla (Germany), Vice President; Mélanie Gallant Dewavrin (France), Treasurer; Natalia Maeva (Bulgaria), Vice Treasurer; Ieva Plume (Latvia), Secretary; Laure Rosé (France), Vice Secretary. It was great to welcome into the European PH family the PH associations of Belarus, Croatia, Serbia, Denmark (Denmark was admitted last year as individual member, this year as full member), Romania, Spain (the association FCHP) and Ukraine (URGHA). We are very proud that our PH community has grown so much in past years: with these newcomers PHA Europe now has 39 member associations from 33 countries!

Updates in PH treatment strategies and surgery

It was a very big honour for PHA Europe to welcome at its 2015 APHEC three key international opinion leaders as its guest speakers: Prof. Sean Gaine, pulmonologist, from the

Mater Hospital in Dublin, and Prof. Walter Klepetko, thoracic surgeon, from the Medical University Hospital in Vienna (AKH) and Prof. Nazzareno Galiè, cardiologist, from the University of Bologna. Prof. Gaine in his lecture summarised the main PAH therapeutic pathways, the clinical trials conducted up to now, which have led to the approval of many PAH drugs and discussed new future trends in PAH management. Prof. Klepetko provided a very comprehensive review of issues related to lung transplantation surgery, including very promising new techniques for bridging and supporting pre-and-post transplant (ECMO, extra corporeal membrane oxygenation). Prof. Galiè closed the APHEC on Sunday with a detailed summary of the new ESC/ERS guidelines for PH, approved in London in September at the ESC Annual Congress (see also article page 8).

Review of the year's activities

The APHEC, as always, provides the opportunity to review the year's activities, including:

- Awareness raising activities: World PH Day and the charity partnership with the Ironman European Championship in Frankfurt (see also Summer 2015 edition of Mariposa).
- Activities in the field of advocacy and lobbying.
- "White Spots"/"Fellowship" capacity building programs.
- Fundraising activities and new ideas for future.
- Educational and information resources (see pages 16-17).

Raising awareness with medical students

Gerald Fischer presented an interesting initiative, carried out at the Vienna Medical University, called "Under pressure", aimed



Prof. Walter Klepetko, Austria



Alina Rubio, Actelion Pharmaceuticals (CH)



Prof. Nazzareno Galiè, Italy





Tim Alwinkle, United Therapeutics (UK)



Alessandro Maresca, Actelion Pharmaceuticals (CH)



Thomas Ernst, Bayer Healthcare (DE)



Stanimir Hasardzhiev, Bulgaria



Prof. Sean Gains, Ireland





at raising PH awareness among medical students, which could serve as a “template” for other countries (see also page 18).

Advocacy and lobbying workshop

In the context of this workshop we had the great pleasure of having as our guest speaker Dr. Stanimir Hasurdjiev, Bulgaria, Member of the Board of the the European Patients Forum (EPF) and Secretary General of the “Patient Access Partnership” (PACT), who gave an overview of the work being carried out in the area and future prospects. Juan Fuertes presented a report on his advocacy activities in the course of the year, with particular reference to his work within several important working groups and task forces. To conclude, I gave a brief overview of the current status of the PHA Europe’s “Call to Action to improve Organ Donation and Transplantation across the EU”, launched officially on European (October 10), which to date has about 90 endorsements.

Advocacy case studies

The aim of this session was to share successful advocacy activities conducted at national level. The results achieved by our members are remarkable and include new national programs for PH, drug reimbursement approval, campaigning for organ donation and transplantation and teaming up with larger organizations for more impact.

Fundraising case studies

This session was also very inspirational as a number of interesting and original ideas for fundraising were put forward. The session included a presentation of a crowdfunding initiative conducted in Spain for a charity by EURORDIS, kindly represented at our meeting by Marta Campabadal.

World PH Day awards

One of the highlights of the APHEC was the award ceremony for the best national awareness campaigns for WPHD: the first prize went to Slovakia and the Czech Republic for a joint project, the second to Belgium and the third to The Netherlands.

Industry partner session

As in past years a session was set aside to meet with our industry partners and discuss common projects and educational resources: Actelion, Bayer, GlaxoSmithKline and United Therapeutics. We take this opportunity to thank them warmly for their commitment to PH and their continued support to PHA Europe throughout the years.

Other activities

Early morning yoga on the beach and special one-to-one consultations on specific issues during breaks and free time were new and much appreciated features of this year’s APHEC. We had great feedback in general about our meeting from all the participants, our wonderful European PH family!

Pisana Ferrari



Thomas Ernst, Bayer Healthcare (DE)



Thuy Linh Vu Thi, Bayer Healthcare (DE)



Ray Pediani, United Therapeutics (UK)



Victor Hoff, GlaxoSmithKline (UK)



Marta Campabadal, EURORDIS



Sebastien Gagnon-Messier, Bayer Healthcare (DE)





Our PH Library: online resources from around the world



Findings from the International Patient and Carer Survey, carried out in 2011 in five European countries (1), revealed that patients have greater expectations towards their care, but often lack the knowledge and the confidence to demand this. Patient organizations emerged as one of the most important sources of information for patients, with two-thirds of those surveyed reporting they looked for information about PAH from patient groups around a range of topics including treatments, travel, doctors involved in PAH and the emotional impact of the disease. In July 2013, an advisory meeting with PHA Europe, PHA US and PHA UK was held to discuss a program that would empower patients to play a more active role in the care they receive, through creating a simple platform to share information.

Our PH Library website

With such a vast array of excellent information and resources available from all the PH organizations worldwide we decided to embark on a project which would make it easier for



patients and families to access all existing patient group materials, harnessed in a structured program that empowers patients to use them more widely. With this in mind, Our PH Library was born. This new website aims to offer a one-stop-shop for people seeking high quality PH information, developed by patient organizations. Our PH Library officially launched on Friday 18th September 2015 at our annual PHA Europe meeting in Barcelona, and received a wonderful reception from all participants. The library hosts over 200 patient group resources from

around the world and 23 different languages are represented on the website. Our PH Library is a joint collaboration between PHA Europe and the Pulmonary Hypertension Association (PHA) and was developed with the support of an educational grant provided by Actelion.

The website provides three modules for visitors to gain an overview about both PH and PAH and the research, treatments and support that is currently available. The index of resources enables the visitor to search for resources by topics, by format (videos, booklets, etc.) and by language. All relevant items are listed and the library provides a direct link to the patient group's resources. This not only raises awareness but also increases traffic to the national association websites.

Feedback post launch

In the first three months since launch, Our PH Library



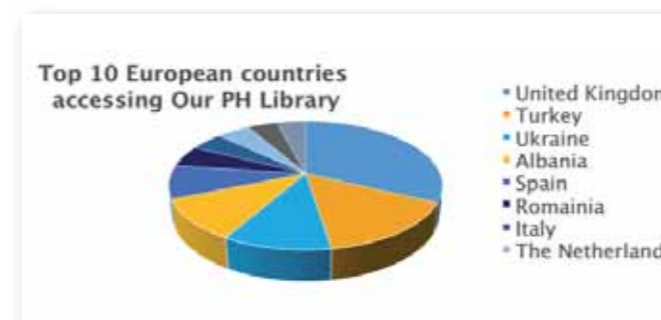
received over 9,000 unique visitors from countries all around the world including India, Vietnam, Egypt and Brazil, with 1,355 visitors returning more than once! The top three most visited pages are Module 1, What is PH, Module 1 What is PAH and the Index of Resources. This demonstrates the value of the library as a truly global resource!

A "Google AdWords" campaign to promote Our PH Library has consistently driven traffic to the website which has achieved 1,441,259 impressions since launch and 11,233 clicks-through via the sponsored links, a click-through rate of 0.78%.

We will continue to optimize the Google AdWords campaign by removing any search terms that aren't relevant to the library and track our progress.

Our PH Library materials

We encourage all our members to share the link to the library as widely as possible. A handy guide with sugges-



tions on how patient organizations may want to promote the library as a resource is available. The guide, which includes resources such as website banners, like the one at the end of the article, can be downloaded from the PHA Europe website at <http://www.phaeurope.org/wp-content/uploads/Our-PH-Library-How-to-guide-.pdf>

Our PH Library Tweet Chat

To support the launch of Our PH Library PHA Europe collaborated with PHA US to host and participate in the first ever tweet chat for the PH community. The tweet chat took place on Monday 12th October 2015 and included a panel of 5 experts in PH led by the Pulmonary Hypertension Association US and involving PHA Europe, expert patient, Alex Flipse, Martha Gonzalez, advocate and mother of a son with PH as well as doctors John Ryan and Patricia George.

Twitter followers were asked to use the hashtag #PHLibrary to join in the conversation and a variety of topics were covered during the hour-long chat including the emotional impact of PAH, patient and carer empowerment and information needs.

Over 200 tweets were posted and the library experienced almost 150 visits during the hour with 23 active participants. The range of experts involved and speed of the responses made this an exciting chat, whilst raising awareness of the wealth of resources available through the Library. With many of our tweets being re-tweeted, we were able reach over 2,700 twitter followers.



Do check out the Library yourself today!
www.ourphlibrary.com

Note

1. *The impact of pulmonary arterial hypertension (PAH) on the lives of patients and carers: results from an international survey 2012.*

<http://www.phaeurope.org/wp-content/uploads/International-PAH-patient-and-Carer-Survey-Report-FINAL1.pdf>

Pisana Ferrari



AUSTRIA

“Under pressure”

On March 10th PHA Austria launched a new project called “Under Pressure”, a lecture about pulmonary hypertension, at the Medical University in Vienna. The latest information about pulmonary hypertension was shown on a big screen, Prof. Irene Lang and her team presented case studies from PH patients and the famous TV scientist Werner Gruber performed spectacular experiments related to pressure. All students who attended our “Under Pressure” lecture received a free T-Shirt. We were able to reach hundreds of students and create awareness. Our intention was that they remember PH in their professional life. See at: bit.ly/1Q8mutT

World record for PH patients

On May 5th the world's strongest man, Franz Müllner, set a new world record to show how patients with PH feel in their daily life. He trained 10 hours on top of Vienna's most famous sight, the giant ferris wheel in the Viennese Prater. Hundreds of spectators gathered to watch the world's strongest man lift

240.000 kilos and ride 200km on a bicycle at a height of 65 meters. The event created high media interest and journalists were able to hold exclusive interviews with the world's strongest man. In the evening the Viennese giant ferris wheel was lit up in our colour - blue - for WPHD. See at: <https://www.youtube.com/watch?v=nxomoVDTJYM>

Europlan Conference in Vienna

The Austrian EUROPLAN Conference for the national action plan for rare diseases took place on May 22nd in the Ministry



of Health in Vienna. Gerry Fischer represents patients with rare diseases in Austria in this commission. He had the possibility to have a two hour personal face to face meeting with Yann le Cam, CEO of EURORDIS, the EUROPEAN RARE DISEASE ORGANIZATION, which was very fruitful (see photo on left).

4th Zoorun

On June 10th we held our 4th Zoorun in Schönbrunn, the oldest Zoo of 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 celebrities participating to the run. We were happy to share an income of over €30.000,- with the Zoo.

Ghostrun

This year we started with a big new project, the “Ghostrun, a costume run for Halloween”. The world famous Viennese Prater set up a big Halloween Party and as part of this great event, we were happy to organize three runs the day before. First there was a run for school classes, in the afternoon we started with a family run and in the evening there was a 6 km course for sport enthusiasts. The runners were dressed up in Halloween costumes. It was a great

success; the people were very delighted and motivated for next year's “Ghostrun”.

Patient meeting

This year we held four educational patient meetings in Vienna, Graz, St. Pölten and Innsbruck, with more than 60 patients each time. With Prof. Irene Lang, Prof. Horst Olschewski and Mrs. Nikola Benjamin, from Rehab Heidelberg, we were happy to welcome many highly qualified speakers. At our meetings the patients had the possibility to interact with other PH patients and learn a lot of the latest developments in PH management from health care professionals. We ended the meetings with a nice buffet and a warm and lively get-together. In addition to the educational patient meetings, we organized patient meetings called “Plaudermeetings” (chat meetings, for psychosocial support) in four different counties of Austria. These meetings were only attended by patients, no industry, no nurses, no doctors and they are attended by more than 30 patients (the numbers are growing rapidly) each.

PH rehab center in Tirol

We are happy that we now have a specialized PH rehabilitation center in Tirol and that two more are being set up and will hopefully be finished by the end of 2016.





Fundraising dinner

On November 13th, we had a great Fundraising Gala Dinner in the Restaurant “Eisvogel”, next to the Viennese giant ferris wheel. The most famous Austrian singer, Rainhard Fendrich, gave an exclusive concert and a famous Austrian TV cook presented a 6-course menu. During the dinner there was an auction and tombola with many special prizes. We were very happy to receive a donation of €80.000,- for the Austrian Patient Association.

15th anniversary

In October the Austrian patient association celebrated its 15th anniversary, as an honour for our work we received a certificate from the umbrella Organisation for Austrian patient initiatives.

Awards

PH Patient Maleen Fischer was happy to be honoured in the Vienna city hall with the “Life Goes On” award. She was nominated in the category “Courage”. Gerald Fischer, President of the Austrian patient association, was announced as “City hero” by a Viennese magazine for his work for PH. There was a large article in a newspaper that is sent to every household in Vienna.



Service for PH patients

As a new service for our members, we started a cooperation with nutritionists and psychologists in all counties of Austria. All our members have access to the same guidance and support. We pay two sessions for each patient and, of course, if they want to continue the therapy, they can follow up on their own, for a special price. We have been receiving more membership applications since we have been calling ourselves “Service Center for PH Patients”. We advertise in the PH clinics with folders on the door of the PH centres and with laminated posters in the waiting area. This gives us visibility at HCP’s and patient level. Our message is: “If you are diagnosed with PH, you are entitled to use our service free of charge”. During the PH Day (Tuesday) in the Vienna University Hospital, we offer a consultant desk in the cafeteria of the hospital. All our patients received a nice Christmas and New Year card with a winter wonder tea.

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



BELGIUM-HTAP

Patients’ association days in the hospitals

The BELGIUM PATIENT PLATFORM (LUSS) is organizing patients associations’ days in several hospitals. The purpose is to give the associations the possibility to inform the patients and the healthcare providers about the different diseases. HTAP Belgique is participating actively and is using those occasions to inform the healthcare providers about PH. Most of the hospitals are not involved in PH but we inform them about the regional hospitals and specialized centers for PH.

European Patients’ Forum (EPF)

HTAP Belgique asbl was representing PH Europe at the Annual General Meeting of the EUROPEAN PATIENTS’ FORUM (EPF). This meeting was followed by a two-day conference entitled “Empowered Patients are an asset to society”. The concept of patient empowerment and other related issues, including involvement and health literacy, were presented. Workshops were organized to discuss the new patient-professional relationship and the role of self-management in chronic diseases.

EUPATI training course

The mission of EUPATI (EUROPEAN PATIENTS’ ACADEMY ON THERAPEUTIC INNOVATION) is “Educating patients on therapeutic innovation”. This consortium is funded by IMI (INNOVATIVE MEDICINES INITIATIVE) in which Eurordis is actively contributing. The project develop educational material, training courses and public information to educate patients and the lay public about medicines development processes. It increase the capacity of patients to be effective



advocates and advisers in medicines research , e.g. clinical trials, with regulatory authorities and ethical committees. I participated to the first cohort of EUPATI trainees and finished the training this month.

EURORDIS: DITA Task Force

Juan Fuertes and myself had the opportunity to participate in the meeting dealing with “Economic evaluation of health technologies and alternatives to QALY based cost-utility analysis”. Health technology assessment (HTA) is a very complex matter and this was already the second meeting that we attended to learn more about it.

Luc Matthysen, HTAP Belgique
www.htapbelgique.be - www.facebook.com/htapbelgique



BELGIUM-VZW

Aalbeke, football Summer of 2015

A football club in Aalbeke did their warming up before each match with T-shirts from the “Get breathless for PH” campaign to create awareness.

Trade fair Gent September 2015

Thanks to patient Noémi (14) and her family we could participate in the annual trade fair of Gent. We were one of the 300 participants in this trade fair which attracts thousands of visitors yearly. Passers-by could measure their lung capacity or have a picture taken with blue lips (to be posted on a “wall of fame”). Our “godmother”, actress Hilde Heijnen, came by and we were able to do a radio interview on a local radio station, who was present at the trade fair.

A group of 20 volunteers were present at our stand and made

this 9-day activity possible. Our godmother, Hilde Heijnen and a colleague of hers, actor Mark Coessens, came by.

Kilimanjaro

Tommy and Katja, brother and sister-in-law of PH-patient Wendy climbed up Mount Kilimanjaro and took a picture on the top with the “Get Breathless for PH” T-shirts to raise awareness. The photo was posted on social media.

National Patients’ Day Kasterlee (Antwerp), 21 November 2015

On the 21st of November we held our annual National Patients’ Day. A group of 60 persons, patients and relatives, came to listen to lectures about sleeping problems for patients with PH and psychological treatment of patients and relatives. In the afternoon people could choose between different workshops on social media, psychotherapy, yoga and

just being together. To finish the day, there was a reception and dinner.

Lectures at National Patients’ Day:

- Professor C. Belge, PH expert, UZ Leuven;
- Kathleen Swinnen, student working on a program about sleeping problems for PH patients;
- Sven Van Lommel, psychologist, UZ Leuven.

Milcobelrun Langemark Langemark (West Flanders), 28 November 2015

The Milcobelrun is an event organized by a milk company where people can run 3,5 km, 7km or 10,5km. Wesley Willaert, father of PH-patient Margot (6 years old), is working in this company and he put together a group of runners to participate in the run. 50 runners were running in a shirt of the “Get Breathless for PH” campaign. Passers by could also measure their lung capacity and buy candy for Music for Life. There were 50 runners with “Get breathless for PH” T-shirts out of the approximately 800 runners for the whole event. Two articles were published in print media about PH-patient Margot.

Walking-tour Lichtervelde Lichtervelde (West Flanders), 12 December 2015

On the evening of the 12th of December there was a walking-tour organized by shop-keepers of Lichtervelde. Each year they choose a charity to donate a part of the income of the entries. This year they choose us a charity. We had a stand with information on pulmonary hypertension.

Christmas fair Torhout Torhout (West Flanders), 13 December 2015

We were also present at the Christmas fair of Torhout. On our stand you could buy drinks, waffles, candy. You could also pay to hear a song, this is done by disk jockey ‘D-Noizz’.

Music For Life Flanders, December 2015

Studio Brussel, a national Flemish radio station, organizes each year an event called “Music For Life”. The purpose of this event (which is always at the end of the year) is to activate Flemish people to organize fundraising actions for a charity of their choice. The charities, like PH-vzw, can register themselves (has to be approved). The radio station also



organizes actions to fundraise (for all registered charities), this year they organized “warmathons”, where you could subscribe to run in different cities of the Flanders region. The five cities now each want the most runners, because then they are the “warmest city” of Flanders! “Music for life” ends with “the warmest week”, where three disk jockeys are playing non-stop music and are camping in the cold. In this week, everyone can “buy” a song for the charity of their choice or go to the



camping-place to present your action on the radio. PH-vzw organized four actions:
<http://dewarmsteweek.stubru.be/organisaties/pulmonale-hypertensie-vzw>:
 - Candy for Life: 23/11/2015 until 23/12/2014: selling candy.
 - Kerstbieren for Life: 11/12/2015 and 19/12/2015: selling of regional beers by vzw De Bierfanaten.
 - Youthhouse Hoje for Life: 20/12/2015: selling of second-hand clothes and a winter-BBQ.
 - One upcoming from CM, a health insurance company, who will run and collect money by sponsoring.

The interest of “Music for life” is not only the fundraising but also the media coverage and the whole of Flanders who is participating on these actions. All of the PH-vzw Board attended.

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



The members of this Association continue their fight because, as they say, they have nothing to lose. The situation in Bosnia and Herzegovina and the attitude towards those suffering from PH, only gives them more energy to strive for the ultimate goals, among which the most important is putting drugs on the “essential” list.
 “Our government can’t be so indifferent to our problems, we have to be strong and persistent in fighting for our lives. We have nothing to lose. We perceive our mission as a historical one and certainly one day we will reach to the ultimate goal”, says Vera Hodzic, President of the Association.
 In addition to fighting for the lives of patients with PH in Bosnia and Herzegovina, members and activists of “Breath” have in the past attended the “Conference for rare disease

patients in Bosnia and Herzegovina”, participated in the celebration of the “International Day of people with rare diseases” and the “World Pulmonary Hypertension Day”, as well as the “Annual PH European Conference”. Young and healthy activists have organized various events to raise awareness about the disease and they are actively seeking sponsors and donors for “Breath” association so that it will be able to work efficiently. They will also support other initiatives such as the “Race for the Cure - Bosnia and Herzegovina”, and of course the “Call to Action on improving Organ Donation and Transplantation across the EU”.

Vera Hodžić, Udruženje građana oboljelih od plućne hipertenzije “DAH” - u Bosni i Hercegovini
ugphbih@gmail.com



BOSNIA AND HERZEGOVINA

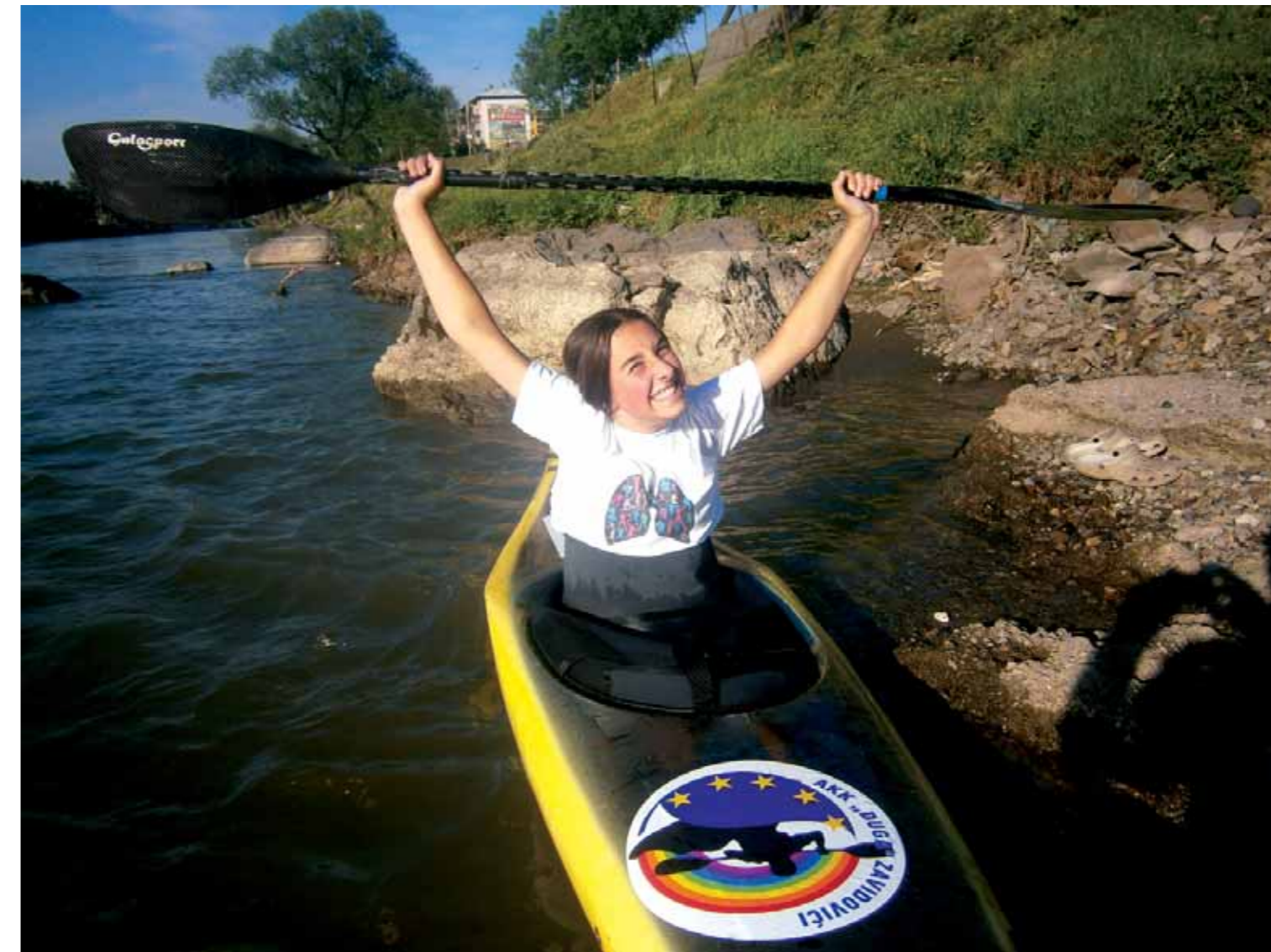
Advocacy and awareness activities with national authorities

The Bosnian PH association “Breath” in the course of 2015 continued with its fight for better conditions for PH patients in every possible way, by meetings, writing letters etc.. In this way they tried to raise awareness of the disease, indicating the problems and trying to reach the competent authorities. In Bosnia and Herzegovina for the time being only the media appear to be interested in PH because they understand the problem and empathize with the patients.

The Association was founded one year ago and since then its members are making efforts in the common struggle to make the drugs available to everyone. The patients in the two entities of Bosnia and Herzegovina, which are the Serbian Republic of Bosnia and Herzegovina and the Federation of Bosnia and Herzegovina are in different positions. In the first entity medications are available and reimbursed, in the other one patients have to pay themselves. Although this fight has been going on since the beginning, until now nothing has really changed. However, thanks to the continued and persistent efforts of the members of the “Breath” association, there are certain signs that things might be moving from this deadlock. The members and activists of “Breath” addressed



directly to the legislative authorities, the Parliament of the Federation of Bosnia and Herzegovina, the entity in which the drug is not available to patients, with the initiative of placing at least sildenafil on the list of “essential” drugs. The initiative was accepted from one Club of delegates and in the future we expect to continue activities to address this issue with a view to improving the position of patients throughout Bosnia and Herzegovina.





BULGARIA-BSPPH

Fundraising photo exhibition for pulmonary hypertension patients

Darin Russev is freelance photographer. His charity photo exhibition to support PH patients, called "No man is an island" was held from the 2nd through to the 16th of April 2015 at the "+ Tova" (Plus That) club of Sofia. The presentation included 21 pictures taken on islands where Darin Russev has traveled in the past few years, including Malta, Cyprus, Sicily, Tenerife, Lefkada and the Azores. All funds from the sale of the photographs were donated for the post-transplantation treatment of Natalia Maeva, who is waiting for a bilateral lung transplantation. "Indeed I was dreaming to hold an exhibition, to share what I saw through the lens. However, the link of my first exhibition to such a real cause is reaching beyond my expectations. The slogan of the exhibition is a reflection of my insight in the necessity to render help. I frankly believe it is possible to raise enough funds for Natalia and I truly appreciate the opportunity to contribute. I am grateful to the persons who made this exhibition possible with the completely voluntary and supportive involvement and the prestige of their names and professionalism. I sincerely thank you!" -



said Darin Russev, the author at the exhibition. The event was organized with the exclusive support of Joana Veleva, founder of the popular club "+ Tova" in the capital, where have repeatedly organized charity events. The selection of the photographs and the layout of the exhibition was a completely voluntary work of Evgeni Dimitrov, founder of BulPhoto and for the organization part we thanks for their time and professional skills Boryana Valeva, designer, Bogdan Metev, printer and the team of CIVITAS, Bulgaria.

Photographer Alexander Ivanov supported the cause as well by donating the funds of the sale of 50 prints of his last album "The Magic Mountain of Pirin" for the medical treatment of Natalia.

The exhibition attracted the attention of the Bulgarian Society for Public Relations and was formally submitted to the newsletter of the association under the column "PReday to PRiate!" ("Transfer to a friend").

"The Blue Lips Disease", as it is known, can affect anyone. Nobody, anywhere in the world is immune. Patients can not breathe enough and get tired after the smallest body efforts,



their extremities swell, their lips and hands turn bluish, they feel shortness of breath. Sleeping with an oxygen mask and walking up stairs is a real ordeal for them. Medications alleviate the disease but not cure the disease. Death is always just behind the corner and the only solution seems to be a bilateral lung transplantation. Urgently. Life might be regained but only if one acts quickly and properly.

Yo-Yo competitors "Breathless" for a noble cause

The Seventh National Yo-Yo Competition was held at the Inter Expo Center on the 5th of September and was a part of gaming competitions included in the tenth edition of the Festival Aniventure - the first and biggest festival for Japanese culture in Bulgaria, which gathers the traditions and the modern pop culture of Japan in the same place.

Over 50 Yo-Yo competitors from all over the country had signed up for participation in the various divisions: "Beginner" (for beginners the duration of the presentation is a minute and a half), "Battle" (participants go out on the stage one opposite the other and alternate which of them will outplay the others), "1A Freestyle", "4A Freestyle" and "5A Freestyle" (the three freestyle divisions are for professionals and each participant has 3 minutes on the stage to show what he can do).

The Yo-Yo masters express their symbolic support to the PH cause to improve knowledge of the disease by remaining "breathless" with their attractive performances for the second consecutive year. Within the framework of the initiative competitors from all over the country combat for the national title and for participation in the finals of the European Yo-Yo competition.

We celebrate the European Day of Donation

For the third consecutive year the Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH), jointly with the Executive Agency for Transplantation and other patients' organizations, friends and partners, celebrated the "European Week of Donorship and Transplantation" (10-18 October 2015). For seven days at a specially organized info corner in the city garden, a lot of passers-by received information materials, amongst which the "Call to Action to improve Organ Donation and Transplantation across the EU". On the Bulgarian part it was supported by the National Patient's Organization, the Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH), the Executive Agency for Transplantation and the Bulgarian Association for Pulmonary Diseases.

Through this initiative we want to create publicity about the problem and the difficulties the patients who need transplantation encounter because we believe that once the problem is better known, this will motivate people to find out more about the possibilities for the donation of organs.

We heard radically different opinions about donorship and transplantations. Young Bulgarian people insist that their desire to be donors should be reflected in their personal documents.

Information Campaign "Raise Hands and Support Pulmonary Hypertension Patients"

During the month of November the Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH) also started



up a photo campaign “Raise Hands and Support Pulmonary Hypertension Patients”, which will last till the end of the year. It is its mandatory condition that all the participants should be photographed wearing lilac gloves symbolically showing one of the symptoms of the disease. Information events were organized on four consecutive Sundays in Sofia, Plovdiv, Burgas and Varna.

As part of this campaign people were handed out a copy of the “Manifesto for Better Diagnostics, Modern Treatment and More Accessible Social Care for Patients with Pulmonary Hypertension”.

BGLUNGTRANSPLANT - Online Platform Dedicated to Pulmonary Transplantations

The Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH), jointly with the National Patients’ Organization and the National Campaign in Support of Donorship BGDONOR realized a joint project - information site www.bglungtransplant.com

The Portal BGLUNGTRANSPLANT was created for people who have one both ordinary and an extraordinary dream - to find a donor who shall save their lives so that they may continue to live in the future being able to give love and warmth to people close to them. Every year nearly 80 Bulgarians fall into cerebral death, but few families decide to donate organs. During the year 2015 three lungs from Bulgarian donors saved the lives of foreigners as no pulmonary transplantations are performed in our country yet. The donors’ organs were presented under EUROTRANSPLANT.

The online platform provides topical information which will

be of use both for the patients in need of pulmonary transplantation and for people close to them as well as for medical doctors working in this direction. The entire procedure from the entry into the official register of the Executive Agency for Transplantation, concerning the recipients for transplantation of a lung up to the transplantation itself and the post-transplantation time period is described in detail. A special place was set aside for the immunosuppressive therapies which are applied in pulmonary transplantations.

Additional Activities

- In June we started the BSPPH Newsletter, which is currently being distributed via Issuu platform for web publishing. It can be found on the following web address: http://issuu.com/bulgariansocietyofpatientswithpulmo/docs/1_newletter_bspph_june. Our second issue is to be published in December.
- We translated the PHA Europe “Call to action to improve Organ Donation and Transplantation across the EU” in Bulgarian and implemented it in both our Association’s web site and in bglungtransplant.com. We also communicated it across other patients organizations and health institutions on a national level to support the initiative.
- We created a Manifesto of PH Support and Advocacy for both web and print distribution.

Natalia Maeva, Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH
www.bspph.net
www.facebook.com/BSPPH.Bulgaria?ref=hl



Participation in the Bulgarian Organ Donation Week
 APH Bulgaria was a co-organizer of the opening event of the Bulgarian Organ Donation Week 2015, in collaboration with the EXECUTIVE AGENCY OF ORGAN DONATION. APH Bulgaria participated in the Organ Donation Week with a posters exhibition. The posters used for the exhibition followed up on the event organized for World Pulmonary Hypertension Day, where national celebrities had their photos taken with blue lips or blue lollipops (see also Summer 2015 Mariposa). All the posters which had been used on that occasion were newly “customized” with a special message in connection with Organ Donation. On the occasion of the



Organ Donation Week APH President Todor Mangarov was interviewed for the BIT TV, together with Dr. M. Dimitrova and T. Borgojiiska, a patient who has undergone lung transplantation (see photos on left).

This is the link to the video with the main highlights of the event and an interview with the APH President. It is in Bulgarian but an English version is currently being put together: <https://www.youtube.com/watch?v=LkmlV4TfwRY>

4th National Conference of PH Patients

The 4th NATIONAL CONFERENCE OF PH PATIENTS took place from the 6th to the 8th of November 2015 in Hisara, at the Hotel Augusta. Medical specialists from all the national PH centers were present at the conference and there were a number of lectures on different aspects of the disease, including treatments and treatment strategies, surgery option, ongoing research and the impact of the disease on the life of patients, in particular the psychological aspects (there was a training session on this topic with a psychologist).

The theme of the conference was “Strong together” and a very well known Bulgarian actress, Maria Patrova, was the testimonial for the event. More than 50 patients attended along with family members, caregivers, friends! 90 medical students also attended the lectures about rare diseases, which were part of the conference.

APH Bulgaria has made a video about the conference: <https://www.youtube.com/watch?v=CRCie5VEZfg&feature=youtu.be>

Todor Mangarov, PHA Bulgaria
www.apph-bg.org
www.facebook.com/aph.bulgaria



CROATIA

How it all started!

It all began in 2014 when I got in touch with the members of the big PHA Europe family. My friend Hall Skaara kindly invited me to a workshop that was held in Oslo from 15-18 January and was attended by other members of the PH associations from Slovenia, Macedonia, Bosnia and Herzegovina, Serbia, Russia, Ukraine and Belarusia. That was also my first meet up with the members of PHA Europe. Hall and Pisana Ferrari showed me their interest for Croatia to join the big PH family. By generous enthusiasm they have showed me what kind of beautiful activity this is all about by investing all of their positive energy to make lives easier for people suffering from PH.

Getting organized and registered

This year was a big turning point for Croatia in the way of getting conscious about PH. I must admit I was unpleasantly surprised when I was talking to people, right after my trip to Norway, about PH and realising they had never heard of this illness. That was just another sign for me to make a move for PH to be heard of. Right after that realisation I started the process of founding the association for people suffering from PH in Croatia and I also organised an

event for World Pulmonary Hypertension Day (WPHD) in the main square in Zagreb, the 1st such event in Croatia. The event was financed by PHA Europe, it was held over two days and gained big media attention which is, I must admit, was well beyond our expectations. We spoke to the doctors who tried, during the event to explain, in the simplest way, what PH is, its symptoms and the ways to diagnose it. Our WPHD event was supported by Goran Čolak, the world's diving record holder, who spoke to the media and held a touching speech by linking his success of holding breath with the patients' inability to breathe in normal conditions. We spent two days by the big pool where anyone who was interested had the opportunity to do diving with Goran and to see what is it like to breathe like people with PH. The event was followed by all kinds of media (TV, radio, press, web).

Collaboration with PH physicians

The Association Plava Krila has also cooperated with doctors of the Pulmonary Hospital in Zagreb who are enthusiastic about the idea to meet patients and present them new achievements and drugs and to exchange information. We were offered free use of space for meetings. Also, they are ready to respond to any activities the association will conduct.

Annual PH European Conference

In September, the PHA Europe big annual conference was held in Barcelona and I was again thrilled with the amount of enthusiasm that comes from all members of this wonderful family. I am grateful for all those wonderful friendships and the



genuine hospitality of the PH family.

As we are still a newly formed association, we do not have too many activities this year, but we do have a lot of good will and enthusiasm to initiate activities and events next year. We look forward to new social gatherings and new events with all members of PH Europe.

Branka Fresl and Zdenka Bradač,
Plava krila, Udruga pacijenata oboljelih od plućne hipertenzije
<http://www.plavakrila.hr/> -
<https://www.facebook.com/PH-Plava-krila-Croatia-1580485492196960/?fref=ts>



CZECH REPUBLIC

**Reconditioning stay in Poděbrady
August 9-16**

Every year, the second Sunday in August marks the starting day of our Reconditioning stay in Poděbrady and this year wasn't any different. Despite the unusually hot weather, when average temperature was above 30°C, our patients, lots of them for their first time, their relatives and friends, our PH specialist and two physiotherapists gathered at spa hotel Zámeček to spend a week of light exercise training. These workouts included breathing exercises, light stretching, short walks along the river Labe and many other activities. As usual, a part of the program was a discussion with Dr. Votavova and as an enrichment of every year's routine our patients chose to visit a glass factory.

**Annual Assembly in Prague
October 17-18**

Despite the beautiful surroundings of the Iron Mountains we decided to change the place of our assembly to the capital city of Prague. This year the assembly took place at a hotel

Chateau St. Havel. The meeting was divided into two days and was opened with a vernissage of paintings of one of our new members who is a patient. The main topic of the assembly was the election of the new Board of our association. As a new President of SPPH Martina Adamová was chosen, she is a CTEPH patient after PEA surgery. We also had to approve new statutes as we are slightly changing the name of our association. Another important topic was the launch of a money collection for an oxygen concentrator for our patients who would like to travel by plane. Last but not least, the assembly was full of interesting presentations by leading Czech PH specialists: Prof. Dr. Michael Ascherman and Prof. Jaroslav Lindner spoke about CTEPH and Dr. Pavel Jansa and Dr. Al-Hiti spoke about the history of pulmonary hypertension and about the development of new drugs for PH.

Martina Adamová
Sdružení Pacientů s Plicní Hypertenzí
www.plicni-hypertenze.cz





FINLAND

New Board and visits to hospitals

This year was a year of administrative changes for PH Finland. In March we had our annual Board meeting and a new President and Secretary were elected. PHA Finland continues making steady progress still with a small group working actively.

In Finland we have 5 general hospitals treating PH patients. Last year we visited the Helsinki Hospital and this year it was the General Hospital in Turku. And next year we plan to make visits to the other hospitals.

Because of long distances it has been difficult to organize meetings, so we have mainly concentrated on keeping in touch with PH patients around Finland through social media. For spring 2016 we are planning our first patient get together and also a general meeting.

New website

This year the web pages for PHA Finland were completed. I received valuable help from the specialist doctor at Bayer, Finland for the translation of the medical texts.

Yoga video

At the end of this year a yoga video will be released done by Jaana Rajahalme, a PH-patient and a yoga instructor, with the support of PHA Europe. The video has been filmed both in Finnish and English. The English version will be distributed to all PH associations in Europe.

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



FRANCE

Main priorities for action

HTAPFrance has 4 main priorities:

- Inform the patients and the community about PAH and help them understand the treatments and care.
- Help the patients and carers find the appropriate solutions to improve their everyday life with the disease and live as normally as possible.
- Make patients and carers meet together and share about their life with the disease.
- Support research.

Annual meeting and regional meetings

There are many means to inform patients and those close to them, or even the public. We at HTAPFrance gather our members once a year in Paris at our annual meeting, a whole day in a (big) hotel, where we split time between actuality and actions of the association, spending time together having drinks and food which makes people speak together, and listening to experts' lectures, with a discussion. As this happens in Paris, as we also wish to ensure that people who live away from Paris also benefit from such meetings, we organise several meetings along these selines in the course of every year. In 2015, regional Meetings took place in Bordeaux



(south western part of France) in April, Mollkirch (near Strasbourg, Alsace, eastern part of France), Arras in October (north of France), Saint Pierre on the Réunion Island (Indian Ocean) in October (taking advantage of a private holiday there) and Rennes in November (Britanny, western part of

France). These meetings are really appreciated by patients and carers. We decide on the subjects treated with the local expert center, and ask the speakers to present in a very understandable way. Dialogue is much easier than in a hospital setting and people are more relaxed. The doctors and professional carers also appreciate those meetings very much, as it allows them to spend much more time with many patients than they can usually spend with a single patient. Also, these meetings have a good influence on patients and carers' mood, because they, at last, find some persons with the same fears or problems that they have to share. For a successful meeting, it is important to have the right venue: accessible, all-in-one (catering and conference), with the right atmosphere which means nice and comfortable but not too formal.

Scientific Committee

To deliver appropriate information, in general, it is important to have good support from the experts. An association may have a formal Scientific Committee, or it may also be informal collaboration. In fact, HTAPFrance has both. It is not always easy to have a formal Scientific Committee to meet available at the same moment. That is why, even if we have a formal Scientific Committee with 16 members*, we never have manage to have more than 10 at the same time in the same room... But when we do, it allows us to have an open discussion with different experts, sharing different opinions and this is extremely interesting and informative. Aside from this kind of meeting, we also need some help all around the year, in the everyday management of the association, responding to patients or carers' medical questions. This is where our informal relationship to the PH experts comes in. We can have a reply from them in a few minutes and be sure in this way that we are giving the appropriate answer to the person who contacts us. It makes us trustworthy on the information we provide. What our members can also experiment is when they are in hospital or need to go to hospital, we can help them understand what is going to happen to them and why such a test or such a medicine is decided for them. We

can help them improve their relation to the professionals. It is in fact, part of empowerment of the patients.

Indeed, empowerment is essential, it is the aim of patient education. We do also participate to Patient Education in several hospitals, for Children with PAH in Paris (Hôpital Necker, reference center), for PAH patients in several centers, and for transplanted patients (in Hôpital Marie Lannelongue, near Paris).

Partnerships with Universities

For a couple of years now, we have developed some partnerships with some universities. The first contact was from the University in Dijon, which was looking for a representative from any patient association and had been told about us. Since then, I have given a lecture to 4th year students, about patients associations and ethics. I turned the talk around to speak of "Rare disease patients associations and ethics: the example of HTAPFrance". This allowed me to raise awareness on PAH and PH. Secondly, a researcher who had done her PhD in Pharmacy in Prof. Marc Humbert's Laboratory (Unité INSERM 999), contacted us for a survey, which we took part in. She is now lecturer herself as well as a thesis supervisor for her students (University in Paris Sud, Pharmacy Dpt). Since then, we have helped several pharmacy students in collecting data about PH (and we were cited as authors ourselves in articles written about these researches). An other partnership with Marie-Camille Chaumais, who invited us to participate in a seminary for Pharmacy Interns about heart-lung and lung transplantation, to give the patient's point of view. We find it is important to respond positively to such demands, as we then get new contacts and we are able to raise issues of interest to us. At the same time the patients who answered the survey were happy that there is research going on about their condition and happy to contribute.

Research on new diagnostic tools and surgery

An important part of the research on PH in France is done in the INSERM U999 managed by Pr. Humbert, which,



among others, has received financial support from the *Fondation pour la Recherche Médicale* (Medical Research Foundation) and whose celebrity mentor (*parrain*) is the French actor Thierry Lhermitte. He recently visited the research unit and met the whole team. The day after, he was on a famous medical programme on TV called "Le journal de la santé" and he chose one of the projects that were presented to him by the research team. He was captivated by the idea of an "electronic nose" that will be able to diagnose PAH from one's breath. This project is very interesting indeed and a huge hope, as it could help diagnose more easily the disease and avoid the diagnostic wavering we know in PAH as well as the first right heart cath. It might not be the most promising project from this research team but it was one that was easy to explain in a few minutes on TV.

See video at:

<https://www.youtube.com/watch?v=P19FTZ2qF6Y>

You will note that Thierry Lhermitte is truly passionate about PAH, which is quite encouraging.

Another project which really gives hope to patients that may not be eligible for a transplantation is the artificial lung, currently being developed in *Hôpital Marie Lannelongue* and U999 INSERM by young Professor Olaf Mercier

(surgeon), Member of the HTAPFrance Scientific Committee. The press has produced many articles on this concrete hope. We will be taking part in the development of the specifications for this product quite soon, which is really exciting...

Awareness raising activities

We at HTAPFrance also do some awareness raising. We do not usually organise an event that is dedicated anymore (we had our ULTRA MARATHON for ten years, but it is a huge work that cannot be done without a stable and very competent organising team, and the team is now... tired !). However, there still are many "good willed people" in our association and many use their own networks, or just their energy, to bring people together. We have had a booth at the Toulouse Marathon for a couple of years now, because some of the organisers of the ultra marathon had some contacts there. For the last edition, on October the 25th, a patient did a 6 minute walk, to raise awareness.

Magali and Philippe Chauveau are a patient and his wife, own a restaurant in *Les gorges du Verdon* (a fabulous place in a breathtaking landscape), and they have raised awareness to our cause with the inhabitants of their village and some villages all around. In september 2015 they organised, for the

third time, a "rustic" awareness event, where they had an information booth to tell people about PH. The second day of the weekend, there was a race with old cars, everyone wearing a HTAPFrance tee-shirt. People could also make donations for the association. These two events were not the only ones that have contributed to awareness and research but I thought they deserved to be talked about.

Our activities at HTAPFrance are many and I cannot even say the number of dates where something happens for us... It is a lot but we still want to do much more and be more organised and professional to be more efficient!

* *Members of our Scientific Committee: Prof.s Gerald Simonneau, Marc Humbert, Olivier Sitbon, Emmanuel Bergot, Ari Chaouat, Bruno Degano, Claire Dromer, Jean-François Cordier, Vincent Cottin (pulmonologists). Prof.s Damien Bonnet, Alain Fraise, Fabrice Bauer (cardiologists); Prof.s Eric Hachulla, Luc Mouthon internal medicine; Prof.s Philippe Dartevelle and Olaf Mercier (surgeons).*

Mélanie Gallant Dewavrin, HTAPFrance
www.htapfrance.com
<https://www.facebook.com/pages/HTAP-FRANCE/288261994529082>





GERMANY

18th annual meeting of ph e.v.

At the 18th Meeting of the patient self-help association pulmonary hypertension e.v. (ph e.v.), from 23 to 25 October 2015, in Frankfurt/Main, the panel of speakers discussed a wide range of topics, including the future of treatment for pulmonary hypertension, including combination therapy, current medical and surgical options, interactions among medicines and necessary follow-up examinations.

Patients and relatives were also actively involved through the participation in a panel discussion with doctors and representatives of ph ev on how the attention to such a serious disease as pulmonary hypertension (PH) can be further improved. In addition to the lectures and the panel discussion various workshops were on the program. The topics of the workshops ranged from the molecular bases of pulmonary hypertension through to weight management and nutrition, exercise and mental training to the effects of chronic illness on partnership and family.

A total of approximately 220 patients, their families and other interested parties attended the event, which was held at the training center of the State Sports Association Hessen.

The PH patient meeting was this year held under the patronage of Social Affairs Minister retired Dr. Erwin Vetter. For their support of the event ph ev thanks the industry partners Actelion Pharmaceuticals Germany GmbH, Bayer

Vital GmbH, Pfizer Pharma GmbH, GlaxoSmithKline GmbH & Co. KG. The association would like to thank also Vivisol Germany GmbH and Heinen + Loewenstein GmbH & Co. KG for oxygen.

ph e.v. Journalist award 2015

Every year the German PH association ph ev grants a Journalist Award of €3.000 for the best PH article. This year's theme was "Together against pulmonary hypertension," and the award was given to Oliver Gondolatsch and Frauke Sievers. The journalists did a patient "portrait" and several interviews, approaching the complex topic from different perspectives. The portrait traces the long ordeal of a patient from symptoms to diagnosis to treatment. It was published on an online portal www.gesundinessen.de. The first Chairman of ph ev, Hans-Dieter Kulla, paid tribute to the journalists' work at the award ceremony. As he rightly pointed out, pulmonary hypertension is often diagnosed late because symptoms such as shortness of breath and difficulty in exercising can be interpreted in many different ways. If left untreated the disease can lead to premature death. Therefore, early diagnosis and targeted therapy are vital.

Donations for educational activities

Representatives of Actelion Pharmaceuticals Germany GmbH

and Bayer Vital GmbH company gave donations to the Board of ph. e.v. in the course of 2015. Actelion held a PAH Forum in February 2015 in Berlin and donated the proceeds of €1.200 euros. Bayer donated exactly €1.112,50 euros from the "Blue Lips" action in May 2015.

How to increase membership and visibility

The first chairman of ph e.v., Hans-Dieter Kulla, underlined the need to get more young members involved in the association.

Professor Heinrike Wilkens of the Department of Internal Medicine V at the University Hospital of the Saarland suggested reaching out to public figures, such as athletes, which could serve as role models.

Many other good suggestions came from the floor: stronger presence at trade shows, articles in the public media, sponsorships for new patients, telephone hotlines, stronger linking of the association's website on the internet.

Professor Horst Olschewski stressed how important it is to create in the population the knowledge that shortness of breath can also be caused by pulmonary hypertension. "If a patient has only the correct diagnosis, the biggest step has been made."

Hans-Dieter Kulla, pulmonale hypertonie e.v.

www.phev.de

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



GREECE

The Hellenic Pulmonary Hypertension, HPH, completed another year with its traditional events and activities that aim to foster hope and solidarity among its members and raise awareness about the rare disease of PH.

- Our first major goal has been to do everything possible to assist our patients to beat the disease. We are very proud and happy to announce that, after a long struggle against bureaucracies, we managed to arrange a life-changing surgery for one of our patients. This is the biggest reward for a patients' association.
- Our second major goal has been to ensure that none of our patients feels alone or alienated. To that end we founded our own guesthouse offering food and accommodation for PH patients that are away from Athens and have no means to pay for their stay. Moreover, we organise on a steady basis special "event days" that breed a feeling of connection among all the members of our family.
- Our third major goal has been to establish in the public mind that there is a rare disease called pulmonary hypertension and that our association is here to make sure that no patient is undiagnosed or wrongly diagnosed. To that end we attend medical conferences and seminars, and we also post medical reports and articles on our website to keep patients and Greek health professionals up-to-date with the latest news. Moreover, we participate in all big sporting

events and we hold information campaigns with large impact to make our rare disease visible. In the second half of 2015, the HPH flag was carried in the following events.

Medical Seminars

Our association follows closely all medical developments in the field and participates in medical conferences and seminars in Greece. On 16-17 October we had the honour to open the proceedings of the third Clinical Seminar of Pulmonary Hypertension that was organised by the AHEPA UNIVERSITY GENERAL HOSPITAL and the HELLENIC COLLEGE OF CARDIOLOGY at the Thessaloniki Concert Hall. Professors Haralambos Karvounis and George Giannakoulis, along with a distinguished team of Greek academics, cardiologists and pulmonologists, as well as international PH specialists - such as Professors Andrea Maria D'Armini, Nazzareno Galiè, and Carmine Dario Vizza - presented all the latest developments and discussed real clinical case studies. On the 14th of December we attended a scientific symposium for health professionals that was held under the auspices of the HELLENIC SOCIETY FOR THE STUDY OF PH and organised by the pharmaceutical company Actelion. Professor Stylianos Orfanos and Cardiologist George Athanasopoulos chaired the symposium, while the keynote speaker was Professor Nazzareno Galiè who presented the new guidelines for the diagnosis and treatment of PH.

"Take a Breath" for PH patients in Athens Marathon

Hellenic Pulmonary Hypertension participated in the original Classic Athens Marathon that took place on November 8th, 2015, along with a record of more than 40.000 runners from all around the world. In that historic sporting event, HPH was represented by ten athletes in the 5km and 10km road races and by fifteen marathon-runners in the authentic 42.5 km Marathon Race. In total, 25 athletes participated on behalf of patients with HPH in the Athens Marathon wearing our special running T-shirts with the slogan "Παρε ανασα για τους ασθενεις με Π.Υ." ("Take a breath for PH patients") printed on the front. So successful was our slogan that throughout the race commentators and spectators on the sides of the street hailed and cheered saying out loud our slogan!

As a woman, you can do it all!

For the third consecutive year, our association organized a charity night dedicated to women only, not just because pulmonary hypertension affects mainly women, but also because women are strong enough to overcome all difficulties and open their arms to all patients. The dinner was held on December 9th at a fabulous modern tavern with live music and a friendly environment. The motto of the night was "As a woman, you can do it all" inspiring all our friends who joined us on that special night. Our special guests included PH specialists Panagiotis Karyofyllis of the ONASSIS CARDIAC SURGERY and Iraklis Tsagkaris of ATTIKO UNIVERSITY HOSPITAL, representatives from Greek health authorities, municipal officials and of course our favorite mascot, Pongo. The thrust of the night was the five stories we heard from patients at different levels

of the disease: Stelios was successfully transplanted; Natalia is waiting to be transplanted; Christina was totally cured after successful surgery; Marianna was non-eligible for surgery; and Maria is waiting for her surgery. The stories of our patients painted a complete picture of what pulmonary hypertension actually means and we thank them very much for sharing their experiences.

Pongo at the biggest Mall of Athens

Our little hero Pongo, the rare purple elephant, visited the Athens Mall on December 12th and 13th to send his Christmas wishes and introduce the concept of "rarity" to his new friends. This was our third year at Athens Mall - the busiest shopping center of Athens - and, once again, we had the opportunity to reach out to a wide audience raising awareness about pulmonary hypertension. After two fantastic days of hard work, we managed to distribute all our leaflets, take hundreds of pictures and *selfiesforPH*, and run out of most of our Christmas souvenirs! For this year, we offered a beautiful handmade good luck charm, a small purple calendar, an array of little Christmas decorations, as well as Pongo soft toys. Also, people could write a wish on a little decoration and hang it on our Christmas tree. As always, Pongo made a huge impression, attracting kids and parents that wanted to learn his story and play with him! Thus, our mission to raise awareness about PH was accomplished in the most perfect manner!

Ioanna Alisandratou, PHA Greece

www.hellenicpulmonaryhypertension.gr

www.facebook.com/HellenicPulmonaryHypertension





HUNGARY

Ironman race in Budapest

For those who have ever seen an Ironman race, it is obvious why the whole of PHA Hungary was extremely excited on the week of August 21-22. Second time in a row an Ironman race was organized in Budapest, capital of Hungary, and PHA Hungary and PHA Europe were represented as official partners of the race.

This year actually two Ironman races were organized: on Friday, 21st of August a 5i50 race, the so called "Olympian distance" was held (1,5 km swim, 40 km bike and 10 km run) and on Saturday, 22nd of August, the so called "half Ironman" or Ironman 70.3 (1,9 km swim, 90 km bike and a half marathon run).

The actual work started on Thursday, because the booth needed to be built up and the beach flags to be fixed and we would have liked to be completely prepared for Friday's work, when Gergely, volunteer for PHA Hungary, raced to raise awareness of PH.

During the two race days the members and the volunteers were really busy: they managed to get in contact with the visitors and with the triathletes as well and informed them about PH. We also managed to get the attention of the children with the blue lollipops, balloons and tattoos. On top of that the branded "GET BREATHLESS FOR PH" arch was set up in the running course, which became a trademark of PH and the triathletes are searching for it in every race in Europe.

Our dream came true and this race also evolved to a cross-border PH meeting: volunteers of the Slovakian PH associ-

ations joined their forces to the Hungarian team.

The event was a real success, so we have already contacted the organizers in November to collaborate in the next year. We have received very positive answer, so we really hope we will meet next year on the weekend of July 30th for the 3rd Ironman Budapest race.

National Patient meeting

The 5th national patient meeting was held by PHA Hungary on the 7th of November 2015 and we invited all the diagnosed PH patients from Hungary. More than 110 persons attended the event and listened to the numerous lectures.

The opening speech by Eszter Csabuda, President of PHA Hungary, was followed by the poem of Petra, a 12 year old child. Petra is not an "ordinary" girl: from her birth her nose is linked to an oxygen tank with a tube. Her fosterer let us know that this little girl has been waiting in the whole year to be part of the event of the association.

In course of the scientific sessions we were informed about the recent developments of PH management and treatments. Dr. Kristof Karlocai, PH expert, held a lecture about possible treatments in Hungary: thanks to the recent changes 9 drugs are available in Hungary for PH. In the case of 3 drugs from these 9 medicaments, case-by-case applications are needed. Dr. Laszlo Ablonczy, a pediatric cardiologist, led us through the success and the difficulties of the management of premature children and teenagers.



We had a lecture about techniques, which make the day-by-day life of the PH patients easier and we also drew the attention to the necessity of making exercises on a daily basis. Vera Major Kardosné, physiotherapist of a PH centre, motivated the audience by presenting different breathing techniques.

During the event there were possibilities to talk with each other, share experiences and of course exchange phone numbers. One of the transplanted PH patients, who will finalize his studies this year in psychology, kindly offered his help, because he experienced the physical burden a PH patient may face and passed through the unpleasant symptoms of PH and is willing to share this.

The event was closed by a guitar performance of a 13 year old child of a PH mother and everybody said good bye with the feeling that it is much easier to be together and belong to a community.

Eszter Csabuda, Tüdőér Egylet
www.tudoer.hu

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





ISRAEL



International Pulmonary Hypertension Conference Tel Aviv, 5 November

This year PH Israel was honored to be invited to the International Pulmonary Hypertension doctors' conference which is hosted every two years by Dr. Yochai Adir, a leading physician in Israel. The two day conference saw the world's experts on Pulmonary Hypertension come together at the Dan Panorama Hotel, Israel. The PH Israel association joined forces with this international conference and extended an invitation to all members of our association, their family and caregivers. After light refreshments and some time for mingling and connecting, approximately 100 members from all over Israel made their way to the impressive conference hall for a panel discussion. The panel was made up of guest speakers Prof. Lewis Rubin (USA) and Prof. Olivier Sitbon

(France). Dr. Adir chaired the panel with PH Israel CEO, Joni Berg, taking questions from the audience. Discussions ranged from healthy lifestyle, nutrition, children and their care and treatment options. A very interesting discussion was held regarding the treatment of patients with a genetic history. The questions proved to be very thought provoking and interesting for all members and it was a wonderful example of how effective coming together to learn from both the experts and the patients can be. At the end of the evening, PH Israel members as well as visiting doctors were shown a screening of the "Short of Breath" Campaign videos. These were very warmly received and appreciated by all!

Maayan Steele, Pulmonary Hypertension Association Israel
www.phisrael.org.il - <http://on.fb.me/1bPDL5v>



ITALY-AIPI

AIPI's annual general assembly and patient meeting was held on the 15th of March and was once again a big success, with over 130 participants attending from all over Italy. The program of the day included a lecture on the latest developments in PH by Dr. Gaia Mazzanti, who works in the PH Unit of the University of Bologna hospital, a presentation on legislation for the disabled in Italy and the annual report of activities. Lunch was followed by live music with Riccardo Rossini, a PH patient who sings wonderfully, in particular the classic Frank Sinatra songs! We also had a professional singer,



Selene Lungarella, whose father is a PH patient and many of those attending sang along and danced as well! As in past years, all those of us who had a lung transplant had their photo taken with the official T-shirt of the regional Organ Donation campaign.

Masks 2016

This year we were very fortunate to have once again as our "testimonial" Federica Pellegrini, gold medal Olympic swimmer, who has also personally set a number of world swimming records. We had a photo shooting with her in May for our 2016 AIPI calender and the photos were exhibited at the Triennale - one of Italy's most prestigious museum - for two weeks in October and in Federica's home town near Venice. The exhibition and calender attracted huge media interest, with almost 80 press, TV and online media clippings and an estimated reach of 36 million (data provided by our communications agency). Federica herself promoted the project and spoke about pulmonary hypertension and the work of AIPI with her family, friends, fans and journalists as well in interviews and on her personal social media channels. A great way to raise awareness of the disease!



New publications

Since the beginning of the year four issues of our quarterly magazine AIPInews have been issued. Our booklet on CTEPH, chronic thromboembolic PH, is currently being printed and another one on organ donation and transplantation is in its final stage of development.

Pisana Ferrari, AIPI Italy
www.apiitalia.it

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



ITALY-AMIP

Another busy year!

AMIP activities during these last months after WPHD were many and, as usual, they were focused on our main targets: patients, doctors and awareness about PH.

As for the patients, phsycological support meetings are organized in several cities and we also encourage social events where patients are invited. The help-line is going on at full speed, our web site and social media are visited daily from many people to keep in touch and socialize but also to ask information or our help in problem solving with institutions, reimbursements or pratical problems. The "family" of PH patients is really a great resource as solutions to big or minor problems are shared among everybody. A great trick that helps in preparing the Flolan infusion, invented by a friend, received the thanks of many patients and the interest of the industry. Someone is already planning to use and improve the idea!

As for the doctors we had the opportunity to be present at many conferences to give voice to the patients. Since May we were in Capri, Catania, Pavia, Roma, Torino. Our regional delegates were also present with our President on several occasions. It is proving very important to be there with the doctors, they now are able to realize what a useful help the patients' association can be in their relationship with institutions and public opinion.

Finally, our awareness campaign towards the general public is always very active. Sport events were organized on our behalf by our testimonials, the runners or the volley players, who are convinced of the value of their mission. Theater soirees were also dedicated to PH. We had the possibility to speak about the illness after several performances. Theatre and



art in general is a new very rewarding field in which to spread information, we are able to meet all sorts of people, not directly connected with PH and, at the same time, AMIP members can enjoy themselves while doing so! A good side-effect is also that awareness and fundraising can join, once we prove to be effective and transparent. People are much more generous and willing to do good than one believes when they trust us.

Vittorio Vivenzio, AMIP Italy
www.assoamip.net

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





LATVIA

Participation in international conferences

PHA Latvia was a co-partner in the project of the Latvian Presidency of the EU Council, together with the oncology support group DZĪVĪBAS KOKS and the PATIENTS' OMBUDSMAN OFFICE. Together with our partners we organized an international conference about "Chronic Diseases: challenges in 21st century Europe", from the patient's perspective and from the perspective of economic activity (Riga, 19-20th March). PHA Latvia was responsible for the Rare Diseases Section's organization at the conference. Three members of PHA Latvia attended the event. Juan Fuertes, representing PHA Europe with a presentation on "Access to Care: Economic and Human Rights" was our guest in the Rare Diseases Section. Ieva Plume, Chair of PHA Latvia, presented a short overview called "Face to Face With Rare Diseases" about patients with rare diseases, like PAH patients.



Physiotherapist Lina Butane, PHA Latvia Board member Ludmila Korlasa and Ieva Plume took part in the the 6th Bayer International PH Nurse Forum 2015 (Riga, 3-4 July). Ludmila, mother of a young man who passed away from CTEPH, assisted by Lina Butane presented the young man's story and spoke of the role of families in support of PH patients. PHA Europe Vice President Pisana Ferrari and Ieva Plume talked about PR activities of patient associations. Lina Butane and Ieva Plume were also present PHA Europe's APHEC (Barcelona, 17-20 September), where they presented the activities of PHA Latvia. Finally, an international workshop of three countries, Lithuania, Russia, Latvia, took place on November 20-21 at the VILNIUS UNIVERSITY CLINIC. Three PHA Latvia participants, Board members Inga Abola, Ludmila Korlasa and Ieva Plume, presented the patients' work and the reimbursement system for medications in Latvia.

Advocacy work

PHA Latvia took part in two work group sessions with experts in Latvia about organ donation and lung transplant. We made pressure on the Health Ministry together with the LATVIAN ALLIANCE FOR RARE DISEASES and a chapter about Rare Diseases (definition according to EU directive) is now present in a draft legislation on public health.

Projects: looking to the future

This year PHA Latvia was very active with grant applications. We did two educational and awareness projects with the support of the Riga City Council and one project supported by the Charity foundation "Ziedot", to buy 100 pulse oximeters for PH patients. The project "Establishment of advocacy and educational tools for people with PAH" was the first PHA Latvia project in the tender of the EEA Financial Mechanism 2009-2014. The aim was the creation of advocacy/educational tools for people with PAH and their relatives. The project's final date is 31.12.2015. This project's results are very practical and useful: a PHA Latvia Advocacy plan 2015-2018, a brochure for people with rare diseases about health care facilities in Latvia and abroad, a presentation for GPs and decision makers about PH patients' everyday life, a "happy stories" video-book about three patients' fighting with PH. We realized two Health camps for patients and their carers, also included in this project, one PHA Latvia capacity building workshop, and two press conferences for media about the project. The project is financially supported by Iceland, Lichtenstein and Norway. It is financed from EEA financial instrument and Latvia. The budget of project is €12.511, the grant sum is € 9.992 and PHA Latvia was self financed for €2.519.

Ieva Plume, PHA Latvia
www.phal Latvia.lv/en
on.fb.me/1ZoYONB - <https://twitter.com/phlatvia>



LITHUANIA

PHA Lithuania members meeting - celebration of organization's birthday (1 year) and WPHD

The Lithuanian Pulmonary Hypertension association is very young. New members are joining us every day. We decided to celebrate World PH Day and PHA Lithuania's 1st birthday simultaneously on the 5th of May. We held a meeting in an informal atmosphere, with non-alcoholic champagne and a big cream cake decorated with the logo of the association. In addition to direct discussions between patients, doctors from our PH centre gave presentations on traveling with PH, emphasizing the main points PH patients need to know when going abroad.

WPHD in Vilnius city centre - Art exhibition

On May the 24th, we held an event to celebrate World PH Day in Lithuania for the first time. We decided to show the disease to the public through the prism of an art and music. A festival took place in the Vilnius city centre. Guests included patients and doctors. They donated money to association by purchasing paintings. In addition, we presented the first issue of "Live and breathe", a newsletter which we developed specifically for PH patients in Lithuania.

International meeting in Lithuania's PH centre

On the 20th of November, our association held a meeting for members of the association and their partners and colleagues, at the PH center. This event can rightly be considered as a conference. During the event, which lasted about five hours, we discussed several important topics, such as the drug reimbursement system in Lithuania, the pharmacy networks,



problems for PH patients when it is very cold in winter and the peculiarities of the treatment of colds for people suffering from PH. In addition, of course the main theme of the event was the Center for PH in Lithuania. Colleagues (representatives of PH associations) from Russia, Latvia, Ukraine and Belarus were invited to join the conference. Unfortunately, due to some unforeseen circumstances representatives of the Belarusian and Ukrainian organizations were unable to participate. Nevertheless, all representatives, patients, doctors and pharmacists were very enthusiastic about the event! The overall positive outcome of the conference and enthusiasm of guests and participants justified all our efforts and we plan to organize an international meeting again next year. We sincerely hope that all representatives will manage to participate in the conference next time. Since the topics of the presentations and the issues raised were interesting and important both for foreign and local representatives, doctors and patients, each report was followed by a lively debate. All parties agreed on the importance of holding informative meetings. At this meeting we presented the patients with the second issue of the "Live and breathe" newsletter.

Anastija Kovaliova,
Žmonių Sergančių Plautinė Hipertenzija Asociacija
www.phalithuania.eu



NETHERLANDS

Our big 24 hour event "Heart for Lungs" which took place June 6-7, was a huge success in terms of raising PH awareness and for fundraising. A check for 45.000 euros was given by PHA NL to the VU Medical Centre in Amsterdam to fund scientific research on PH!

Leny van der Steen, PHA-NL
www.pha-nl.nl





POLAND



TV programme screens

Reaching out to the Polish Parliament

On January 15, 2015 Alicja Morze, President of PHA Polska and Prof. Adam Torbicki participated in the Rare Disease Parliament working group session. One of the session's themes was new treatment possibilities for CTEPH patients. Prof. Adam Torbicki and Alicja Morze explained what CTEPH is and urged the Rare Disease Parliament working group to take a position as regards CTEPH treatment in Poland.

Rare Disease Day event

On February 28, 2015 PHA Polska participated in the World Rare Diseases Day Event in Warsaw. The National Rare Disease Plan was one of the subjects of the speakers' presentations this year. PHA Polska was represented by Alicja Morze, and the Association's patients.

PH Patient meeting

On September 26, 2015 PHA Polska organized a patients meeting in Warsaw with the presence of the leading cardiologist among others: prof. Adam Torbicki and Prof. Marcin Kurzyna. The Polish Association activities were presented by Alicja Morze. Almost 90 patients and their relatives joined the meeting. It was a great occasion for the patients to talk about their problems and benefit from the very interesting presentation of the medical experts. Thanks to Alicja Morze's efforts a large article was published in one of the daily newspapers where Prof. Adam Torbicki described the history of PH treatment in Poland and Alicja Morze talked about the Association's activities. The article was published just before World Heart Day.

World Heart Day

On September 27, 2015, PHA Polska took part in the World Heart Day event organized in Łódź. PHA Polska's stand was visited by well known cardiologists including the Presidents of the POLISH CARDIAC SOCIETY Prof. Piotr Hoffman and Prof. Zbigniew Kalarus. Szymon Majewski - a known TV and Radio presenter - joined the PHA Polska stand and put on a PH T-shirt as a gesture of support for the activities of PHA Polska representatives and volunteers.

Football match for PH

On October 15, 2015 PHA Polska organized a football match between cardiologists and the Bayer Life Team. The idea was to gather both medical experts and the sponsor's representatives to join the event that would be dedicated to raise PH awareness. Two football teams, the Bayer Life Team and the cardiologists



from Pulmonary Circulation Section of the POLISH CARDIAC SOCIETY met in Warsaw to play for PHA Polska Cup. Although the weather was not favorable both teams attracted many fans and supporters. Alicja Morze, handed a beautiful PHA Polska Cup to the winner, the Bayer Life Team.

5th Conference of the Polish Cardiac Society

PHA Polska participated in the 5th Conference of the PULMONARY CIRCULATION SECTION OF THE Polish Cardiac Society. This year the conference took place on October 16-17, 2015 in Warsaw. A great event took place just after the Conference's opening. Prof. Marcin Kurzyna, the Chairman of the Pulmonary Circulation Section of the Polish Cardiac Society and Chairman-elect Dr. Michal Cieurzyński handed a statuette to Alicja Morze thanking her for many years of her devotion and activities for PH patients in Poland. During the two day Conference there were 10 sessions (both poster and nurses' ones) and almost 40 lecturers. PHA Polska's stand was visited by many Conference's participants.

Educational materials

On October 23, 2015 an educational TV programme about PH diagnosis, treatment and everyday life was produced as the results of Alicja Morze's efforts and it was presented on the national TV Channel 1 during the TV programme

"Health. It is time for you". The TV program included both leading medical experts' interviews and PH patient story.

Sports events

Throughout the year a group of volunteers spent many hours of trainings and participated in different kinds of marathons and sport tournaments in solidarity with the PH patients, e.g. the rugby players of Arka Gdynia Team dedicated their training on the National Rugby Stadion for PH patients in Poland; the young swimmers of UKS Tri-Team Rumia together with their coach had a special training for PH patients. There is also a special "Get Breathless" Team Gdynia that gathered volunteers who spontaneously decided to dedicate their sport activities to PH patients. The team members always wear PH T-shirts and they educate the others about the disease and the patients' issues. In July 2015 a member of "Get Breathless" Team Gdynia sailed the famous "Gemini 3" yacht across the Atlantic from Guadeloupe to Poland (4.800 miles). The Team members also took part in the first in Poland Herbalife IRONMAN 70.3.

Alicja Morze, PHA Polska
www.tetniczenadcisnienieplucne.pl
[on.fb.me/10RE2WJ](https://www.facebook.com/10RE2WJ)





PORTUGAL

Trail Running to Santiago de Compostela's Sanctuary

Six days, seven pilgrims, 240 Km, one goal: raising awareness for PH. Along the way, awareness campaigns were carried out with the local people, schools and hospitals in order to alert to the symptoms of the disease. Children were also involved, making paintings and collages about PH, filling balloons to raise public awareness for PH and everyone had their lips painted blue. Local authorities and social media were present at all the events.

Visit to the the Portuguese Parliament

The Portuguese Parliament's Health Committee met with our Association to discuss the problem of non existence of a "chronic patient" status in the Portuguese law, which is hindering access to the treatment for many of them.

Discount card for fuel

Each of the members and volunteers of Portuguese PH Association have now a discount card for fuel which can be used in several Portuguese gas stations. This is an initiative organized with the aim of gathering more associates.

Rare Disease Day

On February the 28th the Portuguese Association, as a member of the Portuguese Alliance for Rare Diseases, was present at the Europlan National Conference. The conference, held in the Portuguese Parliament, aimed to discuss rare disease policy in the light of European guidelines and to identify bottlenecks and actions to be taken to improve care and services for people living with a rare disease.

Participation in Bayer's Forum "Pulmonary Hypertension in focus"

We attended "Pulmonary hypertension in focus", a forum organized by Bayer Health Care. Two presentations were from our association: the first of which was "APHP - past, present and future", presented by Rui Vinagre where the story of APHP, our goals, challenges and difficulties we faced were reported, as well as the main activities carried out in recent years and the projects to develop in the near future. The other presentation was about "Psychosocial support to PH patients", by Catia

Rodrigues, our association's psychologist, where the main goal was to highlight the psychosocial impact of the disease and the importance tole of psychologists. The meeting was also attended by Dr Rui Baptista who talked about PH, describing the disease, diagnosis, treatments, innovations and the future of PH.

Cycling for PH

A Portuguese cycling team is supporting our Association: their suits have our logo and in every race they raise awareness for PH.

Lisbon Marathon

Our Association, in collaboration with Bayer, were represented at Lisbon Marathon, where about 40 athletes dressed a orange "Get Breathless for PH" T-shirt (different from that one of WPHD). This sports event is one of the most emblematic ones for Portugal and our initiative aimed to raise awareness about PH, the difficulties our patients are facing and also to alert to non-diagnosed cases we may have in our country. Among the athletes there were some patients who wanted to show their bravery and perseverance.

Oporto marathon

On November the 8th, PHA Portugal was represented at the Oporto Marathon, which registered a record number, about 4.558 participants. A Portuguese runner wore a suit with our logo. You can see the video with the highlights of the marathon at: bit.ly/1PdE7TW

PHA Portugal was also represented on the Lisbon Marathon on March the 22nd, see photos at: on.fb.me/1JMOWQU

Playing volleyball for PH

The Women's Volleyball team of Académica, a famous Portuguese sport team, is supporting APHP, wearing our "Get Breathless" T-shirts during trainings and at the end of the races.

APHP in Ironman Zurich

APHP was represented in Ironman in Zurich by Gildo Silva, a Portuguese Tri-athlete. He is now representing our association in other sports events and will attend Ironman next year hopefully wearing a PHA Europe tri-suit.



European Organ Donation Day, Lisbon

We supported and attended the European Day for Organ Donation and Transplantation, in Lisbon, on October the 10th. We were involved in several activities and we secured several endorsements for the PHA Europe Call to Action on organ donation and transplant.

Karate Fight for PH

Karate national champions and coaches are supporting our Association and fighting for PH! They are helping us raising awareness particularly with in young people. They are also involved in the planning of next WPH Day!

Christmas lunches

two lunches were held in different regions (North and Center of Portugal) and aimed not only the celebration of Christmas but also fundraising since t-shirts and other materials were sold. We get more members for our Association too, so we think they were very fruitful events.

Patient advocacy

1. In addition to our visit to Portuguese Parliament in order to obtain the chronic patient statute, we developed patient advocacy to improve patient care in hospitals and to promote a reorganization of the hospitals of the south of Portugal. We sent e-mails and letters to: Portuguese Parliament (where we obtained support from one political party); Regional Health Association of South of Portugal; Medical Association and Board Directors of several hospitals.
2. Last week we learnt that a Hospital in Lisbon is refusing the access to treatments to patients living outside Lisbon and the same Hospital is refusing the administration of two new drugs because they are too expensive. These are two inconceivable situations that we will denounce, so next weeks we will fight for this and of course we will keep you informed.

Maria Joao Saraiva

Associação Portuguesa de Hipertensão Pulmonar

<http://on.fb.me/13sawnu>



REPUBLIC OF MACEDONIA

Rare Disease Day 2015

This year our association, APH MOMENT PLUS, became part of the EURORDIS "Friends of Rare Disease Day". For first time we also shared a story from a Macedonian PH patient.

This story was included in the NATIONAL ALLIANCE FOR RARE DISEASES of Macedonia' exhibition called "Hug rarity". The exhibition took place in Skopje on Rare Disease Day itself, the 27th of February, with many guests including the First Lady of the Republic of Macedonia, Mrs. Ivanova, representatives from the Ministry of Health and patients from different rare

diseases organizations. Over 70 media reported on this event. On the 28th February the exhibition was opened to the public in Gevgelija, on the initiative of our association. The audience has the opportunity to see twelve photos of public figures and people with rare diseases, who supported the initiative to raise public awareness of rare diseases. The exhibition aimed to portray the lives of citizens who face daily the challenges that rare diseases bring. The initiative was supported by the Mayor of the Municipality, Mr. Ivan Frangov. This was very big success for APH MOMENT PLUS because we have





chance to be live on TV and in another TV station in a program with special emphasis on PH and what it is like to live with the disease. Additionally we took part in radio programs which were related to health and rare diseases. The best thing of all was receiving a formal invitation for our NATIONAL ALLIANCE FOR RARE DISEASES of Macedonia to become a Member of EURORDIS.

Rare Disease Registry

Pulmonary hypertension is now in the Registry of Rare Diseases in the Republic of Macedonia. A law on Health Protection has introduced brand new articles concerning the establishment of a single electronic data base as part of the Ministry of Health. The new articles oblige the Ministry of Health to establish a registry of rare diseases and patients suffering from rare diseases.

Fund for rare diseases

In 2014 the Macedonian Government established a Fund to cover the cost of drugs for rare diseases. For the implementation of the program the State Budget allotted for 2015 MKD 90 million (equivalent to 1,5 million Euro). But this is not enough. In 2015 a new Excise law was adopted for financing

the Program for rare diseases which allows for 21 new medicines to be provided for 12 rare diseases. By amending the Excise Law, MKD 1(1MKD = 0.017 Euro) will be allocated from each cigarette pack for funding of the treatment of rare diseases in the Republic of Macedonia. That will give a new chance for life for many families. According to projections, the funds would annually amount to about MKD 250 million (4,05 million Euro, additional to the 1,5 million Euro that were already provided through the Ministry of Health).

Sildenafil for PH in Macedonia

From September 2015 our PH patients started with generic Sildenafil.

Press conference in Chaska

One special moment this year was a press conference held in the municipality of Chaska, Veles. We received full support from the municipality of Chaska and the Mayor of Chaska himself. They made available all the local facilities in the municipality of Chaska, including mountain homes, spas, hotels and the hospital for lung diseases of Jasenovo, for PH patients.

Mountain march for PH

The Mountaineering and Sports Association "Green Paradise", from Veles, supported the struggle of PH patients. It organized a mountain march under the slogan "Get on top and take a breath of life". From this year, this mountain march will become a traditional event in support of PH patients.

Famous testimonial for PH

Kiril Lazarov is a Macedonian handball player who currently plays for *Barcelona Handbol*. He is also the captain of the Macedonia national handball team. On 27 January 2012, Lazarov became both the European and World record-holder for goals in a single championship by scoring 61 goals in 7



SERBIA



PHA Serbia is a non-profit association, founded in order to achieve objectives in the field of improving care for patients with pulmonary hypertension and providing information and education for patients, their families and carers.

PHA Serbia started to work officially in September 2015, when we had the honor to attend the Annual PH Conference of PHA Europe, which was held in Barcelona from the 17th to the 20th of September. We were very honored to be accepted as a new PHA Europe member on this occasion (for the moment as an individual member, we will apply for full membership next year).

We are currently finalizing the association's website and preparing some educational materials. After the meeting in Barcelona we also had several meetings with the leading PH doctors in Serbia, where an agreement was reached on a long-term cooperation with them and with their clinics (there are the two main PH clinics in Serbia). We have also been invited to attend the Annual Congress of the CARDIOLOGY SOCIETY OF SERBIA, as special guests, which will establish further cooperation. PHA Serbia has had the opportunity to become familiar with the work of

Gjurgica Kjaeva, President APH Moment Plus
www.phmomentplus.com.mk
<http://on.fb.me/1kUSn5x>



many other such organizations in Europe and this means we have acquired basic knowledge of how to lead a patient association.

We have set out a program for the upcoming year, where we plan to organize PH patient's gatherings and to collect and process scientific and vocational literature related to health care for PH patients. Organizing experts and doctors to work in the education field and to share better information through brochures, seminars and raising awareness about PH are also part of our main goals.

We are ready for cooperation with teams from abroad and we also attempt to obtain rights and the introduction of drugs that have been available for a long time in many other parts of the world. We will contact the media and Government and try to establish an agreement with the Department of Health of the Government of Serbia.

Danijela Pešić, PHA Serbia
www.facebook.com/plucnahipertenzija - danijela@pesic.rs



SLOVAKIA

The objectives of ZPPH for the year 2015 were very clear and well defined. We did our best to give visibility to PH and to raise public awareness, to help patients overcome problems associated with the disease, encouraging them and we also tried to obtain legislative changes in their favor.

Resturcturing the association

This year has been very beneficial for our association in different areas. The structure of our Board has been changed. We involved a professional project manager, who helped us increase our financial income by nearly 30%. Since June we have established PHA Slovakia as a “sheltered workshop”, (*this term is generally used to describe facilities that employ people with disabilities exclusively or primarily*) and this way we have been able to promote the employment of some of our members. These changes brought on further workload, but it also opened up new ways in which we can arrange other activities for our members.

Awareness raising

Throughout 2015 we conducted a campaign to raise the profile of PH, supported by the doctors and health care professionals from The NATIONAL INSTITUTE OF CARDIOVASCULAR DISEASES. We also actively participated in the RARE DISEASE DAY, in cooperation with the SLOVAK ALLIANCE OF RARE DISEASES (charity concert).

**Get breathless for PH**

The most important activity of the year was the “Get breathless for PH” campaign, which we launched in early May for WPHD. Our efforts were rewarded by PHA Europe and, jointly with the Czech PH association, we won 1st prize for the best European project. The project was carried out under the auspices and direct involvement of the Minister of Health. It consisted of a climb to top of the Tatra mountains, a press conference, an information campaign in the Slovak Philharmonic, educational seminars for the public and public 6-minute walk. The media coverage consisted of articles in magazines, websites and social networks throughout the whole year. Overall, there was 15 articles published, including patient stories. We had great cooperation from the Slovak Radio and TV. The short reportage from the WPHD event was broadcast on the TV show *Televikend*. We also participated in the shooting of unique 20-minute reportage on PAH on Slovak Television in a program called *Ambulance*. Part of the reportage was shot in AKH Vienna during a lung transplant, in which Prof. Walter Klepetko, world famous lung transplant surgeon, also participated. We have also gained steady supporters - runners, who only in last year participated in 15 cross-country marathons, the most important being the relay race from Tatras to Danube (345 km long). At the invitation of the Hungarian PH association we attended an information campaign for IRONMAN event in Budapest.

Educational and rehab stay

In 2015 we organized a six day long educational and rehabilitation stay and the participation in the “Concert without barriers”. For the first time ever we held two general meetings in one year, where we were sharing all the information received from the PHA Europe conference in Barcelona. In October, we attended the 10th Congress of the SLOVAK SOCIETY OF CARDIOLOGY, where we handed out brochures and informed attendees about the PH Patient and Carer survey via video playback in an information stand. We also prepared a 5-day educational seminar on a “Support and development program for patient organizations in Slovakia”. Finally, we have prepared two photo books and a new edition of the PH magazine *Fialka*.

Organ Donation and Transplantation

We have expanded our cooperation with associations that bring together patients having undergone organ transplant and with the National Transplant institutions. Together we have completed a successful project to promote organ donation and transplantation, “The Beauty of the Moment”. We have started a new project, “One donor - Seven Lives”, to encourage discussions for medical students, which will continue in 2016. We have participated in the filming of the movie “Seven Lives”, which supports the national campaign to promote the transplant program launched by the SLOVAK TRANSPLANT SOCIETY with the support of the Health Ministry.

Iveta Makovníková

Združenie pacientov s pľúcnou hypertenziou
www.phaslovakia.org - <http://on.fb.me/Ud1DUf>





SLOVENIA



IRONMAN

Društvo za pljučno hipertenzijo Slovenije was present at the first IRONMAN 70.3 in the city of Pula on 20.11.2015. Luka Kobler, husband of Nina Kobler, a PH patient and an active member of our association decided in January that he would run his first IRONMAN for his wife and for all PH patients. Rudi Smolej, a friend of Luka, also decided to join him. They both started

preparing in January for the venture. They started learning the correct swimming technique and started training intensively. Luka also had to buy an appropriate bike. Nine months went by quickly and before they knew it, they were before the starting line along with 1.800 other athletes, cheered on by a huge crowd including members of our association.

The organization of the event, the atmosphere, the volunteers, the judges, the athletes, everything was simply breathtaking. The day before the event, the organizers decided that the athletes were allowed to wear wetsuits. You could spot Luka and Rudi a mile away thanks to their white sports suits with blue lungs.

Both Luka and Rudi were great at all three disciplines. After 1.9 km of swimming, 90 km of cycling and 21 km of running, they reached the finish line and the feelings of accomplishment, success and gratitude overwhelmed both our members and our two heroes.



Medis event

On 26.11.2015 our member Aljaž Prevolšek held a presentation showcasing our association at an event that was organized by the pharmaceutical company MEDIS, with whom we've been cooperating for many years. Pharmacists from the entire country participated in the event. Aljaž also talked about pulmonary hypertension, spreading awareness of the disease.

PH awareness month November

In November we posted regular news updates on our Facebook page focusing on spreading awareness of the disease. The updates were focused on the five types of pulmonary hypertension explaining their characteristics and differences.

Organ donation awareness

Right now we're preparing to launch a campaign to spread awareness of the importance of organ donation in Slovenia. The campaign will be launched in 2016.

Tadeja Ravnik

Društvo Za Pljučno Hipertenzijo Slovenije

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



SPAIN-ANHP

Valencia PH run

We started this year's activities with a very successful event to raise awareness of PH, the "1st Pulmonary Hypertension Solidarity Run" in Valencia on 1st of February. The run was held in memory of Maria Moreno, a PH patient from the association. 1.000 runners participated with the motto, "Stay breathless for Pulmonary Hypertension".

SEPAR local meeting

As usual every year, the SOCIEDAD ESPAÑOLA DE NEUMOLOGÍA Y CIRUGÍA TORÁCICA (SEPAR), in in the course of its winter activities, held a local meeting in Girona on 5-7 of February, where the association presented some new ideas and projects. At the entrance of the place where the meeting was being held the *Habitación HP* (or "PH room") was set up. This is a



"special" room, has household appliances (eg. iron, Hoover...), where people can do some housework. But in a special "PH way", with extra weight, to simulate and

therefore better understand how it feels for a PH patient to do housework such as ironing, cleaning etc. (see photo above).

Other activities of the year

- In February we organized a *Mercadillo Solidario* (charity Market) to collect funds.
- On 8th of June we gave a speech about "How to live with Pulmonary Hypertension", the disease from patient's perspective. In Bayer Headquarters, in front of people who work the ph area
- In February, around the celebrations for RARE DISEASE DAY, Bayer organized a photo contest on the theme "Breathless Moments", and one of our members, Eva García, was among the finalists.



- On March 15 a Solidarity Run was held at the *La Casa de Campo* in Madrid. This event was organized by FEDER, Federación Española de Enfermedades Raras (Spanish Rare Disease Federation), also within the contest of celebrations for RARE DISEASE DAY.
- On March 28 ANHP had a meeting with the *Director General de Atención al Paciente de la Comunidad de Madrid*, the General Director of Patient issues of Madrid.
- On March 10 a meeting of Catalan patients was held in Madrid.
- On 22 April, ANHP attended the "EUPATI Taking of in Your Country - An Interactive Workshop on Implementing EUPATI in Your Country", in Dublín. EUPATI is the European Patients Academy on Therapeutic Innovation-
- To elaborate a document to show the day to day of CTEPH patients. It is created a work group between: ph specialists, and patients from SEPAR and SEC, patients representatives as ANHP.
- A Patient Multidisciplinary Workshop was organized by Actelion on 28 April in Munich, where our association was represented.
- On the 6th of May, within the context of celebrations for World PH Day, a workshop for nurses was organized by ANHP. This is the fifth year that this workshop is being held and every year the number of participants increases. Nursing staff has a very important role to play in the management of our disease.
- Also within the context of celebrations for World PH Day ANHP organized in Parla (Madrid) a charity event where numerous artists donated their art and skills to collect funds for the Association.
- On 13 May there was a PH patient meeting in Madrid.
- On 21 May ANHP was represented in Brussels at the EPF (EUROPEAN PATIENTS FORUM) Annual General Assembly.
- In the last weekend of May, the *Asamblea General de Socios* of ANHP (General Assembly), took place and was a wonderful meeting full of tourism, fun, and in which to be together and share experiences.
- On 5 June a theatre company in Valencia, in support of the "Maria Moreno" initiative, organized a play/musical, "Cats", and the funds from the sales of the tickets were given to the association.
- ANHP representatives were present at the press event for the launch of Opsumit, a new PH drug developed and distributed by Actelion pharmaceuticals, which took place in Madrid on the 2 June.
- ANHP representatives were present at the press event for the launch of Adempas, a new PH drug developed by Bayer

Healthcare, which took place in Madrid on the 9 June and were invited to make a presentation about PH from the patients' perspective.

- On June the 14th we organized our big event to celebrate World PH Day, "Cycling for LiPHe", a bike race where a large number of bikers started from Barcelona and cycled all the way to Girona, with our logos and colours!
- In Zaragoza on the 19 June, during the *Jornada Socio Sanitaria de Enfermería* (Social and Healthcare Day), ANHP was invited to give a speech on "PH's from the patients' perspective"
- At the beginning of September, on 9 September we were



interviewd for the online newspaper called *Revista Digital* about life with rare diseases. In this first edition Pulmonary Hypertension had a special coverage. We were delighted that it was a really extensive article.

- ANHP was present, as in past years, at the Annual General Assembly and PH European Conference organized by PHA Europe in Castelldefels. During the four day event, the different leaders from the European countries attended lectures and took part in discussions of topics of common interest.
- On September 6-7 an event called "Methodology of Clinical Investigations across the Medical Devices Life Cycle" took place in Paris, attended by ANHP representatives.
- The annual *Semana del Corazón* ("Week of the Heart") took place in Madrid and ANHP was present with an information booth.
- During the *Día de la Mercè* (annual festival of religious origins of the city of Barcelona in Catalonia), around the 24th of September, by tradition there is a *Mostra d'Associacions*, where patient associations have a booth and can disseminate information materials to the public.
- The Board of ANHP met, as is customary every year before the year ends, on the 3-4 October. During this meeting decisions are taken, topics are discussed and future projects of the ANHP made.
- On October 7 in Madrid there was the official presentation of the SOCIEDAD ESPAÑOLA DE NEUMOLOGÍA Y CIRUGÍA TORÁCICA (SEPAR) year. Roberto and Eva, two members of the Board attended the meeting.
- On the same day, in Barcelona, there was the official presentation of the book called *El Baile de los Delfines* (Dance of the dolphins), a novel written by our friend and member Julia Villares, whose plot features as one of the characters a small girl with pulmonary hypertension. There was lot of interest from the audience and Julia

answered many questions about life with PH.

- In Lisbon, on the 8 and 9th of October, ANHP representatives took part in the 2nd Conference on European Reference Networks (ERNs).
- On the 18th of October, in Barcelona, ANHP took part in a race called *La Cursa per l'esperança* ("Race for hope") to raise awareness of PH.
- A platform grouping different patient associations was recently founded in Spain. The *Plataforma de Organizaciones de Pacientes* works as a vehicle to connect patient groups with the Health Ministry. On the 29th of October, during the annual assembly, ANHP was officially welcomed as a new member.
- On November the 4th we held a second presentation of the book *El Baile De Los Delfines* (see above), which was attended by the author.
- On the 12th of November we had a meeting of the ANHP Board to discuss how to continue our Project "Cycling for LiPHe".
- The third presentation of the book *El Baile De Los Delfines* took place in Zaragoza on 16 November with the author and Eva, one of the members of the ANHP Board.
- During the congress of SADECA (SOCIEDAD ANDALUZA DE CALIDAD ASISTENCIAL) which took place on 19 November in Malaga there was a roundtable about CTEPH and ANHP was invited to share the podium table with two specialists and make a presentation.
- On the 27 of November, the multidisciplinary PH unit of the *12 de Octubre Hospital* in Madrid organized the 3rd international event for doctors and nursing staff from all around the world. ANHP was invited to give a speech about the patients perspective.
- On november 30th there was a presentation of a new book called *FEDER, la fuerza del movimiento asociativo* ("FEDER, the force of associative movements"). FEDER is the FEDERACIÓN ESPAÑOLA DE ENFERMEDADES RARAS.

ANHP had a number of meetings with other organizations and institutions in 2015:

- First day of health coordination, organized by the General Patients's Board of Madrid (DIRECCIÓN GENERAL DEL PACIENTE DE LA CAM).
- Meeting of NEUMOMADRID, SOCIEDAD MADRILEÑA DE NEUMOLOGÍA Y CIRUGÍA TORÁCICA (Madrid Society for pulmonolgy and thoracid surgery).
- Madrid meeting of FEDER, Spanish Rare Disease Federation.
- First multidisciplinary day of PH in the Valencia region).
- 3rd meeting of rare disease experts (EXPERTOS EN ENFERMEDADES RARAS).
- 10th anniversary of the Spanish Patient Forum (FORO ESPAÑOL DEL PACIENTE).
- Workshop about cross border healthcare (*Atención Sanitaria Transfronteriza*).
- OBSERVATORIO DE ADHERENCIA AL TRATAMIENTO (Observatory for treatment adherence).
- II CONGRESO ESCOLAR ENFERMEDADES POCO FRECUENTES (2nd Scholar Congress of less frequent diseases).
- *Convivir con una enfermedad rara: Un gesto qe lo cambia todo* (Living with a rare disease, a gesture that changes everything", an event organized by FEDER during the Madrid Assembly.
- Ordinary and Extraordinary Annual Assembly of FEDER, Spanish Rare Disease Federation.
- Spanish Cardiology Society meeting (SEC, SOCIEDAD ESPAÑOLA DE CARDIOLOGÍA)
- General Assembly of the Spanish Patient Forum (FORO ESPAÑOL DEL PACIENTE).

Irene Delgado, Juan Fuertes
Asociación Nacional de Hipertensión Pulmonar
www.hipertensionpulmonar.es

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



SPAIN-FCHP

Empathy project

The "Empathy Project" has been the main protagonist for 2015 for the FUNDACIÓN CONTRA LA HIPERTENSIÓN PULMONAR (FCHP) as all the initiatives we have organized have had as their main objective to raise funds for this research project. These initiatives include sports activities, such as the athletics event of Orgaz or the night route of the Guadarrama Cycling Club; charity markets in the Metro of Madrid, Calella and the Green Ecotienda Gata; shows in Alicante or the theatre El Recuerdo; painting exhibitions such as the one for Pablo Romero Cagigal. We also presented a project to Honda to finance a research initiative in molecular genetics. We have participated in the Volunteer Day of Parla, in the Solidarity Race for Hope in the VI Conference of Pulmonary Hypertension in the Hospital Clinic of Barcelona, in the First Day of care coordination, in the presentation of the interactive roadmap for Rare Diseases of the Community of Madrid, in a recording of the SPANISH FEDERATION FOR RARE DISEASES and in Bayer and Actelion initiatives to raise funds. During this year, we attended the annual conference of the Pulmonary Hypertension Association Europe, the match of Champions for Life and Trival concert to enjoy the song "Blue Kisses" which has been written thinking of PH patients. We

have also collaborated with other organizations that support people with rare diseases, such as the SPANISH LIPODYSTROPHIES ASSOCIATION and those affected by ALS. To raise even more funds, we have sold products donated by FCHP's friends and sport clothes provided by Getafe CF. We have also represented the PH patients in the Senate of Spain, we were finalists in the Fundamed, The Global Awards, we have signed collaboration agreements with the Hotel Tres Anclas Gandia and Vigosoft, we have launched a campaign to raise Teaming Group funds for children affected by PH and have launched the FCHP and Actelion Grants to research in pulmonary hypertension.

PH World Day and Ciberes agreement sign

In May, to celebrate World PH Day, we had our first tournament of the Clinic Golf Foundation, attended by personalities like Matias Prats (journalist), Bernd Schuster (football player), Nacho Aranda (journalist), Iñaki Cano, Guillermo Salmeron, Carlos Garcia-Hirschfeld (journalist) or Sergi Arola (Chef). That day we signed an agreement with Manuel Sanchez, who represented

resented CIBERES, CENTRO DE INVESTIGACION EN BIOMEDICA EN RED DE ENFERMEDADES RESPIRATORIAS (Centre for Biomedical Research in Lung Diseases). With this agreement we have become part of the project as a state official partner.

SMS fundraising campaign

We have launched a major fundraising campaign with 400 advertising posters in bus shelters, which will also be enhanced through our social networks and our web page. We are also negotiating to have them in the underground in Madrid and other points of Spain, eg. Barcelona. We also launched a one week campaign to raise funds for the EMPATHY PROJECT through SMS, credit cards and Paypal. This initiative, which for us has had no cost and which is valued at over 100.000 euros was made possible by the PHA Europe and our partner Antonio Ranz Sordo, in collaboration with the companies Zenith, Sanca, Cemusa well as Actelion and GSK laboratories. To help financially, you just have to send a SMS with the word "RESPIRA" to the number 28014. The cost of this message is 1.2 euros, which will go entirely to our Foundation and which we will allocate to the EMPATHY PROJECT. More than 120.000 families around the world will benefit from this project.

Enrique Carazo Minguéz
 FCHP Fundación Contra la Hipertensión Pulmonar
www.fchp.es/es - www.facebook.com/fundacionhp





SWITZERLAND-HTAP REVIVRE

PH group outing

On the 26th of September 2015 the Swiss PH association HTAP-Revivre organized a group excursion. Led by Lydia Benallouch, the association's President, about thirty members went to Broc, in the Fribourg area, to visit the Cailler chocolate factory. The aim of the visit was to better understand how chocolate, a renowned Swiss specialty, is made. The meeting point was at the factory's restaurant, where we had a nice coffee and croissants, well deserved after so many kilometres driving to reach the village. The participants were mostly patients and their spouses or friends, coming from many different parts of the "Suisse Romande". They were very happy to have this opportunity to meet and share a new experience.

The participants were broken up into two groups and were given a device (audio guide) with which to listen, at the push of a button, to an explanation of what they were visiting. The tour showed, in a fun and original way, the entire process which leads to the production of chocolate, from planting the

cocoa trees to picking the fruits to the various production phases and end stage product ready for human consumption. Once the tour was over, those of us with a "sweet tooth" were able to buy some goodies at the factory shop as well as souvenirs and presents. During the remaining part of the day we went to the center of the village to the restaurant "Hôtel de Ville". Here, after a brief welcome speech from the President, who took the opportunity to thank all those who, through their donations, made the excursion possible, we enjoyed a wonderful lunch and live music played on the accordion by one of our members. It was particularly nice to share experiences of the disease, the good and the bad, with others who really know what it means to live with the disease. And to discuss the future of the association, its projects and upcoming activities. At the end of the day we all drove back to our respective homes with a pledge to meet again next year.

Lydia Benallouch-Meier, HTAP Revivre
www.saph.ch/SuisseRomande



SWITZERLAND-SPHV

5th SPHV General Meeting

On Saturday, March the 28th SPHV held its 5th General Meeting in the Congress Hotel in Olten, with 37 members attending. Since the last assembly the number of members of our association has increased from 138 to 200 members, which we were delighted with.

Therese Oesch, who is also a Founding Member, resigned from her position as President of our association and Bruno Bosshard was elected as her successor. The resigning President was nominated "Honorary President" of SPHV with a round of warm applause and thanks for her great work for SPHV in past years.

14th Swiss PH Meeting

On May 30, 2015 the 14th Swiss PH Meeting took place in the Congress Hotel in Olten. 62 members were present.



The new President, Bruno Bosshard, communicated the changes in the Board. In particular, he announced that at the last general meeting, (see previous section) Therese Oesch had

resigned from her position as President, due to health reasons and that the assembly had nominated her Honorary President. At this year's meeting the following two topics were on the program:

1. A presentation by Dr. Natascia Corti regarding the different interactions between drugs, ie. the mutual impact of drugs upon intake (e.g. intestinal), metabolism process in the liver and the excretion through e.g. the kidneys.
2. The social worker Susanne Erns made a presentation about living wills:
 - Do you want to make a living will?
 - How to make a living will.
 - How to use pre-printed forms to make it yourself
 During lunch which followed the discussion, we had time to exchange information and experiences.

11th Company Triathlon

About 240 teams of three people each took part in the 11th

company triathlon in Zürich. Twenty Bayer teams were among the participants and raced for the good cause of PH!

It was the ninth time that Bayer was taking part in this competition, which took place in Zürich one day before the IRONMAN race and which includes 750 meters swimming, 25 kilometers cycling and 7 kilometers running.

Bayer made a donation for each of their participants to our association. More donations were raised with our special tattoo campaign. (see below). Barbara Heise, spokeswoman of Bayer Switzerland, pointed out that PH still is very little known and as a result there are still big delays in getting a correct diagnosis. She also added that the aim of Bayer Switzerland's support to SPHV is to improve quality of life for the patients.

Stick-on tattoos for a good cause

At the company triathlon fifteen members of SPHV distributed stick-on tattoos to the competitors of all companies and also to the spectators.

Bayer donated 5 CHF for each sticked-on tattoo. SPHV also had an information booth at the triathlon venue.

Therese Oesch, Honorary President of SPHV, a PH patient herself, pointed out that the tattoo campaign and the booth were important as they were aimed at raising awareness of PH among as many people as possible.



Bus excursion to Abegg foundation

August 21 was a beautiful sunny day, with perfect weather conditions for our excursion to Riggisberg. We were 25 participants and we started the day at 10 o'clock in the Hotel Egerkingen with coffee. On the way to Riggisberg we had a wonderful view over the Gürbetal and the pre-Alps. Our destination, the Abegg Foundation, has one of the worlds' biggest and most important collection of old textile fabrics. An introductory slide show gave us an understanding of the tasks and objectives of the foundation. Through the past decades, the textile manufacturer Werner Abegg and his wife Margaret, who is an art historian, collected valuable fabrics, wall hangings and clothing, but also work of other kind such as works of a goldsmith, ceramics, paintings and sculptures from famous artists. The collection's objects date from the pre-Christian era to around 1800. In addition to the museum, the Abegg Foundation has an enormous library as well as a studio for textile conservation and restoration. In this studio they collaborate with the Berner college which also conducts university courses in this field. One graduate of this course accompanied us through this special exhibition which had the focus on silk fabrics of the 15th century.

7th PH Family Meeting

This years' excursion led us to the sunniest corner in Switzerland, Ticino! It was a two day trip, from September 12 to 13. Although we did not have perfect sunny weather we did manage to catch each and every ray of sun and had



a lot of fun moments. Daniel and Andrea Heini welcomed the seven families participating in the excursion at our meeting point, which was the main train station in Locarno.

After a short greeting we took the train to Maggiatal. The Römer family welcomed us in the small village of Giugmaglio. Margret Römer grew up in this small village and she was the one who originally proposed to organise our meeting in Ticino. The schedule for the kids included baking bread in the woodstove, painting cloth bags and the visit of three historic castles in Bellinzona as well as the old city. During the baking session and during our walk through the Maggiatal there was time for conversation with the kids affected by this disease. Many topics of this disease have been discussed with Mrs. Römer, who is a PH nurse. One important topic was the conversion from paediatric hospital to the university hospital. The kids stayed overnight in the youth hostel of Bellinzona. We all had a lot of fun and returned home in a very good mood.

IWB-Marathon

The IWB marathon took place in Basel on the 27th of September. This was the second time that Actelion employees took part in this marathon for the PH cause and it was again

a great success. Over 200 participants, employees and families ran 2.600 kilometers in total to raise awareness of PH and to support patient organizations. There were different disciplines, i.e. marathon, half marathon, team run, youth run or a 10 kilometers run. Several members of SPHV were on site to encourage and support the participants. It was great to see that they were all giving their best. Thanks to the commitment of Actelions' staff we again this year received many donations.

8th ph e.v. Meeting

On October 23-25, a group of eighteen SPHV members travelled to Frankfurt am Main for the annual meeting of ph e.v., the German PH association. This year again, the costs for our bus travel was covered by 3 sponsors. Again a big thank you for the support. Once more, we returned home with a lot of motivation and new knowledge.



Open house in the pulmonology division

The Inselspital in Bern held an "Open day" on October 31, under the slogan *Töif schnuufe* - "Breathe deeply".

There were several technical lectures, discussions and exchanges with the specialist teams (doctors, physiotherapists) on nutrition and healthy life styles (including advice on how to stop-smoking). Other activities included:

- Presentation of lung function test and spiroergometry.
- Introduction of the special consultation hour for PH and other lung diseases.
- Sleep/non invasive ventilation: in which case is snoring dangerous?
- Bronchoscopy: tour through the new centre.
- "Slip into our role as examiner"- performance of a bronchoscopy on a model.

SPHV was present with an information booth where interested people had their questions answered by professionals.

Regional Patient Meetings.

In the course of our five regional meetings for PH patients and family members exchanged experiences and information. Mostly the meetings were over lunch and were held in Bern, Chur, Olten, Meggen and Zürich.

Therese Oesch, SPHV

www.lungenhochdruck.ch - <http://on.fb.me/1dfRZ2B>



UKRAINE-SISTER DALILA-PHURDA

In the course of 2015 the LCCF of "Sister Dalila"-PHURDA carried out a number of activities aimed at supporting PH patients and protecting their rights:

- **24.02.2015.** We organized a flashmob involving children, to support patients with rare diseases, in front of the LVIV CITY COUNCIL (City Hall). The event was dedicated to International Rare Disease Day (RDD). Children with their hands formed the official symbol of RDD and chanted the slogan: "A cork and a cork gather you and I, together we will save lives". That same day the campaign "Cork for life", which includes a mass gathering of plastic corks, was launched in Lviv. The campaign now extends to the entire country.
- **28.04.2015.** The LCCF of "Sister Dalila" was accepted by the newly created PUBLIC COUNCIL of the DEPARTMENT OF HEALTH of Ukraine.
- **03.05.2015.** We participated in the sports event "Hodoton"... when the air is left aside", dedicated to the WPHD, in the centre of Lviv.
- **07.05.2015.** The press-center "ZIK" held a joint press-conference, dedicated to WPHD. The participants were LCCF of "Sister Dalila", PHURDA, FC "Karpaty" and a PH physician.
- **09.05.2015.** A football event was held in the stadium "Ukraine" in Lviv, with the participation of FC "Karpaty" and FC "Chornomorets", and dedicated to World PH Day.
- In first ten days of June 2015 we participated in the "Summer School-2015", Barcelona (Spain), organized by the European Organisation for Rare Diseases (EURORDIS).
- The Lviv Regional Registry of patients with PH and the Lviv Regional Register of patients suffering from rare diseases were approved.
- **15.09.2015.** During the LVIV REGIONAL COUNCIL's session Decision n. 1416 approved the "Regional program of improvement of medical care for patients with PH in the Lviv region in 2015-2017". The regional program provides 14 patients in the Lviv region with expensive PH drugs, namely "Revatio" and "Ventavis" for free.
- **17.09.2015.** At the ANNUAL PH EUROPEAN CONFERENCE (APHEC) in Spain PHURDA was voted as

Member of PHA Europe.

- Our association organized and financed the diagnostic work up for a disabled 16 year old orphan girl suffering from Eisenmenger's syndrome, Alina Didusenko, born in 2000, at the MEDIZINISCHE UNIVERSITÄT WIEN, Austria.
- **01.10.2015.** The entertainment center for kids "Children's Planet" hosted the event "Day of cork" within the campaign "Cork for life".
- **22.12.2015.** In a large session hall of the Lviv City Council an event was organized to present the results of campaign "Cork for Life" in 2015". Thanks to the funds raised we were able to purchase a portable nebulizer for the inhalation of "Ventavis", which was handed over to the LVIV REGIONAL CENTER FOR CARDIOLOGY.
- Alina Didusenko (see above) was included in "Health", the program developed by the DEPARTMENT OF HEALTH of the Kiev State Administration, with a budget of 1,970,000 UAH.
- **12.01.2016.** The session of the LVIV REGIONAL COUNCIL approved the budget for 2016, which provides patients with PH in the Lviv region with 3,689,880 UAH.
- **Other.** Placing of city lights and billboards with information about PH; speeches; stories on TV channels "TRK-Lviv", "ZIK", "TRK-Kyiv", "Channel 5", "ICTV", and "1 + 1"; commercials on the radio "Lvivska hvyliya", "Vholos", "Radiolyuks", "Melodia", "HitFm" and "Radiatorok".
- We received a grant from the PHA US for a project for early diagnosis in the Lviv region. This grant is given annually only to 12 countries around the world so it was a great opportunity and success.

All this was possible thanks to our cooperation at international level with PHA Europe, EURORDIS, PHA USA, PHA Canada and others. The learnings from the achievements of the European and American patient organizations in overcoming the problems of PH and support for patients with PH are invaluable.

Oksana Kulish, Sister Dalila-PHURDA
[o_kulish@inbox.ru](mailto:okulish@inbox.ru)





UKRAINE-PHA UKRAINE

Lung transplant

We want to share with all the members of the PHA Europe family a few of our most recent activities.

On the 23th of September we were invited by the department of the Ministry of Health (MOH) which is in charge of treatment abroad, to a meeting to discuss payment for lung transplantation surgery for our three PH patients: Alina Didusenko (AKH Vienna, Austria) Mykhaylo Rozmarytsyn and Olha Tereshchuk (India, Fortis Hospital). For these three PH patients the MOH confirmed that expenses would be covered by the state. We are very happy for this wonderful opportunity given to our PH patients, which is the fruit of a long and finally successful cooperation with the MOH. Unfortunately, the agreement about Alina Didusenko for surgery in Vienna fell through and at the moment it is not possible to transport her even India. We have studied the issue thoroughly, bearing in mind the patients and their needs, and have concluded that India is today the best option for Ukrainian PH patients. Mikhail Rozmaritsin is currently in India on a the waiting list for transplant. At the end of the month the second transplant patient is flying over, and hopefully more will follow. We hope that the delegation which is currently inspecting the clinic in India, composed of a doctor, a cardiac surgeon and Oksana Aleksandrova, will come to a positive conclusion about a long-term cooperation/contract between the MOH in the Ukraine and the Fortis Hospital in India and that our patients will

be sent there in future for lung and heart transplantation, at public expense.

PH Advisory Council

The next good news is, within the context of the National Congress of Cardiologists, on the 24th of September, we were invited by the Director of the PH clinic Prof. Yuriy Sirenko and by leading PH experts in the Ukraine to present our joint project, ie. the creation of an Advisory Council in PHA Ukraine for the purpose of improving information and medical care for patients with PH in the Ukraine, for professional cooperation with the donor organizations and for partnering with the MOH of Ukraine.

Children with PH

More good news: we have started to work on a project for a pediatric PH clinic, in collaboration with Prof. Yemets, Director of the Pediatric Cardiology and Surgery clinic in the Ukraine. We have also made contact with Prof. Maurice Beghetti, leading PH pediatrician from Geneva. Prof. Yemets worked together with Prof. Beghetti in Canada last year so we hope we will making great projects together.

On the 26th of September, together with the Children Cardiology Surgery Center, we held a "Heart Day", a big open air event in a park, for families, during a weekend. During this event we distributed leaflets and Oksana Aleksandrova gave a speech to present the activities of the association.

Budget cuts

We have sad news also... Our Ministry of Finance reduced the funds for the state program for PH patients for 2016 to about 75 million hryvnias. This cut is connected with the general budget reduction for patients with rare diseases in Ukraine. Together with the NATIONAL ALLIANCE FOR RARE DISEASES we will prepare a public action and we hope to achieve some positive changes with regard to the budgetary programs for patients with rare diseases in Ukraine.

PH now on National Rare Disease list!

Thank to our PHA Ukraine teamwork and the NATIONAL ALLIANCE FOR RARE DISEASES, in particular Tatiana Kulesha and Oksana Aleksandrova and the Ministry of Health of Ukraine, all types of PH have been added to the national rare diseases list. It's a very big victory and we are so glad to share this great news with all our PH family.

On the 27th of October 2015 the Ministry of Health of Ukraine officially presented the new additions to the national rare diseases list, see:

http://www.moz.gov.ua/ua/portal/dn_20151130_0.html

Public action for funding of medicines

On the 7th of October 2015, together with the NATIONAL ALLIANCE FOR RARE DISEASES we held a public action called "The life that I will not live", near the Cabinet of Ministers of the Ukraine. The heads of the eight rare disease patient organizations in the Ukraine together explained what our future will be without funds for medicines in 2016. We also sent letters to all officials, and there was even an international letter from the PHA US association to our Minister of Finances, Natalia Ann Yaresko.

Press conference

On the 7th of December, together with the NATIONAL ALLIANCE FOR RARE DISEASES we held a press briefing together with patients with Pompe disease, with the attendance of Maryze Schoneveld Vd Linde, coordinator of the International Pompe Association. She came to the Ukraine to present the European situation with regard to treatment access. After the press briefing we started an all-Ukrainian web petition to the President of Ukraine demanding the implementation of the Law on rare diseases in Ukraine and the funding of treatment for patients with rare diseases, without interruption on a regular basis and free of charge. Here is official petition, we need to reach 25.000 signatures, but only from Ukrainian nationals:

<https://petition.president.gov.ua/petition/18300>

See also the full video version of the press briefing, which had great media coverage: 5 prime time channel news shows!

<https://www.youtube.com/watch?v=jZMH205NoOE>

Oksana Aleksandrova

Ukraine Association of Patients with Pulmonary Hypertension
www.pha.org.ua - info@pha.org.ua





IRELAND

Ireland PH Meeting 2015

The Pulmonary Hypertension Association-Ireland was honoured to be asked to organise the All Ireland PH Meeting, which was held on the 27th of February 2015 in the Hilton Hotel Belfast. Speakers included: Prof P. Corris, Professor of Thoracic Medicine, Freeman Hospital and Ms R. Crackett, PH Nurse Specialist, Freeman Hospital, Newcastle upon Tyne; Mr D. Jenkins, Consultant Cardiothoracic Surgeon, Papworth Hospital, Cambridge; Prof P. McLoughlin, Professor of Physiology, University College Dublin; Dr A. Smyth, Consultant Rheumatologist, Ulster Hospital, Dundonald; Dr K. Walsh, Consultant Cardiologist, Mater University Hospital & Our Lady's Children's Hospital Dublin. The meeting was Chaired by Prof Sean Gaine, Consultant Respiratory Physician, National Pulmonary Hypertension Unit, Dublin and Dr Carol Wilson, Consultant Cardiologist, Belfast. The attendance surpassed our expectations with over 200 doctors and nurses present. We are currently planning the 2016 meeting and we all agree we have a "difficult act to follow".



Patients Support Groups

We have been working very hard to get our meetings up and running. Naturally many patients express disappointment that most things happen in the Capital. However with great support from the patients and their families - things are beginning to happen and we are very optimistic that groups will start to spring up around the country.

Regina Prenderville, PHA Ireland

Halloween party

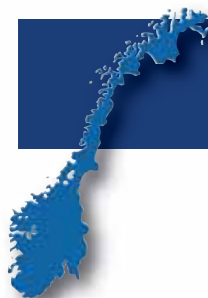
Myself and two friends, Aoife & Karen, arranged a PH Halloween night in our local "country pub", as we live in a small town. All the local children dressed up and we handed out information about PH to the adults. They were very interested in the disease, as none of them were aware of it. I answered their questions and felt very happy that at least a few more people are aware of our plight to publicise information about this awful disease. We raised a small amount of money on the night, which will go towards organising larger awareness campaigns.



Karen Doherty, PHA Ireland

on.fb.me/1KaUHRN

<http://www.pulmonaryhypertension.ie/pha-ireland/>



NORWAY

Patient meeting

The highlight for the Norwegian Pulmonary Hypertension Association is the yearly patient meeting. This is a great opportunity for patients from all Norway to meet, get informed on important issues like disease information, nutrition and exercise for PH patients, legal issues, etc. Another important aspect of the meeting is

the ability for the patients to socialize and share experiences with each other. This year the meeting was held at a lung and heart rehab center in beautiful surroundings a little north of Oslo.



PH rehab

For the fourth year in a row, Feiringklinikken offered a three week long rehabilitation program for Norwegian PH patients. The program is free of charge for the PH patients as the cost is covered by the national health care system. The program offered by the rehab center is excellent and covers a wide range of aspects: initial assessment of physical and mental condition, disease education, nutrition information and hands-on cooking lessons, individually adjusted exercise programs, psycho/social issues with presentations and consultations with psychologists, legal issues, etc.

PAH forum

The medical community runs a yearly conference in Oslo. This year more than 100 PH specialist and health personell from Norway, Denmark, Sweden and Iceland gathered for a full day of PH presentations and panel discussions. International keynote speakers were Dr. Gerhard Diller and Prof. Ardeschir Ghofrani from Germany and Dr Simon Gibbs from the UK. In addition, Norwegian PH specialists also presented at the conference. Two representatives from the Norwegian patient association were also invited and gave a presentation of the Norwegian patient association's activities and offerings.

Medical evening seminars

The pharmaceutical industry runs numerous short evening seminars for PH health personell and general practitioners. A PH specialist is often the keynote speaker and will present the latest PH research, etc. The Norwegian patient association has been invited to several of these meetings and has run presentations informing about their activities and presenting patient stories. This has lead to a greater awareness of the association in the medical community and doctors making their patients aware of the existence of the association, and recommending them to join.

Hall Skåra, PH Norway

www.pha-no.com [http://on.fb.me/TDzyKI](https://on.fb.me/TDzyKI)



SWEDEN

The Swedish association for PH is growing, we are now more than 120 members. To be able to continue to grow, we have to build a strong and sustainable organisation: this has been our main focus this year. To summarize 2015 we are happy to say that we have come a long way. We have met PH nurses, PH specialists and we have established contact persons



from our association in our six national PH centers in Sweden. This fall we are also proud to have become members of Rare Diseases Sweden and we have had our first meeting together.

Patrik Hassel, PHA Sweden

<http://pah-sverige.se/> - [http://on.fb.me/WcaOWZ](https://on.fb.me/WcaOWZ)



UPTRAVI (SELEXIPAG) FDA APPROVAL

On December 21, the U.S. Food and Drug Administration (FDA) approved Uptravi (selexipag) tablets to treat adults with pulmonary arterial hypertension (PAH). Uptravi belongs to a class of drugs called “oral IP prostacyclin receptor agonists”. The drug acts by relaxing muscles in the walls of blood vessels to dilate (open) blood vessels and decrease the elevated pressure in the vessels supplying blood to the lungs. Uptravi’s safety and efficacy were established in a long-term clinical trial of 1,156 participants with PAH. Uptravi was shown to be effective in reducing hospitalization for PAH and reducing the risks of disease progression compared to placebo. Participants were exposed to Uptravi in this trial for a median duration of 1.4 years (Phase III GRIPHON study). Common side effects observed in those treated with Uptravi in the trial include headache, diarrhea, jaw pain, nausea, muscle pain (myalgia), vomiting, pain in an extremity, and flushing.

Uptravi was granted orphan drug designation. Orphan drug designation provides incentives such as tax credits, user fee waivers, and eligibility for exclusivity to assist and encourage the development of drugs for rare diseases. Uptravi is marketed by San Francisco-based Actelion Pharmaceuticals US, Inc. Source: 1.usa.gov/1O6qrhv

UPTRAVI (SELEXIPAG) EMA APPLICATION

The Committee for Medicinal Products for Human Use (CHMP), the scientific committee of the European Medicines Agency (EMA), has issued a positive opinion for the use of Uptravi (selexipag) in PAH. A CHMP positive opinion is one of the final steps before marketing authorization is granted at EU level. The final decision is expected to be issued by early April 2016.

Next PHAE newsletter

The next Mariposa Journal will be issued in July 2016 (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 30th 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!*

PHASE III TRIAL FOR RIOCIQUAT IN CHILDREN

On October 7 2015 Bayer announced the initiation of a phase III trial to evaluate the safety and tolerability of riociguat in children suffering from pulmonary arterial hypertension (PAH). Riociguat has been approved since 2013 for the treatment of adults suffering from this life-threatening disorder of the lungs.

The development and commercialization of riociguat is part of the worldwide strategic collaboration with MSD (through a subsidiary) in the field of soluble guanylate cyclase (sGC) modulation. MSD is known as Merck in the U.S. and Canada.

See more at:

<http://www.epresspack.net/bayer-riociguat/bayer-to-evaluate-adempas-riociguat-in-children-suffering-from-pulmonary-arterial-hypertension-pah/#sthash.FOMgY5vp.dpuf>

FDA ORPHAN DRUG DESIGNATION

On April 2015 Reata Pharmaceuticals, Inc., a biopharmaceutical company dedicated to the development of breakthrough medicines for difficult-to-treat diseases, announced that the FDA Office of Orphan Products Development (OOPD) has granted orphan drug designation for bardoxolone methyl for the treatment of pulmonary arterial hypertension (PAH)

Bardoxolone methyl is currently being evaluated in the LARIAT study, a Phase 2 dose-ranging study examining the safety, tolerability and efficacy of bardoxolone methyl in patients with PAH. LARIAT is a multi-center, double-blind, randomized, dose-ranging, placebo-controlled study. The primary efficacy endpoint is a six minute walk test. For more information on this study, visit:

<http://clinicaltrials.gov/show/NCT02036970>.

Orphan Drug Designation does not alter the standard regulatory requirements for obtaining marketing approval.

2016



February 23-25, Brussels, Belgium

EURORDIS GALA DINNER AND MULTI-STAKEHOLDER SYMPOSIUM

The Black Pearl Gala Dinner is a fund raising event organised by EURORDIS within the context of celebrations for INTERNATIONAL RARE DISEASE DAY. It is followed by a two day Multi-stakeholder Symposium on Improving Patient Access to Rare Disease Therapies.

May 5, Worldwide
5th WORLD PH DAY

PH associations around the world will be taking part in the annual World Pulmonary Hypertension Day 2015. PHA Europe and its affiliates will be running the “Get breathless for PH” awareness campaign, 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 26-28, Edinburgh, UK

8th EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS

This biennial event provides the state-of-the-art of the rare disease environment, monitoring and benchmarking initiatives and brings together all stakeholders – patients’ representatives, academics, health care professionals, industry, payers, regulators and policy makers. It will be preceded by the EURORDIS General Assembly on the 26 May.

June 17-19, Dallas, USA

PHA USA INTERNATIONAL CONFERENCE AND SCIENTIFIC SESSIONS

This event brings together more than 1,500 patients, caregivers, medical professionals and other friends of PHA every two years to share information on the latest research, treatments and lifestyle issues with PH. This year it will commemorate PHA’s 25th anniversary and the theme is “25 Years of Progress: Changing the History of PH”.



August 31 - September 4, Rome, Italy

EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS

PHA Europe will be present at the EUROPEAN SOCIETY OF CARDIOLOGY’S ANNUAL CONGRESS 2016. This Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines from basic research to clinical practice.

September 3-7, London, UK

EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS

PHA Europe will also be present with a booth at the EUROPEAN SOCIETY FOR RESPIRATORY MEDICINE’S ANNUAL CONGRESS 2016. This Congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.



September 15-18, Barcelona, Spain

PHA EUROPE ANNUAL PH EUROPEAN CONFERENCE

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. PH Patient Leaders from 31 European countries attended the 2015 meeting.

Members of PHA Europe and contact details

AUSTRIA



Selbsthilfegruppe Lungenhochdruck
Wilhelmstraße, 19 - 1120 Wien
www.lungenhochdruck.at
info@lungenhochdruck.at

BELARUS

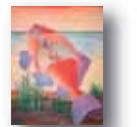


Aid to Patients with Pulmonary Hypertension
Zapadnaya str.13 - 3, Minsk, 220036
www.phbelarus.by - phbelarus@yandex.ru

BELGIUM



HTAP Belgique, Asbl
Première Avenue, 83 - 1330 Rixensart
www.htapbelgique.be - htapbelgique@hotmail.com



Patiëntenvereniging Pulmonale Hypertensie vzw
Rode Dries 10 - 2288 Bouwel
www.ph-vzw.be - hendrik.ramaker@skynet.be

BOSNIA AND HERZEGOVINA



Udruženje građana oboljelih od plućne hipertenzije "DAH" – u Bosni i Hercegovini
Zlatnih ljiljana 33, 72220 Zavidovići, BiH
ugphbih@gmail.com

BULGARIA



Pulmonary Hypertension Association
37 Hadji Dimitar str, ent. B, fl. 2, ap. 3
5800 Pleven
www.apph-bg.org - todormangarov@abv.org



The Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH
1 Geneva str. - 1142 Sofia
www.bspph.net - bspph@gmail.com

CROATIA



Plava krila - Udruga pacijenata oboljelih od plućne hipertenzije
Gorica Jamnička 23 - 10451 Pisarovina
infoplavakrila@gmail.com - www.plavakrila.hr

CZECH REPUBLIC



Sdružení Pacientů s Plicní Hypertenzií
Na Moráni 5 - 128 00 Praha 2
www.plicni-hypertenze.cz
info@plicni-hypertenze.cz

DENMARK



PAH Patientforeningen
c/o Kristian Weber Thomsen
Ole Bruuns Vej 5, 1
DK 2920 Charlottenlund
<http://pah.dk> - pahforening@gmail.com

FINLAND



Suomen PAH-potilasyhdistys ry. PHA Finland
c/o Tuulia Näppi
Keskijuoksu 19 J 38 - 02920 Espoo, Finland
pha.fin@gmail.com

FRANCE



HTAP France
c/o Ludivine Chantraine
Allée des Charmes, 8
21380 Asnières les Dijon
www.htapfrance.com
secretariat@htapfrance.com

GERMANY



pulmonale hypertonie e.v.
Rheinaustraße, 94
76287 Rheinstetten
www.phev.de - info@phev.de

GREECE



H.P.H - Πνευμονική Υπέρταση Ελλάδας
Mail Box 52700,145 72 Drosia, Athens
info@hellenicpulmonaryhypertension.gr
www.hellenicpulmonaryhypertension.gr

HUNGARY



Tüdőér Egylet
19, Cházár András Utca - 1146 Budapest
www.tudoer.hu - csabuda.eszter@t-online-hu

IRELAND



PHA Ireland
c/o Regina Prenderville
56 Eccles Street, Dublin 7, Ireland
<http://www.pulmonaryhypertension.ie/pha-ireland/> - rprenderville@mater.ie

ISRAEL



PHA Israel
13 HaShoshan Street - Beit Shemesh 99590
Israel
www.phisrael.org.il - aryeh35@gmail.com

ITALY



Associazione Ipertensione Polmonare Italiana Onlus
Via Vigoni, 8 - 20122 Milano
www.aipiitalia.it - pisana.ferrari@alice.it



Associazione Malati di Ipertensione Polmonare Onlus
Via Bagnoregio, 51 - 00189 Roma
www.assoamip.net - info@assoamip.net

LATVIA



PHA Latvia
Str. Celtnieku 6a - 35, Salaspils - LV - 2121
www.phlatvia.lv/en/ - info@phlatvia.lv

LITUANIA



Žmonių Sergančių Plautine Hipertenzija Asociacija
Energetikų 28-21 Visaginas, Lietuva
www.phalithuania.eu - kovaliova.nastya@gmail.com

NETHERLANDS



Stichting PHA Nederland
P.O. Box 627 - 3800 AP Amersfoort
www.pha-nl.nl - info@pha-nl.nl

NORWAY



PHA Norway
c/o Hall Skåra
Kantarellgrenda 6 - 1352 Kolsås
www.pha-no.com - hall@pha-no.com

POLAND



Polskie Stowarzyszenie Osób z Nadciśnieniem Płucnym i Ich Przyjaciół
Władysława IV 34a m.15, 81-084 Gdynia
www.phapolska.org
bartosiewicz.agnieszka@phapolska.org
admin@phapolska.org

PORTUGAL



Associação Portuguesa de Hipertensão Pulmonar
Avenida Dr. Luis Navega, 38-42 - 3050 Mealhada
www.aphp-hp.org - mariajsaraiva@gmail.com

REPUBLIC OF MACEDONIA



APH Moment Plus
st.Tanche Kamberov, 29 - 1480 Gevgelia
www.phmomentplus.com.mk
<http://on.fb.me/1ARacM8>
phmomentplus@gmail.com

ROMANIA



Association of pulmonary hypertension patients
Sinaia/Prahova Carol I, nr 11 street
www.phader.eu

RUSSIA



Natasha Charity Fund
c/o Evgeniy Komarov - Kondratevsky prospect
House 57, apartment 6 - St.-Petersburg
www.community.livejournal.com/fond_natasha
otzovitesnam@mail.ru - www.nurm.ru

SERBIA



Plućna Hipertenzija Srbija
ul. Ratka Jovića 17
18210 Žitkovac - Republika Srbija
[danijela@pesic.rs](mailto:danjela@pesic.rs)

SLOVAKIA



Združenie pacientov s pľúcnou hypertenziou, o.z.
Lučenská, 31 - 990 01 Veľký Krtíš
<http://phaslovakia.org/> - hypertenzia.pluc@gmail.com

SLOVENIA



Društvo Za Pljučno Hipertenzijo Slovenije
Slovenska 29, 1000 Ljubljana
dbph.slovenije@gmail.com
www.facebook.com/PljucnaHipertenzija

SPAIN



Asociación Nacional de Hipertensión Pulmonar
Avenida de las Artes, 7
28300 Aranjuez - Madrid
www.hipertensionpulmonar.es
informacion@hipertensionpulmonar.es



FCHP Fundación Contra la Hipertensión Pulmonar
c/o Enrique Carazo Minguez - Calle Pablo Neruda, 39
28980 Parla - Madrid
<http://www.fchp.es/es> - info@fchp.es
<https://www.facebook.com/fundacionhp> - <https://twitter.com/fundacionhp>

SWEDEN



Nätverket för PAH
c/o Patrik Hassel
Kärrtorpsvägen, 37
121 55 Johanneshov
www.pah-sverige.se - patrik@pah-sverige.se

SWITZERLAND



Schweizer PH-Verein (SPHV) für Menschen mit pulmonaler Hypertonie
c/o Bruno Bossard
Im Rossweidli 1 - 8045 Zürich
www.lungenhochdruck.ch - www.sphv.ch
President: praesi@lungenhochdruck.ch
Webmaster: bosshard@lungenhochdruck.ch



Association HTAP Revivre
c/o Mme Lydia Benallouch-Meier
Chemin des Sports 16 - CH - 1203 Genève
www.saph.ch/SuisseRomande
President: lydia_mb@bluewin.ch
Coordinator: monika.sorgemaitre@hcuge.ch

TURKEY



Pulmoner Hipertansiyon Dernegi
Meriç Sokak Milas 2000 Is Merkezi 5A
Blok/26 - Bestepe Ankara
uatli@hotmail.com - www.phdernegi.org.tr/

UKRAINE



Pulmonary Hypertension Ukrainian Rare Disease Association-PH URDA
Furmanska, Street 14 - Lviv, 5
o_kulish@inbox.ru



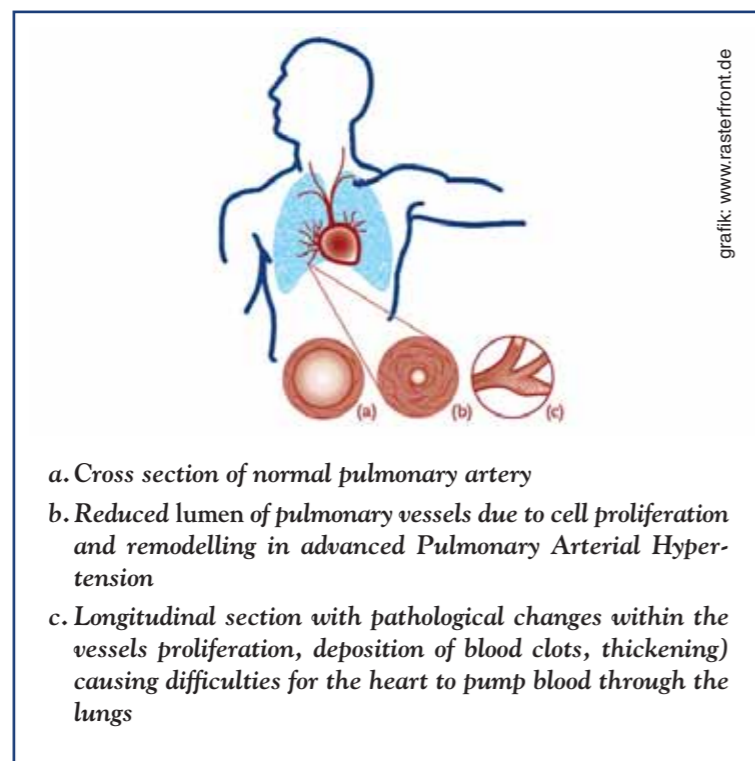
Ukraine Association of Patients with Pulmonary Hypertension
Panasa Myrnoho str.,14 (litera A)
01011, Kiev
www.pha.org.ua - info@pha.org.ua

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 is 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.



Gerald Fischer, CEO - Wilhelmstrasse, 19 - 1120 Vienna
ph +43 | 4023725 - mob +43 6642288888 - fax +43 | 4093528
g.fischer@phaeurope.org - info@phaeurope.org

Pisana Ferrari, COO - Via G.Vigoni, 8 - 20122 Milano
mob. +39 329 9214217
p.ferrari@phaeurope.org

www.phaeurope.org