



PULMONARY HYPERTENSION
Mariposa Journal

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



Editors memo Winter 2016 edition

- Austria
- Belarus
- Belgium
- Bosnia and Herzegovina
- Bulgaria
- Croatia
- Czech Republic
- Denmark
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Israel
- Italy
- Latvia
- Lithuania
- Netherlands
- Norway
- Poland
- Portugal
- Republic of Macedonia
- Romania
- Russia
- Serbia
- Slovakia
- Slovenia
- Spain
- Sweden
- Switzerland
- Turkey
- Ukraine

Dear members, friends and supporters,

The year has just come to an end and we are very proud to present a summary of PHA Europe's main activities and achievements in 2016 in this edition of the *Mariposa Journal*. It has been another very productive year for PHA Europe and its members, with many successful awareness and advocacy initiatives, conducted both at European and national levels. We are also delighted to have been able to reach out to pulmonary hypertension (PH) patients in countries where no patient associations previously existed. As a result of our encouragement and support, the European PH community is continuing to expand!

Raising Awareness

Despite notable progress in terms of new treatments and ongoing research, PH is still a little known disease which leads to late diagnosis for many who have it (a correct diagnosis can take up to 2-3 years). Consequently, raising awareness is a very important part of our mission and is instrumental in raising the profile of the disease, both in the general population and in the medical community.

PHA Europe's main awareness activity revolves around the annual celebrations for World Pulmonary Hypertension Day (WPHD), now in its fifth year. Forty-seven PH patient associations (up from 40 last year, 30 of which are in Europe), across five continents took part in the campaign. The events organised by PHA Europe's member associations as part of WPHD were very successful in drawing media attention and gaining the support of influential public figures, politicians and celebrities. Media coverage was again excellent and the WPHD campaign generated an impressive 218 press and online articles, 106 TV broadcasts and 20 radio broadcasts, reaching potentially millions of people. The online social media campaign for WPHD conducted through the "Thunderclap" platform which reached over three million people; our website saw a high rise in engagement between April and July, including over 6.000 visitors seeking information. The PHA Europe Facebook page also showed impressive results, with content reaching over half a million people.

Advocacy

Advocacy is one of PHA Europe's key activities and vital to driving change in health policies both

at the national and EU levels. The main focus of our advocacy activities is on access to treatment and surgery as these are critical issues for many of our patients across Europe. Not all approved PH drugs are available in all countries across Europe and there are countries where patients do not have access to any drugs at all or to expert centres/surgical facilities. We are also active in advocacy activities aimed at improving the quality of life, specifically, psychosocial support, for patients that the purely medical approach does not address.

Our activities in the advocacy area have a two-pronged approach: the particular, which is specifically focused on PH and related issues, and the more general sphere, involving cooperation with other organisations to influence the European legal framework concerning public health.

At the PH level, we actively support the advocacy activities of our member associations with respect to patient's needs and rights.

Our cooperative relations' work includes the participation in activities organised by scientific societies, mainly the European Society of Cardiology (ESC) and the European Respiratory Society (ERS). PHA Europe is active in the European Lung Foundation (ELF) of the ERS and a member of our staff is sitting on the ELF Council. Recent activities initiated by our Council member include the creation of an Advocacy Working Group, which will further strengthen the work of patient organisations and an International Patient Advisory Council, which will increase cooperation with patient organisations around the world.

PHA Europe also cooperates very actively with the main public health European NGOs: we are members of the Board of the European Patients' Forum (EPF) and sit on the Drug Information Transparency and Access (DITA) task force of EURORDIS, the European Organisation for Rare Diseases. With and through these organisations we cooperate on issues such as the standardisation of Health Technology Assessment and the implementation of the Cross-Border Health Care Directive, which advances the empowerment of patients across Europe. A number of meetings with these organisations have taken place over the year. We also work with the EU institutions, specifically Members of the EU Parliament (MEP's) and officials of the EU Commission.

Our main advocacy activity with the EU institutions this year has been an event on Organ Donation and Transplant in the European Parliament in

Brussels (October 18), hosted by three MEP's, with the participation of a very prestigious panel of speakers, including the MEPs themselves, a very high-ranking official of the EU Commission, the Directors of the Spanish and UK Organ Donation and Transplant national authorities and the representatives of the European federations for liver, heart, kidney and lung diseases. This event followed up on a cross-condition "Call to Action to Improve Organ Donation and Transplant in the EU", launched by PHA Europe in 2015 and endorsed by over 90 organisations at national and international level. PHA's Europe's collaboration with patient federations for diseases affecting other organs has opened up possibilities for greater visibility, wider reach and more political influence. The European Parliament event had an excellent media coverage, with an estimated potential reach of over 78 million. A number of follow up activities are planned for 2017.

Information and Education

PHA Europe is active in the areas of information and education through our journal, *Mariposa*, our website, Facebook and Twitter accounts and the educational and training sessions we hold at the Annual PH European Conference, which are led by internationally recognised experts. Our staff and representatives of our member associations attend scientific congresses, workshops and other public events as participants and/or speakers. This year members of the Board and Staff of PHA Europe took part in over forty such events, where they were able to bring the views and provide patients' insights on topics of importance to us.

Another important information channel is the PH Library (a project developed in collaboration with PHA US), which recently celebrated its first anniversary since launch. The PH Library hosts over 200 patient group resources from around the world in 24 different languages. In just one year the website had over almost 40.000 visits, with 34.000 unique visitors and 55.000 page views, a great result in terms of the dissemination of reliable and timely information concerning PH across the world.

Capacity Building

PHA Europe's ultimate goal is to set in place a European PH community consisting of empowered national patient associations working together to achieve common objectives. To further these aims PHA Europe's "White Spots" program provides start up funds and guidance for new associations and our Fellowship program provides an opportunity for member associations to apply for a paid part-time English-speaking assistant, who can not only help overcome language barriers, but also support to the association in its full range of activities at the national level. In 2016 we provided Fellows to twenty of our member associations.

We also sponsor educational and training opportunities for PH patient leaders through various channels, including the Annual European PH Conference in Barcelona. Our 2016 conference featured sessions on the current treatments and therapies in the pipeline, surgical options, research, paediatric PH, cross-border health, fundraising, advocacy and much more.

The year ended on a very positive note with the news of the official approval of the European Reference Network (ERN) for Rare Lung Diseases, ERN-LUNG, set up by the EU COMMISSION as mandated by EU legislation on rare diseases and cross-border health. ERNs will provide a unique opportunity for clinicians to work across borders in Europe to tackle the challenge of organising care for the scattered patient populations across Europe afflicted by various rare pulmonary conditions. PHA Europe will be actively involved in the work of the ERN-LUNG with two officially designated members serving on the ERN-LUNG European Patient Advocacy Group (ePAG) and one member serving on the core network. We are invited to the launch meeting in Vilnius, Lithuania, in March 2017 and look forward to working on this exciting new project.

We believe that through our active engagement in the areas described above PHA Europe has contributed to some extent to improving conditions for PH patients in Europe. At the same time we are cognizant that we are still far from having achieved our objectives. Until minimal standards of care are met in all countries, across Europe, our collective efforts must continue.

To conclude, we warmly thank our member associations for their enthusiastic participation in our common activities as well as to the other patient associations/federations we have worked with in our EU advocacy activities. We are grateful to our industry partners for their valuable support and look forward to another year of fruitful collaboration.

Pisana Ferrari, CEO PHA Europe

CONTENTS

• In 2016 PHA Europe was present at...	p. 04
• Annual PH European Conference	p. 08
• European Parliament event on Organ Donation and transplant	p. 14
• Collaborative educational projects: PH Library, PAH Diary and Time Matters	p. 18
• News from European PH Associations: <i>Austria, Belgium-HTAP, Belgium-VZW, Bosnia and Herzegovina, Bulgaria-BSPPH, Bulgaria-APH, Croatia, Czech Republic, Estonia, France, Germany, Greece, Hungary, Ireland, Israel, Italy-AIPI, Italy-AMIP, Latvia, the Netherlands, Norway, Poland, Portugal, Republic of Macedonia, Romania, Serbia, Slovakia, Slovenia, Spain-ANHP, Spain-FCHP, Spain-HPE, Switzerland-SPHV, Sweden, Ukraine-Sister Dalila, Ukraine PHA</i>	p. 20
• News from PH Associations Around the world: <i>Latin America, USA</i>	p. 60
• Update On PH treatments and research	p. 61
• Upcoming events in 2016	p. 62
• About PHA Europe and PH	p. 63
• Members of PHA Europe and contact details	p. 64

JANUARY

Brussels (Belgium), January 19

PATIENT ACCESS PARTNERSHIP (PACT)

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

Geneva (Switzerland), January 28

EUROPEAN LUNG FOUNDATION (ELF)

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

FEBRUARY

Amman (Jordan), February 3-7

ANNUAL PH CONFERENCE OF THE SAUDI PH ASSOCIATION

Lecture on “PH from the patient perspective” - *Pisana Ferrari*

Brussels (Belgium), February 24-25

MULTI-STAKEHOLDER SYMPOSIUM

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

Kiev (Ukraine), February 29

RARE DISEASE DAY CONFERENCE ON EU EVOLUTION IN RARE DISEASES LEGISLATION

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



MARCH

Brussels (Belgium), March 21-23

EUROPEAN PATIENTS FORUM (EPF) GENERAL ASSEMBLY

Juan Fuertes ran for the elections and became a Board Member with a 2 year mandate.

APRIL

Brussels (Belgium), April 7

EUROPEAN REFERENCE NETWORK (ERN) LUNG

Core coordination meeting in Brussels - *Juan Fuertes*



Dublin (Ireland), April 14-17

PHA IRELAND ANNUAL PATIENT MEETING

Hall Skaara participated in PHA Ireland’s annual patient meeting. He ran two presentations covering lifestyle and exercise in PH patients.

Zurich (Switzerland), April 21

ELF COUNCIL MEETING

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

Zurich (Switzerland), April 22

EUROPEAN RESPIRATORY SOCIETY (ERS) SPRING MEETING AND EUROPEAN LUNG FOUNDATION (ELF) COUNCIL MEETING

- *Juan Fuertes*

Rome (Italy), April 22-23

EUROPEAN SOCIETY FOR ORGAN TRANSPLANT (ESOT) ANNUAL CONGRESS

Attendance at ESOT Annual Congress Transplant Congress - *Juan Fuertes*

MAY

Buenos Aires (Argentina), May 4-5

CELEBRATIONS FOR WORLD PH DAY

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

MAY

Düsseldorf (Germany), May 11

WORKING GROUP ON ACCESS OF THE EUROPEAN PATIENTS FORUM (EPF)

- *Juan Fuertes*.

L'viv (Ukraine), May 12

ROUND TABLE ON TRANSPLANT

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

Namur (Belgium), May 20

9ème JOURNÉE DU PARTENARIAT

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

Edinburg, May 22

EUROPEAN CONFERENCE ON RARE DISEASES (ECRD)

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



Amsterdam (the Netherlands), May 27

ROUND TABLE OF THE EUROPEAN SOCIETY OF CARDIOLOGY (ESC)

Juan Fuertes attended the Round Table of the ESC and made a presentation on the sustainability of healthcare.

Brussels (Belgium), May 30

MEDICINES FOR EUROPE

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

JUNE

Varna (Bulgaria), June 8-10

ANNUAL CONGRESS OF THE BULGARIAN SOCIETY FOR RESPIRATORY MEDICINE

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

Vienna (Austria), June 9

EUROPEAN PATIENTS FORUM (EPF) BOARD MEETING

- *Juan Fuertes*.

Lisbon (Portugal), June 13-14

EUROPEAN RESPIRATORY SOCIETY (ERS) PRESIDENTIAL SUMMIT

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

Madrid (Spain), June 17

FIRST CONGRESS ON PATIENTS EXPERIENCE

Organized by the “Spanish Institute for Patients’ Experience”. Juan Fuertes made a presentation on the role and need of empowerment of patients’ organizations in advocacy.



Dallas, June 17-19

PHA INTERNATIONAL CONFERENCE

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

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

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

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

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

Rome (Italy), August 27-30
EUROPEAN SOCIETY OF CARDIOLOGY (ESC) ANNUAL CONGRESS

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

London (United Kingdom), September 3-6
EUROPEAN RESPIRATORY SOCIETY (ERS) ANNUAL CONGRESS

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



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

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



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

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

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

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



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

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

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

Meeting organised by Members of European Parliament Jakovic, Vautmans, Tomc and Peterle on the initiative of PHA Europe and as a follow up to the “Call to Action on ODT” launched in 2015 - Pisana Ferrari and Juan Fuertes attended.



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

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

Juan Fuertes attended this annual training session organised by EURORDIS

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



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

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

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

Pisana Ferrari invited to speak on “PAH and the patient perspective”.



Lisbon (Portugal), November 23
HEALTH CLUSTER CONFERENCE

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



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

Juan Fuertes attended as Member of the Board.

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

Presentation of “Health at a Glance”, meeting attended by Juan Fuertes.

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

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



Basel (Switzerland), November 29
“DRUG DISCOVERY DAY”

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



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

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

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

Juan Fuertes made a presentation on Patient Advocacy.

Annual PH European Conference

Barcelona, September 15-18, 2016

The Annual PH European Conference (APHEC) 2016 took place from September 14 to 18 in Castelldefels, near Barcelona (Spain). This wonderful venue, in a small hotel situated in a charming village by the sea near Barcelona somehow feels like “home” to very many of us as we have been coming here since 2010. We have unfortunately “outgrown” our hotel and many had to stay in a nearby one, but at the same time we were delighted that the turnout was so good and that the community is expanding, with new countries attending. This year we welcomed patients from three countries which currently do not have an association yet: Estonia, Cyprus and Kosovo. With our help and support we hope they will be able to start one in their countries in the near future. In total we had 63 PH Patient Leaders from 30 countries attending. And yet again we were very privileged to have a great panel of speakers which included three leading KOLs in the field of PH.

Annual General Assembly

Traditionally the APHEC opens with a speech from the President, followed by the the annual general assembly (AGM). After Luc Matthysen’s speech there was a brief round of introductions of the participants and a warm welcome was extended to the newcomers, the patient representatives from Cyprus, Estonia and Kosovo. The AGM approved the 2015 financial report, presented by the immediate Past President Gerald Fischer and the membership application received from the PH association of Serbia.

Medical guest speakers

This year our guest medical speakers were Professors Irene Lang from Austria, Marc Humbert from France and Maurice Beghetti from Switzerland. Marc Humbert has played a key role in the setting up of the European Reference Network (ERN) for rare lung diseases, ERN-LUNG and this was the topic of his talk. Marc Humbert is the Network Vice Coordinator of the Medical Steering Committee for ERN-LUNG (Coordinator is Thomas Wagner, Frankfurt, Germany). This initiative goes back a few years: developing Centres of Expertise and ERNs in the field of rare diseases was proposed in the Council Recommendation on an Action in the Field of Rare Diseases (2009) and, more recently, in the Cross-Border Healthcare Directive (2011), as a means of organising care for the thousands of heterogeneous rare conditions affecting scattered patient populations across Europe. From 2017, ERNs will be created as legal entities by the European Union. They will provide for the first time a unique opportunity for clinicians to work across borders in Europe in healthcare in order to tackle this challenge. This is a very important development for the PH community as ERN-LUNG will have a section dedicated to PAH and PHA Europe will

play an official role in its work. The very complex and strict approval procedure was still being carried out at the time of the APHEC so Marc Humbert could not confirm yet that ERN-LUNG would be accepted: we were delighted to receive the announcement of its approval on December 15, just in time for the news to be included in this journal!

Irene Lang’s very interesting, comprehensive and clear presentation reviewed progress in PAH over the past years, analysing the current and future possible treatment options and treatment strategies for PAH as well as CTEPH. She spoke also of the new new and promising technique called “balloon pulmonary angioplasty” (BPA), an alternative interventional strategy for CTEPH patients who are inoperable (cannot undergo pulmonary endarterectomy - PEA) or have residual PH post surgery. Over the last several years, Japanese investigators have gained a lot of experience in the use of BPA in CTEPH patients and have gradually refined the interventional technique for this procedure which is now increasingly being used worldwide with very good results.

It was also a great pleasure to welcome Maurice Beghetti and to hear his talk about paediatric PH, a topic which had never before been discussed at our annual conferences. Maurice is an active member of the Board of the Association for Paediatric PH (PePH), founded in 2007 (www.peph-association.org) with the mission of conducting epidemiological research on PH in children and adolescents. In order to reach this goal, the association has established a disease registry, called TOPP (“Tracking Outcomes and Practice in Paediatric Pulmonary Hypertension”). This is a world wide registry which has generated significant information on paediatric PH. In July 2015, the first phase of the registry closed after including 699 patients, of which over 50% were newly diagnosed. Data from TOPP have been successfully published and the second generation of the registry, named TOPP2 is already on the way. The PePH is interested in exploring possible future collaboration with PHA Europe on paediatric PH and we of course would very much welcome this and look forward to future developments.

Training sessions

The APHEC traditionally includes in its agenda training sessions on different topics. Ieva Plume, Member of the PHA Europe Board (Secretary) gave an excellent talk on the “Art of presentation”, with many tips for successful public speaking, including how to prepare, things to avoid, “hooks” to keep the attention of the audience up and useful links for further reading. The second session was about the use of “mascots” in raising awareness of PH. The perfect example of the successful use of mascots is Pongo, the rare purple baby elephant with only one nostril, who cannot breathe well, created by Ioanna Aliysandratou, President of the Greek PH associ-







ation. Pongo has become quite a celebrity in Greece and has traveled all over, including to the US for the PHA Conference and has been used in a number of public events and as an educational tool in public schools. A book with Pongo's story has recently been published in Greek and further activities are planned, including translations into other languages, as requested by many of the participants at the APHEC. Finally, Gerry Fischer have a very inspirational presentation about fundraising where he presented examples of successful events he has organised for PHA Austria (the annual Zoo Run at Schoenbrunn, the oldest zoo in Europe, the Ghost Run for Halloween, and many more) which can easily be reproduced in other countries and for which he is willing to provide support and guidance. The idea came up just after the session to develop a guide (in collaboration with Hall Skaara) for the members, to provide practical organisational advice.

Industry partner session

As in past years, a session was set aside to meet with our industry partners, to hear about future research and other projects, including collaborative educational ones. We were delighted to have representatives of Actelion, Bayer, Bellerephon (a new player in the field), 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.

A special guest from Latin America

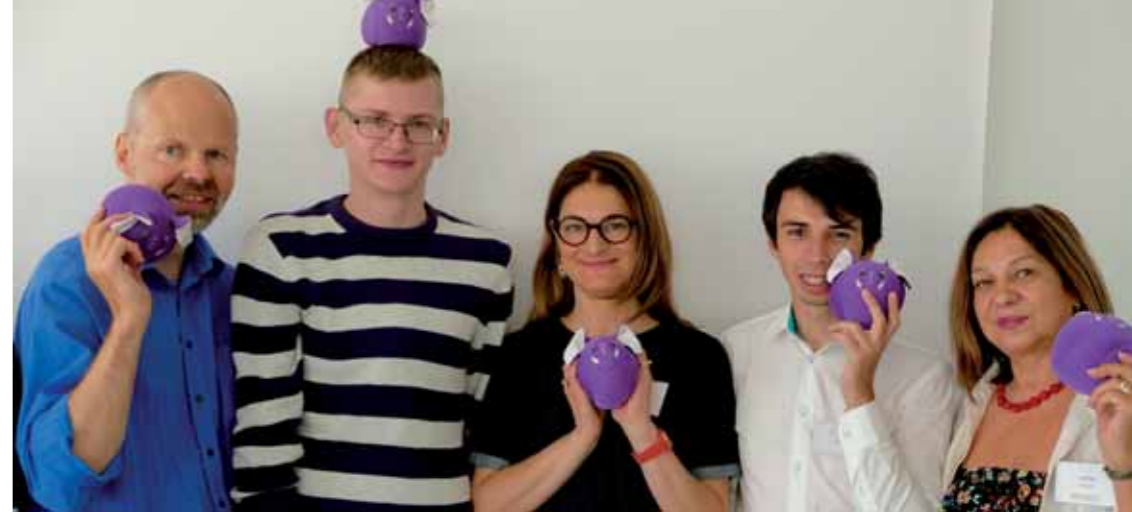
At this year's APHEC we had the great privilege of welcoming Migdalia Denis as a guest speaker. Migdalia is a PH patient herself, she lives in Miami, Florida (USA). Migdalia is Founder of the Venezuelan Society of Pulmonary Hypertension and of the Pulmonary Hypertension Latin Society, founder and leader of the support group for PH patients living in South Florida and Board member of IAPO, the International Association of Patient Organizations, where she represents Latin-America. She is author and co-author of many articles published in science magazines about the advances for PH in Latin America and is Life Coach and leader at many motivational conferences and other events. In her excellent talk she presented the activities of the PH Latin Society and the dramatic challenges PH patient face in some Latin American countries where no drugs or surgery are available.

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 this year went to Serbia, the second to the Republic of Macedonia and third to the Ukrainian Sister Dalila Foundation.

As always some time was set aside for relaxing, talking and just enjoying each others company. It was yet another wonderful PH family gathering!

*Pisana Ferrari
PHA Europe*



EUROPEAN PARLIAMENT EVENT ON ORGAN DONATION AND TRANSPLANT

Brussels, October 18, 2016

Introduction

The highlight of PHA Europe's EU advocacy activities during 2016 was the event organised in the EUROPEAN PARLIAMENT on October 18, hosted by Members of the European Parliament (MEPs) Jakovcic, Vautmans, Tomc and Peterle. Background to this event was our global, cross-condition "Call to Action to improve Organ Donation and Transplant across the EU" launched by PHA Europe on European Organ Donation Day 2015. The Call to Action was endorsed by over 90 national and international organisations and, as part of the campaign, PHA Europe organised contact programmes in Brussels with MEPs, EU officials and other relevant stakeholders, developed a dedicated section of its website with suggestions on how to promote the Call, produced infographics, a video with transplant testimonials and other materials, posted and shared contents on social media and ran a very successful online Thunderclap campaign.

PHA Europe is very grateful to all those who made the event possible, in particular the hosting MEPs and is proud that it featured an impressive panel of speakers including Mr Stefaan van der Spiegel (Team Leader, Substances of Human Origin,

DG Santé, EUROPEAN COMMISSION), the Directors of the Spanish and UK Organ Donation and Transplant national authorities, Dr. Rafael Matesanz and Ms Sally Johnson and representatives of the European patient associations for liver, (ELPA) kidney (EKHA, EKPF) lung (CFE, ECC) and heart diseases (To Transplant and Beyond). The meeting was extremely well attended, discussions were lively and interesting and there was a general consensus on the need to increase cooperation and take some follow-up action in 2017. The event was promoted internally in the European Parliament as well as externally by means of a professional communications agency and the press materials were picked up by almost 70 media outlets across 16 countries (40 in Europe alone) with an estimated potential reach of 78 million people globally.

Aims of the European Parliament event

The event aimed to provide insight on questions such as:

- Does the regulatory framework (opt-in/opt-out) correlate with numbers of organ donors and transplants?
- How important is the role of new technologies in

transplant surgery?

- What are the main challenges in the coordination and logistics around transplant surgery?
- How can access to transplant be made available to patients in countries where there are no or limited surgery facilities?
- How can the delicate issue of family refusals be addressed?
- What are the possible future developments in this field that could improve the number of organ donors and transplants?

All of these issues were touched upon in the course of the discussions and it was agreed that there is no one single factor that can improve the current dramatic shortage of organs. The meeting agenda addressed three main areas: regulatory, logistics and awareness. These sessions were chaired by three hosting MEPs.

Position of the the Members of the European Parliament

In their introductions to the sessions, MEPs Jakovcic, Vautmans and Peterle expressed a strong interest in the issue of ODT, stressing how this is a major public health challenge that requires more attention. MEP Ivan Jakovcic took the initiative earlier in 2016 to launch a Written Declaration on ODT. He underlined that at the end of 2015 there were 59.000 people waiting for a transplant across the EU and that on average, 16 people die every day while waiting. His country, Croatia, is small, but the Croatian National Donor Network (DNC) has made a huge difference; the country is now amongst the leading countries in terms of number of donors per million people (i.e. 54). The DNC was represented at the meeting by Dr. Nikola Zgrablic, personally invited by MEP Jakovcic. The DNC's most well-known product is the organ donor card. This is not legally binding but serves as promotional material, a tool to provoke and launch discussions among family members. And, of course, it also shows a person's willingness to donate organs after death. One million copies of the card have been issued over the last 20 years. Famous politicians, athletes and others have been asked to sign their cards in public. MEP Alojz Peterle said that while the EU remit in the field is limited, current inequalities in public health are unacceptable and many MEPs are speaking in favour of a more favourable interpretation of the Treaty. MEP Hilde Vautmans has a personal interest in illegal organ trafficking as a member of her family has been a victim. She stressed that in some countries ODT systems work better than others and there is much potential for sharing of best practices. The three MEPs all expressed their support for the Call to Action and are open to future collaboration with PHA Europe and other stakeholders on ODT.

EU Commission DG SANTE

Stefaan van de Spiegel (Team Leader of Substances of Human Origin) addressed the regulatory aspects of ODT,



stressing the limited EU level competence in the field of health. The EU's role is to complement national policies, foster cooperation between the Member States and third countries. However, in the field of organ donation, the EU Treaty does call for setting "measures setting high standards of quality and safety of organs and substances of human origin, blood and blood derivatives". Therefore, the Commission has come forward with a Directive on safety and quality of organs, in 2010. Consequently it adopted a Directive to support organ exchange between Member States (2012) and an EU Organs Action Plan (which ended in 2015 and is currently under evaluation). Despite its limited remit the Commission is actively supporting ODT and fostering cooperation in many ways, e.g. financing EUROTRANSPLANT, which coordinates transplant in several countries across Europe, the FOEDUS Joint Action, which connects the organ allocation offices in different countries and pilot projects on chronic Kidney Diseases (supported by Karin Kadenbach MEP) and on social awareness on organ donation entitled EUDONORGA (supported by Gabriel Mato MEP). Mr van der Spiegel said there were reasons to be optimistic as despite everything overall donation rates are going up and there is still potential to learn from each other to improve rates.

National Transplant Societies

Rafael Matesanz presented the "Spanish model", an integrated approach where the focus is on organisation, logistics and training of all those involved in ODT, from A&E doctors to transplant coordinators to the persons who reach out to the families at the moment of passing of their loved ones. Since 1992, Spain has consistently been the country in Europe with the highest number of organ donors (40,2 per million). Some 190 transplant coordination teams are operational in Spain, with 270 medical doctors (part-time or full-time) and 168 nurses (part-time/full-time); a specific organisation focuses on coordinating the coordinators.



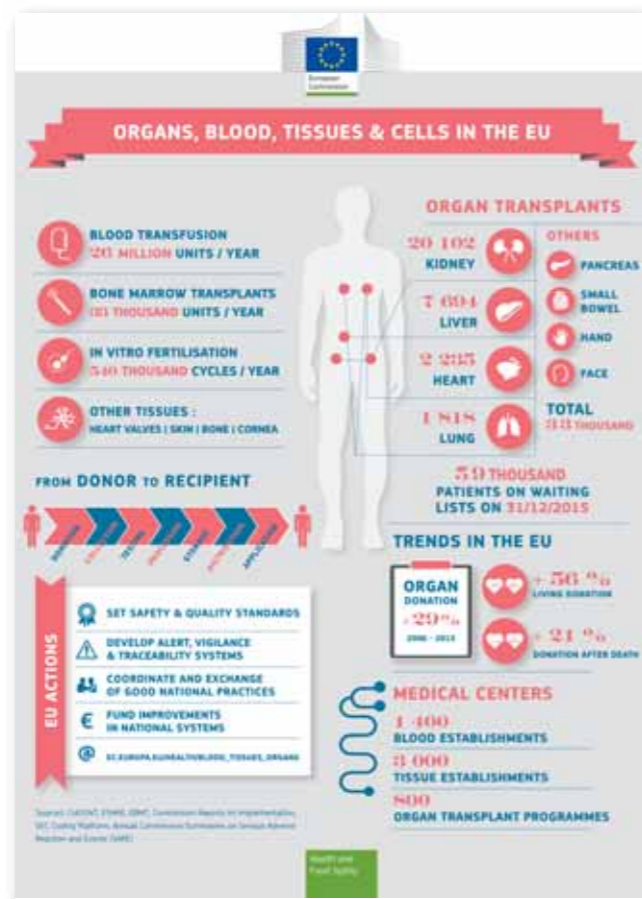
Over 17.000 health professionals have received training including ICU and A&E doctors. As the most effective coordinators probably are intensive care specialists, 1000 of these young specialists have been trained in organ donation over the last 9 years. Dr Matesanz concluded by saying that the key success factors are always the same: trained health professionals and good organisation. He said that it is not fair to blame the population: “if people donate less, it must be something we have done wrong”.

Sally Johnson (National Health Service, UK), provided information on some of the promotional activities undertaken by her organisation to increase awareness of the importance and practicalities of ODT and increase the number of donors. Between 2008 and 2013, an ODT Taskforce was active, focusing on the reorganisation of donation and retrieval services. During that period, the number of donors increased by 50%; however, the transplant numbers only grew by 31%. In other words, there was a need to focus on transplants, not just on donors. Consent was an issue, especially in some communities (black and Asian). This is why the campaign “Taking ODT to 2020” came into being, with the aim to match best performance. An NHS Organ Donor Register was developed which allows people to record a decision about donation. Currently 22.5 million people have recorded their consent; 180.000 have recorded a refusal. A Public Behaviour Strategy was also part of the initiative, with the mission to get families to consent to organ donation on behalf of their loved ones. The objective is to increase the number of people on the Organ Donor Register (ODR) by 50% by 2020, to stimulate conversations and debate about donation, using the ODR as a marketing tool and to present donation as a benefit to families in end-of-life and grieving process.

Patient representatives

The representatives of the four disease areas (heart, lung, liver and kidney) emphasised the importance of ODT in their respective disease areas.

Hilde De Keyser, Coordinator, Cystic Fibrosis Europe (CFE), stated that there are some 40.000 CF patients across Europe.



While management of the condition has improved over the last decades, it is difficult to understand the huge differences in life expectancy between the member states. She stressed that there is a clear lack of awareness of the importance of ODT. As a single patient advocacy organisation, CFE is not in a position to change the situation. However, the organisation can take strong positions and support political initiatives such as the PHA Europe Call to Action as well as practical actions such as EUROTRANSPLANT, which should be expanded. Ms De Keyser also emphasised that more can be achieved in awareness and education if organisations are ready to move forward together.

Angelika Widhalm, Member of the Board of the European Liver Patient Association (ELPA), a liver recipient herself, underlined the importance of organ donation and transplant as this is - in many cases - the only chance to get a new life. One of the barriers to action is the lack of information with respect to registration of patients and waiting list. Awareness campaigns could stimulate progress. There should also be more transparency with respect to surgeons, facilities and choice. The Cross-border Regulation on Patients' Access to Healthcare should be changed so that patients can have access to organs across the border. Mrs. Widhalm called on the MEPs present to support this view and take practical action.

Raymond Vanholder, Chairman of the European Kidney Health Alliance (EKHA) stated that most kidney patients who progress to the end stage come to a point where there is a choice to be made between dialysis and transplantation. In making the choice between dialysis and transplantation, the reimbursement policy of their country may be an issue; in some countries, there is not sufficient financial incentive to default towards transplantation as the preferred option. In the future, he considered as a potential solution that that reimbursement would be aligned for whatever action is taken, once a patient reaches an advanced stage of chronic kidney disease. He also stressed the lack of awareness of both patients as well as the general public about the full benefits of transplant both to the individual and to society. In addition, cultural differences between countries need to be taken into account: some



countries have relatively high rates of living donation whereas others have high rates of cadaveric donation. Efforts must be made to improve awareness and acceptance of both options.

John Fisher, Chairman of “To Transplant and Beyond” talked about his heart transplant, now 16 years ago. His focus was on the donor - in many cases, the donor’s family can stop donation. This goes against the wishes of the donor, and therefore, the rights of the donor should be protected and their wishes should be respected. Unfortunately the existing donor card is not legal - however, it clearly indicates the wish and intention of the donor. In some cases, donation can actually support those who stay behind. In John’s case, his donor saved the lives of 5 people and gave a meaning to the loss of the family member. Are there ways to ensure that the donor’s wishes are respected?

Conclusions

Bringing the meeting to a close, Catherine Hartmann, Secretary General of the COPD Coalition and Vice President of EPHA, first briefly introduced COPD as a chronic non-curable lung disease, affecting some 10% of adult population in the EU. She said that in this field one country in need must be able to seek help and organs from another EU country. ODT is a perfect example of the added-value of being part of the EU, where competences and organs can be shared. The EU has a tremendous role to play in facilitating and supporting exchange of knowledge and expertise, donations at EU level and raising awareness on organ



donation and transplant. She said that Eurotransplant and Scandiatransplant are useful initiatives but too few countries are members of these networks. Spain and Croatia provide examples of what works: training, involvement of critical healthcare professionals and good organisation.

Mrs. Hartmann called on the EU to support the three A’s in organ donation and transplant: Awareness, Availability and Accessibility - which entails more information at national and pan-European levels on organ donation via communication campaigns, supporting ‘opting-out’ systems where the family consent is fully taken into account, sharing information on availability of organs across the EU through IT tools and on-line platforms much more developed than what exists presently and enhanced training of healthcare professionals. She stressed that it is important that representatives of diseases or specific organs work together to improve the conditions of those suffering from a failing organ, and put forward common solutions to address these issues. It is hoped therefore that more associations join the Call to Action and the campaign.



Follow up activities

PHA Europe looks forward to working together with the other federations involved in the EP event. A first meeting is scheduled in Brussels on January 17 2017 with representatives of the lung, liver and kidney disease European federations (EKHA, EKPF, ELPA, CFE, ECC), to discuss possible common future initiatives to improve organ donation and transplant across the EU.

Pisana Ferrari
PHA Europe



Collaborative educational projects: PH Library, PAH Diary and Time Matters

PH Library

September 2016 marked the one year anniversary of “Our PH Library”, home to over 200 PH resources developed by patient groups from all over the world, across 24 different languages. The website, developed as part of a joint collaboration with PHA (US), was launched on Friday 18 September 2015 at our annual PH conference in Barcelona and in the first month alone received an impressive 1.000 visitors. Now, one year older, the website continues to be seen as a valuable tool among the PH community, with visitors from far and wide across Europe, the Americas, Australasia and the Middle East. To provide a snapshot of the success of the Library, we have developed an infographic to highlight the key website statistics from September 2015-September 2016. As you can see there have been over 38.000 website visits, with 34.000 unique visitors and 55.000 pages views. An amazing result for which we also warmly thank Actelion Pharmaceuticals Ltd for its support! It is now important that we keep the library up to date with any new resources that patient associations around the world have developed. If you have developed any new resources in 2016 that you would like included in the Index of Resources page, please contact me at p.ferrari@phaeurope.org with the

details. To continue to drive traffic to the website, we encourage you also to share information about and a link to www.OurPHLibrary.com on your websites and in communication to new members.

If you would like further information about raising awareness of the website and how to add your materials, please download the how to guide from <http://www.phaeurope.org/wp-content/>, which also includes resources for disseminating such as a website/signature banner.



What is truly special about this diary is that each weekly page includes an inspirational quote/tip shared by people living with PAH around the world. Many thanks to all those of you who contributed a personal piece of advice or uplifting thought to the diary – its a wonderful example of our role as mentors to others living with PAH and if we can inspire one more person to more actively self-manage, then we should feel very proud of ourselves!

We have sent 10 copies of the diary to each of the PHA Europe members. If you would like to receive additional copies, please contact me.



PAHuman Diary

We are delighted to have received and shared with all our members copies of the new PAHuman 2017 Diary, developed by Actelion Pharmaceuticals Ltd. The diary is one of the results of work carried out by Actelion in collaboration with patient groups such as ours, to support self-management of the disease. The term self-management or self-care is intended as helping oneself as much as one can with your condition and making the most of the appointments with one's specialist healthcare team. Research has shown that when patients are active in their own care they have better outcomes, so its important that as patient group leaders, we share our tips and tricks on how to manage the condition day-to-day to educate and motivate others to support their overall wellbeing.

Why was the diary developed?

A survey, shared by the PHA Europe member associations and answered by members, demonstrated that 71% of people living with PAH would like to play a more active role in their care. One of the highest rated ideas for a tool to support self-management was a diary that allowed the user to track how they are feeling, write down their goals and daily to-do list, and keep note of things to speak to their doctor or nurse about. Stories from other people living with PAH and their carers were also ranked highly.

What is the purpose of the diary?

The PAHuman 2017 diary allows people living with PAH to:

- Keep track of their personal goals including exercise, diet and social activities
- Record how they are feeling, their appointments and daily to-do list
- Write down questions for their healthcare team in the simple notes pages, so all of their questions and answers are stored in one place
- Log all their important contact information easily
- Find information about other useful PAH resources

Time Matters



PHA Europe's “Time Matters” campaign was launched in 2012 in order to raise awareness of the importance of the “time” element in the diagnosis and treatment of patients with PH. Patients, caregivers and HCPs were invited to share their hopes for the future and give their advice to other people whose lives were affected by PH. This project was supported by Bayer Healthcare, whom we are very grateful to. Over 150 people from 30 countries have shared their hopes and dreams with the community, making a great contribution to awareness of the condition.

Redesign and relaunch of Time matters

Over the past few years there have been significant developments in the treatment of PH: new drugs, new treatment strategies, including combination therapy, and improved surgery techniques, eg. lung transplant (LTX) and pulmonary endarterectomy (PEA). Despite these progresses, the level of awareness of PH is still far from optimal, even among members of the medical profession, and it can still take up to 2-3 years for a correct diagnosis and initiation of treatment. Now, PHA Europe is relaunching the “TimeMatters” campaign among the PH community in order to encourage discussions and debate across the PH community in Europe, in particular through social media, on the different aspects of time, in order to

address this gap and raise the profile of the disease further! The new Facebook campaign started in December with a “Time Matters” month on the theme “The time it takes for people to realise I have PH”, in four different countries: Austria, Israel, Portugal and Serbia. It will end in June 2016. Each of the PH associations in these countries has produced videos, posted contents and encouraged discussions and debate on the monthly theme on their national FB pages. These will now be summarised and shared through the PHA Europe FB page to its 8.000+ followers to further spread the awareness.



AUSTRIA

- In past months PH Austria has organized **patient meetings** with leading PH experts in Vienna, Salzburg, Graz, Linz as well as “Get together” meetings in Vienna, Innsbruck and Linz, the latter with a private theatre performance. The PH meetings are attended by 80 to 100 patients. The Get together meetings are attended by 40 to 60 patients.
- **New booklet:** after more than a year’s work, PH Austria’s Vice President and COO Eva Otter finalized her Patient Social Guide, which illustrates all the possible social support opportunities for PH patients in Austria.
- Eva has an **Info Desk** during the PH Clinic Day on Tuesdays in the Vienna General Hospital, AKH
- **Social Rescue Fund:** PH Austria has created a national “rescue fund” for families who are in a difficult financial situation on account of PH. In past months the association provided support to two families for a total amount of € 5000.--
- **Newsletter:** Eva Otter has issued three editions of the association newsletter, the last one can be found at this link: <http://www.lungenhochdruck.at/wp-content/uploads/2016/11/Newsletter26.pdf>
- **New international contacts:** PH Austria’s President Gerry Fischer had a very nice and informative lunch with Timothy Shriver and his wife. Mr. Shriver is part of the Kennedy family, he was US ambassador in France and is now

Chairman of the Special Olympics.

- **Ghost Run:** for the second year running PHA Austria organized the Vienna Halloween Ghost Run, in the Vienna amusement park Prater. The starting line was in front of the “Jack the Ripper house” where very “ghostly” and creepy sounds helped to create a unique atmosphere. The motto of the run was: “Help us to escape the Reaper”!
- **Fundraising dinner:** this year again PH Austria was the Charity Partner of the restaurant Eisvogel in Vienna. After a great performance of Rock & Roll Hall of Fame member Andy Lee Lang, with musicians of his big band, six highly decorated chefs from different countries cooked a 6-course dinner for 235 VIP’s from different fields: business, politics, sports and art. The result was very impressive - a huge thank you to Actelion.
- **Prevenar 13 is a once-per-life vaccination** which, according to Prof. Horst Olschewski, one of the top European PH specialists, every PH patient should have. Thanks to a collaboration with Pfizer PH Austria was able to offer this expensive vaccination free of charge to all their patients.
- **Bakery:** big thank you to the staff of GSK for baking Christmas cookies for the association, which PH Austria was able to give away for donations



- **Christmas Gift’s:** this year our Christmas gifts for the patients consist of knitted cotton scarfs and hand warmers.
- **Time Matters:** PHA Austria is happy to be part of the new social media “Time Matters” awareness campaign, organized by PHA Europe. We are working on it with great motivation - #Timematters

- **Bike Team and Triathlete Testimonials:** the association’s triathlete testimonials are performing around the world wearing our suits. We also have a team of cyclists doing awareness for PH on every sport event.
- PH Austria sent out a fundraising e-mail to 30.000 addresses in Austria under the title “Blue Baby”.
- **English Website:** the association is working hard on the English version of the website, which should go online soon.



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



BELGIUM-HTAP

Patients’ association days in the hospitals

HTAP Belgique continued this year in its awareness campaign in the hospitals of the French speaking part of the country. The campaign is organized by the LUSS (Belgium Patients’ Platform) and our association has a one day presence in each hospital together with patient groups representing other diseases. The hospitals support and promote these events and give us the opportunity to have discussions with the medical teams in Pulmonology and Cardiology and with the social workers. There has also been some media coverage through interviews conducted by a local TV company.

Meetings with paramedical schools for nurses

For the first time ever HTAP Belgique participated in meetings in the paramedical schools, where it was possible to explain to students in their final year what it really means for patients to live with PH and to discuss with them what the needs of those patients are. The students were very interested and asked lots of questions in relation to their specific training. Next year, we will continue with this very interesting experience.

Patients’ meeting at Saint-Luc hospital

During this meeting patients received explanations about the latest medical treatments and the PH nurse explained how to tackle PH in day to day life. We were given the opportunity to present our association and explain all the activities we are doing. The patients could ask their questions to the medical staff.

Advocacy day at the “Retrouvilles”

During this event our association was located into the village of “Solidarity & Social live”, surrounded by regional NGO’s and mutuality companies (health insurance). We could reach



a lot of people and explain to them what PH really stands for. Next year we will have our own stand.

ERN-LUNG

This year the European Union (EU) opened up the procedure to designate European Reference Networks (ERNs) for rare diseases in Europe. ERNs are networks of medical centers and healthcare providers that are organized across borders so that clinicians and researchers can share expertise, knowledge and resources across the EU. The accreditation procedure is almost over and as of next year the ERNs will be legal entities recognized by the EU. PH will be covered by the Ern-Lung as part of rare pulmonary diseases. Patients are represented and active participants in the ERN via the European Patient Advocacy Groups (ePAGs), created by EURORDIS, the European Rare Disease Organisation. Several representatives of PHA Europe are involved in the ERN-LUNG.

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



Maleen, Otto Schwarz Actelion, UN Envoy Werner Faymann, Zoo director Dagmar Schratzer





BELGIUM-VZW

Gent annual trade fair

Thanks to PH patient Noémi (14), and her family, VZW was able to participate to the annual trade fair of Gent (East Flanders) for the second year. The fair took place between 10-18 September 2016. VZW was one of the 300 exhibitors in this fair, which consistently attracts thousands of visitors. A group of 10 volunteers were present at our stand and made this 9-day activity possible. Passers-by could stop at our stand and measure their lung capacity or have a photo taken with blue lips for our “Wall of fame”. Our “godmother” Hilde Heijnen and Koen De Poorter, actor and comedian, both very

well known Flemish personalities, paid us visit. The event was covered by the media (print, TV/radio, online media) and we had a large number of FB posts, Tweets or videos posted on YouTube.



Hendrik Ramaker,

President Patiëntenvereniging Pulmonale Hypertensie vzw
www.ph-vzw.be - <https://www.facebook.com/PHBelgium>



BOSNIA AND HERZEGOVINA



The Bosnia and Herzegovina PH association “Breath” has been busy throughout the year raising awareness about pulmonary hypertension. This is our continuing mission because awareness of the disease in our country is still at very low. To this end, our association connected with several non-governmental, non-profit associations, and worked with them to organize and participate in several activities which have attracted public attention.

Cardiology and Cancer clinic in Sarajevo

Together with volunteers from the Association “A heart full of smiles” we visited the pediatric Cardiology and Cancer Ward Clinic in Sarajevo. The main goal was to “beautify” the children’s hospital days, to cheer them, laugh and engage them with fun and games. This also gave us an opportunity to talk with patients about pulmonary hypertension.

Raising awareness across Europe and worldwide

Together with the Speleologic-scientific club “Atom”, from Zavidovici, our association implemented two ideas on how to attract attention and raise awareness about pulmonary hypertension. The first initiative took place in July. A group of young and healthy people, led by Zdenko Veljacic, a well known caver and climber, climbed to the highest peak in Europe, Mont Blanc, where they symbolically “breathed” for all patients suffering from pulmonary hypertension. The second initiative took place in August 2016, outside the borders of our continent, with Zdenko Veljacic, as a participant in the international expedition climbed to mount Kilimanjaro and, on top of this mountain, breathed for all patients suffering from pulmonary hypertension of the world.

Educational workshop

Members of our association also participated in the five-day workshop which is traditionally a joint project of the Embassy of Local Democracy and the Italian organization “Strani Vari”, whose primary purpose is the education and entertainment of children of school age. This year’s gathering and summer working with children were organized in several schools in Zavidovici. Otherwise, our members are also volunteers ALD. This was an opportunity to symbolically raise awareness of pulmonary hypertension such as animators all the duration of the workshop were in T-shirts PH Europe.

Organ Donation and Transplant

In the framework of the European Day of Organ Donation our association participated in the activities for dialysis and transplant patients of the Federation of Bosnia and Herzegovina and Sarajevo Canton and thus contributed to raising awareness about the importance of organ donation as for PH patients, and for all other.

Advocacy

In parallel with these activities, our association also reached out to all the national competent institutions in order to provide treatment for all PH patients. Unfortunately, there is a lack of understanding and a lack of interest and feedback. We will keep trying!

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





BULGARIA-BSPPH

Second European Conference on Transplantation and Physical Activity

The Second European Conference on Transplantation and Physical Activity, organized by the Council of Europe was held from 8 to 10 July in Pravets and the Bulgarian host was the Executive Agency for Transplantation. Participants in the prestigious international forum included transplantation specialists, nephrologists, cardiologists, hepatologists and patient associations. Within the forum there was a press conference, introducing the foreign guests: Dr. Bernhard Fattinger, Federal Ministry of Health, Austria and Prof. Dr. Walter Klepetko, Head of Lung transplantation program, Medical University, Vienna, Austria, Prof. Klepetko gave the floor to Natalia Maeva, Chair of BSPPH and she told her story as a patient who got a second chance at life after bilateral lung transplantation in his clinic. "It is very hard to describe the feelings towards the man who reconstructed your new lungs to size", Natalia said. "It sounds eccentric, right? Like ordering a bespoke shirt. My shirt was made by Prof. Shahrokh Taghavi. It took him around 9 hours, on March 9, 2016. For me this is the beginning of my new life, my second birthday! The Iranian with the magic hands is what I called the professor and every day of my stay in the hospital I wanted to meet his eyes. I looked at his eyes to see if there was a problem or everything is okay. My disease had taught me to get information without words, unerringly. For me it was a question of personal responsibility and I made the decision to donate my old lungs for research. I dream of the day when pulmonary hypertension will be fully curable."

This is what Prof. Klepetko said during the press conference: "When we take a lung or another organ from a donor, we take a little of that person's soul. This is the secret to Natalia's youth. I am very happy that we managed to perform this lung transplant for Natalia. I need to say that in order to do this, perfectly organized logistics is required. Also, a year ago Bulgaria and Austria signed a Cooperation treaty for organ donation and transplantation. The Bulgarian Agency for Transplantation provided us with full cooperation and we helped with what we could. In order to make lungs transplants for Bulgarians a regular practice, the society in Bulgaria need to be informed how important it is to provide organs for transplantation to the entire European area. Without organ donations no transplantations can happen. In Natalia's case, despite her general poor condition, the surgery itself went smoothly. We have concentrated the expertise of many specialists in our center. Without regular practice this procedure, which is routine for us, could end badly somewhere else. This is why is in not feasible to make many transplantation centers in Europe. Regarding already transplanted patients, we have organized four centers for follow-up care with our partners from "Eurotransplant". They contact us only for emergencies. We are going to establish such a center for follow-up care here in Bulgaria as well."



The first Regional Conference of the European Patient Access Partnership was held in Sofia

The first Regional Conference of the European Patient Access Partnership - PACT - was opened on September 12, 2016 by the Bulgarian Minister of Health, Dr. Petar Moskov. The topic of the two-day conference was "Cooperation within the region: a way to improve access to quality healthcare in Central and Eastern Europe (CEE)".

For the first time representatives of 25 European countries - politicians, representatives of healthcare institutions, patient organizations, healthcare and trade associations, gathered to discuss challenges and discuss common European solutions for improving patients' access to quality healthcare.

During the official opening Dr. Moskov, as a host of the event, confirmed the necessity of constructive dialogue and common actions in this direction, pointing out to the initiative between the Ministers of Health from Central and Eastern Europe on the issues regarding the increased challenges in medicines policy. The subject of the work meetings in Sofia and Bucharest held in the last several months within the initiative was improving and facilitating the access to efficient treatment, taking into account the current achievements of medical science and ensuring predictability and sustainability of public finance.

Dr. Moskov added that the talks between ministers from the



CEE region, for the purpose of bringing together medicines policies and uniting the efforts of the represented countries, are at advanced stage, and an "Agreement for cooperation on access to effective medical treatment" between Bulgaria and Romania is expected to be signed soon.

During the conference for the first time were announced the priorities for the Bulgarian EU Presidency in 2018 in the healthcare sector, with the main focus being prices and pricing of medicines and improving the access to healthcare for European citizens. Dr. Andrey Kovachev, MEP, confirmed the willingness of the European Parliament to cooperate for changes at European level in improving access to healthcare. Some of the speakers at the conference were representatives of the European Commission, the European Public Health Alliance (EPHA), the Belgian Institute for Health and Disability Insurance, the Standing Committee of European Doctors, the European Alliance for Personalized Medicine, the Platform for International Cooperation on Undocumented Migrants, (PICUM), as well as other representatives of European organizations and institutions. The conference concluded with key recommendations for the countries of the CEE region. One of the participants was Natalia Maeva, Chair of the BSPPH and Member of the Board of PHA Europe.

The main conclusions of the event were summarized in key conclusions regarding the necessity of collaboration between all stakeholders for the sake of finding common effective solutions regarding better access to quality healthcare for patients. Immediately after the conference the Minister of Health hosted a meeting with representatives of the European Commission, the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Association of Generic and Biosimilar Medicines, to discuss the details of the Bulgarian and Romanian initiative for common procurement of medicines.

European Organ Donation Day

For the fourth consecutive year BSPPH, together with the Executive Agency for Transplantation and other patient organizations, friends and partners, celebrated the European Week for Organ Donation and Transplantation (22-29 October 2016). The slogan of the campaign is "A little part

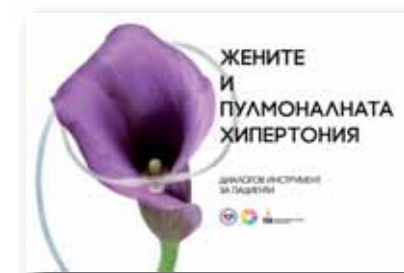
of you can mean the world to someone!"

On October 25 the Faculty of Journalism and Mass Communication of SU "Kliment Ohridski" hosted a public lecture on "Donation and transplantation - generosity and a chance for new life". The event is a part of the European Organ Donation Week and co-organizers are the Bulgarian Association of Transplantation Patients and BSPPH. Dr. Mariana Simonova presented to the students the activities related to organ donation and transplantation, confirming brain death and the importance of organ donation.

Every transplant patient has a unique story; one of them is Natalia Maeva, the Chair of BSPPH and she presented it to the participants. With this initiative we wanted to give publicity to the issue and the difficulties encountered by patients in need of organ transplants, because we believe that when the problem has a face, people are more motivated to learn the options for organ donation. We heard radically different opinions regarding donation and transplantation. Young Bulgarians insist that their wish to become donors must be included in their identity documents. In the spirit of tradition representatives of BSPPH participated in the organ donation parade, held on October 26.

Women and pulmonary arterial hypertension

"Women and pulmonary arterial hypertension" is the name of a brochure aimed at women suffering from PAH in their active age (20-50 years) and also at women at risk of developing this disease. It is a joint project of BSPPH, with the support of PHA and the National Patients Organization. No woman is safe from PAH and global studies show that pregnant women are especially vulnerable. Another significant issue, addressed to a broader audience of women, is the relation between weight-loss medication and the probability of developing PAH. In summary, the brochure covers important issues related to the health of women at risk and the ones already diagnosed with PAH: risks of pregnancy, contra-



ception, emotional breakdowns, how and where to seek help, self-help techniques.

As a continuation of the project the publication will be distributed in the three main medical centers specializing in PH in Bulgaria: the National Cardiology, "St. Anna" Hospital, Sofia, "St. Marina" Hospital, Varna, as well as General Hospital for Active Treatment "Nadezhda" - women's health

hospital and University Obstetrics and Gynecology Hospital "Maichin Dom".

Natalia Maeva, Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH
www.bspph.net

www.facebook.com/BSPPH.Bulgaria?ref=hl



5th National Conference on Pulmonary Hypertension - with international participation

From OCTOBER 07-09 2016, PHA Bulgaria held its 5-th national conference with international participation. The conference was held together with The National alliance of rare disease and The national Agency of Organ Donation.

The event was separate in 2 part: Lectures for medical students about PH and other rare disease and activities for patients. For first time the national conference was with international guests, speaker and patients association leaders and medical professionals from Macedonia, Norway, Romania, Serbia, Slovenia take active part in the patients workshops, lectures, getting to



know each other and having fun. For first time the patients part was mostly orientated to Lifestyle, Activity, Rehabilitation, Diabology, Cooking, Yoga, Sports, we also had a folklore dancing classes. As always there was medical professionals from the National centers of PH and Psychological professional who make a workshops and activ-

ities for teambuilding and support. The reaction of the public was great. For the 3 days of activities we got about 40 patients and 70 medical students.

Active Participation in to European Organ Donation Week

Participating in to information companies in 3 major cities in Bul-



In November 2016 the Croatian PH association "Blue Wings" joined the Croatian Association for Rare Diseases and thus became the twenty fourth nonprofit organization that has joined. Rare Diseases Croatia is social-charity, nonprofit and non-governmental association which gathers other associations with members with rare diseases and individuals who have rare diseases in a unique community of the Croatian area. The main purpose is to achieve, harmonise and protect their individual and common rights and interests.

As an umbrella organisation for RDs in Croatia it brings together:

- Over 700 individuals with rare diseases and their family members.
- 24 non profit organisations acting for the benefit of patients.
- More than 400 different rare diagnoses.

These are some of their most important activities:

- Providing psycho-social help support to its members.
- Marking the international Rare Disease Day.
- Organising national conferences about rare diseases.
- Managing the RareConnect project, the European online community for rare diseases created by Eurordis, European Organisation for Rare Diseases.
- Managing the Croatian Help Line for Rare Diseases.
- Managing the Croatian Orphanet web - Orphanet is the reference portal for information on rare diseases and orphan

garia. On our own organizing information stand and seminar about organ donation in Pleven with participation over 100 people.

"5 years - we share, we believe, we succeed together"

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



drugs, for all audiences. Orphanet's aim is to help improve the diagnosis, care and treatment of patients with rare diseases.

Rare Diseases Croatia has been a member of Eurordis since 2008 and the President of the Alliance, Ms. Vlasta Zmazek, is on the Eurordis Board of Directors.

Pfizer Adriatic PAH forum

This conference was held at the Westin Hotel in Zagreb for three days from the 18th to 20th November 2016. Zdenka Bradač, President of the association "Blue Wings" represented the PH patients. One of the speakers at the conference was Prof. I. Malčić (known as a pioneer in the diagnosis and surgery for PH and also recognized as one of the best pediatricians in Croatia). During the conference there was one very emotional moment when Prof. I. Malčić recognized Ms Bradač as a patient whose life he saved 1982 and on whom he had performed right heart catheterization.

At the conference various topics were covered including diagnostics, new drugs, the exchange of experience at regional level.

New video

Our association is currently in the process of making a video which will be called "two faces of the same diagnosis." The idea is to show people the two sides of PH and for them to develop a better understanding of the disease, that is if someone looks young, healthy and glamorous this does not mean that it is indeed so. The very idea was born in the hospital while Ms Bradač was waiting for the elevator to go to the fourth floor for a medical visit and where she personally experienced an elderly gentleman looking at her and loudly commenting that when he was young he could take the stairs to any floor and also carry heavy things.

Branka Fresl and Zdenka Bradač,
 Plava Krila, Udruga pacijenata oboljelih od plućne hipertenzije
<http://www.plavakrila.hr/> - <http://bit.ly/2hN2aQK>





CZECH REPUBLIC

Celebration of Rare Disease Day 2016

Every year the Czech PH association takes part in the celebration for international Rare Disease Day (RDD). This year the Czech RDD event was held on February 29th at the Zizkov Tower Prague, 216 meters high and entitled "With your head in the Sky". In addition to the representatives of patient organizations and patients' families, a member of the Chamber of Deputies of the Czech Republic from the Committee of Health, David Kasal, M.D., was also invited.

Cardiology Congress in Brno

From May 15 to 18, the Annual Congress of Czech Society of Cardiology took place at the Exhibition Centre in Brno. Representatives of the Czech PH Association could not miss out on this important event. The main goal was to raise awareness of PH among health professionals and especially young doctors through brochures and leaflets and conversations on the topic of PH.

Recondition stay in Poděbrady

Every year, the second Sunday in August marks the starting day of our Reconditioning stay in Poděbrady. This is a one week long stay in a beautiful spa town, 50km from Prague, for PH patients with their families. As in past years, the program was focused on light breathing exercises, muscle stretching work and light workout in the pool. We also introduced some new techniques to strengthen the middle part of the body so as to protect the spine. Our patients also had the opportunity to discuss their problems with a PH specialist.

Meeting of patient organizations with rare diseases

In October 15th our association was invited for the meeting of the Czech Association for patients with Rare Diseases. The most interesting part of the meeting was the participation of the Deputy Minister for Health, JUDr. Lenka Teska Arnoštová Ph.D. The main topic of discussion was the reimbursement of medicines and medical aids in the Czech Republic. There was also a lecture by Mrs. Valuchová from EDA. The EDA is an organisation that helps families with seriously ill children, mainly to teach them how to support and treat their loved ones during their tough lives. This very important psychological support via helpline is free of charge.

Meeting of the Slovak PH Patient association

In November 12th the Slovak PH patient association organized an educational stay in Těrchová. The program varied a lot and was very interesting. We are grateful to the Slovak association for the invitation to attend and also for a chance to make a presentation about activities of the Czech PH association there.

Annual Assembly in Solenice

On the 19th and 20th November 2016 the Annual General Meeting of the Czech PH association was held in the town of Solenice, a very beautiful area near Prague. The hotel itself has a very nice view of the Vltava river and the whole area is surrounded by forests that makes a very good environment for our patients. The program of the meeting

included an educational part with some important basic legal issues related to healthcare in our country as well as some fun activities. This year we had the honor to invite our patron Sabina Laurinová and one of our few PH specialists, Regina Hercikova, M.D. For all participants of the autumn meeting we prepared an excursion to the power station Orlik. This station is one of the largest hydroelectric power plants in the Czech Republic, with the famous Kaplan turbine, which was exhibited in Brussels at Expo 58 and won the gold medal in four categories there. The excursion also included an expert commentary. In the early evening we had a party with a band Taurus, competitions and free entertainment.

New brochure and leaflets for patients and carer

We have prepared a new brochure and leaflets for patients, carers and physicians. These will be sent to print at the beginning of next year. The brochures contain comprehensive information on PH and treatments, whereas the leaflets contain a brief description of the disease and contacts with a form with which new patients can apply to the association.

Our plans for next year

We have a lot of plans for the year of 2017. The most important task is to establish a closer cooperation with two PH centers (Olomouc, IKEM). Furthermore, we are planning to create a TV spot for the Czech TV and print the new brochures and leaflets. We hope also to be able to create a calendar with the PH theme for 2018.

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





ESTONIA

New PH patient association

There was no PH patient association in Estonia until this year and the patients with PH generally did not socialize with each other. There was however a register of PH patients that contained about fifty patients. PH patients are treated in two centres: in Tartu University Hospital and in North Estonia Medical Centre (PERH).

In June 2016 Hall Skåra visited Estonia in order to help organize the patients. This was made possible by the “White Spot” program managed by PHA Europe. Hall contacted and met with

pulmonologist Prof. A. Altraja and Dr. K. Tammekivi from Tartu University Hospital. Hall explained the aims and everyday activities of PHA Europe and patient organisations of other countries. He encouraged to found a patient organisation in Estonia and also invited some patients to attend the annual PH Conference of PHA Europe.

Dr. Kaija Tammekivi, who is also the keeper of the PH patient registry in Estonia, looked for interested patients during the summer. Jaak Nerut agreed to participate in the process and attended the meeting at Barcelona in September. Right after the meeting (the end of September) Dr. Kaija Tammekivi and Dr. Ly Anton organised the first patient meeting in Tallinn. Dr. Ly Anton is cardiologist from the



PERH. Five patients, two doctors and one nurse took part of gathering. Dr. K. Tammekivi made an excellent presentation about PH and available treatment in Estonia. Jaak presented the materials of the Annual PH European Conference and talked about the activities of the umbrella organisation (advocacy, awareness, World PH Day etc.). The participants decided to establish a PH patient non-profit organisation in Estonia. During October and November there have been a discussion about the name of the organisation, aims and activity. The founding meeting is going to take place in the middle of December.

Jaak Nerut



FRANCE

The 3rd « Congrès Patients » organised by HTaPFrance was held near Lyon, on 23, 24 and 25 September. It gathered more than 200 participants, patients, families, carers, and healthcare professionals, among whom the seven French key opinion leaders Professors Marc Humbert, Olivier Sitbon, Gérald Simonneau

(pulmonologists), Damien Bonnet (Cardiologist specialised in pediatric PAH and cardiac congenital defects), Eric Hachulla and Luc Mouthon (Internal Medicine specialists). Luc Matthysen joined us and so did Monika Sorge-Maître with some Swiss patients from HTAP Revivre.

The plenary sessions allowed PH experts to emphasize the progress made in the last 20 years as well as the ones that are still to be made and to give patients and their families the latest information about therapies and research.

Twenty-eight workshops were proposed, with topics as varied as Art-Therapy, PAH and genetics, diagnosis procedure, what is new in transplant, CTEPH treatment and management, PH and exercise; many discussions focused on psycho-social aspects.



HTaPFrance took advantage of the congress to celebrate its 20th anniversary with an improvisational theatre company, a photo studio and an unforgettable fashion show. Thanks to the generosity of its members and benefactors, HTaPFrance could donate 45.000 euros to the INSERM research unit, headed by Prof Marc Humbert.

Laure Rosé, HTaPFrance

www.htapfrance.com

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



GERMANY

19th PH annual patient meeting 2016

The annual meeting of ph e.v. took place in Rheinstetten/Frankfurt am Main from the 28th to the 30th of October 2016. Approximately 250 people took part in the meeting which was also the occasion to celebrate 20 years of the German PH association pulmonale hypertonie e.v. and 15 years of the René Baumgart Foundation. For the last 20 years ph e.v. has provided advice and support to patients with PH and has raised awareness in the general population about this very rare disease. For 15 years, the René Baumgart Foundation has been promoting medical research on PH in children and adults.

The key role that the German PH association has played in past years was clearly highlighted in the speeches of two of the most distinguished members of the PH scientific international community: “Research and treatment of PH have made so much progress over the last few years as hardly any other field of internal medicine,” explained Professor Ekkehard Grünig, head of the Center for PH in the Thoracic Clinic at Heidelberg University Hospital. These advances are also due to the ph e.v.: it brings the actors together and acts as a driving force for research. “The association ph e.v. is a stroke of luck for the further development of therapy for pulmonary hypertension,” stated Professor Werner Seeger, head of the Medical Clinic and Polyclinic II of the University Hospital of Giessen.

Annual Journalist award

Another highlight of the patient meeting was the presentation of the annual journalist award “Together Against Lung Pressure”. This year, the award of 3.000 euros went to the medical doctor and journalist Dr. Anja Braunwarth for her contribution entitled “Lebensretter mit Lungenhochdruck” in the magazine “Volle Kanne” of ZDF, which gives the example of a patient with the (up to now) only curable form PH, chronic thromboembolic pulmonary hypertension (CTEPH).

7.500 Euro donations from “Rad am Ring”

The team “PHenomenal Hope”, which is based in the USA, is increasingly and very successfully drawing public attention to PH: endurance athletes such as runners, cyclists and triathletes compete in competitions to raise funds and show solidarity with those affected. As the German ambassadors of the campaign, Katrin Hetebrügge and Axel Schauf participated together with six friends at the “Rad am Ring”, a 24-hour cycling race at the Nürburgring, and collected a total of € 7.500 which they donated to ph.e.v.

Patients “at the center”

As the Chairman Hans-Dieter Kulla reported, ph e.v. in the 20 years of its existence, has developed into a well-structured community, which puts patients at the center of their actions. The quality of life of those affected by pulmonary hypertension



has improved significantly. Kulla thanked the longtime patron of ph e.v. Dr. Erwin Vetter, former Minister of Social Affairs of the state of Baden-Württemberg, who unfortunately could not be present at the patient meeting for health reasons.

Early diagnosis and therapy are crucial

In PH the blood vessels of the lungs are narrowed, and the blood pressure in the pulmonary circulation - from the heart to the lungs and back again - is abnormally increased. This results in a deteriorated oxygen intake and an increasing overload of the right ventricle. PH may have different causes and forms. The current classification distinguishes five groups: the diseases of the first group are summarized as pulmonary arterial hypertension (PAH). Patients with PH are physically unstable and suffer from shortness of breath. The disease is usually progressive and can lead untreated to death. Therefore, early diagnosis and therapy are vital. Numerous new medicines have been approved in recent years. Prof. Werner Seeger, who has investigated the molecular causes of PH, has contributed significantly to the development of effective drugs. "We have achieved a great deal, but are still not satisfied and there is long way to go still," said Seeger in his speech.

An exciting piece of research history

Seeger's lecture presented an exciting piece of research and treatment history. In the case of PH, several factors are involved: first, the vessels of the lung are narrowed; secondly, the vessel walls are thickened and grow inward; thirdly, pulmonary vessels are lost. These are all important factors when



looking for effective drugs. Researchers are now looking for ways to improve the function of the right heart.

Surgery as a therapy of choice for CTEPH

The current status of the research and treatment of chronic thromboembolic pulmonary hypertension (CTEPH) was reported by Professor Heinrike Wilkens, Managing Director of the Department of Internal Medicine V at the University Hospital of Saarland. CTEPH usually results from an acute pulmonary embolism if the blood clots in the lung do not dissolve and instead a chronic remodeling occurs. If the patient is operable pulmonary endarterectomy (PEA), is the therapy of choice. PEA should, however, only be carried out in experienced PH centers.

"Hit hard and early" - initial combination therapy

In 2015, the European Society of Cardiology (ESC) and the European Respiratory Society (ERS) updated their joint clinical guidelines on the diagnosis and treatment of PH. In order to discuss the ESC/ERS guidelines and their practical implementation in Germany, numerous experts gathered in June of this year at the Cologne consensus conference. The organizer was the working group on PH of the German Society of Cardiology, Cardiac Artery Research (DGK). The spokesman of the working group, Dr. Hans F.E. Klose, Head of the Department of Pneumology of the Second Medical Clinic and Polyclinic of the University Hospital Hamburg-Eppendorf, reported a rethinking from goal-oriented to risk-based therapy. This means that in the case of high risk - if the right heart is markedly enlarged or dyspnoea is already present with slight exertion - several drugs be used in combination right from the onset ("upfront combination therapy").

Information exchange and workshops

In addition to the celebrations and the scientific lectures, the program of the meeting featured some case study reports and various workshops.

Hans-Dieter Kulla, pulmonale hypertonie e.v.

www.phev.de

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



HPH has had another very productive year. They have worked on several different projects.

BPA soon available in Greece for CTEPH patients

The organization has decided that it is imperative that there should be doctors who know how to perform balloon pulmonary angioplasty (BPA) in Greece. BPA is a procedure which can be used in inoperable forms of CTEPH or in case of recurring PH in patients post surgery. The problem in Greece is that the national health service does not cover the costs for patients to have this procedure abroad. HPH is very proud to announce that, after a long struggle against bureaucracy and lack of interest from the government agency in creating a BPA program in Greece, they managed to work against all odds and arranged for two Greek doctors to visit Okayama in Japan and learn the BPA technique from the great professor and world expert of BPA Hiromi Matsubara. Prof. Matsubara will be also visiting Greece to complete the training of the doctors in the best cardiology center the country has. After all of the sessions have been completed it will be possible to perform BPA in Greece. This is a huge achievement because there are patients on the verge of losing their lives who need the procedure urgently. HPH wishes to take this opportunity to thank Prof. Hiromi Matsubara for his generosity to come to Greece with no personal benefit to himself, for paying the largest amount of his ticket because HPH could not afford to cover the expenses and for the interest he has showed on this case. Many thanks also to the two interventional cardiologists Kariofilis Panagiotis (Onaseio Cardiac Surgery Center) and Pappas Christos (Attikon Hospital) who supported our effort.

Surgery for CTEPH abroad

Another great thing HPH achieved is the collaboration with the Kerchkoff clinic in Germany, where they managed to send patients with CTEPH to be operated with an endarterectomy procedure. In the last six months our organization has managed to overcome the bureaucracy and finally we have patients that are treated successfully, which was previously unattainable. It



is important to mention the volunteering help of the Greek people that work in the hospital and in other business in the area. The HPH has built a bridge between the Kerchkoff clinic and the Greek patients with CTEPH.

Invisible patient campaign

Continuing with the "invisible patient" campaign launched for WPHD 2016, HPH are very happy about their annual calendar with the pictures of the "invisible patient". The calendar is already a great success and HPH is able once more to raise awareness of PH throughout the twelve months of the year on our rare illness! Many companies have decided to use our calendars in order to offer it to their partners, the recognition gives us great pleasure because it recognizes the value of our campaign and of course it extends the awareness of PH.

Pongo, the HPH mascot

Pongo, the rare purple elephant, travelled all the way to the United States to take part in the 25th PHA conference in Texas, where he was recognized and glorified by everybody! The next major step is the publication of Pongo's first book with one of the largest bookstore chains in Greece. Pongo is ready to make people all over the world aware of PH as he has already done in Greece with great success. Pongo's book presentation took place on the 7th of December and now he is able through it to support a great work in Greece.

Women in action for PH

Last but not least on the 11th of December we organized the annual "Women in Action for PH". The event has proven over past years to be a great success with women reaching out through our charity event to women with PH, their daily struggles as woman, mother and wife!

Ioanna Alisandrato, PHA Greece

www.hellenicpulmonaryhypertension.gr

www.facebook.com/HellenicPulmonaryHypertension





HUNGARY

Patient meeting 2016

This year, on 4th of November PHA Hungary held its 6th annual patient meeting. Participants gathered from all over the country as well as from nearby Slovakia and Serbia.

PH experts covered many interesting topics including:

- Subcutaneous Remodulin treatment - a patient's personal experience of this treatment supplemented the presentation by the PH physician.
- Pediatric treatment of PAH.
- Exercise suitable for PAH patients - to underpin the importance of exercise a video of the US singer and PH patient Chloe Temtchine (with Hungarian subtitles) was shown to the audience.
- PH treatment from the perspective of the Health Insurance Fund: financial data of the reimbursement and availability of PH treatments.

The meeting ended with exercises shown by a physiotherapist: who highlighted that appropriate and regular movement of the muscles is very important. We learned some breathing and other type of exercises, which can be done on a daily basis at home.

Following the official part of the meeting the attendees could share their experiences with the others in course of a nice lunch. Everybody agreed to meet again next year.

The video summary of the event is available at: <https://www.youtube.com/channel/UCic8ygy3nqJikhoPu9AMpw>

Transplantation in Hungary

On June 30th, the first lung- and kidney transplant was performed in the National Oncological Institution, in cooperation with the Semmelweis University. Mr. György Lang, head of the surgery team, deputy director of the Thoracic Clinic of Semmelweis University, added that combined, simultaneous surgery is very rare even globally and only few centres having the expertise to undertake such interventions. The biggest problem in case of simultaneous lung and kidney transplant is the follow-up, intensive rehabilitation phase, because different liquid-therapy principles apply in case of lung and kidney transplant. The real success was the harmonization of these two therapies. The patient who underwent the operation in June is at his home, under



strict medical control. The first ever transplant surgery in Hungary was made in December of 2015 and the success of the national transplant program launched at that time is corroborated by the fact that it could undertake with full responsibility this complex intervention.

Naszály trail 2016

Gergely Meszaros, volunteer for PHA Hungary, completed a 24,2 km (elevation: 1.055 meters) eco-trail running to raise the awareness of PH.

Ironman Budapest - the show must go on...

For the third year in a row PHA Hungary, members, volunteers and friends, gathered on a sunny morning in Lágymányosi-Bay, river Danube, Budapest to kick-off Ironman (IM) Budapest 2016. This year it was not only the biggest triathlon race (1.700+ triathletes from all over the world) in Hungary, but it also offered lots of possibilities to almost everybody, from the youngest members of the families (Ironkids, Lego-booth, different outdoor activities sponsored by Decathlon) to the ladies (Irongirl, BeFitRun) and the triathletes.

PHA Hungary started the preparation for this event in the spring, which enabled it to deepen the relationship with the organizer and think together how this event could be turned into a real awareness campaign. We believe that we made even a better job than last year, because a special article was posted on the website and Facebook page of the race about PH and PHA Hungary, and even teasers were posted about PHA Hungary and our booth on IM's Facebook - just before the race. On top of the above, a special application was launched by Ironman Budapest for smartphones and under the expo thread PHA Hungary was listed amongst the biggest sponsors. If you clicked on our logo a short description about PH and PHA Hungary popped up.

PHA Hungary was very lucky this year, because in almost all of the races its volunteers, friends represented the PH cause. We had three Ironkids this year (Bence, Dalma, Dorottya), we had Irongirls (Katalin and Edina) and a BeFitRuner, Teodora, who completed a half marathon. This year Gergely doubled previous year's distance and completed the 70.3 race (1,9 km swim, 90 km bike and a half-marathon run).

This year our booth was eye-catching again and attracted lots of visitors. The day was not only challenging to the racers, but our members and volunteers also suffered from the hot weather: the temperature was over 35° C. A video, including interviews with our members, was also made about the event:

<https://youtu.be/ZLwBGWlQxGg>

We are looking forward to next year's event and hope we will have all the dedications and resources which enable us to participate in IM Budapest 2017.

Eszter Csabuda, Tüdőér Egylet

www.tudoer.hu

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





IRELAND

Happy Christmas to all in PH Europe

As I write this article I am preparing the Christmas Newsletter for PH Association - Ireland. On reflection I think 2016 was the strongest year we have had since our association started almost four years ago. We now have monthly meetings in Dublin and we have set up two other venues in the country where meetings are held every second month. It's wonderful to see how friendships have grown over this short space of time. One of our members said to me recently that she thinks "laughter is the best medicine" - this was following one of our meetings which was quite lively! I thought afterwards - this is the best compliment we as group could receive. The aim of our meetings is of course to impart information about PH, to support each other and listen how we have all been since we last met. However I think it is fantastic to know that our members really enjoy coming to the meetings which are not only about Pulmonary Hypertension but that there is a light hearted atmosphere in the room too where many others things are discussed also.

We held a Christmas lunch last week - the first time we have done this and we will certainly continue to include this on calendar of events. It was a very enjoyable afternoon and great to see everybody in such good form.

Ireland PH Meeting 2016

The annual Patient & Family meeting was held on Saturday 16th April - we were delighted and privileged that Hall Skara from PH Europe was in a position to attend and he gave two magnificent presentations. His first presentation was titled 'PH & Lifestyle'. Hall outlined how he monitors his PH. He gave great hope to

those in attendance as he is so passionate about maintaining his fitness without over burdening his body.

Of course the audience was delighted to hear of Hall's wife falling in love with his personal trainer - who is of course his beloved dog Nikko. In Hall's second presentation he spoke about his experience in the rehabilitation centre in Heidelberg. This was very interesting to all and I have noticed over the past year that our patients have become more and more interested in structured exercise training. Hall's presentations are often referred to at our regular meetings. He will be a very hard act to follow!

World PH Day 2017

As soon as we come back after Christmas, we will start working very hard on our World PH Day activities. I often feel that it's soul destroying to put all our energies into one day and then to feel that people have forgotten about us when our 'stories' have been overtaken by something else more sensational in the media. Next year we are planning a more sustained programme of events - nothing is finalised yet - but it will take a lot of work, great enthusiasm and a little bit of luck too!

To all our friends in PH Europe and the PH community across the world, we in Ireland wish you all a very happy and peaceful Christmas and hope 2017 will be filled with much happiness and great health.

Regina Prenderville, PHA Ireland
[on.fb.me/1KaUHRn](https://www.facebook.com/1KaUHRn)

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



ISRAEL

The Israel Pulmonary Hypertension Association has spent a 2016 busy both planning and implementing several activities, advocating, supporting and developing relationships.

Our most recent and extremely successful event was the Patients conference held at the Nir Etzion hotel in the North of Israel.

The overnight conference was attended by 100 participants: patients, family members, care givers and medical representatives. The conference began with a welcome bar - a delicious spread of fresh fruit and crêpes - where everyone had the opportunity to connect and catch up with some relaxed socializing. After a welcome and summary of the years events from both PH Israel Chairman, Joni Berg and CEO Aryeh Copperman, participants were privileged to hear from representatives from the national insurance institute who explained processes, patient rights and how to overcome any bureaucratic challenges that patients might face. The next speaker was the head of the Patient's Rights Association who not only shared experiences and past examples of cases they have dealt with but also urged patients and their families to become more active in their advocacy efforts and to realize that it is crucial to work as a united front in lobbying for anything we feel we need or deserve in the treatment of and living with PH. This lecture and questions and answers session left patients feeling empowered, motivated to push and demand from our government and also eager to assist PH Israel in advocating for PH.

Dr. Avital Avriel, (PH treatment center at the Soroka Medical Center in Beer Sheva) chaired a discussion group with four patient representatives who each shared their experiences of the different medical treatments available in Israel. Each patient spoke of the pros and cons for this treatment, their personal experience of the treatment as well as general information about the treatment. There was also a demonstration of each of the different inhalation pumps. Dr. Avriel was able to facilitate and answer any medical questions.

To end off a perfect day of lectures participants were treated to a musical performance and social evening. A young member of our association, a 23 year old patient along with a female singer, performed beautifully and created the perfect atmosphere for socializing, connecting and relaxing!

Day 2 of the conference kicked off with a photography workshop led by another member of our association. Patients were taught some very useful introductory skills to creative and effective photography - the hotel grounds provided the perfect views surrounded by the Carmel mountains. The day continued with lectures by top doctors and professors from around Israel including Prof. Neville Berkman and Dr. Aluna Matzbaizik.

After a celebratory lunch patients continued to a tour of the Atlit Detainee Camp Museum for some historical enrichment.



This brought the 2017 conference to an end. The conference was enjoyed by all and we were able to move forward with renewed energy and direction for the year ahead! From an advocacy perspective we have been very active this year in applying for 3 new medications (Adcirca, Uptravi and Adempas) to be included in the approved government medical benefits. We hope our efforts will make a difference in the final inclusion of these treatments. We are also focusing on the lung rehabilitation as well as BNP blood testing.

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



Hall Skara, Patricia Ging (Pharmacist), Brian McCullagh (Consultant Respiratory Physician) Sean Gaine, Sally-Ann Breen (Patient) Catherine Norton (Consultant Psychologist) Ciara Heverin (Dietician)





ITALY-AIPI



Elections and new President for AIPI

During this year's general assembly elections were held for the new Board. Leonardo Radicchi, who was Vice President for many years, was elected as the new President. Leonardo was diagnosed with PH when he 18, he is now in his thirties, doing very well on oral monotherapy, has a full time job which involves a lot of traveling, is married and has a little girl. He is very motivated and enthusiastic and we are all sure he will bring a lot of new ideas and initiatives.

New publications

This year AIPI issued a publication on CTEPH, which covers symptoms, diagnosis, treatments and surgery, including the new technique for balloon pulmonary angioplasty (BPA). The booklet contains a number of CTEPH patient testimonials. Another booklet is almost completed and will go to print early in 2017 on lung transplant in PH. This booklet is divided into three parts ("before" the surgery, "during" and "after") and aims to help patient prepare for their surgery by providing tips and advice as well as stories from other patients who have been through it.

Exhibition at the Triennale EXPOGATE

AIPI was offered a very prestigious venue, the Triennale ExpoGate, during the month of August, to exhibit its two PH photographic awareness projects "MASKS", which feature 12 celebrities, including the Olympic Gold Medal swimmer Federica Pellegrini, actresses Maria Grazia Cucinotta, Carolina Crescentini and Valeria Solarino. The 2016 MASKS project and calendar with Federica Pellegrini had a media reach of over 36 million. We are very proud of this result!

Leonardo Radicchi, AIPI Italy
www.aipiitalia.it

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



ITALY-AMIP

Music for PH

This summer and autumn have been busy months for our association: doctors meetings to which our President was invited to share the patients' point of view and experiences, contacts with the institutions to obtain better conditions for PH patients through a collection of signatures on our social media channels, and much more.

We must never forget, though, that awareness campaigns to spread information about PH remains the most important activity and can really save somebody's life. To draw attention and support for our cause this year, for the second time, we were guests at the big annual meeting of the Bersaglieri, which took place in Caserta in October.

Everybody in Italy knows and loves the Bersaglieri: these are soldiers who wear a fantastic feathered hat and, instead of marching, run following their "fanfara" players who run and blow into their wind instruments.

We really could not find better testimonials for our slogan (created by our friend Maurizio Zacchi): "My breath for

those who are left without"!

Maresciallo Agostino Di Rauso, a friend of Lello, AMIP volunteer, introduced Vittorio Vivencio, President of AMIP, as well as a group of AMIP members, to Maggiore Di Paolo, the Commander and organizer of the event. He was so kind and generous as to be immediately engaged and invite us to take part in the gathering.

The venue, the famous Gardens of the Caserta Royal House, was wonderful and our stand was visited by a great number of people crowding the area; many of them volunteered to spread our leaflets all over. The event lasted two days and was a big success, we can proudly say that PH patients are now in the hearts of thousands of Bersaglieri all over the Country.

Vittorio Vivencio, AMIP Italy
www.assoamip.net

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





LATVIA

PHA Latvia organized three main events in 2016: the Annual General Meeting 2016, the 5th anniversary celebrations for the founding of PHA Latvia and a Health Camp for adults and children with rare diseases.

AGM and 5th anniversary of PHA Latvia

The Annual General Meeting 2016 was held on 19th March in Riga with 38 participants. But the 5th Anniversary of establishing of PHA Latvia (July 6) took place in the warm and friendly atmosphere of the Museum of History of Medicine in Riga. Our guests were PH patients, their relatives, siblings, the PHA Latvia project team, our sponsors, and participants from non-governmental organizations. There were 63 people with us to celebrate and give their greetings and good wishes to PHA Latvia. A big surprise for PH community was the short musical performance of popular pop singer Elizabete Zagorska and a beautiful and delicious party cake designed by Zane Lazdina, the only lung transplant patient in Latvia (a former IPAH patient).

Health camp

The Health camp 2016 took place near Tukums, small city in the West of Latvia, during three days in the month of August. There were 42 participants, i.e. ten kids with different rare diseases. PH and other rare disease patients took part in the Health camp with their parents, relatives and carers. It was the first time that we proposed a program of physiotherapy not only for adults, but also for kids and patients' carers. Two physiotherapists provided individual consultations, group activities, and massages for participants of camp. Very popular were the aromatherapy sessions with a psychologist, and a communication master class. The Health camp was organized with support of State Stock company "Latvian Forests" and State Stock company "Loto of Latvia", and other our sponsors.

1st Baltic PH Conference

The Latvian Rare Diseases Research fund launched the 1st

Baltic PH Conference on 23th April, 2016, in Riga. The conference was international with very prominent speakers from University Clinic of Vienna (Austria), PH experts from the UK, Poland, Czech Republic, and Baltic states. PHA Latvia's Chair Ieva Plūme presented the topic "Perspective & Hope: Patients' Point of View" at the Conference.



Advocacy and dissemination of information

PHA Latvia continued in the course of the year to work on improving the health care system for PH patients. It organized two meetings with the authorities of the Ministry for Health regarding the establishment of a PH clinic and consultations about the National Plan for Rare Diseases 2017-2020. Together with the Alliance for Rare Diseases of Latvia PHA Latvia has developed a draft version of a National Plan for Rare Diseases for next period and this draft is supported by Ministry of Health. Unfortunately, the Ministry of Health distanced itself from the issue of a PH clinic and placed all the responsibility on the shoulders of the Clinical University of P.Stradins but the Clinical University authorities are not interested in establishing of PH clinical for better quality of life of PH patients.

Participation in PHA Europe campaigns

PHA Latvia implemented the campaign #BreathofSuccess on its Facebook page and Twitter accounts from September to December 2016. There are photos of CTPEH patients, their relatives, and other PH community participants with brief sentences about their successes in life despite living with a dangerous illness. In October, PHA Latvia supported the PHA Europe information campaign #Call4Transplant with news, pictures, and infographics through its social media channels.

Web page

PHA Latvia launched a new home page www.phlatvia.lv, in 3 languages: Latvian, English and Russian.

Annual PH European Conference 2016 in Spain

As every year, two delegates from PHA Latvia participated in APHEC 2016 in the nice city of Castelldefels in Spain near Mediterranean Sea. Līna Butāne and Ieva Plūme from Latvia shared the experience with other delegates of PHA Europe community and gave inspiration and ideas for future work. Ieva Plūme practical workshop on presentations' techniques at the APHEC 2016.

Ieva Plume, PHA Latvia

www.phlatvia.lv/en/
<https://www.facebook.com/phlatvia/>
<https://twitter.com/phlatvia>



THE NETHERLANDS

During the year there were a number of activities organised for PH patients and for Children with PH. For the children we organised a day in the zoo with parents and brothers and sisters. The parents could talk with each other and the kids had fun in the zoo! There was also a presentation about PH from the medical team of Umcg Groningen, who are specialised in paediatric PH It was a lovely day!

We also organised High Tea's for patients and carers in different regions of the Netherlands. The idea is to make contact with other patients in a informal way. The patients and carers were very happy with these meetings.

Leny van der Steen, PHA-NL

www.pha-nl.nl



NORWAY

European championship in backgammon

The European championship in backgammon was held in Helsingør in October. Helsingør is a small city north of Copenhagen in Denmark and is mostly known for Kronborg Castle, the setting for Shakespeare's play: Hamlet. In the play, Shakespeare called Kronborg Castle Elsinore. This has become the English name for Helsingør.

The European backgammon championship for 2016 took place in a hotel close to the castle and with a nice view to neighboring Sweden (just a couple of miles across the ocean). It is natural that Denmark hosted the championship as Denmark is considered the best backgammon nation in the world.

The championship was open for both individuals and teams. The Norwegian team consisted of six players. The captain of the Norwegian team is the leader of the Norwegian PH association: Hall Skåra. When he was diagnosed with PH eleven years ago, he realized that he needed to find other sports than squash to satisfy his competitive nature. Backgammon seemed to be appropriate since it didn't require any cardiovascular exertion and was fitting for the analytical mind that Hall acquired during his computer studies.

«I played backgammon during my student years in Ohio. However, I now realize that I only played on a beginner level. When I started studying the board game after I was diagnosed with PH, I started reading backgammon books and learning the game from computer software. I joined the local backgammon club in Oslo and started playing competitive backgammon. After six years of hard study, I won the Norwegian backgammon championship. I've had a lot of fun playing backgammon while I've been sick and it's nice to see that a chronic and serious illness does not stop one from performing a mind sport at a high level.»

As one of the top players in Norway, Hall was chosen to be

part of the Norwegian backgammon team. Fifteen European teams were fighting to become European team champions. The top matches were broadcasted and streamed live on Internet. Three commentators were following the games in a separate room analyzing every move made during the streamed matches. "I played a streamed match against one of the best Danish players. I experienced what turns out to be my only drawback when playing long tournament matches: a feeling of fatigue and exhaustion. It effects my mental capacity as it is easy to loose concentration and blunder with some moves. I suffered from this during this match and it was annoying to later watch and hear the brutal and honest commentators as I eventually lost the match against the dane," Hall smiles. "I have to be careful not to use PH as an excuse when loosing matches. Maybe I should simply blame bad dice," Hall says with a laugh.

The teams all wore team shirts. The Norwegian shirts stood out in the crowd. While the other teams wore shirts with the country name in the back, the Norwegian shirts were the «WPHD get breathless» shirts. "All the team members agreed to wear the shirt upon my request, and it was a great way to create awareness for PH among the top backgammon players of Europe."

The Norwegian team had a hard fight against Croatia for a spot in the playoffs. However, they eventually lost and finished in eighth place. And the country that became European champions was not a surprise to anyone: Denmark.

Annual patient meeting

PHA Norway holds a yearly patients' meeting. This year's meeting was held in May and the Swedish PH association was invited to join the gathering. A small group of patients and carers met in Oslo and had a fruitful and interesting meeting. The situation for patients and carers is very similar in the two neighboring countries, and it therefore makes sense to occa-





sionally meet to exchange information. After the patient meeting, the two associations ran a common WPHD event which was a friendly competition between the two rivaling countries during the "Backwards Games".

Rehab program

A three week long PAH rehabilitation program was held in June. This is the sixth year in a row that the rehabilitation center, a little north of Oslo, extends an invitation

rehabilitation program has proven to be very valuable for the patients that participate.

PH on TV

A new TV program has become a hit in Norway. It's called "What is your diagnosis?" Two teams of three try to guess what illness patients suffer from by asking them questions and receiving some hints. This year, Hall Skåra, President of the Norwegian association, was invited to join the program as a participant. The one team consisted of doctors, while the other team consisted of high school students. The latter team was allowed to use Internet to search for their answer, while the doctors were not. The program is a great way to create awareness for diseases as it a national broadcasted program that is viewed by many.



Hall Skåra, PHA Norway
www.pha-no.com - <http://on.fb.me/TDzyKI>



to a rehab program especially designed for PH patients. Many patients join the rehab program every year, while some patients joined the program for the first time this year. The

gathered about 120 patients and their relatives from three cities: Wrocław, Lubin and Wałbrzych. During the meeting a leading Polish cardiologist, Prof. Marcin Kurzyna, who was one of the speakers, presented the results of the International Patient and Carer (ICPS) survey on the impact of PH that was conducted some time ago in five European countries. PHA Polska activities were presented by Alicja Morze - PHA Polska President. Agnieszka Bartosiewicz, PHA Polska VicePresident, gave a lecture on PHA Europe's structure and activities. Both patients' meetings were great occasion for the patients to talk about their problems and benefit from the presentations of the speakers both doctors and patients.

that was visited by many participants of the conference.

PH treatment news

Thanks to the efforts of Alicja Morze, PHA Polska President, a new concentration of trepostinil/Remodulin (10mg) is to be refunded, starting from November 1, 2016. This is a great news for all the patients with an implantable Remodulin pump, who previously did not have any possibility to increase the level of the drug.

Educational calendar

PHA Polska issued a second edition of its PH educational calendar, with photos taken by Grzegorz Morze, PHA Polska President's husband. The calendar also contains information about PH, PHA Poland and a list of PH centers. The calendar is being distributed both to medical experts and staff, PH centers and the patients.

Sports events

During the whole year a group of volunteer participated in different kind of marathons and sport tournaments in solidarity with the PH Patients. 2016 was the second year during which a special "Get Breathless" Team Gdynia dedicated their sport activities to PH patients. The team members always wear PH T-shirts and they educate others about the disease and patients' issues. This year the "Get Breathless" Team Gdynia member finished the Half IronMan Gdynia tournament.

Alicja Morze, PHA Polska
www.phapolska.org - on.fb.me/1ORE2WJ



International Rare Disease Day

On February 26, 2016 PHA Polska participated in the international Rare Diseases Day conference in Warsaw. Many patient organizations and the Ministry of Health representatives took part in the event. During the meeting a pledge was made that a National Rare Disease Plan would be ready before the end of the year. The plan is to be implemented at the beginning of 2017. PHA Polska was represented by Alicja Morze PHA Polska President, Agnieszka Bartosiewicz, Vice President and Maria Golańska-Zabost and Iwonna Kamińska members of PHA Polska.

Patient meetings

During 2016 PHA Poland organized two patients' meetings. The first one took place in June in Kraków and was organized with the Krakow Heart Clinic of Jagiellonski University and the Rare Circulation Disease Center. The meeting gathered almost 130 people. The participants could not only hear about the latest PH treatments but also benefit from the lecture of a psychologist who spoke about psychological consequences of chronic diseases. The second meeting was organized in October in Wrocław and





PORTUGAL

Trail for CTEPH

The Portuguese PH association organized a 15 Km Trail for CTEPH awareness day, on November 20th. The event was sponsored by MSD and Actelion and was attended by almost 300 athletes. The ambassador of the event was Aurora Cunha, a former world running champion. The Trail aimed to raise awareness for CTEPH and raise funds for the Portuguese Association. The initiative had media coverage (radio and newspapers) and the presence of the mayor as well MSD and Actelion representatives.

Attendance at the conference “Understand the Disease: patients first”

The Portuguese PH Association was represented at the conference “Understand the Disease: patients first”, which included a group dynamics session with patients moderated by psychiatrists and sociologists. The disease, its meaning and health literacy were the main themes discussed at the afternoon sessions.

The Portuguese PH association is represented by an athletics team

A Portuguese athletics team has been running for PH since July. They have completed 23 competitions including marathons, half-marathons and trails. Their sportswear has the Portuguese association’s symbol and they use it to raise awareness for PH in the sport events they attend.



Invitation for a Multidisciplinary Team Workshop

The Portuguese PH Association was invited to attend a multidisciplinary team workshop organized by Actelion in Zurich on November 28, to contribute to discussions on self-management in PAH. Our Association shared their recent project, a Mobile App, with the international community.

Maria Joao Saraiva

Associação Portuguesa de Hipertensão Pulmonar

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



REPUBLIC OF MACEDONIA

This year the PH association of the Republic of Macedonia worked hard in many different areas and fought a real war with the institutions.

Rare Disease Day

In February, as it does every year, “Moment Plus” marked international Rare Disease Day. For the entire month, together with other associations from the National Alliance for Rare Diseases, it dedicated its efforts to raising awareness of the struggle facing patients with rare diseases. Moment Plus was directly involved in the campaign called “Hug Rarity”, organised by the Croatian and Serbian Rare Disease national organisations,

which attempted at establishing a Guinness world record and the result of which is awaited for 2017 (largest online photo album of hugs). Two days were devoted to awareness activities in five cities on the 28th and 29th of February with a special program with guests from the institutions, physicians, patients, journalists.

WPHD

Moment Plus also celebrated WPHD on May 8 with its participation in the “Wizz Air Skopje Marathon”, which had over 8.000 participants from 46 countries. In many different ways other people also supported Moment Plus, including a moun-

taineering organisation which conquered a mountain peak carrying this flag with the WPHD slogan “Get breathless for PH”.

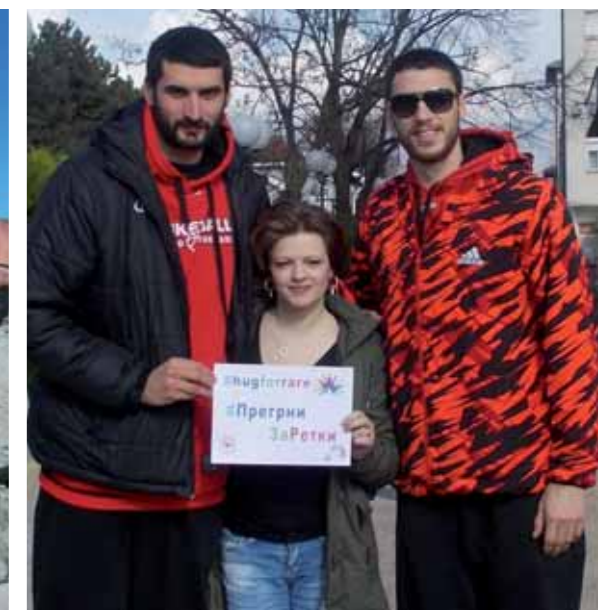
PAH drugs

In June Moment Plus started an awareness and advocacy campaign called “To breathe this summer for patients with PH.” The Republic of Macedonia is facing many difficulties, including economic: it is a country in transition and a non EU-member state. The campaign aimed at obtaining a second drug for PH patients in the country. Moment Plus started a blog about the life of PH and PH carers, which had over 5.000 views almost every day. It also organised several press conferences where a clear message was sent about the urgent unmet needs of PH patients and the fact that lack of treatment is a matter of life and death for them. The information was picked up by a number of internet portals, TV and radio shows. Finally we succeeded in having the recognition of Bosentan as a second drug for patients with PH in the country. All this ended with a big press conference which had a very positive outcome. This was a great reward for all the work we have done. The President of the Commission for Rare Diseases, Prof. Dr. Sofijanovska Aspasija, said that the experience of more developed countries must be reflected also in Macedonia and that it is necessary to approach each patient individually and to provide the necessary medication. She will support the idea of opening a dedicated PH clinic where patients can receive full medical treatment. Moment Plus acknowledges the important role played by PHA Europe in its success and thanks it for its guidance, suggestions and advocacy letters to the authorities.



Gjurgica Kjaeva with Nikola Todorov, Health Minister

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





ROMANIA

The Romanian PH association took part in a meeting organized by Diagnostic Centre of Pulmonology Hospital of Iasi, led by pulmonologist Prof. Traian Mihaescu and Dr. Tesloianu Anda. At the current moment there are 35 patients diagnosed with PH in Iasi, who are

included in the national program.

Bogdan Heinrich Burduja
 Association of pulmonary hypertension patients
www.phader.eu - <http://bit.ly/2a6qNXN>



SERBIA

PH SERBIA was founded 2015 and has been a member of PHA Europe since September 2015. PHA Europe has provided us with strong support for our efforts.

The situation at the time was the following:

- In Serbia there were no PH Centres.
- It was hard to track down any doctor specialized in PH.
- There was only one available drug, Sildenafil, and even that was not fully available.
- O2 therapy was not available for all patients.

What has been done so far

Four PH dedicated clinics have now been established in the four most reputed hospitals in Serbia, with eleven doctors in total making up the PH teams.

In October PH Serbia organized a meeting with all the PH doctors and directors of the four clinics mentioned above. It was generally agreed that it is important to have an association of PH physicians, through which it would be easier for the doctors to put pressure on the government about important PH issues.



An association is currently being registered and, once the procedure is completed, the association will have four main goals:

- Creating a national registry for PAH and CTEPH patients.
- Introducing new medicines for PH treatment, based on the recommendations from 2015 ESC/ERS clinical guidelines for the diagnosis and treatment of pulmonary hypertension.
- Allowing PH patients to travel abroad for lung transplantation, with costs covered by national health insurance.
- Actively participating in "organ donation" programs to raise awareness of the importance of organ donation and to request a law for organ donation.

Thanks to all the efforts of our association there have been new developments also with regards to reimbursement of treatments and, at present, almost all diagnosed PH patients have started using Sildenafil. In addition, all PH patients who need to use O2 therapy can now get stable O2 concentrators paid by the national health insurance. Very importantly, all 20 registered pediatric PH patients in Serbia are now getting Bosentan therapy.

We have also been involved in fundraising to support the PH clinics: we launched a charity SMS campaign which received about 1.700 SMS messages and raised 1.400 euros for our cause. This money will be used to buy oximeters and sphygmomanometers to measure blood pressure for the Serbian PH clinics. Oximeters will be also given away to ER centres in Serbia.

WPHD award

We are very proud to have won PHA Europe's 1st prize for best project about raising awareness of PH-Barcelona 2016

Regional Rare Disease Seminar

PH Serbia participated and represented the PH community in biggest regional seminar for rare diseases in Split, Croatia. This meeting was organized by the national associations for rare diseases of Bosnia, Croatia, Serbia and Slovenia and gathered many different associations from these four countries. As we were the only representatives of PH patients, we actively participated and presented our work and our cooperation with the regional PH associations, with a strong accent on importance of cooperation on regional and European level.

Plans for next year 2017

PH Serbia wishes to actively continue to raise awareness of pulmonary hypertension. We will try to find the best way to draw more media attention through various different events. These are some ideas:

- The publication of books for preschool and kindergarden children, which would contribute towards the integration and inclusion of children with rare diseases amongst other, healthy children.



- An event for WPHD - a big sporting one, e.g. the Finale of the Serbian football Cup, the National Basketball teams of Serbia, Children's sports day and the Hippodrome (equestrian sports).
- Training of medical staff and doctors.
- Seminars and organizing meetings of patients.

Main project for 2017: PH Serbia Team - Inspired by HOPE

We will try to use one of the hardest disciplines to raise public awareness about PH: the Sahara ultramarathon SAHARA RACE 2017 (starting April 30), 7 days continuous running! This is one of the most organized races in the world and it is covered by all media. We plan to have two runners in the team, one world champion and one European champion, who will run in honour of all PH and all lung disease patients in Serbia and around the world. This is the hardest project so far but we will do our best to carry it through and show everyone how patients with lung problems are out of breath. Our competitors will record the whole race, and then we will make a movie out of it. Currently, we are focusing all our energy on finding sponsors for the race. If we are lucky and we manage to find companies who understand the great value of such a project we will be able to realize it: cross fingers!

Danijela Pešić, PHA Serbia

www.facebook.com/plucnahipertenzija - danijela@pesic.rs





SLOVAKIA

Spreading information and raising awareness of PH

This was again a very busy year for PHA Slovakia, here are few of its activities for 2016:

- Production of a video about a 3-year old patient, who was born with PH, called "It goes easier with a smile". The movie, with English subtitles, premiered on public TV in Slovakia during the campaign for WPHD 2016: <https://www.youtube.com/watch?v=17YeMQAUrYY&feature=share>
- Participation in 17 running competitions, the most important of which took place from the 20th to the 21st of August 2016: a 345 km relay race called "From the Tatras to Danube", which took place in extremely challenging conditions.
- On the 19th of July PHA Slovakia participated in a PAH Seminar for GSK employees (26 attended), at the Center for PAH of Slovakia, with two cardiologists and the President of PHA Slovakia, Iveta Makovniková, as speakers. The result is a promise of better financial support and an increased interest in direct involvement of the GSK in the

WPHD 2017 campaign.

- On the 1st of October we took part in a seminar for medical students in Bratislava on cardiac diseases. One part of the seminar was dedicated to PAH, during which the Director of the PAH Center and a PH patient talked about the disease.
- 7th of October 2016 - participation in the annual Slovak Cardiology Congress with an information stand.
- 24th of November - PHA Slovakia, in cooperation with the University Hospital of Bratislava, prepared a regional PH conference for nurses. The estimated attendance was 200-250 participants.
- Media coverage during the year - 26 articles in printed and electronic form, four television and two radio programs.

Activities for the patients

From the 4th to the 9th of September PHA Slovakia organized an educational and relaxation stay for patients with PH. It took place in the spa "Sliač". 29 members of our association attended. The program included information about treatment,

psychosocial support, relaxation, rehabilitation exercises and yoga. The project was funded by a grant from the Ministry of Foreign Affairs of Slovakia. Further activities include a "concert without barriers" and the General Annual Assembly meeting.

Campaign to improve organ donation and transplantation

The aim of this campaign was to increase organ donation in Slovakia. For 3 years PHA Slovakia has been cooperating with the associations for heart, liver and kidney transplant. Our joint activities this year consisted of:

- Support to the PHA Europe campaign and Call to action to improve organ donation and transplantation across the EU - endorsed by seven major organizations in Slovakia. Additionally we invited 13 MEPs to sign the written declaration on organ donation put forward by MEP Jakovcic and presented the campaign to the media and in the course of various seminars.

- Throughout the year we organised, in cooperation with the Slovak Transplant society, student discussion forums in eight universities in order to raise awareness about organ donation. The theme was: "One donor - Seven Lives". The aim was to spread positive information about organ donation.
- From the 30th of October till the 2nd November we, along with other patient associations, organized the first Slovak transplant and dialysis sports games, which saw the participation of 60 athletes in seven sport disciplines. The event was covered in the press, TV and radio. PHA Slovakia member, Jana Guránová obtained 5 prizes.

Iveta Makovniková

Zdruzenie pacientov s pľúcnou hypertenziou

www.phaslovakia.org

<https://www.facebook.com/Zdruzenie-pacientov-s-plucnou-hypertenziou-oz-236811429798179/>



SLOVENIA

Ironman

Društvo za pljučno hipertenzijo Slovenije was present at the second Ironman 70.3 Pula on September 18. Luka Kobler and Rudi Smolej attended the triathlon for the second time, while Marko Podlessek and Grega Ilc attempted their first ever Ironman race. Just like last year our athletes wore wonderful white PH sports suits with blue lungs. People were able to spot them from a mile away because the sports suits stood out so well in the crowd. The main reason for participating in the

event was to raise awareness about PH and we are positive that our heroes achieved our goal above all expectations. The organization of the event, the atmosphere, the volunteers, the judges, the athletes, everything was simply breathtaking. This was the second time we participated in the Pula Ironman and we are planning to take part next year as well. Just being present there, seeing and feeling the atmosphere fills you with hope, enthusiasm and motivation to keep on fighting and spreading awareness of PH. All of our athletes did great in all





three disciplines. After 1.9 km of swimming, 90 km of cycling and 21 km of running, they reached the finish line and feelings of accomplishment, success and gratitude overwhelmed every member of our team.

COLLABORATIVE PROJECTS

In association with Pfizer PHA Slovenia managed to secure three projects to help spread awareness of pulmonary hypertension. The three projects are: the Ljubljana marathon, Facebook advertising and setting up posters about PH in health care clinics.

Ljubljana marathon

On October 30 our association took part in the Ljubljana marathon. The Ljubljana marathon is increasing in size every year and is becoming more and more popular even for professional foreign athletes. This year more than 20.000 runners participated in the event. The preparation for the event began a month before the actual day of the race. We tried to secure as many people to join our running team and to represent every PH patient. We managed to find 20 runners, both male and female, from all age groups, who participated in different races that were held at the event. All of our athletes wore our white running T-shirts with blue lungs. All of the runners completed their races helping us to spread awareness about the disease.



when you hear hoof beats think horses not zebras. They associate common symptoms with common illnesses. But sometimes hoof beats do suggest a zebra." This is the opening line of the video.

The video highlights the biggest problem PH patients are facing in the developed part of the world right now. Doctors sadly misdiagnose pulmonary hypertension patients for years because they simply mistake it for more common diseases. We are expecting approximately 300.000 Slovenians to see the video. That is more than 15% of our entire population.

Setting up posters

In January and February 2017 we will be setting up 100 posters in health care institutions all over Slovenia. Along with the posters the doctors of those institutions will receive two copies of our patient and carer booklets, a short written description of PH and its symptoms and a form to become a member of our association. In case



these doctors diagnose any new PH patients we're hoping to attract some new members to join our association this way. The posters were made by a professional designer and they focus on the symptoms of PH. In the upper part of the poster are 6 zebras and each zebra represents one of the symptoms of PH. We are delighted with the way the poster turned out and are confident that the zebras will attract a lot of attention.

Tadeja Ravnik

Društvo Za Pljučno Hipertenzijo Slovenije

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



This was a year of big changes for ANHP, with the election of the new Board of Directors in June, and of intense activity in many different areas. Here are some of the activities we have organized or taken part in:

- On January 19 ANHP took part in the 2° workshop on "The active patient", organized by Hospital pharmacy ("paciente activo" - Farmacia de Hospital).
- On January 20 we were interviewed for Canal Sur Radio. Angel Lorenzo, who has PH caused by toxic syndrome, represented ANHP. We have presented (again) the book called "El Baile de los Delfines" (Dance of the dolphins), a novel written by ANHP member Julia Villares, whose main character is a small girl with PH.
- On January 29 ANHP attended the workshop "Aula Respira" (Breathing class) in the Hospital Clinic in Barcelona.
- On February 21 the "2nd PH Solidarity Run" was held in Valencia, with the slogan "Get breathless for PH". The run was organized in memory of Maria Moreno, a PH patient from the association. 1.200 runners participated.
- On February 28, we took part in a number of "solidarity concerts" in Madrid. The ANHP presented the association to the attendees.
- On March 3 ANHP attended the Annual Rare Disease Gala organized by Feder, Federación Española de Enfermedades Raras (Spanish Rare Disease Federation) in the Senate in Madrid.
- On March 13 ANHP participated with a stand in the Solidarity Run organized by Feder within the context of celebrations for Rare Disease Day. It was held at the Casa de Campo in Madrid.
- On April 17, ANHP participated in the workshop "Respiratory patient classroom" (aula del paciente respiratorio) in Madrid.
- On April 19 there was a meeting between POP and Ciudadanos (a bank and a political party) in Valladolid, which was attended by Alicia García, ANHP Treasurer.
- On April 21 and 22, ANHP participated in the Congress of Semergen, Sociedad Española de Médicos de atención Primaria (Spanish Society for primary health physicians) in León. ANHP representatives took part in different workshops to learn how to use inhalers, to understand the health system etc. The main topic was the chronic patient and his empowerment.
- On April 23, St Jordi's Day, when the tradition in Barcelona is to offer a book and a rose, the ANHP sold roses and the book "Dance of the dolphins".
- From May 1 to 8, around WPHD 2016, ANHP held a number of sporting and cultural events across Madrid and Barcelona.
- In the first week of June, from the 3rd to the 5th, the

Annual General Assembly (AGM) of ANHP took place in Cuenca and it was a wonderful meeting full of tourism, fun, in which to be together and share experiences.

- On June 3, during the AGM, ANHP presented a new app for PH patients, to help them monitor their condition. The app was designed to be a medication management and educational tool and a resource for patients to keep track of the progress of their condition.
- On June 11 ANHP took part in the Annual Assembly of Feder.
- On June 23 the first meeting of the new ANHP Board of Directors, elected at the AGM, took place.
- On June 29, as a member of the Foro Español de Pacientes (Spanish Patients Forum) ANHP attended their third General Assembly. Irene Delgado, ANHP Secretary, was the official representative.
- On September 15, ANHP attended a lecture entitled "Descubriendo la investigación en las ER" (Discovering research in rare diseases), organized by Pharma Industria.
- On September 16 ANHP attended, as a patient representative, the meeting of the Consejería de Sanidad de Madrid (Health Counsellor of Madrid) with the objective to bring forward proposals for improved management of PH.
- From September 15 to 18 ANHP attended the Annual PH



Facebook advertising

In January 2017 we are going to advertise our Zebra video on Facebook to spread awareness about PH. "Doctors are taught

Conference of PHA Europe in Castelldefels, Barcelona

- On September 25 ANHP participated in the “Week of the Heart” in Madrid, as in past years, with an information stand. The slogan was “Por un corazón feliz” (For a happy heart).
- From October 4 to 7, in Gijón, Asturias, ANHP exhibited again “La habitación de la HAP” (the “PH room”) in the frame of the National Congress of the Spanish Hospital Pharmacy (Sociedad Española de Farmacia Hospitalaria)
- From October 7 to 14, ANHP participated in the “Plataforma de Participación Ciudadana en Sanidad” (Health Citizen Participation).
- On October 21 ANHP, in cooperation with the Hospital 12 de Octubre in Madrid, organized a conference on PH genetics (Jornada Abierta de Genética para Hipertensión Pulmonar), where patients from all parts of Spain attended to be informed about the genetics of their disease. They also had the opportunity to participate in a genetic study. The Association paid the travel and accommodation expenses to the patients when needed. ANHP made a presentation about the benefits and the interest of the associationism.
- From November 2 to 4, ANHP participated in the E-Health National Congress in Madrid, organized by Com.

Salud and AIES, Asociación de Investigadores en E-salud (Association of researchers in E- Health).

- On November 8 ANHP participated in the debate “La investigación se quita la bata, desde el microscopio al medicamento”, in Madrid, organized by Fundación Más que Ideas (Foundation more than ideas).
- On November 17 and 18 ANHP attended the 1st Congress of FENAER-EFA (EFA is the European federation of allergy and airways diseases patients’ associations) in Madrid.
- On November 25 the 5th conference “Open Doors: patient and research” (V Jornada Puertas Abiertas : el paciente y la investigación) took place at the headquarters of Lilly’s Laboratories in Madrid.
- On December 1 ANHP participated in the workshops on oxygen-therapy and apnea organized by Aula INIDRES.
- As every year in December ANHP organized a campaign for the Spanish lottery drawing.

Eva García

Asociación Nacional de Hipertensión Pulmonar

www.hipertensionpulmonar.es

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



Emergency kits in schools and research grants

During the gala event the FCHP project for the development of PH emergency kits was presented to the participants. This project was launched in the course of the year in schools attended by children suffering from PH and have been prescribed oxygen therapy. This is an initiative on which the FCHP had been working on for a long time, in collaboration with Oximesa. According to Enrique Carazo, President of FCHP, “this is a great step forward not only because small children can now count on an effective treatment in case of emergency, but also because of the involvement of teachers and teaching staff in this initiative that allows, step by step, PH to no longer be an invisible disease in our society”. The briefcases, which will be installed in a total of eight schools across Spain, contain an oxygen pump and a kit with the basic instructions for action in case of cardiorespiratory arrest.

Research grants

During the gala event the new scholarships for research projects for the period 2016-2017 were also announced. According to Enrique Carazo “three years after the first call and after having spent more than 60.000 euros, professionals who have received the support of our Foundation have obtained important achievements in reference centers in Spain, in the University Hospital Doce de Octubre, Clinic of Barcelona or the University Hospital Ramón y Cajal”.

Awareness raising and fundraising activities

Enrique Carazo highlighted the important role of people who make donations to cover the research projects through their solidarity SMS campaign called “Breathe”, which was launched a year ago. The funds raised have allowed the FCHP to increase its contribution to the Institute of Health Carlos III and CIBERES, to continue with the services provided by our Foundation and to partially fund the call for scholarships.

The FCHP also raised funds with a concert in Cantillana (Seville) in favor of little Alexandra (a PH patient) and a charity gala in Leganés on the occasion of WPHD. The FCHP has also received donations through charitable markets, theater plays, dance gowns, painting exhibitions, concerts, auctions, football tournaments, paddle tennis, golf... to which it was accompanied by friends like Josema Yuste, Óscar Hígares, Quique Esteban or Nacho Aranda, among many others.

Enrique Carazo concluded by saying that the motto of our seventh anniversary should be: “For an appropriate and innovative treatment for PH. Save lives!”

Enrique Carazo Minguéz

FCHP Fundación Contra la Hipertensión Pulmonar

www.fchp.es/es

www.facebook.com/fundacionhp



FCHP seventh anniversary celebrations

On November 24th the Fundación contra Hipertensión Pulmonar (FCHP) commemorated its seventh anniversary, in Madrid. The highlight of the evening was the official handing over of a check for 80.000 euros to the Institute of Health Carlos III and the Respiratory Diseases Networking Biomedical Research Centre (CIBERES), to fund the EMPATHY research project on this rare, disabling and deadly disease. The Gala event was conducted by journalists and TV presenters Carlos García-Hirschfeld and Marta Solano. Among the attendees there were many friends and supporters of the FCHP,

including Álvaro Roldán, Assistant Deputy Director General for Evaluation and Promotion of Research at the Carlos III Health Institute; María Jesús Martínez Fuentes, Deputy Director General of Information and Patient Care of the Community of Madrid; Marta Varón, Councilor of Social Welfare of the City Council of Parla and María Elena Escalante, delegate of the Spanish Federation of Rare Diseases (FEDER) in Madrid. Dr. Miguel Ángel Gómez-Sánchez, Dr. Joan Albert Barberá, Pilar Escribano and María Jesús del Cerro, as well as Prof. Francisco Pérez Vizcaíno, presented the main advances that have been achieved regarding the EMPATHY Research Project on PH.



SPAIN HPE-ORG

A new patients' organization is created in Spain

Hipertensión Pulmonar España (HPE) has been founded in 2016. It is a patients lead multidisciplinary initiative, based on collaboration between patients and health professionals fostering teamwork. The organization is formed by pulmonary hypertension patients motivated by the need of change.

We believe that it is vitally important to be informed and empowered patients so that we can take responsibility for our own self-care and get involved in decision and policy making, which is our right as patients, and also train ourselves to be part of ethical committees, intervene in the design of medical trials and actively contribute to the good functioning of the European Reference Network.

Our commitment is to promote self-care, co-responsibility and

autonomy for people living with PH, to promote changes in habits that improve the quality of life of patients through the exchange and transfer of knowledge and experiences between patients and experts.

The birth of this new organization responds to the need to cover a gap in the services and support provided in Spain, it is not to compete with other patients' organizations but to complement their work. As a matter of fact, right from the start one of the first activities is the ongoing dialogue to reach a trilateral agreement with two of the existing patients' organizations in the country.

María Rodríguez, Hipertensión Pulmonar España
www.hipertension-pulmonar.com
www.facebook.com/pg/HPSpain.org



SWEDEN

This autumn PHA Sweden organized two successful patient meetings. One together with the PH team of Gothenburg University and one with the PH team of Linköping University Hospital. A total of 120 people came to Gothenburg and Linköping and many of the visitors were relatives or

friends with little knowledge of the disease.



Patrik Hassel, PHA Sweden

<http://pah-sverige.se/> - <http://on.fb.me/WcaOWZ>



SWITZERLAND-SPHV

Patient Meeting - Congress Hotel in Olten January 23



For the first time SPHV organized a get-together only for patients and their families. Willi Oesch welcomed

eleven participants as well as Martin Nobs, a psychologist, to act as moderator of the discussions. After a short introduction on the topic "Pulmonary Hypertension and partners - managing the disease together" everybody was asked to introduce themselves briefly and to talk about what they felt were the greatest issues in dealing with PH together. After the short round of introductions it was pretty clear that the topics would be numerous and diverse and would lead to inspiring discussions. Then Martin Nobs held his lecture about his topic. The group discussion which followed was very lively with many different topics touched upon and interesting exchanges. As a psychologist, Martin was well placed to give advice and tips on how to manage daily life with a patient. All participant expressed the wish to hold another such meeting in January 2017.

6th Annual General Assembly March 19



On March 19 our general assembly was held in the Congress Hotel in Olten. 22 members were present.

President Bruno Bosshard presented the annual report of activities, which was approved by the AGM.

May Walk to the East of Switzerland May 20

This year our annual trip took us from Basel via Olten to a coffee stop in Zürich, where the last guests joined us, to further to the north-west of Switzerland, through south Germany across the vineyards of Hallau and finally to the canton Schaffhausen, where we had lunch in the restaurant Babental. In the afternoon we visited the big waterfall on the Rhine, near Neuhausen. Some members and their traveling companions took the opportunity of stepping on the big rock in the middle of the river. In the evening we drove back home.



Swiss PH Meeting in Olten June 4

At exactly 10 o'clock SPHV President Bruno Bosshard opened the PH Meeting in Olten. He welcomed our guest speaker Dr. Med Rebekka Kleiner, who is working in the Hospital for Pneumology and Sleep Medicine in St. Gallen. In her talk Dr. Kleiner spoke about PH therapies, the current state of research, PH medicines and the effect of diuretics. The "Klostersongers" were our special guests and embellished our meeting with rhythmic spirituals and gospel songs.

12th Company triathlon in Zürich July 23

For the 10th time Bayer took part in this Company triathlon in Zürich, a contest which consists of 750 meters swimming, 25 kilometers cycling and 7 kilometers running. This contest took place as prelude of the "Ironman" in Zürich. The members of our association were invited to encourage and support Bayer's competitors. Bayer donated an amount for every Bayer team which took part in this triathlon to our Swiss PH Association.

Excursion to the glass blowing factory in Hergiswil August 19

With two buses, one from Basel and one from Zürich, we travelled with a lot of members of our association to the "Vierwaldstättersee" to Hergiswil to visit the glass blowing factory. During a tour through the company museum, we learned a lot about the history of glass manufacturing in Switzerland since the 3rd century. The glass factory in Hergiswil was founded in 1817 by the brothers Siegart. We

watched with great interest the workers working with glass compounds on an oven at a temperature of 1.500 degrees centigrade. After the tour we had some time to shop for glass objects in the company's shop.

7th IWB Marathon in Basle September 25, 2016

The 3rd yearly participation in the Basler Marathon was a great success for our association. Altogether, more than 100 Actelion employees and their families took part in this competition, with different distances. They were running more than 1.500 km to raise awareness for PH and to support our association. Some of our members were there to encourage the runners. Our association received a donation for our engagement regarding this rare disease.

20th PH Patient Meeting in Frankfurt am Main October 28-30

From October 28 to 30 a group of about 30 people from our association travelled to the German PH association ph e.v.'s annual patient meeting in Frankfurt. We were listening to the talks about the progress of research and medicine in the field of PH with great interest.

Regional Patient Meetings

This year again, PH patients and their families exchanged a lot of experience and information in the course of five regional PH patient meetings, organized by SPHV. The attendees always met for lunch or a snack followed by discussions. The meetings were held in Bern, Chur, Olten, Meggen and Zürich and were all attended by a Board member.

Our planned activities in 2017

21 January 2017 - 2nd Family Meeting in Olten
8 March 2017 - 1st Board Meeting in Olten
18 March 2017 - 7th SPHV General Assembly in Olten
10 May 2017 - 2nd Board Meeting in Olten
20 May 2017 - 16th Patient Meeting in Olten
9 June 2017 - Day Excursion (asparagus lunch)
9 August 2017 - 3rd Board Meeting in Olten
August/September - 2-Day-Excursion
2-3 September 2017 - PH Children Meeting in Thun

Therese Oesch, SPHV

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



UKRAINE-SISTER DALILA-PHURDA

LCCF of "Sister Dalila", NGO "Pulmonary Hypertension - Ukrainian Rare Disease Association" (PH URDA) organized the following events and activities:

- The Project #BreathOfSuccess as a part of Ukrainian conference devoted to the 50th anniversary of the Lviv cardiac surgery. The leading specialists of Ukrainian and Polish medicine spoke about Chronic thromboembolic pulmonary hypertension (CTEPH), medication treatment of CTEPH as a palliative remedy, surgical intervention, removal of blood clots. There was a direct inclusion from 2 operating rooms, where the surgeries with removal of blood clots for patients with CTEPH were performed. The organizer of the Conference, a medical doctor, heart surgeon of Lviv Regional Hospital, Professor - Lubomir Kulik told about representatives Sister Dalilas Charity Foundation, PHURDA and their work towards supporting PH patients, improvements of life quality and life duration and spoke about thrombolysis in the pulmonary arteries. What we saw was a lively debate between the speakers and conference participants about the diagnosis, medical therapy, surgical intervention in CTEPH. Each participant received a certificate of participation. The Project #BreathOfSuccess was supported by PHA Europe.
- The activities in fundraising: The "Coffee cup" or "Save the life of orphan together with a famous person", a contest Mini Miss & Mister Lemberg 2016, Campaign "Cork of Life", involving the media, television, radio, audio and video production.
- LCCF of "Sister Dalila" received the Award at National Benefactors Rating in the category: "Dynamics of spending on charity in the 2014/2015 years". National Benefactors Rating - an annual national rating, which aim is to promote transparent and accountable philanthropy sector in Ukraine. The organizer of this rating is Ukrainian Philanthropists Forum and LCCF of "Sister Dalila" is a member of it.
- We conducted a social photoshoot of PH-patients together with famous people. Socially responsible photographers,



- professional makeup artists helped with that photoshoot.
- We organized a meeting with children (PH patients) and their parents at Entertaining Children Center "Baby Planet".
- The Campaign InformatyynnyHrim # PH (an Informational thunder) is going on, it consists of videowishes for PH patients from different people.
- The Project "Early diagnosis of pulmonary hypertension in Lviv region" continues, its aim is to overcome the informative barrier about PH in Lviv region, PH symptoms, the importance of early diagnosis and treatment.
- Thanks for volunteers help from Germany and Poland we provided medical facilities by medicines, medical instruments.
- We presented the "Early diagnosis" project, supported by the PHA USA, at the "Leaders Summit" in Dallas, USA, June 17, 2016. We also took part in the 25th International Conference of PHA, and our aim was to establish contacts with PH associations worldwide and use their skills and achievements for the possibilities and needs of Ukraine.
- We took part in the APHEC in Barcelona, where we received an award for organizing a WPHD 2016 event and for the fundraising campaign "Cork for Life". For us,





this award is especially valuable because it is recognition of PHA Europe of our activities in Ukraine.

Plans for 2017

- Creation of a transplant coordinator post in Ukraine.
- Creation of a unified register of recipients.
- Establishing cooperation with clinics in Europe.
- Approval of a uniform registry of patients with PH.
- Approval of a program of free medicines for PH patients in other regions of Ukraine.

- Patenting of new drugs in Ukraine.
- Patenting of a Swan-Ganz catheter.
- Continuation of the project “Early diagnosis of PH in the Lviv region” and the campaign “Cork of life”.
- Developing a successful tool to overcome the informative barrier about PH in Ukraine.

Oksana Kulish, Sister Dalila-PHURDA
o_kulish@inbox.ru



urement of medicines for patients in Ukraine through international organizations at the Ukrainian Ministry of Health, Kyiv. PHA Ukraine, represented by Oksana Aleksandrova took part in the press briefing. The inhibition of the procurement process in 2016 has endangered the lives of orphan disease patients in Ukraine, so PHA Ukraine has applied to the government to immediately accelerate the process of procurement of medicines by international organizations.

- **August 17:** Radio interview on Public Radio, Kyiv, on the development of transplantation in Ukraine and the problems to be solved.
- **August 28:** Training session on “Self-management and the way to solve problems of patients with rare diseases”, Rivne, Ukraine
- **September 8:** Scientific conference on “Rare diseases in medical practice” and exhibition “Orphan patients - a priority of the state”, Kramatorsk, Ukraine. These events were attended by patients with rare diseases, doctors and represen-



tatives of local authorities. Oksana Aleksandrova delivered a short lecture about PH, its causes, symptoms, diagnosis, treatment. This is a very important part of our association's activity, to travel around the different regions of Ukraine, to meet with patients and physicians to share knowledge, because even doctors still know very little about it.

- **September 21-23:** at the XVII National Congress of Cardiologists of Ukraine a session was devoted entirely to PH. Discussions covered the issues of diagnosis, treatment and work of the PH centers. For many cardiologists attending the session, it was important to discuss the problem with the PH center specialist. Oksana Aleksandrova reported on the activities of the PH association and distributed brochures and posters to doctors about PH treatment. It was very rewarding to see that every year PH diagnosis and treatment issues are becoming increasingly important for cardiologists all over Ukraine.
- **October 12:** Charitable auction “ARTvsWAR”, where PHA Ukraine was co-organizer. In this auction there were paintings by patients with rare diseases and combatants in the East of Ukraine. The auction was organized thanks to one of our member and PH patient and talented artist, Maria Prokofieva. Proceeds from the sale of the paintings were used to support families that lost someone in the war.
- **November 10:** Scientific conference “Rare diseases in medical practice” and the exhibition “Orphan patients - a priority of the state”, Cherkasy, Ukraine.
- **November 18:** Scientific-practical conference “Rare diseases in medical practice” and the exhibition “Orphan patients - a priority of the state”, Zhytomyr, Ukraine.

At the same time, we have sent requests to chief cardiologists, chief pediatric cardiologists and Departments of Health of each of the 24 regions of Ukraine in order to verify the list of patients and find out their needs for necessary medications. These needs should be taken into account in each region. This is a very complex and important activity, since procurements are conducted on the regional level, and the patients are not always registered with a doctor in the region, as treatment often takes place in the PH centers in Kyiv or other regions of Ukraine, where there are PH specialists.

PH guidelines

We are glad to inform you that the Protocols for the treatment of PH of children and adults was officially adopted in Ukraine

in 2016 (Ukrainian guidelines). Thus a very important phase of the work initiated by our association a year ago ended. We are also one of the co-authors of these Protocols. The protocols took into account all the latest recommendations of guidelines for PH. Now Ukrainian doctors have clear guidelines for the diagnosis and treatment of PH, approved by the Ministry of Health of Ukraine.

Organ Donation and Transplant

PHA Ukraine has made an analysis in Ukraine on:

1. How many people die waiting for transplants.
2. How much money Ukraine loses by not developing transplantation in the country.
3. What problems need to be addressed for the development of transplantation in Ukraine. We took part in a Round Table meeting on transplantation involving deputies, officials of the Ministry of Health and the leading specialists in this area of medicine.

The bill on transplantation was passed in the first reading, now a revision of the provisions of this bill takes place. A working group for transplantation has been set up in the Health Committee of the Parliament. Also, a working group for transplantation has been set up in the Ministry of Health of Ukraine.

Summary of main activities

- Ensuring the procurement program for pulmonary hypertension drugs.
- Cooperation with 24 regions of Ukraine on the establishment of regional centers of pulmonary hypertension.
- Drafting the bill on transplantation in the Committee of the Parliament.
- Development of the “Orphan Patients - a Priority for the State” Program.
- Activities in the Public Council of the Ministry of Health of Ukraine on patients' issues and in the Rare Diseases Committee.
- Elaboration of the protocol on PH treatment is finished.
- Work in the commission for sending patients abroad for treatment.
- Elaboration of the official register of patients with PH
- Information dissemination on problems of PH patients.
- Information dissemination on transplantation problems.

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



Here are some of the activities organized by PHA Ukraine in the course of the year:

Conferences and events

- **July 7:** the Ukrainian PH association, represented by the Chairman of the Board Oksana Aleksandrova took part in a Round Table in Kyiv, in the Verkhovna Rada Committee (Parliament), to discuss drug procurement by the state budget through international organizations. Purchases through international organizations would help avoid potential corruption issues during the process of procurement of medicines and, therefore, to buy drugs at lower prices. Summing up the meeting of the Round Table, the top echelon of government officials of Ukraine confirmed that the procurement of medical preparations in 2016 will be implemented through international organizations, and also promised to speed up the process.
- **July 12:** a press briefing was organized on the issues of pro-

LATIN AMERICA



When the Latin Society of Pulmonary Hypertension was founded, Spain was the only Spanish-speaking country with an association of patients. By 2016, there are 18 national organizations and 2 support groups specialized in dealing with patients with HP in 14 Latin American countries, including Brazil.

One of the biggest achievements of the Latin PH Society is the success at the Parlatino (Latin American Parliament) to stimulate a Framework Law on Socio-Sanitary Care for rare diseases in Latin America and the Caribbean involving members of the Pan American Health Organization as well. And the highest representation made by Migdalia Denis, president of the LPHS, has been to speak in favor of the rare diseases in the Latin American region before the United Nations Economic and Social Council (ECOSOC) as a member of Rare Diseases International (RDI). In 2015, SLHP was accepted into the International Alliance of Patients' Organizations (IAPO), and in 2016 its representative was elected to the Board of Directors representing

Latin America. This is a transcendental achievement that has led Pulmonary Hypertension to international platforms of high relevance and prestige. This appointment includes representation of Latino patients at the WHO/PAHO General Assembly. In addition, SLHP has been making important international alliances that have allowed it to join the European Rare Disease Organization (EURORDIS), the Ibero-American Association of Rare Diseases (ALIBER), as a member of the European Lung Foundation (ELF) international patients advisory committee.

The SLHP has been invited to participate in the inauguration of the NGO Committee for rare diseases at the United Nations in New York in 2016. Finally, together with PHA Europe, the SLHP has been invited to become a member of Working Group 13 on "Patient Perspectives". At the World Congress of NICE 2018.



Juan Fuertes, PHA Europe



medical research environments, having served as assistant Vice President of the University of California, San Francisco (UCSF) Foundation.

Some of us at PHA Europe had the opportunity to meet Brad personally at the PHA's International Conference in Dallas June 17-19. Others, including myself, were able to meet him in Zurich on November 29 at the multistakeholder workshop on patient self management supported by Actelion. I was also fortunate enough to be able to say goodbye to Rino Aldrighetti in Basel in May.



Good luck Brad and huge thank you Rino for the fantastic work you have done for the PHA and the PH cause worldwide in the past 25 years!

Pisana Ferrari, PHA Europe

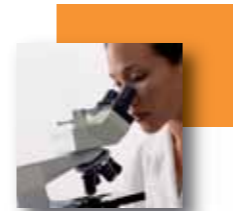
USA

This was a year of big changes in the Pulmonary Hypertension Association (PHA), the USA's oldest and world's largest organisation, founded in 1996. On April 27 an official announcement was made about the nomination of Brad A. Wong as President and CEO. It was also announced that Brad would assume his duties on June 19. Brad, whose appointment by PHA's Board of Trustees coincides with the association's 25th anniversary, is the second CEO in PHA's history (after Rino Aldrighetti). He comes to PHA from the Foundation of the American Academy of Ophthal-



mology (FAAO), where he served as Executive Director. His accomplishments included creating innovative programs, raising the foundation's visibility, establishing strategic partnerships, and increasing and diversifying funding. Brad also brings broad knowledge of academic medicine and bio-

UPDATE ON PH TREATMENTS AND RESEARCH



RIOCIGUAT PATENT CHILD

A treatment study is currently open to patients with Pulmonary Arterial Hypertension from 6 to less than 18 years of age. The study is titled PATENT CHILD and involves the use of the PAH specific medication riociguat. This study consists of two phases: a) Dose titration phase (up to 8 weeks) and b) Maintenance phase (16 weeks) followed by an

optional long-term extension of treatment. Patients willing to participate in PATENT CHILD must be under treatment with standard of care comprising background PAH therapy on stable dose. However, eligible patients should not be under treatment with phosphodiesterase (PDE)-5 inhibitors (such as sildenafil, tadalafil, vardenafil). PATENT CHILD is being conducted at the following countries: Belgium, Germany, Hungary, Italy, Poland, Romania, Spain, UK and also in Turkey.

Further Study details are posted in ClinicalTrials.gov: <https://clinicaltrials.gov/ct2/show/NCT02562235?term=PATENT+CHILD&rank=1>

Next PHAE newsletter

The next Mariposa Journal will be issued in July 2017 (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!*



February 21-23, Brussels, Belgium

BLACK PEARL GALA AND 3rd MULTI-STAKEHOLDER SYMPOSIUM

The Black Pearl Gala Dinner is a fund raising event organised by EURORDIS within the context of celebrations for RARE DISEASE DAY. It is followed by a two day Multi-stakeholder Symposium on Improving Patient Access to Rare Disease Therapies, which brings together patient advocates, payers, HTA bodies, academics, clinicians, policy makers, investors and industry representatives.

March 9-10, Vilnius, Lithuania

3RD EUROPEAN REFERENCE NETWORK (ERN) CONFERENCE

During this conference there will be the awarding ceremony and kick off of the approved ERN's including ERN-LUNG, which has a section on pulmonary hypertension and where PHA Europe is present.



April 10-11, Brussels, Belgium

EPF ANNUAL GENERAL MEETING (AGM) AND LEADERSHIP MEETING

Juan Fuertes, advocacy and access manager at PHA Europe, is sitting on the Board of EPF and will be attending the AGM and Leadership meeting.

May 5, Worldwide

5th WORLD PULMONARY HYPERTENSION DAY (WPHD)

PH associations around the world join forces on WPHD to raise awareness of the disease. In Europe the theme is sports and the slogan is "Get breathless for PH", the idea being that healthy persons race to show solidarity for PH patients who are not able to do any physical activity.



May 19-20, Budapest, Hungary

EURORDIS MEMBERSHIP MEETING

This annual event provides a platform for EURORDIS members and patient advocates for networking opportunities, access to information and sharing experiences.

August 26-30, Barcelona, Spain

EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS

PHA Europe will be present at the ERS Annual Congress 2017. This congress is the largest cardiovascular medicine meeting in the world and covers all disciplines from basic research to clinical practice.



September 9-13, Milan, Italy

EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS

PHA Europe will be present with a booth at the ERS Annual Congress 2017. This congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

September 21-24, Barcelona, Spain

PHA EUROPE ANNUAL PH EUROPEAN CONFERENCE

The Annual PH European Conference (APHEC) is one of PHA Europe's most important yearly events. Leaders from 30 European countries attended the 2016 meeting.



2018 AT A GLANCE

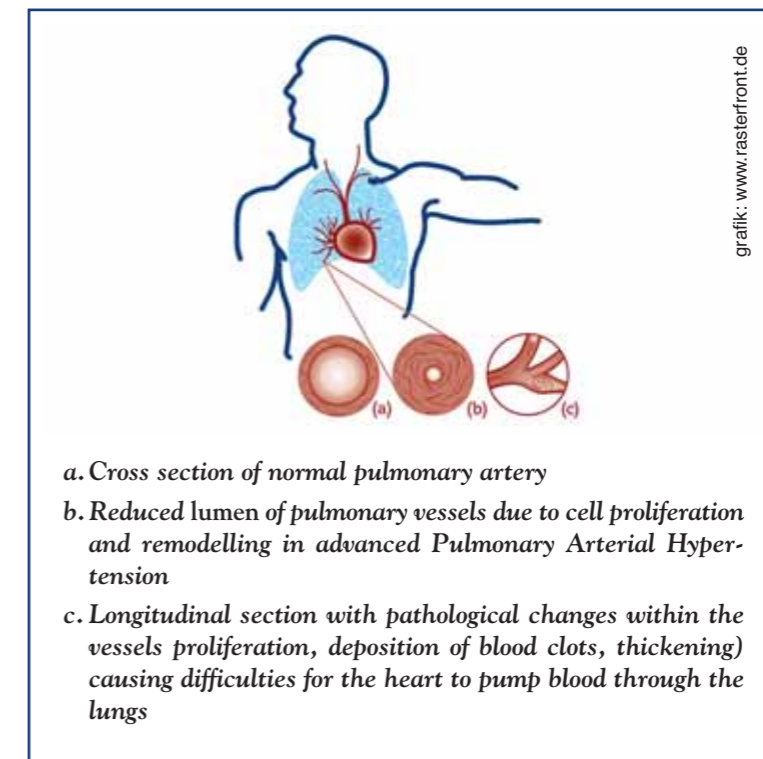
- 6TH WORLD SYMPOSIUM ON PULMONARY HYPERTENSION, Nice, France, February 27-March 1
- 9TH EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS (ECRD), Vienna, Austria, May 10-12
- INTERNATIONAL PH CONFERENCE AND SCIENTIFIC SESSIONS, Orlando, Florida, June 29-July 1
- EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS, Munich, Germany, August 25-29
- EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS, Paris, France, 15-19 September

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 39 Pulmonary Hypertension patient associations across 33 countries. 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.

Members of PHA Europe and contact details

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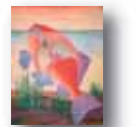


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CZECH REPUBLIC



Sdružení pacientů s plícní hypertenzí, z.s.
Bělehradská 13/7 - 140 00 Praha 4
www.plicni-hypertenze.cz
info@plicni-hypertenze.cz

DENMARK



PAH Patientforeningen
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GREECE



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HUNGARY



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IRELAND



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ITALY



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LITUANIA



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NORWAY



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POLAND



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PORTUGAL



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REPUBLIC OF MACEDONIA



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ROMANIA



Association of pulmonary hypertension patients
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RUSSIA



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SLOVENIA



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SPAIN



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SWEDEN



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SWITZERLAND



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TURKEY



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