



# PULMONARY HYPERTENSION Mariposa Journal

WINTER 2018 • PHA EUROPE'S OFFICIAL JOURNAL • N. 21

PROUD WINNER OF  
THE EURORDIS 2018 BLACK PEARL AWARD  
FOR BEST PATIENT ORGANIZATION



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





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 Friends,

I am delighted to present the Winter 2018 edition of Mariposa. This year was extremely busy and it is a great pleasure to look back on these achievements and projects. We can all be very proud of them!

The year actually started in the winter of 2017, when we received an amazing e-mail from EURORDIS, Rare Diseases Europe, announcing that PHA Europe had been voted as the “Best Patient Organization of the year 2018”! This prestigious award is a huge honor for us and testifies to the appreciation of the hard work and dedication of all of our member associations, volunteers, Board and staff members. You can gain some insights into the EURORDIS Gala Dinner and Awards Ceremony held on 20th of February in Brussels, and even read the complete thank you speech, in this edition of our journal.

The World PH Symposium, which is organized every five years and is the biggest and most important PH specific scientific meeting, took place at the end of February, just after the Gala Dinner, in Nice. PHA Europe had a booth at the congress and the chance to attend the lectures (in some European countries this is becoming an issue as local legislation restricts the audience to medical experts) and meet all the main stakeholders on the PH medical field. The papers with the conclusions have not been finalized yet, however you can learn from this edition how the preparations are made for the symposium and about some of its proposals for the future, which are likely to have a major impact in the coming years.

The Board meeting of the European Reference Network for Rare Respiratory Diseases (ERN-Lung) was organized in Frankfurt in early March. PHA Europe plays an active role in the network and is represented in the highest body in ERN-Lung, the Medical Steering Committee. ERN-Lung provides expert opinions on different rare respiratory diseases and, thanks to previous years' endeavors, the technical background is now fully operational. You can become familiar with the different platforms by visiting the ERN-Lung section in this journal.

In the spring PHA Europe was also invited to a couple of workshops organised by the the European Medicines Agency, where we could present the patients' perspective and positions on different matters, including pediatric issues and collaboration possibilities between different stakeholders. Despite the fact that the entire Summer edition of Mariposa was dedicated to World PH Day (WPHD),

it would be a pity not to mention and reiterate some of its main highlights here. The very first WPHD was held in 2012 in Madrid in the form of a scientific meeting, but it is organized and has been operating in the current way and structure for the past 5 years. In 2018 we fine-tuned some of the details (e.g. the launch of a photo contest and increasing the focus on web-based activities), but we can proudly say that the original concept and idea still works very well: in 2018 alone we had 61 WPHD local events, with almost 45.000 attendees and a great media coverage: 300+ articles and lots of TV and radio spots. The online numbers are even more impressive: this year our Thunderclap awareness campaign for WPHD reached almost 4.5 million people. To put this number and our success into perspective, the hepatitis C community, which is more than 447x bigger (!) than us, reached (only) 16 million people during their yearly campaign.

At the beginning of the Autumn we organized our Annual PH European Conference (APHEC), which serves multiple purposes. The Annual General Assembly is a mandatory part of this gathering, which is, however, supplemented by interesting lectures from top PH physicians and experts from other fields, and different workshops, providing both learning capacity building opportunities.

The activities of the Fall even accelerated as we continued our advocacy work in the annual congress of the European Respiratory Society and our capacity building work in the multidisciplinary workshops in Paris and at the Baltic PH conference.

We would like to thank all our member associations for their dedication and hard work. We are very grateful for the support and collaboration of the wider rare disease community, in particular EURORDIS, the European Lung Foundation, the European Patient Forum, the ePAG representatives of the different ERNs, and, last but not least, our highly-esteemed partners from the medical field. We also warmly thank our industry partners and look forward to further collaboration on common projects.

Let us conclude this Editor's memo with a big applause to Pisana Ferrari, PHA Europe's former CEO, who was the real engine and heart of PHA Europe for many many years. Without her enthusiasm PHA Europe would not be as well-positioned as it is now. We know every change is difficult, but we are confident that we are heading the right direction.

Gergely Meszaros

## Introduction of PHA Europe as the winner of the EURORDIS "Best Patient Organisation" award 2018

"Pulmonary Hypertension Association Europe is dedicated to improving the lives of patients living with pulmonary hypertension (PH) in Europe by working with its members to enhance awareness of PH, promoting optimal standards of care for people living with the disease, ensuring the availability of all approved treatments and encouraging research for new medicines and therapies. Founded in Vienna in 2003, the organisation has grown to a level where it now includes 29 patient associations from 33 countries in Europe. Their Call to Action, which was presented in the European Parliament in 2012, is to improve access to expert care, improve awareness and screening, encourage clinical research and innovation, empower patient groups and ensure the availability of psychosocial support. The European Parliament event on Organ Donation and Transplant in October 2016, initiated by PHA Europe, is an example of how far the organisation has succeeded in reaching out to the decision makers at EU level, thanks to close collaboration with the European patient federations for diseases where organ transplants are relevant. Four representatives from PHA Europe are also members of the ePAG



(European Patient Advocacy Group) network. PHA Europe recently conducted their "White Spots" programme. PHA identified countries in which there are no PH patient associations – White Spots – and consequently, in European countries with more than one million citizens, only two countries remain with no patient associations. PHA continued to grow with their Fellowship programme, which aims to improve communication between member associations. The Annual PH European Conference (APHEC) gives member associations opportunities for capacity building as well as for information and education. The 2016 APHEC featured three international PH medical opinion leaders as speakers, a cardiologist, a pulmonologist and a pediatrician, who provided the attendees with the latest information on treatment strategies, surgery and research.

<https://blackpearl.eurordis.org/previous-awardees/>

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**Brussels (Belgium), February 20**  
**BLACK PEARL DINNER**

PHA Europe was awarded the prize for the “Best Patient Organisation” of 2018 by EURORDIS. Dieter Kulla, Gerry Fischer and Hall Skaara participated in the Black Pearl Dinner in Brussels. Hall held the acceptance speech on behalf of PHA Europe.

**Nice (France), 27 February 27-March 1**  
**WORLD PH SYMPOSIUM**

Traditionally the PH World Symposia, started in Geneva in 1973 and held every 5 years since 1998, have marked the progresses in PH science and has anticipated future developments. PHA Europe was present with a booth and four delegates.



**London (UK), March 20**  
**EMA WORKSHOP**

Hall Skaara spoke at EMA’s conference on the ten year follow up of the implementation of the pediatric EU regulation. Hall was one of eight speakers and represented the patient perspective. EMA’s action plan from the meeting was publicized a few months later.

**Frankfurt (Germany), March 5-6**  
**ERN-LUNG BOARD MEETING**

Gergely Meszaros, who is a Member of the ERN-LUNG Medical Steering Committee, attended the ERN-LUNG Board meeting on behalf of PHA Europe.



**London (UK), May 29-30**  
**EMA AND DG SANTÉ WORKSHOP**

Gergely Meszaros represented PHA Europe and the ERN-Lung in this meeting, the aim of which was to explore where the ERNs, regulatory bodies and the EU might find synergies and work together.

**Vienna (Austria), May 10-12**

**EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS**

The European Conference on Rare Diseases & Orphan Products is the largest multi-stakeholder gathering in Europe for the rare disease community covering research, development of new treatments, healthcare, social care, public health policies. Danijela Pešić attended the conference on behalf of PHA Europe.



**Orlando (USA), June 29-July 1**  
**PHA’S INTERNATIONAL PH CONFERENCE AND SCIENTIFIC SESSIONS**

Gerry Fischer and Hall Skaara were two of the representatives for PHA Europe at the bi-annual international PHA conference in Orlando, Florida. They presented two of PHA Europe’s programs: The White Spot Program and The Capacity Building Program.

**Paris (France), September 15-19**

**EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS**

Juan Fuertes and Gergely Meszaros represented PHA Europe on this event. Gergely ran a presentation about patient expectations as part of the ERS/ERN-LUNG joint symposium.



**Berlin (Germany), September 13-16**  
**PHA EUROPE’S ANNUAL PH EUROPEAN CONFERENCE (APHEC)**

PH representatives from 30 countries attended this year’s APHEC.

**Paris (France), September 21**

**MULTIDISCIPLINARY TEAM WORKSHOP**

A couple of years ago Actelion launched series of multidisciplinary team meetings to discuss how patient involvement and patient self-management can best be addressed. Hall Skaara and Juan Fuertes represented PHA EU at the Paris meeting.



**Vilnius (Lithuania), October 19th**  
**BALTIC CONFERENCE**

Hall Skaara represented PHA Europe at the Baltic conference for PH patient associations. In addition to the three Baltic associations, representatives from Belarus, Russia and Ukraine also attended. Discussions centered on common challenges facing the associations, and rehabilitation for PH patients was also an important topic on the agenda.

**Upcoming events 2019**

**Brussels (Belgium), February 12**  
**EURORDIS BLACK PEARL DINNER**

A fund-raising event organised by EURORDIS within the context of celebrations for RARE DISEASE DAY.

**Brussels (Belgium), February 13-14**  
**3RD EURORDIS MULTI-STAKEHOLDER SYMPOSIUM ON IMPROVING PATIENTS’ ACCESS TO RARE DISEASE THERAPIES**

A series of panel discussions and interactive sessions on how to improve patients' access to rare disease medicines with the aim of producing a roadmap document.

**Brussels (Belgium), February 18**  
**EUDONORGAN SOCIAL AWARENESS EVENT ON ORGAN DONATION, EUROPEAN PARLIAMENT**

A multistakeholder event with the participation of members of the European Parliament (MEPs) with special focus on how to expand the donor pool and the roles of patient associations.

**Madrid (Spain), February 25-26**  
**2ND PH MEDICAL TRAINING FOR DOCTORS**

A PHA Europe funded initiative, now in its second year, to provide PH training to physicians in countries with no or little access to medical/surgical facilities or targeted drugs.

**Bucharest (Romania), May 17-18**  
**EURORDIS MEMBERSHIP MEETING (EMM)**

Each year, EURORDIS holds its General Assembly; every two years this is coupled with with a 2 day capacity-building workshop specifically targeted to its members.

**Paris (France), August 31-September 4**  
**EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS**

The largest cardiovascular medicine meeting in the world, which covers all disciplines from basic research to clinical practice.

**Madrid (Spain), September 28-October 2**  
**EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS**

A congress which involves the top experts in respiratory medicine as well as the entire spectrum of research and practice.

**2020 AT A GLANCE**

- EUROPEAN CONFERENCE FOR RARE DISEASES, 15-16 May, Stockholmsmässan, Stockholm (Sweden)
- PHA’S INTERNATIONAL PH CONFERENCE AND SCIENTIFI SESSIONS, 12-14 June, Anaheim, California (USA)
- EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS, 29 August - 2 September, Amsterdam (Netherlands)
- EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS, 5-9 September, Vienna (Austria)



# Annual PH European Conference

Berlin (Germany), 13-16 September 2018

Do you know what is the current marathon world record and the Annual PH European Conference (APHEC) have in common? Both of them are linked to the same place and time: Berlin, on the third weekend of September! PH patient representatives and leaders from all over Europe, and beyond, gathered from September 13 to 16, in Schmökwitz, a lovely locality near Berlin, surrounded by verdant forests and wonderful lakes. This was a big change, because since 2010 we have always held our annual conference in Barcelona. We hope that our members found it nice and enjoyed their stay.

We are delighted that our members were very well represented at the meeting. PH representatives from 30 countries attended, with an excellent geographical spread: Scandinavian and Baltic countries, Balkan and continental countries, and many more. We were also happy to greet delegates from the new Turkish association.

The APHEC continues to be the most important yearly event. The conference, which traditionally follows the mandatory Annual General Assembly, provides PH patient association leaders with opportunities for education, mutual learning and networking. Networking is becoming more and more important, because it makes it possible to share experiences and learn best practices.

The Annual General Assembly was kicked-off by the President, Hans-Dieter Kulla. In the opening speech he summarized the year's changes, including the reorganization of the structure, of some of the proceedings and the move of the official office address to a different district in Vienna. His speech was followed by the reports from the two PHA Europe departments. The attendees were given a short presentation about the newly launched initiative, the Capacity Building Program (CBP), which replaces the previous "White Spot" Program. Originally the aim of the White Spot Program was to support the setting up of patient associations in all European countries. Nowadays there are hardly any countries within Europe which do not have patient associations. This means that the next step is to help them become "mature". The CBP initiative is very important for the members, and therefore the discussion on unmet patient needs continued on the next day and a complete workshop was dedicated to it. The attendees were also informed about some important details about our EU-level advocacy activities, especially the work made in connection with the European Medicines Agency (EMA) and the European Reference Network (ERN-LUNG).

A membership application was submitted to the Annual General Assembly, but due to the short notice, a decision could not be made. It was also not possible to take a vote on the 2017 Financial Report, despite long discussions, because some accounting details were missing. All the attendees were able to share their standpoints, present their ideas and proposals on how PHA Europe could better serve its members and how

the collaboration with them could be enhanced. Some time was also dedicated to the different national reports: all of the delegates were asked to present the most important project or pressing problem they have in their own country. We heard about many interesting projects and lots of suggestions were put forward. The discussions continued right through the dinner. On the second day the focus was on education and capacity building. Prof. Henning Gall, from the University of Giessen's Lung Center, arranged a virtual "trip" for us. He told us about the world's biggest PAH registry and biobank and about their primary objective, which is to find biomarkers for PH. We heard about the ongoing Pegasus study, which aims to find the correlation between high altitude (eg. flying) and PAH. And we virtually "left" Europe to discover how the Kyrgyz population copes with living at an altitude of 2.500 meters.

The day continued with different workshops. Ieva, from Latvia, ran an excellent workshop and made all the participants work a bit. A delicate issue, namely the provision of medications and lack of resources, had to be resolved in small group discussions, but from different perspectives: from the patient associations', the payers' and the pharmaceutical companies'. Peter, from Sweden, addressed the challenges patient associations are facing in terms of young patients and provided valuable insights into the Swedish register, which is published on a yearly basis. The last presentation was a very interesting one from Tamás Bereczky, who represented the European Patients' Academy on Therapeutic Innovation (EUPATI). Mr. Bereczky presented the possible future model and infrastructure for clinical research, and the resources EUPATI could provide to adapt to these needs. During the presentation he emphasized the importance of patient involvement in the entire research and development (R&D) cycle. His main message was that there is a big need for empowered and expert patients and in order for us to be treated as equal partners we need to educate ourselves. This second day was even busier and tiring than the first one, so that everybody warmly welcomed the evening surprise, which was a boat trip. We were thus able to admire the beautiful lakes, the wonderful colours of the sunset and the untouched nature. We finished the tour in the late evening and when it was dark we moved to the lower deck of the ship to continue chatting. Traditionally, one day of the APHEC is dedicated to our industry partners. These days are very challenging, due to the huge amount of information, but at the same time very interesting, because we get insights into new studies and developments, future research and projects, and also receive some useful tips or practical information at first hand. This year we had as guest speakers representatives from Actelion, Bayer and Arena. Joelle Rebettez and Alessandro Maresta attended on behalf of Actelion. It was interesting to learn details about PHuman, an online e-book, which embraces different very useful resources. The e-book guides you through the different phases



Henning Gall



Prodromos Anthopoulos



Jörgen Persson



Joelle Rebettez



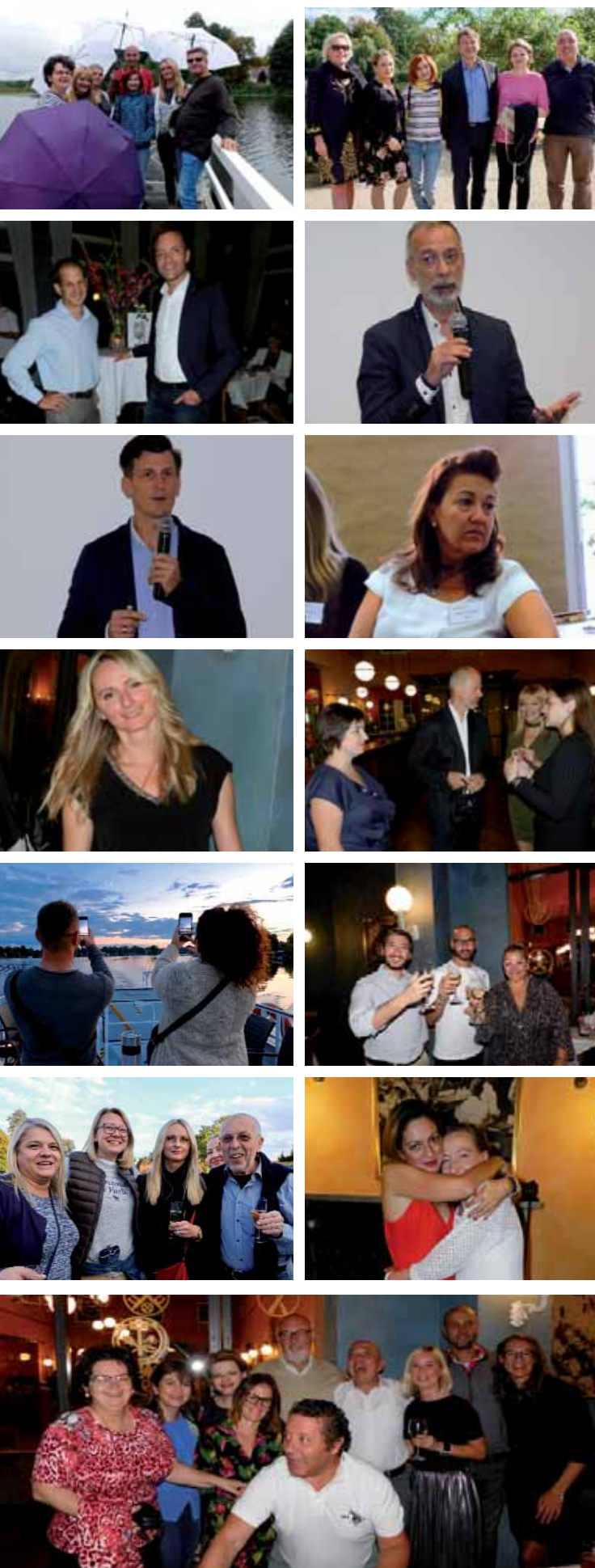












of the disease. A separate section within PHuman is dedicated to young patients, who share their stories, in particular concerning careers and hobbies. The third part is a valuable collection of webinars recorded throughout the year, relating to different, very relevant, topics.

The title of the presentation made by Thomas Ernst and Wolf-Dieter Rakutt, from Bayer, was “PAH: a life to live”. They outlined that there are new ways to approach the condition as PAH has increasingly become, thanks to medications, a chronic disease. It was emphasized that, based on different patient experiences, there is definitely a “life to live” after the diagnosis. However, one’s life needs to be adjusted to the new situation, which is sometimes like a rollercoaster.

We were delighted to also welcome Jörgen Persson, from Arena. Arena is in the process of developing a product which works in a similar way to selexipag, an Actelion drug. Both are oral prostacyclins. Their development has represented a major achievement and has raised huge patient interest, as, potentially, their quality of life could be changed significantly by eliminating the disadvantages of subcutaneous and intravenous infusion. Marie Mascia-Rand, from the Phaware Global Association, shared her thoughts about the power of social media networks and gave us some useful tips on how to best use them.

During the entire conference the restaurant provided a great variety of foods and even the vegetarians and those who are following special diets had an ample choice. It was also interesting to taste some traditional German specialities, and the long awaited Gala Dinner also met all our expectations. We were very happy that the representatives of the pharmaceutical companies joined us, so we could talk with them in an informal context. There can be no Gala Dinner without a celebration: during the dinner we announced the winner of the WPHD photo contest (Slovenia) and the winner of the Thunderclap contest (Serbia), who received a huge applause.

The last day was reserved for a presentation from PH expert Prof. Hanno H. Leuchte, from Krankenhaus Neuwittelsbach, Munich, which had a provocative title: “Therapies in PAH, is your goal my goal?” In his lecture he drew our attention to the fact that the physician’s approach to the condition is based on a scientific perspective, e.g. 6 minutes walking test, lung pressure, and other comparable and measurable data. However, for some patients, quality of life is of high importance, and their focus is more on how they feel and how the side effects can be minimized. Nevertheless, he pointed out that we are talking about the same disease and only our perceptions are different: there is a high correlation between the medical data of the patient’s condition and the way he feels.

We hope that everybody enjoyed the conference and left Berlin with good feelings and renewed energy. We believe that everybody learned a lot and all this new information can now be shared by our members in their respective countries. We look forward to meeting everyone again at the next Annual PH European Conference in 2019, with an even more varied and interesting program.

Gergely Meszaros







# WORLD PH SYMPOSIUM

Nice (France), 27 February-1 March 2018

Gergely Meszaros



The largest PH specific scientific event of the year was the World Symposium on Pulmonary Hypertension, which took place in Nice from February 27 to March 1. Traditionally the PH World Symposia series, which started in Geneva in 1973, have been held every 5 years since 1998. This year was the sixth time that all the PH stakeholders, including physicians, academia, pharmaceutical companies and patient associations, gathered for this worldwide congress. To give you an idea and a rough estimate of the scale of the event, around 1.200 international physicians attended the 5th WSPH in Nice in 2013 and even more are estimated to have attended this year. The symposium is preceded by a long, 18-24 month period of preparatory work of 13 task forces. It was a real honor that a new task force was set up for this edition, solely dedicated to the patients' perspectives, and co-chaired by Pisana Ferrari, the previous CEO of PHA Europe.

The different aspects of PH were divided and linked to the following task forces:

1. Pathology and Pathobiology.
2. Genetics and Genomics.
3. Pathophysiology of the RV and of the Pulmonary Circulation.
4. PH Haemodynamic Definitions and Clinical Classifications and Characteristics of Specific PAH Subgroups.
5. Diagnosis of Pulmonary Hypertension.
6. Risk Stratification and Medical Therapy of Pulmonary Arterial Hypertension.
7. Right Ventricular Assistance and Lung Transplantation.
8. Trials Design and New Therapies for Pulmonary Arterial Hypertension.
9. PH due to Left Heart Diseases.
10. PH due to Chronic Lung Diseases.
11. CTEPH.
12. Pediatric PH.
13. Patients' Perspectives.

The task forces had to deal with reviewing the main achievements of the past 5 years and also discussing and analyzing the available evidences. They also needed to evaluate the possible gaps, if any, in order to outline and define the framework and focus points of future research and fields of collaborative possibilities. However the work of the task forces started well before the congress, as stated above, and it intensified some weeks before the symposium, when the working materials needed to be finalized and be ready to be presented and discussed in detail by the experts and other stakeholders during the congress. Here are a few insights, pending the publication of the proceedings:

- It is indisputable that the biggest change proposed at the symposium is that of the definition of PAH: as per the current definition, a person is considered a PAH patient,

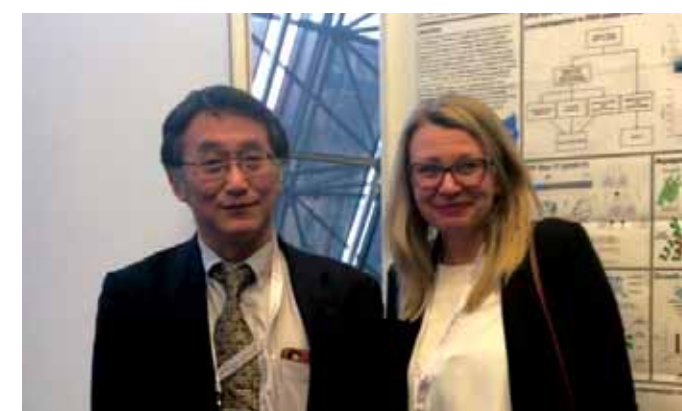
if his/her mean pulmonary arterial pressure (mPAP) is higher or equal to 25mmHG. Going forward the proposal would put this threshold at 20mmHG. This change might have a huge impact on the rare disease classification of PAH due to extending the patient population to "borderline" patients and also drug indications and underlying trials might be subject to review.

- As part of the presentation of Task Force 7, Prof. Walter Klepetko shared his experience with the transplantation of end stage PH patients and raised the question whether patients are not being referred too late for the surgery. He also spoke of the recent scientific expedition to the Kilimanjaro, where he and other physicians from the AKH Lung Transplant Center in Vienna examined the reaction of transplanted PH patients to high altitude. We were extremely happy that in connection with this climb he made a reference to PHA Europe and showed a slide with the World PH Day flag on the top of the mountain!
- In its presentation, Task Force 11 outlined last years' major milestones in the treatment of CTEPH, how the treatment options (medication, PEA and BPA) are defined and used and underlined the excellent results achieved in terms of BPA, in particular in Japan.
- Task Force 12 on pediatrics followed the proposal of the adult PH definition, so they also aim to change the threshold of 25 mmHG (mPAP) to 20 mmHG in children over 3 months. An interesting slide was presented regarding heritable PAH, including known mutations.
- We were really looking forward to the presentation of Task Force 13 on Patients' Perspectives. It started with a touching video of a young PH patient who has sadly passed away, and some very nice pictures and photos, which was followed by the presentation by Migdalia Denis, the President of the Pulmonary Hypertension Latin Society. She raised very timely and relevant questions, which patients are eager to find answers to such as: How long will I live? What will my quality of life be? Am I receiving the best possible treatment? What are my treatment options and will I feel better?

Michael D. McGoon, MD, the co-chair of Task Force 13, pointed out that in order to get a clearer picture about how patients are doing and feeling an aggregate perspective is needed. More emphasis should be put on HRQoL, the Health-Related Quality of Life, which embraces topics ranging from stress, being misunderstood and social isolation to job issues and finances. Also HRQoL should be ranked higher.

More than 90 scientific posters covering a wide variety of PH related topics were presented during the congress, grouped in accordance with the above mentioned task forces.

PHA Europe was well represented at the congress: both Board and staff members attended. Having our booth just next to the entrance, we were able to share our materials with the medical experts visiting the symposium. We not only managed to get in contact with the key opinion leaders in the medical field, but also meet our pharmaceutical company partners.







## COLLABORATIVE EDUCATIONAL PROJECTS

Gergely Meszaros



### PH Human 2019 Diary

With 2019 on the horizon, there are many things to be excited about, including the release of Actelion's PH Human 2019 Diary! Thanks to the valuable feedback and support of PHA Europe's members, the 2019 diary is new and improved and better than ever.

So, what's new?

- A **health tracker** has been added, in order for users to track their pulse rate, weight, edema, breathlessness, dizziness and energy levels.
- The **treatments tracker** has been updated to provide more space and allow users to note when they have started and finished particular treatments.
- **New, slimmer size**, which was specifically requested by PHA Europe members, in order for the diary to be easily carried.
- **New colors**, as requested by our members.
- **53 new, inspirational quotes and tips** from people living with PH and scleroderma.

Thank you to all who provided a quote for the diary, including Irena from Bulgaria who tells us that "Living with PH is only for the strong. Be proud of your life and be proud of yourself". As with last year, copies of the diary have been sent to the

PHA Europe members who requested them. If you have not requested copies and would like to, please contact Gergely Meszaros at [g.meszaros@phaeurope.org](mailto:g.meszaros@phaeurope.org)

### Introducing... the PH Human Diary App!

Since the PH Human Diary began in 2016, there has been increasing demand for a digital resource that helps people living with PH and scleroderma better self-manage their condition, by tracking their appointments, treatments, symptoms and other aspects of their health. Feedback from PHA Europe members on the 2018 diary was that many would love to use a digital, app version to serve this purpose.

Actelion is excited to announce that it will be launching the PH Human Diary App on the Apple and Google stores in January 2019!

Features of the diary app include, a:

- **Calendar** that is synced to your native phone calendar, in order to track appointments and other events.
- **Health tracker** section, to track aspects of your health such as pulse rate and weight. These numbers will feed into graphs that track historic health data and can be printed out to bring to your appointments.
- **Goals** section to set your personal goals and timelines to accomplish these.
- **Medical file** to note treatments and contacts, and includes links to external support resources.

As soon as the app is available in 2019 we will share the download information with you. Watch this space!



### Brochure for PAH patients

A practical guide for living with PAH was elaborated with the title "Living with pulmonary arterial hypertension: Supporting you to manage and achieve your goals".

Following the description of the condition of pulmonary arterial hypertension, the booklet provides useful information and tips on different aspects of patients' daily life, from the work and education point of view, to social support and emotional well-being.

Tips are also provided on how to report side effects, and a couple of quotes make the brochure more colorful.

### PAH Scribble video

Sometimes the simplest way of communication is the most powerful one. This was the reason that living with pulmonary arterial hypertension was visualized in a scribble video through the life of a fictitious patient, Patricia. We can learn about the symptoms and pathology of the disease, the WHO classification and management of the condition, including the ESC/ERS guidelines.

### PAH: life to live

This common initiative aims to address the current changes in the field of pulmonary hypertension, which is attributable to the fact that the disease has changed from a terminal condition to a chronic disease. It means, however, at the same time that we need to be more focused on everyday life's challenges and needs and rehabilitation become more and more important.

Most of the patients feel that their life is like a roller coaster: there are good days and there are not so good days...

The joint development of information materials for PH patients, such as brochures and videos on specific topics, is of special importance for us.

On one hand because it ensures that no aspects are missing that are particularly important from the patient's perspective and on the other hand because it makes the content more precise and comprehensible.

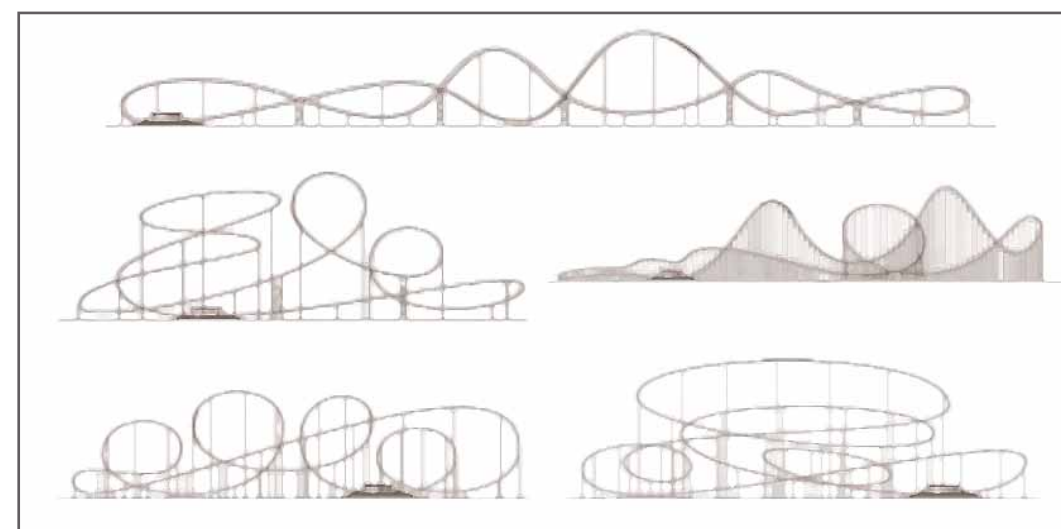
We are delighted that PHA Europe is making the jointly developed materials available on its website so that they are directly accessible to patients and their families.

Thomas Ernst, Bayer AG

- treatment options;
- meaningful resources and support.

A series of short films has been developed to provide some answers to these challenges. Patients with different ages and backgrounds were interviewed and shared their life experiences. Some of the videos featured medical experts from the leading health care centers, who provided their personal perceptions and thoughts. Patient associations were also able to outline their vision in another video which was about how patient associations can support patients and build a bridge between the different stakeholders.

The videos were designed to be informative, but at the same time encouraging and engaging. The ultimate goal was to create a set of resources, which can be easily shared, translated and used all over Europe.



But it is common that patients are in big need of:

- being inspired and reassured that they can live normally, but slowly;
- receiving clear information about their condition and

Only minor editorial and technical work remains to be done and the videos will be shortly available on our media and social network channels. So, stay tuned!



# EUROPEAN REFERENCE NETWORK (ERN-LUNG)

Gergely Meszaros

The second year of the European Reference Network for rare respiratory diseases (ERN-Lung) was very interesting and certainly not less busy than the first one. The working structure was established in the first year, 2017, when ERN-Lung faced a very challenging deliverables list with tight deadlines, for the European Commission, which it completed in a timely manner. The second year's main challenge was to address the technical requirements needed to implement one of the most important parts of the cross-border health care directive. Namely, IT and other infrastructures, a precondition to ensure that the knowledge (and data) travels, and not the patients. ERN-Lung provides a great variety of online platforms - some of them are live and ready-to-use, some of them are still in beta version.

## EXABO

EXABO, the Expert Advisory Board, is a pan-European Internet platform developed within the framework of ERN-LUNG. The original purpose of creating this platform is dedicated to rare respiratory illness, but the device is planned as a common tool for additional illnesses or groups of diseases. This platform will allow affected patients or physicians the possibility to ask experts specific questions in order to gather and improve their knowledge about their condition. In order to ensure an effective operation, different levels of experts will see and deal with the questions raised. The response will be sent via email, users therefore need to share their e-mail address: the platform is planned to be open not only for physicians, but for patients as well.

## CPMS

The CPMS, Clinical Patient Management System, is the heart of the ERN infrastructure and the basic tool for physicians to pool their knowledge to improve diagnosis and treatment. Any member of the ERN network, more specifically, participating health care providers, can submit real

cases into the system. The system can handle different types of images, data, documents, and any relevant information, under the name of the given patients. Based on the data and the request, a panel will review the case and issue a second opinion. I am happy to inform you that the pulmonary hypertension core network already managed to initiate an online consultation on the CPMS platform.

Due to strict data protection rules of the EU's General Data Protection Regulation (GDPR), the full name of the patient is usually not shared, so the system, by law, does not contain sensitive personal data, because the ones uploaded cannot be directly linked to a patient defined by his/her name. Nevertheless, there were some data protection related challenges, which were luckily resolved.

If you would like to learn more about the platform, how it works in practice, you might find the tutorial video developed by the European Commission interesting; it is available at: <https://www.youtube.com/watch?v=mky74DAOYpA>

## Rare Disease Registry Data Warehouse

Registries consisting of accurate, relevant, comparable and reliable sets of data are becoming crucial in terms of care (diagnosis, disease management and outcomes), elaboration and update of guidelines, and management of clinical trials. Moreover, patients are also interested in uploading data and body measurements using their medical and/or smart devices to registries and also get insights of their data stored in such data warehouses. There are also thoughts and proposals about building a so called learning health systems on patient focused registries.

The system envisaged by ERN-Lung is based on patient consent and has three major parts:

1. ERN-Lung registry – consists of basic, healthcare and economic data and disease specific data.
2. ERN-Lung population registry – collecting data from patients directly (possibility of self-recording).
3. Disease specific registries – already existing disease specific registries linked with each other for eg. benchmarking purposes – they will remain outside ERN, but connected to.

Unfortunately, the level of awareness of capabilities and possibilities of ERN-Lung within the physician and patient population is still very low. For instance, the European Union has calls solely dedicated to ERNs. Most recently an application was submitted on eSupport (e-health).

A presentation about patient expectations was made as part of the ERS-ERN-Lung symposium during the annual congress of the ERS (European Respiratory Society) to improve the visibility of ERN-Lung, to build working connections with ERS and, last but not least, to reveal those aspects of the care and research where ERN can bring a real change in the life of

patients. However, we needed to realize from the responses we received during the symposium that even the member health care providers of ERN-Lung have no informational materials to use to promote the ERNs.

This means that there is still lot to do and our objectives for the coming months are to:

- Expand the network of ERN-Lung to Eastern-European countries.
- Promote ERN-Lung.
- Integrate the network of ERN-Lung into the Member States' health care systems.
- Provide full capacities of IT infrastructure.



# THE EMPATHY PROJECT

Gergely Meszaros

The EMPATHY project is an excellent example of how different stakeholders in the field of pulmonary hypertension (PH) can cooperate and build on synergies.

The Biomedical Research Networking Center on Respiratory Diseases (CIBERES) is a multidisciplinary research network of excellence focused on respiratory diseases funded by the Spanish Government. CIBERES brings together researchers from hospitals and research centers around Spain with the main aim of fighting respiratory diseases by fostering excellence in research and transferring it quickly and safely to clinical practice. In 2015 CIBERES launched a Research Program focused on PH. The strategic research project of the PH Program, entitled "New Markers and Therapeutic Targets for the Diagnosis and Treatment of Pulmonary Hypertension" (EMPATHY), aims to identify new activity markers, signals and therapeutic targets for PH, with the ultimate goal of contributing to alleviate and cure the disease.

The main achievements of the EMPATHY project in the period 2015-2018 have been the following:

- Creation of the Spanish PH Biobank, which currently contains samples from more than 420 patients, and the procurement of more than 60 lung explants from patients with PH.
- Development of in vitro and in vivo experimental models for the study of the different forms of PH.
- Development and implementation of advanced imaging techniques for the study of pulmonary vasculature.
- Assessment of circulating endothelial progenitor cells and endothelial microparticles as biomarkers of vascular competence.
- Identification of new potential targets for PH treatment, such as vitamin D, JAK2/STAT3 inhibitors and  $\beta$ 3-adrenergic agonists.
- Development of a national registry for patients with PH associated with respiratory diseases.

Most importantly, during these years, the relationships and collaborations among research groups have been strengthened,



a pre-doctoral training program was established, and the annual Meeting on Pulmonary Hypertension Research, a unique meeting exclusively focused on PH that brings together investigators from different fields that share their results and fosters collaboration between groups, was organized. To undertake the EMPATHY project, the CIBERES PH Program has obtained funding from public and private entities.

The Fundación Contra la Hipertensión Pulmonar (FCHP), one of the PH patient associations in Spain, played an important role and made extraordinary efforts to make the project a great success. As an associate partner they invested a huge amount of time and energy to raise funds to support the research activities. It is possible in Spain to offer a percentage of one's personal income tax to non-profit projects, initiatives and associations. FCHP advertised this possibility and collected funds in this way as well. However, FCHP has not only contributed with funds, but with raising the awareness of the disease and increasing the knowledge about the disease and the project itself. As a result of such activities they managed to drive the attention of funding entities and different types of donors to the project.

We hope that similar projects will be launched in the near future in other countries and building on (cross-border) collaboration they will make the life of PH patients even easier and we finally will find a cure for the disease.

*Based on the summary of Dr. Joan Albert Barberà*





# BLACK PEARL AWARDS

Brussels (Belgium), 20 February 2018

Hall Skaara and Gergely Meszaros



EURORDIS, Rare Diseases Europe, is a non-governmental patient-driven alliance of rare disease patient organisations representing 826 rare diseases in 70 countries. EURORDIS is recognised as the key stakeholder in the field of rare disease and the “voice” of the estimated 30 million people that are affected by rare diseases in Europe.

Every year, on or around Rare Disease Day, in February, EURORDIS organizes an annual event in Brussels: the “Black Pearl Awards”, the aim of which is to recognise the outstanding achievements and exceptional work of those individuals, associations and companies, who are making a difference for the rare disease community. The name of the awards, “black pearl” also has a special meaning and message: it symbolically refers to the uniqueness of the awardees. The guests invited to this Gala Dinner come from the pharmaceutical industry, patient associations, health care providers and research institutions and other relevant organisations. Traditionally other prominent guests also attend. In 2018 we could welcome Princess Astrid of Belgium, sister of the King of Belgium, the First Lady of the Republic of Serbia, the spouse of the Prime Minister of Malta, the Minister for Public Health and Sports of Scotland, and Csaba Kontor, the EU Health Attaché from Hungary. The Rare Disease Day Ambassador for EURORDIS was also present. Sean Hepburn Ferrer is the son of Audrey Hepburn, who lost her life to a rare disease. PHA Europe had four representatives attending the Gala Dinner. In addition to the President, Hans-Dieter Kulla, staff members Gerry Fischer and Hall Skaara and Oksana Kulish from PHURDA (Ukraine) had the great honour of representing the 40 member associations of PHA Europe. Thirteen different prizes were awarded. The most inspiring prize was probably the one awarded to Sammy Basso from Italy. He suffers from a disease which causes early aging and has a major and evident handicap. He received a standing ovation



after his beautiful thank you speech. Another award that was very touching was the one given to Helen and Mikk Cederroth, from Sweden. They have lost three small children to unknown diseases, and have created a foundation (the Wilhelm Foundation, named after their first son), that helps to connect with experts when assessing cases of children who suffer from unknown and serious diseases.

The most sought after prize, however, was probably the prize for the “Best Patient Organisation” in Europe. This year the prize was awarded to PHA Europe! Staff member and leader of the Norwegian association, Hall Skaara, had the honor of receiving the award and giving a thank you speech on behalf of PHA Europe. In his thank you address Hall pointed out that PHA Europe was founded in 2003 and in these 15 years has grown to include 40 European member associations. Hall also pointed out the big difference PHA Europe has made in many countries by providing assistance in setting up new, local, patient associations, which are best placed to address the challenges patients are facing. Hall was a patient himself and it has been almost 13 years since he was first diagnosed.

He used his own experience as an example of how important it is to have an early diagnosis and proper treatment. Access to treatment and other forms of support, such as rehabilitation, are crucial to providing the patients with a good quality of life and to improving outcomes. He also said we only have one life and we need to make the most out of it. His personal contribution to society has been to work for patients suffering for PH and he talked about how this gave his life great value and meaning, which, in turn, helped alleviate the negative consequences of living with a chronic and serious disease.

The event also provided an excellent networking opportunity: the tombola ticket, which was bought by Gerry Fischer and offered to the representative of one of the pharmaceutical companies, won the first prize. Gerry had interesting discussions with the President of EURORDIS, Terkel Andersen, and with CEO Yann Le Cam, about the upcoming European Conference on Rare Diseases in Vienna, and important connections were also established with the representatives of Serbia and Hungary, which serve as a good starting point of further advocacy work.

## What does this award mean to you and your association?

Receiving the EURORDIS award is a huge honour and an unprecedented acknowledgement of the 15 years of hard work for the European pulmonary hypertension community. Through, among others, our “White spot” program, we have expanded our umbrella association to include 40 European members. We support and empower them and we advocate for better access to treatment and to organ transplant. This award will empower us to speak even louder so that our voice will carry to the countries where rare diseases are currently mostly ignored. This is crucial as statistics have shown that the average life expectancy of patients suffering from this incurable disease is only 2.8 years after diagnosis without medication. However, with medication the life expectancy has increased. This gives hope to people like me because I am a PH patient myself. I was diagnosed 12 years ago in Norway and I am a living proof that with early diagnosis and proper care, one can have both a good quality of life and also increased life expectancy. We only have one life and we need to make the most out of it. I, and most people I know, would like to leave a lasting footprint that will not vanish even after the day that we have left this earth. This award helps shape my footprint and the footprint for all the people that have made this success possible. So from the bottom of my PH – sick heart, a big thanks to EURORDIS, the industry partners that support us and do expensive research, the President of our association, our Board, our staff and especially to all our 40 European member associations that work so hard to improve the lives of people, both patients and carers, affected by this rare and serious disease. Thank you very much!





## AUSTRIA

**ZooRun, 20 June**

For our 7th ZooRun we were sold out two months before the event and had 1202 participants, more than the maximum capacity! These ran 6 km through the Vienna Zoo and, in the evening, after the official closing time, there was an after-run party. We split half of the 39.000 euros raised through the event with the zoo and were delighted to have had more sponsors this year than in previous years.

<https://www.youtube.com/watch?v=pkoAkyCVebk&t=47s>

**Ghost Run, 30 October**

We held our 4th Halloween Ghost Run in the Viennese Prater. We had a school class run, a family run and the main competition. We were very happy that we could increase the starters to over one thousand and that we found more sponsors this year than previously. We had excellent media coverage with 16 clippings in the most popular print media and coverage from 3 TV stations, thereby generating a lot of awareness for PH.

<https://www.youtube.com/watch?v=Xu9UTePTiB8&t=75s>

**Infoday, Vienna, 17 February**

A record 102 patients came to our Vienna meeting! Prof. Dr. Irene Lang made several very interesting presentations and was at the meeting until late at night to answer questions from our



patients. Dr. Binder from the AKH (Vienna General Hospital) explained how to read an Echo and for the first time we had a live stream of the meeting on YouTube and Facebook.

**Infoday, Innsbruck, 10 April**

The meeting in the capital of Tyrol, Innsbruck, was very intense in terms of exchanges between patients and doctors. We were able to have some improvements in the structure of the hospital implemented, to make the handling of PH patients easier. We had presentations from our two PH specialised Rehab Centres and, at the end of the meeting physiotherapist Marlene Graf gave a talk about the Feldenkrais Method.

**First joint meeting PH AUSTRIA & SHG Scleroderma, 9 May**

About 50 patients came together in Linz to discuss how we can work more closely together to help each other.

**ECRD European Congress of Rare Diseases, 10-12 May**

The EURORDIS Congress was held this year in Vienna. We were happy to meet friends from PHA Europe.

**Family Day in Vienna, 9 June**

Families from all over Austria came to Vienna to listen to presentations about the services provided by PHA Austria, about the latest medical news in pediatric PH, from Prof. Ralf Geiger, and about financial support possibilities from representatives of the Ministry of Finance and of the Ministry of Social Affairs. PHA Austria covered all costs for the families including travel, hotel and meals. In a parallel workshop Dr. Sulaima Albinni created our first "Youngster WhatsApp Group". We were happy to welcome special guests Hans Dieter Kulla, from Germany, Hall Skaara, from Norway, Oksana Kulish, from the Ukraine.

**Info Day in the capital of Upper Austria, Linz, 29 June**

About 70 patients attended this Info Day. Prof. Dr. Regina Steringer-Marscherbauer gave a very interesting lecture about how to handle PH in everyday life and the psychologist Mag. Wille Wagner gave helpful hints on how to deal with "bad days". At the end of the meeting a specialized breathing therapist showed us how to strengthen our breathing muscles.

**Rare disease congress, Graz, 21 and 22 September**

In our capacity as Founding Members of the Austrian Rare Disease Association, we took a very active part in the yearly Congress 2018, held in Graz.

**First Austrian PH Nurse Forum in Fuschl, Salzburg, 5-6 October**

Fifty-five PH nurses from Austria and one nurse from Switzerland came to this very successful meeting. PHA Austria presented its activities and services and discussions were held about how to increase the cooperation between nurses and the Patient Association. Additionally we had lectures and work-

shops about the latest therapies, guidelines, and rehabilitation possibilities.

**Info Day in Graz, 12 October**

75 Patients attended this meeting, which featured very educational presentations under the medical lead of Prof. Horst Olschewski and many other PH specialists, as well as from representatives of the Austrian authorities.

**Peer to peer mentoring**

Roundtable meetings for patients only! Peer to peer meetings with no agenda, no speeches, but just a nice patient get together and a nice lunch buffet were held in Innsbruck, Vienna and Linz, with over 25 patients in attendance at each meeting.

**SELPERS, a new online platform for PH patients**

Eva and Gerry made a few educational videos for newly diagnosed patients:

<https://selpers.com/kurs/lungenhochdruck-und-angehoerige/>

**Newsletters**

Eva issued four newsletters this year, each with 24 pages. You can see them on our website at [www.phaustria.org](http://www.phaustria.org) - please click on News & Newsletters.

**Media Attention**

This year we had more than 140 media and TV clippings about PH and our activities, with a reach of theoretically the whole nation of Austria.

Very sadly in 2018 we lost 14 members to the disease. We currently have 372 active members in our association in Austria.

Gerald Fischer, PH Austria - Initiative Lungenhochdruck  
[www.phaustria.org](http://www.phaustria.org) - <http://on.fb.me/RzdEcb>







# BELARUS

Hello my friends! I would like to share with you what I consider to be a really exceptional achievement, a feat which I never thought I could accomplish and for which, thinking back, I still experience incredibly positive feelings.

I was born with a heart defect and PAH. No drugs for PAH were available in my country at the time of my birth and are still not available today. In other words PAH patients remain untreated. It would appear, therefore, that as a patient I could put aside all thoughts of physical feats and adventures – the kind of situations where normal people can experience excitement and fun and a huge range of other emotions. But I had this really strong wish, and with the support of my nearest and dearest, and a lot of daring and self-confidence, I managed to do something that for me was unimaginable! My friends made me a very tempting offer to go to the Carpathians to climb the mountain, which I enthusiastically accepted!

With a friendly group of five people we drove over a thousand kilometers to arrive at the place where we would start the climb. Early in the morning we got up and walked about 2 km to the Hook Falls, where landscapes of incredible beauty opened up in front of me, inspiring me and giving me the strength to continue the journey. After a while we stood at the bottom of the mountain. I will not try to hide the doubts I had about my capacity to face such a journey, because even one look at the upcoming vertical climb made me full of fear. Only God knew what I felt, I started, appealing to the Lord for my forces not to leave me. I walked, stepping over stones, tree roots, step by step, approaching the goal, until I had crossed the first 4 km of climb! The most difficult part of the mountain, with a height of 700 meters, still remained. It consisted of large stones, slippery from the rain. My husband was behind me and he constantly repeated: “Don’t look down”... At one point I did look down and the heights made me shake, my head started to spin, my eyes froze with fear, we stopped and I prayed. After that I really felt the ease and strength to overcome my fears, something gave even more confidence. And, at last, miracle happened, everything was behind us, now I was at the top of the mountain, which is 1,550 meters high, after a 4 hour climb! I cannot find the words to describe my delight, my feelings of satisfaction and pride: I made it! I was incredibly happy, everything inside me exulted, the strong wind was invigorating and cooled the mind, thus giving me the opportunity to feel the reality of what was happening - it all happened to me. Thank God! We went back down with a few 3-5 minutes stops. We chose a longer way, which was safer to descend. Believe me, the descent was not much easier than the ascent. Honestly, my forces were running out. We also had to hurry because it was getting dark. I walked in silence, looking at the water-

falls, rocks, and cliffs below. Strangely enough, this did not frighten me any more, my consciousness did not belong to me, I was alone with my thoughts, tiredness and happiness, everything was mixed up together.

I still think of my trip with excitement and great emotion. I am sure that the fact that I have been practicing yoga for five years helped me a lot. This is the only available therapy in our country! We do not have drugs for PAH, the government does not support our patients... Therefore, five years ago, being in a serious condition after giving birth to my second child, I looked at other options for recovery and my choice was proper nutrition, yoga and “chilling” (pouring cold water over myself). A miracle of sorts happened: I completely returned my previous condition, my echo improved, I can walk a lot, run a little, work, visit the yoga center three times a week, and the energy does not end there!

But still I want to believe in the power of goodness and mercy. I hope that one day people in our country with PAH (in a serious condition) will be provided the necessary assistance. Then there will be many more people who will be able to go on breathtaking trips such as mine!

As I have already said we do not have PAH therapy in our country. After I gave birth to my second child my health deteriorated and I started to look for alternatives. Certainly I was worried by the fact that there are no drugs, but I have never let discouragement and bad feelings overwhelm me. And I have never lost heart. If the Lord gave me children, it meant that I should fight for all of us. This was my motivation.

When you start suffering from an illness, a lot of questions come to mind, and not every doctor can answer them. The only information I had was that in our country there was no help for those like me. All the drugs are too expensive and I cannot afford them, as is the case for any other patient. The situation is pretty sad and almost hopeless. But I set a goal for myself: to improve my quality of life. I started learning about the disease from the internet. I was interested in everything: how to strengthen the blood vessels, improve the blood flow, increase saturation, whether there are some exercises suitable for those with heart diseases, what I should avoid, what diet I should adopt, and so on. Having gathered the information, I worked out a plan for my life, including everything important and useful that people with my diagnosis should know.

A huge role in my recovery was played by sports (which were compatible with PH and taking all necessary precautions), yoga (breathing exercises), diet, pouring myself with cold water. I made it a point to ignore what the weather was like outside and I how felt, I decided I must move, I must go to the gym to do yoga, otherwise my health would only get worse. And I cannot afford any

worsening. I have come a long way and I will not stop, for my children.

Seeing the positive results of my hard work made me much stronger, mentally and physically, and little by little I started believing in myself and in the fact that I would be able to help other patients like myself – by motivating them with my own experience.

Some time has passed and, since 2015, I have been the head of the patient association in my country, where we gather together people with the disease. We have a website where we provide patients with information, we work with a psychologist, help people get in touch with medical centers, share personal examples of how different people fight and cope with the disease, translate and publish articles from European medical websites, so as not to miss any possible innovation, new discovery or useful tips. People are inspired by our work, which is the motivation to go further and not to give up. I have a small team of caring people, who work in the association. They not only fill our website with valuable information, but also do a huge job. We try not to miss a single question from any patient and to inform a person as much as possible. On our website you can find the following information: what is PH, the different forms and treatments. There is a large section on rehabilitation, with examples of exercises, and sections on nutrition and on psychological issues, in the form of question-and-answers. With my personal example, I have succeeded in motivating many of our patients, some of whom had given up hope and are now painstakingly working on their health. Yes, we cannot afford drugs, but we do not give up, we do not despair, we continue to live and improve the quality of our lives, and keep getting motivated by positive stories.

Aksana Sniazhko

Aid to Patients with Pulmonary Hypertension

[www.phbelarus.by](http://www.phbelarus.by)

[www.facebook.com/groups/phaBelarus](https://www.facebook.com/groups/phaBelarus)





# BELGIUM-VZW

## PHamily day 2018

After the Summer, in the second part of the year, we held our second "PHamily day", on the 22th of September. The goal of this PHamily day is to bring patients and their family members together in a relaxed atmosphere. This year we went to Bokrijk, an open-air museum in a park in the north of Belgium. Before and after the visit, there was time for the participants to rest and to talk to each other. After the first edition, last year, we noticed that a lot more patients brought their relatives with them, which is good because it improves the understanding of the disease within the family or amongst friends. It's also a good idea to include the children, whether they are patients themselves or they have parents or grandparents with PH.

## Football match with the Get Breathless for PH T-shirts

The same weekend as the PHamily day, a football club, Aalbeke Sport, held a football match with the players wearing the T-shirts of the "Get Breathless for PH" campaign. Thanks to this match they not only raised awareness but also funds for scientific research on PH.



## PHA Europe AGM, ERS and Day of the Carer

In September we were also present at the Annual General Assembly of PHA Europe, in Berlin, the ERS Annual Congress, in Paris, and the Day of the Carer, in Antwerp. This is an event organized by Samana, an organization that is committed to support people with a chronic illness.

## In Flanders with our "PH on Tour"

In October we started our second "PH on Tour", an informative programme where we go around Flanders to visit patients. The program is organised in collaboration with UZ Leuven, one of the Belgian specialised PH centers. The topics of this tour were the World PH Symposium in Nice, the progress of research in Belgium and social facilities in Belgium/Flanders.

## Raising funds and awareness for "Music For Life"

December is traditionally a busy month for our association as it is the month when we organize activities to raise awareness



and funds for "Music For Life". Music For life is an initiative of the national radiostation Studio Brussels. Everyone in Flanders can register an action for the good cause of their choice. Last year's edition brought in 20.000€ for our association, and together with other 2017 donations this meant we were able to give a cheque for 25.000€ to Prof. Dr. M. Delcroix for scientific research conducted in her department. This year's edition has already started well with a pie sale, candy sale, yoga sessions, selling (by auction) signed shirts of racing cyclists like Lars Boom, Marcel Kittel, Dylan Groenewegen, Caleb Ewan, Yves Lampaert, Victor Camenaerts, Sep Van Marcke, and much more...

## A ride from Gent to Leuven

On the 22th of December a "pulmonary peloton" of team PH Belgium will ride from Gent to Leuven and back to raise funds and awareness for pulmonary hypertension. We have warm winters here in Belgium with the "flame" for Music For Life! <https://dewarmsteweek.stubru.be/goededoelen/pulmonale-hypertensie-vzw>

Wim Colle,  
President Patiëntenvereniging Pulmonale Hypertensie vzw  
[www.ph-vzw.be](http://www.ph-vzw.be) - <https://www.facebook.com/PHBelgium>







## BOSNIA AND HERZEGOVINA

### Continuous raising awareness of Pulmonary Hypertension

The year that has just passed was marked by a number of activities organised by our association, the "Association of citizens suffering from pulmonary hypertension "Breath" with one main goal: to raise awareness about this disease. Many athletes, health and sports workers and our fellow citizens helped us in achieving our objective.

### One more mountain climb top for PH

Mount Matterhorn, in Switzerland, was the destination of this year's expedition led by Zdenko Veljačić Veki, a famous Bosnian climber and speleologist. In middle of July, with a team of five members, he started the 4,478 m climb. Despite the fairly good weather, the team failed to make it to the top, on account of technical problems, but this does not take anything away from their deep sense of humanity and solidarity, as this climb was dedicated to patients with pulmonary hypertension in Europe and the world. Zdenko Veljačić, Igor Šišić, Emir Balić, Senad Huskić and Sabahudin Huskić, thank you very much for helping us over the years to raise awareness of this disease, and pointing to the extremely difficult position of patients of pulmonary hypertension in Bosnia and Herzegovina.

### VIII congress of Association of Cardiologists and Angiologists of Bosnia and Herzegovina

A seminar on pulmonary hypertension was held in the framework of the program of this year's 8th Congress of the

Association of Cardiologists and Angiologists of Bosnia and Herzegovina. Thanks to Prof. Dr. Šekib Sokolović, representatives of our Association had the opportunity to speak about our members and the problems we face. Jasmin Jukan and Vera Hodžić explained to the audience our basic goals: drugs for all patients, a registry of patients, a medical center for everyone. Our hope now is that things will start to move because cardiologists from all over the region gave us their support. There was also a great interest in our booth and promotional materials. The Congress was the largest in Bosnia and Herzegovina and gathered 600 participants from 15 countries, 120 local and 34 foreign lecturers.

### Association "Breath" at the meeting in Brussels

Among our activities during the year 2018 was the participation of one of our representatives at a meeting organized by the ELF (European Lung Foundation) and ERS (European Respiratory Society), held in Brussels. Sabina Hodžić was in attendance in the framework of the EPAP (European Patient Ambassador Program), and as a Patient Ambassador shared the experience of patients from our country, in particular by emphasizing the difficult position of patients with pulmonary hypertension. She explained about all the efforts our association has made to improve this position and participants from six other European countries have promised to help us through their human rights representatives in the EU Parliament. This represents another hope for us to improve our difficult position.

### Ajdinovići 2018

In 2018 we continued our successful cooperation with the Association of Physical Culture Pedagogues in Zenica-Doboj Canton and with Professor Amir Muminović. This year, children were taken by the professors of physical culture to the sports and recreation center Ajdinovići where a swimming school had been organised. We thank all the professors, and in particular Amir Muminovic, for their help in raising awareness of pulmonary hypertension among the youngest.

### Recognizing the importance of organ donation

The donor network of Bosnia and Herzegovina, the Association of Dialysis and Transplanted Patients of the Federation of Bosnia and Herzegovina (UDITFBiH), the Association of Dialysis and Transplanted Patients of Canton, each year for the European Organ Donation Day organizes the signing of donor cards. Our Association has always given its support to this initiative because as we all know this is a very relevant issue for patients who are suffering from pulmonary hypertension. Amela Šiljević, Tomislav Žuljević, Nermina Rizvanović and Adnan Fazlagić, thank you for persistence and your continuous work.

In addition to the above mentioned activities it is important to mention that we participated in a thematic TV show and several radio shows, and we had meetings with members of other European organizations with whom we exchanged experiences and talked about the position of people in our countries.

Vera Hodžić, Association of Citizens Suffering from pulmonary hypertension "Breath" - in Bosnia and Herzegovina  
[ugphbih@gmail.com](mailto:ugphbih@gmail.com)







## BULGARIA-BSPPH

### Patients, institutions and experts in the debate on the future of healthcare in Bulgaria

The representative of the European Commission's Directorate-General for "Health and Food Safety", Mr. Filip Domanski, sent a video message for the opening of the 7th Bulgarian National Congress of Patients' Organization, which took place on 26-27 October in the Metropolitan Hotel, in Sofia, Bulgaria. The main topic of this year's congress was the future of healthcare in Bulgaria.

The 7th National Congress of Patient Organizations was implemented under the patronage of the Commission of Healthcare in the National Assembly and the Ministry of Health, with over 150 representatives of patients' organizations from all over Bulgaria, foreign guests from Macedonia and Romania, representatives of the Bulgarian institutions, professional organizations, associations and healthcare unions, insurance companies, health experts and industry.

The event launched with a panel discussion dedicated to the forthcoming reforms of the health insurance model and the changes in the health insurance system with Dr. Daniela Daritkova-Prodanova, Chairman of the Health Commission in the National Assembly, Assoc. Prof. Mihail Okoliyski, expert at the Office of the World Health Organization for Bulgaria and Mrs. Svetla Nestorova, Chairman of the Association of Bulgarian insurers companies. The Ministry of Health was represented by Mrs. Jeni Nacheva - Deputy Minister of Healthcare. The program of the Congress covered the topics of the devel-

opment of the health insurance model in Bulgaria, developments in the field of eHealth, the importance of the national programs for the screening and prevention of socially significant diseases, the use of biosimilar and generic products. During the plenary session: "Exchange of good practices and the role of the nationally representative organization as an effective partner in health" Mrs. Natalia Maeva, Chairperson of BSPPH, successfully presented the project "Pongo, the Rare Purple Elephant". This book is the only children's book in the world so far dedicated to the rare disease pulmonary arterial hypertension. The project was also part of this year's poster session. The participants in the plenary session also learned about the significant work of two other patients organizations: from Macedonia and Romania. Mrs. Biba Dodeva, President of BORKA spoke about exchange of good practices and the role of BORKA as an effective partner in the health system in Macedonia. Also very interesting was the presentation of Mrs. Luminica Valchia, communication manager of COPAC. She presented the programs for cooperation between patient organizations and the R&D industry - practices from Romania. During the second day of the congress all participants unanimously adopted the memorandum.

### Reimbursement of oxygen treatment at home

The full reimbursement of oxygen therapy by the National Health Insurance Fund (NHIF) was the topic of a round table



held on 12 October 2018 in the National Assembly of Bulgaria. Among the participants was Mrs. Natalia Maeva, Chairperson of BSPPH. This was the result of a petition which was signed by over 650 people and tabled in February this year in the "Commission for interaction with NGOs and complaints of citizens" in the 44th National Assembly by the Association of Patients with Respiratory Failure and Lung Transplantation, whose Co-Chair is Natalia Maeva. After a long waiting period and a good cooperation between the Commission for interaction with NGO and complaints of citizens and the Commission on healthcare the first step was done. All stakeholders reached a consensus and solutions have been found quickly for the benefit of all patients in need. The 2019 budget of the National Health Insurance Fund (NHIF) states that all health-insured patients with pulmonary arterial hypertension, idiopathic pulmonary fibrosis, sarcoidosis, and cystic fibrosis (about 400 patients) will be provided with a certain order and criteria protocols to rent for 250 euro per year oxygen concentrators for personal use.

### The "fountain of donors"

Since 2013 BSPPH has been actively involved in initiatives related to the implementation of the "Week of Organ Donation". This year we set ourselves the ambitious task of putting together a long-term project called "Fountains for organ donation", together with the Association of Patients with Respiratory Failure and Pulmonary Transplantation. The Week of Organ Donation was sadly marked by the death of three patients from the Bulgarian waiting list for lung transplantation...

On October 18 we officially marked the beginning of the national movement "Fountains for organ donation", which will be carried out jointly by the Association of Patients with Respiratory Failure and Pulmonary Transplantation, BSPPH, the Ministry of Healthcare and the Executive Agency for Transplantation. The Deputy Minister of Healthcare, Dr. Boyko Penkov, and Dr. Daniela Daritkova-Prodanova, Chairman of the Health Commission in the National Assembly, attended the opening ceremony of the first "fountain" - a monument dedicated to the people who save lives through organ donation.

Launching a new fountain is a centuries-old tradition in Bulgaria and in all the Balkan area. Although we, as double lung transplanted patients, do not know anything about our donors we thank them every day because thanks to the gift of parts of their bodies we received a second chance to live a completely normal and active life. The first fountain of the long-term

project "Fountains for organ donation" was realized in Sofia on the territory of the municipality of Mladost. We are now working on a second one. It will be in Plovdiv on the territory of Thrakia municipality. One "yes" may save up to 8 human lives, so we realized this project as a way to express our gratitude to all organ donors.

### To be an effective patient leader needs training

Patient organisations and patient organisations' leaders are becoming more and more visible actors in the healthcare arena. This is an important and positive change. Nevertheless, it also brings new and bigger challenges.

In 2018 the European Patient Forum (EPF) launched a new capacity building module on "Empowering Leadership and Positive Governance". The module aims at strengthening patient organisations by enhancing their leaders' leadership skills and consequently enabling positive governance in their organisation, with the final objective of supporting patient organisations in positioning themselves as legitimate stakeholders, strong advocates and reliable partners on the national and European health policy environment. The programme targets patient organisations' leaders from across Europe, specifically Bulgaria, Hungary, Poland, Romania, Slovakia and the Western Balkan. The Chairperson of BSPPH Natalia Maeva passed the six-month training course successfully and received her certificate from the EPF. The final module for 2018 took place in Warsaw, Poland. The venue was the Holiday Inn Warsaw City Centre. It was a 2-day event (6-7 October 2018). The initial number of participants planned was 24. Eventually, 23 representatives of patient organisations, participating in current training module, attended the event.

This year the Bulgarian Society of Patients with Pulmonary Hypertension, as a member of the National Patient Organization, participated in the Bulmadica/Bul dental and Mission Health Exhibitions.

Also of note, from 9-12 July the European Medicines Agency (EMA) Working Group met in London to present the results of a Phase III trial for a new drug for pulmonary transplanted patients with proven organ rejection. Ms Natalia Maeva, President of BSPPH, participated in the working group.

*Natalia Maeva, Bulgarian Society of Patients with Pulmonary Hypertension - BSPPH*

[www.bspph.net](http://www.bspph.net)

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## BULGARIA-PHA

The VII National Conference on Pulmonary Hypertension, organized by the Pulmonary Hypertension Association Bulgaria, took place from the 26th to the 28th of October 2018 in Hisarya, in the Plovdiv Province. Within the framework of the Conference the first national patient meeting on Idiopathic Pulmonary Fibrosis was also held.

The Conference was attended by patients from Bulgaria, the Republic of Macedonia, Kosovo, Romania and Moldova. A workshop for rare diseases was held in parallel and was aimed at medical students from the five Medical Universities in the country.

Patients with different forms of pulmonary hypertension took part in the conference, as well as patients who had undergone pulmonary and/or heart transplants. The program of the Conference included a wide variety of topics related to idiopathic pulmonary hypertension, with keynote speaker Dr. Alexander Alexandrov, a cardiologist from the invasive cardiology department at the National Cardiology Hospital, and on idiopathic pulmonary fibrosis, with keynote speaker Dr. Alexander Simidchiev, pulmonologist, Head of the department "Functional diagnostics" of the Medical institute, Chairman of the



Association "Air for Health". Key issues such as sports, nutrition, breathing, relaxation and mental health were covered by speaker Milen Antonov who also spoke of the need for patients with pulmonary diseases to have psycho-social support and mutual assistance. Peer to peer support and mutual help are of vital importance. The Pulmonary Hypertension Association has successfully applied this model of communication for five years and trusts that it will be recognized also by the relatively new association for Idiopathic Pulmonary Fibrosis Association Bulgaria.

*Todor Mangarov, PHA Bulgaria*

[www.apph-bg.org](http://www.apph-bg.org) - [www.facebook.com/aph.bulgaria](https://www.facebook.com/aph.bulgaria)

tions dealing with respiratory illnesses.

- Informing and educating citizens about the prevention of respiratory diseases and the importance of their active role in prevention or early identification, removal and timely inclusion in the treatment and prevention of risk factors, especially the importance of smoking cessation.
- Support for the coordination of professional, scientific and public health activities for the promotion of respiratory health and in the fight against smoking.
- The advancement of professional and scientific cooperation with the European and American associations of physicians in the field of respiratory medicine as well as scientific institutions.
- Support the education and coordination of doctors, nurses and other professionals, as well as legal entities directly or indirectly dealing with respiratory medicine.
- Collecting and providing humanitarian aid for the purposes of the Foundation.

The foundation was founded by the Croatian Thoracic Society with the support of the Mayor and the City authorities, so we believe that the support that they can provide us will be of great importance in our future work.

*Branka Fresl and Zdenka Bradač,*

*Plava Krila, Udruga pacijenata oboljelih od plućne hipertenzije*  
<http://www.plavakrila.hr/> - <http://bit.ly/2hN2aQK>



## CROATIA

Dear friends, time flies so fast... and it is already time for the new Mariposa journal!

We were thinking of what is the most interesting thing we could share with you, and again the choice fell on sports and the success of the Croatian athletes who joyfully wear the PH T-shirts in various competitions and spread awareness of pulmonary hypertension both in our country and in the region where they race, and often reach the winners podium. We would like to single out in particular the half-Ironman race (70.3) in Belgrade (Serbia) of the 24th of September, where five of our competitors participated and won three first places and one third place in the different categories! At the same time, we would like to thank PH Serbia, who helped us with the organization of the accommodation for our competitors, who were with our competitors before and after the race, and of course are responsible for the pictures we share with you at this time. Special thanks to Mirko Glavinić who took the pictures and recorded our success. We wish to continue working in this way on the cross-border project that we started last year

under the name "United4PH" together with PH Slovenia and PH Serbia.

We are currently preparing for the Zagreb Advent Run and hopefully we will be joined by other countries in the same motto, "Get breathless for PH". The race will take place in Zagreb on the 16th of December. Please note that at that time the centre of the city where the race will be held is decorated for Christmas and filled with both local people and tourists from all over the world, because Zagreb has been named one of the most beautiful European cities in the Advent time for two years in a row. Certainly a fact that will help us spread our message and to be seen by as many people as possible.

In addition to sports, we started cooperation with the foundation "Croatian House of Breathing" which was established with the purpose of:

- Promotion of respiratory health and permanent care for the advancement of science and profession in this area, in the City of Zagreb and the Republic of Croatia, and support for the development and upkeep of departments and institu-



## CZECH REPUBLIC

### Celebration of Rare Disease Day 2018

Every year we take part in the celebrations for Rare Disease Day. This year a press conference was organised at the Ministry of Health in support of this event.

### Meeting of patient organizations with rare diseases

On April the 14th our association was invited to a meeting which brought together different Czech associations for patients with rare diseases. The program was varied and full of interesting talks, including two very important ones about palliative care and about specialised centers/clinics for patients with rare diseases.

### Informal patients meeting in Olomouc

From April 27 to 29 our patients organized a meeting in the historical town of Olomouc. It was a friendly weekend meeting



with a tour of the historical city center. We really hope that our patients will cooperate more and more in the future and become a big family where the members can support each other. Our contribution consisted in providing leaflets and sharing them with the patients and at the PH centers.

### Cardiology Congress in Brno

The Annual Congress of the Czech Society of Cardiology took place from May 6 to 8 at the Exhibition Centre of Brno. Representatives of the PH patient association were among the participants. The main objective was to raise the awareness of pulmonary hypertension among health professionals, and





especially young doctors, through brochures and leaflets and conversations about pulmonary hypertension.

#### Cafe

In 2018 we continued with the activity we call “Cafe”, to provide support to patients and their families from different regions of the Czech Republic. Four times per year we organize an informal meeting, where they can ask questions to specialists, establish new friendships and share tips for daily life.

#### Meeting of the Slovak PH Patient association

From June 1 to 3 the Slovak PH patient association organized a climb to Ostredok. The program was varied and very interesting. We are grateful to the Slovak association for the invitation.

#### Recondition stay in Poděbrady

Every year, at the start of August we hold our traditional “reconditioning stay” in Poděbrady. This consists of a week long stay for PH patients and their families in a beautiful spa resort 50 km from Prague. As in past years, the program 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, in order to protect the spine. Our patients also had the opportunity to discuss their problems with a PH specialist. This year for the first time we addressed the issue of psychological support for patients and also their families. Three afternoons were dedicated to psychological relaxation sessions with a psychologist from the Slovakian PH association.

#### Annual Assembly in Želiv

The Annual General Meeting of the PH patient association was held on the 24th and 25th of November in the Premonstratensian monastery Želiv. The meeting included some important information about the disease, but there was also time to relax and have fun. This year we were honoured by the attendance of our patron Sabina Laurinová and of PH specialists from all three PH centers. The program included information about the operation of infusion pumps, about psychological counseling, and new developments in the PH field. We had also organized an excursion to the monastery and a brewery, which included an expert commentary.

#### New brochure and leaflets for patients and carer

We have translated a new brochure for patients and carers about psychological care, translated from the Slovakian association, and full of tips how to live with PH. We would like to send it to print by the end of this year.

#### Our plans for next year

We have a lot of plans for the year of 2019. The most important one is to establish a closer cooperation with two centers for the treatment of PH (Olomouc, IKEM).

Martina Adamová, Sdružení Pacientů s Plicní Hypertenzí  
[www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)



## FRANCE

#### Hiring a social worker

In 2017 HTaPFrance had hired a social worker for up to 8 hours per week. It rapidly appeared that this was not enough, because the disease impacts everyday life to a huge extent not only for the most fragile but also for families which are better-off. However, our budget was not sufficient to pay for more hours, and our young social worker, a mother of a PH child, needed to work more. So she left after six months, and we had to look for a more appropriate system. It took us time, but we found what we think could be a rather good solution for not-so-rich organisations. Our former social worker helped us by posting an ad in a specialised Facebook group. We received nearly 30 offers, among which that of an independent social worker with a long experience in the medical field and a good network. We met her, and she matched straight away with our needs. What is great is that we send her work to do depending on the demands we have and on the budget we can dispose of! She does counselling, but also writes articles and reviews our documents, when needed. We invited her to our children and family week-end to do a lecture. This was one of our objectives for 2017, and we finally reached it this year.

#### Work in progress

We are now concentrating on two specific subjects, also related to social issues: PH and professional life, and housing difficulties for patients waiting for a transplant far from home. First, HTaPFrance wants to better support patients from all ages to optimise their professional life. This means that we first have to better understand what difficulties patients and families face, in order to then be able to advise them adequately. We are currently collecting information, and still need to think on what kind of support we can provide. Secondly, we realised that there was a specific issue for PAH patients that needed a transplant, because most of them are transplanted in the Hospital Marie Lannelongue, near Paris, the reference center for transplant in PAH. In fact transplant appears to be particularly complicated when it is for PAH, compared to transplant for other conditions. As you know, the organ receiver needs to be in the hospital within 2-3 hours of the surgery, which is only possible if you live less than 300 kms away from Paris. Patients may have to move and stay for an unknown period of time near the hospital, and this is costly. Not everyone can afford it and there is no reimbursement. That is why we are searching for one or more sustainable solutions, together with the Hospital Marie Lannelongue, social security and other partners to solve this issue, which is becoming more and more acute, as the number of lung transplants increases (60/year, mostly for PAH).

#### Medications - “lucky France”- does not have them all!

HTaPFrance has had serious worries about selexipag not getting official approval, as macitentan did not get it, quite a novel sit-



uation for our country, where we were used to having all the PH drugs very early. So we feared that the authorities would question the impact of this oral form of prostanoid. We prepared arguments to push this medication forward, as we do consider it is an advance for patients when they do not yet need a more aggressive treatment (subcutaneous or intravenous prostanoid). HTaPFrance got an appointment at the Ministry of Health, and thus, the opportunity to present the patients’ point of view. We know that our action probably is not the only reason for it, but we were relieved to hear that Uptravi was approved at the beginning of November. This is a success, in a context where we did not get Macitentan in France, and inhaled Iloprost will not be initiated here anymore.

#### Good habits and tradition do also good!

In 2018 HTaPFrance organised, as mentioned earlier, its 10th children and family weekend. We welcomed 6 families with PH children and teenagers in the Champagne area. The novelty this year was that two young ladies came as volunteers to help as organisers. One of them came with her companion, and the three of them were very positive examples for the younger ones, and very helpful for HTaPFrance! What was also new is that the participants were mostly teenagers (only one was 9 years old), and one of the patients had invited her boyfriend. Nice to see that a young partner of a PH patient already had a mentor! It means also for us that young people are interested in our association as it is and that it is not necessary to plan dedicated activities, we just need to address subjects that will be useful for them too. In fact the need for socialisation for patients is huge, no matter their age. This is why we encourage them to organise our “Cafés HTaP”, which are informal get togethers in cafés or restaurants.

This year we also organised two regional patients meetings, in Toulouse and Clermont-Ferrand, in which PH experts do lectures and answer questions, and volunteers present the association, gathering a bit more than a hundred people.

We are already planning for the forthcoming year at least 4 regional meetings, our general assembly and our 4th patients’ conference, which we will be happy to tell you about next year, as well as reporting what advances we made in the field of PH and work, and housing for patients on the waiting list. On top of that, we hope to be able next year to tell you more about research projects and results which we are very excited about.

Melanie Gallant-Dewavrin, HTaPFrance  
[www.htapfrance.com](http://www.htapfrance.com)

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## GERMANY

**PH patient meeting 2018, Frankfurt am Main**

The latest developments in the diagnosis and treatment of pulmonary hypertension were the focus of the 21st PH patient meeting held by the non-profit self-help association pulmonary hypertension (ph) e.v. from 19 to 21 October 2018 in Frankfurt am Main. Around 200 participants from all over Germany, but also from Switzerland and France, came to the meeting, which was held in the educational center of the Landessportbund Hessen. The program included scientific lectures and workshops and the conference is also of course very important to make personal contacts and network.

Despite huge progress in the field of PH in the past decades, there is still need for further medical research on the causes and treatment options as well as on educating the public about the disease. The ph e.v. association is committed to addressing these concerns, to supporting patients and their families and to connecting with all the relevant stakeholders.

**Yearly PH Journalist award**

The ph e.v. association annually organises a journalist award titled “United against pulmonary hypertension”, the aim of which is to promote the dissemination of knowledge about pulmonary hypertension. There were two winners this year, Norman Striegel and Kilian Amrhein, who shared the prize of 3.000 euros. “The work of both award winners appeals to a broad audience and leaves a strong emotional impression”, said Hans-Dieter Kulla, Chairman of ph e.v., at the awards ceremony. In his article “New Lungs, New Life”, for the magazine “Wir im Saarland”, on SR Fernsehen, Norman Striegel presented the story of a pulmonary hypertension patient who underwent lung transplant. This multi-year story provided a vivid picture of what it is like to wait for a donor organ, for the patient and family members, and what the transplant means to them. “I am doing very well today,” said the patient, who was present at the award ceremony. The other winner, Kilian Amrhein described, in two articles for the newspaper “Prima Sonntag” of the Aschaf-

fenburg broadcasting company, the story of eleven-year-old Leon, who has also had a lung transplant as a consequence of pulmonary hypertension. The articles, with which the author also called for donations for the family, had an overwhelming response, including in the national media and social networks. “Both authors, with their excellent contributions, have raised awareness not only of pulmonary hypertension, but also of the important issue of organ donation”, said Hans-Dieter Kulla.

**Diagnostics and therapy**

A number of lectures addressed the current state of the definition, classification and diagnosis of pulmonary hypertension, as well as on modern therapeutic strategies, following up on the sixth “World Symposium on Pulmonary Hypertension”, which took place in Nice this spring. The lectures, moderated by Günther Thimm, also addressed special topics and practical problems. Dr. Manuel Richter, from the Gießen University Hospital, spoke of the evolution of “inhalation therapy” for pulmonary hypertension, from the first nebulizers in the 1990s to the I-neb system available since 2006 and the latest inhalation device, Breelib. Both I-neb and Breelib are used to administer iloprost, a stable analog of prostacyclin, which, when inhaled dilates the blood vessels in the lungs, improving the body's oxygenation. Compared with the I-neb, the new Breelib is characterized by a significantly shorter inhalation time and easier application. The initial experience at the University Hospital in Giessen showed that the nebulizer achieved a good distribution of the drug in the small lung vessels, with minor side effects. Prostacyclin analogues such as epoprostenol (the classic form), iloprost and treprostinil (a newer form with a longer half-life), have been used for several years for the treatment of pulmonary hypertension, said Hans-Dieter Kulla. They can be administered intravenously or subcutaneously. Which application is the best and in which cases? This was discussed by Professor Ralf Ewert, of the University Medical Center

Greifswald, and Dr. med. Satenik Harutynova, from the University Hospital Heidelberg, in a joint lecture. Intravenous therapy, with fully implantable pumps, is now considered a safe course of action. Switching from subcutaneous to intravenous administration may improve the functional class. Subcutaneous therapy, in which the drug is introduced into the fatty tissue under the skin via a thin plastic tube and infused with a portable pump, is suitable for testing the effect and tolerability of the prostacyclin analog in a patient prior to intravenous therapy, but also to replace temporarily or permanently intravenous therapy if the implanted pump is removed or malfunctioning. Some patients prefer subcutaneous therapy over time because it gives them a better sense of control. Pain at the infusion site usually subsides, in any case, a thorough education and training of the patient are vital.

**Patients with lung diseases are particularly affected by heat**

“The lungs are the portal organ of climate change”, says Prof. Christian Witt, of the Charité-Universitätsmedizin Berlin. He was personally unable to attend the meeting but his deputy, Dr. Uta Liebers, gave a talk on “Climate Change and Lung Health”. In her presentation she said that the increase in temperature, especially in inner cities, combined with particulate matter pollution and the ozone increase, severely affects the lungs of humans. With heat stress, the likelihood of lung cancer increases significantly, especially in elderly patients. The maximum temperature reached during the day is less crucial than the lack of cooling at night. Therefore, in addition to measures against climate change, strategies to protect humans are also needed. Dr. Uta Liebers advocated for the adaptation of urban structures, for increasing green spaces in cities, providing opportunities for cooling, introducing warning systems and a greater social networking. For lung patients, telemonitoring can reduce the number of hospital admissions. Air conditioning of hospital rooms with capillary tube mats can improve patient mobility and enable earlier discharge.

**CTEPH surgery has excellent long-term results**

Chronic thromboembolic pulmonary hypertension (CTEPH) is a rare but often undiagnosed form of pulmonary hypertension



which can develop following pulmonary embolism. Prof. Heinrike Wilkens of the Saarland University Hospital in Homburg, said that the “World Symposium on Pulmonary Hypertension” in Nice in 2018 revealed that the screening test of choice remains the V/Q scintigraphy, a nuclear medicine method for the assessment of the circulation and ventilation of the lungs. The treatment of choice, if the patient is operable, is pulmonary endarterectomy (PEA), a surgery that provides excellent long-term results. In inoperable patients, pulmonary balloon angioplasty (BPA) may be considered. BPA can also be used after a PEA. Drug therapy is only useful as an adjunct to surgery or in non-operable patients. Lifelong anticoagulation is required in any case.

**Workshops promote active participation of patients**

Numerous workshops were organised, on PH treatment, on everyday life with the disease, exercise and relaxation as well as on relationships and family. Patients and family members were able to actively contribute and ask questions. A much discussed topic, anticoagulation in PH, was addressed during a workshop led by Prof. Heinrike Wilkens, from the Saarland University Hospital in Homburg. In CTEPH life-long use of anticoagulants is considered essential. In pulmonary arterial hypertension (PAH), however, the data available to date are contradictory. Prof. Wilkens suggests shared physician-patient decision-making. He recommends excluding patients who are at risk for anticoagulation, for example, patients involved in activities which could cause injuries or patients who have a history of bleeding complications but, on the other hand, to screen patients at increased risk of thrombosis. He said that more comprehensive studies are needed to obtain better data.





### Every kilometer counts - athletes collect donations

For World PH Day, on May 5, 2018, Actelion Pharmaceuticals organized a fundraiser for PH patients: cyclists pedaled all over Germany, connected via the Internet, and for every kilometer pedaled Actelion gave a donation. At the patient meeting Actelion handed the ph e.v. association a check for 6.500 euros. The "PHENomenal Hope Germany Team", a group of committed athletes who race for PH at various events, also participated in the campaign. The team collected an additional amount of 2.900 euros for PH research from other events, and a cheque for this amount was also given to the ph e.v. at the patient meeting. Andrea Weiler from the "Team PHENomenal Hope Germany" reported on the activities of the athletes: for example, the team organized a bike tour from the University Hospital in Bonn to the Charité Hospital in Berlin. Each participant took on a sponsorship for a young patient with PH. Under the motto "Give PH a Face", sponsors and patients introduced themselves on social media. In addition, the team took part again in 2018 in the challenging 24-hour cycling race of "Rad am Ring", at the legendary Nürburgring.

### Pioneer honored the care of PH patients

In addition to the scientific lectures and workshops, the 21st PH patient meeting also offered information stands, field reports and a cultural program. It was not just about communicating new findings on pulmonary hypertension, but also about exchange and networking. The PH-specialized centers throughout Germany, such as the pulmonary hypertension

center of the Missioklinik Würzburg, are also committed to the dialogue between research, the medical profession and patients. Its longtime senior outpatient nurse Sieglinde Wächter, who is now retiring, was appointed by ph e.v. honored. She has contributed significantly to the development of the care of PH patients in Würzburg.

### ph e.v. thanks sponsors

Pulmonale hypertonie e.v. thanks to the friendly support of the PH patient meeting 2018. its supporting members Actelion Pharmaceuticals Germany GmbH Freiburg, Bayer Vital GmbH Leverkusen and MSD Sharp & Dohme GmbH hair as well as Continentale Betriebskrankenkasse Hamburg, Glaxo-SmithKline GmbH & Co. KG Munich, OMT GmbH & Co. KG Minden and Philips GmbH Respiration Herrsching. The association thanks the companies air-be-c Medizintechnik GmbH Gera, Linde Gas Therapeutics GmbH Oberschleisheim, VitalAire GmbH Lünen, VIVISOL DEUTSCHLAND GmbH Arnstadt and Löwenstein Medical GmbH & Co. KG Bad Ems for the supply of oxygen to patients. Many thanks go to Professor Ekkehard Grünig, head of the Center for Pulmonary Hypertension at the University Hospital Heidelberg, who supported the design of the program.

Sibylle Orgeldinger, pulmonale hypertonie e.v.

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

long term survival guide gives important tips about how to handle the challenges of their every day life. For example, how they should change the way they think about their lives, how to deal with the fact that life after diagnosis is not what it used to be, and the need to accept this as the "new normal". Stress management, staying resilient (flexibility to adapt to ever changing conditions) and planning ahead also helps patients to survive. There is also a separate chapter about how to recognise signs of depression, as this can easily be mistaken for a worsening of the PH (it has similar symptoms but needs special treatment). Tips are also given about how to manage family and friend relationships to ensure that much needed support is given, and to avoid isolation. And, last but not least, there is a chapter on grieving the loss of fellow patients.

### Other activities

Tüdőér Egylet has joined the Hungarian "Lépjünk, hogy léphessenek" (in a rough translation "Let's step up so they can take steps") movement, which advocates for the recognition of the importance of home caregiving (when relatives nurse their loved ones at home) and for an increase in the amount they receive from the government. This awareness raising activity has moved masses of people and achieved a lot of media attention. The result has been that the home caregiving "fee" will be increased to almost to the level of the minimum wage. The next goal of the movement is to ensure that this important work is recognised as a basis for retirement pension



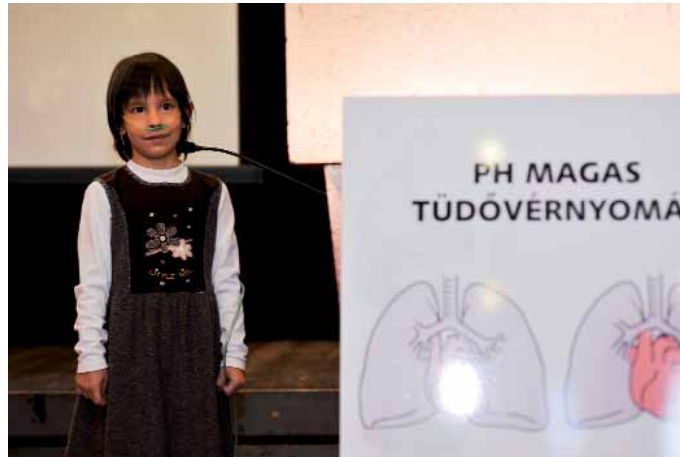
# HUNGARY



In 2018 the Hungarian association celebrated its 10th Anniversary © Every year, in the autumn, we organise a PH specialist- PH Patient meeting, and this year was no exception. At this meeting we always invite the PH patients from Hungary to come and meet with the specialists, listen to professional and scientific presentations and learn about updates related to PH and gain knowledge on how to handle the everyday challenges of living with this condition. We also distribute useful materials. This year we handed out the PHuman 2019 Diary and also a Long term survival guide, which is a translation of a PHA (US) resource, financed by a Tom Lantos award. These materials will be useful tools for patients in their self management and in relations with health care professionals, contributing to achieving optimal care. In particular patients can learn about the importance of keeping track of their health status so that they can share useful information with their health care team. The







since many of those who nurse their relatives at home are unable to work, as it is a 24 hour occupation. Since many of our patients are also in need of home caregiving we felt it our duty to join this movement even if it was not initiated by us. We also participated at the “Empowered patient weekend” organised for the lung transplant patients. Here we have gained information about health savings and prevention related tips that can be useful for PH patients as well. We also took the opportunity offered by PwC and attended the Special Training day for NGOs, where useful presentations were given about tax legislation, project management, GDPR compliance rules and other relevant topics. PHA Hungary was very active throughout the year with the #GetBreathlessforPH initiative. Our PH sport ambassadors (including Gergely) represented us in couple of competitions and raised awareness of PH during high profile races. They took part in Ironman triathlon races, swam across the Danube and ran to the highest peak of Hungary through challenging trails in the forests. We are very grateful and we hope they have already registered for some races for next year!

*Eszter Csabuda, Tüdőér Egylet*

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## IRELAND

### Irish water supports Pulmonary Hypertension Association - Ireland

To mark PH Awareness week (22-28 October 2018) the staff of Irish Water organised a fun run of 5K through Fairview Park in Dublin. This was held on Tuesday, 23rd October. Prior to the run a member of the PH Association - Ireland visited the offices of Irish Water to inform staff about Pulmonary Hypertension. Many had never heard of PH and were very pleased to be involved with the awareness event. Seventy five staff members registered to do the run and we are most grateful to them for their contribution. When all sponsorship monies have been collected Irish Water will organise an official presentation of a cheque made out to Pulmonary Hypertension - Ireland.

### Tallaght Athletics Club

On a beautiful Autumn afternoon in Dublin the Tallaght Athletics Club ran a 5K race in support of one of our patients - Kathy Rooney. Kathy was delighted to be able to participate in part of the walk. The event was covered extensively by the local radio/print media. This was a real fun day when the family pets took part too!!

### Annual Christmas lunch

Thanks to the generous sponsorship received throughout

2018 we are happy that we are in a position again this year to subsidise Christmas Lunch for PH patients and family members. This will be held on Wednesday, 5th December in the Crowne Plaza Hotel. We look forward to welcoming our friends to this event.

### Monthly support group meetings

Our monthly support group meetings are going from strength to strength and are enjoyed by the members of the PH Association. Meetings are held in various locations around the country to alleviate travel distances for our members.

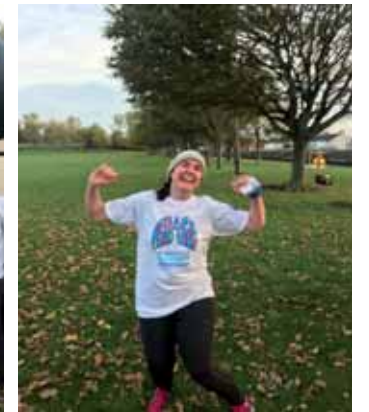
### Plans for 2019

We are very happy to report that staff members of the Irish Prison Service have volunteered to organise a fundraising/awareness day for the PH Association next year. We hope to hold the event as near to World PH Day as possible. The day should attract considerable media attention and we look forward to reporting on the event in the Summer issue of Mariposa.

*Regina Prenderville, PHA Ireland*

[on.fb.me/1KaUHRN](https://www.facebook.com/1KaUHRN)

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







## ISRAEL

This winter a riveting conference was held - participants included the senior doctors in the country and leaders of treatment for Pulmonary Hypertension, as well as senior doctor from Houston, Dr. Adaani Frost. At the conference, Dr. Frost presented a fascinating and wide scoped lecture on all the advances that exist for PH, treatment modifications and dealing with challenges. The lecture discussed when to make changes in treatment, the various treatments available as well as graphs of several new studies which gave a very wide view of existing options. Senior doctors from across the country, together with nurses from the various PH clinics, took part in this conference and enriched their knowledge and understanding of the appropriate care for patients. Prof. Adir (from Haifa), Prof. Kramer and Dr. Belmor from Beilinson Hospital raised examples of unique cases in Israel for discussion. These cases were of female patients with additional conditions and treatments that changed several times during their illness. Dr. Frost gave suggestions and advice from her experience of hundreds of patients. Four representatives of the PH Israel Association participated at the conference and Dr. Frost saw great value and appreciated the close collaboration between the association and expressed the hope that this relationship could be followed through in countries around the world.

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



annual lottery was a nice ending to this wonderful and happy day in the company of old and new friends.

**New services for patients**

Since last year AIPI is proud to offer its members welfare assistance and legal advice. Psychological support has been available for several years via a psychotherapist from Bologna who works pro bono for AIPI.

**Publications**

AIPI's quarterly magazine is the main showcase for membership activities and always presents accounts of PHA Europe projects. This year AIPI also published a guide to lung transplant, with specific advice and indications for those who have to undertake this path. The text was written by Pisana Ferrari and the well-known medical-scientific journalist Minnie Luongo.

**Donations**

This year AIPI decided to make a donation of € 3,000 to ATCOM, Association of patients having undergone a heart transplant, that manages a structure called "Tetto Amico", inside the grounds of the hospital S. Orsola-Malpighi. Here, patients can live free of charge in the pre and post-transplant phase.

**Patronage of scientific events**

In 2018 AIPI have its patronage to two important Italian events organized in Bologna by Prof. Nazzareno Galiè, with the collaboration of Dr. Alessandra Manes and Dr. Massimiliano Palazzini. The first is the "Pulmonary Hypertension by Clinical Cases" conference, held on the 15th and 16th of June, and the second is "Pulmonary Hypertension 2018, new classes of drugs or new treatment strategies?", a con-



## ITALY-AIPI

**Annual general meeting**

Over 100 patients, caregivers, family and friends arrived in Bologna from all over Italy for the annual assembly of AIPI held on May 6th 2018. In addition to the approval of the annual activity report 2018 and financial report 2017, the agenda featured a medical from the international PH specialist Prof. Nazzareno Galiè. Following this there was a talk about the new Italian legislation on disability by expert Adelmo Mattioli. The meeting was followed by a nice lunch and numerous photo sessions, including one of the recipients of lung transplants with the official T-shirt of the Italian organ donation campaign (see next page, picture above). In the afternoon a very amusing performance by the famous Italian comedian Ippolita Baldini. The







ference held on the 23rd and 24th of November. On October 12 we also took part in an event in Milan, organized by AFI, the Association of Pharmaceutical industries, under the patronage of the Lombardy region. Over 450 people attended this meeting titled "The importance of clinical research in health care and the involvement of citizens, patients and the media"

Leonardo Radicchi, AIPI Italy  
[www.aiipiitalia.it](http://www.aiipiitalia.it)

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



Dear friends, it is a great pleasure for us to share with you our associations' activities in the second part of the year 2018.

As you know we help patients in their day to day life to cope with doctors, bureaucracy and psychological problems. In order to do this AMIP cooperates closely with its Scientific Committee, composed of seven doctors who are the heads of of seven specialized PH Centres sit-

uated in Torino, Pavia, Rome, Napoli, Palermo and Catania. In past years we realised that because of physical or economic problems many patients were not able to join the Patient-Doctor meeting we used to organize every year in Rome. So we decided to bring the meeting nearer to the patients! We now hold six different yearly meetings, in the cities where our Scientific Committee Centres are situated.



On June the 9th we were in Palermo. Prof Vitulo explained in a very clear and understandable manner what the current situation is with regard to the diagnosis and treatment of PH and what we can expect for the future. Other doctors and nurses of the Centre were also present and there were more than 60 people listening attentively and asking questions about their condition and their future hopes. It was a very successful meeting, permeated by a true spirit of togetherness and solidarity. The day, full of events, passed so fast that we almost didn't realise that the time was passing.

On June the 16th we were in Pavia, where we met Dr. Ghio, director of the San Matteo PH Centre, and Prof D'Armini, one of the world's top experts in CTEPH and pulmonary endarterectomy. There were over 60 people attending, some of whom had undergone surgery for CTEPH. Those present were able to share their experiences and opinions with others, and small groups of people living in near by areas were formed. These will be able to help AMIP in future in its awareness campaign for an early diagnosis and to help other patient association for organ donation.

On October 13th we met in Aversa (Caserta) where Dr. D'Alto, head of the Naples PH Centre in the Monaldi Hospital, explained what important results we could reach by working together (patients and doctors)! We also had a very interesting speech from Prof Tarantino, a psychologist who is providing support to patients at the Aversa PH Centre. In a year she was able to help about 50 patients and now her project is to start with group psychotherapy. In Aversa we had about 70 attendees.

On October 20th we met in Rome. Here we had the director and doctors from the Policlinico Umberto I PH Centre (Prof. Vizza, Dr. Badagliacca, Dr. Papa) and those from the PH Pediatric Centre Bambino Gesù Hospital (Prof. Parisi, Dr. Alfieri, Dr. De Angelis). I must say that this meeting was even more touching than the others because a part of it was devoted to children affected by PH and to their life expectations. We had a very interesting presentation by Dr. Andrea Masotti, a researcher at the Bambino Gesù Hospital, who explained his project which consists of searching for biomarkers which could give, with a simple blood test, an early PH diagnosis. To conclude, organising all these meetings is hard work: you must consider everyone's needs (doctors and patients'), find the financial resources, convince the patients to come (many do not wish to expose themselves). But our experience tells us that it is a very worthwhile effort: the meetings encourage them to take an active part in the association and organize local awareness raising events.

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

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







## LATVIA

**Success in access**

Our efforts of the past years to achieve access to drugs have now proved successful: since August, PAH is on the positive list for 100% reimbursement. Before we had access to specific medications only for an amount of €14.227 EUR per year per person. Now we have the possibility of having both mono and double therapy. The National Department of Health is additionally looking for a better way to reimburse treprostinil. As result of PHA Latvia's collaboration with the Health Ministry, the Latvian Alliance for Rare Diseases and the Rare Diseases Coordination Centre we have a National Register of People with rare diseases, which includes PH patients. There is also now the possibility to get support for 10 sessions of clinical psychology support per year for rare patients and their carers. These improvements have been carried out within the framework of the National Rare Diseases plan and thanks to the strong participation of PHA Latvia in controlling the plan's implementation.

**Charity project "Support for people with PH"**

Thanks to a part time assistant for persons with disabilities we were able to help our patients with transportation, for visits to clinics, to see their general practitioners, in socializing, for household chores and other daily tasks. And thanks to PHA Latvia's expert pulmonologist Dr. Anda Nodieva and our partners from the oxygen concentrators rental firm, we were able to organise an educational project called "The ABC of Oxygen Therapy" for GPs, doctors, nurses, patients, and families. We

held eight educational seminars in various regions of the country. The educational seminars were very popular among doctors and nurses. We also implemented a "Health hour" with a certificated nurse, who carries out tests to monitor heart health: the level of cholesterol and glucose, the concentration of oxygen, and blood pressure. We had four sessions of the Health hour and it was extremely popular among patients and carers. This project was funded by the "Latvian State Forests" and administrated by the Charity fund "Ziedot".

**International activities**

Marta Augucevica and Ieva Plume participated in PHA Europe's AGM and PH annual conference in Berlin in September. Ieva and Marta presented the advocacy workshop to the delegates at the conference and actively participated in the conference sessions. In October delegates from Latvia Dr.Andris Skride and Dr. Ainars Rudzitis, Cardiologists, physiotherapist Lina Butane, PHA Latvia members Gunita Skaldere-Darmudasa, Ieva Plume, and Sofja Sheviryova, attended the 2nd Baltic PH conference in Vilnius, Lithuania. Ieva Plume led a workshop about how to develop educational materials for colleagues from Estonia, Norway, Lithuania, Ukraine, Russia, and Belarus.

*Ieva Plume, PHA Latvia*

[www.phalatvia.lv/en/](http://www.phalatvia.lv/en/) - <https://www.facebook.com/phlatvia/>  
<https://twitter.com/phlatvia>



## THE NETHERLANDS

**The documentary "The Longest breath"**

On the 25th of September day the highly anticipated documentary "The longest breath" appeared for the first time in the cinema in Utrecht. This premiere was organized for PH patients and health experts. A very interesting, informative and emotional evening! This documentary offers an insight into the relatively unknown world of pulmonary hypertension. The film production portrays a group of healthcare experts in the Netherlands, who commit themselves to the daily care of a small group of vulnerable patients. For more information and the link to the full documentary, see [www.thelongestbreath.com](http://www.thelongestbreath.com)

**Annual meeting for PH children and their families**

The annual day for children with PH and their parents, brothers, sisters was held on the 29th of September. The children went to visit a Zoo and were very lucky to have a lovely sunny day! The parents were able to talk to each other while the children were there and share experiences. A few experts were available to answer (medical) questions. Afterwards the families visited the Zoo together. A very successful day, with a lot of addresses being exchanged between parents.

**Fundraising concert**

A fundraising concert was held on the 21st of October. Many different bands performed for free. A lot of tickets were sold in advance and also a lot of items were sold through an auction. The campaign totaled the nice amount of 10.000 euros for research in one of the expert centers of the Netherlands. A couple of our PH patients organised this event, in collaboration with the Dutch PH Association.

**CTEPH meeting**

A special meeting for patients with CTEPH and their partners was held on the 10th of November. The event was organised by one of the CTEPH expert centers in collaboration with the Dutch PH Association. There was a very interesting program about different treatment options, presented by experts. Two patients had the opportunity to share their experience with BPA and PTE. A very informative day!

*Leny van der Steen, PHA-NL*  
[www.pha-nl.nl](http://www.pha-nl.nl)





# POLAND

- On February 28, 2018 PHA Polska participated in the World Rare Diseases Day conference in Warsaw. Many patient organizations and Ministry of Health representatives took part in the event. PHA Polska was represented by Grzegorz Morze, Maria Golańska-Zabost, Jacek Zabost and Iwonna Kamińska i Tomasz Kamiński - members of PHA Polska.
- From February 27 to March 1, 2018, Agnieszka Bartosiewicz, PHA Poland's Vice President, participated in the 6th World Symposium on Pulmonary in Nice. One of the goals of this meeting was to review the major advances in pulmonary vascular science in the last 5 years.
- In September PHA Poland organized a patient meeting in Łódź, with the cooperation of the local PH centers' experts. The meeting provided a great occasion for both patients and their relatives and carers to talk about their problems and benefit from the presentations of the speakers, who were both doctors and patients.
- On September 25, both Alicja Morze, PHA Poland President and Agnieszka Bartosiewicz, PHA Poland's Vice President, took part in the press conference titled "Life without breath".

During the meeting the results of a report called "PAH - different aspects of patients and caregivers' life" were presented. The report had been prepared on the basis of the survey that was conducted, for the first time in Poland, by the Cognosco company, in August 2017, for Actelion. The project involved medical experts, nurses and patients. PHA Poland was actively involved in the survey and the report's development. The report's results show, among others, that according to the patients the disease negatively influences their physical activity (58%), including climbing the stairs (50%), their employment (47%), everyday activities like shopping (45%). The disease has also a big impact on traveling, family, social and intimate life. One of the speakers was Alicja Morze, who shared her experience as regards the role of a caregiver in PAH patient's life, and Agnieszka Bartosiewicz, who presented our association's projects and PHA Europe activities. A large group of medical experts took part in the conference with, among others, Prof. Marcin Kurzyna - a very well known PH specialist. A special guest of the meeting was Kinga Baranowska, a Polish, famous, high-altitude climber, who was

also an Ambassador for the "Life without breath" project. Kinga is the first Polish female athlete to climb Dhaulagiri, Manaslu and Kangchenjunga, and to have ascended nine out of all fourteen "eight-thousanders". During the meeting she said: "As a high-altitude climber, I know what it means to have shortness of breath, though I rarely experience it, only when I climb. When I first got to know PAH patients I realized that each day they ascend the mountain's tops when they do even very simple everyday activities. This is why I decided to engage in the Life without breath project and encourage others to increase their knowledge of PAH". The press conference gathered both national media and patients and was to underline the importance of an increase of PAH awareness among the general public.

The most important news for Polish PH patients in 2018 was that triple therapy had been introduced and from now on patients can have access to a combined therapy with two or three of the following drugs: bosentan, sildenafil, iloprost or treprostinil or epoprostenol. The doctors can also use epoprostenol with sildenafil and macitentan. Another possible combination is bosentan + riociguat. It will be up to the doctor to decide how to introduce or discontinue the drugs. The good news is that the rules regarding pediatric treatment have been changed too. They can now use a combined

therapy (two or three drugs: bosentan + sildenafil + epoprostenol or treprostinil or iloprost). Both Alicja Morze, PHA Poland's President, Agnieszka Bartosiewicz, Vice President, and Maria Golańska-Zabost, Treasurer, participated in the 8th Conference of the Pulmonary Circulation Section of the Polish Cardiac Society that took place on November 16-17 in Lublin. During the morning session on November 17, Alicja Morze had a lecture on "How we support PAH patients, the association's view". Prof. Adam Torbicki received a special PHA Poland award. Before the conference, there was a general knowledge contest during which the teams of each PH Center had to answer questions about PH. The winner was a team from the European Health Centre Otwock, who received a special "PHA Poland Cup". During the year there were other, very interesting initiatives by PHA Poland supporters who undertook sports challenges. One of them was Krzysztof Sabisz, a young businessman, an alpine climber, who dedicated his run in the New York marathon to PHA Poland. There was also a group of five, fantastic, women who ran in "The Color Run Gdynia" as a "Get breathless for PH" team. Jacek Szymański, father of a child with PH, organized a mountain trip called "Mountain trails for PH patients".

Alicja Morze, PHA Polska  
[www.phapolska.org](http://www.phapolska.org) - [on.fb.me/1ORE2WJ](https://on.fb.me/1ORE2WJ)







## PORTUGAL



### Launch of Upravi in Portugal

PHA Portugal was invited by Actelion Portugal for the launch of Upravi in our country, an event attended by many PH doctors, nurses and representatives of the pharma industry. PHA Portugal made a presentation during which it explained the association's role in providing support to patients and in educating patients about life styles which can improve their long-term prognosis. The feedback was very positive about our focus on putting patients at the centre of care.

### Awareness Trail Running for CTEPH

PHA Portugal organised the third edition of a solidarity trail running (15 km) that took place on October 28th. For those who couldn't run, there was a 10 km walk!

The event aimed not only at raising awareness of CTEPH but also at raising funds. About 300 participants were present at the event and 2.500 euros were raised!

As for previous editions, we were honoured by the presence of a Portuguese celebrity: Aurora Cunha, a retired long-distance runner. She represented our country in three consecutive Olympic Games. Cunha's greatest successes were in road running, at which she was a three-time World Champion. She also won several marathons during her career, including Paris, Tokyo, Chicago and Rotterdam.

We had also the presence of PH doctors, nurses and several CTEPH patients, one of which participated in the 10km walking. This made us very proud!

Several local authorities/entities were also present at the event: the Major, the Board of Directors of a local Hospital, representatives of social solidarity institutions, schools, the International Red Cross and also a representative of Actelion Portugal.

### Patient Associations Meeting

PH was invited to be attend the 3rd Patient Associations' Meeting, promoted by Bayer, on November 20th. The meeting included lectures and workshops and focused on clinical trials in Portugal and the possible involvement of patient associations in the different stages of the process.

Our contribution was based on knowledge gained at the last Eurordis Summer School on Medicines Research and Development, where the subject clinical trials were discussed. PHA Portugal is strongly motivated to participate in therapeutic decisions and implement patient-centric approaches, so the participation in this kind of event is crucial for us as a first step.

Maria Joao Saraiva

Associação Portuguesa de Hipertensão Pulmonar

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



## REPUBLIC OF MACEDONIA

This year on the 10th of October we celebrated the fifth birthday of our association. We took part in World PH Day and, in the second part of the year held various other activities. Great support, as always, came from the Mountainaineering Sports Club KOZUF Gevgelia, which dedicated several climbs to the fight for breath of patients with Pulmonary Hypertension in Macedonia: the peak Ljuboten (2.408 m), Krchin (2.341m) and Chengino Kale (1.760 m). In addition to the club support we had the individual support and climbing of the Galicica Mountain by a young enthusiast and humanist Aleksandar Radicheski, a testimony to the beauty and tradition of the Macedonian people. We also received special support from a woman who promised, and kept her promise, to dedicate every one of her marathons for PH and on those marathons she won the first and second places. Valentina Uzunova ran 10 marathons of 10 km, 13 km, 21 km, expanding our fight for breath everywhere. We had runners on the Skopje Run and Strumica on street marathon too, Jasmina and Zoran. Finally, our Nikolco Georgiev, not only did the Powerman Duathlon for PH, with a run of 40 km plus 150 km cycling, in Zurich, but also ran 42 km on the Swiss City Maratathon Luzern, despite the terribly bad weather. With the support of all these wonderful athletes and friends we will continue in our efforts to raise awareness of PH at the same pace in future!

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







## ROMANIA

May the 15th, 2018, marked the 10 year anniversary of the start of the Pulmonary Hypertension Program in our country. A meeting was held at the Marius Nasta Institute of Pulmonology in Bucharest, attended by patients, patient associations, medical students, health care professionals and national television. There were speeches and interviews about the disease and it was explained that without treatment life expectancy averages 2.8 years. Our Association is an open gateway for patients, associations and researchers across Europe. We aim to bring about internal improvements in



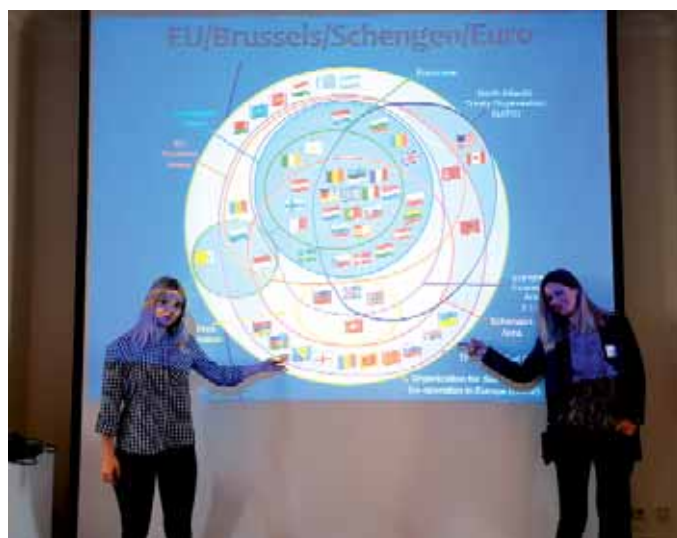
Romania, drawing on the precious information we gather from the international congresses we attend every year.

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



## SERBIA

PH Serbia has been involved in the organisation of all kinds of projects during the autumn, with the following main goals: to raise public awareness of PH, to provide better and easier access to therapies, to promote the importance of transplantation and increase of number of donors. PH Serbia has established an exceptionally good cooperation with all relevant stakeholders in the country: with the Ministry of Health of the Republic of Serbia, with the Republic's Fund for Health Insurance, and also with all the doctors and expert PH teams at the four clinics where we have established specialized PH centers. We also have a very good cooperation with prominent athletes and culture and media figures, who recognized our struggle, our energy and great desire to help all those suffering from pulmonary hypertension in Serbia. We have participated in several seminars



directly dedicated to PH or indirectly related to it through various discussions about rare diseases, orphan drugs, therapy availability, project management, fundraising, better systematic organisation of associations and strategic planning; we've also attended two webinars and 2 tweet chats organized by leading pharmaceutical corporations.

Here is a summary of events organised in the past year:

### Meeting of EPF

- Danijela Pešić together with another young girl with PAH (Amina Berbić), participated in the EPF Patient Advocates' Seminar, which was held in Brussels, Belgium, 20-21 October. Danijela was there in her capacity as President of PH Serbia. It was a two day training meeting where participants were working in groups and discussed communication skills, the management of associations, how to write good projects, etc, which we will apply in future to the work of our organization.
- Cross-border co-operation with Slovenia, Croatia and Serbia: with our excellent team United4PH we participated in two major events, Ironman, in Belgrade, and the largest marathon in the region in Ljubljana (Slovenia). During these two events participants from Slovenia, Croatia and Serbia were competing under one slogan: "Get breathless for PH".

### Book "Story of friendship"

We have written and published a special picture book called "A Story of Friendship". The protagonist of this book is a boy suffering from PH and the main goal of the book is to point out to the importance of accepting kids suffering from rare diseases. We managed to secure the financial means and to print the second edition of this book in an astonishing 3.000 copies. We have organized shows and theater plays free of charge for 3.000 kids and delivered them 3.000 children's books, also free of charge.

### Education

- We have organized an outdoor education excursion about PH, for parents and kids, in the mountains. During this excursion we showed the participants what it feels like to have PH by putting clips on their noses and letting them breathe air only through straws.
- We participated in 2 Tweet Chats and 2 webinars organized by international pharmaceutical companies.
- We also attended the conference about rare disease in Bulgaria, where PH featured high on the agenda.

### Inspired by HOPE team

- Our "Inspired by HOPE" team took part in 14 races and managed to cross more than 4.000 km in the period from September until the 18th of November.
- We took part in the two most prestigious ultra marathon races in Europe - UTMB and Tor de Gaents. For more than 7 months, we have been making a documentary movie about 10 ultra marathon racers who desire to compete at hardest race in Europe - Swiss peaks 330km. They will dedicate this undertaking to all those suffering from PH.

### Plans and future

We are organising a project called "Letter of Hope", where a pilot, member of our "Inspired by HOPE" team, will carry that letter in his little airplane and deliver it to 11 countries around the world. It will be a 15.000 km long trip. He will deliver those letters to Serbian ambassadors in those countries who will then



deliver them to the Ministers of Health. We came up with the idea, and we wrote the letter, which was then signed by doctors and patients. We are preparing a movie about the efforts of the member of our Inspired by HOPE team who is going to climb the highest peak of South America, Aconcagua, in January of the next year. It is third out of 7 highest peaks that he is going to climb and his idea is to dedicate every one of his climbs to patients with PH. We are actively involved in organisation of East European Conference about rare diseases that will take place in Serbia; we are also working on realization of several other major sport events that we are going to take part in.

*Danijela Pešić, PHA Serbia*  
[www.facebook.com/plucnahipertenzija](https://www.facebook.com/plucnahipertenzija) - [danijela@pesic.rs](mailto:danijela@pesic.rs)





## SLOVAKIA

During the course of this year, we organised a number of activities to raise awareness of PAH, to improve patient conditions and their education, as well as joint awareness-raising activities on organ donation and transplantation. Here is a brief summary of some of them.

-In early February, the specialized rare diseases information portal [www.zriedkavechoroby.sk](http://www.zriedkavechoroby.sk) was launched, unique in its content not only in Slovakia, but also in the region of Central Europe. The web portal was presented at a press conference on the occasion of Rare Disease Day and was supported by the Ministry of Health. The Ministry of Health has drawn up a list of centers for rare diseases, consisting of 59 departments, 17 of which have the status of a specialized unit. In the near future, Slovakia will engage in the European Reference Networks (ERNs), with a focus on research for rare diseases.

- This year, we asked for the inclusion of PAH at the Annual General Practitioners' Conference. In the conference program we were given a one hour slot with the title: "From Breathlessness to Pulmonary Hypertension". MUDr. Milan Luknár made a 30-minute professional presentation; Iveta Makovníková's talk focused on topics like problems with diagnosis and PAH awareness-raising activities. The presentations were complemented by a video with patient testimonies. The purpose of the presentations was to provide information to help to achieve an early and proper diagnosis. During the conference, we had an information booth with printed materials.
- A member of our association, Roman Krivánek, was elected to the presidency of the Slovak's Association for the Protection of Patients' Rights, which has a significant place in

influencing the legislative processes.

- Throughout the year, we continued with our "When breath runs out" project, a discussion forum for high school and university students in the form of live libraries. Students at one of the secondary schools prepared work on PAH as a part of their Students' Professional Activities, for which they consulted with our patients, and went on a regional competition. This way they helped us to spread awareness.
- For the members of the association, we organised two 5-day stays. The first one was in May and focused on the physical training of patients with PAH. Patients also had free psychological counseling during their stay. The second stay focused on patient's education (EUPATI project), yoga, breathing and relaxation exercises. The stays included a workshop on creativity, where patients painted their own T-shirts.
- Jana Guráňová, Vice-Chairwoman of the association, who is active in spreading information about organ donation and transplant, participated, within the EUDONORGAN project, in an international meeting in Warsaw and also in the Slovak Transplantology Congress. Based on the literary competition "My Story", designed for patients having undergone an organ transplant, the Slovak Writers created a publication "Live inside of me", based on 15 real stories. One of them was the story of Jana. The aim was to support a campaign to disseminate information on organ donation.

Iveta Makovníková, Zdruzenie pacientov s plúcnou hypertenziou

[www.phaslovakia.org](http://www.phaslovakia.org)

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



## SLOVENIA

In September, our friends and some successful Slovenian sportsmen, Luka Kobler, biathlete Klemen Bauer, mountain runners Peter Kastelic, Nejc Golob and climber Matevž Gradišek, went running on Triglav, Slovenian highest (2864m) mountain, and got breathless while representing our association.

Right after, Slovenia hosted triathlon IRONMAN 70.3, where we also had our representative, Rudi Smolej. We also watched a few of our friends running on a beautiful autumn day on Krk Island Trail 2018, which took place in our neighbour country Croatia. Representatives: Polona Oražem Hočvar, Sašo Hočvar, Rok Ulaga, Tina Žerovnik and Blaž Češarek.

Besides sporting achievements, we organized a huge gathering of our association members and our doctors and nurses from pulmonological department. This kind of gatherings create more of a relaxed atmosphere which allows patients to talk more freely and friendly to their doctors and vice versa. They also help improve the attending members knowledge about the disease and its progress. Our association makes a big effort for our patients to be treated appropriately and with care.

Last but not least was Ljubljanski Maraton, which took place in our capital city of Ljubljana.

Our association, together with PH Serbia, gathered many runners. The atmosphere was amazing despite the rain. Runners:

- 10km: Jana Ilc, Jana Lovšin Peček, Mirjam Lovšin Jakopič, Katja Jovič, Mateja Starc, Mirko Glavinič, Sonja Glavinič, Klemen Babnik, Matej Potočan, Nadan Gregorič, Katja Režonja.
- 21km: Luka Kobler, Nebojša Sarčević
- 42km: Ivan Milosavljević



A great achievement for our country, which we think is definitely worth mentioning, was the first lung transplantation in University Medical Centre Ljubljana. From this day on, patients who need lung transplantation don't need to go to Vienna anymore.

To conclude, the whole purpose of our actions is to make people aware, what is pulmonary hypertension and how serious it is. Our best media for communication with public is Facebook.

Tadeja Ravnik

Društvo Za Pljučno Hipertenzijo Slovenije

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



## SPAIN-ANHP

2018 has been a year with many organizational changes in our association. The members of the board and the staff have been deeply involved in the project. With a lot of effort they have consolidated, once more, the activities of the National Association of Pulmonary Hypertension (ANHP).

### Activities organized by the association.

These are some of the 2018 highlights:

- Thanks to the collaboration of the “Friends of Shiatsu” association, the Madrid members can benefit from this therapy.
- To celebrate World Pulmonary Hypertension Day, on May 5th, the ANHP ran different activities in Madrid:
  - “The PH room” in the University Hospital Ramón y Cajal.
  - We participated in the Solidarity Market in Barajas.
  - We organised the Gala “Solidarity monologues for PH”.
  - We participated in the Rhythmic Gymnastics competition in Orusco.
- The XVI Annual General Assembly was held in Segovia, between June the 1st and 3rd. Before the opening of the assembly Dr. Lavandeira, a lawyer specialized in health, gave a talk on the basic aspects related to disability. Once more the meeting served to share experiences with other people with PH and this was very gratifying.
- One of the members of “The wolf” equipe in the TV show BOOM was wearing our T-shirt in one of the programs. This is the most watched TV contest with an average of 1.7M.

- We have given continuity to the advertising campaign “Become a Hipercoach” thanks to the collaboration of Alberto Cendrero, a sportsman. The goal of this campaign is to increase awareness in the population about PH. In September we organized the “II Triathlon Solidarity” in Siruela, with the collaboration of the Town Hall.
- In September we organized in Valencia the IV Solidarity race, with the slogan “Breathless for PH”, for Maria Moreno”, a PH patient who died. There were 2.000 participants. This year we shared the funds raised with another association for rare diseases.
- The Board of Directors meets in person at least once a year to discuss all the issues related to the association. This year the meeting took place on October 6 and 7 in Madrid.
- The women’s bicycle club of Granada ride for PH was held in September.
- This year we took part, thanks to Julio Hernandez, who was our representative, in the “I Ultraking” in Siruela (Badajoz). There were participants from all over the world.
- In October was held the Madrid members’ meeting to improve the mutual support activities.
- In mid-September we started the Christmas Lottery campaign, which is one of the most important sources of funding for our association

### Participation in events organized by third parties

This year we have participated as speakers in different

meetings, and congress which are organized by other stakeholders, to increase awareness of PH. We have also participated in other informative activities among which we can cite the following:

- We took part in the IX Conference on Pulmonary Hypertension at the Hospital Clínic of Barcelona. This conference is part of the project called “Respira” Classrooms.
- The basket Club Sáenz Horeca Araberri (Pais Vasco), dedicated a match to awareness about PH.
- Our president participated in the Workshop “Presentation Patients SEMERGEN and accessibility augmented” by SEMERGEN (Spanish Society of Doctors of primary care).
- The VIII Trail Sierra de Codés (Navarra) dedicated the fundraising activity to help Pulmonary Hypertension patients and they gave information about this condition to the runners.
- Eva García García, president of ANHP, represented PH patients in the round table called “The patients facing their rights in the day to day” at the conference “Right on Health”.
- Some of the members of our Association participated in a discussion group about the quality of life of patients with Pulmonary Hypertension organized by MSD.
- Our manager participated in the II Congress of Patients of SEPAR, the Spanish Society of Pneumology and Thoracic Surgery, in the discussions on “Ready to ask. Answer in 60 seconds”.

We also took part in different campaigns to raise awareness of PH with the hashtag #AlertaHAP, and with the documentary “In search of the breathless” <https://vimeo.com/266839001>

### Spanish Federation of Rare Diseases (FEDER)

As a member of FEDER we actively participate in campaigns, projects, activities, meetings, etc. they organize. This year we were present at the meetings of the Madrid delegation, which took place in February, May and November, and at the June General Assembly.

In relation to International Rare Diseases Day we participated in the official press conference where our member Ángel Lorenzo was interviewed, and we attended the official ceremony at the Prado Museum, attended by the Queen of Spain. We had a booth at the “IX Race for Hope” at the Casa de Campo in Madrid.

We were present in the Conference “Rare diseases research”, we went to the workshop “Working in network” and we participated in the Formation School of FEDER in Burgos. We also attended the presentation of the study “The social work in rare diseases. Theoretical and practical approach”. Our social worker collaborated for this study.

### Collaboration with other organizations

The collaboration with other related organizations is very important. Our goal is to reach common objectives related to our pathology. We think “Being together we become stronger”. For this reason we are members of other organizations and we





actively participate in their activities. To quote but a few:

- We took part in the meeting of SEPAR (the Spanish Society of Pulmonology and Thoracic Surgery) in order to organize the II Patients' Congress. In November we attended the ceremony for the closing of the SEPAR year.
- In March we took part as a full right member in the General Assembly of FEP (Spanish Patients Forum). And in October we attended the II Patients Associations meeting.
- In May we took part in the Assembly of POP (Patients Organizations Platform). In October, a few members of our Board of Directors, the manager and the social worker participated in the II Patients Congress. In the Extraordinary Assembly of October our manager, Esther Sabando, was elected as a member of the Platform's Board of Directors. In addition this year we attended the presentation of the "Situation Analysis". The social impact and challenges of the patients' organizations in Spain made by this organization with the collaborations of members.
- Our Social worker went to the Summer School, Spanish edition, of EURORDIS in Castelldefels (Barcelona) and our psychologist presented a poster about the quality of life of PH patients at the 9th European Conference of Rare Diseases.
- The manager and the social worker attended the Annual Conference of PHA Europe in Berlin (Germany).
- In September we were taking part in the XXXV Week of Heart in Madrid, with a booth.

#### Rising the profile of the disease

To reach two of our objectives, to give correct and updated information to people with pulmonary hypertension and

their families and to give visibility to the disease we participate in congresses, conference, meetings etc. organized by other associations but related to our aims. We can highlight the following ones:

- II National Conference on Biosimilars.
- Sixth Conference of the Cycle "Our contribution to the state pact of health".
- The presentation "The value of the drug from a social perspective".
- Conference "Adherence to the treatment".
- The Second Protagonists Forum: "A clinical trial is an opportunity for everyone".
- The 3rd Health Fair of the HUCA race in Oviedo, giving information about the ANHP.
- Conference of investigation by and for the patients in the University Hospital of the Princess.
- Conference about the economic experience of the Patient.
- EPF awards.

#### Other activities

Our president has participated in the new construction of the University Hospital of Peace giving her opinion as a Patient. She explained which are the real needs of the patients when they go to the hospital.

We have worked to improve the information of our website. We also attended the ceremony Vitalaire awards where our project "Pulmonary Hypertension, questions and answers in two minutes" received an award.

Eva García, Asociación Nacional de Hipertensión Pulmonar  
[www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)  
<http://www.facebook.com/hipertensionpulmonar>

PAH and family members in the hospital context, comparing the results obtained to assess the congruence between the points of view, and identify feasible action proposals. The results of the study, in which María Rodríguez has participated along with other patients from our organization, will be made public shortly.

#### Support groups

Together with the University of Barcelona, Faculty of Psychology, in the context of the Masters course on Self-Leadership and Group Leadership, we have promoted a quality of life study on the importance of the participation of PH patients and their caregivers in support groups and how this affects their quality of life from a bio-psycho-social aspect. The work was presented in September at the University of Barcelona and will now continue with the control group.

#### Training activities for organisation managers

Fulfilling another of our commitments to carry out our work at the highest and most professional level, we once again participated in the training course for Expert Patients of the EURORDIS Summer School. We also participated in a project Novartis and the European University are collabo-

rating on called "Aula Novartis": a training program for the development of professional skills in the management of patient associations. This is an initiative that aims to enhance knowledge in different disciplines of interest to managers of this type of organization. All this, in order to help them maximize the value of their activities and contribute to their sustainability, thus ensuring that they can offer better benefits to the people they represent and contribute to improving their quality of life.

#### II Separ Patients Congress

The II Separ Patients Congress took place on November 17 in Madrid. This is a very interactive and dynamic conference, where patients, representatives of patient associations and respiratory health professionals are present to debate and reflect on topics of mutual interest. We attended and contributed by organising a workshop on "the control of emotions" together with the FCHP. We also presented one of the patient empowerment programs that we will implement next year.

María Rodríguez, Hipertensión Pulmonar España  
[www.hipertensionpulmonar.com](http://www.hipertensionpulmonar.com)  
[www.facebook.com/pg/HPSpain.org](http://www.facebook.com/pg/HPSpain.org)



#### Non-clinical needs of patients with PAH in Spain: a multidisciplinary vision

This year our association was very active in pursuing its strategic objectives with a number of different initiatives. Our main objective is to push for a holistic view of PH care with the patient as a person, at the center.

Our experience has shown that changes in the national health service cannot be made unilaterally and that it is necessary to seek the engagement of the other stakeholders involved in it. In this sense, a group of experts from different healthcare areas has carried out a qualitative research study

with the objective of collecting information from different points of view: patients, doctors, hospital pharmacists and nurses, about the social and unmet needs of patients with





## SPAIN-FCHP

### 10th anniversary of FCHP, Madrid, November 23

The Foundation Against Pulmonary Hypertension (FCHP) gave a check worth €35.000 euros the persons responsible for the Empathy Project for research on pulmonary hypertension during an event celebrated on the occasion of its 10th anniversary. The event was held at the AC Hotel Madrid Feria and conducted by journalists and television presenters Carlos García-Hirschfeld and Marta Solano.

With this amount, the FCHP has already delivered over €290.000 euros for research since the Empathy project was launched in 2008. This amount has been achieved thanks to the work of hundreds of people who, throughout the year, organised many fundraising activities, such as charity markets, concerts, awareness activities, sports championships, exhibitions or the sale of merchandise, among many others, all over the country. The institutions and private companies that support the work of the FCHP have also played an important role in this collection.

Ten other awards were handed out in recognition of their work in support of PH to the News Service of TVE, the entertainment program Pasapalabra Telecinco, the fiction series TVE Medical Center, the Metro de Madrid, the company Base 100, and sportsmen Dani García Lara and Javier Matallanas, Director of the newspaper As Tv.

The Empathy Project, coordinated by the Center for Biomedical Research in Respiratory Diseases Network (CIBERES), seeks to improve the quality of life of PH patients and to find a cure for this rare, disabling and deadly disease.

### Over 290,000 euros raised in 8 years

During the 10 years that the FCHP has been operating, the association has managed to raise more than €290.000,



which have been allocated to scientific projects and scholarships for professionals working in the fields related to pulmonary hypertension. According to Enrique Carazo, President of the FCHP, “since we launched this Foundation in 2008, our main objective has always been to promote research and raise awareness about this disease. For this reason, the 290.000+ euros collected so far have gone entirely to projects promoted by professionals, training scholarships and the Empathy Project, and represent ten years of incessant work.

The Empathy Project is one of the great hopes for those affected by this disease throughout the world. According to Carazo, “the researchers are working from complementary areas to identify markers that will help in the early diagnosis of the disease and also in developing therapies that will improve the quality and life expectancy of those affected. This year we have had one of the US

researchers, Dr. Vinicio de Jesús Pérez establish contact and identify possible synergies with Spanish researchers. We are very satisfied because the professionals who have received some type of scholarship or financial support from us have taken important steps against pulmonary hypertension, so we will continue to work hand in hand with them to end this disease. We are in the good way”.

### A year of effort and sacrifice in the fight against pulmonary hypertension

During the year 2018, FCHP members have organized numerous activities to raise awareness about the disease and raise funds to allocate to the Empathy Project. Enrique Carazo warmly thanked all the people who have promoted or supported any of these actions: “Fortunately, we have great support from the friends of the Foundation, who are involved with the needs of those affected and their families. Without them, today we could not have delivered these € 35.000 for the Empathy Project!”. Carazo added that “in addition, this year we have continued working from an institutional point of view to make our Foundation a much stronger entity”.

### Informative days

The day after the anniversary event and throughout Friday, FCHP has organized a training conference at the AC Hotel Madrid Feria itself. Patients and their families could attend these workshops for free. Various workshops had been organised on important topics such as respiratory physiotherapy, oxygen therapy and psychological support.

### About Pulmonary Arterial Hypertension (PAH)

Pulmonary Arterial Hypertension is a rare disease, disabling, progressive, fatal, without cure and, in most cases, of unknown origin. It is considered one of the 7,000 rare diseases in the world, according to data from the World Health Organization (WHO), since it affects around 20 people per million inhabitants. However, many people do not know that they have PAH, on account of the large number of misdiagnoses. Potentially, according to specialists, this pathology could affect more than 1.000 people in Spain. The disease is caused by a narrowing of the arteries of the lung, so the blood passes through them with more difficulty and does not oxygenate them correctly. Therefore, the right side of the heart must make an extra effort to pump more intensely and generate higher blood pressure. Over time, due to this excessive work, the heart increases in size and loses effectiveness. In this way, it is increasingly difficult to bring blood to the rest of the body. Until not long ago, a person diagnosed with pulmonary hypertension had a life expectancy of 3 years. Today, a large percentage of affected people live more than two decades with this disease. This has been achieved thanks to the research and the professionals who are dedicated to treating patients and looking for a better quality of life.

Videos, photographs and more information in:

- Web: [www.fchp.es](http://www.fchp.es)
- Blog: [www.conhipertensionpulmonar.com](http://www.conhipertensionpulmonar.com)
- Facebook: [www.facebook.com/fundacionhp](https://www.facebook.com/fundacionhp) #VIIIAniversarioFCHP
- Twitter: [@fundacionhp](https://twitter.com/fundacionhp) #VIIIAniversarioFCHP
- Youtube: [www.youtube.com/fundacionhp](https://www.youtube.com/fundacionhp)

Enrique Carazo Minguez

FCHP Fundación Contra la Hipertensión Pulmonar

[www.fchp.es/es](http://www.fchp.es/es)

[www.facebook.com/fundacionhp](https://www.facebook.com/fundacionhp)







## SWITZERLAND-SPHV

### 3rd Patient meeting, 20 January

#### Exchange of ideas between relatives and those affected

Our 3rd meeting took place in the Congress Hotel in Olten. At 10:00 we welcomed 13 participants as well as Martin Nobs, who is an experienced psychologist, as our speaker and discussion leader for our meeting. After a short round of introductions, the participants started asking questions to Martin and a lively discussion followed during which important aspects of life with PH were raised. There was excellent feedback from the participants about the meeting.

### Regional meeting in Mulhouse, France on 4 February

Laure Rosé, who is the President of HTaP France, invited the members of our association to attend a regional meeting in France. On Saturday, February the 3rd, a small group met in Mulhouse for coffee and cake. There was a lot of exchange of experiences and the afternoon passed by very fast. We have decided to repeat these meetings in future.

### 8th Annual General Meeting on 17 March

On Saturday the 17th of March we held our 8th General Assembly in Olten. Although general assemblies are more likely to belong to the less popular “compulsory” activities, 30 voting members of the association, some with their relatives, came together at the Congress Hotel in Olten. In his impressive annual report for 2017, President Bruno Bosshard showed how successful the association’s activities have been and how favourable the outlook for the future is, so that this “aroused the appetite” for more activities next year. Additionally, during the General Assembly, Susi and Hans were nominated as Honorary Members, in recognition of the great work done for the association.

### Regional meetings

A number of regional meetings were organized in different

parts of Switzerland, to promote exchanges between patients:

- 8th Regional meeting in Chur
- 20 Northwest Swiss PH regional meetings
- 8th Regional meeting in central Switzerland
- 8th Regional meeting in Zurich
- 7th Regional meeting in Bern

### Participation in the Bündner sports day

This year we were able to take part in the Bündner Sports Day. Thanks to the various sports clubs that participated that day, we were able to raise awareness of the PH cause our cause with a lot of different people. Many children and adults took part in the breathing test with the straw, and thus could understand how a person with pulmonary hypertension feels like. The participants were very surprised how restricted the breathing can be! The dancers of the dance school Stellwerk in Chur also participated in the test and were very interested to learn more about the disease.

### 18th Swiss PH meeting in Olten on 26 May

On Saturday, May the 26th, our annual Swiss PH meeting took place at the Congress Hotel in Olten. After coffee, our President, Bruno Bosshard welcomed the numerous members and guests who were present and briefly reviewed the last eventful year. After his speech we heard a very interesting talk by Dr. Med. Kaufmann about “PH and the heart”. This very instructive lecture was also very understandable for those who were not affected by the disease. There were a lot of questions from the audience, very satisfactorily answered by Dr. Kaufmann.

Before the lunch, we enjoyed a wonderful performance of the music trio “Group Lautari”. The trio is currently on a musical tour which will take it from Paris over Appenzellerland to Romania.

### Car trip to Appenzell on 15 June

The car trip started in Zurich, where, after a welcome coffee, we set off for Appenzell, an idyllic town in the canton of the same name. On the way, we were greeted in many places by groups along the wayside. Peter drove us over the Ricken (800m) and Wasserfluh (848m) safely towards Appenzell. When we arrived at the hotel Säntis, on the top, there was snow. After settling in, we were not only able to enjoy the tasty lunch in the romantic hotel Säntis, but also to have a box seat on the tour spectacle. There was beautiful weather, with a light breeze, which was very inviting for a nice stroll through the picturesque town center with its impressive buildings.

### 10th PH family meeting in Morschach from 3 to 5 August

We had six families attending our 10th anniversary meeting. As happens with celebrations, we started our long weekend with an aperitif and drinking a toast! The Swiss Holiday Park Hotel offered a lot of activities. Six children had registered in advance for horse riding. The children were shown by an instructor how to clean and saddle a horse. Every child was allowed to sit on a horse and also shown how to ride it. Since it was already hot in the morning, the horses were only allowed to do their rounds in the shade.

Some of the children decided spontaneously on the Saturday to complete the Flying Fox course. This is a facility with three trails and 18 platforms, where a kick of adrenaline and fantastic views to the lake and mountains are absolutely guaranteed. The teenagers liked it very much. With these hot temperatures, the adults walked around in the forest park in the mean time and tried to take photos of the “flying” teenagers between the trees or over the canyon, high above Lake Lucerne. A very enjoyable day for all!

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





# TURKEY

Hello again from Turkey, after 4 years of silence. Seventeen years after the first patient support group was established by Şamil Hamidullah in 1991, we established our first association, named “Pulmoner Hipertansiyon Derneği” in 2008. We kept it alive for 6 years, but then it collapsed, because of insufficient funding, in 2014. It was very frustrating and disappointing to see all the work, effort and devotion that have been lost since 1991. With the encouragement of some doctors, in particular Ali Akdoğan, MD, and Cihangir Kaymaz, MD, we came together again at the beginning of 2017 and by the 26th of February 2018 we had established our new association, called Pulmoner Hipertansiyon ve Skleroderma Hasta Derneği (Pulmonary Hypertension and Scleroderma Patient Association) in İzmir. Thank you again for welcoming us.

In Turkey we do not have a rare disease patient registry system. So each centre has their own data. One of our goals is to collect all the data and consolidate them in one. Our reimbursement system is directly affected by currency fluctuations. But up to now PAH group medications have luckily not been affected.

Regarding organ donation, we have an “opt-in” system. However, after your death, even if you have decided to donate your organs, your first degree relatives go against your decision and refuse to donate. In 2016, there were 1.997 brain deaths and 40% of them donated their organs. Statistically it means 7 people per million donate their organs.

- We have been lobbying to change the organ donation law since 2006 to a “presumed consent” organ donation model, which in Turkey we call the “Belgium model”. We have conducted several awareness campaigns on this issue.
- We are working to increase awareness for rare diseases for

a registry system since 1991. In 2011 we convinced our government and they established a Coordination Committee for orphan/rare diseases. This committee consists of representatives of the social security program, the Health Ministry, the Ministry of Foreign Affairs and scientific medical associations. After our association collapsed, this committee stopped its activity too. Since Rare Disease Day this year we have been looking for any other possibility to come together with other rare disease organizations. We found this opportunity at the Association of Research-Based Pharmaceutical Companies (AIFD) meeting with 74 patients associations on 2nd of October. There were four rare disease patient associations and we started to collaborate and build up a network between us.

- In March and April we organized a multi-disciplinary patient education programme in Istanbul.
- For each of our “special” yearly recurrences – February 28 Rare disease day, May 5 WPHD and May 29 WSScDay – we prepared a song and launched it on social media together with messages from patients.
- Our association was chosen by Ministry for Internal Affairs with 50 other associations to guide the future of İzmir. And we became a member of the Public-Civil Society Cooperation.
- All the activities of our association have been financed, since the beginning of 2017, by two families. Our main problem is not being able to provide any support to our association, which causes us to worry about our sustainability. I hope all these efforts and devotion won't fly away like the one in 2014.

## Pulmonary Endarterectomy in Turkey

The Marmara Universitesi Tıp Fakültesi Hospital is the only expert centre for PEA in our country and overall their performance is 80 cases per year. Hundreds of patients who might benefit from the procedure aren't receiving it. Overall PEA numbers reach to 550 and CTEPH cure rates are around 90%-95%.

## Balloon atrial septostomy (BPA)

This procedure is successfully being carried out by the Marmara Universitesi Tıp Fakültesi Hospital.

## Lung Transplantation

In Turkey we have lung transplant surgery only for adults. And, because of the lack of organs, transplant is available only for Turkish citizens. Overall numbers reach to 233 and survival rate is 85%. We have two active centres and third one is on the road. There are also two “passive” centres waiting to relaunch again, when the organ shortage problem will be solved. In the meanwhile we are pushing the transplant centres to start to do lung transplants for children and multi-organ transplants, such as liver-lung, heart-lung.

## PH centres and treatments

In Turkey we have ten PH centres and new ones are coming soon. These drugs are available for all: bosentan, sildenafil, tadalafil, inhaled iloprost, macitentan, ambrisentan, and, for CTEPH patients, riociguat. By special permission from the Health Ministry, patients can also have access to IV poprostenol and treprostinil.

This is all from us. It is nice to be with you all again. Still, our economy is far from stable and we do not really know what awaits us. Let us hope for the best.

Kamil Hamidullah,  
Pulmoner Hipertansiyon ve Skleroderma Hasta Derneği  
<https://www.facebook.com/PahSscDernegi/>  
<http://www.pahssc.org.tr/>





## UKRAINE-SISTER DALILA-PHURDA

CF “Sister Dalila”, PHURDA, had a very intense and active summer and autumn.

### XIII International Pulmonary Hypertension Conference “Finding Your Hope”, Orlando, USA

Taking part in a conference such as the PHA's is always very stimulating as it provides opportunities for networking with other patients, patient associations and representatives of pharma companies, for making new contacts and new friends, for gaining new insights into the disease and learning about new developments in the field. The program featured many interesting and useful sessions about PH, these are just a few of the topics covered: changing and combining PH drugs, transplantation and surgical interventions in PH, physical activity and safe exercise with PH, travel with a PH diagnosis, nutrition in pediatric PH patients, managing the side effects of PH drugs, elective surgery and anesthesia in patients with PH, the benefits of inhalation and infusion treatment procedures, etc. The conference was a priceless resource of opportunity and hope for PH. In addition, there was a fashion show, lotteries, painting exhibitions and a memorial wall, where everyone could honor their loved ones lost to PH.

### PHA Europe Annual European PH Conference (APHEC)

It was very nice to see everyone face-to-face again after one year, to share experiences, plans and achievements. The meeting was held in a new venue, in Berlin, which was interesting. We would like to note that the conference was especially useful for those patients, who were participating in the APHEC for the first time. Among others, we heard about an interesting and important report related to the study of PH based on blood tests. We thank the whole PH family for the meeting and nice time together. We are happy that we can learn from each other.

### European Respiratory Society (ERS) Annual Congress

This year the European Respiratory Society's annual congress was attended by over 20.000 people. This is a congress which sees the participation of doctors, researchers, patient organizations and pharma companies: it brings together all those who deal with respiratory diseases. During the congress, we had a number of scheduled meetings, and also made new useful acquaintances. We were able to talk with such giants of medical equipment manufacturers as Philips, Beurer, Flaem, Omron, who were exhibiting a number of new nebulizers and portable oxygen generators. We visited the booths of GSK, Actelion, Ferrer, Novartis and others. We also visited the poster room. There clinics, hospitals, medical centers and pharmaceutical companies presented their latest research data. We met with the State

Rehabilitation Center of Norway and with the New York Transplant Center. The representative of the research center of Sweden, where they actively work on 3D printing of human tissues, told us about the different stages of creation and reproduction of human cells. We also talked to representatives of the pharmaceutical industry. Bayer, for example, presented a study on Riociguat for HIV patients.

We hope that the seeds sown during the congress will bloom into new solutions to the problems of patients with pulmonary hypertension. It was a great experience that gives us a lot of opportunities and resources for our organization and for patients in Ukraine generally.

### ELF Patient Organization Networking Day

During the ERS congress in Paris, the European Lung Foundation (ELF) organized their Patient Organization Networking Day. This was a meeting of patient organizations who were asked to share their achievements related to medical and patient training. We presented the activities of our association in the Ukraine. We also talked about the Memorandum of Understanding the association has signed with PHA Norway and the PHA Europe Capacity Building Program. Furthermore, we mentioned the positive result of doctors in Ukraine and Norway having shared experiences about rehab in PH. A rehab program is very important for patients with pulmonary hypertension, especially if there is limited access to full-scale treatment and medication. Our message to all participants is: “Start to do what you need. Then do what is possible. Soon you will find that you're doing the impossible!”

### 2d Baltic Conference in Lithuania

First of all, we would like to thank Ignas Rudys for the invitation to participate in the conference. The format of the meeting allowed all participants to share their achievements and to suggest solutions that could be used in the future. We heard about the experience and achievements of the Lithuanian association and we also got to know about treatment in Lithuania. There was very interesting seminar and interactive game administered by Ieva Plume and a report from Hall Skaara. In parallel to the patient association conference, there was a medical conference that we also attended and where we heard world famous doctors' reports about news in PH treatment. Afterwards, we talked to doctors and discussed the possibilities for patients in Ukraine.

### “Butterfly in Blue” Project

Butterfly in Blue is our special fashion project where the models are PH patients. The aim is to drive attention to PH through the prism of beauty and to make the patients' voice stronger. This summer, our patients presented national Ukrainian clothes from the “Svarha” brand on St. John's day. Our patients walked on the catwalk together with pro-



fessional models raising awareness of PH with the audience. Another very important fashion event for our “Butterfly in Blue” project took place in September in Canada, during the 22nd Toronto Ukrainian Festival, which is the largest North-American event of its kind. Three Ukrainian PH patients went to Canada to bring awareness to PH. In three days, they participated in eight fashion shows. At each fashion show all the models had blue lips. Our models were on the same stage with public figures like the Mayor of Toronto and the Prime Minister of Canada, Justin Trudeau. Nearly one million people visited this festival! In the Ukraine, our PH models participated in other fashion shows. The first one was during the Lviv Fashion Week and all the models had blue lips. The second fashion show was during the Lutsk Fashion Weekend and again all the models had blue lips. To participate in this fashion show we had to travel to another Ukrainian city. This trip and fashion show gave us a lot of benefits. First we met two new PH patients and then we also met the representatives of the local authorities. There were more than 300 visitors and we used the opportunity to speak about PH. “Butterfly in Blue” helps to break barriers!

### Picnic for Public Organizations

This summer, the Lviv City Council organized a picnic in a park, where all public organizations could meet and present their

projects and activities. We had a booth with printed materials and posters and we gave information to park visitors and to the media. We also had presentations about our two most successful projects: our fight for PH and the “Cork for Life” campaign. This event helped us to find new partners and friends.

### Rehabilitation Program

In 2017 for the first time we learned first hand about rehab for PH patients. One of our patients, accompanied by a doctor, visited one of the rehabilitation centers in Norway. We learned a lot from this experience and we decided to launch a similar rehab program in Ukraine. Thanks to the support of the PHA Europe Capacity Building Program (CBP) and PHA Norway, we launched a rehab program for Ukrainian patients. This is a very big step forward, because we have some problems to proper treatment and access to medication. Now twice a month our patients carry out physical exercises with a rehab specialist, they meet with a psychologist and a dietician. We received positive feedback from our patients. They attend the program and improve their condition. We are happy that we have been able to start a rehab program and we will do our best to expand and improve it in the future.

Oksana Kulish, Sister Dalila-PHURDA-Ukraine  
<http://porvatunok.info/uk/>



# UKRAINE-PHA

## Prayer in support of Ukrainian Orphan Patients 25 February 2018, Kyiv

Representatives of various denominations in the Mykhailivskiy Monastery in Kyiv prayed for the health of Ukrainians with rare diseases. After the church service, all of the participants at the event left paper titmouses with their wishes on the trees. These titmouses are a symbol of the necessary treatment. As the saying goes, it is better to have a titmouse in a hand than a crane in the sky. This expression also applies to our patients - it is better to have a treatment, even if not in full, than not to have it at all.

## IV All-Ukrainian Congress of Orphan Patients 28 February 2018, Kyiv

Patients with pulmonary hypertension and other rare diseases from all over Ukraine came to Kyiv to celebrate International Rare Disease Day. The program of the meeting moments for discussion, a dance master class, a master class for drawing and origami and there was even a skating rink. It was an incredible day! Together we went out to the ice to prove to others and ourselves that we can live an active life if we have support and the necessary treatment!

## Round Table 20 April 2018, Mukachevo, Western Ukraine

The theme of the Round Table is "National List and Access to Treatment for Orphan Patients in the Transcarpathian Region". We tried to find out how the patients with pulmonary hypertension in the Transcarpathian region will be provided with the necessary treatments, which are subject to the provisions of the National List.

## The 9th European Conference on Rare Disease 10-12 May 2018, Vienna, Austria

PHA Ukraine took part in the international conference

organised by EURORDIS, which united representatives of orphan diseases from different countries. Our participation in this conference was useful in terms of exchanging experience with more successful European countries in providing Ukrainian patients with pulmonary hypertension with everything they need - from medicines to legal and psychological support.

## Theatrical rally "Not childish fairy tale about the National List"

16 May 2018, Kyiv

During this rally, we handed an official appeal to the Prime Minister of Ukraine, Volodymyr Groysman, to urgently make changes to the legislative acts of Ukraine to ensure the complete and uninterrupted provision of treatment from the state budget for a number of orphan diseases, including pulmonary hypertension, in all the regions of Ukraine.

## Marathon "Running under chestnuts"

03 June 2018, Kyiv  
A team of supporters of PH patients joined the biggest Ukrainian charity marathon, called "Running under chestnuts". There were so many people participating that it felt like there was no one left in Kyiv who did not participate. The holiday atmosphere that prevailed on Mykhailivska Square infected all those present so that they wanted to jump and run even before the start! The representatives and friends of our association who were taking part in the race were overtaken by the team from the Center for Pediatric Cardiology and Cardiac Surgery, in which the pediatric PH center is located. Even our patient Maria Prokofieva could not resist and ran a little! This support is so necessary for our patients, because running is a dream beyond their reach. On this day, our team ran instead of them. Thanks to charitable donations, we all helped the Center for Pediatric Cardiology and Cardiac Surgery save dozens of little patients' lives. Such moments fill with power!



## International Scientific Conference on Organ Transplantation in Ukraine

25-27 June 2018, Kyiv

For this conference PHA Ukraine organized the visit of the well-known Indian cardiologist and transplant surgeon Dr. K. R. Balakrishnan, who has performed several hundred heart, lung and heart-lung transplants. Among his patients are 54 Ukrainians, 12 of whom were transplanted by Dr. Balakrishnan. For us it was a very important experience, as there is a small category of Ukrainian patients with pulmonary hypertension who will need transplantation in the future. During his stay in Kyiv, Dr. Balakrishnan discussed with his Ukrainian colleagues the prospects of developing transplantology in Ukraine.

## 6th International Summer School Rare Disease & Orphan Drug Registries

10-14 September 2018, Rome, Italy

PHA Ukraine took part in a four-day training course on rare diseases and on the establishment of patient registries. We had an incredible opportunity to do this training at one of the leading institutes for rare diseases in Europe – the National Centre for Rare Diseases, Istituto Superiore di Sanità, Italy. The registers of orphan patients have been working in Europe for many years. The patient community is one of the main forces behind the creation, maintaining and monitoring registers in all European countries. We looked at the practical experience of the Italian organizations to implement the registry for the Ukrainian situation. A register of PH patients will be created in Ukraine eventually, and we tried to get the most information, knowledge and skills to start this process.

## XIX National Congress of Cardiologists of Ukraine 26-29 September 2018, Kyiv

On September 27, a session on pulmonary hypertension was

held at the XIX National Congress of Cardiologists of Ukraine, under the guidance of Prof. Y. Syrenko, who heads the Center of Pulmonary Hypertension for adults in Kyiv. The session on pulmonary hypertension raised a lot of interest at the congress, and the hall where it was held was overcrowded. That day the specialists of our PH Center, established in 2014, during the entire day shared their experience and knowledge with doctors who came from all regions of Ukraine. PHA Ukraine was represented by Iryna Sydorchuk, Inna Burlyai, Iryna Zhuchenko and Oksana Aleksandrova, who made a presentation on the activities of our Association.

## 2nd Baltic PH Conference 19 October 2018, Vilnius, Lithuania

Representatives of patient organizations from Lithuania, Ukraine, Latvia, Estonia, Norway, Belarus and Russia, who take care of patients with pulmonary hypertension, gathered for a working meeting and exchange of experience. There were many questions for discussion and time, as always, was not enough. In our capacity as representatives of PHA Ukraine, we asked our partners about the establishment of registers of patients in their countries, the presence of specialised orphan disease centers, the existence or absence of reimbursement for medicines, and rehabilitation of patients. The answers differed in the different countries and there was a lot of discussion. It was a really warm and incredibly productive meeting. Once again we left convinced that only through joint efforts, by sharing experiences and best practices, can we achieve amazing results in our struggle for the health and lives of our patients!

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## PHINDING YOUR HOPE

PHA's 2018 International PH Conference and Scientific Sessions  
Orlando, 29 June-1 July 2018

Hall Skaara

PHA's International PH conference and scientific sessions were held for the 13th time this summer. The chosen location was Orlando, Florida and the conference ran from June 28th until July 1st. It is the biggest conference of its kind and gathered nearly 2000 members from around the world. These are PH patients, families, caregivers, PH-treating health care professionals and researchers. For some PH international leaders, the conference started on June 28th, one day before ordinary conference, with an international leaders' summit. Forty leaders and associations were represented from five different continents. It was an interesting program that had three objectives:

- Examine case studies.
- Discuss ways that patient associations work within local health care systems.
- Reinforce global and regional networks.

PHA Europe contributed to the program with three speakers: Danijela Pešić, Hall Skaara and Gerald Fischer. Danijela spoke about the impressive work they've done in Serbia related to new accredited PH centers. Here is how Danijela herself describes the presentation:

*We had a privilege and a great honor to deliver a lecture on the following subject: "PH centers in Serbia and the role of associations in their formation"! The organizer gave us 30 minutes for this important subject. First and foremost, we mentioned the importance and influence of PHA Europe on all aspects of our engagements and activities which led to great successes. We then decided to show a movie titled "Life with PAH without therapy" that we have made. Thunderous and spontaneous applause during lecture, but also at the very end, were a good proof that we have shown ourselves in a good light, together with discussion that our presentation provoked, in which vast the majority of attendants eagerly got involved. Everyone in the hall agreed that our presentation was exceptional.*

Gerry presented our White Spot Program, while Hall presented its follow-up: the Capacity Building Program. There were also talks from our South American colleagues and it was interesting to see how much access to medication differed from country to country. It was especially sad to hear about Venezuela where the difficult political situation has totally changed the situation for PH patients. A few years ago, numerous PH drugs were available while none of them are available today! One leader from China also gave an interesting view of the patient situation and association work in her country. They had several PH drugs available and lung transplants were also performed. Furthermore, she talked about the bio sample bank and gene research clinical trials that were running in China now with the help from the patient association.

The summit was definitely a great way to bond with other international leaders and one left with a feeling that we truly are a global PH family!

Here are Gerry's thoughts on the summit:

*The International meeting on the first day was showing again to all of us how important it is to work together and help each other. We heard several very interesting speeches, including the very professional presentation from Danijela. All the speeches were translated simultaneously to Spanish and I could feel during my presentation with Hall, how much interest and respect we get for our work here in Europe. Many associations around the world are still not self-sufficient and we should focus our energy to achieve this goal together. I was especially impressed by the presentation of Brad Wong, President & CEO from PHA, about the way he is running the association in a very clear and effective structure. Unfortunately, Juan could not come to hold his speech, published in the program, about ERNs in Europe, due to passport problems!*

And here is Danijela's summary:

*Major impressions after the first day of the conference were dedicated*

*to international leaders. Everything went perfectly and we had a chance to listen and learn everything about the current situation regarding PH around the whole world.*

For most participants, the conference started the next day. Scientific sessions aimed at health care professional were running in parallel with sessions aimed at patients, families and carers. For those of us that have some good knowledge about the disease, the scientific sessions were of the highest interest. One key topic this year was precision medicine. This is a concept taken from treating cancers, where medication aimed at a special type of cancer and special type of patients (tailor made medicine). The same will, most likely, be true for treating PH patients in the future, according to the scientists. Because there are many different types of PH and also different type of patients. Medication that is especially aimed at certain PH and patient types will probably prove much more effective than a random and all-round type of medication.

In the sessions aimed at the patients, their carers and families, less scientific sessions were held. There were, for instance, sessions for newly diagnosed patients which covered topics related to available therapies, how to continue living and loving life as patient with a chronic disease, debunking PH myths and misconceptions, how to work with PH, traveling with PH, etc. There were also sessions especially aimed at male and female patients. In these sessions, only the given sex could participate. In the male session, for instance, issues like intimacy and not being the breadwinner of the family anymore were discussed. Exercise and PH was also a hot topic that was covered in a session. Supervised exercise for PH patients was highly recommended by the panel of three American PH doctors. Sessions aimed specifically at the different WHO groups were also given. Different kinds of support groups also met - for instance parents with PH sick children. For a complete list of sessions including their handouts, please look here <https://phassociation.org/education-programs/conference/handouts/>. Please also have a look at Regina's excellent report on page ??? which are also available for the members on the "Box" by clicking here <https://bit.ly/2PVob5G>. Here are some words by Gerry about one of the workshops he attended:

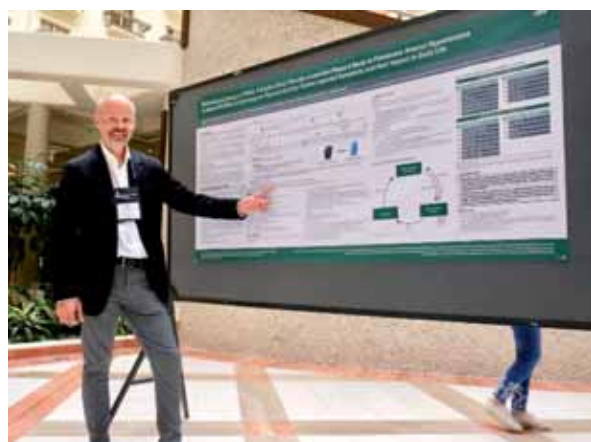
*There were many very interesting workshops, like the fundraising workshop for example. I learned that every activity, even if it is very small and raises only a few hundred Euros, is important to do and will lead to bigger activities in the future. It is also important to encourage patients to do small fundraising activities in their area and we heard from a small business owner that he asked his suppliers to donate, especially during the festive seasons. It would be a good idea to use our International library and implement all successful fundraising ideas from as many countries as possible. Not only fundraising activities which have been done for PH, but every successful fundraising, even if it was for a different cause.*

Danijela also enjoyed the sessions:

*This was also a conference during which leading experts presented us with exceptional lectures about therapies and the course of scientific research. Many lectures also focused on associations and how we can empower them more. It was all presented with practical and concrete suggestions and advices on how we can make our association stronger, more prominent and more financial stable!*

Many of the sessions were run in parallel, meaning that the participants needed to choose one session out of many to participate in. However, some information was given while the entire group was present. This was achieved by running presentations at the lunch and dinner gathering. One especially interesting presentation was given by an award-winning scientist who talked about the importance of gene mutation for the diagnosis and treatment of PH patients. He explained how they had achieved remodeling in mouse models when applying certain types of genes in the mice (BMP9 seemed to be especially important). The interesting thing was that this was achieved in mice with many different types of PH. His hypothesis was, that even if PH was caused by, for instance, congenital heart disease, remodeling of the lung vessels would most likely still be possible through gene therapy since PH, no matter what kind, had a similar effect on the blood vessels in the lungs.

The PH conference is so much more than just attending sessions. All conference participants probably frequently visited the exhibit hall. Here different pharmaceutical companies had stands where you could talk to company representatives and





learn more about their products. Furthermore, Gilead had cooking classes where one could learn about cooking healthy food for PH patients. United Therapeutics had a virtual reality stand where one could see and learn more about the heart and lungs through VR glasses. And Actelion asked participants for help to make a big sign made by wowed strings that will be displayed at their American head office. There was also a stationary bike station with two bikes where healthy participants could bike for 45 minutes on behalf of named PH patients. And handouts of everything from product brochures to ice creams were commonplace.

Danijela seemed to thoroughly enjoy the exhibition area:

*We had a chance to speak with pharmaceutical experts on the Exhibition of Pharmaceutical Industries, who very thoroughly informed us about therapeutic options, but also about proper diets, activities and that can contribute to better quality of patient's life.*

Here are some added words from Gerry:

*Steve van Wormer added a lot of community feeling with his interviews and with his very nice and colorful badges, which one could collect at the different stands in the exhibition area. It was very nice to talk to our sponsors and to make new contacts nearly every minute.*

For the PHA Europe representatives, it was a great way to meet with one of the newcomers in the PH business: ARENA. They are working on a phase three study of an oral therapy. They invited all PHA Europe participants to a lunch and got to know each one of us. They will follow up by contacting each participant in the months to come to discuss possible collaboration during the study.

Here is Gerry's summary of the ARENA lunch:

*It was very nice of ARENA to host a PHAEUROPE lunch in the hotel restaurant. Seven member associations from PHA EUROPE were present and we had a very good time together.*

Danijela also valued the informal pharma meetings:

*During the conference we had a group meeting, and we went to lunch with the representatives of ARENA. They demonstrated great interest and desire for cooperation with associations. As the conference progressed, we also attended several other meetings with key people and representatives of industries and pharma's.*

A poster section was also on display for the entire duration of the conference. The posters were accompanied by an expert who would explain about the trial in question. (The experts were present for three hours of the first day of the conference). Hall was elected to present one of the trials as he is part of a steering committee of a phase four study by Actelion called TRACE (see on the following page). It is interesting to see how many new trials are currently run that will hopefully bring new knowledge and new medication to the field of pulmonary hypertension.

Here are some words by Gerry about the poster stands:

*On the other side of the lobby there was the poster stand with very nice presentations about new drugs, new studies and innovations. Hall can*

*be very proud, not only to be the co-author of an important paper about a study from Actelion with new endpoints, but also being the one who presented the poster to the HCP's. This gave PHA EUROPE also a very good image.*

A sadder part of the conference area, was the memorial wall. Here participants were encouraged to write the name of a former patient that had lost the fight against PH. Each day of the conference the wall got more and more busy with names of loved ones that are no longer with us. A similar tribute was given at a lunch one day. The announcer asked for a moment of silence for those who had passed away and asked participants to call out names of family and friend members of PH diseased. It was a moving experience to sit there in silence and having the silence broken by people calling out names.

It is not often that so many PH patients are gathered in one place. Researchers know how to take advantage of this fact and run a research room at every PH conference.

Conference participants are encouraged to participate in the research and valuable blood samples are collected and important questionnaires are filled out. The researcher who talked about PH gene mutations revealed that his research would not have been possible without blood samples draws at previous PH conferences. He and his team were at the conference also this year to collect more blood samples. Even a German team of scientists had come to Orlando to collect blood for their study. The research room was constantly full of people. Many participants wanted to give their support to PH research that hopefully will benefit us all in the near future.

A fashion show is also a traditional part of the PH conference. This is no ordinary fashion show, since all the models are PH patients. This is a popular and great event that you can read more about on the following page.

At the dinner at the last evening of the conference, a special tribute was given to a very special donor. His wife had passed away from PAH, and now he was an old man thinking about how to pass on his wealth. He had chosen to donate 2.5 million dollars to PHA!

This is the biggest single donation in their history. At the speech at the dinner, he proclaimed that his wife now probably is sitting up in heaven and applauding his decision. He was sure that the money would be well spent by the association.

The evening ending by having an iconic piece in Orlando lit blue. It was their famous Ferris wheel the "Orlando Eye" that was lit up in blue. Finally, it was announced that in 2020 the conference will be held in LA, California. Hopefully, many European PH leaders will be able to join this important and great event at that time.

Danijela summarized her impressions of the conference with these words:

*My personal impression is that the number of representatives are not adequately, considering the importance of this conference, especially if we consider the number of associations in Europe and within PHA*

*Europe, which together make up more than half of the total number of associations in the whole world. This was a tremendous experience, and a place where we could learn a lot. Here we received a great deal of hope and courage to continue stronger and more persistent in an attempt to find and get our rights.*



## TRACE POSTER

Actelion is running a phase four trial called TRACE. Phase four means that the product in question is already on the market. The product name is selexipag and it was approved for the European market after the largest and longest running trial (GRIPHON) in PAH history. The study was recently presented in the poster section in Orlando, USA at the PHA conference.

The special feature about the TRACE study is that Hall Skaara (staff member of PHA Europe and leader of the Norwegian association) is part of the Steering Committee. This might be the first time a patient holds this position as it previously only has been reserved to health care professionals. However, this is a sign of the time as things in the medical field are getting more and more patient centric.

Hall presented the poster in Orlando. He explained that it is a 26 weeks long study involving 100 patients from 30 sites in USA and Europe. The study is ongoing as only 29 patients has been recruited so far. Half the patients will be given the drug selexipag (oral prostacyclin), while the other half will be given placebo pills. All patients will also be given a wrist device (looks like a large arm watch) and a computer tablet. The wrist device will show the time and nothing more. However, it will collect a lot of data about the patient. All activity level will be collected plus the sleep pattern. This data will be uploaded to a central site once a day. The computer tablet will be used to fill out a questionnaire three times during the study. The questionnaire has questions related to the patients well being. Do they feel tired, experience chest pains, can they walk up stairs without problems, etc.

The purpose being the study is to check if a person receiving selexipag will become more physical active than the people receiving placebo. And will the person also experience that his/her condition improves? These endpoints are unusual in PAH studies. Often endpoints are related to six minutes walking distance and to biomarkers (blood tests). However, these patient centric endpoints will probably be more common in future studies as this has been requested by the patients association task force during the PAH symposium for the world's leading PAH specialists that was held earlier this year.

The study will probably run for about two years. Selexipag has, in a previous study, been shown to have a positive health effect on PAH patients. It will be interesting to see if patients on this drug also feel better and becomes more physical active.

## FASHION SHOW

The fashion show is a traditional part of the agenda on the bi-annual PH conference in USA. This year's conference was no exception.

The fashion show at the PH conference is, however, not like any ordinary fashion show. For one, all models are all PH patients. Secondly, it doesn't seem like the clothes worn by the models necessarily are the primary focus of the show. Because as the model proudly walks down the runway, the announcers talks about the models' medical history. Furthermore, they often also tell other facts like what hobbies and interests the models have. Many times these are important facts as the clothes worn will be closely related this.

One PH patient and model has, for instance, a hobby as a hula dancer. She even participates in hula dancing competitions. She, of course, walked the walkway in hula dancing outfit. She certainly was no ordinary hula dancer, however, because have you ever seen a hula dancer with a backpack containing an oxygen supply and with a nasal cannula? And when she showed some hula dancing on the runway, the crowd went wild.

Another model came walking down the walkway in karate outfit. And yes, you guessed it, the model and patient had karate as an hobby. She must have been very skilled, as well, because she had a black belt. The response from the crowd was high as she showed some of her karate kicks. The most cheers, however, were given to the sick children and youths as they walked down the runway. One boy was dressed in a superman costume to let everyone know who his favourite superhero was. Another shy young girl walk the walkway in a zebra outfit and on her back she was a zebra backpack that contained her PH medication pump. And two young girl friends walked the runway in matching skirts and proudly showed their sparkling and matching pump backpacks.

So if you ever plan to participate in the PH conference in USA, don't miss the fashion show. It is truly inspirational to watch as child, youth and adult PH patients proudly walk the runway to overwhelming cheers of their fellow PH patients audience.

Here are three short videos from the fashion show:

<https://bit.ly/2DKUqx5> - <https://bit.ly/2Shi7Bf>  
<https://bit.ly/2PVid19>



## Attendance at 2018 International Pulmonary Hypertension Conference and Scientific Sessions

Regina Prenderville

I was privileged to have been invited to attend the above conference which I found informative, inspiring & encouraging for the future. The meeting was titled “PHinding your hope”.

There were many breakout sessions and workshops to attend. The following are some brief notes I took while attending these sessions:

### SESSION 1

#### Tips & tricks for conserving your energy

This session was conducted by two adults with PH and are both support group leaders. The opening comments were “Life goes on after diagnosis”. PH patients and caregivers need to get the most out of each day by conserving energy, making “me time” and simplifying daily tasks’.

Objectives:

- Learn how to cope with constant demands on your mind and body while living with a chronic disease.
- Gain an understanding of the ways you exert emotional, mental & physical energy during everyday activities.
- Learn how to make life easier.

Key Messages:

- A person with PH who runs a busy family home only needs 3 things... a Maid, a Chef and a Chauffeur!
- There are various levels of activity:
  - Level 1-2 Brushing your teeth, general conversation.
  - Level 2-3 Getting dressed, cooking.
  - Level 3-4 Showering, washing dishes.
  - Level 4-5 Changing the bed linen.

It is estimated that the energy used while showering or washing dishes is the equivalent to walking 3 miles per hour and changing the bed linen is the equivalent to walking at 4 miles per hour.

- The best way to conserve energy is learning to say “no”. Incorporate rest into your schedule-plan for rest, occasionally give yourself a “day off”.
- Use oxygen and mobility devices as prescribed.
- Share household chores.
- Sit when possible while doing daily chores or in the shower.
- Get comfortable with computers by shopping online, paying bills on line and keeping in touch with friends through social media.
- If you like to go to the supermarket, shop at off peak times.
- Avoid bending over at the waist towards the floor; use long-handled devices such as a reacher/grabber.
- When taking shower, keep the room ventilated and don’t let steam build up. The shower should be warm,

not hot or overly long.

- Alternate motions that use the arms. Avoid holding your arms overhead for long periods of time.
- Push heavy items along a counter versus lifting and carrying.
- Keep frequently used items between your waist and shoulder level.
- Plan ahead to avoid rushing (eg. if going somewhere early in the morning, shower the night before).
- Don’t be afraid to ask for help, use handicap parking facilities. Always remember: “There’s no shame in my game!”
- Know your limitations but still try to maintain your independence.
- Finally learn to accept your limitations, this will conserve your emotional energy.

### SESSION 2

#### Communicating in a PH Emergency: Am I prepared?

This session was facilitated by an adult with PH who is a support group leader who told of her medical emergency experience, when she wasn’t prepared.

Objectives:

- Define PH emergency and understand why immediate action is critical.
- Learn how to be prepared & proactive in a PH emergency.
- Learn how to respond to a PH emergency with confidence as your own advocate.

*Medical emergency experienced by speaker:* This session was facilitated by Dawn Jones who related her experience to the audience. One hot summer’s day she was at the beach with her daughter and grandchildren. She decided to paddle in the water and had her pump in her hand. Unfortunately she twisted her ankle on a stone and fell. The pump became submerged in water and although she immediately got out of the water and tried to dry the pump, the alarm started to ring and the pump failed. Her daughter rushed her to the nearby hospital. Dawn tried to explain PH to the doctor on call. She was hysterical trying to explain how important that her IV PH medication cannot be stopped. The doctor tried to sedate her and took her phone from her (she was trying to call her family doctor). There was a very long story about security removing her daughter from the hospital etc and Dawn jumping off the trolley and being man handled by security when... thankfully a nurse in the Emergency Room heard the commotion and asked what was going on. She had experience of dealing with PH before and advised the team on the appropriate procedures. Dawn received IV treatment and thankfully made a full recovery.

### Preparing for a PH Emergency:

- In the past patients were told to always have their documents with them, now everything can be stored on a mobile phone.
- Create a file of all your medical details.
- Save your doctor’s contact details on your phone.
- Scan your latest prescription and relevant documents.
- For continuous infusion therapy, know who to contact for pump-related issues and have emergency contact details.
- When leaving home, always bring a spare pump and extra medication with you.
- Should your phone be locked, allow the facility to call ICE (in case of emergency). Ensure the person you propose knows your condition and can unlock your phone.
- Educate your family, friends and others on how to respond if you have a PH emergency. You could have emergency drills for your home, like a fire drill.
- It is vitally important that whoever your emergency contact is should be fully aware of PH including list of medications and your PH care team’s contact information.

Conclusion:

The above story was a very serious incident and Dawn was traumatised from the experience. However when she related the situation to her PH nurse, they decided between them that they would not write letters of criticism to the hospital and media etc but would be pro-active. The PH nurse wrote to the Director of Nursing in the Hospital and praised the intervention of the nurse who came to Dawn’s rescue. She also wrote to the Medical Director advising him of the incident and proposed that she would arrange an education session for the staff in the ER. She obtained sponsorship and organised an intensive educational session for the staff to ensure a situation like this will never happen again.

### SESSION 3

#### PHinding your hope through fundraising

Like all PH associations, the PHA in the US relies heavily on support from donors to support its mission. The PHA must raise \$9m every year to support the running of the Association.

Objectives:

To encourage volunteers to raise money for the PHA.

Suggestions:

Events organised are very similar to those we organise in Europe, e.g.:

- Fun runs, Walks organised by members of the 240 support groups throughout the country.
- Workplace giving.
- Major “once-off” donations.
- Online donations.
- Making a planned gift through a will or bequests.

List of future events advertised:

It was impressive to see how all of the various support groups across the country came together and created a calendar of future fundraising events.

### SESSION 4

#### Living a new normal

Session description:

When diagnosed with PH, you experience so many changes that you may feel like you’re no longer living your normal life. Three adult PH patients shared strategies on how to cope with the sadness that come with losing aspects of your old life as well as adjusting to living a new life and accepting the new you !

Objectives:

- Understand how even if PH brings on a new normal, you are in control of defining what that normal can look like.
- Understand that a new normal is possible and can be wonderful.
- Learn how to find creative and safe ways to do what you enjoy.

Key Messages

- It’s OK if PH rocks your world at first, but the truth is that this disease does not define you.
- Creating a new normal means figuring out what you can and cannot do anymore, how you can still do things you love, even with PH limitations.
- You have a choice whether you have a healthy or unhealthy new normal: *a healthy new normal* requires you to focus on the things you can control – such as your diet, exercise, compliance with doctor’s orders, self-advocacy with medical teams, self-education about PH – so you feel empowered. *An unhealthy new normal* fixates on





things outside your control and encourages feelings of helplessness, sadness, frustration and anger.

- Be gentle and patient with yourself, finding a new normal may take time and everyone's journey is unique.
- You are not alone when experiencing the frustration of the new normal; reach out to others through support groups.
- Remember it's ok to have bad moments, but not ok to fixate on those feelings.

## SESSION 5

### Managing side Effects of PH Medications

*Session description:*

Dealing with PH symptoms can be emotionally and physically demanding. PH therapies are used to help alleviate the symptoms of the disease but can also cause side effects that one must learn to manage.

*Learning objectives:*

- Understanding the common side effects that PH therapies can produce.
- Decide how you and your PH care team can communicate to discuss side effects that become demanding to optimize your therapy and treatment plan.

### Strategies to manage common PAH medication side effects

*When you start a new medication:*

- Ask your pharmacist about the top likely side effects that you may encounter with your PAH medications.
- Ask about medication prescriptions (over the counter and prescription) that may help alleviate the side effects of your PAH medications.

*After you have started:*

- Communicate with your pharmacist/medical team about the adverse effects you experience.
- There are many solutions that will allow you to continue taking the medication, do not stop the medication

without the approval and intervention of your medical team.

- Ask for help from your pharmacy and if there is a product-specific support programme or online phone resource, make contact.

## SESSION 6

### The journey to a PH Diagnosis

I attended the following session which was presented by doctors. I found it most informative. However, while I have taken notes on the session, I will not report on it since I have neither a medical nor nursing background.

*Session Description:*

The panellists discussed the overwhelming number of tests required for a correct PH Diagnosis. They provided an overview of the diagnostic process, discussed the goals of the various tests and explained what information the test results provided to clinicians.

## SESSION 7

### The basics of PH and WHO Classification Groups

This session was also presented by doctors and I would be apprehensive about reporting on the talk which I found very interesting.

*Session Description:*

Panelists reviewed the basics of PH: how the heart is affected by high blood pressure in the lungs, the difference between high blood pressure in the lungs and high blood pressure throughout the rest of the body, as well as common PH symptoms. Panelists also discussed the different types of PH and the reasons behind the extensive testing that is required for accurate diagnosis and choosing the best treatment plan.

### Informal Meetings

I met with Kristin Books, Director of Fundraising Events

in PHA. I intend keeping in touch with Kristin and hopefully we may benefit from ideas and innovative ideas from the US. I also met with Azalea Candelaria, Vice President, Development. We discussed the problems encountered with constant fundraising and the need for motivation without placing pressure on anybody.

We also discussed the importance of Advocacy. How we should encourage our patients to become advocates for PH by making themselves known to their elected officials. The PHA in the US have a very strong Advocacy and Treatment access team who are constantly fighting on Capitol Hill for the needs of patients. Their current advocacy priorities are:

- To reduce out-of-pocket costs and other barriers to quality care for individuals with PH.
- Fight for PH care, which is driven by the recommendations of an expert physician and not insurance company preference.
- Advocate for health care policy that meets the needs of the PH community.
- Advance research on PH causes, treatments and potential cures.

## CLOSING CEREMONY

*Keynote speaker:*

### Rebekah Calverley, young adult with PH

Rebekah shared her journey from being diagnosed with PH as a toddler and how she found ways to cope with the limitations she was presented with. She spoke of how determined she was to live a full and rewarding life. She became an opera singer, an equestrian, an international corporate banker and a PHA fundraiser.

Rebekah told the story of how she was born in Auckland, New Zealand. She was unwell a lot as a baby and when she was three years old she was diagnosed with a large hole in her heart and her parents were told it was unlikely she would make it to 5 years of age.

When she was eight, her family moved from New Zealand to New Jersey with her Dad's job transfer. She became a patient of Dr Diane Kerstein at the Paediatric PH Centre at Columbia University Medical Centre, which was one of the nation's first PHA accredited centres of Comprehensive Care.

Prior to moving to the US, Rebekah was a keen equestrian, loved singing and spending her days on the ocean. When she was a young girl she was conscious of her limitations but continued trying to keep up with her classmates in the various school athletic activities. She used to run sprints during PE or try to walk and talk at the same time, however she would always end up in the school nurse's office on oxygen etc. She eventually accepted her limitations.

Within the constraints of her illness, she continued horseback riding for several years and began taking voice lessons, performing opera recitals and singing in her church choir.

In college, she majored in Finance and Accounting. She was Student President of the Business school and worked several part-time jobs. She has recently moved into a middle management position with an Australian bank in New York.

Rebekah spoke very emotionally about the support given to her by her family. Her parents Jacinta & Richard have always been there for her and supported her in everything she wanted to do. Because of her determination and stubbornness, her Mum often said "God made your head stronger than your heart". She described her sisters as her 'Bodyguards, her Entourage, her Supporters, her Advocates and her Protectors'. Nothing was impossible when they were growing up, if Rebekah was unable to keep up with others, her sisters just gave her a "piggy back". To this day they are there for her, looking out for her at all times.

She ended her wonderful and emotional presentation with an amazing recital of Puccini's "O Mio Babbino Caro".







## CANADA

**Celebrating 10 years of PHA Canada**

The Pulmonary Hypertension Association of Canada (PHA Canada) celebrated its 10th Anniversary of building a “United PH Community” this year. Founded in 2008, the association marked this special occasion with a number of initiatives, including countrywide anniversary parties and two special issues of its bi-annual community magazine: Connections/Liaison. We also featured a special anniversary website to celebrate our history and the “Eternal PHriends” who helped build our association from the ground up over the years: [www.phacanada10.com](http://www.phacanada10.com)

**New Resources in 2018**

In collaboration with PH medical experts, we were thrilled to release two new bilingual (English/French) resources this year. The first was a series of oral medication info-sheets that cover everything you need to know when prescribed oral medications to treat PH. The other is a series of info-sheets for patients with conditions that put them at increased risk of PH (i.e. connective tissue disease, etc.), which are a part of our Early Diagnosis campaign: [www.SometimesItsPH.ca](http://www.SometimesItsPH.ca). Both of these can be downloaded from: [phacanada.ca/resources](http://phacanada.ca/resources)

**Medical Think Tank**

PHA Canada hosted its first Canadian PH Medical Think Tank in which medical professionals from across the country came together to share and discuss updates around PH diagnosis, management, and research in Canada. This included updates on the very exciting stem-cell research trial in PH patients (SAPPHIRE) that is looking at the long-term safety and effectiveness of “gene-enhanced” cell therapy on PAH patients, a study on the effectiveness of anti-cancer therapy in the treatment of PAH (PARP1), and best-practice research at the leading Toronto CTEPH program.

**Western Regional PH Symposium**

PHA Canada held its annual regional symposium in Vancouver (BC) this year. The event drew 200 PH patients, caregivers, and medical professionals who got a chance to discuss topics related to life with PH, as well as updates on research and treatment. A special reception in honour of our 10th Anniversary opened the event.

**“Life In Purple” November Awareness Campaign**

Every November, members of the Canadian PHamily celebrate PH Awareness Month with special events, fundraisers, and municipal proclamations. This year, our community put on a PHabulous demonstration of periwinkle power from sea to shining sea through our ‘Life In Purple’ campaign, which underlines the impact of PH on patients and their caregivers. The messaging is based on data collected through a Burden of Illness Survey carried out by PHA Canada in 2013: [www.phacanada.ca/LifeInPurple](http://www.phacanada.ca/LifeInPurple)

Michaël Robach. PHA Canada  
[www.phacanada.com](http://www.phacanada.com)  
<https://www.facebook.com/PHACanada/>



## USA-PHA

While the Pulmonary Hypertension Association (PHA) focused its 2018 efforts on PHA’s successful 2018 International PH Conference and Scientific Sessions in Orlando, Florida, we also completed major projects and initiatives in key strategic areas that support PHA’s mission to extend and improve the lives of those affected by pulmonary hypertension (PH).

**Promote Quality Patient Care**

To increase access to quality PH care and ultimately improve outcomes for individuals with PH, PHA continues to expand a nationwide network of PHA-accredited adult and pediatric Pulmonary Hypertension Care Centers (PHCCs). In 2018, PHA accredited three additional Centers of Comprehensive Care and three Regional Clinical Programs for a total of 62 PHA-accredited PHCCs located in 29 states across the U.S. Through these accredited centers, which serve more than 12,000 patients, PHA aims to provide PH patients better access to evidence-based diagnosis and treatment along with a broader range of medical expertise and services. PH Care Centers also provide standardization of care, patient education and increased opportunities for collaboration on clinical care and PH research.

PHCCs also help facilitate improvements in adult and pediatric PH patient care through involvement in the Pulmonary Hypertension Association Registry (PHAR), which enrolls patient volunteers who are starting evaluation and/or treatment at a PHCC. This multi-center patient database collects demographic characteristics, results of diagnostic tests, PH-specific treatments and quality of life metrics from people with pulmonary arterial hypertension (PAH) and chronic thromboembolic pulmonary hypertension (CTEPH) – WHO Groups 1 and 4. In 2018, PHAR expanded to 40 participating PHA-accredited PH Care Centers with 731 patients

enrolled. Researchers and health care professionals may use data collected in the registry to study disease patterns in the hopes of learning more about the disease, as well as developing knowledge of future PH research to learn best practices and develop new PH treatments. PHAR participation is open to any accredited PHCC.

**Catalyze Research for a Cure**

For the past three years, PHA has supported accredited centers participating in PHAR with data analyses of research questions to help improve patient care and to better understand the disease. Registry data has so far led to eight scientific presentations at professional society meetings, including the 2018 American Thoracic Society’s International Congress as well as at PHA’s 2018 Conference. In a new initiative expanding PHA Registry data to a wider audience, research analysis requests for investigators or organizations not participating in a PHAR clinic site will be able to obtain information through our PHAR Data Analysis Service.

PHA leaders attended the 6th World Symposium on Pulmonary Hypertension (WSPH) in Nice, France with more than 1,200 international leaders in PH. PHA President and CEO Brad A. Wong and Board of Trustees member Michael McGoon, M.D. joined Managing Director of PHA Europe Pisana Ferrari to co-lead a new task force to consider the PH patients’ perspectives.

In addition, PHA provided more than \$600,000 in research grants and support to promising researchers in the field, focusing on young investigators, early career grants and innovative adult and pediatric research projects.

**Empower Patients and Caregivers**

Offering support, training, education and resources to the community of those living with PH is core to the PHA mission







# **USA-PHAWARE® RESEARCH NETWORK**

## **About phaware global association®**

phaware global association® was co-founded by pulmonary hypertension community members who together bring unique for-profit expertise to the nonprofit world. phaware® is a virtual 501C3. Working remotely from different areas of the United States, phaware® has adopted a “lean” philosophy so that we can maximize the funding that goes into programming. Our intention is to use technology to create a global footprint and address PH patients’ needs around the world. Co-Founders John Hess, Marie Rand and Steve Van Wormer are all parents of children with pulmonary hypertension and are dedicated to creating better lives for those living with PH as they collaborate with global community members to forge a new course to a cure.

## **phaware® Research Network**

The phaware® Research Network is a formal initiative banding together experts in the fields of technology and research who are working in innovative and novel ways to advance research and patient care.

As the spearheading advocacy group, phaware® leads the effort in selecting the participants and formulating the first PH Research Network dedicated to accelerating studies and working with innovative technology to change the course of treatments. Key partnerships for 2018 included Antidote, CHEST Foundation, Targeted Patient Focus Groups & Expanding our Walk.Talk.Track. Research App Platform.

In 2018, phaware® and Antidote Technologies collaborated on a unique patient engagement model to accelerate lung disease research. This partnership **will help match patients to clinical trials** and provide end-to-end patient recruitment services to pharmaceutical companies and CROs running trials in chronic lung diseases.

Why is this important? phaware® is passionate about finding new and better treatments for those impacted by pulmonary hypertension (PH) and related diseases. Right now, there are more than 90 PH trials currently enrolling patients in the United States (and more in Europe).

Pulmonary Hypertension Trials need more than 21,000 to

take part. With 30,000 patients diagnosed with PH in the U.S., that means that 70% of patients need to participate to maximize research acceleration. Patient awareness of these opportunities is critical, and at phaware®, we will continue to spread the word about this disease and what we can do to stop it. We believe that more efficient patient recruitment and enrollment on the part of researchers is a key solution to this issue.

We’re combined our incredible #phaware community with Antidote’s proven patient engagement services to provide sponsors and CRO’s with the following: unique access to patients affected by PH and related diseases, highly efficient pre-screening technology, effective referral management services to enrollment and insights for feasibility and recruitment planning.

Our new Match tool featured on the clinical trials page of our website is the most effective and efficient way to discover eligibility for open pulmonary hypertension trials and learn more about them. Listen to Tom Krohn, Chief Development Officer at Antidote detail how this collaboration will accelerate lung disease research.

In 2019, our new Match tool will continue to expand to the international market. Patients seeking to participate in clinical trials will be able to quickly and easily find what is available and determine whether or not they are eligible and where the nearest study is located.

## **CHEST Foundation**

Beginning in late 2017, we established a relationship with CHEST Foundation to cobrand a number of PAH and CTEPH educational resources including in both English and Spanish. Materials include: Interactive Patient Resource Guides, What is PAH/CTEPH Infographics, Myths Busted, Q&A about Diagnosis, Treatment and Lifestyle, Pre-diagnosis Patient Checklist, Short of Breath Checklist, Nutrition, Symptoms, Causes, and Risk Factors, etc. These downloadable and shareable digital pieces also feature a dedicated phaware® podcast player on these microsites. This relationship has also helped us reach beyond just PAH, but engaging with experts regarding Sarcoidosis, Scleroderma, etc for ongoing podcast/video content. In 2019, phaware® will collaborate with CHEST to produce a series of CME phaware® podcasts that will be featured on our phawareMD.global microsite to capture and educate medical professionals and reach beyond our affinity group.



and a collaborative effort by PHA and all those in the PH community. In 2018 across the U.S., PHA support group leaders led more than 700 meetings, more than 12,500 volunteers helped organize 49 fundraising events, and PHA members and staff worked together to produce new materials and events.

- PHA’s Understanding PH brochure, newly redesigned and medically reviewed by experts in the PH field, was updated and sent to more than 4,000 patients and health care professionals. PHA’s 28-page flagship publication is designed to provide clinicians and patients a better understanding of PH and what people need to know about diagnosis and treatments.
- An essential packet of information about PH and PHA for the newly diagnosed was redesigned into a booklet called Roadmap to Hope, a guide on how to live the best life one can with PH. PHA has already distributed 2,500 copies since June.
- In 2018, PHA traveled to Milwaukee, Wisconsin and Long Beach, California to share the latest in research, care and advice on living well with PH to individuals with PH, their families and caregivers. Nearly 600 people registered for these free outreach programs called PHA on the Road, designed to bring education and support to individuals with PH where they live.

## **Advocating for the PH Community**

Raising awareness of PH among the public, health care professionals, elected officials and the media happens

throughout the year through such campaigns as World PH Day, PH Awareness Month and CTEPH Awareness Day. To encourage those affected by PH to help promote awareness, PHA created a robust toolkit of online and printed materials, including posters, fliers and fact sheets, social media profile pictures and cover photos, social media sample messages to tweet and post, a customizable press release, PH statistics and associated disease graphics and advocacy tools. The theme of the campaign was “The Right Heart” and featured a blog with stories of inspiration and perseverance from the PH community. The success of the 2018 campaign could be seen in web traffic alone as PHA experienced an average increase in visitor traffic of 33 percent over the preceding three months. PHA’s Facebook page added nearly 400 new followers in November, who engaged through more than 26,000 posts and 30,000 video views. A grassroots effort by the PH community succeeded in gathering proclamations from local, regional and state elected officials all over the U.S. declaring November as PH Awareness Month. This year, PH Awareness Month received national recognition when U.S. Rep. Jamie Raskin (D-MD) read a proclamation into the U.S. Congressional Record in Washington, D.C.

Brad A. Wong, Pulmonary Hypertension Association USA  
<https://phassociation.org/>  
[https://www.facebook.com/pg/PulmonaryHypertension-Association/about/?ref=page\\_internal](https://www.facebook.com/pg/PulmonaryHypertension-Association/about/?ref=page_internal)



**Walk.Talk.Track.™ Research App**

Walk.Talk.Track.™ is a pulmonary hypertension research application developed to determine the quality of life of patients with pulmonary hypertension.

Through an iPhone® and a connected Apple Watch®, Fitbit Charge®, Android® phone, or wearable sensor, we make it very easy for a patient to participate in research surveys and complete activity challenges that are normally done at the hospital. This will help researchers accurately determine how patients feel on a regular basis and how physically active they are; thus allowing researchers to understand more about living with PH.

The current active studies for 2018 are: CHILDREN'S HOSPITAL COLORADO with

Dr. Uyen Truong - Associate Professor CHD - QOL Assessment and 6MWT\* and STANFORD, VERA MOULTON WALL CENTER with Dr. Roham Zamanian - Associate Professor - Self Administered 6MWT\* Validation.

To Learn More listen to John Hess detail phaware's Walk.Talk.Track.™

**"I'm Aware That I'm Rare": the phaware® podcast**

In 2018, we elevated our podcast series of impactful, insightful and most importantly, hopeful stories from members of the global pulmonary hypertension community including PH and CTEPH patients, medical experts, caregivers, nurse practitioners and thought leaders both in the United States and abroad.

New episodes release every Monday and Thursday, with 211 episodes released to date. Find our dedicated landing page here: [www.phawarepodcast.libsyn.com](http://www.phawarepodcast.libsyn.com). "I'm Aware That I'm Rare" phaware® podcast has reached 150,000 unique audio downloads in 110+ countries. Please take a moment to download our free custom phaware® podcast smartphone app on iPhone, Android, and Amazon devices.

Additionally, transcriptions of all interviews are released (every Tuesday & Friday), so that they can be featured as blog posts, news stories, to reach the hearing impaired and more via our relationships with: Medium.com and TheMighty.com.

phaaware® creates evergreen content and provides storytelling within and outside the PH community supporting valuable audio and visual content for interested parties now

available all across the web. Platforms include: Spotify, iHeartRadio, Apple Podcasts, iTunes, GooglePlayMusic, Google Podcasts, RadioPublic, LinkedIn, Tumblr, YouTube, Podsearch, Soundcloud and Stitcher making it easy for anyone, anywhere to listen to this podcast series.

\* 6 Minute Walk Test

**Become #phaware**

LEARN MORE about pulmonary hypertension:

[www.phaware.global](http://www.phaware.global)

GET MATCHED to clinical trials near you:

[www.phaware.global/clinicaltrials](http://www.phaware.global/clinicaltrials)

SHARE YOUR STORY on the phaware® podcast:

[phawarepodcast.libsyn.com/contact](http://phawarepodcast.libsyn.com/contact)

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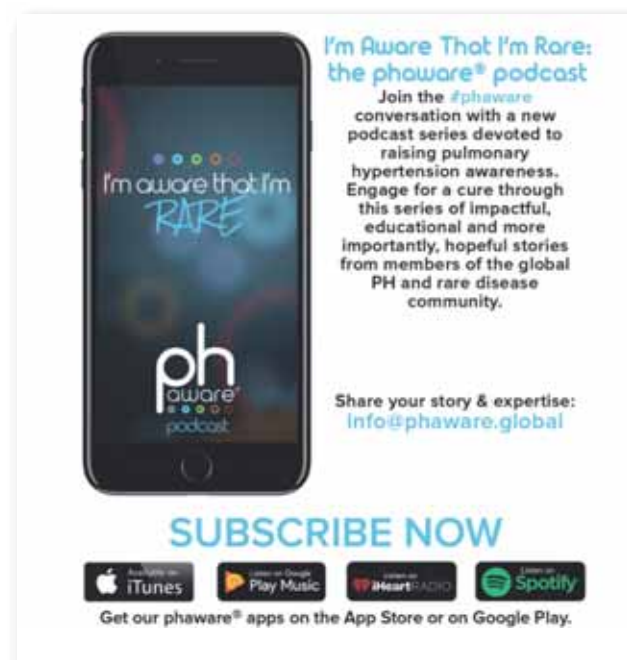
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ENGAGE FOR A CURE: [www.phaware.global/donate](http://www.phaware.global/donate)  
#phaaware

Marie Rand, Phaware Global Association

<http://www.phaware.global/>

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

**Next PHAE newsletter**

The next Mariposa Journal will be issued in July 2019 (Summer edition for World PH Day 2019). The main focus will be the reports from the national member associations about their activities.

We would be very grateful if the members could send their contributions **by the 15th of June 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 PDF will be posted on the PHA Europe website.

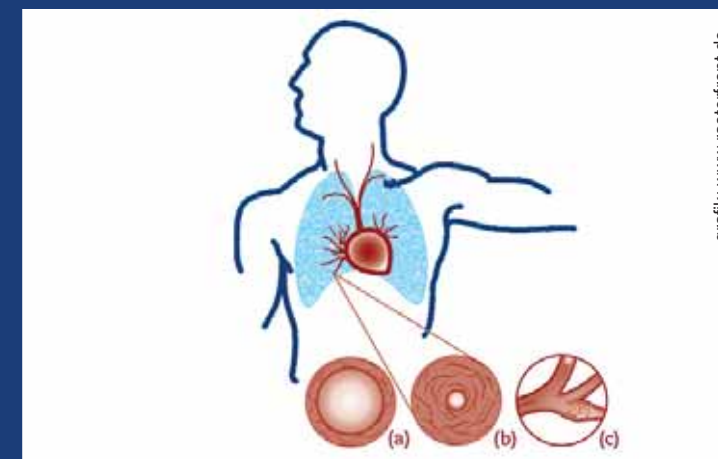
*Many thanks in advance!*

**AIMS OF PHA EUROPE**

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

**WHAT IS PULMONARY ARTERIAL HYPERTENSION?**

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



a. Cross section of normal pulmonary artery

b. Reduced lumen of pulmonary vessels due to cell proliferation and remodelling in advanced pulmonary arterial hypertension

c. Longitudinal section with pathological changes within the vessels proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs

**TREATMENT OF PULMONARY ARTERIAL HYPERTENSION**

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

**THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION**

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



## Members of PHA Europe and contact details

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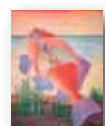


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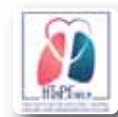
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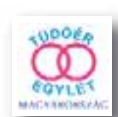
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### REPUBLIC OF MACEDONIA



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st. Tanche Kamberov, 29 - 1480 Gevgelia  
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[phmomentplus@gmail.com](mailto:phmomentplus@gmail.com)

### ROMANIA



Association of pulmonary hypertension patients  
Sinaia/Prahova Carol I, nr 11 street  
[www.phader.eu](http://www.phader.eu)

### RUSSIAN FEDERATION



Natasha Charity Fund  
c/o Evgeniy Komarov - Kondratevsky prospect  
House 57, apartment 6 - St.-Petersburg  
[www.community.livejournal.com/fond\\_natasha](http://www.community.livejournal.com/fond_natasha)  
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Save and Protect  
Prospect Mira 66/2-67 - Nizhnekamsk  
Republic of Tatarstan, 423571  
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### SERBIA



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### SLOVAKIA



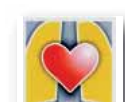
Združenie pacientov s pľúcnou hypertenziou, o.z.  
Lučenská, 31 - 990 01 Veľký Krtíš  
[www.phaslovakia.org](http://www.phaslovakia.org) - [phaslovakia@gmail.com](mailto:phaslovakia@gmail.com)

### SLOVENIA



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### SPAIN



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FCHP Fundación Contra la Hipertensión Pulmonar  
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### SWEDEN



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### SWITZERLAND



Schweizer PH-Verein (SPHV) für Menschen mit pulmonaler Hypertonie  
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### UKRAINE



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