



PULMONARY HYPERTENSION Mariposa Journal

SUMMER 2018 • PHA EUROPE'S OFFICIAL JOURNAL • N. 20



GETTING BREATHLESS FOR PULMONARY HYPERTENSION ON WPHD 2018



Editor’s memo Summer 2018 edition

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Dear PHA Europe members, supporters, friends and family members,

I am delighted to open this issue of Mariposa and thank you all for your amazing participation in, and support of, this year’s World PH Day (WPHD). On the 5th May of 2018, we showed the international community what it is like to live with PH, continuing with our successful “Get breathless for PH” campaign. Healthy people were encouraged to take part in high-energy sports and activities to get breathless, driving awareness of what it is like for people with PH who struggle to breathe. Our aim is to highlight the challenges faced by people living with PH, ensure they get a fast and accurate diagnosis, and ultimately receive appropriate treatment that provides relief from their symptoms.

For the second year in a row, PHA Europe continued to align its WPHD activities across with patient associations from the USA and Latin America, expanding awareness of PH across the globe. This international collaboration allows us to combine expertise and resources, reaching more and more people. An example of this successful collab-

oration was apparent with the Thunderclap campaign. Over 800 supporters signed up to post the same coordinated WPHD message through social media at the same time, and it reached almost 4.4 million people in 300 cities across 53 countries. Local organisations in Europe contributed to the success of this campaign by reaching out to global healthcare organizations, patient groups, large industry and sports clubs for their help. This was a huge boost from last year when we reached 2.5 million people worldwide. An extraordinary campaign, I think you will agree! In Europe, 31 of our hardworking local organizations arranged more than 60 events that were attended by over 40.000 people. Individuals, teams and societies got involved wherever and however they could, creating new opportunities to increase recognition of PH. Events ranged from incredibly personal challenges to community outreach projects, from conquering mountain peaks to a charity market. To name just a few... In Serbia, approximately 70 pilgrims spent just over one week walking to Fatima wearing the PH awareness logo, distributing hundreds of PH and CTEPH flyers in cities and villages as they



LOVE, EMOTION, SOLIDARITY

The photo “Hugs” was presented by Bosnia & Herzegovina for the photo contest. I chose it for the editor’s note because it represents many aspects of the spirit of WPHD although it does not show any logo. It speaks about how important it is that society embrace diversity, accept that there are people who suffer a terrible but invisible disease and that patients need emotional support to get and maintain their quality of life.



went. The President of PHA Bulgaria – a CTEPH patient post-pulmonary endarterectomy surgery – pushed another PH patient in a wheelchair to complete a 5 km race. Our Spanish friends held multiple events attended by over 11.000 people, including a Rhythmic Gymnastics competition, as well as a Comedian’s Gala. In Latvia, 1.7 million TV viewers saw news reports about PH, consisting of cardiologists and prominent politicians, and including the Latvian Prime Minister. PH Israel sponsored one of their top-rated football teams, who wore WPHD T-shirts during matches, and an advertising board placed in the stadium with an explanation of PH was announced at every game (I’m sure it brought them luck as they have reached the finals). In total, the different European activities have generated 337 pieces of media to date, including over 1.805 print articles, 32 tv clips, 24 radio announcements and 95 pieces of online media. PHA Europe associations used the hashtag #World-PHDay nearly 2.000 times on social media. Our message is reaching millions of people, driving awareness of the devastating nature of PH and mobilizing support for those affected. Building on the success of 2017, WPHD 2018 continued to broaden our exposure with specific social media campaigns. This year we ran a series of Facebook adverts with key word targeting, driving people to learn more by clicking through to different PH websites. The adverts received over 6 million



views, reaching almost 1.5 million people, with over 150.000 people clicking on the adverts to find out more about PH. This year’s WPHD also featured two new initiatives, the first of which was a contest for best WPHD photo. Many associations submitted their photos and an external jury, consisting of top physicians, chose the best one. We also had an interesting webinar about CTEPH, with leading expert Prof. Marion Delcroix, a patient testimonial from Patrick Corkery, and information about how ERN-Lung works from Gergely Meszaros. The success of WPHD 2018 is a result of collaboration and sharing best practice among our many members. It is amazing to see so many people working together to build one important day that is felt around the world. On behalf of PHA Europe, I want to thank each and every person who contributed to WPHD 2018, and those who continue to raise awareness for such an important cause throughout the rest of the year. Thanks also to our industry partners, whose support and dedication has helped to achieve another successful WPHD. Let’s keep our momentum and make WPHD 2019 even bigger and even better: together, our voice is thunderous, and I hope will benefit countless people living with PH, for many years to come.

Juan Fuertes, Managing Director PHA Europe

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PHOTO CONTEST PHA EUROPE 2018

In past years World PH Day has become a truly global event, with thousands of people from all continents—Europe, North and South America, Africa, Asia and Australia—joining forces to mark the date. Many different activities to raise awareness of pulmonary hypertension were organized, which had a very wide global reach, on both the traditional media and social media. Hundreds, if not thousands of photos, were taken worldwide on and around World PH Day. All these photos were taken for a reason, whether this be to record the event and keep a memory of it, or to deliver a message. The idea of the World PH Day photo contest was to see which would be considered the most meaningful photo by the associations if they only had the possibility to submit one. Our aim was also to encourage our members to enhance the quality of the pictures and to find a really eye-catching one. The great variety of the photos submitted fully met our expectations. There were photos which showed emotions and solidarity with friends and fellow patients. Others related to personal accomplishments during races, or to the enormous number of people reached by the event, or to showcase the set up and decorations



made for the occasion. There were other photos, however, which reminded us of the "real face" of the disease, the challenges patients face in their day-to-day lives, and the hard work that still lies ahead of us to improve the lives of patients. The difficult task of making a decision about the best World PH Day 2018 photo was taken by a jury consisting of well-known experts from the medical field:

- Prof. Dr. Tof Wagner, Medical Clinic I, Head of the Department of Pulmonology / Allergology, University Hospital Frankfurt, co-ordinator of ERN-Lung.
- Prof. Marc Humbert, Director, INSERM U999, Université Paris-Sud II, Department of Respiratory and Intensive Care Medicine, Hospital Antoine Bécélère, vice co-ordinator of ERN-Lung.
- Prof. Nazzareno Galie, Professor of Department of Specialized, Diagnostic and Experimental Medicine, University of Bologna, vice co-ordinator of PH core network of ERN-Lung.

We are happy to announce that the winner of the photo contest is... PHA SLOVENIA



WPHD 2018 - BELARUS

FOOTBALL AND TENNIS EVENTS MARK WORLD PH DAY IN BELARUS

Yearly celebrations for World PH Day hold a special place in the hearts of all Belarusian patients, facing, as they do, the day-to-day challenges of living with the disease. This year, in May, our association organised two mass sporting events for the occasion: a football match with FC Torpedo-BelAZ, a Belarusian football club based in Zhodino, and a tennis tournament at the "Fox Tennis" club, in Minsk, under the slogan "Let there be Good!". The aim of the two events was to raise awareness and to attract public attention to this rare and devastating disease, as well as to provide support to patients. The football match was held with a great sporting spirit and an incredible atmosphere of kindness and cohesion reigned. It was not just a game to score goals against the other team, but also a symbol of the struggle against a serious, devastating disease. City residents passing by and anyone interested in supporting the PH patient cause were handed out flyers with information about the disease and bank account details for donations, which will be used to purchase oxygen concentrators, a vital instrument for people suffering from PH. It was also possible to show empathy and support to patients by taking pictures with a specially designed selfie frame.

The tennis tournament was no less memorable than the football match. It was a game with very active, passionate fans, driven by the taste of victory and leadership, and, most importantly, by a sense of compassion and support towards patients with pulmonary hypertension. All the participants of the festive events wore T-shirts with the logo of World PH Day.

The day ended with the traditional launching of blue balloons into the sky, which symbolizes lightness, freedom from negative thoughts and the hope for improving the quality of life of patients! Many people took part in the events we held in support of our patients.

We believe in what we do and always follow a simple truth: what comes from the heart, goes up to the heart!

We express gratitude to all our participants and fans for their support and kindness! Let there be Good!

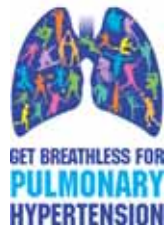
Aksana Sniaghko

Aid to Patients with Pulmonary Hypertension

www.phbelarus.by

www.facebook.com/groups/phaBelarus





WPHD 2018 - BELGIUM

RACING, RUNNING AND WALKING FOR PH



We are already in August; it has been a busy year so far for PH Belgium, with many activities, organised by us or our sympathizers, to raise awareness for pulmonary hypertension and also inform patients in Flanders and bring them together. In February, on International Rare Disease Day, our Vice-President Wendy had the opportunity to give an interview for the Standaard, a national newspaper widely read in the Flemish part of Belgium, about what it is like to live with a rare disease like pulmonary hypertension. We also worked together with RaDiOrg, the Belgium organization for Rare Diseases, on producing pulmonary hypertension information cards, that were distributed in several hospitals in the country. Traditionally, around this period, we also hold our local patient group meetings, where patients and their relatives can meet in different parts of Flanders. We continued with our "PH on Tour" which started at the end of last year. With the "PH on Tour" we visit different places in Flanders with an informative program for patients and their relatives. One such lecture was about pulmonary hypertension and the current treatments available, the other about rehabilitation for PH patients. Both lectures were given by specialists from the UZ Leuven (Flemish PH center). We have noticed that for some patients, the distance from their homes and the duration of

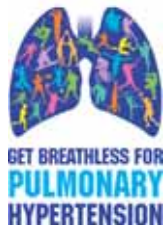


the program represent an obstacle. By going to different places with the same program with the duration of one afternoon, we have actually doubled our reach compared to having just one national patient day as we did before! In the build-up to World PH Day, several sympathizers organized a sporting event to raise awareness and funds for scientific research for pulmonary hypertension. On the 22nd of April, a group of 20 people from TalentIT/Team4Talent ran the "Antwerp Ten Miles" for a young patient, Lies, who is the daughter of one of the employees of this firm. Later that month, on the 28th, Tommy Vansteenkiste, brother of Wendy, who has PH, participated in the "Race Across Italy", an ultra-cycling event, riding 33 hours to overcome the 750 km route and 10.000 metre elevation. Tommy is member of "Team Phenomenal Hope" and races for his sister in their "Let Me Be Your Lungs campaign". He was accompanied by two followers and a vehicle branded with the "Get Breathless for PH" logo on it. Several local newspapers reported on the

story of the brother and sister fighting to bring awareness for PH and there was also a lot of attention to the event with information on PH and the campaigns on social media. The day before WPHD, we were present at UZ Leuven with an information stand, together with Actelion and the specialized nurses of the center. People could do a 6 MWT or ride the home trainer with weights and breathing only through a straw to simulate what it is like to do physical activity with PH. Later that month, there was an "Walk for PH" organized by the Polyando hiking club, who has a PH researcher among its members. During the month of May, we posted each day a fact about PH or a testimony of a patient or relative on our social media.

Wim Colle, Patiëntenvereniging VZW Pulmonale Hypertensie (vzw PH België)
www.ph-vzw.be
<https://www.facebook.com/PHBelgium?fref=ts>





WPHD 2018 - BOSNIA AND HERZEGOVINA

SPORTS CLUBS, CYCLISTS AND MOUNTAINEERS GET BREATHLESS FOR PH IN BOSNIA AND HERZEGOVINA

World PH Day 2018 in Bosnia and Herzegovina was marked throughout the month of May. Our aim was to highlight the problems that patients with pulmonary hypertension are facing in our country in their day-to-day life by organizing a number of different activities. Many sportsmen, sports clubs and sports workers, as well as the media, supported and joined us in these activities. In addition to what we ourselves had already planned, some athletes and sports clubs, who also wanted to be part of the celebrations, organised some own-initiative events. We are very proud of this because it is a confirmation that we have been successful not only in raising awareness of the disease itself, which is already quite an achievement, but also of the difficult position of patients with pulmonary hypertension in Bosnia and Herzegovina. One of the things we are particularly proud of is that we have succeeded in securing the engagement to the PH cause in all age populations - from the youngest to the oldest. We organised a brief lecture for primary school children who

were keen listeners and happily took part in games to make them understand the disease, which we had set up for them. There were members of a team of disabled people who play volleyball who sent the message "Visible to the invisible" with a clear message that they were with us in all of our activities.

We had bicycle and mountain climbers from Bosnia and Herzegovina celebrating World PH Day again this year: thanks to them we are able to raise awareness beyond the borders of our country.

Ismet Skulj, a Bosnian cyclist, for the second time has dedicated one of his bike tours to PH patients. In May 2018, he cycled, alone, a 2.000 km long tour, all the way to the capital of Albania, Tirana. His journey lasted for 14 days and was extremely demanding because the route he went through was extremely tough, with rough and hilly terrain, and crossing four different states. Thanks to his marathon biking trips, dedicated to PH patients, we call him the

world's "PH bicycle traveler".

Zdenko Veljagic, an alpinist and speleologist, dedicated his fourth visit to the summit of an attractive alpinistic destination to our patients.

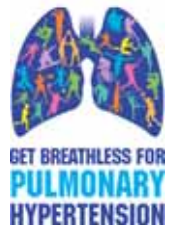
A new expedition to the Matterhorn, 4.448 m, which will be devoted to patients with pulmonary hypertension, due to weather conditions, is scheduled for July this year. After conquering the peaks of Western Europe (Mont Blanc, 4.810 m above sea level), Africa (Kilimanjaro, 5.895 m above sea level) and China (Muztagh Ata, 7.546 m above sea level) with the World PH Day flag, this year a team of mountaineers will reach the demanding peak in Switzerland. Good luck!

In addition to all these outstanding activities, we would also like to mention the activities carried out in cooperation with a local shooting club, a fitness club, bicycle clubs from all over Bosnia and Herzegovina, as well as the social activity "Free hug" on the streets of Sarajevo, in cooperation with the Association "Heart full of smile".

A very big thank you to all our supporters on behalf of all the patients!

Vera Hodžić, Udruženje građana oboljelih od plućne hipertenzije "DAH" - u Bosni i Hercegovini
<http://bit.ly/2aiEJgO>





WPHD 2018 - BSPPH BULGARIA

CLIMB THE WALL AND GET BREATHLESS FOR PH

In 2018 the Bulgarian Society of Patients with PH BSPPH celebrated World PH Day for the 6th consecutive year. The events were held with the support of the Ministry of Youth and Sports, the Ministry of Health, the Bulgarian Society of Pulmonary Diseases and the National Patient's Organization. For the 3rd time, on the 5th May the building of the National Palace of Culture (the biggest convention center in Bulgaria) was illuminated in blue to show the commitment of the Bulgarians to the problems of PH patients. This is the building where the EU Presidency of the Council 2018 was situated up until the 30th of June. On the 4th of May this year, in the sports center "Funtopia", inside the Paradise Center Mall, Sofia, we held a part of the

"Get breathless for PH" campaign, an indoor climbing event involving both children and adults. The event was held under the patronage of Ministry of Youth and Sport. The Chairwoman of BSPPH, Natalia Maeva, who underwent a successful lung transplant in a clinic in Vienna two years ago, personally participated and climbed. In attendance were: Ms. Vania Koleva, Deputy Minister and the Ministry of Youth and Sport, the Chairman of the National Patients' Organization Dr. Stanimir Hasardzhiev, the Director of the Transplantation Agency Dr. Mariana Simeonova, and Dr. Lyubomir Dimitrov, deputy chair of BSPPH.

The Minister of Health sent a special letter of congratulations to the participants of this event dedicated to PH patients.

To date, Bulgarian PH patients do not have access to intravenous prostanoid treatments for pulmonary hypertension. For them it is critically important to have easier access to European clinics which perform pulmonary endarterectomy, as well as lung transplants or combined heart and lung transplants. This would enable them to return to normal life.

Here is what Dr. Lyubomir Dimitrov shared: "I am a pediatric cardiologist and pulmonary hypertension is a part of my job. The disease is very varied. If people have heard of it at all, they usually know of pulmonary arterial hypertension. However, this is only a small part of the total PH population; it is just the tip of the iceberg. Newborns can have pulmonary hypertension. Of course, it is a very specific type of pulmonary hyper-

tension and it is mostly treatable. However it is a fact that infants in the first months after birth die from persistent newborn pulmonary hypertension. It is very important for Bulgaria to renew its Eurotransplant contract because PH patients need to have access to lung transplantation".

Among the participants who climbed the walls of "Funtopia" were the children from Foundation "You are part of us", who have congenital heart malformations.

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

www.bspph.net

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



WPHD 2018 - PHA BULGARIA

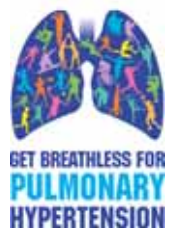
WE ARE FIGHTERS AND WE DON'T GIVE UP:

BE PROUD OF YOUR LIFE AND BE PROUD OF YOURSELF

The PHA BULGARIA and their partners from Autoclub "Sever (Nord)" raised awareness for pulmonary hypertension for World PH Day by organising some sports and informative events. This year the campaign was focused on young adults living with PAH, their careers and achievements in the battle with this rare disease. Therefore, as part of the celebrations, the organisation decided to plant trees around the lake Pantcharevo, near Sofia, as a symbol of youth and the vital need for oxygen for young people's growth and development.

Todor Mangarov, PHA Bulgaria
www.phabulgaria.eu
www.facebook.com/aph.bulgaria





WPHD 2018 - CROATIA

RAISING AWARENESS OF PULMONARY HYPERTENSION ACROSS ALL AGES WITH YOGA AND TRIATHLON

Dear friends and fellow PH fighters,
Let us share with you our contribution for this year to our joint struggle to raise awareness of pulmonary hypertension. We are particularly proud of the success of the Thunderclap campaign, where we had the third highest number of votes, which, for a small country like Croatia, filled our hearts with happiness! We take this opportunity to thank all those who supported us, and share the hope that next year we can, together, achieve even better results. Of all the local events with which we marked World PH Day, I would like to mention the "Yoga Day" first. We spent the day at the popular Lake Jarun, in Zagreb, in a sports recreation centre which gathers crowds of people of all ages daily, practicing yoga and breathing techniques, because the PH patients know best how much each breath is of great significance. We had rain for part of the day but we managed to stay relaxed and make the most of the benefits of the yoga session. We also managed to distribute leaflets and materials containing information on pulmonary hypertension and, most importantly, we had many passers-by joining us. In addition to yoga, we also held a two-day international handball tournament for girls and boys. There were 61 handball clubs with over 600 children and just as many

parents and trainers. They played a mean game and "got breathless" for all those affected by PH in the country, and beyond. We think it is a very important to educate children about the disease, because they are our future. The tournament had a very large number of spectators attending and the news was picked up by the media. The last event of which we are particularly proud of is the participation in the "adrenaline race" (triathlon) where we were represented by our winners from last year's Ironman in Pula (women's team). Unfortunately they did not do as well as last year, but for us, they were absolute winners anyway, because the race was held under very difficult conditions, with many obstacles, but not for a minute did they think of giving up! It is so difficult to choose only a few photographs from so many excellent ones, but we are aware that the space is limited space, so here is a small selection from each of the events.

*Katica Mavračić and Zdenka Bradač,
Plava krila, Udruga pacijenata oboljelih od plućne
hipertenzije*
www.plavakrila.hr
www.facebook.com/PH-Plava-krila-Croatia-1580485492196960/?fref=ts



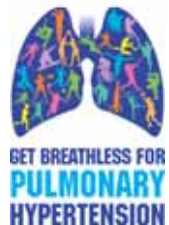
WPHD 2018 - CZECH REPUBLIC

BIRDIE GOLF TOURNAMENT WITH CELEBRITIES AND MEDICAL EXPERTS

This year we organized another Birdie open golf tournament for pulmonary hypertension, our third. The tournament took place on Saturday May 19, 2018 in a resort called Malevil. Malevil is located in a lovely valley in the Lusatian Mountains, in the charming little village of Heřmanice, situated close to the town Jablunné v Podještědí. The tournament itself hosted 26 players and 18 patients with their families. The event was supported by a number of celebrities, as well as by some important figures from our medical field. The actress Sabina Laurinová was the kind patron of the tournament, as in the past two years. From the medical field we were honoured to have, inter alia, the Director of the General University Hospital in Prague, Mgr. Dana Jurásková, and the chief physician of the II. Cardiovascular Surgery Clinic in Prague, Prof. MUDr. Jaroslav Lindner. For all the contestants and the other 18 participants, patients and their families, we prepared an accompanying program in the beautiful resort with zoo and botanical garden. This year we raised 360 euro from the tournament for our patients, with which we plan to buy new and very necessary equipment for them.

Martina Adamová, Sdružení Pacientů s Plicní Hypertenzí
www.plicni-hypertenze.cz
www.facebook.com/Sdružení-pacientů-s-plicní-hyper



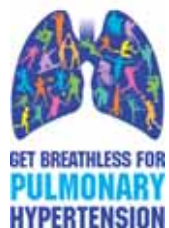


WPHD 2018 - DANMARK

RAISING AWARENESS OF PULMONARY HYPERTENSION WITH MEDICAL CENTRES FOR WORLD PH DAY 2018

PAH Patientforeningen Danmark celebrated this year's World PH Day on the 22nd April 2018. Thirty-four members (patients and their next of kin) participated in the celebration, which was held on a sunny Sunday in Kolding. The day was marked by introducing a new folder with patient stories, which was distributed to the three PH centres in Denmark. Furthermore the participants handed out information materials relating to PH/PAH, the Danish PAH association and PHA Europe.

Bente Rasmussen, PHA Denmark
pah.dk - pahforening@gmail.com



WPHD 2018 - FINLAND

THE "STRAW CHALLENGE" TO SHOW THE LIMITATIONS OF PH

For this year's WPHD, we sent "Get breathless for PH" T-shirts to our members, and a packet of straws, for them to challenge their family members, friends and co-workers to walk up the stairs breathing through a straw, and get the "authentic PH feeling". We also produced and distributed a brochure about PH to our members, that they could easily share to explain about the disease to their friends. Participants were very

excited and also surprised at how hard it is to breath, when breathing is so constrained! We then asked people to post their pictures with the T-shirts and straws on our Facebook page.

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



WPHD 2018 - FRANCE, GERMANY & SWITZERLAND

A DREAM HAS COME TRUE!

The French and German associations celebrated World PH Day together in 2016 and 2017. Last year, in Castelfels, we promised that Switzerland would join the team to make it truly a "dream team". And we did it! HTaPFrance (France), PHe.v. (Germany) and SPHV (Switzerland) met in an open air museum located in the village of Ungersheim, in Alsace (East of France).

"The Écomusée d'Alsace is the largest living open-air museum in France and shows an Alsatian village from the early 20th century. It illustrates what rural life was like in Alsace and invites visitors to find out about popular traditions and art of the region, including buildings and artefacts, craftsmen at work, temporary exhibitions, attractions and events both small and large." We could experience "what life was like in rural Alsace and explore the extraordinary heritage of the Écomusée d'Alsace, with its houses, crafts, cooking, agriculture and also its surroundings with its gardens, river and fields". This wonderful day was full of symbols:

- Our meeting brought together 3 countries and 3 associations. That is unique!
- The flags of our 3 countries waved in the front of the Écomusée.
- Our group was a little panel that represented quite well the PH community of our 3 countries: it was composed of 6 patients (2 men, Philippe and Raymond, and 4 women, Helga, Therese, Sandra and Laure), on different therapies: oral combination therapy, or triple combination therapy

with IV infusion (either Veletri®, or Remodulin®, or iloprost), and oxygen therapy.

- There were also 1 spouse and 2 husbands of patients (Joëlle, Willi and Théo), 1 daughter of a patient (Chloé), et Hans-Dieter who has no link with PH, but who is the dedicated president of PHe.v. and PHAE !
- 4 generations were represented, with for example Helga (88), patient and Oldest Member of PHe.v., Raymond (68), Laure (48), and Chloé (22).

Bringing together patients, family members, friends, associations, countries and generations, this beautiful day showed that living together is possible. And it also showed that thanks to the treatments, if you go your own pace, either by foot or in a wheelchair, you can live better and longer with PH.

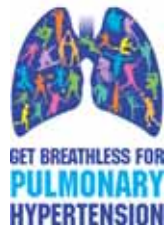
Laure Rosé, HTaPFrance
www.htapfrance.com

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

Pulmonale Hypertonie e.v.
www.phev.de

Schweizer PH-Verein (SPHV) für Menschen mit pulmonaler Hypertonie
<https://www.lungenhochdruck.ch/>
www.sphv.ch





WPHD 2018 - GERMANY

CYCLING, RUNNING AND WALKING FOR PH



We had a very eventful and very active World PH Day this year.

Collecting kilometres for World PH Day via an app

To start with we organised what turned out to be a very big sporting event, under the slogan #HelpHelp. For this purpose we had set up a dedicated group on a fitness app called "Strava", which was open to anyone who wanted to "collect" kilometers to raise awareness of PH and World PH Day by cycling, running or simply walking. Team PHenomenal Hope was joined by many other athletes, as well as physicians specializing in PH and, what we really appreciated, many PH patients. Several of them signed up for the event on the Strava fitness app and sent us, on May 5, reports of their walks, which was great! Many thanks to you all - your kilometers should count double or triple!

The Berlin PH Forum, organized by Actelion Pharmaceuticals Ltd, which also took place on May 5, was joined by over 200 doctors and nurses who are primarily involved in the treatment and research of PH. Many of them used the opportunity to ride a few kilometers during our event on the sidelines of the conference.

We also had a triathlon club from the Darmstadt area with the SF Tria Rossdorf. Several members of the club, acquaintances and friends of ours, took part, already in the last two years, in our (then) smaller bike rides for World PH Day. At this year's event, the longest track on the bike was by group of Hessian cyclists who covered a distance of 407 kilometers!

And yet another highlight: the comedian Wigald Boning, well known from television, was running barefoot around the Dieksee in Holstein Switzerland for us. In terms of endurance sports, Wigald Boning is quite an eccentric, he has done



things like roll over the Alps with a scooter and swim across Lake Constance. When we asked him if he would like to take part in our event, he immediately said yes. We thank you very much, Mr. Boning!

In total, on May 5, 172 activities were recorded in our Strava group covering over 9.000 kilometers!

Thanks to all those who contributed with their kilometers - you are truly awesome!

Actelion Pharmaceuticals Ltd considered our action to be good and not only helped us with the organization but also gave us a donation for every kilometer recorded. The company rounded up the accumulated total of kilometers traveled and driven to 10.000 and donated 50 cents per kilometer. In total, a considerable € 5.000 went to the ph e.v.! We would like to thank Actelion warmly for their support!

Our conclusion: That's exactly what we wanted - a unifying action for the World PH Day, where everyone can join in and everyone can contribute to raising awareness of pulmonary hypertension!

A big thank you to everyone involved in all the different places!

A motorcycle tour for a good cause

This year, on the 5th of May, World PH Day, we organized, for the first time ever, a motorcycle donation tour. To go back one step, the ph e.v. has offered in past years to children affected by PH the possibility to submit a "special wish", via mail, through their parents, to the association. At the annual general meeting in April 2018, the name of the 2018 beneficiary was drawn up and it was Paul. His special wish was an e-scooter! So that is the story behind the motorcycle donation tour!

The start was on May 5 at 11:30 in Obrigheim in Mosbach (Baden) at the Rock'n Bowl in Baden-Württemberg. At 10:00 the first riders arrived to register. Everyone received a bottle of water and a small bag which with a map and information material about pulmonary hypertension. By 11:30 thirty-one riders had come together and the press shot a group photo before all the motorcycles took off in the direction of the PH center in Würzburg.



The route took the riders through the beautiful Odenwald via Eberbach and Amorbach to Miltenberg. Here they took a break on the banks of the Main. The weather was very good, which allowed the riders to enjoy the tour as well.

While the drivers were still on the road, our organizing team from Obrigheim drove to Würzburg, by car, to meet the drivers. The clinic in Würzburg had prepared a very nice buffet for the riders.

At 16:00 the drivers arrived in Würzburg. Dr. Held gave a small lecture on the disease and about World PH Day and we all warmly thanked the drivers. Delicious cakes and sandwiches had been prepared for them. Everybody who wanted could go to the roof terrace of the hospital; from there you can enjoy a wonderful view of Würzburg Castle and the city.

After consultation with the drivers, we drove back to Obrigheim at 17:15. There, another organization team was already preparing a barbecue, so that we could comfortably end the evening with the arrival of the drivers.

At about 18:30 the riders arrived and soon we got together in a big group and there were grilled sausages for everybody. Some drivers came from Mannheim, Heidelberg and Heilbronn area. Therefore, the first ones drove home around 20:00. Others even came from Freiburg and slept one night in Mosbach. Around 23:00 the group broke up.

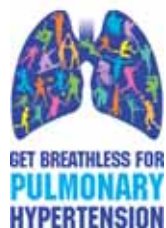
It was a great day. We have experienced a lot and hope that the event can take place again next year.

Thanks to the motorcycle tour we raised 870.70 euros and two donors rounded up the sum to 900 euros, so that in mid-May we were able to hand over to Paul a donation check of 900 euros and he was able to buy his e-scooter. A big thank you again to all those who donated, because without the drivers and the donors it would not have been possible.

Report by: *Carolyn Thurmman*

Hans-Dieter Kulla, pulmonale hypertonie e.v.
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<https://www.facebook.com/pages/Lungenhochdruck-Deutschland/386143468153378>



WPHD 2018 - GREECE

TIME MATTERS WHEN YOU HAVE PH!

RUNNING FOR PH! LOTS OF AWARENESS! LOTS OF HOPE!



The Hellenic Pulmonary Hypertension HPH completed another very successful World PH Day, on its own, without funding from PHA Europe. HPH promoted the umbrella association through all the branded materials and by having the logo of PHA Europe everywhere.

Running a marathon in Crete

For the third consecutive year HPH took part in "Run Greece", in Iraklion Crete, one of the biggest marathons that take place in six different parts of Greece. A team of athletes ran for PH to raise awareness of the difficulties patients have to face for each breath they take! They simulated the continuous "run" of a patient's everyday life, the continuous "marathon" they have, feeling double the tiredness, the dyspnea and weakness, for the simplest activity, of normal people. At the finish line our kiosk was there to welcome all the runners and provide them with water and bananas.

The Run Greece organization honored us and helped us by distributing information leaflets about PH and World PH Day through the runners' bags.

Taking advantage of the presence of members of HPH in Crete we arranged a PH Information Day with a complete educational program for the patients, caregivers and doctors of Crete. We managed to put everyone together so as to have



have an interesting exchange of opinions and a very constructive discussion and conclusions. All the events that took place in Crete were shown on the local TV station, which was very helpful and supportive and presented PH as the main theme of one of its TV shows.

Municipal event for the Attica race

HPH also took part in the first Attica race, on the 27th of May, where 23 municipalities of Athens arranged on the same time a race for a good cause. HPH organized the race for the municipality that it belongs to, with great success. More than 300 people gathered that Sunday morning and ran with the colors and the symbols of PH on the T-shirts in order to pass the message of awareness. The Mayor honored the three first runners with the award medals and three clocks with the very popular slogan: "Time matters when you have PH". This event was the first running event to mark this year's World PH Day. Until now all the events had as main sport cycling and the switch to this new sport was done with great success regarding the participation. Our T-shirts became irresistible as everybody wore one, including the Mayor, and our kiosk was sold out. It was a really exciting Sunday morning, full of balloons in the air and many runners wearing the colors of pulmonary hypertension.

Kiosks with Pongo are a huge success

On the 5th of May, on World PH Day, two teams of enthusiastic volunteers gathered in the two most popular places in Greece. One group was in Ermou Street, the main shopping area in downtown Athens, and the other in the Aristotelous square, in Thessaloniki. Two very spectacular kiosks were installed there to gather all the passers-by and inform them about PH. Of course our rare friend and hero, Pongo, the purple elephant, was there to attract children and their parents, and introduce them to the concept of "rarity". As always, Pongo made a huge impression, and many kids and parents asked to hear his story and play with him.

During the day, the most popular TV channel of Greece interviewed the President of HPH, in front of our kiosk, and made our voice for awareness even stronger. Moreover, during prime time, two interviews, one from a PH patient and one from a PH caregiver, were aired during the daily news of the same TV channel. All this was a great way to raise visibility for PH.

Finally, the uniqueness of this year's action was that the kiosks were very large, in order to attract as many people as possible. Hundreds of people stopped in their tracks on their shopping day to wear a purple ribbon, learn about PH and to ask about the symptoms of PH.

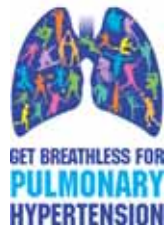
All the World PH Day events were covered by the media, social media and healthcare specialised websites, which obviously contributed to the success of the HPH events!

Ioanna Alissandratou, PHA Greece

www.hellenicpulmonaryhypertension.gr

www.facebook.com/HellenicPulmonaryHypertension





WPHD 2018 - HUNGARY

CONQUERING HEIGHTS TO GET BREATHLESS



Our association was founded in 2008 with 15 members; over the years we have grown to 130. Among our members we have a number of specialised pulmonary hypertension physicians, who are practicing cardiologists, as well as patients and caregivers. Our primary goal, apart from representing and supporting PH patients, is to raise awareness of the disease. Very often our fellow patients wander for years in the maze of the health care system before a doctor finds the correct diagnosis. We have been raising awareness by appearing in the media (magazines, television), where we talk about the symptoms of the disease and the difficulties we are facing.

Over the past 10 years we have organised World PH Day celebrations around sports activities: eg. climbing one of the highest mountains in Hungary, organising 6 minute walking tests on a busy square in the town center, running in the City Park. This year the Hungarian association had two separate events:

- 5 May 2018, Budakeszi Vadaspark (Zoo), Hungary
- 1-3 June 2018, Velka Fatra National Park, Slovakia

Both World PH Day events were in the open air so that participants could enjoy a day outdoors, with the scent of the forests, nature and its small miracles: these are all funda-



mental for a PH patient. The Hungarian celebration was in the outskirts of Budapest, at the Budakeszi Zoo. We invited children and adults, had a tent and spent the day under the trees, in a lovely environment. We had a nice program with games and other high energy activities to make the participants "Breathless for PH". We had presentations from our cardiologists and our physiotherapists helped us to measure blood pressure and oxygen levels. We were delighted to have lots of visitors, members of the association and their children, but also other visitors, passers-by who were attracted to our tent by the games, soap bubbles and balloons. Our volunteers were well organised and did a great job in keeping the children occupied and entertained. Everybody won entrance tickets to the Zoo and to the canopy track.

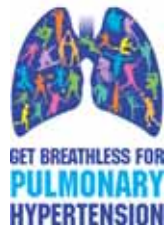
In June we had the privilege to be invited by Iveta and the Slovakian PH association to their WPHD celebration. Besides presenting our association we participated in the walk to a mountain peak. It is a very beautiful tradition that during the walk healthy relatives, friends of patient take the picture of patients with them on the climb. We are proud that Eszter completed the hike, despite the fact that she is a patient. We did not carry pictures but our fellow patients were with us, they were in our thoughts as we climbed up the way. We are very grateful for this opportunity and enjoyed very much celebrating with our Slovakian PHamily.

Eszter Csabuda, Tüdőér Egylet

www.tudoer.hu

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





WPHD 2018 - IRELAND

AN ARDUOUS CLIMB TO MOUNT EVEREST AND OTHER SPORTS EVENTS TO RAISE AWARENESS OF PH

World PH Day 2018 was celebrated at the Everest Base Camp by one of our supporters who undertook the arduous climb in memory of his Mother. Paddy Brennock was accompanied by a team of three other people and of course our PH Teddy Bear. The team members were certainly breathless on many occasions. They climbed 18,150 ft to the top of Kala Pather. The trek took two weeks with an average of 8 hrs spent climbing each day. Paddy raised almost €3,000 for the Irish PH Association. We are extremely grateful that such a major commitment was undertaken in our name.

The Hell and Back challenge was held on 16th June. This is Ireland's toughest physical and mental endurance test. We are very grateful to the 33 volunteers who participated in this event in memory of their dear friend Addis Doyle. Over €2,000 was raised by those who endured extreme discomfort while wading through swamps, scaling walls, ice baths and an avalanche of mud.

On Monday 6th August, history was made. Cobh Ramblers (the Rams) Soccer team played a very important semi final football match against Dundalk (who are the current holders of the Senior National Cup). The Rams were the underdogs and hadn't reached a semi final in this competition for 35 years. The team showed great character while preparing for this crucial

game. Although they had a lot on their minds, they were happy to promote pulmonary hypertension and wore our T-shirts on the pitch while warming up for the match. The Rams were victorious with a 1:0 win. There were enormous celebrations and great euphoria after the match. There was huge interest in the T-shirts which were considered "lucky" and we received great media attention. The Rams have never reached a final of this Championship before and will be wearing the PH T-shirts with pride prior to the Final Match.

As in previous years we are very grateful to the ladies who participated in the Women's Mini Marathon. This is the largest women's event of its kind in the world. Over 30,000 ladies ran in the 10K race which was held on 3rd June 2018. Over €9.5m was raised for various charities this year. We greatly appreciate the participation of the ladies who took part on behalf of the PH Association. We were most grateful to accept almost €2,000 from our generous supporters.

The Irish PH Association continues to organise awareness events and are planning further activities for 2018.

Regina Prenderville, PHA Ireland

www.pulmonaryhypertension.ie/pha-ireland

www.facebook.com/PulmonaryHypertensionIreland



WPHD 2018 - ISRAEL

SOCCER CHAMPIONS FOR PULMONARY HYPERTENSION!

World PH Day 2018 in Israel was a smashing success! It involved using WPHD branding by one of Israel's premier league football team's, "HaPoel Hadera".

The Israel Association for Pulmonary Hypertension understands the far reaching effect of creating awareness and the crucial role this awareness plays in development of treatments, early detection, services and making medications available. We worked for several months researching options for a sporting event which would make the most impact in our community. After much networking and project planning it was decided to create an "event" which saw a collaboration with a high profile sport team. In forming a partnership and sponsoring a large national level sport club we were guaranteed far reaching exposure, thereby creating increased awareness. The idea was for team members to wear the World PH Day 2018 branded T-shirts for training in order to create a hype with players, their families, team supporters, team staff and the general public. Our choice of football team was HaPoel Hadera. This team had great potential, which was realized when Hapoel Hadera was promoted to the premier league. The fact that HaPoel Hadera was able to reach this goal caused a lot of "buzz" and media awareness, as while there was the hope that they would do well - many were still surprised. And so our hopes for greater exposure were realised! Pulmonary hypertension branding was with the team through it all.

Our collaboration included several different aspects which when tied together created a full awareness campaign. The sponsorship started off with a formal ceremony which was held at their first playoff game. PH Israel CEO Aryeh Copperman, one

of our board members Rafi Shushan, and a young female patient were awarded a framed team T-shirt signed by all players and a football ball from the team. The players came out onto the field wearing branded T-shirts and the first few questions were initiated by the spectators - "What are they wearing? What's this about?". This initial intrigue is what we felt would spur on some research and interest and encourage people to find out about PH. The Hapoel Hadera team came onto the field in their branded kit and stood in line, waiting to shake hands with our representatives and get the sponsorship off to a great start!

During the ceremony, the stadium announcer spoke about the association, its activities and possible ways of helping it. The announcer shared with the spectators (as well as the radio and television audience) information about pulmonary hypertension, emphasizing the crucial points: that it is a lung disease which damages the blood vessels between the lungs and the heart and causes severe shortness of breath. To emphasize the severity of the impact of the illness, he shared a unique comparison, that a six-step staircase can cause patients the shortness of breath equivalent to that of a football player who has run the entire field 6 times! This comparison led to an immediate understanding of the severity of the disease by the many spectators who were present at the field. In addition, a leaflet on the subject of the disease explained that patients with pulmonary hypertension suffer from shortness of breath with very little exertion. The explanations included the fact that the symptoms of pulmonary hypertension are similar to other diseases; for example: shortness of breath, dizziness, fainting,



rapid heartbeat, general weakness, chest pain. Due to the similarity patients are often not correctly diagnosed. The announcer then turned to the crowd, “Attention, if you encounter a person and especially a woman who is short of breath after little to no exertion and is not diagnosed – consider that this could be pulmonary hypertension! Get checked! Early diagnosis saves lives!” Following this incredible launch of the sponsorship, the HaPoel Hadera team continued to wear their branded gear for all warm up sessions, at every game. This provided renewed exposure with a new range of spectators each time.

All public relations for the team (which was handled by their own PR team) included information about pulmonary hypertension and the relationship between the team and its sponsor, the Israel Pulmonary Hypertension Association. Of course, all the thousands of people who watched the game and the tens of thousands who watched it on television were exposed to the activities of the association and the importance of early diagnosis of the disease.

One of our most moving moments was a video clip sent to us by the team manager. We saw the team in a group hug saying their pre-game prayers, singing together in their PH branded T-shirts!

This unique collaboration was discussed extensively in the popular TV program Channel 5, the sports channel in Israel. One of the celebrities - Raz Zahavi [who participated in the “Survivor” program] spoke about the importance of cooperation with non-profit organizations in general and the Israeli Association for Pulmonary Hypertension in particular. He emphasised the severity of the disease that makes it difficult for patients to walk even a few meters, and the importance of early diagnosis.

PH Israel CEO Aryeh Copperman was able to take this relationship one step further. He made sure to develop a more personal relationship with the CEO of the team. In the course of this meeting, Aryeh raised his personal story about his

wife’s pulmonary hypertension and the difficult struggle in daily life with this illness as a partner. This personal connection allowed for further exposure, as we were offered more branded signs at stadium events and a long lasting relationship was formed. A large sign with PH Israel Logo and the phrase “Get breathless for PH” was displayed in the stadium. This will give an extended awareness opportunity on an ongoing basis for all visitors to the stadium.

In addition to this sponsorship, PHA Israel continues to see great value and importance in the education of our patients, their caregivers, families, nursing staff and doctors. We focus on education in healthy living with CTEPH and awareness of the different aspects of living with PH. Our annual conference took place over 2 days this year with senior doctors and professors from all PH clinics sharing their knowledge regarding relevant issues for patients, including new developments in treatment. While learning, lectures, workshops are important, so is the social support and a sense of belonging to an association, which understands patients’ struggles, needs and hopes. We feel very strongly that the social aspect of our association as a support system needs to be maintained constantly, and so we ended the conference with a group painting event for patients and their family members. Beginners and experienced painters alike were able to express themselves through paint and brush with a guided painting workshop. The same painting was painted by all, and though each rendition was so different we all created a pathway with trees on each side. The pathway was symbolic of the path of our lives and the trees symbolised the oxygen we so desperately depend on. Most importantly - we laughed, we engaged in creative expression and we left rejuvenated, with more knowledge, understanding and a sense of support.

Maayan Steele,

Pulmonary Hypertension Association Israel

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



WPHD 2018 - ITALY AMIP

WORLD PH DAY 2018 “SPORTS AND ART”

During a beautiful and hot 28 May afternoon (about 30° degrees centigrade in the shade), we held our 2018 World PH Day celebration in Aversa (Caserta), not far from Naples, at the I.C.S. gym “Domenico Cimarosa”.

The guests were from the volleyball school “Normanni Pallavolo”, the Aversa volleyball society, who played a mini volley match.

The children attending were very happy to wear the World PH Day T-shirts, they played mini-volley a lot during the day and took part in group dances. An exhibition was set up for this special occasion with all the beautiful thoughts and poems written by the students of the 2° Circolo Didattico di Aversa. They decided to donate their works to support children affected by pulmonary hypertension, as they are less lucky than them. It was a day full of joy and emotions.

Reading their poems was amazing! Once again we proved that Art and Sports work perfectly together to promote awareness on this severe disease. Thanks to both, our World PH Day launched a positive message of hope.

The awareness campaign we have been promoting for some years with a lot of effort and dedication is now giving its fruits. A special thanks goes to the School Director (Istituto 2° Circolo di Aversa), Dr.ssa Emilia Tornincasa.

This wonderful collaboration between AMIP and the school gave us the reassurance we are not alone in our fight against PH; despite the many problems the school is facing we were able to organise this celebration. We are proud and motivated to go on thanks to all the children and their beautiful works, full of hope and sensibility.

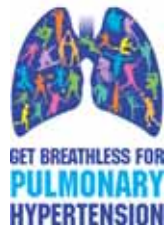
All these beautiful works (last year’s drawings and this year’s poems) will be collected in a book that will be donated to the children of the schools of the region. “Insieme si può!” “Together we can!”

Raffaele Della Volpe, AMIP Italy

www.assoamip.net

www.facebook.com/AssociazioneMalatiDiIpertensionePolmonare?ref=ts&fref=ts





WPHD 2018 - LATVIA

“BREATHE WITHOUT BORDERS” IN LATVIA



This year we celebrated World PH Day with two campaigns: we had a media and social media campaign from the 14th of April to the 28th of May and a picnic for patients and their families at the National Botanical Garden on the 27th of May.

Our events' slogan was “Breathe without borders!” to underline the importance of and value of life and health for PH patients. We presented the media with two stories of PH patients and their fight for access to appropriate medicines during a complicated stage of their illness. The first story was about 22 year old Arina, a girl without access to treprostinil, a potentially life saving drug, and the second was about the life of a mother of seven children, Ilga, who cannot breathe without having an oxygen concentrator 24/7.

These dramatic stories stressing the need for better access to treatment were aired twice, at prime time, in the most popular national TV programs. TV viewers in the evening time were approximately 970.000. The TV3 evening news showed a short interview with cardiologist Dr. Andris Skride, Gunita, a PH patient's daughter, and Inese Kaupere, Head of the Department of Pharmaceuticals of the Ministry for Health.

On TV3's Sunday evening's most popular program, called “Nothing Personal”, powerful and popular journalist Ilze Jau-nalksne talked about the lives of Ilga and Arina and underlined their desire to live.

A journalist interviewed the Health Minister and the State Secretary from the Health Ministry, and asked questions about the National Rare Disease Plan and about access to health care to the Prime Minister of Latvia. We also had a very positive and high level interview with a young PH patient in the weekly magazine “Ir” and an article in the newspaper “Neatkarīgā Rīta Avīze”. The newspaper and magazine totalled a circulation of 684.000 in the period April-May 2018.

The picnic took place in the peaceful and beautiful National Botanical garden and we had 62 participants. It was a celebration of life and the joy of breathing. A qualified nurse assisted by two volunteers organised a “Health hour” during which participants had their level of cholesterol, glucose, and oxygen saturation measured. Patients and their family members received personalised advice about their weight, heart and lung health. The highlight of the event was a wonderful and emotional meditation session, conducted under a blue sky and bright sun, by yoga trainer Laura, followed by deep breathing exercises. We truly felt like we were one strong family after the meditation.

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



WPHD 2018 - LITHUANIA

“OXYGEN” COCKTAILS TO SYMBOLISE THE DIFFICULTIES IN BREATHING

“This year a lot of the things that we presented on World PH day were new for passers-by: this shows how little people know about our disease and their own health,” said the President of PHA Lithuania, Ignas Rudys, after our yearly event, which took place in the heart of Vilnius, the Cathedral square. Many passers-by stopped at our booth, attracted by our “oxygen cocktails”, colourful balloons and playful soap bubbles. Children played and had fun. The bright sunny day also helped a lot as citizens were spending their time outdoors and wandering about Vilnius' old town. Being able to have conversations was a great pleasure for PHA Lithuania's members and patients, who so often lack the opportunities to communicate and meet each other and to spread the word about this rare disease.

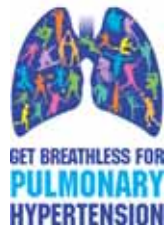
According to the President of PHA Lithuania a lot of people were at first interested in the playful atmosphere, but later were asking questions about PH and carefully reading the brochures and leaflets we had distributed. “Only a small part of people that came to talk to us knew what this disease is about. I and other members of PHA Lithuania tried to provide information and to answer as many questions as we could. The medical staff that showed up at our event were also a great help. Such events are very useful to raise attention for PH as people know very little about the disease and about the way

patients live and the challenges they have to deal with”, said Ignas Rudys.

Any of our visitors who were interested had the opportunity to measure their heart rate and oxygen saturation and compare it with those of PH patients. “Heart rate was not a new thing to anybody, but oxygen saturation was something most people had never heard about or had measured before. So they were surprised to hear about it and to see the comparison with PH patients. We had to explain what effect on patients lives it has and how important for them is to measure it”, Ignas Rudys explained. The lack of information is not just a problem in Vilnius. According to the Ignas Rudys and other members, a lot of tourists were also interested in the event and they also knew very little about it. Mostly it was the tourists from neighbouring countries as well as visitors from Asia and other continents. “Hopefully, at least a small contribution was made in raising awareness in people about the disease and the fact that everyone should take good care of their health, as the disease can affect anyone”.

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





WPHD 2018 - NORWAY & UKRAINE SISTER DALILA

JOINING FORCES ACROSS BORDERS TO RAISE AWARENESS OF PH

The Norwegian PH association did not run a World PH Day event this year in Norway. Instead, they ran an event together with the Ukrainian PH association (PHURDA), in Lviv. The joint event is natural as they had signed a collaboration agreement a couple of years ago. The leader of the Norwegian PH association, Hall Skaara, joined PHURDA for their World PH Day event and also worked with them on the CBP (Capacity Building Program) activities for some weeks. PHURDA's World PH Day event this year was actually a two day event. The first day, they ran a patient meeting at a hospital that they collaborate with. The aim was to offer a rehabilitation program for the Ukrainian PH patients at the hospital. For the meeting, Hall had invited the leading physical therapist from the Norwegian PH rehabilitation center. The meeting was very successful, and valuable connections were made between the Ukrainian rehabilitation center and the Norwegian center. The patient meeting was a great warm up to the actual World PH Day event the next day. PHURDA had decided to implement the "Backward Games" first introduced by the Norwegian association in 2017 in Oslo. The games were held at the the sports stadium and included five types of events performed backwards: 60 meters running, ball throwing, triple jump, egg throwing and logic exercises. At the end there was a award ceremony.

The goal of "The Backward Games" is to make the physician think "backwards" when he/she encounters a patient suffering, for instance, from shortness of breath. Most physicians will immediately suspect asthma, anemia, heart disease, pneumonia, etc. However, it is important that the physician also think "backwards" and consider pulmonary hypertension as a possibility.

The games were a great success. The participants seemed to enjoy themselves immensely and there were a lot of laughter both among the participants and the spectators as the backwards exercises were performed with great enthusiasm. The participants were divided into teams of five with an good mix of healthy and PH participants. The teams came up with great names and the competition among the teams was fierce, but friendly. Both teams and individual achievements were rewarded at the award ceremony.

The competition consisted of participants both from Norway and Ukraine. Maybe it would be an idea to extend the competition to also include more countries in the years to come? Norway and Ukraine will, for sure, volunteer with some strong and experienced backward games teams...

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



WPHD 2018 - POLAND

ATHLETES GET BREATHLESS FOR PH

In 2018 PHA Poland celebrated World PH Day with a number of sports enthusiasts who dedicated their activities to Polish PH patients.

In April, a team of NAVITEST runners, decided to run the 4th Gdańsk Marathon wearing "Get breathless for PH" T-shirts, to support PH patients in Poland. Agnieszka Bartosiewicz, Vice President of PHA Poland, encouraged the runners with her friends and colleagues from NAVITEST during the whole event.

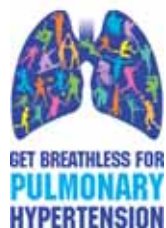
The next gesture of solidarity with PH patients was a special warm-up of the RC Arka Gdynia rugby players, who also wore "Get breathless for PH" T-shirts. The players warmed up in front of their fans who had come to watch the match with RC Lechia Gdańsk. During the break, the speaker explained to the viewers the reason for such a unusual players' outfit and what was PH.

At the end of May, during the road cycling marathon "KaszebeRunda 2018", which gathered more than 2.500 participants, two members of "Get Breathless Team Gdynia", Paweł and Adam Domrazek (father and son), rode 125 km as a gesture of solidarity for PH patients in Poland.

In May, there was a total of 19 published articles about World PH Day, which included detailed information about PH and quotes from Alicja Morze, PHA Poland's President, who highlighted, among others, about the need for an early diagnosis and support for the association's educational activities. All the athletes' wonderful gestures of support, as well as the great media coverage, helped PHA Poland to raise a lot of awareness about PH among the public.

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





WPHD 2018 - PORTUGAL

RAISING AWARENESS OF PH WITH THE MEDICAL COMMUNITY, PATIENTS AND THE PUBLIC



This year World PH Day celebrations were conducted in three different places, at three different moments, targeting different people, but with the same goal: getting breathless for PH!

The first event was held between the 5th and 13th of May: a pilgrimage to Fatima: about 70 pilgrims walked to the famous Fatima Sanctuary wearing yellow vests with our PH awareness logo. They distributed hundreds of PH and CTEPH flyers in the cities and villages where they passed through! They travelled hundreds of kilometres, passed through a lot of places and met people from everywhere!

The second event was on the 20th of May, in Lisbon: a multisport event at one of the most famous stadiums in Portugal (University Stadium). This event involved PH patients and their families, university students, professors and their families. The event featured several sport activities, for people of all ages and tastes: tennis, archery, fencing, judo and a very funny photo-oriented “peddy paper” game! This event had several activities going on at the same time so it required strong staff

to help us all day long to ensure that everything was going well. The final event was held between May 31st and June 3rd: an awareness initiative at the National Congress of Internal Medicine, where the participants (doctors and medical students) were asked to put weights around their wrists and ankles and walk on a treadmill while their heart and respiratory rates were being measured. With this activity we made doctors become more aware of PH by provoking the most common PH symptom – breathlessness. We strongly believe that we have achieved greater visibility for PH with these doctors, especially the newcomers, since they showed great interest in hearing about the disease and the difficulties patients are facing.

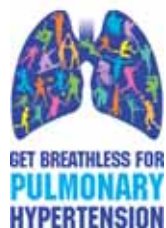
We are very proud of our three moment-event since it was the first time it was attended by three different target-populations: the medical community, PH patients and the general population. In spite of the low interest showed by media or notable figures we strongly believe we have achieved a great visibility. Additionally, for the second time in our World PH Day history, we had a very successful fundraising initiative: during the month of May we sold hundreds of awareness medals engraved with the message “Breath Of LiPhE”!

Teresa Carvalho

Associação Portuguesa de Hipertensão Pulmonar

www.aphp.pt - www.facebook.com/associacaoportuguesaahipertensaopulmonar





WPHD 2018 - REPUBLIC OF MACEDONIA

CARRYING THE PH FLAG TO THE HIGHEST PEAK OF THE BALKANS AND TO THE ALPS



The main event for World PH day was the participation in the Skopje Marathon, which had 10.000 runners. We had runners of all categories with our colours. During the 5 km race, which is part of the marathon, we again had a guest from Bulgaria, Todor Mangarov, President of PHA Bulgaria, a former CTEPH patient who has had successful PEA surgery. He finished the 5 km race, for second year in a row, pushing a wheelchair with a PH patient from the Republic of Macedonia! At this race most of the supporters were normal people, not famous runners. Our goal was to get people to feel for first time what it is like to get breathless, as PH patients do with even very mild exertion.

We had for the fourth year running our traditional climbing and march for patients with PH. About thirty mountaineers climbed to the top of Ljuta from Mount Kadića, in the region of Azot. Members of the Mountaineering societies Cheples, Metalurg and Pelister, from Veles, Bitola and Skopje, organized by the Sport Mountaineering club "Green Paradise" from Veles, climbed a peak at an altitude of 1.670 meters to support patients with the pulmonary hypertension. The mountaineering Sports Club KOZUF Gevgelia climbed the highest peak of the Balkans, Musala, 2.925m, located on Mount Rila, in Bulgaria.

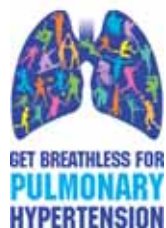


What is really inspirational for us as an association is that we have had support for our cause from people coming from all walks of life. Own-initiatives from individuals who help to make us more visible! For example, three women attended the Avicenna Women's marathon wearing "Get Breathless for PH" T-shirts. We had support from a woman who promised her presence at every marathon she runs under our motto. She ran 21 km at the Skopje marathon, 21 km on Kavadarci and the last beach marathon on Dojran lake, and announced other upcoming marathons. The folklore ensemble "Megdan Bogdanci" supported us on their tour by wearing our branded T-shirts. We had special support from the police on the border between Macedonia and Greece during our preparation for a traditional march with our branded T-shirts. And a group of enthusiastic, adventurous, courageous, kind hearted people who "got breathless for PH" in the Alps, carrying our flag.

We also had smaller events with different people who wanted to be part of the World PH Day campaign, such as the body-building club "Crossfit Skopje" and our cardiologist, Dr. Ivan Milev, who is mountain climbing and sending us photos from his trips wearing our branded T-shirt. In our country it is a "luxury" to have pulmonary hypertension and every day is a struggle with the institutions for medications, so being more visible is vital. We are very proud of what we have achieved in this respect!

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





WPHD 2018 - SERBIA

“INSPIRED BY HOPE” AS THE UNDERLYING THEME OF A VARIETY OF AWARENESS RAISING EVENTS

This year, to make World PH Day even more visible, we chose to mark the entire month of May with different events, at different locations. Here are some of them, which together make one unforgettable series of events which will be remembered by all.

World PH Day at the Serbian Academy of Sciences and Arts

A press conference for World PH Day 2018 was held on the 5th of the May in the Lectures Hall, situated on the first floor of the Polyclinic of the Clinical Centre of Serbia. On this occasion the Deputy Minister for Health, Dr. Meho Mahmutović, gave a speech, together with the Coordinator of National Registry of pulmonary hypertension Prof. Dr Arsen Ristić, and the President of the Serbian PH Association Danijela Pešić. In past years significant improvements have been made in Serbia in terms of the education of medical teams responsible for the diagnostics and treatment of these kinds of patients. In the course of the past year, two patients with severe post-thromboembolic pulmonary hypertension were completely cured by a complex surgical intervention, called carotid endarterectomy (CEA). Two more patients are currently in the preparation phase for this procedure. Some

clear guiding principles for the treatment of patients with severe pulmonary hypertension have also been defined, as well as mechanisms that will allow patients to receive not only monotherapy, which was the case until now, but also more modern and certainly more effective combined therapy, in accordance with European guidelines for good clinical practice.

Regional Summit of cardiologists, pulmonologists, thoracic and cardiac surgeons

A regional summit dedicated to the diagnostics and treatment of pulmonary hypertension took place in Belgrade from the 3rd to the 5th of May. The lecturers were renowned experts from Vienna (Austria), Bad Nauheim (Germany), Ljubljana (Slovenia), Zagreb (Croatia), Bosnia and Herzegovina, and doctors from all clinical centers in Serbia dealing with pulmonary hypertension.

PAH family gathering

This year our association celebrated World PH Day together with over sixty of its members in the truly wonderful setting of the Varedero bar, located on Ada Ciganlija, where our host not only welcomed us but really



made us feel at home. We are very grateful that our members travelled from almost every corner of Serbia to meet with their doctors and fellow patients. And we were also joined by our racers and pilots from the “Inspired by Hope” Team. Thanks to everyone on behalf of PH Serbia for sitting there patiently and listening to everything we had to say. We truly gave our best, within the time constraints and the circumstances, to talk about PHA Serbia and explain that it is not just about Danijela and Mirko, but that many individuals and companies stand side by side with us. There were a lot of emotional moments, emotional and honest. Yes, this is our greatest strength, to be here and to give the best we can. Only as a family can we continue our struggle. There was tremendous respect and an incredibly positive energy between the sportsmen and the members of our association. We, as organizers, were sometimes even confused and were left without words. We are aware that we didn’t manage to thank everyone the way we would have wanted to, but emotions and the moment got the better of us. In any case we are more than happy with the number of people who came and with the great atmosphere during those four or five hours that we spent together. Every moment during our meeting was precious to us, every word of support that we received meant a world to us. We have become a real family, an always expanding family which is getting stronger and stronger every day.

Kids for PH - a Festival of Health

Yes, we made it! We succeeded in taking 200 young



children out of their homes and to keep with us for more than two hours. We succeeded in drawing 200 smiles, 200 kisses and 200 beautiful wishes, and more than 400 beautiful hands were cheering and waving to us without stop! Energy and joy! Kids, thank you! This was possibly one of the most beautiful events that we organized. We did it together with the Preschool Institution Savski Venac and with the support of the Municipality of Savski Venac. It was the third Sports Day for Children that we have organized so far and, to our great delight, the largest, with 200 kids and friends of our association. Key people of the town’s municipality attended, as well as many preschool teachers and some wonderful entertainers from the SARS group. We also had all the the sportsman from the “Inspired by hope” Team and many young volunteers. Everyone gave a tremendous contribution to this exceptionally successful manifestation. Without them all this manifestation would have been so terrific. We are sure that the photos will tell more than words, but we certainly can say that the children ran out of breath for PH, and also left us without words. Thanks to every single one of you for being today here with us. Your support means a great deal to us. We think you are not aware of that, and maybe that’s where our greatest strength lies.

Children’s book about friendship

After more than eight months and a huge effort our book is finally published! The title is “A story about friendship” and we will be sending it to more than 3.000 kids, totally free of charge. This book is the result of our own personal



experience but also of many experiences and recollections of the countless families who have participated in its conception. It is a book which promotes the understanding of diversity among children and inspires hope for a better future for sick children and children with disabilities, who face difficulties in socialization and social integration. It gives hope to their parents and families who experience the dramatic rejection of their children by their fellow classmates and friends. “The main idea is that the book will inspire healthy children to become better people by exercising compassion and understanding for others. In these times of brutality, psycho-physical aggression present from young age, all kind of differences and misunderstandings, austerity and divides, this book will come as much needed read that will ennoble children’s hearts and give them understanding with a hope that they will one day grow into mature, moral and responsible generations...” say the book authors Danijela Knez and Ivan Drajzl.

140 km and 7.000 people for PH

This was yet another grand and very inspiring project for us personally, aimed at attracting attention and raising public awareness about PH, and which was successfully carried out in Ušće, near Belgrade. Our team “Inspired by Hope” organized an event entitled “Day inspired by Hope”. The goal was to run a 140 kilometer ultramarathon race on a 20 meter long improvised track. We were successful in this attempt thanks to people inspired by hope who helped us gather 7.000 people for this extraordinary race and who motivated us to race 140 kilometers in total!

Another, extremely important, part of this event was to try, in a very effective manner, to show to all those interested, what it is to like to live with PH and what ordeals a person with PH has to endure in his or her everyday life.

During this demonstration, all the visitors could see and understand, in a very realistic way, what it means to fight for every single breath. We are very thankful to everyone who was willing to relate and identify with PH fighters in an attempt to understand them even better and to become closer with each other.

The 7.000 people who were running across our small track inspired by hope, and more than 200 of them who had clips



on their noses and were breathing only through straws in their mouths, understood what we are fighting so persistently to finally get an adequate therapy for people diagnosed with PH, a therapy that will reduce their symptoms and significantly extend their lives.

Boško Ćirković-Škabo and Biljana Bursać participated in a panel discussion during which they talked about their experiences of racing in ultramarathons. They also talked, in a very impressive way, about their reasons for still supporting. Thanks to Ultra racer Serbia (Ultra trkač Srbija), thanks to Avalasubotom and thanks to all members of the “Inspired by Hope” Team who selflessly helped us to see all this through the end.

We cannot describe by words alone the happiness and joy that we feel because of your presence. We are also very thankful to great number of racers whom we met only recently, but who despite that came and gave us their support with an honest desire to help us and only because they recognized all our efforts to help the seriously ill PH patients

Finals of basketball league of Serbia: Basketball Club KK Crevna Zvezda vs KK FMP

Before the game started, the finalists of the Super league of Serbia showed their support to PH and PH Serbia by coming out onto the field wearing branded “Get breathless for PH” T-shirts during the team introduction (which is quite rare) and during the intonation of the national anthem of Serbia before the match. During the game, a video spot of PH Serbia was playing on the great video wall. A spot was made out of photos from all the previous events which we have organized wearing World PH DayT-shirts. Also, during the entire match our text banner “Get breathless for PH” was written on all the marketing panels. Speakers in the hall, as well as TV commentators, read our official statements during live stream.

Anđela Obradović and Danijela Pešić, President of PH Serbia expressed their gratitude to the team captains.

“Inspired by Hope” billboard campaign

Our five most famous racers and members of our “Inspired by Hope” team, were photographed for 20 billboards dislocated in central squares with dense traffic and in all major roads in Belgrade.



Press conference

Our press conference on May 5, World PH Day, gathered important authorities such as the Secretary of the Ministry of Health of the Republic of Serbia, Meho Mahmutović, and the President of the Republic Expert Commission, Milika Asanin. The press conference was very well received and had considerable media coverage. Over 25 public relations agencies, as well as the largest and most important news agencies, reported on the press conference. The State television aired a great TV report, dedicated to the press conference, during the most viewed news program, at prime time.

Reaching the highest peak in Europe in support of PH patients

“The Inspired by Hope” team, was formed in an attempt to raise public awareness of pulmonary hypertension and to promote the importance of early diagnosis. This team is comprised out of extraordinary people, first and foremost humanists and athletes who do not spare themselves and their bodies in order to help these seriously ill persons.

“I expand my lungs for you all”: alpinist and extreme climber Aleksandar Milosavljević started practicing alpinism 10 years ago, and went on his first international expedition in 2015. As a member of the “Inspired by Hope” team he has climbed on the highest points of Europe, located on Mount Elbrus, at 5.642 meters above sea level. His life goal now is the same as ours, to reach the 7 highest mountaintops of the world, across seven continents, which is in itself a tremendous challenge, but also



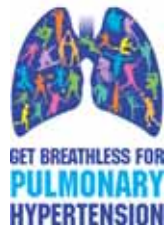
the dream of every climber. He will attempt this in honour of all PH fighters and he will dedicate every conquered peak to them. Next on his list is the highest point of North and South America, the Aconcagua, 6.962 meters of altitude, located in Argentina.

We conclude this report of our activities for World PH Day 2018 with the touching words of Aleksandar Milosavljević: “As I dedicate every conquered mountaintop and every effort I make to someone, in an attempt to promote sports to younger generations, one day I found out about people diagnosed with PH, and reading about that particular disease and its symptoms, I discovered that there is one indescribable similarity... breathing. Breathing at high altitudes is quite reminiscent of the breathing of people with PH, and when they are fighting for their every breath, I too fight for mine somewhere on the heights of cloudy mountains... I was sure, from that point on, that I would dedicate each following peak to those great fighters and people who fight for their every breath the same as I do in hard conditions of high altitudes...!”

Message for all PH fighters:
“I expand my lungs for you all”
In the name of PH Serbia

Danijela Pesic and Mirko Glavinic, PHA Serbia
www.phserbia.rs
www.facebook.com/plucnahipertenzija





WPHD 2018 - SLOVAKIA

CLIMBING TO THE TOP OSTREDOK TO “GET BREATHLESS FOR PH”



As part of the “Get breathless for PH” 2018 campaign, our association prepared for the fourth year in a row an ascent to the main Slovak mountain peak, under the slogan “I’ll Climb For You”. The event was attended by 142 participants.

On the eve of the event, the 1st of June, a seminar was organised in the mountain hotel Kráľova studňa, located in the Veľká Fatra Mountains. During the seminar we talked about PH, we explained the importance of the World PH Day campaign, and many patients shared their life stories. The main focus was on PAH, CTEPH and the disease in young people.

On the 2nd of June, the climb to Ostredok (1.560 m above sea level) took place. 142 participants, including 2 patients with PAH and 2 patients having undergone lung transplant surgery, took part in the climbing. Families, friends, doctors, nurses, as well as other participants from different parts of Slovakia and the Czech Republic, climbed to the top of mountain, carrying photos of patients on their backs. The event was also supported by members of the PH patient associations from the Czech Republic and Hungary, including their respective Presidents. It was organized under the auspices of the Mayor of Banská Bystrica. On 3rd of June, we held a meeting in the city of Banská Bystrica, where the participants planted a rare “Cercis” tree as a symbol of health, clean air, but especially of the lungs that are essential for every living organism on the earth.

The whole event was covered in media with excellent results:

- 9 articles on internet portals;
- 1 reportage on Radio Regina;
- 1 upcoming reportage on Radio Regina - interview with a PH specialist.

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



WPHD 2018 - SLOVENIA

AMAZING SUPPORT IS GETTING BIGGER EVERY YEAR

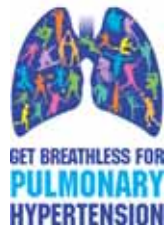
Our sporting events in the peaceful and beautiful natural resort of Mostec have always turned out so well that we decided to organize it there again, for the 5th time running. At the opening of the event, we made the introductions, socialized with old friends and other attendees, distributed the branded T-shirts to our runners, and then started with the 6-minute walking test at 15.30. With the 6-minute walking test, all guests were given a chance to see how patients with pulmonary hypertension feel, when they perform even the easiest physical activities, such as walking. They walked for 6 minutes while breathing only through 2 straws. An hour later, children started their 1 km run. It was touching to see how many kids took part in the run and even some mothers with their babies in carriages. At the end of the 1 km run, the adults started their 5 km one. We also encouraged those who knew they could not run for 5 km to try their best and still go running even if they would have to stop after 2 or 3 km.

Around 400 people participated in our event, including several great Slovenian medical experts for pulmonary hypertension. Such a high number of participants is a great achievement for us, compared to the previous years. We also had a DJ, a zebra mascot, a professional photographer and a filming crew. During our event, we created 2 videos, which we are already using to raise general awareness of pulmonary hypertension. One is about patients and describes the illness, and the other one focuses more on the 6-minute walking test and how healthy individuals experienced it.

There were also several articles about our event in various newspapers and magazines.

Tadeja Ravnik
Društvo Za Pljučno Hipertenzijo Slovenije
www.pljucna-hipertenzija.si





WPHD 2018 - SPAIN ANHP

SPORT, LAUGHS AND SOLIDARITY ON WORLD PH DAY WITH THE ANHP

To celebrate World PH Day 2018 the National Association of Pulmonary Hypertension of Spain ran different activities aimed at both raising awareness and funds for PH.

On the 4th of May we were at the Ramón y Cajal University Hospital in Madrid with our “Experience PH room”. People in this “room” could do daily activities such as making a bed, ironing, sweeping or riding a bike while wearing a 25kg vest, and breathing only through a straw. This simulated what a person with pulmonary hypertension feels every day. Dr. Quezada, Dr. Javier Gaudó and Dr. Salvador Díaz Lobato, pulmonary hypertension specialists, took part in the activity.

On May 6th, we participated in the handicraft jumble sale of Barajas in Madrid. We gave out information materials about the symptoms and consequences of living with pulmonary hypertension, and we also raised funds. The people of Barajas were very supportive and showed great interest in the hearing about the disease.

On the 10th of May, in collaboration with the Association of Solidarity Concerts, we organized the 1st Comedian's Gala in favor of PH. We distributed information materials to the public and we spent a memorable evening, thanks to the comedians Vicente Pulki and Carlos Calvo, who were fantastic. Grethel Gonzalez was the presenter of the event.

To conclude with the activities of this year, we collaborated with the “Rhythmic Gymnastic Kiara Club” in the 3rd rhythmic gymnastics championship in Orusco (Madrid). We gave out materials about our disease and stressed the importance of practicing sports for people's health. We ran a raffle to collect funds. The public and the gymnasts were very interested in the project and they were very happy with their participation.

<https://www.youtube.com/watch?v=jnwf4EYkitc>

Increasing awareness and visibility are our top priorities for all our activities. But for the 5th of May we increase our efforts in this respect. We work very hard to make people know our disease, because to have a correct diagnosis and a proper treatment is very important to improve our quality of life. There is no cure yet but we will never stop until we find it. We would like to say thank you to all the volunteers, their charity work was amazing. Thank you.

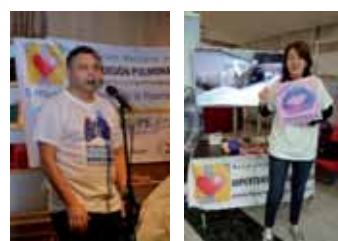
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Eva García

Asociación Nacional de Hipertensión Pulmonar

www.hipertensionpulmonar.es

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



WPHD 2018 - SPAIN FCHP

SOLIDARITY SPORTS EVENTS TO INFORM ABOUT PULMONARY HYPERTENSION

World PH Day is celebrated on the 5th of May every year. Our association takes the opportunity of this event to draw attention to the problems of pulmonary hypertension patients and to get support for PH research. We at FCHP had the support of the European Pulmonary Hypertension Association, PHA Europe, and we went hand in hand in organizing various events to achieve our common goals. Throughout the month, we organised a series of activities, which we have summarised below.

To start with, in May we were given a charity booth by our Venezuelan friends at the Festival Homenaje a la Madre y Patria, where we could sell brooches, bracelets, key rings and other handicrafts made by our friends and family. A big thank you to the organisers for the giving us the space for our booth.

On the 6th of May, Toni and Mauri, two ultramarathon runners, participated in the Transvulcania Race on the Island of La Palma. For six months, they had been preparing this race and engaging with the media to publicize the Empathy Research Project and raise funds for the disease. They did a huge amount of work for the FCHP.

On the 26th of May, Myriam Martinez Rebollo, an ultra marathon runner, ran the Galayos Marathon in Gredos (Ávila). A very difficult 42 km challenge with an elevation of 2.800+ metres. She won third place! Thank you Myriam for supporting the PH cause and for the effort you made for our patients.

To conclude our list of sporting events for World PH Day, our colleague from the FCHP, Laura Ranz, participated in the Desafío Cerro de los Batallones 42Km Fémimas (Madrid). She dedicated her race to the PH cause: “The aim of all my efforts and enthusiasm in taking part in this race was to be able to be on the podium and dedicate my victory to pulmonary hypertension”. A nice message to end the month of May, the month of pulmonary hypertension awareness.

Great challenges, great athletes and great people that made this challenge a challenge for all patients with pulmonary hypertension.

In all of our activities we had the support of local councils, administrations, private companies, and PHA Europe, whom we warmly thank for their collaboration in the fight against this rare, debilitating, progressive and deadly disease.

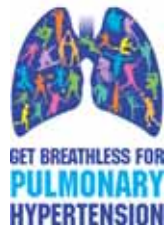
Enrique Carazo Minguez

FCHP Fundación Contra la Hipertensión Pulmonar

www.fchp.es/es

www.facebook.com/fundacionhph





WPHD 2018 - SPAIN HPE ORG

GREAT PARTICIPATION OF THE PUBLIC AND MEDIA REACH FOR OUR ACTIVITIES



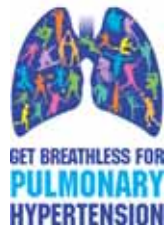
This year we at HPE-ORG are especially proud and pleased with the results obtained in the World PH Day! We had an estimated reach of almost 11.000 people in the course of the five programmed activities, without counting the great coverage in the printed and digital press. But what has filled us with even greater pride, emotion, and gratitude, is the involvement, participation and enthusiasm of all those who helped us with the organization, including the citizens in general and the municipalities where the activities were held. They went to great lengths to support us and we organised everything organized together: institutions, family and friends. The participants included: Dr. Antonio Román Broto, pulmonologist specialised in PH from the pulmonary transplant unit, Roser Escobar Fornieles, case manager at the Hospital

Vall de Hebron, Carmen Hernández, Coordinator of SEPAR, Lourdes Borrell, Councilor for Health and Sport, Mrs. Margarita Llongueras, Councilor of Tourism of Sant Feliu de Llobregat, Blanca Albà Pujol, Sports Councilor of Vilanova i la Geltrú City Council, Jordi Mariné, Professional cyclist who participated in the Olympic Games of Tokyo'64, Christian Méndez, triathlete of the Complex of Sant Feliu de Llobregat, Albert Garcia de the Coordinator in defense of the Bike, the ORG Volunteers of Sant Feliu.

We also thank the institutions who supported us: the Ayuntamiento de Arenas del Rey, Ayuntamiento de Tarragona, Ayuntamiento de Vilanova i la Geltrú, Ayuntamiento de Sant Feliu de Llobregat, Ayuntamiento de Barcelona.

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





WPHD 2018 - UKRAINE PHA

WORLD PH DAY 2018 IN KYIV, UKRAINE



On May 4, 2018, on the eve of World PH Day, PHA Ukraine held a briefing meeting during which it described how patients with PH fight for their lives and for their right to breathe. During the meeting we also discussed the achievements in the diagnosis and treatment of patients with pulmonary hypertension in Ukraine; the problems that hinder the introduction of modern treatments (in particular, under-funding of the state PH program, the absence of official registers and of certified PH expert centers), as well as the issue of the inaccessibility of lung transplantation in Ukraine. The participants also presented the charity "Before and After Transplant", which brings together people who are waiting for organ transplant and those who have already undergone the surgery. On May 5, World PH Day, we went on a boat trip on the river Desna! It was unforgettable! Beautiful winding banks, swallows nestling on sandy slopes, and our seven inflatable catamarans, in which the relatives and friends of the patients took on themselves the physical task of paddling, so that the patients could fully enjoy the atmosphere of the cruise. We stopped at a beautiful meadow, where PH patient Iryna Sydorchuk lead a yoga session. The soft noise of the running water, the spreading willows that sheltered us from the scorching sun, the trill of the birds - all this intertwined with calm and harmonizing exercises gave us the strength to overcome the second stage of the rafting! And how unbelievably delicious seemed the borsch, which awaited us at the finish point! After that we had a wonderful idea together with PH patient Maria Prokofieva and her mother Angela Prokofieva: to draw a triptych especially for the occasion, a picture which is a symbol of the strength and fragility of patients with PH, their desire to overcome the difficulties of the disease and live fully and joyfully! We all took part in this, so that our energy was transferred to this special canvas, whose fate we also determined by a joint decision. Since this is a triptych, we will place one part in our association, the second in the PH Center for adults, and the third in the PH Center for children. In this way the picture will symbolically emphasize and unite our already indestructible bond.

Before leaving, after our barbeque dinner, we sent our wishes to the sky with Chinese lanterns. We thus proved to ourselves and to society that we can live a rich and active life, with proper treatment and support! It was also a great opportunity to talk to each other and share our experiences, because support for each other is extremely important for patients with orphan diseases.

Oksana Aleksandrova
Ukraine Association of Patients with Pulmonary Hypertension
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WPHD 2018 - UKRAINE SISTER DALILA

UKRAINE-NORWAY JOINT WPHD CELEBRATION

This year we celebrated World PH Day together with our PH friends from Norway. We actually celebrated World PH Day as a two day event: May 4th and 5th. The first day was dedicated to a conference. The main focus was on physical exercise, nutrition and psychotherapy for PH patients. On the second day we ran a sport competition called "The Backward Games". The World PH Day events were organized together with PHA Norway. We had a few international guests present. Representative of PHA Europe and the head of PHA Norway Hall Skaara shared his successful story of living with pulmonary hypertension with the participants of the event, which was very valuable. Odd Erling Børstad, sports therapist from the rehab center of the Norwegian Association of Heart and Lungs (LHL), described the peculiarities of rehabilitation of patients with pulmonary hypertension and conducted an hour long workshop for the conference participants with physical exercise. This kind of information was really new and very important for many Ukrainian PH patients. And they got a taste of some low intensity physical exercises followed by relaxation to pleasant music.

Essential parts of the event were the conversation about proper and healthy eating and a session of group psychotherapy by the specialists of the Anna Mazurenko Children's Health Center. All these activities are actually a normal part of a rehab program. Our aim is that thanks to this excellent cooperation between PHURDA and PHA Norway, a rehab program for PH patients will be established also in Ukraine. It was great honour for us that a representative of the Norwegian embassy in Kyiv Petter Bauck came to Lviv in order to participate in the conference.

He held a presentation about the collaboration and links between two our nations. In addition, a representative from "Omron" company presented their new nebulizer.

For the first time, on May 5, 2018, we ran "The Backward Games" which is a concept that was first introduced in Norway. It was an interesting sports event which provided both a lot of fun and competitive time for patients and other guests. The goal of "The Backward Games" is to make the physician think "backwards" when he/she encounters a patient suffering, for instance, from shortness of breath. Most physicians will immediately suspect asthma, anemia, heart disease, pneumonia, etc. However, it is important the physician also thinks "backwards" and consider pulmonary hypertension. The games were held at the sports stadium and included five types of events performed backwards: 60 meters running, ball throwing, triple jump, egg throwing and logic exercises. At the end we had reward ceremony.

The World PH Day event united patients with pulmonary hypertension and their families from different regions of Ukraine. We believe that our cooperation with Anna Mazurenko Children's Health Center with the support of PHA Norway will have great advantage for all PH patients in Ukraine as they might offer rehab services to PH patients in the near future.

We are proud that this World PH Day was organized and run with PHA Norway.

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



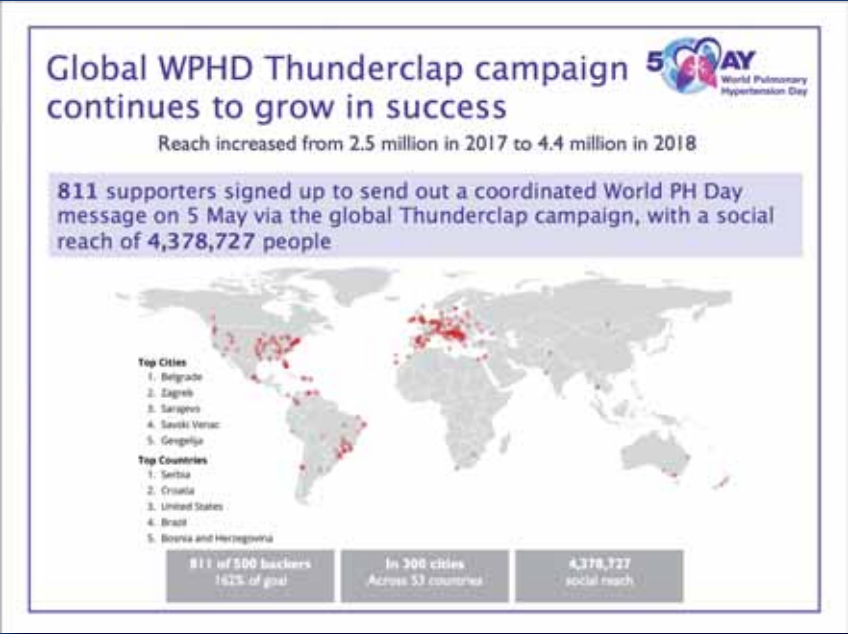
2018 HIGHLIGHTS



just a few... Our message is reaching millions of people, driving awareness of the devastating nature of PH and mobilizing support for those affected.

THUNDERCLAP 2018

The international collaboration with the USA and Latin America for World PH Day 2018 allowed us to combine expertise and resources, reaching more and more people. An example of this successful collaboration was apparent with the Thunderclap campaign. Over 800 supporters signed up to post the same coordinated WPHD message through social media at the same time, and it reached almost 4.4 million people in 300 cities across 53 countries. An extraordinary campaign, I think you will agree!



In Europe, 31 of our hardworking local organizations arranged more than 60 events that were attended by over 40.000 people. Individuals, teams and societies got involved wherever and however they could, creating new opportunities to increase recognition of PH. Events ranged from incredible personal challenges to community outreach projects, from conquering mountain peaks to a charity market. To name

MEDIA CLIPPINGS

BELGIUM



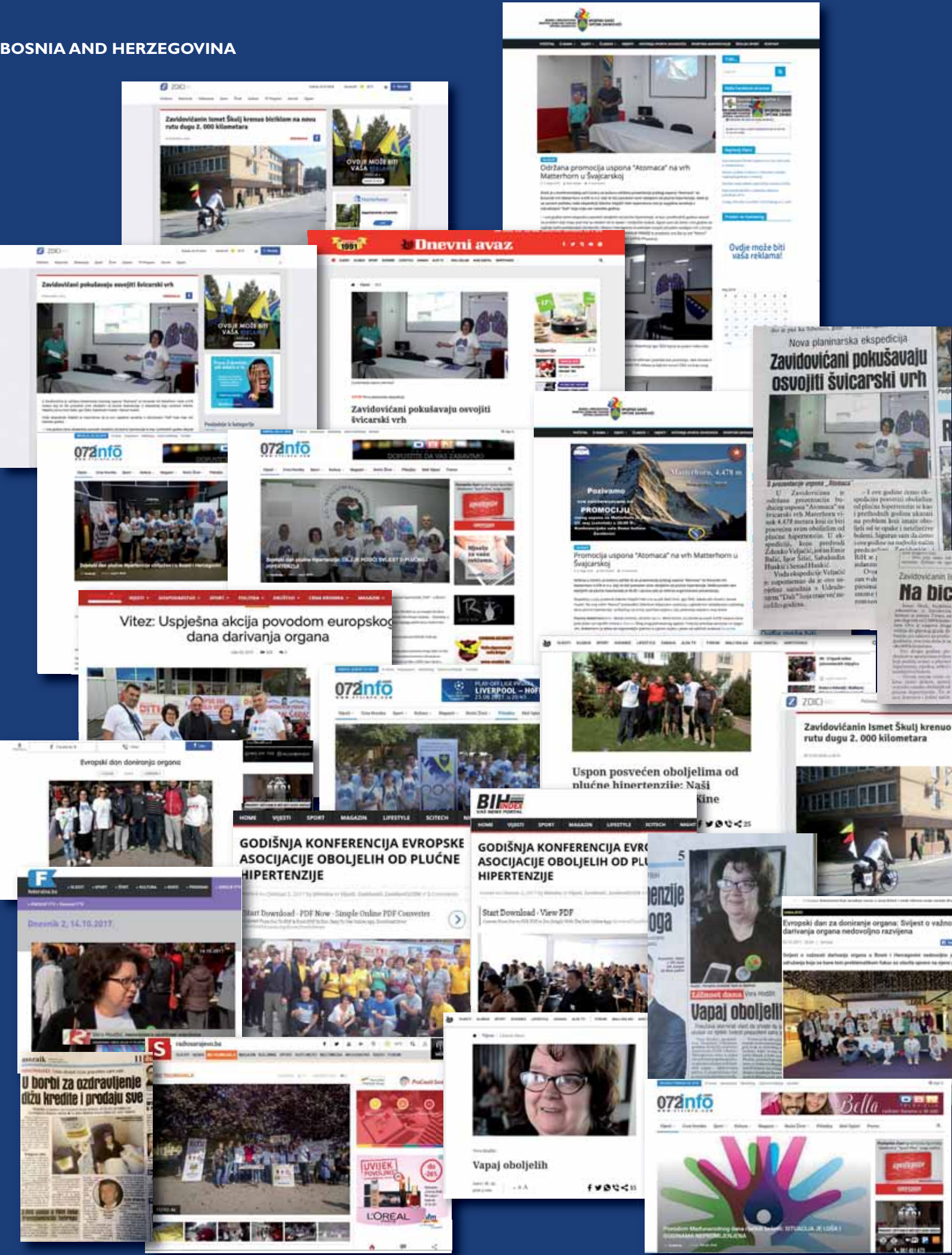
CZECH REPUBLIC



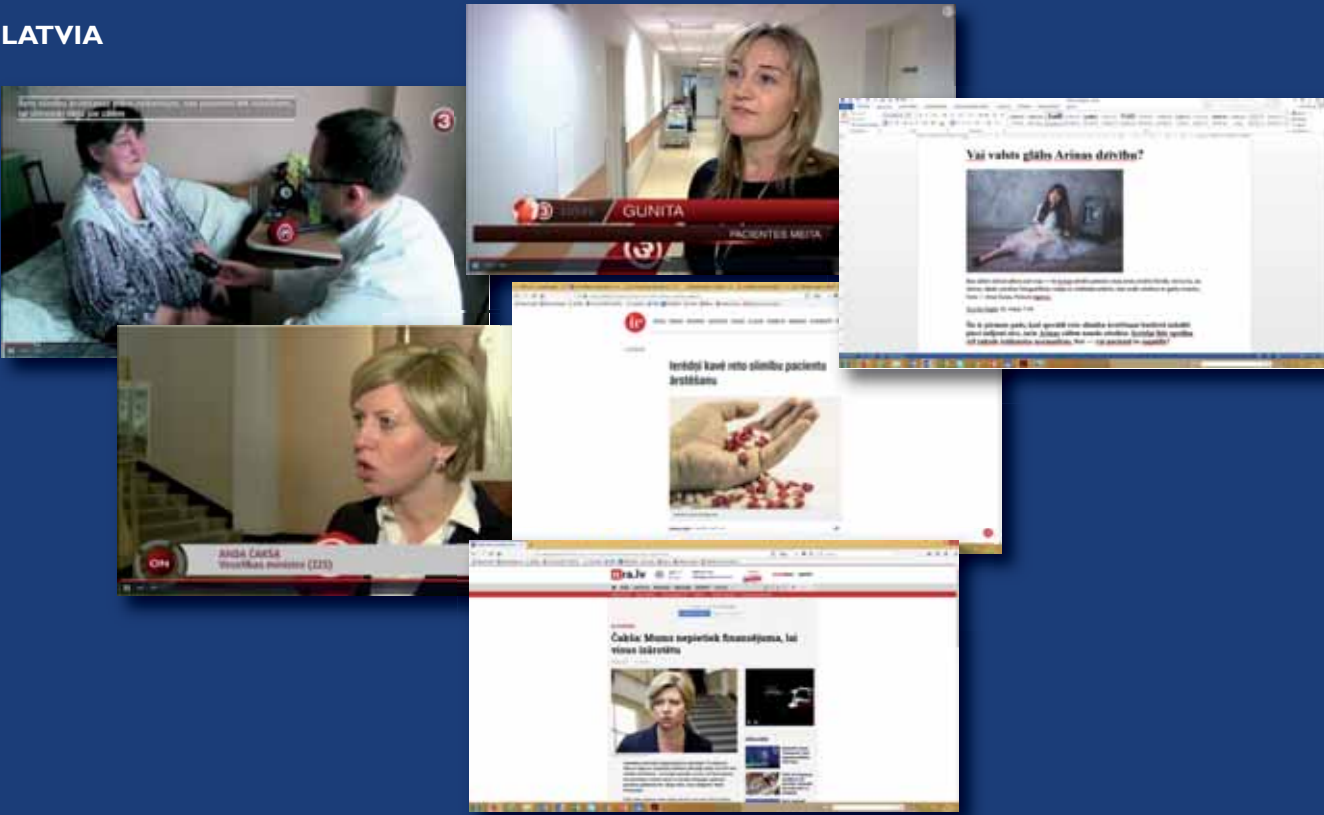
HUNGARY



BOSNIA AND HERZEGOVINA



LATVIA



SLOVAKIA



PORTUGAL



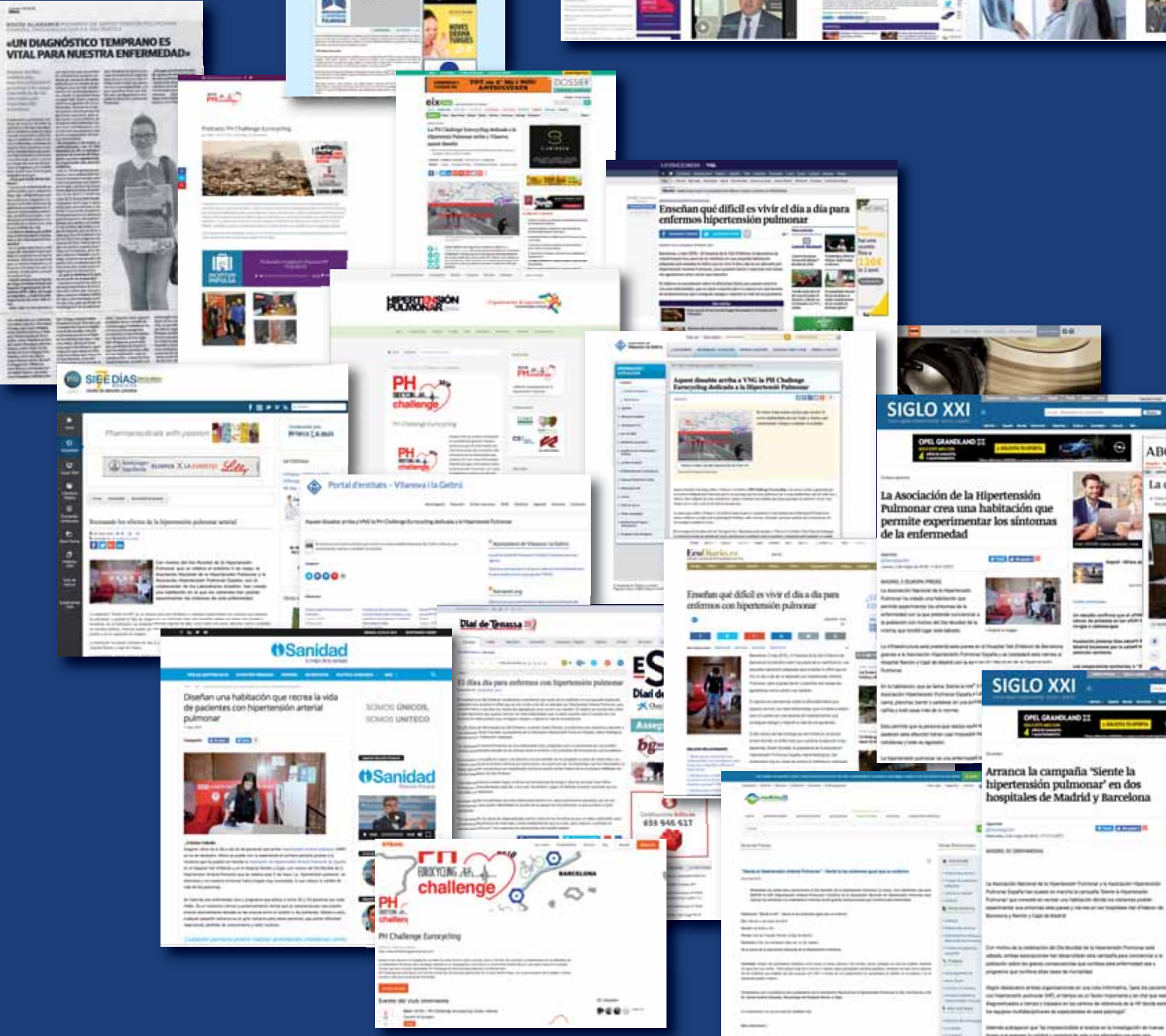
SERBIA



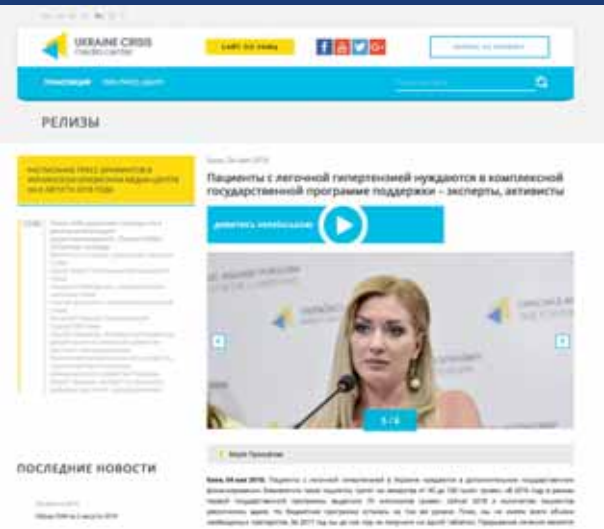
UKRAINE SISTER DALILA



SPAIN HPE



UKRAINE PHA





WPHD 2018

Webinar to close the WPHD celebrations

Gergely Meszaros

PH CLASSIFICATION (NICE 2013 – 2018)

| Group | Description |
|---------|---|
| Group 1 | Pulmonary arterial hypertension (PAH) |
| Group 2 | Pulmonary hypertension (PH) due to left heart disease |
| Group 3 | PH due to lung diseases and/or hypoxia |
| Group 4 | Chronic thromboembolic PH (CTEPH) and ... |
| Group 5 | Unclear or multifactorial mechanisms |

Collet H et al. Eur Heart J 2018;39:1-11. Eur Respir J 2017;40:1601-17.

CTEPH DEFINITION

| | |
|--------------------------------------|---|
| mPAP | ≥25 mmHg (≥20 in the future?) |
| V/Q scan | Abnormal with any mismatched perfusion defect |
| CT scan and/or pulmonary angiography | Abnormal with typical findings of CTEPH |
| Anticoagulation | At least 3 months |

mPAP: mean pulmonary artery pressure.
Poster: Sato J et al. Chest 2013;124:1873-80.

CTEPH Treatment Evolution

- | | |
|---------------------|---|
| 10 years ago | Today |
| • Surgery | • Surgery (PEA) |
| | • Balloon dilatation (BPA, 2012) |
| | • Medical therapy (2013) |
| | • PEA+BPA same time (2015) |
| | • PEA+BPA later (2015-18) |
| | • Medical followed by BPA (2012-18) |
| | • Medical followed by PEA (study, 2018) |

Prof. Marion Delcroix, from KU Leuven, University Hospitals of Leuven, Belgium, opened the webinar and gave a very interesting lecture about CTEPH, with special attention to the work of 11th Task Force of the World Symposium on PH 2018. One of the biggest potential changes is the proposal to change the definition of CTEPH, from the current one (mPAP, mean pulmonary arterial pressure ≥ 25 mmHg), to ≥ 20 mmHg.

During the websinar we also learned about the difference between pulmonary embolism (PE) and CTEPH, and that CTEPH is underdiagnosed and usually misdiagnosed as PE. Prof. Delcroix gave interesting insights into the diagnosis and the diagnostic algorithm of CTEPH as well as the symptoms (including hemoptysis and dyspnea) that patients usually experience. It was emphasized that it takes a long time to get a correct diagnosis of CTEPH and it is highly recommended that patients be referred to a multidisciplinary team. The main reason for late diagnosis is that following PE symptoms can be interpreted as a result of the advanced age of patient or prior smoking habits.

Prof. Delcroix presented the treatment evolution for CTEPH. In the last 10 years new treatment options have been developed, both in terms of drugs and surgery options. The key question is whether the patient is operable or not, and, in general, the surgery is quite complex and can have complications. The medical treatment of CTEPH and the BPA (balloon pulmonary angioplasty) procedure were also explained in detail, with a couple of photos. It is still an open question whether operable patients should receive medical treatment or not.

Nothing great is easy

Patrick Corkery gave us a fantastic insight into his life. Patrick is a swimmer with a big dream: he wanted to swim across the English Channel. He was always a swimmer, but had preferred shorter distances. As of 2013 he started a systematic preparation to accomplish his dream. First he started with a swimming marathon in Lake Zurich, then an even longer swim around the isle of Manhattan. Following these successes Patrick made an attempt on the North Channel from Northern Ireland to Scotland, but due to breathing difficulties his attempt was suspended...

What happened to Patrick? Did he give up his dream? Did he manage to complete open water swimming later on?

You will find the answers and many more interesting details about his private life in the video (see below for link)!

ERN-Lung

The closing session of the webinar was run by Gergely Meszaros, member of the Medical Steering Committee of the European

Reference Network for Rare Respiratory Diseases (ERN-Lung), who made a presentation about ERNs, the cross-border health directive and more specifically on ERN-Lung.

The presentation started with a very short video of the European Commission about ERNs which highlighted the challenges facing the rare disease community and explained that the establishment of the 24 ERNs could provide a solution.

The presentation included details about the definition, working structure, the system of CPMS (used for cross-border data transfer and online conference tools) of ERNs. It is very important to understand how ERN-Lung can assist and help in the life of the patient, because ERNs have a multiple and complex role in care, research, clinical trials, e-health tools, and can ensure efficient use of costly resources and economies of scale.

In order to enlarge the network of ERN-Lung, specifically to Central and Eastern European countries, the status of supporting health care providers was presented in details.

Summary and Q&A

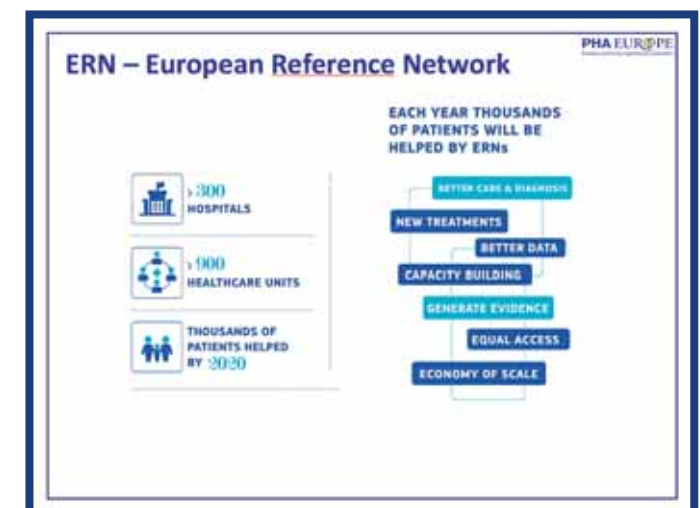
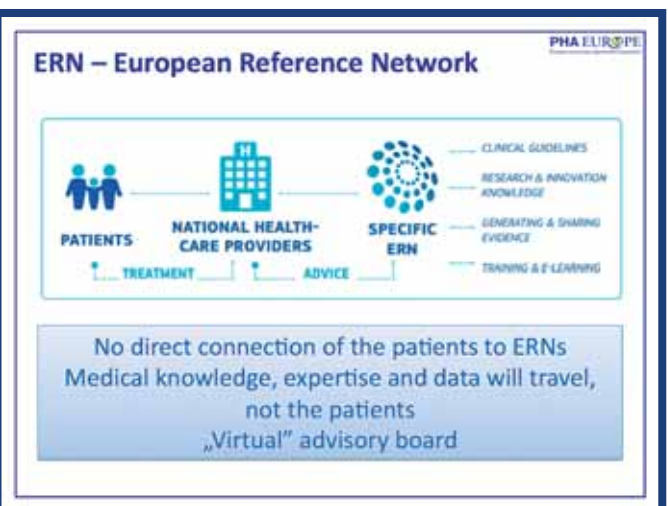
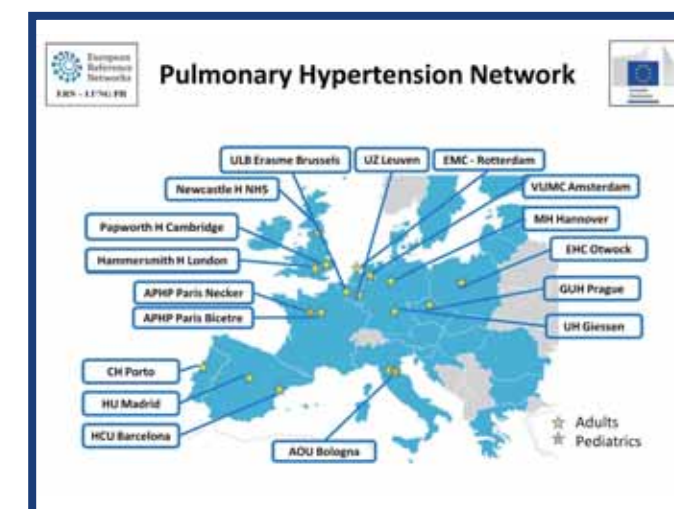
Despite the news about the webinar on the social media channels of the European Lung Foundation (ELF) and PHA Europe, the live webinar was not very well attended, which can be attributed to the summer holidays and the fact that it was the first time such an event had been organised. Interestingly, we received a request for the webinar password from the Middle-East and outside of Europe. Nevertheless, the audience was very active and interesting questions were raised, such as: Is there any screening program for patients who had PE to avoid CTEPH?

How is it determined whether PEA or BPA are to be applied? Which is better?

What caused the clots specifically in Patrick?

How can healthcare providers join the ERN Lung network? If you would like to find out the answer for the above questions, check out Patrick's patient story or simply watch the complete webinar video at:

<https://www.facebook.com/phaeurope/videos/1998384180182968/>



| Year | European Reference Network on rare diseases | Year | European Reference Network on rare diseases |
|------|--|------|--|
| 2018 | European Reference Network on congenital anomalies and rare and shared (CRS) disorders | 2019 | European Reference Network on genetic cancer risk syndromes |
| 2019 | European Reference Network on endocrine conditions | 2020 | European Reference Network on diseases of the heart |
| 2020 | European Reference Network on epilepsy | 2021 | European Reference Network on congenital malformations and rare hereditary disorders |
| 2021 | European Reference Network on kidney diseases | 2022 | European Reference Network on hereditary metabolic disorders |
| 2022 | European Reference Network on neurological diseases | 2023 | European Reference Network on infectious cancer (chemotherapy) |
| 2023 | European Reference Network on inherited and congenital anomalies | 2024 | European Reference Network on hepatological diseases |
| 2024 | European Reference Network on respiratory diseases | 2025 | European Reference Network on cardiovascular diseases |
| 2025 | European Reference Network on skin diseases | 2026 | European Reference Network on rare blood and immunological diseases |
| 2026 | European Reference Network on adult cancer (solid tumors) | 2027 | European Reference Network on immunodeficiency, auto-inflammatory, and autoimmune diseases |
| 2027 | European Reference Network on hematological diseases | 2028 | European Reference Network on transplantation in children |
| 2028 | European Reference Network on congenital diseases and conditions | 2029 | European Reference Network on rare Multisystemic Vascular Diseases |
| 2029 | European Reference Network on neuromuscular diseases | 2030 | European Reference Network on rare Multisystemic Vascular Diseases |

The webinar video was uploaded to our Facebook social media channels, and, without any promotion on our part, the number of the views of the webinar rapidly soared: within 9 days, starting mid August, the video was viewed 573 times. This number is very impressive compared to figures for previous videos, especially taking into account the fact that the video was shared only on Facebook (we are working to publish it through other channels), the fact that we did not promote in any way and that is was during the holiday season.

Upcoming events 2018



August 25-29, Munich, Germany

EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS

PHA Europe will be present at the ERS Annual Congress 2018. This congress is the largest cardiovascular medicine meeting in the world and covers all disciplines from basic research to clinical practice.

September 13-16, Berlin, Germany

PHA EUROPE ANNUAL PH EUROPEAN CONFERENCE

The Annual PH European Conference (APHEC) is one of PHA Europe's most important yearly events. Leaders from 35 European countries attended the 2017 meeting.



September 15-19, Paris, France

EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS

PHA Europe will be present with a booth at the ERS Annual Congress 2018. This congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

October 13, Chisinau, Moldova

EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION

Every year, the European Day for Organ Donation and Transplantation (EODD) provides information on donation and transplantation of organs, tissues and cells. With nearly 6 new patients added to waiting lists every hour in Europe, the number of Europeans waiting for an organ keep growing. This year too, the EDQM calls on all Europeans to think about the problem of organ shortages which leaves thousands of patients sitting on waiting lists.



2019 AT A GLANCE

- EURORDIS BLACK PEARL AWARDS, 12 February, Brussels, Belgium
- EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS, 31 August - 4 September, Paris, France
- EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS, 28 September - 2 October, Madrid, Spain

Next PHAE newsletter

The next Mariposa Journal will be issued in December 2018 (Winter edition). The main focus will be the reports from the national member associations about their activities in the course of the year. It will also feature any other interesting and relevant developments at European and international level. We would be very grateful if the members could send their contributions **by the 30th of October 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!

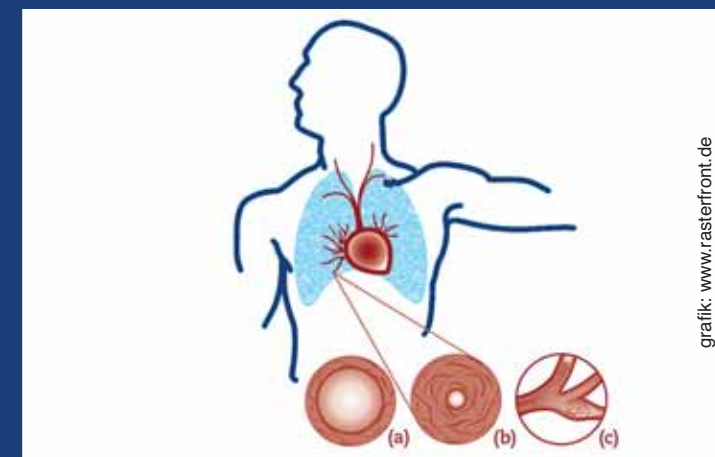


AIMS OF PHA EUROPE

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

grafik: www.rasterfront.de

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

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

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

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

Members of PHA Europe and contact details

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BOSNIA AND HERZEGOVINA



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CROATIA



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CZECH REPUBLIC



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HUNGARY



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ITALY



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LITHUANIA



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POLAND



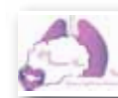
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PORTUGAL



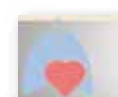
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ROMANIA



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SWITZERLAND



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