



PULMONARY HYPERTENSION Mariposa Journal

SUMMER 2017 • PHA EUROPE'S OFFICIAL JOURNAL • N. 18



Sahara Race for WPHD in Serbia

PUSHING THE LIMITS TO GET BREATHLESS FOR PULMONARY HYPERTENSION



Editor’s memo Summer 2017 edition

Austria
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Ukraine

Dear members, supporters, friends and families, Welcome to the Summer Mariposa! Since the first World Pulmonary Hypertension Day (WPHD) on 5 May 2012, our important annual milestone has been used to combine and highlight our international efforts to raise awareness of, and support for patients with, PH. This year, it was clear that WPHD has grown into a spectacular celebration of our community’s work, and we reached more people with our campaigns than ever before. As in previous years, the PHA Europe WPHD 2017 theme was “Get breathless for PH”. Healthy people were encouraged to take part in high-energy sports and activities to get breathless, demonstrating their solidarity with people with PH who struggle to breathe. Part of our mission is to continue to highlight that patients with PH often endure life-changing physical limitations every day. This year, 35 associations from 30 countries took part in WPHD across Europe, with many more worldwide. It is always amazing to see the creativity of the events organised by the different patient associations for WPHD, and 2017 was no different in this regard. As a result of the great work of our member associations, in Europe alone, over 1 million people attended a total of 58 events, which generated an impressive 425 pieces of media coverage: 16 press agencies, 61 print articles, 225 online media, 77 TV clips and 37 radio announcements, reaching millions of people across Europe. Innovative sporting events ranged from American football training in Poland to indoor climbing in Bulgaria, involving a wide variety of celebrities, sporting legends, experts and journalists to support and publicise the events (almost 200 in total). For the first time, Portugal was supported by famous athletes, who helped to promote the WPHD events through their own social media channels, resulting

in the best attended event they have ever held for WPHD. Ukraine’s PH Urda invited influential doctors, lawyers and patients to a roundtable event to discuss organ donation in Ukraine. Creative awareness campaigns engaged a younger audience with a break dance battle and BMX cycle show in Belarus and recording of a dance video in Spain. Astonishing feats of physical endurance were undertaken by extraordinary individuals this year. Marina Lazic and Jovica Spajic of Serbia pushed themselves to the physical limit in the Sahara Race, the hardest ultra marathon in the world, with Jovica placing first in her age category. One of our Cypriot patient association members joined 10 fellow lung transplant patients and their medical teams, to climb to the top of the Kilimanjaro (5.895 m) as part of a scientific expedition, organised by the Vienna Lung Transplant Centre. Their intention was to show the level of fitness and quality-of-life they had regained as a result of their transplants. Climbers from Bosnia and Herzegovina reached the top of Muztagh Ata, 7.546 m, in China, flying the WPHD flag, to show their solidarity with PH patients. Collaboration has been critical to the success of WPHD 2017. I am delighted to say that, for the first time, PHA Europe combined its expertise and resources with PH patient associations in the US and Latin America. Last year, PHA Europe spoke to the PH audience through social media for the first time, with fantastic results. Not only does social media support the global character of WPHD, with its huge potential in terms of reach, but also gives us the opportunity to reach people who are particularly relevant, through key word targeting. This year, we harnessed this opportunity, yielding results that surpassed all expectations. A central WPHD.org website and Facebook page



for all organisations was established, building a strong sense of global community and support for those affected by PH. Twenty-six times more people visited the WPHD website compared to 2016 and the WPHD Facebook page was seen over 5.3 million times. Our hugely successful Facebook adverts were seen over 9 million times! This channel encouraged four times more people to find out about WPHD compared with last year. PHA Europe, PHA US and Latin America joined forces to create a “Thunderclap” online social media campaign, in three languages (English, Spanish and Portuguese) with a unified message of support to go out on May 5. The Thunderclap reached a spectacular 2.5 million people worldwide. With yet more excitement for WPHD, our first “Global Wave” took place this year. Patients, family and friends were encouraged to take photos and videos of their hands in the shape of a butterfly (symbolising the lungs, as in the Europe PHA logo), and post them on Facebook and Twitter using the hashtag #GlobalWave4PH. The 850+ imaginative posts from from over 20 countries included clever shadow puppets, artistic butterflies painted on hands and group photos at “Get breathless for PH” events. There were also hundreds of imaginative uses

on social media of the phaware app, which allowed users to add WPHD stickers and PH facts to their selfies. We are continually looking for innovative ways to spread awareness of this devastating condition and gather support for those affected. It is vital that patients and healthcare professionals know about PH, and understand how to diagnose and manage the disease effectively. This will help us ensure that patients get the treatment and support they deserve, quickly. New WPHD initiatives from our community, together with the support of our industry partners, have made this the most successful WPHD ever. Finally, I want to thank everyone who contributed to WPHD 2017 and those who have supported our member associations throughout the year. We need to ride the wave of support, continuing our collaboration and communicating with the millions of people we reached with our WPHD campaigns. I look forward to sharing stories of progress and success in the coming year, as well as planning for WPHD 2018!

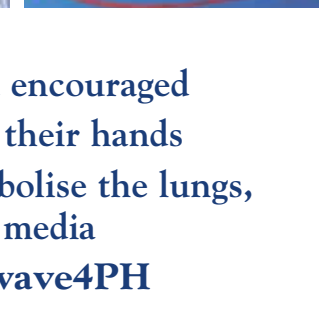
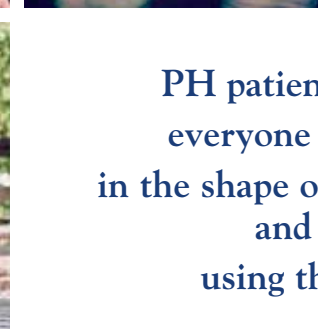
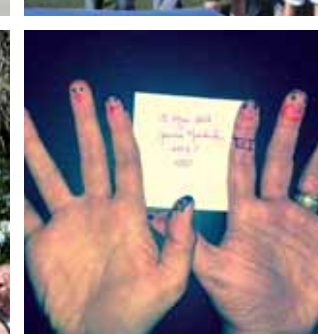
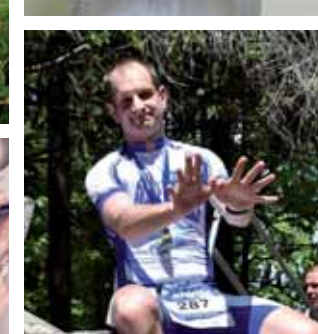
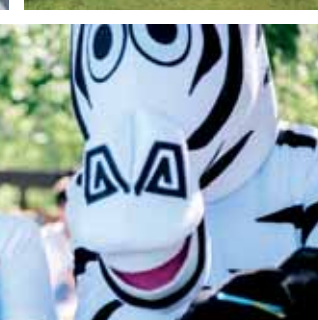
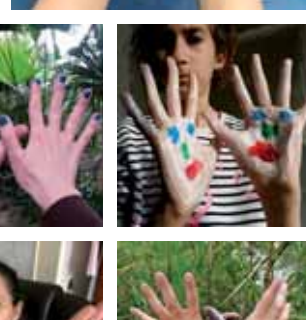
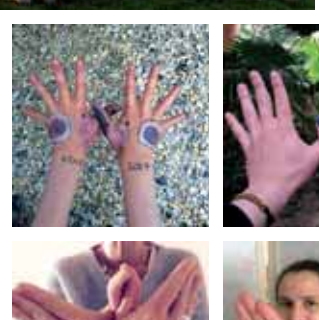
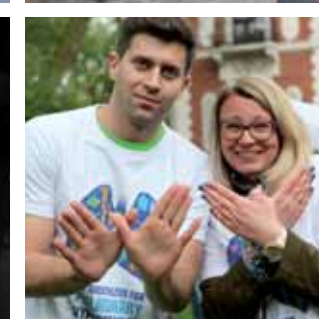
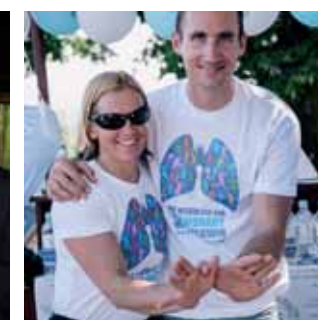
Pisana Ferrari
CEO PHA Europe

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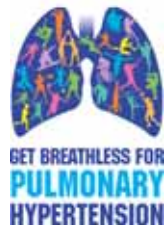


A new initiative for WPHD 2017:
the #Globalwave4PH,
a social media campaign designed
to raise awareness of PH and show unity
for patients with PH across borders



PH patients around the world encouraged
everyone to take photos with their hands
in the shape of a butterfly, to symbolise the lungs,
and post them on social media
using the hashtag #Globalwave4PH





WPHD 2017 - AUSTRIA

HUMAN SIZE FOOSBALL TOURNAMENT

Austria's event for WPHD on May 6th 2017 was a Human Size Foosball Tournament. With the help of Toni Polster, a well-known international soccer player, PH Austria invited patients, association members and its supporters to a day of fun, play and come-together for the PH cause: 7 teams, each consisting of 6 players, "got breathless" playing, with a lot of passion, to make this day count for all people suffering from PH. A team with top VIPs ensured to have the society tv from the Austrian broadcast ORF. The sympathy for children and adults living with this disease was perceivable during the whole day. The media presence, newspapers and TV, as well as association reporters, captured the cozy atmosphere and family touch, even if the event was of significant size, with more than 100 guests (more than 70 wore our Get Breathless for PH T-shirts and took them home). We reached in total an audience of more than 800.000 people, a 10th of our population.

We received as sponsorship funds € 2500 from PHAE, €1000 from Ströck (bakery), €500 Wiesbauer (sausages/meat), € 500 Bauer (insurance company) and €400 on spot donations. We still hope to get more by end of the year, because many guests took our fundraising brochure home for their next company charity activities.

It was very heartwarming to see our 10-year-old patient, Johannes, who had the time of his life hosting and co-moderating with journalist Michael Eschlböck (who has in the past been awarded with the "Golden Romy", as best sports commentator in Germany and Austria). A new star was born! Many thanks to all who made this event possible, especially to Monika Tschida and Eva Otter.

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



WPHD 2017 - BELARUS

BREATHLESS BELARUSIANS SPREAD THE PH MESSAGE

Belarusian PH patients have celebrated WPHD since 2015. Colourful large-scale activities, which are aimed at increasing awareness of PH and at supporting all those who suffer from this disease, take place every year. This year's event for WPHD was held on the 18th of May in the "Park of Culture and Recreation" in Zhodino, a city not far from Minsk, the capital. The slogan for this year was "From Heart To Heart".

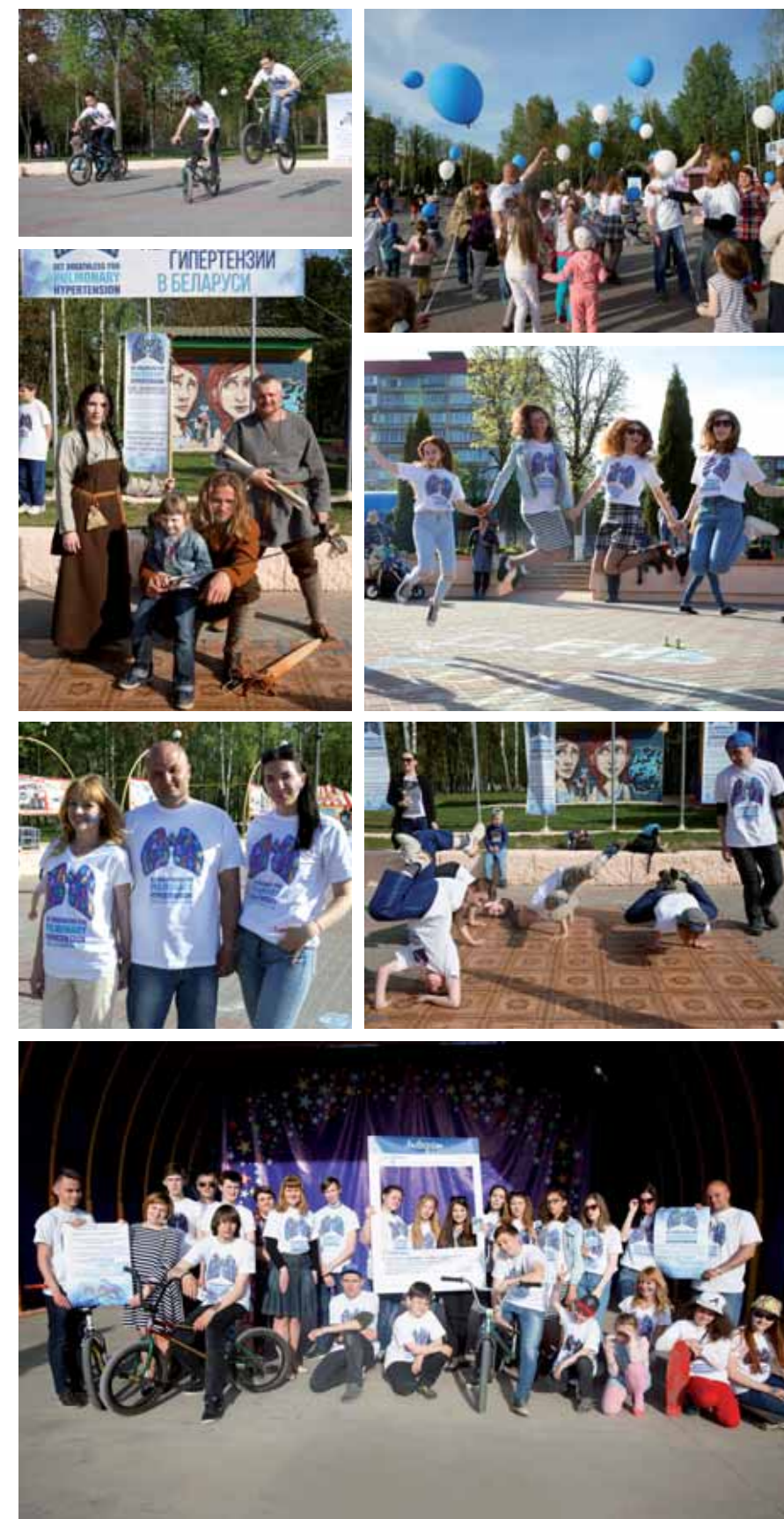
The program of the day was very wide ranging and interesting. There was a spectacular knight tournament, organised by the historical club "Viking", a break dance battle between young talents and a show of cyclists (BMX). Young artists tried their hand at a competition of children's street painting on asphalt.

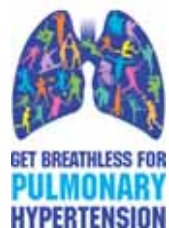
Patients with PH always have to fight with their disease, that is why active games such a tug-of-war and jumping rope, which are of high symbolic value, were organised. Both kids and adults enjoyed playing with soap bubbles. There was also a team specialised in children's entertainment, which has experts in colourful face painting, we had set up a special "selfie-zone", and there was live music - all of which created an atmosphere of happiness, positivity and unity. All participants were dressed in T-shirts with the WPHD logo.

We took the opportunity of WPHD also to organise a campaign for the dissemination of information about PH. Five hundred information flyers were distributed among participants at the event and to citizens. Volunteers gave detailed information about the symptoms of PH and how to diagnose it, about treatment and surgery, to all persons interested.

WPHD 2017 in Belarus ended by a balloon release. We wish to express our gratitude to the youth club in the Zhodino for their valuable assistance in the organization of the event and also to "Zhodinskye navini", and "Zhodinskye vesti" (newspapers) and Sphere TV Channel, for reporting on the event. WPHD this year certainly left its mark in Belarusian hearts. Together we are stronger!

Aksana Sniazhko
 Aid to Patients with Pulmonary Hypertension
www.phbelarus.by
www.facebook.com/groups/phaBelarus





WPHD 2017 - BELGIUM VZW

CLUB BRUGGE WITH BLUE LIPS FOR PH

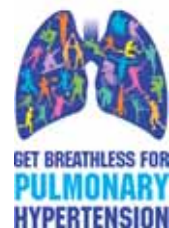
On the 8th of April our association, PH-vzw, was a guest of the Football club Club Brugge, one of the biggest clubs in Belgium, which plays both nationally and internationally, at the home stadium. Before and after the match we gave people blue lipstick to wear to raise awareness for pulmonary hypertension. We also distributed 5.000 flyers to the fans, with the picture of José Isquierdo, player of Club Brugge, and some information about PH. We asked people to send us pictures of themselves with blue lips (our Facebook page for the blue lips campaign @BlueLips-Belgium), and told them we would give the two best ones a prize: a signed shirt of José Isquierdo and a balloon trip. A group of 20 volunteers took part in the action. There were approximately 50.000 people at the stadium. Our "godmother", well known actress Hilde Heijnen, was one of the volunteers who took part. José Isquierdo was the "godfather". He kindly agreed to be part of a video shot in the dressingrooms of the stadium, where he painted the lips

of the members of his team in blue! See <https://vimeo.com/212006311?ref=em-v-share> Michel Preud'homme, trainer of Club Brugge, had a photo taken with Conny and Roland, from our Board. On the 23rd of April, 24 runners, all employees of Talent-IT and Team4Talent, participated in the Antwerp 10 miles. One of the employees of these firms has a 15 year old daughter with PH. For each km that they ran, Talent-IT and Team4Talent gave 1€ to PH-vzw. We received more than 1.500 € for this action! Conny and Roland went to Antwerp to wait for the runners at the finish line. On the 5th of May, we posted different entries on our social media (Facebook/Instagram). One of them was a video, sponsored by Actelion.

Wim Colle, Patiëntenvereniging VZW Pulmonale Hypertensie (vzw PH België)

www.ph-vzw.be

<https://www.facebook.com/PHBelgium?fref=ts>



WPHD 2017 - BOSNIA AND HERZEGOVINA

TAKING PH TO NEW HEIGHTS IN BOSNIA AND HERZEGOVINA

WPHD 2017 celebrations in Bosnia and Herzegovina began in late April, with our first ever patient meeting, which was attended by Hall Skaara from PHA Europe and supported by PHA Europe. This meeting provided a great opportunity for patients in our country to exchange experiences and inform our guest about the very difficult situation of PH patients in our country.

In the course of the month of May our association organised a series of sports activities, in which a large number of athletes, both professional and non professional, took part. Our goal was to raise as much awareness of PH as possible in our country so we reached out to the media and are happy to say that our events were well covered, through web portals, newspapers, radio and TV, as well as social media networks.

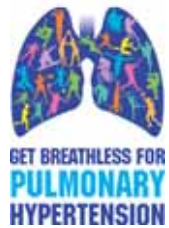
Our sports events included an educational-sports day organised in the beautiful village Kamenica, in cooperation with the Sports Association of Zavidovići; a match for disabled volleyball players, under the slogan "Visible for invisible", organised in collaboration with two sports clubs, UIOK Ilidža-Sarajevo and IOK Zavidovići, and the participation in a European non professional cycling competition from Bosnia and Herzegovina to Albania, a 12 day race covering 1.420 km and crossing 5 different states.

We are very proud of the very recent announcement that our Bosnian-Herzegovinian climbers reached the top of Muztagh Ata, 7.546 m, in China: this expedition was dedicated to WPHD and patients with PH in the world!

We are also very proud of our photo album for the #globalwave4PH on our FB page, which you can visit at <https://www.facebook.com/plucnahipertenzijabosneihercegovine/>, where we collected about 90 photos of people doing the Global Wave not only from Bosnia and Herzegovina, but also from Italy, the Republic of Macedonia, Serbia, Croatia, Sweden, the USA and other countries in Europe and across the world. We will continue to conduct activities to raise awareness of PH to improve the position of the patients in Bosnia and Herzegovina. Our struggle is difficult but we will keep fighting!

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





WPHD 2017 - BSPPH BULGARIA

ADULTS AND CHILDREN ALIKE TAKE THE CLIMBING CHALLENGE FOR WPHD 2017



The Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH) celebrated WPHD this year for the fifth consecutive year. All events were held under the patronage of the Ministry of Youth and Sports, the Ministry of Health, the Bulgarian Society for Pulmonary Diseases and the National Patient's Organization.

The BSPPH organised one of the events for WPHD 2017 on the 4th of May in the sports center "Funtopia", within the Paradise Center Mall, in Sofia. The idea was for children and adults alike to "Get breathless for PH" through indoor climbing. The President of the BSPPH, Natalia Maeva, who had a successful lung transplant in the University Hospital in Vienna, personally participated in the climbing event. In attendance were: the Chairman of the National Patient's Organization Dr. Stanimir Hasardzhiev, the Director of the National Transplantation Agency, Dr. Mariana Simeonova, and Dr. Lyubomir Dimitrov, Deputy Chair of BSPPH.

To date Bulgaria does not have prostanoïd intravenous treatment for PH. Additionally, for PH patients it is critically important to have easier access to European hospitals which perform pulmonary endarterectomy, as well as lung transplants, or combined heart-lung transplants. This would allow them to return to normal life.

Dr. Lyubomir Dimitrov is a Bulgarian pediatric cardiologist who also works with PH patients. He said that the disease is extremely varied, with many different forms. If people have heard of it at all, they usually know of pulmonary arterial hypertension. However, he stressed that this is only a small part of the total morbidity, it is just the tip of the iceberg. He said that newborns can also have PH. This is of course a very specific type of PH and it is mostly treatable. However it is a fact that infants in the first months after birth may die from persistent PH of the newborn.

Among the participants who climbed the walls of "Funtopia" were a number of children from the association "Child's heart", who have congenital heart malformations. We also want to thank for the support of the Balkan Federation of Adapted Physical "Balkans and Black Sea", who also participated actively in the event.

On the 5th of May, at 8 pm, for the second year running, the National Palace of Culture (NDK) building was lit in blue in support of people suffering from PH.

On the 24th May - the Bulgarian Day of Education and Culture - the Bulgarian language edition of the book with the story of the rare elephant Pongo, who was "born" on May 5, was officially presented during an event organised by the BSPPH. The creator of this unique purple character is Ioanna Alisandratoù, the President of Hellenic PH Associ-

ation, who flew in from Greece especially in order to attend the première.

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

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



WPHD 2017 - PHA BULGARIA

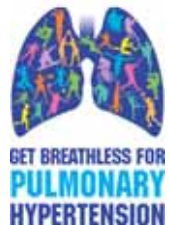
CYCLING FOR PH IN BULGARIA AND BEYOND!

For WPHD this year, PHA Bulgaria organised several different events. The first one was the official presentation, at the Greenwich Book Center in Sofia, of the the book "Life with PH", a collection of 16 PH patient stories. The event was attended by over 100 guests, including the Executive Director of the National Transplant Agency, Dr. Mariana Simeonova, prominent physicians in the field of cardiology and pulmonology, representatives of pharmaceutical companies, patients, family members, journalists. The aim of the event was also to raise funds for the purchase of a mobile oxygen concentrator. As part of the WPHD celebrations the President of the National Alliance of People with Rare Diseases (NADRB), Vladimir Tomov, and Todor Mangarov, President of PHA Bulgaria, took part in this year's "Vitosha 100" cycling tour. Vitosha is a volcanic mountain massif, on the outskirts of Sofia and is one of the most famous and most ridden mountain bike destinations in Bulgaria. The Vitosha tour has been held annually for over 40 years. For the first time this year, at the start-finish of the tour, with the permission and courtesy of the organisers, there was a stand with information materials about rare diseases. PHA Bulgaria also had an active role in the "3rd Workshop on Rare Diseases", which was held in Rousse on May 29. Topics on the agenda included CTEPH and organ donation and transplant. The

patient's point of view was presented by Todor Mangarov, who had just returned from another cycling tour, this time in Cuba! Finally, Todor was also invited by the PH association of the Republic of Macedonia, to take part in the Wizz Air Skopje Marathon, and ran the 5 km non competitive race whilst pushing Gjurgica Kjaeva, PH patient and President of the PH association in Macedonia, on her wheelchair. Quite an achievement!

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





WPHD 2017 - CROATIA

A GIANT HEART FOR PH FROM THE CHILDREN OF CROATIA

It is with great pride and pleasure that we can say that our 2017 awareness campaign for WPHD was very successful! Our project involved an entire school, with all its employees, children and parents. The children were engaged in various sports activities, and who "left their breath" on the sports field in solidarity for all those of us who cannot breathe. Despite the many difficulties we had this year their smiles always gave us hope for a better and more beautiful tomorrow. We used the opportunity of our WPHD event to point out the importance for children of starting sports activities from an early age, and that they should understand how lucky they are to be healthy and to be able to play sports, because unfortunately there are many children and adults who are suffering from PH or other illnesses and are physically limited in many areas, from sports to ordinary everyday tasks. It was wonderful and very emotional to watch the children with their "Get

breathless for PH" T-shirts and how they listened and absorbed each word carefully. We believe that children are the best way to the future and that they can be our little ambassadors to make people aware of the existence of PH. We are very grateful to the school as well as to the local community who contributed with media coverage. At the very end, all participants formed a heart shape with their bodies to say that their hearts are beating together in one big heart, for all the members of the PH community across Europe and beyond! With love from Croatia!

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



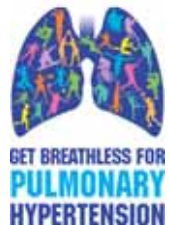
WPHD 2017 - CYPRUS

AN ADVENTUROUS SCIENTIFIC EXPEDITION TO TANZANIA'S HIGHEST PEAK

This year, in June, I had the great privilege to take part in a scientific expedition organised by the Lung Transplant Unit of the Vienna General Hospital (AKH) to coincide with WPHD celebrations. The expedition consisted of 35 people, including 20 doctors and 10 patients having undergone lung transplant in Vienna. The idea was to test how transplanted patients react at very high altitudes and in extreme conditions. We started our trip from Tanzania on the 11th of June. On the 12th of June we started around 8 am with a 5 hour climb till the first camp at 2.650 m. It was the first day so it was not so difficult for us. Every day we had to take blood tests, check our oxygen levels and have ultrasound examination, it was all very organised. On the 13th of June we climbed more than 6 hours up to 3.610 m. There we started to understand how difficult it was going to be! On the 14th of June we woke up and we started climbing again around 9 am. On the 15th of June again the same plan, wake up in the morning and start climbing at 9 am. On the 15th we reached 4.600 m. When we arrived at this camp we were all tired and had difficulty breathing. Throughout all these days I was walking with Samatha, an amazing Italian patient, and we were chatting in Italian. After our lunch there, at 4.600 m, we started to go down to 3.900 m to stay there overnight. On the 16th of June again the same up and down and every day more it was more difficult, but nobody gave up as we were all so excited. The 17th of June was a difficult day, we climbed till 4.674 m and, after our lunch, another 200 meters to go to the next camp. We had only few hours to rest there because at 00:00 we started out, in the wind and cold, for the last stretch, the final 1.000 metres to go to the Uhuru peak at 5.895 m. Samantha was the first to the top on 18 June at 06:00! I was really proud of myself and all of us for this amazing feat. Of the transplanted patients only two dropped out of the program half way but all the other eight made it to the top, and all the doctors and myself, of course. I was happy and proud to be there with the PH colours and the WPHD flag! I did all this because my mom had PH and she has undergone a lung transplant and because I promised to myself that is ever she survived I was going to help and be close to PH patients that need me.

Manos Cheimonis, Cyprus
manoscheimonis@hotmail.com





WPHD 2017 - CZECH REPUBLIC

CELEBRITIES AND DOCTORS TRY THEIR HAND AT GOLF IN SUPPORT OF WPHD

Following the very successful pilot year of 2016, our association PH patients, SPPH, organised another open golf tournament Birdie for WPHD. The tournament took place on Saturday May 14, in the very pleasant surroundings of Sand Martin's Holes in Michalovice. The event was supported by a number of celebrities, as well as by some important figures from the medical field. The actress Sabina Laurinova, for the second year running, was the kind patron of the tournament. One of our leading experts on PH, MUDr. Pavel Jansa, came with his family to support and encourage both the players and our patients and their loved ones. MUDr. Jansa is the leading doctor of the PH center in General University Hospital of Prague, which is one of our three Centers for PH here in the Czech Republic. The tournament itself hosted 37 players. Among them there was the famous Czech singer and actor

Jiří Korn, with his girlfriend Renata Císlarová, and from the medical field the head physician and the Director of the Cardiac center in the General University Hospital in Prague, MUDr. Marek Šetina; the chief physician of the II. Cardiovascular Surgery Clinic in Prague, Prof. MUDr. Jaroslav Lindner; Prof. MUDr. Štěpán Svačina, the chief physician of III. General Internal Medicine Clinic and, last but not least, the head physician of the Clinic of Respiratory Diseases and Tuberculosis, Prof. MUDr. Jiří Homolka with his family. All mentioned above are representatives of General University Hospital in Prague.

For all the contestants and the other thirty participants, patients and their families, we prepared an accompanying program in a form of a "golf academy", where they could learn the basic rules of the game, try the proper way to swing through the golf ball and the putting. At the end of the tournament, apart from the announcement of the best players, amongst whom we could find Jiří Korn or Renata Císlarová, we also implemented a voluntary "putting" competition, and with the money that we obtained, we would like to buy some new necessary equipment for our PH patients.

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

www.facebook.com/Sdruzeni-pacientu-s-plicni-hypertenzi-518282501540862

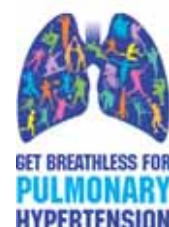


WPHD 2017 - DENMARK

"6 MINUTE WALK" RACE TO UNDERSTAND THE PHYSICAL LIMITATIONS OF PH PATIENTS

It was the first time that our association celebrated WPHD and it was a great success that we are very proud of. We choose to arrange a race where the participants had to compete on who could walk the longest in 6 minutes. Early on, it became apparent that it was one of our competing patients who would win. No doubt due to the fact that they clearly have the most experience with this form of exercise. The weather in Denmark can, however, be quite a challenge. The sun was shining in Odense - the birthplace of world renowned writer H.C. Andersen - right up to the moment where we began. Unfortunately, it suddenly began raining the moment we started the race, which you may be able to see from the pictures. Obviously, the rain is no challenge for the Danish vikings and we had a lovely day.

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

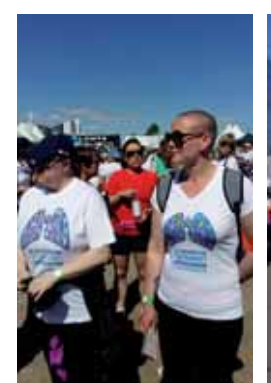
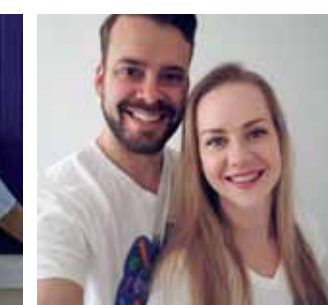


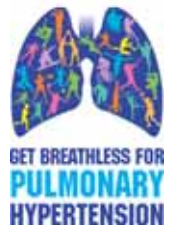
WPHD 2017 - FINLAND

LOCAL CELEBRITY JOINS SOCIAL MEDIA CAMPAIGN FOR PH

For this year's WPHD we organised a social media campaign on Facebook. We sent "Get breathless for PH" T-shirts to our members, nurses and doctors at the University hospitals, and on May 5 we posted everybody's photo, wearing the T-shirts, on our Facebook page. We reached over 1.000 people with the photos and all the posts about WPHD from patients and their friends. We were very lucky to have the support of the famous singer and songwriter Mika Ikonen, who joined in the campaign. Later in May we participated the "Women's 10" running event: this is one of the biggest sport summer events in Finland and there were over 11.000 people running or walking 10 km. I walked that 10 km with three "supporters".

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





WPHD 2017 - FRANCE

FRENCH PH HCPs JOIN THE #GLOBALWAVE4PH FOR WPHD 2017



For the third consecutive year, Isabelle Billerot, Medical Secretary at the French PH National Reference Centre, managed to mobilise a large part of the team to take pictures of themselves with the WPHD materials and logo, and while doing the Global Wave for PH. She had planned everything very well had thought of everything ... Did she have to bribe her "models" with loads of candy, as in previous years? Judging by the smiles on everyone's faces, it seems that everyone joined happily in the game without having to be pushed! Thank you for these nice photos! For us, the patients, and our loved ones, it is heartwarming to see that each member of the healthcare team sees the value of raising awareness about PH and is willing to bring his own personal contribution to the PH cause. Thank you to all of you, Ladies and Gentlemen, Doctors, Professors! And thank you, Isabelle, for your nice reportage! (Kremlin-Bicêtre)

Mélanie Gallant-Dewavrin, HTaPFrance

www.htapfrance.com

<https://www.facebook.com/pages/HTAP-FRANCE/288261994529082>



WPHD 2017 - FRANCE & GERMANY

CROSS BORDER JOINT EVENT FOR FRENCH AND GERMAN PH PATIENTS

On the occasion of WPHD 2017, on May 5, representatives of the German PH ph e.v. teamed up with delegates from the French PH association HTaPFrance in the Upper Rhine, in Breisach, near the border between the two countries, for a joint culinary Rhine cruise. Fifty three persons met at the Breisach shipping company, 33 from Germany and 20 from France. Unfortunately, the weather was not very nice and the temperatures could have been a bit warmer. But that did not affect the mood, for everyone was glad to see each other again, after the joint meeting last year in Strasbourg. During the 2-hour cruise we enjoyed a delicious asparagus menu. It was nice to chat and share experiences with old friends and make new acquaintances. Unfortunately, the weather worsened and when the group set off for the city center, it began to rain heavily.

In Breisach, on that weekend, a trade fair was held and we had a booth for PH, at which passers-by could try a 6-minute walk test under difficult conditions, i.e. breathing through a drinking straw and with a nasal constriction. The aim was to give healthy people an idea of how difficult it is for PH patients to breathe. After a few wet starts, the project was abandoned and we all escaped the rain by going to a nearby café.

Hans-Dieter Kulla, pulmonale hypertonie e.v.



It was a very nice event in spite of the rain. We had much fun and I would like to thank all who helped to organise it. It is now the second time that we arrange a common event and this sets a nice precedent. The French and the Germans could give a good example for other nations! My feeling is that we did not only save money but also demonstrate a sense of community!

Laure Rosé, HTaPFrance



WPHD 2017 - GERMANY

POSTER CAMPAIGN WITH PH PATIENTS

WPHD 2017 started in Germany with a poster campaign. People who receive a diagnosis of PH often fall into a deep hole. It is devastating to learn that you have a life-threatening cardiac/pulmonary disease that is not yet curable. This disease radically changes lives and patients must learn to deal with them. "With our poster campaign, we wanted to show patients, and above all others, that life with PH is not over and that you can still pursue your hobbies", said the President of the German PH Association, Mr. Kulla. The poster campaign features different PH patients, who tell something about

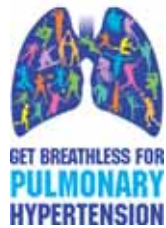
their illness and their hobbies. For example, Bärbel P., who is photographed on her bicycle: "I have PH and I still passionately like to ride my bike". 83-year-old Christa S. shows herself in her self-styled baroque dress and says: "Thanks to the good care I get I can pursue my sewing hobby and even parade in my robes in the group Bellissima".

Hans-Dieter Kulla, pulmonale hypertonie e.v.

www.phev.de

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





WPHD 2017 - GREECE

PONGO THE RARE PURPLE ELEPHANT IS THE STAR OF WPHD 2017!



This year for WPHD we organised four main events! On WPHD we set up information kiosks both in Athens and in Thessaloniki. We also decided to raise awareness among the public in a more interactive way! Apart from the flyers and information, we also gave out to visitors at the booths badges they could write their own personal message on, which followed right after the sentence "I am rare because..."

We also had our annual cycling event in Marousi which proved to be a great success, with a very large number of participants. Mr Patoulis, the towns Mayor and President of the Medical Association of Athens, honored us with his presence and pedaled along with us. Pongo, the Rare Purple Elephant, was there, in both events, to spread the message of rarity in his own unique way!

Another major event was the "Run Greece" marathon in Heraklion, Crete. Apart from the information given out at the booth we also placed 5.000 flyers about PH in the participant's bags.

Our impact? We managed to reach approximately 150.000 people through flyers, social media, press release, via our kiosks, though interviews and internet media news!

Ioanna Alissandratou, PHA Greece
www.hellenicpulmonaryhypertension.gr
www.facebook.com/HellenicPulmonaryHypertension



WPHD 2017 - HUNGARY

HUNGARIAN PH SPORTS AMBASSADORS

"GET BREATHLESS FOR PH"

This year PHA Hungary decided to organise/participate in events which were really specific and likely to attract huge public attention. On top of this, we planned a "breath-taking" event for our members, which was available for the general public as well. Our "breath-taking" event was a hike to one of the highest mountain of Hungary, to Mount Csóványos. The program started with some educational sessions in a guesthouse located at the foot of the mountain and following that we marked WPHD with the hiking. Those of us who were health hiked the way up and in order to make it possible for the patients to reach the top and enjoy the wonderful views, we asked for a special permission and rented a jeep which could transport them: on their own this would not have been possible.

This year we also focused on raising awareness of the disease. To achieve this goal, we asked the help of our PH sports ambassadors, who participated in a couple of races wearing the PH T-shirts. You could see our volunteers in the hills of Vértes where a famous trail running race was held. Our ambassador "got breathless" for PH during the Ultrabalaton,

which was a relay running race where only one round had to be run, but it was 220 km long! The WPHD logo also appeared on top of Hungary, on the hill of Kékes, where a challenging running race ended with the participation of our ambassador.

From previous years we realised that we need to continue our work during the whole year, so we asked our ambassadors to keep up the good work and wear our T-shirts in races going forward.

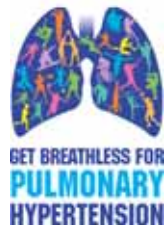
Impact: We have no specific data on an event by event breakdown, but:

- The webpage an article was published about PHA Hungary and its activities has a daily 300.000+ visitors
- The races our PH ambassadors attended had 10.000 + fans and around 100.000 followers/views of videos on Facebook

Eszter Csabuda, Tüdőér Egylet
www.tudoer.hu

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





WPHD 2017 - IRELAND

PHA IRELAND MANAGES TO GET THE IRISH NAVY “ON BOARD” FOR WPHD 2017!

Irish Naval Services support PH

PHA Ireland brought out the big guns this year to raise awareness of PH. We were honoured when the NCOs (non-commissioned officers) of the Irish Navy agreed to nominate us as their chosen charity. Each year the NCOs choose a worthy cause and we were delighted that this year, the Department of Defence agreed that PH was a worthy recipient of their fundraising efforts. Before the NCOs and their superiors launched the campaign they asked for an expert to visit the Naval Base to present a lecture on PH. They had never heard of the disease before the daughter of one of their colleagues was diagnosed. We are most grateful to Dr Sinead Harney from University Hospital Cork who presented the talk on 31st May. This was received with great interest and followed by many, many questions. The campaign started with a cake sale/coffee morning on 19th July. Everything on sale was supplied (free of charge) by many local bakeries. Then to work off the effects of the luxurious confectionary - the main event commenced. On Saturday morning 22nd July the NCOs commenced a Row-athon on Patrick Street in Cork. They rowed the same distance that they patrol when they are on their rescue missions for refugees on the Mediterranean. The Irish Navy patrol the area between Tripoli and Palermo which is 270 nautical miles. The guys and girls rowed from 9am till 5.30 pm. The footfall on the street is approx. 30,000 every Sat-

urday. The event created great interest and many local restaurants & food stores provided complimentary meals and all nutritional needs of the ‘rowers’ throughout the day. The atmosphere on the street was electric! A total of €8,240 was raised on our behalf. We feel very privileged to have been invited to the Naval Base for the graduation ceremony of the NCOs on 10th August 2017. The officers will present the monies raised to us on that date. There were other awareness days organised throughout the year with a Badminton competition, Ladies Mini Marathon and sponsored walks. Contributions from these events raised over €2,500.

PH Lectures

We have always felt that awareness of PH among our medical students is a major priority. On 12th May 2017, Dr Brian McCullough, Consultant Respiratory Physician in the Mater Hospital presented a short talk about PH to the 4th year medical students in University College Dublin. This was followed by an interview with Karen Doherty (one of our patients and great supporter of the PH Association). Dr McCullough asked Karen how she was diagnosed, what were her symptoms, how long was it before diagnosis, type of medication she's on, prognosis etc. The students said they found this novel educational event “fascinating”. We are happy to say that we have been invited to make this type of educational presentation an annual event in the University. It will be widely advertised in advance and we hope it will receive great interest and publicity among students and family doctors. We will plan the lecture to coincide with WPHD.

Regina Prenderville, PHA Ireland

www.pulmonaryhypertension.ie/pha-ireland
www.facebook.com/PulmonaryHypertensionIreland



WPHD 2017 - ISRAEL

PH LECTURES AND HIGH ENERGY SPORTS FOR WPHD IN ISRAEL

For WPHD this year PHIsrael organised an awareness conference in the Sheba medical center. The conference, entitled “Relieving the pressure” was attended by over 80 persons, including patients, family members, physicians and other hospital staff. The Head of the Sheba Medical Center, Dr. Dorit Tekes-Manova, opened the event, e were then honoured to hear opening remarks from Dr. Amir On, Head of the Pulmonary Institute. The schedule continued with Dr Mike Segal, Head of the PH clinic in the Pulmonary Diseases department, who explained where medical research and practice stands currently with regards to PH and what hopes there are for the future. Following this Aryeh Coperman, CEO of PH Israel, discussed the important topic of social welfare for patients, their rights, benefits they are owed from their socialised medical insurance and how to access these rights from the relevant government bodies. He also explained the role of PH Israel, our activities and how we can be of assistance. Aryeh also launched and explained our portable oxygen compressor rental/purchase campaign! This campaign was received with much excitement. Dafna Somach, head nurse in the department spoke of all the small details which are important for patients, hospital staff and care givers to remember when caring for PH patients. Our next speaker, Dr Ronen Reuveni, a physiologist at the Lung Rehabilitation Center, explained the importance of physical activity for a PH patient and the practical ways in which to ensure that all patients stay in good shape! With an awareness theme focusing on sport - we felt it important to empower patients and give them the information they need and the “permission” they often wait for to exercise safely and also to recognise the importance! [Note: with a disclaimer to obviously check with their own physician first].

PH Israel welcomed, for a completely different type of breathlessness, Dr. Uri Leshman, who had the crowd breathless with laughter in his lecture “Concerto de la Comedia”. Our goal was to convey to all present that without a positive attitude and some laughter along the way life is that much harder! The conference ended with a scrumptious dinner which was enjoyed by all!

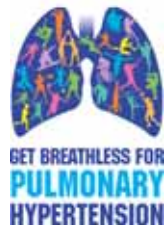
As part of our WPHD events this year a team of runners, including Dr. Avital Avriel, Head of the PH Center at the Soroka Medical Center (biggest medical center in the south of Israel) represented

PH Israel in the Mountain to the Valley Race. This annual group relay race of about 215 km, the oldest in Israel, lasts over 20 hours. The race is divided into 24 parts of about 5-12 km, and the participants race in relay, taking turns. Our PH Israel team was made up of 8 runners. The nucleus was made up of a group of doctors who met during their fellowship in Toronto! What was most heart-warming to us was to see our very own Dr. Avital Avriel, head of the PH Clinic at Soroka Hospital. It is a very challenging race up and down hill, in the amazing landscape of the Galilee. The race began on Thursday morning and by afternoon the temperature was already 36°. The race continued into the night. On Friday the weather was pleasant and cool and the race ended in the settlement of Timrat.

Maayan Steele,

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





WPHD 2017 - ITALY AIPI

SAMANTHA'S WPHD CHALLENGE



Samantha Ciurluini, one of our AIPI members, who underwent a double lung transplant six years ago in Vienna, took part in a scientific expedition to the Kilimanjaro organised by the Lung Transplant Unit of the University of Vienna Hospital (see page 13). All of our members know of this of course and she was cheered on throughout the expedition on our social media. After successfully reaching the opt of the Kililmanjaro at 5895 m, Samantha went on to take part in the World Transplant Games in Malaga where she won several medals for volleyball. Thanks to a friend who is a well known photographer, Gianluigi Di Napoli, Vanity Fair Italy decided to do an article on Samantha and on her successes. Vanity Fair is a very popular magazine in Italy and this gave her and our association wide visibility!

Leonardo Radicchi, AIPI Italy

www.aiipiitalia.it

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

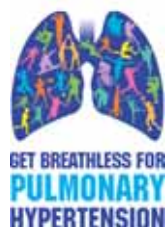
Every child was given a drawing set and was invited to make a drawing, expressing what he or she felt about PH. They had a week's time to prepare for the competition so they also had the time to talk at leisure about it with their families and so spread awareness. They became our young testimonials all around the town!

On WPHD itself day an event was organised where all children were invited to show their work. Every child was wearing the official WPHD day T-shirt. Emotion and enthusiasm were at the highest levels! We had more than 450 children among who's work to chose from to decide on a winner. It was impossible, they all were winners and deserved a prize, so we gave them all a beautiful diploma! The drawings were very nice, some really brilliant.

Raffaele Della Volpe, AMIP Italy

www.assoamip.net

www.facebook.com/AssociazioneMalatiDi-IpertensionePolmonare?ref=ts&fref=ts



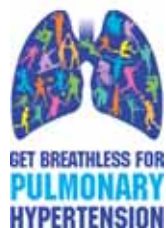
WPHD 2017 - ITALY AMIP

PH AS SEEN BY CHILDREN THROUGH THEIR DELIGHTFUL DRAWINGS

For WPHD this year AMIP organised and sponsored a drawing competition which involved all the children of my town's schools. The theme was: "Pulmonary Hypertension as seen by children". The results were fantastic! Naturally, in order to involve the children we had to explain what PH is, so we visited the schools, distributed our leaflets and were given the possibility to talk to the children. We

told them that PH can affect anybody at any age. We explained that it is a rare disease and what the symptoms are and told them about how PH steals breath from people. At the same time we told them that people affected would be able to fight the illness only if they and their doctors knew it is possible to treat it. Children could help to spread this message, which in turn could save a life!





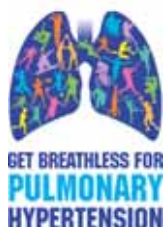
WPHD 2017 - LATVIA

PLANTING THE SEEDS OF HOPE FOR PH PATIENTS IN LATVIA



On May 5, a very sunny and hot Friday, PHA Latvia opened its public event to celebrate WPHD 2017, entitled “Long life tree for PH”, which was organised in collaboration with the Bauska Municipality authorities. Bauska is a city 66 km from the Latvian capital Riga. Four volunteers from PHA Latvia manned the information stand to hand out PH educational materials and give information. The stand had been set up near Bauska’s polyclinic. We also took oxygen saturation and blood pressure measurements. There were 70 visitors at the booth. At 12.00 Bauska’s Mayor, Mr. Raitis Abelnieks, the Head of the Bauska Hospital, Dr. Mirdza Brazovska, and PHA Latvia’s President Ieva Plume gave welcome speeches. After that PH patients, volunteers, and Bauska’s Mayor planted a Ginkgo Biloba tree in front of the Polyclinic, as a symbol for long life, hope, a new beginning and cooperation. Joyful Latvian folk songs were sung as a propitiatory rite for the growth of the tree. The Ginkgo leaf was chosen as the logo for PHA Latvia in 2012 precisely for this reason, as it is a life symbol. After the tree planting a physiotherapist and PHA Latvia Board Member Sandra Šarlovskā showed some active exercises to promote healthy life style, sports, and joy of life, to which the participants joined in.

Ieva Plume, PHA Latvia
www.phalatvia.lv/en/ - on.fb.me/1ZoY0NB
<https://twitter.com/phlatvia>



WPHD 2017 - LITHUANIA

WPHD 2017 ON THE CATHEDRAL SQUARE OF VILNIUS



WPHD in Lithuania was celebrated on the 5th of May, In Vilnius, the capital. The aim of WPHD is to raise awareness and inform people about PH, about PH treatments success and the challenges of patients in one’s country. The Lithuanian association’s volunteer team did a great job this year, as always. We organised a blue and purple coloured celebration on the Cathedral square. City residents and visitors had the opportunity to taste fruity “oxygen” cocktails, to talk with our members about PH, to check their oxygen

saturation levels with the special device for this and to take home information brochures about PH. We also had a special celebration for children: we prepared many different types of candies on our tables for them and every child received a purple balloon as a gift. At the end of May PHA Lithuania’s members met together for another WPHD celebration. This was just a members’ party, with nice food and gifts for everyone and a specially made beautiful and delicious cake with the association’s logo. We talked about the association’s future, about PH treatments in Lithuania, we shared own life stories and disease experiences. Our friends from a local pharmacy gave

two presentations: one about how to treat allergies when you have PH and the other about face and body protection from the sun when you have PH. They were both interesting and a very timely topics. The members of PHA Lithuania are happy to see that every year more and more people are getting to know about our disease and are starting to understand that anyone can be a patient with a rare disease and that this disability is not always visible at first sight.

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



WPHD 2017 - NETHERLANDS

MEMORIAL RUN FOR WPHD ON WHITSUNDAY

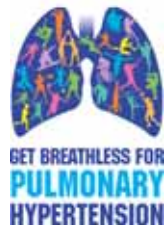
On the 4th of June the 8th edition of the “Andy Voordouw soccer tournament” was organised by PHA Netherlands in Bodegraven, a village on the west of The Netherlands. It is the town where Andy lived. The goal of this event is to raise awareness for PH and funds for scientific research. Andy Voordouw died at the age of 18, from severe PH, and his family organises this tournament every year at Whitsunday (Pentecost). This year two “special teams” joined the competition:

- Andy Voordouw’s family/friends team.
- The “Heart for PHighters” team, who were wearing the special WPHD “Get breathless for PH” shirts.

It was a magnificent day, lovely weather, good atmosphere and exciting soccer matches. Overall 12 teams joined the competition. The team “Heart for PHighters” unfortunately lost their last match in the play off but still won the silver award! At the end of the day a check was presented to PHA Netherlands. Andy’s family managed to raise the huge amount of 3.000 euros. Of course we are very proud and grateful!

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





WPHD 2017 - POLAND

CELEBRITIES JOIN PHA POLSKA FOR AMERICAN FOOTBALL TEAM TRAINING



This year PHA Poland's WPHD event attracted both celebrities, students and the association's fans. Despite bad weather many PH supporters showed up to express their solidarity with patients. Fourteen well-known actors, dancers, TV presenters and sports-women joined a special American football training session. The idea of the event was to put in contrast the possibilities of sportsmen with the physical limitations of PH patients. PHA Polska was represented by Alicja Morze - PHA Polska President, Agnieszka Bartosiewicz - PHA Polska Vice President and PH patients from all over Poland. Prof. Adam Torbicki and Prof. Marcin Kurzyzna - very well known Polish PH experts, were guests of honour of the event. Prof. Marcin Kurzyzna not only joined the event but also took part in the training with the Warsaw Eagles Team. Both medical and lay journalists (36 reporters in total) attended the event. The information about PH and our WPHD event was broadcast 28 times on TV and 14 on the radio news on that day!

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



WPHD 2017 - PORTUGAL

SPORT ACTIVITIES FOR ALL AGES AND FOR ALL TASTES FOR WPHD IN PORTUGAL

In Portugal, World PH Day was celebrated on May the 1st, and was attended by almost 800 people! The event had the collaboration of the Futsal Training School of Sport "Lisboa e Benfica", a futsal academy responsible for the training of future professional players. Sport Lisboa e Benfica is a Portuguese sports club based in Lisbon, Portugal: it has several training schools all over the country, so it was a big honour to have them with us this year.

The event included several sport activities, for people of all ages and for all tastes! During the day, there was a ten-hour Futsal Tournament, with 127 futsal athletes (including insiders, juniors, seniors and veterans). The athletes brought their families and friends to watch the game, so this main event was particularly successful because it was very well attended.

In the breaks of the Futsal matches there were demos of several sports, including: kickboxing, karate, hockey and artistic skating. In the morning, at the same time as the Futsal Tournament was taking place, a Football Match was being played by 22 young athletes who also brought their families to the field. Also in this part of the day, 90 people took to the hills for a 15 Km mountain running and cycling race. For those who couldn't run or cycle, there were two walks (5 and 10 Km) which were extremely well attended, 331 people! At the end of the morning, there was a surprise moment: a Global Wave For PH photographed from a drone from the sky!

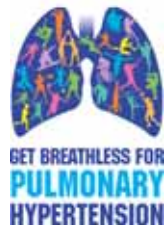
In the afternoon, there was a Zumba Session with 100 dancers getting breathless for PH. At the end of the day the big moment everyone was expecting arrived: a Futsal match with some of the best Portuguese Futsal players! They were very kind because they really supported us in raising awareness for PH and they immediately started to use their Facebook pages to share photos and videos about WPHD and the Global Wave For PH.

This year's WPHD event was very complex, with several activities running at the same time, so we had a staff of 45 people helping us all day long to ensure that nothing was missed or failed.

Thank you to PHA Europe for the support, congratulations to the PH community for your great events and the wonderful work you're doing every year!

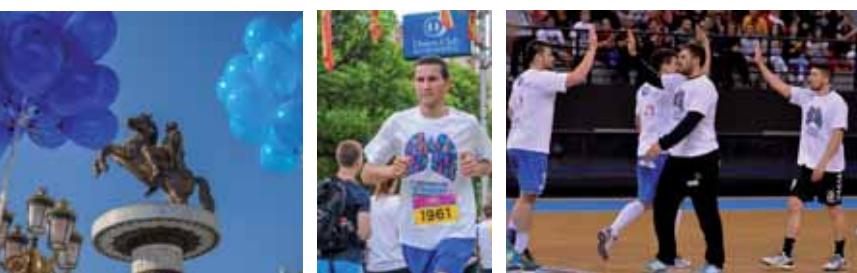
Maria Joao Saraiva
Associação Portuguesa de Hipertensão Pulmonar
www.hp.sunlive.pt - [http://on.fb.me/13sawnu](https://on.fb.me/13sawnu)





WPHD 2017 - REPUBLIC OF MACEDONIA

MARATHON, HANDBALL AND MOUNTAIN CLIMBING FOR WPHD IN MACEDONIA



This year APH Moment Plus' main WPHD event was held on the 7th of May in Skopje, the capital of the Republic of Macedonia. Our organisation was part of the 13th edition of the largest sports event in the country, the Wizz Air Skopje Marathon. This year there were over 8.500 runners from 50 countries. The large number of runners obviously attracted large audiences. Among those who ran there were many celebrities, including singers, athletes, actors, as well as doctors. The Wizz Air Skopje Marathon was organised by the Sports Union of Skopje, and held under the patronage of the City of Skopje, the EU Mission to the Republic of Macedonia and the National Agency of Sports and Youth. Our association had two participants in the 42,195 km marathon, eight in the 21,097 km half marathon and 35 in the 5 km "recreational" race. This year we decided to do something very different from last year. We invited Todor Mangarov, President of PHA Bulgaria to be with us and Todor ran the 5 km race pushing a wheelchair with me in it! Although after 2 km the wheelchair was left practically without any tires we still managed to finish the race! Just amazing! Our goal was simple: to send a message about what it is like to be a CTEPH patient after successful surgery (PEA) and what it is like to be a patient with Idiopathic Pulmonary Hypertension who does not have adequate treatment! The Wizz Air event received wide coverage: it was broadcast live support from the national MTV station, other private TV station and most popular radio stations in Macedonia and abroad. After the Skopje Marathon, handball players of the Vardar and Metalurg teams also supported WPHD. These two clubs are very famous in Macedonia and this match was broadcast live on one of the most famous TV station in our country. Vardar is now the European handball champion. Hosts and guests at the match wore our "Get breathless for PH" branded T-shirts PH. Finally I would like to thank the wonderful mountaineering societies "Green Paradise" Veles and Kozuf, who supported us again this year with new amazing achievements!

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



WPHD 2017 - RUSSIA

FIRST WPHD CELEBRATIONS FOR PHA RUSSIA "HELP AND SAVE"

PHA Russia "Help and Save" is a new association and it was therefore the first time we took part in WPHD. Our main event was in Kazan, Tatarstan Republic, Russia. There was 54 participants altogether: patients, doctors and lawyers from Moscow, Saint Petersburg, Samara, Ivanovo, Izhevsk. During the first part of the meeting we had a welcome coffee with very nice tatar traditional delicacies. This was a good opportunity to meet each other before main conference. The second part consisted of presentations and discussions with doctors and lawyers. We could call this a sort of "medical and legal school for patients".

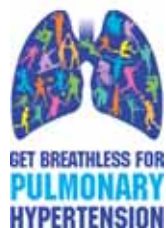
The President of PHA Russia "Help and Save" Lilya Yarullina opened the meeting. She spoke about the new association, its founding members and the first steps. In addition, she explained the association's projects and goals for the future. The next speaker was Chingis Mahmutov, the Chairman of the Public Committee of the Ministry of Health. He commended the work of patients' organisations. He gave us the very good news that some doctors, who work with PH children will shortly start to work in the hospital in Kazan. Some of these doctors came to the WPHD conference.

Our special guest at the event was Nataliya Tsareva, Professor of Pulmonology at the Moscow Scientific Research Institute. Her speech was about PH treatments, combination therapy, life after lung transplantation and pregnancy when you have PH. She also spoke about how to live a normal healthy life with PH. The next speech was from our lawyer Farit Ahmadullin. He explained about the legal process involved in the drug reimbursement process and how lawyers can help PH patients.

At the end of the event all took photos, did a nice Global Wave for PH and ended with balloons being launched in the air to symbolise the hopes of patients. Over dinner time we celebrated WPHD with invited artists. It was a very funny and warm evening for all of us. Similar events were organised in Kirov and Nijny Novgorod, for those who could not come to Kazan.

Lilya Yarullina, PHA Russia "Help and Save"
lilya-belle@yandex.ru





WPHD 2017 - SERBIA

ASTONISHING FEATS OF PHYSICAL ENDURANCE IN SERBIA FOR WPHD

The Serbian PH patient association, for this year's WPHD celebrations decided to organise several different events spread over several days, in order to try to get more attention from the media and keep the momentum up over a longer period of time. So we decided to organise four big events and to participate in several smaller ones. Two events were big and significant. The first one was the Semi-final of the Serbian Football Cup, which had more than 15.000 spectators at the stadium. The players of both teams and the judges arrived on the field wearing the WPHD T-shirts with the slogan "Get breathless for PH". The main speakers at the stadium and the TV commentator read out our long report about our global project to raise awareness of PH. The game was broadcast live and seen by about 500.000 TV viewers! Our second big event was for children, for whom we organised a "Sports day - Festival of Health" during which we addressed in the most emotional way possible a strong message about the importance of raising public awareness about rare and difficult diseases such as PH.

The remaining events aimed at getting the attention

of the public over longer period. For the first one, we formed a special team within our association and called it "Inspired by HOPE". The team was made of the best world ultramarathon runners, both male and female, who took part for us in the most difficult race in the world: the Sahara Race, 250 km through the Namibian desert. The race started on the 30th of April and ended on the 6th of May and our PH competitors had excellent results. Jovica Spajic took the second place and Marina Lazic the 7th! We chose this, certainly the toughest sports discipline, to approach the public in the most impressive and original way possible, to tell them how the everyday life of people with PH is, fighting day and night for just one more breath. Two of the most important Serbian TV channels, during all 7 days of the race, reported twice a day on our team and the mission, which ran in a specially designed equipment in the name and in the honour of all PH patients in the world, with the clear and only aim to draw the general public's attention to the existence of PH and emphasize the importance of establishing a diag-

nosis as early as possible, which is essential for the future prognosis of people with PH. Every day there were reports about the race on the most popular news stations, telling about the special significance of the mission and why the competitors were racing and that's how it was all 7 days, in 14 different news stations, so a huge audience got almost all the key information related to PH. In fact, every day we provided content for the speaker's text, a paragraph with key sentences regarding the PH and the key points. The information about PH was also picked up by several important and significant web portals including the largest and most visited portal, Sport Club. We received over 200.000 "likes" for this project, on the Facebook pages of Jovica, Marina, "Inspired by HOPE" and PHA Serbia, with a lot of comments and "shares". Over 4.000 posts and the "letters of hope" that the competitors received during the 7 days of the race. The whole nation was proud of our team and certainly there is no person who didn't have during these 7 days enormous sympathy and who didn't feel the enormous pride because we do have such people among us. You can imagine how proud Danijela and I felt!

Our other event consisted of branding with PH the main central hall of the largest shopping mall in Serbia! Large banner 5m x 3m with recognisable lungs on the T-shirt and 12 large hanging posters, with 24 key messages related to PH, were hanging from the ceiling of the central cupola, located in such

a way that each visitor of the shopping mall had to pass beside or beneath it. The branding was there for one entire month, from the 10th of May to the 6th of June. There were more than 900.000 visitors in that month in the shopping mall (an average of 30.000 per day)! Under the cupola there were every day great and important events that attracted even more visitors. We distributed more than 5.000 flyers and brochures and gave information about PH and the prognosis of people suffering from PH.

The race and the branding of the shopping mall gave us excellent results. We were invited to the most popular TV stations in Serbia and the region, but what is the most important, we were invited to meetings in the Ministry of Health and the Republic Fund. We were also invited to visit two new hospital centres because they showed interest to cooperate with our association and to establish their clinics and special PAH teams!

Our "Inspired by HOPE" team will proudly continue to run in the name of all PH patients in the world. In September they will participate in the Ultramarathon race on Tahoe 200 Endurance Run-California USA, while in October the most challenging project, the Amazonia race is waiting for us. Greetings from PH Serbia team!

Danijela Pesic and Mirko Glavinic, PHA Serbia

www.phserbia.rs

www.facebook.com/plucnahipertenzija



WPHD 2017 - SLOVAKIA

THIRD EXPEDITION TO THE TATRA MOUNTAIN TOP FOR THE SLOVAKIAN PH ASSOCIATION

As part of the WPHD campaign for 2017, PHA Slovakia organised the third climb to the peaks of Slovak mountains with the theme "I will climb for you".

The project was divided into two parts. The first part was focused on the media. A press conference took place on the 2nd of May with the participation of 28 journalists and TV editors. At the end of the press conference Slovak celebrities, popular singer Tomáš Bezdeda and the actor, singer and comedian René Štúr, planted two shrubs as a symbol of healthy lungs and invited the general public to the climbing event. On the 5th of May we conducted an information campaign at the Slovak Philharmonic in Bratislava.

The second part of the project was carried out on from May 26 to 28 in the Low Tatra mountains. The





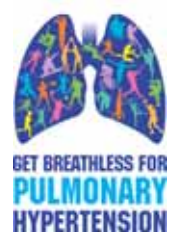
event was attended by 172 participants, including 14 patients. On the evening the day before climbing, an informative seminar was held at the Liptov Hotel in Jasna about the importance of the campaign and the illness, in which patients presented their life stories. The topic of the seminar was transplantation and PH in children. On 27th of May we left to climb the mountain Siná (1.560 m above sea level) with the motto "I will climb for you". 162 person including 3 PH patients and one patient who had undergone lung transplant surgery climbed to the top of the mountain. They carried 21 photos of patients with PH on their backback.

As a symbol of health, clean air, but especially of the the lungs, which are essential for every living organism on earth, the participants of the meeting planted 25 spruce trees, each bearing the name of a patient with PH. The motto "Grow your lungs" was really appropriate, as the surrounding forests were significantly destroyed and devastated by the construction works taking place in the neighborhood. The whole event was filmed by the Slovak television for the Televíkend TV show and the most popular commercial television Markíza for the „Reflex“ TV show, for which they have also recorded the story of a 5-year-old Matka with PAH.

We are very proud of our media coverage!

- 12 internet articles
- 2 articles in nation-wide magazines
- 1 reportage for the main news in Slovak television
- 3 reportages for the TV shows Televíkend and Reflex - currently in preparation

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



WPHD 2017 - SLOVENIA

TEAMING UP WITH THE FIREFIGHTERS FOR A HIKING DAY IN ŠMARNA GORA

For three years in a row our association has organized a running event in the nature park in Mostec, in Eastern Slovenia. The events organized there were always very pleasant and we managed to attract many participants every year. However, we never managed to get much media attention, which is why we decided to try something different this year. On the 18th of May we organized a hiking event on Šmarna Gora,

a very popular hill near Ljubljana, the capital. At 13:00 our team of patients and organizers began gathering at PGD Tacen, a firefighter association. To reach the top of Šmarna Gora an average person needs about 30 minutes and some parts of the hill are on steep terrain. Sadly it's a hike that's impossible for all PH patients. Luckily the firefighters of PGD Tacen kindly offered to drive all of our patients

and equipment to the top of the hill with their all-terrain vehicle. Some of our patients have never been on the top of Šmarna Gora, some haven't been able to make it to the top due to PH. It was a very emotional moment when we reached the top of the hill and the patients were able to see the beautiful vast view of the Alps, Ljubljana and the green countryside of Slovenia. A moment captured on video by a national news TV filming crew.

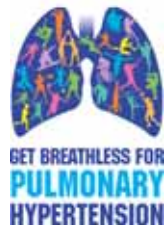
The goal of the event was to convince as many people as possible to join our team at the top of Šmarna gora throughout the day. We have invested a lot of time and effort to spread the news of our event. We even hired a PR agency to help us with our efforts. That decision surely paid off. We managed to secure a much better media coverage this year and the turnout at our event was also very satisfactory. To spread awareness of the disease we organized a 6-minute test at the top of the hill. We also handed out T-shirts to visitors that posted a "selfie" of themselves wearing our T-shirts on various social media with the hashtags "WorldPHDay" and "GlobalWave4PH".

We even prepared our own branded water bottles that were given to every participant at our event. Our team was big enough to provide quality information to everyone that wanted to learn more about PH. Many kids were present at the event and we had medals, T-shirts and pinwheels prepared for them as well.

We hired a professional photographer who made everlasting memories of the event. Three well known Slovenian athletes also participated in the event: Raša Sraka, the President of the sports committee OKS, former judoka who represented Slovenia in the Olympic games in Athens 2004 and London 2012, Petra Robnik the Secretary of the sports committee OKS, former alpine skier who represented Slovenia in the winter Olympic games 2006 in Torino, and Anže Berčič, a young and promising slalom canoeist; participant of the European championship in 2017.

Tadeja Ravnik
Društvo Za Pljučno Hipertenzijo Slovenije
www.pljucna-hipertenzija.si
www.facebook.com/PljucnaHipertenzija





WPHD 2017 - SPAIN ANHP

A SPECIAL “PH ROOM” SHOWS WHAT DAILY TASKS ARE LIKE WHEN YOU HAVE PH

The National Association of Pulmonary Hypertension of Spain took part again in the WPHD 2017 celebrations with a number of different activities. The aim of these activities was of course to increase the awareness in the general public of the symptoms, diagnosis and treatment of PH.

On the 27th of April, thanks to the collaboration of the Bohemia Association and the students and parents of the Miguel Hernández school of Getafe (Madrid), it was possible to record a video called “4 Generations “get breathless for PH”. Roughly 100 people, from 3 to 92 years of age, joined in this dance video. These persons had been given information about the PH its symptoms and characteristics. The video was published on our website and on our social media networks and other platforms on the 5th of May and now has had more than 2.000 views: <https://www.facebook.com/Hipertension-Pulmonar/videos/10156141754524676/>

On the 5th of May, we were in the “La Paz” Hospital with our “PH room” thanks to the collaboration of Actelion. A lot of people, more or less 150, private persons, doctors and nurses of La Paz Hospital participated in the activity and now they all know more about PH.

On the 6th of May in Parla (Madrid) we held the III Gala Eva García for PH. Several volunteers,

including comedians Miguel 925 and Fernando “El pelao”, singers and dancers made us have a great evening. Patricia Sanfrutos (from M80 radio) was the presenter.

The last event was the on the 27th of May when we celebrated the Charity concert of “Dones per la pau” (Women for peace)”. Before the concert, the public heard a conference about the PH symptoms and characteristics by Dr. Enric Domingo from the “Val d’Hebron” Hospital in Barcelona. The singer Lidia Pujol participated in this concert as a volunteer.

We are very proud that the news of our activities for WPHD 2017 were broadcast on Madrid’s Community public television and “Canal Metro” of Madrid (the Madrid underground is the third longest in the world and it has screens in many stations), and we have thus made a very positive contribution to raising awareness of PH in our country.

We would like to warmly thank the numerous volunteers who have contributed to the success of our activities and those who sent us their congratulations.

Eva García

Asociación Nacional de Hipertensión Pulmonar

www.hipertensionpulmonar.es

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



WPHD 2017 - SPAIN FCHP

SOLIDARITY EXPEDITION TO THE TOP OF THE IBERIAN PENINSULA

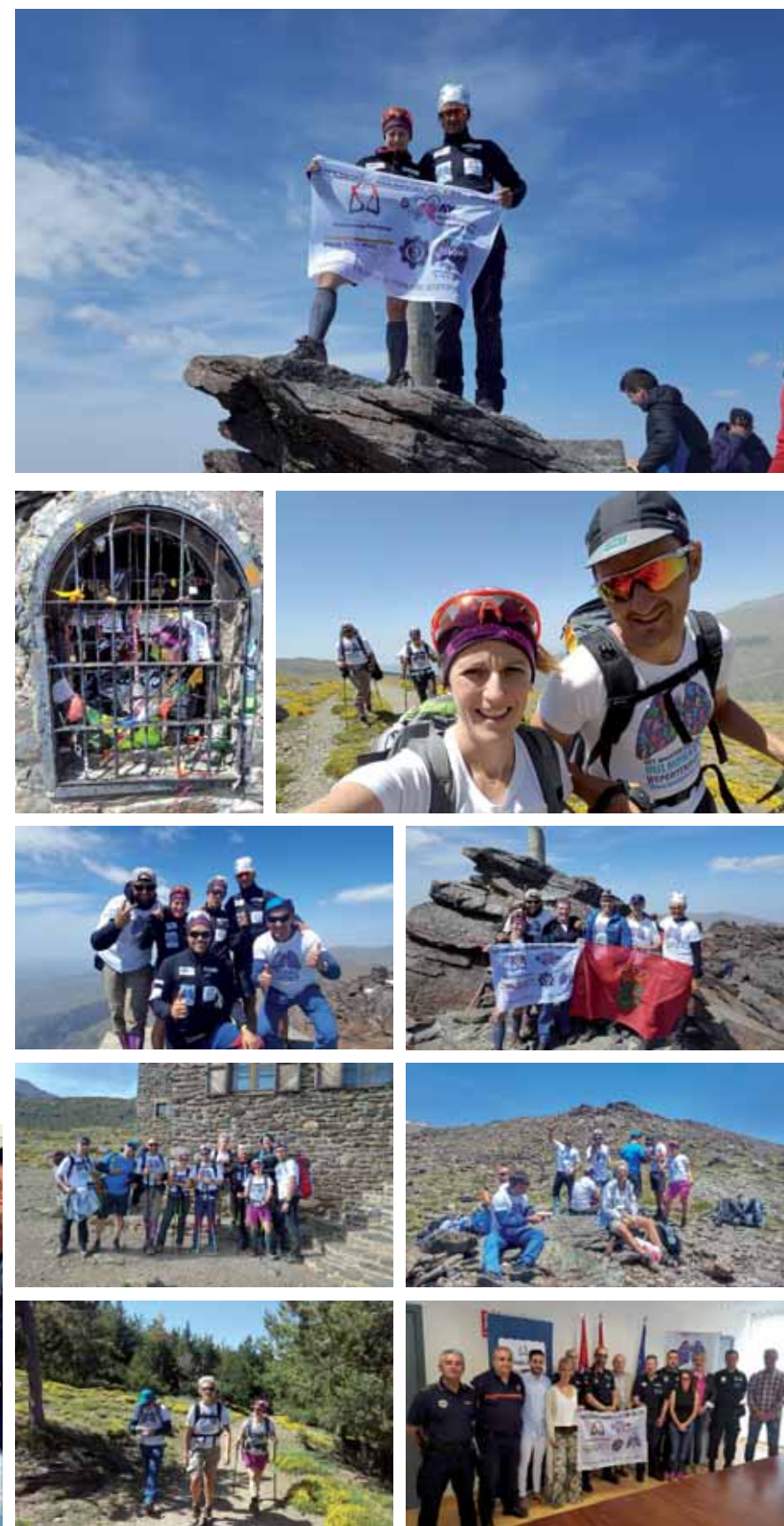
FCHP’s WPHD’s activity this year consisted in a challenging “solidarity expedition” to the very top of the Iberian Peninsula. Mulhacén is the highest mountain in continental Spain, it is part of the Sierra Nevada range in the Cordillera Penibética and the elevation is 3.479 m. Nine people in total made the ascent and the idea was that they could feel a little of the symptoms of PH, who are in many ways similar to those of people at high altitudes: headache, dizziness, difficulty breathing and walking...). Apart from being a sporting event, we wanted to complement it with information about PH so that it would also be an awareness raising activity. We are proud of the interest and recognition that this event received and we would like to thank the following people who gave us their unconditional support and contributed to its success: Mr. Luis Martínez Hervás (Mayor of Parla- Madrid), Mr. Javier Molina (Councilor for Security and Sports of the City Council of Parla), Mrs. Marta Varón (City Councilor of Parla City Council), five agents of the Local Police of Parla, D. Damian Gascón, D. Juan José Alcántara Llamas, D. Manuel Buenosvinos, D. Rafael Samper, D. Javier A. Miguélez, climber and expert in respiratory physiology Dr. Myriam Martínez Rebollo (Dr. Biomédica Martínez) and Dr. Miguel Ángel Gómez Sánchez (specialist PH cardiologist). News of our solidarity expedition was widely reported in social media networks and in the City Council of Parla and reached a very large number of people.

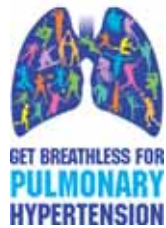
Enrique Carazo Mínguez

FCHP Fundación Contra la Hipertensión Pulmonar

www.fchp.es/es

www.facebook.com/fundacionhp





WPHD 2017 - SPAIN HPE ORG

HUMAN TOWERS AND CATALAN COUNTRY DANCING IN BARCELONA



On the 5th of May HPE-ORG Spain, with the collaboration of the Sant Feliu de Llobregat City Hall in Barcelona, organised different activities in the main square of the city. The event was supported by the Mayor of Barcelona, the coordinator of SEPAR, the Spanish Respiratory Society, Dr. Carmen Hernández and other researchers and doctors from the Hospital Clínic of Barcelona. Patients and family members came from all parts of Catalunya to take part in the event. We were very fortunate to have the participation of the "Castellers" of the city, who make "human castles", a popular tradition of the Catalan culture. The Castellers are all united by their activity of making human castles, which requires cooperation and team work, the courage to face constant challenges, as well as the hope to continue to be on the top (in the world of Castellers!). For people with PH also these principles are also valid, in addition there is the will to continue breathing.

During the event we also organised other activities including archery, a zumba class, climbing, cycling, volleyball, and a balloons release. Finally we organized a Country dance and we were able to gather about three hundred people dancing for PH, quite an achievement!

The City Council gave us an information booth to disseminate educational materials and raise awareness of PH for three consecutive days. The "PH room" was presented at the 38th Trade and Industry Fair of Baix Llobregat, thanks to the support of Actelion Farmacéutica. Dr. Barberá, PH expert from the Hospital Clinic of Barcelona, Jordi San José Buenaventura, Mayor of the city, Lourdes Borrel, Health Councilor, and Miquel Iceta, Catalan socialist politician, visited us and encouraged us with their support.

All of us at HPE-ORG are very satisfied and happy with the success of our WPHD and we are also very proud to do our bit to give a contribution to the "Get breathless for PH" campaign.

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



WPHD 2017 - SWEDEN

MULTISTAKEHOLDER MEETING IN STOCKHOLM TO DISCUSS THE FUTURE OF PH

On May the 5th, WPHD, representatives from healthcare, patient organisations, politics and the pharmaceutical industry gathered in Stockholm. The meeting was very successful and resulted in a decision to jointly draft a national action plan how to develop PAH and CTEPH care in Sweden. After the meeting we dressed up for this nice picture, all of course wearing our WPHD "Get breathless for PH" T-shirts!

Patrik Hassel, PHA Sweden
<http://pah-sverige.se/>
<http://on.fb.me/WcaOWZ>



WPHD 2017 - SWITZERLAND SPHV

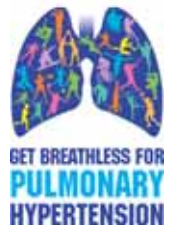
CYCLING FROM SWITZERLAND TO LIECHTENSTEIN FOR THE ANNUAL SLOWUp

On Sunday May 7, 2017 our association was present at the "SlowUp" event in Buchs, a town in the canton of St. Gallen. SlowUp is an annual cycling race. It's basically a 44 km counter-clockwise loop through Switzerland and Liechtenstein, with a connection halfway down the middle. Along the way there are several stops for games and prizes.

Full of motivation, some of our members met at the fairground of Buchs to represent our association. We were allowed to distribute some information materials and brochures about PH. Thanks to our brochures "Pulmonary Arterial Hypertension" and "PAH in childhood" we had very good opportunities to effectively inform people about the condition. Unfortunately, the weather was very rainy and there were less participants at the SlowUp than usual. Also, due to health problems, some of our registered members could not attend. However, we hope to be present again next year at the 2018 SlowUp!

Therese Oesch, SPHV
www.lungenhochdruck.ch
<http://on.fb.me/1dfRZ2B>





WPHD 2017 - UKRAINE PHA

WATER SPORTS, YOGA AND BREATHING EXERCISES FOR WPHD IN KIEV



This year PHA Ukraine organised its WPHD event in the Sports and Entertainment Complex "X-Park" on the Trukhanov Island, near Kyiv. Exactly in this park we spent our first WPHD in 2014, when we planted a linden tree with leaves in the form of a heart, to commemorate the event. At that time we had agreed to meet and visit our tree, on which the leaves-hearts should become more, not less. Just as the number of our patients would not decrease.

We spent a very nice day with our patients and their relatives, our doctors and representatives of other public organisations for rare diseases. We had sports and entertainment on the water, yoga and dance classes for our patients, with simple breathing exercises and dance moves. Also there was the presentation of a book of poetry by our patient Iryna Sydorchuk and a music show with the participation of the famous Ukrainian jazz band Ivan Blues & Friends. To end the WPHD 2017 celebrations we launched hundreds of balloons into the sky and made wishes.

A very big thank you to the patients and their relatives for coming and for their enthusiastic participation.

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



WPHD 2017 - UKRAINE SISTER DALILA

THE COLOUR BLUE AND BUTTERFLIES SET THE THEME FOR WPHD IN L'VIV

Press conference

This year our celebrations for WPHD started with a press conference on "Donation from deceased people in Ukraine" attended by Dr. Kostiantyn Rudenko, medical specialist at the Ministry of Health of Ukraine and the Deputy Director of medical and coordination work at the M.M. Amosov National Institute of Cardiovascular Surgery, Dmytro Sherembei, the head of the Coordinating Council of the All-Ukrainian Network of People Living with HIV/AIDS, a representative of the Ukrainian Church and a special guest from PHA Europe, Juan Fuertes.

Fashion show "Butterfly in Blue"

The theme of the fashion show took after the Global Wave for PH, where the butterflies symbolically represent the lungs. There were 20 models, aged 3 to 66 years, who were all are PH patients who came to Lviv from all over Ukraine. It was an outstanding event for them in their lives. Participation in this show helped patients feel and perceive themselves differently and more positively, and the public attending could see that patients with PH only differ from normal people because they find it difficult to breathe. The designers worked individually with each model, so each look was unique. All the clothes combined the blue colour and a mandatory accessory - a butterfly. This unusual show started also unusually - with the strong sound of breathing of patient with pulmonary hypertension. All patients received the outfits as presents. During the preparations our aim was to use a new positive approach to attract attention to the problems. After the fashion show there was "silent"

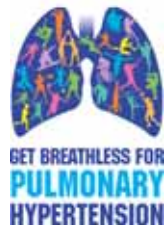
auction, which aim was to gather money for a 26-year old PH patient, who needs a heart and lung transplantation. More than 300 people took part in the fashion show including public figures, deputies, representatives of local authority, doctors and mass media.

Round Table on Organ Donation and Transplant

On May 5 in Lviv our association organised a Round Table on "Donation from deceased people in Ukraine". The aim was to discuss and determine the mechanisms of development of donation from deceased people: organizational, legal, medical, ethical and religious aspects, readiness of the society to accept donation, the international experience and to clarify the legal problems of this issue. Among the speakers there were Kostiantyn Rudenko, main cardiologist specialist at the Ministry of Health, Juan Fuertes, Board member of PHA Europe (Spain), Ondrei Dostal, head of medical and pharmaceutical practice at PrivetsterhouseCoopers (Prague), Father Andrii Lohin, administrator at Metropolitan Andrei Sheptytskyi Hospital (Lviv). At the end of the event we prepared a resolution to send to the competent authorities to intensify the development of a national transplant system! The meeting was very interesting, with a very lively debate and great enthusiasm to act together! The lack of transplantation facilities in Ukraine leads to thousands deaths of Ukrainian. We lost in those days Mariana Kizyuk, our ward who needed heart & lung transplantation.

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





WPHD 2017 - AROUND THE WORLD

USA

PHA JOINED GLOBAL CAMPAIGN TO RAISE AWARENESS OF PH AND NEED FOR ACCESS TO CARE

The Pulmonary Hypertension Association (PHA) collaborated with organizations around the world to celebrate World PH Day with activities to raise awareness of the need for better access to care for people living with pulmonary hypertension (PH). The global PH community established May 5 as World PH Day in 2012 with 22 PH patient organizations, 10 rare and affiliated disease groups and eight scientific societies endorsing it as an annual occasion for collectively raising global awareness about the disease.

The 2017 global campaign drew an unprecedented number of visitors to the WorldPHDay.org website, a central virtual location established by several PH organizations to draw people from all over the world to learn about PH and resources available through 80 global PH organizations to people living with the disease, their loved ones and clinicians. With a focus on the need to raise awareness of the importance of access to care, the 2017 global World PH Day campaign extended through the month of May. At PHA, we recognize that in many parts of the world people living with PH do not have access to the 14 FDA-approved treatments that are available in the United States. Access to care is a concern not only for adults around the globe living with PH, but also for pediatric patients in the United States - for whom there are no FDA-approved therapies. Additionally, individuals in the U.S. also face challenges in access to care.

PHA collaborated with PHA Europe and PHA Latin America to update WorldPHDay.org with



new tools to help raise awareness and make patient and health care professional resources available worldwide. Working together, each association developed an online toolkit to give people ways to share messages in both English and Spanish about the importance of awareness, early diagnosis and access to care for PH. The online outreach for World PH Day 2017 exceeded our expectations, bringing 52,622 users with 78,740 page views to WorldPHDay.org from April 18, the campaign's pre-launch date, through the end of May, compared to 2,185 users and 4,451 page views within the same period in 2016.

The global effort to support World PH Day began on April 18 with a pre-campaign Thunderclap call from PH organizations asking people in our collective social media networks to let us invite their social media friends to take part in our May 5 World PH Day outreach. The pre-launch effort gave the campaign access to 2,570,717 social media participants in 200 cities in 62 countries across six continents.

In conjunction with the global effort, PHA launched Periwinkle Hearts Around the World, a social/digital media campaign effort that targeted undiagnosed U.S. patients with a call to action to bring them to PHAssociation.org. Of note, the May 5 launch came as we began transitioning our 26-year-old PHAssociation.org web platform to a new user friendly digital mobile-accessible platform. Traffic from WorldPHDay.org accounted for some of the uptick in web traffic on the updated site where we experienced significant increases over the prior year in traffic to our patient resource pages. Periwinkle Hearts Around the World focused on raising awareness for patients with conditions associated with PH who may not be aware that they are at risk for developing the disease. PHA also sought to open a dialogue about improving PH care on Twitter and Facebook. Participants called for fewer barriers to health care coverage for life-saving treatments, greater awareness of the disease among non-PH specialists and the need for closer reliable treatment centers for the many who must travel far from home to receive quality PH care.

Throughout May, PHA continued to promote memes and digital advertising outreach informing targeted audiences about PH-associated diseases. PHAssociation.org pageviews for the month received nearly double the amount of traffic compared to the same period in 2016. We saw similar increases in our "About PH" and "PHCC/Find a Doctor" pages. The largest increase was in traffic to our local support group pages, which increased 300 percent from 2016 to the same period this year.

WorldPHDay.org provided links for people around the world to connect with local resources. The site directed people living in the U.S. to PHAssociation.org - where they found PHA's many resources, including support groups, informational materials, myPHA - PHA's patient and caregiver social networking site - telephone support lines and toolkits for those who wish to engage with others in the community to fight PH. Health care professionals found information about networking opportunities; PHA Online University, where they can earn CME/CE credits; and PHA's PH Professional Network (PHPN) Symposium, an educational gathering for PH-treating health care professionals - in and outside of the U.S. - which takes place Oct. 5-7 in Bethesda, Maryland. PHA's May awareness drive included social media, digital advertising, local fundraising and activism, and celebrity involvement. PHA advocate and supporter Don Stevenson, also known as the "Pacing Parson," completed a 500-mile walk in support of World PH Day. At 81, the retired minister and former U.S. Marine has walked a total of 5,500 miles in support of the PHA community, including a 3,000-mile journey across the U.S.

PHA celebrity ambassador Terrence J participated in the campaign through social media messaging and digital public service ads (PSAs) that included a video posted on YouTube and Facebook that has

received more than 75,000 combined views. In addition, national recording artist



and PHA celebrity champion Traci Braxton, who stars alongside her family in the WE tv hit reality show Braxton Family Values, appeared in digital PSAs. Traci's

sister, Grammy Award winning artist Toni Braxton, has lupus; her son has rheumatoid arthritis; and her sister, national recording artist Tamar Braxton-Herbert, has battled pulmonary emboli (PE), blood clots in the lungs. Researchers find that up to 9 percent of lupus patients also have PH and while rare, PH can also be a complication of rheumatoid arthritis. One form of PH, Chronic thromboembolic pulmonary hypertension (CTEPH), is believed to occur in up to 4 percent of patients who suffer from an acute PE.

The U.S. campaign ended with a Facebook Live mini-concert, on May 30, featuring PHA celebrity champion Chloe Tentchine, a YouTube sensation who has PH. The concert drew more than 1,500 live attendees - to facebook.com/PulmonaryHypertensionAssociation - who watched Chloe debut her new single, RISE. Chloe, based in Los Angeles, Calif., has battled PH for about nine years. Propelled to YouTube fame as a vocalist, guitarist and pianist, she performs tethered to an oxygen canister, which she has affectionately named Steve Martin. She was misdiagnosed for five years before officially being diagnosed with PH on March 4, 2013. Her 30-minute concert and question and answer session has received more than 5,000 views. During the live event, more than 239 people commented or asked questions, and an additional 234 people engaged with PHA with "likes", "loves" and Facebook emoji. More than 90 people shared the social media event with their friends.

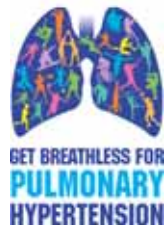
We are grateful to PHA Europe, PHA Latin America and all the global organizations that made this year's World PH Day a success.

Brad A. Wong, President & CEO
Pulmonary Hypertension Association (USA)

<https://phassociation.org/>

https://www.facebook.com/pg/PulmonaryHypertensionAssociation/about/?ref=page_internal





WPHD 2017 - AROUND THE WORLD

LATIN AMERICA PH LEADERS FROM LATIN AMERICA MEET IN PERU TO CELEBRATE WPHD

On May 5, 2017, the Latin Society for Pulmonary Hypertension (SLHP) celebrated World PH Day, Día Mundial Hipertensión Pulmonar, at the Foresta Hotel, Lima, Peru. The event was coordinated by the SLHP (presided by Migdalia Denis) and the PH association of Peru, AHPP (directed by Cancio Espinoza). This important event, which is held every year, was sponsored by Bayer, Actelion and Novartis. During the meeting, a group of Latin American PH Leaders, as well as patients and relatives from Peru, shared experiences and acquired skills and knowledge to take back to their respective organisations.

In the Auditorium of the Naval Medical Centre Surgeon Major Santiago Távara, two activities were carried out simultaneously.

One of the activities focused on the celebration of WPHD with lectures on PH, followed by a question and answer session and concluding remarks.

The other activity consisted of the “Market access SLHP Workshop”, aimed at Latino leaders, to

strengthen capacities and train high-impact leaders to influence national agencies.

- Module I: Present and Future of Market Access.
- Module II: Identifying Objectives for Action.
- Module III: Communicational Synergy and Conflict Management.

The Workshop was led by José Josan and Migdalia Denis, included the program of the event details the aspects developed in both activities.

The participants in this significant meeting expressed their satisfaction for the joint, constructive, solidaristic, pluralistic and inclusive work for the benefit of the patient organisations of Latin America.

As part of the activities to celebrate WPHD, and using the slogan “Together We Are More”, the PH patient associations and support groups of Latin America carried out various activities in each country.

The SLHP sends a message of support and thanks to all those groups that worked with dedication and effort for this celebration.

Migdalia Denis

Sociedad Latina de Hipertensión Pulmonar

<http://www.sociedadlatinahp.org/>

www.facebook.com/www.sociedadlatinahp.org?ref=ts

ref=ts



USA

PHAWARE JOINS WPHD WITH NEW FEATURES FOR ITS PHAWAREAPP365!

This year, phaware global association and PHA Europe invited PH community members from around the world to share their photos and selfies taken during the celebrations for WPHD. A variety of awareness stickers and PH facts were added to the phaware365 Global Selfie app. Users snapped selfies, decorated their photos, customized them with WPHD stickers and PH facts and shared their #WorldPHDay photos on Facebook, Instagram, Twitter and on the app's phaware365 Global Selfie Stream. In the weeks leading up to WPHD usage of the app jumped from 25+ daily sessions to 100 to 250 daily sessions! There are over 500 “active devices” (iPhone and android) currently using the phaware365 app, of which 240 were identified as “new” that downloaded it in April/May - which can be attributed to this WPHD push. There were over 2.000 sessions, (meaning how many times a user went in to decorate a photo, in April and May). Many members of PHA Europe were also featured during April and May on the phaware® podcast. Search #WorldPHDay on phaware's podcast page to hear stories from: Spain, Norway, South Africa, Serbia, Latvia, Ukraine and Italy! Phaware also arranged for their “I'm Aware That I'm



Rare” PSAs to run in over 80 Galaxy movie theatres and IMAX screens throughout the month of May in selected cities in California, Nevada and Washington, beginning on WPHD. The objective was to raise awareness of PH to movie goers during one of the biggest movie months of the year.

Steve Van Wormer, Co-Founder & President
phaware global association

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

www.phaware.global/phaware365

www.phawarepodcast.libsyn.com

REST OF THE WORLD



We are really delighted that so many countries across the world celebrated WPHD 2017, here are just a few posts picked up from social media from South Africa, Canada, Australia, Singapore, UK... We apologise in advance if we have missed anyone! We also thank the amazing athletes who race under the Team PHenomenal Hope banner to fight PH around the world.



MEDIA CLIPPINGS

AUSTRIA



IRELAND



GERMANY



LATVIA



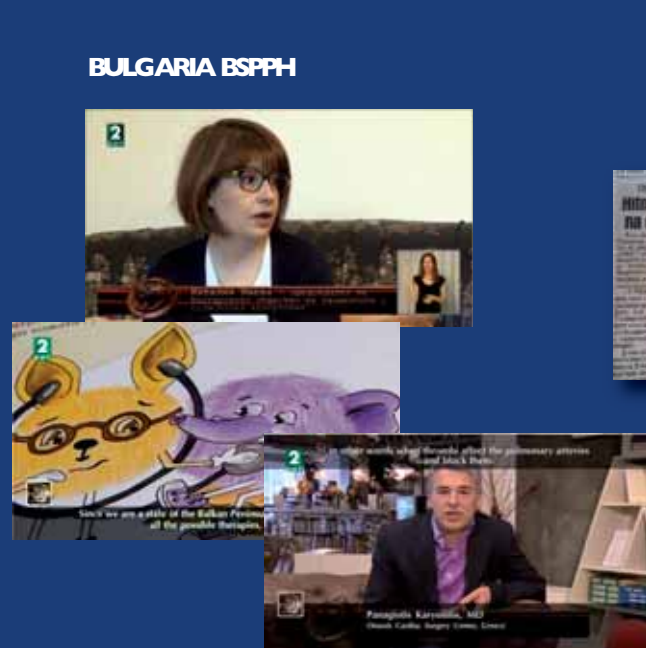
ITALY AMP



ITALY AIP



BULGARIA BSPPH



BOSNIA AND HERZEGOVINA



GREECE



ISRAEL



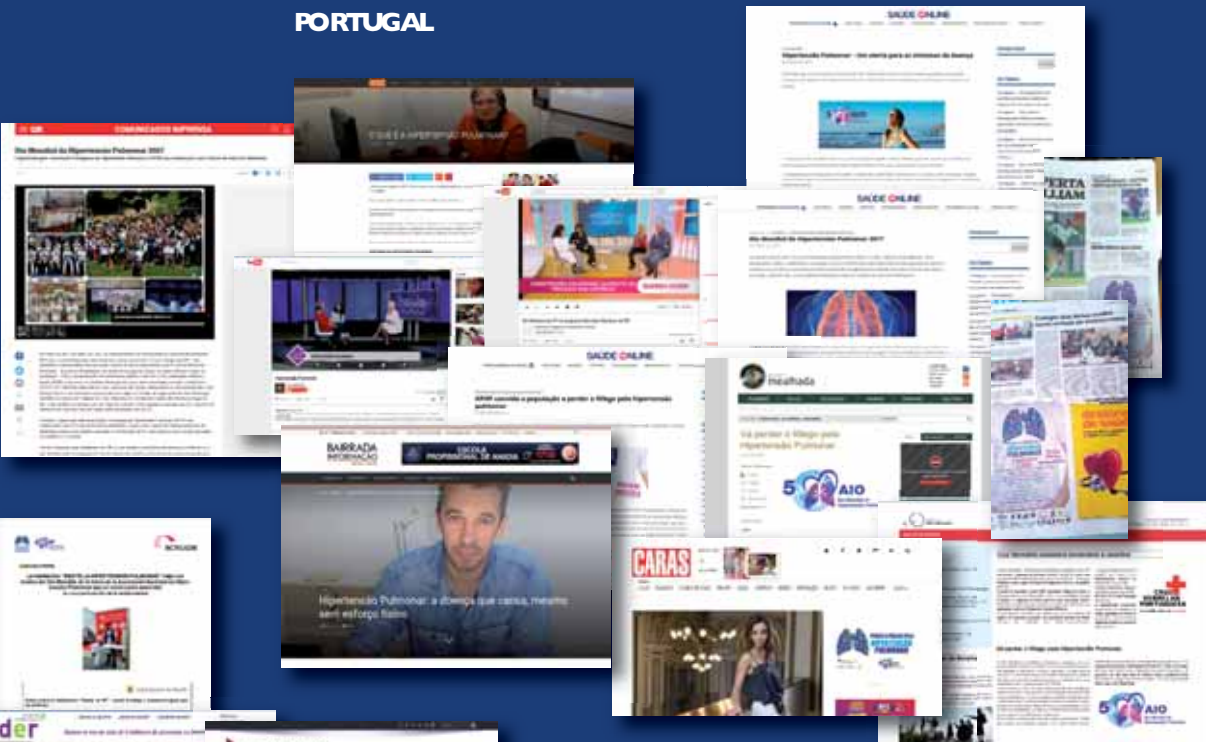
CZECH REPUBLIC



REPUBLIC OF MACEDONIA



PORTUGAL



POLAND

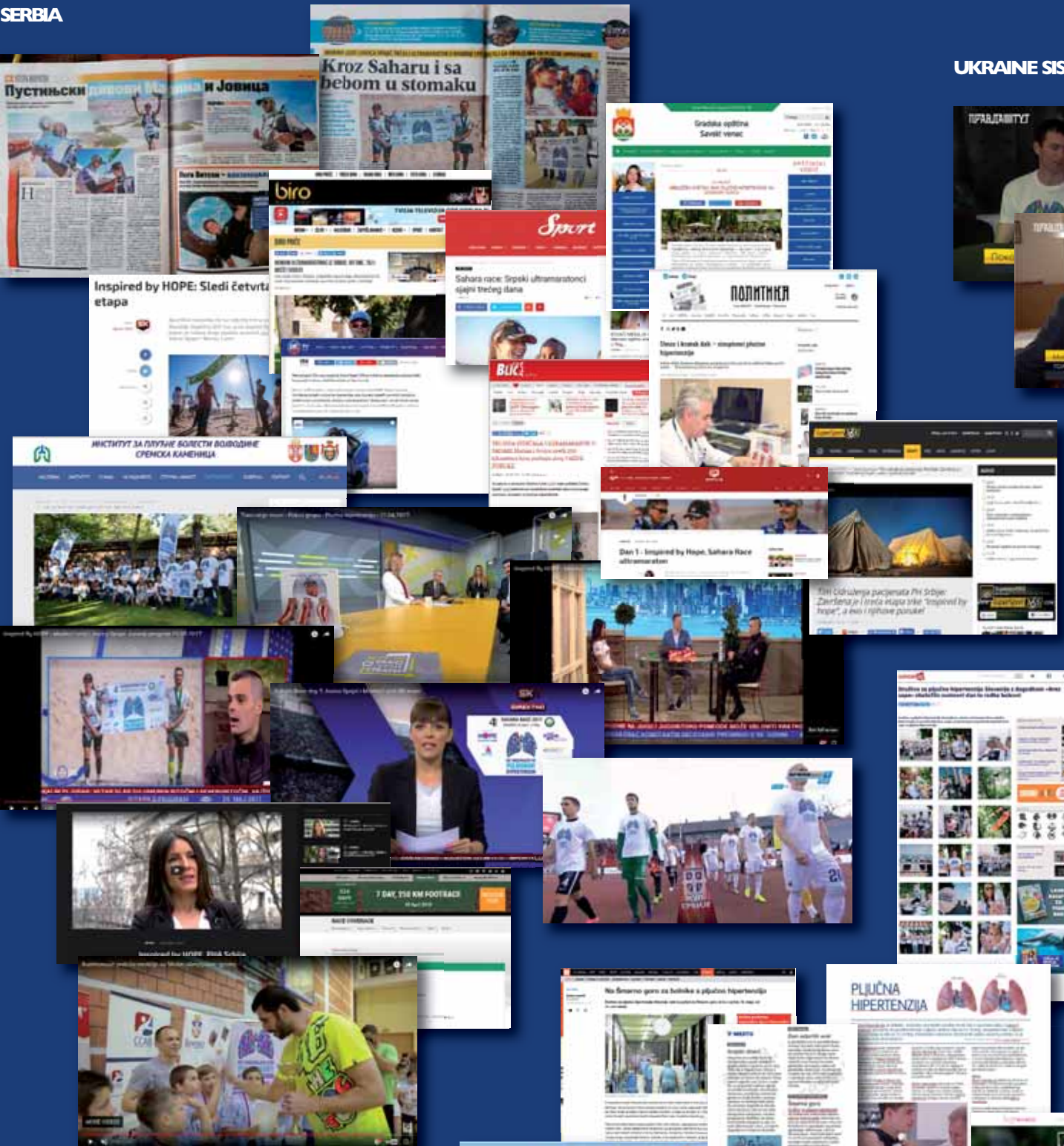


SPAIN ANHP

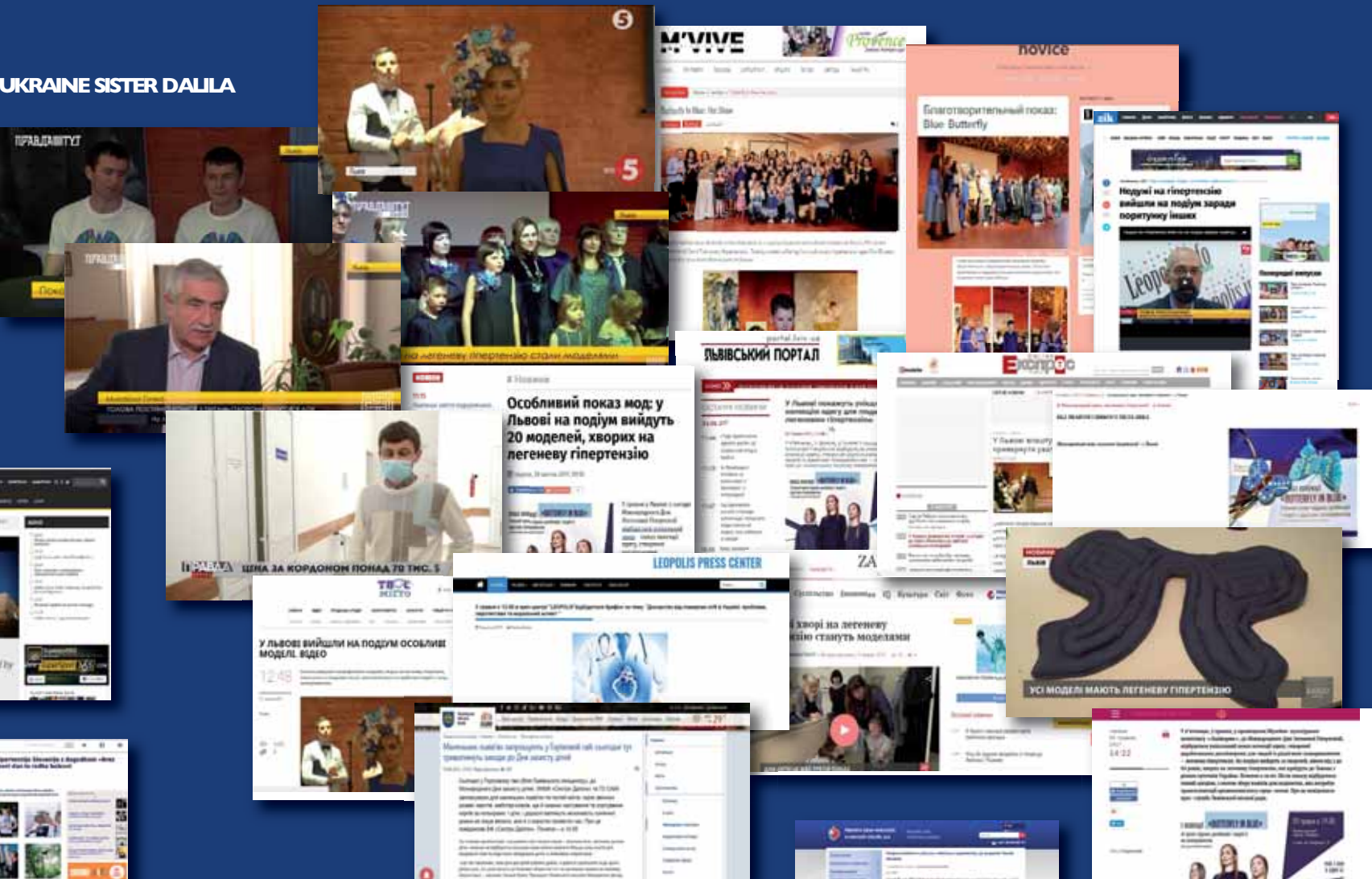


SPAIN FCHP

SERBIA



UKRAINE SISTER DALILA



SLOVAKIA



SLOVENIA



THE BEST WPHD VIDEO CLIPPINGS
FROM AROUND THE WORLD

AUSTRIA

<https://youtu.be/0Ie5W0YWcTI>



BELGIO, VZW

<https://www.facebook.com/clubbrugge/videos/10155368162983254/>



BOSNIA AND HERZEGOVINA

<https://www.youtube.com/watch?v=cVQpiBZU0d0>



BSPPH BULGARIA

<https://www.bnt.bg/bg/a/bez-barieri-kak-se-lekuva-pulmonalna-khipertoniya>



BSPPH BULGARIA

<https://www.bnt.bg/bg/a/intervyu-s-yoanna-alisandrata>



BSPPH BULGARIA

<https://www.bnt.bg/bg/a/intervyu-s-d-r-panayotis-kariofilis>



HUNGARY

<http://bit.ly/2vpCrSq>



IRELAND

<http://bit.ly/2uRF0Co>



PORTUGAL

<https://www.youtube.com/watch?v=K61vFU5J-sw&feature=youtu.be>



SPAIN ANHP

<https://www.facebook.com/Hipertension-Pulmonar/videos/10156228560639676/>



SPAIN ANHP

<https://www.facebook.com/Hipertension-Pulmonar/videos/10156141754524676/>



SPAIN FCHP

<https://www.youtube.com/watch?v=U3yTEoStqJM&t=105s>



SPAIN HPE

<https://www.youtube.com/watch?v=Jpt1aj68w90&feature=youtu.be>



REPUBLIC OF MACEDONIA

<https://www.youtube.com/watch?v=hnZDhK07A3Y>



COLOMBIA

<https://www.facebook.com/Achpa.co/videos/1579764452042424/>



SOUTH AFRICA

https://www.facebook.com/pha.southafrica1/videos/1853277354936837/?h_ref=ARSmq3ArQCO7_ixFOAcv3aYi0dXgK3DxTOY9LoNmgm2bjvEAnk-EVYQhee_oPOqcAmY



BE PHENOMENAL

<http://bit.ly/2wdITAi1>



Members of PHA Europe and contact details

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BELGIUM



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VZW Pulmonale Hypertensie (vzw PH België)
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BOSNIA AND HERZEGOVINA



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LATVIA



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POLAND



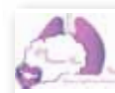
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PORTUGAL



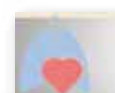
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FCHP Fundación Contra la Hipertensión Pulmonar
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<https://www.facebook.com/fundacionhp> -
<https://twitter.com/fundacionhp>

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President: praesi@lungenhochdruck.ch
Webmaster: bossard@lungenhochdruck.ch



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www.saph.ch/SuisseRomande
President: lydia_mb@bluewin.ch
Coordinator: monika.sorgemaitre@hcuge.ch

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Pulmoner Hipertansiyon Derneği
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UKRAINE



Pulmonary Hypertension Ukrainian Rare Disease Association-PH URDA
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kulish609@gmail.com



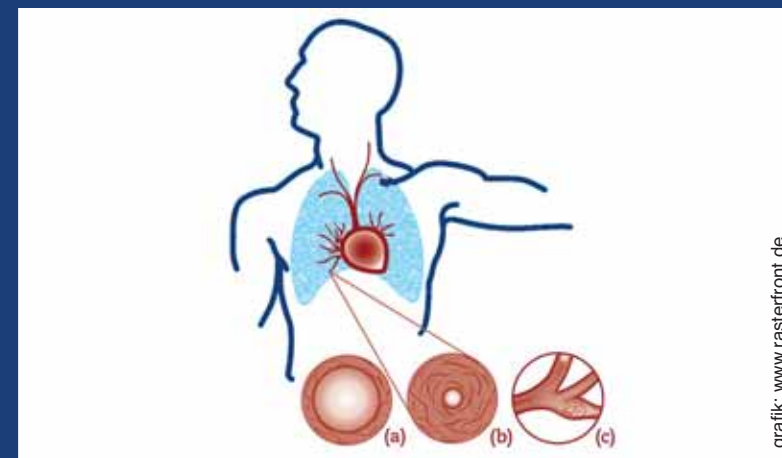
Ukraine Association of Patients with Pulmonary Hypertension
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www.pha.org.ua - info@pha.org.ua

AIMS OF PHA EUROPE

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

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

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



- a. Cross section of normal pulmonary artery
- b. Reduced lumen of pulmonary vessels due to cell proliferation and remodelling in advanced Pulmonary Arterial Hypertension
- c. Longitudinal section with pathological changes within the vessels proliferation, deposition of blood clots, thickening) causing difficulties for the heart to pump blood through the lungs

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

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

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

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

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