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Celebrating WPHD in Belarus

"GETTING BREATHLESS FOR PH" CAMPAIGNS FOR WORLD PH DAY 2016!

PHA EUROPE
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Editor's memo
Summer 2016 edition

Dear members, supporters, friends and families,

the Summer Mariposa is here! This year more countries than ever participated in World Pulmonary Hypertension Day (WPHD), with each patient association hosting inspiring events to show their support for patients around the world. In this special edition of the newsletter, we will take you on a tour of all the amazing events that were organized for WPHD this year.

WPHD 2016 saw a wide variety of activities including the 'Get Breathless for PH' campaign, which aimed to increase understanding of important PH symptoms, and the #BreathofSuccess social media campaign, a celebration of positive stories from the PH community, with a focus on chronic thromboembolic pulmonary hypertension (CTEPH). Numerous #BreathofSuccess stories were shared online, not only by patients with CTEPH, but also by a wider audience who shared their hopes and wishes for CTEPH patients.

A record 30 European PH patient associations held 'Get Breathless for PH' and #BreathofSuccess activities this year! The innovative events ranged from a Viking Splash Bus tour around Dublin to an international backwards sporting event in Oslo. To help us raise awareness and fly the flag for PH patients around the world, our member associations enlisted the support of world famous figures from the participating countries. In Bulgaria alone, we were lucky enough to have soprano Christina Angelakova as well as the Minister of Health Petar Moskov and the Minister for Sports Krasen Kralev.

This year, to help the patient associations share their message of hope, we developed 'Get Breathless for PH' and #BreathofSuccess customizable e-postcards and made them available to download from the PHA Europe website. Over 200 people downloaded the e-postcards, to raise awareness of PH in their own countries. We are exploring the option of providing a WPHD 'Thank you' e-postcard for sharing with patient groups, as well as promoting the e-postcards via PHA Europe Facebook and Twitter channels. Stay tuned for updates!

For the first time ever, we launched two Thunderclap social media campaigns on 5th May: one sharing a message globally from PHA Europe and the second coming from the Latin American PH Society. An amazing 457 supporters signed up to send out a coordinated WPHD message in Europe, which read: "I am supporting #WPHD May 5 to show solidarity with pulmonary hypertension patients who struggle to breathe". This message achieved a social reach of 533.069 people. A further 500 people supported the WPHD Latin American PH Society Thunderclap, which reached an amazing 2.473.423 people. In total, these inspirational messages reached over 3 million people around the world, a fantastic result!

Our member associations are always developing new ways to raise awareness of this devastating condition. This year, PHA Europe took its first step into digital communication, by speaking to the PH audience via Facebook. We were able to identify those who were already having conversations about PH and provide them with more information on how they could be part of WPHD. Over 4 million people saw our adverts, which encouraged over 35.000 people to visit the pages of local patient associations to learn more about our activities.

PHA EUROPE
European pulmonary hypertension association

As a result of the great work of our member associations, so far, in Europe alone, we have generated an impressive 218 press and online articles, 106 TV broadcasts and 20 radio broadcasts, across 23 countries. The PHA Europe website saw a high rise in engagement between April and July, including over 6.000 people visiting the website for more information and over 7.000 visits to the 'What is CTEPH' page after viewing the PHA Europe Facebook page on their mobile. The PHA Europe Facebook page saw even better results, with the Facebook content reaching over half a million people and over 5.000 people liking, sharing or commenting on the WPHD posts. As a result, the PHA Europe Facebook page now has an impressive 8.809 likes - a great result.

WPHD activities also took place in Australia, Asia, North and South America, so that in total 47 patient associations across all continents contributed to spreading awareness!

As I end this note, I want to express my gratitude to all those who helped make this WPHD the most successful yet. It is vital that patients are diagnosed early and treated at expert centres, and that research into improved treatments for this rare and often-overlooked condition continues. Thanks also to Bayer Healthcare, MSD and Actelion, whose partnership and dedication has helped to achieve the most successful WPHD since its inception as well as to all our other industry partners for their continuing support to our association.

Finally I would like to thank Regina Prenderville for the excellent and very inspiring summary of the recent PHA International Conference in Dallas, the largest and most important event of the year in the field of PH.

Pisana Ferrari
CEO PHA Europe

CONTENTS

WPHD 2016 - AUSTRIA

AUSTRIA BOUNCES IN BUBBLES FOR WPHD

To mark WPHD 2016, the Pulmonary Hypertension Association of Austria hosted a “Bubble Soccer Tournament” which was attended by over 200 people! The day included an under-16 tournament and an adult knock-out tournament, with six teams playing in inflatable “Get Breathless for PH” branded bubbles. The match was a great success with many spectators watching the humorous game of football. Participants could also visit the booth on the day which provided “Get breathless for PH” t-shirts, lollies and information on PH for the large numbers of visitors and supporters. The day ended on a high with a tombola competition and prizes donated by a number of local companies.

The PH Association also organised a Zoo Run as another fun and engaging way of raising awareness for PH patients around the world. The run included a 6 km course which gave runners the unique opportunity to run through some of the oldest zoos in Europe, with the animals as the spectators. The first of its kind, the event was watched by many and saw 1.800 starters.

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







WPHD 2016 - BELARUS

BREATHLESS BELARUSIANS SPREAD THE PH MESSAGE

The main event to raise awareness of WPHD in Belarus this year took place on 4th July in a park in Minsk. People gathered in the park and were given information about PH, as well as seeing a hip-hop flashmob organised by children’s dance group CCT City Dance. Everyone present received a flyer containing further information about the condition. The event was covered by tut.by, the leading Belarusian/Russian-language web portal in the country. This allowed the message to spread beyond the people who attended and raise awareness of PH across Belarus.

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







WPHD 2016 - BELGIUM VZW

HTAP Belgique get active for WPHD

In Antwerp on 5th May a range of engaging sporting activities were held in order to raise awareness of pulmonary hypertension on WPHD. The first of the events was a five-a-side football match played by children. All of the children wore WPHD t-shirts and were awarded medals for their efforts by the real football players from KVM, a local football team. Three days later a hockey match was held for WPHD, with all of the participants sporting their WPHD t-shirts. A midsummer night's 5km, 10km and 15km run was held around Gent, a beautiful city in Northwest Belgium. The event was organised by Gent Loopt and was a great success with over 5.000 runners taking part. The final event to mark the special day was the Milcobel run, supported by 50 runners wearing "Get breathless for PH" t-shirts. Twelve of the participants even won places to go on an amazing trip on the Rupel to sail in the lovely Ostend region.

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

WPHD 2016 - BOSNIA AND HERZEGOVINA

A Breath of fresh air for Bosnia and Herzegovina

BREATH (Udruženje građana oboljelih od plućne hipertenzije "DAH"), the PH patient association in Bosnia and Herzegovina, marked WPHD with a range of activities to raise public awareness of the condition. First aid classes were held in schools across Zaridovići in partnership with the Red Cross. These classes focussed on educating people on the symptoms of PH, and students left with a much greater appreciation of the impact of the condition. Afterwards, an exhibition match was then held in the town between women's handball champions HZRK Gude-Autoherc and the local team, ZRK Krivaja Zavidovići. This exciting game included a well-received half-time presentation on PH from Vera Hodzic, president of the PH association BREATH.
Meanwhile, people across Bosnia & Herzegovina came together for an open-water rafting event on the beautiful river Krivaja, with the help of volunteers wearing "Get Breathless for PH" shirts. This annual tradition of open water rafting has a high profile in the area and the involvement of all the volunteers, and their knowledge of PH, helped to bring awareness of the condition to an even greater number of people.
BREATH volunteers are proud to announce that WPHD was a success, and one they hope to carry on with in their ascent of Mont Blanc in July and Kilimanjaro in August - taking on some of the most treacherous mountains in the world!

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

GET BREATHLESS FOR
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WPHD 2016 - BSPPH BULGARIA

BOUNCING FOR BULGARIA - CELEBRATING WPHD!

The Bulgarian Society of Patients with Pulmonary Hypertension joined the global PH family in celebrating WPHD on 5th of May this year.

Olympic heavyweight boxing bronze medalist Tervel Pulev, world-famous mezzo soprano Christina Angelakova and TV presenter Mira Dobreva supported the "Get Breathless for PH" campaign in a TV spot shown on BNT and BNT 2, the two main channels from Bulgaria's state broadcaster. The 30-second interview was aired 20 times throughout the day, starting in the morning and ending in evening prime-time.

The spot was also uploaded to YouTube (www.youtube.com/watch?v=G5Hi2E4_LfE) and Facebook (www.facebook.com/BSPPH.Bulgaria), where it served as the centre piece of a social media campaign to raise awareness of pulmonary hypertension, as well as support and encourage patients with the condition.

The Bulgarian PH Society also organized a Kangoo jump session in association with the government and various patient associations, where 50 participants exercised wearing special low-impact exercise shoes. As well as getting breathless to increase awareness of PH, participants watched a live Skype interview conducted with Natalia Maeva, chair of the Bulgarian PH society, shortly after her recent lung transplant surgery in Vienna. The event was promoted nationwide by a number of media outlets and had the support of Dr Petar Moskov (Minister for Health) and Krasen Kralev (Minister for Sport). In the evening, The Bulgarian Palace of Culture was illuminated in purple in support of WPHD. Altogether, the events were reported in 14 articles and interviews on the radio, in newspapers, on TV and in online media.

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

GET BREATHLESS FOR
PULMONARY
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WPHD 2016 - PHA BULGARIA

BULGARIA'S TOUR OF HOPE FOR WPHD

For WPHD this year, Todor Mangarov, Chairman of the Bulgarian Pulmonary Hypertension Association and a CTEPH patient, cycled 3.200 km across Africa. This mammoth bike ride was to raise awareness for PH patients and show that a dream could still be possible despite a diagnosis of PH. Todor's epic journey criss-crossed Djibouti, Kenya, Tanzania and Malawi. To "Get breathless for PH" he took in stony deserts, passed through the Equator and finished at the coast. Well wishers, including local government and embassy officials, the media and the police, cheered him on his way.

Todor underwent surgery in 2011 which gave him the hope to perform such a feat. The journey highlighted that with early diagnosis, modern treatments and reliable monitoring, PH sufferers can lead normal, active and fulfilling lives.

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

WPHD 2016 - CROATIA

Croatia rules the waves for WPHD

On the 5th May, for WPHD, members of the Croatian Pulmonary Hypertension association went live on Open Radio to share their story of living with PH with a smile on their face, even with a difficult diagnosis. They talked about the symptoms of PH, how to diagnose it and the treatment options. Open Radio inducted them into their "Register of Happiness" as an example of people who fill the lives of others with positivity, despite their own problems.

On 17th May, Croatia PHA were once again on the airwaves with Radio City and handball coach Hrvoje Pekera to promote their upcoming handball tournament for PH on 22nd May. They educated listeners about PH and promoted the tournament under the motto "Stay out of breath for PH". The tournament was attended by over 100 players from teams around the country. The event was very popular with players, coaches and supporters who were all informed about PH. With the teams coming from all over Croatia, the hope is to spread awareness of PH across the country.

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 2016 - CZECH REPUBLIC

Czech Republic brings pulmonary hypertension to the "fore"!

WPHD 2016 celebrations in the Czech Republic teed off at the Mladá Boleslav golf course in Bohemia, where 34 golfers played a round of golf in aid of the Czech PH association. The event was attended by 76 participants altogether, including Czech actors Sabina Laurinová and Miroslav Šimůnek. The event was also attended by the notable Professor Tomáš Zima, Principle of Charles University, and his wife Dr Marek Šetina; Professor Lindner Jaroslav; Professor Svačina Stěpán and Professor Jiri Homolka – whose wife, Marcela Augustova, won the contest for the longest drive.

The event was a great success and was reported on Prima TV, a major national TV channel in the Czech Republic, raising the profile of pulmonary hypertension across the country.

Martina Adamová
Sdružení Pacientů s Plicní Hypertenzí
www.plicni-hypertenze.cz
www.facebook.com/Sdružení-pacientů-s-plicní-hypertenzí-518282501540862





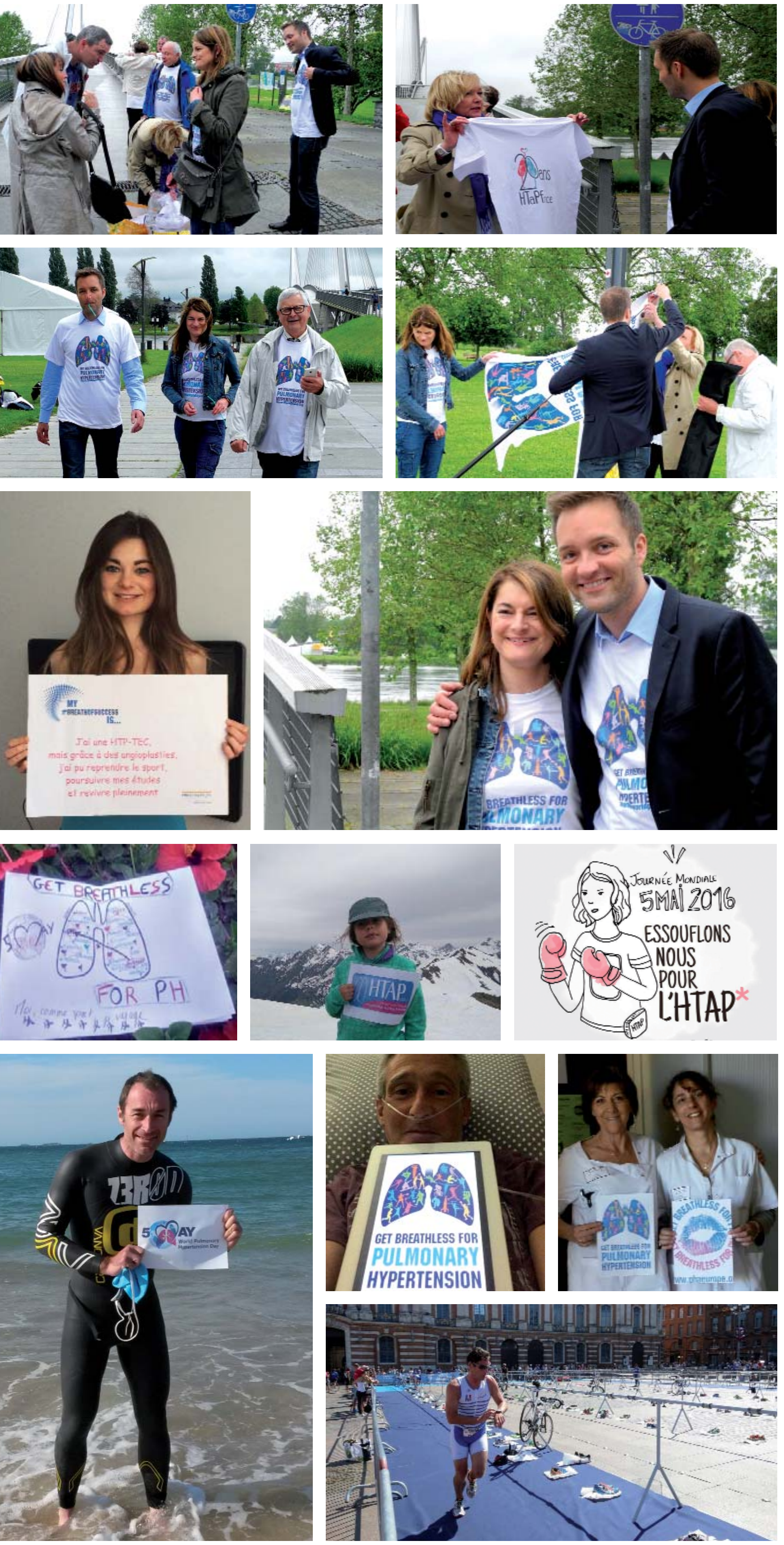






WPHD 2016 - FRANCE

French volunteers strive for a better life for PH patients



For WPHD 2016, HTAP, France's PH association, centred its activities around two online campaigns – one focusing on chronic thromboembolic pulmonary hypertension (CTEPH) and the other on PH in general.

The 'Get breathless for PH' campaign involved scores of PH patients and healthy volunteers, who sent in pictures of themselves 'getting breathless'. This highlighted the contrast between the levels of activity that patients can achieve when compared with healthy volunteers.

The #Breathofsuccess social media campaign for CTEPH asked patients to send in positive stories of living with the condition. Several patients were identified by the association through this activity. One example was 21-year-old student Alexia, who previously required a wheelchair for mobility. After a successful angioplasty, she has been able to go traveling on her own this year – a serious 'breath of success' and an inspiration for PH patients everywhere!

To celebrate 20 years of partnership with the German PH Association – the other oldest association in Europe – a joint event was held in Strasbourg, where participants could take a 6-minute walk test wearing a nose peg to simulate the symptoms of PH. The two associations hope to carry on their successful partnership for the next 20 years and beyond!

On the same day, an 'aquathlon' took place in Carantec, Britanny, where a PH booth was curated by the organisers to raise awareness of the condition. The organiser of this booth was competing in the first of five races he plans to complete in the next 5 months for PH, in honour of his daughter's friend who was born with PH. The next day, the girl died from a complication of an operation – a stark reminder of the acute need that still faces patients with PH.

Finally, on 19th June, teams from HTAP France and Hôpital Marie Lannelongue joined together to run 'La Course des Héros', a charity race in Paris. The teams included post-transplant patients, carers, surgeons and nurses – a beautiful symbol of the collaboration needed to tackle PH!

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

WPHD 2016 - GERMANY

Rolling on the Rhine and around the Nürburgring for WPHD

As part of WPHD 2016 public events and sporting activities took place across Germany. The events aimed to highlight the level of effort required to live with pulmonary hypertension, as well as to raise public awareness of this disease.

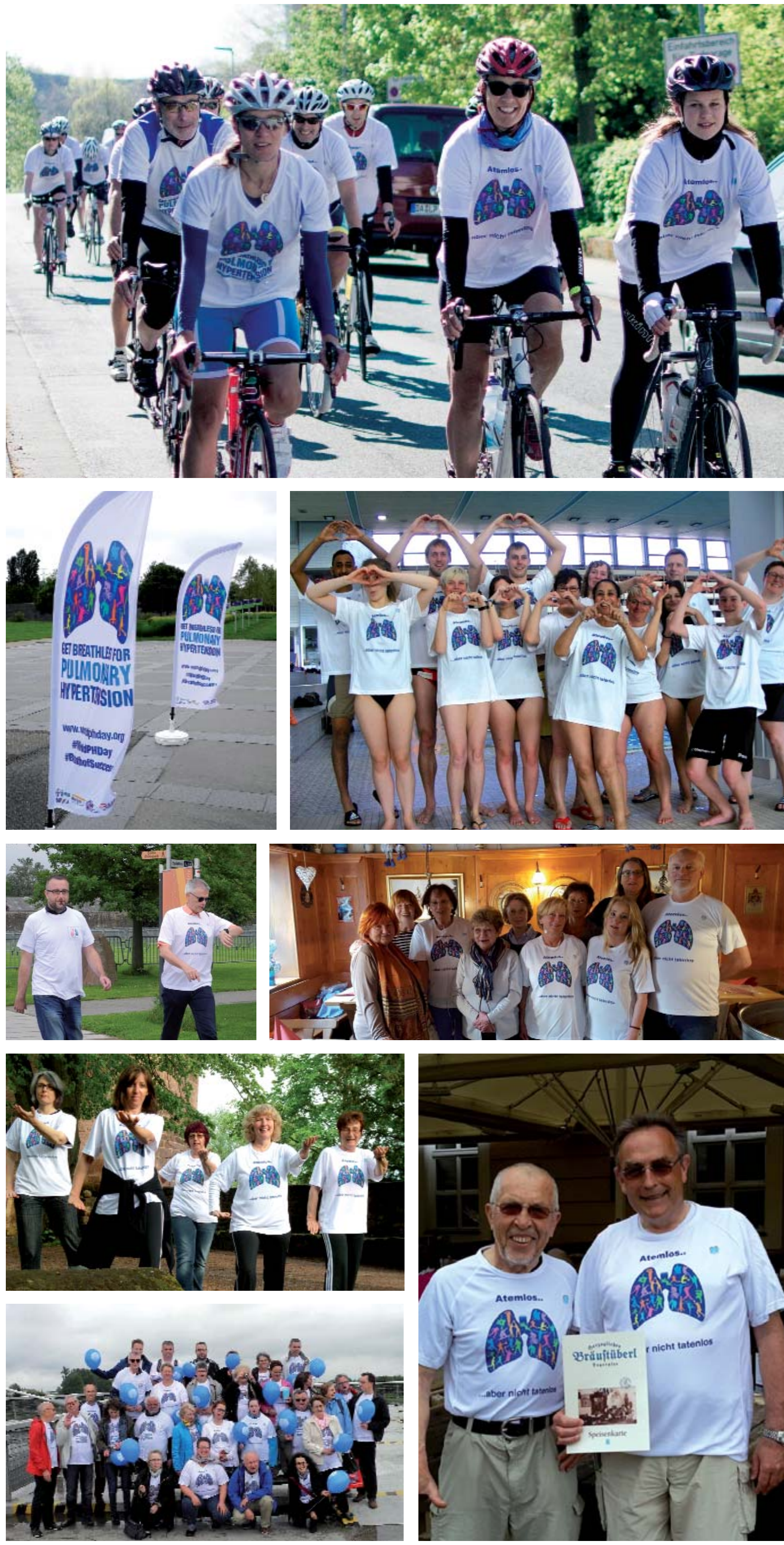
The German PH Association organised a joint event with their sister association in France, HTAP France, to raise awareness in in the picturesque cities and towns along the border. They met on the elegant Passerelle double bridge over the River Rhine, a very busy thoroughfare used by pedestrians and cyclists to avoid motorised traffic. The campaign focused on pedestrians, offering brochures containing information about PH and offering them to take part in a 6-minute walk test to help them understand the difficulties facing PH patients.

On the day, a 'Pulmonary Hypertension Bike Ride' took place in Roßdorf, near Darmstadt. The road tour was organised by triathletes Katrin Hetebrügge and Axel Schauf from Roßdorfer skiers. In total, twenty five athletes took part, to raise awareness and funding for the condition. The group posed for photos, wearing WPHD t-shirts, before beginning the bike ride. Cyclists prepare to 'get breathless' for WPHD!

The organisers, whose five-year-old daughter Greta suffers from idiopathic pulmonary arterial hypertension (IPAH), were pleased with the many participants that got involved. Katrin and Axel also plan to take part in a gruelling 24-hour cycle race around the famous Nürburgring, which they hope will raise even more awareness of the condition. Greta's parents are German ambassadors for the American 'Team Phenomenal Hope' – an organisation made up of runners, cyclists and triathletes which has hosted various sporting events in the United States to raise money for the treatment of pulmonary hypertension. The launch at Nürburgring is the German Association's first launch.

The events received very positive coverage in Air and Lung magazine, and Katrin and Axel hope to replicate this year's success in 2017!

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



WPHD 2016 - GREECE

Greek heroes help show the “Invisible Patient” for WPHD

Greece supported WPHD by running and cycling to “Get Breathless” for the PH patient.

On WPHD, the fourth annual cycling event took place in front of the Academy of Athens. A happy crowd joined Olympian Lampros Papakostas in the race and released purple hot air balloons at the end of the day. At the same time, enthusiastic volunteers handed out information about PH and the “Invisible Patient” to the general public in Monastiraki and Aristotelous Squares. Posters of the “Invisible Patient” were also placed around the squares.

The Greek Pulmonary Hypertension association held a photoshoot of PH patients and caregivers in the King’s Estate in the Parnitha Mountains. The patients wore white masks to represent the invisible sufferer who is not socially recognised in his daily struggles with PH. The images by photographer Labrini Sotiriou were powerful and received a lot of public attention.

Along with events around WPHD, the Run Greece marathon, a collection of six races across Greece, helped the PH cause with teams supporting “Get breathless for PH,” which represented a PH patient’s daily struggles. Every competitor finishing the race received an information leaflet on PH in their goody bag.

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

WPHD 2016 - HUNGARY

Breathless for PH at Lake Balaton

For WPHD 2016 PHA Hungary held several different activities to raise awareness of PH. To start with, a series of educational interviews were broadcast on two Hungarian radio programs. The top PH Medical expert in our country, Dr. Kristof Karlocai, took part in these interviews and thus had the opportunity to speak about WPHD, about the ‘Get breathless for PH’ campaign theme linking sports activities to the challenges of everyday life for PH patients and also about the activities of PHA Hungary. One of our members, who is in charge of the organization of sports events, ensured that an educational article about WPHD, PH and PHA Hungary be made available on their webpage (http://findyourlimits.hu/hirek/56). Additionally, some Facebook entries were also posted on their account to generate traffic towards the educational article as well as to PHA Hungary’s webpage.

In May, over 1.500 runners ran until they were breathless in the scenic surroundings of Lake Balaton in aid of WPHD and all pulmonary hypertension patients. Runners participated in 6.5 km, 10.5 km, half-marathon, and marathon races along the shore of the lake. A number of volunteers, both runners and spectators, wore ‘Get Breathless for PH’ t-shirts, raising awareness of the condition and strengthening the partnership between the PHA Hungary and the local sports community.

The sports related activities of PHA Hungary for WPHD 2016 are not over yet! At the end of July, PHA Hungary will have a booth at Ironman Budapest and we hope that our volunteer(s) will manage to complete the race!

During the course of this year we plan to continue to build up and strengthen the association by continuing to form partnerships with local organisations across the country, to create solidarity between PH patients and the Hungarian people.

Eszter Csabuda, Tüdőér Egylet
www.tudoer.hu
https://www.facebook.com/pages/Tüdőér-Egylet/151123348280359

WPHD 2016 - IRELAND

Luck of the Irish for WPHD!

It was a win for pulmonary hypertension in Dublin, as WPHD was celebrated with the help of the unstoppable Dublin Senior Football Team. Fresh from winning the Gaelic Football Championship and League, and still wearing their football boots, the team hopped onto the WPHD Viking Splash Bus to support PH patients by taking a tour of the city.

The bus tour kicked off at St Stephen's Green, where in the midst of the hustle and bustle of the city, lots of people gathered in excitement to watch a busker rock out on his electric guitar. The WPHD team handed out materials and chatted to the audience to spread the awareness message.

PH patients, consultants, nurses and children embarked on the bus tour around the city, visiting top tourist spots whilst proudly wearing WPHD t-shirts and holding white and purple balloons in solidarity.

The Gaelic Athletic Association, the biggest sporting organisation in Ireland, helped to spread the word on social media. It is safe to say the day was a great success in driving awareness of PH. The presence of the victorious Dublin Senior Football Team certainly helped bring attention to WPHD!

Regina Prenderville, PHA Ireland
Karen Doherty, PHA Ireland
www.pulmonaryhypertension.ie/pha-ireland
www.facebook.com/PulmonaryHypertensionIreland

WPHD 2016 - ISRAEL

Runners helped 'Give PH a hand' in a 5km night run

The Israel Association of Pulmonary Hypertension celebrated WPHD 2016 with the Kiryat Gat Night race. Along with support from Jay's Athletes, 120 runners aged 9–69 ran the 5km or 10km course wearing the 'Get Breathless' t-shirts. There was a festival-like atmosphere in Kiryat Gat park, where runners could warm up with Zumba dancing, boxing and group stretches along with five-a-side matches before the run.

In the PH Israel tent, runners received their 'Get Breathless for PH' water bottles. Runners and supporters were also encouraged to draw around their hands on a banner for PH with the slogan 'Give PH a hand' which had a large hand with a symptom of PH on each of the fingers. Following the race Dr Avital Avriel, who had recently competed, gave a talk to the runners on PH and the treatments now available. It was estimated that 2.000 people attended the event with many PH patients finding the information they received very valuable.

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

WPHD 2016 - ITALY AMIP

Italy flies high for WPHD

For WPHD 2016 the Associazione Malati di Ipertensione Polmonare (AMIP) organised a kite flying contest for their patients and caregivers in the beautiful coastal town of Salerno. This year WPHD coincided with AMIP's annual meeting. This gave patients and families the chance to share their concerns with and understand new developments in treatments for PH.

The contest was aimed at harnessing the power of the wind in support of PH patients. A flash mob of kites filled the sky, one kite for every patient present. Participants received T-shirts and kites sporting the "Get breathless for PH" logo as well as information on PH. The day rode a wave of good feeling and enthusiastic support from the many children present. And despite the lack of wind - which is a strange event by the sea - the kites soared through the energy and the power of love!

Vittorio Vivenzio, AMIP Italy
www.assoamip.net
www.facebook.com/AssociazioneMalatiDiIpertensionePolmonare?ref=ts&fref=ts

WPHD 2016 - LATVIA

A deep sea dive for WPHD

The Pulmonary Hypertension Association of Latvia celebrated WPHD 2016 with an unusual diving event in partnership with the Riga Municipal Police Rescue Department.

In the lead-up to WPHD, PHA Latvia launched a contest on their Facebook page, imploring followers to guess what was in the mysterious PHA box. The most interesting suggestion (rather than the correct one!) won a pulse oximeter.

On the day, police divers descended to a depth of 7 meters to recover the box and retrieve the flag of the Latvian PHA. The Head of Riga Municipal Police Rescue Department Valters Pless, was joined by PHA Latvia Chair Ieva Plūme, who spoke about the importance of recognizing the symptoms of PH. Cardiologist Andris Skride also spoke, highlighting the main symptoms of PH, the importance of oxygen for divers and patients with PH, before going on to praise the event organizers. More than 50 volunteers, PH patients and their caregivers went on to join a march through Riga's city center, from the River Daugava to cinema Citadele, led by TV showman Juris Steinberg carrying the flag. A fundraising event was held at the cinema for the rest of the afternoon, raising €156 through t-shirt sales and stalls featuring hairdressers and henna artists.

The event was reported by an amazing 17 websites, 2 national newspapers, 3 national TV stations and 3 national radio stations, resulting in 18.324 impressions on social media!

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

WPHD 2016 - LITHUANIA

Breathing is beautiful in Lithuania on WPHD

On the 5th May, events celebrating WPHD took place across Lithuania – from Kaunus to Vilnius, via Klaipėda.

The Lithuanian PH association organised a yoga class for PH patients in Kaunas. With the help of experts from the association, a specialist yoga coach was taught about the condition, which allowed him to design a special set of exercises focusing on breathing. This session was such a success that it has a weekly class in Vilnius, where the national centre for PH is located. Not only has this taught many patients valuable breathing techniques, it now serves as a social hub for patients to meet and talk about their condition.

A cycling marathon also took place around Vilnius, starting out at the Hill of the Three Crosses, a sacred site near the town centre. The hill is steep - many of the patients had never been able to climb it - but with the help of healthy volunteers and their friends, the group were able to get to the top! Patients and volunteers then cycled around the city wearing "Get breathless for PH" t-shirts, raising awareness of the condition around the city.

In Klaipėda, brochures were also distributed along the seafront to tourists and residents. Yacht teams along the shore gladly pitched in, wearing WPHD t-shirts and helping with the distribution of leaflets. A great deal more people now know about the PH association and how it can help people living with PH.

The caring, attentive people who the association reached in cities across Lithuania responded very well to the WPHD message and now know more about the everyday impact of the condition.

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

WPHD 2016 - NORWAY & SWEDEN

The Backward Games at Bislett Stadion!

This year, for the first time ever the Norwegian and Swedish associations ran a joint WPHD event. This began with a meeting in Oslo, which connected the two associations. As small neighbouring countries, with similar languages and healthcare systems, it made sense to join forces on the special day.

The event, called Baklengslekene, which roughly translates to The Backward Games in English, was held at the Bislett Stadion in Oslo.

The idea behind the Backward Games is that PH can be regarded as a "backwards" disease. When a patient visits a doctor with shortness of breath, the first assumptions are common illnesses. However, it is important the doctor thinks "backwards" and considers the possibility of PH. Leaflets were also made to highlight this point and handed out at the Backwards Games.

Participants competed in several "backwards" sporting events: participants walked/ran 60 meters backwards, performed triple jump backwards and threw a ball backwards. The competition culminated in a backwards mind game and an egg toss competition in which partners tried to toss each other a raw egg without breaking it. The two teams competing were - naturally! - Norway and Sweden. Both teams, which consisted of both PH patients and healthy supporters, were very eager to win the day for their country!

The event turned out to be a very fun occasion with participants wearing wigs in the country flag colours. As the scores were added up at the end of the event it was apparent that it was going to be very close between the two countries: after four events the score was 2–2, with the last event being won by the Swedish team.

The participants and organisers had a fantastic time at the event, raising awareness of PH across Norway and Sweden. The two associations are keen to welcome more competitors to the 2017 Backwards Games!

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

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

WPHD 2016 - POLAND

TV Celebrities ‘Get Breathless’ for Polish PH patients special steeplechase

PHA Polska members were joined by celebrities and TV presenters for a steeplechase which represented the daily struggles PH patients endure, including everyday obstacles that are often seem insurmountable for people living with PH.

Professor Marcin Kurzyna, a well-known Polish PH specialist, was the guest of honour and not only educated TV reporters and journalists but also raced the whole track himself.

There was strong representation from local high schools. The track record was set by Sergiusz Ryczel with a time of just 1.05 minutes.

The whole event was supported online with a Blue Lips campaign over Facebook and Instagram, where participants were encouraged to share pictures of their lips painted blue or with blue kisses on their cheeks.

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

WPHD 2016 - PORTUGAL

Portugal has a “Breath of Success” supporting “Get Breathless for PH” on WPHD

In Anadia on 7th May, 150 patients played an active role in a conference on PH. The day started with talks by Dr Vera Nunes on sexuality in PH patients and Dr Ana Paula Dinis on new treatment options for PH patients. Later everyone visited the Alianca Underground Museum & Winery and took part in a relaxation and breathing session.

After lunch, the afternoon was packed with professional sports demonstrations. Aveiro Gymnastic School and TV 90 Bad Düben gave acrobatic and artistic gymnastic displays. There were further demonstrations by the National Track Cycling Team and the Portuguese Karate Club. Throughout the day CTEPH patients gave heartfelt testimonials with videos and photos about living with their disease.

On 5th May in Lisbon, 80 people attended another event called “Smile, Breathe and Educate”. This get-together launched a new project to make available physical and respiratory rehabilitation to Portuguese PH patients similar to those existing in other countries. It is hoped the project with have a positive impact on the quality of life of PH patients with increased mobility and reduced disease-related complications.

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

WPHD 2016 - REPUBLIC OF MACEDONIA

APH “Moment Plus” Get Breathless for PH in the Wizz Air Skopje 2016 Marathon

The Macedonian Association of Pulmonary Hypertension team took part in the Skopje marathon along with over 8.000 runners from 46 countries. A record number took part in this 12th edition of the race. There were four events: the marathon; half-marathon; relay marathon and finally the 5km race. Four young girls from the APH Moment Plus team won the team marathon event.

In the two days leading up to the event, the APH Moment Plus team were present to support runners in registering and during the course of the day had a stand to provide information to runners and spectators. All the runners were easy to spot in their Get Breathless for PH t-shirts. Meanwhile the supporters carried flags and banners for PH. The race was covered on national television and had many celebrity participants.

As well as the Wizz Air marathon, APH Moment Plus teamed up with the mountaineering society ‘Green Paradise’ from Veles, with groups climbing mountains throughout the region and waving ‘Get Breathless for PH’ flags on the summit.

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















WPHD 2016 - ROMANIA

Running around Romania to raise PH awareness

WPHD 2016 was marked by an educational event on PH which took place at the University of Tirgu Mureş, which featured a prestigious panel of guest speakers from Romania, Poland and Austria. Among these were Prof. Adam Torbicki (Poland) and Prof Irene Lang (Austria). Topics for discussion ranged from surgical treatment to new medications for PH, via the idiosyncracies of the Romanian healthcare system. The panel also comprised Professor Ion Coman, Professor Bogdan Miron and Professor Carmen Ginghina, who gave attendees from patient associations a greater appreciation of the both the art and the science of PH treatment.

On the same day, a community run took place in Sinaia. This annual event commemorates the life of Professor Adrian Ghioca, and has taken place every year since 2006. This year, a number of volunteers wore ‘Get Breathless for PH’ shirts to raise awareness of the condition among race participants and spectators. WPHD 2016 in Romania was a very positive experience, and there are plans to organise a summer camp to continue this success.

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




WPHD 2016 - RUSSIA

Raising Russian recognition of PH

In the run-up to WPHD special educational sessions were held to raise awareness of PH. Members of the public, led by the Tatarstan Republic's Head Cardiologist Albert Galiyavich, explored issues and solutions for PH patients. The audience shared their concerns about access to diagnosis and treatment of PH, and the potential for better treatment in future.

On 5th May, WPHD was marked with a flash mob organised by administrators of the PH social site, Vkontakte group, and the PH patient association "Spasti i sokhranit". The flash mob was aimed at raising awareness of PH to champion early diagnosis and increase patient access to specialist medical care and treatment.

A Yantra yoga masterclass was held at Chernoe ozero, a local Kazan park. The class included breath detection and assessment, breath relaxation in different postures and purifying Yantra yoga pranayama – specially tailored for people living with PH. The class was open to people of all ages and health states. All that was needed to take part was a mat, pillow, blanket and comfortable clothes.

The 'Running hearts' marathon, sponsored by Adidas, was held in support of patients with heart disease and PH. Participants included Olympic and Paralympic champions, actors, journalists, media personalities and many others.

Following WPHD, the third 'Right for cure' congress, dedicated to the day, took place in Moscow on 26th May 2016. The event focused on the rights of PH patients to be treated. The format was an analytical talk-show with leading Russian experts in the field of PH. The organizer and permanent host of the Forum – President of the Patient league, Alexander V. Saverskiy – opened the Congress.

Ministry of Health representatives and other federal authorities, leading pharmaceutical companies, commercial companies and experts took part, as well as more than 200 patient communities, charity funds and other public organizations.

Evgeniy Komarov, Natasha Charity Fund
www.community.livejournal.com/fond_natasha
otzovitesnam@mail.ru - www.nurm.ru

WPHD 2016 - SERBIA

Serbian super league teams FC Red Star and FC Vojvodina raise awareness for PH

In the lead-up to WPHD, the 'Eternal Derby' between FK Red Star and Partizan Belgrade saw players walk onto the pitch in front of 40.000 fans wearing 'Get Breathless for PH' t-shirts. The match was seen on TV by an estimated 1 million people, and over 100 accredited reporters and photographers were on hand to spread the PH message in Serbia and across the whole Balkan region. The significance of the event was highlighted by the stadium announcer and the TV commentator for the spectators at home – bringing awareness of the condition to an enormous number of people.

There was a flurry of activity across the country on 5th May: Over 15.000 supporters at the Karađorđe stadium watched Red Star face off against FK Vojvodina, and at least a further 750.000 watched at home. Not only did the players line up wearing WPHD t-shirts, but the importance of the event was acknowledged and praised by the TV commentators, as well as the players on Twitter, Facebook and Instagram.

The Belgrade Open show-jumping competition saw 48 contestants from across Serbia competing. Overall and category winners received their awards wearing WPHD t-shirts, and the 5th hurdle was emblazoned with the WPHD logo, symbolising the hurdles that PH patients overcome in normal life. The event was reported on TV and radio stations, newspapers and websites in Serbia, and ten eminent doctors from across Serbia were on hand to speak to the media. Overall, WPHD was a big success in Serbia, and efforts to increase public knowledge of this debilitating condition continue!

Danijela Pešić, PHA Serbia
www.phserbia.rs
www.facebook.com/plucnahipertenzija

WPHD 2016 - SLOVAKIA

FROM MUSIC TO MOUNTAINEERING: SLOVAKIA SUPPORTS WORLD PULMONARY HYPERTENSION DAY 2016

As the first of many events supporting WPHD in Slovakia, the PH Slovakia association (Združenie pacientov s pľúcnou hypertenziou) held a successful press conference at the Café Štúr in Bratislava. The event brought together doctors from the National Cardiology Institute, PH patients and journalists from all types of media. The President of the Slovakian PH association, Iveta Makovníková, hosted the prestigious event, which also included an informative presentation from Dr Milan Luknar, Cardiologist at the Center for PAH Özata NÚSCH in Bratislava, as well as patients who described their own experiences of living with condition.

WPHD events continued the following day with a national television segment, showcasing a powerful film which featured a live interview with Iveta Makovníková and patient Daniel Káčer. The broadcast can be viewed at https://www.rtvs.sk/televizia/archiv/10363/94468). Iveta Makovnikova also held a radio interview on the same day, telling the people of Slovakia about her experience of PH.

For WPHD itself, the Slovak Philharmonic Orchestra gave a special performance. The day was a great success and attendees, which included 13 PH patients and two specialist doctors, were entertained, but also educated about PH in general.

WPHD was also championed by sport enthusiasts from across Slovakia, representing the 'Get Breathless for PH' campaign across various competitions, including the CSOB marathon, the National Run Devin-Bratislava and many more.

On the 4th June, 91 participants (including four PH patients, 48 doctors and health workers NÚSCH as well as family, friends, and colleagues) and two volunteer members of the mountain rescue service climbed the Brestová peak (1.903 m above sea level) in the Western Tatras mountain range. The climb was chosen to illustrate how a patient with PH exerts as much energy and effort walking a few meters as a healthy person does on such a challenging climb. In a symbolic gesture, the participants carried photographs of PH patients so they could be part of the challenge! The expedition was a great success, with 26 articles published and was even filmed by a Slovak television crew. Soon to be shown on the popular TV show 'Televíkend' at the end of the June 2016!

Congratulations to all who took part in these fantastic WPHD events – especially the amazing PH patients who successfully completed the Brestová hike!

Iveta Makovníková
Zdruzenie pacientov s plúcnou hypertenziou
www.phaslovakia.org - http://on.fb.me/Ud1DUf

WPHD 2016 - SLOVENIA

SLOVENIA MAKES THE MOST OF WPHD: RUNNING IN MOSTEC

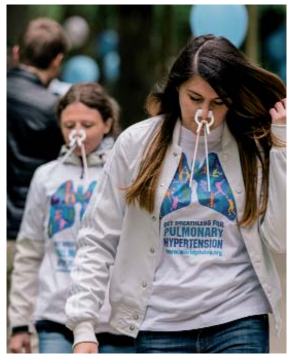
This year, to mark WPHD the Slovenian Pulmonary Hypertension association Pljučna Arterijska Hipertenzija repeated its popular outdoor event at the beautiful Mostec nature reserve, Ljubljana, on Thursday 19th May. Starting in the afternoon, this family event included a range of activities focused around 'Getting breathless for PH'. The races were tailored for children and adults, with a 1km run for children under the age of 14, and a 5km run for the adults. In addition to the races, the day featured performances from a well-known DJ, a Zebra mascot and children's entertainer Živka Nagajvika.

In order to generate greater understanding of what it feels like to live with PH, people were encouraged to take part in a 6-minute walking test - with a twist! Supplied with special nose pegs and only two straws to breathe through, groups of 3-4 healthy people at a time had to complete the challenge. The reduced breathing capacity this equipment creates helped people to get a glimpse of what a PH patient lives with constantly.

We also produced an informative video about PH, which included highlights from this year's WPHD event (the English version of this film can be viewed at http://bit.ly/2amkMIQ).

A big thank you to all who made this event such a success - in total, over 150 people attended, with a lot of the runners coming straight from work in order to support WPHD!

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



WPHD 2016 - SPAIN ANHP

THE INNOVATIVE APP FOR PH PATIENTS
SPAIN SUPPORTS WPHD

To mark WPHD 2016, the ANHP held a number of sporting and cultural events across Madrid and Barcelona. From an indoor cycling masterclass to a series of Zumba classes, different sports were used as a fun and challenging way to celebrate the day and raise awareness of PH. After the events, participants were also encouraged to continue to share their knowledge of the condition and raise awareness amongst others in Barcelona, Madrid and Girona.

A flash-mob also took over the magnificent Plaza del Casal del Joven, wearing 'Get Breathless for PH' t-shirts and encouraging the audience to ask participants about PH and learn more about the condition. The association also chose the 5th of May as the day to launch a new app for PH patients to help monitor their condition. The app was designed to be a medication management and education tool and a resource for patients to keep track of the progress of their condition.

As additional activities ANHP also held a solidarity show in the Theater Dulce Chacon and a psychology workshop for nursing staff supported by MSD.

These fantastic events raised awareness of PH significantly across Spain, meaning many more in the country are now aware of the difficulties that PH patients face every day.

Maria Rodríguez
Asociatión Nacional de Hipertensión Pulmonar
www.hipertensionpulmonar.es
http://www.facebook.com/hipertensionpulmonar

WPHD 2016 - SPAIN FCHP

PILATES AND PADEL FOR PULMONARY HYPERTENSION
SPAIN SUPPORTS WPHD

To mark WPHD, the FCHP association hosted a Pilates master class at Gym Forus Parla in solidarity with PH patients, teaching useful breathing techniques to people with and without the condition. A series of awareness sessions were held for school children, with the help of local triathletes. The students 'Got breathless for PH' and learned to appreciate the difficulties that PH patients suffer every day, while discovering more about the condition.

Following these sporting events, an exhibition of the paintings of the well-known artist Pablo Romero Cagigial, as well as a football tournament, golf game and a series of padel (also known as paddle) matches were all held on the weekend of the 21st May.

To ensure as many as possible could partake in WPHD activities, a gala was also held in partnership with the local council in the town of Leganés. The gala was a great success and was featured on local television!

Finally, to mark of the final occasion of WPHD, Dr Alvarez from Ramon y Cajal Hospital and Prof. Perez-Vicaino from Complutense University in Madrid received grants to continue their important work in PH research.

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

WPHD 2016 - UKRAINE PHA

UKRAINE "GETS BREATHLESS" WITH SALSA FOR WPHD 2016

Patients and supporters held an online flashmob and Salsa Marathon to "Get Breathless for PH" to mark WPHD 2016. The Salsa Marathon ran from the 5th to the 21st of May and achieved widespread coverage, including television broadcast – reaching a wide audience and educating the public about PH.

PH patient Antonina Yeresko, a choreographer and dancer, directed and performed dance about the life of people with pulmonary hypertension, which was so impressive that it drew tears from many spectators. The Salsa Marathon was also attended by Amador Lopez, a famous Ukrainian choreographer and celebrity who helped organize the flashmob.

On the 21st of May, prior to the final of the Salsa Marathon, there was also a patient conference. It was so important to see everyone join in the fight against the disease – doctors from the Center of Pulmonary Hypertension for adults of the Institute of Cardiology named Stragesko and the Center of Pulmonary Hypertension for children of the Institute of Children's Cardiology and Surgery. There were a variety of talks on treating PH and a special emphasis on making treatment available for orphaned children across the country.

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

WPHD 2016 - UKRAINE SISTER DALILA

UKRAINE SISTER DALILA MAKES A DIFFERENCE TO THEIR LOCAL PH WARD ON 5TH MAY

To mark WPHD 2016, over 400 children ran in a "Get breathless for PH" race supported by Miss Lviv 2016. The runners all wore "Get Breathless for PH" t-shirts to raise awareness of PH and were able to educate the spectators about the condition. The association also organised a round table to help solve the issue of transplantation within the Ukraine. The group brought together experts and patients to support a bill to promote transplants, all under the slogan "Saving even one life is an investment in the future".

Children in Lviv also helped raise the public consciousness of PH by collecting "Corks for Life". The children collected over a ton of plastic corks, and sorted them by colour and sold them to a recycling company. With the money raised the association was able to buy an oxygen generator for a PH ward in a local hospital – making a positive difference for all future PH patients in the country. We are very proud of this result!

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

MEDIA CLIPPINGS

AUSTRIA

Lungenerkrankungen immer ernst nehmen!

STEHT IHRE LUNGE UNTER DRUCK?

PAH-Guidelines ändern den klinischen Alltag

ÖKG Tagung 2016

Run for Charity 2016

Initiative Lungenhochdruck – meine Freunde sagen: „lauf mit" – meine Lunge sagt „Nein"!

Nanu! Giraffe macht Laufrekord im Tiergarten jetzt Beine

Die Neuen im Vergleich

PAH – Pulmonal-arterielle Hypertonie

Erlebnis-Läufe in Wien boomen wie nie zuvor

Ein Lauferl für die Langhälse!

Herzinsuffizienz mit erhaltener Linksventrikelfunktion

BELGIUM

© Gazet van Antwerpen / www.gva.be.

Nieuwbouw Zennester Hombeek jaartje uitgesteld

Zesde Midzomernachtrun

met spelers KVM

HLN LIVE MECHELEN

BOSNIA AND HERZEGOVINA

Dnevni avaz

Uspješno realizovan međunarodni 16. Krivaja rafting

16. KRIVAJA RAFTING: I rafteri u akciji podizanja svijesti o plućnoj hipertenziji

SPORT ZDK

Grude bolje od Krivaje, prije utakmice data podrška oboljelim od plućne hipertenzije

Udruženje "Dah" obilježava Svjetski dan plućne hipertenzije

LIJEK ZA PLUĆNU HIPERTENZIJU 800 €

Prvakinje BiH slavile i u Zavidovićima

Sabina Hodžić

CROATIA

Humanitarni turnir Dječaci Gorice 'bez daha'za oboljele od plućne hipertenzije

Pobijedili čazmanski dje

Zagrali rukomet za

BULGARIA BSPPH

С открит урок по какво дишане в София ще бъде отбелязан Световният ден на пулмоналната хипертония

GREECE

Pharma Journal

ONMED.GR

Lung Disease

PULMONARY HYPERTENSION

ACTELION

IATROPEDIA

CZECH REPUBLIC

JPM

JENPROŽENY.CZ

Daruj dech pro plicní hypertenzi

TOP STAR 1.6.2016

IRELAND

Dubs breathe life into campaign

HUNGARY

ISRAEL

ynet

יותר קוק דם ריאתי

GERMANY

Radteam PHenomenal Hope für eine Zukunft

Das Ziel ist Heilung – Radfahren für die PAH-Forschung

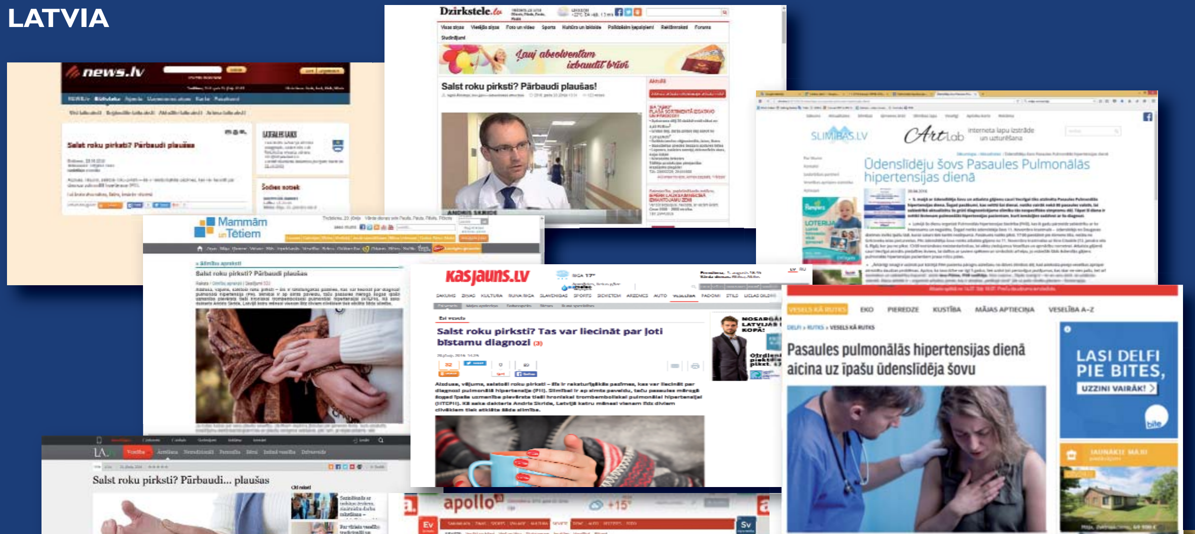
Diagnose: PAH

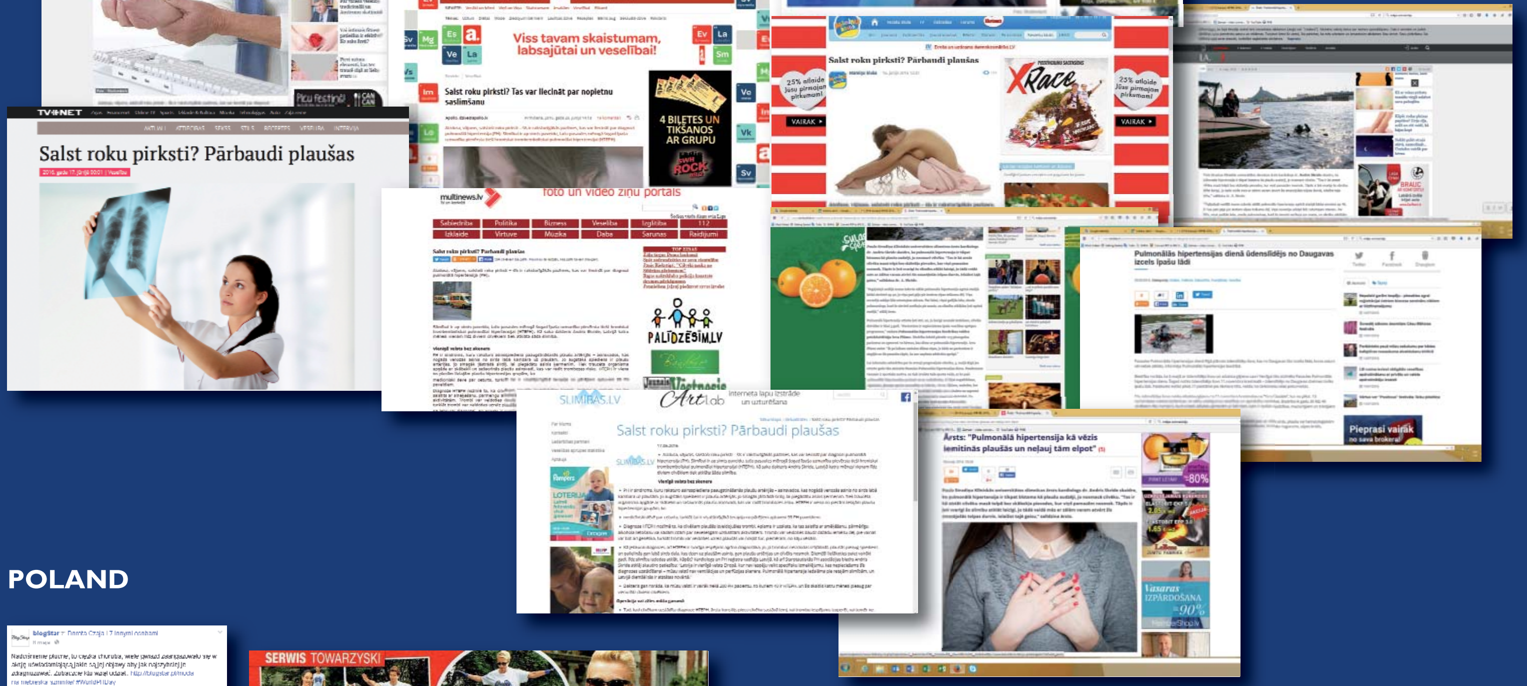
Lungenhochdruck PAH

Wir für PAH-Patienten

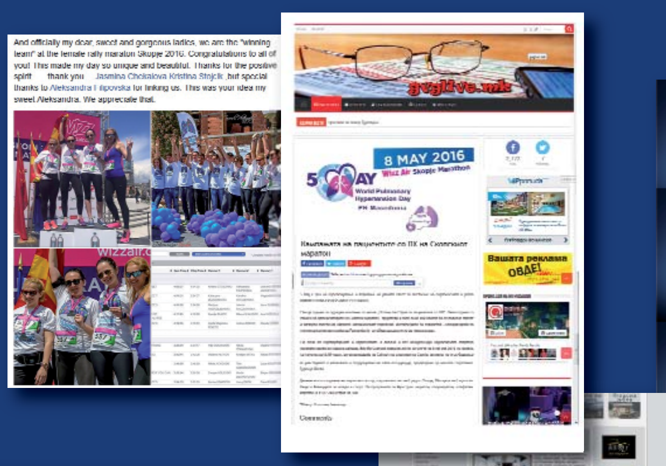
ACTELION

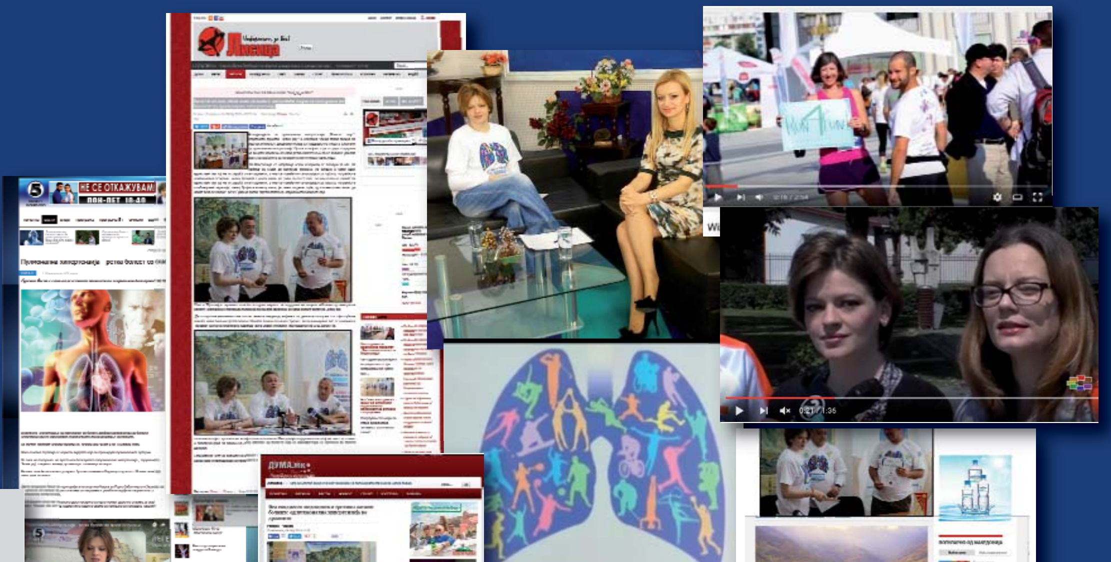
LATVIA





REPUBLIC OF MACEDONIA

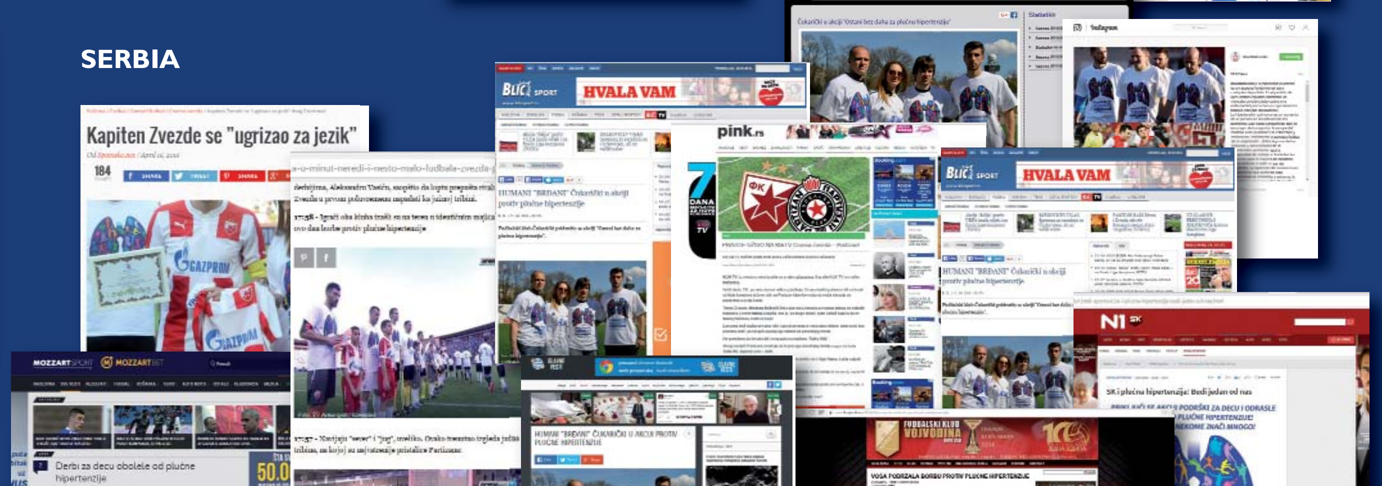


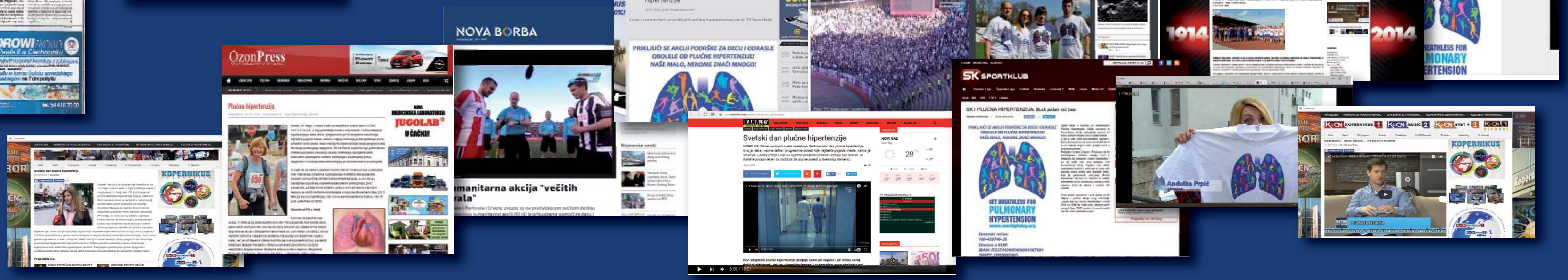


POLAND

PORTUGAL

SERBIA



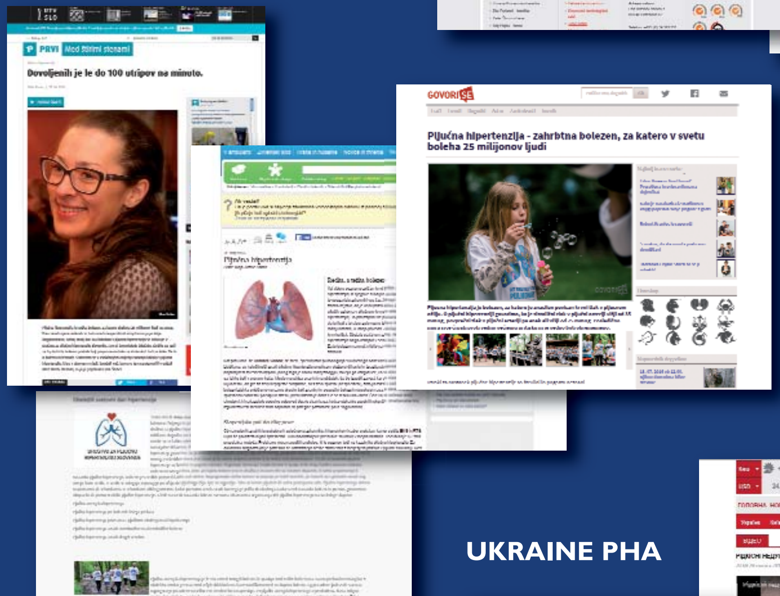


SLOVAKIA

Modrejúce pery môžu upozorňovať na vážne ochorenie

Vo štvrtok je Svetový deň pľúcnej hypertenzie

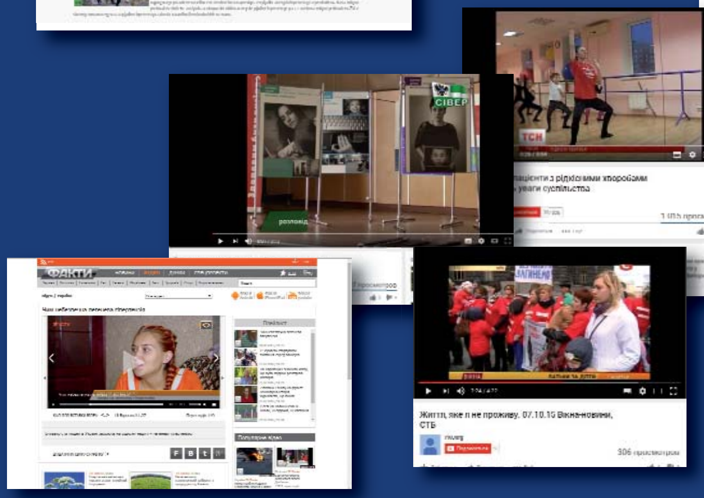
SLOVENIA



Dovoljenih je le do 100 utripov na minuto.

Pljučna hipertenzija - zahrbtna bolezen, za katero v svetu boleha 25 milijonov ljudi

UKRAINE PHA



SPAIN ANHP

La habitación "Siente la Hipertensión Arterial Pulmonar" en Madrid

"Un aliento para vencer" en el Día Mundial de la Hipertensión Pulmonar

Afectados por hipertensión pulmonar piden mejorar su diagnóstico y evitar que se confunda con otras patologías

El municipi commemora el Dia Mundial de la Hipertensió Pulmonar

UKRAINE SISTER DALILA

У Львові обговорять одну із найважливіших проблем трансплантації в Україні: ефективне функціонування системи трансплант-координаторів

THE BEST WPHD VIDEO CLIPPINGS FROM AROUND THE WORLD

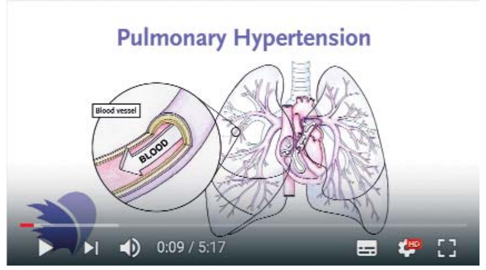
ANTILLE
www.youtube.com/watch?v=QtGXbnNtp

BULGARIA, BSPPH
www.youtube.com/watch?v=G5Hi2E4_LfE

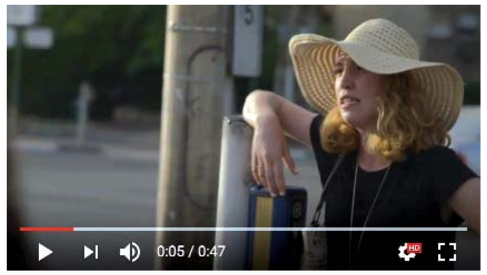
BULGARIA, BSPPH
www.youtube.com/watch?v=wSd-vGdTUeCw

BULGARIA, PHA
www.youtube.com/watch?v=3YO33PkKOUY

CANADA
www.youtube.com/watch?v=CTiR34DNK04



ISRAEL
www.youtube.com/watch?v=PcEI3tg8Ch8&feature=youtu.be

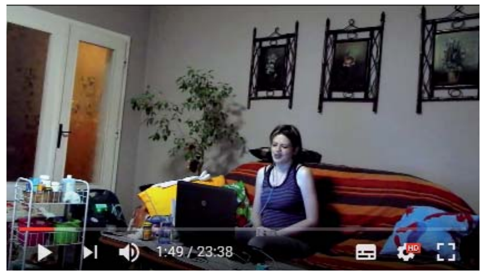


LATVIA
www.youtube.com/watch?v=zcy-Oh6-wb0

NORWAY
www.youtube.com/watch?v=vUCLupa0OG0&feature=youtu.be

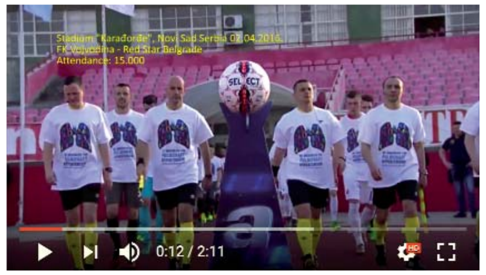
PORTUGAL
www.youtube.com/watch?v=YrWMZyTwT64

REPUBLIC OF MACEDONIA
www.youtube.com/watch?v=WZSsseu-FOKgfE



REPUBLIC OF MACEDONIA
https://www.youtube.com/watch?v=bqh-TuOXmiPc

SERBIA
www.youtube.com/watch?v=NLKhYUPKviM



SERBIA
www.youtube.com/watch?v=4Ms25zX6Mew

SERBIA & RUSSIA
https://www.youtube.com/watch?v=Pwi7mopZTLQ

SLOVAKIA
https://www.youtube.com/watch?v=O0VrV8DsVjk

SLOVENIA
www.youtube.com/watch?v=tpc770SIhVc

UKRAINE SISTER DALILA
www.youtube.com/watch?v=_whROudqF2s

WASHINGTON, USA
https://www.youtube.com/watch?v=VlqisNua9rk

25 years of progress: changing the history of PH

PHA International Conference, Dallas, 17-19 June 2016

Regina Prenderville, Project Manager, Pulmonary Hypertension Association Ireland

The Pulmonary Hypertension Association, USA (PHA) held its 12th bi annual conference in the Omni Hotel, Dallas, Texas in June 2016. Over 1.500 patients, families and healthcare professionals attended for the largest gathering of the PH community in the world. I was very privileged to attend this amazing meeting and have listed some of my notes below.

Farewell to a great leader

The conference was tinged with a little sadness as it marked the retirement of the PHA's first CEO and President – Rino Aldrighetti, who retired after 17 years of service that began when he became the organisation's first employee.

In his honour, two significant awards were announced at the Conference. These awards / grants will support the work of the PHA to advance research and patient care. The President of Actelion Pharmaceuticals USA – Bill Fairey announced the establishment of the Aldrighetti Research Award for Young Investigators. The new six year PHA grant award will support the career of young investigators who are likely to make a strong and sustained impact in PH research.

The second award – The Rino Aldrighetti Leadership Award was announced by Dr Bruce Brundage – representing the PHA's founders, its scientific leadership council, PH Professional Network, Board of Trustees and staff. This award will enable an individual who has demonstrated exceptional leadership in addressing the vision that PHA embraces. The fund will also make it possible for awardees to receive a significant monetary award to further their work.

New President & CEO

We were introduced to the new President & CEO – Brad A Wong. Brad comes to the PHA from the Foundation of the American Academy of Ophthalmology (FAAO) where he served as Executive Director. His accomplishments included creating innovative programmes, raising the foundation's visibility, establishing strategic partnership and increasing and diversifying funding. Brad also brings broad knowledge of academic medicine and biomedical research environments, having served as assistant Vice President of the University of California, San Francisco (UCSF) Foundation. The search for PHA's new CEO included a thoughtful yearlong process that started with information gathering from the PH community, including patients, caregivers, medical professionals, Board members and industry leaders. Roger Towle, who recently assumed the role of Chair of the PHA's Board of Trustees said – 'We are confident that Brad embodies the special qualities needed to lead the PH community in achieving our vision of a world without PH, empowered by hope'.

Meetings/Workshops:

There were many interesting parallel sessions - workshops and scientific meetings. Panels of experts led educational sessions for patients and family members. All sessions provided the opportunity for open interaction and discussion.

I will not write about medical presentations/discussions as I am not qualified to do so and fear I could misrepresent findings etc.

I found the following sessions most informative and interesting:

1. U.S. PULMONARY HYPERTENSION REGISTRIES

Dr Michael McGoon made a very interesting presentation on Registries in the USA.

What is a registry? '… an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population, defined by a particular disease, condition or exposure and that serves one or more predetermined scientific, clinical or policy purposes'.

The importance of Multi-Center Registries of PH patients was outlined. Since the causes of PH are diverse and may differ from one country to another due to many factors, it is important that multi-centre registries are conducted.

It is estimated that the incidence of PH in the developing world is 5-6 times greater than in the developed world. This can be due to lack of personal finance, poor social conditions, housing etc.

Dr McGoon spoke of the NIH Registry (National Institute of Health) 1981-85 / 1988. This was the era of no effective treatment. The number of participating patients was 187 who had primary PH and came from 32 US centres. The median survival rate of patients at that time was 2.8 years.

The REVEAL (Registry to EValuate EArly & Longterm PAH) Registry was conducted between 2006-2009 – this was the era of multiple drug availability and combination therapy. The number of participating patients was 3.515 and came from 55 US Centres. The median survival rate of patients was >7 years.

Future goals: To collect data from CCC's (Comprehensive Care Centres) to assist with quality improvement by assessing adherence to guidelines and outcomes

Note: Details of a new PHA Registry have been announced – See below: 6.(ii) Go PHAR Research – a virtual walk to benefit the new PHA Registry (PHAR)

2. RAISING AWARENESS THROUGH MEDIA/SOCIAL MEDIA

A presentation was made by Kelly Williams, Vice President Communications & Marketing in PHA. Kelly can be contacted on kellyw@phassociation.org

Kelly gave a very impressive presentation on 'Corporate Social Responsibility' – (CSR). We were shown television advertisements (on PH awareness); these appeared in the middle of important televised Presidential Campaign events etc. An illuminated poster for PH awareness was also given space on Time Square New York for a number of weeks. All of this media coverage was given free of charge. Kelly is very happy to support us in any way. We were reminded that people need to hear a message 7 times before it registers on the brain – so a once off advertisement is no use – this needs to be a planned and sustained campaign.

Resources

Like PHA's Facebook page: facebook.com/PulmonaryHypertensionAssociation

Follow PHA on Twitter and Instagram: @PHAssociation

Sign up for and share PHAs weekly PHANews e-newsletter: phanews.org/subscribe

Join PHA and get Pathlight magazine quarterly: phassociation.org/Join#Levels

Join PHA's Media Action Network: phassociation.org/MediaActionNetwork

3. PUBLIC AWARENESS CAMPAIGNS/ FUNDRAISING - Europe

Gerry Fischer – PHA Europe

We were very proud to hear Gerry Fischer speak about the great success we are enjoying with the growth of PHA Europe. Membership now includes 39 PH associations from 33 countries across the continent of Europe. In his presentation he outlined many of Europe's awareness day events – which were both colourful and outstanding. Gerry also spoke about the importance of support from the media - the value of gaining support of the paparazzi should never be underestimated. We should also keep in mind that billboard companies give free space in low season.

For many years we have heard Gerry encourage us to approach companies regarding their Corporate Social Responsibility. He advised about making contact with suppliers of non specific PH medicine – oxygen inhalers, pumps, syringes, disinfectants etc. We should be aware that major pharmaceutical companies have different departments - media, commercial, ethics, CSR, research & advocacy – these should be considered when seeking support.

Adriana Posada, Mexico – Representing Spain at PHA meeting

Adriana was diagnosed with idiopathic pulmonary arterial hypertension in 2005, four months after her first symptoms appeared. She remembers feeling happy to finally know what was making her feel so bad. She knew her life would change completely, but also knew she would find a way to live with it. She works as an Accountant in Mexico and is a very strong advocate for PH – her presentation was very motivational.

Fundraising/awareness events in Spain were outlined by Adriana e.g, Golf Tournaments, Cycling races, Charity dances and a very interesting Flea Market which is held annually in the subway of Madrid railway station. This year the market will be held for its 9th successive year. Initially second hand clothes in good condition were sold but over the years the quality of clothes, both old and new have become very upmarket.

Danijela Pesic – PH Serbia

Danijela told the audience that she was diagnosed with PH at the age of two and has been living with PH for over 30 years. She is the founder of PH Serbia. This year she organised a soccer match in Serbia (when many famous players from the Champions League wore the PH T shirts) to promote our cause. She outlined the key elements of a successful campaign – e.g, planning in advance, have clear goals, obtain as much media support as possible, take risks.

Oksana Kulish – PH Ukraine

Oksana spoke about PH activities in the Ukraine. Some of her biggest achievements have been founding PHURDA, providing medical, psychological and legislative support for patients with PH. She has set up an organisation named HEALTH to help get the necessary drugs for Alina, a PH patient. Last year Oksana's association was awarded a Tom Lantos grant and additionally the organisation got approval for free medicine supply to all adult PH patients in Lviv (a region in Western Ukraine) for 2015-2017.

4. ADVOCACY

This presentation was given by Martha Gonzalez from Ecuador. Martha is a Lawyer and an activist. She was inspired to fight

PH when her son was diagnosed with Pulmonary Hypertension when he was one year old. She acknowledged that it is not easy to be an advocate but with a good team – anything is possible. There are 3 different types of advocacy:

- Individual advocacy – educating medical professionals about PH and your needs.
- Political advocacy – asking those in Government to do or change something.
- People – who do you know with a connection to the power holder(s)? Personal connections, Voters, Social Media etc.

To be an advocate we must have specific goals. Our messaging tools should be

- Education vs persuasion.
- Human impact vs financial impact.
- Humour vs anger.

If you get the opportunity of an appointment with an influential person – be prepared:

- Identify your needs.
- Have a team in place – patients, caregivers, health professionals, lawyers etc.
- Have a patient's story – that is appropriate to sell your idea.
- Plea for change – explain the urgency of your goal.
- Bring relevant material with you and leave a folder containing all of this .
- Thank the person for seeing you and follow up with a 'thank you note'.
- Become a follower on their Twitter account.
- Invite them to a support group meeting.

Martha's accomplishments include winning two Tom Lantos grants from the PHA to start her outreach to the PH communities of Latin America, though she says her biggest accomplishment is being a Mum and a carer to her son Daniel – who is now 12 years old.

5. SUPPORT GROUP MEETINGS

There were many sessions for Caregiver Support, PH Parents, PH kids & PH teens. I attended patient support group meetings and note the same benefits / disappointments with support group meetings appear to be very common worldwide. Some patients in the USA travel up to 200 miles to attend support group meetings – sometimes the numbers in attendance could be around 100 – other times numbers can be as low as 7.

In the 1990s patients who wanted to meet other patients had to travel to one of only eight support groups in the USA – now patients and their friends/family members can attend one of 245+ groups nationwide. People involved in PH support groups report that the educational, social and moral support they receive helps strengthen their resolve to fight the disease. PHA defines a successful support group as two or more PH patients who come together to end isolation and share their experiences.

The financial burden of Pulmonary Hypertension was a very strong topic and many carers say they work to pay the enormous cost of medical insurance. With medication, errands, pharmacy calls, meals and everything in between – who can keep up? Carers discussed the fatigue and isolation endured when trying to cope with work and home life. It is vital that support groups are utilised by both patients & carers to help prioritise, stay balanced and staying organised.

Support group organisers are encouraged to invite politicians and other influential personnel to attend group meetings.

6. CAMPAIGNS

i. Congress

The federal programmes and government agencies have a powerful effect on PH access to treatments and research towards a cure. The US congress decides how much money to spend on these programmes and agencies each year. Delegates were advised to sign a petition on behalf of PHA to ensure more funding for research / standard of care for PH patients. Those affected by PH were also encouraged to share their stories and educate Members of Congress.

ii. #Heart2CurePH Campaign

#Heart2CurePHCampaign is a multi-media integrated marketing and advertising campaign that uses donated and social media to raise awareness about Pulmonary Hypertension and the PHA. This campaign, sponsored by Actelion, Bayer and Reata and pro-bono services advertisers across the US is enjoying phenomenal success. The campaign was launched in November 2015, is raising unprecedented public awareness about PH & the PHA. To date the PHA has received more than $34.1 million in advertising value free of charge.

During the meeting Terrence J. (actor and TV host) and YouTube sensation Chloe Temtchine (PH patient) shared their talents with the audience.

Terrence J.

Terrence serves as the celebrity ambassador for PHA, sharing messages of hope and a #Heart2CurePH with his platform as an actor and star with a huge following on social media. He is very well known in the USA and hosts a reality TV series, Coupled - he has also appeared in a number of movies. He will participate in an upcoming public awareness campaign for PHA.

Chloe Temtchine

Chloe is a singer and gave a beautiful performance to a packed audience. Her voice and YouTube presence have made her a sensation and helped to raise awareness for PH. She has lived with PH since 2013 and has partnered with PHA for a number of fundraisers. While in 'Critical Care' soon after her diagnosis, Chloe wrote 'Be Brave' a song about her journey that has become an anthem to many in the PH Community.

The meeting coincided with the debut of Chloe's new music video starring children living with PH. Terrance J was among the first to share the video, tweeting the announcement to over 2 million Twitter followers.

iii. Go PHAR Research – steps up for cure

The PHA are putting their hearts into a cure and are confident that care will come from research. Members of the PHA community have joined the Go PHAR Research – a virtual walk to benefit the new Pulmonary Hypertension Association Registry (PHAR) and the continued roll out of PHAR into the centres of comprehensive care accredited PH care centres.

GoPHAR is the key to helping answer research questions with real world data to advance care and quality of life for people living with PH. The program differs from past registries, that were privately funded and only addressed specific questions.

The Go PHAR Research initiative was launched at the PHAs 2016 International conference in June 2016. Over 230 people had joined at that time and had pledged more than $25.000 in support.

Go PHAR Research Quick Facts

- Every registrant pledging to raise a minimum of $100 will receive a Withings "GO" activity tracker – free of charge.
- This fundraising initiative was inspired by Diane Ramirez, a 29 yr old survivor of PH who walked a personal goal of almost 100 miles last October in support of the registry.
- Regardless of your stamina as a person with PH, a family member or a friend – YOU can join PHA in raising funds for PHAR.
- The inaugural event lasts until 31st October 2016.
- Further info from www.GoPHAR.org

7. AWARDS

During the conference PHA presented a number of awards to individuals for their efforts to advance care through awareness, advocacy and service of the PHA community as follows:

- *Outstanding Allied Health Professional – Glenna Traiger*, a PH Clinical Nurse Specialist from the David Geffen School of Medicine at UCLA.
- *Outstanding Physician Award – Dr. Richard Channick*, a pulmonologist at Massachusetts General Hospital and Harvard Medical School with a strong history in PH treatment and clinical research.
- *Outstanding Caregiver – Martha Gonzalez*, a caregiver and activist who has been fighting PH since her son, Daniel, was diagnosed when he was barely a year old. She brings the voices of PH patients to Capitol Hill as she advocates for Bill H.R. 3520.
- *Outstanding Citizen – Nicole Stafford*, an active member in the PH community who was diagnosed with PH in 2011. She hosts her annual Nicole Phriends golf outing and other fundraisers every year.
- *Outstanding Young Citizen – Eliana Elderete*, a 12-year-old girl who was diagnosed at age six months. She raises disease awareness and participates in advocacy and fundraising projects.
- *Outstanding Support Group Leader – Diane Dewaulder*, who became a support group leader in Texas six years ago. She has conducted events to raise funds and awareness in her fight against PH.

PERIWINKLE PIONEERS

At the PHA 2016 conference individuals and groups responsible for advancing care for PH patients was announced. The following European PHA Global Leaders are recognised as Periwinkle Pioneers (in alphabetical order)

- Pisana Ferrari (Italy)
- Gerry Fischer (Austria)
- Juan Fuertes (Spain)
- Melanie Gallant-Dewavrin (France)
- Bruno Kopp (Germany)

8. EXERCISE & NUTRITION

I attended a number of presentations on the importance of exercise & diet for patients. The following considerations should be adhered:

Eating Issues

- Dietary habits can play a big part in the management of your PH.
- Eat more fruit & vegetables as well as whole grains to add fibre to your diet.
- In an effort to avoid the intake of fat, cholesterol & sodium – try to limit eating out.
- Use spices & fresh herbs to add more flavour to foods.
- Learn to cook more at home so you know what you're eating.

Exercise

- Stretch, breath right, maintain your bones & muscles.
- Yoga improves your overall health and can be done by anyone regardless of their disability (e.g. Chair Yoga).
- Low dose exercise – walk short distances – it all adds up to a healthier you!
- Listen to your body – don't ever overdo exercise.
- If you are nervous about exercising – don't exercise alone.
- Yoga instructor in audience commented that those on oxygen should be instructed to breathe correctly by taking deeper breaths?

Sodium/Fluid Balance

- Be sure to take all diuretics that your PH doctor has ordered.
- Weigh daily, as instructed by your doctor.
- Sodium in your diet can be reduced by eliminating processed foods from your diet .
- Maintain the proper fluid intake – additional fluid can make it much harder to breath

9. MEDIA SUPPORT

A suite on the 15th Floor of the Omni Hotel was taken over for media, interviews, recording of a video (speakers & delegates) etc. This was organised by Steve Wormer whose son Lucas was diagnosed with PH 9 years ago. Lucas is now 13 years old and has made great progress since he has received the correct treatment. Steve is credited with creating the Zebra video and also the PHAware campaign. His ongoing work for PH and the story of how Lucas was diagnosed can be read by clicking onto **www.phaware.global**

10. PATIENTS' STORIES

At our final meeting on Sunday morning, two amazing presentations were made by PH patients. I spoke with both after the meeting and asked if they would share their presentations with me – they were very happy to do so, please see below.

Perry Mamingonian, Fresno, CA

Good morning everyone! I don't know about you but I've really been enjoying this Texas hospitality! We've experienced some of the best PH education here at conference, and one thing I've learned is that all of our journeys are unique but our paths have brought us all together by PHA. I'm humbled by amazing devotion and work the PHA staff does for all of us.

When I was diagnosed with pulmonary hypertension at age 48, I thought my life was over. The truth is, it was just beginning, and I credit the power of this community for teaching me that I was wrong.

Like many of us, for several years prior to my diagnosis I experienced shortness of breath during normal activity. My primary care doctor thought it was due to age, lack of exercise and excess weight, and I had no reason to doubt him. But in early 2009, I began to feel flu-like symptoms which would not improve. Then one morning while driving to work, I began to cough uncontrollably – another pre-diagnosis symptom I developed. I had just exited the freeway and was headed toward a major intersection as my head started to spin and slip into unconsciousness. My last thought before blacking out was, "I'm going to die." But when I woke up, I was covered in white light and for a brief moment I thought, "It's true. When you die you really see a white light". But when I lifted my hand, it was just the airbag that was covering my head. Somehow, my car had drifted to the side of the street and struck a parked car. No one was hurt but me. But my injuries were severe and a passerby called an ambulance.

Once I was in the hospital and explained that I had passed out, the doctors began running tests to figure out why. One test after another showed nothing, until an ultrasound of my heart revealed an enlarged right-ventricle. The cardiologist recognized it as a sign of pulmonary hypertension and called in a PH specialist, Dr. Vijay Balasubramanian, Community Regional Medical Center, Fresno, CA. and he confirmed my diagnosis. At first, all I understood was "hypertension", and I expected them to give me pills and send me home. But Dr. Bala (as we call him) calmly explained that it was very serious and that unless I began treatment immediately I would get much worse. I appreciated his concern and honesty, and after 16 days in the hospital I was released on infused prostacyclin therapy. But I was just focused on the physical, not the mental effects of this disease. My life had been turned upside-down. I was unable to return to work, and because I blacked out in the car accident my driver's license was suspended. I was single, alone and completely dependent on my family and friends for help. It all made me very angry, and I'm sure many of the people in this room know the exact kind of anger I'm talking about. We didn't have a support group in Central California at that time, and although I was aware of other resources for help, I was just too stubborn to use them.

Several months into my diagnosis, I received a phone call that would ultimately change my life. My specialty pharmacy had a patient advocate who was part of a team hosting a PH conference in San Francisco, and she encouraged me to go. She felt that the education and opportunity to meet other patients would benefit me. But I was reluctant at first. I didn't even have a driver's license. But she was persistent, and pushed me to go. So I earned back my suspended license and attended the conference. It was my first experience with the PH Community – which I would later come to see as a PHamily. I learned so much about living with this disease, but more importantly, the patients and caregivers I met were so friendly and inspiring that I learned from them that there can be life after diagnosis. For the first time in months, my outlook was positive.

Shortly after I returned home, two nurses in Fresno started a support group and we began to form our own PH family. Over the past seven years, I've learned that we are more than just patients coming together to share similar problems – we are all unique people: husbands and wives; mothers and fathers; brothers and sisters; sons and daughters – all coming together to help to us cope and support each other, and sometimes even laugh and cry together. In short, we are a PHamily.

I'm grateful for all this community has given me, so I feel a desire to give back. In 2010, I was asked to be a co-leader of our support group, and I soon became active in advocacy. With the help of our members, we've convinced several local congressmen to co-sponsor each of the last three PH bills in Congress. In 2011, I had an idea to ask our state capitol to issue a proclamation for Awareness Month. But I wanted our representatives to be aware of the power and scope of this PH community, so I contacted all the California leaders asking permission to include their names in the request. I began friendships with many, but one became special – Susie Alvarez from Los Angeles.

Susie and I, both from California, finally met in person in Florida (of all places) at the 2012 PHA Conference. We began a friendship and over the next 18 months would see each other more frequently at various PH-related events. Soon I began to develop feelings for her beyond friendship, but I was reluctant to admit it. Being middle-aged with PH gave me confidence issues, but Susie sensed my feelings and coaxed me to admit them. When I explained my reluctance to her, she told me that I was wrong – that having PH is no reason to deny ourselves the things that make life worth living. If anything, it's a reason to embrace life even more. We've been together for almost three years now, and became engaged last summer.

Looking back, I remember how angry I was after my diagnosis. Today, all I feel is gratitude for all I've received since then. I'm grateful for my friends and relatives, my healthcare team, the devoted staff at PHA, and to all of you – this amazing PHAMILY. But most of all, I'm grateful for Susie, who showed me that hope and love is still possible with pulmonary hypertension.

Susie Alvarez, Los Angeles, CA

Hello PHamily!! Happy Father's Day!!

You may be asking yourself how YOU are connected to each person in this room who has joined our group today for Brunch. Let me begin by giving you a positive Message of Hope. We are all ONE PHamily looking towards the day a cure for Pulmonary Hypertension is found. The global PH community is counting on each one of you to join the global cause to help find a cure for PH by getting involved and motivated to raise awareness of this chronic, life-changing, often misdiagnosed, complex, and rare disease. Invite your family, friends, and community members to join you in educating the community by sharing your PH story. Each story is unique and only you as a patient, caregiver, family member or friend who's life has been touched by PH can tell it!!

The story of MY journey begins in 1983. At the young age of 21, I moved to Los Angeles to accept a full time job. My life was full with family events, work projects, vacations, and much fun and promise. While attending evening college classes for working adults, I began to notice I was short of breath during my busy day. I continued to keep up with my daily work routine, but had to drop my college exercise classes as I could not keep up with the physical activity the courses required.

However, on June 30, 1992, my life was forever changed. Without warning, I had a crushing pain in my chest as though someone was sitting on it. The paramedics arrived and took me to Cedars Sinai Hospital in Los Angeles. During the week I was there, several tests were performed each day to find out why I was so sick. I remember coming in and out of consciousness and not knowing what day or time it was. Then on the morning of Saturday, July 4, 1992, the pulmonologist entered my room and gave me news that would forever change my life. He says "We found out what's wrong with you. You have pulmonary hypertension, which is a fatal lung condition for which there is no cure. Go home, get your affairs in order, and the best we can tell you is that you have five years to live. We will send you home with an oral medication (Vasotec) to delay the progression but your illness will progressively get worse, and eventually you will need a lung transplant." Then he left the room.

My mind went into a fog, I felt so confused and very scared. I was hyperventilating through my tears. My family lived miles away and I did not have the strength to pick up the phone and call them. I was alone in a cold hospital room and had just received the most devastating news someone could ever hear. I remember grabbing the nurse by the arm, crying all night, asking: WHAT IS PULMONARY HYPERTENSION AND HOW DID I GET IT?

Over the next four years, my symptoms progressively worsened. I was short of breath, fatigued, and dizzy most of the day. In 1996, I was referred to a PH center for further treatment. My life was forever changed again when I visited the Liu Center for Pulmonary Hypertension in Torrance, Calif. I met a cardiologist, Dr. Ronald Oudiz, and his mentor and PH center director, Dr. Bruce Brundage, who knew what PH was and how to treat it. I was also referred to UCLA Medical Center, evaluated and placed on the transplant list for a double lung transplant. I did not know at that time, but the therapy I was placed on, an IV medication (epoprostenol-Flolan) delivered by a medical pump, was the ONLY FDA approved medication available at that time to treat PH. I remained on the transplant list for 13 months. The IV Flolan was slowly improving my quality of life and I was removed from the transplant list.

In 1996 I began attending local support groups and PH-related events nationwide. In 2011, I volunteered to become co-leader of the Greater L.A. PH support group at UCLA Medical Center/VA Hospital, Los Angeles. I reflected on my journey at this stage of my diagnosis and believed that helping others' in their time of need is a confident and selfless act that all of us can achieve every day. I had personally benefited by the generous donations of time, research, and funds gifted by many generous donors to PHA, people like yourself here today who have saved my life in so many ways, and felt the call to "give back" by volunteering my time to support other patients who were diagnosed with PAH.

I attended the 2012 PHA International Conference in Orlando FL. While volunteering at the registration desk, I met Perry Mamigonian, a support group leader and PH patient who had emailed me the year before seeking support of other Ca support group leaders to secure a proclamation for November's PH Awareness month. Diagnosed only 3 years, Perry was inspired to meet a long term survivor of 20 years. I clearly remember Perry reaching out and giving me a hug, expressing his message of inspiration to me that he had never met a long term PH survivor!! We chatted and exchanged contact information and continued to communicate after Conference.

In 2012, I attended PHA's Congressional Luncheon/Lobby Day at the Capitol in Washington, D.C., to seek co-sponsorship of the Pulmonary Hypertension Research and Diagnosis Act (H.R.2073) and the importance of early diagnosis through PHA's Early Diagnosis Campaign Perry was also invited to join the group for the luncheon. The night before the luncheon, Perry and I enjoyed dinner and took a walk around downtown Silver Spring, MD sharing our journey stories together. We talked about my experience living alone with a rare disease and the amazing amount of support the PHA Conference provides to patients and families and the opportunity Lobby Day provided to meet with members of Congress and advocate for PH causes that would help many patients.

After Conference, we continued to support and attend PHA events in California. We traveled 210 miles to visit one another in our home towns of Los Angeles and Fresno, attended CA PH support group meetings, special events, and PHA California Chapter events. We discovered we shared a love to volunteer as support group leaders and were inspired to fundraise and accept speaking invitations asking us to share our stories of hope. The Fresno CA and Greater L.A. PH support groups of Southern California each founded and host an annual fundraising Walk. We are so inspired to see the PH community gather and watch the attendance grow larger each year.

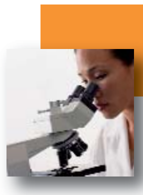
I felt in my heart I had found a special person who loved me for who I was, who accepted the PH journey I had experienced, and looked forward with excitement for what we planned to accomplish together, (pause) as co-patients and caregivers in love. Our PH doctors and nurses expressed AMAZEMENT at our union and gave their support to get our story out to other patients who need to hear of patients, like us, who are living life and surviving their diagnosis!!

I'm often asked why I do so much for PHA. My answer is that I was once a newly diagnosed patient, living alone, and so afraid of dying without understanding PH. I've survived beyond the five-year timeline that I was given 24 years ago. My journey was not easy by any means. As a long-term survivor, every day is a blessing for me and keeps me motivated to work towards awareness, support, and hope for a cure.

Thanks so much for allowing us share our journey stories with you today. Please continue to support the efforts of the Pulmonary Hypertension Association and the PHA Chapters. Your efforts WILL help so many lives in unbelievable ways.

11. FASHION SHOW

It would be remiss of me not to mention the Fashion Show which was held during the course of the Conference. Many patients modelled casual, business & formal wear which allowed the concealment of pumps. However, I think everybody would agree that the children stole the show! The event was co-hosted by Eliana Elderete, who was diagnosed with PH when she was 6 months old and celebrated her 13th birthday in July this year. She is on IV Remodulin and was the first PH patient to undergo the non-traditional Potts Shunt in New Mexico. Eliana won the Outstanding Young PH Citizen award at the meeting.



UPDATE ON PH TREATMENTS AND RESEARCH

UPTRAVI (SELEXIPAG)
MARKETING AUTHORIZATION FROM THE EUROPEAN MEDICINES AGENCY

Selexipag (commercial name "Uptravi") was granted marketing authorisation valid throughout the European Union on 12 May 2016. Uptravi had previously been approved by the U.S. Food and Drug Administration (FDA) on December 21, 2015.

Uptravi belongs to a class of drugs called "oral IP prostacyclin receptor agonists". The drug acts by relaxing muscles in the walls of blood vessels to dilate (open) blood vessels and decrease the elevated pressure in the vessels supplying blood to the lungs. It is a drug targeting the prostacyclin pathway in PAH. Uptravi is indicated for the long-term treatment of PAH in adult patients with WHO functional class II-III, either as combination therapy in patients insufficiently controlled with an endothelin receptor antagonist (ERA) and/or a phosphodiesterase type 5 (PDE-5) inhibitor, or as monotherapy in patients who are not candidates for these therapies. GRIPHON, a global, RCT multicenter pivotal Phase III study, was designed to demonstrate a prolongation of time to the first morbidity/mortality event for selexipag compared to placebo and to evaluate the safety of selexipag in PAH patients. Uptravi was shown to be effective in reducing hospitalization for PAH and reducing the risks of disease progression compared to placebo. Participants were exposed to Uptravi in this trial for a median duration of 1.4 years. Common side effects observed in those treated with Uptravi in the trial include headache, diarrhea, jaw pain, nausea, muscle pain (myalgia), vomiting, pain in an extremity, and flushing.

Uptravi is marketed in Europe by Actelion Pharmaceuticals, Switzerland.

Source: http://bit.ly/2as2PVM

2016

August 31-September 4, Rome, Italy
EUROPEAN SOCIETY OF CARDIOLOGY ANNUAL CONGRESS
PHA Europe will be present at the European Society of Cardiology's Annual Congress 2016. This Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines from basic research to clinical practice.

September 3-7, London, UK
EUROPEAN RESPIRATORY SOCIETY ANNUAL CONGRESS
PHA Europe will also be present with a booth at the European Society for Respiratory Medicine's Annual Congress 2016. This Congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

September 15-18, Barcelona, Spain
PHA EUROPE ANNUAL PH EUROPEAN CONFERENCE
The Annual PH European Conference (APHEC) is one of PHA Europe's most important yearly events. It provides PH patient leaders with the opportunity for sharing information and experiences, mutual learning, networking, education and skills development. PH Patient Leaders from 31 European countries attended the 2015 meeting.

October 14-15, Sophia Antipolis, France
ESC EDUCATIONAL COURSE ON PH
This yearly international course has as its target audience mainly cardiologists, pulmonologists and other specialists involved in PH care. PHA Europe is regularly invited to attend and to present the patient perspective in the context of the G6, a meeting which brings together the major stakeholders in PH.

EUROPEAN SOCIETY OF CARDIOLOGY

EURORDIS
Rare Diseases Europe

November 3-4, Paris, France
EURORDIS COUNCIL OF EUROPEAN FEDERATIONS (CEF) MEETING
The Council of European Rare Disease Federations provides a platform for the exchange of experiences and information across federations working for different diseases or group of diseases.

2017 AT A GLANCE
- Eurordis Awards & Black Pearl Evening 2017, *Brussels, Belgium, February 21*
- European Society of Cardiology's Annual Congress, *Barcelona, Spain, August 26-30*
- European Respiratory Society Annual Congress, *Milan, Italy, September 9-13*
- PHA Europe Annual PH European Conference, *Barcelona, Spain, date to be defined*

Next PHAE newsletter
The next Mariposa Journal will be issued in December 2016 (Winter edition). The main focus will be the reports of 2016 activities from the national member associations. It will also include news of activities from other associations around the world, updates on research and treatments and any other interesting and relevant developments at European level. We would be very grateful if the members could send their contributions by the **30th of October at latest.** These may be sent in the national language and we will provide for translation. Any photos should have a minimum resolution of 1 MB. The newsletter will be available in PDF format and in a printed version. The PDF will be posted on the PHA Europe website. Printed copies will be sent by normal post to the national associations. *Many thanks in advance!*

Members of PHA Europe and contact details

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BELGIUM

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

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

BOSNIA AND HERZEGOVINA

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

BULGARIA

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

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

CROATIA

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

CZECH REPUBLIC

Sdružení Pacientů s Plicní Hypertenzí, z.s.
Bělehradská 13/7 - 140 00 Praha 4
www.plicni-hypertenze.cz
info@plicni-hypertenze.cz

DENMARK

PAH Patientforeningen
c/o Kristian Weber Thomsen
Ole Bruuns Vej 5, 1
DK 2920 Charlottenlund
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FINLAND

Suomen PAH-potilasyhdistys ry. PHA Finland
c/o Tuulia Näppi
Keskijuoksu 19 J 38 - 02920 Espoo, Finland
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FRANCE

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c/o Ludivine Chantraine
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21380 Asnières les Dijon
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pulmonale hypertonie e.v.
Rheinaustraße, 94
76287 Rheinstetten
www.phev.de - info@phev.de

GREECE

H.P.H - Πνευμονική Υπέρταση Ελλάδας
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info@hellenicpulmonaryhypertension.gr
www.hellenicpulmonaryhypertension.gr

HUNGARY

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IRELAND

PHA Ireland
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56 Eccles Street, Dublin 7, Ireland
http://www.pulmonaryhypertension.ie/pha-ireland/
rprenderville@mater.ie

ISRAEL

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13 HaShoshan Street - Beit Shemesh 99590
Israel
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ITALY

Associazione Ipertensione Polmonare Italiana Onlus
Via della Spiga, 10 - 06135 Ponte S. Giovanni-PG
www.aipiitalia.it - presidente@aipiitalia.it

Associazione Malati di Ipertensione Polmonare Onlus
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www.assoamip.net - info@assoamip.net

LATVIA

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LITUANIA

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

NETHERLANDS

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

NORWAY

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

POLAND

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Wladysława IV 34a m.15, 81-084 Gdynia
www.phapolska.org
Alicja.morze@phapolska.org
Agnieszka.bartosiewicz@phapolska.org

PORTUGAL

Associação Portuguesa de Hipertensão Pulmonar
Avenida Dr. Luis Navega, 38-42 - 3050 Mealhada
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REPUBLIC OF MACEDONIA

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

ROMANIA

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

RUSSIA

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

SERBIA

Plućna Hipertenzija Srbija
ul. Ratka Jovića 17
18210 Žitkovac - Republika Srbija
danijela@pesic.rs

SLOVAKIA

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

SLOVENIA

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Slovenska 29, 1000 Ljubljana
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SPAIN

ANHP Asociación Nacional de Hipertensión Pulmonar
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informacion@hipertensionpulmonar.es

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

SWEDEN

Nätverket för PAH
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Kärrtorpsvägen, 37
121 55 Johanneshov
www.pah-sverige.se - patrik@pah-sverige.se

SWITZERLAND

Schweizer PH-Verein (SPHV) für Menschen mit pulmonaler Hypertonie
c/o Bruno Bossard
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President: praesi@lungenhochdruck.ch
Webmaster: bosshard@lungenhochdruck.ch

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

TURKEY

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UKRAINE

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Ukraine Association of Patients with Pulmonary Hypertension
Panasa Myrnoho str.,14 (litera A)
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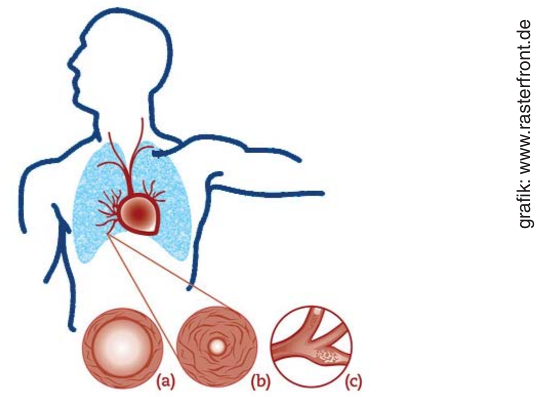
AIMS OF PHA EUROPE

Pulmonary Arterial Hypertension causes breathlessness and is a rare, progressive and currently incurable lung disorder. PHA EUROPE, European Pulmonary Hypertension Association, was founded in 2003 and is registered in Vienna, Austria, as an international non profit organisation. PHA EUROPE is an umbrella organization bringing together 39 Pulmonary Hypertension patient associations from 33 countries 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.



grafik: www.rasterfront.de

- 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 is an ever increasing number of therapies available for the effective treatment for Pulmonary Arterial Hypertension, which improve the quality and length of life. The aim for the present should be to ensure that all patients with Pulmonary Arterial Hypertension have access to centres of excellence in the diagnosis, management and ongoing treatment of this disease.

PHA EUROPE
European pulmonary hypertension association

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