



PULMONARY HYPERTENSION Mariposa Journal

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GIANT FERRIS WHEEL IN VIENNA TURNS BLUE IN HONOUR OF WORLD PH DAY!



Editor's memo

Summer 2015 edition

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Dear members, supporters, friends and families,

the Summer Mariposa is here! We know you have been looking forward to this special edition featuring the exciting array of events you all conducted to mark World Pulmonary Hypertension Day (WPHD) 2015. Carrying on the theme from previous years, your “Get Breathless for PH” activities have been truly inspirational including flashmobs, sporting events, social media activities and even a new World Record! We want to thank you warmly for your continued support, dedication and hard work in raising awareness, educating the public, lobbying for improved treatment options and optimal care for those living with PH.

Through our joint efforts, a little known condition, pulmonary hypertension (PH), is increasingly being made known across the world. More and more celebrity endorsers and influential public figures are joining our cause, including political leaders and health ministers, sporting heroes such as The World’s Strongest Man, Franz Müllner, Olympic Gold Medal swimmer Federica Pellegrini, World Champion free diver, Goran Čolak, as well as the world-known Riverdance group, rock bands "Beni and Non Stop" and "Neverland" and singing sensation Iván Gardesa. These are only a handful of the big names that pledged their support and proudly stand in solidarity with PH patients - it’s incredible to see them sharing in our successes and raising the profile of PH.

Twenty five countries in Europe united together this year to “Get Breathless for PH”, with each country



putting their own unique twist on events, ranging from Irish dancing from our Gaelic friends in Ireland to the breathtaking feat of climbing the snowy peaks of Rysy Mountain by members and supporters of the Czech and Slovakian associations. WPHD activities took place in many other countries across the globe including Australia, Canada, China, Latin America, the Middle East and the U.S.A - meaning PH awareness was spread across 45 countries in five continents!

This year we also introduced the #BreathofSuccess initiative to the campaign, an educational, story-sharing activity that aims to increase understanding of chronic thromboembolic pulmonary hypertension (CTEPH), the only type of PH to have potentially curative surgery without having to resort to lung transplant. One of the highlights of the #BreathofSuccess campaign was the inspirational film of Gabriele, who underwent successful thromboendarterectomy surgery for CTEPH. His account of the severe limitations with the disease prior to surgery, to post surgery and being able to play and coach the sport he loves again was truly touching to watch. #BreathofSuccess continues throughout the year and we hope to see many more positive stories being shared!

This year again the media played a vital role in accelerating the reach of WPHD. Due to all of your amazing work and newsworthy activities, we generated over 500 press/online articles, and almost 100 TV/radio broadcasts! Social media also proved to be a great platform to drive momentum and helped us to spread our messages even further. The PHA Europe Facebook and Twitter pages received a huge surge in page visits and “likes” throughout the campaign indicating increased levels of engagement.

For the second time in the history of WPHD, we launched our “Thunderclap” online social media campaign: 158 people signed up to send out a coordinated message from their Facebook, Twitter and Tumblr channels on May 5, garnering a social reach of 139.694 people - a rise from last year! Over 2.125 uses of the #WorldPHDay and #BreathofSuccess hashtags ensured that PH featured

prominently in the online health and public policy conversation.

More success came in the form of our collaboration with the Ironman European Tour, as it proved once again to be a powerful outreach initiative. As the Official Charity Partner of the Ironman European Championship in Frankfurt our presence at the race exposed our message to thousands of spectators and our articles in the official Ironman newsletters ensured thousands more found out about PH. Six brave athletes took part in the grueling triathlon proudly wearing our branded race suits on behalf of PHA Europe and thousands “rang the bell” under the “Get breathless for PH” branded arch on a hot spot of the race course to raise money for the local German PH association - pulmonale hypertonie e.v.

All of these inspiring activities were supported by our updated WPHD toolkit, as well as a whole host of branded materials which you all put to great use, judging from all the fantastic photos taken!

As I close, I want to thank each and every one of you again for your remarkable contribution and perseverance in our pursuit for improved treatment and care for those living with PH. A very big thank you also to our industry partners, Actelion and Bayer Healthcare, whose partnership and dedication to WPHD has allowed us to grow from strength to strength every year.



As you turn to the next page and bear witness to all of the successes we have achieved in 2015, let us take this time to celebrate our collective accomplishments and to look forward to even more success in the future.

Gerald Fischer
PHA Europe President

See more WPHD and IRONMAN photos at:
<https://www.facebook.com/pages/Pulmonary-Hypertension-Association-Europe/141060385915366>

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WPHD 2015 - AUSTRIA

WORLD'S STRONGEST MAN ACHIEVES NEW WORLD RECORD TO MARK WPHD

In support of WPHD, the strongest man in the world, Franz Müllner, achieved a new world record by exercising for an extraordinary ten hours on top of one of Austria's most famous sights, the Wiener Riesenrad (Viennese Giant Ferris Wheel) to show how exhausted a patient with PH feels on a normal day doing everyday activities.

At 9am, Gerry Fischer, President of the Austrian Patient Association, Werner Gruber, a famous television personality and Karlheinz Hora, the borough mayor, gave the starting signal for Franz to begin his impressive world record attempt. Hundreds of spectators gathered to watch the world's strongest man lift 240.000 kg and ride 200 km on a bicycle at a height of 65 meters.

PHA Austria's booth was directly in front of the Wiener Reisenrad and next to the main entrance of the Viennese Prater. For a donation of €15 minimum, visitors could buy a ticket to enter the VIP cabin to watch Franz Müllner complete his world record attempt. In addition, ticket holders received a "Get Breathless for PH" T-shirt, a blue lips lollipop and a blue balloon, in support of WPHD. The Vienna giant ferris wheel was lit up in our color blue

for WPHD. The event created high media interest, and journalists were able to hold exclusive interviews with the world's strongest man.

Congratulations to Franz Müllner, who achieved a new world record in support of WPHD!

See video at:

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

A dream comes true for 7-year-old PH patient

In addition to the world record attempt, PHA Austria was also able to grant 7-year-old PH patient Johannes' wish of riding in a Lamborghini. Police escorts gave him an exciting tour through the city of Vienna and Johannes even got to sit on Franz Müllner's bespoke motorbike!

Gerald Fischer
Selbsthilfegruppe Lungenhochdruck
www.lungenhochdruck.at
www.facebook.com/pages/Lungenhochdruck-Austria/141174239237050





WPHD 2015 - BELARUS

BELARUSIAN PH ASSOCIATION CAREGIVING TRIUMPH



The Belarusian Pulmonary Hypertension association, “PH Patient Help”, hosted an interactive day to educate and raise awareness of PH for WPHD this year. The event, held at the Minsk Regional Hospital (Belarusian Medical Academy of Post-graduate Education) - an institution providing essential advice and training for medical professionals - provided the opportunity for a lively discussion surrounding treatment and management of PH amongst physicians, patients and caregivers. An inspirational speech by Aksana Sniazhko, President of “PH Patient Help”, opened the proceedings, highlighting their efforts to support people living with PH in Belarus. Professor Igor E. Adzerikho MD, member of the European Society of Cardiology and Professor of Clinical Pharmacology and Therapeutics, also attended the event and spoke about the complexities of the condition.

Thanks to the efforts of patients, caregivers and association members involved in the meeting and ongoing campaigning efforts, the Cardiology Center at Minsk Regional Hospital agreed to provide free hospitalization and monitoring of PH patients every six months.

After the event, attendees including patients and caregivers participated in a series of group activities including a yoga class - introducing useful breathing exercises. These activities provided an opportunity to reflect as a group on personal experiences of living with PH. The day ended with the triumphant release of balloons into the air during a group flashmob - spreading the PH message far and wide.

Alongside the caregiving triumph, news about the event spread throughout the country as national newspaper Belarus-MTZ Review reported on the day's proceedings - ensuring more and more people across Belarus are educated and aware of PH.

Aksana Sniazhko,
PHA Belarus

<https://www.facebook.com/groups/phaBelarus/>



WPHD 2015 - BELGIUM

MORE THAN JUST A DAY: BELGIUM HOSTS AN EXCITING 3 MONTH PROGRAM OF WPHD ACTIVITIES

A whole host of events were conducted in Belgium to mark WPHD across a three month period, reinforcing the fact it is important to raise awareness of pulmonary hypertension on an ongoing basis, beyond May 5 itself.

WPHD gains wings

Seven brave runners including Stephanie Gross, the stepmother of a little girl who was diagnosed with PH, took part in the Wings for Life World Run held in Breda, The Netherlands. Collectively the group rose close to €4.000 in donations for the local PH association - a great result that will really make a difference.

Heracles Lier Hockey Club ‘Get Breathless for PH’

The all-female hockey team proudly displayed their support for PH patients by wearing the “Get Breathless” campaign T-shirts during one of their league games. The team put in a fantastic performance winning the match 3 -0!

Out of the Blue! Blue Lips Campaign rallies support from local school children

Alongside the “Get Breathless for PH” activities, the Blue Lips Campaign saw school children, teachers and families paint their lips blue in solidarity with PH patients. They also assembled in a lip formation and released blue balloons with cards attached to them - upon the cards were messages of hope and support written by the children and members of the Belgian PH association.

Mid-summer night's run in Ghent

In June, “Get Breathless for PH” activities continued on when over 5.000 runners participated in a 10 km run in the city of Ghent. More than 70 of these athletes ran especially for the Belgian PH association to raise awareness of this devastating condition by wearing “Get Breathless for PH” T-shirts.

An exercise in empathy

A popular flea market in the region of West Flanders had a different type of stall on June 28. A





PH stand was set up where tourists were encouraged to “get breathless” by running on a cross trainer with a nose clip and breathing through a straw to experience the symptom of breathlessness associated with PH. The exercise proved very successful, with many remarking on the difficulty of such a task and empathizing with those who live with this condition every day.

Flashdance! Dancing flash mob helps raise awareness of PH among general public

On Saturday, July 11, the Belgian PH association joined forces with the Inner Motion dance company to treat onlookers with an impromptu performance. The spectacle grabbed the attention of passers-by in the Torhout market. Alongside the dance, local volunteers educated members of the public about the impact of PH and how they could support the WPHD cause.

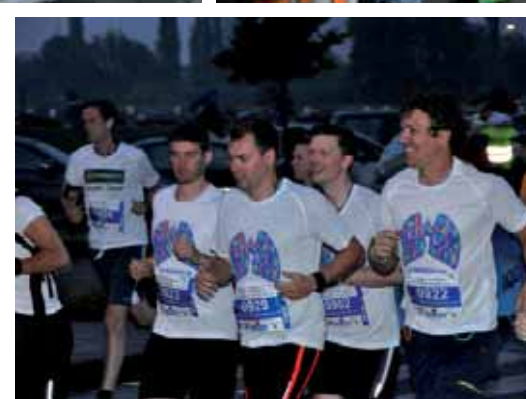
All of these great events are captured on the new bilingual (French and Dutch) PH website which was launched by PH-VZW and HTAP Belgique on May 5. Make sure you take a look: www.ph-vzw.be

Hendrik Ramaker

Patiëntenvereniging Pulmonale Hypertensie vzw

www.ph-vzw.be

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



WPHD 2015 - BOSNIA AND HERZEGOVINA

TAKING A BIG BREATH FOR PH

The PH association for Bosnia and Herzegovina, the “Association of Citizens Suffering from PH”, hosted a sports day in a local gymnasium. Over 120 pupils from the local school were invited to participate in the “BREATH” physical exercise activities at Rizah Odžekić Zavidovići gymnasium, alongside WPHD supporters. Activities included a 6 Minute Walk Test, breathing through straws and balloon blowing competitions - to simulate the feeling of breathlessness that people with PH experience on a daily basis.

The “BREATH” activities drew the attention of local media who attended to witness young and old “get breathless” for people with PH. The event was reported in a number of local publications including B&H, Dnevi avaz, Federalna ba and News Blic.

Vera Hodzic, Udruženje gra ana oboljelih od plu ne hipertenzije “DAH” - u Bosni i Hercegovini

<https://www.facebook.com/pages/Plu%C4%87na-hipertenzija-BiH/265476183610173>





WPHD 2015 - BSPPH BULGARIA

THOUSANDS GATHER TO CLIMB STAIRS AND “GIVE BREATH” FOR WPHD IN BULGARIA



WPHD Media launch

The Bulgarian Society of Patients with Pulmonary Hypertension (BSPPH) launched its 2015 WPHD event on April 29 with a media conference, held in the Bulgarian News Agency (BTA). During the press conference emphasis was given to the serious problems and challenges faced by patients with PH in Bulgaria, as well as on the need to raise awareness of the disease with health professionals and the Bulgarian general population, especially for people from small towns. One of the topics discussed was CTEPH and pulmonary endarterectomy (PEA) surgery opportunities. For the third consecutive year, the BSPPH marked the World Day of Pulmonary Hypertension, and the event of May 5th was held under the auspices of the Mayor of Sofia Yordanka Fandakova and supported by the Bulgarian Society for Lung Diseases and the National Patient Organization. For the first time, the campaign had a formal media partner - the Bulgarian National Television.

“Give breath” initiative

On May 5, the Bulgarian Society of Patients with Pulmonary Hypertension invited people to climb stairs and “Give Breath” in front of the National Theater “Ivan Vazov”, in the City Park, to show their support to those affected by pulmonary hypertension. Dr. Stanimir Hasardzhiev and Natalia Maeva, Chairman of the BSPPH and a PH patient herself, attended the official opening of the event, where a 1.6 m purple staircase was installed in front of the theater, situated in Sofia, Bulgaria. For many PH patients, climbing stairs is an activity that can be very difficult. The campaign, “Give Breath” aimed to raise awareness amongst the public of the issues PH patients face every day. The Mayor of Sofia, Yordanka Fandakova, supported the event in



which thousands participated, including some famous faces! In return, participants received a “Get Breathless for PH” T-shirt, educational materials and blue lollipops in the shape of lips.

The Minister of Healthcare, Dr. Petar Moskov, formally supported the WPHD campaign by sending a congratulatory address in which he pointed out that "prevention and early diagnosis of rare diseases are one of the main priorities of the current management of the Ministry of Health. Please accept my deepest respect for the efforts of all of you who for the third time join the global WPHD campaign. I believe that in future, by means of dialogue and desire for cooperation, we will continue to work together for the sake of our common goal - to prolong survival and improve quality of life of all patients affected by pulmonary hypertension." The event was a huge success, resulting in 140 media coverage clippings, including five television broadcasts, ten radio broadcasts and 123 online and print clippings.

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

www.bspph.net

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



WPHD 2015 - PHA BULGARIA

CELEBRITIES STRIKE A POSE WITH BLUE LIPS FOR WPHD!

In support of WPHD, PHA Bulgaria organized a colorful outdoor exhibition, in front of the National Theatre in the Sofia city center. The exhibition featured posters of local celebrities, including actors, singers and journalists, all of whom had been photographed with blue lips. The celebrities stood in solidarity with pulmonary hypertension patients, who sometimes experience a blue/purple tinge to the lips as a symptom of the condition. Each photo was accompanied by a personal message for PH patients. The exhibition was displayed in the city for two weeks and attracted a large number of people. The exhibition was also accompanied by a PHA Bulgaria stand where PH patients and medical students distributed educational materials to visitors. The exhibition was such a success that PHA Bulgaria is planning to extend the event into other Bulgarian cities next year! Additionally, together with the Agency of Organ Transplantation, PHA Bulgaria organized and con-





ducted two seminars for medical students. The main topic of the first seminar was PH, including discussions around organ donation and transplantation. Students were very lucky to also attend a seminar led by Prof. Walter Klepetko, a renowned transplant surgeon from Austria, on “Non-malignant lung diseases”. As a thank you for his participation, PHA Bulgaria presented Prof. Klepetko with an icon of St. Ivan Rilski, protector of Bulgarians, on behalf of patients with PH in Bulgaria.

Todor Mangarov, PHA Bulgaria

www.apph-bg.org

<https://www.facebook.com/aph.bulgaria>



WPHD 2015 - CROATIA

CROATIAN WPHD PREMIER “SWIMMING” IN SUCCESS

This year, the WPHD community expanded to another country as supporters in Croatia joined the campaign for the first year! World free-diving record holder, Goran Čolak, launched the events in May with a diving activity. For this “Breath of Success” event, members of the public were invited to dive with Goran and professional divers in a swimming pool set up in the center of Zagreb. Diving is an activity which challenges your ability to breathe. This experience is much like the struggle for breath that people with pulmonary hypertension experience on a daily basis when carrying out everyday tasks. Alongside the swimming pool, a photography exhibition also showcased underwater moments under the theme “Breath of Success”.

To add their voices to the campaign, the Mayor of Zagreb, Mr. Milan Bandić, attended the proceedings

alongside members of the City Council and physicians. Mr. Bandić made a pledge to support people with PH wherever possible, demonstrating the importance of events such as these to spread awareness amongst policy makers, as well as the general public.

Thanks to the work of the organizations - PHA Europe and Blue Wings - the first Croatian WPHD activity was a resounding success, providing the first opportunity to speak publicly about this debilitating condition. The local media, including television, radio and online outlets, also attended to report on the “Breath of Success” initiative. Here’s to the second event in Croatia in 2016!

Zdenka Bradac, Plava Krila

<https://www.facebook.com/pages/PH-Plava-krila-Croatia/1580485492196960?fref=ts>

<https://www.facebook.com/pages/PH-Plava-krila-Croatia/1580485492196960?fref=ts>





WPHD 2015 - FRANCE

CANDLES SHINE A LIGHT ON WORLD PULMONARY HYPERTENSION DAY IN FRANCE

HTAP France launched a campaign asking people to take photos of themselves blowing out candles and to share the pictures on the association's Facebook page. People living with PH, their friends, families and colleagues took part in the mass "blow out" with each providing a unique twist in their snapshots.

The campaign was supported by highly regarded key opinion leader, Professor G rald Simonneau and his Pulmonology Department at Bic tre Hospital

located in Le Kremlin-Bic tre. This support saw cardiologists, pulmonologists, nurses, and administration staff all getting involved to show their solidarity, and to raise awareness of this life-threatening condition.

M lanie Gallant-Dewavrin, HTAP France

www.htapfrance.com

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



WPHD 2015 - GERMANY

POSE FOR THE CAMERA: GERMANY BRINGS WPHD INTO FOCUS

For WPHD in Germany, people pouted and posed for photographs to add to a giant blue lips photo collage as part of the "Blue lips initiative", a contribution to raising awareness of pulmonary hypertension. Following the blue lips photo session, people were invited to get involved in a static cycling challenge. For every image taken and kilometre cycled, Bayer donated  1 to support patients with PH, raising a grand total of  1.112,50!

Blue lips are one of the key signs of breathlessness seen in PH patients and activities like this make it possible that we continue to raise awareness of and increase understanding of PH to ensure early and accurate diagnosis.

The Hospital Martha-Maria Hall-D lau, with 200 photos of blue lips and 9.2 kilometers cycled, was the most successful participant of the action.

R ttges, Roland Koch Woehlte and Thomas Kleckers, a "family reunion", were running the Baden-Marathon Karlsruhe for our project also last year, wearing the T-shirts of PHA Europe and the ph ev. Our "Marathon Men" were very often asked about the eye-catching motif and they were happy to pass on information. A great "thank you", because you made a very valuable contribution to raising awareness of PH!



Hans-Dieter Kulla, pulmonary hypertension e.v.

www.phev.de

<https://www.facebook.com/pages/Lungenhochdruck-Deutschland-pulmonale-hypertonie-ev-phev/386143468153378>

Marathon Dream Team pulmonary hypertension continues running for PH

On April 25, 2015, the Metro Group Marathon took place in Dusseldorf. The runners Christian





WPHD 2015 - GREECE

SIX EVENTS, THREE CITIES, TWO WEEKS!
GREECE GOES ALL OUT FOR WPHD



The Hellenic Pulmonary Hypertension (HPH) organized six exciting events in Greece to raise awareness of pulmonary hypertension for WPHD this year.

The activities started on April 25, when an all-day educational event was held at the “Mall Athens”, the largest shopping and leisure center in Greece. A team of enthusiastic volunteers distributed information leaflets and flyers inviting the public to upcoming events, whilst HPH’s mascot, Pongo - the rare purple elephant, entertained children and families. Pongo educated the children and families about PH and invited them to wear a purple ribbon in support of WPHD. Hundreds of people stopped tracks in their shopping day to learn about PH and were keen to ask the volunteers about the symptoms of PH. Some people even offered to make donations and wanted to join the volunteer team!

On April 26, the volunteer team and Pongo took part in an international environmental campaign, “Let’s Do It - Greece”, where they helped to clean a school and its surroundings in Dionysos, near the HPH head office. This was a global movement which drew the attention of millions of people across the world. Meanwhile, the Hellenic Athletics Federation organized “Run Greece”, in six major Greek cities. HPH took part in the race in

Herakleion, the capital of the Greek island Crete, which saw more than 4.000 people running, including 150 of the HPH team, to raise awareness of PH among the general public. At the finish line, a swarm of purple balloons were released in the sky to show support for PH patients.

On WPHD itself, a press conference was held at the Theocharakis Foundation, opposite the Hellenic Parliament, in the heart of Athens. The topic was “Pulmonary Hypertension and the situation in Greece 2015”. The panel of speakers included two PH specialists: Dr. Eftychia Demerouti, cardiologist and Head of the PH Unit at the Onassis Cardiac Surgery Center of Athens and Dr. George Giannakoulas, Academic Lecturer in Cardiology and Head of the Adult Congenital Heart Disease Centre at the University Hospital of AHEPA. The press conference was chaired by Ms. Ioanna Alissandrato, President of HPH and a PH patient herself. Over 40 health journalists attended the press conference and over 100 pieces of press coverage were generated.

Additionally, the volunteer team ran an all-day event where HPH representatives educated the general public, as well as hundreds of tourists, about the causes, symptoms and prognosis of PH, distributing information leaflets and purple ribbons. This



also provided an opportunity to reignite the “Selfie for PH” campaign, where passers-by took “selfies” in front of HPH’s banner, holding their noses.

Finally, the highlight of the WPHD calendar was the annual bike ride through Athens. HPH’s stand was situated outside the Hellenic Parliament, in the city center and the bike ride’s starting point was at the Tomb of the Unknown Soldier. Hundreds of white balloons with the slogan “Take a Breath” were given to participants, to take on their journey through the historic sites of the city, to support PH patients. The atmosphere through the city was incredible and the turnout was higher than ever before! T-shirts, hats and medals with the “Take a Breath” slogan were also given out to cyclists crossing the finish line.

To top off the big finale, balloons were released to the sky over the Hellenic Parliament and Athens city center. The series of exciting events was extremely successful in bringing together PH patients, carers, families, friends, specialists and volunteers from all over Greece, to raise awareness of PH.

Ioanna Alissandrato, PHA Greece
www.hellenicpulmonaryhypertension.gr
<https://www.facebook.com/HellenicPulmonaryHypertension?fref=ts>



From left to right, Dr. George Giannakoulas, Ioanna Alissandrato and Dr. Eftychia Demerouti





WPHD 2015 - HUNGARY

HUNGARY GOES “CRAZY” FOR WPHD!

Each year, over 3.000 athletes participate in a three day race around one of the biggest lakes in Hungary, Lake Velence. This year, PHA Hungary collaborated with the event, known as the “Crazy Triathlon”, to help people understand the symptoms of pulmonary hypertension. The event was open for anyone to take part, including families and professional athletes.

The exciting event included different cycling races, such as mountain biking, road cycling and family tours with games, as well as swimming and running races. The aim of the races was for participants to cover as much distance as possible within 30 minutes. Similarities were drawn with the six-minute walk test for PH patients and the races enabled people to better understand the main symptom of PH - breathlessness. PH expert and Vice-President of PHA Hungary, Dr. Kristof Karlocai, also gave a presentation to participants, who were eager to learn more about PH.

The event attracted people of all ages and all walks of life. The youngest volunteer was 12-year-old Tibor Gergely Csabuda, who ran on behalf of “Get Breathless for PH” and achieved a 55km distance in the Cycling Mini Marathon on the second day - it was a great achievement! PH IRONMAN Ambassador, Robert Szaniszló, achieved second fastest racer in the running competition and PHA Europe Board Member, Gergely Meszaros, also participated in the event. Eszter Csabuda, President of PHA Hungary, closed the day's events, com-

menting, “We did not expect this event to be such a success. We met so many people and really raised awareness of PH. I would like to thank all the assistance we received from the patients and volunteers. Same time next year! Get Breathless for PH!”

Hungarians reflect on PH by the waters of River Danube

Meanwhile, in the city of Vác, WPHD events were a vision of serenity as over 50 people took part in a 50 minute yoga class by the River Danube. Amongst the participants taking part in the “Surya Namaskar” yoga exercise were members of PHA Hungary, yoga fans, PH family members and friends. Young and old took part, with even toddlers getting involved in the breathing and stretching movements! For the other children, a bouncy castle encouraged everyone to “Get Breathless of PH” whilst arts and craft activities took place on the shores of the river. The event finished with a group photo - a #SelfieforPH - with all those who had helped bring PH awareness to the streets of Vác.

Eszter Csabuda, Tüdőér Egylet

www.tudoer.hu

<https://www.facebook.com/pages/T%C3%BCd%C5%91%C3%A9r-Egylet/151123348280359?fref=ts>

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Egylet/151123348280359?fref=ts





WPHD 2015 - IRELAND

RIVERDANCE CAST KICK HEELS TO THE SKY FOR PH

Toes were tapping as the cast of “Riverdance” joined the WPHD campaign in Dublin alongside PHA Ireland. The world-famous dance troupe performed a routine while wearing the “Get Breathless for PH” T-shirts, in a spectacle of fast-paced Irish dancing, to help raise awareness of PH.

Regina Prenderville, from PHA Ireland, commented: “Pulmonary hypertension is a dreadful, devastating disease and we are trying to raise awareness of this. We’re asking able-bodied people to “Get Breathless for PH” because people with this disorder are breathless all the time.” The dancing and awareness-raising showcase garnered the attention of key Irish media titles, including the Irish Independent and The Irish Times, who reported on WPHD and the work of PHA Ireland through visual multimedia news articles.

Regina Prenderville, PHA Ireland

Awareness day in Dublin mall

I feel it’s very important to raise awareness about PH here in Ireland. I have lived with this rare

condition for the past ten years and if anybody has ever asked me what my disease is called, they’ve never heard of it! Then I often find myself explaining what it is and how it affects my life. The reply is always the same: “but you look well”!

I recently arranged for an awareness day in my local shopping centre. We had lots of leaflets, explaining exactly what PH is. We handed one of these leaflets to every single customer who passed us by. A lot of them were very interested and wanted to know more. So myself and Sal (my PH pal), explained our condition.

By the end of the day we were exhausted, but felt wonderful that we got our message out. It was a very successful day and I’m looking forward to our next one! My parents, sisters, niece and friends were a fantastic help on the day. I couldn’t have done it without them!

Karen Doherty, PHA Ireland

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

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



WPHD 2015 - ISRAEL

CROWD-FUNDED VIDEO SERIES LAUNCHED IN ISRAEL TO RAISE AWARENESS OF PH

On May 28, crowds from all areas of Israel came together to support WPHD 2015. An extensive event took place at the Soroka Medical Center, in Beer Sheva, in the south of Israel. The south is an area which is populated by all the peoples of Israel (Jews, Arabs, Bedouins) many of whom have in the past not had access to medical care, due to the long distances and efforts required for transport and coordination of treatment. The new center and our work with the center will enable these PH patients and their families to have access to a higher level of PH care and awareness than they have ever known.

Six minute walk test

After a short welcome and light refreshments participants took part in a 6-minute walk simulation and were then asked to blow up a bright blue PH branded balloon. The aim of this activity was to demonstrate the breathless sensation that PH patients experience whilst walking even the shortest of distances.

Crowd-funded video series launch

May 5 celebrations at Beer Sheeva included the presentation of a series of short videos, developed by PH Israel. The videos form part of a crowd-funding

campaign, soon to be launched, based on the theme of “shortness of breath”- raising awareness of PH and encouraging timely diagnosis.

Senior doctors at the new PH treatment center address participants

Whilst dining participants were treated to a series of lectures by PH physicians leading the new treatment center. Other key speakers included the CEO of the PH Israel, who shared insights into the medical benefits afforded to PH patients, a report from the Chairman of PH Israel and a personal story from one of the members, who shared her experiences, her PH coping mechanisms and some anecdotes. This informative and inspiring evening brought people together, helping to raise further awareness of PH and WPHD. As the halls of the hospital were filled with blue balloons, symbolic of the blue lips that are sometimes associated with PH, the participants marching through, in their branded T-shirts, couldn’t be missed by onlookers throughout the hospital.

Maayan Steel, PH Israel

www.phisrael.org.il

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





WPHD 2015 - ITALY AIPI

THE OLYMPIC GOLD MEDAL SWIMMER, FEDERICA PELLEGRINI, JOINS THE TEAM FOR WPHD



AIPI, Associazione Ipertensione Polmonare Italiana, showed their support for WPHD by partnering with Federica Pellegrini, Olympic Gold Medal swimmer. Federica has already taken part in the past in other activities to raise awareness of PH for AIPI and she is now working on a project for 2016. Federica posted a photo of herself sporting a WPHD T-shirt and blue lipstick with Pisana Ferrari, the President of AIPI. Federica also shared the picture on her personal Facebook page, which has 85.000 followers and retweeted it to her Twitter account, with 342.000 followers! The photo was also posted on the AIPI Facebook account (6.000 views) and Twitter page (19.000), making the total social media views an astounding 450.000! What a fantastic response to just one picture!

Pisana Ferrari, AIPI Italy
www.aiipiitalia.it
<https://www.facebook.com/AIPIItalia>



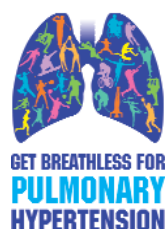
with all the members. Unfortunately, he could not be there in person as he was supporting PH at an important event, the “3rd Focus on Pulmonary Hypertension” meeting. We were also able to share our good wishes with the PH specialists from around the world gathered at the third Focus on Pulmonary Hypertension.

The day ended on a high, with prizes for all the race winners, as well as WPHD T-shirts and educational leaflets for all those that took part.

To learn more about the day, please visit our website below and watch our video. The video can also be found on our Facebook page, the various athletes’ websites and Vimeo - reaching an amazing 2,000 views and counting!

<http://www.assoamip.net/world-ph-day-2015/>

Vittorio Vivenzio, AMIP Italy
www.assoamip.net
<http://on.fb.me/15HMVP0>



WPHD 2015 - ITALY AMIP

ITALY FIGHTS PH IN THE GLADIATORS’ RING FOR WPHD

Members of AMIP, the “Association of Patients of Pulmonary Hypertension” in Italy gathered in a quaint little town called Tivoli - a World Heritage Site known for its art, history and beauty. Everyone met at Bleso Theater, which was once the home of gladiators fighting heroic battles, just like our patients today are fighting against pulmonary hypertension.

The members were joined by local athletes, who ran an amazing 43 km marathon across the famous Villas d'Este, Gregoriana and Adriana. The young athletes of Gricignano Aversa (Naples) also played volleyball in the Bleso Theater, which was situated at the starting line of the race.

On the day, we heard from our Volley Coach, Lello, a PH patient who was one of the first to be diagnosed

with chronic thromboembolic pulmonary hypertension (CTEPH) in Pavia, Italy in 1996. Since his diagnosis many years ago, hundreds of other CTEPH patients have also been accurately diagnosed and undergone life-changing surgery, which has now become a more routine operation in Pavia. Everyone at the event was encouraged by Lello’s positive story and heard first-hand what a huge impact successful treatment can have on a patient’s life.” Many of the athletes who “got breathless” on the day built lasting relationships with the PH patients and empathized with the day-to-day struggles of living with PH - both athletes and patients supported each other to achieve their goals.

Vittorio Vivenzio, President of AMIP, shared his words of inspiration via a video message from Capri





WPHD 2015 - LATVIA

CLIMBING HIGH FOR PATIENTS WITH PH

PHA Latvia's theme for WPHD 2015 centered around the slogan "Appreciate that you can breathe!" campaign, which culminated in a show-stopping finale at the Riga Central Railway Station on Monday May 18. The event started with a media briefing that included an influential panel of speakers: Riga City Council Health Department Chief Inga Solovjova, Latvia's best climber Kristaps Liepins, PH specialist cardiologist Dr. Andris Skride and several PHA Latvia Board Members. After the briefing Kristaps Liepins took to the stage to climb to the 46-meter-high Clock Tower, a famous city landmark. On reaching the top, Kristaps Liepins flew the "flag of hope" representing PHA Latvia in a display of unity with patients across the country. Throughout the evening, cardiologist Dr. Skride, physiotherapist Lina Butane and two volunteers from the Medicine Department, University of Latvia provided expert information about PH to the public. The information tent attracted around 100 people and over 200 people witnessed the incredible climbing display.

To round off the day, we held a flash mob "Share Your Breath!" - which saw over 100 people inflate

balloons as a symbol of support for PH patients. The awareness campaign was covered by a multitude of different media, including TV, newspapers, monthly magazines, radio, internet TV channels and also created a buzz on social media. We also shared the real life stories of PH patients - Liva Brizga and Indra Plume. The Editor in Chief of the magazine "Health" published an interview with Ieva Plume. Overall 85 pieces of media coverage was generated reaching an estimated audience of over nine million!

The campaign was a fantastic success, achieving visibility and public awareness of WPHD and PH in Latvia, educating the general public about PH and highlighting the current situation around treatment to health care professionals and policy-makers. We also secured a new and very influential supporter: the Riga City Council. Thank you to everyone for your support!

Ieva Plume, PHA Latvia

www.phalatvia.lv/en/

<https://www.facebook.com/pages/PHA-Latvia/381660625192318?fref=ts>





WPHD 2015 - LITHUANIA

“THE BREATH” - SHOWCASING PH IN PICTURES

PHA Lithuania marked WPHD for the first time on May 5 this year, focusing on PH patients and association members before engaging the wider community. To start the day off, we met with our doctors in the Vilnius PH Center to discuss living with the condition, and exchange experiences such as “how to travel with PH”. It was a meeting between “friends”!

In order to raise awareness of PH among the public, a bigger event was hosted on May 24. During this event, we educated people about PH and what it feels like for patients suffering from the condition, as awareness about PH is very low. We decided to do this by representing PH through art. On a sunny Sunday in the Vilnius city center the art exhibition “The Breath” was launched, showcasing the best pictures associated with breath, air and disease. Blue butterflies looked like lungs, other images repre-

sented the blood system and the sea breeze blew like breath. During the exhibition, jazz music played to keep everyone entertained and a compère talked about PH and our association. All visitors were provided with the association’s brochure and journal to take home to ensure they fully understood PH and knew how they could help patients in the future. Through WPHD we sought to prove to the public, and especially to patients, that PH it is not something ugly that should be hidden, but that it demonstrates uniqueness. We all agree that our goal was reached!

Anastasija Kovaliova
Lithuania, Žmoni Sergan i Plautine Hipertenzija
Asociacija
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WPHD 2015 - NETHERLANDS

24 HOURS FOR PH

The Netherlands marked WPHD on June 6-7. However, they did not just mark the day; they marked every single hour with the event “24 hours Care for Lungs”.

A PH-patient organized this great event with many volunteers. 24 hours of activities were supported by PHA Netherlands to raise awareness of pulmonary hypertension. Many hospitals, sports teams, PH patients and volunteers walked, ran and played football for WPHD.

The all-girl sports team, Mainteam, proudly displayed their support for the cause by wearing “Get Breathless” T-shirts as they played football in memory of their friend Ilse who sadly died of PH.

A fundraising event was also held to mark the day, which together with selling refreshments and souvenirs, managed to raise a hugely impressive 37.000 Euros in 24 hours! The funds raised will go towards scientific research for PH.

All in all, it was a truly extraordinary day’s work!

Leny van der Steen, PHA Nederland
www.pha-nl.nl
<https://www.facebook.com/pages/Stichting-PHA-Nederland/315678588490887>





WPHD 2015 - POLAND

POLAND “GETS BREATHLESS” IN SOLIDARITY WITH PH PATIENTS

PHA Poland organized a four hour event in the center of Warsaw, during which high profile celebrities and PH patients across the country “got breathless for PH” by taking part in sports activities. A highpoint of the day saw Polish celebs cycling 190 km on exercise bikes over the course of the four hours.

Two very important and well-known Polish cardiologists also joined this year’s PHA Poland event to show their support for PH patients across the country: Professor Adam Torbicki MD, Head of the Department of Cardiovascular and Pulmonary Thromboembolic Diseases CMKP and Professor Piotr Hoffman, President of the Polish Cardiac Society. The event was also joined by the Cross-Fit DOC sportsmen and DEFENDO ALLIANCE team. One of the highlights of the day was a live concert performed by the band “Lzy”. Their lead singer, Adam Konkol, has PH and provided great inspi-

ration and entertainment for everyone attending. The event attracted hundreds of people, including local and national media. In total, 60 news items were published, all of which were positive, securing an audience reach of over half a million!

Throughout the country, WPHD supporters organized their own sporting “Get Breathless” events, posting photographs of their sporting and workout sessions on social media, raising further awareness in Poland.

Agnieszka Bartosiewicz, PHA Polska

www.phapolska.org

<https://www.facebook.com/pages/Polskie-Stowarzyszenie-Os%C3%B3b-z-Nadci%C5%9Bnieniem-P%C5%82ucnym-i-Ich-Przyjaci%C3%B3%C5%82/1438211746452788?fref=ts>

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WPHD 2015 - PORTUGAL

PORTUGAL PROUDLY SUPPORTS WPHD WITH A PLETHORA OF AWARENESS EVENTS

Portugal held a myriad of activities to mark WPHD this year. All the activities had the support of several sponsors: the City Council of Coimbra (authorization for garden and bridge), Luso Mineral Water (who provided water for all) the Sanfil Hospital (two nurses were present at the events, performing lung function tests) and the *Escola Profissional Vasconcellos Lebre* (who lent chairs, tents and a van).

All aboard! Athletes unite for WPHD!

Sailors from all over the world united in Coimbra, Portugal, to take part in the international regatta. PHA Portugal's presence at the event meant that the 1.000 athletes participating in the race were able to learn about PH, helping to raise awareness of the life-threatening condition. At the starting line, volunteers from PHA Portugal gave away WPHD merchandise and two health specialists performed lung function tests to measure how well a person can breathe in and out something PH patients suffer with on a daily basis serving to highlight the debilitating nature of the disorder.

Fun and games in support for WPHD

A massive game of paper chase took place by Mondego's River, drawing over 50 participants - young and old! The fun continued with face painting, bouncy castles and children's entertainment. Close to

100 children got involved in the activities, wearing their WPHD T-shirts with pride!

Human chain formed in the heart of the city

A human chain of 90 people was formed on the famous Pedro e Inês bridge, in the heart of Coimbra. Several people took part: members of PHA Portugal, PH patients, rowing athletes, tourists, residents, and representatives of Bayer and Actelion. After the human chain, there was a musical performance, attended by all the people present in the human chain. In addition, the tower of the University of Coimbra was illuminated red from May 5-9, shining a light on the challenges faced by those living with PH.

Climbing to "give breath" for PH patients

300 runners "got breathless for PH" by climbing the 125 steps of the Monumental Staircase of Coimbra. At the finish line, participants were encouraged to blow into heart-shaped balloons to "give breath" as a gesture of support for PH patients as those living with the condition struggle to do everyday tasks such as climbing stairs.

Overall, the WPHD events were very successful and received five pieces of print coverage and three TV interviews, as well as radio coverage. PHA Portugal welcomed new members and was pleased to see



children getting involved in the campaign, showing an interest in PH, and wanting to learn more about the condition.

See videos at: <http://on.fb.me/1GvZGdS> and <http://on.fb.me/1VImE2s>

Maria Joao Saraiva

Associação Portuguesa de Hipertensão Pulmonar
www.aphp-hp.org - <http://on.fb.me/1If4SKw>





WPHD 2015 - REPUBLIC OF MACEDONIA

MACEDONIAN MASSES SHOW SUPPORT FOR WPHD



On the streets of Bogdanci, in the Republic of Macedonia, WPHD supporters limbered up ready for a tug of war to “Get Breathless for PH”. The traditional game drew a large crowd who cheered, encouraged and photographed the two teams throughout the closely fought battle of “tugging rope” in aid of people with PH.

Many people had their dancing shoes on as dance flashmobs appeared all over the Republic of Macedonia. Children from dance group Mystic - an international award winning troupe - performed in the Skopje city mall, alongside 75 children and 15 adult volunteers. They all burst into a spontaneous zumba routine, whilst flyers were distributed and balloons launched in the air.

The capital city, Skopje, also bore witness to the illumination of a monumental landmark, the fountain known as “Warrior on a Horse”. The fountain was illuminated in purple for three days at the same hour as a sign of support for PH patients across the world.

The media of the Republic of Macedonia were invited to a press conference hosted by the Mountaineering society called Green Paradise and the PH patient association APH Moment Plus. Moving patient testimonials from Gjurgica Kjaeva, Ljubica Timova, and Dalibor Nikolovski highlighted the challenges faced by those living with the condition. Their stories were greeted with empathy by a captivated audience of journalists. Green Paradise performed an honorary march called “Climb a Mountain, Take a Breath for Life”, which will now be performed annually to mark WPHD. The local mayor, Mr. Panovski, attended the press conference and pledged his support by allowing those living with PH a free stay at a well-known healing spa designed especially for people with lung disorders. The event resulted in nine high profile feature pieces in popular news outlets such as Republika, Duma and GVGLive.

A concert rounded off the WPHD festivities. One of Macedonia’s most famous rock bands - “Beni and Non Stop” performed. Two hundred T-shirts were distributed among the crowd and more than 300 attendees showed their support for the cause.

Gjurjica Kjaeva and Ljubica Timova, APH Moment Plus
<https://www.facebook.com/APHmomentplus?fref=ts>





WPHD 2015 - RUSSIA

GIANT INFLATABLE LUNGS CREATE AIR OF EXCITEMENT IN RUSSIA FOR WPHD

Huge inflatable lungs with the “Get breathless for PH” artwork were constructed in the Sokolniki Park, Moscow, to mark Russia’s first WPHD event. The lungs acted as a symbol of support for PH patients as passers-by were encouraged to “get breathless” by blowing up balloons which were then attached to the giant structure.

Members of the public wrote well wishes and words of encouragement for PH patients on the ground in chalk, while others drew positive pictures creating a colourful expression of sympathy and solidarity for PH patients.

The event attracted visitors of all ages, but it is safe to say the bubble-blowing game attracted the attention of lots of children! Volunteers played games with children, spoke to people about PH itself, and handed out information brochures. The day finished with a balloon release

in the sky, symbolising release from the serious condition.

A press conference was held prior to the event, where experts including Dr. Tamila V. Martinyuk, Head of the the PH department at the Myasnikova Cardiology center, and Dr. Kirill V. Mershin, a cardio-surgeon, discussed the new treatment opportunities for PH and chronic thromboembolic pulmonary hypertension (CTEPH).

Russia’s first WPHD event proved to be a real success, with hundreds of visitors getting involved and taking part in the event to show their support for PH patients. Here’s to next year!

Evgeniy Komarov, Natasha Charity Fund
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WPHD 2015 - SLOVAKIA & CZECH REPUBLIC

SLOVAKIAN AND CZECH HILLS AND HALLS ALIVE WITH THE SOUND OF PH AWARENESS

“I will climb for you”: Patients and families climb the Rysy Mountain for people with PH

On June 19, 150 association members from Slovakia and the Czech Republic (98 from Slovakia and 52 from the Czech republic) gathered at the beautiful mountain hotel Popradské pleso, in the High Tatra mountains. An educational PH workshop had been organized, which included presentations from physicians alongside a moving film about PH patient Daniel. The film, entitled “Daniel and his life”, told the inspirational story of his life-changing lung transplant surgery.

Inspired by Daniel’s story, 115 persons began the climb of the Rysy Mountain the next morning, on June 20, an astounding task which involved climbing to 2.503 meters above sea level! Daniel led the march up the (at times) snowy peak, alongside PH patients their families, friends, patient organization members and 55 physicians. Those climbing included four members of the mountain rescue service and a rescue dog. Twenty four members of the group carried photographs of PH patients on their backbacks to the top of the mountain in support of people with PH.

During the climb, participants experienced the breathlessness associated with PH, highlighting how even a few steps can cause people with PH to struggle for breath. The group included well-known figures

including the Minister of Health for Slovakia and the Slovak Free Diving Champion, who delivered a presentation on how to control your breathing. She also spread the PH message to her online community, through a series of posts on her website, to encourage further support for people with PH. Journalists from national TV channels recorded a short documentary about the mountain climb, which featured on the popular TV channel Teleweekend. The news was also picked up by multiple magazines and online media. The outreach for Facebook alone was 20.000! A great success in spreading WPHD awareness even further!

And more getting breathless...

A number of additional activities also took place, arranged by the Slovakian patient organization. These included athletes racing for WPHD in the 100 km World Run, a Slovak radio station takeover with a special show dedicated to the social difficulties for PH patients, the involvement of the Slovak association sports team “Patients with PH” at the relay running competition “Volkswagen Slovakia Run and Fun” and even a sprint up to the top of one of the highest buildings in Bratislava - the UFO - all 23 floors of it!

A special concert for WPHD

The acoustics of the Philharmonic Hall in Bratislava were filled with music on May 5, as the

PH Association in Slovakia organized a special concert for WPHD. Music rang out in support of people with PH whilst educational materials were handed out to attendees and a photographer captured the day’s events, including a photo of the WPHD team with the *Solamente Naturali* ensemble performers.

The day started with a press conference to educate the media about pulmonary hypertension, with 30 journalists in attendance - an incredible result! The conference, held at the Sky Bar in Bratislava, included presentations from Dr Eva Goncalvesová, Cardiologist Milan Luknár and members of the National Institute of Cardiovascular Diseases. Attendees listened to the compelling story of Jana Guráňová, a PH patient who has undergone lung transplantation and Hana Halasová, a patient who underwent pulmonary endarterectomy for chronic thromboembolic pulmonary hypertension (CTEPH). Both stories moved the audience with first-hand accounts of living with different forms of this debilitating and life-threatening condition.

An en-masse release of “Get Breathless for PH” balloons marked the finale of the press conference, gaining the attention of people on the street as they flew into the sky. The event was a great success, with two of the biggest newspapers in Slovakia, SME and Pluska, publishing positive articles about the day.

See video at: <http://bit.ly/1IhGzeW>

Iveta Makovníková

Združenie pacientov s pľúcnou hypertenziou

www.phaslovakia.org - <http://on.fb.me/1fWcRjs>

Regina Votavová, Sdružení Pacientů s Plicní Hypertenzí

www.plicni-hypertenze.cz





WPHD 2015 - SLOVENIA

SLOVENIAN SUPPORTERS SPRINT TO THE FINISH LINE

Two flags marked the start and finish of a 5 kilometer running race for WPHD in Slovenia. The event, hosted by the Slovenian PH Association, took place in the natural beauty area of Mostec, near Ljubljana. Activities kicked off with a 6 Minute Walk Test, the standard non-invasive exercise test used in the diagnosis and ongoing management of pulmonary hypertension. During the test, participants were challenged to block their noses and breathe only through a straw to recreate the struggle for breath experienced by PH patients on a daily basis. A prize-giving ceremony was held for those who raced and attendees were rewarded with a nice lunch. There was an animator for children throughout the event, Pika Nogavička.

Before the event the Slovenian PH Association association had joined forces with a childrens art

colony: 200 children were asked to paint zebras especially for the occasion. We chose some of those zebras painted by the children and made a huge poster which was presented at the event. The pictures that were painted by the children will be donated to the Cardiology and Pulmonology clinics in UKC Ljubljana for other children to see, copy or just have fun with.

Other activities at the WPHD event included a concert by the well known group "Gino and Band". Support was also shown for WPHD in medical centers across Slovenia, where branding was displayed to encourage people to "Get Breathless for PH" like those in Mostec.

Tadeja Ravnik, Društvo Za Pljučno Hipertenzijo Slovenije
www.pljucna-hipertenzija.si
<http://www.facebook.com/PljucnaHipertenzija>





WPHD 2015 - SPAIN

A TOUR DE FORCE FOR SPANISH PH PATIENTS

#CyclingforliPHe

To mark WPHD this year, the Spanish patient organization Asociación Nacional de Hipertensión Pulmonar (ANHP) gathered supporters for a Barcelona to Gerona cycling ride, #CyclingforliPHe. Through sponsorship from PHA Europe, Actelion and Bayer, WPHD supporters raced the 130 km route and were joined by two PH patients who rode in tandem with two other cyclists. The Vice President of ANHP, María Rodríguez, a PH patient herself, also rode in a show of solidarity for people with PH. Hundreds lined the route between Barcelona and Gerona, where, upon crossing the finish line, racers were welcomed by the Deputy Mayor of Gerona. ANHP members presented a “wish box” filled with the hopes for a better future for PH patients and their caregivers to the Deputy Mayor. This gesture acted as a symbol of encouragement for further support from local policy makers, for improved PH treatment and management. #CyclingforliPHe became hot news as it was reported on by both radio and newspapers in the region. It is hoped that in future years, #CyclingforliPHe will continue to grow, with the race evolving to over 7.000 km between Algeciras, Spain and Athens, Greece.

ANHP Gala

This year ANHP hosted its first “Gala”: a dancing, flamenco, theatre, music and circus extravaganza

to raise awareness of PH to a wider audience. More than 250 people came to enjoy the show, including some PH patients, their family members and friends. All were also treated to a rock performance by the band “Neverland” and pop songs from Eurovision hopeful Iván Gardesa, a young Spanish singer.

Nurturing Nurses

Nurses also got involved in WPHD activities with a Bayer-sponsored nurse workshop hosted by ANHP psychologist, Aldo Aguirre. Aldo, who is currently undertaking a PhD in psychological care for PH patients, guided the nurses through a series of presentations and exercises. The advice and tips provided will be useful for nurses in their day-to-day work in order to help patients handle the heavy psychological burden of living with PH. The events hosted by the ANHP for WPHD demonstrate the importance of wider awareness raising initiatives as well as targeted healthcare professional events to ensure optimal care for people living with PH.

Irene Delgado and Juan Fuertes,
Asociación Nacional de Hipertensión Pulmonar
www.hipertensionpulmonar.es
<http://on.fb.me/1MmkkFA>





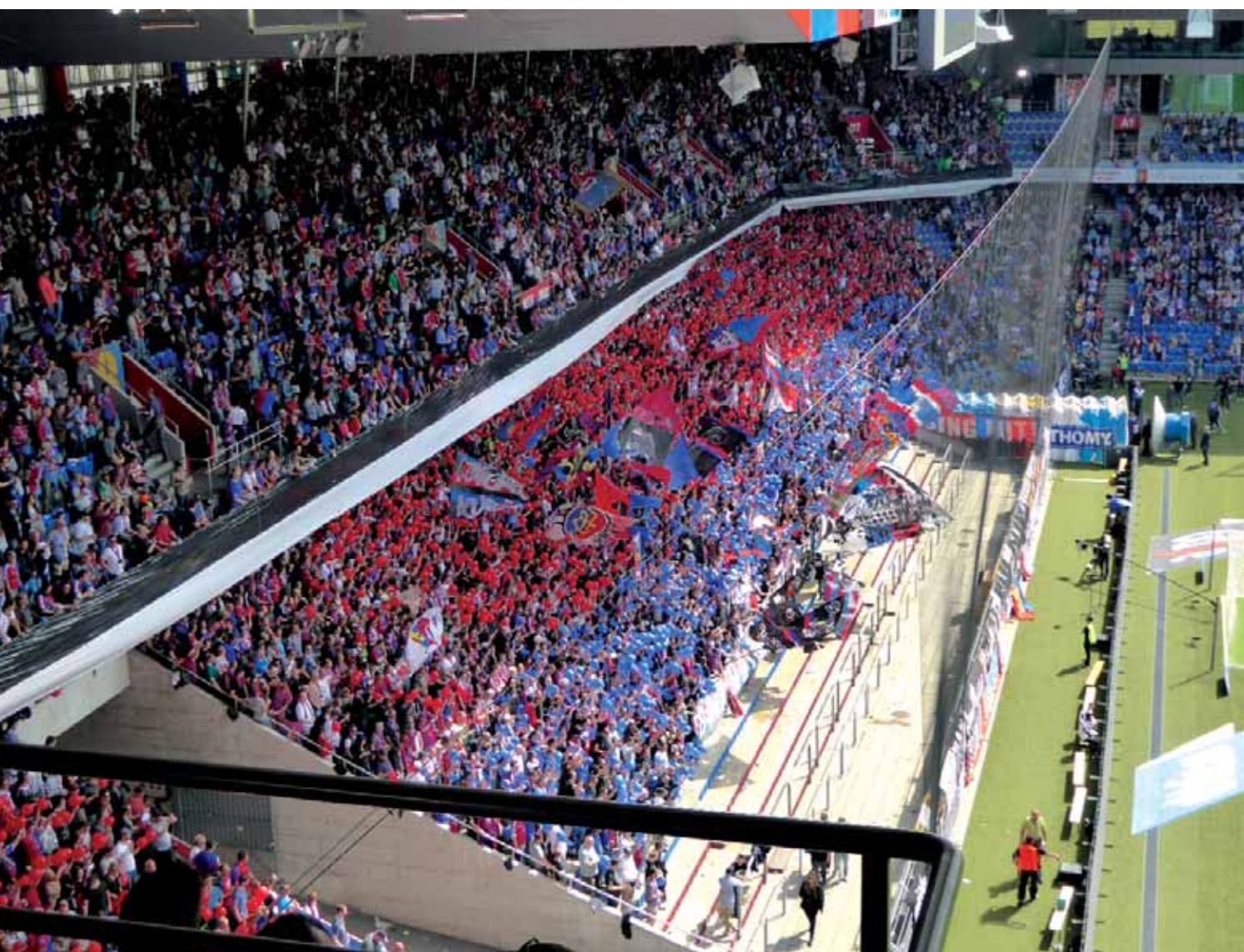
WPHD 2015 - SWITZERLAND

INDIACA AND INSIGNIA INSTRUMENTAL IN RAISING AWARENESS OF PH IN SWITZERLAND

In Switzerland, two high profile events took place for WPHD, with media in attendance and an overall audience of thousands! The Women's Gymnastic Club of Bützberg hosted an evening "Indiaca tournament" which saw 12 teams of around 100 people gather to "Get Breathless for PH". Indiaca is a highly dynamic and fast moving game, much like volleyball, where teams of 5-7 players must hit the Indiaca (akin to a badminton shuttlecock), over a central net, with their hand. Members of the Swiss Pulmonary Hypertension Association (SPHV) Board even took part, including Vice President Hans Hug, who both played and refereed. The event resulted in regional media coverage including newspapers Bernerzeitung, Langenthaler Tagblatt, Obergerzeitung and Neue Oberaargauer Zeitung and the radio station NEO.

Meanwhile, in Basel, SPHV supporters and members attended the Super League Soccer game of FC Basel again Young Boys Bern, where they displayed WPHD branding whilst handing out information about PH. With Swiss Regional Television in attendance, this activity is hoped to have reached thousands of Swiss football supporters through the lens of the television cameras.

Therese Oesch, SPHV
www.lungenhochdruck.ch
<https://www.facebook.com/pages/Lungenhochdruck-Schweiz/111565582240897>





WPHD 2015 - UKRAINE PHA

SEVENTY-SEVEN WPHD SUPPORTERS IN THE KIEV HALF-MARATHON

1.600 km and counting in support

Seventy-seven WPHD supporters joined the 6.200 participants in the Kiev half-marathon, racing to raise awareness of PH. Along the track, athletes passed through a giant inflatable “Get breathless for PH” arch and rang the attached bell in aid of PH, sending out a supportive clang across the city. The President of the National Alliance of Rare Diseases in Ukraine, Tetyana Kulesha, also ran 5 km to show her support to the cause. On the sidelines, WPHD supporters wearing “Get Breathless for PH” T-shirts distributed flyers and temporary tattoos to spread the message even wider. After the event, a memorial dinner in honor of PH patients who had passed away in the year prior was attended by patients, physicians, surgeons and psychologists - all of whom provided their insights regarding PH treatment and management and the importance of taking steps forward together.

One of the nation’s favorite sports - football - was also involved as players from FC Karpaty and FC Chornomorets donned WPHD T-shirts during their match on May 10.

Policy Progress for PH

A number of meetings were also held throughout the country in a bid to transform policy for people with PH. The Parliamentary Committee of Health gathered to hear about issues surrounding access to PH treatment, government funding and access to specialists/expert centers. In response to a presentation by the President of the Ukrainian PH Association, a letter was received from the Head of the Committee confirming that the issues had been escalated to the Minister of Health and the Prime Minister of Ukraine, regarding the need to allocate a separate budget and government program to support the 102 patients with PH in Ukraine. As part of a Cardiology Congress, educational sessions were also hosted by the Ukrainian patient organization highlighting challenges in the treatment and management of the condition.

The multitude of events in Ukraine provided essential moments to take PH awareness to the masses on - and around - WPHD.

Ocsana Aleksandrova, PHA Ukraine

<http://pha.org.ua/> - www.facebook.com/pha.org.ua



WPHD 2015 - UKRAINE SISTER DALILA

THE LONG WALK TO “GET BREATHLESS FOR PH”

The region of Lviv, Ukraine, welcomed WPHD supporters to its streets in May for a special walk through the city entitled “Hodonon”, organised by the PH charity foundation “Sister Dalila”. Lviv was brought to life as participants passed by major points of interest including the city monuments and the Opera House. Among those joining the march were para-athletes, school children, disability sports groups, representatives from the Lviv City Council and Social Services, the Union “Samopomich” and volunteers from two local businesses - the entertainment complex “Children’s Planet” and a business club called “Tickets for Success”. As the locals cheered the WPHD ambassadors through the streets, journalists captured the action on film, for TV channels TRK-Lviv, Zik and 24.

Upon returning to the starting point, balloons were released

into the air - symbolizing the efforts to “blow away” the impact of PH through the work of patient groups, government and physicians. A special activity also took place where people with PH were asked to identify their “Breath of Success” moment to celebrate their personal successes. The day’s events ended with an inspiring and heartwarming visit to St Ann’s Church to speak with Sister Dalila, after which live music brought the occasion to a rousing close.

As part of WPHD celebrations the Lviv football club “Karpaty” went to the football field wearing WPHD T-shirts. There was also a WPHD banner.

Ocsana Kulish, Charity Foundation Sister Dalila
<https://www.facebook.com/profile.php?id=100008303044326&fref=ts>





WPHD 2015 EUROPE - IRONMAN

AN ADVENTURE IN THE HEAT DURING THE IRONMAN EUROPEAN CHAMPIONSHIP 2015

PHA Europe was proud to be the Official Charity Partner for the IRONMAN European Championship which took place in Frankfurt on July 5. This is the third year in a row that PHA Europe is actively involved in the IRONMAN EUROPEAN TOUR, as part of the celebrations for WPHD.

Ironman is possibly one of the toughest endurance events in the world. Athletes start with a 3.8 km swim, followed by 180 km race on bicycle and then complete a 42,2 km marathon to the finish line. In many ways IRONMAN is a mirror of the struggle that many pulmonary hypertension patients have to go through, especially those who have no access to best care and basic pharmacological treatments. These patients make a superhuman effort to move forward and get to a finish line that means quality time with their loved ones, but the effort is simply too taxing for their bodies and we often suffer their premature loss. In these last three years IRONMAN has provided us a perfect platform to raise awareness about PH and hopefully also to save some lives.

International representation, diversity and union

PHA Europe had six champions competing for PH. They come from Germany, Hungary and the UK. All of them finished the European Championship and proudly wore the PHA Europe tri-suit. The representation we had on the race course reflects our reality. Men and women, different backgrounds and different circumstances but common goals. The main one is to give purpose to their objective of completing the IRONMAN ordeal; they generously offered their effort to raise awareness of PH.

Andrea Helmuth, a 5-time IRONMAN athlete from Germany, gave us one of the best photos of the "Get Breathless for PH" arch. Andrea is petite but her enthusiasm and resources are way bigger than her body so when she was passing under the arch she could not miss ringing the bell and, as an Ambassador should do, she used her diplomatic skills to get another athlete to lift her and ring an awareness raising call for PH!

But let us not forget our team manning the booth at the expo area. The most engaged German group of volunteers worked throughout the four days to inform about what it means to live with PH. There is much to say about all of them. Thomas and Regina were the champions in talking to people. Thomas suffered from chronic thromboembolic pulmonary hypertension (CTEPH) and he is getting better and better after the surgery that saved his life. Roman took over 1.000 photos that you will be able to enjoy in our social media publications. And we had the very special contribution of Mathias, who came with Silke, his mother, and Caro, his sister. Mathias is 14 years old and was diagnosed with PH at the age of eight. It was incredible to see him run and keep the pace with passing athletes to tell them about PH and why they would be ringing the bell during the race. Not even those who know that patients don't look sick would have been able to guess that Mathias is a patient himself.

The German volunteers could have done it all by themselves but we wanted to reflect that PHA Europe extends throughout the EU and we had supporting staff from Austria, Hungary, Italy and Spain. Barbara got us the salute of MERCEDES BENZ and Gergely became an "Iron PH Hero" because he worked tirelessly from 3 a.m. to late at night the day of the race. You should not miss his photos of the start of the race taken from a boat and those taken at the finish line.

It was a busy time for all of us with all the T-shirts and tattoo distribution, speeches at the race briefings and the pasta party where Jan Frodeno, who became the European IRONMAN 2015 Champion, signed a "Get Breathless" T-shirt. Alberto and Juan walked up and down an average of 10 km per day to make everything run smoothly, and Pisana put the ribbon handing the check to the German association in the late evening, after the race.

Jan Frodeno, a big champion who broke the mould

Olympic champion Jan Frodeno set a new IRONMAN-Frankfurt record in spite of the scorching heat that day; it took him only 7 hours and 49 minutes to enter the history of the European Championship. But he also made a very special contribution. Professional athletes always worry to not lose a nanosecond during the race but Frodeno took his time to ring the bell for PH. The bell ringing was the cherry on the pie but, as mentioned above, he also took the time to sign a "Get breathless for PH" T-shirt and pose for a photo with us!

The PH bell rang nonstop from 11:30 a.m. to 10:00 p.m. We thank all the athletes for that sound that still lingers over the streets of Frankfurt!

Juan Fuertes

PHA Europe field manager Ironman Frankfurt



Andrea Helmuth, PH Ambassador, ringing the bell at Ironman Frankfurt



Andrea Helmuth, PH Ambassador



Robert Szaniszló, PH Ambassador



PHA Europe booth at expo area, Ironman Frankfurt



From left: Juan Fuertes, Roman Kopp and Gergely Meszaros





I am Andrea Helmuth, from Germany. Hardly any sane athlete would purposely engage in a full IRONMAN without the proper training and preparation. A disease hits you unprepared; henceforth determines your everyday routine and thoughts. PHA Europe was the reason I decided to start at IM Frankfurt this year - four days before it took place and without the proper training and preparation. Don't get me wrong, it's not that I wasn't trained at all. I look back on more than ten years of experience in endurance sports, and from the five IM I did within these years, I knew what I was getting myself into when I walked towards the starting line on Sunday. From my own personal experience, I knew that a positive attitude, a strong mindset, and the support from your family and friends comforts you. Every mile I passed was for a good cause: raise awareness for a disease barely recognized and extremely underestimated. "Get breathless for PH" is more than a catching motto but rather the epitome of Sunday's IRONMAN in the scorching heat of Frankfurt and I am proud of my close finish (in 14:47:42) on behalf of the Pulmonary Hypertension Association Europe.



Jan Frodeno, IRONMAN European Champion, with Alberto Rivas from PHA Europe



Jan Frodeno, IRONMAN European Champion 2015



Matthias and his mum Silke



Juan Fuertes speaking at pasta party



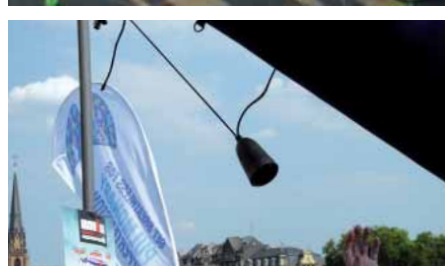
Pasta party at Ironman Frankfurt



Jan Frodeno wins the European Championship 2015



Mercedes Benz supports PHA Europe



My name is Robert Szaniszló, I am from Hungary. I started doing sports early in my life and have tried different kinds of sports competitively: ski, grass-ski, skateboard, tennis and athletics. After a few years I started taking running seriously (long distance) and went to many local competitions (10k, half-marathon, marathon). My personal best in half-marathon is 1:29:41. I really like half-marathon distance so after plenty of running I was looking for another challenge two years ago. That was the first time I heard about triathlon. It was a sprint distance race, but it was incredible. After this race I decided to enter for the BalatonMan 70.3 (Half-Ironman). On this occasion I met Gergely Meszaros, from the Hungarian PH association and that was how I made the connection to PH and became PH Ambassador for Ironman Budapest 70.3 in 2014. This year I was again PH Ambassador at the Frankfurt European Championship. This was awesome, and hot! I appreciate that I could represent you on this amazing event and show how strong PH patients are. I would like to say thank you to all of you, Pulmonary Hypertension Association Europe, Tüdőér Egylet and to all athletes and spectators, who participated in the event. See you next time.



Matthias, the youngest of the German volunteers at IRONMAN Frankfurt





WPHD 2015 - AROUND THE WORLD

AN AMAZING TOTAL OF 45 COUNTRIES ACROSS FIVE CONTINENTS CELEBRATE WPHD

AUSTRALIA

POLITICIANS “GET BREATHLESS” DOWN UNDER TO BETTER UNDERSTAND PH

On Monday March 23, Australian political decision-makers gathered in Canberra alongside MP David Gillespie to attend an educational briefing about pulmonary hypertension (PH).

Almost 70 people attended the event to learn and/or share their experiences of pulmonary arterial hypertension and chronic thromboembolic pulmonary hypertension (CTEPH). Event speakers included the Pulmonary Hypertension Association of Australia, two well-respected medical thought leaders and a patient suffering from inoperable CTEPH.

An exercise bike was used to demonstrate what it feels like to struggle to breathe - one of the key symptoms of PH - which prevents patients from carrying out everyday activities, such as walking short distances or climbing stairs.

To spread awareness of PH even further, PHA



Australia and Bayer partnered with IRONMAN Australia 2015. Rebecca Hoschke, an IRONMAN ambassador - who knows what it is like to feel extremely breathless - said, “I can understand how difficult it would be to suffer from PH and to be constantly short of breath without having a finish line in sight.” Rebecca encouraged politicians to try the exercise bike to get breathless in unity with PH

suffers and to further understand their limitations. “Events such as today provide hope that people are listening, learning and committing to help spread awareness and compassion. It is also a chance for continued work into finding a sustainable cure”, said Chris McGrath from PHA Australia.



PHA Australia
www.phaaustralia.com.au

CANADA

CANADA IS PAINTED PURPLE FOR WPHD

Famous monuments were lit up in purple in Canada to raise awareness of pulmonary hypertension this WPHD. The initiative called “Paint Canada Purple for WPHD” saw community members requesting their local monuments to be lit up, including the Toronto City Hall, the Montreal Olympic Stadium and the Langevin Bridge in Calgary, in a bid to illuminate as many monuments as possible.



The illuminations aimed to represent the blue-purple tinge that can sometimes be associated with the lips and fingers of PH patients, raising awareness of the condition amongst the wider public in an eye-catching way. The campaign was initially launched in 2014 by PH patient Loretta, when she lobbied for Toronto's iconic CNN tower to be lit up in purple, and was successful in doing so! Her achievement prompted others to request for their local monuments to be turned purple. It is thanks to Loretta that the “Paint Canada Purple for WPHD” campaign is proving to be an ongoing success!

PHA Canada
www.phacanada.ca/

CHINA

PH-OTOGRAPHY EXHIBITION: CHINA BRINGS PH INTO FOCUS



On May 5 - May 10, the iSeek Pulmonary Hypertension cultural center, a Chinese non-governmental PH organization, held an awareness event called “Seeking Blue Lips”

to raise awareness of PH. The group constructed a booth, in the popular Beijing news plaza, which featured a photography exhibition that depicted the life of Chinese people living with PH.

Many PH patients enthusiastically participated in the day's activities - handing out flyers, sharing their experiences and taking pictures with the public who had painted their lips blue.

Iseek Cultural Centre
www.iseek.org.cn

CENTRAL AND SOUTH AMERICA

NO ESTAS SOLO! YOU ARE NOT ALONE!

No estas solo! - this was the slogan for the WPHD 2015 campaign in Latin America, which kicked off with an educational program held in Guadalajara, Mexico, in



collaboration with the local association. The 2-day program included capacity building workshops and advocacy training. Nine Latin America countries were involved in some way in WPHD 2015: Argentina, Bolivia, Brazil, Colombia, Ecuador, Peru, Paraguay, Uruguay, Venezuela. One central American country celebrated WPHD, Costa Rica, and further up North, Puerto Rico.

Sociedad Latina de Hipertensión Pulmonar
<http://www.sociedadlatinahp.org/>
www.facebook.com/www.sociedadlatinahp.org?ref=ts

SOUTH AFRICA

RIGHT TO THE TOP OF KILIMANJARO



It is absolutely amazing of Krynauw Otto and his friends: they took “Creating Awareness of PH in South Africa” right to the top of Mount Kilimanjaro! Thanks guys, you are real PHriends!

PHA South Africa
<http://www.phsa.co.za/>

UNITED KINGDOM

CHARITY CONDUCTS

CLASSICAL CONCERT FOR PH



Music aficionados gathered for a special WPHD concert from the renowned Festival Chamber Orchestra and internationally acclaimed conductor Stephen Barlow. The concert

was hosted by a global charity, the Pulmonary Vascular Research Institute, and saw popular pieces from the classical catalogues of Mozart and Bach, brought to life by the orchestra in support of those living with the life threatening heartlung condition PH. See video at: <https://www.youtube.com/watch?v=ZiQ5qDfLivU>

Pulmonary Vascular Research Institute
www.pvri.info/

USA

A DISEASE OF MANY STRIPES

The PHA designed a special WPHD celebration social media pin with the message, “PH: A disease of many stripes,” to symbolize the diagnostic challenges and how PH comes in different forms, sometimes without a known cause and in other cases, associated with other diseases. PHA members shared the pin with their followers to lead them to PHAssociation.org to learn more about PH, find healthcare resources and/or make an online donation.



“BLUE LIP KISS FOR PH”



Join Cordelia Skuldt, an 11-year-old living with PH, in the “Blue Lip Kiss Challenge”!

Check out her

video on www.teamphenomenalhope.org/cordelias-blue-lip-kiss-challenge and get motivated! Here is how to take the challenge. See video at: <https://www.youtube.com/watch?v=oGYqr1vzFfI>

Julia Friedrich, International Program Associate
<http://www.phassociation.org/>
www.facebook.com/PulmonaryHypertensionAssociation

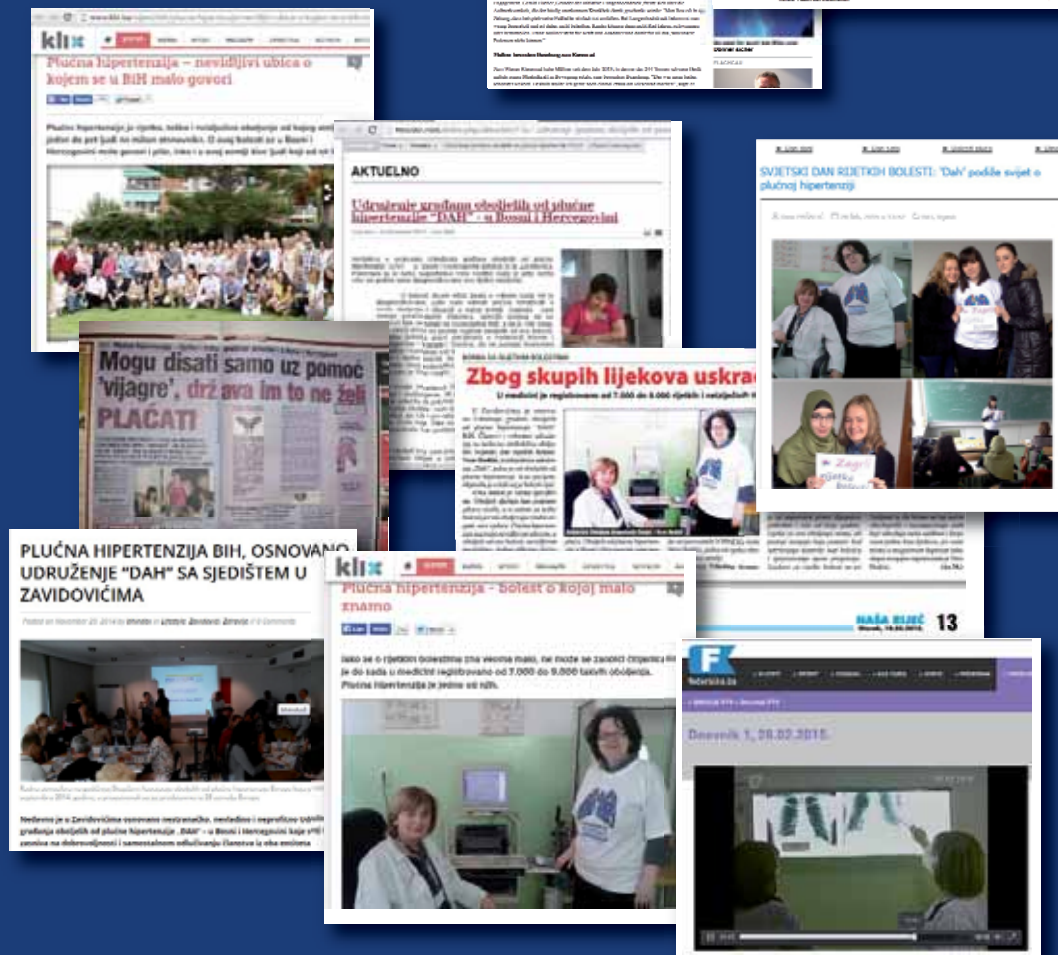
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MEDIA CLIPPINGS

AUSTRIA



BOSNIA AND HERZEGOVINA



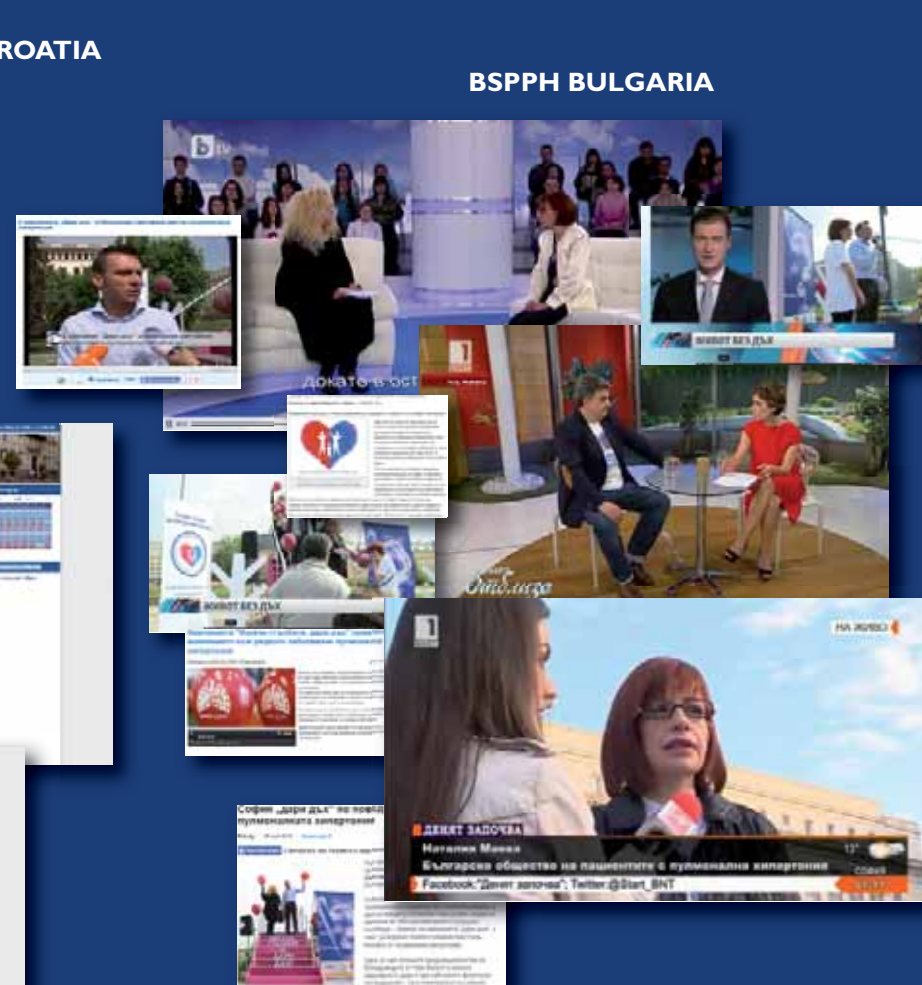
PHA BULGARIA



HUNGARY



CROATIA



BSPPH BULGARIA



GREECE

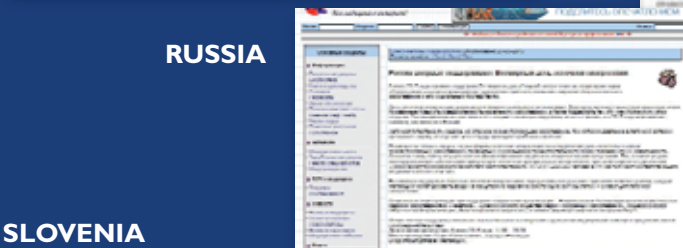




REPUBLIC OF MACEDONIA



NORWAY



RUSSIA

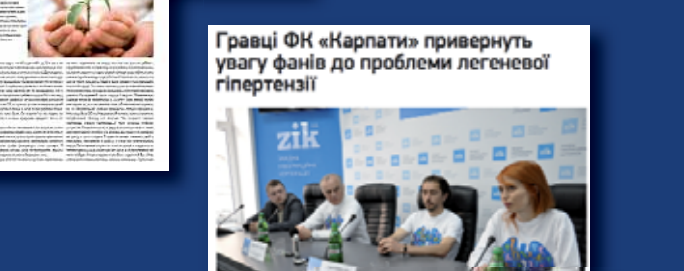


SLOVENIA

UKRAINE SISTER DALILA



PORTUGAL



2015

UPCOMING EVENTS

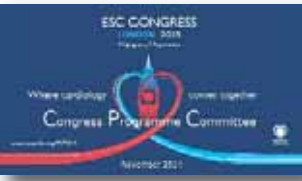


August 22 - Budapest, Hungary
IRONMAN BUDAPEST

PHA Hungary will participate for the second year running in IRONMAN Budapest, with the support of PHA Europe and will have a booth, information materials, beachflags, banners and a branded arch. To make this event more memorable and develop it into a regional PH event PHA Slovakia was invited to the event, who happily accepted the invitation. On August 21st an IRONMAN 5i50 race will be held in which PHAEurope Board Member Gergely Meszaros will “get breathless for PH”.

August 29-September 2 - London, UK
EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS

PHA Europe will be present at the EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS 2015. This Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines from basic research to clinical practice.



September 26-30 - Amsterdam, Netherlands
EUROPEAN RESPIRATORY SOCIETY'S ANNUAL CONGRESS

PHA Europe will be present with a booth at the EUROPEAN SOCIETY FOR RESPIRATORY MEDICINE'S ANNUAL CONGRESS 2015. This Congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

September 2-3, Brussels, Belgium
6TH ANNUAL CONFERENCE OF THE EUROPEAN PUBLIC HEALTH ALLIANCE

The conference theme is "Towards a European Union for Health - From Health in All Policies to EU Governance for Health and Well-Being?" PHA Europe is a Member of the EPHA and a representative will attend the conference.



September 17-20 - Barcelona, Spain
PHA EUROPE ANNUAL PH EUROPEAN CONFERENCE

PHA Europe will be holding its 2015 Annual PH European Conference in Castelldefels (Barcelona). PH Patient Leaders from 33 European countries will attend this meeting.

October 10, Lisbon, Portugal
EUROPEAN DAY FOR ORGAN DONATION AND TRANSPLANTATION

PHA Europe, together with its members and supporters, will be launching a “Call to Action to improve organ donation and and transplantation across the EU”. A number of awareness and advocacy activities are planned around the date of the European Day for Organ Donation.



2016 AT A GLANCE

- EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS, Edinburgh, Scotland, May 26-28
- PHA USA INTERNATIONAL CONFERENCE AND SCIENTIFIC SESSIONS, Dallas, USA, June 17-19
- EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS, Rome, Italy, August 27-31
- EUROPEAN RESPIRATORY SOCIETY'S ANNUAL CONGRESS, London, UK, September 3-7

The next Mariposa Journal will be issued in December 2015 (Winter edition). It will also feature reports from the national associations about activities in their countries, updates on research and treatments and any other interesting and relevant developments at European level. We would be very grateful if the members could send their contributions by the 15th 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

AUSTRIA

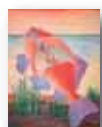


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BOSNIA AND HERZEGOVINA



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Žmonių Sergančių Plautine Hipertenzija
Asociacija
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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 Pulmonary Hypertension patient associations across Europe. The primary objective of PHA EUROPE is to establish a narrow cooperation between the members and the European institutions, international organizations and public institutions worldwide and work towards achieving the best possible standards of care for all European Pulmonary Hypertension patients.

WHAT IS PULMONARY ARTERIAL HYPERTENSION?

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



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

TREATMENT OF PULMONARY ARTERIAL HYPERTENSION

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

THE FUTURE FOR PULMONARY ARTERIAL HYPERTENSION

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