



PULMONARY HYPERTENSION Mariposa Journal

SUMMER 2013 • PHA EUROPE'S OFFICIAL JOURNAL • N. 10



GETTING BREATHLESS FOR PH ACROSS EUROPE FOR WORLD PH DAY!



Editor's memo Summer 2013 edition

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Dear members, supporters and friends,

welcome to this special edition of the Summer 2013 Mariposa Journal, which reports on the inspirational activities from the “Get Breathless for Pulmonary Hypertension (PH)” campaign and IRONMAN Europe, to mark the second World Pulmonary Hypertension Day (WPHD).

In the forthcoming winter edition of Mariposa, we look forward to updating you as usual on congresses we have attended and spoken at this year, in addition to other activities outside of the WPHD celebrations.

Led by PHA Europe and supported by Bayer HealthCare and Actelion, the “Get Breathless for PH” and IRONMAN activities formed part of a unique collaboration, enabling a breathtaking season of WPHD events centered around the day itself, 5 May 2013.

Building on the success of the inaugural WPHD, hosted in Spain in 2012, the campaign saw over 30 patient groups unite for this truly inspirational day to raise awareness for PH patients across Europe and the rest of the world.

The objective of the “Get Breathless for PH” campaign stemmed from a united wish among national patient groups to raise awareness of PH among patients, members of the public and the medical community, as it is a condition that is little known

outside of the PH community. National patient group leaders championed the campaign throughout Europe, rallying thousands of enthusiastic supporters along the way to spread the word about this devastating condition.

“Get Breathless for PH” activities first launched on the ski slopes of Japan and continued with sports matches, concerts, flash mobs, dances and fun runs in different countries, with excitement peaking on WPHD itself when the Pope offered a powerful message of encouragement to all PH sufferers during a Sunday Service in Rome.

The campaign attracted the attention of the media worldwide, boosted by a host of celebrities who advocated the cause. Highlights included Latvia’s sports day which was opened by Olympic walking champion Aigars Fadejevs, whilst in Greece the Deputy Minister of Health, Marios Salmas, launched a city bike race cheered on by over 3,000 supporters.

Building on these activities, PHA Europe’s collaboration with IRONMAN Europe further harnessed the intercultural appeal of sport in this ongoing bid to highlight the plight of PH patients worldwide. Kicking off in Lanzarote, Spain, PHA Europe was present at a number of other IRONMAN Europe races, including, Austria, France, Germany and Norway, and are due to attend the final race in Switzerland later this month.



As part of the campaign, bold and memorable branded materials were developed along with a campaign highlights video which showcased the campaign to the patient and non-patient communities.

In order to effectively communicate the powerful messages at the heart of the campaign and raise awareness of PH on a global stage, an extensive WPHD Toolkit was created to connect patient groups from across the world via social media and share photos, videos and information surrounding the activities. Linked through the hashtag - #WorldPHDay - the social media coverage generated an astounding 19,000 mentions on Twitter, Facebook and other social sites and over 200 pieces of traditional media coverage were secured.

We would like to thank everyone that participated and helped make this year’s event the success it was! A very special thank you goes to the Pulmonary Hypertension Association, for having developed the dedicated WPHD website, www.worldphday.org. This website, originally developed in English, was translated into Chinese, Portuguese, and Spanish and played a very important role, not only in listing all the events around the world but also in providing opportunities for people to get involved in PH advocacy. It has had well over 4,000 visits and 22,000 page views from 96 different countries (from every continent except Antarctica)!

We are also very grateful to the PH physicians who agreed to wear our “Get Breathless for PH” t-shirts at the football match which took place during the World Symposium on Pulmonary Hypertension (WSPH) in Nice in February (see photo). The WSPH is the world’s most important scientific event in PH, taking place every five years, and it is a great honor for us to have received endorsement for our campaign from the world’s key medical opinion leaders!

As a result of the dedication, enthusiasm and support of



everyone involved in celebrating WPHD, the huge achievements of this year’s campaign provide us with a great stepping stone to build upon successes and pave the way for future campaigns, to ensure that 5 May is firmly established as a milestone throughout the world.

We are extremely proud of the results from this first global campaign and look forward to another successful WPHD in 2014! Thank you to all for your invaluable support!

Gerald Fischer
PHA Europe President

WPHD photos at:
<https://www.facebook.com/pages/Pulmonary-Hypertension-Association-Europe/141060385915366>
www.worldphday.org

WPHD video at:
http://youtu.be/G1kG5q_CtFU
<http://www.phaeurope.org/projects-activities/world-ph-day/>

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WORLD PH DAY 2013

AUSTRIA KICKS-OFF WPHD IN STYLE



As football has by far the biggest following of any sport in Vienna, Austria kicked-off their WPHD activities with a football tournament and opened it up to everybody, including club players and the public. Before the tournament got underway, all participants were given a “Get Breathless for PH” t-shirt which they wore in style throughout the matches. The tournament was a great experience and we had plenty of laughs and also informed many people about PH, who previously had little knowledge of the illness.

At the end of the tournament, there was a big awards ceremony during which the top three teams

received a trophy. The event was publicized through Facebook, and was a huge success! Rainhard Fendrich, one of Austria’s most famous singers, also supported WPHD day by wearing a “Get Breathless for PH” t-shirt (see photo top right). To top it off, Austrian football legend Toni Polster (see photo, middle left) agreed to do a radio advertisement to talk about PH on WPHD and to our delight it was broadcast on all major radio stations for the entire weekend!

Gerald Fischer, Selbsthilfegruppe Lungenhochdruck
www.lungenhochdruck.at



Reinhard Fendrich, one of Austria's most popular singers, endorses the “Get breathless” campaign



Toni Polster, Austrian football legend, during his radio ad about PH





WORLD PH DAY 2013

BELGIUM PUTS UP A FIGHT FOR WPHD

Belgium's campaign took on PH with the support of professional lightweight boxing champion J.P. "Junior" Bauwens, who showed youngsters how to keep their guard up against PH. Junior knows what it is like to fight both in the ring and in real life. He is the eldest brother of seven, and four of his brothers are autistic. When Junior fights in the ring, he is fighting for his mother and his family. Vice Chairman of PH-VZW, Wim Colle, rounded up some enthusiastic sparring partners for Junior, and found plenty of youngsters willing to "Get Breathless for PH". Junior and his trainer taught everyone that it is important to never give up, and to hit PH where it hurts! Mental strength is of vital importance in the boxing world and Junior showed everyone how to pick themselves

up when they are in a corner and remain strong. WPHD this year bonded us by one common factor: there were no black eyes but we all had blue lips, to represent the symptoms of PH. Wim Colle gave an interview to the press which secured media coverage in the local newspapers, and Junior also agreed to take up sponsorship of Belgium's PH Organization so that we can continue to raise awareness of PH.

Together, we must keep throwing punches to fight the condition!

Hendrik Ramaker,
Patiëntenvereniging Pulmonale Hypertensie vzw
www.ph-vzw.be

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





WORLD PH DAY 2013 BOOGYING IN BULGARIA FOR PH PATIENTS



The Bulgarian Society for Patients with PH (BSPPH) celebrated WPHD for the first time this year. Under the patronage of the Mayor of Sofia, Yordanka Fandakova, the awareness raising event was held in an unusual and attractive location - in front of the National Palace of Culture in the capital of Bulgaria, Sofia. Bulgaria embraced the campaign theme "Get Breathless for PH" by focusing on sports, dance and movement within the active community of people who wanted to help raise awareness and inform the non-patient community about this rare and devastating condition. The main event of the day was a massive dance lesson, which had the goal of involving as many people as possible in order to support those patients with PH. Dancing enabled everyone to get involved and experience what it feels like to be "breathless" - one of the most unpleasant symptoms of the condition.

"It is very important to talk more about PH and to provide the patients in Bulgaria and their families

with the psychological, medical and social support they need. In addition to the medical burden, this condition has a serious social aspect, which is why such an event in Bulgaria in which people can participate, demonstrate their commitment to patients and provide emotional support, is as important as the performance of treatment" said Natalia Maeva, Chairman of the BSPPH.

All the activities was also published on the specially created platform, www.bezdihanie.bg Natalia Maeva, gave interviews to: Darik radio, Bulgarian National Radio, SKAT TV, NEWS 7 TV and Evrokom TV. The event had wide coverage with online press and other media. See videos at <https://www.facebook.com/photo.php?v=10151714164181833> (promo). <https://www.youtube.com/watch?v=5t0P6AKX9I4&feature=youtu.be> (event).

Daniela Naydenova - BSPPH
www.bezdihanie.bg - <http://on.fb.me/13sawnu>





WORLD PH DAY 2013

CZECH REPUBLIC BREATHES LIFE INTO PH



Situated on the banks of the Vltava river, in a multifunctional sport and relaxation center, Žluté Lázně (Yellow Spa), with a beautiful backdrop and one of the most spectacular views of Prague - the Prague Castle and Hradčany, the Czech Republic PH Association held its sports event to celebrate WPHD in style. Our patients, their families, friends and our PH doctors participated in football, tennis and table tennis. Because a lot of our visitors were children, there was also a playground to entertain our younger guests. It was a great opportunity for the healthy people among us, to "Get Breathless" by playing sport and experiencing the feeling of shortness of breath, something that PH patients experience in their everyday lives. The event proved to be a great chance to breathe life into PH and have fun doing so! Following this fantastic sporting event we also participated in the XXI Annual Congress of the Czech Society of Cardiology. WPHD t-shirts and leaflets were distributed amongst medical professionals from the Czech Republic to raise awareness of the disease and WPHD. See video at <http://www.youtube.com/watch?v=aWEio-GoCbkU&feature=youtu.be>

Kateřina Nováková
Sdružení Pacientů s Plicní Hypertenzí
www.plicni-hypertenze.cz



From left: Veronika Jelinkova, Prof. Javel Pansa, Katerina Nováková





WORLD PH DAY 2013

PEDALING FOR PH IN ATHENS



Embracing the theme of sport, the newly founded organization, PH Greece, chose cycling to mark this year's WPHD. It was felt that cycling was the perfect choice as it focuses on the cardiovascular system and, at the same time, promotes entertainment, commuting, protection and improvement of health and, last but not least, respect for nature and the environment. PH Greece used the slogans "Time Matters" to stress the importance of early diagnosis and raise awareness as part of PH Greece's successful "Get Breathless for PH" event. This is only the beginning for PH Greece, many more events will be organized in the future so watch this space! The easygoing planned cycling route allowed everyone to participate, including children. St. Sophia church in Psychiko was the perfect start point and the signal to get going was given by the Deputy Mayor, Mr. Galanis. As the cyclists headed off a huge cluster of balloons were released into the sky creating a beautiful spectacle for the crowd as well as surprising the cyclists and Mayor! We carefully planned the route to take 6 minutes to remind people of the 6 minute walk test for PH patients. The finishing point was at the OAKA Stadium, which hosted the 2004 Athens Olympic Games. Here, the athletes of the Hellenic Cycling Federation made a symbolic circle around the spectators, marking the end of the cycling race.

As spectators took their seats in the Olympic Stadium, the first speech was given by Deputy Health Minister Mr. Salmas, who committed to support PH Greece in all issues and promised to be generous in supporting the needs of the patient association. The President of the Athens Medical Association went on to acknowledge the problems faced by PH patients and added his complete support. Two distinguished medical experts, Dr. Kariofyllis and Dr. Orfanos, addressed the audience, pinpointing the joint efforts which should be made both from the PH Association and the medical community, to give and do their very best for patients.

The president of PH Greece, Mrs. Ioanna Alissandratou, concluded the event by thanking all the speakers, participants and audience, and PHA Europe for its continued assistance and spoke of the key actions taken by the Hellenic Association, promising a healthy and powerful organization with such strong partners. See video at https://www.youtube.com/watch?v=iUMUlh2Hxvc&feature=player_embedded

Ioanna Alissandratou, PHA Greece
www.hellenicpulmonaryhypertension.gr
<https://www.facebook.com/PulmonaryHypertensionGreece>



Dr. Kariofyllis, PH specialist physician (right) with Ioanna Alissandratou, President of PH Greece (center)





WORLD PH DAY 2013

HUNGARY KICKS UP A STORM FOR WPHD

Tüdőér Egylet, the national patient organization of Hungary, invited all the members and volunteers to celebrate WPHD in the heart of Budapest, Vörösmarty tér. The day kicked off with a press conference in the well known traditional patisserie "Gerbaud". After introductory words from the Chair of the organization, Eszter Csabuda, the Deputy Chair and Head of the Cardiopulmonary Department at the Semmelweis University, Kristóf Karlócai, gave information about the concept of WPHD, its philosophy and his personal experiences working with patients living with PH. Professor Tamás Forster, the Director of Cardiology at the University Szeged, explained what pulmonary hypertension is and how learning about the initial symptoms could help ensure early diagnosis.

The second part of the day was held in the square in which a 50m long walk was marked. All the walkers were supplied with WPHD t-shirts and got ready to walk for WPHD armed with number markers and timers. As part of the program a competition was

launched which saw healthy volunteers try and match the time taken to walk two laps of the course by a PH patient. The winner was the volunteer who walked the distance in the closest time to the target patient. Many rounds took place before a powerful storm suspended the program, wind turning over decorations and blowing away the air-balloons. Heavy rain soaked everybody to the bone in seconds. This unexpected adventure resulted in a closer solidarity between patients and passers-by and spirits were kept high. Despite being stopped by heavy rain this year our hopes remain high for next year!

The Hungarian media embraced our initiative and significant media coverage was secured. Tüdőér Egylet received many e-mails and telephone calls from PH patients and the public wanting to tell their story and show their huge appreciation for the efforts made to help raise awareness of this devastating condition.

Eszter Csabuda, Tüdőér Egylet
www.tudoer.hu





WORLD PH DAY 2013

IRELAND'S LADIES "GET BREATHLESS" IN DUBLIN



From left: Yveta Makovnikova, Jana Guranova, Dominika Tepla and Veronika Jelinkova

On 17 March the Irish Ladies Rugby Team made history by winning the much coveted 6 Nations & Grand Slam trophies. Having previously beaten their old rivals, England, Scotland, Wales and France, the final match was against the Italians, on a cold miserable day in Milan. The match was tough and was far more punishing than any other in their historic campaign. The opposition were physically bigger, the pitch was hard and muddy and temperatures were freezing - but the Irish dug in and managed to overcome their Italian rivals and were victorious in their battle to be the winners! Such is their generosity, commitment and appreciation of health, that they were able to find time during their busy schedule to launch our "Get Breathless for PH" campaign on their training grounds in Donnybrook, Dublin. To mark their achievements on the pitch the Irish Government hosted a very special celebration for them in Farnleigh House and they were hailed Ireland's newest heroines.

Next up was the Dublin Ladies Mini Marathon, the biggest all-female event of its type in the world. The race has been held for the past 30 years and this year attracted over 40,000 ladies to the streets of Dublin. It is a major charity event and over €130m has been raised for various charities since the race started in 1983. There were many t-shirts worn on the day, supporting and advertising the various charitable organizations throughout the country. Our ladies very proudly wore the "Get Breathless for PH" campaign t-shirts and crossed the finishing line in the sweltering heat - most unusual for Ireland! On WPHD itself Susan Sheehan organized an afternoon tea which raised a hugely impressive total of €3,250 for the Pulmonary Hypertension Association. A big thank you to Susan, her friends, family and neighbours for their kindness to support a worthy cause.

The final event was "Hell & Back", one of Ireland's toughest physical and mental endurance challenges. This gruelling obstacle course was over a 12 km stretch in Belmont Estate, Co. Wicklow at the foot of the sugar loaf mountain (which acted as an obstacle itself)! The challenge is designed to push contestants to their limits, they are tested and tormented both physically and mentally, but all in the name of fun and for a good cause! The fastest time for completing the course was 50 minutes, the slowest 3 hours. Our 8 brave contestants finished in around 1.50 minutes and we are so grateful to them for their support and willingness to get well



and truly breathless for Pulmonary Hypertension! Coming up soon: Maeve Donohoe, veteran at Ireland's most famous dance company, Riverdance has pledged to "Get Breathless" in a performance at the Mater University Hospital Dublin. These dancers really and truly get breathless in their brilliant performances. Patients and visitors will be able to come and see the brilliant performance while learning about the "Get Breathless for PH" awareness campaign.

Regina Prenderville, PHA Ireland

<http://www.pulmonaryhypertension.ie/pha-ireland/>
<http://on.fb.me/16CAxgi>





WORLD PH DAY 2013

ISRAEL PUTS THE PUBLIC THROUGH THEIR PACES FOR WPHD



Israel's Pulmonary Hypertension Association commemorated WPHD with two successful programs based on the theme of sports and fitness.

To start Israel's campaign 70 adults and children participated in a 10 km run held in the center of the country. Participants wore the specially branded WPHD t-shirts and a booth at the event provided information about PH. Photos of the run were published on PH Israel's Facebook page and many of the participants shared the pictures with their friends and families to spread the news.

On WPHD itself a crowd of over one hundred people gathered at the Namal, a prominent entertainment complex at the site of the former Tel Aviv port. A "Six Minute Walk" was conducted which included PH patients, their families and supporters. Breathing through balloons whilst walking was used to evoke the debilitating experience of PH, capturing the attention of many passers-by

Timed to coincide with WPHD, an extensive interview including background on PH was published on Ynet, one of the country's leading online

news services. The interview, with PH Israel's Board Member, Oshrat Zemach, provided readers with a broad knowledge of the condition, spreading awareness throughout the country. The director of PHA Israel, Aryeh Cooperman, was featured in a radio interview where he discussed the condition and highlighted the collaboration between PH Israel and PHA Europe.

Other recent activities included a meeting of PH Israel leaders with Prof. David Langleben of Montreal, a leading authority on PH who provided insight concerning pathogenesis, diagnosis, and promising research relating to treatment and case management. Dr. Benjamin Fox, a PH specialist at the Rabin Medical Center in Petach Tikva also participated and related new developments on the part of the lay leaders.

Yosef Gotlieb, PH Israel

www.phisrael.org.il

<https://www.facebook.com/groups/379880662041245/?fref=ts>

41245/?fref=ts





WORLD PH DAY 2013

THE POPE ENCOURAGES PH PATIENTS ON WPHD IN ROME

To coordinate efforts with all the PH organizations around the world and to get as much visibility as possible, Italy's PH patient association AMIP took part in the Rome Marathon, a big international event that brings thousands of athletes to Rome from all over the world.

The difficult part was to find the runners willing to take part in such an enduring event. The hard work paid off and the AMIP team was rewarded with a real treasure: Maurizio Zacchi and Francesco Paro, members of "Podistica Solidarietà", an association whose purpose is to "run for a good cause". The perfect match! A few days before the run the sporting champions and many of their colleagues met Giorgia, a young PH patient who underwent a lung-heart transplant last year.

Just before Marathon day and in front of the Marathon Village, a six minute walk test for PH patients and their athletes was organized. To make it a fairer match the athletes noses were closed and they had to breath through a straw to better understand how PH patients feel living with this condition. Inside the Village a presentation was held and medals were given; the event was streamed

live on the AMIP website and a photo album was uploaded onto Facebook. It had more than 500 visits in 24 hours.

On the morning of the Marathon, runner Maurizio explained to his colleagues that they were going "to send a message 42 km long" about a rare, severe disease. Maurizio and Francesco both donated their Marathon medals to Giorgia.

To conclude Italy's campaign a surprise flash mob in St. Peter's Square was held. AMIP's President, Pisana Ferrari, joined the AMIP group. To catch the interest of the media and the eye of the video cameras broadcasting the Pope's Sunday speech to the world, everybody begun to blow a cloud of soap bubbles containing their very own breath into the sky. Each bubble represented PH patients around the world. President of AMIP, Vittorio Vivenzio, had asked the Pope a special prayer for PH patients and their families and everyone's breath was blown into the bubbles whilst they listened out for the prayer.

IT WORKED! Although it was different than what they had imagined, it immediately hit the Press and photos and articles were published.



They had to brave the heavy rain that made it impossible for their bubbles to fly high, the incredible crowd, the broken loud-speaker that prevented them from hearing Pope Francis' words when he addressed them his encouragement...but it worked! Nobody can imagine how happy they were, all together, wet, tired, but happy!

Luisa Sciacca della Scala, AMIP Italy

www.assoamip.net

<http://on.fb.me/15HMVP0>





WORLD PH DAY 2013

LET THE GAMES BEGIN!

LATVIA HOSTS CHARITY SPORTS DAY

Latvia's WPHD turned into a beautiful and active holiday among friends and families through charity "Get Breathless for PH" sports games held in Salaspils, near Riga, the capital of Latvia. The event attracted great interest with 224 participants ready to "Get Breathless for PH" on a sunny spring day. Among them there were teams of adults, children and representatives from non-governmental organizations and Games' supporters Salaspils District Council. The day was hosted by popular actors Agnese Zeltina and Viesurs Vizulis with the World ashihara-karate champion Vitaly Bereznev opening the games.

The games included streetball, football, darts, hurdles, as well as a mind relay and questions about heart health and PH. Participants were also able to enjoy aerobics, children's karate, gymnastics and break-dancing demonstrations. For people who were not able to take part in the sports activities, two PH

doctors, Ainars Rudzitis and Andris Skride, were on hand to check people's health and enable participants to undergo a six minute walk test.

The campaign also included a cultural theme with the highlight being a performance from the choir "Sōla", from the Latvian Academy of Culture and gold medalists of 7th World Choir Games in Cincinnati, USA.

T-shirts, lollipops, water and juices from SIA "Futurus Food" were distributed to all participants at the games and the winners from each discipline received gift certificates from the Adventure Park "Mezakakis" and other great prizes, including online store "Toys.lv", and "Get Breathless" 2013 mugs. Two lucky winners - Marcis from Gulbene and Darja from Salaspils - won a brand new bike each from cycle store "Velo Atlaides".

The charity sports games attracted the attention of both the Latvian and Russian media with the event



reported in newspapers, online, on social media as well as being broadcast across several TV channels, including National channel LTV1 and the regional channel. Interviews with Ieva Plume, President of PHA Latvia, Dr. Ainars Rudzitis and Dr. Andris Skride, PH experts in Latvia, and Zane Lazdina, a PH patient in need of a lung transplantation, were also featured in the national news.

Importantly, these games helped to raise money for three PH patients living in Latvia - Zane (31), Jurijs

(27), and Alexander (30). Sadly, it is impossible to get a lung transplantation or endarterectomy in Latvia and the high cost of healthcare abroad makes such treatment inaccessible for these patients. As such a special bank account has been opened to raise the funds these patients are desperately in need of.

Ieva Plume and Anna Galvina, PHA Latvia

www.phalatvia.lv/en/

<http://on.fb.me/Vx0udp>





WORLD PH DAY 2013

A KNOCK-OUT EVENT FOR POLAND



Warsaw and one of the most popular buildings in the city. The boxer's fans came to see him and participate in the event. The main TV news stations and a group of photo journalists arrived at the Palace where volunteers distributed information both about PH and the event.

Following a quick blood pressure check, Przemek Saleta climbed the stairs and was still fresh for many TV and radio interviews afterwards.

Professor Adam Torbicki - the famous Polish cardiologist joined the event and talked about PH during his interviews for the media.

Pulmonary Hypertension Association (PHA) Polska was represented by Piotr Manikowski, PHA Polska President, Agnieszka Bartosiewicz, PHA Polska Management Member, Alicja Morze and PH patients from all over Poland. Furthermore, there were other people in the city who voluntarily joined the WPHD campaign and dedicated their training to PH patients and put their photos on Facebook.

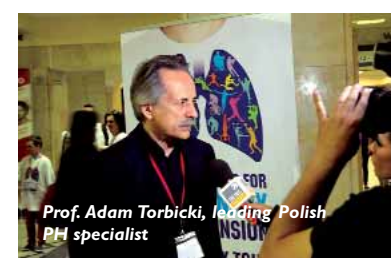
The event secured great coverage from the main national TV stations. Information about PH and WPHD was broadcast nine times on the main TV news that day and both print and online media reported on WPHD almost 50 times. The articles not only covered news about the event, but most importantly they published information about PH. This PHA Polska event really helped to raise awareness about PH among Polish citizens and was a resounding success. See video at: https://www.youtube.com/watch?feature=player_embedded&v=OhQho45n3us

Agnieszka Bartosiewicz, PHA Polska
www.tetniczenadciśnienieplucne.pl
<http://on.fb.me/Rzeo0U>

Kickboxing World Champion "Gets Breathless" for Polish PH patients and climbs the highest building in Warsaw, Poland.

Before Przemek Saleta, Kickboxing World Champion, a Polish and European professional boxer, climbed the highest building in Warsaw on WPHD in Poland, he was a guest on the Morning News of the main national TV station. Both he and Prof. Marcin Kurzyna from European Health Centre Otwork talked about the symptoms of PH.

Installed with a portable camera, so everybody could watch his efforts via the internet, Przemek Saleta climbed almost 763 stairs at the Palace of Culture and Science in Warsaw – the symbol of



Przemek Saleta, Polish Kickboxing World Champion, being interviewed after climbing to the top of the Palace of Culture and Science



WORLD PH DAY 2013

PORTUGUESE PATIENTS SHOW GREAT STRENGTH ON WPHD

Deep in the heart of the Bussaco National Forest, the Portuguese Association for Pulmonary Hypertension (PAPH) marked WPHD under the slogan "Breathe and get breathless to live and fight for health care" with the support of patients, their families and friends.

The event began in the morning, with a conference entitled 'Pulmonary Hypertension - past, present and future' given by Dr António Diogo Nunes, Director of the Cardiology Hospital Center, North Lisbon, followed by the presentation of a project developed by PAPH, entitled "Psychological intervention group: The patient and PH", by psychologist Dr Cátia Rodrigues.

Following the conference, a round table was also held, which allowed people to share their personal stories of those living with PH. These patients and their families took a trip touched by personal stories. Fatigue, failure and shame, the unfeasibility to perform simple tasks like shopping, carrying even with light weights or climbing stairs, was overtaken by a surgery in the case of Mr. Agostinho Duarte.

Alexandra Pinto left his testimony of a young woman who became pregnant and discovered she has PH. She was hospitalized for nine months, is in a life-threatening situation because of her clinical condition, and is waiting for cardiopulmonary transplantation requiring oxygen 24 hours a day.

The hotly awaited sports event took place in the woods of Bussaco National Forest, attended by over 60 people, including patients, their families, friends, and doctors. Patients who participated in the events demonstrated incredible strength and strong will to complete the events of the day.

During the day there were some pauses for Tai Chi and Gigong to help patients to relax and regain their breath. The relaxing activities were followed by a lunch after which the Samba School "Amigos da Tijuca" livened up the afternoon with a surprise "Get breathless for PH" routine.

This was a landmark day for many patients, who had participated in these initiatives for the first time surrounded by the wonderful scenery and surroundings of the Bussaco National Forest.



The intention of this celebration was to disseminate information about the disease, increase early diagnosis, promote access to health care and specific treatments to improve the quality and life expectancy of patients. The campaign also aimed to unify criteria for international recognition of Centres of Excellence for PH and promote research for new treatments needed to effectively control this condition. To help spread further awareness, PAPH will be organizing a cycling event and a Flashmob to complete the set of events, so watch this space!

Maria Joao Saraiva
Associação Portuguesa de Hipertensão Pulmonar
www.aphp-hp.org - <http://on.fb.me/13sawnu>





WORLD PH DAY 2013

SLOVAKIA VOLLEYBALLS TO SUCCESS

Volleyball was the name of the game for Slovakia's "Get breathless for PH" campaign. Together with volleyball club, Polar, in Veľký Krtíš, nine teams from around the country attended this event and played non-stop for 12 hours on two volleyball courts. The opening of the tournament was attended by PH patients, physicians and members of Slovakia's PH Association, and began with a speech from Slovak PHA president Iveta Makovníková, in which she honored and remembered all patients who had passed away due to this devastating condition with a minute of silence. MD. Milan Luknár, a cardiologist at the Center for PAH in Bratislava briefly spoke to the audience about the issues surrounding PH. The program was complemented by two video spots and a performance of young Karate fighters, and activity continued through the afternoon with a Zumba dance. Visitors could familiarize themselves with signs and symptoms of the condition through various leaflets, which were distributed by hostesses and they could also test their health with a diagnostic tool. The

campaign was widely publicized in the press: on websites, social networks and on national radio Regina. The event was also supported by national singer Tomáš Bezdeda along with local private sponsors. During the event, a patient's meeting was held, introduced by a short video about the story of a Slovakian patient, who is waiting for lung transplantation. MD. Milan Luknár held an expert presentation on the issue of PH and Psychologist, Pavla Nôtová, informed the audience about a psychological project, which is dedicated to patients who are on specific treatment. The main event on the agenda was the presentation of the results of the Patient and Carer Survey by Peter Makovník, which was conducted in late 2011 in five European countries. The presentation concluded in discussion and the completion of questionnaires that were filled in by all patients and carers. Milan Luknár and Iveta Makovníková attended three broadcast shows on Slovak Radio, one of which was an hour of live broadcast answering ques-



tions on PH sent in by listeners. They were also invited to the news TV channel JOJ and a show called Fokus-family, which aired live on Slovak television. In those shows, two patient stories were told and participants responded to audience questions. The session had an excellent response and was covered widely in the press and on the internet.

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





WORLD PH DAY 2013

MIXING IT UP FOR WPHD IN SLOVENIA'S CAPITAL CITY



The Slovenian patient group got breathless for PH with an epic football and basketball tournament in Ljubljana.

Both tournaments kicked off in the Park Ježica stadium at the same time, enabling the spectators to watch all of the games simultaneously. There were four football and four basketball teams competing against each other and even though the athletes' main aim was to raise awareness of PH, they managed to put up quite a show and pull off some spectacular moves!

Each team played a total of three games and at the end of the day six football and six basketball matches were played. After each game, the spectators were entertained by more than twenty Slovenian celebrities who were kind enough to participate in the event. Nataša Kragelj, Ksenija Rebeka Matkovič, Iris Ošljaj, Maja Založnik, Uroš Zagožen, Nessy, S.W.A.G. and Martina Šraj really set up a celebratory mood with their singing. Some amazing dancing talents like Nastja Lakner, Ladies Dance Team and Lil' Getness were present as well. Two young Slovenian rappers really mixed it up with their art of rapping. Last but not least, the famous dog trainer Amadea Colja and her two dogs made throwing and catching Frisbees seem like child's play. The main goal of the event was to raise awareness of the condition amongst the professional and non-professional community. The goal was achieved thanks to a flexible variety of promotional means and many Slovenian celebrities, such as Sani Bečirovič, Hannah Mancini and Katarina Čas, who supported the event. Behind the scenes, patient organization members, with the help of Urška Krek and Jan Vehar, managed to issue a large number of press releases, detailing information about the event as well as the disease. Thanks to their efforts, a great deal of newspaper articles were written. The team also succeeded in spreading awareness of the condition further by giving interviews for radio shows and appearing on national TV shows.

In addition to the fantastic media coverage, posters were displayed all over Koper, one of the biggest cities in Slovenia. In the capital of Ljubljana, the poster of the event was displayed on a big screen in the city center and on smaller screens on all city buses before and after the tournament took place.

Klara Klančar, Društvo Za Pljučno Hipertenzijo Slovenije
<http://www.facebook.com/PljucnaHipertenzija>





WORLD PH DAY 2013

RUSSIA'S GREAT CITIES HOST WPHD



Russia marked WPHD for the first time this year, beginning with two dedicated conferences in Moscow and Saint-Petersburg. The main goals of the meetings were to highlight the issue of the provision of PH medicines and to raise awareness about PH among healthcare professionals. The conference was attended by representatives from the Ministry of Health, the pharmaceutical firm Actelion, the

charity fund "Natasha" and the non-governmental organization "Russian Society of Rare (orphan) Diseases". During the conference patients were educated on writing letters to the Ministry of Health and how to conduct an effective dialogue with the authorities as well as discussing the medical aspects of PH and PAH the treatment options available. The second conference, held in Moscow, was entitled "The decision of actual problems of patients with PAH in the regions of the Russian Federation" and was attended by several representatives from different regions of Russia. They presented the situation of the provision of drugs for patients with PH, the prevalence of PH in different regions, the problems of diagnosing PH and the issue around the lack of well-trained PH specialists in Russia.

A running theme of both conferences was the need to establish a Russian Association for PH, to help solve the problems around PH and attract the attention of government as well as highlight the issues faced by people with rare conditions like PH.

*Evgeniy Komarov and Yana Yakovleva,
Natasha Foundation
www.ph-sos.com*

SINGING FOR PH IN SWITZERLAND



On June 30 the Swiss PH patient association SPHV organized a charity concert to raise awareness of PH for WPHD in Birsfelden, in the Basel canton. The concert featured the Schützenchorli group from Aarberg, singing traditional yodelling songs, and a Monastery Choir. The highlight was the internationally acclaimed Oesch's musical family. The concert was preceded by a presentation on PH by family members of two young patients. About sixty volunteers contributed to the success of this initiative. After the concert there were grilled sausages and french fries for all and over 40 different cakes donated for the cause by hard-working bakers.

*Therese Oesch, SPHV
www.lungenhochdruck.ch*



WORLD PH DAY 2013

"GETTING BREATHLESS FOR PH" AROUND THE WORLD

A few PH associations around the world wore our t-shirts for their WPHD events! A "Get Breathless for PH" ski tournament took place in Hokkaido, Japan, in February. iSEEK China had a "Get Breathless for PH" stair-climbing competition and used the t-shirts for other non-sports events as well. The t-shirts were further used at a parade rally in Chile, at a WPHD event in Costa Rica and at a patient meeting organized by PHA Australia in memory of a little boy who has passed away from PH. Many thanks to all on behalf of PHA Europe!



- Top two photos: Parade organized in Chile for WPHD.
- Middle, right: iSeek members and volunteers at the "Get breathless for PH" stair climbing event for WPHD.
- Left: Ski tournament in Hokkaido, Japan. The little girl is called Milka, aged 4 and a PH patient. Her parents are pro-skiers.
- Bottom left and middle: Sports event organized in Costa Rica with some volunteers wearing the "Get breathless for PH" T shirts.
- Bottom right: Patients, family members and volunteers at WPHD patient meeting organized by PHA Australia.



WORLD PH DAY 2013

IRONMAN LANZAROTE, SPAIN



From left: Irene Delgado, Princess Alexia of Greece and Juan Fertes



Harnessing the theme of sport, PHA Europe teamed up with the IRONMAN European Tour to raise awareness of pulmonary hypertension as part of its “Get Breathless for PH” campaign for WPHD.

Over the past 35 years IRONMAN athletes have tackled what is widely considered the toughest one-day endurance event in the world. The races start with a 3.8 km swim, followed by a 180.1 km bike ride and ends with a grueling 42.2 km run to the finish line!

Lanzarote was the first of six races in Europe which saw IRONMAN and PHA Europe join forces as part of the “Get Breathless” campaign to help raise awareness of PH and PHA Europe. The steep slopes and strong winds make Lanzarote the toughest course in the Tour.

Three PH representatives were fortunate enough to attend this great race, including Irene Delgado, ANHP President, Alberto Rivas, a volunteer from ANHP, and myself, representing ANHP and PHA Europe. Two patients also joined us as volunteers to help man the booth on the last day of the exhibition.

The national PH organizations are truly the pillar of PHA Europe and their role at the IRONMAN events is fundamental and greatly appreciated. Due to

IRONMEN GET BREATHLESS FOR PULMONARY HYPERTENSION!

The European Pulmonary Hypertension Patient Association (PHA Europe) has teamed up with IRONMAN to raise awareness of pulmonary hypertension (PH) as part of its “Get Breathless for PH” campaign.

The IRONMAN race is probably the toughest one-day endurance event in the world. 180.2 KM bike ride and 42.2 KM run, all while competing for PHA Europe. Three athletes, Roberto Rodriguez, Patricio Doucet and Marc Martinez, have joined the “Get Breathless” challenge and raced for PHA Europe and the Spanish National PH Patient Association (“Asociación Nacional de Hipertensión Pulmonar”). People suffering from PH find everyday life so hard that they completely forget about the devastating condition that affects many aspects of their life. In stark contrast, all three athletes managed to complete a 3.8 km swim, a 180.2 km bike ride and a 42.2 km run, all while competing for PHA Europe. Marc Martinez Morales came first in his age group and has qualified to enter the IRONMAN World Championship to be held in Hawaii in October.

The athletes, like PH patients, rely on support from family and friends to help with the challenges they face. Roberto said:

“One has to make a lot of sacrifices to compete – it takes a lot of time and it is very important to have support from family and friends.”

Roberto’s biggest supporter is his 12-year-old son who is very proud of his Dad. Marc’s father is a constant source of support and Patricio’s friends have followed him to help him get going for the last few grueling hours.

The IRONMAN athletes know that they pushed themselves to the limit. Patricio explained that he had heard the bike ride was very tough – partly because it was so hot and windy – but he said:

“Competing for PHA Europe pushed me on and inspired me to finish the race.” Roberto found running the hardest – he said, “I kept going but I had to walk at times.”

Choosing from the crowd of spectators, Marc’s solution for a fewing line of spectators on his bike ride was simple – “no energy bars.”

People suffering from PH are pushed to their physical limits every day and there is no time. The athletes, who have helped raise awareness of the disease, as well as the need for research and new treatments, Juan Fertes, the representative from PHA Europe and the Spanish patient association, said:

“The team at Lanzarote had a very positive feeling about the impact of our attendance at IRONMAN. Athletes and spectators saw our banners and beach flags and wondered what PH is and were able to tell them all about it.”

3.8 KM swim
180.2 KM bike ride
42.2 KM run

ROBERTO RODRIGUEZ
Age: 36
Single with 12-year-old son
Lives in Lanzarote
Restaurant owner
Completed the race in:
13 HOURS 4 MINUTES 24 SECONDS
Position: 25th

MARC MARTINEZ MORALES
Age: 33
Single
Lives in Lanzarote
Hotel specialist complex maintenance
Completed the race in:
11 HOURS 4 MINUTES 35 SECONDS
Position: 22nd

PATRICIO DOUCET
Age: 37
Single
Lives in Lanzarote
Hotel specialist complex maintenance
Completed the race in:
11 HOURS 4 MINUTES 35 SECONDS
Position: 22nd

Watch this space for reports from the next PHA EUROPE IRONMAN race which will take place in:
→ 2014 Ironman, Berlin, Germany
→ 2015 Ironman, Nice, France
→ 2016 Ironman, Lanzarote, Spain
→ 2017 Ironman, Zurich, Switzerland

excellent forward planning everything went as we had hoped and everyone was keen to chat with athletes and spectators, involving them with our activities at our stand and distributing branded t-shirts as takeaways as well as taking many photos!

We were pleased to have three athletes involved in the race to fly the flag for PH patients across the globe, including Marc Martinez, Roberto Rodriguez and Patricio Doucet (see insert). Marc Martinez came 25th in the overall race and first in the under - 24s category. He is now preparing for the final of his category in Hawaii and will be proudly wearing PHA Europe and ANHP branded race gear!

All three athletes who ran for PH were invited to speak at the Awards Ceremony and we also had the opportunity to address the crowd at the “Parade of Nations” held the day before the race.

Our branding was very prominent at the event and we gained a great deal of attention from five PHA Europe beach flags near the entrance to the transition area where athletes change from swimwear to bike gear.

The VIP stage was a very visible area of the site and part of the race route and our sixth beach flag was raised at the VIP stand at the starting line along

with banners which got the attention of the public present at the start of the race. Several more banners were positioned by the race course barriers at the finish line.

All in all, the PH team in Lanzarote were very pleased with the impact of our presence at the event. Social networking sites have been very engaged with the photos and the athletes were very sympathetic and supportive of PH. Spectators will have seen the banners and beach flags and we had lots of people enquiring about further information. Furthermore, two doctors who were participating in the Lanzarote IRONMAN race also came to the booth to enquire about PH.

To top things off we even managed to have a VIP interested in our work, Princess Alexia of Greece, who visited us and was eager to hear more about PH and even agreed to have a photo taken in support of PHA Europe and ANHP.

Attending the race was very exciting and a real privilege for us all!

Juan Fertes
PHA Europe Ironman coordinator
Asociación Nacional de Hipertensión Pulmonar



WORLD PH DAY 2013

IRONMAN BERLIN, GERMANY AND NICE, FRANCE



Following the success of Lanzarote the IRONMAN experience has been an increasing success with every country for different reasons. The lessons learned and the great cooperation with the organizers made the impact of PHA Europe's presence at each race even stronger.

The city of Berlin hosted the IRONMAN race for the first time ever this year and proved to be very successful. The PHA Europe branded arch, introduced in Nice and used at all the IRONMAN races which followed, saw thousands of athletes ring the bell as they ran through, drawing attention to PH and showing their support for our cause.

Nice was the most impressive of the IRONMAN events in terms of size. So impressive that we ran out of materials to give away in just two days! In Nice we had a very special contribution from athlete Patrick Garcin. Patrick competed the cycling part on a Vélo bleu, a non-professional bicycle used for public transportation in Nice which was branded with HTAP, PHA Europe and WPHD logos. His video of the race has been watched by more than 3,500 people on YouTube. The bell proved popular and members cheered on the athletes to ring it in support of PH. It was almost too popular as after thousands of rings, the rope of the bell was in strands!

PH national organizations are the core of PHA Europe, and they are the most important workforce for patient advocacy and support. Their involvement and commitment at the IRONMAN races has been priceless. Thank you all for an excellent work!

Juan Fuertes
PHA Europe Ironman coordinator



Patrick Garcin, racing with WPHD, PHA Europe and HTAP stickers, on a Vélo Bleu



WORLD PH DAY 2013

IRONMAN KLAGENFURT, AUSTRIA AND HAUGESUND, NORWAY



From left: Jutta Ulbrich (Bayer) and Martina Schmidt (Actelion)

Everybody in the team of the Austrian patient association was very excited to go to the beautiful lake in Carinthia called "Wörthersee" to be part of the Klagenfurt IRONMAN race. The atmosphere, emotions, family feeling and the constant tension in the air was incredible and we were more than overwhelmed by the experience. All of the 3,000 participants of the IRONMAN race seemed to have a genuine interest in PH and we were able to distribute flyers, show videos from events such as the Pasta Party and make announcements over the speakers for the whole weekend. Our branded arch with the bell was placed in the city center of Klagenfurt. The bell was rung so hard that the cord eventually broke in the evening but was touched thousands of people along the way, raising awareness for PH. It even made it onto the prime time sport news in Austria, ORF1, where it was seen by more than half a million people! The most amazing impression at IRONMAN was to see non-professional, ordinary community from our everyday life competing to achieve the goal of being an IRONMAN. The spirit and determination of ordinary people to complete this challenge was unbelievable - they do not give up and give every last



ounce of energy to make it, some even crawl across the finish line. This inspiration and spirit is something that we should strive to transmit to our patients during the challenges which they face every day. Finally, before the last of the races in Zurich, we have to praise Haugesund for the biggest impact on Facebook so far. Over 7,000 people visited PHA Europe's Facebook page and athletes have made an impressive impact reaching 1,000 interactions just for this race. This is really something to write home about!

Gerald Fischer, PHA Europe President



Bayer team racing at Ironman Klagenfurt



Actelion team racing at Ironman Klagenfurt



Our guests from Japan Ironman Klagenfurt: Yuki and Yeiko



From left: Gerald Fischer with the winner of Ironman Klagenfurt, Andrea Raleert



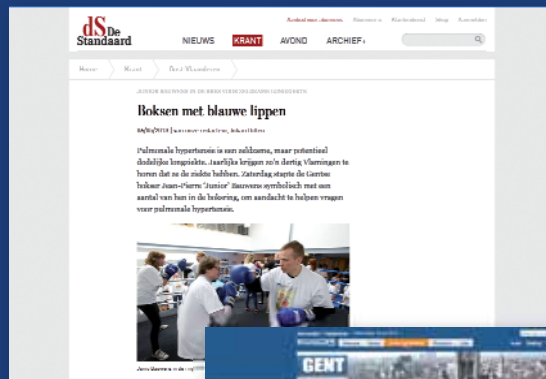
Hall Skaara and Juan Fuertes with one of the athletes



Finish line at Ironman Klagenfurt with PHA Europe logo all along the sides!



ITALY



GREECE



LATVIA



HUNGARY



POLAND



BULGARIA





WORLD PH DAY 2013

A UNIFYING WEBSITE HELPS WORLD PH DAY REACH ITS POTENTIAL

In order to make World Pulmonary Hypertension Day a more global effort this year, the PH associations around the world decided that we would need a website. Pisana Ferrari of PHA Europe noticed that the Lupus Foundation had an excellent website for their World Lupus Day. The World PH Day website (www.worldphday.org) borrows their idea of having a map with different regions that visitors can click on to get events happening in that area, which has been a great success for the PH associations.

To build the website, PHA (USA)'s web developer Diane Greenlaugh used her expertise to lead a discussion on what would be possible and what (in her experience) was needed, along with leaders from various associations around the globe - Huanghuan from iSEEK in China, Chris McGrath of PHA Australia, Paula Menezes of ABRAF in Brazil, Pisana Ferrari of AIPI in Italy and PHA Europe, Denneys Niemandt of PHA South Africa, and Joni Berg of PHA Israel. Holding a Skype call from all time zones of the world was no easy task, but thanks to several peoples' willingness to stay up very late, it was a success and great example of worldwide cooperation.

The teamwork did not stop there; PHA Europe provided a logo (and consequently, a color scheme) for the day based on the logo used last year by the Asociación Nacional de Hipertensión Pulmonar in Spain, PHA (USA) provided the labor and URL to

create the website, and everybody provided feedback along the way to improve the website and catch any errors. The entire website, originally in English, was translated into Chinese, Portuguese, and Spanish for readers around the world, making it a massive and thorough tool for both education on PH and to help people get involved in PH advocacy and awareness activities near them.

Besides listing local events for PH advocates to attend, the website provides opportunities for people to get involved from their homes: <http://www.worldphday.org/ParticipateFromAnywhere>. There are instructions on how to both spread awareness online and how to share about PH in the local media. Additionally, a mosaic of PH warriors around the world provides inspiring stories to teach people about the realities of living with PH (<http://www.worldphday.org/WorldwidePhoto-Mosaic>). Similar pictures were also taken and shared on other websites used around the world, such as Facebook and the Chinese social media website Weibo (<http://www.weibo.com/phachina>).

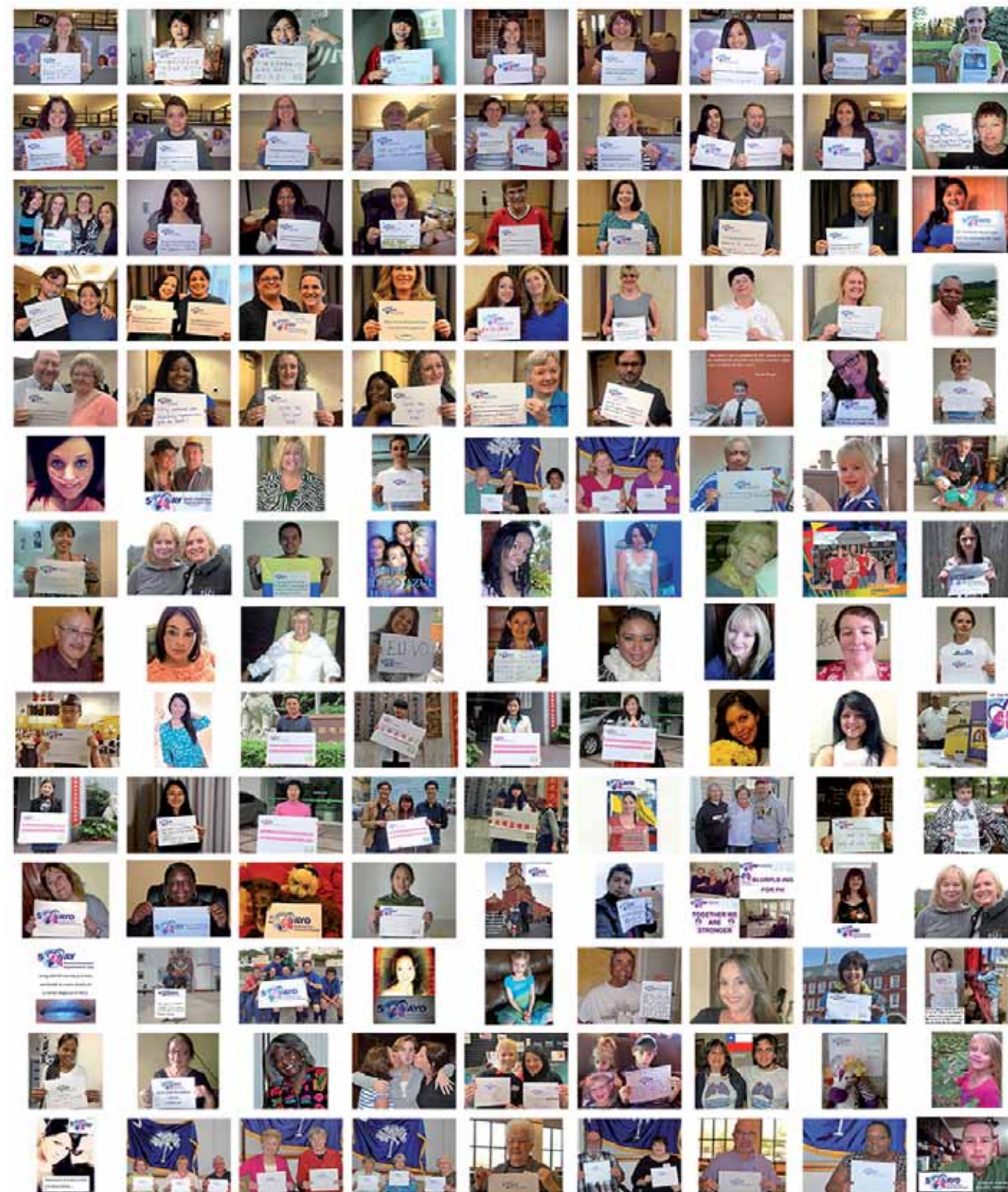
Post-World PH Day, the homepage has changed to a slideshow, showing the events from around the world this World PH Day. Almost every association - and some countries that do not yet have an association - had some sort of World PH Day event, so the global slideshow is an amazing compilation that will help you get a feel for the global reach of the

events. The slideshow includes almost 200 photos of people having fun and spreading awareness around this May 5th.

The website itself was a great tool for spreading awareness and understanding of PH. It has had well over 4,000 visits and 22,000 page views from 96 different countries (from every continent except Antarctica)! While most visitors are from the U.S., China, Mexico, and Brazil, people from Benin to Bhutan have learned about PH online. Watching the

PH community around the world work together to create something so global and large-scale has been nothing short of inspiring. We have no doubt that the reach and scale of both World PH Day and the website will be even bigger next year!

Julia Friederich
International Program Associate,
Pulmonary Hypertension Association
www.phassociation.org - <http://on.fb.me/RIFUOC>



2013

**August 31 - September 4, Amsterdam, The Netherlands****EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS**

PHA Europe will be present as an exhibitor at the EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS 2013. This Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines from basic research to clinical practice.

September 7-11, Barcelona, Spain**EUROPEAN RESPIRATORY SOCIETY'S ANNUAL CONGRESS**

PHA Europe will also be present with a booth at the EUROPEAN SOCIETY FOR RESPIRATORY MEDICINE'S ANNUAL CONGRESS 2013. This Congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

**September 11-15, Barcelona, Spain****PHA EUROPE GENERAL ANNUAL MEETING**

PHA Europe will be holding its 2013 GENERAL ANNUAL MEETING in Castelledefels (Barcelona) September 11-15. PH Patient Leaders from 28 European countries have confirmed their participation (see photo GAM 2012 on left).

2014 AT A GLANCE**Summary of main events:**

- EUROPEAN CONFERENCE ON RARE DISEASES, Berlin, Germany, May 8-10
- PHA USA INTERNATIONAL CONFERENCE, Indianapolis, Indiana, June 20-22
- EUROPEAN SOCIETY OF CARDIOLOGY, Barcelona, Spain, August 30-September 3
- EUROPEAN SOCIETY OF RESPIRATORY MEDICINE, Munich, Germany, September 6-10
- EUROPEAN SOCIETY OF CARDIOLOGY, EDUCATIONAL COURSE ON PH, Sophia Antipolis, France, Autumn 2014

Next PHAE newsletter

The next Mariposa Journal will be issued in December 2013 (Winter edition). It will 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 beginning of November at latest**. These may be sent in the national language and we will provide for translation. Any photos should have a minimum resolution of 2 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**

Selbsthilfegruppe Lungenhochdruck
Wilhelmstraße, 19 - 1120 Wien
www.lungenhochdruck.at
info@lungenhochdruck.at

BELGIUM

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

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

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
bgspph@gmail.com - www.bezdihanie.bg

CZECH REPUBLIC

Sdružení Pacientů s Plicní Hypertenzí
P.O. Box 47, Praha 4, 14021
www.plicni-hypertenze.cz
info@plicni-hypertenze.cz

FINLAND

PHA Finland
c/o Tuulia Näppi
Keskijuoksu 19 J 38 - 02920 Espoo, Finland
pha.fin@gmail.com

FRANCE

HTAP France
c/o Ludivine Chantraine
Allée des Charmes, 8
21380 Asnières les Dijon
www.htapfrance.com
secretariat@htapfrance.com

GERMANY

pulmonale hypertonie e.v.
Wormser Straße, 20
76287 Rheinstetten
www.phev.de - info@phev.de

GREECE

Association of Support and Mutual
Help for PH Patients
32, Lokridos Str. - 17778 Tayros - Athens
www.phagr.com - barlas_phagr@yahoo.gr

HUNGARY

Tüdőér Egylet
19, Cházár András Utca - 1146 Budapest
www.tudoer.hu - csabuda.eszter@t-online.hu

IRELAND

PHA Ireland
c/o Regina Prenderville
56 Eccles Street, Dublin 7, Ireland
<http://www.pulmonaryhypertension.ie/pha-ireland/> - rprenderville@mater.ie

ISRAEL

PHA Israel
13 HaShoshan Street - Beit Shemesh 99590 Israel
www.phisrael.org.il - aryeh35@gmail.com

ITALY

Associazione Iperensione Polmonare
Italiana onlus
Via Vigoni, 13 - 20122 Milano
www.aiptitalia.it - pisana.ferrari@alice.it

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

Polskie Stowarzyszenie Osób z
Nadciśnieniem Płucnym i Ich Przyjaciół
ul. Wieluńska 3, 81-084 Gdynia.
www.phapolska.org
bartosiewicz.agnieszka@phapolska.org
admin@phapolska.org

PORTUGAL

Associação Portuguesa de Hipertensão
Pulmonar
Avenida Dr. Luis Navega, 38-42 - 3050 Mealhada
www.aphp-hp.org - mariajsaraiva@gmail.com

RUSSIA

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

SLOVAKIA

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

SLOVENIA

Društvo Za Pljučno Hipertenzijo
Slovenije
Slovenska 29, 1000 Ljubljana
dbph.slovenije@gmail.com

SPAIN

Asociación Nacional de Hipertensión
Pulmonar
Avenida de las Artes, 7
28300 Aranjuez - Madrid
www.hipertensionpulmonar.es
informacion@hipertensionpulmonar.es

SWEDEN

Nätverket för PAH
c/o Patrik Hassel
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
Im Rossweidli 1 - 8045 Zürich
www.lungenhochdruck.ch - www.sphv.ch
President: praesi@lungenhochdruck.ch
Webmaster: bossard@lungenhochdruck.ch

TURKEY

Pulmoner Hipertansiyon Dernegi
Meriç Sokak Milas 2000 Is Merkezi 5A
Blok/26 - Bestepe Ankara
www.pha-turkey.com - info@pha-turkey.com

OFFICE AUSTRIA:

Gerald Fischer, President - Wilhelmstrasse, 19 - 1120 Vienna - tel. +43 1 4023725 - fax +43 1 4093528 - info@phaeurope.org

OFFICE ITALY:

Pisana Ferrari, Vice President - Via G. Vigoni, 13 - 20122 Milano - mob. +39 348 4023432 - p.ferrari@phaeurope.org

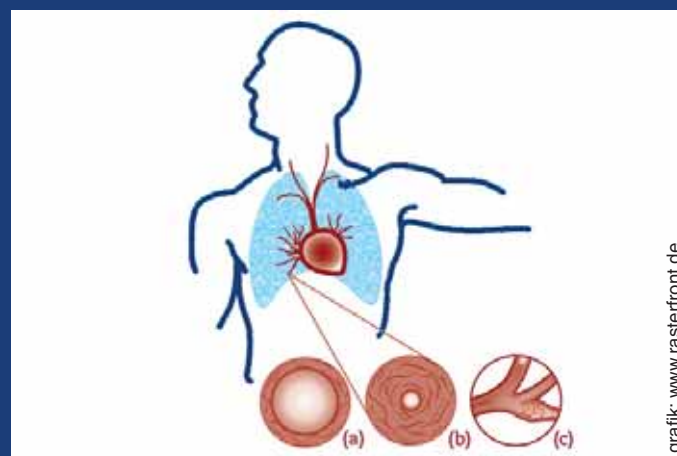
www.phaeurope.org

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.