



# PULMONARY HYPERTENSION Mariposa Journal

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**"GETTING BREATHLESS FOR PH" CAMPAIGNS FOR WORLD PH DAY 2014!**

**PHA EUROPE**  
European pulmonary hypertension association

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# Editor's memo Summer 2014 edition

- Austria
- Belgium
- Bulgaria
- Czech Republic
- Finland
- France
- Germany
- Greece
- Hungary
- Ireland
- Israel
- Italy
- Latvia
- Netherlands
- Norway
- Poland
- Portugal
- Republic of Macedonia
- Russia
- Slovakia
- Slovenia
- Spain
- Sweden
- Switzerland
- Turkey
- Ukraine

Dear members, supporters, friends and families, a very warm welcome to this special summer edition of the Mariposa journal which focuses on telling the story and celebrating the success of this year's "Get Breathless for Pulmonary Hypertension" activities to mark World Pulmonary Hypertension Day. Thanks to your continued support, hard work and dedication to raising awareness of PH, the results of this year's campaign have surpassed our dreams and expectations; with an exciting array of flashmobs, sporting events and social media activities taking place all over the world and putting PH firmly on the map. Health Ministers, IRONMAN athletes, yo-yo champions, physicians, celebrity sports reporters, professional high jumpers and basketball teams, musicians, synchronized ice skaters, celebrity singer Michael Buble and even Justin Timberlake - to name but a few - were among the thousands of people that came together to mark World PH Day this year, putting their names next to yours as supporters of this important cause that means so much to us all. This year, 20 European countries joined forces to "Get Breathless for PH" - from a balloon flashmob in Tel Aviv to a sporting extravaganza in the historical square of Prague and a marathon through the woods and hills of Tivoli - we got breathless and raised awareness of PH in the city streets and rural suburbs and cascaded our message from the mountain tops. World PH Day activities also took

place in 12 Latin American countries, Australia, Canada, China, Ghana, Indonesia, Oman, South Africa, and the U.S. - meaning a total of 40 countries rallied together to raise awareness for World PH Day 2014, building on the 30 that united together last year. The campaign was reported by the media worldwide, with more than 150 press articles, 20 TV clips and 25 radio announcements generated to date and over 2,200 uses of the #WorldPHDay hashtag. This year we also launched the first ever World PH Day Thunderclap - a social media flashmob - for which 314 people signed up to send out a coordinated World PH Day message from their social media channels on 5 May, with a social reach of 124,000 people. This proved to be a fantastic way of driving momentum and awareness for the campaign on World PH Day itself. Momentum of another kind was generated by the IRONMAN athletes who "got breathless" by participating in Europe's toughest triathlon in support of PH patients. For the second year running, we are proud to be the only official charity partner of the IRONMAN European Tour and we have already had a strong presence at the races, with a total of 59 athletes running for PH in Spain, Klagenfurt, Nice, Frankfurt and Zurich and with upcoming presence at the last of our sponsored races in Copenhagen. Through these races, our message has reached up to a potential 1 million attendees and our articles in the IRONMAN newsletters have been distributed



to over 100,000 recipients. Outside of Europe, PH awareness activities also took place at the IRONMAN Australia and South Africa races. All of these inspiring activities were supported by our updated World PH Day toolkit, which included guidance on how to organize flashmobs, social media know-how and a wealth of "Get Breathless for PH" branded materials which were produced and used all around the world - as you will see in the fantastic photos in the following pages. These results have demonstrated the strength of the unique and fruitful collaboration between us, Actelion, Bayer Healthcare and the IRONMAN European Tour which leverages our unique network of patient groups, the media expertise of Actelion and Bayer Healthcare and the reputation of a globally renowned sporting platform to really capture the hearts and minds of the public. This collaboration was also shortlisted for an "Excellence in Healthcare Collaborations and Partnerships" award at Communicate this summer - a prestigious communications awards event. Speaking of awards, we are also delighted that World PH Day won the "Global PR Breakthrough of the Year award" at the Global PR Week Awards in May 2014. This is testament to your hard work and dedication and we would like to take this opportunity to thank everyone involved in making World PH Day the successful global campaign that has rightly come to be known as. As a final thought, in the spirit of us joining together to raise awareness of PH for World PH Day, I leave you with the



words of poet Mattie Stepanek, who wrote for peace and on behalf of people with disabilities and children with life-threatening conditions: "Unity is strength... when there is teamwork and collaboration, wonderful things can be achieved".

Gerald Fischer  
PHA Europe President

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

## CONTENTS

• <b>World PH Day 2014 Europe - National events</b>		
- AUSTRIA	p. 4	- SPAIN p. 38
- BELGIUM	p. 6	- UKRAINE p. 40
- BULGARIA BSPPH	p. 8	- FRANCE p. 42
- PHA BULGARIA	p. 10	- TURKEY p. 43
- CZECH REPUBLIC	p. 12	• <b>World PH Day 2014 Europe - IRONMAN</b> p. 44
- FINLAND	p. 14	• <b>Media clippings</b> p. 48
- GERMANY	p. 16	
- GREECE	p. 18	• <b>World PH Day 2014 - Rest of the world</b>
- HUNGARY	p. 20	- AUSTRALIA p. 52
- ISRAEL	p. 22	- CHINA p. 53
- ITALY	p. 24	- GHANA p. 53
- LATVIA	p. 26	- LATIN AMERICA p. 54
- POLAND	p. 28	- USA p. 55
- PORTUGAL	p. 30	• <b>Upcoming events 2014</b> p. 56
- REPUBLIC OF MACEDONIA	p. 32	• <b>What is Pulmonary Hypertension?</b> p. 57
- SLOVAKIA	p. 34	• <b>Members of PHA Europe and contact details</b> p. 58
- SLOVENIA	p. 36	





## WORLD PH DAY 2014 - AUSTRIA

# “HOPE SPRINGS ETERNAL” STEALS THE LIMELIGHT IN AUSTRIA



### Flying high

A flashmob was organized in the Vienna Prater in collaboration with the Austrian Kite Society. Huge kites with the “Get Breathless for PH” logo were flown over the Prater to raise awareness of PH. PH patients and their families, all wearing the “Get Breathless for PH” t-shirts, were invited to attend the event which drew in a big crowd.

### Medal of honour

On April 23rd I had the honour of being awarded the Golden Medal of Honor (the *Goldenes Verdienstkreuz fuer Verdienste um die Republik Österreich*) for special achievements of the Republic of Austria from the Austrian President Heinz Fischer. The festive celebration took place in the Chancellery building ceremonial hall. The medal was handed to me by the Austrian minister of Health Alois Stoeger for my work for PHA AUSTRIA, PHA EUROPE and for being an active part in writing the national Austrian action plan for rare diseases. Press, TV stations and of course my family were present.

### Hope springs eternal

My daughter Maleen’s book has been launched in Austria, with an exceptionally huge media attention (Maleen is a PH patient on IV prostanooids since she was four years old). It was the biggest awareness event in Austria for PH in the past 15 years. Thanks to our industry sponsors, who offered an additional budget, Maleen’s book was translated into English and will be available by end of August. The sales price includes a 5\$ coupon that can be given by the buyer to a patient association of his choice. 346 Patient Groups from around the world are listed in the book with their contact details. Every one of these 346 PH groups will receive a free sample of the book with a letter from PHAE. The profit of this edition of Maleen’s book will be donated to PHAE. We are hoping that Maleen’s story will give hope and positive support to the whole PH family around the world.

Gerald Fischer  
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## WORLD PH DAY 2014 - BELGIUM

# GETTING ACTIVE FOR PH IN BELGIUM

### Getting active for PH

On 5 May, we joined staff at Bayer to take part in an event to “Get Breathless for PH” by walking on treadmills to raise money for the patient organization. Noémi, aged 13, and Charlotte (who recently underwent a transplant), aged 15, both have PH and talked to the staff about living with the condition. Chairman Hendrik Ramaker and Prof. Marion Delcroix also talked at the event - attended by over 100 people - to mark World PH Day.

### Virtual action on Facebook and Twitter

A virtual campaign was launched on 5 May. The idea was to run, cycle or walk for PH by posting your activity on Facebook and Twitter using the hashtag #phbelgium @phbelgium. This campaign is still running so we hope to keep up the involvement and excitement!

### Feeling blue? Blue Lips Campaign rallies support for people with PH

A month long Blue Lips Campaign saw school children, families, celebrities and even politicians getting involved in raising awareness of PH. Supporters painted their lips blue in solidarity with

patients and took pictures of themselves, causing a viral sensation when posted on social media. So far 250 photo postcards have been collected and the number keeps growing!

### Mid-summer night run in Ghent

The “Get Breathless for PH” activities culminated on 21 June, when over 5,000 runners participated in a 10km run in the city of Ghent. 30 of these athletes ran especially for our PH association to raise awareness of this devastating condition.

### Media coverage

A number of online media covered our campaign for World PH day, including *PassionSanté.be*, *l'avenir.net*, *topicsanté.be* and *Knack.be*. A radio interview for *Radio 2* and an article in the *Gazet van Antwerpen*, the 3rd biggest newspaper in Flanders, and biggest newspaper in the region of Antwerp, are planned in the coming month.

Hendrik Ramaker  
Patiëntenvereniging Pulmonale Hypertensie vzw  
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[www.facebook.com/PHBelgium?fref=ts](http://www.facebook.com/PHBelgium?fref=ts)







## WORLD PH DAY 2014 - BULGARIA BSPPH

# “MARCH OF HOPE” SUPPORTS PATIENTS WITH PH IN BULGARIA

### Series of events celebrate WPH Day in Sofia

This year Bulgaria celebrated World Pulmonary Hypertension Day on 17 May with a mass “March of Hope”. A great number of supporters took on the three-hour steep trail in the Vitosha Mountains near Sofia, climbing 1,367 meters to show their support for the patients with PH.

The “March of Hope” was an effective metaphor for the condition of patients with PH and through this walk with nature it revealed to participants what it means to be constantly breathless, one of the most recognizable symptoms of the condition.

Alongside the “March of Hope”, personal video messages by famous Bulgarian influencers, including bloggers, professors, singers and activists were published. Specially designed information materials - flyers and brochures, posters, demonstration of yo-yo skills and a collection of blue palm prints - were distributed, another symbolic act of solidarity with PH patients.

For the second consecutive year the campaign was held under the patronage of the Sofia Mayor - Mr. Yordanka Fandakova. More than 4,000 people were engaged in the activities around the campaign and received informative materials about PH.

The campaign received significant media exposure and was covered by more than 15 national and specialized media publications. Facebook engagement and personal video messages from the endorsers of the “March of Hope” reached 58,000 views.

“We really want to thank all those people who literally lost their breath in the “March of Hope” and did this entire mountain route to support us. For us this means a lot”, said Mrs. Natalia Maeva, Chairwoman of the Bulgarian society of patients with PH.

### “Get breathless for PH” 2013 campaign wins prestigious award

The 2013 “Get breathless for PH” campaign supporting was awarded with 3rd prize in the category “CSR projects for NGOs” at the oldest and most reputable contest in the field of Public Relations in Bulgaria - the PR Prize 2014, organized by the Bulgarian Society for Public Relations. The BSPPH campaign is one of 48 projects which competed in the 14th edition of this contest. “It was really rewarding to work on the campaign and we are pushing to make it better each year. We are very happy with the award. A special thanks to all team of CIVITAS GLOBAL BULGARIA” said Natalia Maeva, President of BSPPH. The good news about the

award was covered in the media landscape, in Bulgaria On air TV channel, Darik Radio and as well as in different online portals.

### Young Bulgarian Yo-Yo player supports “Get Breathless for PH”

In the autumn of 2013, when the national yo-yo contest was held, many players, including the two time National Champion, Konstantin Tudjarov, supported BSPPH, dedicating their wins to the “Get Breathless for PH” campaign. The city of Budapest, Hungary, hosted the European yo-yo championships. The masters of yo-yoing from all over Europe demonstrated various tricks which were hugely impressive. The 2013 Bulgarian National Champion Konstantin Tudjarov was a relatively fresh face in the top ranks of the competition but that didn't stop him from defeating the former World Champion, and taking 4th place in the biggest yo-yo event in Europe. George Stoyanov, also a National Champion yo-yoed his way throughout the championships in support of PH. This year in early August, for the first time in history, the World Yo-Yo Contest will be held in Europe - Prague to be exact. We expect our boys to reach the top spots! We'd like to thank the young players who dedicated their participation in this prestigious competition to our PH campaign. Thank you!

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

[www.bspph.net](http://www.bspph.net)

[www.facebook.com/BSPPH.Bulgaria?ref=hl](https://www.facebook.com/BSPPH.Bulgaria?ref=hl)







## WORLD PH DAY 2014 - PHA BULGARIA

# MEMBERS OF THE PUBLIC “TAKE A BREATH” WITH PH PATIENTS

On May 7, pulmonary hypertension (PH) patients shared their stories with the nation as PHA Bulgaria (APH Bulgaria) and the National Alliance of People with Rare Diseases (NAPRD) partnered to hold an impactful press conference at the Bulgarian News Agency. The press conference provided a candid reflection on what life is like for patients living with PH in Bulgaria.

Later the same day, patients gathered outside the Bulgarian Ministry of Health to demonstrate how even gentle exercise can take a huge toll on people suffering from PH, leading to breathlessness, fainting and fatigue. As part of the “Take a Breath with Me” campaign, people with PH performed low-impact exercises in front of a crowd of journalists and passers-by so that people could see first-hand the effects of physical exertion on PH-sufferers. Members of the public were invited to ‘take a breath with me’ by breathing air through a straw, with a peg on their nose, to understand the struggle for breath that people with PH experience on a daily basis.

The combination of strong, patient-focused case

studies and an immersive, experiential stunt paid off, with these World PH Day activities gaining coverage across two television channels, radio and several print and online media outlets. These results are an amazing reward for the dedicated work of all involved!

And the hard work didn’t stop at raising awareness of PH among the general public. APH Bulgaria and NAPRD have extended their partnership to deliver a number of training sessions for medical professionals at universities in Sofia, Pleven and Haskovo, with additional seminars planned in Burgas and Varna. As a rare condition, the symptoms of PH can even be overlooked among healthcare professionals. With early diagnosis essential for a good prognosis, so we hope that the benefits of educational activities such as these will be seen for many years to come!

*Todor Mangarov, PHA Bulgaria*

[www.apph-bg.org](http://www.apph-bg.org)

[www.facebook.com/aph.bulgaria](http://www.facebook.com/aph.bulgaria)







## WORLD PH DAY 2014 - CZECH REPUBLIC

# VISITORS OF PRAGUE'S OLDEST SQUARE GET NEW LESSON IN PH

We wanted our World Pulmonary Hypertension Day activities to make a big impact. Situated in front of the Prague Castle and Hradčan, Hradčanské Square boasts the most magnificent and famous views of Prague. This is why the Czech pulmonary hypertension patient organization chose Hradčanské Square, one of the oldest squares in the capital, as the location for our event.

The event began in the morning and was attended by crowds of people, Czechs and tourists alike. There was an anchorman who encouraged passers-by to visit our booth situated in the center of the square. Visitors were invited to experience the symptoms of PH and get breathless by doing light workouts on our fitness machines. During the day, our health care professionals measured oxygen saturation in their blood using a pulse oximeter, before and after visitors commenced a period of light exercise. After the workout they could discuss their condition with doctors and physiotherapists and they were given leaflets with information about pulmonary hyper-

tension and a blue lip lollipop as a small thank you present for getting breathless!

Following the event we issued a press release with information about the event's success and details about PH. Thanks to the effort of our PH team, several articles were published on news portals and appeared on key social networks. Before the event, visitors were able to learn about the activities via Prague's most popular radio station - Radio City - which broadcasts information throughout the day.

The event's objective was not only to disseminate information about the condition, its symptoms and the importance of early diagnosis but also to highlight the importance of our PH patients association, which brings like-minded people together - because what's more important than that...

Regina Votavová  
Sdružení Pacientů s Plicní Hypertenzí  
[www.plicni-hypertenze.cz](http://www.plicni-hypertenze.cz)



Katerina Nováková being interviewed



Prof. Javel Pansa being interviewed







## WORLD PH DAY 2014 - FINLAND

# A PHOTO FINISH FOR PHA FINLAND ON WORLD PH DAY!

On May 25, 100 bright white "Get Breathless for PH" t-shirts stood out among a sea of pink, as women of all shapes and sizes launched in to a fun 10km challenge called Women's Ten, one of the most popular annual sports events in Helsinki. Thousands of women gather in Helsinki for Women's Ten on May 25 each year, which calls on women of all ages to walk, jog or run a spectacular 10km course, surrounded by beautiful coastal scenery. Media and spectators swarm to the event, so PHA Finland (Suomen PAH-potilasyhdistys ry) made the most of the opportunity to use this hugely popular and enjoyable day to raise awareness of pulmonary hypertension (PH). Even before the race started, PH was in the spotlight when the Women's Ten magazine published a full page article about PH, the work of PHA

Finland and the story of Jaana Rajahalme who has been living with PH for many years. This article, added to active promotion of the "Get breathless for PH" T-shirts on the Women's Ten Facebook page, which led to a surge of interest from race participants wanting to get their hands on the T-shirt. On the day itself, the 100 T-shirts were gone within two hours, long before the race even started! Information brochures, blue lips lollipops and World PH Day-branded balloons were also snapped up. This was an unprecedented success and it was wonderful to see so many women switching their pink Women's Ten T-shirts for the unmistakable bright white t-shirts of World PH Day, to show their support as they took to the course to "Get Breathless for PH". With all the promotion, both at the race and in



advance of it, many women were interested in finding out more about PH, and even a celebrity - Finnish pop singer Irina, who performed at the event - showed her support and cheered on the crowd!

Women's Ten was a successful and enjoyable day for all and PHA Finland looks forward to building on these activities next year.

Jaana Rajahalme,  
Suomen PAH-potilasyhdistys ry. PHA Finland  
<http://on.fb.me/1tSxFwR>



PH Finland members with the famous Finnish singer Irina Saari (center)







## WORLD PH DAY 2014 - GERMANY

# POSE FOR THE CAMERA: GERMANY BRINGS WORLD PH DAY INTO FOCUS

### Awareness activity at PH medical centers

The German Pulmonary Hypertension Association marked World PH Day with stands at 11 expert medical centers. The stands were decorated with the campaign posters and attracted interest from passers-by who took photos of themselves with blue lips.

### Destination Ironman! PH advert attracts train travelers seeking “breath-taking” adventure

In addition, several German train companies published our eye catching posters highlighting the

IRONMAN partnership with PHA Europe in their guide books, and encouraged travelers to attend the local Frankfurt race.

*Hans-Dieter Kulla, pulmonary hypertension e.V.*  
[www.phev.de](http://www.phev.de)

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







**WORLD PH DAY 2014 - GREECE**

## PURPLE CELEBRATIONS LIGHT UP THE ACROPOLIS



The Hellenic Pulmonary Hypertension (HPH) was very active for this year's World PH Day, organizing and participating in a series of events during the first fortnight of May. PH Greece intensified its efforts to reach a larger audience and raise awareness about pulmonary hypertension by providing information in a number of ways, such as participating in running and cycling events, promoting the purple ribbon symbolizing PH awareness and attending PH-related scientific conferences.

On 27th of April, an enthusiastic group of people gathered in the old city of Athens to get peddling for PH for the second consecutive year, with the goal of making cycling a customary part of World PH Day. Not only is the action of cycling tightly connected to the respiratory and cardiovascular system, but it is also a perfect way to attract the attention of the public. A happy crowd of people joined together on the Sunday morning in the busiest and most beautiful part of Athens, with a big smile on their faces, the purple ribbon on their chest and a huge hot-air balloon with the PH logo flying over their heads. Hundreds of purple balloons filled the sky and were given out by our volunteers to people of all ages creating an amazing spectacle in the streets under the Acropolis. PH Greece took many important steps to advance

the recognition of the association. On 30th of April, Minister of Health, Mr Adonis Georgiadis, held a working dinner with PH patients and PH specialist doctors. It was a very constructive meeting and the president of HPH, Ioanna Alisandratou, took the opportunity to inform the Minister about a whole range of issues relating to PH. A few days later, the Greek PH Medical Conference was held and concluded with some important decisions being made, including the establishment of a Scientific Committee on PH to facilitate research and communication between PH specialists.

Sunday 4 May was a full day for PH Greece. Embracing once again the theme of sports, PH Greece was present for the Athens Half Marathon, an event on a grand scale, attracting more than 10,000 runners each year. Five of our volunteers took part in the race wearing the iconic "Get Breathless for PH" t-shirt. Later that day, PH Greece got together with other patient associations in an event that took place to foster solidarity and present good practices and innovative ideas to an interested audience as well as to each other. The purple ribbon was also sent out to PH specialists in hospitals of Athens and Thessaloniki where the doctors wore it on their chests for the whole following week,



from 5 to 11 of May. PH Greece has made consistent efforts to expand its reach beyond Athens and on the weekend of 10-11 May we found ourselves in Thessaloniki - the second biggest city of Greece - to listen to new findings about PH and spent a fruitful day informing the public about PH.

*Ioanna Alisandratou*  
PHA Greece

[www.hellenicpulmonaryhypertension.gr](http://www.hellenicpulmonaryhypertension.gr)  
<https://www.facebook.com/PulmonaryHypertensionGreece>







## WORLD PH DAY 2014 - HUNGARY

# A JAM-PACKED DAY OF EVENTS MARKS WORLD PH DAY IN HUNGARY

As part of World Pulmonary Hypertension Day this year, Tüdőér Egylet, the Hungarian PH Association, held its event in City Park, a location popular with locals for sport and recreation. PHA Hungary organized a number of diverse and varied programs with a particular focus on sport, especially running. We were extremely lucky to secure the involvement of Dávid Szántó, a Hungarian celebrity TV sports reporter who participated in the event and helped with the event organization.

The program started with an extraordinary biology lesson from Kristóf Karlócai, MD, Vice President of PHA Hungary, who informed the audience about PH through a question and answer session. Following the educational discussion, a traditional Hungarian dancing group provided a great performance wearing “Get Breathless for PH” t-shirts. The participants

were eager to race against triathlete Róbert Szaniszló and so we went on to the running track, which was set up in the woody area of City Park. The full distance was approximately 2,5 km and over 150 runners took on the challenge. Some of the racers accomplished the track breathing through straws to mimic the feeling felt by people with PH.

The tired runners were welcomed over the line with refreshments and were awarded with small gifts and a certificate. Following the announcement of the results, the participants were asked to blow up as many balloons as they could. The task was to keep the air inside the balloons for as long as possible, which was hugely enjoyed by all the children. Towards the end of the day, Róbert Szaniszló provided some insight into the training regime and his triathlon races, which was greatly welcomed.



Throughout the event, different activities entertained the participants, including a juggler and a “reflex gate”, which was capable of testing the speed of a player, along with other games which tested the skillfulness of the participants. In contrast to last year, the weather was on our side and based on the smiles, everybody had a really great time.

PHA Europe and the Hungarian association will be at Ironman Budapest on August 24.

*Eszter Csabuda, Tüdőér Egylet*  
[www.tudoer.hu](http://www.tudoer.hu)







## WORLD PH DAY 2014 - ISRAEL

# Balloons fill the skies in Tel Aviv



A surprise flashmob was held in the Weizman mall, Tel Aviv, for this year's World PH Day. The event saw a huge gathering of patients, family, friends and participants release blue balloons to symbolise the symptoms of PH while the song "Letter to my brother" by Elai Botner and Kobi Aflalo was played to an audience. We hoisted a huge banner with the words: "Pulmonary hypertension international awareness day - if you have unexplained shortness of breath, perhaps it is Pulmonary Hypertension. See your physician". There were some great photographs of the day and we also made a very moving video featuring PH patients and the CEO of our organization to raise awareness of this devastating condition.

Yosef Gotlieb, PH Israel

[www.phisrael.org.il](http://www.phisrael.org.il)

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







## WORLD PH DAY 2014 - ITALY

# MARATHON RUNNERS FLY THE FLAG FOR PH ACROSS ITALY



Our World Pulmonary Hypertension Day campaign began last year when we decided to look for two runners to represent us in the Rome Marathon. Skip forward to 2014, and we now have hundreds of athletes running in support of PH, who know what the condition is and are proud to be spreading greater awareness of it. This partnership has led to a beautiful friendship between pulmonary hypertension patients and athletes - both supporting each other to achieve their goals.

A few days before the run that brought thousands of people to Rome, we took to the front of the Marathon Village performing a 6 minute walk with athletes and patients. Everybody was very curious about what we were doing. Fortunately, "our" athletes were answering the questions alongside us - it was their mission too, to talk about PH and spread the word! On the day of the actual run we were all together, gathered in anticipation of the start. The competitors were running 42km, we were (slowly) walking 5km in the Roma Fun Race. It was raining but two patients managed to arrive at the finish line with our group. We were all holding our banners

and wearing our t-shirts. It was a day full of joy and amusement, Vittorio had an interview on TV and, what's more, all our members and friends were happy to be there.

Finally, we'd like to mention the Tivoli Marathon that was organized expressly to mark World PH Day. AIPI and AMIP were in attendance with Marzia Predieri representing her Association, AIPI. Everybody knew why we were in that fantastic spot and "lending our breath to PH patients". The athletes ran along Tivoli's Roman villas and through the hills and woods nearby, while we did our job assisting the athletes along the way at the various pit stops. The athletes were proud to wear the "Get Breathless" t-shirts during the race and for those who couldn't run whilst wearing them, they were excited to put them on as soon as they reached the finish line. We are sure that many will go on to proudly wear their t-shirts in future races.

Vittorio Vivenzio, AMIP Italy  
[www.assoamip.net](http://www.assoamip.net)  
<http://on.fb.me/15HMVPO>







## WORLD PH DAY 2014 - LATVIA

# JUMPING HIGH FOR PH IN LATVIA

This year, popular Latvian sportsmen, young people and young physicians supported pulmonary hypertension (PH) patients with high jumps in Old Riga near the Freedom Monument. On 5 May PHA Latvia launched the event “78 jumps that take your breath away!” in honour of the 78 Latvian pulmonary hypertension patients.

Eminent Latvian athletes performed high jumps: Madara Onuzane and Janis Vanags, both Latvian high jump champions, Zanna Juskane, biathlonist in the 2014 Winter Olympics games, Gatis Praulitis, Junior champion in biathlon in both Latvia and Sweden and Natalija Cakova, a popular athlete.

The event was opened by Ieva Plume, PHA Latvia President, who roused an audience to participate in the 20 second flash mob where more than 70 participants held their nose and held their breath to raise awareness for patients with PH. During the public show, jumpers and journalists participated in a 6 minute walking test, and children drew pictures of a heart and lungs.

The PHA Latvia event had huge success in the media. The campaign was featured on all the TV news programs and most popular TV channels (Five TV reports, radio, newspapers, and online media). We have also appeared in articles online and in the newspaper *Neatkarīga Rita Avīze*, which wrote about the CTEPH patient Alexandr Korlass. There was also an extensive article featured in analytical magazine *Ir* about Ieva Plume and the fundraising for PH patient Zane Lazdina's lung transplantation. Another article appeared in weekly magazine *Ievas Veselība* with a cover page about Ieva Plume's experiences as a patient and as PHA Latvia President.

Ten students from the Medicine Department of University of Latvia took part as volunteers in our positive and energetic event which was hosted by well-known TV moderator Juris Steinbergs.

To finish on more good news - on 16 April, under the expert guidance of Prof. W. Klepetko, Zane Lazdina underwent double lung transplantation.



The surgery was successful and Zane has returned home to Latvia after a post-surgery course and rehabilitation at the Vienna University Clinic. She feels very happy and expresses her warmest thanks to everyone for the support received. Zane is the first patient in Latvia to have new lungs.

Ieva Plume, PHA Latvia  
[www.phalatvia.lv/en/](http://www.phalatvia.lv/en/)  
<http://on.fb.me/Vx0udp>







## WORLD PH DAY 2014 - POLAND

# POLAND “GETS BREATHLESS” IN SOLIDARITY WITH PH PATIENTS

PHA Polska organized a mammoth three hour World Pulmonary Hypertension Day event in the centre of Warsaw to encourage Polish celebrities to join an outdoor training session in solidarity with Pulmonary Hypertension patients. The celebrities were all great sports and participated in the cycling fitness sessions, which members of the public could also join. During the day, volunteers distributed approximately 850 World PH Day flyers to participants, guests and Warsaw citizens. Actors, singers, TV presenters, fashion models and a Kickboxing World Champion joined our event in support of this great cause. All participants got “Breathless for PH” and together reached over 259km on the fitness bikes in solidarity with Polish PH patients.

As well as receiving a great deal of attention from members of the public in Warsaw, our event also attracted a lot of interest from the media. Both

national and local TV and radio stations covered the event. In total, 50 news items were published, all of which were positive, securing an audience reach of over half a million!

Roughly 1,000 people took part in our event over the course of the day and more than 200 people took photos with the #WorldPHDay poster.

In addition to this, people from all over Poland who were not able to attend on the day pledged their support by dedicating their training sessions to PH patients and publishing their training photos on Facebook.

Agnieszka Bartosiewicz, PHA Polska

[www.tetniczenadciśnienieplucne.pl](http://www.tetniczenadciśnienieplucne.pl)

[www.facebook.com/pages/Polskie-Stowarzyszenie-Osób-z-Nadciśnieniem-Płucnym-i-Ich-Przyjaciół/1438211746452788?ref=hl](https://www.facebook.com/pages/Polskie-Stowarzyszenie-Osób-z-Nadciśnieniem-Płucnym-i-Ich-Przyjaciół/1438211746452788?ref=hl)

[warzyszenie-Osób-z-Nadciśnieniem-Płucnym-i-Ich-Przyjaciół/1438211746452788?ref=hl](https://www.facebook.com/pages/Polskie-Stowarzyszenie-Osób-z-Nadciśnieniem-Płucnym-i-Ich-Przyjaciół/1438211746452788?ref=hl)



Przemek Saleta, Polish kickboxing World Champion







## WORLD PH DAY 2014 - PORTUGAL

# A “FLYING” FLASHMOB IN PORTUGAL

In Portugal, we celebrated World Pulmonary Hypertension Day on 10 May in the public space of Oporto city, where four activities were held: a cycling event, a mega zumba class, a balloon release and finally a flashmob. Thirty cyclists rode through the legendary streets of Oporto, 110 people released their energy to the rhythm of Zumba in the beautiful gardens of the Crystal Palace and 60 children from the Dance Centre of Oporto initiated an amazing flashmob to hundreds of spectators at the Francisco Sá Carneiro Airport.

To raise awareness of Pulmonary Hypertension, these activities intended to get participants tired and breathless, not because they were sick, but because they were conducting a physical activity. This activity aimed to raise awareness in order to encourage early diagnosis and promote access to specific healthcare and treatments, which could increase patients' life expectancy. We believe that this event will contribute to the consolidation of international cri-

teria for the recognition of the Centres of Excellence in PH and to the promotion of research of new treatments needed to control this condition.

In addition, we launched a campaign on Facebook throughout the month of May which designated a “Blue Kiss” to every “Like” on the APHP page. To participate, people had to take a “selfie” with their lips painted blue, and the most original photo was awarded with a one-night stay in a four-star hotel (with a Spa treatment included) in Luso, a beautiful village in the centre of Portugal.

The activities had a resounding media success and also really engaged the public, in the gardens of the Crystal Palace and at the airport, where hundreds of people who previously had no knowledge of the condition were educated.

Maria Joao Saraiva

Associação Portuguesa de Hipertensão Pulmonar  
[www.aphp-hp.org](http://www.aphp-hp.org) - <http://on.fb.me/13sawnu>







## WORLD PH DAY 2014 - REPUBLIC OF MACEDONIA

### SINGING, DANCING AND PLAYING FOR WORLD PH DAY



A number of great events were held in the Republic of Macedonia to mark this year's World Pulmonary Hypertension Day.

There was an honorary marathon for patients with PH with young musicians performing on the violin and piano. A group of young ballerinas also danced for PH as well as Hip Hop performers and Zumba dancers. Famous Macedonian musicians and bands also took to the stage in support of the cause. The day attracted media coverage from TV news and Radio.

To top off our activities, a famous basketball team "Kozuf" which is in the Premier League wore our t-shirts to an event which was broadcast on Macedonian national television.

Gjurgica Kjaeva, APH Moment

<https://www.facebook.com/pages/APH-moment-Macedonia/1404172929805917?fref=ts>







## WORLD PH DAY 2014 - SLOVAKIA

# MEDIA EXCITEMENT ENSURES PH IS TOP OF THE AGENDA IN BRATISLAVA

To mark World Pulmonary Hypertension Day in Slovakia, 13 doctors from The National Institute of Cardiovascular Diseases took part in the mini marathon NUTRILITE, along with 1,550 other runners. Patients and volunteers supporting Pulmonary Hypertension joined the runners on the 4.2 km long run through the streets of Bratislava, showcasing posters and other materials about PH. The event gained some great media coverage which was reported on commercial TV JOJ. The press conference highlighted the involvement of the PH group and we distributed leaflets and lollipops to attendees. The event was covered by TV personality Markiza, who supported our efforts and discussed PH during the event. This great press coverage ensured that PH was top of the agenda for the 2,000 attendees and awareness of the condition was hugely increased.

### Professional workshop and photographic exhibition

Our association, along with four other patient associations launched a project called "The Beauty of the Moment", which brings patients

together after an organ transplant, as well as supporting the transplantation and donor program in Slovakia. Part of the project involves a photographic exhibition of patients before and after organ transplantation. Currently, we are holding public exhibitions in 11 of the largest cities in Slovakia. In each of these cities, there is an opening ceremony, workshops and other accompanying events such as health checks and professional lectures. The first exhibition was held on the 4 March in the Slovak National Theatre in Bratislava. Every association taking part in the project prepares an opening ceremony, which precedes the specialized program. Each exhibition runs for four weeks.

A scientific seminar which focused on PH and lung transplantation took place at the first event hosted by PHA Slovakia, which opened on 25th of April in Nitra. Lectures were delivered by specialist PH doctors, clinical psychologists, physiologists and pneumologists, who practice in Vienna. A three-part movie was premiered during the exhibition which captured patients' everyday lives before and after transplantation. The first part of the



movie was awarded 1st place in the documentary category at the competition in Baden-Baden in October 2013. Along with members of the public, patients also attended the event to share their stories, as well as several journalists who published reports and appeared on talk shows about the event and the condition of PH. At the end of the official workshops, an opening exhibition was held at the Andrej Bagar Theatre where printed materials on PH were displayed, as well as a large banner showing celebrities with blue lip lollipops.

Both of these events were attended by leading figures from the health industry, insurance industry, as well as chief physicians and directors of hospitals, the vice-mayor of the city and current mayor's deputy also attended, placing PH firmly on the map in Slovakia.

*Iveta Makovníková*

*Združenie pacientov s pľúcnou hypertenziou*

[www.phaslovakia.org](http://www.phaslovakia.org)

<http://on.fb.me/1kyocHg>







## WORLD PH DAY 2014 - SLOVENIA

# LJUBLJANA GETS BREATHLESS AND LEARNS ABOUT PH

On 1 May 2014, the Slovenian pulmonary hypertension organization, *Društvo za pljučno hipertenzijo Slovenije*, organized a marathon in a nature resort called Mostec in Ljubljana, the capital of Slovenia. The organizers of the event gathered at the chosen location in the morning. We started to prepare for the event, setting up 400 balloons and two beach flags, all of which had the event logo "Get Breathless for Pulmonary Hypertension" printed on them. We also prepared the track for the marathon by decorating it with additional balloons. When everything was ready the visitors started to gather.

Due to our great display, we had no problem attracting attention. We explained to the visitors what we were doing, explained what pulmonary hypertension is and why it's important to know about the condition and its symptoms. We also handed out our t-shirts to them and most were happy to pose for a photo!

Whilst busy handing out t-shirts we got started with the 6-minute walking test. The two beach flags marked the starting line and turning point of the walking track. The participants held their noses and were only able to breathe through two straws. When they finished we measured their vital signs

and some of them gave a short interview. We heard a lot of comments such as: "I didn't expect this to be so hard" and "I can't believe some people have to live like this every day."

There was a huge amount of interest in our 6-minute walking test but we were keen to get our marathon underway. More than 40 people participated, all wearing our t-shirts and most of them managed to finish the 5,000m race with ease.

We hired a band, Gino & band, to play at our event and they started playing shortly after the marathon was finished. They played a variety of songs in different languages and they really managed to rock the place! At that time we also gave our guests a free lunch.

More than 1,000 people were present at the event and overall we managed to hand out all 500 t-shirts, flyers that we made specifically for the event and many blue lips lollipops. Our World PH Day activities had a very good media coverage and we are extremely pleased with its results in terms of awareness raised in the general public.

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







## WORLD PH DAY 2014 - SPAIN

# SPAIN LEFT CATCHING ITS BREATH AFTER A MIND BLOWING WORLD PH DAY EFFORT

The Spanish National Pulmonary Hypertension Association (ANHP) engaged patients, nurses, daring athletes and members of the public in a huge array of activities to mark World PH Day this year. These activities provided a perfect opportunity to raise awareness of a little-known disease and create a solid foundation of support with the public for future engagement and awareness campaigns.

### Sporting bonanza leaves crowd breathless with excitement

To kick things off, patients and athletes grabbed a racket and donned their lycra for the “Fuenlabrada combo”, where people chose to take part in either a tennis tournament or a double spinning (cycling on stationary, mounted bicycles) marathon. Wearing their WPHD t-shirts with pride, patients jumped on to their bikes and demonstrated their fighting spirit against a disease which often makes physical activity a huge challenge. In solidarity with PH patients, a group of athletes got breathless as they cycled while breathing through straws so that they could experience what PH feels like. Committed as the athletes were, ‘cheating’ was quickly authorized and participants were told to breathe through their nose to avoid risk of fainting and falling off their bikes!

The Mayor of the city, Manuel Robles Delgado, was among the many members of the public who showed up to offer his support, and he was both astonished and humbled by the activities put on in support of those with PH. The day’s activities were crowned with a “Get Breathless” dance competition, with the winners being awarded €500 in return for a promise to perform a street dance in support of World PH Day later in 2014.

### Spanish patients take the campaign to new heights in Toledo

As if cycling wasn’t enough, brave pulmonary hypertension patients set themselves a second endurance challenge with the “Get Breathless” Walk of Toledo. Patients from all around Spain gathered for a 30 minute walk up the famously steep slopes of the historical city of Toledo. This is no easy venture for people whose everyday activities can be physically exhausting.

### Children and nurses aren’t forgotten

In other parts of town, children at *Ramón y Cajal Hospital* were entertained by a theatre group and the ANHP released “Get Breathless” balloons outside the entrance, in a spectacular and unmissable display.



Nurses are central to the support of PH patients, whose day-to-day lives are heavily affected by the condition. Yet, there is a lot of stress associated with caring for PH patients and coping with the effects of clinical worsening. To help support nurses in their vital role, ANHP facilitated a workshop, “Care for yourself so that you can Care”, to provide nurses with the tools to cope with the day to day pressures of their role and continue providing excellent care to patients.

### Mallorca IRONMAN is a fiesta of fun in support of PH patients

Celebrations weren’t just held in mainland Spain. World PH Day was also marked in Mallorca, at the annual half IRONMAN race. Thousands of spectators gathered to watch the gruelling triathlon, in which 3,600 athletes faced a 1.9km swim, 90km bike before culminating in a 21.1km half marathon (all in a single day!). Ten participants from across the

world took part in the IRONMAN as official PHA Europe entrants. These courageous men and women took part in one of the toughest endurance tests in the world to raise awareness and support for patients with PH. Juan Fuertes, coordinator of ANHP, said: “For people with pulmonary hypertension, every day is like an IRONMAN race. The Association is very grateful to the ten athletes who have competed in support of PH patients, enabling us to propel a little-known, overlooked yet life-threatening condition onto the global sporting stage.” During the competition, athletes passed under an arch with the slogan “Get Breathless for PH”, where they rang the bell to show support for PH patients. This helped raise funds for the ANHP.

Irene Delgado, Juan Fuertes  
Asociación Nacional de Hipertensión Pulmonar  
[www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)  
<http://www.facebook.com/hipertensionpulmonar>







## WORLD PH DAY 2014 - UKRAINE

# UKRAINE STANDS UNITED WITH PH PATIENTS ACROSS THE COUNTRY

World Pulmonary Hypertension Day was held in Ukraine for the first time on 16 May 2014 in Kyiv with a number of great activities.

First up was an action flashmob. Together with patients, volunteers and supporters, we gathered at the entrance to the Cabinet of Ministers. Officials who went to work in the morning on that day were offered to put a plastic bag over their head and experience breathing like our patients. They sensibly refused and instead were provided with flyers showing photos of our patients. It received a lot of press attention and we gave interviews to four leading newscasters, who covered the day in a report as well as being published in ten other news outlets - a great response!

We invited our patients from all regions of our country and 50 of them were able to join us. Unfortunately not all doctors could attend the event which was expected due to the recent unrest in the east of the country.

As part of the campaign we visited the representatives of the Cabinet and the Ministry of Health and passed an official letter from PHA Ukraine and the Society of Patients with PH, listing the main problems related to the treatment and care for patients with PH in the Ukraine. We had a great response and subsequently, have become members of the Public Council under the Ministry of Health allowing

us to input into all subsequent steps.

Just before noon we arrived at the launch of the first PH center in Ukraine on behalf of the Heart Institute Strazhesko. Cardiology specialists spoke about the center's work, the basis for diagnosis and the hospitalization of patients with PH.

After that it was to the outdoor park for extreme sports and entertainment on the water. Our patients rode on catamarans and kayaks and healthy people, their families and volunteers "got breathless" to understand what it feels like for our patients with PH. After the watersports, there was a ceremonial launch of balloons into the sky with the wishes of each patient. It was really amazing! Then all together we planted a linden tree as a symbol of the life and breath of our planet, once a month we have agreed to gather together with patients to water our tree and bring our warm smiles to encourage it to grow.

Later there was a performance of extreme athletes, racing pulses and respiration which mimicked the breathless state of our patients, followed by an entertaining concert - live guitar music party.

The event was extremely successful, our patients were happy and the event resonated strongly with the media and society as a whole.



On behalf of all 85 patients with PH who live in Ukraine, we express our heartfelt thanks to our strong and inspiring PH family, including PHA Europe. If it wasn't for your enthusiasm and support we would not have been able to achieve what we did for patients with PH in Ukraine!

Ocsana Alexandrova  
PHA Ukraine

<http://pha.org.ua/>  
[www.facebook.com/pha.org.ua](http://www.facebook.com/pha.org.ua)







## WORLD PH DAY 2014 - FRANCE

### A SOAPY SUCCESS IN FRANCE



For World PH Day 2014, HTAP France launched a campaign asking people to take photos of themselves blowing soap bubbles and to share the photos on the association's Facebook page.

The success of the campaign reached an unanticipated peak when the secretary of the national PH Reference Center attended HTAP's annual General Assembly and showed great interest in the World PH Day initiative. On the evening of 6 May, the French association had a pleasant surprise when the same secretary of the Center sent in some photos of the PH team - working at the Pulmonology Department of highly regarded key opinion leader, Professor Gerald Simonneau at Kremlin Bicêtre - 'Getting Breathless for PH'. Using her personal camera, the secretary took photos of the team blowing up a balloon or blowing soap bubbles, promising a candy to all those that agreed to take part. Next year, to encourage even more participation we will send them some "Get Breathless for PH" t-shirts!

Mélanie Gallant-Dewavrin, HTAP France

[www.htapfrance.com](http://www.htapfrance.com)

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



## WORLD PH DAY 2014 - TURKEY

### PHANTASTIC AND PHROSTY EVENTS MARK WORLD PH DAY IN TURKEY

A special ice-hockey match was organized for World Pulmonary Hypertension Day, in partnership with Bayer, to raise awareness of PH and turned out to be the attraction of the day in Ankara, on 5 May 2014. We were honoured to welcome Pascal Nouma, a former football player, to the match, who "Got Breathless for PH" with a local ice-hockey team in support of our cause. In addition to this, a special dance was choreographed by the local synchronized ice-skating team dramatizing life for PH patients and their symptoms.

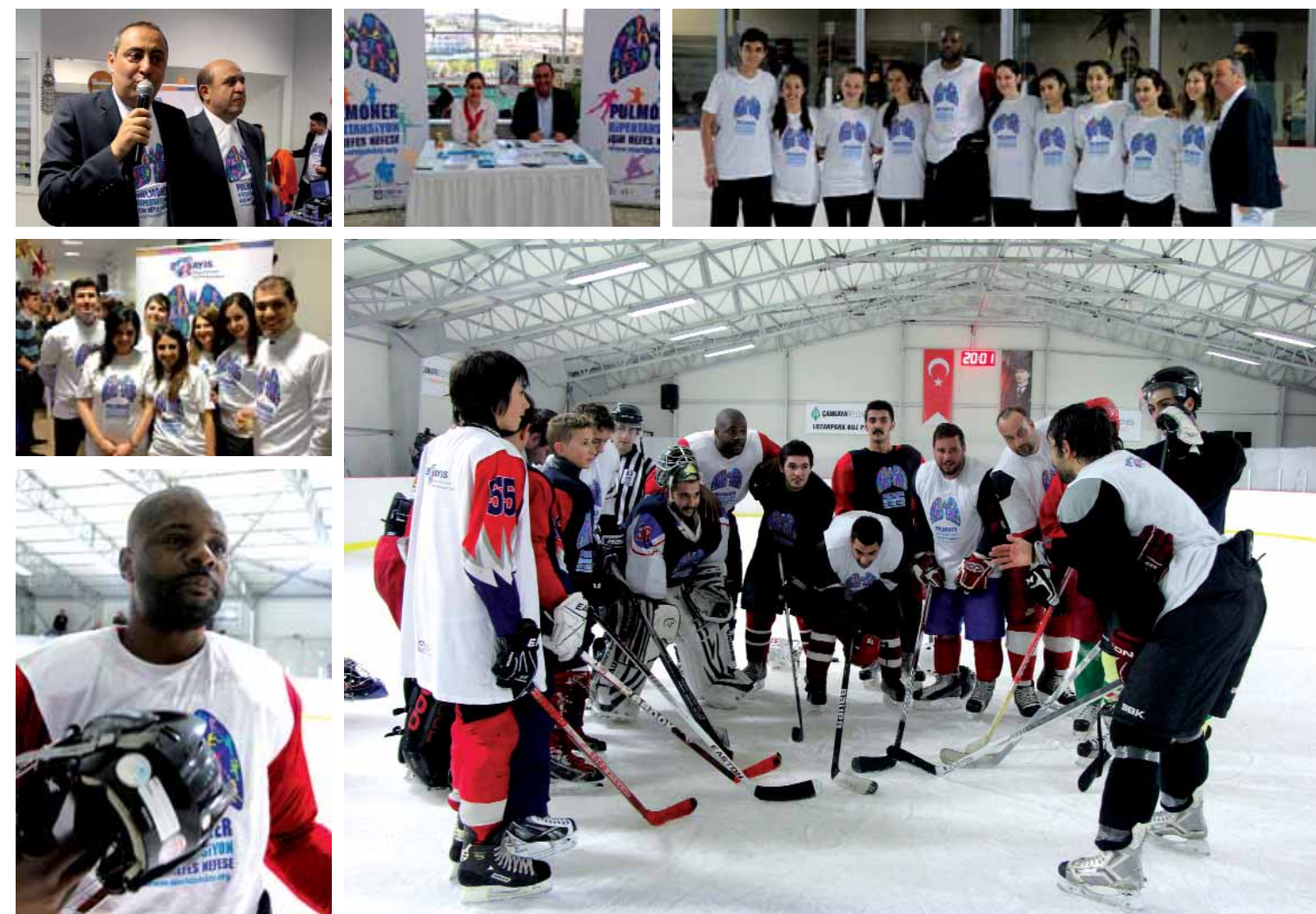
Overall there were approximately 100 participants, including physicians, patients, friends and relatives who all wore "Get Breathless" t-shirts in support of the day.

There was a lot of interest from the media around the event thanks to celebrity participation and it was a hot topic of discussion the next day. The president of the Turkish patient association received a 'promise' from the Social Security Institution (SSI-the payer institution) that following the "Get Breathless" event, they would be pleased to organize a multi-stakeholder meeting, in which patients, physicians, industry and SSI would be involved, to discuss the challenges and possible solutions in the PH field, which is a great achievement and milestone to be proud of.

Umit Atli

Pulmoner Hipertansiyon Derneği

[www.phdernegi.org.tr/](http://www.phdernegi.org.tr/)







## WORLD PH DAY 2014 EUROPE - IRONMAN

### IRONMEN GET BREATHLESS AND RING, RING, RING THE BELL FOR PH PATIENTS



PH Ambassador M. Martin, Nice



Volunteers at Ironman Mallorca



PH Ambassador K. Chaib, Ironman Nice



PH Ambassador B. Ma, Nice



Start of the race at Ironman Klagenfurt



IRONMAN athletes tackle 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!

For Pulmonary Hypertension patients, every day is like an IRONMAN race as even everyday activities, like climbing the stairs, can leave patients struggling to breathe.

PHA Europe is delighted to be an official charity partner of the IRONMAN European Tour for a second consecutive year, allowing us to propel a little-known, overlooked and yet life-threatening condition onto the global sporting stage.

We have already shown a strong presence at IRONMAN Mallorca, Nice, Klagenfurt, Frankfurt and Zurich and are looking forward to an equally strong presence at IRONMAN Copenhagen on 24 August. Thousands of athletes have already run under the "Get Breathless for PH" branded arch, ringing the bell to show support for PH patients and raising money for local PH associations.

A "Get Breathless for PH" exhibition stand at all of these venues has also provided educational information to thousands of attendees. Those brave enough also tested their lung function with the popular lung function test.

Thanks to our bright and colorful attendance at these races, our message has reached up to a potential 1 million attendees and our articles in the official IRONMAN newsletters have already reached a readership of over 100,000. Response from athletes and attendees has been more encouraging than we could have ever imagined, with 59 athletes running on behalf of our cause at the six races and sporting the "Get Breathless for PH" race suits.

Amongst these brave athletes was Bojan Atanassow, a 32 year old Mechanical Engineer from Germany who is currently living in Switzerland. Like many people with PH, Bojan has had to overcome his own struggles. He completed his first short-distance triathlon in 2011 but always found swimming a challenge. However, through encouragement and dedicated training with his racing partners, Michael Martin and Karim Chaid - who also raced for PHA Europe in Nice - Bojan competed in his first full-distance IRONMAN on 29 June. This was an incredible feat for someone who admitted swimming isn't his greatest strength:

"Me and swimming will never be friends, and I am still a far-from-perfect swimmer. However, I am really proud to be supporting people with PH and highlighting, among some of the fittest people in the world, that for some people every day is as great a challenge as IRONMAN".

What a great message of inspiration for PH patients!



Athletes ringing the bell at Ironman Zurich



PH Ambassador E. Jager, Ironman Zurich



Juan Fuertes speaking at the Pasta party



Expo area at Ironman Mallorca



Patrick Fischer at press conference at Ironman Zurich



Ironman Klagenfurt



Volunteers at Ironman Frankfurt





## Volunteers and IRONMEN 'Get Breathless' together

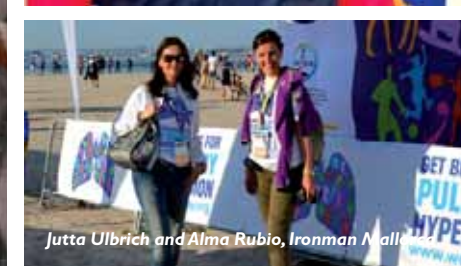
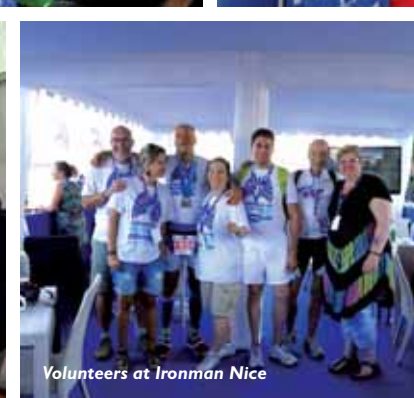
I had the pleasure and honour of representing PHA Europe at three Ironman races (Mallorca, Nice and Frankfurt). At these races, we had enthusiastic teams of volunteers from twelve member associations helping us with the activities at the booth and race. Whether we had blue skies or dark clouds, unbelievable heat or heavy rain, this did not stop our PH ambassador IRONMAN athletes "Getting Breathless for PH". Nor did it stop our courageous volunteers from putting in lots of hard work and long hours to make the event a success. As the athletes battled with breathlessness during some of the most challenging endurance courses in the world, our volunteers battled to tell our story and raise awareness of PH.

The PHA Europe booth housed an extremely popular lung function test - attendees blew into the device with all their might and the greater their lung functions, the more lights lit up on the lung function test display. Even some of the fittest athletes failed to light the display to the very top and those that did received a great round of applause and a "Get Breathless" t-shirt. Everybody walked away from the booth having learnt an important message - "nobody can take their lungs for granted".

We might look healthier, stronger and in better shape than the person next to us but our lungs might tell a different story. This is a powerful message indeed!

Juan Fuertes

Asociación Nacional de Hipertensión Pulmonar  
PHA Europe field manager Ironman Mallorca, Nice and Frankfurt



## From breath-taking scenery to breath-taking IRON courage

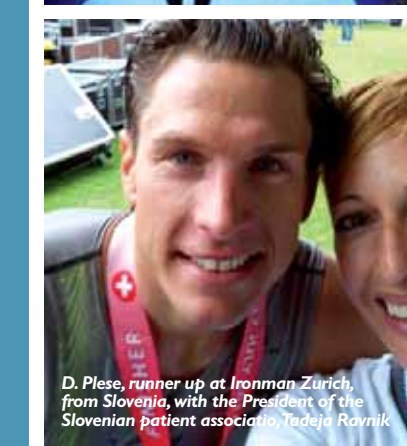
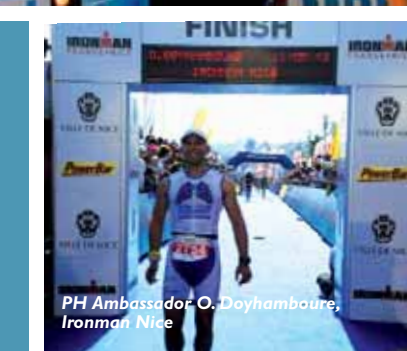
On Sunday 29 June, I visited the beautiful Austrian district of Klagenfurt, just across the border from my home in Friuli Venezia Giulia, in Northern Italy.

On any other day of the year, your breath would be taken away by the rolling hills, soaring mountains and postcard-perfect lake. Not on this day. On 29 June, the IRONMAN European Tour came to Klagenfurt and 3,500 men and women from all walks of life launched themselves into one of the most gruelling triathlete courses in the international sporting calendar. Demonstrating breath-taking courage and determination, the athletes ran into the water at the sound of the starting canon to embark upon a 4km swim, a 180km bicycle ride and a 40km run.

We witnessed true Corinthian endeavour as man pitted against himself and against nature. The surging mass of swimmers in the alpine lake evoked images of the D-Day landings; the bicycle ride called to mind the knights-errant of medieval times and the run imitated the back-breaking training exercises completed by Olympic athletes. These scenes were the result of a healthy explosion of energy, releasing months of training and preparation in a bid to complete one of the toughest triathlons known to man.

The IRONMAN contest is a truly unique event and seeing these courageous athletes get behind the "Get Breathless for PH" campaign, and getting breathless in solidarity with PH patients is a breath-taking thing indeed.

Luigi Deciani, guest at Klagenfurt Ironman  
Text translated from Italian by Robin Saikia



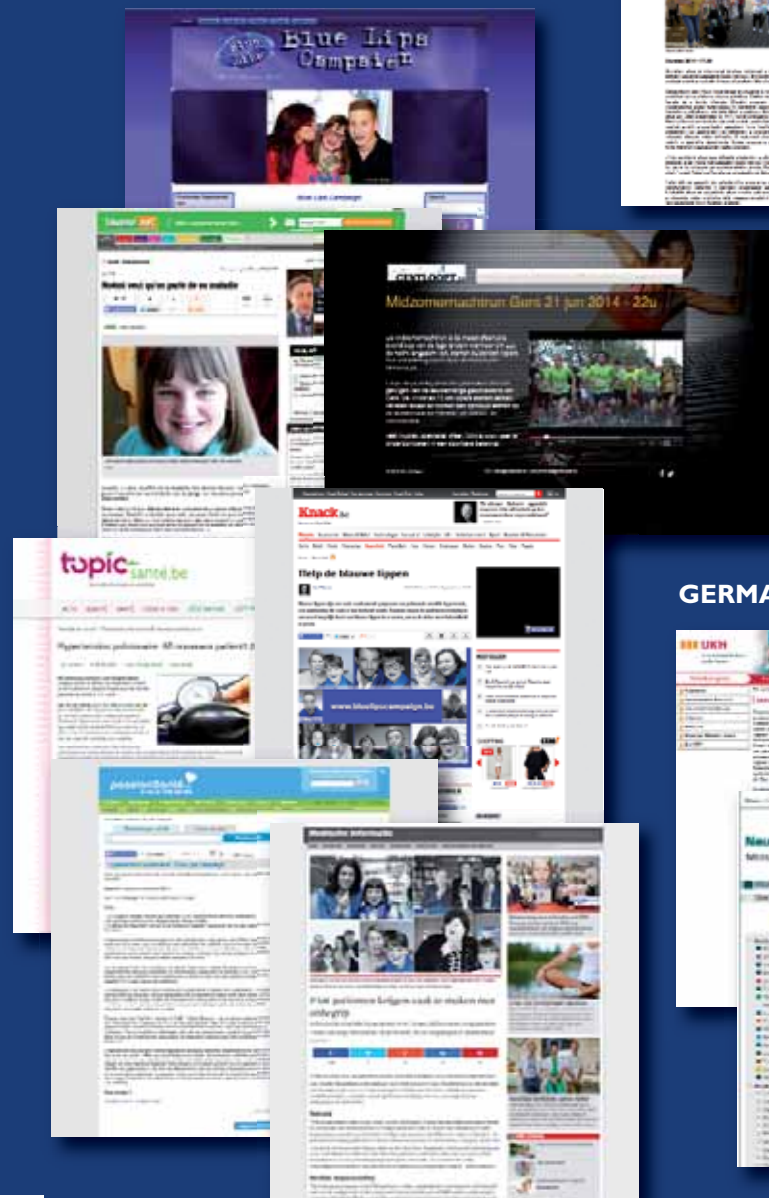


# MEDIA CLIPPINGS

AUSTRIA



BELGIUM



GERMANY



GREECE



CZECH REPUBLIC



BSPPH BULGARIA



FINLAND



ITALY





# PORTUGAL

# REPUBLIC OF MACEDONIA

# ISRAEL

# POLAND

# SLOVAKIA

# SLOVENIA





## WORLD PH DAY 2014 - AUSTRALIA

# IRONMAN GOES DOWN-UNDER AS BELLS RING OUT IN SUPPORT OF PH PATIENTS



On the eve of May 5, members of the Pulmonary Hypertension Association Australia (PHAA) gathered on the mid-north coast town of Port Macquarie, on the New South Wales for the start of IRONMAN to mark this year's World PH Day. More than 2000 athletes took part in the gruelling IRONMAN triathlon that included a 3.8km swim, 180km bike ride and 42km run. PH patients and their families, along with the PHAA Treasurer Secretary and employees from Bayer, manned the Pulmonary Hypertension tent near the finish line to welcome athletes home. The tent was a hive of activity and was surrounded by many of the 20,000 spectators throughout the day.

Over the course of the event, the team handed out nearly 2,000 PH-branded cowbells to cheer on the athletes and conducted a PH condition awareness bike exercise activity, raising nearly \$400 for the charity, while PHAA treasurer Chris McGrath conducted an interview for the public broadcaster ABC radio.

Federal Member for Lyne, Dr David Gillespie MP, representing the Prime Minister Hon. Tony Abbott, visited the tent and spoke with the PHAA members about their experiences with the condition. "I realize the difficulty doctors have picking up a rare disease because so often it can appear as something else, so it's good you can raise awareness around it", Dr Gillespie, MP said. Speaking to Kylie Bevan, the mother of 10-year-old Fate who was diagnosed with the condition two years ago, Gillespie added: "It is great your boy can still be with his friends at school."

PHAA treasurer Chris McGrath said: "This day is beyond what I expected. To hear IRONMAN PH ambassador Jason Shortis (with more than 75 IRONMEN under his belt) speak to 2,500 people at the VIP event prior to the race was simply amazing to help raise the profile of PH." During the speech Shortis asked the athletes to ring the PH bell as they went past the tent. It didn't stop ringing throughout the entire running leg along the water of the picturesque coastal town on a beautiful autumn day.

Adrian Dolahenty from Bayer who PHAA partnered with for the event, said: "The event cemented the solid relationship the PHAA and Bayer has, resulting in a deeper level of understanding of the disease amongst this community of athletes and supporters who know just what it's like to get tired and breathless. This was a brilliant concept requiring a herculean effort that was executed so well."

The last word must go to Viv McGrath, whose son Alex died of PH five years ago when he was six-years-old: "Let's get breathless for PH."

PHA Australia

[www.phaaaustralia.com.au](http://www.phaaaustralia.com.au)



## WORLD PH DAY 2014 - CHINA

# PROMINENT DOCTORS GATHER IN BEIJING TO GET PATIENTS' VOICES HEARD

In partnership with Bayer, China ran a very successful event in Beijing to mark this year's World Pulmonary Hypertension Day. The event, hosted by ISeek, was attended by more than 100 participants including payers, policy-makers, physicians, patients, NGOs, research organizations and journalists. Throughout the event we called for increased awareness of PH and highlighted the unmet need of patients, as well as the need to get PH treatment reimbursed.

Many of the leading medical experts in PH came to the event to show their support, including Prof. He Jianguo, Prof. Wang Chen, Yang Yuanhua, Prof. Cheng Zhaozhong, and many other top opinion leaders in China. A call-to-action letter: "Caring for PH patients" was also signed by around 50 participants at the event.

Keynote speeches were delivered by Prof. Cheng Xiansheng (the most respected physician in the PH area, Fuwai Cardiovascular Disease Hospital) and Prof. Wang Chen ( Director from Ministry of Health, former director from Chaoyang Hospital), Rino



Aldrighetti (President of PHA in the U.S), and Jun-Shuai Liu ( Director from Qingdao medical insurance administration). This was very important to ensure all patients had their voice heard.

Iseek Cultural Centre  
[www.iseek.org.cn](http://www.iseek.org.cn)



## WORLD PH DAY 2014 - GHANA

# A GOAL FOR WORLD PH DAY IN GHANA



A "Get Breathless for PH" event took place for the first time in Ghana in the form of a charity football match in Accra, Ghana's capital city. For those living in Ghana, football is their national sport and an important part of their culture.

Organized by Susanne, a midwife from Berlin Charité hospital and volunteer for health charity, Nima e.V, the game was set up in support of World PH Day.

The players all wore "Get Breathless for PH" t-shirts and had lots of fun competing and "getting breathless" in support of our cause. The event was a big success and enabled all those involved to experience how those living with PH feel during their day to day lives. Through sport, everyone who participated was able to get behind World PH Day and enjoy raising awareness of PH.





## WORLD PH DAY 2014 - LATIN AMERICA

# LATIN AMERICAN COUNTRIES JOIN TOGETHER FOR WORLD PH DAY

Twelve Latin American countries joined together to raise awareness of pulmonary hypertension as part of the 2014 World PH day campaign. The campaign kicked off with a huge opening event on 29 April in Medellín, Colombia. Migdalia Denis, President of the Latin America Society (*Sociedad Latina de Hipertensión Pulmonar*), who organized the event alongside several of the national PH patient associations, opened the ceremony, which was attended by over 120 people and featured presentations from numerous prestigious medical speakers from across Latin America and the USA. The event attracted huge media attention: four interviews on national and pan-regional TV, five radio interviews, conducted during peak listening hours, seven articles were generated in major daily newspapers and five articles were secured in top health magazines. Here is a round-up of the activities that took place throughout Latin America:

Argentina organized a PH conference with over 80 attendees on 9 May in Córdoba. In Brazil, a 15 km bicycle race, pedalada, was organized on 4 May in the city of Recife. A virtual seminar was organized by the Chilean patient association on 12 May to discuss the latest medical advancements in PH, led by Dr. Héctor Cajigas, Director of the PH program at the Henry Ford Health Center. The Colombian patient association organized a talk with patients, family members and physicians, on 9 May in the nation's capital, Bogotá. In Costa Rica, World PH Day was marked by a 2 km walk organized in collaboration with the *Hospital Calderón Guardia*. The activity was filmed and aired live on *Canal 6 Repretel - Television de Costa Rica*! In Paraguay, the Institute of Social Welfare organized an awareness event on

5 May in one of the nation's most beautiful nature parks. The Mexican PH patient association organized a walk in the Parque Viveros de Coyoacán on 4 May. Martha Arenas, President of the association, provided information about PH to the public, alongside physicians from the National Cardiology. An "Awareness Day", was organized by the Uruguayan association. In El Salvador, Wilfred Castro, President of the *Asociación Salvadoreña de Hipertensión Arterial Pulmonar* gave a live radio interview for Radio Ysua 91.7 FM on 5 May. Lastly but by no means least, in Venezuela the first meeting for PH patients was organized by the PH Clinic of the *Hospital Militar Dr. Carlos Arvelo* in Caracas, led by Dr. Alejandro Cortez.

To mark World PH Day, the Latin American PH Society and Bayer also organized an educational workshop on PH, called a "Breath of Fresh Air", for Latin American journalists, in Medellín, Colombia. 14 journalists from across South America took part in the informative session. The media learned about the symptoms of PH from world renowned experts in the field. Journalists were also informed about the importance of early diagnosis - which can have a direct impact on the survival rate and quality of life of patients - and the need therefore to disseminate information and raise awareness of PH. The workshop ended with a very touching moment when participants received "Get Breathless for PH" t-shirts from local children with PH.

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Migdalia Denis, President of SLHP, WPHD event in Medellín (Colombia)



Medellín (Colombia)



Paraguay



Dr. Douglas Olivares speaking in Medellín (Colombia)



## WORLD PH DAY 2014 - USA

# A PH-ENOMENAL PERFORMANCE IN THE USA

Despite a busy pre-Conference season in the United States, the Pulmonary Hypertension Association did not let the momentum of World PH Day slide by them! PHA used April and May to host awareness-raising and fundraising activities around the country. As Team Phenomenal Hope, a four-woman team led by a PH specialist at University of Pittsburgh School of Medicine, prepared for their daunting cross-country non-stop Race Across America, PHA decided to encourage them in their difficult preparations by hosting Unity Miles events across the country. In mid-April, more than 70 groups of people in 30 states and Puerto Rico walked, ran, or rode bikes to cover enough miles to symbolically cross the U.S. Dr. Patty George, leader of Team Phenomenal Hope, said that the Unity Miles truly inspired her to keep training, and later to keep pedaling as she raced. A few weeks later, the U.S. PH community had the opportunity to participate in a forum that the Food and Drug Administration (FDA; the government agency that regulates food and medications in the United States) held to re-examine the criteria that the agency uses to approve drugs. The FDA chose only a few disease communities to hear from, so it was an honor for PHA to be able to organize attendance both in-person and online at the forum, so that the PH community could share their needs and desires in new medication approvals. World PH Day itself saw two important awareness-raising activities. First, people across the nation participated in an Online Awareness Day, where they posted about PH on social media and took pictures of themselves wearing purple, blue, and zebra print to post on Facebook and Instagram. This year, several celebrities tweeted or Facebooked support for

World PH Day, including Michael Bublé, Laura Dern, Florence Henderson, and Queen Latifah.

Second, PHA kicked off their "Media Blitz" campaign, to encourage people across the nation to contact their local TV and radio stations, requesting that those stations play any of the three English and Spanish-language PSAs about PH, early diagnosis, and pediatric PH research. With everybody's continued participation, the PSAs are getting more and more play, well beyond just the original contracts with major English and Spanish TV and radio networks and even on the U.S. online streaming website Hulu.com.

PHA was also happy to be able to participate in other nation's World PH Day celebrations. Rino Aldrighetti, PHA president, and Julia Friedrich, PHA's International Program Associate, participated in the Saudi Association for PH's regional medical meeting in Muscat, Oman, to work with them as they set up more of a non-medical patient support structure. Rino then went on to Beijing, China to give a presentation to government officials and medical professionals, to add pressure to iSEEK China's fight for access to PH treatments.

PHA was happy to be able to participate in the worldwide statement about pulmonary hypertension that World PH Day allows, and looks forward to an even more exciting and effective May 5th next year!

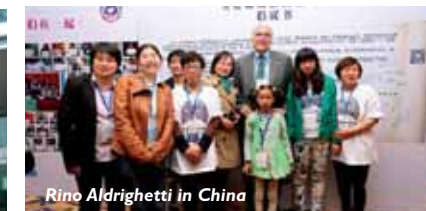
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FDA Forum with PH patients



FDA Forum with PH patients



Rino Aldrighetti in China



Unity Mile event San Juan (Puerto Rico)



2014



### August 24, Copenhagen, Denmark & Budapest, Hungary IRONMAN

PHA Europe will be present with a stand and many activities at the IRONMAN Copenhagen and Budapest races. The Ironman partnership is part of the global campaign to raise awareness of PH for World PH Day. PHA Europe was present also at Ironman Mallorca, Nice, Klagenfurt, Frankfurt and Zurich (see also pages 44-48).

### August 30-September 3, Barcelona, Spain EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS

PHA Europe delegates will be present at the EUROPEAN SOCIETY OF CARDIOLOGY'S ANNUAL CONGRESS 2014. This Congress is currently the largest cardiovascular medicine meeting in the world. It covers all disciplines from basic research to clinical practice.



### September 6-10, Munich, Germany 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 2014. This Congress involves not only leading experts in respiratory medicine, but also in the entire spectrum of research and practice.

### September 17-21, Barcelona, Spain PHA EUROPE GENERAL ANNUAL MEETING

PHA Europe will be holding its 2014 GENERAL ANNUAL MEETING in Castelldefels (Barcelona) September. PH Patient Leaders from 27 European countries attended the 2013 meeting.



### October 14-15, Paris, France COUNCIL OF EUROPEAN FEDERATIONS

PHA Europe will be taking part in the annual meeting of the EURORDIS Council of European Federations, which brings together representatives of rare disease federations in Europe. This meeting will include educational and training sessions.

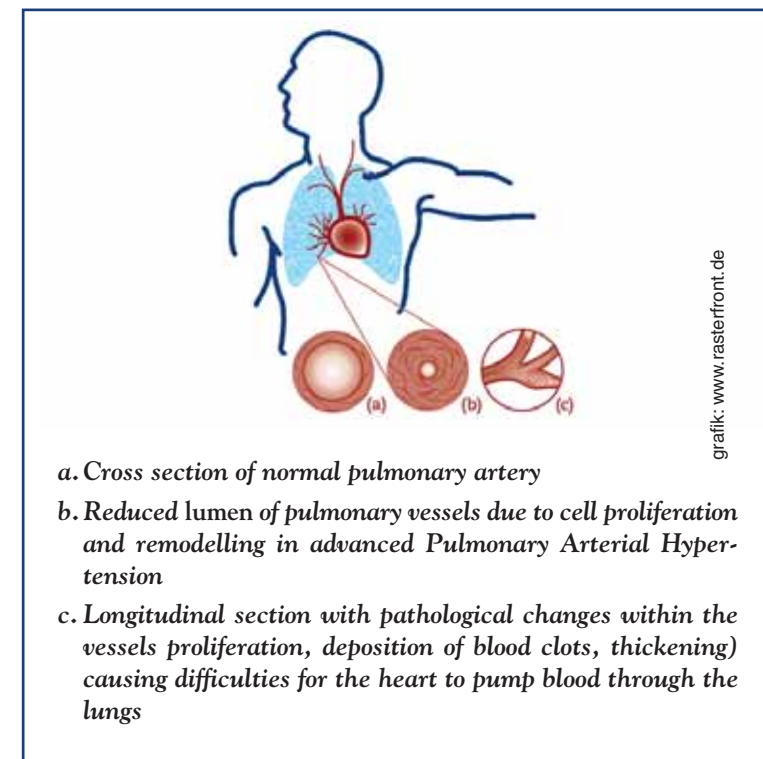
**PHA EUROPE**  
European pulmonary hypertension association

### 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.



### 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.

### Next PHAE journal

The next Mariposa Journal will be issued in December 2014 (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!*



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