



# PULMONARY HYPERTENSION MariposaNews

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SPRING ISSUE OF THE NEWSLETTER OF PHA EUROPE,  
EUROPEAN PULMONARY HYPERTENSION ASSOCIATION

- Austria
- Belgium
- Bulgaria
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**MAJOR AWARENESS INITIATIVE PUTS PH ON THE MAP ON RARE DISEASE DAY**

Report and photos of PHA Europe's *Breathtaking* awareness campaign launched on international Rare Disease Day, 28 February 2011

## Editors Memo

Dear friends,

I am delighted to introduce Mariposa's Spring 2011 special edition reporting on PHA Europe's *Breathtaking* awareness campaign. This campaign, led by PHA Europe and supported by Bayer HealthCare, was successfully launched on 28 February 2011, International Rare Disease Day (RDD). RDD is an annual event coordinated by the European Organization for Rare Diseases (EURORDIS) and the National Organization for Rare Disorders (NORD).

Organizing the campaign is a landmark event for PHA Europe. It is the first time that Pulmonary Hypertension patient associations in Europe have united to raise awareness on this disease. Two main events were held in Brussels and Vienna, and national activities took place in seven other countries across Europe including Bulgaria, Germany, Hungary, Norway, Poland, Portugal and Spain. Campaign materials were also distributed in the Czech Republic (medical press) and Italy and some awareness raising was organized in Slovakia. This edition of Mariposa News contains detailed reports on all the activities and on media coverage achieved.

More awareness about PAH is important not only for the patients themselves ("finding" the patients, earlier diagnosis and treatment) but also for medical professionals, national governments and EU institutions.

As we all know, despite considerable progress in diagnosis and treatment over the last 15-20 years, PH patients still have many problems and unmet needs. First and above all, the level of awareness and knowledge of the disease among the general population and the medical profession is still very low. Even now, PH is often not diagnosed; when it is, it is diagnosed late. As a result, patients very often start treatment late, when the disease is in an advanced stage, worsening their prognosis and quality of life. Additionally, not all patients in Europe have access to all approved drugs and the availability of surgery also differs from country to country.

PHA Europe believes that all patients should be able to benefit from the invaluable support provided by patient associations. That's the reason for our "White Spots" program (no countries without associations!). Patient associations can provide patients and their families with practical advice for day-to-day living; the means to exchange experiences with other patients; information in plain language about PH and treatment options; guidance on access to drugs, pensions, or insurance, and economic support. Patient associations can benefit patients through advocacy, lobbying and awareness campaigns. As PH is a rare disease, joining forces across borders is vital in order to have influence here in Europe and through-out the world.

Finally, patient associations can greatly benefit from working together at European level, sharing achievements, and learning from each other. Different cultural backgrounds provide a wide and enriching range of views and ideas. You will see that even within the context of a common awareness campaign each country has provided its unique and personal contribution.

We are proud of the results obtained with our first campaign and hope to involve more countries for an even more successful 2012 program.

Thank you to all for your invaluable support!

Gerald Fischer  
President PHA Europe

PS. We have just been informed by EURORDIS that "our" video, "My *Breathtaking* story", won third prize in the annual EURORDIS video contest for Rare Disease Day! This video was filmed as part of our *Breathtaking* campaign and features PH patient Rosie and her family, from Belgium.

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## Breathtaking campaign 2011, an overview

PHA Europe launched its *Breathtaking* awareness campaign on February 2011, International Rare Disease Day, under the patronage of the European Organization for Rare Diseases (EURORDIS).

Designed to demonstrate the impact of Pulmonary Hypertension on persons affected by the disease, the campaign focused on the more rare type of PH, Pulmonary Arterial Hypertension (PAH) using very powerful imagery to communicate its severity. Images of a woman, a young boy and an elderly man, each with blue lips and a blue hand around their necks, were featured. Blue lips are one of the signs of PH and the hand around the neck symbolizes the breathlessness and sense of suffocation that goes with the disease. These attention grabbing images created more awareness of the need for early, accurate diagnosis and appropriate treatments to improve the lives of people living with all types of PH.

Train stations and other crowded places were chosen to hold awareness events. One of the two international launch events took place in one of the busiest metro stations in Vienna, headquarters of PHA Europe and the Austrian PH patient association. The other launch event was held in Brussels, seat of the EU institutions, in Brussels Central Station, one of the largest train and metro stations. Leading cardiologists and several PH patients, as well as representatives from PHA Europe, were interviewed by media to provide their perspectives on this life threatening condition.

From the beginning the campaign was open to other PHA Europe member associations to ensure that the messages reached as many people as possible. When the campaign was first presented to PHA Europe members at the end of 2010, it was great to see how many of them volunteered to take part and organize activities in their own country.

All the campaign materials were translated into eleven languages and printed and distributed by member groups. In relatively short time they organized different types of awareness raising events from placard posting and distribution of flyers at train stations to concerts, seminars,

press conferences, sports events etc. Many also took part in the national celebrations for Rare Disease Day.

Each country brought its own personal touch thus making the campaign truly unique. Some of the highlights include Nils Paul Skara's basketball team playing with blue lipstick for PH in Norway, mimes dressed in black with hands and lips painted in blue in Hungary, singers in national traditional dress in Bulgaria, PHers running for PH in Spain, and Rosie's touching "patient diary" video in Belgium.

Member associations managed to raise considerable interest from the media. Many of PHA Europe's patient leaders were interviewed on TV, radio and press: 95 media outlets across seven European countries - Belgium, Austria, France, Germany, Norway, Spain and Switzerland - covered the launch. In addition, coverage appeared on websites with global reach, including CNBC and Yahoo Finance. Coverage in top newspapers was also secured in Austria and Belgium. A multimedia news release featuring photos and video footage were distributed to almost 1000 journalists, with over 100 using this material which was also placed on video sharing websites. Sites were specifically chosen to provide the largest possible potential audience.



from left: Campaign coordinators Gerald Fischer and Pisana Ferrari (PHA Europe), Jutta Ulbrich and Thomas Bertschik (Bayer, Berlin) and Maria Patey (Ketchum Pleon, UK)

All of this would not have been possible without the support of Ketchum Pleon, UK and in particular Maria Patey, and Jutta Ulbrich and Thomas Bertschik from Bayer Healthcare. THANK YOU!

We are very proud to say the follow up on the campaign seems to be equally promising. At national level, there are many more initiatives being organized and the associations themselves are getting more members, more phone calls etc. At European level, EURORDIS has just invited PHA Europe to present the campaign in Paris at the end of June at an international workshop of the Council of European Federations. They wish to use it a case study on how to organize a successful common campaign around Rare Disease Day!

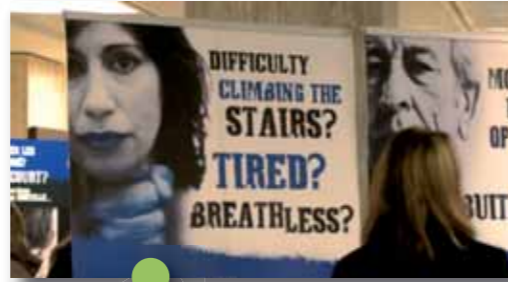
Pisana Ferrari  
Vice President PHA Europe



# MAJOR AWARENESS INITIATIVE PUTS PH ON THE MAP ON RARE DISEASE DAY



Pop stars and patients delivered the 'Breathtaking' message in Vienna



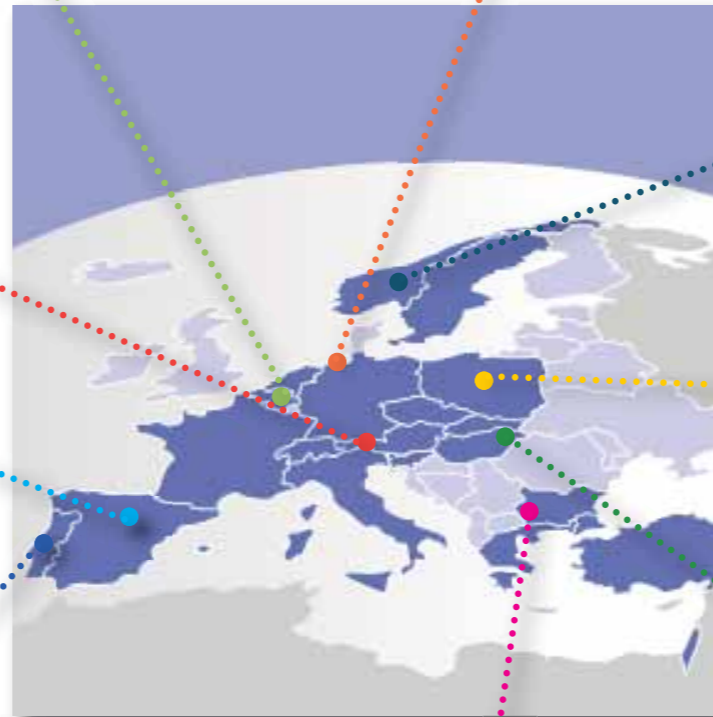
Climbing the stairs to increased awareness in Brussels Central Station



On track for PH awareness in six major city train stations across Germany



Blue lips team gets the ball rolling for PH awareness in Norway



Spain's race for hope produces a winning result for PH awareness



RDD wishes reach the sky, and awareness of PH soars across Poland



Portugal's media attention is a PHantastic success!



Bulgaria rocks, thanks to PHA Bulgaria and the National Alliance of People with Rare Diseases



The magic of pantomime spells out the PH message in Hungary





Prof. Walter Klepetko, AKH Vienna



One of the two international campaign launch events took place in Vienna, headquarters of PHA Europe and PHA Austria. The Vienna event revolved around one of the busiest metro stations in Vienna, Schwedenplatz. *Breathtaking* campaign placards were posted on the walls, stairs and floors as well as on revolving advertisement boards. Another six metro stations had large LCD displays with 122 infoscreens in 42 metro stations displayed *Breathtaking* information (see photos). A unique feature of the Vienna event was the "branded" bus parked in front of the station and carrying powerful images of the campaign. The morning radio on 28 February carried news of the campaign, generating a lot of interest, and crowding the bus for hours. On board the bus hostesses gave out PH information and educational material, along with flyers and *Blue Lips* lollipops which were also handed out around the station. At 10.30 a press conference was held in a very well known and upscale restaurant, Motto am Fluss, just across the station on the Wien river. This space was made available for free. Speakers at the press conference included Gerald Fischer, PHA Austria President; Regional State Secretary for Health, Mrs Sonja Whesely; Prof.

Walter Klepetko, world renowned lung transplant surgeon from the Vienna General Hospital, AKH; Prof. Leopold Stiebellehner, pulmonologist from the AKH; Prof. Ina Michel-Behnke, paediatric cardiologist; and Eva Otter, a PH patient. Many journalists attended the press conference and asked many insightful questions. One of the highlights of the press conference was the participation of famous Austrian musician, actor and entertainer Rainhard Fendrich, a personal friend of Gerald Fischer, who had taken part in a number of awareness raising events for PHA Austria. Gerald Fischer was later interviewed by state TV and asked to give his perspectives on PH.

Follow up: the bus with the *Breathtaking* images drove around Vienna as part of the regular bus service and was seen by thousands per persons. "A great achievement at patient level is the incredible participation at the regional patient meeting held in Linz shortly after the campaign. Linz is a small town but over 100 patients and family members turned up, an unprecedented result", says Gerald Fischer, "Thank you to Eva Grassmugg for the excellent organization".



Speakers and guests at press conference at Motto am Fluss restaurant, Vienna



LCD display with *Breathtaking* posters



Distributing *Breathtaking* material at Schwedenplatz Station, Vienna







Above: Pisana Ferrari at the press conference  
Right: Rosie and Luc Matthysen from the Belgian francophone PH Association



Prof. Jean Luc Vachiéry, Hôpital Erasme-ULB



Hendrik Ramaker and Gust Caelen from the Belgian Flemish PH patient association

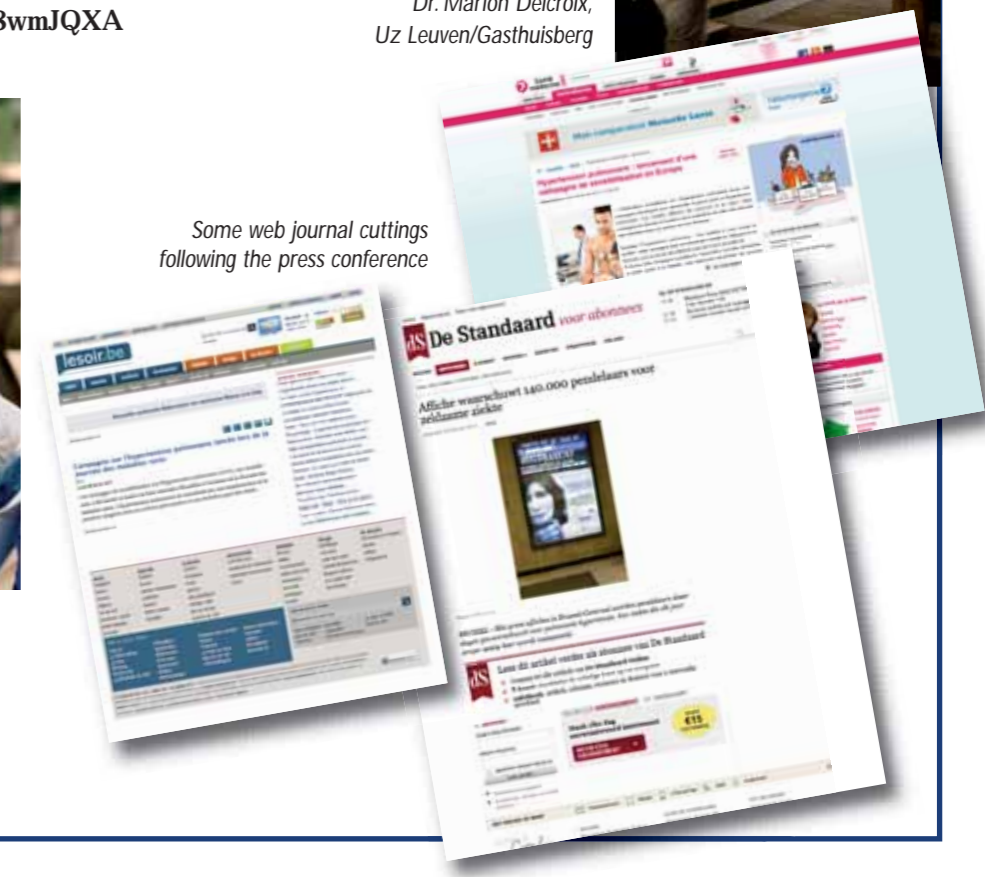
The other of the two international launch events took place in Brussels, the seat of the European Union. As commuters climbed flights of stairs in Brussels Gare Centrale (Central Station) their attention was grabbed by the powerful *Breathtaking* campaign posters on the walls, stairs and floors. From very early in the morning, during peak rush hour, members of the Ketchum Pleon team were busy distributing flyers and blue lollipops to passers-by. Later on in the morning a *Breathtaking* booth was set up and PHA Europe's Belgian guests started arriving: Rosie and Luc Matthysen from the francophone patient association and Gust Caelen and Hendrik Ramaker from the Flemish patient association. Leading Belgian cardiologists, patient representatives, and Pisana Ferrari, Vice President of PHA Europe, attended

the press conference at the booth around 11 am. Prof. Jean Luc Vachiéry from Hôpital Erasme-ULB and Prof. Marion Delcroix from the Uz Leuven/Gasthuisberg, were the two key medical speakers. They and some patient representatives were later interviewed by media to provide their perspectives on PH. A number of journalists attended and many questions were put forward to the speakers. A few of the journalists joined the rest of the group as they walked back to the Hotel Meridien just across the road for lunch.

Watch this link for coverage of the Brussels event and interview: <http://www.mediapool.co.uk/ketchum/ph/WebFilm.html>  
See Rosie's "My Breathtaking story" at: <http://www.youtube.com/watch?v=h17q8wmJQXA>



Dr. Marion Delcroix, Uz Leuven/Gasthuisberg



Some web journal cuttings following the press conference





Todor Mangarov, President of PHA Bulgaria speaking at a PH seminar at Medical University of Plevan



The *Breathtaking* campaign in Bulgaria revolved around three main events in Plevan, the home town of PHA Bulgaria president Todor Mangarov. The Bulgarian association, set up in recent years, has had very close cooperation with the National Alliance of People with Rare Disease from early on, chaired by Vladimir Tomov. The first of the three events was a rock concert organized in one of Plevan's main squares on February 27 in collaboration with the National Alliance. The concert was free and had as its motto "Rare but equal". Four bands performed at the concert: a young band from Plevan and three others well known throughout Bulgaria: the trio of Petsko, Vasko the Patch, and Signal. As they are very popular the event had a vast attendance and large success, as can be seen from the photos. Large placards of the *Breathtaking* campaign were on the stage and hundreds of flyers were distributed. The official EURORDIS logo for Rare Disease Day also featured prominently on the stage. Another highlight of the concert was a local

music group in traditional Bulgarian national dress. The rock concert was covered extensively in local media. There were a series of publications and reports in "Directions and TV Plevan Sprint". The Deputy Mayor of Plevan presented his greetings. A PH seminar was also held to discuss the problems of rare diseases and specific guidelines for future work on the 28th of February at the Medical University of Plevan. Lecturers included five of the most famous professors in the medical university. *Breathtaking* materials and flyers were also posted and distributed at a charming children's operetta in the concert hall of the Music School in Plevan on the 25th of February attended by hundreds of families with children. *Breathtaking* materials were also distributed around Plevan and articles published in local newspapers. The celebrations for Rare Disease Day in Bulgaria were focused on Plevan but the event was covered by national media as well.



Four bands performed at the rock concert organized on one of Plevan's main squares



Children's operetta in the concert hall of the Music School in Plevan







Karlsruhe station



PHev volunteers at Rare Disease Day event, Medizinische Hochschule Hannover, MHH Campus



Hannover station



The German PH association, PHev, was the first to join the campaign. PHev President Bruno Kopp decided that the main focus of the campaign should center around train stations, traditionally crowded with thousands of people every day. Six of Germany's biggest cities were chosen and almost 1,000 placards were posted and thousands of flyers distributed in and around stations and other key spots in Berlin, Leverkusen, Karlsruhe, Bruchsal, Stuttgart, Frankfurt, Freiburg, Heidelberg and Hannover. In Hannover an information booth was set up in the University Medical Centre, where patient association volunteers gave information and educational material about PH and other rare diseases. Doctors delivered lectures about rare diseases and the German

health system. The German umbrella organization ACHSE presented itself to visitors. The initiative received wide TV media and press coverage. "I think this was fantastic to coordinate Rare Disease Day all over Europe. It was a good idea and a helpful opportunity to have the posters. We wouldn't have been able to organize and pay for this ourselves. Regional activities wouldn't have attracted attention in the same way. During the campaign we had a significant increase of contacts on our website. The poster campaign was accompanied by media outreach and our agency counted 33 articles. Little strokes fell big oaks! A sincere praise to Pisana and the team", said Bruno Kopp, PHev President.



Bruchsal station



Placard posting in Büchenau



Frankfurt station



Berlin station







Distributing flyers and mimes performing at Western Railway Station in Budapest



The main focus of the Hungarian association's campaign was Budapest, Hungary's capital. Over a quarter of of Hungary lives in the capital and neighbouring cities/villages. Events were held in both the Western Railway Station and Underground station, the busiest in the city. Reports of both events featured on M1, one of the Hungarian nationwide TV channels. At the Budapest railway station a press conference featured Eszter Csabuda, President of Tüdőér Egylet the Hungarian PH patient association; Dr. Kristóf Karlócai, Vice President and cardiologist; Orsolya Rakonczi, a member of the association and Dr. András Temesvári, a cardiologist. In the underground station at an information point hundreds of passers-by met with Tüdőér Egylet members and exchanged information. Posters from the campaign were placed in numerous spots and flyers and promotional gifts (balloons, fridge magnets, Blue Lips lollipops) were handed out to passers-by. A highlight of the event was the performance of the artists from the Mimage Pantomim Theatre. Dressed in black with painted blue lips and blue hands, they mimicked symptoms of the disease, raising enormous interest among the public and journalists. It was such a success that they were asked to repeat their performance three times in the same day. Placards printed with the *Breathtaking* designs remained in place for one month. After the campaign the mobile placards were transported to Balassagyarmat and were presented at Dr. Kenessey Albert Town Hospital. The Hungarian association also exhibited at a very big event



organized by the Hungarian Federation of People with Rare and Congenital Diseases (RIROSZ) for Rare Disease Day in Castle Vajdahunyad, City Park, Budapest. Prof. Dr. Miklós Réthelyi, the Minister for National Human Resources opened the event. Tüdőér Egylet joined RIROSZ as an institutional member a few weeks before this event and was therefore able to participate as an exhibitor. Around 40 media featured Rare Disease Day in Hungary, including the most viewed TV channels (M1, Duna TV, HírTV - NewsTV), most read dailies (Népszabadság, Metropol), magazines and websites (nol.hu, gyogyhir.hu, vital.hu, hazipatika.hu, weborvos.hu, mti-press etc.).

Follow up: the number of the visits to the Tüdőér Egylet website increased rapidly after RDD, and the number of members also increased starting just half an hour after the interview held at Duna TV! Many e-mails and phone calls are still coming in from people wanting information or to thank the association for its work. Tüdőér Egylet has also received invitations to national events which will draw further attention of medical experts to PH and contribute to raising awareness. It is hoped that this will bring about more opportunities for fund raising. Mrs. Hedvig, Kovácsné Schuster, points out that "It is important to note the measurable impact of the *Breathtaking* campaign, which affected the members of Tüdőér Egylet, namely that they could give a helping hand to their fellow-beings with this heads-up".



Tüdőér Egylet booth at RIROSZ event at Castle Vajdahunyad



RIROSZ event at Castle Vajdahunyad





Hall Skaara is the President of the Norwegian PH patient group and lives in Oslo. The PH group in his country is still quite small and would not have been able to organize a big event on its own so Hall decided to use other channels. He had the great idea of asking his son, who is one of Norway's top league basketball players, to get involved. Nils Paul was very happy to contribute to raising awareness on the disease his dad lives with.

Advertisements for the home games in the local newspaper were arranged (36,000 subscribers) and a message was posted on the team's web page (most visited basketball page in Norway: [www.barumbasket.no](http://www.barumbasket.no)). An article was also published on the team's home page.

During home games *Breathtaking* posters were put up on display in the entrance area. The team members painted their lips blue and handed out flyers on February the 28th in Oslo. They also played a game with blue lips! This was a big hit with press and TV as basketball is a pretty "macho" sport and the idea raised great curiosity and interest.

Hall Skaara made a very nice video of the basketball game and its blue lips players. "Honouring his father" (with English subtitles) is available at: <http://www.youtube.com/watch?v=LGMu5Zamyic> The President of PHA USA featured the video in his blog. "Hopefully this will create some extra awareness of our work and the Rare Disease Day also in the States" says Hall Skaara. <http://pharino.blogspot.com>.

Hall and his son were also invited to "God morgen Norge", a popular morning talk show on TV, with several hundred thousand viewers, and many articles were published regarding their appearance. The God morgen Norge TV show is now available with English subtitles.

Follow up: Nils-Paul's team won the national basketball championship! Hall and his wife attended the last game on Sunday 10th of April in North-Norway with 2,000 spectators and national TV present. The video "Honouring his father" is one of the nine finalists in the EURORDIS annual photo and video contest for Rare Disease Day.



Hall Skaara and his son interviewed at "God Morning Norge", a popular morning TV show



Some web journal cuttings and blog posts



Medication can stagnate the progression of the disease if diagnosed at an early stage.



Nils-Paul Skaara and his team playing with blue lipsticked



This is, after all, a macho sport!



This means a lot to me since my dad has this disease.

NILS-PAUL SKÅRA

The making of "Honouring his father" a video featuring Nils-Paul Skaara and his team playing with lips painted blue



The Polish Pulmonary Hypertension Association participated in the *Breathtaking* campaign with many different activities, including posters, distribution of flyers, advertisements in buses, large outdoor screens, ads in papers and a press conference. Placards from the *Breathtaking* campaign were posted in 12 major cities: Warsaw, Cracow, Gdańsk, Gdynia, Sopot, Bydgoszcz, Przemyśl, Jelenia Góra, Katowice, Wrocław, Lublin, Szczecin - in hospitals, health centers, universities, churches, book shops, pharmacies, restaurants and libraries. Leaflets were distributed in hospitals, health centers and on the streets. One of the association's members is a medical sales representative and she distributed hundreds of leaflets to medical specialists. *Breathtaking* posters were placed in buses in Warsaw, Lublin, Bydgoszcz, Poznań, Szczecin. Some of the posters were shown on special LCD monitors mounted in different forms of public transport. In two big cities, Bydgoszcz and Szczecin, outdoor screens were used (see photo). "Metro" is a very popular newspaper in Poland, distributed free of charge near train stations, bus stops, and main pedestrian crossings. PHA Poland placed ads in "Metro" in Cracow and Warsaw (circulation of 120,000 in Warsaw and 35,000 in Cracow). The Polish PH Association also sent a special letter to all Polish PH health centres to inform them about the *Breathtaking* campaign and attached posters and leaflets. PHA Poland's first-ever press conference was held at the Polish Press Agency (PAP). Speakers included Prof. A. Biedreman from the

Institute of Cardiology in Warsaw, Dr. M. Kurzyna from the PH Clinic in Warsaw, a representative from the Rare Disease Forum and patients from the Polish PH Association Agnieszka Bartosiewicz and Piotr Manikowski. "Everyone at the press conference including journalists, specialists in the medical field and friends of our Association listened to us very carefully and after the conference we received great applause. It was a big success for us and I am proud to have been a part of it", says Agnieszka. "One of our members was also at a special event, "Kolosy", a big, weekend meeting of travellers, alpinists and sailors. Our association distributed posters and leaflets. Famous Polish alpinist Anna Czerwińska was very interested in hearing about PH because alpinists also have a big problem with breathing at high altitudes. She signed our posters." Members of the Polish Association took part in activities organized for Rare Disease Day in their country. This big event was located in a beautiful city park in Warsaw, Łazienki. Representatives of the medical world, the head of the Health Ministry Ewa Kopacz, media, journalists and associations of rare disease patients and families were invited to the conference. During the event Prof. Adam Torbicki, Dr. Marcin Kurzyna and nurses from the PH Clinic in Warsaw supported the Polish Association. After the conference, all members were asked to write short notes with their own wishes about rare diseases. All notes and cards were tied to white and blue balloons and freed into the sky!



PHA Poland's first-ever press conference at the Polish Press Agency



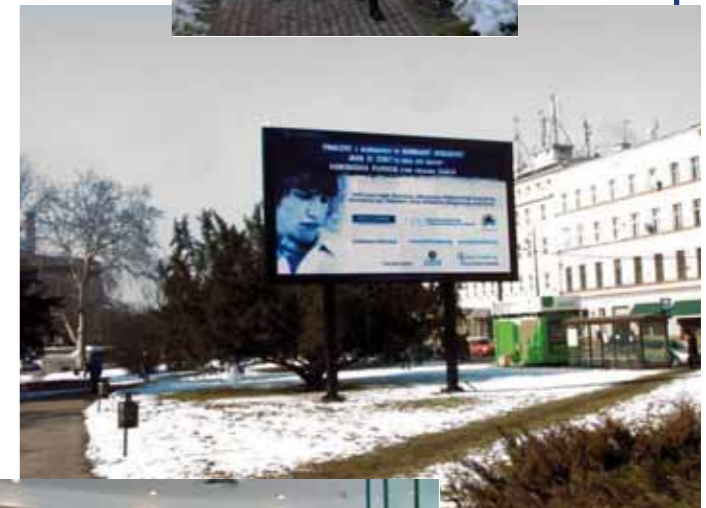
Famous Polish alpinist Anna Czerwińska signing Breathtaking posters



Rare Disease Day celebrations in Łazienki, Warsaw



Third from left: Prof. Adam Torbicki second from right: Agnieszka Bartosiewicz



Placard posting and outdoor screens in major Polish cities



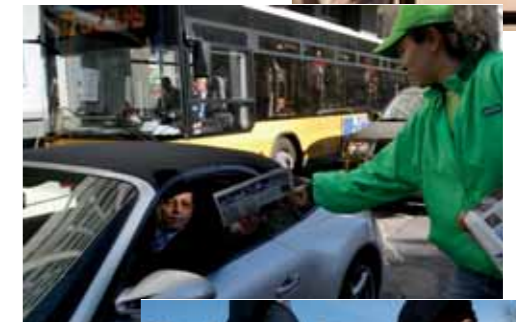


Metro and Destak newspapers with Breathtaking materials distributed in seven Portuguese cities



The Portuguese campaign focused on seven cities: Lisboa, Porto, Aveiro, Braga, Coimbra, Guimarães, and Leiria, disseminating information about rare diseases, specifically PH, through press and TV. Press releases were sent to major TV networks (RTP1, RTP2, SIC, TVI) and newspapers (Expresso, Sol, Diário de Notícias, Público). Information was widely distributed through Facebook. The Campaign was then featured in two very popular newspapers: Metro (401,000 readers) and

Destak (455,000 readers) in all the seven cities. An interview with the President of the Portuguese PH Association, Maria João Saraiva, featured in Destak and Metro newspapers. On February 28 Maria was interviewed by TVI 24 Saude (Health), a TV program about medicine (see photos). Post-event coverage was organized in two monthly health-related magazines: "Saúde e Bem-Estar" (circulation: 30,000) and "Vida Saudável" (circulation: 32,000).



Maria João Saraiva, President of the Portuguese patient association, on TVI 24 Saude (Health) a program about medicine, on 28 February 2011







The Spanish PH Association ANHP took part in the *Breathtaking* campaign through a very extensive program of placard posting in Barcelona and by involving local health authorities. Additionally, it took part in other Rare Disease Day-related events in the country.

Barcelona Metro Stations: *Breathtaking* placards were posted in 39 metro stations in Barcelona with long staircases. It is estimated that the posters were seen over 1million times by passengers each day during the 15 days.

Race for Hope in Madrid: the Spanish Federation of Rare Diseases (FEDER) organized the Race for Hope at the Casa de Campo de Madrid. Nearly 3,000 participants ran to support this cause and the Spanish PH Association, ANHP, had a stand and *Breathtaking* campaign leaflets and lollipops. ANHP friends Eva and Andrea were the most courageous of the PH patients and ran with the other participants. You can see Eva and her entourage of PH fighters in their shirts featuring the ANHP logo here, and giving interviews to TV crews.

Check it out at: [www.hipertensionpulmonar.es](http://www.hipertensionpulmonar.es)

Involving local health authorities: the Spanish association also involved the health authorities, with Catalonia taking the lead in support for PH. The Catalanian Health Authority posted the *Breathtaking* campaign leaflet on their website.



Race for Hope in Madrid organized by the Spanish Federation of Rare Diseases



Visitors to the Spanish Health Ministry's site will also find information about PH in the Rare Disease section.

"We are proud to say that pulmonary hypertension is the first rare disease with specific information about its symptoms and treatment within the entire section. We thank Drs Altabella Magrinyà for their interest and support", says Juan Fuertes, ANHP coordinator.

Additionally, 1,500 leaflets were distributed to hospitals and Dr Pilar Escribano from the 12 de Octubre Hospital was quoted in the Spanish press release.

Irene Delgado, ANHP President commented that "Taking up the challenge at national level of organizing the *Breathtaking* campaign has been quite an experience. Spain is not different from the other countries we know. Trying to sensitize the health authorities and the general public about a rare disease is like fighting windmills. However, the sheer folly of involving Health Authorities in our fight has become an example and the support of the Departament de la Salut is a role model for the Health Departments of the Regional Governments in our country".

Follow up to RDD: the campaign's impact will continue throughout the year because it will be included it in the activities of ANHP, leading up to the beginning of 2012, the Spanish Year of Rare Respiratory Diseases.



Placards where posted in 39 metro stations in Barcelona





CZECH REPUBLIC

The Czech PH Patient Association contributed to the campaign by publishing the *Breathtaking* campaign poster in "Medical Tribune", the only newspaper about medical science, clinical practice and healthcare in the country. Its total readership includes 48,000 doctors, pharmacists, and other healthcare professionals.

"Medical Tribune" reaches out to:

- 5,500 members of Society of General Practice, CMA JEP;
- 4,500 subscribers from other medical fields, mainly internal medicine;
- 2,600 pharmacies (Czech Pharmacy Chamber);
- 1,500 surgeons (CSS CMA JEP);
- 700 oncologists (COS JEP - Czech Oncology Society);
- 600 diabetes doctors in cooperation with Diabetes Association;
- 250 auditing practitioners (SAP CMA JEP);
- 1,200 hospital management personnel;
- 930 pharmaceutical industry management personnel;
- 400 medicine and pharmacy faculties' management personnel and opinion;
- Leaders in all medical disciplines, professional societies' chairpersons, medical societies' and associations' representatives;

- Participants in all major congresses, conferences and seminars in the Czech republic.



SLOVAKIA

Slovakia contributed to raising awareness of PH on Rare Disease Day by organizing a press conference on the 28th of February. News of the press conference was aired on Slovakian TV JOJ and an article was published in the magazine "Plus jeden deň", see <http://www.pluska.sk/slovensko/regiony/iveta-caka-pluca-z-viedne.html#>

During the press conference, the Head of the Transplantation Division at the National Institute of Cardiovascular Diseases in Bratislava, Dr. Eva Goncalvesová, and Dr. Milan Luknár, spoke about the medical aspects of PH. Iveta Makovnika, President of the Slovakian PH association, described some of the issues related to day to day life with the disease and the association's activities.

This was followed by individual interviews with reporters. There were about thirty journalists attending the press conference.



from left: Dr. Milan Luknár, Iveta Makovnika and Dr. Eva Goncalvesová at the press conference



ITALY

Luisa Bonelli (AMIP) and Pisana Ferrari (APII) were unfortunately not able to actively take part in the *Breathtaking* campaign on account of previous commitments with the national associations they represent.

AMIP was putting the finishing touches to the DVD of patient interviews, which is posted on the association website at: <http://www.vimeo.com/20636471>

Pisana was busy helping the national members with their RDD events and also preparing for APII's 10 year anniversary celebrations on April 3rd.

Both did however send the *Breathtaking* campaign press release and materials in Italian to a number of newspapers and press agencies and spread the word in every possible way they could. A couple of web journals and one of Italy's top newspapers, Corriere della Sera, picked up the news and wrote about it.

Some follow up is planned for late June at a scientific conference on PH in Bologna. This conference will provide the opportunity to speak about the results of the campaign.



SWITZERLAND - Schweitzer PH-Verein



Disease Day held in the Kursaal Bern on the 19th of February 2011. The theme of the event was "health care inequalities". ProRaris, the Alliance of Rare Diseases in Switzerland, organized some lectures and discussions on this occasion. Thirty rare disease patient associations were present, some with a stand, including the Swiss PH patient association SPHV, represented by Vice President René Emmenegger and Mrs Renate Schor. Over 400 people attended.

The Swiss Patient Association SPHV did not take part directly in the *Breathtaking* campaign but was involved in national events organized around Rare

"Knowledge heals"!: this was the theme of a big event in Basel on Rare Disease Day which informed national authorities about the problem of rare diseases with the aim of raising public awareness.

SPHV had an information booth at this event (see photo on left). Speakers from the medical world, politics, economy, and patients presented and discussed findings and knowledge on rare diseases, their impact on individuals, research, and the whole society at an accompanying symposium.





## Conclusions

Dear friends,

We would like to end this special edition with our warmest thanks to all those who contributed to making the campaign so successful. We can be really proud of the results achieved with this first collective effort, all the more so in consideration of the fact that we started planning very late. Everything ran incredibly smoothly considering there were so many organizational aspects involved and very tight deadlines. For a couple of months there were literally hundreds of e mails going back and forth across the whole of Europe between the members and the coordinating team. Everyone responded promptly and with great enthusiasm and this is possibly one of the greatest achievements.

As far as our campaign objectives are concerned, we are very very pleased with the media coverage data sent to us by the Ketchum Pleon in late March. According to this report, 110 media outlets across seven European countries - Belgium, Austria, France, Germany, Norway, Spain and Switzerland - covered the launch of the campaign. In addition, coverage has appeared on over 50 websites with global reach, including CNBC (daily readership 577,479) and Yahoo Finance (daily readership 54,383). Top tier coverage was also secured in Austria and Belgium including Nachrichten.at, Teletext, Der Standard, De Standaard Online and Het Nieuwebald. Further afield, the release was picked up in India and Thailand. Through the multi-media news release (MNR), photos and video footage

were distributed to 905 journalists, with over 100 choosing to download material from it, such as photo and video links. The tone of articles produced was generally very positive, with several choosing to include video footage in reports. In addition to appearing on the MNR, the B-roll and patient diary were placed on video sharing websites, through PR Newswire. These sites were specifically chosen to provide the largest possible potential audience.

Recent developments include the very flattering invitation from EURORDIS to present the *Breathtaking* campaign in Paris at the end of June at an international workshop of the Council of European Federations. EURORDIS wishes to use *Breathtaking* as a case study on how to organize a successful common campaign around Rare Disease Day. And it is wonderful that Rosie's touching "patient diary" has won third prize at the EURORDIS' annual video contest for Rare Disease Day and Norway's "Honouring his father" is among the nine finalists.

We will need to fine tune some of the organizational details and hopefully involve more member associations but we are confident that our 2012 campaign will be just as successful as this year's edition!

Again many thanks to you all for all the hard work and efforts put into this exciting truly pan-European project!

*Pisana and Gerry*

### Next edition of Mariposa News

The Summer 2011 issue of the PHA Europe newsletter is due out in **August 2011**.

The first part of the new Mariposa will contain, as in previous editions, reports and photos of activities organized by PHA Europe member associations in the period which goes from January to June 2011. We would be very grateful if you could send your contributions by **the end of June at latest**. You may send these in your own language and we will provide for translation. We stress the importance of respecting this deadline as the new Mariposa must be finalised and printed before the European Society of Cardiology's (ESC) Annual Congress in Paris 27-31 August 2011. PHA Europe will be present with a booth at the ESC Congress and we will be distributing all our most recent materials. The new Mariposa will also include reports of recent scientific events, updates on PH treatments and new developments at EU institution level.

All member associations will receive the PDF version via e mail and twenty copies of the printed newsletter by normal post. If you need more copies please contact Pisana Ferrari at +39 348 4023432 or p.ferrari@phaeurope.org.

We are working on building up a comprehensive European mailing list with and would greatly appreciate any input on this.

*Many thanks in advance!*

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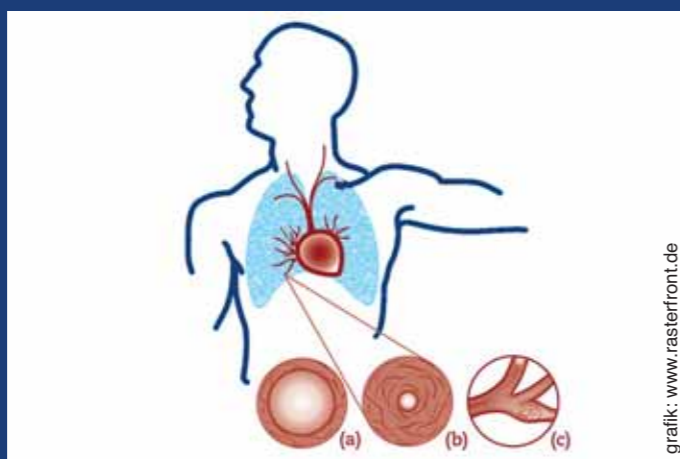


## AIMS OF PHA EUROPE

Pulmonary 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.