



# PULMONARY HYPERTENSION MariposaNews

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EUROPEAN PULMONARY HYPERTENSION ASSOCIATION



## EUROPE RAISES ITS HANDS FOR RARE DISEASE DAY

*Report and photos of PHA Europe's Breathtaking awareness campaign  
for Rare Disease Day, 29 February 2012*





# “BREATH TAKING” ACROSS EUROPE: NATIONAL REPORTS OF THE BIG DAY

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

Welcome to the Spring 2012 edition of Mariposa News. This is a special issue reporting on PHA Europe’s “Breathtaking” awareness campaign. The campaign, led by PHA Europe and supported by Bayer HealthCare, was launched on International Rare Disease Day (RDD), 29th February 2012, under the patronage of Eurordis, the European Organization for Rare Diseases. RDD is an annual event coordinated by Eurordis and the National Organization for Rare Disorders (NORD). 63 participating countries from five continents joined the 2012 program, 33 of which were European. Thousands of patient groups and their partners organized all kinds of awareness events. PHA Europe’s 2012 “Breathtaking” campaign saw the participation of 16 pulmonary hypertension patient associations from across Europe (six more than last year) with many interesting and exciting events successfully organized by the national PH leaders. The following countries were involved: Austria, Belgium, Bulgaria, Czech Republic, Finland, Germany, Hungary, Italy,

Latvia, Norway, Slovenia, Slovakia, Portugal, Poland, Spain, and Switzerland. The objective of the “Breathtaking” campaign was to increase awareness of PH among the general public and the medical community, with particular emphasis on the symptoms and the need for timely diagnosis and treatment. Early diagnosis is a key issue in PH. 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 and, even when it is, diagnosis is often delayed by up to 2-3 years. As a result, patients very often start treatment late, when the disease is already at an advanced stage, worsening their prognosis and quality of life. An accurate and early diagnosis and early treatment can really mean the difference between life and death. The striking “Breathtaking” materials were designed to reflect the symptoms of PH and the importance of time in PH. Images of a young woman, a little girl, a young boy and an elderly man, each with blue lips and a blueish com-

plexion, were featured. The accompanying text stressed the importance of seeking medical care at the very onset of symptoms. The campaign’s launch event was held in Brussels, the hub of many major EU institutions, and featured a dance performance at one of Brussels’ most prestigious historical sites, the Galerie de la Reine. The dance routine was choreographed to convey the impact of PH on patients’ lives and was performed by a locally renowned dance group. 2,000 members of the public received information about PH on postcards and were given blue lip balm and blue-lip lollipops to represent the symptoms of the condition. In addition, a press conference was held with members of the PHA Europe Board, Belgian PH patient representatives and key Belgian PH medical opinion leaders. The Brussels event alone generated over 300 pieces of international media coverage, reaching an estimated 2.5 million people. Each of the 16 national affiliate associations taking part in the campaign brought its own personal touch to the organization of local events. Highlights included celebrities being photographed with blue-lip lollipops in Austria, a stunning pantomime play in Bulgaria, a traditional choir singing in Latvia, top league basketball team playing with

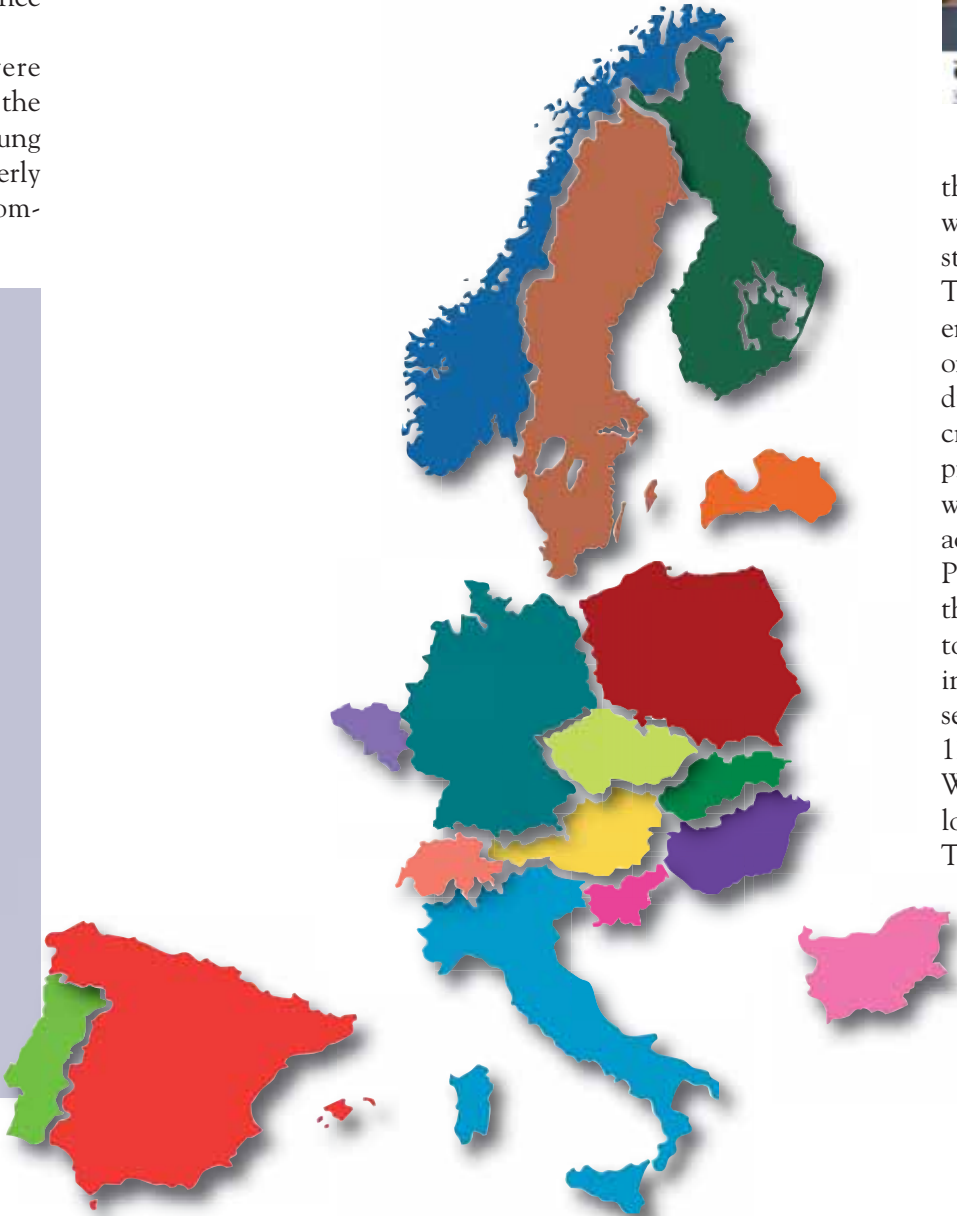


their lips painted blue in Norway, a collective six-minute walk test in the heart of Budapest (Hungary), and a unique street event in Poland. The enormous amount of media interest and attention generated by the “Breathtaking” campaign across Europe, proves once again how important it is - especially in the case of rare diseases - to join forces across borders in order to reach critical mass and make an impact. The campaign has also proven that even “young” and relatively small associations, when empowered by working within a larger group, can achieve incredible results. PHA Europe wishes to recognize the great efforts put into the campaign by the national affiliates by granting an award to the three best projects. The winners will be announced in June by the PHA Europe Board and the awards presented at the General Annual Meeting taking place from 12th - 16th September in Barcelona. We are very proud of the results of our 2012 campaign and look forward to another successful program in 2013. Thank you to all for your invaluable support!

Gerald Fischer  
President PHA Europe



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# Austria says lights, camera, PH!

The campaign in Austria involved two main activities: the dissemination of campaign materials across the country and working with celebrities to help raise awareness of PH.

Over 2,500 posters were put up in Vienna, 300 of which had real oxygen masks attached to them for even greater impact. 150 giant billboards were positioned at the main university clinics across the country. For the second part of the campaign, a host of celebrities were photographed holding up a blue lollipop, one of the key campaign materials. Local and international photographers were recruited and tasked with taking as many photos of the celebrities as possible. What better and more glamorous way to pass

the PH message along? The results were absolutely amazing: over one hundred actors, singers, pop stars and other VIPs agreed to be part of the campaign and feature in a wonderful photo gallery. Prominent among the international celebrities are Maximilian Schell (first row, third from right) the world-renowned Austrian actor and film director (Academy Award winner in 1962). Other celebrities include American actress and singer, Rose McGowan, from the TV series *Charmed* (first row second from left), and Jonathan Banks, American film and TV actor, who best known movies are *Beverly Hills Cop* and *Flipper* (first row, first photo on the right, with his wife Genara).







# Dancers lead the way for PH in Belgium

The launch of the 2012 “Breathtaking” campaign was held in the “capital” of the European institutions, Brussels. The key event was a stunning performance by a well-known Belgian dance troupe led by Isabelle Bernaerts in one of Brussels's most beautiful and historical sites, the Galeries Royales Saint-Hubert. The dancers performed their interpretation of the symptoms and emotions experienced by pulmonary hypertension patients: fear, anxiety, fatigue and shortness of breath. With the aid of various props, the dancers showed how difficult it can be for patients to accomplish simple acts of everyday living such as climbing stairs (see photo below). Hostesses distributed postcards, blue lollipops, blue lip balms and other “Breathtaking” materials to

passers-by and “Breathtaking” posters were displayed throughout the gallery. Shortly after the dance performance, a press conference was held in a private room at the famous restaurant Aux Armes de Bruxelles. Speakers included the leaders of the two Belgian PH associations, Luc Matthysen for HTAP Belgique, and Gust Caelen and Hendrik Ramaker for VZW; leading PH physicians Prof. Marion Delcroix (Universiteit Katholik Leuven) and Jean-Luc Vachiéry (Erasmus-ULB Brussels) and Gerald Fischer, the PHA Europe President. Pisana Ferrari (PHA Europe Vice President) and Juan Fuertes (ANHP, Spain, PHA Europe EU coordinator) were also present and took part in some of the filming and interviews.

The impact of this event was truly exceptional. It generated over 300 pieces of international media coverage including four Belgian national editorial articles, one international editorial article, 297 online articles and two radio and television broadcasts. The estimated reach was 2.5 million people. The event also featured on social networks with 287 Facebook “Time to Breathe” application posts and 50+ Tweets.

A video of the event can be viewed at:

[www.rareconnect.org/it/community/pulmonary-hypertension](http://www.rareconnect.org/it/community/pulmonary-hypertension)







## A truly “Breathtaking” day in Bulgaria

The “Breathtaking” message in Bulgaria was conveyed through a beautifully orchestrated pantomime play during which the performers simulated the symptoms and emotions of living with pulmonary hypertension. The play was staged in two of Sofia’s busiest shopping malls. The idea was to grab the public’s attention and help them to become acquainted with the disease through a “story”. Leaflets and blue lollipops were distributed while the plays were taking place and “Breathtaking” roll-up posters were displayed in the malls. Around 2,800 people received information (1,000 during the lunchtime performances and 1,800 during the evening). The team received a huge amount of positive feedback from members of the public

as well as around 100 requests for more information. In addition, “Breathtaking” posters were displayed, and leaflets disseminated, in the six Bulgarian Medical Universities in Sofia, Pleven, Varna, Plovdiv, Stara Zagora inspire the students to focus on PH. Press releases about PH and photos and information about the pantomime play were issued to both general and specialist media and journalists were invited to attend the event. Media coverage of the event was fantastic. In particular, Prof. Nina Gocheva, Head of the Department of Cardiology at the National Heart Hospital, made a guest appearance on *Morning with BBT* (national state tele-



vision). She talked about rare diseases, focusing on pulmonary hypertension. She stressed the fact that it is extremely important for people who experience shortness of breath while performing daily activities to visit their doctor. At the end of the interview, the TV host made an announcement about the campaign and the pantomime plays. Articles about the Bulgarian event featured in a number of newspapers and online. Dr. Arman Postadziyan from the Clinic of Cardiology, University Hospital Sveta Anna Sofia, was interviewed by the newspaper *Monitor* and explained why pulmonary hypertension is so dangerous and what people should do if they experience the symptoms. He also mentioned that the treatment of idiopathic pulmonary arterial hypertension is covered by the national health service in Bulgaria. Dr. Elena Dimitrova, from the same medical center, was interviewed by the health portal *Puls.bg*. Other articles and photos of the event were published on a number of websites including *az-jenata.bg*, *start.bg* and *rare-bg.com*.





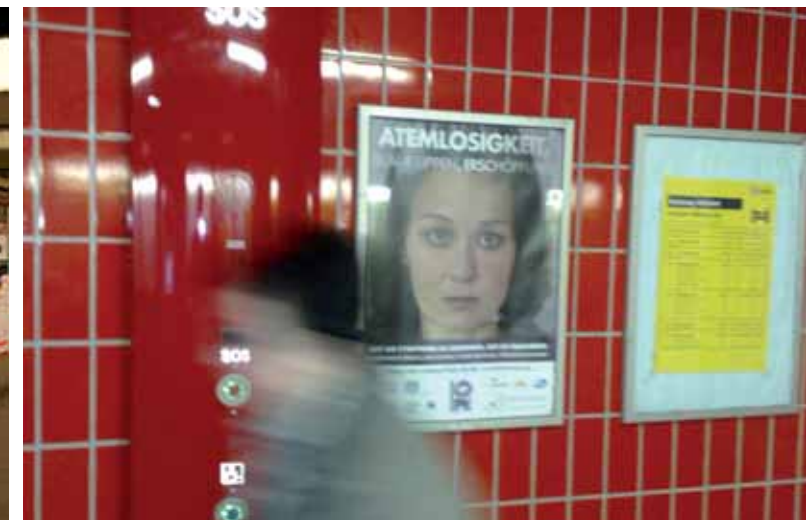


# Germany bravely carries on with “Breathtaking” activities



Over 1,500 “Breathtaking” placards were posted and thousands of flyers distributed in and around train and metro stations and other key spots in six of Germany’s biggest cities: Karlsruhe, Frankfurt, Leverkusen, Berlin, München, Hamburg. The poster campaign was accompanied by media outreach.

Bruno Kopp, President of the German patient group phev, very sadly passed away after many years of illness just as the campaign was being organized. The fact that the association decided to go ahead anyway with the campaign was as a brave and wonderful gesture to be much commended by the entire European PH community.







# Hungarian journalists get breathless for “Breathtaking”



Tüdőér Egylet has been supporting pulmonary hypertension patients in Hungary since 2008. On Rare Disease Day 2012, the Hungarian association took part in the “Breathtaking” campaign with an event in downtown Budapest. The aim of the campaign was to raise awareness and attract the attention of the general public to PH in a new and original way. A “six-minute walk test”<sup>\*</sup> was organised on Budapest’s most beautiful square, Vörösmarty. Patients and passers-by walked back and forth along a specially-prepared multi-laned track for six minutes. Expert physiotherapist performed the pre- and post-walk assessments, including pulse and oxygen saturation before and after the walk and also the distance walked. Each participant received a certificate with detailed information of his or her exercise capacity.

Passers-by and even journalists waited in line to participate in the walk and its success was such that the event lasted for over two hours. One can imagine the number of the people involved, as more than twenty “rounds” were held. In course of the tests, Dr. Karlocai, Vice President of the Hungarian association and leading Hungarian PH expert, made a presentation and responded to requests for additional information. “Breathtaking” roll up posters were displayed in the square and blue lollipops and other “Breath-taking” materials were distributed by volunteers.

Before the walk, a press conference was convened in the nearby Cafe Gerbeaud by the President of the Hungarian association, Eszter Csabuda, Dr. Kristóf Karlócai, and Dr. László Ablonczy, a paediatric cardiologist. The press briefing was attended by 18 journalists.

Both the event and press conference were a great success. On February 29th, Dr. Kristóf Karlócai was interviewed for Info Radio, Hungary’s leading news radio show with a reach of around three million households in Budapest and the vicinity. The event was also reported on the evening news of the Hungarian State television (MTV), the main national TV channel which is watched by an average of 2.5 million people. The news featured the Vörösmarty square event and an interview with a PH patient.

Many other online media picked up the story and reported the event, including *Házipatika.com*; Hungary’s leading online health information source, *Medical online.hu*; the online version of Professional Publishing, the biggest professional medical publisher of the country; *50plusz.hu*, a health-issue site targeting the middle aged and seniors; *Informed.hu*, an influential Hungarian portal mainly visited by policy makers and doctors; *egeszsegbolt.hu* and *üzlet.hu*, healthcare and business portals; *Webbeteg.hu*, the most popular site for members of the public, and *Hirekma.hu*, a daily news portal.

<sup>\*</sup> The six-minute walk test is a standard procedure to evaluate exercise capacity in patients with pulmonary hypertension. In addition to distance walked, dyspnoea on exertion (Borg scale) and finger O<sub>2</sub> saturation are recorded.







## Italy raises the sail for PH



AIPI and AMIP, the two PH patient associations in Italy, joined forces to organize the Italian “Breathtaking” event for 2012. When discussing how to implement the campaign in an original and creative way, a link to a sport was identified as a great way to attract large numbers of people and secure media attention. Sailing was recognized to be the ideal sport because both air and time are critical to success in a sailing race and key factors in PH and its treatment. The Italian Sailing Federation (FIV) gave their patronage to the campaign and Veronica Fanciulli, Silver Medal at the 2010 Singapore Olympics, offered to be the celebrity “Godmother”.

The “Breathtaking” event was organized around the Junior Winter Optimist and Surfboard Championship which took place on the 26th February in Civitavecchia, the port of Rome and one of the largest in Italy. The project was presented at the main Italian nautical fair (BigBlu) a few days prior to the event.

On the day of the race, more than one hundred children gathered in their boats. Just before setting off for the race, thousands of balloons with blue lip logos were launched into the air. Everyone involved wore “Breath-taking” blue hats, and many had blue lip prints on their cheeks. The boats all had blue ribbons attached. A booth was positioned at the nautical center where the race was taking place, with roll-up “Breath-taking” posters. Postcards, blue lollipops and other “Breath-taking” materials were given out to all those attending the race.

The event was covered by Italy’s main online news, TG1 online. A photo gallery with pictures taken by one of Italy’s best known photographers, Gianluigi Di Napoli, was posted on Repubblica online, Italy’s most widely-read newspaper. The race was also mentioned on the Roma Uno TV channel and there were many articles in various other press.

A video of the event is available at:

[www.youtube.com/watch?v=7nFYmEEi8Uc](http://www.youtube.com/watch?v=7nFYmEEi8Uc)







# Latvia in harmony for RDD

Singing as a symbol of the importance of breathing for human life was chosen as the theme for the “Breath-taking” campaign in Latvia. Singing also has a special meaning for the country, which has been famous for its traditional choir singing for centuries and a young generation of singers has dedicated itself to maintaining ancient traditions and promoting them across the world. Two very well know Latvian choirs were involved in the “Breathtaking” event.

On the 29th February, the campaign opened at the two most popular shopping centres in the Latvian capital of Riga. The *Sola* choir performed in the *Galerija Centrs* and the choir of the *Stockholm School of Economics* performed

at the *Alfa* shopping centre. During and after the concerts hostesses distributed postcards, blue lollipops and other “Breathtaking” materials to passers-by. Throughout the day, hostesses also distributed materials at the popular shopping centre by the central railway station and at the popular shopping centre *Mols*. During the campaign in the shopping centres our hostesses passed information about PAH to more than 2 000 passers-by.

Prior to the start of the campaign, PHA Latvia obtained free public advertising spaces and “Breathtaking” posters were displayed throughout Riga from the 28th of February to the 4th March and again from the 19th to the 31st of March.



A press conference was held on 29th February at the European House in Riga in collaboration with the rare disease association Caladrius. Leading PH physician Dr. Andris Skride gave a presentation on PH and PHA Latvia and answered questions from journalists. On the same day, PHA Latvia organized a workshop in collaboration with social partners and industry representatives. The meeting agenda included legislative problems in PH, the importance of psycho-social support, partnership opportunities and a presentation of PHA Latvia’s new website. Media coverage for the “Breathtaking” campaign in Latvia was excellent, with four articles in the daily press, three reports in national news agencies, one television interview and eight articles/press releases on websites. Newspaper articles include an article in the popular national newspaper *Diena* and two articles in the most subscribed to newspaper in Latvia, *Latvijas Avīze*. The story was also carried by the main national news agency of Latvia, *LETA*, and by the second largest news agency, *BNS*. The national TV channel *LTV1* featured an interview with Dr. Andris Skride about PH and “Breathtaking” campaign on the morning TV programme *Labrīt Latvija*.







## A slam dunk for PH awareness in Norway



As with last year's RDD campaign, PHA Norway worked with the Norwegian elite men's basketball team, *Bærum Basket*, in 2012. The main attraction was a basketball game for which the players painted their lips blue. Posters in the ticket area and around the court ensured that all the spectators knew that the blue lips symbolized a symptom of PH. Spectators were also given flyers and blue lollipops as they entered the arena. An added dimension at this year's game was that, when they learned about the campaign, the competing team also wanted to play with their lips painted blue.

A couple of days prior to the match, the team had a stand at northern Europe's largest shopping mall, *Sandvika Storsenter*. The players were dressed in their blue jerseys, had their lips painted blue, and handed out flyers and lollipops to passers-by. Pulmonary hypertension is a rare disease but, during the two hours the team were on-stand, they encountered a woman who was tested annually due to a congenital disease that might cause PH. Another young woman who visited the stand was more directly affected by the disease as she had lost a newborn baby to PH.

A full-page newspaper advertisement featuring the captain of the basketball team was run prior to the match. The advertisement stated that, to become Norwegian champions the previous year, he had performed "Breathtaking" plays on the court. His father, however, has a disease that literally takes his breath away. The advertisement listed the symptoms of PH and stated that, while 200 people in Norway have been diagnosed with PH, 200 additional people are likely to have the disease without knowing it. The readers were encouraged to contact their doctor if they, or anyone they knew, experienced any of the symptoms. A press release was also sent out to media prior to the match. A radio station responded to the press release and the president of the Norwegian association was interviewed on live radio about RDD 2012 and PH.





# Poetic performance highlights PH in Poland

The Polish Association of People with Pulmonary Hypertension and their Friends took part in the “Breathtaking” campaign for Rare Disease Day 2012. Leaflets were distributed and posters displayed in key locations in both large and small cities. Advertising was displayed on buses and interviews given to radio, television, internet and print media. The association also participated in the national Rare Disease Day celebrations.

The main event took place in the capital, Warsaw. A brief and very poetic performance was given by actors from the *Warsaw Theatre Puszka* in the heart of the city, near the entrance to the subway and close to the *Palace of Culture and Science*. In a snowy fairy-tale setting, one of

the main characters wore huge wings, printed with an X-ray image of lungs to symbolize this vital organ. Long red sheaths of cloth were attached to the wings to represent the pulmonary arteries. The “butterfly” walked among the actors miming everyday activities and showing the great difficulty of doing them as a PH sufferer. A young woman, a painter, a photographer, a model, a housewife and a soccer player were all represented. They simulated their difficulty in breathing by covering their mouths with paper bags. During the performance, volunteers and students in blue T-shirts distributed postcards and blue lollipops. Before the event, Agnieszka Bartosiewicz, a representative of the PH association, and Dr Małgorzata Żuk,

a doctor from the Child Health Center, gave interviews for *Polsat News*.

“Breathtaking” campaign activities also took place in Tricity (Gdynia, Gdańsk, Sopot) and other cities in the Pomerania region, as well as Debica, Tarnow, Katowice, Bydgoszcz, Chojnice, Sepólno Krajeńskie, Toruń and other towns in the Kujawsko-Pomorskie region. Posters and leaflets were also distributed in Dębica, Tarnów, Katowice, Kraków, Busko-Zdrój, Gryfice, Poznań, Wrocław, Żary, Żagań, Zielona Góra. Thousands of posters were displayed in universities, medical centres, libraries, churches, restaurants, cafés, shops, shopping malls, conference centres. The Vice President of the Polish Association Alicja Morze (a PH patient) and her husband Grzegorz Morze were nominated for *Man of the Year 2011* for their activities to raise awareness of PH among the community of Pomerania. Media coverage included TV and radio interviews (Radio Gdańsk and Polskie Radio) and articles in a number of Polish newspapers and magazines including *Polska The Times* *Dziennik Bałtycki*, *Gazeta Lubuska*, *Express Gdyniński* and articles on the internet.

A video of the event is available at:

[http://www.youtube.com/watch?v=tqAZ7\\_s8W\\_8&feature=related](http://www.youtube.com/watch?v=tqAZ7_s8W_8&feature=related)







# Slovakia orchestrates a “Breathtaking” campaign for RDD



In 2012, the Slovakian patient association ZPPH participated in the “Breathtaking” campaign for the second year in a row. The campaign launched on the 29th February with a press conference at the restaurant *Brasserie la Marine* in the shopping center in Bratislava. The press conference was attended by dozens of journalists, Slovak radio and the television channel Bratislava. At the press conference, Prof. Eva Goncalvesová, President of the Slovak Society of Cardiology, gave a presentation about the establishment of the PH Center in Bratislava. Dr. Milan Luknár, Vice President of ZPPH and leading PH physician at the PH Center in Bratislava, spoke about the effects of PH, and Dr. Marta Hajková, senior consultant of the Department of Pneumology and Physiology, spoke about lung transplantation. In her presentation Iveta Makovníková, President of ZPPH, stressed the importance of campaigns and other activities, such as Time Matters, the PH Call for Action in the European Parliament and World PH Day, to raise awareness of PH. Patients were also invited to talk about their disease. The campaign continued in the shopping center where a booth had been set up. Hostesses handed out leaflets and blue lollipops to visitors and measured blood saturation and pulse rates. Educational materials and gift items were also sold. Patients and doctors were present to give additional information to people interested in the disease. On the same day, ZPPH President Iveta Makovníková and Vice President Dr. Milan Luknár attended the first congress of the Slovak Rare Disease Day which was held under the auspices of the Minister of Health of Slovakia and of Eurordis, the European Rare Disease Organization. Dr. Luknár spoke about the importance of referral centers for PH. On the 1st March, a working dinner was held for doctors, cardiologists, pneumologists and the patient organization. The dinner was held in order to enhance cooperation between the associations and it fulfilled its purpose. Following the dinner, members of the ZPPH attended the Slovak Philharmonic Orchestra concert in *Reduta* where “Breathtaking” materials were distributed to patrons. In the city of Liptovský Mikuláš, in the northern part of the country, further activities were organized by patients. The campaign coordinator was a patient who had undergone a lung transplantation only three months before. Over 1,500 flyers and postcards, 1,000 lollipops and 150 brochures about the diagnosis of PH were distributed. A video of the event is available at:

<http://www.youtube.com/watch?v=yOlc1i1JWYA>







# Slovenian celebrities unite to mark Rare Disease Day

The campaign in Slovenia kicked off on the 22nd February with an interview featuring Klara Klancar, President of the PH association, and Dr. Barbara Salobir, University of Ljubljana and PH physician on the national television program *Good Morning Slovenia*. This was followed by a one hour interview with Klara Klancar for Radio Veseljak on the day prior to RDD. On 29th February, at 9 am, the Slovenian PH association convened its annual assembly, hosted by the Center of the Hospital of Ljubljana, bringing together patients, family members, PH experts and local celebrities. Medical opinion leaders attending the meeting included Drs. Barbara Salobir, Matjaž Turel and Janez Remškar from the University of Ljubljana, and Dr. Mitja Košnik, Director of the Golink Hospital and specialist in

lung disease. Some of the Slovenia's most prominent artists, media and sports personalities also attended and had their photos taken with blue lollipops. Guests included singers Vili Resnik, David Grom, Saška Hren, Sara Kobold, Nena Zaneli and Iris Ošljaj, radio conductors Barbara Pirh and Gregor Bolčina, actress Tina Gorenjak, author Nastja Klevže, 18-time national motocross champion Sašo Kragelj and the 2012 World Cup female ski jumping team. At 12 o'clock, a press conference was held with many local journalists from press, TV and radio. "Breathtaking" campaign materials and lollipops were also distributed in shopping malls in Maribor, Koper and Celje. Advertising space on buses in Isola, Pirano and Ljubljana featured "Breathtaking" posters for one week and twenty days

in Capodistria. Two young and talented journalists, Jan Vehar, Urška Krek, provided invaluable support for the event. <http://www.youtube.com/watch?v=OfgsXBUaCdI>

Page 24 from left: Saška Hren, Gregor Bolčina, Nastja Klevže, Nena Zaneli, Iris Ošljaj with Gena Zaneli and Sara Kobold, Sašo Kragelj, Katja Fašink.

Page 25 clockwise: Klara Klancar with Barbara Pirh, Dr. Barbara Salobir with National TV, Klara Klancar and Vili Resnik, Matej Korošec with Klara Klancar and Dr. Salobir on TV show, Tina Gorenjak, the 2012 world cup female ski jump







Destak had a double page feature including a picture of the campaign and an interview with Dr. Maria João Saraiva. T-shirts with the campaign poster image on the front were worn by the distributors of both newspapers. Coverage in health related magazines included *Saúde e Bem-Estar* (circulation: 30,000) and *Vida Saudável* (circulation: 32,000).



## Spain stops traffic with their “Breathtaking” messages

Together, Dr. Gaudó and Dr. Sueiro from Ramón y Cajal Hospital wrote an article on PH to distribute to the media. Ramón y Cajal Hospital is aiming to become a leader for PH in Spain under Dr. Sueiro's direction. The article was released to the media together with a

The second activity for the 2012 “Breathtaking” campaign was a 45 second spot on *Sálvame* a television show with two million viewers. The host of the show, Jorge Javier Vázquez, discussed the problems related to the diagnosis of PH and finished with the words “sin aliento”, the Spanish translation chosen for “breathtaking”. Last, but not least, members of the ANHP members distributed 2,500 leaflets at their local pharmacies. The leaflets were given out by the patients themselves allowing recipients direct contact with someone who is actually experiencing what it means to live with the disease.







## Beyond RDD in the Czech Republic

The Czech patient association took part in the “Breath-taking” campaign by issuing press releases to all the main media. Reports were posted in 12 media outlets and blogs, with the potential reach of 17 million. In addition Dr Pavel Jansa, a leading PH physician in Prague, was interviewed for the CRo2 Prague radio show *Contact* and *Metropol*



TV. In the TV show Veronika Schächterová, a PH patient, was also interviewed. “Breath-taking” posters and materials will be also used at the Czech Congress of Cardiology in Brno (May 13-16) where the association had a booth, (see photo) and will be used at a meeting of the members of SPPH in Seč June 16-17.



## Focusing on the importance of unity in Finland

Rare Disease Day in Finland started early at the central Forum-shopping center in Helsinki. Tuulia Nappi and Jaana Rajahalme from PHA Finland, together with volunteers and members of other Rare Disease Associations, met at the shopping center. Colourful stands had already been set up with big bunches of yellow balloons. Jaana and Tuulia gave out PHA-Finland brochures and blue lollipops and informed passers-by about PH and the open event at the Little Parliament Building. It was a great opportunity to network with other members of the Rare Disease Group, including the new president of the Finnish Rare Disease Group, Kristina Franck. Tiina Eloranta, a Finnish journalist, interviewed Jaana and took photos of the PHA group and wrote an article for Heart Association Magazine, and for the web-pages of the Heart Association, about RDD, and Jaana's personal story of life with PH.

Before 12:00, some of the group walked to the Little Parliament Building where the official RDD program was starting. Others stayed at the shopping center to give out



more brochures, balloons and lollipops. The RDD event started with greetings from the President of the day, Jukka Sariola, from the Muscle Disease association and a video greeting from Yann Le Cam, CEO of Eurordis. There were speakers from different rare disease associations, including Marika Kiikala-Siuko from the Breathing Association's Rare Disease Group. Two patients spoke about their disease and their life. Finland's Social Affairs and Health Minister Ms. Paula Risikko was the “godmother” of the event. Research professor Helena Kääriäinen spoke about European cooperation between national rare diseases groups. Elina Nykyri, President of a new Finnish umbrella organization, HARSO, spoke about on the importance of “Rare Diseases united”. There was also an opportunity for open discussions. It was a very successful day which united the rare disease associations taking part in the day's events, and also contributed to raising awareness of rare diseases amongst the general public.



## Sweden builds relationships with the rare diseases network

Though not a member, PHA Sweden was invited to a conference organised by Rare Diseases Sweden on 29th February. The conference began with the grand opening of the National Competence Centre for Rare Diseases, The main objective of the centre is to gather, develop and spread knowledge on rare diseases and their consequences. The day was extremely rewarding and the focus of “being rare” was shown from many different angles. A key theme of the day was how we in Sweden can be better at managing the gaps in healthcare, and in society at large, including areas such as a lack of communication and information sharing and the need for a holistic approach. These gaps affect everyone, but



it is clear that those with rare diseases are likely to be most affected.

That afternoon, patient association representatives discussed the theme of patient power, led by Anders Olauson, the chairman of the European Patients Forum. Anders began by pointing out that the power of patient organizations is strong and that it continues to increase. The discussion was extremely interesting with much talk about the responsibility that comes with having this power, as well as what the groups want to accomplish in the future. PHA Sweden definitely has much in common with the member associations of Rare Diseases Sweden and looks forward to developing future cooperations.



## Switzerland puts Rare Disease Day on the map

HTAP Revivre, the PH association in Suisse Romande, hosted a booth at the International Rare Disease Day celebrations organized by Proraris, the Swiss Rare Disease Organization, in Lausanne on the 25th of February. Lydia Benallouch, President of association, Monika Sorge-Maitre and other members of the organisation were present at the booth to distribute campaign materials (in German and French), meet with other rare disease associations and attend some of the sessions and debates. The event was very interesting and contributed significantly to raising awareness of the difficulties and needs of Swiss patients, and their families, and their need for support in their daily lives, whether at the level of care and treatment facilities, or at the administrative level of integration into society.





## M





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