

PHA EUROPE

FOR THE PATIENTS: EARLY DIAGNOSIS, BEST TREATMENT,
BETTER QUALITY OF LIFE, FINDING A CURE

February 2012 monthly update

1. MARIPOSA NEWS WINTER EDITION

The Winter 2011 edition of PHA Europe's official journal, Mariposa News, was issued in early January 2012. The journal covers events taking place in the second half of 2011, including reports of PHA Europe initiatives (General Annual Assembly, Time matters campaign, etc.) as well as the most important European scientific events (ESC and ERS Annual Congresses, PH Annual Update in Bologna, ESC PH Educational course in Sophia Antipolis, etc.). Extra copies of the printed version are available on request (p.ferrari@phaeurope.org).



- Awareness and screening
- Clinical research and innovation
- Psycho-social support
- Empowerment of patient groups

Meetings with a number of important stakeholders on the European scene have been scheduled in May, the highlight being a presentation to the European Parliament (EP). Further details to follow shortly.

4. "TIME MATTERS" WHEN YOU HAVE PH: NEW FACEBOOK APP

"Time matters", a web campaign to raise awareness about the importance of "time" in PH, was launched in the second half of 2011 and will carry through 2012 collecting photos and posts from patients and family members in Europe and around the world. The website, which was originally set up in English, is now online in 14 other languages. A new Facebook app designed for the "Breath-taking" campaign now allows patients, family members, friends and supporters to send a "Time to breathe" message and thus contribute to raising awareness of the disease. www.phtimematters.com



2. "BREATH-TAKING" AWARENESS CAMPAIGN FOR RARE DISEASE DAY 2012

The 2012 edition of PHA Europe's "Breath-taking" campaign was successfully launched on Rare Disease Day in Brussels on 29th February 2012. The campaign launch event took place in central Brussels, with a number of activities taking place, including a very well known Belgian dance group performing a routine reflective of the impact of PH and "Breath-taking" postcards and materials, blue lip balms and blue lollipops being handed out to passers-by in the historical Galerie de la Reine. A press conference was organized with key Belgian PH medical opinion leaders Prof. Marion Delcroix and Prof. Jean-Luc Vachiéry, representatives of the Belgian Flemish and French-speaking PH patient associations and PHA Europe President Gerald Fischer as speakers. The Brussels event had over 300 pieces of international media coverage with an estimated reach of 2,5 million. Many other interesting and exciting "Breath-taking" campaign activities were organized around Rare Disease Day 2012 by PHA Europe affiliate associations in 15 other countries: Austria, Bulgaria, Czech Republic, Finland, Germany, Latvia, Hungary, Italy, Norway, Slovakia, Slovenia, Spain, Poland, Portugal and Switzerland. Reports and photos are currently being collected from our the member associations and will be published in the Spring (special) edition of Mariposa, News due out at the end of April.

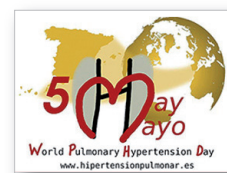


5. MARIPOSA NEWS SPRING SPECIAL EDITION:

The Spring 2012 issue of Mariposa News will be a special edition devoted almost entirely to the "Breath-taking" campaign (as was done in 2011). We kindly remind all the members having taken part in the campaign to send their contributions (and photos) as soon as possible and in any case no later than March 20. 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 News must be sent out before the end of April 2012. Thank you in advance!

6. WORLD PH DAY 2012!

Preparations are now well on the way for the first World PH Day! This very important event, promoted by ANHP, the Spanish Pulmonary Hypertension Association, is being held on May 5, in Madrid. The World PH Day has received the endorsement of international PH associations and leaders from five continents and many scientific societies and organizations worldwide (including ERS, EURORDIS, NORD, ORPHANET, EUROPEAN LUNG FOUNDATION etc.). The event has an outstanding programme and a very prestigious panel of speakers. www.wphd.es



3. PHA EUROPE "POSITION PAPER" ON PH

Within the context of the ERS 2011 Annual Congress in Amsterdam, on September 26, PHA Europe convened a roundtable meeting of international medical PH experts and PH patient leaders in order to initiate work on a common policy brief addressing the many unmet needs of pulmonary hypertension patients. A first draft circulated shortly after the meeting has subsequently been revised to take into account comments and amends from various roundtable members. The final version is due out at the end of March. The call for action contained in the policy brief identifies five key areas:

- Centers of excellence

7. GENERAL ANNUAL ASSEMBLY 2012

The date and venue for PHA Europe's 2012 General Annual Assembly are now set and a "Save the date" e-card has been posted to all the members. The meeting will take place September 12-16 in Castelldefels (Barcelona). We are now working on a draft agenda for the meeting which will be issued shortly to the members for their suggestions and comments.

Gerald Fischer, President
Pisana Ferrari, Vice President
PHA Europe, European Pulmonary Hypertension Association