



PHA EUROPE

EUROPEAN PULMONARY HYPERTENSION ASSOCIATION

October 2011 monthly update

1. NEW PH PATIENT ASSOCIATIONS

We are delighted to inform you that a PH patient group has now formally been set up in Finland. Our congratulations to Jaana Rajahalme, Tuulia Nappi and Seija Suomaki for all the hard work over the past few months in order to achieve this great result and warmest wishes for the future!

2. PHA EUROPE "POSITION PAPER" ON PH

PHA Europe has convened a European PH Leaders Meeting in Vienna on 11 December 2011 to discuss the current status and future steps to take with regard to a common "Position Paper" on PH. Further to the very successful roundtable meeting held in Amsterdam on September 26 with key medical opinion leaders and patient associations from Europe, USA and Latin America a first draft is now being finalized and this will be reviewed and discussed at our meeting in Vienna. More details to follow in the next Mariposa News.

3. "TIME MATTERS"

"Time matters", our new web campaign to raise awareness on PH, is well under way with about ninety posts and photos uploaded from patients and family members in Europe and around the world. The website, which was originally set up in English, is now online also in Dutch, German, Hungarian, Italian, Norwegian, Polish and Spanish. It is currently being translated into a second batch of languages (Bulgarian, Czech, French, Hebrew, Portuguese, Slovakian, Swedish and Turkish) and these new versions should be available in the next few weeks. More languages will be added at a further stage, the idea being of course to facilitate the participation of PH patients and family members from as many national associations as possible. Thank you to all our PH patient leaders for their contribution and support, we hope to have many many more posts in the next few weeks and months! www.phmatters.org



4. NEW PHA EUROPE WEBSITE

The relaunch of the PHA Europe website, with a new graphic layout and more advanced functions is currently being finalized and is due to go live in the next five to six weeks. In addition to the home page which will be in English, the website will contain sub-domains with a common text in different languages and direct links to the national association websites, to the Time matters campaign and to PH discuss (see below).

5. "PH DISCUSS"

"PH Discuss" is a new website that will enable our members to download & upload important documents and files in an easy manner. Also the platform acts as a simple Forum to have organized discussions throughout all of our countries. Please watch the detailed explanations on the Youtube video on the front of www.phdiscuss.org and create your username in order to participate in the discussions. The Forum will be constantly updated and monitored in order to facilitate its usage.



6. RARE DISEASE DAY 2012

We are currently in the final stages of putting together a draft concept for the PHA Europe awareness raising campaign for Rare Disease Day 2012 (29 February). The project will be presented at our meeting in Vienna on 11 December (see above, point 2, Position Paper on PH). We

had twelve countries involved last year, we hope that even more will join next year's edition!

7. MARIPOSA FALL/WINTER EDITION: deadline for contributions is 26 November!

The Fall/Winter edition of Mariposa News will be issued in mid December 2011. The main focus will be the PHA Europe General Annual Assembly held in Barcelona September 8-11 with a special report and photos of the event. Other recent events that we will be reporting on are the ESC Educational Course in Sophia Antipolis and the EURORDIS workshop in Paris on Rare-Connect. We will also be covering current and future PHA Europe activities and projects including "Time Matters", the new website and proposed campaign for Rare Disease Day 2012.

National reports: as always, the first section of Mariposa News will be devoted to the activities of the national PH associations. We kindly remind all the associations who have not done so yet to send their contributions (and photos) as soon as possible and in any case no later than the 26th of November. 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 December 2011. Thank you in advance!

8. GENERAL ANNUAL ASSEMBLY 2012

A vote among our members was recently taken to make a decision about where to hold our next General Annual Assembly (the three proposed venues were Vienna, Barcelona and Antalya). It was a close match but in the end the majority of our members expressed the wish to go back to Castelldefels (Barcelona), for the third year in a row. One of the key factors of the success of this venue is the relaxing location in a small village by the sea with a charming hotel all to ourselves. September 13-16 have been pencilled in as possible dates (to be confirmed shortly).

9. NEW BOARD 2012-2014

As this is our last update before the end of the year (Mariposa replaces the next monthly update) we are very happy to introduce our new PHA Europe Board which will serve 2012-2014:

- President: Gerald Fischer (Austria)
- 1st Vice President: Pisana Ferrari (Italy)
- 2nd Vice President: Mélanie Gallant-Dewavrin (France)
- Secretary: Luisa Sciacca della Scala (Italy)
- Vice Secretary: Gergely Meszaros (Hungary)
- Treasurer: Luc Matthyssen (Belgium)
- Deputy Treasurer: Hall Skaara (Norway)
- Auditor 1: Hendrik Ramaker (Belgium)
- Auditor 2: Juan Fuertes (Spain)



11. MEMBERSHIP FEES 2012

| Association budget in € | | Fees in € |
|-------------------------|---------------------------|-----------|
| less than | 10.000,00 | 20,00 |
| between | 10.000,00 and 99.999,00 | 50,00 |
| between | 100.000,00 and 499.999,00 | 100,00 |
| between | 500.000,00 and 999.999,00 | 500,00 |
| more than | 1.000.000,00 | 1.000,00 |

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Gerald Fischer, President
Pisana Ferrari, Vice President