

PHA EUROPE

European pulmonary hypertension association

for the patients

Update of recent activities

1. GREAT SUCCESS FOR THE FIRST WORLD PULMONARY HYPERTENSION DAY MAY 5

It was great to be in Madrid on May 5 to attend the first World PH Day, organized by the Spanish PH association ANHP. I really feel that this event will mark a very important milestone for the entire international PH community. The presentations were extremely interesting and the panel of speakers exceptional (see below). We will be preparing a full report of the scientific sessions for the Summer edition of Mariposa News. See PHA Europe's Facebook page for more photos: <http://www.facebook.com/pages/Pulmonary-Hypertension-Association-Europe/141060385915366>.



Speakers at WPHD, from left at back: Prof. Miguel Angel Gomez Sanchez (12 de Octubre Hospital, Spain), Prof. Gerald Simonneau (Antoine Beclère, France), Cecilia Martinez (Mexico, Sociedad Latina de Hipertension Pulmonar), Prof. Nazzareno Galiè (University of Bologna, Italy), Dr. Lewis Rubin (Emeritus Professor of Medicine, UCSD), Irene Delgado (President ANHP, Spain), Dr Jaime Morales (Sociedad Latina de Hipertension Pulmonar), Rino Aldrighetti (President PHA), Juan Fuertes (ANHP, Spain). Front row, from left: Gerald Fischer (President PHA Europe), Denneys Niemandt (President PHA South Africa).



Left: Irene Delgado, President of the Spanish PH Association ANHP, organizer of the event, with members of the association. Right: Noriko Murakami, President of PHA Japan, Peter Makovnik and Yveta Makovnikova (President of the Slovakian Patient Association).

2. STAKEHOLDER MEETINGS IN BRUSSELS MAY 8 AND 9

On May 8 and 9 Pisana Ferrari and I were in Brussels for an intensive round of meetings with relevant health and research stakeholders. This "meeting programme" aimed to introduce PHA Europe and its issues to relevant policy makers and stakeholders, to inform them of the PH Policy Brief and Call to Action and its upcoming launch and to create a basis for future cooperation. We met with the offices of seven Members of the European Parliament (MEPs), all of whom are involved with the MEP Heart Group (an internal group of Parliamentarians which works to get heart health issues higher on the EU policy agenda) from different EU countries: Ireland, Portugal, Finland, Belgium, Austria and Romania. We also met with three high-level EU Commission officials from DG Research, and heard about the interesting new perspectives opening up with Horizon 2020 and the EU Health for Growth programmes. The first is a new and broad research initiative which provides funding to research in a number of areas including health; the second is a programme that funds practical projects in the health arena, based on specific annual priority themes. Meetings were also held with key health stakeholder organisations, i.e. the Standing Committee of European Doctors, the European Patient Forum and the European Public Health Alliance – three of the most active and influential EU level patient and health organizations. Pisana and I were extremely pleased to note the high level of interest in our activities, our organisation as well as in our upcoming launch event (see below). This is promising in terms of raising awareness of our issues and our organisation. As a first step to increase the visibility and credibility of PHA Europe at EU level, it is fair to say that the meeting programme was highly successful. For those interested, a full report of the meetings is available.

3. PH POLICY BRIEF LAUNCH EVENT JUNE 6

Preparations are well on their way for the presentation of our Call to action on PH in the European Parliament on June 6 in Brussels. It is truly an honour to have Austrian MEPs Hannes Swoboda (Head of the Socialist group of the European Parliament) and Karin Kadenbach (MEP Heart Group) as co-hosts of the event whose agenda features other prestigious speakers such as Dr. Paola Testori-Coggi (Director General of DG SANCO, Health department of the EU Commission) and PH Roundtable experts Nazzareno Galiè (University of Bologna, Italy) Simon Gibbs (Imperial College, UK) and Jean-Luc Vachiéry (Erasmus, ULB, Belgium). Full report and photos will follow in next update and newsletter.

4. MARIPOSA NEWS OUT THIS WEEK

The spring 2012 edition of Mariposa News is out this week. It is a special edition covering PHA Europe's "Breathtaking" awareness campaign for Rare Disease Day.

Gerald Fischer, President
PHA Europe, European Pulmonary Hypertension Association