

PHA EUROPE

European pulmonary hypertension association

for the patients

March 2012 monthly update

1. ONLY TWO WEEKS TO GO TO THE FIRST WORLD PULMONARY HYPERTENSION DAY!

May 5 2012 will mark a very important milestone for the PH community worldwide with the first international PH day being organized by the Spanish PH association ANHP. The event has received the endorsement of PH associations and leaders from five continents and many scientific societies and organizations worldwide (including the EUROPEAN RESPIRATORY SOCIETY, EURORDIS, NORD, OPHANET, the EUROPEAN LUNG FOUNDATION). It has an outstanding programme and a very prestigious panel of speakers. For further details see: www.wphd.es

2. LAUNCH OF PULMONARY HYPERTENSION POLICY BRIEF IN THE EUROPEAN PARLIAMENT

On June 6, PHA Europe will organize the formal launch of its Policy Brief/Call to Action, which is currently being finalised. The event will take place in the European Parliament in Brussels, and Austrian MEPs Hannes Swoboda (Head of the Socialist group of the European Parliament) and Karin Kadenbach (MEP Heart Group) have kindly agreed to act as hosts. Other speakers include Paola Testori-Coggi (Director General of DG SANCO, Health department of the EU Commission) and PH Roundtable experts Simon Gibbs (Imperial College, UK) and Jean-Luc Vachiéry (Erasmus, ULB, Belgium). Participants will include representatives of the EU Commission, Council of Ministers and European Parliament as well as relevant patient and health professionals' organisations. In advance of the launch event a round of meetings has been set up to present PHA Europe to some key EU stakeholders including MEPs, EU Commission officials from DG Research, representatives of the European Patients' Forum and European Public Health Alliance. Pisana Ferrari and I are very honoured to have this opportunity. A full report of these meetings and launch event will follow.

3. INTERNATIONAL PULMONARY HYPERTENSION ONLINE COMMUNITY NOW LIVE!



RARECONNECT, the Rare Disease Communities project, first started with a community for a little known disease group called CAPS. The project is part of the strategic partnership signed in 2009 between Eurordis (European Organization for Rare Diseases) and NORD (US National Organization for Rare Disorders). The 5-language platform now covers 20 rare disease-specific communities, including most recently in March 2012, a community for Pulmonary Hyper-

tension. The main idea behind the project is to create an online social network for patients and caregivers living with rare diseases in order to enable the sharing of experiences and increase access to quality information. PHA Europe and the PHA USA collaborated to develop the

PH Community along with EURORDIS and NORD. The website is split into three sections: **What**, **Meet**, and **Learn**. The **What** section features patient stories and blog style updates from patients and patient organization representatives. The **Meet** section is a forum, moderated by volunteers and offers human translation services across five languages: English, French, Spanish, Italian, and German. Since patients and families are spread thinly across the globe, it is vital to create a space where information can be shared with the best possible translation. The **Learn** section is a resource of information in the form of frequently asked questions, documents, recently published news and scientific articles, upcoming events, and patient organization's contact information. People interested in discussing PH register on RareConnect. After registering, a user can upload their story on living with the disease through a link in their profile page. The story then automatically is added to the **What** section and is translated into all of the platform's languages.

<http://www.rarediseasecommunities.org/en/community/pulmonary-hypertension>

4. PHA EUROPE "POSITION PAPER" ON CHRONIC RARE DISEASES

The European Commission and EU Member States has launched a reflection process to respond to the growing challenge of chronic diseases. As part of this reflection process, on 15 March the Commission invited stakeholders (e.g. patient organisations, health professionals and healthcare providers) active in the field of on chronic diseases to come forward with their views of the required actions and priorities. A discussion paper, addressing the areas of healthcare, research, information technology and the role of the EU and national governments, provided guidance to the consultation.

PHA Europe has responded to the consultation, underlining:

- the need for a more comprehensive approach to chronic conditions and a focus on less known conditions such as pulmonary hypertension;
- the importance to focus on secondary and tertiary prevention, and not only on primary prevention;
- the importance of psychosocial support;
- the need to recognise the important contribution of patient organisations;
- the need for improved (access to) treatment and more research in that field;
- the need for more awareness and training of health professionals.

For more information:

http://ec.europa.eu/health/major_chronic_diseases/consultations/index_en.htm

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PHA Europe, European Pulmonary Hypertension Association