

PHA EUROPE

European pulmonary hypertension association

for the patients

Update of recent activities

I. GREAT SUCCESS FOR PHA EUROPE'S CALL TO ACTION IN THE EUROPEAN PARLIAMENT

Brussels, June 6

PHA Europe's PH Policy brief and Call to action were presented to the European Parliament in Brussels in the course of a very successful launch event on June 6. MEP Mrs Karin Kadenbach (MEP Heart Group) served as host, with the support of MEP Dr Hannes Swoboda (Chairman of the EP Socialist group). "Our"



European Parliament launch event, meeting room

speakers included Roundtable members Pisana Ferrari (PHA Europe Vice President), Prof. Nazzareno Galiè (University of Bologna, Italy), Dr. Simon Gibbs (Imperial College, UK), and Jean-Luc Vachiéry (Hôpital Erasme ULB, Belgium). I introduced the Call to Action and the five key messages; Dr. Paola Testori-Coggi, Director General of EU Commission DG SANCO (Health and Consumers), addressed assembled guests about EU action in cardiovascular disease and pulmonary illness and Dr. Laurent Nicod, Scientific Committee Chair at the European Respiratory Society, lent his support to our initiative. Guests included Members of European Parliament and representatives from DG Research, DG SANCO, the European Patients' Forum, and the Standing Committee of European Doctors, among others. A number of the PHA Europe Policy brief Roundtable members were also present as well as the Board of PHA Europe.

There is no doubt that we have taken a giant step forward for persons living with PH on 6 June. Our success would not have been possible without the



From left: Dr. Laurent Nicod, Dr. Simon Gibbs, MEP Karin Kadenbach, MEP Dr. Hannes Swoboda and Gerald Fischer



Dr Paola Testori-Coggi, Director General of DG SANCO (Health and Consumers)

ongoing guidance and support of all our Roundtable members (PH physicians, nurses, international PH patient associations and PHA Europe's industry partners) to whom we express our sincerest gratitude.

Our challenge moving forward will be to secure organisational endorsements for our Call to Action, and to disseminate to as wide an audience as possible our key messages: to improve access to expert care, improve awareness and screening, encourage clinical research and innovation, empower patient groups, and assure availability of psychosocial support.

The final text of the PH Policy brief, the executive summary and a full report of the launch event (presentations and audience debate) will be available shortly on our website at www.phaeurope.org

A photo album of the EP launch event has been posted on PHA Europe's Facebook page. See: <http://www.facebook.com/pages/Pulmonary-Hypertension-Association-Europe/141060385915366>

2. MARIPOSA NEWS SUMMER EDITION

The summer 2012 edition of Mariposa News is due out in mid-August. It will contain, as always, a section on the activities of PHA Europe's member associations. There will also be reports and photos of the EP launch event (see above), the PH World Day (Madrid, May 5), the European Conference on Rare Diseases (Brussels, May 22-25) and the International PH Nurse Workshop (Barcelona, May 8-9) as well as news of the latest EU developments in the health and research areas.



3. PHA EUROPE GENERAL ANNUAL MEETING

Preparations are well on their way for PHA Europe's General Annual meeting scheduled for September 12 to 16. For the third year running the venue will be Castelldefels, near Barcelona. Fourty PH patient leaders from twenty countries across Europe have already confirmed their attendance. The key medical guest speaker is Dr. Simon Gibbs (Imperial College, UK). The five-day meeting has a very intense schedule and wide-ranging agenda. Items for discussion include:

- follow up to the PH Policy brief launch event at EU and national level;
- ideas for PH World Day 2013;
- "Breathtaking" and future awareness initiatives;
- PHA Europe affiliate Empowerment program 2013;
- Fundraising for PH;
- the importance of social media and online PH communities (eg. Rare-Connect).

Gerald Fischer, President

PHA Europe, European Pulmonary Hypertension Association