

PHA EUROPE

European pulmonary hypertension association

for the patients

PHA Europe newsletter - October 2013

PHA Europe at ESC Annual Congress, August 31-September 4, Amsterdam



PHA Europe booth at ESC Congress 2013 in Amsterdam - Marzia Predieri (AIPI, Italy)

PHA Europe was present at the 2013 Congress of the EUROPEAN SOCIETY OF CARDIOLOGY (ESC) with a booth and two representatives: Vice President Pisana Ferrari and Marzia Predieri from the Italian PH Patient association AIPI. The ESC Congress had almost 30,000 registered delegates from all over the world. Many sessions in both the ESC and the ERS events (see below) were devoted to Pulmonary Hypertension. Being present on occasions such as the ESC and ERS with representatives and up-to-date materials is essential in terms of opportunities for education, networking, dissemination of information and awareness raising.

PAH Patient and Carer Survey poster at ERS Annual Congress September 7-11, Barcelona

Vice President Pisana Ferrari (Italy), Juan Fuertes (ANHP Spain) and Regina Prenderville (PHA Ireland), represented PHA Europe at the Annual Congress of the EUROPEAN RESPIRATORY SOCIETY (ERS), where the association also had a complimentary booth within the World Village area. More than 20,000 delegates attended the 2013 Annual Congress, which is Europe's largest annual scientific gathering in the field of respiratory medicine.

We are very honoured that the ERS accepted the poster we submitted, summarising the key findings of the International Patient and Carer Survey, which was presented in the course of a poster session dedicated to PH. The ERS Congress provided a wonderful opportunity to promote the results from the survey, which underline the need to recognize carers as individuals alongside the patients and provides a compelling argument for both to receive a more comprehensive standard of care, including psychosocial support. Optimum PAH management would require a multidisciplinary approach including physicians, nurses, social workers and psychologists.



from left: Prof. Sean Gaine (Ireland), Pisana Ferrari and Prof. Andrew Peacock (Scotland) in front of the scientific poster on the "Impact of PAH on the lives of patients and carers" at ERS 2013, Barcelona

PHA Europe celebrates its ten year anniversary at the General Annual Assembly, September 11-15, Barcelona



The General Annual Meeting (GAM) represents one of PHA Europe's central activities. It is a key driver for activity and engagement and plays a crucial role in inspiring, supporting, educating and motivating its members. This year's GAM marked PHA Europe's ten year anniversary. The association was founded in September 2003 in Vienna by a small group of PH Leaders from 8 countries, on the initiative of Bruno Kopp (President of PHeV, the German PH association). We have come a long way since then, with increased membership (currently standing at 29 associations from 25 countries), and many successful activities in the areas of awareness, advocacy and lobbying, as well as support to patient associations through specific programs ("Fellowship" and "White Spots" programs). The turnout in Barcelona was great: 27 countries represented, of which four were newcomers: Denmark, FYROM (Former Yugoslav Republic of Macedonia), Serbia and Ukraine. Highlights of the meeting include Prof. Gérald Simonneau's very interesting presentation summarising 20 years of progresses in the areas of PAH and CTEPH treatments, surgery, management strategies, drugs recently approved and research on new molecules. Other sessions at the GAM were devoted to advocacy at EU and national level, social media and communications, awareness raising, future projects for PHA Europe. Three associations received awards for the best WORLD PH DAY (May 5) national campaigns (1st prize Poland, 2nd Bulgaria BSPPH and 3rd Greece) and special mentions were given to Ireland and to the Italian patient association AMIP (for its flash mob on St Peter's Square on Rome on May 5 where the Pope publicly sent his greetings to PH patients).

Photos of the GAM are available on our FB page at: <https://www.facebook.com/media/set/?set=a.637486019606131.1073741840.141060385915366&type=1&l=96394684fa>

Full report to follow in Winter 2013 edition of Mariposa Journal

Gerald Fischer, President

Pisana Ferrari, Vice President

PHA Europe, European Pulmonary Hypertension Association