

PHA EUROPE

European pulmonary hypertension association

for the patients

PHA Europe newsletter - October 2014

The European PH community meets in Barcelona for its 11th General Annual Meeting (GAM)



PH Leaders from 27 countries at the GAM 2014: Austria, Belgium, Bosnia & Herzegovina, Bulgaria, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Latvia, Lithuania, Norway, Netherlands, Poland, Portugal, Republic of Macedonia, Slovakia, Slovenia, Sweden, Spain, Turkey, Ukraine

a vacant position as Secretary. The remainder of the first day was dedicated to medical and life style issues and it was a very big honour for PHA Europe to welcome as its guest medical speakers two key opinion leaders in the field, Prof. Werner Seeger, from the University of Gießen (Germany), and Prof. Ekkehard Gruenig from the University of Heidelberg (Germany). Prof. Seeger gave a wonderful lecture in which he summarised 20 years of progress in the areas of PH treatments and management strategies and looked at future developments with regard to research on new molecules. Prof. Gruenig spoke about the importance of rehabilitation in PH and the results of his research in past years in this field which provide substantial evidence that rehabilitation has a very big role to play alongside drugs in the treatment of PH. Integrated and multi-disciplinary care is something that PHA Europe has been advocating for over many years and rehabilitation is a very significant component of this, together with psycho-social support. Another area which is not often addressed is nutrition and a brief session was also devoted to this topic with Nils-Paul Skaara, a nutritionist from Norway.

PH Patient Leaders from 27 countries attended this year's edition of the GAM. After the welcome speech and introductions we started with the annual assembly, during which the yearly report and 2013 accounts were presented and there was a vote on the membership applications from the PH associations of Bosnia Herzegovina, Denmark, Lithuania and the Republic of Macedonia. A new member of the Board, Juan

Fuertes, was also co-opted to fill

The GAM as always provides the opportunity to present the year's projects and activities, such as the 2014 World PH Day campaign, with 22 countries taking part in Europe and 40 worldwide, the charity partnership with IRONMAN (7 races), and the scientific events, congresses, meetings, training sessions that our Board members attended in the course of the year. We reported and reviewed PHA Europe's "capacity building" programs: the "Fellowship" project, now in its 2nd year (English-speaking part time assistant for the national PH associations) and the work of the "White Spots" task force (start-up support for new associations). There was a training session on fundraising with Carmen Netzel, a Spanish professional in this field, in particular with a view to making the World PH Day a recurrent annual fundraising event. Another very interesting session was the one on advocacy at EU and national level presented by Christine Marking, our Brussels-based EU affairs consultant. As in past years one day was dedicated to our industry partners which provided, inter alia, the opportunity to discuss common projects and new educational resources. One of the highlights of this part of the GAM was the brilliant lecture from Prof. Brendan Whittle, from the William Harvey Research Institute, UK, on the history of prostacyclins.

The atmosphere of the GAM was, as always, warm and friendly. It was great to meet old and new friends to share and learn from each other. A full report will follow in the Winter 2014 edition of the Mariposa Journal, due in December. More photos of the GAM at: <http://on.fb.me/1wXcx6y>



Three associations received awards for the best World PH Day national campaigns: 1st prize Portugal, 2nd Republic of Macedonia, 3rd Czech Republic

Gerald Fischer, President
Pisana Ferrari, Vice President

PHA Europe, European Pulmonary Hypertension Association

