

# PHA EUROPE

European pulmonary hypertension association

*for the patients*

PHA Europe newsletter - September 2012

## PHA EUROPE'S GENERAL ANNUAL MEETING A GREAT SUCCESS!

Barcelona, September 12-16



PHA Europe's General Annual Meeting (GAM) provides a forum for European PH patient group leaders to spend time together and have opportunities for sharing information and experience, mutual learning, networking, education, and skills development. The GAM welcomes and engages member association leaders and serves as a platform to showcase European and national initiatives and activities.

The 2012 meeting took place from September 12 to 16 in Castelldefels, a small village near Barcelona, Spain. It was a pleasure and honour for PHA Europe to welcome thirty-nine PH patient group leaders representing twenty countries across - and even outside - Europe (Austria, Belgium, Bulgaria, Czech Republic, Finland, France, Germany, Hungary, Ireland, Israel, Italy, Latvia, Norway, Netherlands, Poland, Slovenia, Slovakia, Spain, Sweden, Switzerland). It was a special pleasure to welcome our three new members, the Bulgarian association BSPPH, PHA Finland and PHA Ireland. Altogether, almost sixty persons participated in one way or another in this year's GAM as, in addition to the patient representatives, there were several invited speakers and pharmaceutical industry guests.

This year's very intense five-day agenda included sessions on a wide range of topics of common interest.

Medical updates were provided by two distinguished members of the international PH scientific community. Prof. Simon Gibbs (Imperial College, UK, see photo on right) spoke about current PH management and treatments, endpoints for future clinical trials and new drugs in the pipeline; Prof. Horst Olschewski (University of Graz, Austria), about PH research at the Ludwig Boltzmann Institute (Austria), in particular on non-invasive ways to measure cardiac output.

Skills development is another important part of the GAM. This year's agenda included a session on effective advocacy at national and European levels lead by Christine Marking, an established EU public affairs consultant based in Brussels. The session was designed to motivate and empower members to advocate for issues important to persons living

with PH. Advocacy skills will be important in communicating, for example, the key messages in PHA Europe's PH Policy Brief and Call to Action, launched in June 2012 in the European Parliament, and in the PAH International Patient and Care Survey. This survey, conducted across five European countries, was completed earlier in the year and the findings, which were officially presented at the GAM, highlight the practical, social and emotional impact of the disease on the patient and carer and their information needs.

Other workshops provided opportunities for participants to discuss and brainstorm key challenges and future priorities for PHA Europe and to set up a number task forces for future action.

Social media play an increasingly important role in disseminating information and raising awareness, so it was of great interest to have one-to-one sessions as well as a public session with Patrick Fischer, from Limeforce Social Media, on how to implement a common online platform for PHA Europe with unified websites and Facebook pages. The aim is to be ready for a joint online campaign for next World PH Day, May 5 2013. It was also a great honour to have as guest speakers Denis Costello and Robert Pleticha, who are managing the Eurordis online rare disease community RareConnect ([www.rareconnect.org](http://www.rareconnect.org)).



Our meeting culminated in a gala dinner featuring an awards ceremony where first, second, and third prizes were given to Slovenia, Latvia, and Slovakia, respectively, for the best 2012 Rare Disease Day campaigns. Poland received a special mention for its Rare Disease Day campaign, and the Asociación Nacional de Hipertensión Pulmonar (Spain) was recognised for organizing the first World PH Day, held May 5, 2012.

Photos of the GAM have been posted at:

<http://www.facebook.com/media/set/?set=a.470161789671889.81891693.141060385915366&type=3>

A full report will follow in the Winter edition of the Mariposa Journal.

Gerald Fischer, President

Pisana Ferrari, Vice President

PHA Europe, European Pulmonary Hypertension Association