



# PHA EUROPE

EUROPEAN PULMONARY HYPERTENSION ASSOCIATION

September 2011 monthly update



## PHA Europe's General Annual Meeting 2011

PHA Europe held its General Annual Meeting in Castelldefels (Barcelona, Spain) September 8-11. The meeting had an exceptional turnout, with 46 patient leaders and representatives from 22 countries attending: Austria, Belgium, Bulgaria, Czech Republic, Finland, France, Hungary, Germany, Israel, Italy, Latvia, Netherlands, Norway, Poland, Romania, Russia, Slovenia, Slovakia, Spain, Sweden, Switzerland and Turkey. The three day program featured a wide ranging agenda covering many items of common interest. It was a great honour to have as guest speakers distinguished representatives of the European PH medical and nursing professions, of EURORDIS, the European Rare Diseases Organization, of our main Industry Partners Actelion, Bayer, GlaxoSmithKline and Pfizer and of the international communications agency Ketchum Pleon.

One of the key sessions was devoted to sharing and discussing the problems encountered at national level by PH patients with respect to access to treatments and surgery options, highlighting the need for more effective advocacy and lobbying to improve conditions for patients across Europe. Other topics discussed include: how to reach out to new countries to extend PHA Europe membership, tackling the challenges involved managing a PH patient group, making better use of the new social media, new ideas for fundraising for PH, using patient stories as communication tools, building online communities. The GAM also provided a good opportunity to review some of this year's activities, such as the pan-European "Breathtaking" awareness campaign for Rare Disease Day 2011 (28 February), and to discuss new and future projects: the new website, the PHA Europe grant program for "young" patient associations, the setting up of a PH "Rare Diseases Online Community" with EURORDIS, the "Time matters" awareness campaign and the PH Position Paper project (see below). During the GAM ample time was allowed for the participants to meet informally to share experiences and to get to know each other better. It was a great pleasure to welcome for the first time new PH patient groups from Slovenia and Latvia, the representatives of PHA Romania and the Russian PH Foundation and two patients from Finland in the process of setting up a new PH patient group in their country. During the GAM PHA Europe also held its Annual General Assembly. The main

items on the agenda were the President's report on the year and approval of the 2010 financial accounts as well as the elections for the new PHA Europe Board 2012-2014 which will serve as of next January.

## ESC and ERS Annual Congresses, PH Expert Roundtable meeting

PHA Europe participated as exhibitor at both the European Society of Cardiology's Annual Congress in Paris and the European Society of Respiratory Medicine's Annual Congress in Amsterdam. During the ERS, PHA Europe convened an PH Expert Roundtable meeting which was held on September 26. This meeting brought together representatives of international PH patient associations, of the European Rare Disease Organization EURORDIS, of the leading PH medical community and of the pharmaceutical industry involved in PH. The aim was to address some of key challenges still facing PH patients such as: the need for more awareness on the disease, delays in diagnosis, barriers in access to treatment and surgery across Europe, lack of specialized centres, need for psycho-social support and for more research. Our goal over the next few months is to agree on a framework for a Position Paper that will inform policy makers about the impact of appropriate responses to developments in PH-related treatment and care.

## "Time matters" in PH

The new PHA Europe web campaign to raise awareness of PH has just been launched. The theme of the campaign is TIME and why it is so important in PH. Patients and family members are encouraged to post their photo and hopes for the future at [www.phtimematters](http://www.phtimematters)

Further details of the GAM (including photos), of the ESC and ERS Congresses, of the PH Expert Roundtable meeting and Time matters campaign will be included in the next Mariposa News, Fall/Winter 2011 edition.

Gerald Fischer, *President*  
Pisana Ferrari, *Vice President*