

# PHA EUROPE

European pulmonary hypertension association

*for the patients*

PHA Europe newsletter - May 2014

## World Pulmonary Hypertension Day 2014 - May 5



Events to celebrate WORLD PH DAY in support of patients and their families are being held all over the world by national patient associations in Europe, North America, Latin

America, Asia, Africa, Australia and New Zealand. Read all about WPHD at: <http://www.worldphday.org/>

In Europe alone pulmonary hypertension (PH) patient associations from 22 countries have held or are organizing events to raise awareness of PH: <http://www.worldphday.org/AttendAnEvent/Europe>

The theme for PHA Europe's 2014 World PH Day campaign is "GET BREATHLESS FOR PH." Harnessing the universal intercultural appeal of sport, people around Europe passionate about helping those living with PH will be organising sporting activities to "get breathless." This imitates the experience of being breathless felt by many PH patients during everyday activities such as walking to the car or climbing the stairs. This powerful way of highlighting the restrictions on physical activity faced by PH patients will help to raise wider awareness of PH and bring to the forefront the challenges these patients face.

As part of the "GET BREATHLESS FOR PH" campaign for World PH Day 2014, PHA Europe has partnered with the IRONMAN European Tour for a second year and is its Official Charity Partner in six European countries:

<http://www.phaeurope.org/projects-activities/ironman-2014>

This partnership will see some of the world's toughest athletes endure a gruelling 3.8 km swim, 180.1 km cycle and a 42.2 km run (all in one day!) to raise awareness of PH and show solidarity with people affected by the disease. At each race, athletes can show their support and raise money for a local patient organization by ringing the bell beneath a "GET BREATHLESS FOR PH" arch. A PHA Europe exhibition stand hosted will offer further information about PH, the opportunity to compete in a lung function test, plus a range of branded give-aways and prizes.

The first race in Mallorca on May 10 was a huge success, with people lining up for our lung function test at the booth and thousands ringing the bell. Our ten athlete "PH Ambassadors" were racing in our branded racesuits and came to our booth to be interviewed and photographed. Our online THUNDERCLAP online campaign to raise awareness of PH has also been very successful, with over 120,000 social reach, well over our target!

<https://www.thunderclap.it/projects/10449-pulmonary-hypertension-day>

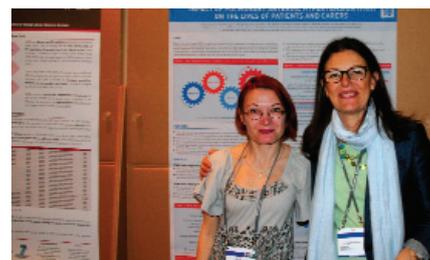
At 12 o'clock on May 5 THUNDERCLAP blasted a message about WPHD to all these contacts across social media networks at the exact same time to create a high-impact wave of publicity for WPHD.

## Eurordis Membership Meeting & 7th European Conference on Rare Diseases, Berlin, May 8-10

We are very honoured that the scientific poster on "The impact of Pulmonary Arterial Hypertension on the lives of patients and carers" was one of the 200 selected to be presented during the 7TH ANNUAL CONFERENCE ON RARE DISEASES (ECRD) in Berlin.

The poster summarises the key findings of the International Patient and Carer Survey, conducted in 2010-2011 by a Steering Committee which included representatives of PHA Europe, PHA US, PHA UK, and distinguished members of the international medical and nursing professions.

The survey findings 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 psycho-social support. The poster had previously been exhibited at the World Symposium on PH (Nice, February 2013) and at the Annual Congress of the European Respiratory Society (Barcelona, August 2013).



from left: Ieva Plume, President of PHA Latvia, and Pisana Ferrari, Vice President of PHA Europe



left: Dr. Domenica Taruscio, Director of the Italian Rare Disease Institute and European Leader

## PHA Europe's next General Annual Assembly Barcelona September 17-21

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. The next edition is scheduled for September 17-21, in Castelldefels, Barcelona. 55 Patient leaders from 27 European countries attended the 2013 GAM.

## Next Mariposa Journal - July

The Summer 2014 edition of the MARIPOSA JOURNAL will be out at the end of July and will feature, inter alia, the main highlights from WPHD 2014.

Gerald Fischer, President  
Pisana Ferrari, Vice President

PHA Europe, European Pulmonary Hypertension Association