

PHA EUROPE

European pulmonary hypertension association

for the patients

PHA Europe newsletter - August 2014

Great success for the the 3rd edition of World Pulmonary Hypertension Day (May 5th)!

This year, 20 European countries joined forces to "Get Breathless for PH"! World PH Day activities also took place in 12 Latin American countries, Australia, Canada, China, Ghana, Indonesia, Oman, South Africa, and the U.S. - meaning a total of 40 countries rallied together to raise awareness for World PH Day 2014, building on the 30 that united together last year. The campaign was reported by the media worldwide, with more than 150 press articles, 20 TV clips and 25 radio announcements generated to date and over 2,200 uses of the #WorldPHDay hashtag. This year we also launched the first ever World PH Day Thunderclap - a social media flashmob - for which 314 people signed up to send out a coordinated World PH Day message from their social media channels on 5 May, with a social reach of 124,000 people. This proved to be a fantastic way of driving momentum and awareness for the campaign on World PH Day itself. Momentum of another kind was generated by the IRONMAN athletes who "got breathless" by participating in Europe's toughest triathlon in support of PH patients. For the second year running, we are proud to be the only official charity partner of the IRONMAN European Tour and we have already had a strong presence at the races, with 60 athletes running for PH in Mallorca, Klagenfurt, Nice, Frankfurt, Zurich, Copenhagen & Budapest. The Summer 2014 edition of the Mariposa Journal has a full report of the World PH Day events, see: <http://www.phaeurope.org/wp-content/uploads/Mariposa-n12-summer-2014.pdf>

A showreel with the highlights of the campaign can be viewed at: <https://www.youtube.com/watch?v=MnoCVuq-CSc&feature=youtu.be>

Other PHA Europe activities 2014

World PH Day was one of the central events for 2014, but this has been a very busy year for PHA Europe with many activities in other areas: advocacy initiatives at national and EU level, programs to support existing and new PH associations in Europe, training sessions attended by our representatives and opportunities to attend/speak at prestigious scientific meetings. To mention but a few, in March we were present in London at the SIR JOHN VANE ANNUAL CONGRESS and in May we presented the results of the International Patient and Carer Survey (IPCS) on "The impact of PAH on the lives of patients and carers" at a poster session at the 7TH EUROPEAN CONFERENCE ON RARE DISEASES in Berlin. We had interesting opportunities to give the PH patient perspective to members of the nursing profession, a very important stakeholder for disease management, at educational meetings organised in Copenhagen in March and Vienna in June. We attended meetings of the EUROPEAN PATIENTS' FORUM (EPF) and the EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA). PHA Europe representatives have been active in the EURORDIS DITA TASK FORCE (Drug Information Transparency and Access) and the EUROPEAN LUNG FOUNDATION'S Patient Advisory Committee and have attended training sessions of the EUPATI (European Patients Academy on Therapeutic Innovation), EUNETHA (European Health Technology Assessment) and the EURORDIS SUMMER SCHO-



Kids dancing hip-hop as part of a flash mob for WPHD in the Republic of Macedonia



Blue balloon flash mob for WPHD in Tel Aviv, Israel



PH Ambassador M. Martin, Ironman Nice



World PH Day sporting event in Slovenia

OL for patient advocates. A separate newsletter on our activities in the areas of advocacy will be issued shortly.

General Annual Assembly, September 17-21, Barcelona

Sixty PH Patient Leaders from 31 European associations representing 27 countries will be meeting in Barcelona for the 2014 General Annual Meeting (GAM). This year's GAM will feature medical updates from internationally renowned specialists in PH (Prof. Werner Seeger, University of Giessen, Germany and Prof. Ekkehard Gruenig, University of Heidelberg), sessions devoted to reviewing the association's activities of the year and training sessions on capacity building, advocacy and lobbying. More details will follow in the next newsletter which will be out at the end of September 2014.

Other upcoming events: ESC and ERS annual congresses

PHA Europe representatives will be present at the annual congresses of the European Society of Cardiology (ESC) in Barcelona 30.8.-3.9. and the European Respiratory Society (ERS) in Munich 7.-11.9. We are very happy to see that, as in past years, many sessions at both the ESC and the ERS events are dedicated to Pulmonary Hypertension.

Gerald Fischer, President
Pisana Ferrari, Vice President

PHA Europe, European Pulmonary Hypertension Association