

PHA EUROPE

European pulmonary hypertension association

for the patients

PHA Europe newsletter - October 2015

Big success for our Annual PH European Conference (APHEC)

Seventy-two pulmonary hypertension patient leaders from 31 countries took part in the 2015 edition of the APHEC. The program started with our Annual General Assembly, with the elections for the new Board and Auditors and the vote on new membership applications. It was a great pleasure to welcome into the European PH community, associa-



tions from new countries: Belarus, Croatia, Romania and Serbia, as well as new associations from Spain and the Ukraine, bringing the total membership base of PHA Europe to 39 associations from 33 countries. Our prestigious panel of medical speakers included key international thought leaders Prof. Sean Gaine, respiratory physician from the Mater Hospital in Dublin, Ireland, Prof. Walter Klepetko, thoracic and lung transplant surgeon from the Vienna Medical University, Austria and Prof. Nazzareno Galiè, cardiologist, from the University of Bologna, Italy. Topics covered include the latest developments in PH treatments and transplant surgery and the presentation of the recently adopted European Society of Cardiology/European Respiratory Society clinical guidelines on pulmonary hypertension, of which Prof. Galiè was co-Chairman. During the session on advocacy we were honoured to have as our guest speaker Stanimir Hazardjev, who is the Secretary General of the European Patient Access Partnership (PACT). For our fundraising session Marta Campabadal joined us from EURORDIS, the European Organization for Rare Diseases, to present a successful example of crowdfunding carried out on behalf of a Spanish charity. One day was devoted to our industry partners, which provided the opportunity to hear about new developments in the pipeline and discuss collaborative educational projects. One of the highlights of the APHEC was the award ceremony for the best national awareness campaigns for World Pulmonary Hypertension Day 2015: the first prize went to Slovakia and the Czech Republic for a joint project, the second to Belgium and the third to The Netherlands. More details about the APHEC will follow in the winter edition of the Mariposa Journal.

PHA Europe's Call to Action to improve Organ Donation and Transplantation across the EU

In recent months PHA Europe has taken the initiative to develop a cross-condition "Call to Action with the aim to improve Organ Donation and Transplantation (ODT) across the EU". In this paper we call on the European Commission, the European Parliament, the Member States and relevant European and national-level stakeholders to help

improve the availability of organs and to support better access to organ transplantation. We are proud to have received many high level endorsements for our Call to Action, including European professional societies and other public health stakeholders (ERS, ELF, EURORDIS, EPF, EPHA) as well as a number of lung, heart and kidney related associations (EFA, EHN, EKHA, FED-ERG). We hope many more will come! Awareness and advocacy activities are planned around the Call to Action throughout 2016.

See at: <http://bit.ly/1hsoG0p>



European Organ Donation Day, Lisbon, October 10



Juan Fuertes with Rafael Matesanz, founder of the Spanish Organización Nacional de Trasplantes

The EODD is organized annually by the Council of Europe on the first Saturday of October. This year the celebrations took part in Lisbon. PHA Europe was represented by its advocacy manager Juan Fuertes and members of the Portuguese PH association. As part of its activities around the Call to Action on ODT, PHA Europe launched a "Thunderclap" online campaign in support of the EODD and an intense awareness raising activity through its social media channels. The

Thunderclap campaign in one month reached 150.000 persons and our social media pages saw a dramatic increase in reach for EODD (170.000 for Twitter and 68.000 for FB). A single photo, showing four members of our community, who have undergone transplant, had over 5.000 reach, 800 "likes" and 57 "shares". We were also very proud that many important associations supported the Call to Action through social media on the day itself (ERS, ELF, EURORDIS etc.).

Launch of "Our PH Library", October 12

"Our PH Library" is a website that has been developed by PHA Europe and PHA US, in collaboration with a web development firm and with an educational grant from Actelion Pharmaceuticals Ltd. The website provides information and a library of more than 200 high quality resources developed by patient groups around the world on PH, for individuals diagnosed with the condition and their family members/carers. The library includes an easy search function, which enables users to search for resources on specific topics related to the disease, for example "travel" and find relevant materials. "Our PH Library" was launched with a very successful Tweet Chat, hosted by the PHA on October 12, which had 200 posts, 23 active participants from 8 countries across 4 continents and almost 3.000 direct followers.



<http://www.ourphlibrary.com/>

Gerald Fischer, President

Pisana Ferrari, Vice President

PHA Europe, European Pulmonary Hypertension Association