

PHA EUROPE

European pulmonary hypertension association

for the patients

PHA Europe newsletter - March 2015

New pulmonary hypertension patient associations in Europe



The European pulmonary hypertension (PH) community is rapidly growing: in recent months new PH patient associations have been set up in Belarus, Croatia, Romania and Serbia. At this rate there will soon be no more “white spots” left in Europe - we call “white spots” countries where there are no PH patient

associations and this is also the name of PHA Europe’s support program for associations just starting out.

- Belarus: <http://on.fb.me/1870vQX>
- Croatia: <http://on.fb.me/1EP49eW>
- Romania: <http://htap.ro>
- Serbia: <http://on.fb.me/1BIMDOe>

Activities of the PHA Europe member associations

The year has only just started but our member associations have already been very active. Here are just a few examples of events which have taken place or are scheduled for the first quarter:

- Spain: over 1.000 runners took part in the very successful race for PH organized by the Spanish PH association ANHP on February 4.
- Ireland: on February 27 PHA Ireland organized a very successful scientific event on PH in Dublin, which featured a wide ranging program and excellent line-up of speakers.
- Austria: the Austrian PH association held an educational event for over 150 medical students at the Vienna Faculty of Medicine on March 10. The event, called “Under pressure”, featured attractive visuals for the invitation and program and “trendy” give away T shirts. A great way to get the medical students involved!
- Latvia: the PH association in Latvia has organized, jointly with the Latvian Chronic Diseases Association, a large scientific event in Riga on March 19 and 20.



Successful advocacy in Europe

In the Republic of Macedonia, also thanks to very active advocacy and lobbying on the part of the rare disease alliance and the local PH association, a law was recently adopted whereby a small percentage of the national tobacco tax will be set aside to fund access to rare disease drugs. In Poland a new PH treatment programme has introduced changes which will have a very significant beneficial impact for patients. In Bulgaria the government has recently adopted a regulation by which PH patients will be able to have lung transplant surgery abroad (there are currently no surgery facilities in Bulgaria) with the

costs covered entirely by the national health service. In the Ukraine funding for the treatment of rare diseases for 2015 was recently increased by 50%.

“MEP Interest Group on Access to Healthcare”

Juan Fuertes, Member of the PHA Europe Board, attended the launch meeting of the “MEP Interest Group on Access to Healthcare” in the European Parliament on January 27. PHA Europe actively promoted this important initiative among its members, encouraging them to invite and involve their national MEP’s.

International Rare Disease Day

PHA Europe was also very active in supporting Rare Disease Day among its member associations. PHA Europe representatives attended the Eurordis Policy Event and Black Pearl Gala Dinner in Brussels on February 24.



Sir John Vane Annual Conference on prostacyclins



It was an honour for PHA Europe to be invited to attend the annual Sir John Vane conference on prostacyclins held in London March 6 and 7. Sir John Vane was awarded the Nobel prize in 1982 for his discovery of the use of prostacyclin in pulmonary hypertension. The conference had a very interesting program and key PH experts as speakers. Full report to follow. Photo on left: Pisana Ferrari, PHA Europe Vice President, with Lady Daphne Vane, wife of the late Sir John Vane.

Recent PHA Europe publications

PHA Europe has recently published the Winter 2014 edition of its Mariposa Journal, covering all the activities of the member associations in the course of the year and its first Annual activity report. This report describes the association and its aims, how it is managed, its main activities and achievements and also contains a workplan for 2015. The Mariposa journal and annual report can be downloaded from the PHAEurope website at:

www.phaeurope.org



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