

Euro-HSP GA 2017

June 17, 2017 - 14:30 to 18:00

Place: Hotel Catalunya, Via Catalogna 22, Alghero (SS) Italy

Agenda:

1. Welcome

Everyone re-introduced themselves. Two of the three doctors from the morning session stayed for the beginning of the GA.

2. Annual report from the president (Dorthe)

- Activity report 2016-2017
Accepted. Available online.

3. Annual report from the treasurer (Martin)

- Report for 2016
Accepted. Available online.
- Budget for 2017
Accepted. Available online.

4. Report from our scientific board (Jean)

We agreed to work more with Scientific bodies to be patient representatives on their respective panels, and not simply observers, for example SPATAX and JPND, and hopefully other projects as they come up (NeurOmics, EMCL,...). Jean also agreed that we should look at and agree to or not a shortened version of involvement in the JPND project by 25 June (online).

Report online as ppt.

5. Reports from conferences.

Dorthe spoke on the Council of European Federations (CEF) meeting in Paris, France, the RD-Connect/ Patients Advisory Council (PAC) meeting in Berlin, Germany and the EURORDIS membership meeting in Budapest, Hungary. Jean spoke on SPATAX in Paris. The summaries will be online.

6. Elections: Board of Directors

- President (2 Years)

Marina accepted the nomination on condition of revisiting it at one year (next year's GA) because she expects the following year to be very busy. Everyone agreed to vote and re-visit at GA 2018. Marina voted unanimously as President.

- Vice-President (1 year)

Hermien accepted the nomination and was voted in unanimously.

- Treasurer (2 years)

Martin accepted the nomination for two more years and was voted in unanimously.

- Secretary (1 year)

Ingerid was nominated and reluctantly accepted the nomination. She would prefer to do it with help, especially for her English. Marina suggested the help could come from Lori, not a member, from Austria. Rob to propose changing the By-laws in order to allow individuals to be on the Board. Vote to take place online when the proposal is ready. In the meantime, Ingerid is voted in unanimously with the understanding that Lori will help out once she is a member.

- Scientific advisor (2 years)

Jean accepted re-nomination and was voted in unanimously for two more years.

- The vacant seat on the Board (2 years)

Dorthe's idea is to nominate Morten in January 2018 from her organization as Danish delegate to Euro-HSP Board. At the GA 2018 Morten, Adam (UK) and Eduardo (Spain) may run for the vacant seat(s).

- Webmaster

Dorthe graciously accepted to continue doing the website work for at least one more year, but if anyone is interested in doing it, she would gladly train them so they can take over. We also talked a little on perhaps using FB more and be more active on the website maybe put on videos, etc.

7. Strategic action plans for the future

- Rob presented on Euro-HSP making an Action Plan that needs to be adhered to.

- HSP Best Practices Manual

Jean had sent around a proposal for a Best Practices Manual that only Peter had time to look at, and thought it was difficult.

Hermien believes she can turn out a first draft of Best Practices in two months. Following Rob's Action Plan, she will work closely with Jean to move forward. Rob suggested monthly or at least trimester-ly teleconferences to keep everyone informed. This will also be able to be used as a fundraising tool for Euro-HSP once it is available. The coordinator is the President, who will make sure times are respected, etc Lori offered to see if some of the "best practices" can be turned into videos which may be more appetizing to some public.

- GA and annual meeting 2018

Next GA could be in Vienna. As EURORDIS is in Vienna 10-12 May 2018, we could combine the two events. Lori to investigate.

- New members: enlargement of the Federation to all European countries. Dorthe will continue working on contacting potential members.

We need to get UK and Spain more involved, as well as continue to look at Germany...

- Funding: Pharma companies, Eurordis Grant, etc?

Rob to compile the drugs available and the companies that make them and reintroduce Euro-HSP to them, under the guide of Morten. We must consider the products we can offer (Best practices, Data Sharing, etc)

8. Other business

Questions from Frank about using the international logo answered. Dorthe to report back to him.

9. Evaluation of GA and annual meeting.

surveymonkey available at <https://www.surveymonkey.com/r/K93JJFF>