



Euro-HSP GA 2015

May 31, 2015 - 14:00 pm to 18:00 pm

Place: Hotel Rafael Atocha, Calle Méndez Álvaro, 30, 28045 Madrid. Room ?

Agenda:

1. Welcome and introductions
2. Annual report from the president (Dorthe)
 - Activity report 2014-2015
 - Website www.eurohsp.eu Webmaster ?
3. Facebook <https://www.facebook.com/groups/eurohsp/> (Rob)
4. Online communities www.rareconnect.org (Dorthe)
5. Annual report from the treasurer (Marina)
 - Report for 2014
 - Budget for 2015 (including our GA in Madrid)
6. Election of the Board of Directors (agreed on at GA 2014)
 - President (Dorthe accepts re-nomination for 2 years)
 - Treasurer (Marina accepts re-nomination for 2 years)
 - Scientific Advisor (Jean accepts re-nomination for 2 years)
 - Extra members?
 - Vice-president/Secretary in 2016
7. Report from our scientific board (Jean)
 - Status
 - Plans
8. Reports from conferences
 - CEF meeting in Paris (Dorthe)
 - EPF/CBHC conferences in Tallinn, Estonia, and Spain (Dorthe/Fina)
 - RBP conference in Rome, Italy (Jean)
 - PAC/RD-Connect meeting in Palma, Mallorca (Dorthe)
 - EUPATI conference in Dublin, Ireland (Rob)
 - EURORDIS Rare Disease meeting in Madrid

9. Strategic action plans for the future
 - GA and annual meeting 2016
 - New members: enlargement of the Federation to all European countries
 - Funding: Pharma companies, Eurordis Grant, Crowdfunding and Kickstarter
10. Other business

Euro-HSP Annual Meeting

June 1, 2015 - 10:00 - 14:00

Place: Farmaindustria, Calle Maria de Molina 54, 7º Madrid. Board Room

Agenda:

- Points to learn from each other in the future (see minutes from 2014)
 - Best Practices Manual - why/why not (Fina)
- The international HSP meeting - we will be discussing this more broadly with the International Group, but to help give us direction, please prepare a statement with these goal-seeking questions in mind...
- National Groups mission and vision...
- *What is the National purpose?*
- *What business are HSP patient groups in?*
- *What is the preferred future for people with HSP?*
- *What does success look like? (*For example, the Australian foundation is in the business of facilitating and funding research to find an effective treatment for HSP that is affordable and widely available globally in the shortest possible time frame. Secondly, they also provide information, education and social support for people in the HSP community.)*
- *Common interests: the values by which patient groups work (I suggest you all look at your national mission statements) (*For example, geography is almost irrelevant to Australia... national boundaries are largely meaningless with respect to the research we support, whom we fund, who can join our community, and so on. We do not have membership fees, rather we focus on encouraging people to give donations to fund HSP research and to take on fundraising as well. We have no funds/budget allocated to run the Foundation. Everyone is a volunteer who is expected to carry their own costs and no one gets paid anything for anything.)*
- *Future: Realistic collaborations and working relationships*
- Evaluation of GA and annual meeting

Chair of the meeting: Rob Camp

Dorthe
May 2nd, 2015