



Minutes for Euro-HSP GA 2016

June 25, 2016 - 14:30 pm to 19:30 pm

Place: Alliance Maladies Rares, EURORDIS, rue Didot 96, 75014 Paris, Salle Pétunia.

Present: Marina, Tomas and Georgia (I), Hermien and Peter (NL), Martin and Karin (CH), Eduardo (E), Ingerid (N), Jean (F), Diana, Povl and Dorthe (DK).

Agenda:

1. Welcome and introductions

As we had new participants, the meeting started after a short welcome and introductions of everyone.

2. Annual report from the president (Dorthe)

- Activity report 2015-2016

Past activities: Everyone agreed with the report. Future activities: We agreed to add short personal reports from activities like RareDiseaseDays and other awareness events like Potato Pants events and Walk´n Roll. Dorthe will add RDD 2016 and PP in Italy 2016 in the activity report 2015-16.

- Website www.eurohsp.eu Wanted: New webmaster

The Umbraco manual and Dorthe´s personalized manual are both in English and ready for a new webmaster. No one wanted to take over, so Dorthe will continue for another year. All delegates were asked to look for a new webmaster to take over next year. We need to publish more info about national activities - and get more photos of active persons with HSP in order to make the website more interesting.

3. Annual report from the treasurer (Marina)

- Report for 2015

Everyone agreed. The report will be available online.

- Budget for 2016

Everyone agreed.. We will try to cover the lunch and also dinner expenses by the Eurordis grant. The report will be available online

4. Election 1: Member to the Board of Directors

- The vacant seat on the Board (The BoD recommends Martin)

Unanimous agreement.

5. Election 2: Board of Directors

- Vice-President (Marina accepts re-nomination for 2 years)

Unanimous agreement.

- Treasurer (For 1 year) (The BoD recommends Martin)
Unanimous agreement.
- Secretary (For 2 years) (The BoD recommends Hermien)
Unanimous agreement.

The new BoD:

<i>President:</i>	<i>Dorthe Lykke</i>
<i>Vice-president:</i>	<i>Marina Zapparoli</i>
<i>Treasurer:</i>	<i>Martin Ott</i>
<i>Secretary:</i>	<i>Hermien Rimmelink</i>
<i>Scientific advisor:</i>	<i>Jean Bénard</i>
<i>Member of the BoD:</i>	<i>Ingerid Ringheim</i>

6. Report from our scientific board (Jean)

Status: the board has had no meetings, because of lack of money and projects. Jean gave a presentation on the goal for a scientific board and also a presentation on a survey on research money from the national associations. He also showed a list of research grants of ASL-HSP France 2009-17.

Plans: We need to make a list of prioritized research projects. We must define a project and then involve the scientific board for advice. A project could be our "HSP Best Practices". We also need to raise money for this project.

7. Reports from conferences

- CEF meeting in Paris, France (Dorthe)
Dorthe talked about the European Reference Networks, RareConnect, RARE-Bestpractices project by Eurordis and Eurordis membership criteria. Will be available online.
- EURORDIS ECRD conference in Edinburgh, Scotland (Dorthe)
Dorthe talked about some of the sessions: Progress with sequencing technologies, Rare Navigators and platforms for registries and research. Will be available online.

8. HSP Best Practices Manual

- Points to be discussed and agreed on (Dorthe):

Who is the manual meant for?

This question started a very long and fruitful discussion, and we did not follow the suggested agenda points. At the end of the discussion, we agreed on the following:

The target group: patients, carers and professionals

The content: The manual should include information, recommendations and best practice. It should be written in general terms. Later it could be translated into national languages.

Goal: the draft manual should be finished by next GA 2017.

Outline: Hermien and Dorthe will make an outline based on Ataxia Best Practices. Hermien will send a draft to Dorthe before July 26. When the outline is agreed on by everyone, everyone will be asked to choose chapters to edit.

Coordinator: Dorthe

Working groups:

*Scientific matters: Jean and Hermien will work together.
Children: Marina and Georgia will work together with Jean.*

9. Strategic action plans for the future

- **GA and annual meeting 2017**

The meetings will take place in Sardinia on June 10-11, 2017. Marina will arrange social events the day before and the day after for the participants.

- **New members: enlargement of the Federation to all European countries**
Dorthe has worked out a list of SPATAX participants from countries, which are not represented in Euro-HSP. She will update our e-mail text and info-letter for potential members and contact the SPATAX participants.

Jean proposed a list of benefits for UK HSP to enter Euro-HSP. Dorthe will contact Adam Lawrence. Jean's slide will be available online.

- **Funding: Pharma companies, Eurordis Grant, ?**

*Pharma companies: we will adapt our current letter, when we have defined a project.
Eurordis grant: we will apply again next year.*

Jean proposed to contact footwear companies for funding.

10. Other business

HSP International logo: We will not register the logo until we need to.

Patient registries: Hermien handed out a correspondence. Marina told about regional registries in Italy.

Minutes for Euro-HSP Annual Meeting

June 25, 2016 - right after the GA.

Agenda:

- **Reports from the national associations**

- **Updating the info sheet**

The updated information is in red. Will be available online.

- **Updating the drug list**

Chantal Tallaksen, a member of our scientific board, has sent these comments: Sirdalud is prescribed more seldom in Norway now because it doesn't have a better effect than other anti-spastic drugs. Dantrolene is seldom used now because of severe side effects. The list will be available online with the Spanish update.

- **Potato pants events**

Marina and Georgia told about the Italian Potato Pants event, which took place in Rome in May. They will write a short essay about it for our website.

- **Workshop: HSP Best Practices Manual (skipped)**

- **Reimbursement forms (Dorthe)**

Dorthe handed out the reimbursement forms to the delegates and advised on the procedure.

- **Evaluation of GA and annual meeting**

Everyone agreed that the meetings had been very fruitful, as we finally made a big step forward with our action plan about HSP Best Practice.

Chair of the meetings: Diana Holm, DK

Dorthe / June 28, 2016