

GA 2016, agenda 2a.

Activity report 2015-2016

Meetings, conferences and events

2015

May - Madrid, Spain

Dorthe and Fina participate in the EURORDIS membership meeting on May 28-30. Focus was on ERN: See: <http://www.eurordis.org/news/eurordis-membership-meeting-2015-focuses-european-reference-networks>

May - Madrid, Spain

Euro-HSP 5th GA and Annual Meeting on May 31 and June 1. <http://eurohsp.eu/events-meetings/past-events-meetings/ga-2015.aspx>
We agreed on 2 Projects: Patient Registries and HSP Best Practice.

May - Madrid, Spain

The 1st International HSP meeting takes place on June 1-2. <http://eurohsp.eu/1st-global-sp-group-leader-meeting.aspx>

September - Copenhagen, Denmark

Dorthe arranges the 4th Danish annual HSP/Ataxia awareness event "Walk´n Roll" in Copenhagen on September 12.

October - Paris, France

Dorthe participates in the 8th CEF workshop in Paris on October 28-29. See <http://eurordis.org/content/european-disease-specific-federations>

2016

February - Copenhagen, Denmark

The Danish HSP association participates in the RareDiseaseDay walk in Copenhagen and Århus on February 28, arranged by Rare Diseases Denmark.

February - Paris, France

The French HSP association participates in the RareDiseaseDay event in Paris, arranged by Eurordis.

May - Edinburgh, UK

Dorthe participates in the 8th European Conference on Rare Diseases & Orphan Products - ECRD - on May 26-29: Game Changers in Rare Diseases - Delivering 21st century healthcare to rare disease patients: Together we can change the future!

<http://www.rare-diseases.eu/>

May - Rome, Italy

Giorgia arranges the 1st Italian HSP awareness event "Potato Pants" in Rome.

Upcoming meetings and conferences

June - Paris, France

Jean, Hermien and Dorthe participate in SPATAX conference on June 23-25.

June - Paris, France

Euro-HSP 6th GA and Annual Meeting on June 25-26.

November - Paris, France

Dorthe participates in the 9th CEF workshop in Paris on November 3-4.

Euro-HSP members

At present Euro-HSP has seven full members: Spain, France, Norway, Denmark, Italy, The Netherlands and Switzerland and 1 affiliated member: the Swedish Facebook group.

During the past year, we have again contacted individuals, organizations and institutions in various European countries trying to get in contact with HSP people and get new members. We need to work further on that in the coming year.

Euro-HSP history

HSP International

In connection with our GA and EURORDIS membership meeting in Madrid in May 2015 we met with the presidents of HSP Australia, HSP USA and HSP UK + members of AEPEF, Spain. At this meeting we created "HSP International" in order to work together in the future. <http://eurohsp.eu/1st-global-sp-group-leader-meeting.aspx>

In the spring of 2016 the logo was agreed on:



Research

At the moment we're playing an active role in rare disease research by our representation in the RD-project and RARE-Best Practices and we're also looking for other ways of participating in research projects.

Fundraising

Eurordis has accepted our application for a grant in 2016 and supported us with 1,650€ for our GA and Annual Meeting.

We need to apply for funds in order to fulfill our project: HSP Best Practices - a guideline for people with HSP.

We have an updated drug list, which shows the prescriptions for HSP sufferers and the firms, which produce the products. Earlier we have contacted Novartis for a

grant but the firm declined our application. It's our plan to contact the other firms shortly and later petition for funding. Other methods are to be investigated.

Dorthe
June 18, 2016