

HHT Europe Annual Meeting



Madrid
October, 18-19th, 2019

Madrid
18.10.19

Board of Directors:

- **Christina Grabowski** – Morbus Osler – Germany – **President**
- **Tone Soderman** – HHT Norge – **Vice President**
- **Marcello Bettuzzi** – HHT Onilde Carini – Italy – **Treasurer**
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- **Karen Druckman** – HHT Swiss – **Board member**
- **Luisa Maria Botella** – HHT Espana – **Board member**

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HHT Europe Annuale Meeting - Madrid 2019

FRIDAY October 18th 2019

Higher Council for Scientific Research-Biological Research Centre:

- 10 - 11.30 am Visit to Luisa Maria Botella's Lab + meeting with Lab Director and Spanish Rare Disease Network

Hotel Nuevo Boston:

- 2.00 - 2.30 pm. Registration and welcome
- 2.30 - 3.00 pm. Welcome message, round of introductions and goals of the meeting - Christina Grabowski & Tone Soderman

THEME 1: UPDATE ON THERAPIES AND RESEARCH

- 3.00 - 3.30 pm. Summary of Puerto Rico Outcomes - Luisa M^a Botella
- 3.30 - 4.00 pm. The Spanish Approach on HHT (Sclerotherapy, Tacrolimus). Dra. Sol Marcos
- 4.00 - 4.30 pm. Coffee Break
- 4.30 - 5.30 pm. Questions and debate

THEME 2: COOPERATION FOR PROGRESS

- 5.30 - 6.00 pm. International Guidelines - Update on VASCERN - RESULTS OF HHT WG - Claudia Crocione
- 6.00 - 6.30 pm. HHT CAB - Where we were and next steps - Ralf Schmiedel & Karen Topaz Druckman
- 6.30 - 7.00 pm. Questions and Debate
- 20.00 pm. Dinner

SATURDAY October 20th

Hotel Nuevo Boston:

- 8.30 am Registration and Welcome

THEME 3: ACTIONS AND BEST PRACTICES FOR QUALITY OF LIFE

- 8.30 - 9.00 am. HHT Europe Strategies: State of the Art of the Orphanet Guide in Emergencies - who has developed since last year and next steps to make it accessible. Dara Woods
- 9.00 - 9.30 am. How to access orphan drugs: "Challenge to get to the therapies - a lot of effort and cooperation." Rocio García Cañamaque, (Founder León Research)
- 9.30 - 10.30 am. Round table on 2020 joint actions for guides and material to make everyday life and communication easier for HHT Families.
- 10.30 - 11.00 am. Coffee Break

THEME 4 - HHT CENTERS ACROSS EUROPE - geography yesterday, today and tomorrow.

- 11.00 - 11.30 am. Needs of patients vs different stages of relations with HHT Centers. Anne Goustille
- 11.30 - 12.00 am. European Excellence Criteria - and integration of ERN's in National Health care systems . Claudia Crocione
- 12.00 - 12.30 pm. Questions and Debate
- 12.30 - 2.00 pm. Lunch Break

THEME 5: RAISING AWARENESS AND COMMUNICATION

- 2.00 - 2.30 pm. Presentation of the draft of the Website. Bienvenido Muñoz
- 2.30 - 3.00 pm. Where and how we are communicating and better cooperation for the future. Karen Topaz Druckman and Claudia Crocione
- 3.00 - 4.00 pm. Questions and Debate
- 4.00 pm. END OF MEETING