

MINUTES OF THE EUROPEAN HUNTINGTON ASSOCIATION BUSINESS MEETING

VIENNA - AUSTRIA 13TH SEPTEMBER 2018

Board Members Present

- Astri Arnesen; Svein Olaf Olsen; Beatrice de Schepper; Dina de Sousa; Filipa Júlio; Barbara D'Alessio; Danuta Lis

Apologies:

- André Willems

Number of Participants attending the Meeting:

- 64

Number of Associations attending the Meeting:

- 28 associations from 25 countries

AIHER/Italy, Huntington Liga/Belgium, SHA/Scotland, LIRH Foundation/Italy, AICH-ROMA onlus/Italy, Canarian HDA/Spain, LHS/Denmark, Romanian HDA, Huntington Network/Italy, Dutch HDA/the Netherlands, AHF and Ding-ding-dong/France, Russian HD association, DHH/Germany, Finnish HDA, RHS/Sweden, Polish HDA, Greek HDA, APDH/Portugal, Israel HDA, Czech HDA, HDCY/Cyprus, Bulgarian HDA, Hungarian HDA, HDA/England and Wales, HD onlus/Italy, SHV/Switzerland, HDAI/Ireland

Special guests:

- Huntington's Disease Association of Oman
- 4 family members from India

PROGRAM

1. Welcome by Astri Arnesen, President

Around 60 persons registered to attend the EHA Business and Astri Arnesen, the EHA President, gave a warm welcome to all the participants.

2. Choice of Chair and Referent

Svein Olaf was appointed as Chair of the Meeting and Filipa as the Referent. All the attendees had the chance to present themselves, with the guidance of Svein Olaf.

3. Presidents' Report

Before presenting the activities that the EHA promoted in the last 2 years, Astri asked the Board Members to come to the front and to briefly present themselves to the audience.

Astri presented the main activities that EHA developed during the 2016–2018 period, asking the attendees to follow the paper report that was handed to them at their arrival at the meeting. Some of the themes that were presented by Astri:

- “Stronger Together”
- Sofia Conference
- “HD on the Move”
- “Ask the Doctor”
- Activities in Russia and Malta
- Bea’s activities in Belgium and other countries
- EHDN collaboration and Survey
- Other collaborations with different organizations, such as EFNA, EURORDIS, European Reference Network on Rare Neurologic Diseases, European Medicines Agency, etc.
- 2 projects for an EU call (quality of life and e-health interventions)
- “HD on the Bike”

Astri asked the HD-COPE members to go to the front and present themselves and the work that they have been doing for the HD global community to the audience. Astri also announced that the 2019 EHA

Conference will take place in Bucharest– Romania and that everyone was invited and should spread the word.

4. Treasurers' report by Svein Olaf Olsen

Before presenting the EHA financial status to the audience, Svein Olaf shared the process between the EHA and Teva pharmaceutical company, as a way to acknowledge the role of the Associations in standing up for patients' rights. After presenting the figures to the attendees, Svein Olaf asked for ideas for projects to be financially supported by EHA, as currently there is enough money to implement concrete things within the HD European community. Several topics were raised (app training and e-learning by the Swedish Association; networking and strategies to empower the national Associations by one of the Italian Associations representatives and Filipa; translation of books, by the Cypriote Association; audit and inventory of things that everyone is doing so not to reinvent the wheel, by the representative of the Huntington Association of Republic of Ireland).

5. Election for the Board 2018–2020

The current Board members were re-elected to continue their work for the EHA for two more years with the unanimity of the EHA members attending the Business Meeting.

6. Approval of New Members

Hungary, Greece and Gran Canaria – Spain representatives were welcomed into the EHA family and acknowledged as new members of EHA.

7. Appointment of Representative to the EHDN Executive Committee

Astri was unanimously approved to continue her work in this group for two more years

8. Appointment of Representative to the EHDN Scientific and Bioethics Advisory Committee

Dina was unanimously approved to continue her work in this group for two more years

9. Presentations

- Alzbeta Muehlbaeck – “Ask the Doctor” service
- Catherine Martin – HDYO action plan for training young professionals
- Bernhard Landwehrmeyer – European Reference Network.

10. Discussion in Groups

Svein Olaf divided all the attendees into smaller groups and each Board member monitored and guided the debate at the group level. Each group was asked to come up with 3 topics that they would like to see addressed at the EHA 2019 Conference.

The topics suggested by the different groups were the following:

Group A.

The format should be more about personal stories, testimonies and inspirational speeches and less professional and/or theoretic; also, the presentations should include examples of low-income countries and high-income countries.

These topics were raised by the group members:

- The importance of psychological counselling, genetic counselling, holistic interventions on a regular basis for the whole family (not just the HD patient)
- Sexuality (common problems, causes, strategies to deal with it)
- Raising Children in an HD family (family examples, couples, testimonies).

Also, the group thinks that a kind of “Patron” for HD should be selected and presented at this conference, as well as a challenge like the “Ice Bucket” for ALS.

Group B.

These topics were raised by the group members:

- What can I do before the symptoms start
- Good practices for families – how to tell children about HD
- Working groups with different subjects
- What Family Associations are doing/Projects
- Palliative and Late Stage Care at home
- Presentations about what is EFNA and EURORDIS

Group C.

These topics were raised by the group members:

- How to address language barriers
- Physiotherapy – hands on; Practical things on physical activity in HD
- Ask Panel
- Discussions in Smaller Groups based on stages of the Disease
- Neurologist especially trained for HD – lifestyle recommendations
- Advisory/Counselling for couples on reproduction choices
- Presentation of different testing procedures/steps from different countries
- Care homes – training for care homes

Group D.

These topics were raised by the group members:

- Sexuality
- HD in elderly people
- Nutritional Management
- Local Policies regarding the Predictive Testing
- Importance of Connecting (people, experiences, etc.)

Group E.

These topics were raised by the group members:

- Nursing homes in all EU countries
- How to support family caregivers
- Best practices on how to follow a patient from the very beginning to the very end (for professionals)
- European rights

Group F.

These topics were raised by the group members:

- The parents training session
- Better understanding and giving space to local culture
- Sexuality
- Practical workshops for caregivers

Group G.

These topics were raised by the group members:

- Workshops (limit to maximum of 30 people or split into more groups)
- Physical activity
- Update on clinical trials in lay terms
- “Ask Anything” workshop
- Psychotherapy guidelines
- Training of Trainers (specialists)

Group H.

- Sexuality and relations: how to handle “inappropriate” behaviors or movements; involuntary moves/aggressive moves; caregiver psychiatrist suggested to talk about this
- Advanced Care Planning for the Family: involve the family in the care plan, the family knows patients best so should be involved to make a good plan early on; also involve the patient early on; attention to details – the small things matter!; invite representative

from care home; put procedures in place to ensure the plan or information is being used in a good way; give opportunities for family to give feedback

- How to Raise Money for the Organization: marketing and business strategies; how to be visible
- Workshops in small groups – maximum 10 people

11. Plenary Close-Up

Astri thanked everyone for attending and providing important input for the next EHA Conference. The EHA wished everyone a productive EHDN meeting.