

Minutes of the European Huntington's Association Business Meeting The Hague, September 15th 2016

Board Members Present: Beatrice de Schepper; Astri Arnesen; Svein Olaf Olsen; Filipa Júlio

Apologies: André Willems, Asun Martinez

Representatives from Country Associations : Russia, Sweden, Switzerland, France, Israel, Cyprus, Bulgaria, Norway, Portugal, Poland, Czech Republic, Netherlands, Finland, Belgium, Romania, Italy, Scotland, Germany, Ireland, Lithuania

Agenda

1. Welcome

Bea de Schepper, President of the EHA, welcomed all and handed the role to Astri Arnesen, Vice-President of the EHA and soon to be elected the new President of the European Huntington Association.

2. Short Presentation

Astri introduced the President of the Dutch Huntington Association, who gave a short communication about the history and mission of the Organization.

3. Choice of chair and referent

Svein Olaf Olsen, Member at Large and Filipa Júlio, Secretary of the EHA have taken on the roles of chair and referent of the Business Meeting.

4. President's Report

Svein Olaf welcomed all and asked Bea to present her Report of the main activities of EHA since the last Business Meeting in Barcelona 2014.

Bea pointed out that, together with Astri and Svein Olaf, her main mission in the last two years has been the expansion of EHA, with the organization of the 1st EHA congress in Warsaw in 2015, and the support of new HD organizations throughout Europe (namely, in Bulgaria, Cyprus, Lithuania, and Romania). Bea said that the EHA congress in Warsaw was a success, with a complex organization that involved many meetings and close work with sponsors, speakers and participants.

An important part of Bea's work has to do also with her participation as the representative of HD European families in several scientific and research group meetings in different countries in Europe. Bea described her role in many fundraising events for HD cause.

Finally, Bea stated that after 12 years as President of EHA, she felt it was the right

time to make room for a new President, Astri Arnesen. Bea will continue to be involved with the EHA, as Liaison Officer.

Bea received a standing ovation from all the attendees and Astri gave her a gift on behalf of all the European Associations as a symbolic reward for her continuous work for the HD cause.

5. Balance

Before the balance, all the attendees presented themselves, stating their name and country of origin and giving a brief summary of their role in their national HD Association. About 20 Associations were represented at this meeting.

Svein Olaf presented the Balance of EHA as for September 2016 and it was highlighted that there was a large increase in the Association funds, thanks to the partnerships that were implemented during the last years between EHA and several sponsors and organizations.

6. Presentation of the Strategic Plan

Astri Arnesen presented a powerpoint with EHA's strategic plan for the upcoming years. Some of the themes that were addressed during this presentation:

- Goals of EHA
- EHA's new website, with a special emphasis in the video "Postcards from Palm Springs" and the several new contents of the site
- New Associations – and the intention of EHA to continue to support the national efforts of small uprising associations
- Sponsors and Pharmaceutical Companies and the need for cooperative work with the patients Associations
- Research and Political Groups and Organizations and the need to lobby for the HD cause
- Support for Young People (not only HDYO, but also EHA)

7. Presentation of "Stronger Together!"

Next, Astri presented "Stronger Together!", an EHA project to be set between 2016 and 2019 that aims to mobilize the HD community for taking part in research, under the moto "Empowering the HD community for a better future!" The main goals of this project are:

- • increase the speed on recruitment to Enroll
- • increase speed in recruitment to clinical trials
- • reduce drop-out from Enroll
- • reduce drop-out from clinical trials
- • increase the speed on regulatory approval processes

8. Election for the Board 2016-2018

Svein Olaf presented the candidates and positions for the new EHA board as follows:

Astri Arnesen – President
Barbara D’Alessio – Vice-President
Filipa Júlio – Secretary
Andrè Willems – Treasurer
Bea de Schepper – Liaison Officer
Svein Olaf Olsen – Member at Large
Dina de Sousa – Member at Large
Danuta Lis – Member at Large

Representatives from the National Associations unanimously approved the new Board Members.

It was also approved that the EHA EEIG is moved to Norway.

9. Appointment of Representative for the EHDN Executive Committee

Astri Arnesen was unanimously approved to be the EHA representative for the EHDN Executive Committee and CHDI Foundation.

10. Appointment of Representative for the EFNA (European Federation of Neurological Associations)

Bea de Schepper was unanimously approved to be the EHA representative for the EFNA (in which she is also a Board Member).

Dina de Sousa is going to be the EHA Representative for the SBAC (Scientific and Bioethics Advisory Committee) in EHDN.

11. Discussion in Groups

All the attendees gathered in small groups to debate some important topics involving EHA mission and activities. The groups discussed answers for the following questions:

- Given the strategy, what should be the main focus for EHA?
- What can EHA do to be a resource for your Association?
- What kind of contribution can you or your association give to the EHA work?
- Regarding the ongoing HD research and the EHA project “Stronger Together!”, what are the most important challenges you experience in your country?
- What should EHA focus in this respect?
- Do you know any resource persons we can contact in order to develop a stronger collaboration?

12. Plenary Discussion

At the end, each group selected a spokesperson to give voice to their message. Some collective ideas about the EHA main focus:

- Arrange EHA conferences / debate groups
- Exchange information
- Help to establish new HD organizations
- Cooperation
- Spread knowledge about HD
- Psychological, legal, social support
- Bring more clinical trials to Europe

Some collective ideas about EHA as a resource for national associations:

- Create an e-learning platform
- Hand out educational materials in different languages
- Standardize information (act as one voice)
- Serve as an HD contact database

Some collective ideas about what the national associations can give to EHA:

- Volunteer work
- Spread EHA information in local language
- Translators

Some collective ideas about what are the most important challenges in each country:

- Poor understanding/diagnosis of HD
- Lack of specialized care facilities and professionals
- Few people attending the meetings
- Few professionals attending the meetings
- Networking
- Few knowledge about HD in the clinical world

Some collective ideas about what should EHA focus in this respect:

- Knowledge
- Support
- Lobbying for HD at an international level

The last question remained unanswered.

The meeting closed with encouraging words from Astri and Dina de Sousa about the importance of EHA meetings and the support and cooperation between all the "Huntingtonians".

The EHA board thanked all in attendance and invited everyone to visit the EHA Booth at the 9th EHDN Plenary Meeting.

Sofia – Bulgaria was indicated as the next place for the EHA Conference in 2017.