



Minutes of the European Huntington Association's General Assembly Amsterdam, September 25th 2021

Present: Albert Counet (Ligue Huntington Francophone Belge – Belgium); Andrada Ciuca (Asociatia pentru Huntington din Romania – Romania); Anette Carlsson (Huntington Foreningen I Sverige - Sweden); Anne Lennon Bird (Huntington's Disease Association of Ireland – Ireland); Astri Arnesen (Landsforeningen For Huntington's Sykdom - Norway, EHA); Beatrice de Schepper (Huntington Liga Flanders - Belgium, EHA); Claudia Azañedo (EHA Communication Manager); Danuta Lis (Polskie Stowarzyszenie Choroby Huntingtona - Poland, EHA); Dina de Sousa (Scottish Huntington's Association - Scotland, EHA); Elisabetta Caletti (Huntington Onlus – Italy); Filipa Júlio (Associação Portuguesa dos Doentes de Huntington - Portugal, EHA); Ghislaine Gate (L'Association Huntington France - France); Giorgos Papantoniou (Huntington's Disease Association of Cyprus - Cyprus, EHA); Ludovica Camilla Busi (Lega Italiana Ricerca Huntington E Malattie Correlate Onlus – Italy); Marco Salvadori (NOI Huntington– La rete italiana dei giovani - Italy); Marina Tretyakova (Orphan People – Russia); Marios Papantoniou (Huntington's Disease Association of Cyprus - Cyprus); Mia Ala (Suomen Huntington Yhdistis RY – Finland); Naim Ozdemir (Huntington Derneği - Turkey); Nira Dangoor (Israeli HD Association– Israel); Patricia Towey (Huntington's Disease Association of Ireland – Ireland); Pauline Lund (Landsforeningen For Huntington's Sykdom – Norway); Rob Haselberg (Vereniging Van Huntington – The Netherlands); Saija Ristolainen-Kotimäki (Suomen Huntington Yhdistis RY - Finland, EHA); Svein Olaf Olsen (Landsforeningen For Huntington's Sykdom - Norway, EHA, IHA); Uliana Kartseva (Orphan People – Russia); Vladimir Václavík (Spoločnosť Pre Pomoc Pri Huntingtonovej Chorobe – Slovakia); Zaynab Umakhanova (Orphan People – Russia, EHA)

1) Welcome by President Astri Arnesen

Astri welcomed all the EHA General Assembly (GA) attendees and invited everyone to briefly present themselves. Astri presented the meeting agenda and suggested Svein Olaf Olsen to be the meeting moderator and Filipa Júlio to be the meeting reporter.

2) Approval of agenda, meeting moderator and meeting reporter

Everyone approved the agenda, the meeting moderator, and the meeting reporter.

3) President's report 2018-2021

Astri presented some of the European Huntington's Association (EHA) main actions and initiatives during a timeframe that includes one year and a half of normal times and one year and a half of abnormal times (2018-2021)

- The EHA has now two new members, Malta and Turkey, and also two new associations are potentially joining in, Iceland and Croatia. Astri asked Vladimir to explain the contact he has been having with Croatia, which he did.
- Astri showed a video with memories from EHDN Vienna Meeting 2018 and the EHA Business meeting.
- Astri mentioned the EHA Bucharest Meeting 2019, and invited the EHA GA attendees to follow the link and see the photos and videos of that event.
- HD week in Romania, Russia and Bulgaria – HD families come together and meet with HD specialists. Astri said that hopefully this can be a good project for new and rising EHA members such as Turkey.
- From Belgium with Love (and equipment) – Bea explained this initiative, which consists in collecting medical equipment that is no longer used in Flemish medical units (chairs, beds, rollators, lifts, special bathtubs, etc.), storing them and then organizing the shipping to families and clinical units in underserved countries such as Bulgaria, Slovenia, Romania and Poland.
- Moving Forward – Astri explained that this is a project that is kind of a follow-up from Stronger Together. Filipa presented some of the Moving Forward main actions: a briefly mention to the first phase of the project, “Let's start moving forward” and the multi-national survey done during that time; initiatives and plans in Russia and Spain; the communication skills training course for HD professionals that is being planned - “Let Us Talk”; and the brand new Moving Forward webpage <https://ehamovingforward.org/>. Albert asked for further details about the Moving Forward webpage and said that the “online library” corresponds to an old dream of his Association, that is to have everything available in one single click, in one single site, in plain language; therefore, Albert said that he believes it would be great if the EHA/Moving Forward team could partner/coordinate with Ligue Huntington Francophone Belge and also join forces with the HD French Association to have a French version of the site. Ghislaine agreed and said that L'Association Huntington France is also interested and available to

collaborate with Moving Forward. Marco said that it is a very interesting project and asked if the project wants to involve the local associations, as the Association he represents, NOI Huntington– La rete italiana dei giovani, is a youth organization that is run by and targets exactly the same groups that Moving Forward wants to reach – i.e., young HD family members. Astri said that the project will thrive to expand to new countries and that new partnerships will be very appreciated.

- From HD-COPE to HD-CAB – Astri explained the reasons for EHA leaving HD-COPE and described the new coalition, HD-CAB (HD Community Advisory Board), that gathers EHA, IHA and HDYO.
- Advocacy for better access to treatment and support – Astri presented some of the advocacy efforts done by the EHA at a European level:
 - Meeting between different EHA members in Amsterdam to debate what should be the EU lobbying approaches for the future
 - Meetings with MEPs in the EU Parliament in Brussels
 - Virtual Roundtable (together with EFNA)
 - Consensus Statement on Improving Access to Care and Treatment for HD Patients and Families – petition in 5 languages to raise awareness and support
- HD TrialFinder site (<https://hdtrialfinder.net/en/home/>) – Astri presented this online tool created by EHA to help HD families find survey, studies and trials happening in Europe
- HealthE-RND project (<https://health-e-rnd.eu/>) – Astri also mentioned this EU funded project that intends to promote e-health for rare neurological disorders. The EHA is one of the partners and the webpage of the project was set up by EHA
- May Awareness Month campaign

4) Treasurer's report

Svein Olaf reported about the financial status of the EHA – numbers referring to 2019 and 2020. Albert asked about the exchange rate between Euro and Norwegian Krone, as the numbers presented are in NOK, so they seem very high when in fact are not that high, and it can be a little difficult to follow. Svein Olaf explained that the current rate is around 1 EUR = 10 NOK, so the number should be roughly divided by 10. Also, Svein Olaf presented a report about how the EHA is being funded, with a list where the industry related income is around 31% and the non-industry related income is about 68%. Rob asked about what the perspectives are for 2021 and Svein Olaf said that the future looks very promising in terms of budget and results for the EHA for the current year.

The President's report and the Treasurer's report were accepted by the EHA GA attendees. These reports are going to be shared online.

5) Election of EHA Board

Svein Olaf presented the list of EHA Board member candidates for the next term. Running for re-election:

- Astri Arnesen (President/CEO)
- Beatrice de Schepper (Liason Officer)
- Danuta Lis (Member at Large)
- Dina de Sousa (Member at Large)
- Filipa Júlio (Secretary)
- Svein Olaf Olsen (Member at Large)

New candidates:

- Giorgos Papantoniou (Member at Large)
- Saija Ristolainen-Kotimäki (Member at Large)

Giorgos and Saija presented themselves to the EHA GA attendees.

The new EHA Board was accepted by the EHA GA attendees.

6.) Appointment of representative to the EHDN Executive Committee (EC)

7) Appointment of representative to EHDN Scientific and Bioethics Advisory Committee (SBAC)

8) Appointment of representative to European Federation of Neurological Associations (EFNA)

Svein Olaf informed the EHA GA attendees that the new EHA Board proposed the following members to represent the EHA in external organizations:

- European Huntington's Disease Network Executive Committee – Astri Arnesen
- European Huntington's Disease Network Scientific and Bioethics Advisory Committee - Dina de Sousa
- European Federation of Neurological Associations – Filipa Júlio

The EHA GA attendees accepted these proposals.

BREAK

After the formal part of the EHA GA, there was a more informal part to discuss how to proceed the EHA advocacy work.

Astri presented three main topics for debate:

- Map the needs – Benchmarking report

The benchmark project or benchmark score card is a project similar to one done in idiopathic pulmonary fibrosis. The main goal is essentially to make an inventory and compare the resources available at each EU country to care for people affected by HD. The idea is to have both input from patients and care providers to do this, as they do not always agree about the existing resources and the quality of the services available. Astri said that the EHA received funding to do this (from Uniquere and Prylenia) and so we will be able to contract a project manager to handle this work. This project will involve things such as developing a list/map about what is there in the country, which services exist, set up a survey to get feedback from patients and professionals, proceed with data analysis and write down a report to give back the main results to the HD community and stakeholders.

- Plans and proposals for further actions and collaborations to advocate and intervene at a EU level, namely try to do a follow-up on the consensus statement

What can EHA do to help present this document to the different stakeholders

- Communication plan - a communication working group to be more involved at the EU level and design EU campaigns

The idea is to have a working group that will be responsible to bring ideas to the table and design international campaigns to raise awareness about HD.

Astri randomly divided the group into three different breakout groups to debate these topics.

After this debate, the groups joined again and each of them made a summary about the main ideas and suggestions discussed.

Some of the things brought up in the group discussion:

- The benchmark project is a very good idea that will need funding and, ideally, a mix of family members and professionals assigned to do it
- The benchmark report is seen as a helpful tool, not just a survey and not just a study; it should include practical requests to the politicians so that it can be used as a call for action
- The Associations should be able to provide input and be allowed to comment during the development of the survey questions
- There is the need to help the national associations to have the resources to produce work to do this report
- Other topics debated during the breakout were the benefits of having both professionals and family members on the Board of the national associations (so that families are not so fragile) and the need to have the local/regional associations coming together and strengthening the voice of HD families at a country level (e.g. Spain as a good example compared to France or Italy).

As a final call for action, Astri asked the EHA GA attendees if anyone was interested in becoming more involved in the communication working group and be in contact with Claudia. Vladimir, Marco and Ghislaine offered to collaborate in this. Anette suggested that Susanne Zell from the Swedish Association may also be part of this.

The take home message was that it is really valuable to meet, discuss and learn how things are done in the different countries and associations. And that this can be done in the virtual format too. But hopefully everyone will make it to Bologna in September 2022.