

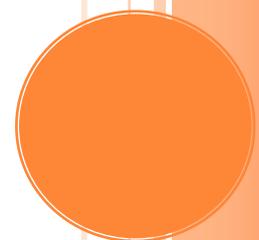


Photo: Filipa Miguel

During the last three years EHA has continued to grow in number of member associations and activity level. EHA has contributed to more activities, better awareness and more influence for HD affected all over Europe. The community is growing and gets stronger every day. Research is making remarkable progress, and there are several promising clinical trials ongoing. EHA has taken a leading position and is a voice for better access to treatment and care and we work with our members to coordinate campaigning on both European and national level.

Presidents report, Astri Arnesen

18.09.2021



# EHA 2018-2021

*Together - forwards and upwards!*

## Board

Board elected at the business meeting in September 2018: President Astri Arnesen, Norway, Vice-President; Barbara d'Alessio, Italy, Secretary Filipa Julio, Portugal, Treasurer Danuta Lis, Poland; Liason Officer Bea de Schepper, Belgium, Board Member Svein Olaf Olsen, Norway; Board Member Dina de Sousa, Scotland.

Before the pandemic the board met face-to-face 3 times pr year. The last face-to-face board meeting was in Madrid in February 2020. Since then all meetings have been virtual. The board works well together and all members participate active in internal discussions and in activities and meetings outside EHA. The board members are also active in their respective national associations. In June 2021 Barbara d'Alessio decided to step down and left the board. She has not been replaced as we were only a few months away from the election in September.

## Staff

Since last report EHA has increased number of people hired to work for the association. Astri Arnesen is contracted as CEO in a full time position. Claudia Azanedo, has a consultancy contract as full time Communication Manager. She took over the position after Maiken Arnesen in February 2021.

Phyllis Kitema is contracted as Organisational Secretary in a 50% position. She has been on maternal leave since September 2020 and will start work again in November 2021.

Filipa Julio has since September 2020, a consultancy contract as full time Project Manager for "Moving Forward".

Zaynab Umakhanova is since July 2021 contracted full time as National Coordinator in Moving Forward in Russia.

*"I meet so many people from other countries and when we talk about HD you can feel, .. we are not alone we are a very big HD Family!!"*

## Redirection of registration from Norway to Belgium

In 2020 the board decided to move EHA from Norway to Belgium. The reason was that the Norwegian association for Industry partners (LMI) has strict rules on how they can support patient organisations. These rules differ from the ones that apply

on the European Level and made hurdles for our opportunities to request for funding from Industry. Throughout 2020 Bea de Schepper, board member and based in Belgium, assisted us in arranging all the practicalities and have the registration done in accordance with Belgium registration. All was finalized and officially approved early 2021.

### New associations

Since last business meeting there has been established 3 new HD associations. The HD association in Malta was acknowledged and formally registered in 2019. In Slovakia the association was restarted in 2019 after being a “sleeping” organisation for several years. In January 2021 the Turkish Huntington Association was registered. In September 2020 we organised a national meeting together with a few HD specialists and family members in Iceland. It was a hybrid meeting. The meeting was a success but so far there has not been taken steps to have an association set up and registered in Iceland.

### Conference

In September 2018 EHA was actively involved in the EHDN conference in Vienna. We produced several videos from the conference. The EHA business meeting had more than 60 people attending from 26 countries.

October 4-6 2019, the European Huntington Association conference, Stronger Together – Better Together, was held in Bucharest, Romania.

220 professionals and family members were gathered in Romania to meet others and to learn more about Huntington’s disease. You can read more about the conference here: <http://eurohuntington.org/stronger-together-better-together/>

### HD Week

In 2018 the Romanian association and EHA developed together a concept named HD Week. This is a program where family members and patients come together for several days to meet with HD experts, learn about HD and talk with each other. In September 2018 the first HD week was arranged in Cluj Napoca in Romania. The following years the program has been adopted and adapted in Russia and Bulgaria. The program has born fruit and the associations in Russia and Bulgaria has managed to get public funding to arrange similar meetings.

### From Belgium with love

Liason officer, Bea de Schepper, has continued to organize transports with specialized HD equipment from Belgium. One to Czech Republic in 2019. The next transport is going to Burgas in Bulgaria and will be sent before the end of 2021. The equipment comes from Belgium HD families or carehomes who no longer needs it, and Bea collects it in her barn. It’s chairs, wheelchairs, beds, rullators etc.

## From Stronger together to Moving Forward

From 2016 to the end of 2019 we had the project Stronger together about mobilizing the HD community to be informed, support and take part in HD research if feasible. Stronger together was primarily funded by CHDI. In 2020 we started a new project call Moving Forward. The project is directed towards presymptomatic HD gene carriers and people at-risk and have 5 objectives:

1. Increase trial awareness
2. Increase Health Literacy and Reduce Therapeutic Misconception and Misestimation
3. Reduce the Impact of Perceived Barriers to Study Participation
4. Build Up the Site Team Skills
5. Increase Clinical Trial Readiness

Filipa Juliò was engaged as project manager in September 2020. We started with a pilot project named Let's start Moving Forward and did a survey to map knowledge about and attitudes towards HD research. The results have been presented at several conferences, webinars, and are documented in a paper "Perceptions about Research Participation among Individuals at Risk and Individuals with Premanifest Huntington's Disease: A Survey Conducted by the European Huntington Association"

All stakeholders in the HD community show great interest in this project.

In July 2021 we contracted with Orphan People, the HD association in Russia and had a national coordinator hired to work for Moving Forward in Russia. In October we will contract with the Spanish National association and have a national coordinator working part time for Moving Forward. We have ongoing discussions with the Huntington Liga in Belgium and the Dutch association to explore potential for having a Flemish/Dutch coordinator.

Moving forward has received funding from Novartis, Roche, PTC and EFNA. We will continue to work on funding opportunities from both industry and foundations etc.

## From HD-COPE to HD-CAB

HD-COPE (HD-Coalition for Patient Engagement) was established in 2017 together with HDSA and HSC. EHA recruited 10 family members into the group. HD-COPE was consulted by several pharma companies. Towards the end of 2020 it was impossible for us to agree with the coalition partners on how to proceed and we chose to leave the coalition. The main disagreements were about including HDYO and IHA as partners to ensure global representation, transparency and rotation of responsibilities between the coalition partners and management of ad boards.

In the spring 2021 we formed a partnership with IHA and HDYO and have set up a group named HD-CAB (HD-Community Advisory Board). The group is going to have 25 family members from all 6 continents. We organise training sessions to educate and prepare the Team Members for their role as consultants to industry and other stakeholders. First Advisory Board will be organised early November 2021. Astri Arnesen is chair for HD-CAB for the first two years. In October a HD-CAB webpage will be launched.

### EHDN Collaboration

In 2018 Astri was reappointed as the EHA representative in the Executive Committee of EHDN, Dina was reappointed to the SBAC (Scientific and Bioethical Advisory Committee) reviewing research projects. Astri, Dina and Giorgos have been represented in the program committee for the EHDN 2020 and 2021 virtual conferences. Astri is active in the EHDN working group for Multidisciplinary Treatment and Care.

### Other European partnerships

EHA is an active member of European Federation for Neurological Associations (EFNA). Bea has been the treasurer in EFNA for several years but stepped down in 2021. Astri was elected to the board in the spring 2021. In December 2020 EFNA and EHA arranged a round table conference about access to treatment and care

Since 2016 we have been involved in European Reference Network for Rare Neurological Diseases (ERN-RND). Astri has been a patient representative (ePAG) since 2016. In 2020 Nataliya Grigorova from the HD association in Bulgaria has also been ePAG.

EHA is since June 2018 a full member of Eurordis. Eurordis is providing support to the ePAG training, exchange of experiences, etc.

Dina de Sousa and Mara Andrade has represented EHA in meetings with industry organized by European Medicines Agency.

### EHA coordination of patient representation in research projects:

EHA has been responsible for coordination of patient representation, so-called PPI (Patient Public Involvement) in DOMINO-HD, HEALTHE-RND, IDEA-FAST, SEEING-HD and Huntington's Disease Burden of Illness Study. The studies have all had delays due to the pandemic, but they are moving forward and the Disease Burden study will soon deliver the first report.

## Advocacy for better access to care and treatment

In February 2019 18 people representing the most of the EHA member associations in EU met in Amsterdam to discuss how we can work together to put HD on the EU policy agenda. In September 2019 we met with EU MEP's in Brussels from Belgium, Portugal, Sweden, Hungary and Italy. We were well received by all of them. We planned for a follow-up meeting in the spring of 2020, but this had to be postponed and cancelled due to the pandemic. In December 2020 we organized a round table conference together with EFNA. The conference had several MEP's as speakers as well as the chair of EHDN and European Reference Network-Rare Neurological Diseases (ERN-RND), as well as the European Brain Council and Eurordis. A consensus statement came out of the meeting. In February 2021 we organized a Zoom meeting to continue the discussion about how we can coordinate and take action to prepare European and national authorities for a future with approved medicines for HD. One conclusion in this meeting was the need for more awareness and knowledge about HD.

## Raising awareness

Communication, information, and awareness has been a priority for EHA throughout this period. The resources for Communication Manager have been increased and since September 2020 this job has been a full time position. In 2019 we were able to get funding to set up the webpage [www.hdtrialfinder.net](http://www.hdtrialfinder.net) The page is available in English, Russian, Spanish, German, Dutch and French.

In 2021, as part of the Moving Forward project, we have set up a webpage <https://ehamovingforward.org/>, currently available in English and Russian and soon to be available in Spanish. This webpage aims to be a valuable resource to find reliable, updated, and clear information about HD symptoms, research, and care

As part of our contribution in HEALTHE-RND we have set up the webpage: [www.health-rnd.eu](http://www.health-rnd.eu) The webpage can be used to advocate for implementation of eHealth services as it will have content describing the opportunities the project delivers and how patients and families benefit from this support.

Rare Disease Day and May awareness month has been marked in social media campaigns every year. In 2020 and 21 it has been online campaigning only. In 2021 we shared a petition for people to sign and support the consensus statement that came out after the Round Table conference. We also created a logo and a Facebook Frame. These resources were used by many of the EHA member associations and shared broadly.

When the pandemic hit in March 2020, we immediately turned to online meetings and activities. In April we organized a webinar in collaboration with ERN-RND about the pandemic and HD. 14 HD experts from 14 countries contributed and

were able to provide guidance to people in their own language. This demonstrates the fantastic strength, collaborative spirit, and solidarity in the HD community. You can see the webinar here: <https://www.youtube.com/watch?v=cDfsqBFem4>

From October to December 2020 we had webinars every week covering a variety of topics. We continued the webinars in February, March and May. They are all available on the EHA webpage: <http://eurohuntington.org/recorded-webinars/>

We experienced good interest and participation in the webinars and they became an important part of our networking during the long period of lockdown, uncertainty and travel restrictions. We expect to keep organizing webinars also post-Covid, but with less frequency.

For the next few years we will continue to work with the main activities already ongoing and develop these further. We propose to have two new members into the board to ensure some rotation and to have new perspectives and opinions.

**Sponsored by:**

