

Presidents report European Huntington Association VZW, 2021-2022

Board

The last face2face General Assembly (GA) was organized in Vienna September 2018. The planned GA in 2020 was postponed due to the pandemic situation. In 2021 we decided to arrange a virtual GA on September 25. The board elected here was:

Astri Arnesen, Norway - President
Filipa Julio, Portugal - Secretary
Bea de Schepper, Belgium – Treasurer and Liaison officer
Danuta Lis, Poland – Member at large
Svein Olaf Olsen, Norway – Member at large
Dina de Sousa, Scotland – Member at large
Saija Ristolainen, Finland – Member at large
Giorgos Papantonio, Cyprus – Member at large

The board has met regularly in virtual meetings + 2 face2face meetings, one in Amsterdam in 2021 (September) and one in 2022 in Bologna (April). In addition the board has extensive communication via emails, phonecalls etc. The collaboration within the board works very well.

New associations

Since the previous GA in 2021 one new association has been formally established in Iceland. Sveinn Viðar Guðmundsson is the president based in Reykjavik. With this new EHA member we have associations from 33 European countries. This is a very good representation for a rare disease. Nevertheless we want to continue to work to support the establishment of associations in new countries. We also experience big differences in the contact and involvement of the members. Nevertheless we regard the contact and communication with the member associations to be good. Especially the smaller associations express that they are happy for the support and assistance from EHA.

Partnership/collaboration

EHDN

Astri has been appointed as EHA representative to the Executive Committee of EHDN since 2012. She will no step down and the board is suggesting that Dina de Sousa replace her.

Dina de Sousa has been patient representative in the Scientific Bioethics Advisory Committee (SBAC) since 2016. She is stepping down this year. EHDN has decided to appoint a new representative.

Astri is active in the Multi-disciplinary Treatment and Care Working Group. The Working Group is coordinated by Ruth Veenhuizen (NL), Marleen van Valsem (NO) and Astri. The last year they have produced a Position Paper with the title: *What we don't need to prove in multidisciplinary treatment and care for Huntington's Disease patients*. The objective for the paper is to publish a consensus statement about the importance of Multidisciplinary and Holistic approach to HD patients and families. In short, the conclusion is that we have sufficient evidence to make clear recommendations. The paper is in press.

EFNA

Bea de Schepper has been part in the EFNA board for many years. the last couple of years only as associated board member as she has continued to support the board with financial issues. Bea stepped out of all responsibilities earlier this year.

Astri was elected to the EFNA board as Secretary General in 2021.

We regard EFNA to be an important partner for us and lately they have been very successful in having Neurology added to the political health care agenda and priority list. The campaign OneNeurology has been done in close collaboration with the European Academy of Neurologist (EAN) and WHO. EFNA is doing a lot of advocacy and campaigning towards EU policy makers and the European Commission. Among the most important is the Parliamentary Interest Group Brain, Mind and Pain where 43 members of the EU Parliament has signed up with their support

<http://www.brainmindpain.eu/register-of-supporters/>

European Reference Network for Rare Neurological Diseases (ERN-RND)

The network was set up by the EU in 2016. Astri has been active as patient representative since 2017. Natalia Grigorova joined as patient representative in 2021. ERN-RND has 6 disease groups and Huntingtons and choreas is one. In 2022 the network has organized 2 webinars specifically on HD, in addition to several disease overarching webinars: <https://www.ern-rnd.eu/education-training/past-webinars/>

EHA organized a group to help shape the patient journey, a document to describe the needs for HD patients and families throughout the disease progression: <https://www.ern-rnd.eu/patient-journey-huntingtons-disease/>

Astri was appointed to the ERN-RND management board this year. Dr Holm Grassner at the University Hospital of Tuebingen is coordinator for the network.

We regard the ERN-RND to be of great importance as this is an infrastructure put in place by the member states in EU and should be an important part of the clinical health care system within each country. Things move in the right direction, but a lot of work is still needed in order to have the expertise flow to the right patients at the right time. We see that the associations can play an active role in advocating for participation in the ERN-RND as well as implementation into the national health care system.

HD-CAB (<https://hd-cab.org/>)

The partnership with the International Huntington Association and HDYO in HD-CAB is working very well. Tina Leggett is engaged to help coordinate. HD-CAB has had 1 virtual ad board with PTC in 2021 and another virtual with Novartis in March 2022. In Bologna we will organise face2face ad boards with PTC and Uniqure. The profits from the ad boards will be distributed between the partnering associations as a compensation for time and efforts dedicated to make the group work well.

Moving Forward

Project manager Filipa Julio is working full time with the project. For 2021 we had an agreement with the Russian association Orphan People and Zaynab Zumakhanova worked full time as country coordinator from July 2021. Main activities were several face-to-face meetings in different cities in Russia and a survey for family members. The results from the survey were guiding the set-up of an online training for professionals in January 2022.

In 2021 we contracted with ACHE (Association Corea Huntington Espana) and Ruth Blanco was hired as country coordinator part time. The main activities have been doing a survey for family members and organize a face-to-face meeting mainly for people at-risk or presymptomatic genecarriers. The topic was dealing with the uncertainty.

The project has also focused a lot on adding quality content to the webpage <https://ehamovingforward.org/> and a forum has been set up <https://ehamovingforward.org/community/>

Thanks to the help from volunteers and the project coordinators the page is available in 6 languages. The objective is to be a online library for HD and help guide people to high quality content with general information about HD, HD research and support.

In 2022 we expand the project and will have a cooperation with Huntington Liga in Flanders. One of the first steps will be to do a survey and map needs and wishes from the family members at-risk or with a know gene-status but mainly presymptomatic.

Benchmarking report

In December -21/January -22 we put together a survey to map access to treatment and support. We had a reference group who provided input to the surveys – one for family members and patients and one for health care professionals. Filipa took on the responsibility to analyse the results. The survey was translated into 20 languages! This was possible again with the help of volunteers in the associations. We received close to 650 responses from family members and close to 180 from professionals. The first preliminary results will be presented at the General Assembly in Bologna and we will start the discussion about how to make best possible use of these results.

Communication

Being visible and sharing information is an important part of our role. Claudia Azañedo has been working full-time as a Communication Manager since February 2021. She is responsible for our web pages: www.eurohuntington.org content is decided in collaboration with Astri ; www.ehamovingforward.org content is decided and produced by the project manager and the country coordinators; www.hdtrialfinder.net content is in close collaboration with Dina, www.health-rnd.org in collaboration with Astri ; <https://hd-cab.org/> in close collaboration with Tina Leggett.

In addition to the web pages, Claudia is responsible for the activities on social media as well as to make videos, leaflets, newsletters etc.

In 2021 we helped put together a video presenting the program of Triplet Therapeutics and we recorded a video about the Novartis program. She also joined the 'HD Week' in Varna and helped Nataliya to film and edit a video for the Bulgarian Huntington Association.

Webinars

Since the last General Assembly in Amsterdam 2021, we have organized 3 webinars. January with Roche presenting findings in the data from the Tominersen program. In May Prilenia presented about the PROOF-HD trial. And at the end of May Dimitri Poffé told about his bike adventure in Latin America.

May awareness month

Claudia has been in charge of creating the online communication campaign for May Awareness Month 2021 and 2022, in collaboration with the EHA communication group created by Astri, Claudia and Saija, in which people from EHA member associations also participate.

This year, the May Awareness Month campaign consisted of several posters, a banner and a social media icon that were translated into more than 12 languages. All aimed to raise awareness for Huntington's Disease and create unity between Associations and the community during the whole campaign.

We managed to reach an average of 1000 people per post during that month. The publication with the best statistics was the final video "The Voice of the HD Community", with 2600 people reached and more than 35 interactions. In this video, we asked HD patients, family members and professionals 3 questions about their challenges and what kind of support they will need.

Online training for professional care givers

The Swedish HD association has developed an online training for professional caregivers: <https://huntington.se/utbildningar/vara-webbutbildningar/basic-training-english-version/> Last year they got support from Roche and Novartis to make an English version of this basic training. The association for England and Wales (HDA) has used the training in a pilot with 6 care homes. This training is just finished and we are eager to learn from the experience and explore opportunities to expand the use of the training. We would also like to have it translated to additional languages.