



EHA 2016-2018

Towards a stronger HD community

Photo: Filipa Miguel

The past two years have been a wonderful journey for the European HD community. EHA has contributed to more activities, better awareness and more influence for HD affected all over Europe. The community is growing, developing new networks and is more active than ever before. The future looks much brighter than the past, but there is yet a lot of hard work to be done.

Presidents report, Astri Arnesen

13.09.2018



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Board

Board members: Astri Arnesen, Norway, President; Barbara d'Alessio, Italy, Vice-President; Filipa Julio, Portugal, Secretary; Andrè Willems, Belgium, Treasurer; Bea de Schepper, Belgium, Liason Officer; Svein Olaf Olsen, Norway, Board Member; Dina de Sousa, Scotland, Board Member; Danuta Lis, Poland, Board Member

The board has met 5 times for face-to-face meetings. In addition to the board meetings we have an extensive email contact.

All work in the board is non-payd. But since September 2016 the EHA project *Stronger together* was funded by CHDI foundation. This funding has allowed Astri Arnesen to work full-time with the project, as well as part time job for Maiken Arnesen to administer the webpage and social media and produce videos, articles etc.

Since June 2018 EHA hired a secretary, Kristin Myrstad, part time. This is a consequence of increased activity and we see a potential for further growth in the years to come.

New associations

Since last business meeting there has been established 3 new HD associations, one in Hungary, one in Gran Canaria and most recently, one in Greece. We have visited Bosnia and hoped to have an association set up there, but unfortunately this is now on hold.

“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!!”

Stronger together

This project is the most important part of the EHA activities the past two years. The combination of the CHDI funding and the EHA network is a huge resource. The projects main aim is to raise awareness of the importance of family contribution to the ongoing research and to have more people involved. EHA board members have both organized and participated in meetings to talk about Enroll-HD and other studies and clinical trials. The webpage and the Facebook presence are impactful tools that reach out with information and connect people. By the help of volunteers, we provided

subtitles for the Postcard from Palm Springs in 10 languages. The most popular Facebook posts seem to be about the clinical trials. A movie about the Ionis/Roche trial reached more than 19.000 on Facebook and the video was seen by more than 8.000 people. The video about the Wave trial reached almost the same interest by numbers. You find the full reports on *Stronger together* here: <http://eurohuntington.org/2016/11/05/stronger-together-a-new-project-launched-by-the-european-huntingtons-association/>

Conference

The conference in Sofia, Bulgaria, gathered 250 participants from 26 different countries. The general feedback from the conference was very positive, and a lot of people reported that they felt encouraged and empowered by the strength of the community. EHA was able to financially support around 60 participants. East European countries was prioritized for this support.

The conference introduced a new concept: *Hd on the move*. In the morning we organized a walk/run from the hotel. The activity was very well received and will be repeated during the EHDN 2018 conference.

Ask the doctor

In December 2016 we launched **Ask the doctor**. This is an online service where people can ask questions, anonymously if they want to. Dr Alzbeta Muehlbaeck is in charge of the service. She is a neuropsychiatrist with a profound experience in HD. If needed she consults colleagues for multi-disciplinary expertise whenever needed. The service has pr July -18 received 65 requests from 15 different countries all over the world. We regard this service to be of high value and a very good option to get in touch with an HD expert. In a lot of cases people are guided to an expert closer to where they live and encouraged to take contact with the HD association. Dr Muehlbaeck does this service as a volunteer for EHA. We will consider if the service can be extended and potentially involve other experts.

Russia

EHA supported HD family meetings in Russia in 2017. Our Russian member association, Orphan People, managed by Marina Tretiakova, organized the meetings in St.Petersburg and Nizny Novgorod. There is a great need for family members to have more information about HD and to have the support of the lay community. We consider extending the collaboration with Orphan People on new activities in Russia – a vast country with more than 140 million inhabitants.

Malta

Malta is a small country with only 400.000 inhabitants, but the prevalence of HD seems to be quite high. There is no specialized service for HD. The association have been run by one single person for many years. In collaboration with the Maltese contact person, LIHR foundation (with Vice-President Barbara d'Alessio and neurologist Ferdinando Squitieri), Italy and Caritas, Malta, EHA supported a family meeting late 2017. For the first time 18 people for 6 different families was together and learned about HD and could ask questions. We consider arranging more meetings and potentially also organize consultations with the Italian neurologist. This will be done in close collaboration with the Maltese health authorities and experts as it is a clear goal to have the Maltese health system provide better services to the HD families.

From Belgium with love

Liason officer, Bea de Schepper, has organized three transports with specialized HD equipment from Belgium. One to Slovenia in 2017 and two to Czech Republic 2018. 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. The plan is to find a partner in Bosnia or any of the neighbouring countries and send a new truck to them sometime in 2019.

HD Coalition for Patient Engagement – HD-COPE

To have HD-COPE established has been the most important action taken by EHA to strenghten patient advocacy in HD. The coalition was formally established in September 2017 together with the American and Canadian HD associations. It has received financial support from CHDI for the first 3 years. HD-COPE is run by two members from each association. From EHA it is Astri and Svein Olaf taking part in the Executive Committee. In the HD-COPE team we have 20 patient advocates, 10 from Europe, 6 from US and 4 from Canada. The team met for the first time in February 2018 in London. The European members were chosen in close collaboration with the member associations. The criteria we used to pick a heterogenous group was: HD status, geography, gender, age. The whole team has done an advisory board with Roche. In addition, there have been online communication where Roche get feedback on their trial protocol etc. One American and one European team member is part of the Roche trial steering committee. This is the first-time patient representatives are included like this. The 6 American members, 1 Canadian and 2 European members have recently met with Uniqure. And here in Vienna the European members will meet with Wave. The whole team will have a new

face-to-face meeting in New York late February 2019. EHA is active to have better global representation and in 2019 we will have China, Latin America, Africa and Oseania in involved.

Patient advocacy

In November 2017 Teva Pharmaceuticals decided to terminate the Open-Pride trial in practically one days' notice. This abrupt termination came as a big surprise to the investigators and for a lot of the participants it was a huge disappointment. EHA reacted very strongly on this and Svein Olaf and Astri had several meetings with TEVA to express our discontent with the way the participants were treated. One Russian and two Italian participants did video interviews and talked about how they had worsened after the termination of the trial. The videos were sent to the management and CEO in TEVA. Despite promises that compassionate use would be available for the participants, this never came into real practise because the procedures required was very complicated and time-consuming.

EHA has also advocated for TEVA to apply for approval of Austedo in Europe. So far there is no action taken from TEVA to have an approval here.

To learn more about how people experience taking part in Enroll-HD we have developed a survey. The survey has been piloted by Barbara and LIHR. It will now be launched in some German clinics. So far, the 56 responses in the survey shows that participants are happy to be part of the study and regard it to be of high importance to both themselves and the HD community in general.

EHDN Collaboration

Since 2012 Astri has been the EHA representative in the Executive Committee of EHDN. Dina has since 2016 been in the Scientific Bioethics Advisory Committee, SBAC, reviewing research projects. Astri, Dina and Giorgios (Cyprus) have been represented in the program committee for the EHDN 2018 conference. EHA and EHDN shared a booth on the conference for the European Academy of Neurology (EAN) in Lisbon, June 2018. EHA supported the Portuguese Association and Filipa in organizing an HD meeting during the EAN conference. Bea, Barbara, Dina and Astri are active in the EHDN working groups for Standard of Care, Genetic testing and Quality of Life.

In 2017 EHA took over the webpage on Physical Activity called Active Huntingtons: <http://eurohuntington.org/active-huntingtons/> The resource

is developed by the EHDN working group on physiotherapy. It is now in the process of being translated to Russian.

We regard the collaboration with EHDN to be good and we see a lot of potential to develop this further. That is the reason behind a SurveyMonkey to our members about how they collaborate today and what they want for the future.

Other European partnerships

EHA is an active member of European Federation for Neurological Associations (EFNA). Bea is treasurer in the EFNA board. We have participated in three EFNA meetings in Brussels and the general assembly each year. In addition we have had participants at courses in Dublin, Lisbon and Brussels. We all find the courses good and useful.

EHA is since June 2018 a full member of Eurordis. Dina participated in the Eurordis Summer school and Astri in the Winter school in 2018. The program was about patient advocacy and research. We see it as useful to be part of the bigger Rare Disease community and it's fruitful to meet other patient representatives and learn from their experiences. Even with all the differences we share a lot of the challenges.

In 2016 EHA received a request to have a patient representative in the European Reference Network for Rare Neurological Diseases (ERN-RND). Astri is a member of this patient advocacy group together with others from Ataxia, Dystonia and several other rare diseases.

EHA is now registered as a partner at the European Medicines Agency (EMA). We regard the registration as an acknowledged representative and partner to be an important recognition and enables us to be more present and active in regulatory issues. This will be relevant and important in the nearest future as more clinical trials will be executed and hopefully drugs being applicable for approval.

Other projects:

EHA has been participating in applying for **2 projects in an EU call**. The call is called Joint Program on Neurological Diseases, JPND. HD is mentioned as one of six diseases in this call. One of the HD projects is about life-style intervention, led by Monica Busse and the other about e-Health, led by Jiri Klempir and Alzbeta Muehlbaeck. EHA has been very active particularly in the application for a 6-country project to measure the impact of e-Health consultations and online group activities on quality of life. It's expected to have the decision of the call within October 1st. You find more information about the call here:

<http://www.neurodegenerationresearch.eu/initiatives/annual-calls-for-proposals/open-calls/health-and-social-care-2018/>

Hd-on-the-bike. In August -18 the event HD-on-the-bike was arranged in Liege, Belgium. The aim was to encourage physical activity and raise awareness. August the 17th 32 people biked for HD in Les Ardennes. Danuta was able to recruit 9 people from Poland to go to Belgium and take part in the race. The two fastest riders in the team *HD on the bike* were from Poland. More information: <http://eurohuntington.org/2018/08/29/a-race-for-awareness-video/>

HDden no more. EHA was participating in the HDden no more event at the Vatican, Rome on May 18th 2017. Danuta managed to gather a big group from Poland and take part with all the rest of us. It was a very special experience to be present and hear Pope Francis tell people to not be ashamed and hide no more: <http://eurohuntington.org/the-personal-stories/>

Photo contest. The HD community was invited to participate in a photo contest and exhibition at the Vienna conference. The invitation was published on Facebook. Orphan People is organizing the contest and exhibition. Between 40 and 50 photos will be exhibited at the conference center. The aim is to have people express themselves and be visible. HDden no more.

Conclusion

The last two years have been very active thanks to a wonderful proactive and positive board and the funding from CHDI allowing Astri to work full-time. We hope our support and activities have contributed to improve the situation for at least some of the HD affected throughout Europe. The board asks for renewed trust and that the business meeting allows us to continue for the next two years.