



**Minutes of the European Huntington's Association General Assembly
Online, 30th April 2025**

EHA Board Members: Astri Arnesen (Norway); Danuta Lis (Poland); Dina de Sousa (Portugal); Filipa Júlio (Portugal); Saija Ristolainen-Kotimäki (Finland); Svein Olaf Olsen (Norway)

EHA Team: Beatriz Campaniço; Jarelys Lopez; Ruth Blanco (Spain)

EHA Members: Marie Short (Scotland), Naim Ozdemir (Turkey), Marios Papantoniou (Cyprus), Patricia Towey (Ireland), Manuel Stefani (Italy – Huntington Onlus), Birgitte Havskov (Denmark), Albert Counet (Belgium – Wallonia), Ghislaine Gaté (France), Vladimír Václavík (Slovakia), Annette Carlsson (Sweden), Nataliya Grigorova (Bulgaria), Hubert Aviolat (France), Sorcha McPhillips (Northern Ireland), Violetta David (Hungary), Nikola Krejčířová (Czech Republic), Zdeňka Vondráčková (Czech Republic), Livar Holland (Norway), Andrada Ciucă (Romania), Francesco Villa (Italy – Huntington Onlus), Zivile Navikiene (The Netherlands)

Apologies: Giorgos Papantoniou, Rob Haselberg

29 Attendees

21 associations from 21 countries

1. Welcome by President Astri Arnesen

Astri Arnesen welcomed participants. Unfortunately quite a number of the members had not seen the invitation and information sent 60 days ahead of the GA. Several reported that after they had received an individual reminder, they had found the original email in the spam. The GA agreed to accept the agenda and invitation despite these technical issues. The EHA administration will for the future make sure that we get the information shared in a way that prevent it from going into the spam.

2. Approval of Agenda, Meeting Moderator and Referent

The Agenda for the EHA General Assembly was approved.
Svein Olaf Olsen was appointed as Meeting Moderator.
Filipa Júlio was appointed as Meeting Referent.



3. President's Report 2024

Astri Arnesen highlighted the Board's Activities in 2024, including in-person meetings in Porto and Strasbourg, as well as regular online meetings.

She then introduced new team members, including Beatriz Campaniço Campaniço, as the new communication manager, Ruth Blanco, who is taking on some of Astri Arnesen's responsibilities and is the new EHA COO, and Jarelys Lopez, who is helping with scientific content production. Beatriz Campaniço briefly introduces herself as the new communication manager from Portugal.

Beatriz Campaniço presented the webpage and social media statistics for the organization, highlighting growth in followers and reach across platforms. She mentioned the launch of a monthly newsletter with a good opening rate.

Astri Arnesen added that they manage multiple web pages, conduct webinars, and run campaigns for rare disease awareness.

Filipa Júlio then provided an overview of the Moving Forward project (<https://ehamovingforward.org/>), which targets young people affected by HD across Europe. She highlighted key achievements in 2024, including online sessions, webinars, social media campaigns, and the publication of a book by a young man at risk of HD. The project also expanded its actions to new countries (Italy, Czech Republic) and started a psychological support service in Romania. Andrada Ciuca presented some details about this service.

Astri Arnesen also provided an update on the EHA's advocacy efforts. The EHA is working with other neurological associations under EFNA to push for policy changes, hosting meetings in the European Parliament and participating in conferences. The HD Community Advisory Board (HD-CAB) (<https://hd-cab.org/>) provides insights to companies planning clinical trials, with three advisory boards held last year.

Albert Counet requests information on rare disease plans from other countries as Belgium is overhauling theirs.



4. Financial Report 2024

Saija Ristolainen-Kotimäki presented the financial report for EHA in Belgium and Norway – see financial documentation. documents. Saija emphasizes the importance of EHA's financial independence due to diverse funding sources. The main costs are salaries and honorariums, followed by project expenses and travel costs. The financial report is being published on the EHA webpage. The documents will be shared to all members together with the minutes from the GA.

Budget 2025

The Board discussed the budget for 2025, which is approved without objections.

5. Discharge of Board of Directors

The GA discharged the board of directors for the 2024 reports.

6. Election to the Board

2 Board members will step down – Danuta Lis and Rob Haselberg.

Candidates for Board elections: Filipa Júlio, re-election

Svein Olaf Olsen, re-election

Vladimír Václavík (Slovakia) as a new candidate.

All 3 was elected for a 2 year term.

7) Election of representative to the Executive Committee of EHDN.

The Board suggested Dina de Sousa to be re-elected. Dina has been in the EC the last 4 years. She was elected as the EHA representative for a new 2 year term.

= Closing of the Formal Part of the EHA General Assembly =

After the GA Astri Arnesen discussed the upcoming EHA conference in Bucharest in September, encouraging members to attend and register early. The conference will include a membership meeting to discuss preparing for potential drug approvals and influencing related processes.



Filipa Júlio and Beatriz Campaniço presented an update on the Huntington Academy project (<https://huntington-academy.org/>), an e-learning platform created by a consortium composed by the European Huntington Association, the Ligue Huntington Francophone Belge (Belgium), the Bulgarian Huntington Association (Bulgaria), and the Asociación Corea de Huntington Española (Spain) to provide education and training for both formal and informal caregivers of people with HD.

The team presented the project background and goals, shared the comprehensive content creation process, demonstrated the platform's features and announced its official launch on May 28th, 18:00-19:30, encouraging wide participation:

<https://us02web.zoom.us/meeting/register/7eUv5Ey1Tw2YsTGTYcrUnw>

The General Assembly concluded with Astri Arnesen thanking Danuta Lis for her years of service on the EHA Board since 2012 and promising a more formal acknowledgement in Bucharest.

Saija Ristolainen-Kotimäki acknowledged the importance of volunteers for EHA's work.