

# 2025

# EHA CONFERENCE



Ramada Plaza Hotel,  
Bucharest, Romania



2025 September  
25th-28th

Shaping our Future Together  
*We are the change*


## AGENDA

Provisional Programme V1.1  
(Updated 3 April 2025)


### European Huntington Association Conference 2025



#### Thursday, September 25

 16:00 – 19:30

- ◆ Arrival and Check-in
- ◆ Registration Desk Open
- ◆ Optional Activity: *Explore Bucharest*


 16:00 – 19:30

 **Room Africa**

- ◆ EHA Membership Meeting



#### Friday, September 26

 **09:00 – 11:00 Room Europe**

-  09:00 ◆ *Opening and Event Overview – Astri Arnesen*
-  09:15 ◆ *Welcome from Romanian Hosts – Ramona Moldovan & Andra Ciuca*
-  09:30 ◆ *What Future Are We Creating? Åsa Petersen + HD-CAB Family Member*
-  10:15 ◆ *What support has helped me live better with the situation? Speakers: Luis Aguilar, Vlado Vaclavik, Jessica Köhli, Wouter De Maeyer, Anne Elisabeth Saldarriaga, moderated by Filipa Julio & Saija Ristolainen-Kotimäki*




#### Coffee Break

 **11:00-11:30 Foyer Room Europe**



#### Social Activities & Debriefing Sessions

 **11:30-13:00**

Facilitators: *Rudy, Svein Olaf, Saija, Dina, Filipa, Andra*

Pool Time

Football

Let's go for a walk!

Coffee&Meet

Yoga (Prior registration  
required)

Debriefing  
Sessions

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Friday, September 26



Lunch

13:00-14:00 Red Pepper Restaurant



Room Europe

Room Mincu

Room  
North  
America



14:00

**HD Basics – Debunking Myths: Alžbeta Mühlbäck**

**Multidisciplinary Care in HD: Sandra Bartolomeu**

**Romanian Session:**



15:00

**Caring for the Carer + Panel Discussion: Marina Pavlou, Anne Elizabeth Saldarriaga, Claudia Villa, Vlado Vaclavik**

**Triple C Model – Human Needs in Care: Janine van Duijvenvoorde**

**Romanian Association**

**Multidisciplinary Treatment in the Netherlands: Ruth Veenhuizen**



Coffee Break

16:00-16:30 Foyer Room Europe & Mincu



Room  
Europe

Room Mincu

Several Rooms  
Peer Groups for HD families



16:30  
-  
18:00

**Debriefing Sessions with Filipa / Andra**

**Workshop for HD Professionals- Norwegian Networking**

**Partners** with Svein North America  
**Gen -** with Saija&Giorgos South America  
**Gen +** with Dina& Rob Asia  
**At Risk** with Claudia Africa

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Saturday, September 27

📍 09:00 – 11:00 Room Europe

- 🕒 09:00 ♦ *Review of the Day – Astri Arnesen*
- 🕒 09:15 ♦ *EHA Work Overview - Filipa Julio, Ruth Blanco, Dina de Sousa*
- 🕒 10:00 ♦ *Somatic Instability and Phenotypes – Saúl Martínez-Horta*
- 🕒 10:30 ♦ *Participating in Clinical Trials – Jane Davis & Gareth Child*



Coffee Break

📍 11:15-11:45 Foyer Room Europe



Room Europe

Room Mincu

Room North  
America

🕒 11:45  
*Life Choices & Communication  
in HD: Emmi Nuppula, Jessica  
Köhli, Julie Skarberg,  
moderated by Astri Arnesen*

*Oral Care and HD:  
Annette Carlson*

*Psychology and HD:  
Regina Gospodinova*

🕒 12:15  
*Genetic Testing Debate: Luis  
Aguilar, Claudia Villa, Giorgos  
Papantoniou, Rob Haselberg –  
Moderated by Filipa & Andra*

*Speech Therapy and  
HD: Eléonore Barbier*

*Neuropsychiatric  
Care: Dr. Erik van  
Duijn*



Lunch

📍 13:00-14:00 Red Pepper Restaurant

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### Saturday, September 27

#### Room Europe

#### Room Mincu

🕒 14:00 *Neurorehabilitation in HD: Saúl Martínez-Horta*

🕒 14:00 *Occupational Therapy and HD: Eva Escalera*

🕒 15:00 *Emotions and Behavior in HD: Åsa Petersen*

🕒 15:00 *Juvenile HD: Jenna Heilman (HDYO) & Maike Oosterloo*



#### Coffee Break

📍 16:00-16:30 *Foyer Room Europe & Mincu*

#### Room Europe

#### South America

#### North America

#### Room Mincu

🕒 16:30 *Palliative Care in HD: Dr Erik van Duijn & Saija Ristolainen-Kotimäki*

🕒 16:30 - 18:00  
*Workshop for HD Professionals by HD Academy, moderated by Jarelys López, Olivier Graf, Regina Gospodnova*

🕒 17:15 *Shared Decision-Making in HD: Zayd Jedidi & Javier Lafuente*

🕒 16:30 - 18:30  
*Time, Temporality, Culture & Wellbeing: Francesco Ripanti & Giorgos Papantoniou*

🕒 16:30 - 18:00  
*Cinema Session*



#### Social Activities & Debriefing Sessions

Facilitators: *Rudy, Svein Olaf, Saija, Dina, Filipa, Andra*

📍 18:30-19:30

Pool Time  
 Football

Let's go for a walk!  
 Coffee&Meet

Yoga (Prior registration required)

Debriefing Sessions



#### Dinner

📍 20:00 *Red Pepper Restaurant*

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## AGENDA

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Sunday, September 28

📍 09:00 – 13:00 Room Europe

- 🕒 09:00 ♦ *Review of the Day – Astri Arnesen*
- 🕒 09:15 ♦ *Clinical Trials & Biomarkers: Rachael Scahill*
- 🕒 09:45 ♦ *Clinical Trial Updates + Q&A - Moderated by Åsa Petersen & Astri Arnesen*
  - *Wave (15') • UniQure (15') • Roche (7') (Others will be added)*



Coffee Break

📍 10:45-11:15 Foyer Room Europe & Mincu

- 🕒 11:15 ♦ *Trial Recruitment in Current & Upcoming Studies: Åsa Petersen + Pharma Reps – Moderated by Astri Arnesen*
- 🕒 12:00 ♦ *From Approval to Access (HTA Speaker - TBC)*
- 🕒 12:30 ♦ *Conclusions & Goodbye by Astri Arnesen & Romanian Association*



Lunch

📍 13:00-14:00 Red Pepper Restaurant

### Current EHA Conference 2025 Sponsors

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## + INFO

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### Open to All

The programme is aimed at all HD patients and families, as well as health professionals.



We will offer practical sessions to share inspiring experiences and testimonials, strategies to improve care and support, as well as updates on ongoing trials and research in simple and accessible language.

We will also provide sessions for self-care and time to share leisure moments.

### Conference Registration

The registration form to attend the conference will be available at <https://eurohuntington.org/>. The **registration fee covers** access to meetings, activities, coffee breaks, lunches for 3 days, and the Saturday dinner.



*Special rates for young HD family members under 30 and for Romanian attendees.*

*Special prices for early registration until August 15th.*

### Accommodation

Please note that **the registration fee does not cover accommodation expenses**, but we **will offer special rates for conference attendees in the conference hotel (Ramada Plaza 4\*) (subject to availability)**. Check all the available options on the conference webpage.



### Language

The conference will be held in English (*except for the Romanian Association specific session*). We aim to provide alternative translation systems in different languages for the sessions in the main auditorium (Europe).

