



EHDN & Enroll-HD, 12th – 14th September 2024, Strasbourg, France

EVENING SESSION FOR EARLY ARRIVALS ON WEDNESDAY, 11th SEPTEMBER 2024

17:30 – 19:30 **EVENING SESSION: Social Cognition in HD**

Chaired by Sarah Mason and Hugh Rickards

1. Biomarkers Associated with Social Cognitive Deficits in HD
Esther Cubo
2. Assessing Social Cognitive Deficit in HD
Asmus Vogel
3. Living with Social Cognitive Deficit in HD
Sarah Mason
4. Panel Discussion

THURSDAY, 12th SEPTEMBER, 2024

07:30 – 08:30 **REGISTRATION DESK**

08:30 – 08:45 **WELCOME AND INTRODUCTION**

Chaired by Astri Arnesen, Anne Rosser, Christine Tranchant, Patrick Weydt

08:45 – 09:45 **HD: Experiences from HD Family, Clinic, Laboratory**

Chaired by Filipa Júlio and Åsa Petersén

Speaker: Anne Elizabeth Saldarriaga Velez Magnusson, Alexandra Durr, Erich Wanker

09:45 – 10:15 **KEYNOTE LECTURE: History of Unstable Repeat Expansions**

Chaired by Frédéric Saudou

Speaker: Jean-Louis Mandel

10:15 – 10:45 **BREAK**

10:45 – 11:45 **EHDN 20 YEARS: Special Lectures**

Chaired by Patrick Weydt

Speaker: Bernhard Landwehrmeyer, Patrik Brundin, Anne Rosser

11:45 – 12:30 **SHORT COMMUNICATIONS**

Chaired by Kathrin Reetz and Eric Reits

12:30 – 14:30 **LUNCH and POSTER VIEWING**

14:30 – 15:30 **PARALLEL SESSIONS I**

A. Novel Disease Mechanisms and Corresponding Therapeutic Targets in HD

Chaired by Nicole Deglon and Romina Aron Badin

1. Advancing the understanding of HAP40's function and its role in HD
Manuel Seefelder
2. Epigenetic dysregulation in Huntington's disease
Karine Merienne
3. Genetic engineering to the rescue of HD
Nicole Deglon

B. Cognitive Symptoms and Rehabilitation in HD

Chaired by Anne-Catherine Bachoud Levi and Saul Martinez

1. Cognition – oriented treatments in HD – evidence for cognitive training?
Katharine Huynh
2. Speech: A predictor of clinical features in HD
Remy Nguyen
3. Language disintegration in HD
Arnau Puig-Davi
4. Panel Discussion



15:30 – 16:00

BREAK

16:00 – 17:00

PARALLEL SESSIONS II

A. Metabolic Dysfunction in HD and Related Neurodegenerative Disorders

Chaired by Luc Dupuis and Patrick Weydt

1. **Going red on PolyQ diseases: Targeting muscle and mitochondria in SBMA**
Maria Pennuto
2. **Going green on PolyQ diseases: Defining proteostasis of plants for human disease intervention**
David Vilchez
3. **Imbalance between tRNA supply and mRNA codon demand triggers peripheral neuropathy: Possible implications for HD**
Erik Storkebaum

B. Palliative Care in HD: Myths and Potentials

Chaired by Jaime Kulisevsky and Alzbeta Mühlbäck

1. **Advance care planning**
Berend Feddersen
2. **Palliative care in HD**
Eric van Duijn

17:00 – 17:15

SHORT BREAK

17:15 – 18:00

EHDN BUSINESS MEETING

Chaired by Anne Rosser

18:00 – 18:45

CECI N'EST PAS L'EUROBUZZ

Speaker: Ed Wild

18:45 – 22:00

NETWORKING EVENING

Posters, finger food & drinks

FRIDAY, 13th SEPTEMBER, 2024

08:30 – 08:45

WELCOME AND INTRODUCTION

Speaker: Cristina Sampaio, Jenna Heilman, Anne Rosser

08:45 – 10:15

UPDATE ON ONGOING CLINICAL TRIALS

Chaired by Ahmad Aziz and Tiago Mestre

1. **SOM Biotech**
Raúl Insta
2. **Prilenia**
Michael Hayden
3. **Sage Therapeutics**
Maddie Pantoni
4. **uniQure**
Ed Wild
5. **Roche**
Peter McColgan
6. **Wave**
Jane Atkins
7. **VICO**
Scott Schobel
8. **PTC**
Amy-Lee Bredlau



10:15 – 10:45

BREAK

10:45 – 11:45

UPDATE ON PLANNED CLINICAL TRIALS

Chaired by Lena Hjerminde and Tim McLean

1. **Alnylam**
Kevin Sloan
2. **Atalanta**
Serena Hung
3. **exoRNA**
Zhong Pei
4. **reMYND**
Gerard Griffioen
5. **Alchemab**
Donna Finch
6. **Rgenta**
Travis Wager

11:45 – 12:15

KEYNOTE LECTURE: Huntington's Disease Now – Mechanisms and Therapeutics

Chaired by Alexandra Durr

Speaker: Sarah Tabrizi

12:15 – 14:00

LUNCH and POSTER VIEWING

⇒ **SPECIAL SESSIONS 13:00 – 14:00**

a. **HDYO: Genetic Testing and Participation in Research**
Speaker: Jenna Heilman

b. **The HD Fellowship Programme Alumni**

Chaired by Juliana Bronzova
Speaker: Fionnuala Margreiter and Zaruhi Tavadyan

c. **Implication des Associations de Patients dans le Parcours de Soins des Patients HD**

Chaired by Christine Tranchant
Speaker: Albert Counet, Marguerite Garcia Reseau, Marc Issandou

14:00 – 15:30

PARALLEL SESSIONS III

A. Genetic Modifiers and Somatic Mosaicism

Chaired by Hoa Nguyen and Mahmoud Pouladi

1. **The "ticking DNA clock": Somatic expansion of the Huntingtin CAG repeat and its biological sequelae**
Bob Handsaker
2. **Mechanisms of molecular pathogenesis in HD**
Nathan Heintz
3. **Investigating intergenerational CAG variability**
Davina J. Hensman Moss
4. **A novel molecular assay to quantify DNA repair synthesis in the HTT exon 1 as readout of somatic instability in HD**
Verónica Ines Brito

B. Global Impact of HD

Chaired by Jean-Marc Burgunder and Claudia Perandones

1. **Global clinical epidemiology of HD**
Alex Medina
2. **Molecular HD epidemiology**
Ahmad Aziz
3. **Global HD disease burden economic and care access issues**
Anne-Catherine Bachoud-Levi
4. **CHDN, CHDA Discussion**
Cao Xi, Feng Luyang

C. Occupational Therapy: Lessons Learned from other Clinical Conditions

Chaired by Astri Arnesen and Dina De Sousa

1. **Pediatric movement disorder Insights for client-centered occupational therapy in HD**
Hortensia Gimeno
2. **Walking the talk for dementia - an immersive experience to empower people with dementia**
Fernando Aguzzoli-Peres
3. **Panel Discussion and Q&A**
Alexandra Fisher



15.30 – 16:00

BREAK

16:00 – 17:00

PARALLEL SESSIONS IV

A. Development and Aging in HD

Chaired by Anne Rosser and Christian Neri

1. Contribution of an abnormal brain development to HD
Sandrine Humbert
2. Revealing striatal development and its involvement in HD
Joseph Canals
3. Supercentenarian genes and HD pathogenesis
Juan Botas

B. Observational Clinical Study Highlights

Chaired by Robert Doot and Swati Sathe

1. Tap-HD
Stephen Smith
2. Shield-HD
Gabe Phelan
3. iMark
Daniel van Wamelen

C. The Importance of Psychological Support in HD

Chaired by Rob Haselberg and Saija Ristolainen-Kotimäki

1. Growing up in families with HD
Siri Hagen Kjølås
2. "I understand we are not alone" - Psychological support for people at risk and people with PreHD
Filipa Júlio
3. Panel Discussion
Jane Simpson and Maria Dale

17:00 – 17:15

SHORT BREAK

17:15 – 17:45

KEYNOTE LECTURE: CAG Triplet Repeat Disorders

Chaired by Åsa Petersén
Speaker: Harry Orr

17:45 – 18:30

SHORT COMMUNICATIONS

Chaired by Flaviano Giorgini and Davina Hensman Moss

18:30 – 18:50

SPECIAL TALKS: Hidden no More and Trailers for the Movie Night

Chaired by Filipa Júlio
Speaker: Charles Sabine

18:50 – 19:00

SUMMARY AND POSTER AWARD

Chaired by Flaviano Giorgini

19:00

MOVIE NIGHT

ROOM A: Berlin

The Present
– by Timothy Dhalleine (18 min)

La Luz - the Cuidadores of Barranquitas
– by Gindel Delgado (20 min)

ROOM B: Bruxelles

Little Movement
– by Sergio Gridelli and Maaïke van de Westeringh (20 min)

'Dropvla' and cathetersigarettes; heroes of the Huntington home
– by Annemieke Schakelaar & Freke Remmers (25 min)



SATURDAY, 14th SEPTEMBER, 2024

08:30 – 08:45

WELCOME AND INTRODUCTION

Chaired by Bernhard Landwehrmeyer, Eileen Neacy, Cristina Sampaio

08:45 – 10:00

Practical Deployment of HD-ISS in Clinical Research

Chaired by Chris Ross and Sarah Tabrizi

1. **HD-ISS Overview: Opportunities and challenges for the future**
Cristina Sampaio
2. **Using the HD-ISS for Planning Clinical Trials**
Jeff Long
3. **Panel Discussion: Using the HD-ISS**
Walid Abi-Saab, Peter McColgan, Amy-Lee Bredlau, Glenn Morrison

10:00 – 10:30

BREAK

10:30 – 11:30

PARALLEL SESSIONS V

A. Advances Obtained Through Enroll Part 1: Biomarkers and Modelling

Chaired by Irina Antonijevic and Hilary Wilkinson

1. **Enroll-HD samples and data - scope and distribution**
Katrin Barth
2. **How the GWAS exemplifies what you can do with Enroll data**
Jong-Min Lee
3. **NfL plasma data from Enroll-HD samples to explore this biomarker**
Doug Langbehn
4. **Modelling using Enroll-HD data – focus on PIN HD**
Jim Mills

B. Advantages and Challenges of Decentralized Visits

Chaired by Selene Capodarca and Gail Owen

1. **UHDRS remote**
Sam Frank
2. **LSA-HD-SIF**
Sarah Weingast
3. **Kinect-HD study, Neurocrine**
Erin Koppel
4. **Remote blood collection**
Lauren Byrne
5. **Panel Discussion**

11:30 – 12:00

FLASH POSTER PRESENTATIONS

Chaired by Christine Capper-Loup and Joel Perlmutter

12:00 – 13:00

LUNCH and POSTER VIEWING

13:00 – 14:00

PARALLEL SESSIONS VI

A. Advances in Enroll Part 2: Clinical Trial and Clinical Study Support

Chaired by Yuan Huang and Jen Ware

1. **Enroll-HD support of clinical trials**
Jenny Townhill
2. **Placebo arm in Generation HD vs Enroll-HD data**
Marcelo Boareto
3. **Platform Studies: HD-Charge**
Jamie Hamilton
4. **Envisioning the future of clinical research with Enroll-HD 2.0**
Joaquim Ferreira

B. Best Practices in Study Coordination - Part of Something Bigger

Chaired by Ruth Fullam and Noopur Modi

1. **Enroll-HD Best Practices Bonanza**
Selene Capodarca and Jenny Callaghan
2. **Strategies for attracting, recruiting, and maintaining younger populations**
Bonnie Hennig-Trestman
3. **Scheduling and managing Enroll-HD with other studies**
Katie Andresen
4. **Parallel studies using Enroll-HD sites (iMark)**
Monika Hartmann



- 14:00 – 15:00 **KEYNOTE LECTURE: Use of Innovative Trial Designs to Accelerate Drug Development in HD**
Chaired by Rebecca Fuller and Lauren Byrne
Speaker: Michael Panzara
- 15:00 – 15:30 **BREAK**
- 15:30 – 16:30 **The Next Frontier of Enroll-HD**
Chaired by Lexi Mansbach and Jenne Coler Dark
1. **Enroll-HD 2.0: What is Changing and Why**
Swati Sathe
 2. **selfEnroll**
Matt Roche
- 16:30 – 17:30 **ADVANCES IN ENROLL-HD PART 3: Novel Clinical Trial Design**
Chaired by Brian Beers and Juliana Bronzova
1. **Early Development Trials Phase I/II, the Need to go Early and how to do it**
Priyantha Herath
 2. **Early Phase Biomarker Strategy, Possibilities from Imaging/ PET as a Target Engagement Biomarker**
Andrew Wood
 3. **Bridge Model – Variation of “Seamless phase II to III trial”**
Tiago Mestre
 4. **Bridging to Clinical Benefit**
Patrick Weydt
 5. **Panel Discussion and Q&A**
- 17:30 – 18:00 **EHDN AND ENROLL-HD 2024: Wrap-Up**
Chaired by Eileen Neacy and Cristina Sampaio