



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

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 Stephan von Hörsten

1. **Advancing the understanding of HAP40's function and its role in HD**
Manuel Seefelder
2. **Pyroglutamic acid formation as a cross disease mechanism in AD/PD/HD: preclinical target validation in HD**
Stephan von Hörsten
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. **Cognitive rehabilitation**
Katharine Huynh
2. **Speech: A predictor of clinical features in HD**
Remy Nguyen
3. **Language disintegration in HD**
Arnau Puig-Davi



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 Mühlböck

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

L'EUROBUZZ

Speaker: Jeff Carroll, Leora Fox, Rachel Harding, Sarah Hernandez, Ed Wild

18:45

NETWORKING EVENING

Posters, finger food, drinks & music

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

10:15 – 10:45

BREAK

10:45 – 11:45

UPDATE ON PLANNED CLINICAL TRIALS

Chaired by Lena Hjerminnd and Tim McLean

11:45 – 12:15

KEYNOTE LECTURE: Lessons Learnt from Clinical Trials and Future Challenges

Chaired by Alexandra Durr

Speaker: Sarah Tabrizi

12:15 – 14:30

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: Marguerite Garcia Reseau, Vinciane Gorissen, Marc Issandou



14:30 – 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**
Steve McCaroll
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**
Coa 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**
Alexandra Fisher

15:30 – 16:00

BREAK

16:00 – 17:00

PARALLEL SESSIONS IV

A. Development and Aging in HD

Chaired by Karine Merienne and Anne Rosser

1. **Developmental contribution 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**
Cameron Harwood
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 Ása Petersén
Speaker: Harry Orr



- 17:45 – 18:30 **SHORT COMMUNICATIONS**
Chaired by Flaviano Giorgini and Caterina Mariotti
- 18:30 – 18:50 **SPECIAL TALKS: Hidden no More and “The Present”**
Chaired by Filipa Júlio
Speaker: Charles Sabine and Dimitri Poffé
- 18:50 – 19:00 **SUMMARY AND POSTER AWARD**
Chaired by Flaviano Giorgini
- 19:00 **MOVIE NIGHT**
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| The Present
– by Timothy Dhalleine
(18 min) | Little Movement
– by Sergio Gridelli and Maaïke
van de Westeringh (20 min) | La Luz - the Cuidadores of
Barranquitas
– by Gindel Delgado (20 min) |
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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
Cristina Sampaio
 2. The Application of the HD-ISS to Legacy Datasets
Jeff Long
 3. Panel Discussion using HD-ISS
- 10:00 – 10:30 **BREAK**
- 10:30 – 11:30 **PARALLEL SESSIONS V**
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| A. Advances Obtained Through Enroll Part 1: Biomarkers and Modelling
Chaired by Irina Antonijevic and Hilary Wilkinson | B. Advantages and Challenges of Decentralized Visits
Chaired by Selene Capodarca and Gail Owen |
| <ol style="list-style-type: none"> 1. Enroll-HD samples and data - scope and distribution
Olivia Handley 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 | <ol style="list-style-type: none"> 1. UHDRS remote
Sam Frank 2. LSA-HD-SIF
Sarah Weingast 3. Kinect-HD study, Neurocrine
Erin Koppel 4. Remote blood collection
Lauren Byrne |
- 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 Ferriera

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 Henrik Zetterberg

Speaker: Michael Panzara

15:00 - 15:30

BREAK

15:30 - 16:30

ENROLL-HD 2.0: What is coming?

Chaired by Lexi Mansbach and Louise Vetter

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