



EHDN Clinical Research Congress 2026 22nd – 24th October 2026, Kraków, Poland

Status Oct 05th

THURSDAY, 22nd OCTOBER, 2026

07:30 – 08:30 REGISTRATION DESK

08:30 – 09:00 WELCOME AND INTRODUCTION

Chaired by Patrick Weydt, Cristina Sampaio, Danuta Lis and Krzysztof Jan Klęczar

09:00 – 09:45 PLENARY SESSION I: HD Burden - Family and Patient Perspective

Chaired by Åsa Petersén

Speakers: Charlotte Spearing, Marianna Ellison-Klimontowicz, Greg Witkowski and William Gray

09:45 – 10:30 PLENARY SESSION II: Navigating the Therapeutic Pipeline in Huntington's Disease

Chaired by Swati Sathe and Pavlina Stefanova-Konstantinova

1. **The Race to treat Huntington's disease: where have we come over the past decade**
Anne Rosser
2. **Future Challenges and Opportunities in the Clinical Development of Huntington's Disease Therapies**
Cristina Sampaio
3. **Panel Discussion and Q&A**

10:30 – 11:00 **BREAK**

11:00 – 12:00 PARALLEL SESSIONS I

A. Learning Across Neurodegenerative Diseases: Clinical Trial Innovation, Design, and Ethics

Chaired by Patrick Weydt and Ruben van Eijk

1. **Lessons and innovations in clinical trials for Amyotrophic Lateral Sclerosis**
Ruben van Eijk
2. **Looking back - looking forward: insights into clinical trial design and determination of clinical meaningfulness**
Michael Hayden
3. **Placebo-controlled surgical trials: an ethical overview**
Cindy Towns

B. Psychological interventions in Huntington's Disease: a Transdiagnostic Perspective

Chaired by Docia Demmin and Lucienne Van der Meer

1. **Keeping Yourself in Mind: Acceptance and Commitment Therapy programmes for people affected by Huntington's Disease**
Sarah Gunn
2. **GUIDE HD: Results from the first psychological randomised controlled trial to reduce anxiety**
Maria Dale
3. **Moving forward: What are the lessons from GUIDE HD for testing and delivering psychological interventions?**
Jane Simpson

12:00 – 13:30 **LUNCH and POSTER VIEWING**



13:30 – 14:30

PARALLEL SESSIONS II

A. Digital Biomarkers and Artificial Intelligence

Chaired by Jean-Marc Burgunder and Matt Roche

1. Sensitivity, Validity, and Utilization of the HD Digital Motor Score in Clinical Trials

Jonas Dorn

2. Q-Motor Outcomes at 3 Years after AMT-130 HTT-Lowering Gene Therapy

David Margolin

3. AI-Powered Digital Twins: Applications and Opportunities in Clinical Trials

Ann-Kathrin Schalkamp

4. Panel Discussion and Q&A

B. Social Cognition

Chaired by Sarah Mason and Rebecca Fuller

1. Reading minds missing people: Ecological validity problem in social cognition

Erin Heerey

2. Cling Film, Text Messages and Work - Three ethnographic stories of early social cognitive change in Huntington's disease

Alex Fisher and Clare Eddy

3. Clinical Vignettes

Sarah Mason

4. Panel Discussion and Q&A

14:30 – 14:35

Transition BREAK

14:35 – 15:15

EHDN BUSINESS MEETING

Chaired by Patrick Weydt and Åsa Petersén

15:15 – 15:45

BREAK

15:45 – 16:45

KEYNOTE LECTURE I: Genetic Testing and Genetic Modifiers

Chaired by Nayana Lahiri and Hoa Huu Phuc Nguyen

Speaker: Alexandra Durr

16:45 – 17:45

DEBATE: Implementation of Genetic Modifier Data into Clinical Practice – Are we there, yet?

Chaired by Nayana Lahiri and Hoa Huu Phuc Nguyen

Speaker: Michael Hayden, Alexandra Durr, Robert Klitzman, Ashleigh Mclellan and Darren Monckton

17:45 – 22:00

NETWORKING EVENING

Posters, Art Exhibition, Finger Food & Drinks



FRIDAY, 23rd OCTOBER, 2026

08:00 – 08:45 PLENARY SESSION III: Access and Affordability for the HD Community

Chaired by Hugh Rickards and Jenna Heilman

1. **HEATED (Huntington's Equal Access to Effective Drugs). The story so far.**
Hugh Rickards
2. **Access to effective HD drugs: the global perspective**
Ignacio Muñoz-Sanjuan
3. **What are the barriers to access to effective drugs in HD and how do we overcome them?**
Josie Godrey
4. **Panel Discussion and Q&A**

08:45 – 09:45 UPDATE ON ONGOING CLINICAL TRIALS

Chaired by Jenny Townhill and Ralf Reilmann

1. **Alnylam**
Sarah Tabrizi
2. **VICO Therapeutics**
Scott Schobel
3. **Skyhawk Therapeutics**
Meghan Miller
4. **Placebo Response in Recent HD Randomized Clinical Trials**
Jeffrey Long
5. **Panel Discussion and Q&A**

09:45 – 10:00 BREAK

10:00 – 11:00 PARALLEL SESSIONS III

A. Modifiers of Huntington's Disease: Genetic, Biological, and Preclinical Perspectives

Chaired by Marta Biagioli and Vahri Beaumont

1. **PMS1/MLH1 variants and drugging the PMS1 ATPase site**
Tom Massey
2. **MED15 as a Non-MMR Modifier of Huntington's Disease**
Mahmoud Pouladi
3. **hiPSC cell models**
Mike Flowers

B. Glymphatic Imaging

Chaired by Daniel Claassen and Andrew Wood

1. **Why the Glymphatic System Deserves Our Attention**
Daniel Classen
2. **Imaging Human Glymphatic Function with Intrathecal Contrast: From Method to Clinical Readout**
Per Kristian Eide
3. **Imaging the Glymphatic System in Huntington's Disease and Neurodegeneration: Implications for Monitoring and Neurotherapeutics**
Manus Donahue

11:00 – 11:30 BREAK

11:30 – 12:30 KEYNOTE LECTURE II: The Ubiquitin Proteolytic System - From a Hypothetical Assumption of Why it Should Exist to Human Diseases and Drug Development

Chaired by Hoa Huu Phuc Nguyen

Speaker: Aaron Ciechanover (Nobel Prize Winner for Chemistry 2004)



- 12:30 – 14:30 **LUNCH, POSTER VIEWING and SPECIAL SESSIONS**
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|--|---|--|
| <p>a. A Collaboration of Global Advocacy presented by HDYO, EHA and IHA
13:15–14:15
Chaired by Jenna Heilman, Astri Arnesen and Svein Olaf Olsen</p> | <p>b. EHDN/MDS-ES Fellowship Meeting
13:00–14:15
Chaired by Juliana Bronzova and Fionnuala Margreiter</p> | <p>c. Local Language Session
13:00–15:30
Chaired by Danuta Lis and Daniel Zielonka</p> |
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- 14:30 – 15:30 **SHORT COMMUNICATIONS I (Presentation of selected abstracts)**
Chaired by Davina Hensman Moss and Jiří Klempíř
1. **Nuclear mHTT Toxicity Drives Transcriptome Wide Splicing Defects in Huntington’s Disease Mouse Models**
Libo Yu-Taeger
 2. **Lowering the HTT1a transcript as an effective therapy for Huntington’s disease in a knock-in mouse model**
Aikaterini Papadopoulou
 3. **Dissecting functions of FAN1 that protect against HTT CAG repeat expansion in disease-relevant cellular models of Huntington’s Disease**
Claire Pimblett
 4. **Development of Ultra-high Sensitive HTT Immunoassays on the NULISA Platform for the Measurement of HTT Proteins in Human Cerebrospinal Fluid**
Barbara Baldo
 5. **Early Subcortical Molecular PET Changes Across Huntington’s Disease Stages: results from the iMarkHD Study**
Manuela Moretto
 6. **Harmonise-HD: A harmonised, traceable multi-cohort longitudinal dataset for biomarker validation across the Huntington’s Disease Integrated Staging System**
Arsalan Dezhkam
 7. **The Journeys of Non-Affected Parents within Families with Huntington’s disease**
Elizabeth Furr
 8. **Psychological Care in Huntington’s Disease: Development of a National Consensus-Based Practice Guide**
Kasper van der Zwaan
- 15:30 – 16:30 **PLENARY SESSION IV: Advanced Biomarkers**
Chaired by Hilary Wilkinson and Niels Skotte
1. **Lipidomics and new biomarkers**
William Griffiths
 2. **PENK & NEFL**
Niels Skotte and Hilary Wilkinson
 3. **HD YAS 3.0**
Rachael Scahill
- 16:30 – 17:00 **BREAK**
- 17:00 – 18:00 **PANEL DISCUSSION: Clinical Trial Communications in Context - Rules, Responsibilities, and Community Expectations**
Chaired by Emily Gantman and Ed Wild
Panel: Charlotte Spearing, Mai-Lise Nguyen, Rachel Harding and David Anderson



SATURDAY, 24th OCTOBER, 2026

08:30 – 09:15 EHDN LIGHTNING PRESENTATIONS

Chaired by Duncan McLauchlan and Agnieszka Fiszer

1. **Lightning Presentation on awarded EHDN Strategic Funds**
Nayana Lahiri, Camilla Ekwall and Cheney Drew
2. **The expanded HTT CAG repeat is a DNA repair hotspot where unscheduled DNA synthesis serves as a sensitive biomarker of somatic instability**
Verónica Inés Brito
3. **LTS-201: An AAV Gene Therapy Targeting MSH3 for Huntington's Disease**
Jang-Ho Cha
4. **LQT-23: a small molecule MSH3 inhibitor targeting somatic instability in Huntington's disease**
Caroline L. Benn

09:15 – 10:15 PLENARY SESSION V: Efficacy Demonstration - Standards, Measures and Endpoints

Chaired by Ahmad Aziz and Jamie Hamilton

1. **Analysis of Enroll-HD TMS training data**
Matt Roche
2. **Analytical Considerations for Contextualizing Outcomes and Estimating Treatment Effects in Huntington's Disease Clinical Trials with Partial or no Internal Control Using External Cohort Data**
Angelika Caputo
3. **MCID within the context of other Neurodegenerative disorders**
Glenn Stebbins

10:15 – 10:45 BREAK

10:45 – 11:45 SHORT COMMUNICATIONS II (Presentation of selected abstracts)

Chaired by Mayke Oosterloo and Arun Karpur

1. **Upregulation of FAN1 with ASOs as a potential therapeutic strategy for triplet repeat disorders**
Laura Heraty
2. **Small RNAs in CSF capture early and stage-specific molecular changes in Huntington's disease**
Marina Herrero-Lorenzo
3. **Ultra-sensitive & rapid assessment of somatic CAG expansions in HD patient CSF**
Mustafa Mehkary
4. **HD-DRUM rhythmic training in Huntington's disease: Results from a randomised controlled feasibility trial including motor and brain microstructural signals**
Claudia Metzler-Baddeley
5. **Speech Captures Much of the Neuroanatomical Signal Predicting Clinical Status in Huntington's Disease**
Robin Louiset
6. **Experiences of living with an intermediate allele or reduced penetrance rate predictive test result for Huntington's disease: An interpretative phenomenological analysis**
Sarah Gunn



7. Developing a DNA extraction and High-throughput MiSeq sequencing protocol to quantify repeat length variability at the HTT CAG repeat in Huntington's Disease sperm

Sangeerthana Rajagopal

8. Enroll-HD 2.0: Updates to the Enroll-HD observational study

Swati Sathe

11:45 – 12:45 From Clinical Trial Progress and Regulatory Perspectives

Chaired by Bernhard Landwehrmeyer and Daniel Weintraub

1. Regulatory perspectives on trial innovation and clinical meaningful outcomes

Elena Hernández Martínez de Lapiscina

2. Tominersen: GENERATION HD2 Results and Key Learnings

David Hawellek

3. Votoplam: Phase 2 Results and Phase 3 INVEST-HD study update

Beth Borowsky

4. Panel Discussion and Q&A

Elena Hernández Martínez de Lapiscina, David Hawellek, Beth Borowsky, Anne Rosser and Dina De Sousa

12:45 – 13:10 SUMMARY AND POSTER AWARD

Chaired by Nayana Lahiri, Hoa Huu Phuc Nguyen and HDYO ambassador

13:10 – 13:15 FAREWELL

Chaired by Patrick Weydt and Cristina Sampaio