

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

**Preliminary programme – status Sept 22*

THURSDAY, 22nd OCTOBER, 2026

07:30 – 08:30 REGISTRATION DESK

08:30 – 09:00 WELCOME AND INTRODUCTION
Chaired by Patrick Weydt, Cristina Sampaio and Danuta Lis

09:00 – 09:45 PLENARY SESSION I: HD Burden - Family and Patient Perspective
Chaired by Åsa Petersén
Speakers: Charlotte Spearing, Greg Witkowski, William Gray and Marianna Ellison-Klimontowicz

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. **Talk III**
   TBA
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

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

b. EHDN/MDS-ES Fellowship Meeting
13:15–14:15
Chaired by Juliana Bronzova and Fionnuala Margreiter

c. Local Language Session
13:00–15:30
Chaired by Danuta Lis and Daniel Zielonka

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 Fur
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

9. **Lipidomics and new biomarkers**
   William Griffiths
10. **PENK & NEFL**
    Niels Skotte and Hilary Wilkinson
11. **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**
   Peter McColgan
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, Peter McColgan, Beth Borowsky, Anne Rosser and Dina De Sousa

12:45 – 13:10 SUMMARY AND POSTER AWARD
Chaired by Nayana Lahiri and Hoa Huu Phuc Nguyen

13:10 – 13:15 FAREWELL
Chaired by Patrick Weydt and Cristina Sampaio