

## EHDN Plenary Meeting, Sep. 16 – 18, 2022, Bologna, Italy

### FRIDAY, SEPTEMBER 16th, 2022

**07:30 – 08:30**      **REGISTRATION DESK**

**08:30 – 09:00**      **WELCOME AND INTRODUCTION**

Chaired by Anne Rosser, Patrick Weydt, Astri Arnesen, Pietro Cortelli

**09:00 – 10:30**      **PLENARY SESSION I: 150 years of Huntington disease**

Chaired by Anne Rosser and Charles Sabine

**1. Living with HD**

Charlotte Raven and Ed Wild (30 min)

**2. Mutant Huntingtin: Molecules, Models, Medicines**

Gillian Bates (30 min)

**3. Wild-type Huntingtin: Evolution, Structure, Function**

Elena Cattaneo (30 min)

**10:30 – 11:00**      **BREAK**

**11:00 – 12:30**      **PLENARY SESSION II: New genetics of HD**

Chaired by Hoa Huu Phuc Nguyen and Flaviano Giorgini

**1. Genetic Modifiers in HD and somatic mosaicism**

Darren Monckton (30 min)

**2. CAG repeat sizes in a healthy population - correlation with imaging data**

Larissa Arning (20 min)

**3. FAN1 as genetic modifier for HD progression**

Joe Hamilton (20 min)

**4. Genomic modifiers in clinical practice and therapy**

Galen Wright (20 min)

**12:30 – 14:00**      **LUNCH and POSTER VIEWING**

**14:00 – 15:00**      **PARALLEL SESSIONS I**

**A. HTT structure and function**

Chaired by Chiara Zuccato and Frederic Saudou

**1. HTT/HAP40 complex in the pathophysiology of HD**

Stefan Kochanek (20 min)

**2. HTT role in neuronal transport**

Frederic Saudou (20 min)

**3. HTT exon 1 aggregation and PTMs code**

Hilal Lashuel (20 min)

**B. Digital Endpoints**

Chaired by Ralf Reilmann and Ahmad Aziz

**1. Digital endpoints – a perspective from Multiple Sclerosis bridging to HD**

Marcus D'Souza (15 min)

**2. Digital endpoints in Parkinson's disease – where are we?**

Andrea Pilotto (15 min)

**3. Lessons learnt from digital markers in the Tominersen program**

Jonas Dorn (15 min)

**4. Lessons learnt from Q-Motor and Q-Cog in HD trials**

Robin Schubert (15 min)

**15:00 – 15:30**      **BREAK**

**15:30 – 17:00** **PLENARY SESSION III: Approaches to quality of life and clinical management of HD**

Chaired by Alzbeta Mühlbäck and Giorgos Papantoniou

**1. Session Introduction**

Alzbeta Mühlbäck (5 min)

**2. Coping with Symptoms of HD – Patient Story**

Tess Persson (10 min)

**3. Quality of Life and PROMs for HD**

Steve McKenna (20 min)

**4. Management of the Psychiatric Symptoms in HD**

Duncan McLauchlan (20 min)

**5. Managing Cognitive Symptoms and Neurocognitive Rehabilitation**

TBD (20 min)

**6. Panel Discussion (15 min)**

**17:00 – 17:30** **BREAK**

**17:30 – 18:30** **Working Groups Session**

Chaired by Michael Orth and Kristina Becanovic

**18:30 – 19:15** **SHORT COMMUNICATIONS I**

Chaired by Maria Björkqvist and Marco Onorati

**19:15 – 20:00** **Evening session: Special Lecture by Nora Guthrie**

Chaired by Michaela Winkelmann and Patrick Weydt

**20:00** **DINNER ON YOUR OWN**  
**Gene banner and lay event**

**SATURDAY, SEPTEMBER 17th, 2022**

**08:00 – 09:15** **MEET THE EXPERT BREAKFAST SESSION\***

**09:30 – 11:00** **PLENARY SESSION IV: Update on ongoing clinical trials**

Chaired by Sarah Tabrizi and Astri Arnesen

**1. Prilenia**

Michael Hayden (10 min)

**2. UniQure**

David Cooper (10 min)

**3. Wave**

Michael Panzara (10 min)

**4. PTC**

Brian Beers (10 min)

**5. TBD (10 min)**

**6. SOM Biotech**

Catherine Scart (10 min)

**7. Panel Discussion (30 min)**

**11:00 – 11:30** **BREAK**

**11:30 – 12:15** **SHORT COMMUNICATIONS II**

Chaired by Katrin Lindenberg and Anne Norremolle

**12.15 – 13.00** **Business Meeting**

Chaired by Anne Rosser

- 13.00 – 14:30** **LUNCH and POSTER VIEWING**
- 14:30 – 15:30** **PARALLEL SESSION II**
- A. The use of biomarkers in clinical trials of neurodegenerative disorders**  
Chaired by Maciej Figiel and Lauren Byrne
- 1. Neurofilaments as biomarkers across neurodegenerative disorders**  
Henrik Zetterberg (30 min)
  - 2. A novel ultrasensitive huntingtin assay to measure huntingtin protein in a polyglutamine length-independent manner**  
Douglas Macdonald (15 min)
  - 3. An update on iMAGeMHTT - mHTT PET tracer development in the clinic**  
Aline Delva (10 min)
  - 4. Outro - a perspective of unmet biomarker needs for HD therapeutic development**  
Lauren Byrne (5 min)
- B. Neurodevelopment/Pediatric/juvenile HD**  
Chaired by Sandrine Humbert and Peggy Nopoulos
- 1. Axonal growth defects during development contribute to early HD signs**  
Mariacristina Capizzi (20 min)
  - 2. Growth and development of the striatum in children and adolescents at risk for HD**  
Peggy Nopoulos (20 min)
  - 3. Huntington disease in Kids**  
Ferdinando Squitieri (20 min)
- 15.30 – 15:45** **BREAK**
- 15:45 – 16:45** **PARALLEL SESSION: III**
- A. White matter changes in HD**  
Chaired by Åsa Petersen and Mahmoud Pouladi
- 1. Oligodendrocyte dysfunction in Huntington disease**  
Mahmoud Pouladi (20 min)
  - 2. Glial-specific transcriptomic changes in HD**  
Anna Williams (20 min)
  - 3. Imaging white matter changes in HD**  
TBD (20 min)
- B. Multidisciplinary care**  
Chaired by Ruth Veenhuizen and Monica Busse
- 1. Session Introduction (5 min)**
  - 2. Moral deliberation and dilemmas in multidisciplinary care**  
Ruth Veenhuizen (10 min)
  - 3. Moving against resistance: implications for physiotherapy and physical activity**  
Una Jones (12 min)
  - 4. Managing the transition from independence**  
Manon van Kampen (12 min)
  - 5. Nutrition decision making**  
Margret Knoll (12 min)
  - 6. Panel Discussion (10 min)**
- 17:00 – 17:45** **PLENARY LECTURE I: Lessons learnt from other neurodegenerative disorders: Protein vaccination to treat RAN translation in C9ORF ALS**  
Chaired by Patrick Weydt  
Speaker: Dieter Edbauer
- 17:45 – 18:15** **PLENARY LECTURE II: HD-ISS - a primer for use in clinical research**  
Chaired by TBD  
Speaker: Sarah Tabrizi
- 18:15 – 19:00** **ROUND TABLE DISCUSSION: What do results from clinical trials mean?**  
Chaired by Jean-Marc Burgunder  
Speaker: Serge Bakchine, Henrik Zetterberg, Bernhard Landwehrmeyer and TBD
- 19:00 – 23:00** **NETWORKING EVENING**  
Finger Food, Drinks & Music // Photo exhibition 'Abandonment: From Landscapes to Mindscapes' by EHA

SUNDAY, SEPTEMBER 18th, 2022

08:00 – 09:15 MEET THE EXPERT BREAKFAST SESSION\*

09:30 – 11:00 PLENARY SESSION V: Advanced Therapies for Huntington's Disease

Chaired by Anne Rosser and Romina Aron-Badin

1. **Introduction – overview of challenges in delivering advanced therapies to the brain in HD**  
Romina Aron-Badin (15 min)
2. **How do we innovate? Challenges of delivering substances to the brain and trial design issues**  
Liam Gray (15 min of delivery)  
Cheney Drew (15 min on trial design)
3. **What is new? Example of cell therapy**  
Leslie Thompson (15 min)
4. **What is new? DBS**  
Jan Vesper (15 min)
5. **Discussion** (15 min)

11:00 – 11:30 BREAK

11:30 – 12:30 PLENARY SESSION VI: Update on planned clinical trials

Chaired by Tim McLean and Bernhard Landwehrmeyer

12:30 – 13:00 LATE BREAKING NEWS: TBD

Chaired by TBD

13:00 – 13:30 ROUND-UP AND POSTER AWARDS

Chaired by Patrick Weydt and Åsa Petersen

## \*MEET THE EXPERT BREAKFAST SESSIONS:

1. **HD in Italy and in Italian**, chaired by Chiara Zuccato and Antonio Fontana➔ **Saturday, Sept 17<sup>th</sup>, 8:00 – 9:15: Integrated Care Pathway for Huntington's Disease //  
Percorso Diagnostico Terapeutico Assistenziale per la Malattia di Huntington**

Guest: Cesa Scaglione

➔ **Sunday, Sept 18<sup>th</sup>, 8:00 - 9:15: Basic Research and Clinical Trial //  
Ricerca di Base e Sperimentazioni Cliniche**

Guest: Caterina Mariotti

2. **HD for beginners**, chaired by Ahmad Aziz and Bernhard Landwehrmeyer3. **Young people and HD**, chaired by Jenna Heilman and Rebecca Mason from HDYO4. **Psychiatric Session about sexuality and intimacy**, chaired by Alzbeta Mühlbäck and Gila Bronner5. **Eating and Swallowing**, chaired by Falk Schradt and Angela Nuzzi