

## 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

**09:00 – 10:30**     **KEYNOTE SESSION: 150 Years of Huntington's Disease**

Chaired by Anne Rosser and Charles Sabine

**1. Living with HD**

Charlotte Raven and Ed Wild

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

Gillian Bates

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

Elena Cattaneo

**10:30 – 11:00**     **BREAK**

**11:00 – 11:15**     **Remembering Lesley Jones**

Speaker: Anne Rosser and Sarah Tabrizi

**11:15 – 12:45**     **PLENARY SESSION I: New Genetics of HD**

Chaired by Hoa Huu Phuc Nguyen and Flaviano Giorgini

**1. Genetic Modifiers in HD and Somatic Mosaicism**

Darren Monckton

**2. Non-pathogenic CAG Tract and Gray Matter Microstructure in the Human Brain**

Larissa Arning

**3. FAN1 as a Genetic Modifier for HD Progression**

Joe Hamilton

**4. Genomic Modifiers in Clinical Practice and Therapy**

Galen Wright

**12:45 – 14:00**     **LUNCH and POSTER VIEWING**

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

**A. HTT Structure and Function**

Chaired by Chiara Zuccato and Frédéric Saudou

**1. HTT/HAP40 Complex in the Pathophysiology of HD**

Stefan Kochanek

**2. HTT Role in Neuronal Transport**

Frédéric Saudou

**3. HTT Exon 1 Aggregation and PTMs Code**

Hilal Lashuel

**B. Digital Endpoints**

Chaired by Ralf Reilmann and Ahmad Aziz

**1. Digital Endpoints – A Perspective from Multiple Sclerosis Bridging to HD**

Marcus D'Souza

**2. Lessons Learnt from the Roche HD Digital Monitoring Programme**

Jonas Dorn

**3. Lessons Learnt from Q-Motor and Q-Cog in HD Trials**

Robin Schubert

**15:00 – 15:30**     **BREAK**

- 15:30 – 17:00**     **PLENARY SESSION II: Approaches to Quality of Life and Clinical Management of HD**  
Chaired by Alzbeta Mühlbäck and Giorgos Papantoniou
- 1. Session Introduction**  
Alzbeta Mühlbäck
  - 2. Coping with Symptoms of HD – A Patient Story**  
Tess Persson
  - 3. Quality of Life and PROMs for HD**  
Steve McKenna
  - 4. Understanding Emotions and Psychiatric Aspects of HD**  
Åsa Petersén
  - 5. Management of the Psychiatric Symptoms in HD**  
Duncan McLauchlan
  - 6. Panel Discussion**
- 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 SESSIONS\***
- 09:30 – 11:00**     **PLENARY SESSION III: Update on Ongoing Clinical Trials**  
Chaired by Sarah Tabrizi and Astri Arnesen
- 1. Prilenia**  
Michael Hayden
  - 2. UniQure**  
Ricardo Dolmetsch
  - 3. Wave Life Sciences**  
Danlin Xu
  - 4. PTC Therapeutics**  
Amy-Lee Bredlau
  - 5. SOM Biotech**  
Catherine Scart
  - 6. Triplet Therapeutics**  
Irina Antonijevic
  - 7. Panel Discussion**  
Dina de Sousa and all Plenary Session Speakers
- 11:00 – 11:30**     **BREAK**
- 11:30 – 12:15**     **SHORT COMMUNICATIONS II**  
Chaired by Katrin Lindenberg and Anne Nørremølle
- 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

**2. A Novel Ultrasensitive Assay to Measure Huntingtin Protein in a Polyglutamine-length-independent Manner**

Douglas Macdonald

**3. An Update on iMAGEmHTT - mHTT PET Tracer Development in the Clinic**

Aline Delva

**4. A Perspective of Unmet Biomarker Needs for HD Therapeutic Development**

Lauren Byrne

**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

**2. Growth and Development of the Striatum in Children and Adolescents at Risk for HD**

Peggy Nopoulos

**3. Huntington's Disease in Kids**

Ferdinando Squitieri

15.30 – 15:45

**BREAK**

15:45 – 16:45

**PARALLEL SESSION: III**

**A. White Matter Changes in HD**

Chaired by Åsa Petersén and Mahmoud Pouladi

**1. Oligodendrocyte Dysfunction in HD**

Mahmoud Pouladi

**2. Early White Matter Pathology in the Fornix in HD**

Sanaz Gabery

**3. Glial-specific Transcriptomic Changes in HD**

Anna Williams and Sunniva Bøstrand

**B. Multidisciplinary Care**

Chaired by Ruth Veenhuizen and Monica Busse

**1. Moral Deliberation and Dilemmas in Multidisciplinary Care**

Ruth Veenhuizen

**2. Moving Against Resistance: Implications for Physiotherapy and Physical Activity**

Una Jones

**3. Managing the Transition from Independence**

Manon van Kampen

**4. Nutrition Decision Making**

Margret Knoll

**5. Panel Discussion**

16:45 – 17:00

**BREAK**

17:00 – 17:45

**KEYNOTE LECTURE: 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

**KEYNOTE LECTURE: HD-ISS - A Primer for Use in Clinical Research**

Chaired by Cristina Sampaio

Speaker: Sarah Tabrizi

18:15 – 18:45

**SPECIAL REPORT: Towards an Understanding of the Post-treatment and Mechanistic Aspects of Tominersen**

Chaired by Jean-Marc Burgunder

Speaker: Peter McColgan

- 18:45 – 19:30**     **ROUND TABLE DISCUSSION: What do Results from Clinical Trials Mean?**  
Chaired by Jean-Marc Burgunder and Patrick Weydt  
Speaker: Henrik Zetterberg, Bernhard Landwehrmeyer, Jessica Koehli, Anne Rosser, Peter McColgan and Irina Antonijevic
- 19:30 – 23:00**     **NETWORKING EVENING**  
Posters, finger food, drinks & music  
Photo exhibition 'Abandonment: From Landscapes to Mindscapes' by the European Huntington Association

**SUNDAY, SEPTEMBER 18th, 2022****08:00 – 09:15**     **MEET THE EXPERT BREAKFAST SESSIONS\*****09:30 – 11:00**     **PLENARY SESSION IV: Advanced Therapies for HD**

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
- 2. How Do We Innovate? Challenges of Delivering Substances to the Brain and Trial Design**  
Liam Gray and Cheney Drew
- 3. What is New? Cell Therapy**  
Leslie Thompson
- 4. What is New? Deep Brain Stimulation DBS**  
Jan Vesper
- 5. Discussion**

**11:00 – 11:30**     **BREAK****11:30 – 12:30**     **PLENARY SESSION V: Update on Planned Clinical Trials**

Chaired by Tim McLean and Bernhard Landwehrmeyer

- 1. AskBio**  
Nathalie Cartier-Lacave
- 2. Sage Therapeutics**  
Aaron Koenig
- 3. Roche**  
Peter McColgan
- 4. Annexon**  
Henk-André Kroon

**12:30 – 13:00**     **ROUND-UP, POSTER AWARDS AND FAREWELL**

Chaired by Patrick Weydt, Åsa Petersén and Anne Rosser

**\*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 Landwehrmeyer

**3. Young People and HD**, chaired by Jenna Heilman and Rebecca Mason from HDYO

**4. Psychiatric Session about Sexuality and Intimacy**, chaired by Alzbeta Mühlbäck and Rainer Hoffmann

**5. Eating and Swallowing**, chaired by Angela Nuzzi, Cornelius Werner and Beate Schumann-Werner