

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. HD genomic modifiers: emerging biological, clinical and therapeutic insights

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

Bernhard Landwehrmeyer

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**
Anne Rosser
- 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 17th, 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 18th, 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