

## FRIDAY, SEPTEMBER 14th, 2018

07:30 - 08:30 REGISTRATION DESK

08:30 - 09:00 WELCOME AND INTRODUCTION

09:00 - 10:30 **KEYNOTE SESSION I: Past, Present, Future**

Chair: Jean-Marc Burgunder (Bern, Switzerland) / Co-Chair: Astri Arnesen (Søgne, Norway)

**1. Learning from the History of Huntington's Disease**

*Peter Harper (Cardiff, UK)*

**2. Where are we Now**

*Alexandra Dürr (Paris, France)*

**3. The Silver Linings Playbook – A Future Outlook**

*Ed Wild (London, UK)*

**4. Family Perspective**

*Astri Arnesen (Søgne, Norway)*

10:30 - 11:00 BREAK

11:00 - 12:30 **PLENARY SESSION I: WHAT'S NEW IN HD BIOLOGY? Insights into Pathogenic Pathways and Therapeutic Targets**

Chair: Lesley Jones (Cardiff, UK) / Co-Chair: Erich Wanker (Berlin, Germany)

**1. Recent Breakthrough in Resolving the Structure of Huntingtin**

*Stefan Kochanek (Ulm, Germany)*

**2. Chaperone Biology and Huntington Aggregation**

*Harm Kampinga (Groningen, The Netherlands)*

**3. Large-Scale Functional Analysis distinguishes Pathogenic, Non-Pathogenic, and Compensatory Transcriptional Changes in HD**

*Juan Botas (Houston, USA)*

**4. Huntington's Disease and the Genetics of CAG Repeat Expansions**

*Lesley Jones (Cardiff, UK)*

12:30 - 14:00 LUNCH + POSTER VIEWING

14:00 - 15:00

### PARALLEL SESSION I

#### Science Session I: EHDN Projects

Chair: Anne Rosser (Cardiff, UK)

Co-Chair: Patrick Weydt (Bonn, Germany)

**1. Dysphagia in HD (Seed Fund Project)**

*Falk Schradt (Ulm, Germany)*

**2. Nucleolar Activity and Mutant Huntingtin (Seed Fund Project)**

*Rosanna Parlato (Ulm, Germany)*

**3. Isotype-Specific HDAC Inhibition (Seed Fund Project)**

*Bob Lahue (Galway, Ireland)*

**4. CAG length as a modifier (Datamining Project)**

*Ahmad Aziz (Leiden, The Netherlands)*

**5. Quality-adjusted Life-Years and Huntington's Disease (Datamining Project)**

*Colin Green (Exeter, UK)*

#### Clinical Practice Session I: Care in HD

Chair: Asa Petersen (Lund, Sweden)

Co-Chair: Astri Arnesen (Søgne, Norway)

**1. Implementation of Scottish National Care Framework**

*John Eden (Paisley, UK)*

**2. Presence and Treatment of Psychiatric Symptoms in HD**

*Karen Anderson (Washington D.C., USA)*

**3. Caring for Carers**

*Gyozo Pék (Debrecen, Hungary)*

15:15 - 16:15 **SHORT COMMUNICATIONS I**

Chair: Sandrine Humbert (Grenoble, France) / Co-Chair: Jocelyne Caboche (Paris, France)

16:15 - 16:45 BREAK

16:45 - 18:15 **PLENARY SESSION II: Dialing Huntington Down**

Chair: Douglas Macdonald (Los Angeles, USA) / Co-Chair: Nicole Déglon (Lausanne, Switzerland)

**1. Gene Editing Approaches for HD Therapy**

*Beverly Davidson (Philadelphia, USA.)*

**2. AAV5-miRNA HTT Lowering Therapy**

*Pavlina Konstantinova (Amsterdam, The Netherlands)*

**3. HTT lowering small molecule program**

*Anuradha Bhattacharyya (New York, USA)*

18:15 - 18:45 **Q&A Panel Discussion**

19:15 - 20:45 **Meet the Expert Sessions (for students and family members only)**

**DINNER ON YOUR OWN**

**08:00 - 9:15 BREAKFAST TEACHING COURSES**

- **Career in Research for Young Professionals**  
*Emma Yhnell (Cardiff, UK), Thomas Massey (Cardiff, UK), Chiara Scaramuzzino (Grenoble, France), Fionnuala Margreiter (Niederau, Austria)*
- **HD Clinical Trial Participation: Maximize Chances of Involvement**  
*Jenny Townhill (Cardiff, UK)*
- **Overview of Different Established Therapies (Dysphagia, Language and Communication, Behavior in a Residential Setting)**  
*Falk Schradt (Ulm, Germany) and Angela Nuzzi (Bari, Italy), Welmoed Lieftrinck (Katwijk, The Netherlands)*
- **Guilt and Huntington's Disease**  
*Marina Pavlou (Cyprus) and Andri Anastasiou (Cyprus)*
- **Genetic Counselling and Narrative Practices: A Model of Support for Individuals impacted by Huntington's Disease**  
*Rhona Macleod (Manchester, UK) and Mariangels Ferrer Duch (Bowdon, UK)*

**09:30 - 11:00 PLENARY SESSION III: Keeping Brain Cells Functioning – Can we slow Disease Progression**

Chair: Jan Frich (Oslo, Norway) / Co-Chair: Hoa Huu Phuc Nguyen (Tübingen, Germany)

**1. Environmental Modulation of Motor, Cognitive and other Deficits in Rodent Models of HD and other Neurodegenerative Diseases**

*Stephan von Hörsten (Erlangen, Germany)*

**2. Brain Training in Huntington's Disease**

*Marina Papoutsis (London, UK)*

**3. Prospects for exercise and physical activity in HD – what next?**

*Monica Busse (Cardiff, UK)*

**11:00 - 11:30 BREAK****11:30 - 12:30****PARALLEL SESSION II****Science Session II: EHDN Working Groups**

Chair: Jean-Marc Burgunder (Bern, Switzerland)

Co-Chair: Michael Orth (Ulm, Germany)

**1. EHDN Think-Tank Activities**

*Michael Orth (Ulm, Germany)*

**2. Juvenile Onset Working Group**

*Oliver Quarrell (Sheffield, UK)*

**3. Cognitive Working Group**

*Jaime Kulisevsky (Barcelona, Spain)*

**4. Physiotherapy Working Group**

*Katy Hamana (Cardiff, UK)*

**5. Young Adults Working Group**

*Catherine Martin (Glasgow, UK)*

**6. Driving Task Force**

*Rients Huitema (Groningen, The Netherlands)*

**Clinical Practice Session II: PSYCHOLOGICAL AND PSYCHIATRIC SESSION**

Chair: Hugh Rickards (Birmingham, UK)

Co-Chair: Andrea Higgins (Dublin, Ireland)

**1. Treatment of Irritability in HD**

*Karen Anderson (Washington D.C., USA)*

**2. Psychological Therapies in HD**

*Andrea Higgins (Dublin, Ireland)*

**12:30 - 14:00 LUNCH + POSTER VIEWING****14:00 - 15:30 PLENARY SESSION IV: LIVING WITH HD**

Chair: Bernhard Landwehrmeyer (Ulm, Germany) / Co-Chair: Astri Arnesen (Søgne, Norway)

**1. How to Cope with HD – dealing with symptoms in your everyday life**

*Mathias Falk (Sweden)*

**2. Growing up in an HD family – Taking on Responsibilities**

*Victoria Emerson (UK)*

**3. Having Children at Risk – Being a Parent**

*Birgitta Falk (Sweden)*

**15:30 - 16:00 BREAK****PARALLEL SESSION III****16:00 - 17:00 SHORT COMMUNICATIONS II**

Chair: Nayana Lahiri (London, UK)

Co-Chair: Silvia Gines (Barcelona, Spain)

**16:00 - 17:00 Workshop: Talking to Kids about HD**

Chair: Bonnie Hennig-Trestman (USA) and HDYO

**17:00 - 17:45** **PLENARY SESSION V: EHDN BUSINESS MEETING**

Chair: Jean-Marc Burgunder (Bern, Switzerland)

Co-Chair: Anne Rosser (Cardiff, UK)

- Update since the last plenary meeting
- EC and SBAC elections
- EHDN Strategic Plan

**17:45 - 18:30** **DEBATE: "Whose Information is it anyway?"**

Debate about Confidentiality in a Huntington's Case

Chair: Bernhard Landwehrmeyer (Ulm, Germany)

Speakers:

Seth Rotberg (Chicago, USA)

Anne Rosser (Cardiff, UK)

Aad Tibben (Leiden, The Netherlands)

**19:00 - 23:00** **NETWORK EVENING**

**SUNDAY, SEPTEMBER 16th, 2018**

**08:00 - 9:15** **BREAKFAST TEACHING COURSES**

- **Availability and Use of Clinical and Genetic Data and Biosamples from Enroll-HD**  
*Mette Gilling Nielsen (Copenhagen, Denmark), Peter Holmans (Cardiff, UK), Seung Kwak (Princeton, USA), Anka Ehrhardt (New York, USA)*
- **Palliative and Late Stage Care**  
*Tom Stor (Beekbergen, The Netherlands), Jeanette Laterveer (Overduin, The Netherlands)*
- **Understanding the Biology of Wild-Type and Mutant Huntingtin for Clinical Applications**  
*Sandrine Humbert (Grenoble, France), Frédéric Saudou (Grenoble, France)*
- **Why Working with Young People is Vital: The Tools and Resources you need**  
*Catherine Martin, Chandler Swope and Matt Ellison (HDYO)*
- **Management of HD Symptoms**  
*Carsten Saft (Bochum, Germany), Klaus Seppi (Innsbruck, Austria)*

**09:30 - 11:00** **PLENARY SESSION VI: CLINICAL TRIALS**

Chair: Ralf Reilmann (Münster, Germany) / Co-Chair: Dina de Sousa (Edinburgh, UK)

**1. Results of the Amaryllis Trial**

*Marielle Delnomdedieu (Cambridge, USA)*

**2. Precision-HD: An Allele Specific Approach to Huntingtin Lowering in HD**

*Michael Panzara (Boston, USA)*

**3. Results of the Legato Trial**

*Ralf Reilmann (Münster, Germany)*

**11:00 - 11:30** **BREAK**

**11:30 - 12:30** **KEYNOTE SESSION II: Huntingtin-lowering antisense oligonucleotide trials in the clinic**

Chair: Lesley Jones (Cardiff, UK)

**1. Effects of IONIS-HTRx (RG6042) in Patients with Early Huntington's Disease, Results of the First HTT-Lowering Drug Trial**

*Sarah Tabrizi (London, UK)*

**2. Roche**

*Schott Schobel (Basel, Switzerland)*

**12:30 - 13:00** **Q&A Panel Discussion**

**13:00 - 13:30** **ROUND-UP III (LESSONS OF EHDN 2018) AND POSTER AWARDS**

Jean-Marc Burgunder (Bern, Switzerland)