EHDN 2016 PLENARY MEETING PROGRAM

THURSDAY, SEPTEMBER 15, 2016

16:00-22:00 Registration Desk

FRIDAY, SEPTEMBER 16, 2016

07:30-08:30 Registration Desk

WELCOME AND INTRODUCTION
(King Willem Alexander)

08:30-08:40 Jean-Marc Burgunder (University Bern), Astri Arnesen (EHA)

08:40-09:00 EU Policy on Rare Diseases
Jaroslaw Waligora (Rare diseases Policy Officer, European Commission)

PLENARY SESSION I: What’s New In HD Biology? Insights into Pathogenic Pathways and Therapeutic Targets
(King Willem Alexander)

Chair: Lesley Jones (Cardiff University)
Co-chair: Flaviano Giorgini (University of Leicester)

09:00-09:20 RAN Translation in HD
New Starts and Directions: Understanding the Role of Hidden Expansion Proteins in HD
Laura Ranum (University of Florida)

09:20-09:40 Somatic Expansion of Repeat Sequences in DNA
Instability of DNA Repeat Sequences: What it means when Long Repeats go on getting Longer
Darren Monckton (University of Glasgow)

09:40-10:00 Exploring Mitochondrial Dysfunction and Dynamics in HD
Cellular Powerplants: How and Why they go Wrong in HD
Flaviano Giorgini (University of Leicester)

10:00-10:20 An overview of Energy Metabolism in HD as a Therapeutic Target
Cellular Powerplants: How we might correct their Dysfunction in HD
Robert Pacifici (CHDI)

10:20-10:30 Panel discussion

10:30-11:00 TEA/COFFEE BREAK

PLENARY SESSION II: Switching Huntingtin Off: Gene-Targeted Therapies
(King Willem Alexander)

Chair: Sarah Tabrizi (University College London)
Co-chair: Jean-Marc Burgunder (University Bern)

11:00-11:20 RNA Targeted Therapies, Mechanisms and Challenges of Delivery in HD
Douglas Macdonald (CHDI)

11:20-11:40 RNA Targeted Therapies – the Experience from SMA and Duchenne’s Muscular Dystrophy
Francesco Muntoni (University College London)

11:40-12:00 DNA Targeted Therapies – Zn Finger Approach
Matt Chiocco (Shire)

12:00-12:30 Panel discussion
12:30-14:00 LUNCH AND POSTER VIEWING

14:00 – 15:00 PARALLEL SESSION I:

SCIENCE SESSION:
LARGE ANIMAL MODELS IN HD

(King Willem Alexander)
Chair: Marta Valenza (University Milano)
Co-Chair: Jenny Morton (University of Cambridge)
Conceptual Overview: What Model to use for what Purpose?
David Howland (CHDI)
Leaders not Followers: Sheep as Large Animal Models of HD
Jenny Morton (University of Cambridge)
HD Minipigs – Behavioral and Imaging Protocols transitioning into Preclinical Trials
Ralf Reilmann (George Huntington Institute)
Longitudinal Assessment of a Non-human Primate Model of Huntington’s Disease
Anthony Chan (Emory University)
Panel Discussion

CLINICAL PRACTICE SESSION:
ENROLL-HD

(Mississippi)
Chair: Tim McLean (EHDN)
Co-Chair: Jamie Levey (EHDN)
How does Enroll-HD facilitate the conduct of Clinical Trials?
Tim McLean (EHDN)
How does Enroll-HD advance Human Research in HD?
G. Bernhard Landwehrmeyer (University of Ulm)
How does Enroll-HD help improve Care?
Jan Frich (University of Oslo)

15:15-16:15 SHORT COMMUNICATIONS I: Scientific Presentations

(King Willem Alexander)
Chair: Michael Orth (University of Ulm) and Maria Björkqvist (Lund University)
Systemic Administration of a Novel Aav Variant Results in widespread and efficient Gene Transfer in R6/2 Mice
Pamela Farshim (University College London)
Striatal Neuropathology induced by Hypothalamic Overexpression of Huntingtin Fragments using Adeno-associated Viral Vectors in Mice
Rana Soylu (Lund University)
Detection of the Aberrantly Spliced Exon 1 – Intron 1 Htt Mrna in HD Patient Post Mortem Brain Tissue And Fibroblast Lines and Comparison of the Effect of a pure Cag Repeat and mixed Cagcaa Repeat on the Extent to which the Htt Gene is aberrantly spliced in Knock-In Mice
Gillian Bates and Nadira Ali (University College London)
Cognitive Training Improves Disease Symptoms in a Mouse Model of Huntington’s Disease
Emma Yhnell (Cardiff University)
HD Clarity: A Multi-Site Cerebrospinal Fluid Collection Initiative to facilitate Therapeutic Development for Huntington’s Disease
Ed Wild (University College London)

16:15-16:45 TEA/COFFEE BREAK
PLENARY SESSION III: Keeping Brain Cells Functioning - Targeting Neural Recovery and Replacement
(King Willem Alexander)
Chair: Monica Busse (Cardiff University)
Co-chair: Jean-Marc Burgunder (University Bern)

16:45-17:05 Can Exercise and Physical Therapy alter Disease Progression in Huntington's Disease
Lori Quinn (Columbia University)

17:05-17:25 Exercise Induced Brain Repair in Neurodegeneration: What can we learn from Parkinson’s Disease
Beth Fisher (University of Southern California)

17:25-17:45 HD Brain-Train: Neuroplasticity as a Target to Improve Function in Huntington’s Disease
Marina Papoutsi (University College London)

17:45-18:05 Is Cell Replacement a Feasible Option for Huntington’s Disease
Anne Rosser (Cardiff University)

18:05-18:15 Panel Discussion

ROUNDUP I: Lessons of the Day
(King Willem Alexander)

18:15-18:30 Ethan Signer (CHDI) and Allan Tobin (University of California)

WELCOME EVENING

19:00-19:30 Podium Talk: Adventurer with a Cause (Mississippi)
Lysle Turner (South Africa)

19:00-21:00 Poster Viewing

19:30-21:00 Film: The Inheritance (Mississippi)

19:30-21:00 Film: Twitch (King Willem Alexander)

19:30-21:00 Meet the Experts
For HD Family Members and Students

Mental Health Problems of HD
Erik van Duijn, Alzbeta Mühlbäck, David Craufurd
Languages: Dutch, German, English
Room: Amazon

Everyday Life as an HD Gene Carrier
Michael Orth
Languages: German, English, Spanish
Room: Yangtze 2

Clinical Trials: What does it mean to be in a Clinical Trial
Berry Kremer, Ralf Reilmann
Languages: Dutch, German, English
Room: Yangtze 1

Advanced Care
Anthony Lechich, Tom Stor
Languages: Dutch, English
Room: Africa

Coping as a Caregiver and Family Member
Aad Tibben, Astri Arnesen
Languages: Dutch, English, Norwegian
Room: South America
SATURDAY, SEPTEMBER 17, 2016

BREAKFAST TEACHING COURSES

08:15-09:30  HD for Non-Clinicians (Amazon)
             G. Bernhard Landwehrmeyer (University of Ulm)

08:15-09:30  Management of Motorphenotype (Yangtze 1)
             Ralf Reilmann (George Huntington Institute Münster)

08:15-09:30  Management of Psychiatric Symptoms (Mississippi)
             Hugh Rickards (National Centre for Mental Health, Birmingham) and
             Erik van Duijn (University Leiden)

08:15-09:30  Care and Advanced Care (Yangtze 2)
             Martha Nance (University of Minnesota)

09:45-10:30  KEYNOTE SESSION I:
             HD Outside the Box - Conjecture and the Biology of Huntington’s Disease
             (King Willem Alexander)
             Speaker: Ethan Signer (CHDI)
             Chair: Allan Tobin (University of California)

10:30-11:00  TEA/COFFEE BREAK

11:00 – 12:30  PARALLEL SESSION II:

             SCIENCE SESSION:  CLINICAL PRACTICE SESSION:
             NRF2 AND OXIDATIVE PSYCHOLOGICAL AND PSYCHIATRIC
             STRESS - BIOLOGICAL RATIONAL AND SESSION
             DRUG DEVELOPMENT (Mississippi)
             (King Willem Alexander)
             Chair: Robert Pacifici (CHDI)
             Co-Chair: Henry Jay Forman (University of Southern
             California)
             Chair: Maria Dale (Leicestershire Partnership NHS
             Trust)
             Co-Chair: Lucienne van der Meer (University Leiden)
             Development of an Nrf2-KEAP1 protein-protein
             disruptor for proof of concept
             Alberto Bresciai (IRBM Science Park)
             Importance of Personal Relationships in early life
             and Adulthood, based on Research Data
             Lucienne van der Meer (University Leiden)
             Genetic tools to validate and measure Nrf2 in HD
             Jeff Johnson (University of Madison)
             When life becomes too burdensome: suicidal
             ideation and behavior
             Erik van Duijn (University Leiden)
             What can HD learn from the development of
             DMF/Tecfidera for Multiple Sclerosis
             Brian Wipke (Biogen)
             Overview of Predict data, with an emphasis on
             behavioral and cognitive aspects
             Jane Paulsen (University of Iowa)

             Panel Discussion
             Panel Discussion

12:30-14:00 LUNCH AND POSTER VIEWING
PLENARY SESSION IV: Living with HD
(King Willem Alexander)
Chair: G. Bernhard Landwehrmeyer (University of Ulm)
Co-Chair: Astri Arnesen (EHA)

14:00-14:20 Living with HD – a Scientist’s Perspective
Jeff Carroll (Western Washington University)

14:20-14:40 Living with HD – an Artist’s Perspective
Emilie Hermant (DingDingDong)

14:40-15:00 Living with HD – a Mother’s Perspective
Anne Lennon Bird (Huntington's Disease Association of Ireland)

15:00-15:20 Living with HD – a Physician’s Perspective
Martha Nance (University of Minnesota)

15:20-15:30 Panel discussion

15:30-16:30 SHORT COMMUNICATIONS II: Scientific Presentations
(King Willem Alexander)

Chair: Patrick Weydt (University of Ulm) and Juliana Bronzova (EHDN)

DNA Repair Pathways as a Common Genetic Mechanism Modulating the Age at Onset in Polyglutamine Diseases
Davina Hensman Moss (University College London)

Huntingtin Gene Repeat Polymorphisms Affect Risk of Lifetime Depression in the General Population
Ahmad Aziz (University Leiden)

Neural networks linked to emotion processing modulated by intranasal oxytocin in Huntington’s disease gene-carriers
Izelle Labuschagne (Australian Catholic University)

Huntington’s Disease Patients Are ‘Stuck In A Rut’: Objective Testing Of Apathy in Huntington’s Disease
Duncan McLauchlan (Cardiff University)

Transcranial Direct Current Stimulation and Cognitive Training for Working Memory in Huntington’s Disease
Clare Eddy (National Centre for Mental Health Birmingham)

16:30-17:00 TEA/COFFEE BREAK

PLENARY SESSION V: EHDN Business Meeting
(King Willem Alexander)
Chairs: Jean-Marc Burgunder (University Bern) and Anne Rosser (Cardiff University)

17:00-17:45 Update since the last Plenary Meeting
EC and SBAC Elections
Strategic Plan
Data Mining Projects

ROUNDUP II: Lessons of the Day
(King Willem Alexander)

17:45-18:15 Ed Wild (University College London) and Jeff Carroll (Western Washington University)
GEORGE HUNTINGTON COMMEMORATION

18:30  Bus transfer from World Forum Main Entrance to Strandclub Doen!

19:15-20:00  George Huntington Commemoration
Alice Wexler (Los Angeles, USA)

20:00-23:30  Networking

23:00-24:00  Bus return shuttle

SUNDAY, SEPTEMBER 18, 2016

BREAKFAST TEACHING COURSES

08:15-09:30  Genetic Counselling
(Amazon)
Marina Frontali (CNR - The Institute of Translational Pharmacology) and David Craufurd
(Manchester University)

08:15-09:30  Clinical Trial Primer for Patients and Family Members
(Yangtze 2)
Juliana Bronzova (EHDN) and Astri Arnesen (EHA)

08:15-09:30  Enroll-HD for Scientists
(Mississippi)
Raymund Roos (University Leiden)

08:15-09:30  Enroll-HD for Family Members
(Yangtze 1)
Jamie Levey (EHDN)

09:45-11:30  PLENARY SESSION VI: Clinical Trials
(King Willem Alexander)
Chair: Juliana Bronzova (EHDN), Co-Chair: Tim McLean (EHDN)

1.  RECENTLY COMPLETED CLINICAL TRIALS IN HD

First-HD/ARC-HD
Claudia Testa (VCU Parkinson’s and Movement Disorders Center)
Cysteamine
Dominique Bonneau (CHU d'Angers)
Action HD
Harald Gelderblom (Charité in Berlin)
Exert-HD
Monica Busse (Cardiff University)
Pride-HD
Michael Hayden (Teva)

2.  ONGOING CLINICAL TRIALS
G. Bernhard Landwehrmeyer (University of Ulm)

3.  UPCOMING CLINICAL TRIALS
Cristina Sampaio (CHDI)

4.  FURTHER DEVELOPMENT OF CLINICAL ASSESSMENT TOOLS FOR HD

Tool Development and Enroll-HD
G. Bernhard Landwehrmeyer (University of Ulm)
Q-Motor
Ralf Reilmann (George Huntington Institute Münster)
11:30-12:00 TEA/COFFEE BREAK

12:00-12:45 KEYNOTE SESSION II: HD for Me
(King Willem Alexander)

Speaker: Sarah Winckless
Chair: Charles Sabine

ROUNDUP III AND POSTER AWARDS
(King Willem Alexander)

Meeting Adjourn/Closing Remarks
Jean-Marc Burgunder (University Bern) and Charles Sabine

14:15-18:45 Optional Visit to Topaz Care Home Overduin (registration mandatory)