Scientific Programme

11:00 - 12:00  Arrival & registration

11:15 - 12:00  Lunch

12:00 - 12:05  Welcoming and Introduction  Oliver Gardiner (London, UK)

12:10 - 12:50  SESSION 1: Research Updates
- Basic Research Highlights
- Clinical Research Highlights  Signe Beck-Nielsen (Aarhus, Denmark)
  Thomas Carpenter (New Haven, USA)

12:55 - 14:25  SESSION 2: Optimising the management of XLH
- Introduction to the Panel by Moderators
- Mini-presentations followed by Panel Discussion. Topics to Include: Prevalence, Growth, Dosing, Challenges, etc.

Moderating:
Wolfgang Högler (Linz, Austria)
Karl Insogna (New Haven, USA)

Paediatric:
Thomas Carpenter (New Haven, USA)
Agnès Linglart (Paris, France)
Leanne Ward (Ottawa, Canada)
Dieter Haffner (Hannover, Germany)

Adults:
Kassim Javaid (Oxford, UK)
Richard Keen (London, UK)
Erik Imel (Indianapolis, USA)
Maria Luisa Brandi (Florence, Italy)

14:25 - 14:50  Coffee break & light refreshments

14:50 - 15:45  SESSION 3: Biomechanics & Complications of XLH Beyond Rickets
- Dental (basic science and management)
- Muscle Study Data
- Biomechanical function in Adults with XLH: Osteoarthritis, Osteophytes, and Enthesophytes.

Catherine Chaussain (Paris, France)
Karl Insogna (New Haven, USA)
Carolyn Macica (North Haven, USA)
SESSION 4: Novel therapy/therapies in XLH

- Gene therapy in XLH (Liver)
- Bone targeted Gene Therapy (viral vectors)

Volha Zhukouskaya (Paris, France)
Aaron Schindeler (Sydney, Australia)

16:25 - 16:40
Coffee break

SESSION 5: Global Health Disparities and Access to Care

- The International XLH Alliance: Results from the IXLHA International Patient Survey
- A conversation with the patients.
- The Inequality of XLH: Global disparities in knowledge and care – XLH: Whole Body, Whole Life, Whole Family

Oliver Gardiner (London, UK)
Tenna Toft Sylvest (Copenhagen, Denmark)
Elizabeth Olear (New Haven, USA)
Marian Hart (Indianapolis, USA)

17:30 - 17:45
Highlights and key messages

Karl Insogna (New Haven, USA)

17:45 - 17:50
Closing remarks

Oliver Gardiner (London, UK)

Programme Organising Committee
Agnès Linglart (France)
Artemis Doulgeraki (Greece)
Dieter Haffner (Germany)
Elizabeth Olear (USA)
Karl Insogna (USA)
Oliver Gardiner (UK)
Pol Harvengt (Belgium)
Tenna Toft Sylvest (Denmark)
Thomas Carpenter (USA)

March 2022