ERN ITHACA Board Meeting, Paris

Day 2: Plenary - dec 2 - Hybrid (In-person & Online)
Pre-Agenda - Board Meeting, nov 2026

- **8h30 Opening**

PLENARY 1 CHAIR: Alain , Sally

- 9h00 Welcome and introduction _ 2026: the present of ITHACA; Alain Verloes, Sally Lynch
- 9h15 ERN ITHACA Activity report, Assessment of past year, Workplan, Activities to come: Alain Verloes, Sally Lynch
- 9h45 ERN ITHACA Budget overview; Grant monitoring; HCP performance review: Mathias Falkenberg

Presentation

- 10h00 Building Bridges Across ERNs: Collaboration with MetabERN: François Eyskens, Antwerp University
- 10h15 Online Inherited Metabolic Disorders (OIMD) – A comprehensive online guide to the diagnosis and treatment of IMDs: Johannes Zschocke, Innsbruck Medical University

10h30-11h Coffee break

PLENARY 2 WG CHAIR: Mathias

- 11h00 WG Research & Innovation Zeynep Tümer, Marco Tartaglia
- 11h15 WG CPMS - ITHACA's Clinic: Adela Chirita-Emandi
- 11h30 WG Education and Training: Laurence Faivre, Giuseppe Zampino
- 11h45 WG Guidelines & Proms: Agnies Van Eeghen, Katalin Szakszon

12h00-13h00 Lunch break

PLENARY 3 CHAIR : Anne

Presentations

- 13h00 The Future of ERNs: Insights from the French Ministry of Health and a BoMS Member: Anne Sophie La Pointe, Cheffe de la mission maladies rares - France
- 13h20 Why parental perspectives matter in prenatal genetic counselling: CNVs and mosaicism: Stina Lou, Aarhus University

WG

- 13h45 WG Fetal Medicine: Gijs Santen
- 14h00 WG ILIAD : Gerieke Been, Marije Van Der Geest
- 14h15 ERDERA /SOLVRD Lisenka ??

14h45 Coffee break

PLENARY 4 CHAIR : Anne

15h15 European University Diploma in Rare Disease Research: Exploring Collaboration Opportunities with ERN ITHACA: Kaan Mert Güven

- 15h35 new challenges, Young Geneticists Committee (ESHG-Y): Silvia Kalantari, Mathys Weber
- 15h50 WG SBoD: Giovanni Mosiello, Jean-Marie Jouannic
- 16h05 WG NDD: Tjitske Kleefstra, Christiane Zweier
- *16h20 ???*
- 16h25 Patient Advisory Board : Dorica Dan , Tanja Zdolsek Draksler

16h45 "ERN 3 - Panel discussion: Bridging Grant - strengthening synergies and empowerment of HCPs: Sally Lynch, Alain Verloes
17h30 Intermezzo: Sally Lynch
18h00 Closing remarks: Alain Verloes
19h30 Joint Dinner at La Coupole "Joséphine Baker" – Registration Closed, Capacity Reached