



AGENDA

RARE DISEASES SAG

Chair: Dr. Risto Lapatto

EAP Winter Meeting 2022

Hilton Grand Place, Brussels, Belgium | Saturday, 3 December 2022

08:00 - 09:00

- 1) Welcome and approval of the agenda, apologies, introductions
- 2) Approval of the minutes Spring Meeting, Valletta Malta, 13 May 2022.
- 3) 8.10 Ukrainian children with a rare disease help, data collection 3 + 2 min
- 4) 8.15 News from UEMS Multidisciplinary joint committee on rare and undiagnosed diseases 3 + 2 min
- 5) 8.20 News from the European Reference Network's (ERNs) Consultation possibilities for non-members, databases 5 + 5 min
- 6) 8.30 Newborn screening projects: Screen4Rare and Screen4Care 5 + 5 min
- 7) 8.40 Marc de Graauw/Liesbeth Siderius: From first feature to rare disease co-management with digital tools 12 + 3 min
- 8) 8.55 Any other business and general discussion: A look into 2023 - 5 min

Please send any questions, remarks, or proposals in advance to: risto.lapatto@hus.fi