

ESPGHAN-ERN working group meeting 2022

Copenhagen, June 22nd 12:30- 14:00

Agenda

1. Welcome, and the paediatric landscape within ERN RARE-LIVER: Marianne HJ (5-10 min)
 1. The paediatric structure within ERN RARE-LIVER.
 2. Quality of the monitoring data
2. New databases within R-LIVER (25min)
 1. BA: Ekkehard Sturm
 2. ALF: Dominic Lenz
 3. Vascular diseases
3. Highlights from some of the working groups (20 min)
 1. Transition: Ruth De Bruyne
 2. Platform for designing clinical trials for rare liver disease ERN/ESPGHAN/EASL: Ekkehard Sturm
4. Where is “ERN RARE-LIVER” 5 years from here with focus on paed-adult and ESPGHAN synergy: Ansgar Lohse (10-15 min)
5. How do we create synergy between HepCom and ERN RARE-LIVER? Giuseppe Indolfi (10-15 min)
6. What is next? Discussion with Ansgar Lohse and Guiseppe Indolfi (10 min)