


Agenda ERN Members' Meeting 2021 - Friday 03.09.21

12.00  **Registration / Lunch**


13.00 **Welcome, State of the Network** (Ansgar Lohse)
Room A (Airport 1-4)

13.15 **R-Liver Presentation** (Christoph Schramm)
Room A (Airport 1-4)

13.30 **External Speaker 1**
Room A (Airport 1-4)
Clinical Trials for rare diseases (Ralf-Dieter Hilgers)

14.00 **Group Session 1 – Transversal Groups**

Room A (Airport 1-4)	Room B (Terminal)	Room C (Airport 5)
Workshop on Clinical Trials for rare diseases (Lead: Ralf-Dieter Hilgers)	Quality control, quality of registry data - Workshop (lead: Christoph Schramm)	Patients: Unmet Clinical Needs (Leads: José Willemse and Angela Leburgue)

15.00  **Coffee Break**

15.15 **Group Session 2 – Transversal Groups**

Room A (Airport 1-4)	Room B (Terminal)	Room C (Airport 5)
Primary Biliary Cholangitis Group Meeting (Lead: Frederik Nevens)	Quality of Life Group Meeting (Lead: Tom Gevers)	Future development of R Liver: new registries and challenges to manage (lead: Christoph Schramm)

16.15 **Plenary Session 1**
Room A (Airport 1-4)
Presentations from Transversal Working Groups
QoL Working Group (Tom Gevers)
Transition Working Group (Maciej Janik)


16.35 **Plenary Session 2**
Room A (Airport 1-4)
ERN Future Structure and Strategy: Discussion

17.15 **News from the Patient Representatives**
Room A (Airport 1-4)

17.30 **Highlights of CPMS**
Room A (Airport 1-4)
Case presentation from Aachen (Pavel Strnad)
Case presentation from Nijmegen (Romée Snijders)
Case presentation from Hamburg (Britta Zecher)

18.00 End of the first day's programme

18.25 Meet up for bus transfer to Scientific Dinner
Departure Transfer 18:30

19.00  **Scientific Dinner**
Dinner at the Alster lake, Restaurant "Bobby Reich"

21.30 Bus Transfer back to Radisson Hotel Airport

Agenda ERN Members' Meeting 2021 - Saturday 04.09.21

08.00 CPMS Session - optional

Room A (Airport 1-4)
Registration and Helpdesk (Gustav Buescher, Aileen Franke)



Coffee

08.30

Group Session / Disease Working Groups

Room A (Airport 1-4)	Room B (Terminal)	Room C (Airport 5)
Sclerosing Cholangitis Group Meeting (Lead: Annika Bergquist)	Acute Liver Failure Group Meeting (Lead: Dominic Lenz)	Alpha-1-Antitrypsin Deficiency Group Meeting (Lead: Pavel Strnad)

09.40 Plenary Session 1

Room A (Airport 1-4)
Presentations from Disease Working Groups
Vascular Liver Disease (Aurélie Plessier and Valérie McLin)
PLD (Joost Drenth)
Wilson's Disease (Piotr Socha)
Rare Liver Tumours (Kornelius Schulze)
Biliary Malformations (Jan Hulscher)
Acute Liver Failure (Dominic Lenz)
AATD (Pavel Strnad)
Biliary Atresia (Claus Petersen)
Genetic Cholestatic Disease (Ekkehard Sturm)
PSC
AIH (Marcial Sebode)
PBC (Frederik Nevens)

11.20

Coffee Break

11.40 External Speaker 1

Room A (Airport 1-4)
Best Practices from ERKNet (Franz Schäfer)

12.00 External Speaker 2

Room A (Airport 1-4)
Crossborder healthcare - video presentation (Ines Hernando, EURORDIS)

12.30 Plenary Session 2

Room A (Airport 1-4)
Future Activities (Ansgar Lohse)
Summary and Farewell (Ansgar Lohse)

13.00

Lunch to go

13.30 Internal Management Board Meeting

Room A (Airport 1)

11.08.21/AF