

Agenda ERN Members Meeting 2021 - Friday 03.09.21

Registration / Lunch 12.00 - 13.00h

13.00 **Welcome** (Ansgar Lohse)

State of the Network

13.15 **R-Liver** Presentation (Christoph Schramm)

13.25 **Clinical Trials for rare diseases** (Ralf-Dieter Hilgers)

14:00 **Subgroup Session 1 – Transversal Working Groups**

Room A	Room B	Room C
Quality control, quality of registry data - Workshop	Quality of Life Group Meeting	Patients: Unmet Clinical Needs

15.00 ☕ **Coffee Break**

Subgroup Session 2 – Transversal Working Groups

Room A	Room B	Room C
Workshop on Clinical Trials for rare diseases (with Ralf-Dieter Hilgers)	Surgery?	Registry Team Meeting

16.10 **Plenary Session**

Presentation of results from Transversal Working Group meetings

16:30 **External Speaker**

Crossborder healthcare - video presentation
(Ines Hernando, EURORDIS)

16:50 **News from the Patient Representatives**

17.05 **Highlights of CPMS**

Case presentation (Pavel Strnad)
From Nijmegen (Thijs Barten)
From Tübingen (Ekkehard Sturm)
From Hamburg (Britta Zecher)

17.45 **Plenary Session**

18.15 Meet up for bus transfer to Scientific Dinner
Departure Transfer 18:20

18.45 🍴 **Scientific Dinner**

Dinner at the Alster (lake). Restaurant: Bobby Reich

21.45 Bus Transfer back to Radisson Hotel Airport

22.07.21/LR

Agenda ERN Members Meeting 2021- Saturday 04.09.21

08.00 Room A

CPMS Session


Registration and Helpdesk
(G. Buescher, A. Franke)

 Coffee

08.30 **Plenary Session**

Subgroup Session 3 / Disease Working Groups

08.40	Room A	Room B	Room C
	Acute Liver Failure	Vascular Liver Disease	Sclerosing cholangitis

10.00  **Coffee Break**

Subgroup Session 4 / Disease Working Groups

10.10	Room A	Room B	Room C
	Alpha-1-Antitrypsin Liver Disease	Primary Biliary Cholangitis	Biliary Atresia?

11.30 **Break**

11.40 **External Speaker**


Best practices from ERKNet (Franz Schäfer)

12.00 **Future Activities** (Ansgar Lohse)

Workshops, Visits to members, Training Videos. Specialist Nurses, Clinical Exchange

12.30 **Plenary Session**

Presentation of results from Disease Working Group meetings

13.30  **Lunch Break**

14.30 **Plenary Session**

Discussion, Summary and Farewell

14:40 **End of Members' Meeting**

14:50 **Internal Management Board Meeting**