

# Members' Meeting Agenda

## Friday, 1 September 2023

- 10.00 ePAG Meeting (optional)  
PBC disease working group meeting (optional)
- 12.00 **Lunch and registration**
- 13.00 Plenum · Welcome and Agenda, State of the Network  
Ansgar W. Lohse
- 13.15 Plenum · Relaunch Website  
Sabina Bernhardt
- 13.20 Plenum · Patient Empowerment  
What is EURORDIS? · Matt Bolz-Johnson  
Unmet Clinical Needs Project · Angela Leburgue  
The ERN RARE-LIVER Youth Panel: a young people  
advocacy group · Karsten Vanden Wyngaert
- 14.05 Plenum · Highlights of CPMS  
Case presentation · Refractory AIH · Martti Färkkilä  
Case presentation · Autoimmune mimicry:  
crossing EU borders · Gustav Buescher
- 14.25 Plenum · Presentations from Disease Working Groups  
(5 min. each)  
Primary Biliary Cholangitis · Nora Cazzagon  
Acute Liver Failure · Dominic Lenz  
Biliary Atresia · Ekkehard Sturm  
Hemochromatosis · Antonello Pietrangelo  
Wilson's Disease · tba  
Genetic Cholestatic · tba  
Primary Sclerosing Cholangitis · tba
- 15.10 **Group Photo**
- 15.20 **Coffee Break**
- 15.50 **Workshop · Group Meetings**  
What can the ERN and its members do  
to empower patients?
- 16.50 Plenum · Presentations from Transversal Working Groups  
Transition of Health Care · Ruth de Bruyne  
Quality of Life · Tom Gevers  
Liver Disease during pregnancy · Willy Visser
- 17.10 **Coffee Break**
- 17.30 Plenum · Q.RARE.LI · Annika Braun
- 17.45 Plenum · Update on 'Quality of life of patients living  
with vascular liver diseases - A quantitative study'  
Aurélie Plessier
- 18.00 **End of first day**
- 18.00 Working Group Meetings 1 · Transition of Health Care
- 18.30 **Reception**
- 19.00 Scientific Dinner · Announcement Awards

## Saturday, 2 September 2023

- 08.30 **Working Group Meetings 2**  
AATD Alpha-1 Antitrypsin Deficiency  
VLD Vascular Liver Disease  
PLD Polycystic Liver Disease  
Quality of Life
- 09.20 **Working Group Meetings 3**  
Wilson's Disease  
Acute Liver Failure  
Biliary Atresia  
Pregnancy
- 10.10 **Coffee Break**
- 10.30 Plenum · Presentations from Disease Working Groups  
(5 min. each)  
AIH Autoimmune Hepatitis · Marcial Sebode  
PLD Polycystic Liver Disease · Renée Duijzer  
AATD Alpha-1 Antitrypsin Deficiency · Pavel Strnad  
Biliary Malformations · tba  
Rare Liver Tumours · tba  
Vascular Liver Disease · tba
- 11.20 **Workshop Outcome · Presentation of key  
suggestions patient empowerment**
- 12.05 Plenum · Plans for the future · Aurélie Plessier ·  
Juan Carlos García-Pagán · Ruth de Bruyne
- 12.20 Plenum · R-LIVER · Christoph Schramm
- 12.35 Plenum · Industry collaboration · Ansgar W. Lohse
- 12.45 Plenum · Summary and Farewell · Ansgar W. Lohse
- 13.00 **End of the Meeting and Lunch**

All plenum activities like workshops  
and presentations will take place on  
the first floor (**Festsaal**).

Coffee Breaks, Lunch and Dinner  
will be served on the ground floor  
(**Gartensaal**).

For conservational reasons no food or  
drinks are allowed on the first floor.