October 2026



Dear members, partners and friends of ERN RARE-LIVER,

We would like to share three important reminders and upcoming deadlines for the coming days, including next week's ERN RARE-LIVER Online Members' Meeting.

Further updates from across the network will be shared during the Online Members' Meeting.

ERN RARE-LIVER Online Members´ Meeting 2026 - 14 October

The ERN RARE-LIVER Online Members' Meeting will take place on Wednesday, 14 October 2026, from 17:00 to 19:00 CEST via Zoom.

The meeting is open to everyone interested in ERN RARE-LIVER across our centres, including representatives, clinicians, fellows, nurses and other colleagues.

Please find the agenda on the ERN RARE-LIVER website, including the programme and speakers.

Join via Zoom:
https://uke-de.zoom-x.de/j/62211471337?pwd=uiDqnEucb82phkVF7qdccypKJI4sCm.1

The meeting will include updates from across the network, presentations from the Disease Working Group projects, two CPMS case discussions, an update on the R-LIVER Registry, and information on upcoming developments within ERN RARE-LIVER.

We look forward to welcoming many colleagues from across the network.

Registration for the ERN RARE-LIVER Members' Meeting 2027

The next **ERN RARE-LIVER Members' Meeting** will take place in Hamburg on 21–22 January 2027 under the overarching theme **"Implementing rare liver disease care across Europe."**

Registration is open until **16 October 2026**:
https://ec.europa.eu/eusurvey/runner/ERNRARELIVER_MM2027

Each **Full Member and Affiliated Partner** may nominate one funded participant. In addition, colleagues who are invited to give a presentation during the plenary programme are also eligible for funding. For funded participants, ERN RARE-LIVER will cover **two nights of accommodation and travel reimbursement according to the European Commission unit cost rules.**

Additional colleagues from Full Members and Affiliated Partners are very welcome to attend but will need to cover their own travel and accommodation costs. **Collaborative Partners** are also welcome to participate; however, travel and accommodation are not funded by ERN RARE-LIVER.

Further information is available on the meeting webpage, or you can register directly here.

Biliary Malformations Survey – Deadline 16 October

The Biliary Malformations Disease Working Group is conducting an international Delphi survey to define a **Core Quality Indicator Set for the care of patients with choledochal malformation.**

Healthcare professionals, patients, parents, patient representatives and other stakeholders with experience of or an interest in choledochal malformation are invited to participate.

Find the survey here:
https://app2.welphi.com//Pages/RedirectPage.aspx?2alOFDmGzw5m0p2vHOpedF0n++37T5+v53Hdqeby8iM=

Round 1 closes on **16 October 2026**.

Please feel free to share the survey with relevant colleagues, patients and other potential participants within your centre and professional network.

Thank you for your continued engagement and support of ERN RARE-LIVER. We look forward to seeing many of you at the **Online Members' Meeting next week**.

Best regards,

The ERN RARE-LIVER Office Team

Visit us on our website

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