

June 2025



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

As we move into summer, we are excited to share some highlights and updates from a vibrant and eventful spring. May brought valuable in-person exchanges at both the EASL and ESPGHAN congresses, where many of our members reconnected.

In this edition, we also reflect on recent developments in our communication strategy and look ahead to future events — including the newly announced ACADEMY 2026.

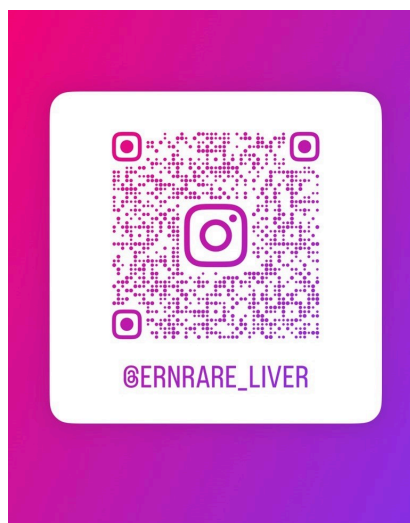
The ERN RARE-LIVER Office

News

Follow ERN RARE-LIVER on Instagram!

We are now on **Instagram** – sharing news, behind-the-scenes insights, events, collaborations with other ERNs, and stories from across our network. You will also get a closer look at **people** and **projects** that shape ERN RARE-LIVER.

After a network-wide decision, we have officially said goodbye to **X** – so make sure to follow us on [Instagram](#) and stay connected!



CPMS 2.0 Live Case Discussions successfully launched

We are pleased to share that our first [CPMS Live Case Discussion](#) took place on 6 June, featuring an engaging and complex case "*Unclear acute hepatitis in pregnancy with liver enzyme elevations in the thousands – what would you do?*". Two experts of pregnancy-related liver diseases discussed this difficult case, with many participants joining the discussion. It was good to see that all the virtual features of the new CPMS 2.0 system work, offering great opportunities for challenging live discussions in the future.

These sessions will now take place every two months. If you have an interesting case you would like to present, please do not hesitate to contact the [ERN RARE-LIVER CPMS Helpdesk](#) — we are always happy to assist and support you throughout the process.

ERN RARE-LIVER ACADEMY 2026 at University Medical Centre in Groningen

The [University Medical Centre Groningen](#) has been selected to host the ERN RARE-LIVER ACADEMY 2026, featuring a paediatric focus, but also of major interest to young adult hepatologists.

Following a competitive selection process with several excellent applications, we look forward to an inspiring event. Updates on the detailed agenda and the application process for young clinicians will be shared soon.

EASL Issues New Guidelines for Wilson Disease, Liver Transplantation, GChD and AIH

The European Association for the Study of the Liver (EASL) has recently published updated Clinical Practice Guidelines for **Wilson Disease, Liver Transplantation, Genetic Cholestatic Diseases (GChD), and Autoimmune Hepatitis (AIH)**.

Several ERN RARE-LIVER members were actively involved in the development of these guidelines, contributing their expertise to ensure high quality, evidence based recommendations.

New Disease-Specific Information Available

We are happy to announce that new disease-specific information for both patients and clinicians is now available on our website. The latest additions cover **Hepatitis Delta Virus (HDV)** and **Alveolar Echinococcosis (AE)**. Multilingual flyers are currently in development and will be made available soon.

Applications

Application Period Still open:

Horizon Call 2025: Funding Opportunity for Multinational Clinical Studies

Under the Horizon Europe Work Programme 2025, several calls are currently open for application. This includes a funding opportunity for multinational clinical studies of orphan devices and/or breakthrough devices (HORIZON-HLTH-2025-03-IND-03-two-stage). The deadline for the first stage of the two-stage application process is **16 September 2025**.

For more information, please consult "Horizon Europe Work programme (2025) – Cluster 1".

Call for Research Projects on LPAC Syndrome

The ALBI France Association and the Fondation Maladies Rares have launched a 2025 research call to support biomedical projects focused on LPAC syndrome – a rare liver disease linked to intrahepatic gallstones. The call aims to advance pathophysiological understanding, diagnostics, and treatment strategies for

LPAC. Up to €30,000 are available for projects with a maximum duration of 24 months. Applicants must be based at public research institutions within the EU.

For more information, please click [here](#). The deadline for applications is **11 September 2025**.

Meetings & Events 2025

Past Events

ERN RARE-LIVER Highlights from EASL 2025

ERN RARE-LIVER joined with a visible and active role in the EASL Congress, held from 7–10 May 2025 in Amsterdam.

Key activities included a dedicated meeting with specialist nurses and a productive session with the ePAG Leads and Board Representatives. ERN RARE-LIVER was also represented in the **Track Hubs (Public Health)**, where a member of the ERN Youth Panel delivered an excellent joint presentation with our ePAG Co-Lead Wiebke Papenthin.

A highlight was the annual ERN Reception, where around 90 members and partners gathered for networking and informal exchange. Ansgar W. Lohse opened the evening with a warm welcome.



ERN RARE-LIVER at ESPGHAN 2025

ERN RARE-LIVER was present at ESPGHAN 2025 in Helsinki (14-16 May) with a dedicated booth, actively engaging with the paediatric hepatology community — an essential area within the network.

A central moment was the well-attended **Paediatric Session**, where members of ERN RARE-LIVER presented updates from their Working Groups, addressed

current paediatric gaps and objectives, and invited open discussion.

In addition, transition of care was a key topic in one of the sessions, with several ERN RARE-LIVER members contributing their presentations to a wide audience.



Upcoming Events

ERN RARE-LIVER Youth Panel Workshop in Hamburg

From 14-16 July young patients from across Europe will come together in **Hamburg** for a two-day Youth Panel Workshop.

The programme will be diverse, including personal exchange, peer support, collaboration with the ERN Office, and contributions from young clinicians. The event is co-
led by Janne Suykens and Karsten Vanden Wyngaert (Ghent University Hospital). We look forward to hearing their valuable perspectives!



ERN RARE-LIVER Online Members' Meeting 2025



The next ERL RARE-LIVER Online Members' Meeting will take place on **22 October 2025**. Official timing and programme details will be shared soon. In the meantime, please check our website regularly for updates.

Save the Date: ERN RARE-LIVER Members' Meeting in Prague 2026

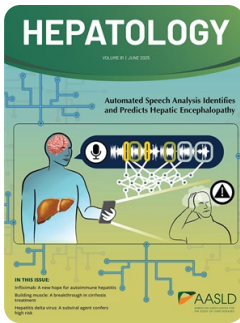
The next ERN RARE-LIVER Members' Meeting will take place **from 13–14 February 2026 in Prague**, hosted by IKEM Prague (Institute of Clinical and Experimental Medicine).

The agenda will include a Paediatric Strategy Meeting of ERN RARE-LIVER. Further details will follow soon. For questions, please contact the ERN RARE-LIVER Office.



Publications

AIH



Efficacy and safety of infliximab in patients with Autoimmune Hepatitis

This multicenter retrospective study evaluated infliximab in 42 patients with autoimmune hepatitis (AIH) unresponsive to standard therapies or with concurrent autoimmune diseases. Infliximab induced clinical remission in 75% of non-responders to second line and in 46% of patients failing third line therapies. Treatment was discontinued in 3 patients (1 for anaphylaxis and 2 others developed infliximab antibodies). The findings suggest infliximab is a promising rescue option for difficult-to-treat AIH.

IgG4

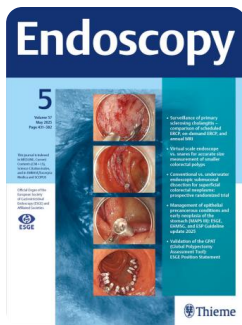


UPLIZNA® (inebilizumab), a CD19-targeting monoclonal antibody, has been approved by the FDA as the first targeted therapy for IgG4-RD.

In the **phase 3, MITIGATE trial**, a multicenter, randomized, double-blind, placebo-controlled study, **inebilizumab reduced flare risk by 87%** versus placebo (HR 0.13; 95% CI: 0.06–0.28; $p < 0.001$) and lowered the annualized flare rate (rate ratio 0.14; 95% CI: 0.06–0.31; $p < 0.001$).

Median follow-up was 52 weeks. Flare-free, treatment-free remission occurred in 39% vs 13% (OR 4.68; 95% CI: 2.21–9.91; $p < 0.001$), and flare-free, glucocorticoid-free remission in 38% vs 11% (OR 4.96; 95% CI: 2.34–10.52; $p < 0.001$). **Serious adverse events occurred** in 18% with inebilizumab vs 9% with placebo.

PSC

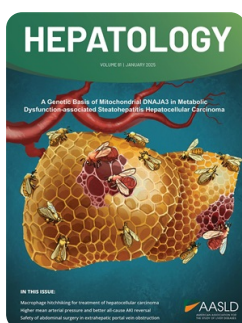


Surveillance of primary sclerosing cholangitis – a comparison of scheduled or on-demand ERCP with annual MRI surveillance: a multicenter study

In PSC the optimal strategy to assess disease progression and screen for cholangiocarcinoma (CCA) – the main cause of death of PSC patients – remains unclear.

- Three different surveillance strategies were compared and their effect on patient outcomes: scheduled ERCP, MRI/MRCP surveillance or on demand ERCP.
- In this large multicenter study it was demonstrated that a surveillance strategy based on scheduled ERCP and individual risk stratification is associated with an improved overall prognosis and a significantly decreased cumulative incidence of CCA compared with on-demand ERCP based on current EASL Guidelines.
- This reduction is attributed to systematic screening for biliary neoplasia using brush cytology and timely liver transplantation before the development of CCA.
- Additionally, it was shown that scheduled ERCP is associated with the lowest rate of fibrosis progression and improved outcomes over time.

VLD



Abdominal surgery in patients with chronic non-cirrhotic extrahepatic portal vein obstruction: A multicenter retrospective study

Information about the morbidity and mortality associated with abdominal surgery in patients with non-cirrhotic extrahepatic portal vein occlusion (EHPVO) is scarce. This multicenter retrospective study evaluates the outcomes of 76 patients with EHPVO undergoing abdominal surgery and found that 37% experienced an unfavourable outcome defined as major bleeding, serious postoperative complications, portal hypertension related events, or death.

Risks were especially high in patients with a history of ascites or those undergoing surgeries other than

cholecystectomy or abdominal wall procedures. Compared to 126 matched controls without EHPVO, these patients had significantly higher rates of major bleeding and portal hypertension related complications. The study emphasizes the significant perioperative risks associated with EHPVO and provides information suggesting that while EHPVO remains a high-risk condition, certain surgical interventions may be safely considered with appropriate risk stratification.

Fontan-associated liver disease



Non-invasive assessment of severe liver fibrosis in patients with Fontan-associated liver disease: The VALDIG-EASL FONLIVER cohort

Fontan-type surgery is a palliative approach for congenital heart disease with univentricular physiology. Over time, this often leads to Fontan-associated liver disease (FALD) and progressive liver fibrosis. This multicentre European study of 217 adult post-Fontan patients found severe liver fibrosis to be highly prevalent (47.9%), with a correlation observed between older age, impaired functional status and worse systemic haemodynamics. In order to overcome the limitations of conventional non-invasive models, the authors developed the FonLiver risk score: a new tool combining liver stiffness measurement (VCTE-LSM) and platelet count in order to predict severe fibrosis. This score demonstrated robust diagnostic performance (AUROC 0.81) and can be easily implemented in routine clinical practice. The earlier detection of advanced fibrosis and timely interventions to optimise Fontan circulation and improve long-term outcomes may be enabled by the implementation of FALD screening protocols, including the FonLiver score.

Surveys



Your Voice Counts: Help Shape Our Upcoming Patient Webinar Topics

This survey is just for **patients and families** — we want to hear your ideas and questions for our next ERN RARE-LIVER Patient Webinar Series. Your input helps us make webinars that meet your needs.

ERN RARE-LIVER Talks

17/06/2025 - Transition in PSC (+IBD) - **past**

The recording will be available soon on our website and EASL Campus so you will not miss anything! Thank you for your understanding.

15/07/2025 - Choledochal Malformation - Diagnosis, Risks, Treatment and Complications

We invite you to share any questions or topics you'd like to see addressed in our upcoming talks. Submit your questions [here](#).

If you are interested to host a talk or take part as a speaker, please contact Juan Carlos García-Pagán who is the lead of the Training and Education Committee of ERN RARE-LIVER (JCGARCIA@clinic.cat).

Patient Representatives

ePAG Meetings: New Format with Special Guests

The **ERN RARE-LIVER Patient Representatives** have introduced a new element to their regular meetings: each session now features a special guest who shares brief insights on a specific topic — such as the ERN Registry, Patient Pathways, or other ongoing initiatives.

This new format fosters dialogue, strengthens collaboration, and brings fresh perspectives into the patient advocacy work within the network.

“Talk to Heal” Project at the Paediatric Hospital of Coimbra

The second Talk to Heal session, focused on Alpha-1 Antitrypsin Deficiency (AATD), was successfully held at the Paediatric Hospital of Coimbra, following the positive response to the first session on Autoimmune Hepatitis (AIH).

The interactive format once again fostered meaningful exchange between young patients, families, and experts with active involvement from members of the **ERN RARE-LIVER Youth Panel**. Another session is planned for autumn 2025. We will keep you updated!



Visit us on our website



ERN RARE-LIVER

University Medical Centre Hamburg-Eppendorf, Martinistraße 52, 20251, Hamburg

You received this email because you subscribed to our newsletter.

[View in browser](#) | [Unsubscribe](#)