October 2026

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

Following a successful Online Members' Meeting with strong attendance across the network, we now look ahead to our Members' Meeting in Hamburg on 21–22 January 2027. The meeting will focus on "Implementing rare liver disease care across Europe", with a dedicated paediatric session on 20 January.

This issue also features the first Youth Panel newsletter, new Working Group pages, recent publications and updates on upcoming webinars, workshops and the ERN RARE-LIVER ACADEMY 2027.

Thank you for your continued involvement and contributions to the network.

The ERN RARE-LIVER Office

News



Introducing "What's the Scoop?" – our first ERN RARE-LIVER Youth Panel newsletter

We're pleased to share the first edition of *What's the Scoop?*, the ERN RARE-LIVER Youth Panel newsletter! Meet the young people behind the panel, read their personal stories and discover how they are

turning lived experience into action. From peer support and the transition to adult care to highlights from EASL 2026, this edition explores what matters to young people living with rare liver diseases—and how their voices can help shape better care.

Read the first edition here and share it with your patients, colleagues and networks.

ERN RARE-LIVER Working Group Pages on the ERN RARE-LIVER Website

The ERN RARE-LIVER Working Groups now have dedicated pages on the ERN RARE-LIVER website. Each page introduces the group's focus and objectives, its leads and its current projects. The pages offer an overview of the work taking place across the network. Visit them to find out more about each group and the activities it is involved in.

If you would like to participate in an ERN RARE-LIVER Working Group, please follow this link.

ERN RARE-LIVER Workshops 2027

Two workshops have been confirmed for 2027:

- **First Expert Multidisciplinary Workshop on Alveolar Echinococcosis: From Diagnosis to Therapy** (on behalf of Beate Grüner, Silvio Nadalin, Anja Lachenmayer and the Alveolar Echinococcosis Disease Working Group)

- **Recanalisation in Cirrhotic and Non-Cirrhotic Portal Vein Thrombosis** (on behalf of Aurélie Plessier, Juan Carlos García-Pagán, Marco Senzolo and the Vascular Liver Disease Working Group)

Further details on the dates, venues and programmes will follow on the ERN RARE-LIVER website.

Calls

Applications open: ERN RARE-LIVER ACADEMY 2027

The ERN RARE-LIVER ACADEMY 2027 will take place on 22-23 April 2027 in the Paris metropolitan area, jointly organised by the AP-HP centres Beaujon, Saint-Antoine and Bicêtre, with the support of FILFOIE.

The ACADEMY will bring together 20 young clinicians from across Europe for two days of expert lectures, interactive workshops and case-based discussions on adult rare liver diseases, with a special focus on the transition from benign liver tumours to liver cancer.

Applications are open until 4 November 2026.

We encourage you to share this opportunity with fellows, residents and other interested colleagues in your department.

Apply here

Past Meetings & Events

ERN RARE-LIVER Online Members´ Meeting 2026

On 14 October 2026, we held our annual Online Members' Meeting, bringing together network members and patient representatives to share updates, discuss ongoing projects and outline future priorities.

Organisational updates included the positive results of the interim project review by HaDEA, news on the upcoming EU funding period, the leadership transition in April 2027, and preparations for the onsite Members' Meeting in Hamburg on 21-22 January 2027.

The main programme featured contributions from the ePAG and Youth Panel, updates on training and education, presentations from several Disease Working Group projects, interactive clinical case discussions through CPMS, and developments in the R-LIVER Registry.

Thank you to all speakers and participants for their valuable contributions and continued engagement in the network.

ERN RARE-LIVER Strategy Meeting on 15-16 September in Hamburg

An ERN RARE-LIVER Strategy Meeting took place at University Medical Centre Hamburg-Eppendorf (UKE) on **15–16 September 2026**. Network Coordinator Ansgar Lohse and the coordination team met with representatives of the grant beneficiaries in Paris, Barcelona, Copenhagen and Ghent. They were joined by new Management Board members Tudor Pop (Emergency Clinical Hospital for Children Cluj-Napoca), representing ESPGHAN, and Mara Cananzi (University Hospital of Padua), who brings additional paediatric expertise, as well as patient representatives from the ePAG and Youth Panel.

Discussions focused on the network's priorities and planning for the next grant, covering all work packages with particular attention to CPMS and the R-LIVER Registry. Topics also included training, transition of care, patient involvement, collaboration between paediatric and adult care, and network governance.

Upcoming Meetings & Events

ERN RARE-LIVER Members´ Meeting 2027 in Hamburg

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

Participants will include representatives of Full Members and Affiliated Partners, members of the Youth Panel, and patient and parent representatives.
A dedicated paediatric session will again take place the day before, on 20 January 2027.

Registration is now closed. Details of the agenda and programme will be shared shortly. Further information is available on the meeting webpage.

EURORDIS Black Pearl Awards 2027 - Save the Date

The 16th EURORDIS Black Pearl Awards will take place at Cardo Brussels on **Monday, 15 February 2027.** Held as part of the celebrations for Rare Disease Day, the awards recognise people and organisations making a difference for the rare disease community.

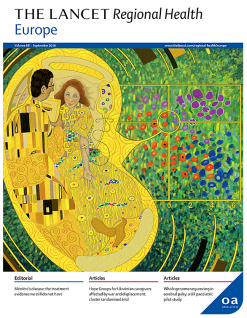
Patient representatives may also be interested in the EURORDIS Photo Award, which offers an opportunity to share a photograph that reflects life with a rare disease and raises awareness of the community's experiences.

Publications



Patient pathways for rare liver diseases: a European template developed by ERN RARE-LIVER

A European template for patient-centred pathways in rare liver diseases has been developed within ERN RARE-LIVER through collaboration between healthcare professionals, patient representatives, patient organisations, and EURORDIS. The framework covers the full patient journey, from pre-diagnosis to long-term follow-up, and aims to support more coordinated and harmonised care across Europe. It also includes key questions to facilitate shared decision-making. Patient pathways may help clinical recommendations and patient priorities into practical, coordinated models of care.

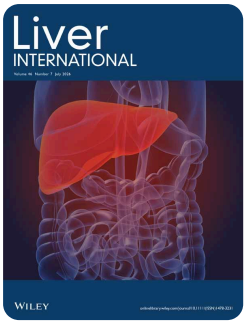


Crisis Readiness for Rare Disease Populations: Lessons from the European Reference Networks

A study involving all 24 European Reference Networks (ERNs) assessed their responses to COVID-19 and the war in Ukraine. While 91.6% reported disruptions during the pandemic and 83.3% supported Ukrainian patients, 70.8% still lack effective emergency plans. Key challenges include limited access to specialised care, shortages of medicines and healthcare professionals, and disrupted diagnostic services.
The authors propose a 10-point crisis preparedness plan to ensure continuity of care, calling for formal recognition of

ERNs as emergency response hubs with dedicated funding.

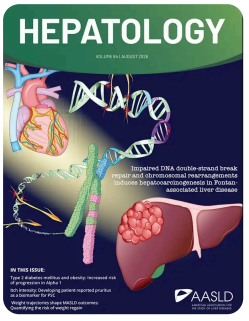
AIH



How Real Is Seronegative Autoimmune Hepatitis?

This editorial discusses the diagnostic challenges and true prevalence of seronegative autoimmune hepatitis. It questions whether some cases are genuinely seronegative or instead reflect incomplete or inadequate antibody testing. The authors emphasize the importance of liver biopsy and careful clinical assessment when conventional autoantibodies are absent.

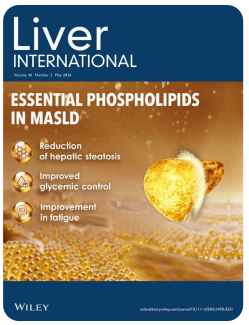
AATD



Amplification of genetic and metabolic factors in alpha-1 antitrypsin deficiency

This study was conducted to evaluate the impact of obesity and diabetes mellitus on individuals with and without alpha-1 antitrypsin deficiency. The analysis included Pi*ZZ adults, *Pi**MZ and non-AATD individuals. Among Pi*ZZ participants, diabetes and obesity were associated with higher transaminases, more frequent surrogates of advanced liver fibrosis, and an increased risk of hepatic endpoints during follow-up. Overweight was associated with a decreased risk of pulmonary endpoints. These data demonstrate the interaction between genetic and metabolic risk factors in AATD and provide evidence for patient management.

BA



Echocardiography, Bile Acids and Spleen Stiffness to Rule Out High-Risk Varices in Children With Biliary Atresia

This study was performed to define tools to rule out high-risk varices in children with biliary atresia and portal hypertension, with the objective of reducing the number of endoscopies. In children under 3 years old, a model combining indexed right atrium area from echocardiography and serum bile acid concentration achieved a 37% spared endoscopy rate with no missed high-risk varices. In children over 3 years old, spleen stiffness ≤30 kPa was associated with a 41% spared endoscopy rate and no missed high-risk varices.

Portal Hypertension



Aetiology, diagnosis and complications of portal hypertension in children and adolescents

The first of two reports arising from ESPGHAN's 2024 monothematic conference on paediatric portal hypertension highlights a key distinction: variceal bleeding does not necessarily signal end-stage liver disease in children with chronic cholestatic disorders. It also draws attention to complications affecting cognition, growth and cardiopulmonary function.



Management of portal hypertension in children and adolescents

The second report from the same conference turns to management: for children with extrahepatic portal vein obstruction, meso-Rex bypass is preferred when anatomy allows because it restores physiological portal blood flow. The authors also review bleeding prevention and treatment, highlighting the limited paediatric evidence for non-selective beta-blockers.

PSVD



Porto-sinusoidal Vascular Disease is Associated with Gastrointestinal Disorders in Common Variable Immunodefiency

A French retrospective study identified PSVD in 68 of 386 patients with predominantly antibody deficiencies, including 63 of 267 with CVID. Gastrointestinal complications were present in 90.5% of CVID patients with PSVD and preceded liver disease in 84% of cases by a median duration of 10.7 years. The 20-year probability to develop PSVD after CVID diagnosis was estimated at 38.7% in patients with gastrointestinal complications versus 11.7% in those without. Low naïve CD4+ T-cell counts, low IgA levels and lymphoproliferation were also independently associated with PSVD. These findings support a potential role for intestinal barrier dysfunction and T-cell impairment in CVID-related PSVD.

HDV



Progression to cirrhosis in chronic hepatitis D with mild-to-moderate fibrosis: Insights from a multicenter European cohort

This multicenter European cohort study evaluated real-world outcomes in 168 adult patients with chronic hepatitis D virus (HDV) infection and mild-to-moderate fibrosis (baseline METAVIR F0–F2 or transient elastography liver stiffness measurement [TE-LSM] <10 kPa). Over 20% of patients progressed to cirrhosis during a median 5-year follow-up. Baseline liver stiffness measured by transient elastography was the strongest independent predictor of progression, with a threshold >7 kPa identifying patients at substantially higher risk, while FIB-4 provided prognostic value when TE-LSM was unavailable. In contrast, ALT and HDV-RNA levels did not predict fibrosis progression. These

findings support the use of non-invasive markers for early risk stratification and prioritization of HDV therapy.

Other



Early discharge after paediatric liver biopsy: A prospective observational study

How long should children be observed after percutaneous liver biopsy? In this prospective study, patients were assessed before biopsy and followed according to their bleeding risk. No major complications occurred, and the two minor bleeding events were both identified within 6 hours in high-risk patients. The study presents a structured risk-based approach to post-biopsy observation and early discharge for further evaluation in paediatric practice.



Acute severe cholestatic hepatitis and lymphopenia characterize pediatric hepatitis-associated aplastic anemia

Early recognition of hepatitis-associated aplastic anaemia (HAAA) remains challenging. In this two-centre retrospective paediatric cohort, acute severe cholestatic hepatitis with markedly elevated ALT levels and early lymphopenia emerged as characteristic features preceding bone marrow failure. As hepatic recovery was common in most patients, the findings suggest that early lymphopenia may serve as a valuable clinical clue to identify children who require close haematological follow-up.

Webinars & Talks

03 November 2026

17 November 2026





The Good, the Bad and the Metabolites – Azathioprine or MMF for Autoimmune Hepatitis?

Join webinar

Current Medical and Surgical Management of Alveolar Echinococcosis

Join webinar

Youth Panel

ERN RARE-LIVER Youth Panel Workshop in Ghent

On 18–19 September, six young people from five countries came together in Ghent for a two-day Youth Panel workshop. Part of the workshop focused on communication with young people: what helps create a good conversation, what can make communication difficult, and what young people expect from those engaging with them. The discussions provided valuable principles and practical insights that can help guide future communication with young people.

The workshop also focused on “How to Youth Panel”, looking at what the panel needs to survive and thrive in the longer term. Through a SWOT analysis and group discussions, participants reflected on the panel’s strengths and challenges, what motivates young people to take part, and what is needed to keep participation meaningful and sustainable.

The ideas and feedback gathered over these two days will help shape the further development of the Youth Panel and how young people are involved in our activities.

Visit us on our website

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ERN RARE-LIVER is one of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States. The ERN is funded by the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or any other body or agency of the European Union. Neither the European Union nor any other body or agency of the European Union can be held responsible for them.