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AUGUST 2023

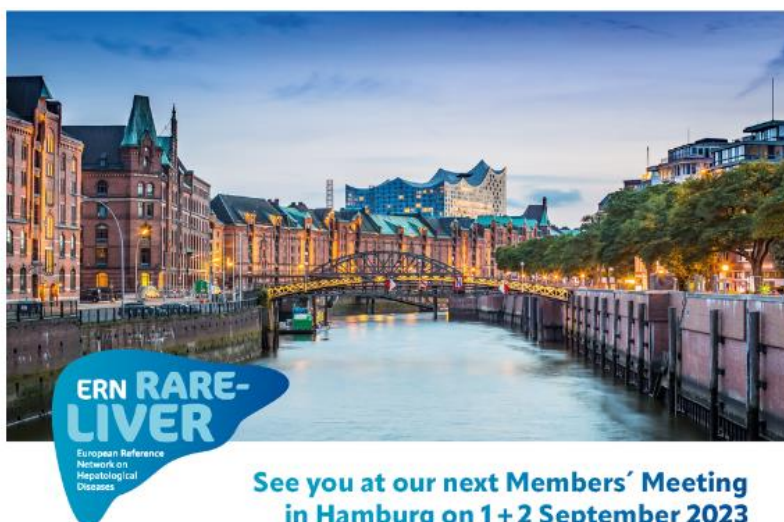


**European
Reference
Networks**



NEWSLETTER

Welcome to our next newsletter!



**See you at our next Members' Meeting
in Hamburg on 1 + 2 September 2023**

Dear ERN RARE-LIVER community,

The summer break has only just begun, but it has already made something clear to us: the issues and needs of our community are as diverse as the weather conditions in Europe with heavy rains in the northern part and lots of heat and sunshine in the south of Europe. Thus, it is good that we will soon be meeting in person in order to update ourselves on our activities at recent workshops and congresses, but also to set ourselves new old goals, for example to revive our flagging participation in CPMS.

We hope you enjoy this newsletter, and you all have a wonderful summer. We are looking forward to seeing most of you on our Members' Meeting in Hamburg.

The ERN RARE-LIVER Team in Hamburg

Contact ERN RARE-LIVER TEAM

ERN RARE-LIVER Members' Meeting



The ERN RARE-LIVER team is happy to invite you to our upcoming Members' Meeting on 1 and 2 September 2023 at University Medical Centre Hamburg-Eppendorf in "Erika-Haus".

This year the prominent topic will be patient empowerment, introducing the first cross-ERN Youth Panel. There will also be CPMS Case presentations as well as group meetings and presentations from our Disease Working Groups. You can find more information, a preliminary agenda as well as the reimbursement information on our website.

If you are interested to organise our next year's Members' Meeting 2024 please note the deadline: 18 August 2023.

[See website](#)

Our ERN RARE-LIVER Community was very active in CPMS in the past and we have been praised by the EU for this as a showcase project.

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UPCOMING WORKSHOP

The Research Workshop on Primary Sclerosing Cholangitis associated with Inflammatory Bowel Disease



The Research Workshop on Primary Sclerosing Cholangitis associated with Inflammatory Bowel Disease will take place 28 – 29 August in Padua discussing the impact of IBD activity on PSC and risk of colorectal cancer, treatment specificities in PSC-IBD, IBD course before and after liver transplantation and Pouchitis and pouch failure in PSC-IBD.

[More information](#)

SCIENTIFIC NEWS

EBAR - European Biliary Atresia Registry of the ERN RARE-LIVER

Biliary Atresia (BA) is a rare paediatric liver disease with an estimated prevalence of 1 / 14.000-21.000 births in Europe (~270 cases / year). Management of BA is challenging as only 50% of patients in Europe are treated in centres with a multidisciplinary team.

To face this unmet clinical need, the prospective ERN RARE-LIVER Biliary Atresia Registry (EBAR) was implemented in the up-and-running R-LIVER registry.

EBAR is open to all members and non-members of ERN RARE-LIVER. Contributors retain ownership of entered data and will be compensated financially.

EBAR - European Biliary Atresia
Registry of the ERN RARE-LIVER



[New register](#)

SCIENTIFIC PUBLICATIONS

Patient reported outcome measure thresholds: The next step in the management of polycystic liver disease

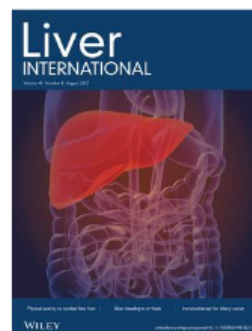


Editorial by Renée Duijzer (Nijmegen) and Tom Gevers (Maastricht) published in the United European Gastroenterology Journal referring to a large Belgian study on newly established thresholds of PLD disease-specific PROMs to aid management decision-making of when to start volume reduction therapy and how to assess treatment effect.

[Link to publication](#)

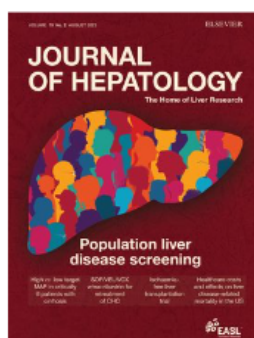
Patient reported quality of care in primary sclerosing cholangitis

Management and follow-up strategies for primary sclerosing cholangitis (PSC) vary. The aim of the present study was to assess patient-reported quality of care to identify the most important areas for improvement. Congratulations to our members from various ERN Centres.



[Link to publication](#)

A major research gap: the use of anticoagulants in cirrhosis



This review analyses the preclinical and clinical data supporting anticoagulation in people with liver cirrhosis. The authors discuss the past and current challenges in assessing the safety and efficacy of anticoagulants in cirrhotic patients and identify the needs to define the proper role of anticoagulants in managing patients with cirrhosis.

[Link to publication](#)

NEWS + EVENTS

EURORDIS launched a new Mental Wellbeing Partnership Network



EURORDIS has launched the Mental Wellbeing Partnership Network to support the response to the impact rare diseases have on the mental wellbeing of a patient. The Network is open to patient representatives, clinicians and researchers who are active in the rare disease and mental healthspace.

The Mental Wellbeing Partnership Network is calling for people living with rare diseases to join the new Partnership Network, where patient representatives will partner with experts to identify common mental health needs and guide future actions in this field. If you missed the first webinar on the Impact of Rare Diseases on Mental Wellbeing in July, you can find it on the website.

[More information](#)

EURORDIS: Black Pearl Awards: Nominate your Candidates



The nomination for next **EURORDIS Black Pearl Awards** are open.

This is an opportunity to put the spotlight on those who are making real change in the rare liver disease community and provide them with international recognition for their hard work and incredible accomplishments!

You can nominate any individual, organisation or company, or even yourself, for any of the 13 categories available. Learn more about the awards and submit your own nomination [here](#).

Nominations deadline: 31 August 2023

[Nominate here](#)

FUNDING OPPORTUNITIES

EU4Health funding opportunity for orphan medical devices

The **Call for proposals of a program on orphan medical devices, in particular targeting paediatric patients** by EU4Health is currently open and might be interesting for ERN RARE-LIVER members and partners. The grant will fund two projects over 1 up to 3 years covering 250k € each.



Deadline for submission is 17 October 2023.

Reference: EU4H-2023-PJ-11

[Detailed information](#)

Statement for ERN RARE-LIVER publications

We are happy to state that members and working groups of ERN RARE-LIVER are becoming more and more active, also causing an increasing number of surveys.

While this is a very positive trend, there is an increasing need to motivate people to participate. To do this and to harmonize the way we deal with publications that come out of the scientific surveys, we would like to ask you to please include in your scientific surveys a statement with the main aim of the survey.

The statement below will let people know what they gain from participating:

If data are published, the paper will have the authorship of the core group, who will write the paper, and as final author the name of the (group) lead of the ERN RARE-LIVER, and all individual contributors will then be listed as part of this group or included in the acknowledgements.

Please always remember: Publications can only be counted as **ERN RARE-LIVER publications** when the following three criteria are fulfilled: Main authors come from at least two centres from at least two member states and the ERN RARE-LIVER is acknowledged.

If you have any interesting scientific news, we would be glad to share it in our next newsletter.

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NEWSLETTER



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