

November 2023



European  
Reference  
Networks



Newsletter #12

Welcome to our next newsletter!



**Dear members and friends,**

We hope that you all had a wonderful summer and an active starting into the autumn season. Our Members' Meeting in September was a big success with more participants than ever before and a wide variety of topics that we discussed.

For the first time, we videotaped the presentations from our working groups and show them on the “specific news” section of our homepage. You will find the link below. The strategy meeting of our Management Board coming up in December is another date to define where we are going and what we would like to achieve in the next years.

We hope you enjoy reading this newsletter and maybe send us some ideas for the next one.

Have a wonderful autumn!

The ERN RARE-LIVER Team in Hamburg

[Contact Office Team](#)

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## Bilbao Summary



**European Economic  
and Social Committee**

The European Reference Networks (ERNs) were the central theme of a conference in Bilbao this October organised by the Spanish ministry of health as part of their presidency of the European Union. At this high-level conference there was impressive agreement across all players that the ERNs are an exemplary success story, and that many non-European countries envy the EU for having developed such an instrument for improving patient care in this difficult field. The president of the European Commission, Dr. Ursula von der Leyen, was cited as labelling the ERNs the “most successful innovation” in the field of health policy.

At this conference the European Economic and Social Committee (EESC) urged the European Union to launch an action plan stepping up cooperation between ERNs and the national health systems. The main goal is to provide better diagnoses, treatment and care to people living with a rare disease.

The conference was preceded by an ERN Coordinator Group meeting in Bilbao to talk about the core activities in all ERNs, the status and plans. Other topics on the agenda were Network agreements, the Expansion of disease, a Database on ERN Guidelines and guidelines for ultra-rare diagnoses as well as the cooperation with clinicians from European countries that are politically not eligible to participate in ERNs.

[More information](#)

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# Coordinators' Meeting in Luxembourg

Following the Bilbao conference, the coordinators of the ERNs met with the DG-Santé of the European Commission and representatives of the governing body, the board of member states in Luxembourg for a highly constructive discussion of the next steps ahead.

Amongst other points, the 5-year evaluation of all the 24 ERNs was summarised and discussed. Altogether the evaluation had very positive results, much more positive than most players had expected. It appears that on the basis of this strong performance, all ERNs will be able to continue their work, and the concerted effort of all ERNs to improve the care of patients with rare diseases will be supported probably in the long-term, with a particular effort to attempt a better integration into national health care systems.

[Evaluation Report](#)

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## New Video: COVID-19 Update for patients with rare liver diseases



As a patient with a rare liver disease, what do I need to know about COVID-19 in autumn 2023?

In autumn 2023 the situation is different compared to the last COVID-19 years. New virus mutants have appeared, new vaccines have been developed and patients are less afraid as immunity to this virus is now widespread. Prof. Ansgar Lohse, Coordinator of ERN RARE-LIVER gives his assessment of the situation and has some tips and advice.

[See website](#)

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



Biliary Atresia (BA) is a rare liver disease of infancy with unclear etiology potentially leading to biliary cirrhosis and liver failure in early life. BA is still one of the main indications for paediatric liver transplantation.

Meanwhile, the **European Biliary Atresia Registry** (EBAR) is implemented in the European Reference Network RARE LIVER to analyse and improve care for BA. EBAR can facilitate standardization of care, implementation of novel therapies and connect centres to drive research on Biliary Atresia.

You can find more information on our website.

[See website](#)

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## Welcome to our new Junior Lead in Vascular Liver Diseases: Sarah Raevens

**Sarah Raevens** from Ghent University Hospital is the new junior lead representative for the ERN vascular liver disease group, together with Giulia

Tosetti who has held this position for some time. Valerie Mclin and Aurélie Plessier are senior representatives of the vascular group.



Here is a short introduction from Sarah to our ERN RARE-LIVER family:

“I am staff member at the Department of Gastroenterology and Hepatology at the Ghent University Hospital. My clinical interests revolve around cirrhosis, portal hypertension, and vascular liver disease.

I supervise research projects that explore the complexities of portal hypertension, with a particular focus on understanding vascular biology in cardiopulmonary complications.

Outside of my professional life, I have a strong passion for travelling and like to attend (rock) concerts.”

Happy to have you on board, Sarah.

[Find our working groups](#)

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## Maciej Yanik takes over as the new adult lead of the Quality of Live working group

The Quality of Life working group has been particularly effective and is addressing a topic of utmost importance to us and our patients.

**Tom Gevers**, who successfully led the group during recent years, is stepping down as lead of the group and handing over to **Maciej Yanik** from Warsaw, who has been active in this group right from the beginning.

In addition, **Ewa Wunsch**, who has been very active in this group despite not working at an ERN RARE-LIVER member centre, has been appointed as External Expert.

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## Call for new webinars



The logo for ERN RARE-LIVER, featuring the text "ERN RARE-LIVER" in white, bold, sans-serif font inside a blue, irregular shape that resembles a liver.

## Join our Webinars

Teaching each other via Webinar is an important part of our educational activities. Not only is this a wonderful chance to train fellows as well as experienced colleagues, it is also a chance to present your special expertise, and thus you and your centre, to the wider audience of the ERN RARE-LIVER.

Please let us know, if you are interested to host a Webinar or contribute a talk in a Webinar – and the Training Working group will consider your application in shaping our educational programme.

[See latest webinar](#)

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## Remember to use our central consultation tool CPMS

CPMS is one of the most important tools offered by the European Commission to support physicians in their goal of improving the care of patients with rare and complex diseases.

Many member centers of ERN RARE-LIVER have already made very good use of this tool and have already helped hundreds of patients by basing diagnosis and treatment on the advice of international experts. For those who haven't used this tool yet, please give it a try. We're here to help you use it, and you'll soon see the many benefits, both in direct patient care and as an educational tool.



Marcial  
Sebode



Juliane  
Gaenge



Gustav  
Büscher



Ida  
Schregel



Renée  
Duijzer

**Hamburg**

Autoimmune Liver Diseases and miscellaneous

**Nijmegen**

Structural and Vascular  
Liver Diseases

Our CPMS Helpdesk Team is available for assistance when needed. You can find a flyer with more information on our website. Please contact us for help, if you need!

[Contact Helpdesk Team](#)

## News from the ERN RARE-LIVER ACADEMY



As you hopefully all know from our social media posts, our next **ERN RARE-LIVER Academy takes place on the 14 + 15 March 2024 in Copenhagen, Denmark.**

The organisers of this next Academy are **Marianne Hørby Jørgensen**, paediatric hepatologist from Rigshospitalet in Copenhagen, Denmark, and **Marianne Samyn**, paediatric hepatologist from King's College Hospital in London, UK.

ERN RARE-LIVER offers and sponsors up to 20 places to young fellows in the field of paediatric and adult hepatology in rare liver diseases.

If you are interested, please send us:

1. CV and list of publications
2. Letter of motivation
3. Letter of recommendation from an ERN member centre

**The application period will start on 1 November and end on 15 December 2023.**

More information on our website will follow soon.

[Send application](#)

## Scientific News

### EASL-ERN position paper on liver involvement in patients with Fontan-type circulation



Approximately 1 in 10,000 infants are born with a univentricular heart and are unlikely to survive without cardiac surgery.

Fontan-type surgery is the final step in the sequential palliative surgical treatment of infants born with a univentricular heart, and it is usually performed in infants between the ages of 2 and 4 years. The resulting long-term haemodynamic changes promote liver damage, leading to Fontan-associated liver disease (FALD).

This EASL-ERN position paper offers a clear definition and description of FALD and provides guidance for staging and management of different clinical scenarios.

The ERN RARE-LIVER Community thanks all ERN RARE-LIVER members' who worked on this valuable paper; Audrey Payancé, Ruth De Bruyne, Henkjan J. Verkade, Pierre Emmanuel Rautou and Juan-Carlos García-Pagán.

[Read publication](#)

**ERN endorses EASL Clinical Practise Guideline**



# on liver disease in pregnancy

The new EASL Clinical Practice Guidelines on the management of liver diseases in pregnancy is out!

The ERN management board is happy to announce the endorsement of this new guideline. This guideline covers both gestational liver disorders and acute and chronic hepatic disorders occurring coincidentally in pregnancy.

ERN RARE-LIVER affiliates made a vital contribution to the creation of this guideline with Catherine Williamson chairing the panel, which included Michael Heneghan, Hanns-Ulrich Marschall and Ulrich Beuers among others.

ERN RARE-LIVER representatives Gunilla Ajne, Kirsten Boberg, Verena Keitel, Aldo Maina, Piotr Milkiewicz, Christoph Schramm, Rinna Salupere, Erica Villa and Willy Visser worked on this guideline as part of the Delphi panel.

Thank you all for your valuable work on this important topic!



[Read publication](#)

## Immune responses and clinical outcomes after COVID-19 vaccination in patients with liver disease and in liver transplant recipients



Comparative assessments of immunogenicity following different COVID-19 vaccines in patients with distinct liver diseases are lacking. SARS-CoV-2 specific T cell and antibody responses were evaluated longitudinally after one to three vaccines alongside COVID-19 clinical outcomes.

After three COVID-19 vaccines, patients with liver disease generally develop robust antibody and T-cell responses to vaccination and have mild COVID-19. However, LTR have sustained no/low antibody titres and

appear most vulnerable to severe disease.

[Read publication](#)

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## Treatment responses and outcomes in patients with autoimmune hepatitis and concomitant features of non-alcoholic fatty liver disease

Non-alcoholic fatty liver disease (NAFLD) and steatohepatitis (NASH) affect 17–46% of Western countries, making coexistence with other liver diseases inevitable. The authors investigated the prevalence and clinical significance of NAFLD/NASH or the components of metabolic syndrome (MetS) in a large multicentric cohort of patients with autoimmune hepatitis (AIH).



[Read publication](#)

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**European Reference Network for hepatological diseases  
ERN RARE-LIVER**

**Universitätsklinikum Hamburg-Eppendorf, I. Medizinische Klinik  
und Poliklinik Zentrum für Innere Medizin, Hamburg**

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