



European
Reference
Networks



NEWSLETTER December 2022

Welcome to our next newsletter



Dear ERN RARE-LIVER
community,

Only a couple of days before Christmas we would like to extend our best wishes for a **Merry Christmas and a Happy New Year** to all of you, your local teams, and your patient groups!

In addition, we would like to share with you our latest news on the experience of several of our members with the **Clinical Exchange Programme**, and report on the **Plasmapheresis Workshop** in Copenhagen. There are some further meetings coming up like our next **online Members' Meeting**. And - most importantly - our new training event, the **ERN RARE-LIVER EASL ACADEMY**.

[Contact ERN office](#)

NEW ERN RARE-LIVER EASL ACADEMY



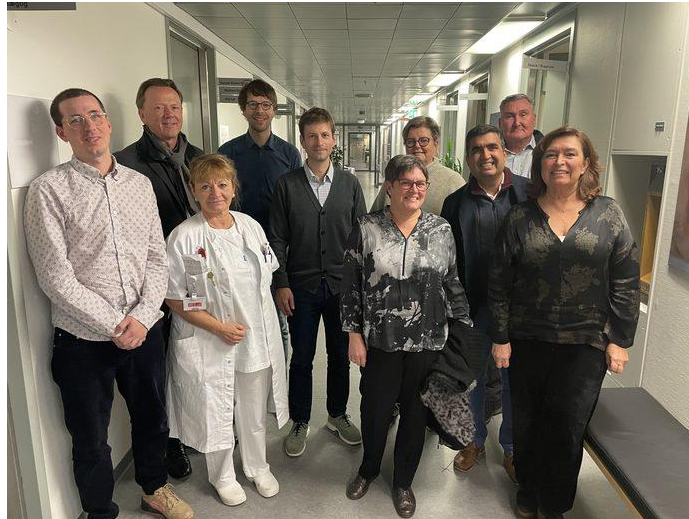
Our new **ERN RARE-LIVER EASL ACADEMY** website is online and the application phase starts now!
You can find all information on date, location, target group and requirements as well as the application form on our website.

The **ERN RARE-LIVER EASL ACADEMY** is our new training programme for young physicians in the field of rare liver diseases.

[ERN website](#)

GENERAL NEWS & EVENTS

Plasmapheresis Workshop, 22-23 November in Copenhagen



Acute liver failure in children is such a rare disease that collaboration, data recording and research are needed across Europe, and this requires standardization of treatment and data recording.

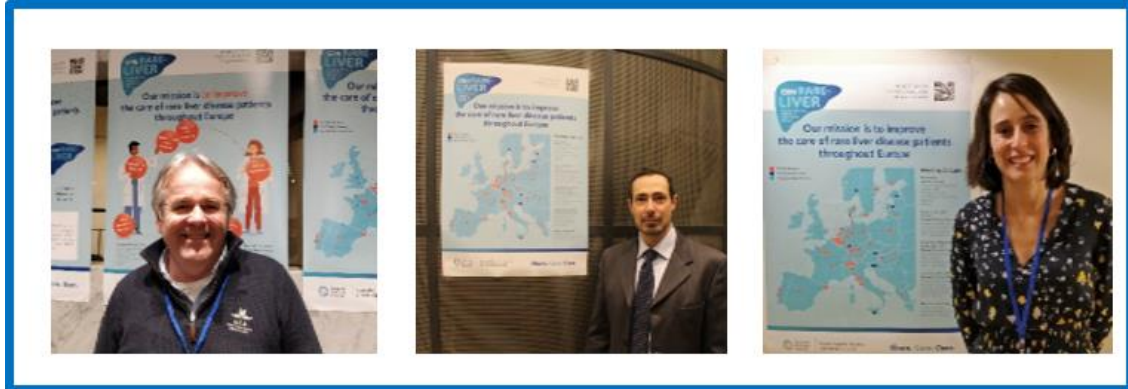
Reason enough to organize a Plasmapheresis Workshop at Rigshospitalet in Copenhagen in November where representatives from children's hospitals in Spain, Germany, UK and Denmark met for networking and a working meeting.

The meeting was also attended by representatives of the two European Reference Networks (ERN) "TransplantChild" and "RARE-LIVER" as well as researchers and clinicians from the paediatric and adult fields at Rigshospitalet.

The participants jointly took the first step toward establishing a protocol for the treatment of children with acute liver failure in the five European centres involved.

[See the news on our website](#)

Clinical Exchange Programme ended – time for a review



For ERN RARE-LIVER the **Clinical Exchange Programme** was a great success, sending a big number of professionals to various University Hospitals all over Europe, like the Netherlands, Spain, Denmark, Germany and Poland. Initially planned to spend 44 exchange packages, ERN RARE-LIVER actually could spend 17 more packages because other ERNs took less advantage of the programme. Additionally, meetings like the Portal Vein Thrombosis Meeting (PVT) in Paris in November were supported by the programme.

Read some personal statements why this programme should be continued.

[ERN website](#)

UPCOMING EVENTS

Save the date!

Online Members' Meeting 2 February 2023, 18:00-20:00 (CET)

What to expect:

Latest news of the network, R-Liver and CPMS

Updates from the working groups

Agenda and detailed information about speakers are coming up soon on our website

Graft-Injury-Group meeting 2023

We want to draw your attention on the Graft-Injury-Group meeting in Tübingen, Germany on 2-3 February 2023.

Leading translational and clinical researchers from paediatric and adult hepatology from all over Europe are welcome.

You can find more information on our website like the agenda, different topics and sessions as well as the map that shows you how to get there.



[Read Flyer](#)

The countdown to Rare Disease Day 2023 starts!



The countdown to Rare Disease Day 2023 has begun. The 16th edition of the day, which is coordinated by EURORDIS with national events coordinated by National Alliance, will take place on 28 February 2023.

The day is a key moment in the year for raising awareness of rare diseases and working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease.

If you plan any activities, please let us know.

[Find more information](#)

Share your experience



We would be happy if you share your experience with our ERN RARE-LIVER team. Just send us a couple of lines and some pictures from your last workshops, webinars or different get togethers and we can share them in our newsletter.

[Learn More](#)



**And finally, again:
The Hamburg team wishes you a Merry
Christmas and a Happy New Year.**

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