

January 2025



2025

Dear members and friends of ERN RARE-LIVER,

Happy New Year to everyone! May 2025 bring you lots of love, laughter, and joy.

With best regards

The ERN RARE-LIVER Office Team

Looking back

2024 was an eventful and important year for ERN RARE-LIVER!

Reorganisation and Growth:

- The ERN Office now consists of 4 Project Managers (Hendrik Matthies, Nagham Issa, Kari Klein, Jemina Schrod) and a Scientific Officer (Caren

Ramien), as well as 1 Data Manager (Felix Braun). Have a look at the team [here](#).

- We have newly staffed the **ERN CPMS Helpdesk** in 2024, consisting of the office as well as junior clinicians from Hamburg, Copenhagen, Paris, Malta and Barcelona. The helpdesk is available to answer all of your questions about CPMS and CPMS 2.0. Please [contact us](#) and we will pass you on.
 - We have welcomed **5 new Collaborative Partners** (centres in Innsbruck, Kiev, Florence, Brussels, Santander) in 2024, some of whom we are in close dialogue with and who are and will be an asset to our Disease Working Groups.
 - There has been a lot of activity within the **Youth Panel** (the young ERN RARE-LIVER patient representatives), e.g. statues have been drawn up, videos have been produced and webinars have been organised.
 - The group of our **European Patient Representatives (ePAGs)** was reorganised this year and gained new members, with currently 16 active members. To strengthen the structures and develop perspectives, the ePAG Leads and Board Members met in Paris in October 2024.
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Events and Meetings:

- We look back on 2 successful **Online Members Meetings** (February and October 2024). In these meetings, new projects of the ERN RARE-LIVER Working Groups were presented and the current status and future perspective of R-LIVER and CPMS were discussed.
- In March 2024, we had an exceptionally productive **ERN ACADEMY** in Copenhagen, with more than 20 fellows participating and working together in the spirit of the academy 'Growing up with liver disease'.
- In Spring 2024 we were represented at both **EASL and ESPGHAN** conferences in Milan. We had our own ERN RARE-LIVER Reception at EASL in a nice location, traditionally on Thursday evening, which is also being planned for this year's EASL conference in Amsterdam.
- We had **6 webinars** in 2024 with an average of about 70 participants per webinar. The best attended event was the roundtable discussion initiated by ERN RARE-LIVER after the EMA recommendation to revoke obeticholic acid/Ocaliva. The ERN statement prior to the webinar can be read [here](#).

- In 2024 ERN RARE-LIVER funded the workshop ‘Therapeutic Plasma Exchange’ organised by the **Paediatric Acute Liver Failure Working Group** in Madrid. Each year, ERN RARE-LIVER has a specific budget to fund workshops for the Disease Working Groups.
- In December 2024, we had the kick-off meeting of the **ERN Overarching Transition Group**. This brought together representatives from all ERNs to jointly pursue and further develop transition activities. For more information, please contact the ERN RARE-LIVER [Office](#). Please also have a look at the [Transition of healthcare template](#) provided on our website.

Looking forward

ERN RARE-LIVER Members’ Meeting 2025

We are very happy to see you at our **Members’ Meeting in Barcelona** from **23-24 January 2025**. The main topics are the presentations of the working groups, as well as other exciting highlights (CPMS Case Discussions, R-LIVER, etc.).



See you soon!

ERN RARE-LIVER ACADEMY 2025



For more information, the detailed programme and speakers, please visit our [ERN RARE-LIVER ACADEMY](#).

The **ERN RARE-LIVER EASL ACADEMY 2025** will be hosted from **10-11 April** by the University Hospital of Heidelberg. The focus of the academy will be on translating clinical practice guidelines into real-life care.



The **EASL Congress 2025** will take place from **7-10 May 2025** in Amsterdam, where ERN RARE-LIVER will have a congress booth. There will also be an **ERN RARE-LIVER Reception**, which is traditionally on the Thursday evening of EASL conference (**8 May**). Please save the date, more information will follow soon.



ERN RARE-LIVER will also be represented at [ESPGHAN](#) from **14-17 May 2025**. We look forward to meeting and networking with our paediatric members and partners at the conference. We intend to also have an **ERN RARE-LIVER Meeting**, more information about this will follow soon.

European Commission (EC) Monitoring Exercise 2025

We ask all of our Full Members and Affiliated Partners to submit your data regarding the required indicators to us by **21 February 2025**. We will forward the data to the European Commission. Please contact the [office](#) if you have any questions.



We would like to ask you to stay on time so we can complete the monitoring of 2024 smoothly. Thank you!

ERN RARE-LIVER Webinars

We will have numerous webinars in 2025 with new topics and formats, including a patient-focussed webinar series. Please have a look at our website, where we have linked the future webinars planned so far and where you can find detailed information.

If you are interested to host a webinar 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).



Visit us on our website



ERN RARE-LIVER

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