

[View this email in your browser](#)

ERN RARE-LIVER Members' Meeting September 2022



European
Reference
Network

Hepatological Diseases
(ERN RARE-LIVER)

NEWSLETTER

Welcome to our next newsletter!



Dear members and friends,

It was wonderful to see so many of you in person again in Hamburg on 9th and 10th September. The new members of the ERN office found it exciting to see the network in action, especially given the recent increase in the number of partners and the progress seen in the working groups.

If one thing is for certain, it is that this is an exciting time for our ERN. We are already looking forward to our next annual meeting on 1st and 2nd September 2023, with a programme just as stimulating and filled with group sessions and lectures.

For now, we are still enjoying the success of the meeting and would like to share with you the highlights. **We have collected some impressions during the meeting and merged them into a short video.**

[Watch Video](#)



New Logo

The new logo of ERN RARE-LIVER, which was introduced at the Members' Meeting, can be used by all Full Members and Affiliated Partners and will be sent to you upon request.

Certificates of Attendance can also be sent to you upon request.

How to use the ERN Collaborative Platform

The slides that were shown during the numerous interesting presentations are stored on the ERN Collaborative Platform. Please follow this path to view the presentations:

[Go to webgate](#)

1. Login with your EU login (the same one that you use for CPMS), or create a new account
2. Access the network RARE-LIVER or proceed with “Search & join networks”
3. Click on “Library” – Meetings - Members' Meeting September 2022

[Email us if you have any comments or questions](#)

New Collaborative Partners

The voting on the three centres that applied for Collaborative Partnership was overwhelmingly favourable. Therefore, we express our warm welcome to our new Collaborative Partners:

- University Hospital of Montpellier, France
- Hôpital Avicenne, AP-HP Paris, France
- University Clinical Centre of Serbia, Belgrade

Industry Cooperations



In the interest of transparency, and in order to protect our visible independence, we have had some discussions within the Management Board and some working groups of ERN RARE-LIVER about the terms for our

interaction with industry and other commercial partners. In view of some uncertainties in recent months, we consider it important to set rules that the network and its members should follow. At the end of the discussion process we came up with five rules that we voted on, and that received an unanimous support by all the members:

1. The overarching goal is to improve patient care.
2. Core operations and decisions of the ERN RARE-LIVER need to be entirely independent.
3. All interactions should comply with the EFPIA code of practice.
4. All individual interactions need to be approved by the hospital (HCP).
5. Cooperation as Working Groups Leads or Management Board Member needs to be approved by the relevant working group and the Management Board, and needs to be transparent in the public domain (website). Individual members of the ERN RARE-LIVER should not cooperate with companies in the name of ERN RARE-LIVER.

You will soon find the conflict of interest form on our website!

GENERAL NEWS & EVENTS

Transition Working Group

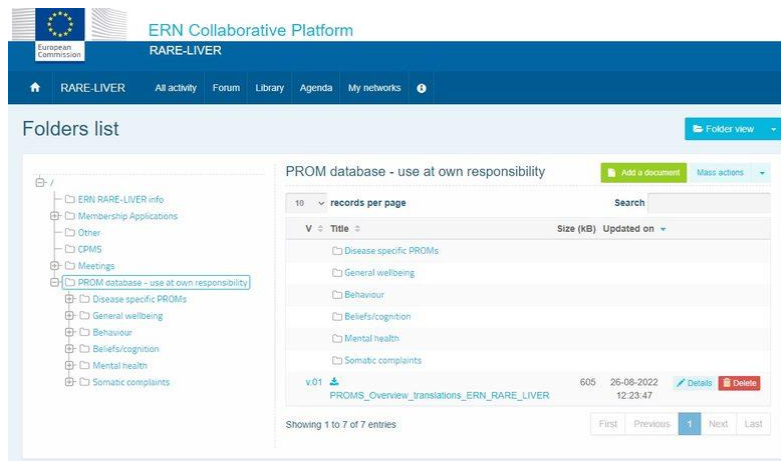


On behalf of the Transition Working group lead and members, João Madaleno, Isabel Goncalves, and Ruth De Bruyne, and as announced during the members' meeting, **ERN RARE-LIVER** are forwarding you the request below.

Please invest ten minutes of your time to complete the very important survey. **The survey will be online until 15th October.**

[Link to survey](#)

HRQoL PROM repository



The ERN RARE-LIVER Quality of Life (QoL) working group created a repository of patient-reported outcome measures (PROMs), that are used in studies conducted by the QoL-group. The repository contains an overview of the PROMs as well as available translations. Where PROMs are available from external sources, the links are given. If they were translated within an ERN-project, the translations are provided for download. Please note, that we make no warranties for the accuracy of the documents – use of the provided translations is at own responsibility. If you use a PROM within a project of the ERN RARE-LIVER that is not yet listed in the repository, please feel free to share it with us.

[Open repository](#)

1. Login with your EU login (the same one that you use for CPMS), or create a new account
2. Access the network RARE-LIVER or proceed with “Search & join networks”
3. Click on “Library” – PROM Database

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

[Contact us](#)

Transition of care

A workshop will be held in Ghent early next year to use the data collected.

[Learn More](#)



Training and Education: Your input is wanted!

The aim of the recently composed training and education committee has set up a teaching programme. Its members are Juan Carlos García-Pagán (Barcelona), Isabel Gonçalves Costa (Coimbra), Anja Geerts (Ghent) and Claus Petersen (Hannover). Before the group will initiate any training or education meetings or courses, we would like to learn more about your wishes, priorities and ideas. If you have not done so already, please take a moment to go through the following survey and feel free to make comments and suggestions.



[Read survey](#)

Follow-up survey on COVID-19 in patients with Autoimmune Liver Diseases

We have set up a follow-up survey of the anonymous, patient-oriented online survey about the vulnerability of patients with Autoimmune Liver Diseases (AILD) towards a severe course of COVID-19 that was conducted in 2020. The follow-up survey aims to ensure a broader view of the situation of patients with AILD and to continuously investigate affectedness and possible risk factors.

We would appreciate your support by distributing the information on this survey. The survey will be online until 30 September 2022 and the link below can be directly shared with patients.

[Support survey](#)

We are looking for new patient representatives



We would like to inform you of an initiative co-developed by the European Reference Networks (ERNs) and EURORDIS: **The recruitment of new European Patient Group (ePAG) advocates to join the different ERNs.**

This recruitment is based on a gap analysis exercise which identified the following gaps:

- **Country underrepresentation:** Patient organisations from **Eastern and Northern European countries**;
- **Poor Disease area coverage:** Patient organisations covering Genetic Cholestatic Disease, Biliary Atresia, Biliary Malformations, Alpha-1 Antitrypsin Deficiency, Polycystic Liver Disease, and Acute Liver Failure

We encourage patient representatives to share this message within their community.

If you or any of your members have questions or want information on the specific requirements for Patients Organisations to apply, the required skills and experience for candidates and the application process, please contact

[EURORDIS](#).

Recruitment period extended until September 30th, 2022

[Read more](#)

FUNDING OPPORTUNITIES

Mobility Fellowship funding opportunity



The **last round for the Research Mobility Fellowships funding opportunity** by the European Joint Programme on Rare Diseases (EJP RD) **will open on 3 October 2022**. The call aims to support PhD students, postdocs, and medical doctors in training to undertake scientific visits fostering specialist research training outside their countries of residence.

The exchange can be carried out **(1) within the same ERN (Full Members and Affiliated Partners)**, **(2) between different ERNs (Full Members and Affiliated Partners)**, or **(3) between ERN Full Members / Affiliated Partners and non-ERN institutions**.

The research mobility fellowships are meant to cover stays of **four weeks to six months**.

[Find more Information](#)

Research training workshops call: Deadline 1 October 2022



The **ERN Research Training Workshops funding opportunity** is now open for applications until **October 1st**. The goal of the workshops is to train **researchers and clinicians affiliated to ERN- Full Members or – Affiliated Partners in relevant topics on research in rare diseases**. Training themes may include **innovative research methodologies, diagnostic research topics, interdisciplinary treatment approaches, such as gene therapy and transplantation, etc**. Moreover, the workshops will be aiming to provide a cross-ERN added value.

The workshops will be delivered as **two-day events**. The costs for the workshop organization will be covered up to a limit of **€25,000** (venue, administrative, audio-visual and IT facilities essential for the workshop, catering, travel and accommodation expenses of workshops participants and invited speakers, if envisaged).

The workshops selected for funding will be attended only by individuals affiliated to ERN institutions. Participants will be selected by the coordinator of the ERN managing institution and the workshop organizer based on pre-defined criteria.

[Find more Information](#)

German Liver Foundation announces fellowship

Deutsche
_Leberstiftung

The German Liver Foundation promotes scientific exchange between research institutions in the field of hepatology by awarding networking fellowships. A fellowship is possible if at least one of the two participating research facilities is located in Germany and the two participating research institutions are located at different institutions.

[Learn More](#)

UPCOMING WEBINARS

The ERN RARE-LIVER Webinars are open to all

Our educational webinars are primarily aimed at physicians, and open to all. If you would like to suggest a topic, the office would be very happy to hear from you.

We are planning a couple of interesting webinars for the upcoming months. Please check out the schedule here.

[Overview Webinars](#)

Visit us per email or on our website



Follow us on social media:



Co-funded by the European Union



Copyright © 2022, ERN RARER-LIVER, All rights reserved

Want to change how you receive these emails?
Here you can [unsubscribe](#).