

## 2025 at once glance

**Dear members, partners and friends of ERN RARE-LIVER,**

As we convene to our annual meeting in Prague next week, we would like to give you a very brief summary of key developments of our large and growing network with its plentiful activities.

This is an excellent basis for our further development and the annual meeting, which will be attended by more than 120 representatives from across the ERN RARE-LIVER network, will be an excellent opportunity to reflect on past achievements and address new challenges and chances. We are looking forward to the further development of our wonderful network.

**The ERN RARE-LIVER Office**

### CPMS



European  
Commission

### CPMS 2.0

Clinical Patient Management System

- **CPMS Activity:** 60 new panels in 2025 matched 2024 levels and marked a +33% increase compared to 2022–2023.
- **CPMS Helpdesk:** From 2026 onwards, Maria Dias Lopes (Hospitais da Universidade de Coimbra, Portugal) will join the Helpdesk. The team comprises of **6 clinicians** from the network – a clinician-led structure

unique among all other ERNs.

- **CPMS Meetings:** ERN RARE-LIVER held **3 live case discussions** in 2025, each attended by approximately 40–50 participants.
- **DG SANTE Updates:** Major CPMS updates in 2025 included the participation of Ukrainian centres and the launch of the CPMS mobile app on Google Play and the App Store.

## Visibility & Outreach

**1.032**

Newsletter Recipients

**659**

Monthly YT Visitors

**8.393**

Website Views

**4.118**

LinkedIn Clicks

**243**

Instagram Followers

**939**

Downloads

## Training & Education

### ERN Liver Podcast

The ERN LIVER Podcast was launched on Spotify in 2025, with **2** episodes released to date.

### ACADEMY 2025

The ACADEMY brought together **20** young fellows in Heidelberg, including patient representatives.

### Clinical Exchange

**6** clinicians participated in the first round of the Clinical Exchange Programme in 2025.

### Patient Pathways

**3** Patient Pathways were finalised in 2025 (NCPVT,

### Webinar/Talk Series

**11** webinars were held in 2025, with an average of

### Working Groups

**20** Working Groups, including **1** newly esta-

PSVD, PLD) and are now available on the website.

57 participants per session.

blished group: Hepatitis D Virus (HDV).

### EASL Guidelines

5 Clinical Guidelines were newly endorsed in collaboration with EASL.

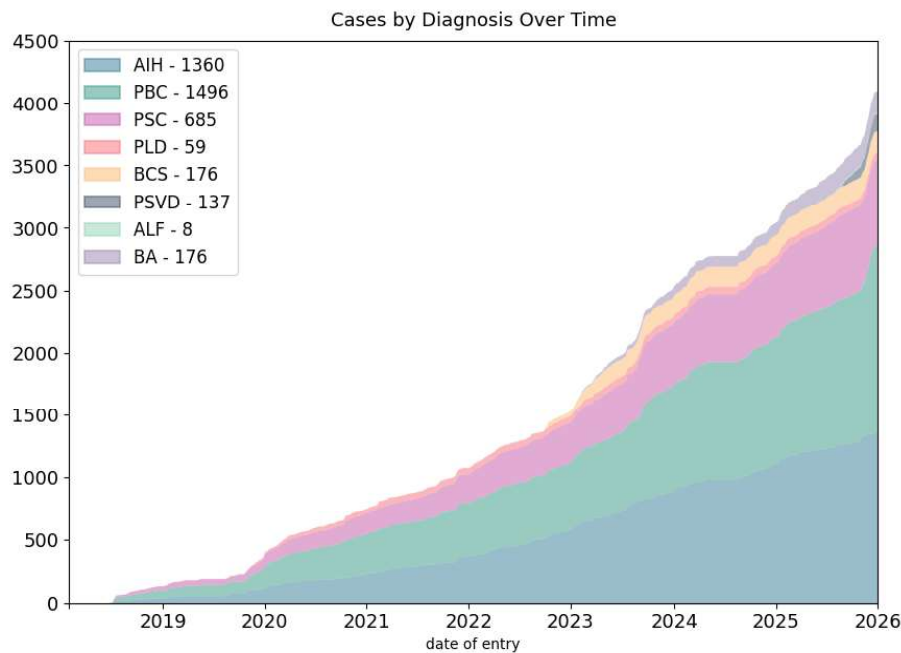
### Publications

34 publications were highlighted in the newsletters in 2025.

### Flyers

More than 800 flyers were sent to our member centres in 2025.

## R-LIVER



- **Case contributions:** 1,080 cases were contributed across all diagnoses covered by R-LIVER.
- **PSVD study:** Launched in 2025, with over 140 cases added within a few months.
- **BCS study:** Re-launched alongside the PSVD study after being dormant since 2023.
- **PVT study:** Development started in 2025 and is being finalised in early 2026.

# Meetings & Conferences

**2**

Members' Meetings

**5**

Workshops

**1**

ACADEMY

**2**

Conferences

**2**

Site Visits

**1**

Youth Panel Meeting



# Patient Engagement



- **Working Group Participation**: **70%** of Disease Working Groups include at least 1 patient representative.
- **ePAG Meeting Performance**: **4** online ePAG meetings in 2025, including **2** sessions with guest speakers.
- **Scientific Contributions**: More than **20** publications with ePAG involvement as of 2025.
- **ePAG Activities**: **4** presentations to wider professional audiences.

## Paediatric & Transition Activities

### Overarching ERN Transition Group

The Overarching Transition Working Group, with **53** members, was initiated in 2025 by ERN RARE-LIVER.

### Overarching ERN Youth Panel

The Overarching Youth Panel was initiated in 2025 by ERN RARE-LIVER. There are **30** participants up to date.

### ERN RARE-LIVER Youth Panel

The Youth Panel consists of **16** members from 18-30 years old. 12 meetings and 1 workshop took place in 2025.

### Parent/Paediatric Advocacy

The ERN has placed a focus on parent advocacy and is aiming to establish a Parent Panel.

### ERN RARE-LIVER Paediatric Activity

Around **30%** of all ERN clinicians are paediatric, as is the representation in the Working Groups.

### Talk to Heal at CHUC Coimbra

This paediatric project in Coimbra brought young patients, parents, and clinicians together.

## Upcoming



### Members' Meeting Prague 2026

The ERN RARE-LIVER Members' Meeting will take place from 13-14 February 2026 in Prague.



### ERN RARE-LIVER ACADEMY 2026

The ERN RARE-LIVER ACADEMY will take place in Groningen from 1-2 April 2026.



### ERN Transition Workshop 2026

The overarching transition workshop in Ghent will take place on 27-28 February 2026.



### ERN Workshop Applications 2027

Applications for the 2027 workshop are now open; more information is available on our website.



### Clinical Exchange Programme Part 2

The deadline for the second Clinical Exchange funding period in 2026 is 30 April.



### EASL ERN Reception 2026

The ERN Reception at EASL 2026 will be on Thursday, 28 May 2026, more details will follow.



Visit us on our website



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