



ERN RARE-LIVER: Collaborative Partnership

Thank you for your interest in **Collaborative Partnership of the ERN RARE-LIVER**. We would welcome you as a Collaborative Partner, subject to you agreeing to:

- Participate in the **Clinical Patient Management System (CPMS)**: A minimum of two CPMS cases to be uploaded on the system per year.
- Participate in the **prospective registry of ERN RARE-LIVER (R-LIVER)**: DTA and other documents have to be in process.
- At least one centre representative should participate in at least one working group.
- The centre should submit photos, information and names of the contact persons for the homepage presentation.

CPMS is a web-based clinical software application designed to facilitate secure cross-border collaboration among ERNs, with the aim of enhancing the diagnosis and treatment of rare or low prevalence complex diseases. Collaborative Partners can apply for a guest account. For additional details about the platform and instructions on how to register, kindly consult the following webpage: [CPMS \(rare-liver.eu\)](https://cpms.rare-liver.eu). You can access the CPMS platform here: <https://cpms.ern-net.eu/login/>.

R-LIVER is the prospective registry of ERN RARE-LIVER, which currently focusses on Autoimmune Liver Diseases, Polycystic Liver Disease, Vascular Liver Diseases and Biliary Atresia. We have prepared a welcome package that contains all necessary information and documents concerning the registry. Contact our office team to be provided with more information on this package: ern.rareliver@uke.de. For further information, please consult the following webpage: [R-LIVER Registry \(rare-liver.eu\)](https://rare-liver.eu).

ERN RARE-LIVER Working Groups: Each centre should participate in at least one working group. The ERN RARE-LIVER office will put you in contact with the group leads. For an overview of groups, please consult the following webpage: <https://rare-liver.eu/about/governance#team-5-28>.

If you agree to these terms, please fill in the Collaborative Partnership Form, sign and return the form to ern.rareliver@uke.de.

For any queries send us an email to ern.rareliver@uke.de or call +49 40 7410 52995.



ERN RARE-LIVER: Collaborative Partnership Form

Name of the Centre		
Address		
Centre Website URL		
Local Lead/Centre Representative		
Name of local lead	Contact Email	Profession
Further colleagues to be involved in the ERN		
Name	Contact Email	Profession

Clinical Practice Area (tick as applicable)	Adult <input type="checkbox"/>	Paediatric <input type="checkbox"/>
Transplant (tick as applicable)	Adult <input type="checkbox"/>	Paediatric <input type="checkbox"/>

Particular Clinical Expertise	
Research interests	
Expectations from ERN collaboration	
What can you bring to the network?	

R-LIVER application status (tick as applicable)	Already participating <input type="checkbox"/> Application in progress <input type="checkbox"/>
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Specialist Rare Disease Areas and patient numbers (please indicate year): _____

Disease	New patients/year from the applying centre	Overall patients numbers
Primary Biliary Cholangitis (PBC)		
Autoimmune Hepatitis (AIH)		
Primary Sclerosing Cholangitis (PSC)		
Paediatric AILD (AIH, PSC, ASC)		
IgG4-related Sclerosing Cholangitis		
Genetic Cholestatic Disease		
Polycystic Liver Disease (PLD)		



Biliary Atresia (BA)		
Choledochal Cyst		
Alpha-1-Antitrypsin Deficiency (AATD)		
Wilson Disease		
Cystic Liver Disease		
Vascular Liver Disease (VLD)		
Intrahepatic Cholangiocarcinoma		
Other rare liver tumours (CCA/HCC, HEHE&HAS, NET, Fibrolamellar hepatocarcinoma, Hepatoblastoma)		
Rare causes of Acute Liver Failure		
Liver Disease in Pregnancy		
Hemochromatosis		
Other (please specify):		

Name: _____, Date: _____

Signature: _____