



ERN RARE-LIVER: Collaborative Partnership

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

- Participate in the **Clinical Patient Management System (CPMS)**: three cases should be entered in CPMS by at least one guest user before being accepted as a Collaborative Partner.
- Participate in the **prospective registries of ERN RARE-LIVER (R-LIVER)**: adding the required number of newly diagnosed patients as shown below: DTA and other documents have to be in process.
- At least one centre representative should participate in a working group.
- The centre should beforehand submit photos, information and names of the contact persons for the homepage presentation. (Form attached separately).

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: <https://rare-liver.eu/healthcare-professionals/cpms>. 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. Other registries will be incorporated into the R-LIVER to become ERN RARE-LIVER registries in the future. 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: <https://rare-liver.eu/registry>.

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"/>

Requirements to participate in R-LIVER:

Disease area	New patients/year from the applying centre
AIH	
Paediatric AILD (AIH, PSC, ASC)	
PBC	
VLD	

PLD	
BA	
PSC	

Specialist Rare Disease Areas and patient numbers for the past year (please indicate year): _____

Disease	Overall patients numbers
Primary Biliary Cholangitis (PBC)	
Autoimmune Hepatitis (AIH)	
Primary Sclerosing Cholangitis (PSC)	
IgG4-related Sclerosing Cholangitis	
Genetic Cholestatic Disease	
Biliary Atresia	
Choledochal Cyst	
Alpha-1-Antitrypsin Deficiency (AATD)	
Wilson Disease	
Cystic Liver Disease	
Vascular Liver Disease	
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: _____