

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.

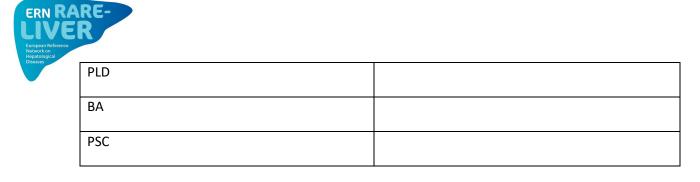
If you agree to these terms, please fill in the Collaborative Partnership Form, sign and return the form to ern.rareliver@uke.de.

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 Repre	esentative			
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	Paediatric
Transplant (tick as applic		Adult	Paediatric	
Particular Clinical				
Expertise				
Research interests				
Expectations from ERN				
collaboration				
Conaboration				
What can you bring to				
the network?				
R-LIVER application state		Already	participating	
			Applicati	on in progress
Requirements to participa	ate in R-LIVER:			
Disease area		New natient	s/year from the app	olving centre
AIH		TVCVV patient	s, year nom the upp	orymig centre
7111				
Paediatric AILD (AIH, PSC, ASC)				
, ,				
PBC				
VLD				
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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: ,		
Signaturo			
Signature:			