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). 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).

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		Paediatric	
Transplant (tick as applicable)		Adult		Paediatric	

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	
	Application in progress	

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		
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: _____