

ERN RARE-LIVER
Specific Criteria for Full Membership

Rare or Complex Disease(s), Condition(s) or Highly Specialised Intervention(s)	Minimum Number of Patients (Visited, Treated or Followed) Per Year	Number of New Patients Per Year	Number of Procedures Per Year
Primary Biliary Cholangitis (PBC, formerly Primary Biliary Cirrhosis)	100	10	
Autoimmune Hepatitis (AIH)	50	5	
Primary Sclerosing Cholangitis (PSC)	50	5	
IgG4 Disease	20	2	
Genetic Cholestatic Disease	10	2	10
Biliary Atresia	20	2	15
Choledochal Cyst	2	2	
Alpha-1 Antitrypsin Liver Disease	20	5	
Wilson's Disease	5	2	
Cystic Liver Disease	5	2	
Vascular Liver Disease	60	20	
Intrahepatic Cholangiocarcinoma	24	12	
Hepatobiliary tumors with stem cell features & mixed types (CCA/HCC)	10	5	
Hepatic epithelioid hemangioendothelioma & Angiosarcoma	10	5	
Fibrolamellar hepatocarcinoma	10	5	
Hepatoblastoma	10	5	
Primary hepatic neuroendocrine tumors (NET)	10	5	
Rare causes of acute liver failure	2	2	
Liver disease in pregnancy	5	5	