

ERN on hepatological diseases (ERN RARE-LIVER)

Rare liver diseases can cause progressive liver injury leading to fibrosis and cirrhosis. The complications of cirrhosis can lead to death and, in many cases, the only effective treatment is liver transplantation. Fatigue, pruritus in cholestatic conditions, and pain and abdominal swelling in cystic conditions significantly affect quality of life.

In paediatric patients, delay in diagnosis, and failure to thrive and attain developmental milestones are additional key factors, along with the challenge of transition in care through adolescence.

ERN RARE-LIVER addresses three disease themes: autoimmune liver disease, metabolic biliary atresia and related liver disease, and structural liver disease. The network will, for the first time in liver disease, fully integrate adult and paediatric care with a focus on the needs of transitional populations and the implications for families with a genetic diagnosis.

The development of up-to-date guidelines is a priority. Care guidelines will be



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implemented in collaboration with the European Association for the Study of the Liver (EASL) and the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN). This will be supported by the standardisation of key diagnostic and prognostic tests.

Clinician awareness of rare liver disorders and equitable access to rapidly evolving treatment options are major challenges to be addressed.

NETWORK COORDINATOR

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