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 patients' quality of life.

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

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

Up-to-date guidelines are a priority. Care guidelines, supported by the standardisation of key diagnostic and prognostic tests, are 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).

ERN RARE-LIVER aims to address the significant challenges of clinicians' awareness of rare liver disorders and equitable access to rapidly evolving treatment options.

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