ERN RARE-LIVER

- Would you like to improve patients care in your rare disease community?
- Are you a patient, parent or caregiver of a patient with a rare disease?
- Do you like to communicate with people from other countries?

Join us!

What You Need to Join

- Basic proficiency in English (the working language of the ERN RARE-LIVER network).
- Availability to participate in regular online meetings and project activities.
- Willingness to represent not only one's own interests, but the interests of all those affected
- For patients: a letter of recommendation from your patient association

Are you interested in joining the ERN ePAGs? Scan the QR-Code or email us at ern.rareliver@uke.de to learn more.

European Reference Network | Hepatological Diseases (ERN RARE-LIVER)

ERN RARE-LIVER

European Reference Network on Hepatological Diseases

ERN RARE-LIVER European Patient Advocacy Group (ePAG) for patients and parents

Empowering Voices, Enhancing Lives:

Uniting Rare Liver Patient Representatives Across Europe

European Reference Network | Hepatological Diseases (ERN RARE-LIVER)

Patients' and caregivers' voices are essential to improving the care of both adults and children with rare liver diseases. Therefore, we need your help.

What is an ePAG?

- What is an ERN? **'ERN' stands for European Reference network,** an organization within the EU which aims to improve care of people with rare diseases.
- What is ERN RARE-LIVER? ERN RARE-LIVER is one of the 24 networks within the ERNs, where health professionals, patients, and caregivers work together to fulfill the aims of ERN RARE-LIVER.
- The ERN RARE-LIVER European Patient Advocacy Group (ePAG) is a dedicated network of patient advocates from across Europe.
- The ERN RARE-LIVER is committed to incorporating the views and voices of patients and their relatives in it's strategy and decision making.

People with rare liver diseases, their relatives, their parents, and their caregivers have essential knowledge to identify gaps, discuss improvements, and give input to research projects. So, your insight and lived experience are very much required for the progress of care for people with rare liver diseases.

Why do we need you?

- Work together with a network of patient representatives to drive positive change and improve care for individuals with rare liver diseases.
- **Play an essential role in shaping projects**, initiatives, and policies within ERN RARE-LIVER.
- Participate in regular meetings to share experiences, discuss developments, and advance the interests of rare liver disease patients and their families.
- Advocate for better healthcare, resources, and support systems for children and adults with rare liver diseases.

What We're Looking For

- Individuals with lived experience of a rare liver disease, and parents of children with rare liver diseases.
- **An interest in collaborating with others across Europe.**
- Motivation to contribute ideas, attend meetings, and participate in projects that benefits patients and the patient community.

Share. Care. Cure.