ERN RARE-LIVER
European Reference Network on Hepatological Diseases

Youth Panel
Young people shaping rare liver care across Europe

Who we are We are a group of young people from across Europe living with rare liver diseases. We all come from different countries and have different experiences, but we share one thing in common: we know what it's like to grow up and navigate the healthcare system with a rare condition. Through the Youth Panel, we work together to make sure our experiences are heard and used to improve care for others.

What we do Our role is to bring the perspective of young patients into the ERN RARE-LIVER network. Over the past year, we've been involved in research projects, conferences, and workshops, while also working on ways to make healthcare easier to understand and navigate.

Current and Future Projects

- ERN RARE-LIVER Patient Webinar Series
- Position paper on psychosocial care
- Grant proposals and conference abstracts
- lived-experience stories and FAQs
- Involvement in ERN RARE-LIVER disease and transversal working groups
- Improve digital reach and enhancing youth-friendly resources
- Mentorship program
- Peer community platform
- Youth panel framework for Cross-ERN adoption

Turning experience into action A big part of what we do is turning our own experiences into something useful for others. For example, we've been developing simple tools to help young patients feel more prepared for appointments, for example what questions to ask, what to bring, and what to do afterwards. These are things many of us had to figure out on our own, so we want to make that process easier for others.

Why transition matters One of the main topics we focus on is something called transition – the move from paediatric (children's) care to adult healthcare.

For many of us, this is a difficult step. Suddenly, you're expected to manage your own care, speak up in appointments, and understand complex information often without much support. We're working to improve this by sharing our experiences, contributing to research, and helping develop more structured and supportive approaches for future patients.

Growing together We had a meeting in person for the first time in Ghent (2023), and it helped us connect, share ideas, and start building projects together. Since then, we've also represented the Youth Panel at international meetings and awareness campaigns, helping to make young people with rare liver diseases more visible. We had our last workshop together in Hamburg (2025), and look forward to building on our projects together in Ghent again in 2026!

Looking ahead We're continuing to build on this work. In the coming year, we'll focus on strengthening the Youth Panel, developing new projects (like peer support and communication tools), and continuing to work with healthcare professionals to improve care.

Want to learn more?
Scan the QR code

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