# FIRST EDITION SEPT 2026:
# WHAT'S THE SCOOP?

## WELCOME

Welcome to the first edition of the ERN RARE-LIVER Youth Panel 'What's the Scoop?' - where we highlight the latest news, stories, achievements and happenings in the ERN RARE-LIVER Youth Panel.

We are incredibly proud of the voluntary time and effort our group of young adults dedicate to making this Panel a success. As facilitators, we are honored to support their ultimate goal: to increase the involvement and visibility of our panel, ultimately improving access to high-quality, patient-informed, multidisciplinary care across Europe.




This edition will tell you who the youth panel is, our journey over the past few years, what matters to young people, how we turn experience into action, featuring a few of our Youth Panel members and outline what is next for us.

Janne Suykens & Kari Klein

## WHAT IS THE YOUTH PANEL?

The **ERN RARE-LIVER Youth Panel** is a group of young patients representing rare liver diseases within ERN RARE-LIVER (European Reference Network for rare liver diseases).



We are young people from 11 different countries who strive to make a difference and be the voice of many patients living with liver diseases. We advocate for **change** and a **better quality of life**. We take part in workshops, create informative materials, and contribute to projects that make a real impact.

*"I joined the Youth Panel because when I was little, I felt really alone when I had the diagnosis and that´s something I really want to make a difference with the ERN Youth Panel because I really think we can make people feel less alone with the panel"*

**KIONA, YOUTH PANEL MEMBER**



# OUR MISSION

We focus on addressing challenges in the transition from paediatric to adult care, highlighting difficulties faced during this period, and collaborating with healthcare professionals to find solutions. Our mission is to ensure that **young patients' voices are central** to discussions and policies that impact the rare liver disease community across Europe.

Our active participation in scientific events, the development of position papers, and our involvement in various working groups show that we are growing and striving to change the medical perspective on patients.




*"When a doctor didn't consider my feelings and when I had some challenging days they only considered the things they had to, but not my feelings and they didn't give me time to process."*

**PATIENT TESTIMONIAL PRESENTED AT EASL 2026**

Change begins with the courage to express what we feel!

*"We are young people from different countries, but we share the same mission: to make our voices heard as patients."*



# WHAT MATTERS TO YOUNG PEOPLE

## Looking beyond the diagnosis

Living with a rare liver disease affects much more than medical care. During the 2025 Youth Panel Workshop in Hamburg, members shared the issues that matter most to them and discussed how to turn these experiences into practical actions.

The strongest theme was the importance of connection and feeling understood. Young people highligthed the need for peer suport, experience-based guidance and a strong sense of community, particulary at times when lliving with those diseases feel isolating



**Members also identified several priorities for the future:**

### YOUTH-FRIENDLY INFORMATION

Making information about diseases, research and care pathways easier to understand and access is an essential step towards empowering young patients to actively participate in their own care.

### PSYCHOSOCIAL SUPPORT

Recognising that emotional and social needs are an assential part of living with a rare disease-not only during periods of crisis, but also as part of routine care; so they should receive the same attention as clinical outcomes.

### STRONG PATIENT VOICE

Involving young people in research and healthcare can help to raise awareness and ensure that lived experience informs future healthcare policies and services.

### PEER SUPPORT AND MENTORSHIP

Connecting young people with others who have lived through similar experience is an important way to support newly diagnosed young people, reduce uncertainty and strengthen confidence throughout their healthcare journey.

The Panel members also emphasised the importance of being seen as a whole person, not simply as a patient or diagnosis. This means having space to talk about everyday life, education, relationships and everything that can come with growing up with a rare liver disease.

# TURNING EXPERIENCE INTO ACTION

## Big Yellow friday




**Yellow** is often considered a forbidden colour for patients with liver diseases, as it represents jaundice, something that most of us have experienced.

On March 13, 2026, ERN RARE-LIVER's social media channels turned yellow as a symbol of **Big Yellow Friday**. This day aims to raise awareness of liver diseases in children and young people. The Youth Panel made its voice heard on this day by sharing answers to common questions that many patients ask themselves in their daily lives.

**"How open are you about your disease?"**

*"Over time, I've learned that for me it's best to be as open as possible about my condition. Real friends are understanding and considerate when you have to cancel because you're not feeling well. They also accept it when you decline alcohol. Over the years I've had very positive experiences with being open about it, especially in a university environment, and I keep noticing that more people than you'd think have some kind of condition. That helped me realize that I'm actually not as alone with this issue as I once thought. I also think it's very important that the people close to me are informed in case of emergencies. So don't be afraid to be honest! Your disease is part of your life and being open about it has helped me to accept that."*

**YOUTH PANEL MEMBER**

## EASL

EASL is the **home of hepatology**, where innovation and healthcare come together. Alanis and Lara had the opportunity to actively participate in the EASL Congress as representatives of the entire panel and, most importantly, as a voice for young patients.



Throughout the four-day congress, they advocated for the specific needs of young people living with rare liver diseases and had the opportunity to participate in several scientific workshops. They delivered a session on improving communication between young patients and healthcare professionals, with the special participation of doctors and patient representatives. During the presentation, they highlighted the challenges young people face and emphasized the importance of truly patient-centred care, focusing not only on the disease but also on the person living with it.

The message they wanted to convey was heard loud and clear: "Take our concerns seriously."

*"By participating in the EASL Congress, we have helped write a new chapter in patient involvement. We hope to make a positive difference for everyone facing the emotional challenges that often accompany a rare or chronic disease and for those learning to live with their condition."*

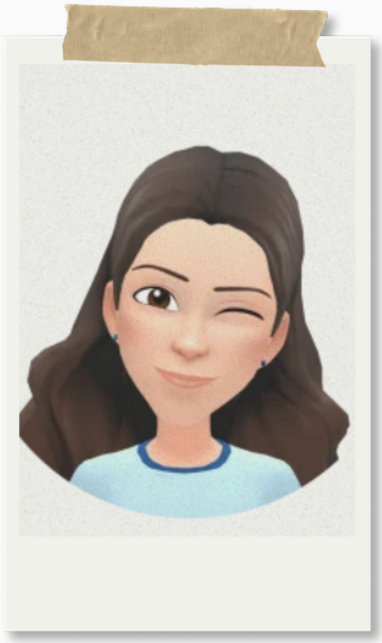
**ALANIS AND LARA , YOUTH PANEL MEMBERS**

# VOICES FROM THE YOUTH PANEL

## BEHIND EVERY DIAGNOSIS IS A PERSON, A STORY AND A LIFE

One of the most important parts of the younth panel is creating space for young people to share their experiences in their own words.

In this section we invite you to get to know two members of the Youth panel through their own experiences. Their stories show some of the different challenges, emotions and experiences that can come with living with a rare liver disease, and the importance of knowing you are not alone.



**Lara — My Story with Autoimmune Hepatitis**
Diagnosed at 17. Now 22.

At 17, Lara was diagnosed with autoimmune hepatitis after a long process of tests and uncertainty. One moment, she believed she was healthy; the next, she found herself surrounded by doctors, questions and undeniable evidence that something had changed.

Although receiving the diagnosis was difficult, Lara also felt a sense of relief once she finally knew what was happening. Throughout the process, the support of her family, friends, teachers and medical team helped her face the uncertainty and keep moving forward.

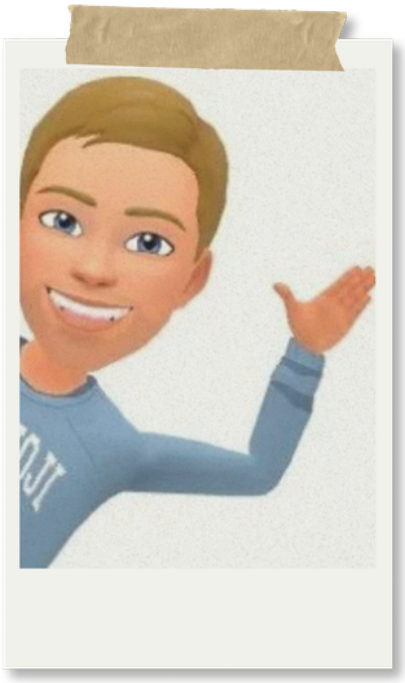
Her brother, in particular, inspired her to be brave and helped distract her from her own worries. Today, Lara is still learning how to live with AIH — but she knows she does not have to do it alone.

**THE MESSAGE:**

""I have AIH" and I invite other young people to say it out loud, share their experience and remember that you are not alone. Join me, now it's your turn!"

**Silas — My Story with Alagille Syndrome**

Diagnosed at 20. Now 27.



Silas was born without the main bile duct. For many years, doctors belived he had biliary atresia, and it was not until he was 20 that genetic reseacrh led to the correct diagnosis of Alagille Syndrome.

His childhood involved several major medical challenges. After an unsuccessful Kasai procedure, Silas received his first liver transplant at the age of three. Years later, he needed another transplant because his first one failed within 48 hours due to major blood clot, leaving him critically ill, so he ultimately received two liver transplants within one week.

Recovery took time, and later, during his teenage years, Silas experienced recurring infections in his bile duct. These complications are the reason he is now waiting for his fourth liver transplant.

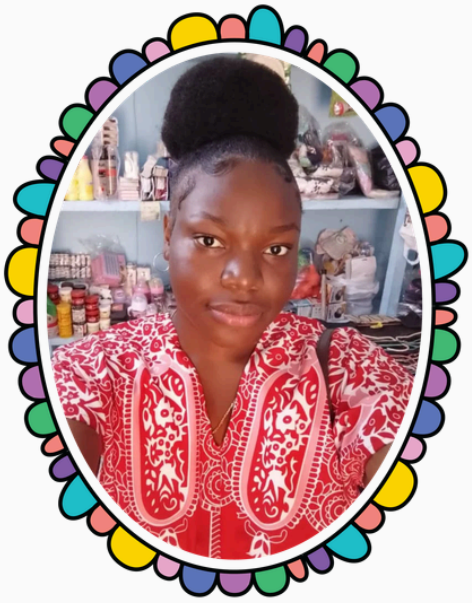
Despite everything he has been through, Silas reflects on how people can adapt to the circumstances they are given. For him, this is simply the life he has always known- although he admits that waiting for a phone call that could come tomorrow or in a year can be extremely difficult.

**THE MESSAGE:**

"People are incredibly good at adapting to the situation thay are given¨

Silas history is a reminder that living with a rare disease is not only about medical procedures and hospital visits, it is also about adapting, finding your own way and continuing to live your life despite uncertainty.







# Summer












# WHAT COMES NEXT?

## STAY CONNECTED. STAY INVOLVED!

The Youth panel newsletter is not just about sharing what we have done - it is also a space for your voice, ideas and experiences.

### YOUR VOICE MATTERS

*Would you like to contribute to our next edition?*
Share your experiences, ideas, projects or topics that matter to you as a young person living with a rare liver disease. We can include it in the next edition!




### WHAT TO EXPECT NEXT?

**Youth Panel Workshop 2026:** Updates and outcomes, including ideas and next steps that come out of the meeting.

**Youth panel activities:** Updates from our online meetings, ongoing projects and opportunities to get involved in 2027

### STAY CONNECTED

Scan the QR codes
to follow our journey:

**Social media**

**Website**

## We will catch up with you in 2027!

*Our next What´s the scoop is planned for Rare Disease Day 2027.*
*Until then, stay connected, stay involved and remember:*
***THE FUTURE OF THE YOUTH PANEL IS BUILT TOGETHER!***