



### What You Need to Join

- A passion to represent the interests of young patients and work closely with the ERN.
- Basic proficiency in English.
- Availability to **participate in regular online meetings** and project activities.

JOIN THE

# ERN Youth Panel

Are you interested in joining the ERN Youth Panel?

Email us at [ern.youthpanel@uzgent.be](mailto:ern.youthpanel@uzgent.be).





## About

- The ERN Youth Panel is a group of young patients across Europe and all ERNs representing rare and complex diseases.
- Our goal is to **empower young people to advocate for their unique needs** and experiences and ensure their voices are central in shaping healthcare practices.
- 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 disease community across Europe.
- European Reference Networks (ERNs) connect experts and hospitals across Europe to share knowledge and improve care for rare diseases. These networks make it easier for specialists to work together, no matter where patients live.



## Why Join?

- Play a vital role in advocating for young people with rare diseases and influencing initiatives, projects, and policies within ERN.
- **Collaborate with a network of young patient** representatives to drive positive change and improve healthcare outcomes.
- Participate in regular meetings to share experiences, advocate for better healthcare, resources, and support systems tailored for young adults with rare diseases.

## What We're Looking For

- Young adults (18-25) with a rare disease who are passionate about patient advocacy OR a sibling (18-25) of someone with a rare disease that is not able to articulate their experience.
- **Enthusiastic and motivated individuals** who are willing to contribute ideas, attend meetings, and engage in projects that benefit the youth patient community.

**Share. Care. Cure.**