

FIN Young Adults Community Manifesto

Our Shared Values & Community Commitment

Why This Manifesto Exists

- The FIN Young Adults Community exists to create a safe, supportive and empowering space for young people affected by Fabry disease.
- This manifesto reflects who we are, how we support one another, and the values that help protect this community for everyone.
- It is not a list of rules. It is a shared agreement about how we show up for ourselves and for each other.

Our Community Vision

- Every young adult affected by Fabry deserves a place where they feel understood.
- The freedom to share their experiences openly.
- The choice to participate in ways that feel right for them.
- Support in navigating life with Fabry.
- Opportunities to grow, learn and use their voice if they wish.

Our Core Values

- Respect & Kindness – We treat each other with dignity, compassion and empathy.
- Safety & Trust – We help create emotionally safe spaces and respect confidentiality.
- Authenticity & Honesty – Members are encouraged to be themselves without pressure.
- Inclusivity & Belonging – We welcome diversity in experiences, backgrounds and identities.
- Choice & Personal Pace – Participation is voluntary and flexible.
- Mutual Support & Responsibility – We contribute to a positive and respectful environment.
- Integrity in Sharing Information – We encourage evidence-based and respectful discussion.
- Empowerment & Voice – All levels of engagement are valued equally.

What We Ask From Our Members

- Respect fellow community members.
- Support a safe and welcoming environment.
- Protect confidentiality and trust.
- Engage respectfully in discussions.
- Be mindful of diverse experiences within Fabry.

What Does Not Belong in This Community

- Disrespectful or harmful behaviour.
- Discrimination or exclusion.
- Sharing private information without consent.
- Promotion of misinformation or unsafe medical advice.
- Commercial or promotional use of the community.

Our Commitment as FIN

- Protecting the community as a safe space.
- Involving young adults in programme design.
- Supporting members at different engagement levels.
- Promoting ethical advocacy and representation.
- Continuously improving based on community feedback.

Our Shared Promise

- This community belongs to all of us.
- We grow it together through kindness, honesty, respect and care.
- Living with Fabry can be challenging, but no one should face it alone.

Membership Acknowledgement

- I have read and understand the FIN Young Adults Community Manifesto and commit to supporting these values.