Plain-Language Summary of the Study

What is this study about?

This study explores what it is really like to live with Glanzmann Thrombasthenia (GT) a very rare inherited bleeding disorder. While doctors understand how to treat bleeding, much less is known about how GT affects daily life, emotions, relationships, school, work, and families.

The aim is to hear directly from people with GT and their caregivers to understand the "hidden burden" that often isn't captured in medical records.

Why is this needed?

People with rare diseases often face unique challenges that healthcare systems don't see, such as:

- Constant fear of bleeds
- Stigma and misunderstanding
- Difficulty at school or work
- Emotional strain on families
- Struggles accessing knowledgeable healthcare

Because GT is extremely rare, these experiences are not well documented. This study hopes to fill that gap.

Who can take part?

- Adults (16+) living with GT (self-reported diagnosis is fine)
- Caregivers, such as parents, partners, siblings, or other family members
- Young people under 16 can take part with parent/guardian consent

Around 30 – 40 interviews will be conducted, and recruitment may continue until enough patterns are identified.

What will participants do?

- Take part in a 45–60 minute interview by video call or telephone
- Talk about their experiences living with or caring for someone with GT

- Choose whether or not the interview is recorded
- Skip any questions or stop at any time

Topics include daily life, emotional wellbeing, relationships, work or school experiences, healthcare experiences, and challenges navigating treatment.

Participants receive a £50 digital voucher as a thank-you.

What are the risks?

There are no physical risks, but some people may find recalling medical or emotional experiences upsetting. Interviewers are trained in trauma-informed practice and can pause or stop the interview at any time.

Support resources will be provided if needed.

How will my information be protected?

Your privacy is a priority. The study follows GDPR and UK data protection laws.

- Interviews are anonymised (names, places, and details removed)
- Each person gets a code like GT001
- Audio recordings are deleted after accurate transcription
- Only the research team sees the anonymised transcripts
- Data is stored securely on encrypted servers
- No information is shared with clinicians, funders, or outside organisations
- Data is kept for 10 years, then securely destroyed

Hemab ApS funds the study but has no access to identifiable interview data.

What will happen to the results?

Results will be used to:

- Create a full research report
- Publish findings in scientific journals
- Share summaries with patient organisations
- Produce a clear, plain-language summary for participants

- Support better healthcare communication and patient resources

Only anonymous, combined findings will be shared, no identifying details.

Who is running the study?

The study is sponsored and led by EquiPath Analytics Limited, with Principal Investigators Amy Owen-Wyard and Stacey McGeown. The funder (Hemab ApS) has no involvement in study design, interviews, analysis, or reporting.

Ethics approval from a recognised Research Ethics Committee (REC) will be obtained before the study begins.

Why does this study matter?

By sharing the experiences of people with GT and their caregivers, this study hopes to:

- Improve understanding of the real impact of GT
- Identify unmet needs in healthcare and support
- Strengthen patient advocacy
- Guide future research
- Support better, more compassionate care