

## Participant Information Sheet (PIS)

### ***Exploring the Hidden Burden of Living with Glanzmann Thrombasthenia: A Qualitative Study***

**Sponsor:** EquiPath Analytics Limited

**Funder:** Hemab ApS

**Principal Investigators:** Amy Owen-Wyard & Stacey McGeown

#### **Introduction**

You are invited to take part in a research study. Before you decide, please read this information carefully. It explains why the study is being carried out, what participation involves, and your rights. Taking part is voluntary. You can ask questions at any time.

#### **What is the purpose of the study?**

Glanzmann Thrombasthenia (GT) is a rare inherited bleeding disorder. While medical treatment is documented, far less is known about how GT affects emotional wellbeing, daily life, relationships, education, work, and family roles. This study aims to explore these experiences in depth. Understanding the hidden burden of GT will help improve support services, patient information, healthcare communication, and future research.

#### **Why have I been invited?**

You have been invited because:

- You are an adult (16+) living with Glanzmann Thrombasthenia **or**
- You are a caregiver, parent, partner, or family member supporting someone with GT.

A medically confirmed diagnosis is **not required**; self-reported GT is acceptable. We aim to interview around 30 people.

### **Do I have to take part?**

No. Participation is entirely your choice.

If you decide to take part:

- You will sign a consent form.
- You can withdraw at any time without explanation.
- Your healthcare, services, or benefits will not be affected.

### **What will taking part involve?**

If you agree to participate:

1. You will take part in a **45–60 minute interview** by secure video call or telephone.
2. A trained researcher will ask about your experiences with GT, including emotional, practical, and healthcare challenges.
3. With your permission, the interview will be audio-recorded. If you prefer not to be recorded, the researcher will take notes instead.

You do not have to answer any questions you do not wish to.

### **Are there any risks?**

There are no physical risks. Some people may find parts of the conversation emotional or difficult. If this happens:

- You can pause or stop the interview at any time.
- We can provide details of support resources.
- The team is trained in trauma-informed interviewing and safeguarding.

### **Are there any benefits?**

There is no direct personal benefit. However, your experiences may help:

- improve awareness and understanding of GT
- shape future support for people with GT
- highlight unmet needs in healthcare

- support the development of patient-centred resources

You will receive a £50 digital voucher as a thank-you for your time.

### **How will my information be kept confidential?**

Your privacy is extremely important.

#### **Your data will be handled as follows:**

- Interviews will be anonymised, removing all names and identifying details.
- You will be assigned a participant ID code (e.g., GT001).
- Audio recordings will be permanently deleted once transcribed.
- All data will be stored on secure, encrypted systems.
- Only the research team will have access to anonymised data.

### **How long will data be kept?**

Your anonymised data will be stored for 10 years, then securely destroyed.

### **Who will see my data?**

No identifiable information will be shared with:

- clinicians
- advocacy groups
- researchers outside the study
- funders, including Hemab ApS

Anonymised quotes may be used in publications or presentations but will not identify you.

### **What will happen to the results?**

Results will be shared as:

- a study report
- academic publications or conference presentations
- summaries for patient organisations

- a plain-language summary for participants

Only anonymised findings will be used.

### **Who is organising and funding the research?**

The study is:

- **Sponsored by:** EquiPath Analytics Limited
- **Funded by:** Hemab ApS

Hemab ApS provides financial support only. They **will not** have access to interview data, recordings, or any identifiable information. They will not influence analysis or reporting.

### **Who has reviewed the study?**

This study has been reviewed and approved by a UK Research Ethics Committee (REC).

It has undergone:

- ethical review
- safeguarding and risk review
- scientific review
- data protection assessment

### **What if I have questions, concerns, or a complaint?**

#### **Contact the research team:**

**Amy Owen-Wyard**

Principal Investigator

Email: amy@epalimited.com

Phone: 07510310324

## **What happens next?**

If you would like to take part:

1. Let the research team know.
2. You will receive a consent form.
3. An interview time will be arranged at your convenience.

Thank you for considering taking part in this study.

Your insights can help improve the lives of people living with Glanzmann Thrombasthenia.