SICKLE CELL
PRODIGY

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Survivor Database Participation Consent & Privacy Policy

Care for What Comes Next — Together, Beyond Treatment

Purpose of This Document

This document explains how your information will be collected, used, stored, and protected if you choose to participate in the Sickle Cell Prodigy Survivor Database.

Our goal is to ensure that you feel fully informed, respected, and in control of how your information is used. Participation is completely voluntary.

About the Survivor Database

The Survivor Database is a patient-centered initiative developed by Sickle Cell Prodigy to:

- Capture real-world experiences of individuals who have undergone bone marrow transplant or gene therapy
- Support connection within the survivor community
- Improve understanding of long-term outcomes and quality of life
- Inform patient-centered education, research, and advocacy

This database is designed to complement—not replace—clinical research by elevating lived experience as meaningful data.

What Participation Involves

If you choose to participate, you may be asked to:

- Complete a questionnaire about your health, treatment, and survivorship experience
- Provide optional demographic and contact information
- Participate in follow-up surveys over time (if you opt in)

How Your Data Will Be Used

Your information may be used to:

1. Improve Patient Support & Education

- Develop resources for patients and care partners navigating treatment and recovery
- Inform programs such as peer support, wellness tools, and survivorship education

2. Inform Research & Advocacy

- Generate de-identified insights about survivorship experiences
- Support collaborations with clinicians, researchers, and institutions
- Contribute to reports, presentations, and publications

3. Strengthen Community Voice

- Elevate lived experience to inform healthcare systems and policy discussions

De-Identification & Confidentiality

Your privacy is a top priority.

- Your data will be de-identified before being used for research, reporting, or external sharing
- This means your name, contact information, and identifying details will be removed

- Data will be presented in aggregate form (e.g., grouped insights, trends)

We will never share your identifiable information without your explicit permission.

Data Storage & Security

We take appropriate measures to protect your information, including:

- Secure, password-protected systems
- Restricted access to authorized team members only
- Ethical data handling practices aligned with nonprofit and research standards

We are committed to maintaining confidentiality, integrity, and responsible data stewardship.

Voluntary Participation & Withdrawal

Your participation is completely voluntary.

You have the right to:

- Decline participation
- Skip certain questions
- Withdraw from the database at any time

If you choose to withdraw:

- Your identifiable information will be removed from active records
- Previously de-identified data may still be used in aggregate analyses

Contact & Follow-Up

If you choose to provide your contact information, we may:

- Invite you to participate in follow-up surveys
- Share opportunities to contribute to research or community initiatives

You may opt out of contact at any time.

Risks & Considerations

Participation involves minimal risk. However:

- Some questions may be personal or emotionally sensitive
- You are encouraged to answer only what feels comfortable

We aim to create a respectful, trauma-informed experience for all participants.

Benefits of Participation

While there is no direct financial benefit, your participation helps:

- Improve support for future patients and families
- Shape more equitable and patient-informed care models
- Strengthen representation of lived experiences in research and advocacy

Consent Statement

By participating in the Survivor Database, you acknowledge that:

- You have read and understand this consent and privacy information
- You understand how your data will be used
- Your participation is voluntary
- You may withdraw at any time

You will be asked to confirm your consent before submitting your responses.

Contact Information

If you have questions about this initiative or your data, please contact:

Sickle Cell Prodigy
contact@sicklecellprodigy.org
www.sicklecellprodigy.org

Our Commitment

At Sickle Cell Prodigy, we are committed to:

- Centering patient dignity and autonomy
- Practicing ethical and transparent data use
- Building trust with the community we serve

Your story matters—and we are honored to steward it with care.