

Checks and Balances: Keeping Sickle Cell Research Safe

It's natural to be careful about joining research. Medical research hasn't always been fair or safe, especially for those living with SCD and for other communities of color, where research has not always provided the support or attention needed. Stories of harm, neglect, and exclusion still matter today.



How Things Have Changed

Today, there are strong laws and guidelines in the United States to keep research safe and fair. For example, the Food and Drug Administration (FDA) sets strict rules for how research is done. Other important protections include:

The Common Rule – a federal policy that requires all research involving people to respect their rights, keep their information private, and make sure participation is always voluntary

Institutional Review Boards (IRBs) – independent groups that review and approve research studies before they begin, making sure studies are safe and treat people fairly

The Belmont Report – a set of guiding principles for all research in the US, emphasizing respect, fairness, and care for people who take part

HIPAA (Health Insurance Portability and Accountability Act) – laws that protect the privacy of your health information during research

These laws and guidelines act as “checks and balances” to protect your health, your rights, and your voice every step of the way. Researchers must follow these rules to make sure your safety and well-being always come first.

Making an Informed Choice: What to Ask Before Joining a Study.

When you're deciding whether to join a research study, you should never feel rushed or pressured. You have the right to say "no" or "not yet," and you can always ask questions. Here are some helpful questions and reminders for SCD families considering a study.

Some Questions to Ask Your Research Team:

- Can you explain the purpose of this study in plain language?
- What are the potential side effects in this clinical trial? Have there been any deaths under this protocol?
- What are the possible risks and benefits for someone with SCD?
- How will my health and privacy be protected during and after the study?
- Who can I contact if I have questions or concerns during the study?
- What happens if I want to leave the study early?
- How often and how will the results be shared with me and the SCD Community?
- What will be done with my data and biospecimens during and after the study?
- If the study involves collecting my or my family member's stem cells, can we discuss options for storing them after the study ends?
- Will I receive results from any tests completed during this study?
- What is required from me?
- What is the inclusion and exclusion criteria for this study?
- Does this study follow standard of care?
- What am I required to pay for these procedures versus what is the clinical trial paying for?

Reminders

- It's okay to take your time before deciding.
- You have the right to ask any question.
- You can bring a family member or friend to help you understand.
- You can say "no" at any time, for any reason.
- You don't have to join a study if you're not comfortable.



You're never alone.

A good research team doesn't just hand you a form. They walk you through it, allow space for you to ask questions, and make sure you feel respected every step of the way.

- Every study must share contact info, so you know who to call.
- An Institutional Review Board (IRB) composed of an independent group of experts, reviews all studies before they begin, ensuring the study is ethical and fair.
- Once the study begins, a dedicated monitoring team regularly checks in to ensure everything stays on track.

Safe Research Principles

Safe research doesn't just happen. It's a shared promise between researchers and the SCD Community. By knowing your rights and staying informed, you play a powerful role in shaping how research is done. When families and researchers work together with trust and respect, research can be safer, more meaningful, and better for everyone.



A note about this resource

This resource was co-created with members of our SCD National Community Advisory Board (NCAB). [Learn more](#) about how the NCAB is shaping the future of SCD research and care across the ASH Research Collaborative® (ASH RC) Network.

The ASH RC created CABs so you can learn about the research happening in Sickle Cell and help shape it. CAB members are individuals living with SCD, parents, partners, caregivers, advocates, and community organizations, each bringing vital perspectives to the table.

As a CAB member, you join a supportive community working to make sure research reflects the needs, voices, and values of those most affected. You'll also be part of something bigger: a movement to center the SCD Community voice in research. Your insights help ensure that research remains grounded in lived experience. Together, we can improve the lives of those most affected by SCD.

Interested in joining a local CAB in our Network?
[Contact us](#)

