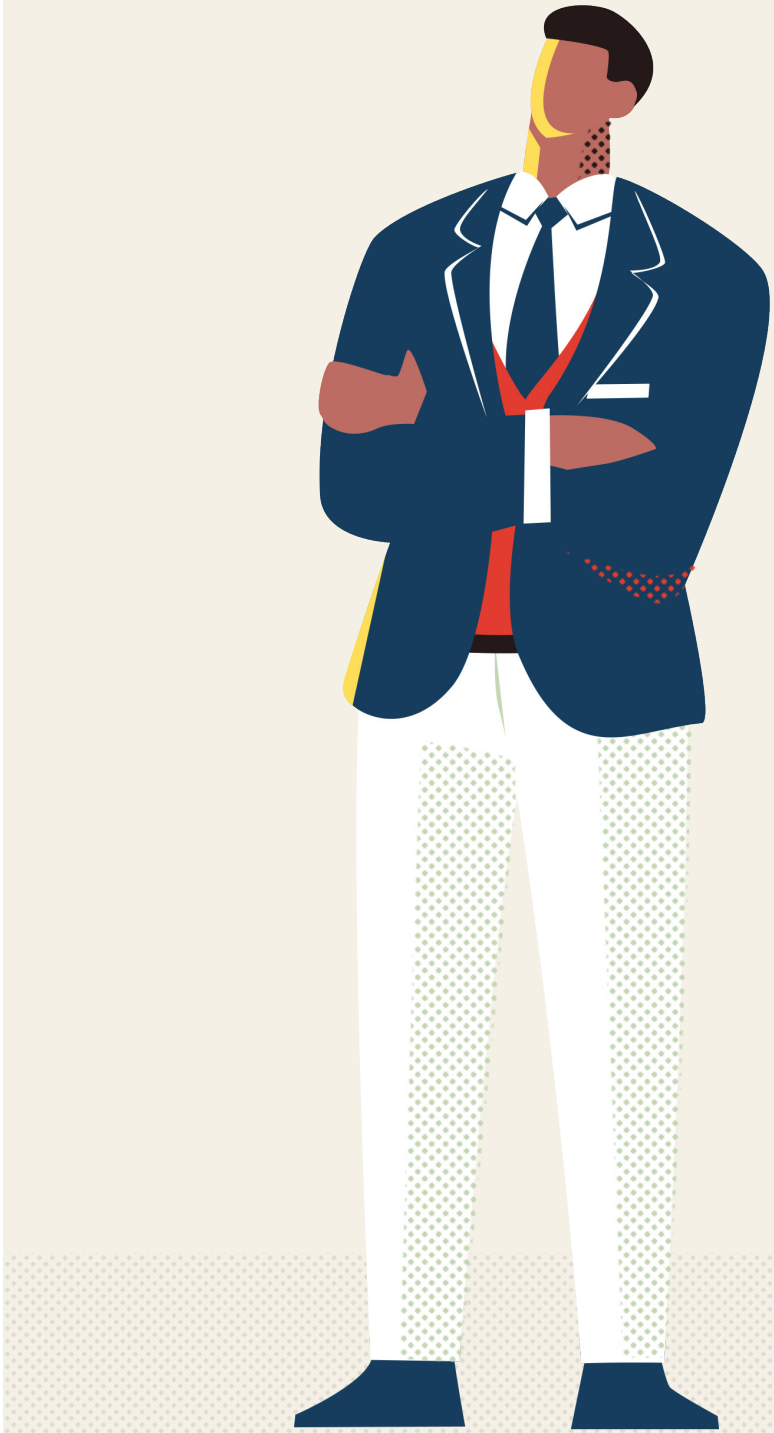
Why Join Clinical Trials for Sickle Cell Disease?

Clinical trials help find new and better ways to identify and treat diseases. By joining a trial for Sickle Cell Disease, you may gain access to new treatments before they are widely available. More importantly, your participation helps researchers improve our understanding of the disease and develop better care for individuals with sickle cell disease.

Participants in clinical trials often receive investigational treatments and medical care at no cost. By participating, you help advance treatments for Sickle Cell Disease and potentially help future patients live healthier lives.

ASH RESEARCH COLLABORATIVE®
Accelerating Progress in Hematology



Patient Safety is the Top Priority

Before a new treatment reaches clinical trials, it undergoes extensive testing in laboratories. This process involves numerous stages, including studies in test tubes and animals to evaluate the treatment's effectiveness and safety, ensuring that any potential risks are identified and addressed early on. The U.S. Food and Drug Administration (FDA) and independent review boards ensure that all trials follow strict guidelines to protect participants' rights and welfare.

Evaluation and Phases

Before a trial begins, the trial doctor will discuss your medical history to ensure the trial is a good fit for you. This discussion covers your condition, lifestyle, and any questions or concerns you may have.

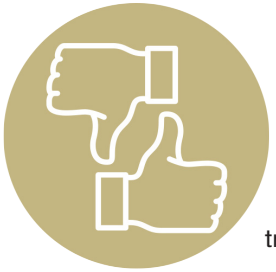
Clinical trials go through several phases to study the safety, dosage, and effectiveness of treatments. Each phase involves a different number of patients and lasts for different amounts of time, ensuring thorough evaluation before approval.

In clinical trials, patients are often randomly assigned to different treatment groups. This process helps researchers compare the investigational treatment to standard therapy or a placebo, ensuring unbiased results.

After the trial, researchers analyze the collected data and publish the results. This process may take one to two years, but participants can track progress online or through the trial care team. Sometimes, participants may continue receiving the investigational treatment if it's beneficial.

Phase 1

Study safety, side effects, and dosage of treatment



Phase 2

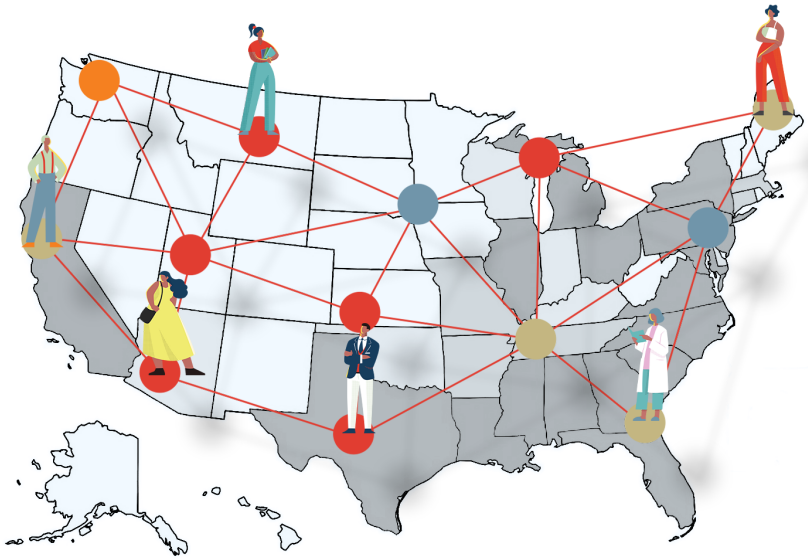
Learn about treatment effectiveness and further study the safety of treatment

Phase 3

Confirm effectiveness and monitor safety while comparing to other treatments and collecting more information

Phase 4

Provide additional information after approval, including risks, benefits, and best use



Heat map is a representation of the estimated population distribution of individuals living with SCD in the United States. (Source: Hassell, 2010)

Making an Impact

No matter the outcome, your participation helps advance our understanding of sickle cell disease. The ASH Research Collaborative, established by the American Society of Hematology, is committed to improving lives through research. By connecting our Network of researchers to the SCD Community, we aim to increase effective treatment options and improve care for individuals with the disease.

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.

Interested in joining a local CAB in our Network? Contact us

As a member of one of our local CABs, you'll join a supportive group of people who understand what it's like to live with and care for someone with SCD. We invite you to share your experiences and discover the innovative clinical research being conducted in our Network that's transforming SCD care. Together, we can improve lives of those most affected by SCD.

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Hassell, K. L. (2010). Population estimates of sickle cell disease in the U.S. American Journal of Preventive Medicine, 38(4), S512–S521.