



Hope *on the* Horizon

Research is the key to finding new treatments and a universal cure for sickle cell disease.

The William E. Proudford
Sickle Cell Fund, Inc.*



Clinical studies are critical to the drug development process

Through clinical studies, teams of medical professionals find new ways to diagnose, treat, and cure diseases. Treatments may include new drugs that are being used in humans for the first time, new surgical procedures, or new ways to use existing treatments. The goal of the study is to determine the safety and effectiveness of the therapy, device, or procedure.

Clinical studies can also simply observe patients — to improve the diagnosis process and the quality of life for people with chronic illnesses. Both healthy people and those with a disease or illness may participate in clinical studies. Clinical studies offer many potential benefits to people with sickle cell disease, including:

- Access to new treatments before they are widely available
- Regular and careful monitoring of the disease by a team of medical professionals
- Opportunities to learn more about advancements in sickle cell treatments

The drug development process

The journey from thousands of molecules (Stage 1) to one approved drug (Stage 5) can take more than a decade. Clinical studies—and the heroes who participate in them—are the key to finding new treatments that are both effective and safe.

We believe that one day researchers will find a universal cure for sickle cell disease.

\$1.4 BILLION

Average amount of money it takes to develop a new drug.

12 YEARS

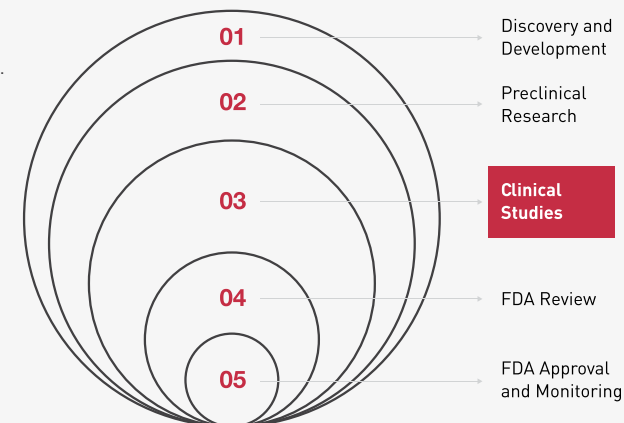
Average time it takes to develop a new drug.

5 IN 5,000

Number of drugs that make it to human testing.

1 IN 5 DRUGS

Number of drugs approved for use by humans.





African Americans and Clinical Studies

African Americans are typically underrepresented in clinical studies, which means that the medical world is lacking information that could be helpful in finding the next treatment or cure.

The Future

Despite a troubling history, today's clinical studies are safer than ever before. **Institutional review boards** that include both scientists and lay people oversee most studies to help keep participants safe. **Informed consent laws** require clinical researchers to provide participants with complete information about the study, including benefits and risks. Better – and more – treatments, and even a universal cure, for sickle cell may be near if patients continue to participate in clinical studies.

LEARN FROM THE PAST.

WORK TOWARD A BETTER FUTURE.

You → Clinical Studies → Hope

When you participate in a clinical study, **you contribute** to important research that can help **save and improve lives!** Twenty-five (25) sickle cell clinical studies have been halted in recent years because of low enrollment. We can't find treatments for sickle cell disease — or better yet, a universal cure — without clinical studies.

Talk to your doctor. It's easy!

We want to make it easy for you to talk to your doctor about clinical studies. Take our "Ask Your Doctor" sheet to your physician to start a conversation about clinical studies. There are 5 questions that will help you learn more about studies in your area.

This brochure is provided for information purposes only and does not replace the expertise of a qualified health care provider or procedures put in place by authorized persons to fully inform patients about participation in clinical studies.



Want more information about clinical studies?



U.S. National Library of Medicine
clinicaltrials.gov



Sickle Cell Disease Association of America
sicklecelldisease.net/scdaa-trial-finder



The William E. Proudford Sickle Cell Fund, Inc.
wepsicklecell.org/clinical-studies

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Our vision is a world
without sickle cell disease

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