YOUR PARTICIPATION IS IMPORTANT

#PastClinicalStudies
Remember taking penicillin or some other antibiotic as a kid to stay healthy?

In 1989 a group of SCD patients participated in the Penicillin Study, a clinical study that proved penicillin prevented life-threatening infections for SCD patients. Those SCD study participants contributed to your current treatment and helped provide treatment for millions of others living with SCD globally.

#NewTreatmentOptions
In the past, studies have ended due to low study participation. Without your participation, new treatment options or cures for SCD cannot be created. Finding new therapies for SCD requires the participation of SCD patients.

#PayItForward
It takes all of us to move sickle cell research forward.

As a study participant you are making a vital contribution towards new treatment options for your future and for future generations of SCD. To put it simply, you are the future of SCD.

QUESTIONS TO ASK BEFORE PARTICIPATING

Before deciding whether you want to participate in a clinical study, be sure you have answers to the following questions. #BeInTheKnow

• What is being studied and why?

• What are the benefits? How about the risks? Any side effects?

• What will I have to do as a participant?

• Who will oversee my medical care during the study?

• How long will the entire study last?

• Will I be paid and/or reimbursed for my participation?

HOW TO PARTICIPATE

If you are interested in a participating in a clinical study, it is important to know as much as possible about the study.

To learn more about clinical studies or to look up ongoing clinical studies for sickle cell disease visit SCDstudies.com, an online platform to help you identify and enroll in clinical studies. #TreatmentsForSickleCell

SCDSTUDIES.COM

CLINICAL STUDIES FOR SICKLE CELL

#TreatmentsForSickleCell

Current Drug Therapies for SCD
Clinical Study Terminologies
Your Participation Is Important
Questions to Ask Before Participating
How To Participate

References

• Learn About Clinical Studies; ClinicalTrials.gov
• NIH Clinical Research Trials And You; NIH.gov

To learn more about clinical studies visit scdstudies.com
CURRENT DRUG THERAPIES FOR SCD

There are very limited amount of treatment options for people living with sickle cell disease (SCD).

Once hydroxyurea was made available to the public, it took almost 20 years for the Food and Drug Administration (FDA) to approve another SCD drug therapy.

The current FDA approved drug treatment options for SCD:

**Hydroxyurea**
- It works by increasing fetal hemoglobin, a type of hemoglobin that is stronger at binding to oxygen. This helps prevent the sickling of red blood cells
- Approved in 1998 by the FDA

**L-Glutamine**
- Approved for the reduction of complications associated with SCD
- Approved in 2017 by the FDA

There are many other conditions that researchers have made great progress in finding treatments. These breakthroughs are in part due to successful enrollment of patients in clinical studies.

It is important for us to get proactive about clinical studies— to contribute towards more treatment options for SCD in the future.

#MoreSCDTreatments

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**Clinical study:** A clinical study, or clinical trial is a research study to investigate how safe and effective a therapy is.

**Informed Consent:** A document that outlines important information about the study including the benefits and risks.

**Institutional Review Board (IRB):** Ensures the study is ethical and that the rights and welfare of the study participants are protected.

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COMMON CONCERNS ABOUT CLINICAL STUDIES

*I’m honestly nervous about the side effects.*

The FDA requires the investigator to prove and provide safety data collected before, during and after the study. There are years worth of steps a therapy must undergo to ensure your safety before participating in a study.

Unanticipated side effects can occur, which is why it is important for any therapy to undergo this rigorous process. Ultimately it is up to you, along with your healthcare provider and your support system to make an informed decision and determine what is best for you.

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*I am just a guinea pig for another disease population.*

A SCD study is designed specifically for the SCD patient population. However along the way, researchers may discover new ways the therapy works, which may include additional patient populations that could potentially benefit from the therapy.

An example is the case of hydroxyurea and its original use in cancer. Researchers discovered that cancer patients who took hydroxyurea experienced increased levels of fetal hemoglobin. This finding was important and was leveraged to benefit the SCD patient population.

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*What about the United State’s past mistreatment of study participants?*

In the past, there were unethical studies conducted against African Americans in the United States, notably the Tuskegee Syphilis Experiment.

Over the past five to six decades, updated regulations by national and international government agencies along with other independent ethical committees have enforced regulations to ensure participant safety and privacy.