

Here are 5 things you can do.

Take time to find out more about some important things:

- ❶ Where and how to get tested.
- ❷ Where to get reliable advice and counseling about test results.
- ❸ What Hemoglobin is (Hee-mo-glo-bin is a term you may hear).
- ❹ What you should tell other family members about the Trait and why.
- ❺ Anything else you want to know about Sickle Cell Disease and Trait.

Individuals with Sickle Cell Trait should inform their doctor about their condition. If you have further questions please contact:

Your local Sickle Cell Disease Organization: Quest to Cure
www.questtocure.org



Office for Children with Special Healthcare Needs
602-542-1860 or 1-800-232-1676
<http://www.azdhs.gov/phs/ocshcn>

Raising Special Kids
602-242-4366
Toll Free: 800-237-3007
Fax 602-242-4306
www.raisingpecialkids.org



National Coordinating and Evaluation Center
Sickle Cell Disease and Newborn Screening Program
Contact National Coordinating and Evaluation Center:
410-528-1555 (Phone)
410-528-1495 (Fax)
1-800-421-8453 (Toll Free)
www.sicklecelldisease.net

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GETTING TESTED FOR GENES THAT CAN CAUSE SICKLE CELL DISEASE

FIND OUT WHY AND HOW TO GET TESTED



WHY TO GET TESTED

1. TO PLAN FOR FUTURE CHILDREN

COULD YOU EVER HAVE A BABY WITH SICKLE CELL DISEASE?

You can find out. Be aware of these FACTS:

- **Getting BOTH parents tested is the best way to find out.**

The different genes for Sickle Cell Disease have to come from BOTH parents - not just one. Getting the right test will let you know if either one of you has:

- A Sickle gene (S)
- Any other genes that could combine with an (S) gene to cause Sickle Cell Disease in any of your future babies.

- **The Sickle gene (S) DOES run in one or both of your families:**

- IF you already have a child with either Sickle Cell Trait or Disease-
- IF someone in your family or your partner's family has Sickle Cell Trait or Sickle Cell Disease.

Just be aware that people in your family may carry a Sickle gene (S) and not know it. Most people with Sickle Cell Trait (AS) don't even know that they have it. Why? The condition does not make them sick.

- **Sickle Cell Disease is a serious disease of red blood cells.**

It can also be quite painful. So, testing is important if you plan to have other children in the future. If you already know someone with the disease, you may be aware of this.

- **People of African descent are not the only ones affected.**

The Sickle gene (S) can also be present in people with family roots in Spain, Portugal, Italy, Greece, the Middle East and Asia. They, too, can have children with Sickle Cell Disease and should get tested.

2. TO BE SURE THAT PREVIOUS TEST RESULTS WERE DETAILED AND ACCURATE - PLAN TO GET RE-TESTED IF YOU THINK:

- **You have serious problems due to Sickle Cell Trait.**

Some people have found that they have a form of the Disease – not the Trait.

- **Your first test results were not detailed or accurate.**

For example, a "Sickle Cell Solubility Test" does not give detailed results. It gives a "positive" or "negative" result for the (S) gene only.

HOW TO GET TESTED

1. BE AWARE OF WHAT A "USEFUL" TEST IS

Find out if you can possibly have a baby with Sickle Cell Disease, in the future. Here are some facts: First, be aware that some blood tests are more useful than others. The best tests give detailed results. They can find the (S) gene. But they can also find OTHER genes that combine with (S) and cause you to have a child with some form of Sickle Cell Disease. Ask your doctor to explain this. Results that are not detailed can mislead you.

2. GET HELP FINDING THE MOST USEFUL TEST

Talk to your doctor, or call the local Health Department, to get tested. Ask to have the test that gives you the most detailed results. Avoid tests that only give a "positive" or "negative" result. They only look for the (S) gene. "Electrophoresis" and "DNA Analysis" give detailed results. "Electrophoresis" is pronounced (ee-lek-tro-for-ee-sis).

3. GET THE RESULTS AND ASK QUESTIONS

Talk with your doctor or a genetic counselor. Then, you can make the decisions that are best for you and your family.

