# **Get Screened to Know Your Sickle Cell Status**

# TO FIND OUT WHETHER YOU OR YOUR LOVED ONE

has sickle cell disease (SCD) or sickle cell trait (SCT), blood tests must be done to screen for these conditions. Arming yourself with this information is referred to as knowing your sickle cell status.

## What is sickle cell screening?

Screening for sickle cell means testing a person's blood for abnormal types of hemoglobin:

- Hemoglobin is a substance inside the red blood cell that delivers oxygen to all organs in the body.
- There are many types of altered hemoglobin, but people with SCD or SCT make a form of hemoglobin which is abnormal and it is called hemoglobin S or sickle hemoglobin.
- A blood test for hemoglobin S or sickle hemoglobin can tell you if your hemoglobin is normal, you have SCD or SCT (carrier status) or if you have another type of abnormal hemoglobin.

## Why should I (or my child) get screened for sickle cell?

- Getting screened to know your sickle cell status is extremely important at child-bearing age because SCD and SCT can be passed down to children through their parents' genes (Visit <u>http://</u> www.cdc.gov/ncbddd/sicklecell/facts.html for more information).
- Knowing if you have sickle cell trait is important because you could have a baby with SCD if your partner also has SCD, SCT or another abnormal hemoglobin gene (like hemoglobin C or Beta-thalassemia).
- All newborns should be screened for sickle cell, even if they look healthy. If left undetected and untreated, SCD can lead to severe health problems and even death, early in childhood.

## When should sickle cell screening occur?

## At birth:

- Newborn babies should be screened for sickle cell status (SCD or SCT), as early as 24-48 hours after birth.
- In the U.S. (all 50 states and the District of Columbia), babies are screened for sickle cell status as part of the newborn screening program.
- A positive newborn screening test means your baby likely has a condition reported but you need more testing by your baby's doctor to know for sure.



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Both SCT and SCD are conditions that are genetically inherited or passed down from your parents.



SCD is different from SCT; one cannot turn into the other. SCD causes many disabling symptoms like anemia (causes a person to feel tired, weak or short of breath), severe pain, or even stroke. SCT does not make you sick. In fact, screening tests might show that you have SCT and yet you usually never have physical symptoms.

#### In adulthood:

• Screening for sickle cell status may be done as part of the care you and your partner receive before or during pregnancy, or after your baby is born.

## What tests should be done?

The best tests to tell you whether you or your child is at risk for having SCD or SCT are:

 Complete blood count (CBC) – this test screens for anemia, a condition that occurs when not enough oxygen is delivered to the cells of the body due to the presence of abnormal hemoglobin. A Mean Corpuscular Volume (MCV) should be sent as part of the CBC as abnormalities can identify the presence of abnormal hemoglobin such as beta thalassemia trait.

#### AND;

• Hemoglobin electrophoresis, high performance liquid chromatography (HPLC), or DNA testing which may be used to find out the type of hemoglobin present in a person's blood.

### What tests should not be used?

• Results from sickle cell solubility tests may be misleading and SHOULD NOT be used to determine sickle cell status.

#### Where can I get tested?

- All infants born in the United States after 2006 should have their newborn screening information as part of his or her medical record, including sickle cell status. Contact your child's physician for more information.
- Ask your physician, local health-clinic, or community based sickle cell disease organization for testing locations near you.
- You may also contact the Sickle Cell Disease Association of America (SCDAA) at (800) 421-8543 or visit their website at <u>www.sicklecelldisease.org</u> to find testing locations in your community.





Where can I find more information about sickle cell disease and sickle cell trait?

For more information about sickle cell, visit: <u>http://</u> <u>www.cdc.gov/ncbddd/</u> <u>sicklecell/index.html</u>