

SUGGESTED WEBSITE REVISIONS/ REVIEW OF RESOURCES

Titilope Fasipe, MD, PhD
Sickle Cell Advisory Council Meeting
November 3, 2017

AREAS OF FOCUS

- SCD Main: <http://dshs.texas.gov/newborn/sickle.aspx>
 - suggested making more general, with a “click for more information” link
- SCD Other: <http://dshs.texas.gov/newborn/celltrait.shtm?terms=sickle%20cell%20disease>
 - suggested making more detailed (pretty much switching with above)
- Sickle Trait: <http://dshs.texas.gov/newborn/sctrait.shtm>
- Your Baby Has Trait:
<http://dshs.texas.gov/newborn/trait.shtm?terms=sickle%20cell%20disease>
 - suggest changing name to “FAQs about Sickle Trait” and having a link on above trait page
- Topic Search
- Advanced Search

MAIN PAGE

dshs.texas.gov/newborn/celltrai.shtm?terms=sickle%20cell%20disease

- Currently this is a random page that you can only search for.
- Change title to Sickle Cell Disease
- Suggest making this main page with links to “More Info” and “Trait”

Sickle Cell Disease
Sickle Cell Anemia
Sickle Cell Trait

- Change main button to “Sickle Cell”
- Sublinks:
 - change Sickle Cell Anemia to Sickle Cell **Disease**
 - Sickle Cell Trait

The screenshot shows the Texas Department of State Health Services website. The page title is "Sickle Cell Disease and Sickle Cell Trait". The main content area features two images of red blood cells: one showing normal, smooth cells and another showing sickle-shaped cells. Below the images is a paragraph explaining that sickle cell is a group of related disorders affecting red blood cells, caused by a change in the genes that make hemoglobin. It notes that sickle cell disease is inherited and passed from both parents. A list of symptoms follows, including pneumonia, organ damage, painful erections in men, swelling of hands and feet, complications during pregnancy, chest pains and trouble breathing, blood in urine, fever, stroke, leg ulcers, infections, jaundice, gallstones, anemia, and pain.

TEXAS
Health and Human Services

Texas Department of State Health Services

Advanced

Inicio en español
Text Size: + -

Topics: A B C D E F G H I J K L M N O P Q R S T U V W X Y Z All

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Home > Newborn Screening > Sickle Cell Disease and Sickle Cell Trait
Sickle Cell Disease and Sickle Cell Trait

Sickle Cell is a group of related disorders that affect a person's red blood cells. It is caused by a change in the genes that make hemoglobin. Hemoglobin S is the most common but there may be other variations in hemoglobin that in combination with hemoglobin S may cause problems. It affects males and females equally. **Sickle cell disease** is inherited. That means it is passed from mothers and fathers to their children when both parents have the disease or trait. It is not contagious. People with **sickle cell disease** have periods of well-being and stages of illness. The periods of illness are called sickle cell crises.

With **sickle cell disease** a person's red blood cells can become hard, sticky, and shaped like sickles. **Sickle cell disease** is a serious health problem. These problems can include:

- pneumonia
- organ damage
- painful erections in men
- swelling of hands and feet
- complications during pregnancy
- chest pains and trouble breathing
- blood in urine
- fever
- stroke
- leg ulcers
- infections
- jaundice
- gallstones
- anemia
- pain

SCD MAIN PAGE

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Home > Newborn Screening > Sickle Cell Disease (SCD) Sickle Cell Disease (SCD)

Sickle cell disease (SCD) is a hereditary blood disorder that affects hemoglobin, the substance in red blood cells that carries oxygen. There are several types of SCD, the most common being Sickle Cell Anemia (Hb SS Disease). SCD is found predominantly in the African-American population but is also seen in people of other ethnic groups. These ethnic groups include individuals from parts of the Middle East, Central India, and countries bordering the Mediterranean Sea, especially Italy and Greece.

Learn More About This Condition

- [The Infant and Young Child With Sickle Cell Anemia](#)
- [Sickle Cell Anemia: A Parent's Guide for the School Age Child](#)
- [Anemia de células falciformes: Una guía para padres de niños en edad escolar \(Spanish\)](#)
- [Sickle Cell Disease: A Resource for the Educator](#)
- [Things To Know About Sickle Cell Trait](#)
- [Lo Que Debe Saber Sobre El Rasgo Falciforme \(Spanish\)](#)
- [Homozygous Beta Thalassemia Major also known as Cooley's Anemia](#)
- [Hemoglobin C Disease](#)
- [Hemoglobin Sickle C Disease](#)
- [Hemoglobin E](#)
- [Splenic Sequestration Crisis](#)
- [Sickle Cell Anemia and Stroke](#)
- [Anemia De Célula Falciforme y Ataques \(Spanish\)](#)
- [Sickle Beta Zero Thalassemia](#)
- [Talasemia Falciforme Beta Cero \(Spanish\)](#)
- [Sickle Beta+ Thalassemia](#)
- [Aplastic Crisis](#)
- [Crisis Aplástica \(Spanish\)](#)
- [Chest Syndrome](#)
- [Síndrome de Pecho \(Spanish\)](#)
- [PAIN in the Child with Sickle Cell Disease](#)
- [DOLOR en el Niño con Enfermedad de Célula Falciforme \(Spanish\)](#)
- [Pneumococcal Infection and Penicillin](#)
- [Infección Neumocócica y Penicilina \(Spanish\)](#)
- [Priapism](#)
- [Priapismo \(Spanish\)](#)



Sickle cell disease is a hereditary blood disorder that affects hemoglobin, the substance in red blood cells that carries oxygen.

MORE INFO PAGE

Suggest making this the "more information page"

Publications

SUMMARY OF “OLD” RESOURCES

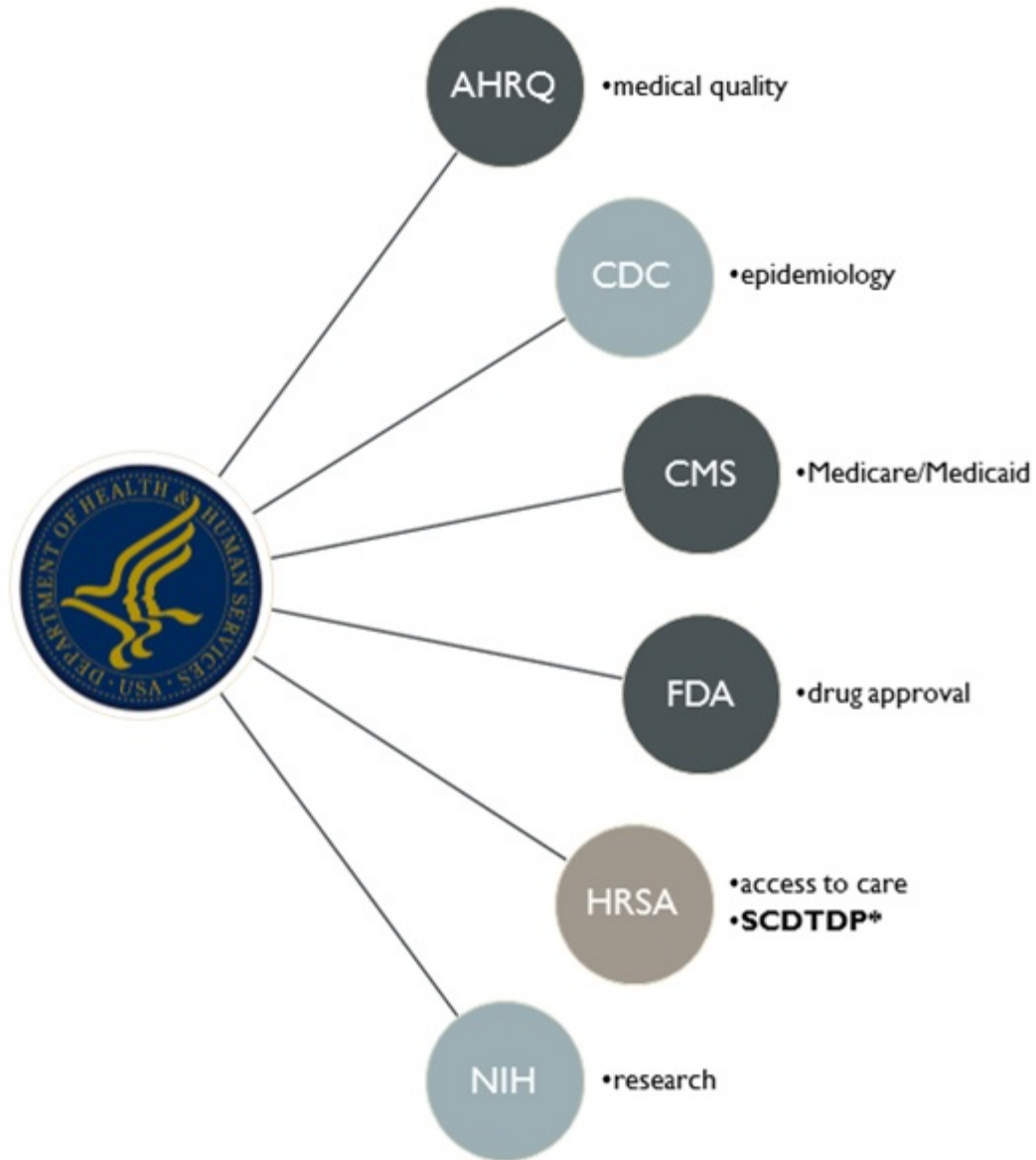
Education

- American Society of Hematology (general and health care providers)
<http://www.hematology.org/Foundation/6836.aspx>
<http://www.hematology.org/Clinicians/Priorities/4669.aspx>
- Centers for Disease Control and Prevention
<https://www.cdc.gov/ncbddd/sicklecell/index.html>
- National Heart, Lung, and Blood Institute
<https://www.nhlbi.nih.gov/health/health-topics/topics/sca>
- Sickle Cell Disease Management Tool www.sickleoptions.org

National Recommendations

- Suggest removing 4th Edition of SCD Management resource (outdated)
- NIH Expert Panel Report (2014)
https://www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/Evd-Bsd_SickleCellDis_Rep2014.pdf
- Plus “New” Resource

ADD “NEW” RESOURCE



*Sickle Cell Disease Treatment Demonstration Program, 2017

- Overseen by Health Resources & Services Administration (HRSA)
 - 4 Regional Coordinating Centers: **Heartland#**, Midwest, Northeast, Pacific
- NICHQ – National Coordinating Center
 - <http://www.nichq.org/project/sickle-cell-disease-treatment-demonstration-program>

SCD MORE INFO PAGE

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TRAIT PAGE



Texas Department of State Health Services

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[Home](#) > [Newborn Screening](#) > Things to Know About Sickle Cell Trait

Things to Know About Sickle Cell Trait

[En Español](#)

Sickle cell trait is an inherited blood condition. It is not a disease. It occurs when a person has one gene for normal hemoglobin and one for sickle hemoglobin. (Hemoglobin is a protein in red blood cells and carries oxygen to your body.) Genes control the physical makeup of a person, such as height and eye color. Every person has two genes for hemoglobin. One gene is inherited from the mother and one from the father. To have sickle cell trait means a person carries one gene for sickle cell hemoglobin. This gene can be passed along to his or her children.

Most people with sickle cell trait lead completely normal lives. But they may have severe problems with very extreme physical activity. It is important that your doctor knows if you or your child have sickle cell trait. Very rarely individuals with sickle cell trait can have additional problems such as a very rare form of kidney cancer found only in individuals with sickle cell trait.

What Can Happen If You Have Sickle Cell Trait?

Sickle cell trait is passed from mothers and fathers to their children. When one parent has sickle cell trait and the other parent has sickle cell trait or another hemoglobin trait (such as hemoglobin C or beta-thalassemia), there is a one-in-four chance that their baby will be born with significant sickle cell disease. There is a one-in-two chance that their baby will be born with a trait and a one-in-four chance that their baby will not have sickle cell disease or a trait.

People with sickle cell trait usually show no outward signs of it. It is not contagious. It rarely, if ever, affects health. People with the trait will not get sickle cell disease.

What is Sickle Cell Disease?

Sickle cell disease is an inherited blood disease that is very serious. A person with this disease has an abnormal hemoglobin in the red blood cells. Changes in the red blood cells cause them to be shaped like a "sickle." These blood cells are weak and sometimes get very stiff. They can get trapped in the blood vessels and harm blood flow. This can sometimes cause intense pain anywhere in the body. It can also damage body tissues and organs over time. Some serious problems can cause death.

Who Can Have Sickle Cell Trait?

People of different ethnic backgrounds can have sickle cell trait. These include Hispanics, Greeks, Italians, East Indians, Saudi Arabians, Asians, Syrians, Turks, Cypriots, Sicilians, Caucasians, and others. African Americans have the highest rate of sickle cell disease and sickle cell trait in the U.S. About one in every 400 African-American babies is born with the disease, and about one in every 12 is born with sickle cell trait.

All newborns in Texas are tested for sickle cell disease and trait.

How Can You Find Out If You Have Sickle Cell Trait?

It is very important to know if you or your spouse or partner have the sickle cell trait before you have a baby.

People with sickle cell trait will never get the disease. But they carry a gene that could affect their children. If both partners carry a trait for an abnormal hemoglobin, even if it is not the same one, they may have a baby with a serious blood disease.

If you were born in Texas after November 1, 1983, you may get your newborn test result by contacting your birth doctor or your birth hospital.

Resources

- Sickle Cell Disease
- Sickle Cell Anemia
- Sickle Cell Trait

SICKLE CELL TRAIT

[Go to Word Document](#)

FAQS TRAIT PAGE

dshs.texas.gov/newborn/trait.shtm?terms=sickle%20cell%20disease

- Found by search engine only
- Suggest changing title to “FAQs About Sickle Cell Trait”/ “Frequently Asked Questions About Sickle Cell Trait”
- Allow to be a link on bottom of main sickle trait page



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Sickle Cell Disease - So Your Baby Has The Sickle Cell Trait

1. **What is sickle cell trait?**

To have sickle cell trait means one carries a gene for sickle cell anemia which can be passed along to his/her children. As a carrier of this gene your baby has red blood cells that contain some sickle hemoglobin, but far less than the person with sickle cell anemia. (Hemoglobin is in red blood cells and carries the oxygen to your body. Sickle hemoglobin is an abnormal type of hemoglobin.)

In most cases people with sickle cell trait lead completely normal lives. It is important that your doctor knows your baby has sickle cell trait.

2. **How did my baby get sickle cell trait?**

Getting sickle cell trait is like getting the color of ones eyes, it is inherited from parents. Your baby inherited a normal hemoglobin gene from one parent and an "S" or sickle gene from the other parent.

3. **Will my baby have sickle cell anemia?**

NO! Sickle cell trait will not turn into sickle cell anemia.

4. **Will my baby become anemic from having sickle cell trait?**

Usually a person with sickle cell trait does not become anemic and leads a healthy and normal life and requires no treatment.

5. **How long will my baby have the trait?**

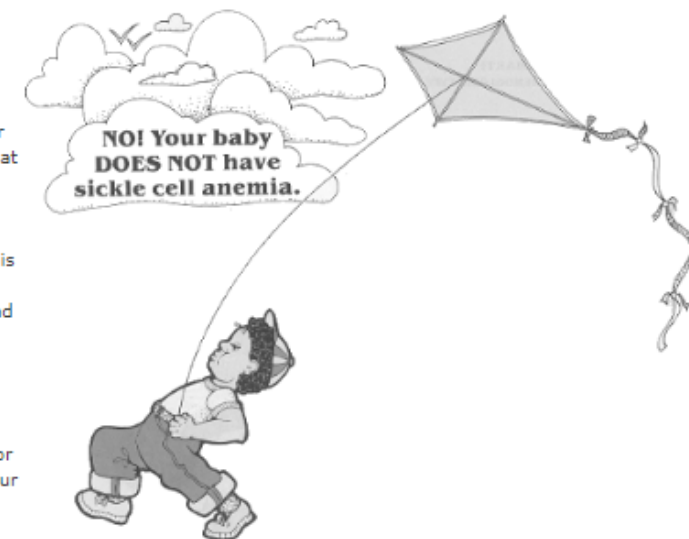
Just as your baby will have the same color eyes, skin, and hair, he/she will always have sickle cell trait.

6. **Is sickle cell trait contagious?**

NO! Sickle cell trait is not contagious. You cannot catch sickle cell trait like measles or a cold. Sickle cell trait is inherited from parents.

7. **Will I have a baby with sickle cell anemia?**

No one will know until you get tested. The fact that your baby has the trait tells us that at least one of the parents has the trait (either mother or father). **If only one parent has the trait then they CANNOT have a baby with sickle cell anemia. If both parents have sickle cell trait then each baby has a 25% chance (or 1 in 4) of having sickle cell anemia.**



TOPIC SEARCH

Topics: A **B** **C** D E F G **H** I J K L M N O P Q R S T U V W X Y Z All

Shigellosis	Emerging & Acute Infectious Disease Branch	Irina Cody Wendy Albers Venessa Cantu	512-776-6611 512-776-6326 512-776-6648
Sickle Cell	Newborn Screening	Newborn Screening Unit	512-776-3957
Silicosis Reporting	Environmental and Injury Epidemiology and Toxicology Unit	Emily Hall Ketki Patel	512-776-2652 512-776-3723

- Remove Cooley's Anemia and place under "C" category
- Add to "B" category – "Beta Thalassemia Major"

- Add to "H" category either
 - Hemoglobin Disorders
 - Page would list all, including SCD

AND/OR

- Each one individually
 - Hemoglobin C Disease
 - Hemoglobin E (Disease)

[Home](#) > Health Topics

Content Related To: Sickle Cell

Related Content	Date Modified
Things to Know About Sickle Cell Trait	12/14/2016 02:52:14 PM
Cooley's Anemia	
Sickle Cell Disease and Sickle Cell Trait	
Sickle Cell Anemia: A Parent's Guide for the School Age Child	11/11/2011 09:39:13 AM
Hemoglobin Sickle C Disease	6/20/2011 09:43:19 AM
PAIN in the child with Sickle Cell Disease	2/25/2011 09:08:12 AM
Sickle Beta Zero Thalassemia	2/25/2011 08:59:31 AM
Sickle Cell Anemia and Stroke	2/25/2011 08:58:27 AM
Sickle Cell Disease: A Resource for the Educator	2/25/2011 08:34:51 AM
Sickle Beta+ Thalassemia	12/7/2010 01:09:46 PM

Main page: change name to "Sickle Cell Disease: General/Main/?"

Arrange alphabetically or by "relevance"

Last updated October 25, 2012

HEMOGLOBIN DISORDERS

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ADVANCED SEARCH

Typing "sickle cell disease" or
"sickle cell"

Search Filter Search


Results 1 - 10 of 110 for sickle cell. (0.06 seconds)

 [STEPS-0153 Sickle Cell](#) 11/1/2017 8:18:17 PM
STEPS-0153 Sickle Cell
ID=8589957794 Size=0 KB

 [Sickle Cell Disease and Sickle Cell Trait](#) 11/1/2017 8:18:17 PM
Sickle Cell Disease and Sickle Cell Trait ...Sickle Cell is a group of related disorder equally. Sickle cell disease is inherited. That means
ID=2377 Size=3 KB

 [Sickle Cell Disease - So Your Baby Has The Sickle Cell Trait](#) 11/1/2017 8:18:17 PM
Sickle Cell Disease - So Your Baby Has The Sickle Cell Trait ...What is sickle cell sickle cell anemia which can be passed along to his/her children. As a carrier
ID=36233 Size=3 KB

 [Things to Know About Sickle Cell Trait](#) 11/1/2017 8:18:17 PM
Things to Know About Sickle Cell Trait ...En Español Sickle cell trait is an inherited father. To have sickle cell trait means a person carries one gene
ID=2475 Size=4 KB


 [Sickle Cell Disease \(SCD\)](#) 11/1/2017 8:18:17 PM
Sickle Cell Disease (SCD) ...Sickle cell disease (SCD) is a hereditary blood disorder SCD is found predominantly
ID=2479 Size=4 KB


 [Sickle Cell Advisory Committee](#) 11/1/2017 8:18:17 PM
Sickle Cell Advisory Committee ...Purpose The purpose of the Sickle Cell Advisory and sickle cell trait. The 25 TAC §37.420 establishes
ID=12884904637 Size=2 KB


Basic Search **Advanced Search - HTML**


Search Filter Search


Results 1 - 10 of 97 for sickle cell disease. (0.06 seconds)


 [Sickle Cell Disease and Sickle Cell Trait](#) 11/1/2017 7:17:39 PM
Sickle Cell Disease and Sickle Cell Trait ... cause problems. It affects males and females equally. Sickle cell disease is inherited. That means It is not contagious. People with sickle cell disease have periods of well-being and stages of illness. The periods
ID=2377 Size=3 KB


 [Sickle Cell Disease - So Your Baby Has The Sickle Cell Trait](#) 11/1/2017 7:17:39 PM
Sickle Cell Disease - So Your Baby Has The Sickle Cell Trait ...What is sickle cell trait? To have sickle cell trait means ... one carries a gene for sickle cell anemia which can be passed along to his/her children. As a carrier
ID=36233 Size=3 KB

 [Things to Know About Sickle Cell Trait](#) 11/1/2017 7:17:39 PM
) , there is a one-in-four chance that their baby will be born with significant sickle cell disease. There is a one-in-two ... sickle cell disease or a trait. People with sickle cell trait usually show no outward signs of it It is not contagious. It rarely, if ever, affects health. People with the trait will not get sickle cell disease. What
ID=2475 Size=4 KB

 [Sickle Cell Disease \(SCD\)](#) 11/1/2017 7:17:39 PM
Sickle Cell Disease (SCD) ...Sickle cell disease (SCD) is a hereditary blood disorder ..., the most common being Sickle Cell Anemia (Hb SS Disease). SCD is found predominantly
ID=2479 Size=4 KB

 [Sickle Cell Advisory Committee Members](#) 11/1/2017 7:17:39 PM
the needs of individuals with sickle cell disease; two physicians specializing in hematology; two members ... of the public who are either an individual with sickle cell disease or a parent of a person with sickle cell ... with sickle cell disease. Dr. Fasipe obtained a Bachelor of Science in biology from The University of Texas
ID=12884904638 Size=10 KB

 [Sickle Cell Advisory Committee](#) 11/1/2017 7:17:39 PM
is to raise public awareness of sickle cell disease and sickle cell trait. The 25 TAC §37.420 establishes ... Disease Learn about Sickle Cell Trait Read ACT and FACT sheets related to sickle cell disease ...Sickle Cell Advisory Committee
ID=12884904637 Size=2 KB

 [Sickle Beta+ Thalassemia](#) 11/1/2017 7:17:39 PM
BA-ta Plus Thal-a-SEE-me-a) is a "mild" form of sickle cell disease. Your child's red blood cells ... or like donuts, your child's red blood cells are somewhat small, pale and misshapen. Because Sickle Beta ... occur with sickle-thalassemia. The sickled red blood cells in sickle-thalassemia, somewhat like those
ID=2492 Size=3 KB

TOOLKIT?

- May not be necessary due to external websites/links (or we can use “toolkit” name for a cluster of the resources on the site.)
- Instead perhaps a TX-specific resource booklet for SCD families

RESOURCE BOOKLET EXAMPLE

Go to Word Document

- Per Toni: Let's develop a resource booklet of all the different associations and clinics across the state. With information on what service/resource is available from each.
- Model: Beyond the Diagnosis Family Support Booklet
 - <http://www.texaschildrens.org/sites/default/files/uploads/documents/beyond-diagnosis-2017-10-23.pdf>