

# Sickle Cell Disease in Babies



State law requires that all babies have the newborn screening test before leaving the hospital. A few drops of blood were taken from your baby's heel and tested for certain diseases. Your baby now needs more testing as soon as possible to determine what type of sickle cell disease the baby has. The doctor will also ask one or both parents to take a blood test. Your baby needs to be seen by a pediatrician, pediatric hematologist (children's blood specialist) and/or a sickle cell disease special care clinic.

**California Department of Health Services**  
Newborn Screening Program  
Genetic Disease Branch  
[www.dhs.ca.gov/gdb](http://www.dhs.ca.gov/gdb)

The logo for the California Department of Health Services Genetic Disease Branch. It features a map of California on the right and a circular emblem on the left containing a genetic diagram with four figures and the text "DEPARTMENT OF HEALTH SERVICES" and "GENETIC DISEASE BRANCH".

## Why Does My Baby Need More Testing?

Your baby's test showed a "positive" result for sickle cell disease. More testing is needed to find out what type of sickle cell disease the baby has.

Babies can look healthy at birth and still have sickle cell disease. If untreated, this disease can cause severe health problems.

## What Is Sickle Cell Disease?

Sickle cell disease is an inherited disease that affects the special protein called hemoglobin which is inside our red blood cells. Red blood cells have an important job. The hemoglobin in red blood cells pick up and carry oxygen from the lungs and take it to every part of the body.

A person with sickle cell disease makes a different kind of hemoglobin. This causes the red blood cells to change their shape. Instead of being smooth and round, the cells became hard and sticky. Their shape looks like a banana or like a sickle, a hand tool used to cut wheat or tall grass. It is this sickle shape of the red blood cells that gives "sickle cell" disease its name.

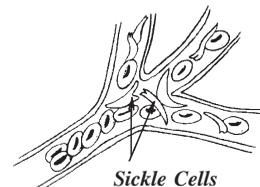


*Normal red blood cells.*



*Sickle red blood cells.*

The hard, sticky sickle red blood cells have trouble moving through small blood vessels. Sometimes they clog up these blood vessels so that blood can't bring oxygen to the tissues. This can cause pain and/or damage to these areas.



*Hard sticky sickle cells clogging up a small blood vessel.*

## How Does a Baby Get This Disease?

A baby with sickle cell disease inherited a gene from each parent. Both parents must carry the gene for a baby to inherit this disease.

## Is Sickle Cell Disease Common in the World?

About 1 in 4,400 babies in California (about 100-125 babies a year) are born with this disease. Sickle cell disease is more often found in people whose families came from Africa, Mexico, Central America, India, the Middle East, and parts of Europe and Asia. However, anyone can have sickle cell disease.

## What Should I Do Right Now?

- Return to the doctor's office or hospital lab as instructed so your baby can have more testing to determine what type of sickle cell disease the baby has. The doctor will also ask one or both parents for blood samples to test.
- Follow the doctor's advise on treatment. This will probably include taking your baby to a pediatric hematologist and or sickle cell disease special care center.

## What Symptoms Should I Look for?

One of the most serious problems that infants with sickle cell disease can have is infections. There are, however, many ways to prevent and treat infections, especially if they are found quickly.

## What Are the Types of Sickle Cell Disease?

There are many different types of sickle cell disease. The two most common types are sickle cell anemia (SS disease) and sickle "C" disease (SC disease). Sickle beta thalassemia disease (S beta thal disease) is another type, but is less common. Some types of sickle cell disease cause fewer problems than others. For example, SC disease is often less serious than SS disease.

## How Is This Disease Treated?

Sickle cell disease is a life-long condition for which there is currently no cure. However, with proper treatment, people with sickle cell disease can enjoy long, productive lives, living well into middle and late adulthood.

The best way to help your baby is to learn as much as you can about the disease and to make sure your baby gets the best health care possible. The child with sickle cell disease has special needs and must have regular medical care to stay as healthy as possible. The baby's doctor needs to know the type of disease your baby has because each type is treated differently. Children with certain types of the disease are given penicillin every day to help prevent infections.

Since sickle cell disease affects different people in different ways, no one can know how serious the disease will be for your child.

## Where Can I Get More Information?

Call the doctor or the Newborn Screening staff listed below for any questions or concerns.

