



## Presumed Sickle Cell Disease (FS)

### What is newborn screening?

Newborn screening is a blood test to check for conditions that can be hidden at birth. Soon after birth, a nurse takes a few drops of blood from your baby's heel. With newborn screening, many conditions can be found and treated early.



### What does my baby's newborn screen show?

The newborn screen reported that your baby has fetal and sickle hemoglobin. There is no normal hemoglobin. Hemoglobin is

a part of the red blood cells. **This newborn screen results suggests that your baby has sickle cell disease.** Your baby should follow up with a hematologist, a doctor who specializes in blood disorders, by 1 month of age.

### What is sickle cell disease?

Sickle cell disease (SCD) has also been called sickle cell anemia, SS disease, or hemoglobin S disease.

Sickle Cell disease is a medical condition that affects the shape of red blood cells. Red blood cells carry oxygen to the body. Usually, red blood cells are round and flexible. This shape helps them to move easily in the blood vessels. A person with SCD has red blood cells that are curved into a shape like a letter C or a "sickle" shape. They also become stiff. The different shape and stiffness can cause these cells to affect how blood flows through blood vessels, and can even block blood flow. This can cause pain and infections. A person with sickle cell disease is born with it. People cannot catch sickle cell disease from being around a person who has it. Many babies with SCD are born healthy and do not show symptoms until they get closer to their first birthday. Some children with SCD are generally healthy, while others may need special medical care.

#### KEY POINTS:

- With newborn screening, sickle cell disease can be found and treated early.
- Some children with sickle cell disease will be generally healthy, while others may need medical care.
- Your baby should be seen by a specialist called a hematologist by 1 month of age for follow up testing.
- Your doctor may prescribe a medication called penicillin to help prevent infection.
- Notify your doctor as soon as possible if your baby has a fever.

Connecticut Department of Public Health

Connecticut Newborn Screening Program • 860.920.6628

Connecticut Newborn Diagnosis and Treatment Network • 860.837.7870

Adapted, with permission, from the Minnesota Department of Public Health

## What causes sickle cell disease?

SCD is inherited. This means it's passed from parent to child through genes. A gene is part of your body's cells that stores instructions for the way our body grows and works. Genes come in pairs—you get one of each pair from a parent. Your baby has to inherit a gene for sickle cell from both parents to have SCD.



## What happens next?

Your baby should be seen by a hematologist before they are 1 month old. The hematologist will talk to you about the best plan for your baby. Your doctor or hematologist may prescribe a medication (antibiotic) called penicillin. Penicillin can help to prevent infection. If your baby has a fever, it is important to let your doctor know as soon as possible. All children with sickle cell disease who have fevers greater than 101°F should be seen by a doctor right away.

## What if I still have questions?

We understand that this can be an overwhelming and emotional process. Many families have questions and concerns. The Connecticut newborn Diagnosis and Treatment Network (the Network) is available to put you in touch with the best resource. To reach the Network, you can call 860-837-7870, Monday-Friday, 8:30am-4:30pm. You also have the option of speaking with a genetic counselor now, or in the future, about sickle cell disease. We also recommend the website [www.babysfirsttest.org](http://www.babysfirsttest.org) as an accurate and informative resource.

**This fact sheet was written for information purposes only. It should not replace medical advice, diagnosis or treatment.**