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 indicates that your baby has fetal and sickle hemoglobin. There is no normal hemoglobin; **this newborn screen is indicative of sickle cell disease.** Your baby should follow up with a hematologist, a doctor who specializes in blood disorders, by 1 month of age.

KEY POINTS:

- **With newborn screening, sickle cell disease can be found and treated early.**
- **Some children with sickle cell disease may be generally healthy, while others may need special care.**
- **Your baby should be seen by a specialist called a hematologist by 1 month of age.**
- **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.**

What is sickle cell disease?

Sickle cell disease (also called SCD) is a condition in which the red blood cells in your body are shaped like a sickle (like the letter C). Red blood cells carry oxygen to the rest of your body. In most people, red blood cells are round and flexible. They flow easily in the blood. A person with SCD has red blood cells that are stiff and can 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 may be generally healthy, while others may need special care.

Connecticut Department of Public Health
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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 he/she is 1 month old. The hematologist will talk to you about the best plan for your baby. Your doctor or hematologist may prescribe a medication 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 fevers greater that 101F in children with sickle cell disease should be promptly evaluated by a doctor.

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. We also recommend the website 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.