Sickle Beta Plus Thalassemia (FSA)

What is newborn screening?

Newborn screening is a blood test to check for conditions that might 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, normal hemoglobin, and sickle hemoglobin. **This means that there is a possibility your baby could have a sickle cell disorder called Sickle Beta Plus Thalassemia.** Your baby should follow up with a hematologist, a doctor who specializes in blood disorders, by 4 months of age.

KEY POINTS:

- **There is a possibility your baby could have sickle beta thalassemia. More testing is needed to know for sure.**
- **With newborn screening, sickle beta plus thalassemia can be found and treated early.**
- **Your baby should be seen by a specialist called a hematologist by 4 months of age.**
- **Sickle beta plus thalassemia is a less severe sickle cell disorder.**
- **Notify your doctor as soon as possible if your baby has a fever.**

What is sickle beta plus thalassemia?

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.

Sickle beta plus thalassemia (also called FSA) is a less severe sickle cell disorder. Many babies with FSA are born healthy and do not show symptoms until later in childhood. In people who have sickle beta plus thalassemia, symptoms can range from very mild to somewhat severe. Some problems can include low blood count, pain, and risk of infection.

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What causes sickle beta plus thalassemia?

Sickle cell disorders are inherited. This means they are 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. One parent carries sickle trait, which causes no health problems for him or her. The other carries the trait for beta plus thalassemia, which sometimes causes a low blood count, but usually no symptoms. When these traits come together in the same person, the result is sickle beta plus thalassemia.

What happens next?

Your baby should be seen by a hematologist before he/she is 4 months old. The hematologist will talk to you about the best plan for your baby. This may include a test called electrophoresis. This test involves taking a small amount of blood from your baby and sending to the laboratory. In some cases, the test will show that the baby simple has sickle cell trait, for which no additional follow-up or treatment is needed. 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.

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