

When Baby has a Confirmatory Test for a Hemoglobin Disorder

A small sample of your baby's blood was collected soon after birth and sent to the DHEC Public Laboratory for testing. This testing is called "Newborn Screening". In South Carolina, newborns are tested for several genetic and biochemical disorders. Sometimes, a second test is needed to help doctors decide if your baby has one of these disorders. In many cases, the second test will be normal. However, if your baby does have one of the newborn screening disorders, early treatment will give him or her the best chance to grow up healthy.

Because unusually formed blood cells were found in your baby's first test, he or she could possibly have a hemoglobin disorder.

What are hemoglobin disorders?

Hemoglobin disorders are genetic disorders that affect the way red blood cells are made. They are found in people of all background and races. Sickle Cell Disease is usually found in people whose ancestors came from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and Mediterranean countries such as Turkey, Greece, and Italy.

The most common type of hemoglobin disorder found in the United States is Sickle Cell Disease. Around 1 in 365 African American babies; 1 in 16,300 Hispanic-American babies; and 1 in 2,500 of all races & ethnicities is born with a sickling disorder like Sickle Cell Disease each year.

Sickle Cell Disease can cause many problems including misshaped red blood cells, anemia, severe pain, and a high risk for infection.

How will I know if my baby really has a hemoglobin disorder?

If your baby's newborn screening result showed unusually formed blood cells, he or she may have a hemoglobin disorder. The newborn screening test will be confirmed, and additional tests may be done to help the doctors determine if your baby has a hemoglobin disorder. Usually, the results of these tests take a few weeks to come back. You will also be referred to a doctor who specializes in these kinds of disorders called a hematologist.

What do I need to do until I know the final results?

Your baby may not have any symptoms at first. But you will need to follow your doctor's instructions very carefully. If your baby seems to be getting sick, call your doctor right away.

How are hemoglobin disorders treated?

Babies with Sickle Cell Disease may take an antibiotic like penicillin each day to reduce infections. There are other medicines and treatments that may be used to help control Sickle Cell Disease, such as hydroxyurea.

Other hemoglobin disorders are usually not as severe as Sickle Cell Disease. Some may not even need treatment.

What else should I do to keep my baby as healthy as possible?

Don't forget to keep all of your well baby check-ups. Seeing the doctors regularly and following their instructions are the best things you can do to help your baby grow and develop well.

Where can I find more information?

Internet Resources: <http://www.babysfirsttest.org/>