

Parent Information Sheet for Positive Newborn Screening Test Result for **SICKLE CELL-BETA THALASSEMIA DISEASE**

Why do we screen babies for Abnormal Hemoglobins?

Hemoglobin is the part of the red blood cell that carries oxygen. Sometimes a person has a different type or types of hemoglobin. Some abnormal hemoglobins can cause problems. Babies who have sickle cell disease or sickle beta thalassemia may get serious infections. It is important to find out which babies have this disease so they can get early medical attention. Treatment can lower the risk of infection.

What does a positive screening test result for sickle cell-beta thalassemia disease mean?

A positive test means that your baby needs to have a new blood test to check for sickle cell-beta thalassemia disease. The first test was a screening test. More testing must be done to find out if your baby has sickle cell-beta thalassemia or not.

How can sickle cell-beta thalassemia disease affect a baby's health?

A person with sickle cell-beta thalassemia disease will always have it. Genes, passed down from both parents, cause this disease. This disease is like sickle cell disease. This disease can cause very low blood counts, strokes, episodes of pain, and lung damage. These children can get very serious infections. They must take antibiotics to lower the risk of infection. It is very important that these antibiotics start as soon as possible.

What should I do?

To find out whether or not your baby has sickle cell beta-thalassemia, a new blood test will be done. You and your baby's doctor need to discuss the test results.

Make sure that your baby has a new blood sample collected and tested as soon as possible. If your doctor puts your baby on antibiotics, you must give the medicine as directed.

How can I get more information?

You can obtain more information from your baby's doctor. Your doctor may want your baby to see a specialist.

You might want to consider genetic counseling to discuss testing options and family risks. If you wish to schedule an appointment, call (402) 559-6800 or (800) 656-3937

Some of the specialists in blood diseases are at the Nebraska Medical Center (402) 559-7257 and also at Omaha Children's Hospital (402) 955-3950.

If you live outside of the Omaha/Lincoln areas, other options to see a specialist might be available. Some areas have special clinics and some may have telemedicine visits available.