

Parent Information Sheet for Positive Newborn Screening Test Result for SICKLE CELL 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 of hemoglobin. These abnormal hemoglobins can cause problems. Babies who have only sickle hemoglobin may get infections that can cause death. 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 disease mean?

A positive test means that your baby needs to have a new blood test to check for sickle cell disease. The screening test showed the hemoglobin that causes sickle cell disease. This is just a screening test. More testing must be done to find out if your baby has sickle cell disease or not.

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

A person with sickle cell disease will always have it. Genes, passed down from both parents, cause this disease. The disease can cause severely low blood counts, strokes, and episodes of pain. There can also be damage to the lungs and kidneys. Children with sickle cell disease can get very serious infections. They must take antibiotics to prevent infection. It is very important that these antibiotics start as soon as possible.

What should I do?

A test result that shows only sickle cell hemoglobin may mean that your baby has sickle cell disease. To be sure, you and your doctor need to discuss the test results and get a new test. **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 James Harper, MD at the Nebraska Medical Center (402) 559-7257 and David Gnarra, MD 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 tele-medicine visits available.

