

Parent Information Sheet for Positive Newborn Screening Test Result for Beta Thalassemia Major

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 only F hemoglobin are not making any of the usual Hemoglobin A. It is important to find out which babies have this disease so they can get medical attention..

What does a positive screening test result for F only/ Beta Thalassemia Major mean?

A positive test means that your baby needs to have a new blood test to check for Beta Thalassemia. The screening test showed only F hemoglobin. This is a screening test. More testing must be done to find out if your baby has Beta Thalassemia or not.

How can Beta Thalassemia affect a baby's health?

A person with Beta Thalassemia will always have it. Genes, passed down from both parents, cause this disease. This disease can cause very low blood counts or anemia. This can be treated with transfusions of normal red blood cells. It is important to determine if your baby will need transfusions.

What should I do?

A test result that shows only F hemoglobin may mean that your baby has Beta Thalassemia. 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.**

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 in pediatric hematology.

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.

Department of Health & Human Services

