

Parent Information Sheet for POSITIVE Newborn Screening Test Result for a HEMOGLOBIN E 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. It is important to find out which babies have abnormal hemoglobins so they can get early medical care.

What does a positive screening test result for a hemoglobin E disease mean?

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

If the second test shows Hemoglobin E, it may not be able to tell if your baby has Hemoglobin E disease or Hemoglobin E-Beta thalassemia. Testing of the parents' hemoglobin may help to decide which disease is present. It might also be necessary to do testing of the baby's blood again in a few months.

How can Hemoglobin E disease or Hemoglobin E-Beta Thalassemia affect a baby's health?

A person with these conditions will always have them. Genes, passed down from both parents, cause these diseases. A baby with a hemoglobin E gene from both parents has Hemoglobin E disease. A baby with a hemoglobin E gene from one parent and a beta thalassemia gene from the other parent will have Hemoglobin E-Beta Thalassemia.

People with Hemoglobin E disease may have low blood counts. They may have small red blood cells seen on a blood test. This does not require any treatment.

People with Hemoglobin E-Beta Thalassemia may have symptoms that are more serious. They might need blood transfusions.

What should I do?

To find out if your baby has a hemoglobin E disease, a new blood test will be done. You and your baby's doctor will need to discuss the test results and the possibility of any other testing. **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.

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.

