

Parent Information Sheet for Positive Newborn Screening Test Result for Hemoglobin C Disease

Why do we screen babies for abnormal hemoglobins?

Hemoglobin is the part of the red blood cell that carries oxygen. Sometimes, a person makes a different type or types of hemoglobin. Some abnormal hemoglobins can cause problems. Babies who have only C hemoglobin may have low blood counts. 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 hemoglobin C disease mean?

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

How can hemoglobin C disease affect a baby's health?

A person with hemoglobin C disease will always have it. Genes, passed down from both parents, cause this disease. This disease can cause very low blood counts. People who have hemoglobin C disease are always likely to have at least somewhat low blood counts. Because this hemoglobin does not cause sickle cells to form, people with hemoglobin C disease do not have the serious side effects seen with sickle cell disease (i.e., stroke, infections and episodes of pain).

What should I do?

A test result that shows only C hemoglobin may mean that your baby has hemoglobin C disease. To be sure, you and your baby's doctor need to discuss the test results and get a new test. **Make sure your baby goes in for a new blood sample to be collected and tested as soon as possible.** If it turns out that your baby does have hemoglobin C disease, your doctor will help you understand your family's risks.

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.

