#### **NEWBORN SCREENING FACT SHEET FOR PARENTS**

#### POSITIVE SCREENING TEST RESULT FOR SICKLE CELL TRAIT

### What does this screening result for Sickle Cell <u>Trait</u> mean?

A screening test result that is positive for sickle cell trait means that your baby's blood has <u>both</u> normal cells as well as sickle cells in their blood.

You may have heard about sickle cell anemia. Sickle cell anemia and sickle cell disease are very different from sickle cell trait. A baby with sickle cell trait will <u>never</u> have sickle cell anemia. While <u>much less</u> serious to a baby than sickle cell disease, it is an important part of your baby's health.

## How can Sickle Cell Trait affect your baby's health?

Sickle cell trait does not usually cause problems for babies who have it.

### What should a parent do with this test result?

Your baby's doctor will want to get a new blood sample from your baby for a test to be sure that he/she has sickle cell trait. If your baby has sickle cell trait, make sure to ask your baby's doctor if the medical record includes this information. This should help avoid more testing.

When your child is older, be sure that he/she knows about the sickle cell trait and that it might pass to his or her children. If the other parent has sickle cell trait (or some other trait), there is a risk of the baby having sickle cell disease.

A doctor can provide information about sickle cell trait in adults when your child grows up. Some problems have been reported in a small number of adults with sickle cell trait.

# Why is this test result important to you, the parent?

Many people do not know that they have sickle cell trait. If you have sickle cell trait, you may pass the gene that causes sickle cells to your children.

If <u>both</u> parents have sickle cell trait, <u>they have</u> <u>a 1 in 4 chance of having a baby with sickle</u> <u>cell disease</u>. This 1 in 4 chance is true for <u>every</u> pregnancy.

#### How can I get more information?

You can obtain more information from your baby's doctor, about blood traits and about other specialists who are available.

You might want to consider genetic counseling to discuss testing options and family risks. If you wish to schedule an appointment, call (402) 559-6418 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.

