

Hemoglobin E Disease Information for Parents

What is hemoglobin?

- Hemoglobin is a part of our blood that carries oxygen to the body.
- Hemoglobin can be influenced by genes that are passed from parents to children.

How do we know that my child has Hemoglobin E Disease?

- Pennsylvania has a newborn screening program that screens for many different medical conditions.
- A very small amount of your baby's blood was collected at the hospital in the first few days of life.
- Your baby's newborn screen showed us that your baby's red blood cells are a little different than other babies.
- Hemoglobin E disease may cause a decrease in hemoglobin (this is called anemia) and may need to be treated as your baby grows.

What do we do now?

- We will refer your baby to a special doctor called a hematologist for further testing and to confirm diagnosis. This will happen by 3 months of age.
- Please tell healthcare providers in hospitals, emergency rooms, or clinics that your child has Hemoglobin E disease. This will help them take better care of your child.