

**ACT SHEET FOR POSITIVE  
NEWBORN SCREENING RESULT (FE)  
HEMOGLOBIN EE OR E BETA ZERO THALASSEMIA  
(Hb EE or Hb E  $\beta^0$ )**

**Meaning of the Screening Result:** Hemoglobin FE pattern on newborn screen is highly suggestive of homozygous hemoglobin E. Infant may also have hemoglobin E beta zero thalassemia.

**YOU SHOULD TAKE THE FOLLOWING ACTIONS:**

- **Contact a specialist in hemoglobinopathies for consultation or referral on diagnostic evaluation and management.**
- **Contact the family** to inform them of the screening result.
- **Repeat NBS to confirm FE result.**
- Evaluate the infant with a complete blood count with reticulocyte count at first visit and at six months.
- If the child develops significant anemia, consult a specialist in hemoglobinopathies.
- **Report results** to Nebraska Newborn Screening Program.

**Condition Description:** Individuals with hemoglobin FE are homozygous for hemoglobin E or compound heterozygous for hemoglobin E and beta zero thalassemia.

**Clinical Expectations:** Individuals with **Hb EE** are not anemic but have microcytosis and target cells on blood smear. Clinical expression in **Hb E  $\beta^0$  is variable with the most severely affected requiring life-long transfusion, splenectomy and treatment for iron overload.**

**Confirmation of Diagnosis:** Confirmation may be done by **submitting a repeat dried blood spot filter paper specimen.** Parental or DNA studies may be done as indicated.

**Pediatric specialists in hemoglobinopathies are available through the centers at Children's Hospital (402) 955-3950 and UNMC/NE Medical Center (402) 559-7257.**