

## EHDI State to State UNHS Follow-up Guidelines

1. When the newborn is a resident of one state but is born in a hospital in a bordering state:
  - a. The UNHS screen should be completed and recorded on the state-of-birth blood collection card
  - b. The screening results should be shared with the child's state-of-residence
  - c. Follow-up should occur in accordance with the UNHS screening policies of the state in which the child resides
  
2. When the newborn is born in one state but is transferred for critical care to a tertiary level NICU in a bordering state:
  - a. Same as 1.a The newborn UNHS screen should be completed and recorded on the state-of-birth blood collection card
  - b. If the UNHS screen is not obtained prior to transfer, the UNHS screen should be completed and recorded on the blood collection card of the state where the tertiary care NICU is located (border state)
  - c. The screening results should be shared with the child's state-of-residence
  - d. Follow-up should occur in accordance with the UNHS screening policies of the state in which the child resides
  
3. When the newborn's family permanently relocates to another state prior to the completion of re-screening or diagnostic testing
  - a. The EHDI Program in the child's state-of-birth should notify the EHDI Program in the family's new state-of-residence with results to date and the EHDI state-of-residence program should assume responsibility for any further follow-up that is needed
  - b. In addition, the EHDI Program in the child's state-of-birth should notify the parents and/or primary care provider of the need for further follow-up in the family's new state-of-residence
  - c. The EHDI contacts in the state-of-birth and the state-of-residence should collaborate on the follow-up process
  - d. When follow-up is performed by the EHDI Program in the state-of-residence, the final screen results or diagnostic results should be forwarded to the state-of-birth EHDI Program where the screening was initiated, so the case may be closed

The HIPAA Privacy Rule recognizes the need for public health programs to access protected health information (PHI) to conduct public health activities to prevent or control disease, injury or disability. The Privacy Rule\* expressly permits release of PHI relating to newborn screening, without individual authorization, from a covered entity to state public health departments or agencies contracted, by public health departments, to provide newborn screening follow-up.

\*<http://www.cdc.gov/mmwr/preview/mmwrhtml/m2e411a1.htm>