



State-to-State Newborn Screening 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 newborn screen should be obtained on the state-of-birth blood collection card and testing performed in the state-of-birth.
 - b. Follow-up should occur in accordance with the newborn screening policies of the state in which the birth occurs.

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 screen should be obtained on the state-of-birth blood collection card and testing performed in the state-of-birth.
 - b. If the newborn screen is not obtained prior to transfer, the newborn screen should be obtained on the blood collection card of the state where the tertiary care NICU is located (“bordering state NICU”); and testing, reporting, and follow-up should be in accordance with the newborn screening policies of the state where the tertiary care NICU is located.

3. When the newborn’s family permanently relocates to another state prior to completion of follow-up:
 - a. The newborn screening program in the state-of-birth is responsible for assuring that follow-up is completed.
 - b. For positive, unsatisfactory, or early newborn screens, the newborn screening follow-up program in the state where the birth occurs (state-of-birth) should notify the parents (or newborn’s primary care provider) of the need for further follow-up.
 - c. In those situations where follow-up is to be assisted by the newborn screening program in the state-of-residence, the newborn screening follow-up contacts in the state-of-birth and the state-of-residence should coordinate the follow-up process, including the decision about when the case will be closed.
 - d. When follow-up is performed by the state-of-residence, the final newborn screening results should be forwarded to the newborn screening program in the state where screening was initiated.



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>