Newborn Screening Webinar Series:
Babies in the NICU

Sarah Bradley, MS, CGC
Follow-up Supervisor
New York State Newborn Screening Program

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New Regulation: SACHDNC Recommendations

• Recommendations from the Department of Health and Human Services’ (DHHS) Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC)
  • “Initial NBS specimens should be collected in the appropriate time frame for the newborn’s condition but no later than 48 hours after birth, and
  • NBS specimens should be received at the laboratory as soon as possible; ideally within 24 hours of collection.”

• New York State Department of Health (NYSDOH) endorses these recommendations, although the new regulation is actually more stringent (collection at < 36 hours).
New Regulation: It’s Here!

• “Newborn Screening for Phenylketonuria and Other Diseases,” Subpart 69-1 of Title 10 (Health) of the Official Compilation of Codes, Rules and Regulations went into effect on February 13, 2019
New Regulation: Where to Find It

Title: SubPart 69-1 - Newborn Screening for Phenylketonuria and Other Diseases

Effective Date
02/13/2019

Baby born → Specimen collection → Specimen sent to lab → Specimen arrives at lab
Baby born

Transferred to NICU

Specimen collection

Specimen sent to lab

Specimen arrives at lab
Transfer to Another Hospital

- If a newborn is transferred to another hospital, the birth hospital should collect initial screen and notify receiving hospital that specimen was collected.
- Receiving hospital is responsible for collecting any repeat screens needed.
- Receiving hospital should follow recommended procedure for NICU admissions.
NICU Admission

- If newborn requires admission to NICU prior to collection of initial screen, specimen should be collected at admission prior to interventions (blood transfusion/TPN)
- Repeat screen at 48-72 hours after birth
- Third screen done at discharge or at 28 days after birth (whichever comes first)
NICU Admission

- If newborn requires admission to NICU prior to collection of initial screen, specimen should be collected at admission
- Repeat screen at 48-72 hours after birth
- Third screen done at discharge or at 28 days after birth (whichever comes first)
- Please check the ‘Repeat Specimen’ box on the filter paper when submitting these and fill out the prior lab ID field!
No change from the guidelines on specimen collection for premature and/or sick infants, approved by the Clinical and Laboratory Standards Institute (CLSI; ILA31-A), which is posted on our website.

https://www.wadsworth.org/programs/newborn/screening/providers/specimen-collection
Special Circumstances Surrounding Specimen Collection

Premature \& Sick Infants: Guidelines on specimen collection for premature and/or sick infants, approved by the Clinical \& Laboratory Standards Institute (CLSI, LA31-A), recommend specimen collection upon admission to a neonatal intensive care or special baby care unit. If the specimen is collected when the infant is less than 24 hours of age, collect another specimen when the infant is 48-72 hours of age. A third specimen is required at discharge or 28 days of age, whichever comes first. Every effort should be made to obtain a specimen prior to transfusion and/or administration of Total Parenteral Nutrition (TPN) or other treatments which can affect screening results.

Guidelines for Collecting Specimens for Babies in the NICU:

- First Newborn Screening Specimen
  - Collect upon admission to the Neonatal Intensive Care Unit, if not already collected
  - Newborn will probably be less than 24 hours of age
- Second Newborn Screening Specimen
  - Collect at 48-72 hours of life
  - Collect if first specimen was collected at < 24 hours of age or if newborn weighed < 2000 grams at birth
- Third Newborn Screening Specimen
  - Collect at 28 days of life, or discharge, whichever comes first
  - Collect if newborn weighed < 2000 grams at birth

Transfusion: The optimal specimen collection time is when the newborn is older than 24 hours of age. However, transfusions may invalidate some screening results by masking the presence of a hemoglobinopathy or galactosemia. If the infant is to receive a transfusion, every effort must be made to collect a specimen prior to transfusion. Infants receiving transfusions with no prior newborn screening test need two specimens collected: one at three days or more after the most recent transfusion and one at four months after the final transfusion.

Total Parenteral Nutrition (TPN) - Hyperalimentation: The optimal collection time is when the newborn is older than 24 hours of age. However, even small amounts of TPN may invalidate some screening results for the acylcarnitines and amino acids. If the infant is to receive TPN, every effort must be made to collect a specimen prior to treatment. Infants receiving
NICU Interventions

- If newborn requires transfusion or TPN, the hospital should collect a NBS specimen prior to any transfusion or administration of TPN.
- If specimen is not done prior to transfusion and/or TPN, the hospital should wait to collect initial screen until 72 hours after administration of transfusion and/or TPN.
  - Hospital should schedule repeat specimen for no later than 120 days after final transfusion and/or TPN.
Transfusions

- If newborn screen is collected prior to RBC transfusion, was screen negative or detected a trait, no follow-up is needed.
- If a specimen was NOT collected prior to RBC transfusion, the baby was NOT screened for Hemoglobinopathies, Galactosemia, or Biotinidase Deficiency.
  - These babies should be monitored for clinical signs of these disorders.
  - To evaluate for Hemoglobinopathies, submit a specimen 120 days after final transfusion or determine maternal trait status.
Special Care Nursery

- Some babies are admitted to Special Care Nursery for sepsis work-up, hypoglycemia or monitoring
- If these babies are not receiving TPN or transfusions, they may follow the standard newborn screen collection protocol
Questions?

- Please email questions to nbsinfo@health.ny.gov

- We will do our best to respond individually, and will also compile all the questions in a ‘Frequently Asked Questions’ document which will be posted on the NBS website.
Upcoming Webinars
New Regulation: Webinar Series

• Requests for repeats: September 19, 2019 @ noon

• Process improvement: October 3, 2019 @ noon

• Referrals to specialty care centers: October 10, 2019 @ noon

• Birth attendants: October 17, 2019 @ noon