Nebraska Newborn Screening Program 2011

FAQ's

Frequently Asked Questions About Screening of NICU Admissions

In 2011 the Nebraska Newborn Screening Program adopted via regulation, the Clinical and Laboratory Standards Institute's guidelines for screening of premature, low birth-weight and sick newborns admitted to neonatal intensive care units (I/LA-31-A).

These require:

1) The collection of a NBS upon admission to an NICU or Special Care Nursery. If a baby is to be transferred to another health care facility, collection of a newborn screen is still required prior to transfer.
2) The NICU is required to verify that the NBS was collected or must draw one upon admission. For babies whose first specimen is collected at < 24 hours of age, a repeat shall be collected at 48-72 hours of age.
3) For babies who are < 2000 grams at birth and whose first specimen was collected at < 24 hours of age, a third specimen should be collected at 28 days of life, or upon discharge if that occurs first.

FAQ's:

1) Does this mean that if a baby's first newborn screen (NBS) happens after 24 hours of age it is not necessary to get a discharge NBS even if they are in the NICU?

> Yes if the baby is > 2000 grams at birth. Babies < 2000 grams at birth still need the 28 day or discharge screen. It is probably less likely that the < 2000 gram babies will be getting their screen at ≥ 24 hours of age, but there will be some.

2) What about the baby's with GI obstruction or meconium ileus that might be in the regular nursery for close to 24 hours and then start to show signs of problems. They could easily be transferred to NICU and have their first screen on admission at greater than 24 hours. If this is the case, are they included in the recommendation to get a discharge newborn screen?

> No, they are not, if their first screen is normal and was collected at ≥ 24 hours. However, the GI problem still needs to be reported to the newborn screening laboratory at (412) 220-2300 as previously recommended. This is because the IRT used for screening for Cystic Fibrosis may be falsely normal in babies with gastrointestinal obstructions or meconium ileus, and the laboratory will run the 36+ mutation panel as a better screen for CF in these cases.

3) Since the recommendations for serial screening for NICU admissions recommend 3 screens for babies with screens collected at < 24 hours, and < 2000 grams in order to get sufficiently reliable results for the many conditions screened, will the lab report look different?

> Yes. All reports for repeat screens collected for babies whose first specimen was collected at < 24 hours will now show results for all conditions screened, not just the amino acid profile and congenital hypothyroidism results. This will include some babies who are discharged at < 24 hours

but not transferred to NICU's. This decision was made to standardize and simplify processes in the newborn screening laboratory which helps reduce the opportunity for error.

4) Won't this require more babies to get more specimens than they use to?

The idea behind the standardized practice is to be as certain as we can, that reliable screening results are available for every baby, with the least amount of specimens. In some cases this will prove to reduce the number of specimens required because it will avoid babies getting their first specimen collected post transfusion. In those cases, repeat testing and follow-up gets drawn out several months until the babies own hemoglobin type rather than the transfused hemoglobin is represented in the results.

In other cases, it may be that the third specimen would not otherwise have been collected. The laboratory and Newborn Screening Program are looking at ways to monitor to see if this becomes a problem. Frequently however, we see babies with drawn early specimens repeated at a few days who then have abnormal screens due to hyperalimentation which is apparent with multiple amino acid elevations on screen results. These babies usually require a third screen anyway. Waiting until day 28 will avoid multiple repeats as many of the babies will be off hyperalimentation by then. Again, the laboratory and program are devising ways to monitor the outcomes of this new screening algorithm to try to identify and mitigate any unforeseen problems. When results are significantly abnormal, a confirmatory specimen will usually be recommended.

5) We have a NICU to which we transfer babies in-house. It has been our practice to collect the first newborn screening specimen at > 24 hours to avoid having to repeat. Sometimes the in-house transfers include babies who are < 2000 grams. Does this mean we will now have to collect specimens early, and then collect the repeats?

The Newborn Screening Program can not approve, endorse or otherwise educate about any practice outside that which is required in the regulations. However, the Program and laboratory will be monitoring the data to see if this results in substantially more babies having early specimens. It may be difficult to distinguish which < 24 hour samples occur because of early discharges or because of in-house NICU transfers. It may be helpful to record on the filter paper "in-house NICU transfer" if possible.

6) Re: "Each hospital NICU should assign a contact person through which newborn screening information can be coordinated". Should this coordinator be from the lab or NICU? How have other facilities addressed this? We can understand how a coordinator might be helpful in the event of a NICU baby who is still in the facility and needing a re-collection. Would there also be scenarios where the coordinator would play a role for infants that have been discharged?

In Nebraska there are a few hospital NICU's that have had a coordinator/key contact person for newborn screening issues for years. (That's where we "borrowed" the idea from!). In one situation the Unit Secretary coordinates communication about newborn screening needs and does an outstanding job. A key element that may be important to making this successful is making sure the coordinator, (whether they are a phlebotomist, nurse or unit secretary) has good access to patient and electronic system information. In higher level NICU's, it may be the nurses who most often collect the specimens (vs. normal newborn

nursery where it is almost always phlebotomy personnel). So perhaps it should be a consideration of whomever is most involved, with the need to know. In addition there can be advantages to having the newborn screening coordinator also have a role in discharge planning and documentation. They are then vested in making sure they document to which health care provider the baby is being discharged so they will know in case additional testing needs to be done. If your NICU patients participate in the TIPS tracking program for the NICU grads, that "coordinator" might also be an important link in educating parents about newborn screening and follow-up as well.