Regulation Revisions Incorporating
Clinical and Laboratory Standards Institute Guidelines ILA/31-A
"Newborn Screening for Preterm, Low-Birth Weight and Sick Newborns"
Frequently Asked Questions (and Answers)

Q: We have a sub-set of newborns who are admitted to the NICU for evaluation and are classified as "feeders and growers". They do not receive any treatments such as blood transfusions or TPN. Many times they come directly from Labor and Delivery and were never admitted to the normal newborn nursery. Do we have to get the newborn screen upon admission to the NICU for these babies or can we wait till they are at least 24 hours of age?

A: These babies generally are not admitted for higher level NICU care, but for special care beyond the normal nursery where they can be under a little more intensive watchful eye. The NICU may have the latitude within Nebraska's regulation to wait and collect the specimen after 24 hours. The regulation 2-005.01B states:

> "Newborns transferred to neonatal intensive care units (NICU) must have a specimen collected prior to transfer, and information communicated as required at 181 NAC 2-005.01E3. **The attending physician at the hospital NICU must verify and otherwise ensure a specimen is collected prior to the provision of any treatment, excluding respiratory treatment**."

If the NICU finds upon admission that the newborn does not already have a specimen collected, the attending physician needs to order the screen and make sure it occurs *before treatment*. For the sick babies, that's probably immediately. For the well babies generally only admitted for evaluation and as "feeders and growers," you may be able to wait till 24 hours of age, ***if*** tight enough procedures are in place to **ensure no treatments occur before the screen** is collected.

Q: With all these babies getting their newborn screens collected so early now (< 24 hours) we're seeing a lot more who have abnormal screen results for congenital hypothyroidism (CPH), congenital adrenal hyperplasia (CAH) and cystic fibrosis (CF) on that first screen. Isn't this more of a burden on the system than before?

A: This was one of the anticipated results, but since Nebraska has always (since 1996) required specimens to be collected before transfer to the NICU, we did not expect the substantial increase in numbers we are seeing. It is likely that many NICU's were admitting patients with lower treatment needs (e.g. level 1) and were able to successfully wait until the newborns were at least 24 hours of age before collecting the screen on babies who were not receiving TPN or transfusions. (See information in the above Q&A).

Keep in mind that the repeat screen collected @ 48-72 hours almost always has normal results for CPH, CAH, CF, so as not to unnecessarily alarm parents and health care providers.

Q: On some of these babies who have their specimen's collected early and have inconclusive results for one or more of the conditions of CPH, CAH or CF, the laboratory report is really challenging to understand. Which comments go with which result?

A: We acknowledge this can be complicated and are in discussion with the laboratory about ways to make it more clear. In the meantime, here is information about reading the laboratory report:

Every lab report has the standard comment listing the abbreviations for the conditions screened by the amino acid and acylcarnitine profiles. To link the rest of the comments back to the results and interpretation columns it is important to know which tests screen for which conditions.

> All babies get a T_4. This is the primary screen for congenital primary hypothyroidism (CPH). If the T_4 is low (in the bottom 10%ile) the specimen will be tested for TSH. If the T_4 is low AND the TSH is elevated, this will be noted in comments.
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> All babies get a 17-OHP. This is the primary screen for congenital adrenal hyperplasia (CAH). If the 17-OHP is elevated, it will reflex to an extracted 17-OHP thought to reduce much of the interference often seen in results on specimens from premature infants. If the 17-OHP or 17-OHP with the Extracted 17-OHP are elevated you will see comments.
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> All babies get an IRT tested. This is the primary screen for cystic fibrosis. If the IRT is elevated it will reflex to test for the ΔF508 mutation associated with CF. If one copy is found, a second reflex test will look at a 36+ mutation panel. Comments relative to the IRT and DNA will be related to the cystic fibrosis screen.
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> Frequently on repeat screens, babies will have been started on TPN. This is usually apparent on the test for the amino acid profile as multiple amino acids will be elevated. You will see a separate comment for this.