Implementing New Guidelines for Newborn Screening in the NICU

State Newborn Screening Programs are critical public health services aimed at screening every child born for specific genetic, endocrine and metabolic conditions that if left untreated, can lead to severe disability or death.

There are ~ 39,000 births in Iowa each year and approximately 10% of all births in Iowa are preterm, low birth weight or transferred to the NICU.

Preterm Birth and Newborn Screening

It is well recognized that premature, low birth weight or sick newborns are more likely to falsely screen positive for one or more of the newborn screening tests. These false positives are generally correlated with:

- Lower thyroid stimulating hormone
- Higher amino acids
- Lower medium and long chain acylcarnitines

This 10% also makes up over a third of the follow-up workload required for the newborn screening program due to the <u>high false positive rate in this population</u>.

Transfusions, parental nutrition, medications and timing of the test in the neonatal intensive care units (NICU) can affect the validity of the newborn screening test.
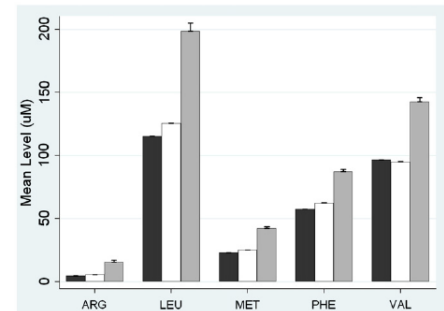

Fig. 1. Mean concentrations of the essential amino acids, arginine (ARG), total leucine (LEU), methionine (MET), phenylalanine (PHE) and valine (VAL) by gestational age. Black bars represent the mean concentration for gestational age ≥37 weeks, white bars represent gestational ages 33–36 and gray bars represent gestational ages 24–32 weeks. Standard errors of the mean are given above each bar.

Addressing False Positive Screens

To address these challenges the Clinical and Laboratory Standards Institute (CLSI) developed a guideline for screening preterm, low birth weight and sick newborns in 2009. Recent surveys have shown that despite the recommendations many physicians caring for newborns in the NICU are unaware of its existence and that only 25% of states have adopted or were planning to adopt the recommendations (James Cummings. *AAP News*. April, 2012).

Iowa has not yet adopted the recommendations.

False positives have adverse impact on parents AND require additional testing which can add to the stress on the baby.

Policy Recommendation

Develop and disseminate a uniform set of guidelines to be implemented across the state. These guidelines will align with the national recommendations, will provide for better utilization of resources and will decrease false positives in this special population of newborns.

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