KANSAS NEWBORN SCREENING QUARTERLY NEWSLETTER

December 2011

Kansas Department of Health and Environment
1000 SW Jackson St.
Topeka, KS 66612

Reminder: When requesting copies of lab reports, we need a faxed request on official letterhead. Please include infant's and mother's names, date of birth, who is requesting report and where to fax report. Fax requests to:

785-296-2950 or 785-296-0978
(Follow-up) (Laboratory)

CHANGES TO NBS LAB REPORTS BEGIN 1/1/12

Effective January 1, 2012 there will be a change to the Kansas Neonatal Screening Reports **for specimens collected before 24 hours of age**. Results for Congenital Adrenal Hyperplasia (CAH), Congenital Hypothyroidism (CH), and Cystic Fibrosis-Immunoreactive Trypsinogen (CF-IRT) are not reliable on specimens collected before 24 hours of age. The report will read **INVALID RESULT** for these disorders, and will no longer give a specific test result or interpretation. A repeat screen taken after 24 hours of age will be required to obtain valid results for CAH, CH and CF-IRT. This change is being implemented to reduce the number of false positive results for these conditions and only affects samples collected prior to 24 hours of age.

Please contact the NBS Laboratory at 785-296-1650 if you have questions.

NEW LINK WITH VITAL RECORDS

In January 2011, the VRV Web system, which is used to file birth certificates electronically, will be updated to include a lab tech user. This means birthing facilities will have the capability to enter the blood spot card number and other collection information directly into VRV. Relevant fields on the blood spot card, such as infant's/mother's name, date of birth, etc. will be transferred electronically from the VRV birth record to the Neonatal Lab. Thus the information associated with each blood spot card will be current and correct.

The goals of the project are to:

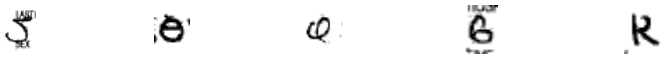
- Have correct and complete information in the Neonatal Lab information system
- Eliminate demographic errors on the blood spot card
- Verify that each infant had a newborn screen collected
- Serve as a cross check for Vital to ensure sure all birth records have been received (in their system)

The Newborn Screening Program will select 3-4 collection facilities to serve as pilot project locations beginning in January. If you are interested in participating please contact Linda Williams at lwilliams@kdheks.gov or 785-296-3617.

More information about the project's progress will be in future newsletters, so stayed tuned!

WHAT LETTER IS THIS?

When filling out the demographic information, please print, using all capital letters, and write legibly. It is often difficult to interpret handwriting. Test your skill on deciphering some actual submissions:



S or **J** **E** or **O** **L** or **E** or **O** **G** or **B** or **6** **R** or **K**

Answers: S, O, O, 6, K

"BIG SHOUT OUT"

Top collection facilities for 3rd Quarter 2011!

Facility Name	Facility Total	Total Unsat %	BSC Unsat %
SALINA REG HEALTH CENTER	294	0.0	0.0
HAYS MEDICAL CENTER	175	0.0	0.0
NEWTON MEDICAL CENTER	112	0.0	0.0
NEOSHO MEMORIAL HOSPITAL	105	0.0	0.0
WILLIAM NEWTON MEM HOSP	70	0.0	0.0
PROVIDENCE MEDICAL CENTER	248	0.4	0.0
NEWMAN REGIONAL HEALTH	134	0.7	0.7
MERCY REGIONAL HEALTH CENTER	286	1.0	0.7
SAINT JOSEPH MEDICAL CTR	624	1.1	0.8
OVERLAND PARK REG MED CTR	847	1.8	0.9
PEDIATRICS ASSN OF OLATHE	111	1.8	0.0
COFFEYVILLE REG MED CTR	54	1.9	0.0
KANSAS UNIV MED CTR	503	2.0	0.4
ATCHISON HOSPITAL	50	2.0	0.0

2011 APHL NEWBORN SCREENING & GENETIC TESTING SYMPOSIUM

The Association of Public Health Laboratories (APHL) held the 2011 Newborn Screening and Genetic Testing Symposium from November 7—10. Three NBS staff members, Linda Williams, Colleen Peterson, and Junqian (June) Carroll attended. Ms. Carroll was the first author on a poster entitled "Kansas Experience with Neonatal and Maternal Carnitine Deficiency". Co-authors were Peterson and Stacey Sandstrom.

The poster examined fifty-eight newborns reported with carnitine deficiency in Kansas from January 2009 to May 2011. Out of those fifty-eight abnormal screens, four newborns were diagnosed with carnitine uptake deficiency (CUD) and 3 newborns had secondary carnitine deficiency associated with 3MCC or MCAD. One case of maternal carnitine deficiency was identified. The poster discussed the tandem mass spectrometry (MS/MS) cut-off value for free carnitine (C0) to identify CUD and the results of these positive cases, including the previously unidentified carnitine deficiency in a mother.

Congratulations to June, Colleen and Stacey for presenting this poster at a national venue!

Above: June Carroll with her poster.

Ho, Ho, Ho… Hemoglobin

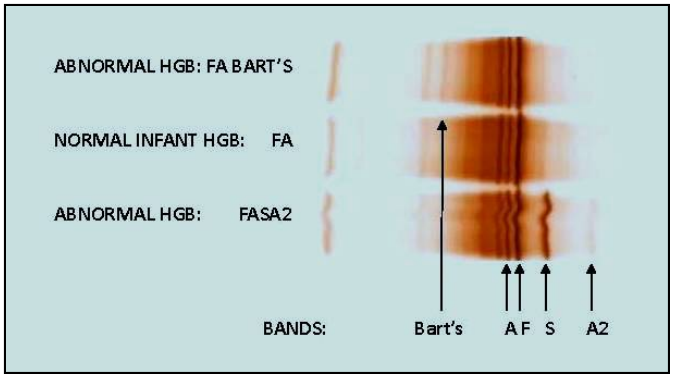
The Kansas Newborn Screening laboratory screens infants for the presence and levels of hemoglobin (Hgb) protein types A, A2, S, C, D, E, F, G, and Bart's. The presence, absence or levels of these Hgb proteins can serve as indicators of hemoglobinopathies such as sickle cell disease, α-thalassemia and β-thalassemia. Hgb proteins detected other than those screened for by the lab are categorized as hemoglobin V (variant) and are reported as abnormal hemoglobin types. The expected Hgb type for a newborn infant is FA (high amounts of Fetal Hgb present and low levels of Adult Hgb present). As the infant ages, levels of Hgb A rise, while the levels of Hgb F decrease.

The Newborn Screening laboratory identifies the presence of aberrant Hgb types using a technique called isoelectric focusing (IEF). IEF uses both electric current and pH to cause charged particles (i.e. Hgb proteins) to migrate to a specific location on a gel. First, reagents are added to the dried blood spot to release the Hgb proteins. The mixture is then applied to an agarose gel. Current is applied and the Hgb proteins migrate across the gel to their pH neutral location (isoelectric point). This creates a banding pattern, which allows the technician to identify individual Hgb proteins and their relative abundance.

At a Glance—3rd Quarter (July—September)

Total # of Samples Tested:	11,550
Total Unsatisfactory Samples:	398
Average Percent Unsatisfactory Samples:	3.4 percent
Total Unsatisfactory Blood Spots:	226
Average Percent Unsatisfactory Blood Spots:	2.0 percent
Goal for Unsatisfactory Blood Spots:	2.0 percent

Hemoglobin Gel Results



Above: Common hemoglobin types with banding patterns

FY2011 ANNUAL REPORT

The FY2011 NBS Annual Report is available on-line at:

kdheks.gov/newborn_screening

The report contains a parent's story, program information, annual data for samples, diagnosed infants and much more. Be sure and share this valuable report with your stakeholders and staff!

CONTACT US!

Kansas Department of Health and Environment

LABORATORY:	1-785-296-1650 (Phone)
	1-758-296-0978 (Fax)
FOLLOW-UP:	1-785-291-3363(Phone)
	1-785-296-2950 (Fax)
ORDER CARDS:	1-785-296-1623 (Phone)
	1-785-296-1641 (Fax)