

KANSAS NEWBORN SCREENING FOLLOW-UP Newsletter



Kansas Department of Health and Environment
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Topeka, KS 66612

This newsletter is for birthing facilities and midwives who are practicing in the state of Kansas. This is intended to be a resource document and platform for program updates.

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KHEL Updates

To request specific information to be featured in the Quarterly Newsletter, please contact Annie Gile at (785)296-3617, or agile@kdheks.gov.

Failed CCHD Follow-Up: What to Expect

NBS F/U Staff will be calling to verify:

- ♥ RUE/Foot O2 saturation
- ♥ Symptoms
- ♥ Diagnostic Testing
- ♥ Pediatric Cardiologist
- ♥ Outcomes



Critical congenital heart disease (CCHD) Reporting

Some babies affected with CCHD can look and act healthy at first, but within hours or days after birth they can have serious complications.

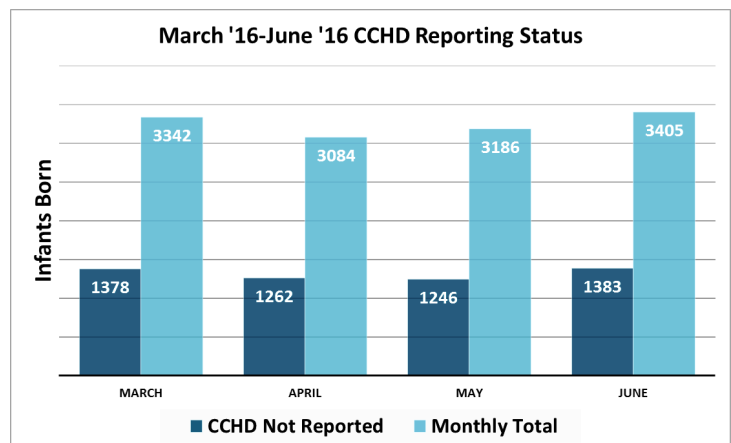


In 2013, the Kansas Newborn Screening Program began a Quality Initiative to increase CCHD screening in Kansas. In order to track this, birthing facilities can now report CCHD screening results via the birth certificate, just like hearing screenings! Unit clerks, nursing staff, and even midwives are also able to report CCHD data via the birth certificate with a Kansas VRV Authorization Request.

NBS Follow-Up staff is currently tracking the number of babies with reported CCHD results in comparison to the total number of babies born in Kansas (see chart below). Currently, 88% of facilities in Kansas are reporting CCHD results. Although only 12% facilities in Kansas are not reporting, this represents an average of approximately 1300 infants per month for whom Kansas has no screening data. Reporting CCHD via the birth certificate supports NBS staff in short term follow-up, including ensuring appropriate referrals and diagnostic testing.

The Kansas Newborn Screening Program would like to give a big **THANK YOU** to all Kansas birthing facilities who are reporting CCHD results— keep up the good work!

If you would like for more information on CCHD Reporting, please contact Annie Gile at (785)296-3617, or agile@kdheks.gov.



*Reporting CCHD via the Electronic Birth Certificate.

“The quality of the newborn screening results are only as good as the quality of the specimen.” Colleen Peterson

**Tips on Timeliness:
Double-Checking Demographics**

The Kansas Newborn Screening Program tests an infant’s blood spot for 29 different disorders, 12 of which are time-critical. **This means that hours count when it comes to collection, shipping, receiving, and processing newborn screening specimens.** Unsatisfactory samples or cards that are missing vital demographic information can cause deadly delays in this process. When filling out the newborn screening demographic card, please double-check:

- ✓ **Birth Date and Time**
- ✓ **Birth Weight**
- ✓ **Collection Date and Time**
- ✓ **Primary Care Physician**

Making sure the demographics section is accurate, correct, and legible can save precious time in the event of an abnormal result.

Coming Soon

The Newborn Screening Follow-Up Program is switching to CleoStream, an electronic faxing system. This will help streamline our process of sending faxes to providers, but it means that our fax number is changing! **Our new fax number is 785-559-4245.** Any faxes sent to our old number will be forwarded for a limited amount of time. If you have questions or concerns about your fax reaching us, please call Newborn Screening Follow-Up at 785-296-0109.



“TOP FACILITIES THAT MAKE IT LOOK EASY!”

Our Statewide Unsatisfactory Goal is to be ≤1.3%

Facility Name	2ND QTR Total Samples	2ND QTR Total Unsat	2ND QTR AVERAGE MONTHLY UNSAT %
ATCHISON HOSPITAL	32	0	0.00%
BOB WILSON MEM GRANT CO HOSP	5	0	0.00%
CHEYENNE COUNTY HOSPITAL	7	0	0.00%
CLAY CO MEDICAL CENTER	17	0	0.00%
COFFEYVILLE REG MED CTR	69	0	0.00%
CUSHING MEMORIAL HOSPITAL	26	0	0.00%
GOVE CO MEDICAL CENTER	13	0	0.00%
GREAT BEND REGIONAL HOSPITAL	78	0	0.00%
HOLTON COMMUNITY HOSPITAL	7	0	0.00%
MEMORIAL HOSPITAL-MCPHERSON	29	0	0.00%
MERCY HOSPITAL-MOUNDRIDGE	1	0	0.00%
MORRIS CO HOSPITAL	4	0	0.00%
MUNSON ARMY HEALTH CENTER	1	0	0.00%
OSBORNE CO MEM HOSPITAL	5	0	0.00%
PROVIDENCE MEDICAL CENTER	126	0	0.00%
ROOKS COUNTY HEALTH CENTER	12	0	0.00%
SABETHA COMMUNITY HOSPITAL,INC	5	0	0.00%
SAINT JOHNS HOSPITAL	1	0	0.00%
SO CENTRAL KS REG MED CENTER	36	0	0.00%
STANTON CO HOSPITAL	7	0	0.00%
WAMEGO CITY HOSPITAL	2	0	0.00%
NEWTON MEDICAL CENTER	125	1	0.80%
VIA CHRISTI HOSP MANHATTAN INC	303	3	0.99%
NEOSHO MEMORIAL HOSPITAL	84	1	1.19%

Questions? CONTACT US!

www.kdheks.gov/newborn_screening

- LABORATORY:** 1-785-296-1652 (Phone)
1-758-296-0978 (Fax)
- FOLLOW-UP:** 1-785-296-0109 (Phone)
1-785-559-4245(Fax)
- ORDER CARDS:** 1-785-296-1623 (Phone)
1-785-296-1641 (Fax)

KANSAS HEALTH AND ENVIRONMENTAL LABORATORIES

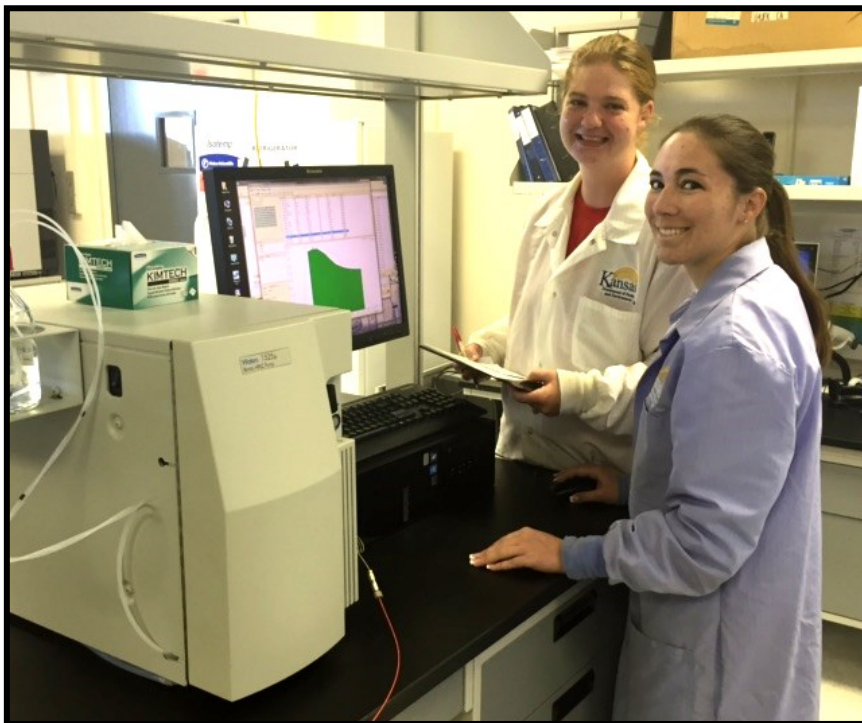
NEONATAL LAB UPDATES

KDHE NBS Laboratory Upgrades Detection Method for Inborn Errors of Metabolism

The Kansas Department of Health and Environment (KDHE) Newborn Screening Panel consist of 29 detectable disorders that can be sub-categorized as metabolic disorders, hematologic disorders, and endocrinopathies. Metabolic disorders are genetic conditions that result in the disruption or hindrance of metabolic pathways such as the catabolism of amino acids, fatty acids, or organic acids. Metabolic pathways are coordinated, in part, by large networks of enzymes. Potential causes of disruption include the production of functional enzymes at insufficient concentrations, partially functional enzymes due to reduced activity, or dysfunctional enzymes.

One method to determine whether a newborn's metabolism is functioning properly, is measuring concentrations of enzymatic products or by-products by tandem mass spectrometry (MSMS). Previously the most widely used tandem mass spectrometry based method for detecting in-born errors of metabolism was a derivatized assay that relied on the butylation of amino acids, acylcarnitines and free carnitine and the NBS laboratory used the PerkinElmer® Quattro NeoGram Derivatized method using Quattro MSMS instruments. The KDHE NBS Laboratory purchased and installed two new Tandem Quadrupole Detector (TQD) MSMS instruments. Validation studies and assessment for accuracy, precision, reportable range, analytical sensitivity, specificity, and established reference intervals for the new TQDs were performed. The NBS Laboratory began implementation of the upgraded PerkinElmer® Neobase™ Non-Derivatized MSMS method to measure blood levels of amino acids, free carnitines and acyl carnitines in newborns on Wednesday, August 24, 2016.

While retaining equivalent analytical performance the new PerkinElmer® NeoBase™ non-derivatized TQD MSMS method requires only four steps compared to the twelve steps necessary in the previous PerkinElmer® Quattro NeoGram Derivatized method. Benefits of the new PerkinElmer® NeoBase™ non-derivatized TQD MSMS method are that specimen preparation time is reduced and the new non-derivatized method has the capability to measure succinylacetone (SA or SUAC). Up to now, the primary marker for Tyrosinemia type I was the amino acid, tyrosine. However, tyrosine is not an ideal primary marker because increased tyrosine levels are not always visible when specimens are taken at the usual sampling time of 24-72 hours of age. In contrast, SA accumulates at an early stage in Tyrosinemia type I cases with the result that it is the better choice as the primary marker to signal this disorder. The most notable difference is that the SA analyte will replace tyrosine as the primary marker for Tyrosinemia I. Other benefits include that there will no need to wait for all specimen plates to be processed prior to starting the daily MSMS instrument runs as plates can be loaded on the TQD MSMS instruments as each plate is prepared. Previously available only in very high-end triple quad mass spectrometers, T-Wave™ collision cell technology allows for increased acquisition speed and hence improved sensitivity. Faster acquisition speed also means that more analytes can be detected without extending assay time.



Pictured: KHEL Microbiologists, Kelley Hale and Nicole Matocha, with the new TQD MSMS instrument



Earlier last month, Kansas Health and Environmental Laboratories (KHEL) said goodbye to the Neonatal Lab Manager, Colleen Peterson. She retired after 19 years of service to the state of Kansas. We wish her the very best of luck in her newly retired life!