

Kansas Department of Health and Environment ~ 1000 SW Jackson St. Suite 200 ~ Topeka, KS 66612

Newborn Screening Panel

What does Kansas Newborn Screening Program (NBS) screen for from the blood spots? Twenty-eight different disorders are screened, using various laboratory tests and technologies. Here is the list of disorders screened in Kansas:

- ◆ **Biotinidase deficiency**
- ◆ **Congenital adrenal hyperplasia**
- ◆ **Cystic fibrosis**
- ◆ **Congenital hypothyroidism**
- ◆ **Galactosemia**
- ◆ **3 Hemoglobin disorders***
- ◆ **6 Amino acid disorders**
- ◆ **5 Fatty acid disorders**
- ◆ **9 Organic acid disorders**

For more information about each of these, visit our website:

www.kdheks.gov/newborn_screening

* other hemoglobin's and traits may also be identified.

Meet the NBS Follow-Up Staff



Left to right: Michelle Black, Janice Conklin, Jamey Kendall, and Jena Callen-Scholz

Michelle Black ~ NBS/SHCN Care Coordinator ~ (785)291-3366

Janice Conklin ~ Administrative Assistant ~ (785)296-0109

Jamey Kendall ~ NBS Follow-Up Coordinator ~ (785)291-3363

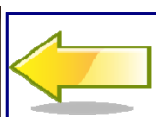
Jena Callen-Scholz ~ NBS Educator ~ (785)296-3617

At a Glance—2nd Quarter 2015

Total # of Samples Tested:	11,124
Total Unsatisfactory Samples:	386
Percent Total Unsatisfactory Samples:	3.47 %
Goal for Unsatisfactory Blood Spots:	< 1.3 %

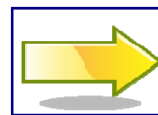
STACK THEM UP THEN LAY THEM DOWN

The bloodspot cards used for the Newborn Screening metabolic testing are considered a medical device by the Food and Drug Administration (FDA). We've discussed the need to keep track of the expiration date but we also need to remind facilities how to store the cards as well as how to dry them once the sample is collected. A good mantra might be "stack them up, then lay them down". Unused cards should be stored stacked up on their side, as shown below left. This prevents the filter paper on the bottom of the stack from getting compressed, which can compromise its ability to allow an even distribution of the sample throughout the paper matrix. Once the sample is collected, the cards should be laid down and spots should not touch anything, as shown below on the right. If the card is hung to dry the sample may flow towards the bottom, again compromising the even distribution of the sample throughout the filter paper. Please make sure staff know how to store and dry cards correctly!



STACK THEM UP

LAY THEM DOWN



Critical Congenital Heart Defect (CCHD)

Also known as Critical Congenital Heart Disease, CCHD is one of the most common birth defects among infants in the United States (approximately 7,200 infants diagnosed annually), accounting for 30 percent of infant deaths due to birth defects. In September 2011, U.S. Department of Health and Human Services' Secretary Kathleen Sebelius recommended that CCHD screening be added to the Recommended Uniform Screening Panel in the United States. Infants born with a CCHD are at a significant risk for death or disability if their condition goes undiagnosed after birth. The preferred method of screening for CCHD is pulse oximetry, a non-invasive, low-cost test. In November 2013, the KDHE-NBS Program launched a quality initiative to increase awareness of CCHDs and ensure that all babies in Kansas are being screened for CCHD after birth. The project focused on assurance of prompt care, connection to resources, short- and long-term follow-up, systems to support hospital-based data collection, management, evaluation and quality assurance, and improvement of overall health outcomes for infants with CCHD. KDHE-NBS has provided education and training to birthing facilities regarding screening for CCHDs, as well as technical assistance and support in order to obtain the goal of 100% of Kansas babies being screened for CCHD. As of June 2015, 98.6% of birthing facilities are screening for CCHD's and 99.6% of all babies born in Kansas birthing facilities are being screened.



Samples Rejected Due to Transportation Delays

An increase in samples arriving at our laboratory more than ten days after being collected has continued to be seen. These samples are rejected and have to be redrawn. Many were delayed in the US Mail, based on postmarked date. We strongly urge collection facilities to submit samples through UPS, FedEx or a courier to ensure prompt delivery to our laboratory. This not only avoids an unnecessary recollection, but it also provides timely results.

ACCURATE INFORMATION

Just a friendly reminder... the information provided on the blood spot cards is critical in order to process the cards in a timely manner. While most cards have accurate information, occasionally some are missing information therefore delaying processing. If the correct information is not reported, facilities need to submit a NBS Data Correction Request Form. When submitting this form, please include any supporting documentation when requesting a corrected/amended report. Please fax form to (785)296-0978.

CONTACT US!



www.kdheks.gov/newborn_screening

LABORATORY: 1-785-296-1650 (Phone)
1-758-296-0978 (Fax)

FOLLOW-UP: 1-785-296-0109 (Phone)
1-785-296-2950 (Fax)

ORDER CARDS: 1-785-296-1623 (Phone)
1-785-296-1641 (Fax)

"TOP FACILITIES THAT MAKE US SMILE!"

*Remember the Goal is to be $\leq 1.3\%$ *



Facility Name	Facility ID	Total # of Samples	Total # of Unsats	2ND QTR AVERAGE MONTHLY UNSAT %
ATCHISON HOSPITAL	40	36	0	0.00%
CHEYENNE COUNTY HOSPITAL	250	6	0	0.00%
MINNEOLA DIST HOSP	270	1	0	0.00%
RANSOM MEMORIAL HOSPITAL	590	44	0	0.00%
KEARNY CO HOSPITAL	880	54	0	0.00%
LABETTE HEALTH	950	57	0	0.00%
MUNSON ARMY HEALTH CENTER	1020	1	0	0.00%
MERCY HOSPITAL-MOUNDRIDGE	1120	6	0	0.00%
MEMORIAL HOSPITAL-	1140	28	0	0.00%
COFFEYVILLE REG MED CTR	1240	69	0	0.00%
MORRIS CO HOSPITAL	1260	7	0	0.00%
SABETHA COMMUNITY HOSPI-	1300	17	0	0.00%
NEOSHO MEMORIAL HOSPITAL	1330	72	0	0.00%
OSBORNE CO MEM HOSPITAL	1380	2	0	0.00%
REPUBLIC CO HOSPITAL	1520	16	0	0.00%
ROOKS COUNTY HEALTH CEN-	1580	8	0	0.00%
STANTON CO HOSPITAL	1890	7	0	0.00%
CITIZENS MEDICAL CTR	1950	42	0	0.00%
PROVIDENCE MEDICAL CENTER	2040	140	0	0.00%
HANOVER HOSPITAL	7460	1	0	0.00%
ST LUKE'S SOUTH HOSPITAL	868	180	1	0.56%
NEWTON MEDICAL CENTER	740	137	1	0.73%
HUTCHINSON REGIONAL MED.	1510	134	1	0.75%
KANSAS UNIV MED CTR	2060	491	4	0.81%
NEWMAN REGIONAL HEALTH	1070	96	1	1.04%
MENORAH MEDICAL PARK	6060	187	2	1.07%
GREAT BEND REGIONAL HOSPI-	92	88	1	1.14%
SUSAN B ALLEN MEM HOSP	170	86	1	1.16%