

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

**SEPTEMBER IS
NEWBORN SCREENING AWARENESS MONTH**

REGIONAL TRAININGS

Trainings on Newborn Screening were held in June 2011 at regional locations—Overland Park, Hays, Garden City, Lawrence and Wichita. One hundred eight people representing over forty-seven facilities associated with newborn screening attended the three hour trainings. What a great turn-out!

This year's focus was to engage attendees as partners, and to provide them with the necessary tools to educate parents and health-care providers about newborn screening. One take away message was to not call this the "PKU test" (see article below). Although actual sample collection was not part of the training; quality assurance of newborn screening samples was emphasized. Linda Williams, KDHE, encouraged facilities to partner with their Quality Director to develop an on-going quality assurance program for newborn screening samples. Laura Ross, KHEL, presented a simplified, yet informative hour on proteins, hormones, fats and DNA and how those components are identified through Kansas' newborn screening tests. The feedback for the training was extremely positive.

In the short-term, the rate for unsatisfactory was reduced in July for those facilities who had a staff member at a training—2.8 percent to 2.4 percent. Let's keep that downward trend going!

It was good to meet so many of our newborn screening partners. Thanks to all who attended!

(Photo below: Training at Garden City)



Each September the Kansas Newborn Screening Program joins other screening programs nationwide in an effort to increase awareness of the importance of newborn screening. Please use every opportunity within your facility to inform and educate parents about this life-saving program.

One simple blood-spot can save a child's life!

At a Glance—2nd Quarter CY 2011

Total # of Samples Tested:	10,722
Total Unsatisfactory Samples:	339
Percent Total Unsatisfactory Samples:	3.2 percent
Total Unsatisfactory Blood Spots:	166
Percent Total Unsatisfactory Blood Spots:	1.5 percent
Goal for Unsatisfactory Blood Spots:	< 2.0 percent



THIS IS NOT "THE PKU TEST"

It's time to get on board and start using correct terminology when referring to newborn screening. All too often, we hear nurses, lab staff and physicians referring to the newborn screen as the "PKU test". Since Kansas screens for 28 disorders, including PKU, it is important that professionals convey correct information to parents and co-workers. Education starts with you! If you hear someone say "the PKU test" please remind them it is so much more.

It is the **"NEWBORN SCREEN" OR "NEONATAL SCREEN"**.

NEW GOALS SET FOR UNSATISFACTORY SAMPLES

In 2008, the Kansas Newborn Screening Program set a goal of 2.0% unsatisfactory cards submitted for testing. This goal included both unsatisfactory blood spots + missing demographic information. Since then, the overall average has dropped from 11.2% in July 2008 to 3.0% in July of this year! This progress has occurred because collection facilities have made an effort to improve the number of acceptable samples. We want to acknowledge everyone's work towards lowering the average unsatisfactory samples. **But now it is time to reach even further.** The national average for 2010 was 1.30% total unsatisfactory samples submitted; Kansas' rate was 3.89% - three times the national average. We need to get Kansas's rate in line with other states.

We will begin using the 1.30% as a statewide goal in October, so we hope you join us in this effort!



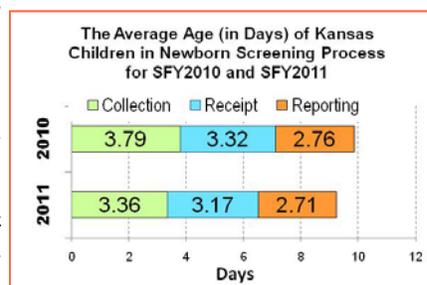
SHIPMENT OF BLOOD SPOT CARDS

In the last newsletter, we discussed how to properly dry a blood spot card. Now we need to discuss some basic rules when shipping blood spot cards.

- ◆ **DO NOT BATCH.** Do not wait until you have multiple cards to send. Many of the disorders we detect can be life-threatening within days of birth. State regulations require shipment of samples within 24 hours of collection. Samples received more than 10 days from collection are unsatisfactory and need to be redrawn.
- ◆ **USE PROPER ENVELOPES.** We recommend using a water-resistant envelope large enough to accommodate the card without folding. Multiple cards may be sent in one envelope; however remember to put enough postage when using USPS.
- ◆ **CONSIDER YOUR TRANSPORT OPTIONS.** Many facilities use a daily courier, UPS or FedEx to deliver the samples which allows for quick delivery. While the USPS is an acceptable method of shipment; we encourage facilities to consider a shipping method that is quick and includes a mechanism to track sample delivery.

NOTE: All samples received **prior to 10:30 a.m. Monday—Friday** are processed that day. Samples received after that time are processed the following business day.

The graph (right) shows average times in days from birth to sample collection, to sample receipt at the Kansas State lab and to final screening report by the lab. Turn-around times for sample collection and transport to the lab need to be improved upon for faster screening results.



HOLD THE MAYO PLEASE - SANDWICH IMMUNO-ASSAY TESTING FOR HYPOTHYROIDISM



Congenital hypothyroidism (CH) occurs when the thyroid gland fails to develop or function properly.

The thyroid gland produces hormones that are important for regulating growth, brain development and metabolism.

In 80 to 85 percent of babies with congenital hypothyroidism, the thyroid gland is absent, abnormally located, or too small. In the remaining 15-20% of cases, the thyroid gland looks normal, but it does not produce any or enough hormones. If untreated, congenital hypothyroidism can lead to developmental delay or mental retardation and poor growth. CH can affect as many as 1 in 3000 live births.

The Kansas State Newborn Screening Laboratory screens for CH by measuring the amount of thyroid stimulating hormone (TSH) in the blood. High levels of TSH can help determine if a baby has CH.

To test for TSH levels in the infant's specimen, the laboratory uses an AutoDELFLIA instrument to perform a sandwich immunoassay. Dried blood spots are punched into individual wells on micro-titer plates containing antibodies that bind TSH molecules to the bottom of the well.



The plates are loaded onto the AutoDELFLIA where a buffer containing a second fluorescent labeled antibody is added to each well. This labeled antibody binds to a different site on the TSH molecule, "sandwiching" the TSH molecule between the plate bound antibody and the fluorescent-labeled antibody. The AutoDELFLIA determines the concentration of TSH in each specimen based on the intensity of the fluorescence in each well. The more TSH molecules present, the more labeled antibodies bind and the higher the intensity of the fluorescence. Elevated TSH concentrations may indicate an infant is having a problem with thyroid function.

At left: AutoDELFLIA instrument.



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)

"BIG SHOUT OUT"

Top collection facilities for 2nd Quarter 2011!



Facility Name	Facility Total	Total Unsat %	BSC Unsat %
VIA CHRISTI HOSPITAL	76	0.0	0.0
MERCY HOSPITAL-INDEPENDENCE	57	0.0	0.0
NEWMAN REGIONAL HEALTH	88	1.1	1.1
SOUTHWEST MEDICAL CENTER	159	1.3	0.6
SAINT JOSEPH MEDICAL CTR	553	1.3	0.9
SALINA REG HEALTH CENTER	282	1.4	0.0
NEOSHO MEMORIAL HOSPITAL	69	1.4	0.0
SHAWNEE MISSION MED CTR	1065	1.5	0.9
LAWRENCE MEMORIAL HOSPITAL	267	1.9	0.7
GREAT BEND REGIONAL HOSPITAL	98	2.0	0.0