



# KANSAS NEWBORN SCREENING QUARTERLY NEWSLETTER

March 2011

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

## Welcome to the 1st Newborn Screening Newsletter!

### At a Glance—4th Quarter 2010

Total # of Samples Tested:	11,286
Total Unsatisfactory Samples:	724
Percent Total Unsatisfactory Samples:	6.4 percent
Total Unsatisfactory Blood Spots:	541
Percent Total Unsatisfactory Blood Spots:	4.9 percent
Goal for Unsatisfactory Blood Spots:	< 2.0 percent

The KS Newborn Screening Program will begin publishing a quarterly newsletter to provide updated information and remain in contact with Kansas Newborn Screening stakeholders. This electronic newsletter will be accessible to birthing hospital staff members, midwives, parents, advocates and physicians.

Highlights from the KS NBS screening program will be included in each newsletter. If you have questions about the information or ideas for newsletter inclusion, please submit them to Linda Williams at: [lwilliams@kdheks.gov](mailto:lwilliams@kdheks.gov)

We look forward to hearing from you!

### DID YOU KNOW?

Unsatisfactory blood spot cards can:

- Cost your hospital money to collect a repeat sample.
- Delay needed follow up and/or diagnosis and treatment for an infant.
- Be prevented with training and quality checks within your facility.



### EXAMPLE OF GOOD BLOOD SPOTS:



## New Screening Protocol for Cystic Fibrosis Implemented on December 1, 2010

On December 1, 2010, the Kansas Health and Environmental Laboratories (KHEL) went live with a new screening protocol for cystic fibrosis (CF) using blood spots cards. KHEL performed a three month pilot project prior to implementation. The previous protocol used for CF was IRT/IRT in which the immune-reactive trypsinogen (IRT) levels were tested on an initial blood spot card. If the specimen IRT levels were elevated, a second specimen was requested. A sweat chloride test was recommended if the second specimen also had abnormal levels of IRT to determine if the infant had cystic fibrosis.

The new protocol is known as IRT/DNA. KHEL determines the IRT levels using only the initial blood spot card. If the confirmed IRT levels are elevated above normal; a DNA test is performed. The DNA test looks for mutations within the cystic fibrosis trans-membrane regulator (CFTR) gene. The panel tested at KHEL includes 40 of the most common CF mutations (including the 23 mutations recommended by the American College of Medical Genetics). A sweat chloride test is performed at a Cystic Fibrosis Center when one or more mutations are detected. In Kansas, CF Centers are located at KU Medical in Kansas City and Via Christi in Wichita. A sweat chloride test is also recommended if the IRT level is  $\geq 170$  ng/mL without any detected DNA mutations.



The new protocol has:

- ◆ reduced the number of required second blood spot samples
- ◆ reduced the number of infants sent for a sweat chloride test
- ◆ decreased the turn-around time for the infant sweat test referral.

Questions about the new protocol?

Contact Colleen Peterson at 785-296-1650

To see the CFTR mutations detected by our laboratory, please go to:

[www.kdheks.gov/neonatal/download/Disorders\\_and\\_Deficiencies\\_Table2.pdf](http://www.kdheks.gov/neonatal/download/Disorders_and_Deficiencies_Table2.pdf)



## REGIONAL TRAININGS COMING SOON!



The KS Newborn Screening Program (NBS) will provide regional trainings in May and June. The focus of the trainings will be sample collection, laboratory testing and newborn screening conditions. Similar trainings were held in 2009 with very positive feedback. A large collection facility shared that “the trainings turned their unsatisfactory rate around,” and they now have one of NBS’s lowest unsatisfactory specimen rates in the state. More information regarding dates and locations will be announced soon.

Please email Linda Williams at: [williams@kdheks.gov](mailto:williams@kdheks.gov) if you want to be on the mailing list for these trainings.

### HOW TO HANDLE ADOPTIONS

When a newborn is adopted, it is important to remember that the information submitted on the blood spot screening card will appear on the lab report. If an adoption is closed, it is imperative that the birth mother’s information, baby’s birth name and mother’s PCP are **not** included on the specimen card. When collecting samples from infants who are in the process of being adopted, **please put the adoptive mother’s information on the card.** PLEASE DO NOT PUT THIS INFORMATION ON AN ATTACHED NOTE. For medical record purposes, KS NBS only reports information that is submitted on the collection card.



### “BIG SHOUT OUT”

#### COLLECTION FACILITIES WITH THE LOWEST UNSATISFACTORY RATES FOR 4TH QUARTER 2010!!

Facility Name	4th quarter 2010 Total # of Samples	4th quarter 2010 Total Unsat %	4th quarter 2010 BSC Unsat %
WILLIAM NEWTON MEM HOSP	63	0.0	0.0
SUSAN B ALLEN MEM HOSP	72	1.4	0.0
SAINT FRANCIS HOSPITAL	254	1.2	0.8
KANSAS UNIV MED CTR	472	1.9	1.1
PROVIDENCE MEDICAL CENTER	245	1.2	1.2
SALINA REG HEALTH CENTER	306	2.0	1.6
LABETTE HEALTH	61	1.6	1.6



### REMEMBER WHY WE SCREEN!

#### PROVIDING EVERY CHILD A HEALTHY OUTCOME THROUGH NEWBORN SCREENING:

- QUALITY SAMPLES
- QUALITY TESTING
- QUALITY FOLLOW-UP

*TREAT EVERY CHILD AS IF IT’S YOUR OWN!*

### HELPFUL HINTS FOR COMPLETING THE BLOOD SPOT CARD:

Complete and correct demographic information on the blood spot cards is necessary for NBS lab and follow-up staff. Please remember these important items:

- **Print legibly** and use **capital letters**.
- Indicate if this is an **initial or repeat sample** at the top of card.
- **Date and time of birth, date and time of collection, and infant’s weight** are all necessary for blood spot testing.
- **Mother’s phone number** is required in case contact is necessary.
- **Mother’s zip code** is essential to verify residential area.
- The physician listed should be the **infant’s primary care physician**—not the mother’s OB/GYN, the resident or the physician on call. One exception is when the infant is in the NICU—the NICU physician should be listed.
- If a birth clerk completes the card prior to collection; it is the collector’s responsibility to **ensure the information on the card is correct** by asking the mother to review the information.
- Always remember to include the collection facility’s **neonatal ID** number.
- Remember to keep the **pink copy** for your records.

### Do you want to save yourself time?

Need a NBS lab report? Need to **update** information on a newborn screening? Save yourself time by faxing your report requests and updates directly to the NBS Laboratory at:

**785-296-0978 (NBS Laboratory Fax)**



You will receive a reply within 24 hours.

(Excluding weekends and holidays observed by the State of Kansas)

**Lab operation hours are 7:00 A.M.—4:30 P.M. Mon—Fri.**

**Plan ahead!** Fax your requests in when pulling charts for upcoming appointments!

### CONTACT US! WE’RE HERE TO HELP!

[www.kdheks.gov/newborn\\_screening](http://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)