

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

**SEPTEMBER IS
NEWBORN SCREENING AWARENESS MONTH**

Newborn Screening Panel

In celebration of National Newborn Screening Awareness Month, it is a good time to remind everyone what the Kansas Newborn Screening Program screens 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 hemoglobins and traits may also be identified.

New LIMS for Kansas Labs

The Kansas Health and Environmental Laboratories are busy working to implement a new laboratory information management system (LIMS). The project is on track for implementation in the fall of 2013. The new system will be web-based, which means results will be easily accessible to facilities and health-care providers. A separate task force has been formed for the health and environmental testing to ensure that our customers needs are met. Newborn screening sample information will be submitted electronically, which will eliminate the need to decode handwriting. In addition, a link with Vital Records will provide the lab with the legal name of the infant.

More information to come! If you have questions or suggestions, please contact Linda Williams at: lwilliams@kdheks.gov



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 2012

| | |
|---|---------------|
| Total # of Samples Tested: | 10,966 |
| Total Unsatisfactory Samples: | 431 |
| Percent Total Unsatisfactory Samples: | 3.9 percent |
| Total Unsatisfactory Blood Spots: | 360 |
| Percent Total Unsatisfactory Blood Spots: | 3.3 percent |
| Goal for Unsatisfactory Blood Spots: | < 1.4 percent |



Fall Cleaning

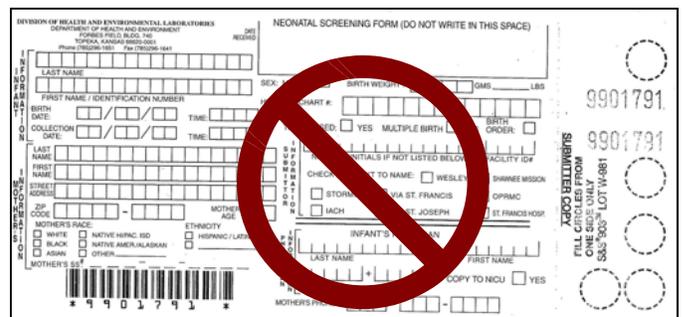


Time to search those cupboards, nooks and crannies to see if your facility still has any of the below newborn screening forms.

In last quarter's newsletter we highlighted the correct forms to use when collecting newborn screens. However, we are still receiving old forms, which are shown below. **These forms are more than ten years old and should not be used.** Many of them are being rejected because the filter paper no longer absorbs the blood as it should and the result is an uneven saturation.

Clean house! Find these and return unused to our lab.

See the current form on page two of this newsletter.

NEONATAL SCREENING FORM (DO NOT WRITE IN THIS SPACE)

9901791

9901791

2000 BELLWEGS
FULL CIRCLE FROM
ONE CENTER FROM
585-503-1481 LOT 1481

HOW OLD IS TOO OLD FOR NEWBORN SCREENING?

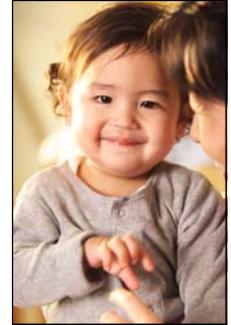


Recently, many states have been asking the question—how old is too old for newborn screening? The answers vary, but most states have an upper age limit ranging from 6-12 months. In Kansas we do not reject samples due to age; however, the cystic fibrosis screening test will be reported as “No Result” for samples collected after the infant is 90 days old. The immune-reactive trypsinogen (IRT) levels drop as a child ages, so the IRT is no longer a valid screening test for cystic fibrosis in an older infant.

It is also important to remember normal cutoff values are determined by analyzing results of normal infants tested at the Kansas Health and Environmental Laboratory. Since the vast majority of our samples are collected between 24—72 hours of age, the cutoffs will be based on those samples’ results. The older the child, the more likely the cutoff values may not be as valid. Therefore, we do not suggest using newborn screening as a mechanism to screen an older child who may show clinical signs of a disorder.

One exception would be for an infant adopted at an older age. The newborn screen can be performed with the understanding that the results may not be as accurate as for a neonate.

If there are concerns about the age of an infant, please contact our laboratory for assistance: 785-296-1650.



Samples Rejected Due to Transportation Delays

This past quarter has seen a dramatic increase in samples arriving at our laboratory more than ten days after being collected. 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.

THE CORRECT BLOOD SPOT CARD

How do I know I'm using the correct card?

- ◆ There is **blue ink** on the card.
- ◆ There is an **orange biohazard sign** on the protective cover.
- ◆ There is an **expiration date** on the card.



Look for the expiration date each time a card is used.

Welcome to Two New NBS Staff

Newborn Screening welcomes two new staff members:



Casey Guccione
Microbiologist
Neonatal Laboratory



Daniel Gibbons
Program Consultant
NBS Follow-up

“TOP FACILITIES THAT MAKE US SMILE!”

Four facilities met the goal of <1.4% unsatisfactory samples for 2nd Quarter 2012!



| Facility Name | Total # of Samples | Total Unsat % | Unsat Blood Spots % |
|---------------------------|--------------------|---------------|---------------------|
| HAYS MEDICAL CENTER | 183 | 0.0 | 0.0 |
| LABETTE HEALTH | 65 | 0.0 | 0.0 |
| PROVIDENCE MEDICAL CENTER | 188 | 0.5 | 0.0 |
| SALINA REG HEALTH CENTER | 286 | 1.0 | 0.7 |



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)