

Kansas Department of Health and Environment
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Topeka, KS 66612

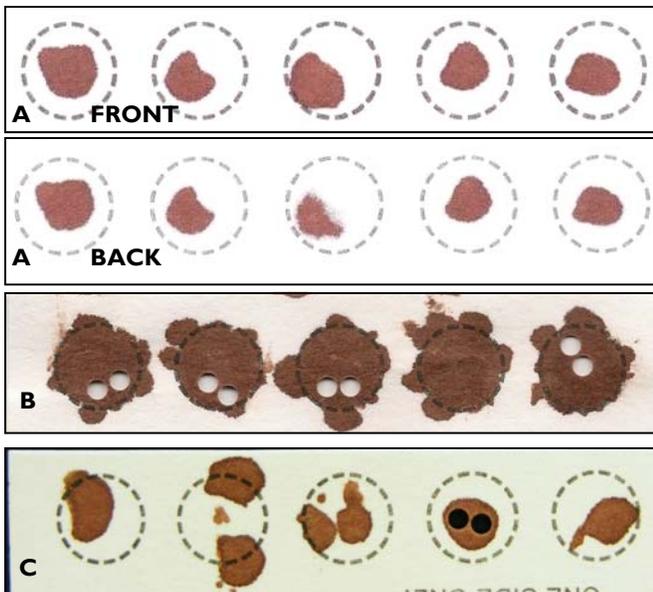
REVIEW OF NEWBORN SCREENING BASICS

NEW KDHE LOGO

The State of Kansas is unveiling a new logo for all state agencies. This will allow the State to have a cohesive look that's readily identifiable with constituents. Look for this new logo to appear on all of our publications and correspondence in the future.

Welcome to the second Newborn Screening Newsletter! In this edition we will review some of the basics of newborn screening and introduce you to a permanent article about a lab procedure and follow-up for a screened disorder. This month we focus upon the disorder Galactosemia. We've also included a list of the facilities who had low unsatisfactory sample rates. We will continue to highlight those locations that collect more than 50 samples per quarter and reach the goal of less than or equal to 2.0 percent total unsatisfactory samples. Ask us how we can help your facility be on this list!

EXAMPLES OF UNSATISFACTORY BLOOD SPOTS:



A = Spots too small and blood not soaked through to back

B = Multiple spots applied using a capillary tube

C = Spots too small and appears that heel has touched card

REGIONAL TRAININGS THIS MONTH

"ESSENTIALS OF NEWBORN SCREENING"

June 13—Overland Park	1 p.m.—4 p.m.
June 15—Hays	1 p.m.—4 p.m.
June 16—Garden City	9 a.m.—12 p.m.
June 22—Lawrence	1 p.m.—4 p.m.
June 30—Wichita	1 p.m.—4 p.m.

SPACE IS LIMITED TO 50 ATTENDEES PER SITE!

More information at: <http://kuahec.kumc.edu/conferences.html>

Contact KUMC AHEC Office to register:
620-235-4040 or ahcepitt@kumc.edu

At a Glance—1st Quarter 2011

Total # of Samples Tested:	10,829
Total Unsatisfactory Samples:	469
Percent Total Unsatisfactory Samples:	4.3 percent
Total Unsatisfactory Blood Spots:	281
Percent Total Unsatisfactory Blood Spots:	2.6 percent
Goal for Unsatisfactory Blood Spots:	< 2.0 percent

PARENTS—A CRITICAL LINK AND HOW YOU CAN HELP

A number of parents reported that they were unaware that a newborn screening sample was taken from their infant. We need your assistance to ensure that parents are part of this important screening process. The "Newborn Screening For Your Baby's Health" brochure should be given to **every** parent prior to collecting the blood spot from their baby. This brochure gives parents the basic information about the newborn screening test performed on their child. If parents would like more detailed information, they can be directed to our website: www.kdheks.gov/newborn_screening.

Parents wonder how they will find out the results of the newborn screen. All results are faxed to the physician indicated on the collection card. The physician on the collection card should be the **infant's** primary caregiver. When screening results indicate a need for a repeat test or further diagnostic testing, a letter is mailed to the mother at the address she provided. If it is critical that the mother be contacted immediately, newborn screening follow-up calls the phone number indicated on the card. The collection facility staff should confirm the information provided on the blood spot card is accurate. We recommend that the information provided is reviewed with the mother prior to collecting the sample on her infant.



THE BLOOD SPOT CARDS—WHAT MAKES THEM SO SPECIAL?

Have you ever noticed that the blood spot cards have a lot number and expiration date on them? What makes them so special? Because these cards are approved by the Food & Drug Administration. The blood spot collection area is made up of a filter paper that is designed to absorb blood in a specific way. Be careful not to touch the filter paper area of the card with your hands; as any residual oils can impact the filter paper's ability to absorb properly. The filter paper is calibrated so the testing lab can quantify the results based on what the expected amount of blood is in a given sized punch. This is the reason our lab has certain acceptance criteria for the blood spots.

Because the cards are calibrated, it is very important that the cards are stored on their sides as shown in this picture - and not stacked on top of one another. If the cards are stacked, the filter paper on the bottom could be compressed and unable to absorb the blood as expected which might cause inaccurate results.



The cards each have a barcode identifier on them. This identifier is scanned by the KHEL prior to shipping, so each batch of cards is associated with a particular facility. For this reason, it is important not to "share" your cards with another facility.

After the blood sample is collected, the card needs to dry at room temperature for 3 hours on a flat surface and away from direct heat or sunlight.

Be certain that the protective cover does not touch the blood spots while drying. One drying option is to use a Whatman Dry Rack. Contact Linda Williams at 785-296-3617 to order a complimentary sample pack.

Cards should be sent to the State Laboratory within 24 hours of collection. More about shipment of samples in the next newsletter.

Meanwhile be sure and read the story about GALT and check out the caution about mailing samples in the summer heat.



SEE SPOT ... GLOW

The Kansas Newborn Screening Laboratory utilizes a modified Beutler fluorescent spot test to determine the presence or absence of a functional galactose-1-phosphate uridyl transferase enzyme (or GALT for short). The absence of a functional **GALT** enzyme would indicate that a patient could not process the sugar galactose. In this test, laboratory staff combine an infant's dried blood spot with several reagents and enzymes to simulate biochemical processes that occur when galactose is processed by the body. The dried blood spots and reagents incubate and then the mixture is hand spotted onto filter paper. These spots are allowed to dry and are then examined under UV light. Patient's dried blood spots that have a functional GALT enzyme for the reactions in this test produce a fluorescent molecule called NADPH. This causes the spotted filter paper to glow under ultra-violet light. Patients lacking the GALT enzyme cannot complete the biochemical processes and do not produce NADPH. Their spots do not glow.



Reagents are added to dried blood spots and incubated.



Mixture is hand spotted onto filter paper.



Normal patient spots glow under UV light. Abnormal patients (GALT absent) do not.

Abnormal specimen (no fluorescence)

Normal specimen (fluorescence)

When the laboratory identifies a positive GALT, the follow-up team is immediately notified. The PCP listed on the card is notified by phone and fax. If the enzyme is totally absent, consultation with a specialist is requested so that further diagnostic testing can be ordered. If the screen result is partially absent, a repeat screen is requested. Kansas has identified 3 Duarte Galactosemia infants since July 2008. Duarte is a milder form of classic galactosemia. It is important to remember the following about GALT:

- ◆ Missing enzyme which causes inability to metabolize galactose, which is a by-product of lactose.
- ◆ Treatment is the elimination of milk and dairy products from diet.
- ◆ If untreated, can cause blindness, mental retardation and death.



The GALT enzyme is particularly sensitive to heat. With the Kansas summer heat upon us, it is imperative that blood spot cards are not placed in outside mailboxes to be picked up, as this may inactivate the enzyme and cause false positive results.

TOP COLLECTION FACILITIES IN 1st QUARTER 2011



Facility Name	Facility Total	Total Unsat %	BSC Unsat %
NEWTON MEDICAL CENTER	131	0.0	0.0
KANSAS UNIV MED CTR	467	0.9	0.4
NEWMAN REGIONAL HEALTH	101	1.0	0.0
SALINA REG HEALTH CENTER	289	1.4	0.3
OVERLAND PARK REG MED CTR	819	1.6	1.0
SUSAN B ALLEN MEM HOSP	62	1.6	0.0

CONTACT US! WE'RE HERE TO HELP!

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)