KANSAS

NEWBORN SCREENING PROGRAM

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Kansas

Department of Health and Environment

Kansas Newborn Screening

Newborn screening is a way to identify babies who may have serious medical conditions. These conditions may not be visible at birth, but can be treatable if diagnosed early. Early treatment of these conditions can prevent against more serious illness, disability or death. Newborn screening tests include:

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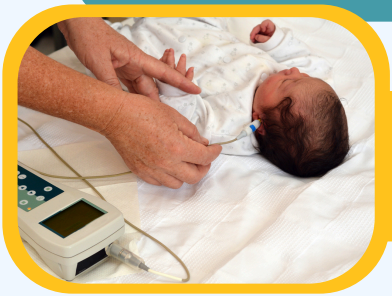
Pulse Oximetry Screening
(Critical Congenital Heart Disease)

Blood Spot Screening
(Genetic or Congenital Disorders)



Hearing Screening

If your baby has an abnormal blood spot screen or does not pass the hearing or heart screening, it is crucial that you follow-up as recommended. Early detection and intervention will result in the best possible outcome for your baby.

If you have questions, please refer to the appropriate contact information provided on the back of this booklet.

1. _____

Hearing Screening

What is it looking for?
The hearing screen is a quick and effective way to determine if your baby can hear sounds needed to learn language.

How is it done?
The hearing screen is safe and is often completed in about 10 minutes while your baby is sleeping. There are two different types of hearing screens that can be performed based on the equipment available at the facility, AABR and OAE.

How will I find out the results?
Hearing screen results are often shared within 24 hours of the screening. It is important that the birthing facility/provider have your baby's doctor so they can send them the results. Even if a baby passes the hearing screen, it is possible for hearing loss to develop later. If you have concerns about your child's hearing, contact your child's primary care provider.

What if my baby does not pass?
If your baby does not pass the initial screen, you will be asked to bring your baby back to the birthing facility or audiologist for a hearing screening within two weeks. It is important to identify hearing loss early because it is critical for speech and language development.

Pulse Oximetry Screening

What is it looking for?
Pulse oximetry screening looks for low levels of oxygen in the blood that may indicate a problem with the heart or lungs. Critical Congenital Heart Disease (CCHD) occurs when a baby's heart does not develop normally.

How is it done?
Pulse oximetry is fast, simple and accurate. It can be performed when a baby is at least 24 hours old by a healthcare provider. A small sensor is placed on the baby's right hand and either foot allowing a connected device to measure the baby's oxygen levels.

How will I find out the results?
Pulse oximetry results are immediate and will be shared with you by the screening facility or your baby's provider.

What if my baby does not pass?
A rescreen or additional diagnostic testing (such as an echocardiogram) will be requested to determine the cause of low oxygen saturation levels.

If any of the results from the additional testing are of concern for CCHD, then your baby may need to see a pediatric cardiologist. Babies with CCHD need surgery within the first year of life. Each baby with CCHD will require a unique treatment plan developed for their particular heart defect.

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Blood Spot Screening

What is it looking for?
The blood spot screening looks for a variety of metabolic and genetic disorders. A list of disorders can be found at **nbss.ks.gov**.

How is it done?
A few drops of blood are taken from your baby's heel and put on a special paper. The Kansas Health and Environmental Laboratory (KHEL) then performs the testing.

How will I find out the results?
The state laboratory will notify the facility where your baby's newborn screen was collected. If there is an abnormal result, the Newborn Screening Follow-Up Program will notify you and the baby's Primary Care Provider listed on the blood spot collection card. Be sure to ask about your baby's results at your first well child checkup.

What if my baby does not pass?
An abnormal screen does not necessarily mean your baby has one of these conditions. Your baby's provider has received information on next steps when an abnormal result has been indicated. As some conditions can be time critical, it's extremely important to follow the recommendations that your baby's provider received.

What happens to the blood after the screening?
Abnormal results are retained for a longer period for validation and training purposes. There are cases in which de-identified abnormal results can be shared with surrounding states to help validate testing procedures and instrumentation. No unauthorized sharing of Personal Health Information (PHI) from the blood spot collection is shared with outside entities.

Frequently Asked Questions

I have no family history. Should my baby still be screened?
Yes. Families with no family history and/or parents who have already had healthy children can still have a child affected by one of the conditions on the newborn screening panel. Many babies with a condition have no family history.

What if my baby looks healthy?
Many of the conditions Kansas screen for are not visible through a regular examination. With many of these conditions, babies may look normal and appear healthy at birth and even into infancy. Newborn screening identifies infants at risk for one of the conditions on the newborn screening panel, providing the opportunity for early intervention before the condition progresses. Early identification allows for early intervention and has shown to improve outcomes for babies affected by a condition on the screening panel.

How much does blood spot screening cost?
Blood spot screening is free of charge. Kansas state statutes require that every baby born in Kansas be screened for all metabolic and genetic conditions on the newborn blood spot screening panel at no cost to families.

Why do some babies need to have a repeat blood spot screen collected?
A repeat screen can be requested for several reasons. Your baby's provider or the specialist for the condition identified will inform you if a repeat screen or diagnostic testing is necessary for an out-of-range result. A repeat screen may also be requested when the first screen was invalid or unsatisfactory, meaning the lab is unable to conclusively test the specimen that was received.

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Can I pay to have my baby screened privately?
Yes, however, private laboratories may not screen for all conditions on the Kansas newborn screening panel. Additionally, some conditions on the NBS panel are sent for second tier testing which may not be provided with private testing. For more information about private laboratory testing speak with your baby's healthcare provider.

What causes these conditions?
Conditions on the newborn screening panel can be the result of several factors. Some conditions are genetic, while some are not. If hearing loss or another condition is detected in your baby's screening, your baby may be referred to a genetic counselor for more testing to determine if the cause is related to genetics.

How is the hearing screening performed?
Unlike hearing tests for older children and adults, newborn hearing screening does not require active participation from your baby. Instead, a small screening device will play soft sounds while it measures how your baby's inner ear or hearing nerve responds.

Why is pulse oximetry important (CCHD)?
While prenatal ultrasounds may detect some cases of CCHD, not all can be detected before birth. Screening shortly after birth ensures that your baby does not have a CCHD. A baby with a CCHD may require emergency care and identifying it while in the birth setting can lead to more timely treatment and better outcomes for the baby.

Where can I find more information on Kansas Newborn Screening?
To find a list of conditions screened or for more information about the Kansas Newborn Screening Program, visit **nbss.ks.gov** or scan the QR code on the back of this pamphlet.

Need help remembering the results?

Use the space below to record your baby's screening results.

Hearing Screening Passed Not Passed

Follow-up appointment: ___/____/___ at_____

Notes:_____

_____

_____

Pulse Oximetry Screening Passed Not Passed

Follow-up appointment: ___/____/___ at_____

Notes:_____

_____

_____

Blood Spot Screening

First Well Checkup: ___/____/___ at_____

Notes:_____

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Contact Us:

Kansas Newborn Screening Laboratory
1115 SW Harrison Street
Topeka, KS 66612
(785) 296-1620

Kansas Department of Health and Environment
Newborn Hearing/CCHD Screening Program
(785) 368-7167

Newborn Screening Follow-Up Program
(785) 291-3363

To learn more about newborn screening, visit:

nbss.ks.gov

Or scan the QR code below