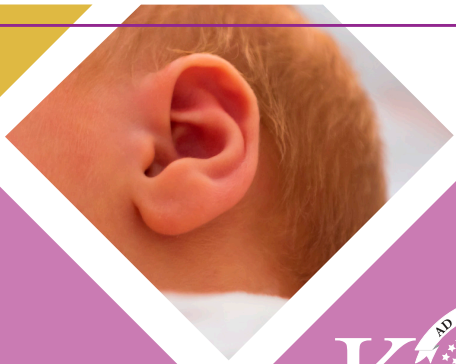

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Kansas

Department of Health and Environment

KANSAS

NEWBORN SCREENING PROGRAM

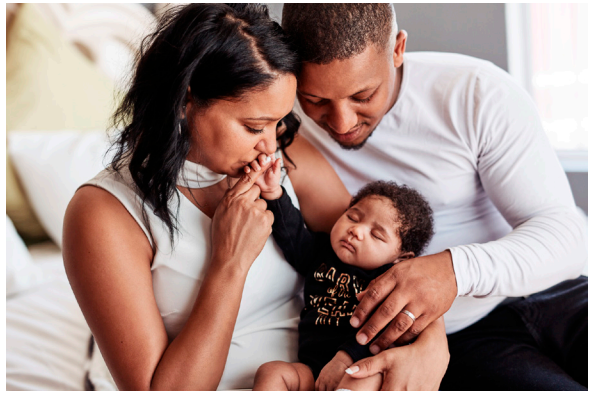
Kansas Department of Health and Environment
Bureau of Family Health
Special Health Services

Newborn Screening Program Updates

What has changed with Kansas Newborn Screening?
Since February 2020, three conditions have been added to the Kansas Newborn Screening panel:

- **Spinal Muscular Atrophy (SMA) –** added February 2020
- **Two Lysosomal Storage Disorders (LSDs) –** added January 2021
  - Pompe
  - Mucopolysaccharidoses I (MPS I)

Why are these changes important?
With the addition of these conditions, Kansas' babies are now screened for 34 of the 35 conditions recommended by the Federal Advisory Committee on Heritable disorders in newborns and Children, and more Kansas babies will benefit from this important public health program. Like all other conditions on the Kansas Newborn Screening panel, babies with these inherited disorders can appear normal at birth. Symptoms of these conditions often do not appear until the disorder has already caused significant and permanent damage to the body. Early detection and treatment of these rare conditions can help prevent serious illness, disability, or early death.



Newborn Screening Program Updates

If my baby does not pass one or more of the newborn screenings, what questions should I ask?
After an abnormal screening, additional diagnostic testing is necessary to confirm whether your baby has one of the conditions screened for. Talk to you baby's doctor and make sure to get answers to the following questions:

- What kind of diagnostic testing needs to be completed?
- Who will do the testing and when will the testing take place?
- Are there any signs or symptoms I should look for between now and then?
- What should I do if I see any of those signs and symptoms?
- What is my next step in this process?

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:

- Hearing Screening
- Pulse Oximetry Screening (Critical Congenital Heart Disease)
- Blood Spot Screening (Genetic or Congenital Disorders)

Due to the importance of identifying these conditions early, state law requires that newborns receive screens listed above. If you have questions, please refer to the appropriate contact information provided on the back of this booklet.

If your baby does not pass a newborn screening, it is crucial that you follow-up as recommended. Early detection and Intervention will result in the best possible outcome for your baby.

Hearing Screening

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

How is it done?
Hearing screening is safe and will not hurt. It can be done in about 10 minutes. There are two types of screens done for hearing loss depending on the equipment available to the birthing facility or local audiologist, AABR and OAE. Neither test will make your baby uncomfortable and they are often done while your baby is asleep.

How will I find out the results?
A healthcare provider/audiologist will talk with you about the results of your baby's screening. Please make sure you tell your provider the name of your baby's doctor so they can send them the results. If your baby passed the hearing screen, you should continue to monitor any signs of late onset hearing loss.

What if my baby does not pass?
If your baby does not pass or is missed at the birth screening, make sure he or she is screened as soon as possible. Please take your baby back to the birthing facility or audiologist for a hearing screening within two weeks. It is important to find hearing loss quickly, because babies whose hearing loss is not found early may have a hard time learning language.

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 occurs when a baby's heart does not develop normally.

How is it done?
Pulse oximetry is fast, simple and accurate. It can be used on babies soon after they are born. Hospital nursery staff will do the screening when the baby is at least 24 hours old. A small sensor is placed on the baby's right hand and a foot allowing a connected device to measure the baby's oxygen levels.

How will I find out the results?
Your baby's doctor or a nurse will tell you the results of the pulse oximetry newborn screen.

What if my baby does not pass?
Your baby will not pass if:

- Your baby has a low level of oxygen
- There is a 3 percent difference between the reading in your baby's hand and foot.

At this point, a rescreen or complete physical examination will be completed to determine why your baby did not pass the screening. There may be several reasons, including respiratory problems or infections.

Blood Spot Screening

What is it looking for?
The blood spot screening looks for a variety of metabolic and genetic disorders. A full list of all disorders screened for can be found in this booklet.

How is it done?
A few drops of blood are taken from your baby's heel and put on a special paper. The state public health laboratory then does the testing.

How will I find out the results?
The Newborn Screening Program will notify your baby's provider. If there is an abnormal result, you will get a letter letting you know the next steps. Ask about your baby's results at your first well child check-up.

What if my baby does not pass?
If you get a call from your baby's provider, it does not always mean your baby has one of these medical conditions. It is important to take your baby for further testing as soon as possible.

What happens to the blood after the screening?
Most blood samples are destroyed one month after being received. Personal information associated with remaining samples is removed and samples may be used for training purposes to improve the Newborn Screening Program. Parents may request that their baby's sample not be used for these purposes by submitting their request in writing to:

Neonatal Laboratory Manager
Kansas Health and Environmental Laboratories
6810 SE Dwight Street
Topeka, KS 66620

What will my baby be screened for?

AMINO ACIDEMIAS
- Argininosuccinic Aciduria (ASA)
- Citrullinemia, Type 1 (CIT)
- Homocystinuria (HCY)
- Maple Syrup Urine Disease (MSUD)
- Classic Phenylketonuria (PKU)
- Tyrosinemia, Type 1(TYR-1)

ORGANIC ACIDEMIAS
- Glutaric Acidemia, Type 1 (GA-1)
- 3-Hydroxy-3-Methylglutaric Aciduria (HMG)
- Isovaleric Acidemia (IVA)
- 3-Methylcrotonyl-CoA Carboxylase Deficiency (3-MCC)
- Methylmalonic Acidemia—Cobalamin disorders (Dbl-A,B)
- Methylmalonyl-CoA Mutase Deficiency (MUT)
- Beta-Ketothiolase Deficiency (βKT)
- Propionic Acidemia (PROP)
- Holocarboxylase Synthetase Deficiency (MCD)

ENDOCRINE
- Congenital Adrenal Hyperplasia (CAH)
- Primary Congenital Hypothyroidism (CH)

FATTY ACID OXIDATION DISORDERS

- Carnitine Uptake Defect & Carnitine Transport Defect (CUD)
- Long-chain L-3 Hydroxyacyl-CoA Dehydrogenase Deficiency (LCHAD)
- Medium chain acyl-CoA dehydrogenase deficiency (MCAD)
- Trifunctional protein deficiency (TFP)
- Very Long-chain Acyl-CoA Dehydrogenase Deficiency (VLCAD)

HEMOGLOBINOPATHIES

- Sickle Cell Anemia (Hb SS)
- Hemoglobin SC disease (Hb SC)
- Sickle Beta-Thalassemia (Hb Sβ)

OTHER

- Biotinidase Deficiency (BIOT)
- Cystic Fibrosis (CF)
- Classic Galactosemia (GALT)
- Severe Combined Immunodeficiencies (SCID)
- Critical Congenital Heart Disease (CCHD)
- Hearing Loss

If you would like to learn more about these conditions, visit our website for further information and appropriate next steps: www.kdheks.gov/newborn_screening.

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:

_____

_____

To learn more about newborn screening, visit:

www.soundbeginnings.org

www.kdheks.gov/newborn_screening

KANSAS

NEWBORN SCREENING PROGRAM

Contact Us:

Kansas Department of Health and Environment

Special Health Services

Newborn Hearing Screening Program: 785-368-7167

Newborn Metabolic Screening Program: 785-291-3363

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