



**KANSAS**  
NEWBORN SCREENING PROGRAM

**Kansas**  
Department of Health and Environment  
Division of Public Health

**Kansas Newborn Screening Program Overview**

**Kansas** Department of Health and Environment Division of Public Health

**Kansas Newborn Screening Program**



**Meet Gavin James – born in Wichita, Nov. 2010**




Metabolic & Genetic Conditions  
*plus*  
Hearing Loss


**34,000+**




**FREE**

*To protect and improve the health and environment of all Kansans*



# Kansas Newborn Screening Program




Division of Public Health  
Newborn Screening Program  
Curie Stone Office Building  
1000 SW Jackson St., Suite 220  
Topeka, KS 66612

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Fax: 785-509-4245  
www.kshhs.gov/newborn-screening


Lee A. Harmon, M.D., Secretary      Laura Kelly, Governor

**Elevated Immunoreactive Trypsinogen/DNA (IRT/DNA) Lab Report**  
Kansas Newborn Screening Program

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# Kansas Newborn Screening Program



Began in 1965	31 Conditions Added Since		Adding 3 New Disorders
Screening for Phenylketonuria (PKU)	1977 – Congenital Hypothyroidism (CH) 1984 – Galactosemia (GALT) 1993 – Hemoglobin Disorders 1999 – Hearing Loss 2008 – 22 additional metabolic and genetic disorders including organic, fatty, and amino acid disorders	2017 – Severe Combined Immunodeficiencies (SCID) 2018 – Critical Congenital Heart Disease (CCHD) 2020 – Spinal Muscular Atrophy (SMA)	Have approval to add 3 more conditions including: → Two Lysosomal Storage Disorders → X-Linked Adrenoleukodystrophy (X-ALD)

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**Kansas** Department of Health and Environment  
Office of Public Health

**Kansas Newborn Screening Program**

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NEWBORN SCREENING PROGRAM

**For every baby born in Kansas...**

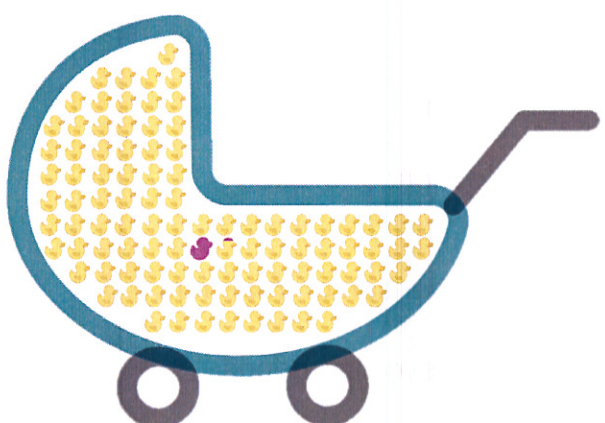
- Birthing Facility Staff (Nurses, Lab Technicians, Midwives, etc)**
  - Collect a blood spot sample
  - Conduct CCHD test
  - Complete hearing screen
- Blood Spots Sent to State Lab for Analysis**
  - CCHD and Hearing Results Submitted on Birth Certificate
- Results Reported to Follow-Up Team**
  - Follow-Up Contacts PCP to Ensure Timely Referral or Repeat Screen
  - Lab Faxes Final Lab Report to PCP
- PCP Referral to Specialist**
  - Diagnostic Testing to Confirm Diagnosis
- Timely Treatment Begins**

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**Kansas** Department of Health and Environment  
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- **Babies appear normal at birth**
- **All conditions are treatable**

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## Kansas Newborn Screening Program



### Gavin is a Newborn Screening Success Story



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## Kansas Newborn Screening Program



### Success is...

- Every baby in the state receives a newborn screen
- Screening results are accurately reported out to meet or exceed national timeliness goals
- Identifying infants who will benefit from early intervention or treatment
- Growing the program and accommodate Kansas' evolving needs

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# Kansas Newborn Screening Program



## Success is...



**Growing**  
 the Newborn Screening  
 Program to support the  
 needs of Kansas  
 Families

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# Kansas Newborn Screening Program

## Baby Reyna – born in Garden City, Nov. 2017



- Appeared normal at birth
- Newborn screening results NORMAL

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## Kansas Newborn Screening Program

### Baby Reyna – born in Garden City, Nov. 2017



- Growing concerns during first few months
- Low leg tone & missed gross motor milestones
- Soft coughs
- Quiet cries at 9 months old

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## Kansas Newborn Screening Program

### Diagnosis at 10 months old

Spinal Muscular Atrophy (SMA)



#### Treatment has stopped the progression

- Regimen of daily therapy for breathing
- Breathing assistance at night
- Weekly Therapy
  - Aqua therapy
  - Occupational therapy
  - Physical Therapy
  - Speech Therapy

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## Kansas Newborn Screening Program



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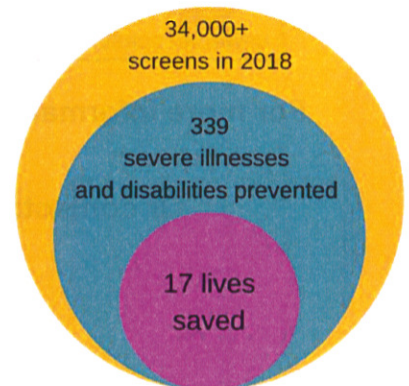


## Kansas Newborn Screening Program





Early Detection = treatment **BEFORE** permanent disability or death

- Prevent or reduce additional healthcare costs
  - Complications
  - Hospitalizations
- Reduce costs of treatment, therapies, and special education
- Saves lives



*To protect and improve the health and environment of all Kansans*

 **Kansas Newborn Screening Program** 



## The Newborn Screening Bill...

...ensures that KDHE can continue to provide a quality program “to protect the health and welfare of newborns for treatable disorders.”

...ensures that the Newborn Screening Program can continue to grow to meet Kansas’ evolving needs.

...ensures that all Kansas newborns with rare conditions are identified early without financial barriers.

*To protect and improve the health and environment of all Kansans*

 **Kansas Newborn Screening Program** 



**KANSAS**  
NEWBORN SCREENING PROGRAM

# Thank You!

**For more information visit:** [www.kdheks.gov/newborn\\_screening](http://www.kdheks.gov/newborn_screening)

**Or contact:** Shawn Manos  
Newborn Screening Program Manager  
785.291.3363  
[Shawn.M.Manos@ks.gov](mailto:Shawn.M.Manos@ks.gov)

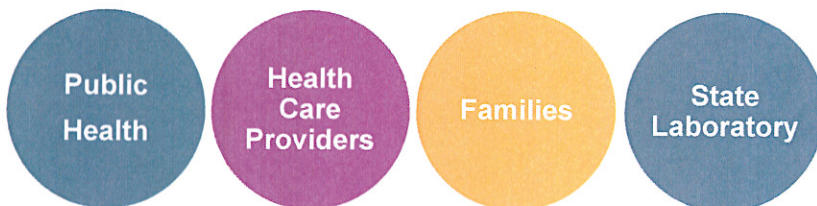
*To protect and improve the health and environment of all Kansans*



# KANSAS NEWBORN SCREENING PROGRAM

Since 1965, newborn screening has ensured the best possible outcomes and quality of life for all Kansas babies.

Newborn screening in Kansas is a crucial public health service that only works with collaboration between:



## Quick Facts

**Free for KS Families!**

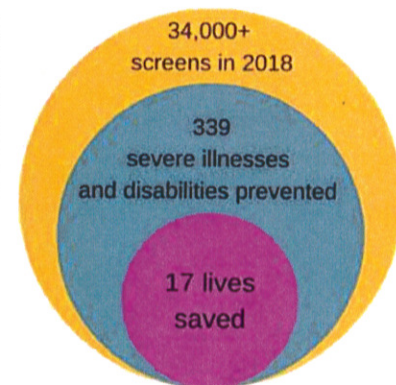


Approximately 1% of infants screened are diagnosed.

32 Conditions Currently on the Kansas Screening Panel

3 More Conditions Planned

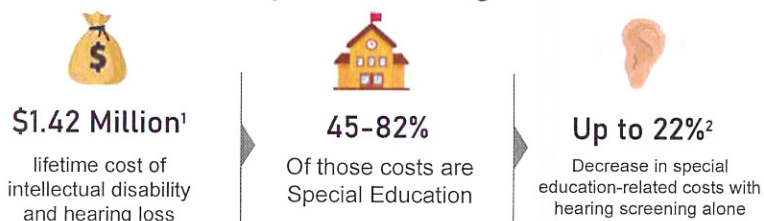
Our screening panel includes 30 genetic disorders, hearing loss, and critical congenital heart disease. We are adding more conditions!



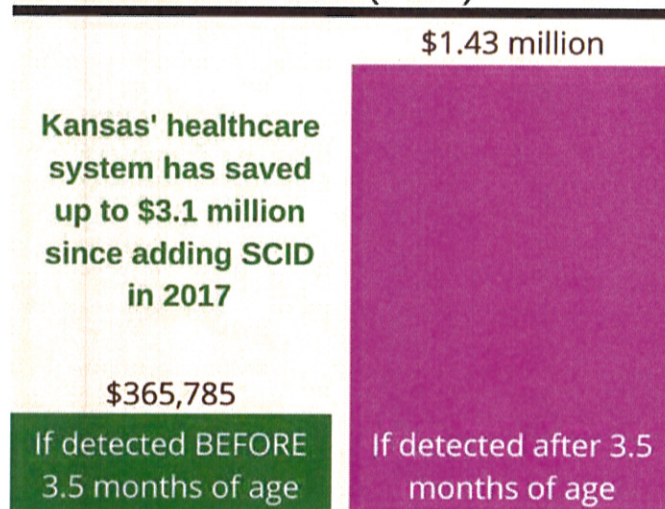
## Why it Matters

- All disorders screened for by Kansas Newborn Screening are **treatable**.
- Detecting and treating heritable conditions early in life saves lives & saves money** from health complications and repeated hospitalizations associated with these disorders.
- Early detection and treatment **prevents intellectual disability and decreases special education costs**.

### Individual Lifetime Costs for Intellectual Disability and Hearing Loss



### Treatment Costs of Severe Combined Immunodeficiency Disease (SCID)<sup>3</sup>

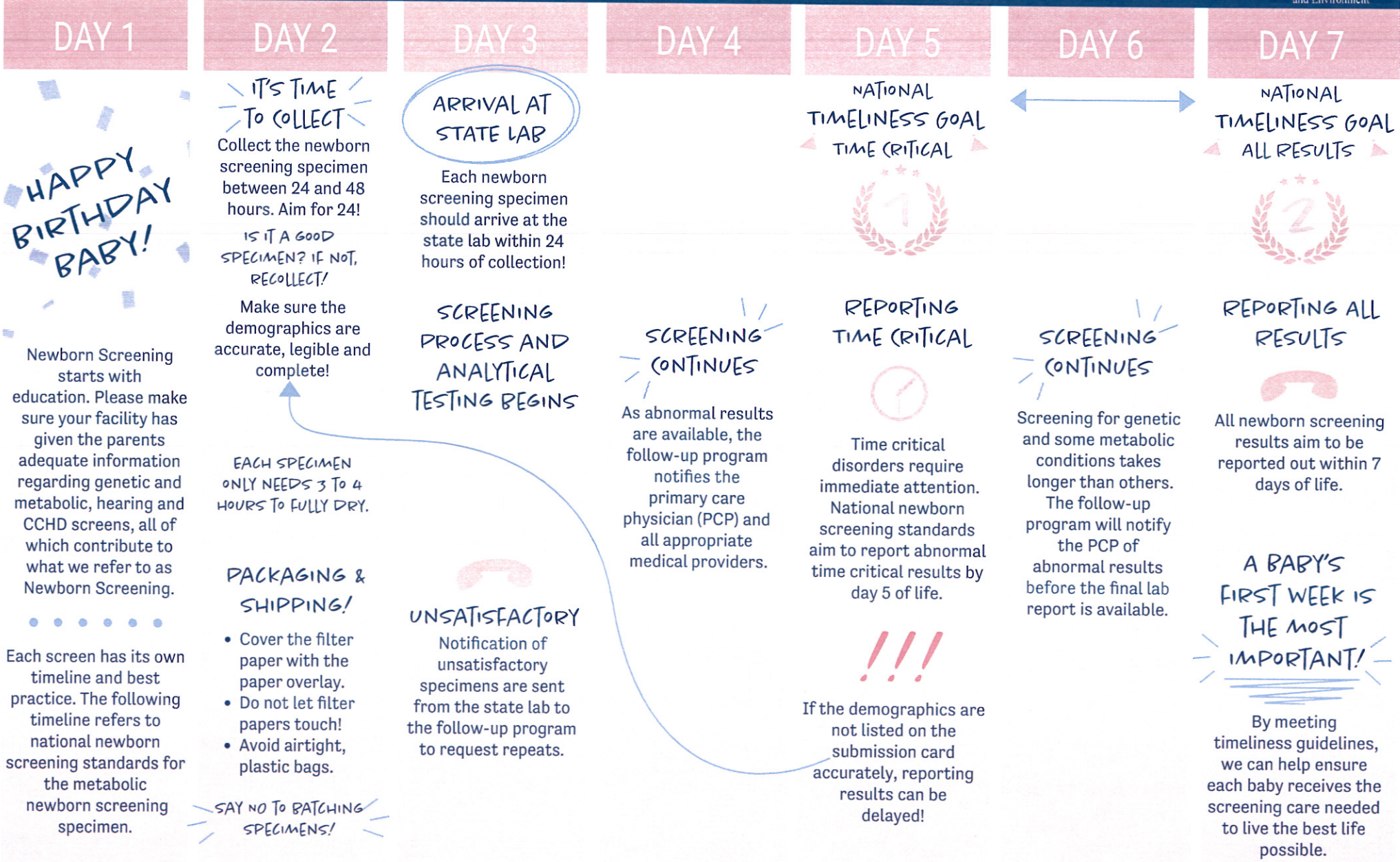


1. CDC. *MMWR* 2004, 53(3), 57-59. 2. Grosse, Scott D. (2007). Education cost Savings from Early Detection of hearing Loss: New Findings. *Volta Voices*, 14(6), 38. 3. Kubiak, C., Jyonouchi, S., Kui, C., Garcia-Lloret, M., Dorsey, M.J., Sleasman, J., Zborzek, A.S., Parez, E.E. (2014). Fiscal Implications of Newborn Screening in the Diagnosis of Severe Combined Immunodeficiency. *The Journal of Allergy and Clinical Immunology In Practice*, 2(6), 697-702.

# BABY'S FIRST WEEK



EVERY HOUR COUNTS! LET'S START THE WEEK OFF RIGHT!



## 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.

1. \_\_\_\_\_

## 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.

\_\_\_\_\_ 2.

## 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 ( $\beta$ KT)
- 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 S $\beta$ )

### 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](http://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:

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### Pulse Oximetry Screening

Passed

Not Passed

Follow-up appointment:     /     /     at \_\_\_\_\_

Notes:

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### Blood Spot Screening

First Well Checkup:     /     /     at \_\_\_\_\_

Notes:

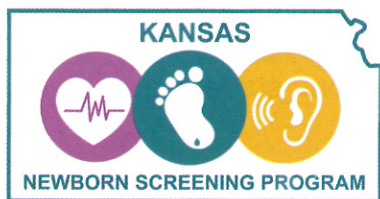
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**To learn more about newborn screening, visit:**

[www.soundbeginnings.org](http://www.soundbeginnings.org)

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



### 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