

# September is Newborn Screening Awareness Month

## What is Newborn Screening

Most babies are born healthy. Some, however, are born with rare but serious medical conditions that may not be visible at birth. Newborn screening is an essential public health service that allows health professionals to identify and treat rare conditions. Newborn screening in Kansas consists of three types of tests:

- Hearing screen to detect hearing loss
- Pulse oximetry screening to detect critical congenital heart defects
- Heel stick to collect a small blood sample to detect 30 genetic or metabolic conditions

The best time to conduct these screens is between 24 and 48 hours after birth.

Millions of babies are screened each year in the United States. More than 13,000 of those are identified as having a rare condition like cystic fibrosis, sickle cell disease, hearing loss, or critical congenital heart defects.<sup>1</sup>

## Kansas Quick Facts

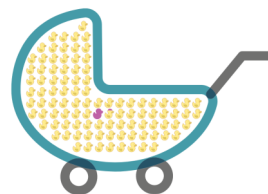
### Free for KS Families!

Newborn screening ensures the best possible outcomes and quality of life for all Kansas babies.

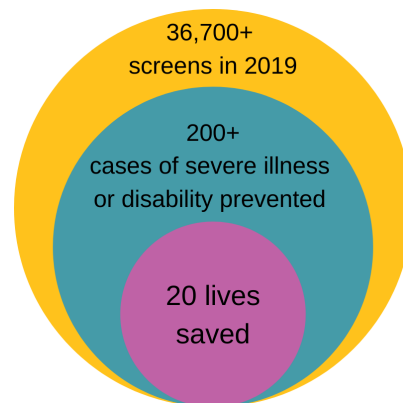
32 Conditions Currently  
on the  
Kansas Screening Panel

3 More Conditions Planned

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



Approximately 1% of infants screened are diagnosed.



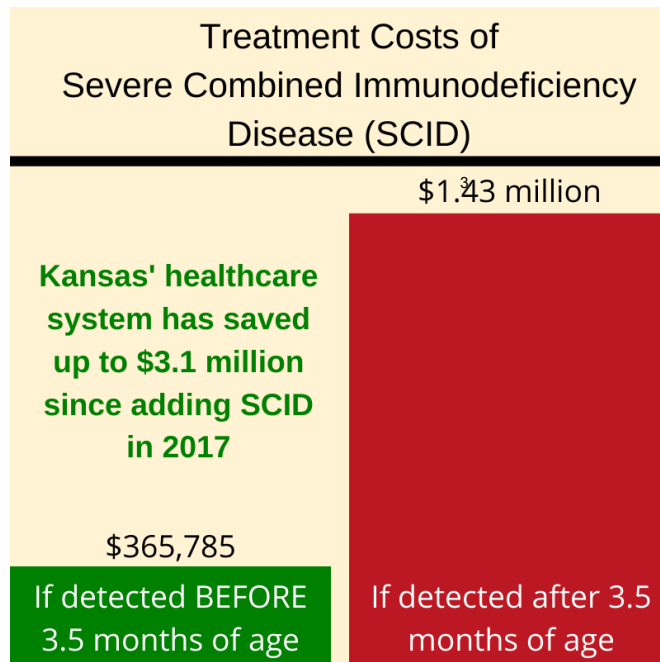
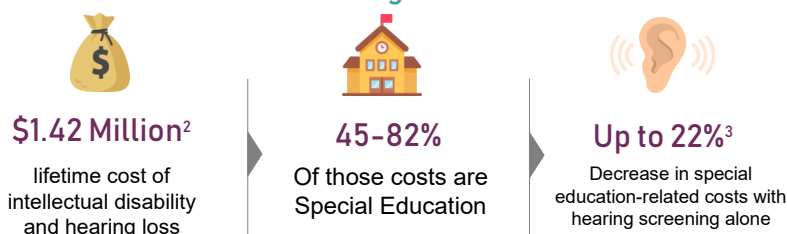
1. CDC. (2019). Fulfilling the Promise—Ensuring the Success of Newborn Screening throughout Life. <https://www.cdc.gov/parents/infants/newborn-screening-success.html>

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## 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



## What can I do as a Provider?

- ⇒ Talk to expecting parents about newborn screening *before* their expected due date. Parents receive a lot of information after the baby is born and it can be overwhelming to keep track of everything. Providing education about newborn screening early and often allows families to absorb the information, ask questions, and be prepared to expect the screening after their baby is born.
- ⇒ Provide newborn screening educational resources in your office. Kansas Newborn Screening brochures are available in English and Spanish at no cost from the Newborn Screening Program. Email [kdhe.newbornscreening@ks.gov](mailto:kdhe.newbornscreening@ks.gov) or call (785) 291-3363 to request brochures.
- ⇒ Offer prenatal education or connect expecting parents to locally available prenatal education. Most prenatal educators review newborn screening as a part of their courses.
- ⇒ Emphasize that NBS is most often the only way to detect these rare and serious conditions before symptoms appear.
- ⇒ Emphasize that it is a *screening* and that it's important to follow up with the baby's pediatrician if they receive an abnormal result. Only additional diagnostic testing can confirm the presence of a condition.
- ⇒ Educate yourself about newborn screening and the disorders that Kansas screens for.
- ⇒ Use KS NBS's Facebook Frame and Hashtags (#NBS2020KS) during the month of September.

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.,Perez, 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.

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## Resources for Providers

### General Health Professional Resources

- Baby's First Test Information for Health Professionals: <https://www.babysfirsttest.org/newborn-screening/health-professionals>
- KS NBS - Parent Conversations Script: [https://www.kdheks.gov/newborn\\_screening/download/Parent\\_Conversation\\_Script.pdf](https://www.kdheks.gov/newborn_screening/download/Parent_Conversation_Script.pdf)

### Prenatal Providers

- Baby's First Test Information for Prenatal Providers: <https://www.babysfirsttest.org/newborn-screening/prenatal-providers>
- KS NBS - Midwives Toolkit: [https://www.kdheks.gov/newborn\\_screening/midwives\\_toolkit.htm](https://www.kdheks.gov/newborn_screening/midwives_toolkit.htm)

### Pediatric Providers

- Baby's First Test Information for Pediatric Providers: <https://www.babysfirsttest.org/newborn-screening/pediatric-providers>
- KS NBS - Physician's Toolkit: [https://www.kdheks.gov/newborn\\_screening/physician\\_toolkit.htm](https://www.kdheks.gov/newborn_screening/physician_toolkit.htm)
- KS NBS Physician's ACT Sheets: [https://www.kdheks.gov/newborn\\_screening/info\\_professionals.htm](https://www.kdheks.gov/newborn_screening/info_professionals.htm)

### Newborn Screening During COVID-19

- KS NBS COVID-19 Guidance for Families: [https://www.kdheks.gov/newborn\\_screening/download/Families\\_NBS\\_Recollecting\\_Specimens\\_during\\_COVID-19\\_Guidance.pdf](https://www.kdheks.gov/newborn_screening/download/Families_NBS_Recollecting_Specimens_during_COVID-19_Guidance.pdf)
- KS NBS COVID-19 Guidance for Physicians: [https://www.kdheks.gov/newborn\\_screening/download/Physicians\\_NBS\\_Recollecting\\_Specimens\\_during\\_COVID-19\\_Guidance.pdf](https://www.kdheks.gov/newborn_screening/download/Physicians_NBS_Recollecting_Specimens_during_COVID-19_Guidance.pdf)
- Baby's First Test - Coronavirus (COVID-19) and Newborn Screening: <https://www.babysfirsttest.org/newborn-screening/coronavirus-covid-19-and-newborn-screening-0>

## Resources for Parents

### What is newborn screening?

- ExpectingHealth.org's "Navigate Newborn Screening" FREE educational module: <https://www.expectinghealth.org/programs/navigate-newborn-screening>
- [BabysFirstTest.org](https://www.babysfirsttest.org)
- KS NBS - Critical Congenital Heart Defects: [https://www.kdheks.gov/newborn\\_screening/CCHD.htm](https://www.kdheks.gov/newborn_screening/CCHD.htm)
- Newborn Hearing Screening in Kansas: [SoundBeginnings.org](https://www.soundbeginnings.org)

### What conditions does Kansas screen for?

- Baby's First Test Kansas State Profile: <https://www.babysfirsttest.org/newborn-screening/states/kansas>
- KS NBS Conditions Information for Parents: [https://www.kdheks.gov/newborn\\_screening/info\\_parents.htm](https://www.kdheks.gov/newborn_screening/info_parents.htm)

### What happens after the screen?

- Baby's First Test - Responding to Results: <https://www.babysfirsttest.org/newborn-screening/responding-to-results>



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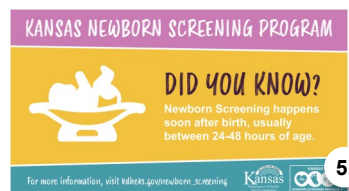
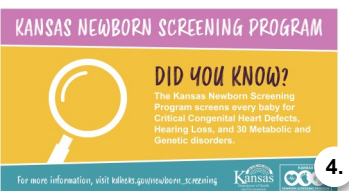
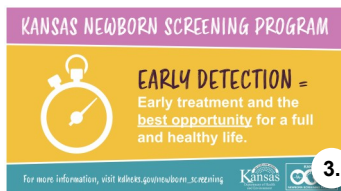
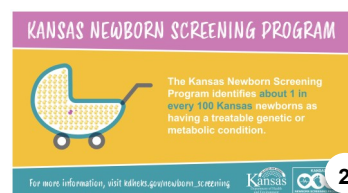
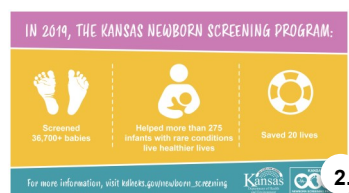
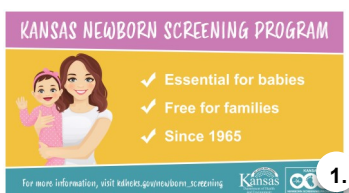
## Social Media

### Facebook Frame



In Facebook, go to your profile picture & select the camera icon. Choose Add Frame. Search for KS Newborn Screening & set for one month.

### Suggested Images



### General Images

### Suggested Messages

1. Newborn screening is an essential public health service that allows healthcare providers to identify infants with rare and serious conditions before symptoms appear. Kansas has provided this service free of charge since 1965.
2. Newborn screening helps babies get the care and treatment they need to have the best possible health.
3. Most babies are born healthy. Some, however, are born with rare and serious conditions that can cause permanent disability or even death.
4. The Kansas Newborn Screening Program (KS NBS) screens every baby born in Kansas for 32 rare and serious conditions at no cost to families. KS NBS is adding more conditions to their panel so that we can save more lives.
5. Newborn screening happens soon after birth. It's important to ask your pediatrician about your baby's newborn screening results and follow their advice if your baby receives an abnormal screening.

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