Hot Topics in Kansas: Neonatal Care

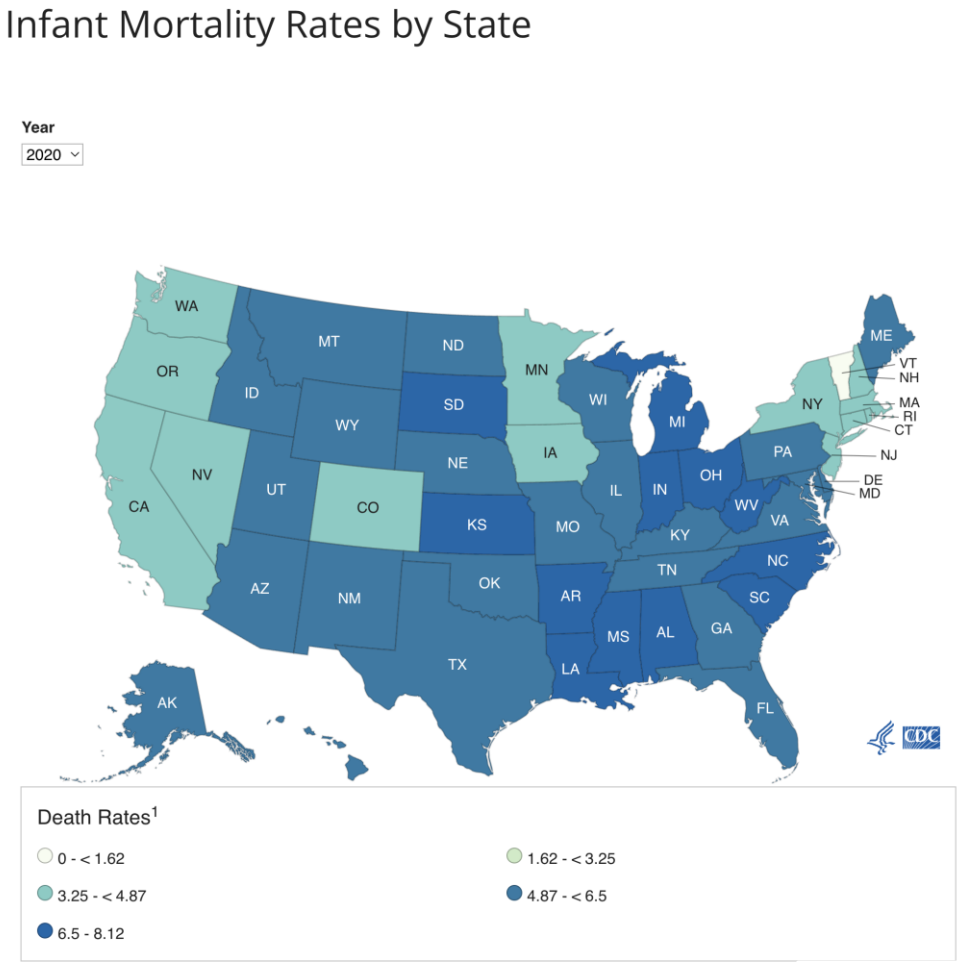
Kourtney Bettinger, MD, MPH, FAAP

April 25, 2023

Overview

- KS Infant Mortality Rate
- Breastfeeding in KS
- Newborn Screening
- Congenital Syphilis
- Perinatal HIV Transmission and Breastfeeding
- New AAP Guidelines
- Neonatal Abstinence Syndrome Update
- Gaps in Newborn Care

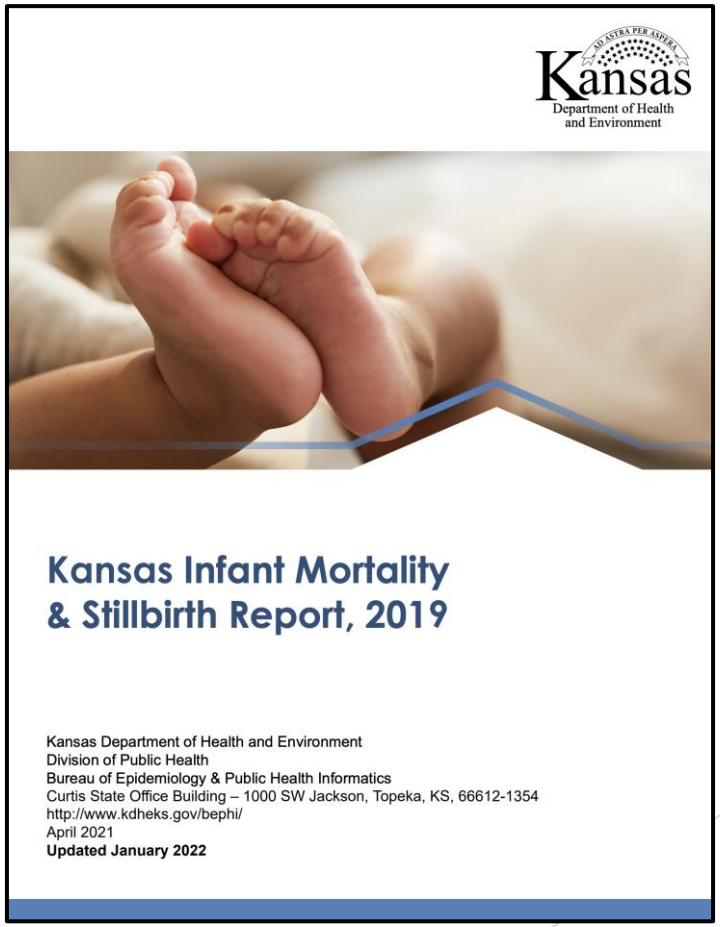
Infant Mortality Rate



https://www.cdc.gov/nchs/pressroom/sosmap/infant_mortality_rates/infant_mortality.htm

Kansas Infant Mortality & Stillbirth Report, 2019

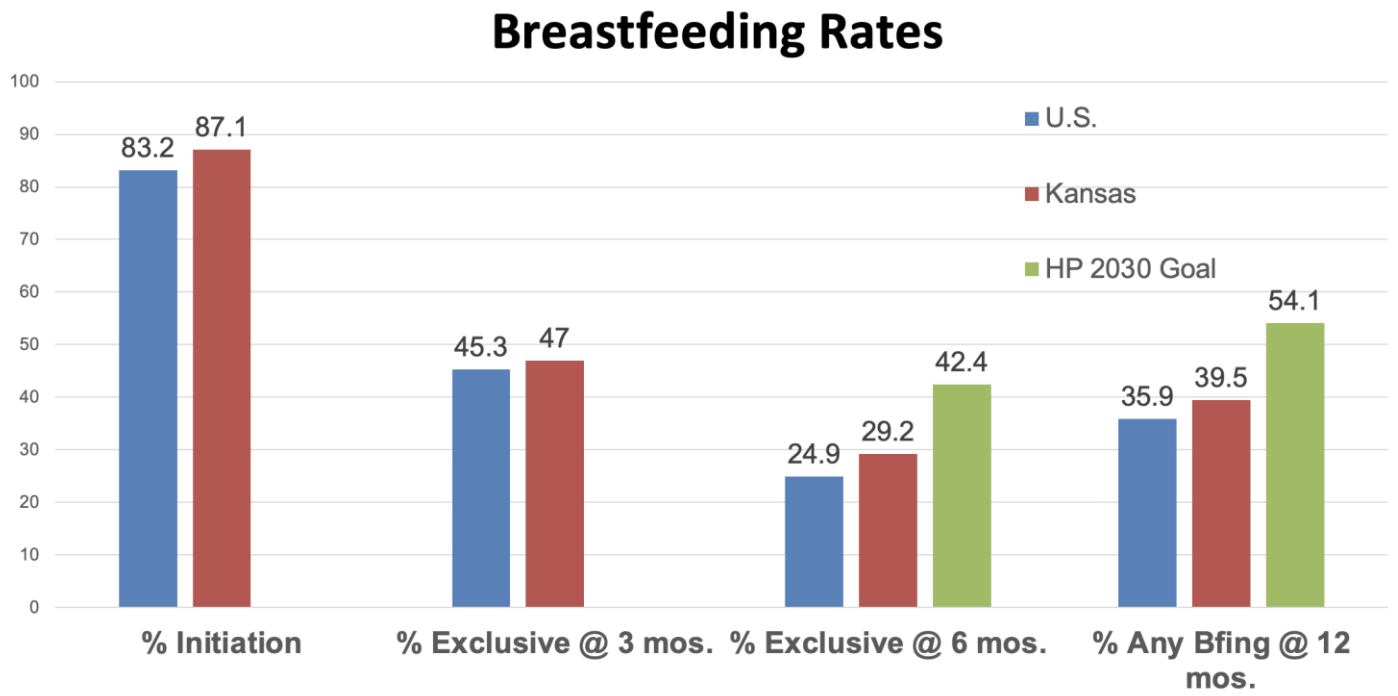
- KS IMR 5.3 in 2019
  - KS IMR among non-Hispanic White births 4.1
  - KS IMR among non-Hispanic Black births 10.7
  - KS IMR among Hispanic births 6.4
- Leading causes of infant mortality 2015-2019
  - Congenital anomalies 23.9%
  - Sudden Unexpected Infant Death (SUID) 19.0%
  - Short gestation and low birth weight 17.3%
  - Maternal complications of pregnancy 6.1%



https://www.kdhe.ks.gov/DocumentCenter/View/10419/2019-Infant-Mortality-and-Stillbirth-Report-PDF

https://www.breastmilkcounts.com/breastfeeding-101/skin-to-skin/#:~:text=It%20is%20a%20special%20bonding,baby%20finishes%20his%20first%20feeding.

Breastfeeding in Kansas



Source: 2019 Births, National Immunization Survey, Centers for Disease Control and Prevention, Department of Health and Human Services

Kansas Breastfeeding Coalition, Inc.

Breastfeeding in Kansas

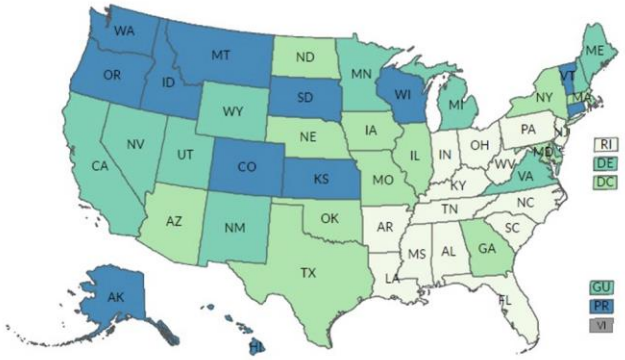
Kansas Ranks 14th in the Nation

% of infants exclusively breastfed through 6 mo.

2018

Percent of infants who were exclusively breastfed through 6 months †‡§

View by: Total



Kansas – 32%

Value
15.8 - 23.6
23.7 - 27.3
27.4 - 30.1
30.2 - 37.3
Data unavailable

Quantile

Legend Settings

† Exclusive breastfeeding is defined as ONLY breast milk - No solids, no water, and no other liquids.

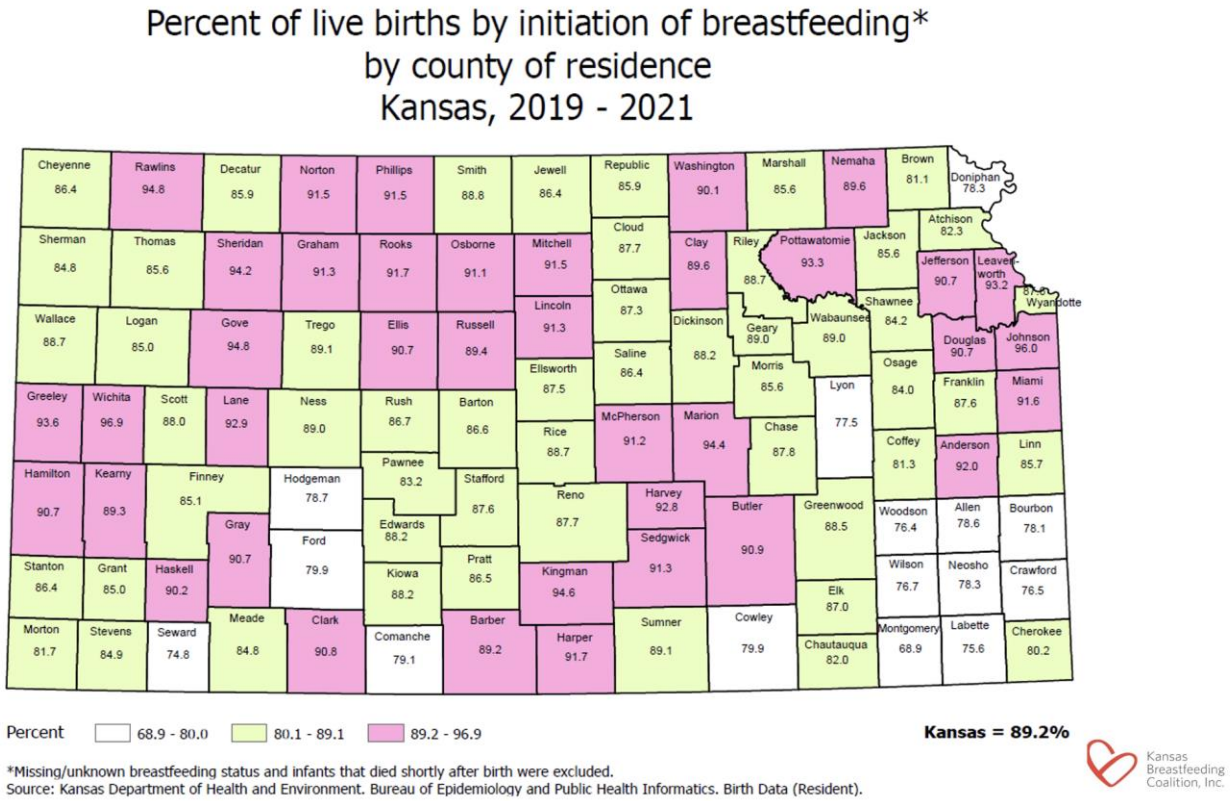
‡ Breastfeeding rates through 2008 births are based on the National Immunization Survey's landline sampling frame.Starting with 2009 births, rates are based on the National Immunization Survey's dual-frame sample that includes respondents surveyed on landline or cellular telephones.If you would like more information about the sampling methodology and the impact of adding a sample of cellular telephone respondents to the National Immunization Survey, you can visit https://www.cdc.gov/breastfeeding/data/nis_data/survey_methods.htm.

§ Only breastfeeding rates based on a dual-frame sample that includes respondents surveyed on landline or cellular telephones are included in trend graphics.If you would like more information about the sampling methodology and the impact of adding a sample of cellular telephone respondents to the National Immunization Survey, you can visit https://www.cdc.gov/breastfeeding/data/nis_data/survey_methods.htm

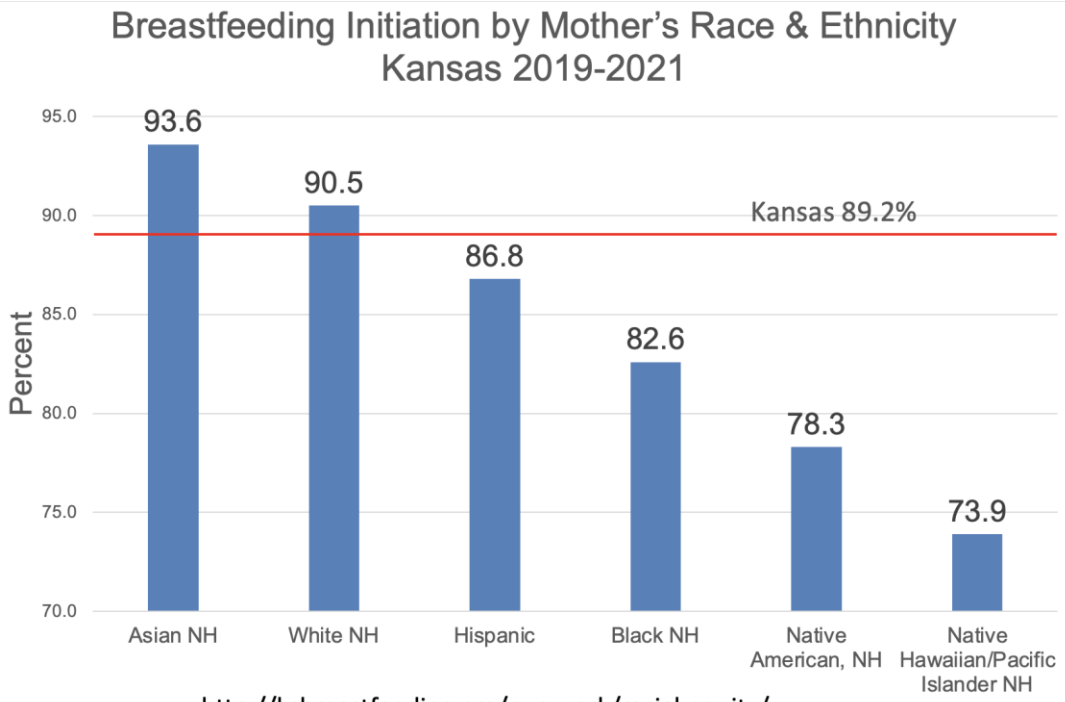
Data Source: National Immunization Survey

Kansas Breastfeeding Coalition, Inc.

Breastfeeding in Kansas



Breastfeeding in Kansas



http://ksbreastfeeding.org/our-work/racial-equity/

Note: NH = non-Hispanic
Source: Birth Certificate Data (Resident), 2019-2021, Bureau of Epidemiology and Public Health Informatics, Kansas Department of Health and Environment

Kansas Breastfeeding Coalition, Inc.

Baby-Friendly Hospital Initiative

Our Philosophy

These are the basic tenets of BFUSA's philosophy and approach:

1. Human milk fed through direct breastfeeding is the optimal way for human infants to be nurtured and nourished.

There is no question that breastfeeding is the optimal feeding and caring method for the health of both, the baby and the mother. An abundance of scientific evidence concludes that mothers and babies who breastfeed experience improved health outcomes and lower risks for certain diseases. Breastfeeding is the natural biological conclusion to pregnancy and an important mechanism in the natural development of the infant.

2. The precious first days in the birth facility should be protected as a time of bonding and support not influenced by commercial interests.

Hospitals and birthing centers wield enormous influence over the first days of life and play a critical role in determining breastfeeding success. Before the Baby-Friendly Hospital Initiative began to take hold across the US, commercial interests significantly influenced infant feeding practices in ways that undermined breastfeeding. Baby-Friendly facilities are centers of support in which evidenced-based care is provided, education is free from commercial interests, *all* infant feeding options are possible, and individual preferences are respected.

3. Every mother should be informed about the importance of breastfeeding and respected to make her own decision.

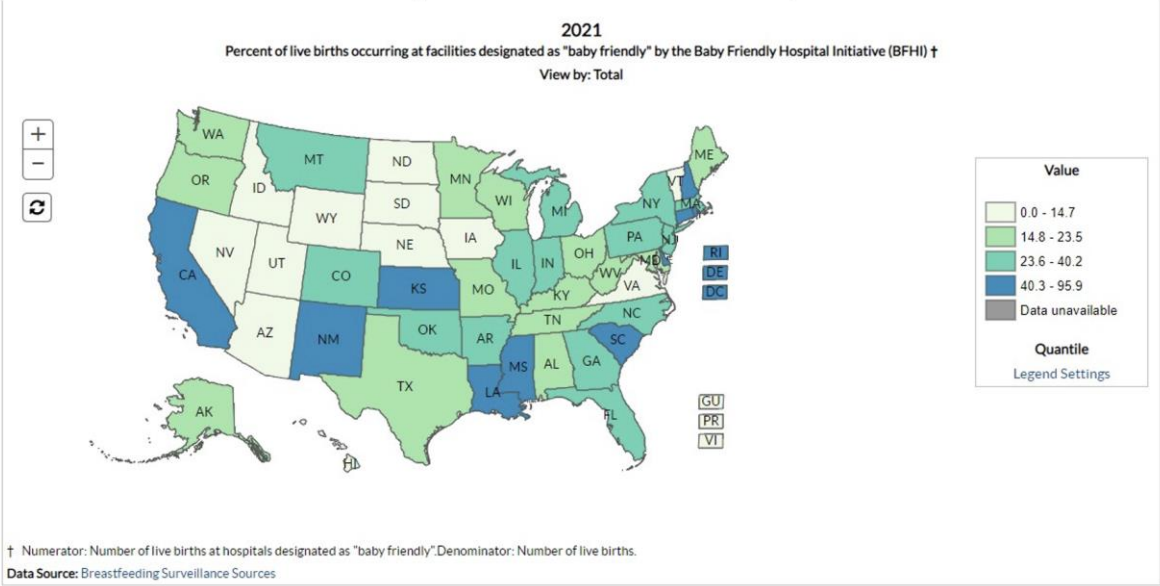
We aim to ensure that every mother is fully informed of the importance of breastfeeding and to the help she needs to achieve her breastfeeding goal. We respect that breastfeeding is not possible for some families in certain situations, that supplementation is sometimes medically appropriate, and that some mothers will decide not to breastfeed. Every mother has the right to evidence-based information, free from commercial interests to help her decide how to feed her baby and should be equally supported and treated with dignity and respect for her infant feeding decision.

https://www.babyfriendlyusa.org/about/

Baby-Friendly Hospitals and Kansas

Kansas Ranks 8th in Nation!

56.8% of babies at born in "Baby-Friendly Hospitals" compared to 29.1% nationally



Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion, Division of Nutrition, Physical Activity, and Obesity. Data, Trend and Maps [online]. [accessed Mar 27, 2021].
URL: https://www.cdc.gov/nccdphp/dnpao/data-trends-maps/index.html.

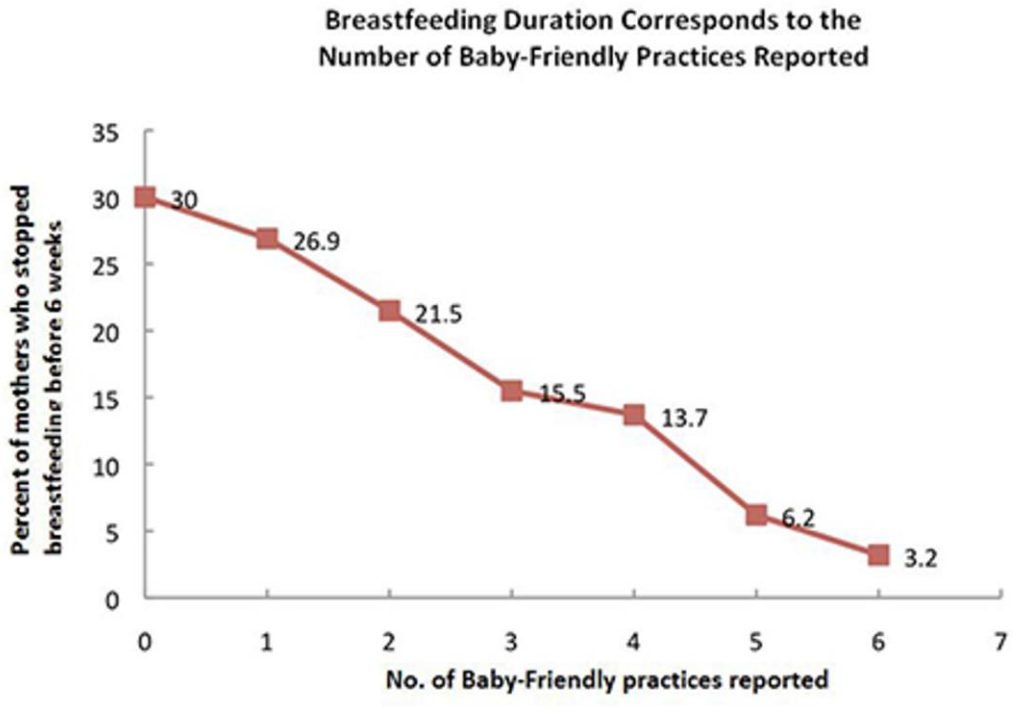
Kansas Breastfeeding Coalition, Inc.

Baby-Friendly Hospitals in Kansas

- AdventHealth Ottawa
- AdventHealth Shawnee Mission
- Citizens Medical Center, Colby
- Hays Medical Center
- LMH Health, Lawrence
- Pratt Regional Medical Center Salina Regional Health Center
- St. Catherine Hospital (Garden City)
- University of Kansas Health System, St. Francis Campus, Topeka
- University of Kansas Hospital, Kansas City
- Via Christi Hospitals Wichita – St. Joseph

Kansas
Breastfeeding
Coalition, Inc.

Baby-Friendly and Breastfeeding



DiGirolamo AM et al. Pediatrics 2008;122:S43-S49

Kansas Breastfeeding Coalition, Inc.

https://www.breastmilkcounts.com/breastfeeding-101/skin-to-skin/#:~:text=It%20is%20a%20special%20bonding,baby%20finishes%20his%20first%20feeding.

Newborn Screening - Background

- Started in the 1960s with dried blood spot screening for certain metabolic conditions
- Goal of identifying conditions that are not otherwise recognizable in the newborn period but benefit from early detection (in other words, there is an early intervention that improves the outcome)
- Federal government sets the Recommended Uniform Screening Panel of 37 conditions, but specific screening components determined by each state
  - Hearing screen
  - Critical congenital heart disease screen
  - Blood spot screen
- All* babies should undergo newborn screening regardless of place of birth, health insurance, gestational age, etc.

https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Newborn-Screening-for-CCHD.aspx
https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html

Newborn Screening in Kansas

- Constantly striving for improvement in processing time, percentage of babies screened, conditions covered, and streamlining abnormal results
- Goal of aligning with the Recommended Universal Screening Panel
- Advisory Council appointed by Secretary of Health
- Blood spot screen is provided at no cost to babies/families

https://www.kdheks.gov/newborn_screening/download/NBS_Filter_Paper_Dried_Blood_Spot_Unsatisfactory_Codes_Poster.pdf

Newborn Hearing Screen/SoundBeginnings

Approximately 2 to 3 babies per 1,000 are born with a hearing loss. Of babies with hearing loss, about 90% are born to hearing parents.

http://www.soundbeginnings.org/physicians.htm

Newborn Hearing Screen/SoundBeginnings

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Hearing screening test for all babies no later than 1 month of age
Diagnostic evaluation no later than 3 months of age if baby failed the hearing screening
Early intervention no later than 6 months of age if baby is diagnosed with a hearing loss

http://www.soundbeginnings.org/physicians.htm

Newborn Hearing Screen/SoundBeginnings

There are two screening methods that may be used:

- **Automated Auditory Brainstem Response (AABR)**—This screen measures how the hearing nerve and brain respond to sound. Clicks or tones are played through soft earphones into the baby's ears. Three electrodes placed on the baby's head measure the hearing nerve and brain's response.

- **Otoacoustic Emissions (OAE)**—This screen measures sound waves produced in the inner ear. A tiny probe is placed just inside the baby's ear canal. It measures the response (echo) when clicks or tones are played into the baby's ears.

Both screens are quick (about 5 to 10 minutes), painless, and may be done while your baby is sleeping or lying still. One or both screens may be used.

https://www.healthychildren.org/English/ages-stages/baby/Pages/Purpose-of-Newborn-Hearing-Screening.aspx

Newborn Hearing Screen/SoundBeginnings – Kansas Data

- 2021:
  - 36,362 births
  - 36,016 screened
  - 100 true positives
- 2022:
  - 36,247 births
  - 35,847 screened
  - 68 positives (not all have been confirmed as true positives)

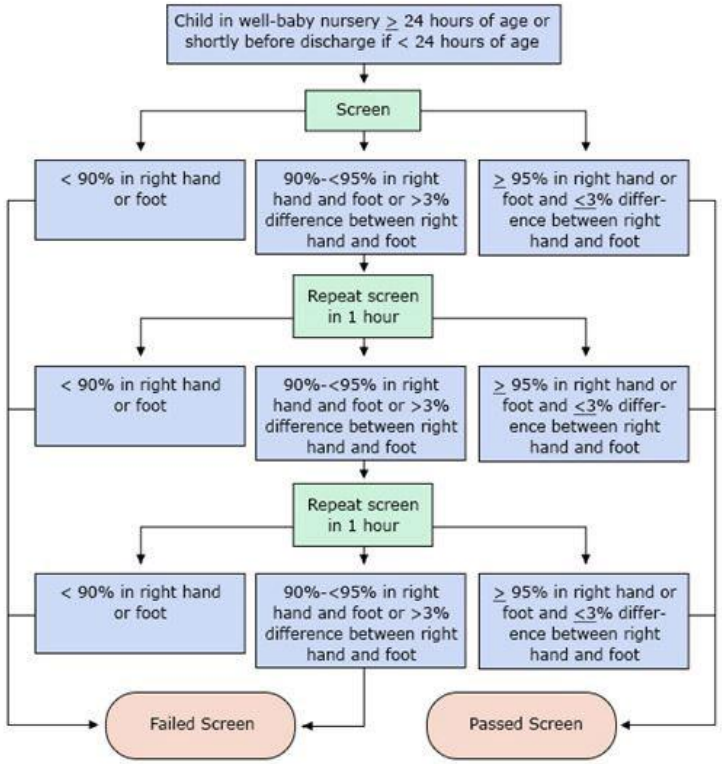
https://www.breastmilkcounts.com/benefits/good-for-babies/

Critical Congenital Heart Defect Screening

- Goal is to catch babies with CCHDs who are asymptomatic
- An estimated 875 babies are true positives in the USA each year
- In 2021, Kansas had 41 failed screens that resulted in three diagnoses of a CCHD

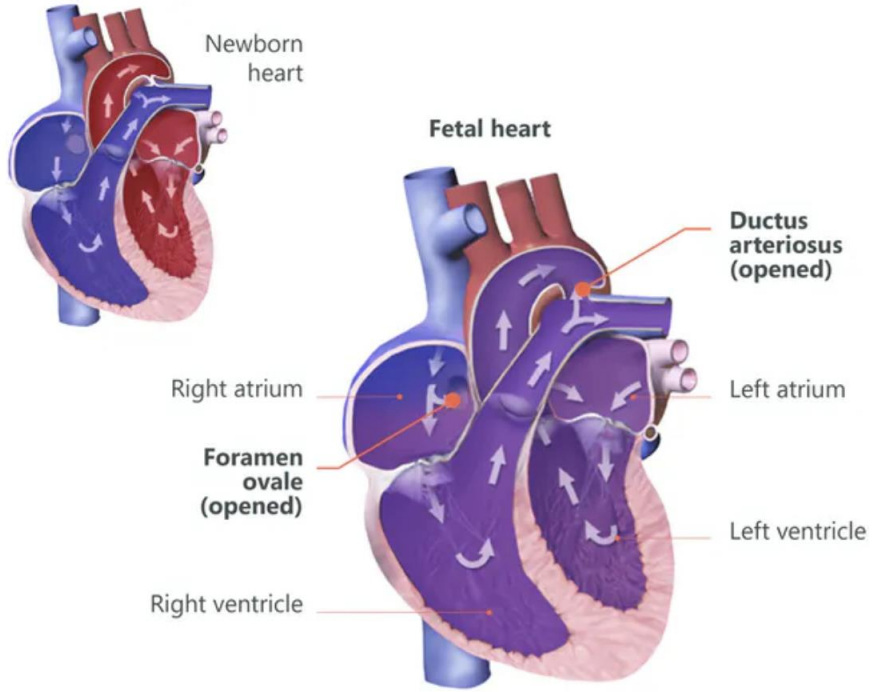
https://www.cdc.gov/ncbddd/heartdefects/screening.html

Critical Congenital Heart Defect Screening



https://www.cdc.gov/ncbddd/heartdefects/hcp.html

Fetal/Neonatal Heart Physiology



https://concordneonatal.com/cordclamping/

Critical Congenital Heart Defects

- Hypoplastic left heart syndrome
- Pulmonary atresia
- Tetralogy of fallot
- Total anomalous pulmonary venous return (TAPVR)
- Transposition of the great arteries
- Tricuspid atresia
- Truncus arteriosus

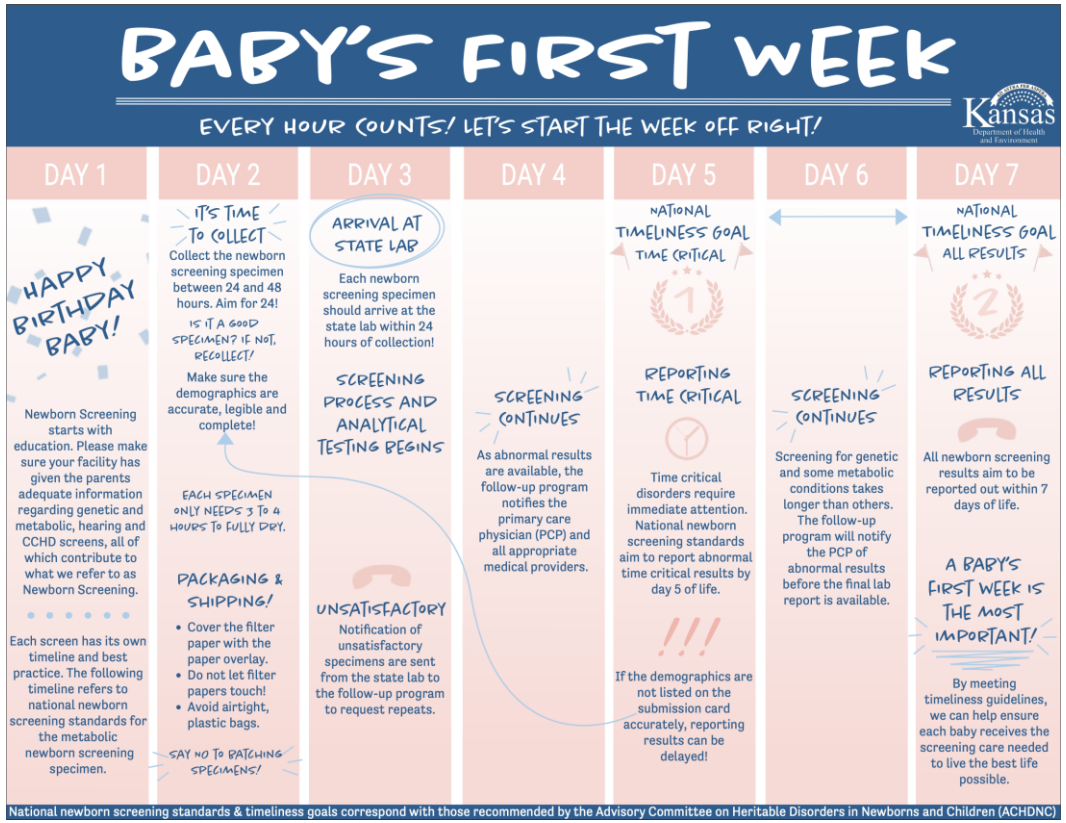
https://www.cdc.gov/ncbddd/heartdefects/hcp.html

Non-CCHD Causes of Failed CCHD Screen

- Hemoglobinopathy
- Hypothermia
- Infection/sepsis
- Lung disease
- Persistent pulmonary hypertension
- Non-critical congenital heart defect
- Other hypoxic conditions

https://www.cdc.gov/ncbddd/heartdefects/hcp.html
https://www.breastmilkcounts.com/breastfeeding-101/skin-to-skin/#:~:text=It%20is%20a%20special%20bonding,baby%20finishes%20his%20first%20feeding.

Blood Spot Screen



https://www.kdheks.gov/newborn_screening/download/Babys_First_Week.pdf

Blood Spot Screen

- Amino acid disorders
  - Argininosuccinic aciduria (ASA)
  - Citrullinemia, type I (CIT)
  - Classic phenylketonuria (PKU)
  - Homocystinuria (HCY)
  - Maple syrup urine disease (MSUD)
  - Tyrosinemia, type I (TYR I)
- Fatty acid oxidation disorders
  - Carnitine uptake 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)
- Lysosomal storage disorders
  - Mucopolysaccharidosis type-I (MPS I)
  - Pompe (POMPE)
- Endocrine disorders
  - Congenital adrenal hyperplasia (CAH)
  - Primary congenital hypothyroidism (CH)
- Hemoglobin disorders
  - S, beta-thalessemia (HbS/ßTh)
  - S, C disease (Hb S/C)
  - Sickle cell anemia (Hb SS)
- Organic acid conditions
  - 3-hydroxy-3-methylglutaric aciduria (HMG)
  - 3-methylcrotonyl-CoA carboxylase deficiency (3-MCC)
  - Beta-ketothiolase deficiency (BKT)
  - Glutaric acidemia, type I (GA-1)
  - Holocarboxylase synthetase deficiency (MCD)
  - Isovaleric acidemia (IVA)
  - Methylmalonic acidemia (cobalamin disorders) (Cbl A, B)
  - Methylmalonic acidemia (methylmalonyl-CoA mutase deficiency) (MUT)
  - Propionic acidemia (PROP)
- Other disorders
  - Biotinidase deficiency (BIOT)
  - Classic galactosemia (GALT)
  - Cystic fibrosis (CF)
  - Severe combined immunodeficiency (SCID)
  - Spinal muscular atrophy (SMA)

Newborn Screening - Updates

- Impact of COVID
- New phone tree
  - 785-291-3363
- LabOnline began 3/1
  - https://labreports.kdhe.ks.gov/
- X-Linked Adrenoleukodystrophy pilot starting 5/1
- New website launch this summer
- Revamping notification letters to parents and PCPs

Newborn Screening – 2020 Data

- 35,643 infants screened
- 760 infants had out-of-range blood spot screens and referred for diagnostic testing
- 56 infants diagnosed with conditions
- Most commonly diagnosed conditions:
  - Congenital hypothyroidism
  - Cystic fibrosis
  - Sickle cell disease

https://www.breastmilkcounts.com/getting-prepared/baby-behavior-whats-normal/

Congenital Syphilis

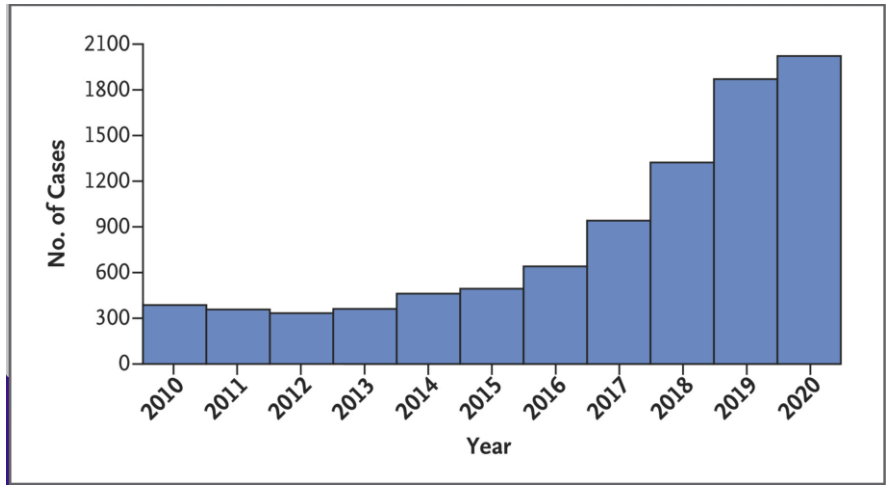
- Is on the rise in our state and country
- Can cause miscarriage, stillbirth, neonatal death, prematurity, and low birth weight
- Can cause babies to have deformed bones, severe anemia, hepatosplenomegaly, jaundice, blindness, deafness, meningitis, rashes
- Babies who are asymptomatic at birth can develop symptoms later; they may have developmental delays and/or seizures; they can even die later
- Is preventable!

https://www.cdc.gov/std/syphilis/stdfact-congenital-syphilis.htm
https://www.cdc.gov/nchhstp/pregnancy/effects/syphilis.html#:~:text=Syphilis%20can%20be%20treated%20effectively,syphilis%20should%20be%20treated%20immediately.
AAP Red Book, 2021-2024

Congenital Syphilis in the U.S.

- Rates of congenital syphilis have had an alarming increase
- In 2021, 2,855 cases of congenital syphilis
- Syphilis rates are climbing and it's becoming more widespread, too
- By 2019, 50% of counties across the country reported at least one syphilis case in a woman of reproductive age

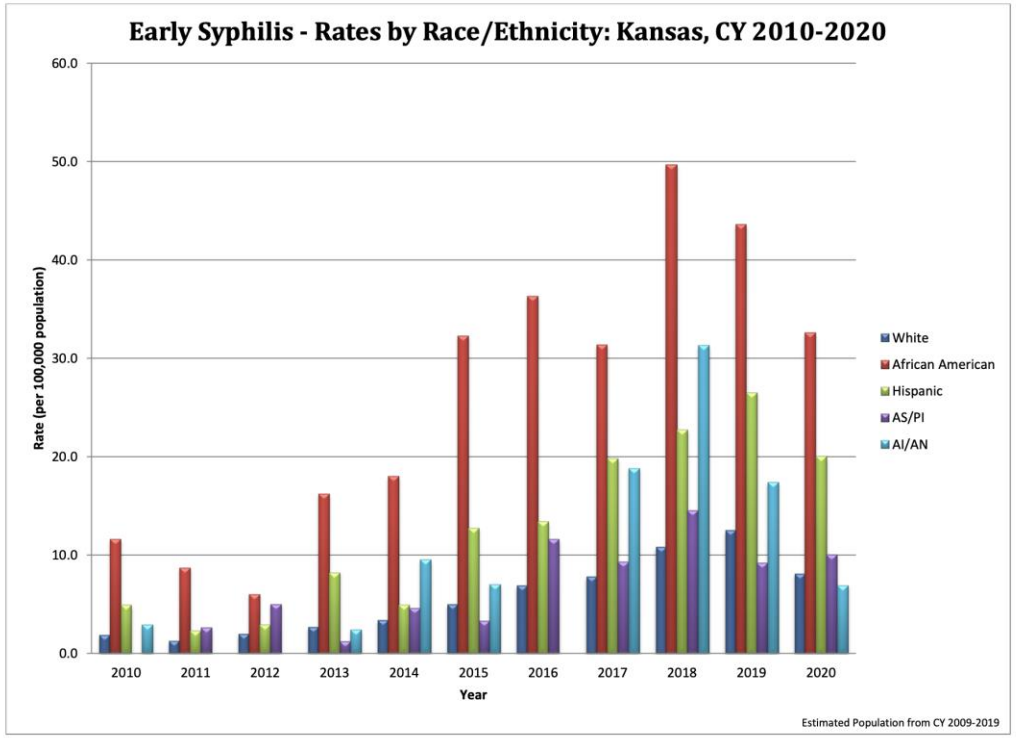
Reported cases of congenital syphilis among U.S. infants born 2010-2020



https://www.cdc.gov/std/statistics/2021/default.htm#:~:text=Congenital%20syphilis%2C%20the%20most%20tragic,and%20over%202%2C800%20cases%20reported.

Bowen VB, McDonald R, Grey JA, Kimball A, Torrone EA. High Congenital Syphilis Case Counts among U.S. Infants Born in 2020. N Engl J Med. 2021 Sep 16;385(12):1144-1145. doi: 10.1056/NEJMc2111103. PMID: 34525291.

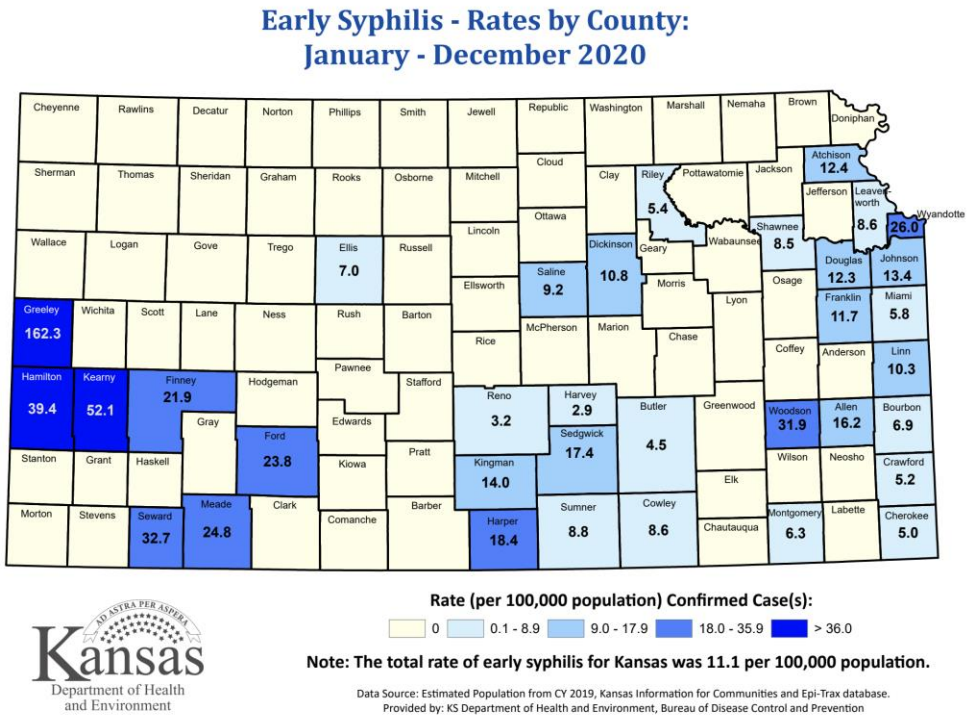
Syphilis in Kansas



Data from Kansas Information for Communities and Epi-Trax

https://www.kdhe.ks.gov/ArchiveCenter/ViewFile/Item/2232

Syphilis in Kansas



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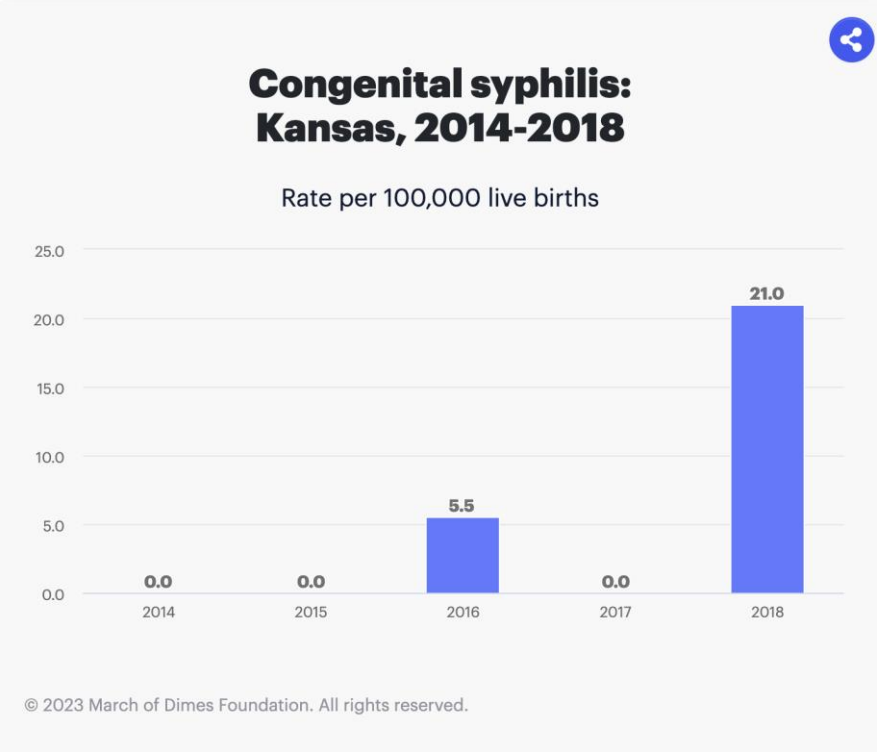
Congenital Syphilis in Kansas



- The state requires testing in the first trimester
- CDC recommends testing those at high risk and/or who are in high morbidity areas also be tested in the third trimester and when admitted to deliver

https://www.marchofdimes.org/peristats/data?reg=99&top=10&stop=149&lev=1&slev=4&obj=1&sreg=20

Perinatal HIV Transmission

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

From: **Achieving Elimination of Perinatal HIV in the United States**

Pediatrics. Published online April 18, 2023. doi:10.1542/peds.2022-059604

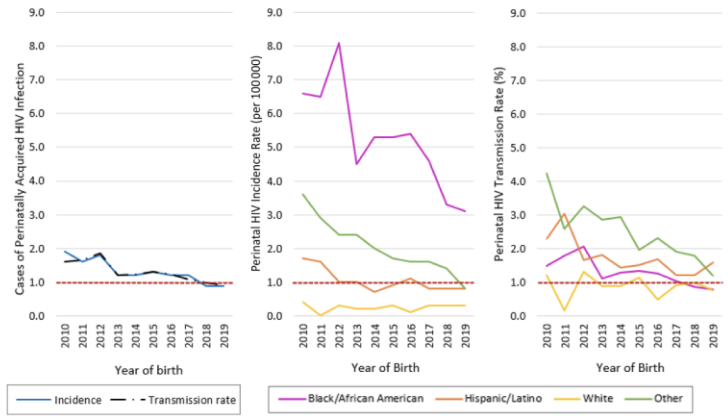


Figure Legend:

Diagnosis rate and transmission rate of perinatally acquired HIV among persons born in the United States, by year of birth, overall, and by mother's race/ethnicity, 2010–2019. Diagnosis rates are per 100 000 live births (National HIV Surveillance System). Transmission rates are percentage of perinatally acquired HIV diagnoses among live births to women with an HIV diagnosis at delivery (National HIV Surveillance System; National Inpatient Sample, Healthcare Cost and Utilization Project). Hispanic/Latino persons can be of any race; other race includes American Indian/Alaska Native, Asian, Native Hawaiian/other Pacific Islander, and multiracial persons.

Date of Download: 4/24/2023
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HIV+ Birthing Persons and Breastfeeding

- CDC no longer advises against breastfeeding by HIV+ birthing persons if they have achieved and maintained viral suppression through antiretroviral therapy
  - Recommend shared decision-making after counseling
  - Full recommendations:
    - https://www.cdc.gov/breastfeeding/breastfeeding-special-circumstances/maternal-or-infant-illnesses/hiv.html

New AAP Guidelines in 2022

FROM THE AMERICAN ACADEMY OF PEDIATRICS | POLICY STATEMENT | JUNE 21 2022

Sleep-Related Infant Deaths: Updated 2022 Recommendations for Reducing Infant Deaths in the Sleep Environment

Rachel Y. Moon, MD, FAAP ✉; Rebecca F. Carlin, MD, FAAP; Ivan Hand, MD, FAAP;
THE TASK FORCE ON SUDDEN INFANT DEATH SYNDROME AND THE COMMITTEE ON FETUS AND NEWBORN

FROM THE AMERICAN ACADEMY OF PEDIATRICS | CLINICAL PRACTICE GUIDELINE | AUGUST 05 2022

Clinical Practice Guideline Revision: Management of Hyperbilirubinemia in the Newborn Infant 35 or More Weeks of Gestation

Alex R. Kemper, MD, MPH, MS, FAAP ✉; Thomas B. Newman, MD, MPH, FAAP; Jonathan L. Slaughter, MD, MPH, FAAP; M. Jeffrey Maisels, MB BCh, DSc, FAAP; Jon F. Watchko, MD, FAAP; Stephen M. Downs, MD, MS; Randall W. Grout, MD, MS, FAAP; David G. Bundy, MD, MPH, FAAP; Ann R. Stark, MD, FAAP; Debra L. Bogen, MD, FAAP; Alison Volpe Holmes, MD, MPH, FAAP; Lori B. Feldman-Winter, MD, MPH, FAAP; Vinod K. Bhutani, MD; Steven R. Brown, MD, FAAFP; Gabriela M. Maradiaga Panayotti, MD, FAAP; Kymika Okechukwu, MPA; Peter D. Rappo, MD, FAAP; Terri L. Russell, DNP, APN, NNP-BC

Neonatal Abstinence Syndrome Update

- KPQC's NAS Initiative ran 2018-2020
- Nomenclature has evolved to neonatal opioid withdrawal syndrome (NOWS)
- Use of Eat, Sleep, Console model over Modified Finnegan Scoring becoming more widespread
- Non-pharmacologic interventions continue to be the gold standard initial care for babies at risk for NOWS

Gaps in Newborn Care

- Racial inequities
- Safe sleep modeling and counseling
- Tobacco cessation counseling and support
- Optimal breastfeeding support
- Vitamin K, erythromycin, and hepatitis B vaccine administration
- Newborn screening for every baby
- Car seat safety counseling/checks
- Paid parental leave

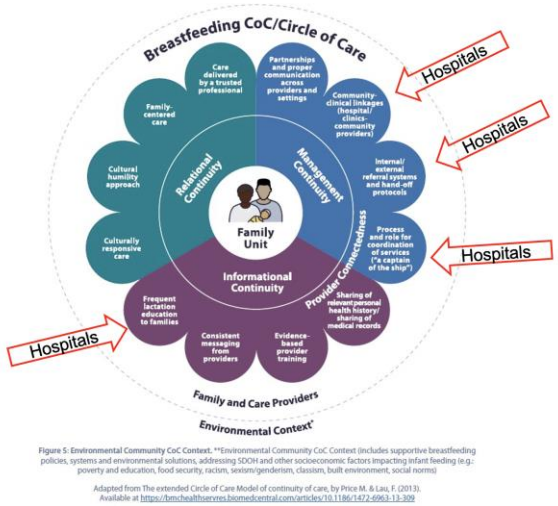

Figure 5: Environmental Community CoC Context. **Environmental Community CoC Context (includes supportive breastfeeding policies, systems and environmental solutions, addressing SDOH and other socioeconomic factors impacting infant feeding (e.g.: poverty and education, food security, racism, sexism/genderism, classism, built environment, social norms)

Adapted from The extended Circle of Care Model of continuity of care, by Price M. & Lau, F. (2013). Available at https://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-309

Kansas Breastfeeding Coalition, Inc.

Please keep up your 4th Trimester Initiative efforts!

Wrap-up

- Questions?
- Email me anytime with questions and/or feedback: kbettinger@kumc.edu
- A huge thank you to KDHE's newborn screening staff, Brenda Bandy with the Kansas Breastfeeding Coalition, and my colleagues in the KU Newborn Nursery including our Medical Director, Dr. Whitney Pressler, for helping me put this together

https://www.breastmilkcounts.com/breastfeeding-101/skin-to-skin/#:~:text=It%20is%20a%20special%20bonding,baby%20finishes%20his%20first%20feeding.