

Kansas
Kansas Birth Defects Program

Purpose: Surveillance

Partner: Hospitals, Environmental Agencies/Organizations, Universities

Program status: Interested in developing a surveillance program

Start year: 1985

Earliest year of available data: 1985

Organizational location: Department of Health
(Epidemiology/Environment, Maternal and Child Health, Vital Statistics)

Population covered annually: 36,395

Statewide: Yes

Current legislation or rule: K.S.A. 65-1,241 through 65-1,246

Legislation year enacted: 2004

Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics. Live births and stillbirths (fetal deaths) information are used as part of the Birth Defects Information System (BDIS). Thirteen anomalies (and 'other' congenital anomalies) are listed on the birth certificate and are reported, however, these are not linked to ICD-9 codes. In addition to major birth defects, low birth weight ($\leq 1,200$ grams), low Apgar scores (≤ 5 at five minutes), seizure or serious neurologic dysfunction, and significant birth injury [skeletal fracture(s), peripheral nerve injury, and/or soft tissue/solid organ hemorrhage which requires intervention] are also reported to BDIS.

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition

Residence: In state and out of state births to Kansas residents and in-state births to out of state residents

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation

Vital records: Birth certificates, Stillbirth (fetal death) certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Reports

Pediatric & tertiary care hospitals: Reports

Other sources: Physician reports, Kansas Health Information Network

Case Ascertainment

Coding: ICD-9-CM/ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), In Kansas, birth defects (congenital anomalies) are collected through four data sources: live birth certificates, stillbirth (fetal death) certificates, Kansas Health Information Network and the congenital malformations and fetal alcohol syndrome reporting form. The live birth and stillbirth (fetal death) certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to Auris (the Birth Defects Information System). Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into Auris.

Database collection and storage: SQL Server

Data Analysis

Data analysis software: SAS

Quality assurance: Office of Vital Statistics conducts verification on live birth and stillbirth (fetal death) certificate data.

Data use and analysis: Baseline rates, Rates by demographic and other variables, Time trends, Grant proposals, Ad-hoc upon request (e.g. cluster investigations)

System Integration

System links: Link case finding data to final birth file

System integration: Our program has a link with vital statistics records. The Birth Defects program uses the same data system (Auris) and shares information with Newborn Hearing Screening and Newborn Metabolic Screening program.

Funding

Funding source: 50% General state funds, 50% MCH funds

Other

Web site: http://www.kdheks.gov/bfh/birth_defects.htm

Contacts

Alyson Dalrymple, MPH

Kansas Department of Health and Environment

1000 SW Jackson, Suite 220

Topeka, Kansas 66612-1274

Phone: 785-296-6134

Fax: 785-559-4280

Email: Alyson.Dalrymple@ks.gov

Jamie Kim, MPH

Kansas Department of Health and Environment

1000 SW Jackson, Suite 220

Topeka, Kansas 66612-1274

Phone: 785-296-6467

Fax: 785-559-4280

Email: Jamie.Kim@ks.gov

DATA TABLES

Kansas
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Anencephalus	25 <i>2.0</i>	0 <i>0.0</i>	9 <i>3.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	34 <i>1.9</i>	
Anophthalmia/microphthalmia	<5	0 <i>0.0</i>	0 <i>0.0</i>	<5	0 <i>0.0</i>	<5	
Anotia/microtia	<5	0 <i>0.0</i>	9 <i>3.8</i>	<5	0 <i>0.0</i>	12 <i>0.8</i>	
Aortic valve stenosis	9 <i>0.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	10 <i>0.5</i>	
Atrial septal defect	731 <i>57.4</i>	65 <i>52.8</i>	121 <i>40.2</i>	20 <i>33.4</i>	<5	970 <i>53.3</i>	
Atrioventricular septal defect (Endocardial cushion defect)	18 <i>1.4</i>	<5	7 <i>2.3</i>	<5	0 <i>0.0</i>	29 <i>1.6</i>	
Biliary atresia	15 <i>1.5</i>	<5	<5	<5	0 <i>0.0</i>	21 <i>1.5</i>	
Bladder exstrophy	<5	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	<5	
Choanal atresia	<5	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	6 <i>0.6</i>	
Cleft lip alone	69 <i>5.4</i>	6 <i>4.9</i>	15 <i>5.0</i>	<5	<5	95 <i>5.2</i>	
Cleft lip with cleft palate	31 <i>2.4</i>	<5	7 <i>2.3</i>	<5	<5	44 <i>2.4</i>	
Cleft palate alone	85 <i>6.7</i>	<5	17 <i>5.6</i>	<5	0 <i>0.0</i>	106 <i>5.8</i>	
Cloacal exstrophy	<5	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	5 <i>0.7</i>	
Clubfoot	98 <i>7.7</i>	7 <i>5.7</i>	21 <i>7.0</i>	<5	<5	131 <i>7.2</i>	
Coarctation of the aorta	24 <i>1.9</i>	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	29 <i>1.6</i>	
Common truncus (truncus arteriosus)	9 <i>0.9</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>0.6</i>	
Congenital cataract	10 <i>1.0</i>	0 <i>0.0</i>	<5	<5	0 <i>0.0</i>	13 <i>0.9</i>	
Congenital posterior urethral valves	<5	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	5 <i>0.7</i>	1
Craniosynostosis	71 <i>7.1</i>	6 <i>6.2</i>	13 <i>5.4</i>	<5	0 <i>0.0</i>	94 <i>6.5</i>	
Deletion 22q11.2	<5	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	5 <i>0.7</i>	
Diaphragmatic hernia	22 <i>1.7</i>	<5	9 <i>3.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	32 <i>1.8</i>	
Double outlet right ventricle	<5	<5	<5	0 <i>0.0</i>	0 <i>0.0</i>	5 <i>0.3</i>	
Ebstein anomaly	<5	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	<5	
Encephalocele	10 <i>1.3</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	12 <i>1.1</i>	
Esophageal atresia/tracheoesophageal fistula	18 <i>1.4</i>	<5	<5	<5	0 <i>0.0</i>	24 <i>1.3</i>	
Gastroschisis	45 <i>3.5</i>	<5	12 <i>4.0</i>	0 <i>0.0</i>	<5	63 <i>3.5</i>	
Holoprosencephaly	<5	<5	<5	0 <i>0.0</i>	0 <i>0.0</i>	10 <i>0.5</i>	
Hypoplastic left heart syndrome	6 <i>0.6</i>	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	7 <i>0.5</i>	
Hypospadias	197 <i>30.1</i>	30 <i>47.6</i>	31 <i>20.1</i>	5 <i>16.6</i>	0 <i>0.0</i>	270 <i>28.9</i>	1
Interrupted aortic arch	5 <i>1.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	5 <i>0.7</i>	

Kansas
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Limb deficiencies (reduction defects)	31 <i>2.4</i>	<5	<5	0 <i>0.0</i>	0 <i>0.0</i>	38 <i>2.1</i>	
Omphalocele	29 <i>2.3</i>	5 <i>4.1</i>	10 <i>3.3</i>	<5	0 <i>0.0</i>	49 <i>2.7</i>	
Pulmonary valve atresia and stenosis	34 <i>2.7</i>	<5	11 <i>3.7</i>	<5	0 <i>0.0</i>	50 <i>2.7</i>	
Rectal and large intestinal atresia/stenosis	23 <i>1.8</i>	<5	5 <i>1.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	31 <i>1.7</i>	
Renal agenesis/hypoplasia	23 <i>1.8</i>	<5	5 <i>1.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	32 <i>1.8</i>	
Single ventricle	0 <i>0.0</i>	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	<5	
Small intestinal atresia/stenosis	15 <i>1.2</i>	<5	6 <i>2.0</i>	<5	0 <i>0.0</i>	24 <i>1.3</i>	
Spina bifida without anencephalus	21 <i>1.6</i>	0 <i>0.0</i>	13 <i>4.3</i>	<5	0 <i>0.0</i>	35 <i>1.9</i>	
Tetralogy of Fallot	19 <i>1.5</i>	<5	5 <i>1.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	25 <i>1.4</i>	
Total anomalous pulmonary venous connection	<5	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	<5	
Transposition of the great arteries (TGA)	10 <i>0.8</i>	<5	<5	<5	0 <i>0.0</i>	16 <i>0.9</i>	
Tricuspid valve atresia and stenosis	<5	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	5 <i>0.5</i>	
Trisomy 13	<5	0 <i>0.0</i>	<5	0 <i>0.0</i>	0 <i>0.0</i>	<5	
Trisomy 18	15 <i>1.2</i>	<5	7 <i>2.3</i>	<5	0 <i>0.0</i>	26 <i>1.4</i>	
Trisomy 21 (Down syndrome)	150 <i>11.8</i>	9 <i>7.3</i>	40 <i>13.3</i>	9 <i>15.0</i>	<5	211 <i>11.6</i>	
Turner syndrome	19 <i>3.1</i>	<5	<5	0 <i>0.0</i>	0 <i>0.0</i>	25 <i>2.8</i>	2
Ventricular septal defect	221 <i>17.3</i>	13 <i>10.6</i>	65 <i>21.6</i>	7 <i>11.7</i>	<5	311 <i>17.1</i>	
Total live births	127,456	12,309	30,104	5,989	837	181,997	3
Male live births	65,407	6,304	15,392	3,021	430	93,286	
Female live births	62,049	6,005	14,711	2,968	407	88,710	

Kansas
Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	61 <i>3.8</i>	<5	63 <i>3.5</i>	
Trisomy 13	<5	<5	<5	
Trisomy 18	18 <i>1.1</i>	8 <i>3.5</i>	26 <i>1.4</i>	
Trisomy 21 (Down syndrome)	118 <i>7.4</i>	91 <i>39.3</i>	211 <i>11.6</i>	
Total live births	158,860	23,127	181,997	3

Notes

1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
2. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
3. Data for total live births include unknown gender.

General comments

- *Data for totals include unknown and/or other.
- Data for conditions include probable cases.