Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Genetic Clinics, Laboratories,
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 56,000
Statewide: Yes
Current legislation or rule: Kentucky Revised Statute 211.660 Kentucky birth surveillance registry - Department's authority to promulgate administrative regulations. Effective: July 15, 2002
Legislation year enacted: 1992

Case Definition

Outcomes covered: KBSR collects information concerning birth defects, stillbirths, and high-risk conditions for Kentucky residents birth to age five. Diagnoses include the following ICD-10 codes:• All congenital anomalies codes - Q00-Q99• Metabolic/storage disorders - D80-D82, E70-E72, E74-E83, E88, and all subcategories.• Teratogens (noxious influences) - P04.0-P04.9. • Zika Virus Disease - A92.5And any additional condition deemed necessary for public health surveillance.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (A fetal death of twenty (20) completed weeks' gestation or more, calculated from the date last normal menstrual period began to the date of delivery or in which the fetus weighs three hundred fifty (350) grams or more.)
Age: Up to 5 years of age
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Newborn CCHD Screening, NAS Public Health Reporting Registry
Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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.), Tests and procedures, 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, Prenatal care, Prenatal diagnostic information, 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: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Online database developed in-house

Data Analysis

Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Birth records from vitals statistics are linked with all cases in the KBSR database. Data from the state Newborn CCHD Screening database and the state Neonatal Abstinence Syndrome Reporting Registry are incorporated into KBSR.

Funding

Funding source: 100% CDC grant

Other

Web site: https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/kbsr.aspx
Surveillance reports on file: Birth Defect Specific Fact Sheets (English and Spanish) and Data Briefs; Contact of Partners; 10-Year Report

Contacts

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DATA TABLES

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

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Anencephalus	43	7	2	1	0	55	
	1.9	***2.9***	***1.4***	***3.6***	***0.0***	***2.0***	
Anophthalmia/microphthalmia	24	2	2	0	0	31	
	1.1	***0.8***	***1.4***	***0.0***	***0.0***	***1.1***	
Anotia/microtia	15	1	5	0	0	21	
	0.7	***0.4***	***3.4***	***0.0***	***0.0***	***0.8***	
Aortic valve stenosis	25	0	1	0	0	28	
	1.1	***0.0***	***0.7***	***0.0***	***0.0***	***1.0***	
Atrial septal defect	6,524	1,304	452	164	8	8,875	
	292.5	***540.4***	***310.8***	***586.1***	***312.5***	***322.3***	
Atrioventricular septal defect (Endocardial cushion defect)	87	11	4	0	0	111	
	3.9	***4.6***	***2.8***	***0.0***	***0.0***	***4.0***	
Biliary atresia	12	3	2	1	0	21	
	0.5	***1.2***	***1.4***	***3.6***	***0.0***	***0.8***	
Bladder exstrophy	7	1	0	0	0	9	
	0.3	***0.4***	***0.0***	***0.0***	***0.0***	***0.3***	
Choanal atresia	29	2	0	0	0	31	
	1.3	***0.8***	***0.0***	***0.0***	***0.0***	***1.1***	
Cleft lip alone	90	4	1	2	0	99	
	4.0	***1.7***	***0.7***	***7.1***	***0.0***	***3.6***	
Cleft lip with cleft palate	155	11	13	3	0	186	
	6.9	***4.6***	***8.9***	***10.7***	***0.0***	***6.8***	
Cleft palate alone	154	11	7	1	0	182	
	6.9	***4.6***	***4.8***	***3.6***	***0.0***	***6.6***	
Cloacal exstrophy	3	0	0	0	0	4	1
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Clubfoot	472	37	35	10	0	577	
	21.2	***15.3***	***24.1***	***35.7***	***0.0***	***21.0***	
Coarctation of the aorta	130	7	6	1	0	151	
	5.8	***2.9***	***4.1***	***3.6***	***0.0***	***5.5***	
Common truncus (truncus arteriosus)	19	0	2	0	0	23	
	0.9	***0.0***	***1.4***	***0.0***	***0.0***	***0.8***	
Congenital cataract	23	6	0	0	0	32	
	1.0	***2.5***	***0.0***	***0.0***	***0.0***	***1.2***	
Congenital posterior urethral valves	16	3	0	0	0	20	2
	1.4	***2.5***	***0.0***	***0.0***	***0.0***	***1.4***	
Deletion 22q11.2	16	3	1	0	0	21	
	0.7	***1.2***	***0.7***	***0.0***	***0.0***	***0.8***	
Diaphragmatic hernia	56	4	6	1	0	71	
	2.5	***1.7***	***4.1***	***3.6***	***0.0***	***2.6***	
Double outlet right ventricle	44	12	1	0	0	63	
	2.0	***5.0***	***0.7***	***0.0***	***0.0***	***2.3***	
Ebstein anomaly	16	1	1	1	0	19	
	0.7	***0.4***	***0.7***	***3.6***	***0.0***	***0.7***	
Encephalocele	25	3	2	1	0	33	
	1.1	***1.2***	***1.4***	***3.6***	***0.0***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	52	6	0	2	0	62	
	2.3	***2.5***	***0.0***	***7.1***	***0.0***	***2.3***	
Gastroschisis	114	5	5	2	0	130	
	5.1	***2.1***	***3.4***	***7.1***	***0.0***	***4.7***	
Holoprosencephaly	55	5	2	2	1	66	
	2.5	***2.1***	***1.4***	***7.1***	***39.1***	***2.4***	
Hypoplastic left heart syndrome	45	5	2	0	0	56	
	2.0	***2.1***	***1.4***	***0.0***	***0.0***	***2.0***	
Hypospadias	1,027	106	28	11	0	1,216	2
	89.4	***87.3***	***38.0***	***78.2***	***0.0***	***86.1***	
Interrupted aortic arch	19	3	0	0	0	25	
	0.9	***1.2***	***0.0***	***0.0***	***0.0***	***0.9***	
Limb deficiencies (reduction defects)	85	8	4	3	0	104	
	3.8	***3.3***	***2.8***	***10.7***	***0.0***	***3.8***	

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

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total***	**Notes**
Omphalocele	49	5	1	1	0	60	
	2.2	***2.1***	***0.7***	***3.6***	***0.0***	***2.2***	
Pulmonary valve atresia and stenosis	112	14	5	0	0	134	
	5.0	***5.8***	***3.4***	***0.0***	***0.0***	***4.9***	
Pulmonary valve atresia	9	3	1	0	0	13	
	0.4	***1.2***	***0.7***	***0.0***	***0.0***	***0.5***	
Rectal and large intestinal atresia/stenosis	109	12	9	1	0	138	
	4.9	***5.0***	***6.2***	***3.6***	***0.0***	***5.0***	
Renal agenesis/hypoplasia	103	12	13	3	1	134	
	4.6	***5.0***	***8.9***	***10.7***	***39.1***	***4.9***	
Single ventricle	16	2	0	0	0	23	
	0.7	***0.8***	***0.0***	***0.0***	***0.0***	***0.8***	
Small intestinal atresia/stenosis	65	10	8	3	0	92	
	2.9	***4.1***	***5.5***	***10.7***	***0.0***	***3.3***	
Spina bifida without anencephalus	78	3	4	1	0	95	
	3.5	***1.2***	***2.8***	***3.6***	***0.0***	***3.5***	
Tetralogy of Fallot	83	16	2	3	0	117	
	3.7	***6.6***	***1.4***	***10.7***	***0.0***	***4.2***	
Total anomalous pulmonary venous connection	24	3	4	1	0	35	
	1.1	***1.2***	***2.8***	***3.6***	***0.0***	***1.3***	
Transposition of the great arteries (TGA)	79	7	1	1	0	91	
	3.5	***2.9***	***0.7***	***3.6***	***0.0***	***3.3***	
Dextro-transposition of great arteries (d-TGA)	73	7	1	1	0	85	
	3.3	***2.9***	***0.7***	***3.6***	***0.0***	***3.1***	
Tricuspid valve atresia and stenosis	21	3	1	0	0	26	3
	0.9	***1.2***	***0.7***	***0.0***	***0.0***	***0.9***	
Trisomy 13	31	2	3	2	0	40	
	1.4	***0.8***	***2.1***	***7.1***	***0.0***	***1.5***	
Trisomy 18	52	19	5	0	0	78	
	2.3	***7.9***	***3.4***	***0.0***	***0.0***	***2.8***	
Trisomy 21 (Down syndrome)	277	24	25	7	0	367	
	12.4	***9.9***	***17.2***	***25.0***	***0.0***	***13.3***	
Turner syndrome	36	1	3	1	0	43	4
	3.3	***0.8***	***4.2***	***7.2***	***0.0***	***3.2***	
Ventricular septal defect	1,335	171	104	31	2	1,726	5
	59.9	***70.9***	***71.5***	***110.8***	***78.1***	***62.7***	
Total live births	**223,030**	**24,129**	**14,544**	**2,798**	**256**	**275,341**	**6**
Male live births	**114,859**	**12,137**	**7,363**	**1,406**	**119**	**141,280**	
Female live births	**108,164**	**11,992**	**7,181**	**1,392**	**137**	**134,054**	

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

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	127	2	130	
	5.4	***0.6***	***4.7***	
Trisomy 13	32	7	40	
	1.4	***2.3***	***1.5***	
Trisomy 18	41	37	78	
	1.7	***12.0***	***2.8***	
Trisomy 21 (Down syndrome)	202	141	367	
	8.6	***45.7***	***13.3***	
Total live births	**234,917**	**30,864**	**275,341**	**6**

Notes

1. Data for this condition begin in 2016.
2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
3. Data for this condition include cases with stenosis and hypoplasia.
4. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
5. Data for this condition exclude inlet ventricular septal defect and common atrioventricular canal type ventricular sepatal defect.
6. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.