Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Legislators
Program status: Currently collecting data
Start year: 1980
Earliest year of available data: 1980
Organizational location: Arkansas Children's Hospital
Population covered annually: 39,000
Statewide: Yes
Current legislation or rule: Acts 1985, No. 214
Legislation year enacted: 1985

Case Definition
Outcomes covered: Major congenital malformations, 740.000-759.990 (ICD10: Q00.0-Q99.9), plus select others outside this range in live birth, stillbirth, and terminations. All traceable stillbirths without birth defects are collected as well.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: Birth to second birthday
Residence: In and out of state births to Arkansas residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Stillbirth records
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Physician reports

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 chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All elective abortions, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA, 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, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access, MS SQL Server

Data Analysis
Data analysis software: SAS, Access
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, Monitoring outbreaks and cluster investigations, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, 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: No.

Funding
Funding source: 100% General state funds

Other
Web site:
https://www.archildrens.org/research/research-programs-and-centers/arkansas-reproductive-health-monitoring-system/arhms

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DATA TABLES

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Birth Defects Counts and Prevalence 2014 - 2017 (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	12	2	1	1	0	17	
	1.2	*0.7*	*0.6*	*2.1*	*0.0*	*1.1*	
Anophthalmia/microphthalmia	15	7	2	2	0	27	
	1.5	*2.4*	*1.3*	*4.3*	*0.0*	*1.8*	
Anotia/microtia	31	5	4	0	0	48	
	3.1	*1.7*	*2.5*	*0.0*	*0.0*	*3.1*	
Aortic valve stenosis	40	4	1	1	0	49	
	4.0	*1.4*	*0.6*	*2.1*	*0.0*	*3.2*	
Atrial septal defect	402	128	25	23	2	635	
	39.8	*43.6*	*15.7*	*49.0*	*20.8*	*41.6*	
Atrioventricular septal defect (Endocardial cushion defect)	75	23	2	5	0	110	
	7.4	*7.8*	*1.3*	*10.7*	*0.0*	*7.2*	
Biliary atresia	3	0	0	1	0	4	
	0.4	*0.0*	*0.0*	*2.8*	*0.0*	*0.4*	
Bladder exstrophy	2	0	0	0	0	2	
	0.4	*0.0*	*0.0*	*0.0*	*0.0*	*0.3*	
Choanal atresia	7	2	0	0	0	10	
	0.7	*0.7*	*0.0*	*0.0*	*0.0*	*0.7*	
Cleft lip alone	52	7	0	0	0	64	
	5.2	*2.4*	*0.0*	*0.0*	*0.0*	*4.2*	
Cleft lip with cleft palate	71	10	4	3	0	98	
	7.0	*3.4*	*2.5*	*6.4*	*0.0*	*6.4*	
Cleft palate alone	84	11	2	0	1	110	
	8.3	*3.7*	*1.3*	*0.0*	*10.4*	*7.2*	
Cloacal exstrophy	2	1	2	0	0	5	
	0.2	*0.3*	*1.3*	*0.0*	*0.0*	*0.3*	
Clubfoot	201	43	13	7	4	295	
	19.9	*14.6*	*8.2*	*14.9*	*41.5*	*19.3*	
Coarctation of the aorta	60	6	5	3	0	77	
	5.9	*2.0*	*3.1*	*6.4*	*0.0*	*5.0*	
Common truncus (truncus arteriosus)	4	3	0	0	0	7	
	0.5	*1.4*	*0.0*	*0.0*	*0.0*	*0.6*	
Congenital cataract	36	10	4	1	0	53	
	3.6	*3.4*	*2.5*	*2.1*	*0.0*	*3.5*	
Congenital posterior urethral valves	9	4	0	0	0	14	1
	1.7	*2.7*	*0.0*	*0.0*	*0.0*	*1.8*	
Craniosynostosis	108	18	2	3	2	139	
	10.7	*6.1*	*1.3*	*6.4*	*20.8*	*9.1*	
Deletion 22q11.2	11	1	1	0	0	13	
	1.5	*0.5*	*0.8*	*0.0*	*0.0*	*1.1*	
Diaphragmatic hernia	46	6	2	2	0	59	
	4.6	*2.0*	*1.3*	*4.3*	*0.0*	*3.9*	
Double outlet right ventricle	15	5	2	1	0	30	
	1.5	*1.7*	*1.3*	*2.1*	*0.0*	*2.0*	
Ebstein anomaly	17	1	0	1	0	20	
	1.7	*0.3*	*0.0*	*2.1*	*0.0*	*1.3*	
Encephalocele	10	4	0	1	0	18	
	1.0	*1.4*	*0.0*	*2.1*	*0.0*	*1.2*	
Esophageal atresia/tracheoesophageal fistula	21	3	0	1	0	29	
	2.1	*1.0*	*0.0*	*2.1*	*0.0*	*1.9*	
Gastroschisis	62	14	3	3	2	94	
	6.1	*4.8*	*1.9*	*6.4*	*20.8*	*6.2*	
Holoprosencephaly	12	2	2	2	0	21	
	1.2	*0.7*	*1.3*	*4.3*	*0.0*	*1.4*	
Hypoplastic left heart syndrome	42	6	2	3	0	55	
	4.2	*2.0*	*1.3*	*6.4*	*0.0*	*3.6*	
Hypospadias	553	108	9	10	2	707	1
	106.1	*72.8*	*11.2*	*41.8*	*40.4*	*90.2*	
Interrupted aortic arch	4	2	1	0	0	8	
	0.5	*0.9*	*0.8*	*0.0*	*0.0*	*0.7*	

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Birth Defects Counts and Prevalence 2014 - 2017 (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**
Limb deficiencies (reduction defects)	30	13	2	2	3	54	
	3.0	***4.4***	***1.3***	***4.3***	***31.2***	***3.5***	
Omphalocele	22	5	1	0	1	33	
	2.2	***1.7***	***0.6***	***0.0***	***10.4***	***2.2***	
Pulmonary valve atresia and stenosis	124	33	8	3	0	181	
	12.3	***11.2***	***5.0***	***6.4***	***0.0***	***11.8***	
Pulmonary valve atresia	6	8	0	0	0	15	
	0.6	***2.7***	***0.0***	***0.0***	***0.0***	***1.0***	
Rectal and large intestinal atresia/stenosis	31	14	4	1	0	58	
	3.1	***4.8***	***2.5***	***2.1***	***0.0***	***3.8***	
Renal agenesis/hypoplasia	26	5	2	1	1	37	
	2.6	***1.7***	***1.3***	***2.1***	***10.4***	***2.4***	
Single ventricle	5	1	0	0	0	7	
	0.5	***0.3***	***0.0***	***0.0***	***0.0***	***0.5***	
Small intestinal atresia/stenosis	37	13	2	1	0	61	
	3.7	***4.4***	***1.3***	***2.1***	***0.0***	***4.0***	
Spina bifida without anencephalus	35	9	1	0	0	51	
	3.5	***3.1***	***0.6***	***0.0***	***0.0***	***3.3***	
Tetralogy of Fallot	52	13	1	2	0	72	
	5.2	***4.4***	***0.6***	***4.3***	***0.0***	***4.7***	
Total anomalous pulmonary venous connection	19	6	2	1	0	31	
	1.9	***2.0***	***1.3***	***2.1***	***0.0***	***2.0***	
Transposition of the great arteries (TGA)	28	7	0	0	1	41	
	2.8	***2.4***	***0.0***	***0.0***	***10.4***	***2.7***	
Dextro-transposition of great arteries (d-TGA)	21	4	0	0	1	27	
	2.1	***1.4***	***0.0***	***0.0***	***10.4***	***1.8***	
Tricuspid valve atresia	6	1	0	0	0	8	
	0.8	***0.5***	***0.0***	***0.0***	***0.0***	***0.7***	
Trisomy 13	10	1	0	1	0	12	
	1.0	***0.3***	***0.0***	***2.1***	***0.0***	***0.8***	
Trisomy 18	18	9	2	0	0	30	
	1.8	***3.1***	***1.3***	***0.0***	***0.0***	***2.0***	
Trisomy 21 (Down syndrome)	141	29	14	8	1	215	
	14.0	***9.9***	***8.8***	***17.1***	***10.4***	***14.1***	
Turner syndrome	11	2	0	1	0	14	2
	2.3	***1.4***	***0.0***	***4.4***	***0.0***	***1.9***	
Ventricular septal defect	645	131	43	19	3	929	
	63.9	***44.6***	***27.1***	***40.5***	***31.2***	***60.8***	
Total live births	**100,927**	**29,360**	**15,880**	**4,691**	**963**	**152,794**	
Male live births	**52,108**	**14,836**	**8,052**	**2,393**	**495**	**78,395**	
Female live births	**48,819**	**14,524**	**7,828**	**2,298**	**468**	**74,399**	

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Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	91	3	94	
	6.6	***2.0***	***6.2***	
Trisomy 13	10	2	12	
	0.7	***1.3***	***0.8***	
Trisomy 18	22	8	30	
	1.6	***5.2***	***2.0***	
Trisomy 21 (Down syndrome)	129	83	215	
	9.4	***54.2***	***14.1***	
Total live births	**137,413**	**15,301**	**152,794**	

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. Prevalance is calculated per 10,000 female live births.

General comments

*Data for totals include unknown and/or other.
-Data for conditions from 2017 are provisional.
-Data for conditions include probable cases.