Oklahoma

Oklahoma Birth Defects Registry (OBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Data used to educate public in the Oklahoma initiative to reduce Infant Mortality
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992 abbreviated data
Organizational location: Department of Health (Screening and Special Services)
Population covered annually: 52,000
Statewide: Yes
Current legislation or rule: 63 - 1-550.2
Legislation year enacted: 1992

Case Definition

Pregnancy outcome: Livebirths (20 week gestation and greater), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, * We collect all gestational ages but only those 20 week gestation and greater are included in most analyses and annual reporting.), Elective terminations (20 weeks gestation and greater, * We collect all gestational ages but only those 20 week gestation and greater are included in most analyses and annual reporting.)
Age: 24 months after delivery
Residence: Oklahoma

Surveillance Methods

Case ascertainment: Active Case Finding
Vital records: Birth certificates, Death certificates, Medical Examiner's autopsy reports; Stillbirth certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.)
Other sources: MFM/Neonatology Case Conference

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 neonatal deaths, All prenatally diagnosed or suspected cases
Coding: CDC coding system based on BPA

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, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access

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, Baseline rates, Rates by demographic and other variables, Time trends, Observed vs. expected analyses, Referral, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file

Funding

Funding source: 40% MCH funds, 60% Genetic screening revenues

Other

Web site: obdr.health.ok.gov
Surveillance reports on file: Yes

Contacts

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DATA TABLES

Oklahoma

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	21	7	13	4	2	49	
	1.3	***2.8***	***3.5***	***4.8***	***0.7***	***1.9***	
Anophthalmia/microphthalmia	29	1	6	1	5	43	
	1.8	***0.4***	***1.6***	***1.2***	***1.8***	***1.7***	
Anotia/microtia	16	3	12	6	4	42	
	1.0	***1.2***	***3.2***	***7.2***	***1.4***	***1.6***	
Aortic valve stenosis	51	0	8	1	7	68	
	3.2	***0.0***	***2.1***	***1.2***	***2.5***	***2.6***	
Atrial septal defect	628	93	124	31	85	968	
	39.1	***37.3***	***33.2***	***37.1***	***30.7***	***37.4***	
Atrioventricular septal defect (Endocardial cushion defect)	91	14	22	8	13	150	
	5.7	***5.6***	***5.9***	***9.6***	***4.7***	***5.8***	
Biliary atresia	7	6	2	0	3	18	
	0.4	***2.4***	***0.5***	***0.0***	***1.1***	***0.7***	
Bladder exstrophy	4	2	1	0	0	7	
	0.2	***0.8***	***0.3***	***0.0***	***0.0***	***0.3***	
Choanal atresia	34	3	3	0	7	47	
	2.1	***1.2***	***0.8***	***0.0***	***2.5***	***1.8***	
Cleft lip alone	74	7	12	1	16	110	
	4.6	***2.8***	***3.2***	***1.2***	***5.8***	***4.2***	
Cleft lip with cleft palate	115	12	31	8	17	183	
	7.2	***4.8***	***8.3***	***9.6***	***6.1***	***7.1***	
Cleft palate alone	132	7	20	4	22	186	
	8.2	***2.8***	***5.3***	***4.8***	***7.9***	***7.2***	
Cloacal exstrophy	1	0	0	0	0	1	1
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	308	40	78	22	50	501	
	19.2	***16.0***	***20.9***	***26.3***	***18.0***	***19.3***	
Coarctation of the aorta	121	13	21	1	23	179	
	7.5	***5.2***	***5.6***	***1.2***	***8.3***	***6.9***	
Common truncus (truncus arteriosus)	11	1	2	0	0	14	
	0.7	***0.4***	***0.5***	***0.0***	***0.0***	***0.5***	
Congenital cataract	24	2	2	2	1	32	
	1.5	***0.8***	***0.5***	***2.4***	***0.4***	***1.2***	
Congenital posterior urethral valves	18	4	1	1	3	28	2
	2.2	***3.1***	***0.5***	***2.3***	***2.1***	***2.1***	
Craniosynostosis	110	11	23	2	24	173	
	6.8	***4.4***	***6.1***	***2.4***	***8.7***	***6.7***	
Deletion 22q11.2	6	3	3	0	1	13	
	0.4	***1.2***	***0.8***	***0.0***	***0.4***	***0.5***	
Diaphragmatic hernia	62	7	15	3	8	95	
	3.9	***2.8***	***4.0***	***3.6***	***2.9***	***3.7***	
Double outlet right ventricle	43	6	8	3	11	72	
	2.7	***2.4***	***2.1***	***3.6***	***4.0***	***2.8***	
Ebstein anomaly	13	0	2	1	4	20	
	0.8	***0.0***	***0.5***	***1.2***	***1.4***	***0.8***	
Encephalocele	13	3	9	0	1	26	
	0.8	***1.2***	***2.4***	***0.0***	***0.4***	***1.0***	
Esophageal atresia/tracheoesophageal fistula	44	4	5	1	3	57	
	2.7	***1.6***	***1.3***	***1.2***	***1.1***	***2.2***	
Gastroschisis	101	12	20	0	13	147	
	6.3	***4.8***	***5.3***	***0.0***	***4.7***	***5.7***	
Holoprosencephaly	19	8	5	0	3	35	
	1.2	***3.2***	***1.3***	***0.0***	***1.1***	***1.4***	
Hypoplastic left heart syndrome	53	6	10	1	8	81	
	3.3	***2.4***	***2.7***	***1.2***	***2.9***	***3.1***	
Hypospadias	308	51	30	9	48	447	2
	37.3	***40.1***	***15.8***	***21.0***	***33.8***	***33.7***	
Interrupted aortic arch	19	3	2	2	1	27	
	1.2	***1.2***	***0.5***	***2.4***	***0.4***	***1.0***	

Oklahoma

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**
Limb deficiencies (reduction defects)	67	11	16	2	21	118	
	4.2	***4.4***	***4.3***	***2.4***	***7.6***	***4.6***	
Omphalocele	44	6	11	1	7	70	
	2.7	***2.4***	***2.9***	***1.2***	***2.5***	***2.7***	
Pulmonary valve atresia and stenosis	123	11	36	10	19	199	
	7.7	***4.4***	***9.6***	***12.0***	***6.9***	***7.7***	
Pulmonary valve atresia	26	2	9	2	3	42	
	1.6	***0.8***	***2.4***	***2.4***	***1.1***	***1.6***	
Rectal and large intestinal atresia/stenosis	82	9	23	9	12	135	
	5.1	***3.6***	***6.1***	***10.8***	***4.3***	***5.2***	
Renal agenesis/hypoplasia	117	15	30	6	15	184	
	7.3	***6.0***	***8.0***	***7.2***	***5.4***	***7.1***	
Single ventricle	8	3	5	0	1	18	
	0.5	***1.2***	***1.3***	***0.0***	***0.4***	***0.7***	
Small intestinal atresia/stenosis	55	5	12	2	8	82	
	3.4	***2.0***	***3.2***	***2.4***	***2.9***	***3.2***	
Spina bifida without anencephalus	73	1	18	4	9	106	
	4.5	***0.4***	***4.8***	***4.8***	***3.2***	***4.1***	
Tetralogy of Fallot	79	6	13	6	12	117	
	4.9	***2.4***	***3.5***	***7.2***	***4.3***	***4.5***	
Total anomalous pulmonary venous connection	19	7	5	2	4	37	
	1.2	***2.8***	***1.3***	***2.4***	***1.4***	***1.4***	
Transposition of the great arteries (TGA)	65	8	10	2	5	91	
	4.0	***3.2***	***2.7***	***2.4***	***1.8***	***3.5***	
Dextro-transposition of great arteries (d-TGA)	61	7	10	2	3	84	
	3.8	***2.8***	***2.7***	***2.4***	***1.1***	***3.2***	
Tricuspid valve atresia and stenosis	35	7	7	4	5	58	
	2.2	***2.8***	***1.9***	***4.8***	***1.8***	***2.2***	
Tricuspid valve atresia	22	4	5	2	4	37	
	1.4	***1.6***	***1.3***	***2.4***	***1.4***	***1.4***	
Trisomy 13	11	2	5	2	1	21	
	0.7	***0.8***	***1.3***	***2.4***	***0.4***	***0.8***	
Trisomy 18	40	12	15	2	5	74	
	2.5	***4.8***	***4.0***	***2.4***	***1.8***	***2.9***	
Trisomy 21 (Down syndrome)	178	29	54	12	27	301	
	11.1	***11.6***	***14.4***	***14.4***	***9.7***	***11.6***	
Turner syndrome	17	2	4	0	4	28	3
	2.2	***1.6***	***2.2***	***0.0***	***3.0***	***2.2***	
Ventricular septal defect	866	114	221	40	115	1,364	
	53.9	***45.7***	***59.1***	***47.9***	***41.5***	***52.7***	
Total live births	**160,589**	**24,924**	**37,401**	**8,352**	**27,717**	**259,040**	**4**
Male live births	**82,505**	**12,722**	**18,998**	**4,290**	**14,184**	**132,727**	
Female live births	**78,081**	**12,201**	**18,403**	**4,061**	**13,533**	**126,308**	

Oklahoma

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

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	144	3	147	
	6.2	***1.1***	***5.7***	
Trisomy 13	12	9	21	
	0.5	***3.3***	***0.8***	
Trisomy 18	41	33	74	
	1.8	***12.1***	***2.9***	
Trisomy 21 (Down syndrome)	181	120	301	
	7.8	***43.9***	***11.6***	
Total live births	**231,581**	**27,332**	**259,040**	**4**

Notes

1. Data for this condition begins 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 female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
4. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.