Delaware

Delaware Birth Defects Registry (DBDR)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Birthing Centers, Newborn Screening, Delaware Healthy Mothers and Infants Consortium
Program status: Currently collecting data
Start year: 2010
Earliest year of available data: 2007
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 11,000
Statewide: Yes
Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects
Legislation year enacted: 1997

Case Definition
Outcomes covered: Selected major birth defects, selected metabolic defects, genetic disorders, and fetal/infant mortality.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Greater than 350 grams; in the absence of weight, 20 weeks gestation or greater), Elective terminations (Greater than 350 grams; in the absence of weight, 20 weeks gestation or greater)
Age: Birth to 1 year
Residence: In-state births to state resident

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Cancer registry, AIDS/HIV registry, Newborn blood spot screening program
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
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Midwifery 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 stillborn infants, All neonatal deaths, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, 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, 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: Redcap

Data Analysis
Data analysis software: SPSS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data)

Funding
Funding source: 40% General state funds, 60% MCH funds

Other
Web site: http://dhss.delaware.gov/dhss/dph/chca/dphbdr1.html
Surveillance reports on file: Analysis of the 2007-2012 Delaware Birth Defects Registryhttps://dhss.delaware.gov/dhss/dph/chca/dphbdr1.htmlBirth Defects, Delaware Profile 2010-2017https://dethrives.com/wp-content/uploads/2021/05/Data_Brief_BirthDefects.pdf

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DATA TABLES

Delaware

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	2	2	0	0	0	4	
	0.7	***1.4***	***0.0***	***0.0***	***0.0***	***0.7***	
Anophthalmia/microphthalmia	1	4	2	0	0	7	
	0.4	***2.8***	***2.7***	***0.0***	***0.0***	***1.3***	
Anotia/microtia	13	1	5	1	0	20	
	4.6	***0.7***	***6.8***	***3.1***	***0.0***	***3.7***	
Aortic valve stenosis	8	1	3	0	0	12	
	2.9	***0.7***	***4.1***	***0.0***	***0.0***	***2.2***	
Atrial septal defect	79	55	32	7	1	175	1
	28.2	***38.0***	***43.2***	***21.4***	***93.5***	***32.1***	
Atrioventricular septal defect (Endocardial cushion defect)	18	16	12	2	1	51	
	6.4	***11.1***	***16.2***	***6.1***	***93.5***	***9.4***	
Biliary atresia	1	1	0	0	0	5	
	0.4	***0.7***	***0.0***	***0.0***	***0.0***	***0.9***	
Bladder exstrophy	2	1	0	0	0	3	
	0.7	***0.7***	***0.0***	***0.0***	***0.0***	***0.6***	
Choanal atresia	3	3	1	0	0	7	
	1.1	***2.1***	***1.4***	***0.0***	***0.0***	***1.3***	
Cleft lip alone	9	2	4	1	0	16	
	3.2	***1.4***	***5.4***	***3.1***	***0.0***	***2.9***	
Cleft lip with cleft palate	14	4	5	1	0	25	
	5.0	***2.8***	***6.8***	***3.1***	***0.0***	***4.6***	
Cleft palate alone	18	9	4	1	0	32	2
	6.4	***6.2***	***5.4***	***3.1***	***0.0***	***5.9***	
Cloacal exstrophy	1	0	0	0	0	1	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Clubfoot	41	19	9	2	0	74	3
	14.7	***13.1***	***12.2***	***6.1***	***0.0***	***13.6***	
Coarctation of the aorta	12	5	2	2	0	21	
	4.3	***3.5***	***2.7***	***6.1***	***0.0***	***3.9***	
Common truncus (truncus arteriosus)	0	2	2	0	0	4	
	0.0	***1.4***	***2.7***	***0.0***	***0.0***	***0.7***	
Congenital cataract	8	1	0	1	0	10	
	2.9	***0.7***	***0.0***	***3.1***	***0.0***	***1.8***	
Congenital posterior urethral valves	3	6	1	0	0	10	4
	2.1	***8.2***	***2.7***	***0.0***	***0.0***	***3.6***	
Craniosynostosis	14	10	3	1	0	29	
	5.0	***6.9***	***4.1***	***3.1***	***0.0***	***5.3***	
Deletion 22q11.2	5	3	1	0	0	9	
	1.8	***2.1***	***1.4***	***0.0***	***0.0***	***1.7***	
Diaphragmatic hernia	6	2	2	1	0	11	
	2.1	***1.4***	***2.7***	***3.1***	***0.0***	***2.0***	
Double outlet right ventricle	3	2	3	1	0	10	
	1.1	***1.4***	***4.1***	***3.1***	***0.0***	***1.8***	
Ebstein anomaly	0	1	1	0	0	2	
	0.0	***0.7***	***1.4***	***0.0***	***0.0***	***0.4***	
Encephalocele	5	2	0	0	0	7	
	1.8	***1.4***	***0.0***	***0.0***	***0.0***	***1.3***	
Esophageal atresia/tracheoesophageal fistula	7	6	1	0	0	14	
	2.5	***4.1***	***1.4***	***0.0***	***0.0***	***2.6***	
Gastroschisis	11	6	4	1	0	23	
	3.9	***4.1***	***5.4***	***3.1***	***0.0***	***4.2***	
Holoprosencephaly	1	3	3	0	0	7	
	0.4	***2.1***	***4.1***	***0.0***	***0.0***	***1.3***	
Hypoplastic left heart syndrome	3	1	1	1	0	6	
	1.1	***0.7***	***1.4***	***3.1***	***0.0***	***1.1***	
Hypospadias	125	67	13	11	1	220	5
	86.5	***92.1***	***35.5***	***64.1***	***232.6***	***79.2***	
Interrupted aortic arch	0	0	1	0	0	1	
	0.0	***0.0***	***1.4***	***0.0***	***0.0***	***0.2***	

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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**
Limb deficiencies (reduction defects)	24	11	6	2	0	43	
	8.6	***7.6***	***8.1***	***6.1***	***0.0***	***7.9***	
Omphalocele	5	4	2	0	0	11	
	1.8	***2.8***	***2.7***	***0.0***	***0.0***	***2.0***	
Pulmonary valve atresia and stenosis	32	32	8	2	0	75	
	11.4	***22.1***	***10.8***	***6.1***	***0.0***	***13.8***	
Pulmonary valve atresia	4	1	1	0	0	6	
	1.4	***0.7***	***1.4***	***0.0***	***0.0***	***1.1***	
Rectal and large intestinal atresia/stenosis	16	10	1	1	1	29	
	5.7	***6.9***	***1.4***	***3.1***	***93.5***	***5.3***	
Renal agenesis/hypoplasia	19	5	4	1	0	29	
	6.8	***3.5***	***5.4***	***3.1***	***0.0***	***5.3***	
Single ventricle	1	0	0	1	0	2	
	0.4	***0.0***	***0.0***	***3.1***	***0.0***	***0.4***	
Small intestinal atresia/stenosis	5	7	3	0	0	15	
	1.8	***4.8***	***4.1***	***0.0***	***0.0***	***2.8***	
Spina bifida without anencephalus	4	6	5	1	0	16	
	1.4	***4.1***	***6.8***	***3.1***	***0.0***	***2.9***	
Tetralogy of Fallot	10	9	3	0	0	22	
	3.6	***6.2***	***4.1***	***0.0***	***0.0***	***4.0***	
Total anomalous pulmonary venous connection	3	3	2	0	0	8	
	1.1	***2.1***	***2.7***	***0.0***	***0.0***	***1.5***	
Transposition of the great arteries (TGA)	11	3	2	1	0	17	
	3.9	***2.1***	***2.7***	***3.1***	***0.0***	***3.1***	
Dextro-transposition of great arteries (d-TGA)	10	3	2	1	0	16	
	3.6	***2.1***	***2.7***	***3.1***	***0.0***	***2.9***	
Tricuspid valve atresia and stenosis	2	3	0	0	0	5	
	0.7	***2.1***	***0.0***	***0.0***	***0.0***	***0.9***	
Tricuspid valve atresia	1	2	0	0	0	3	
	0.4	***1.4***	***0.0***	***0.0***	***0.0***	***0.6***	
Trisomy 13	4	2	2	0	0	8	
	1.4	***1.4***	***2.7***	***0.0***	***0.0***	***1.5***	
Trisomy 18	1	3	5	1	0	10	
	0.4	***2.1***	***6.8***	***3.1***	***0.0***	***1.8***	
Trisomy 21 (Down syndrome)	39	26	25	5	1	97	
	13.9	***18.0***	***33.8***	***15.3***	***93.5***	***17.8***	
Turner syndrome	2	1	1	0	0	5	6
	1.5	***1.4***	***2.7***	***0.0***	***0.0***	***2.3***	
Ventricular septal defect	206	92	63	19	0	387	7
	73.6	***63.6***	***85.1***	***58.0***	***0.0***	***71.0***	
Total live births	**27,975**	**14,476**	**7,402**	**3,277**	**107**	**54,474**	
Male live births	**14,450**	**7,273**	**3,659**	**1,715**	**43**	**27,763**	
Female live births	**13,525**	**7,203**	**3,743**	**1,562**	**64**	**22,078**	

Delaware

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

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	23	0	23	
	5.0	***0.0***	***4.2***	
Trisomy 13	5	3	8	
	1.1	***3.4***	***1.5***	
Trisomy 18	2	8	10	
	0.4	***9.1***	***1.8***	
Trisomy 21 (Down syndrome)	46	51	97	
	10.1	***57.8***	***17.8***	
Total live births	**45,647**	**8,827**	**54,474**	

Notes

1. Data for this condition include atrial septal fenestrations and exclude atrial septal defects that self-close (not present after a month), which are considered patent foramen ovales.
2. Data for this condition include Pierre Robin anomalies with cleft palate.
3. Data for this condition, for the 2015 cohort and beyond, exclude talipes (varus, calcaneovarus, valgus, calcaneovalgus) or other varus/valgus deformities of feet.
4. Data for this condition include only cases involving surgical intervention. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
5. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
6. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
7. Data for this condition include probable cases only if the defect was found prenatally and the fetus died without a confirmatory autopsy.

General comments

*Data for totals include unknown and/or other.
-Data for all heart defects require an echocardiogram report.