

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

Registry <https://dhss.delaware.gov/dhss/dph/chca/dphbdr1.html> Birth Defects, Delaware Profile

2010-2017 https://dethrives.com/wp-content/uploads/2021/05/Data_Brief_BirthDefects.pdf

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	23	0	23	
	<i>5.0</i>	<i>0.0</i>	<i>4.2</i>	
Trisomy 13	5	3	8	
	<i>1.1</i>	<i>3.4</i>	<i>1.5</i>	
Trisomy 18	2	8	10	
	<i>0.4</i>	<i>9.1</i>	<i>1.8</i>	
Trisomy 21 (Down syndrome)	46	51	97	
	<i>10.1</i>	<i>57.8</i>	<i>17.8</i>	
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 ovaes.
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. Prevalence 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.