

## Maryland

### Maryland Birth Defects Reporting and Information System (BDRIS)

**Purpose:** Surveillance, Referral to Services

**Partner:** Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators

**Program status:** Currently collecting data

**Start year:** 1983

**Earliest year of available data:** 1984

**Organizational location:** Department of Health (Epidemiology/Environment, Prevention and Health Promotion Administration Maternal Child Health Bureau)

**Population covered annually:** 75,000

**Statewide:** Yes

**Current legislation or rule:** Health-General Article, Section 18-206; Annotated Code of Maryland

**Legislation year enacted:** 1982

#### Case Definition

**Outcomes covered:** Selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome until 2009, then all significant birth defects

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Or  $\geq$ 500 grams weight; reports accepted on fetal deaths  $<$ 500 grams or  $<$ 20 weeks gestation if sent to us.), Elective terminations (Reports accepted on terminations  $<$ 500 grams or  $<$ 20 weeks gestation if sent to us. BDRIS has no specific legal authority to collect information on terminations. Maryland does not require that any certificate be filed with Vital Records for a termination unless the body is transported for burial.)

**Age:** Newborn

**Residence:** All in-state births

#### 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:** Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Sickle Cell Disease, Critical Congenital Heart Defect follow Up Program

**Delivery hospitals:** Primary source: sentinel birth defects hospital report form; electronic reporting began 5/1/13

**Pediatric & tertiary care hospitals:** transfers from delivery hospitals, if screening not done at delivery hospital.

**Other sources:** Midwifery Facilities

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All fetal death certificates

**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, 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:** Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

**Database collection and storage:** Access, Mainframe, Visual dBASE, SAS, ASCII files; as of 5/1/13 data stored on vendor server

#### Data Analysis

**Data analysis software:** SAS

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, 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, Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness

#### System Integration

**System integration:** As of 5/1/13, the birth defects data collection is integrated into the same electronic system in which we collect hearing and CCHD screening data.

#### Funding

**Funding source:** 100% General state funds

#### Other

**Web site:** <http://phpa.dhmd.maryland.gov/genetics/SitePages/bdris.aspx>

**Surveillance reports on file:** All reports submitted to CDC

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## **DATA TABLES**

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

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Anencephalus	6 <i>0.4</i>	3 <i>0.3</i>	4 <i>0.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	19 <i>0.5</i>	
Anophthalmia/microphthalmia	2 <i>0.1</i>	3 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	11 <i>0.3</i>	
Anotia/microtia	6 <i>0.4</i>	0 <i>0.0</i>	1 <i>0.2</i>	1 <i>0.4</i>	0 <i>0.0</i>	16 <i>0.4</i>	
Aortic valve stenosis	2 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	7 <i>0.2</i>	
Atrial septal defect	94 <i>6.0</i>	97 <i>8.3</i>	5 <i>0.8</i>	2 <i>0.7</i>	2 <i>31.7</i>	277 <i>7.6</i>	
Atrioventricular septal defect (Endocardial cushion defect)	8 <i>0.5</i>	7 <i>0.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	38 <i>1.0</i>	
Biliary atresia	2 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	2 <i>0.1</i>	
Bladder exstrophy	2 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	6 <i>0.2</i>	
Choanal atresia	7 <i>0.4</i>	3 <i>0.3</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	14 <i>0.4</i>	
Cleft lip alone	13 <i>0.8</i>	11 <i>0.9</i>	8 <i>1.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	69 <i>1.9</i>	
Cleft lip with cleft palate	32 <i>2.0</i>	8 <i>0.7</i>	6 <i>1.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	85 <i>2.3</i>	
Cleft palate alone	46 <i>2.9</i>	17 <i>1.5</i>	6 <i>1.0</i>	5 <i>1.9</i>	0 <i>0.0</i>	143 <i>3.9</i>	
Cloacal exstrophy	3 <i>0.2</i>	4 <i>0.3</i>	1 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>0.2</i>	
Clubfoot	49 <i>3.1</i>	32 <i>2.7</i>	13 <i>2.2</i>	1 <i>0.4</i>	0 <i>0.0</i>	193 <i>5.3</i>	
Coarctation of the aorta	19 <i>1.2</i>	15 <i>1.3</i>	0 <i>0.0</i>	5 <i>1.9</i>	0 <i>0.0</i>	68 <i>1.9</i>	
Common truncus (truncus arteriosus)	3 <i>0.2</i>	1 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>0.2</i>	
Congenital cataract	1 <i>0.1</i>	3 <i>0.3</i>	1 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>0.2</i>	
Congenital posterior urethral valves	3 <i>0.4</i>	3 <i>0.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	11 <i>0.6</i>	1
Craniosynostosis	1 <i>0.1</i>	1 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	8 <i>0.2</i>	
Deletion 22q11.2	4 <i>0.3</i>	2 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	7 <i>0.2</i>	
Diaphragmatic hernia	19 <i>1.2</i>	9 <i>0.8</i>	1 <i>0.2</i>	1 <i>0.4</i>	0 <i>0.0</i>	70 <i>1.9</i>	
Double outlet right ventricle	9 <i>0.6</i>	15 <i>1.3</i>	2 <i>0.3</i>	4 <i>1.5</i>	0 <i>0.0</i>	61 <i>1.7</i>	
Ebstein anomaly	4 <i>0.3</i>	1 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	8 <i>0.2</i>	
Encephalocele	3 <i>0.2</i>	4 <i>0.3</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	15 <i>0.4</i>	
Esophageal atresia/tracheoesophageal fistula	24 <i>1.5</i>	7 <i>0.6</i>	0 <i>0.0</i>	3 <i>1.1</i>	0 <i>0.0</i>	54 <i>1.5</i>	
Gastroschisis	33 <i>2.1</i>	14 <i>1.2</i>	1 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	74 <i>2.0</i>	
Holoprosencephaly	3 <i>0.2</i>	6 <i>0.5</i>	1 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	20 <i>0.6</i>	
Hypoplastic left heart syndrome	9 <i>0.6</i>	5 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	36 <i>1.0</i>	
Hypospadias	166 <i>20.5</i>	113 <i>19.1</i>	43 <i>14.3</i>	24 <i>17.4</i>	0 <i>0.0</i>	638 <i>34.4</i>	1
Interrupted aortic arch	16 <i>1.0</i>	13 <i>1.1</i>	0 <i>0.0</i>	2 <i>0.7</i>	0 <i>0.0</i>	62 <i>1.7</i>	

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

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Limb deficiencies (reduction defects)	9 <i>0.6</i>	9 <i>0.8</i>	5 <i>0.8</i>	0 <i>0.0</i>	1 <i>15.8</i>	49 <i>1.4</i>	
Omphalocele	9 <i>0.6</i>	9 <i>0.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	35 <i>1.0</i>	
Pulmonary valve atresia and stenosis	11 <i>0.7</i>	9 <i>0.8</i>	1 <i>0.2</i>	2 <i>0.7</i>	0 <i>0.0</i>	49 <i>1.4</i>	
Pulmonary valve atresia	3 <i>0.2</i>	2 <i>0.2</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	13 <i>0.4</i>	
Rectal and large intestinal atresia/stenosis	10 <i>0.6</i>	7 <i>0.6</i>	1 <i>0.2</i>	1 <i>0.4</i>	0 <i>0.0</i>	24 <i>0.7</i>	
Renal agenesis/hypoplasia	16 <i>1.0</i>	9 <i>0.8</i>	6 <i>1.0</i>	3 <i>1.1</i>	0 <i>0.0</i>	68 <i>1.9</i>	
Single ventricle	1 <i>0.1</i>	3 <i>0.3</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	9 <i>0.2</i>	
Small intestinal atresia/stenosis	3 <i>0.2</i>	9 <i>0.8</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	25 <i>0.7</i>	
Spina bifida without anencephalus	20 <i>1.3</i>	10 <i>0.9</i>	5 <i>0.8</i>	2 <i>0.7</i>	0 <i>0.0</i>	68 <i>1.9</i>	
Tetralogy of Fallot	36 <i>2.3</i>	17 <i>1.5</i>	1 <i>0.2</i>	2 <i>0.7</i>	0 <i>0.0</i>	94 <i>2.6</i>	
Total anomalous pulmonary venous connection	1 <i>0.1</i>	1 <i>0.1</i>	1 <i>0.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	11 <i>0.3</i>	
Transposition of the great arteries (TGA)	13 <i>0.8</i>	3 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	34 <i>0.9</i>	
Dextro-transposition of great arteries (d-TGA)	9 <i>0.6</i>	3 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	27 <i>0.7</i>	
Tricuspid valve atresia and stenosis	0 <i>0.0</i>	3 <i>0.3</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	10 <i>0.3</i>	
Tricuspid valve atresia	0 <i>0.0</i>	3 <i>0.3</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	10 <i>0.3</i>	
Trisomy 13	2 <i>0.1</i>	5 <i>0.4</i>	3 <i>0.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	32 <i>0.9</i>	
Trisomy 18	11 <i>0.7</i>	16 <i>1.4</i>	6 <i>1.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	80 <i>2.2</i>	
Trisomy 21 (Down syndrome)	78 <i>4.9</i>	54 <i>4.6</i>	31 <i>5.2</i>	7 <i>2.6</i>	0 <i>0.0</i>	325 <i>9.0</i>	
Turner syndrome	4 <i>0.5</i>	2 <i>0.3</i>	0 <i>0.0</i>	1 <i>0.8</i>	0 <i>0.0</i>	13 <i>0.7</i>	2
Ventricular septal defect	99 <i>6.3</i>	98 <i>8.4</i>	7 <i>1.2</i>	9 <i>3.3</i>	0 <i>0.0</i>	344 <i>9.5</i>	
<b>Total live births</b>	<b>157,911</b>	<b>116,701</b>	<b>59,231</b>	<b>27,027</b>	<b>631</b>	<b>362,831</b>	<b>3</b>
<b>Male live births</b>	<b>81,054</b>	<b>59,291</b>	<b>30,152</b>	<b>13,773</b>	<b>309</b>	<b>185,279</b>	
<b>Female live births</b>	<b>76,853</b>	<b>57,403</b>	<b>29,077</b>	<b>13,254</b>	<b>322</b>	<b>177,539</b>	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	35 <i>1.2</i>	2 <i>0.3</i>	74 <i>2.0</i>	
Trisomy 13	10 <i>0.3</i>	11 <i>1.4</i>	32 <i>0.9</i>	
Trisomy 18	28 <i>1.0</i>	32 <i>4.2</i>	80 <i>2.2</i>	
Trisomy 21 (Down syndrome)	100 <i>3.5</i>	114 <i>14.8</i>	325 <i>9.0</i>	
<b>Total live births</b>	<b>285,922</b>	<b>76,854</b>	<b>362,831</b>	<b>3</b>

**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. Prevalence is calculated per 10,000 female live births.
3. Data for total live births include unknown gender.

**General comments**

\*Data for totals include unknown and/or other.