

## Utah

### Utah Birth Defect Network (UBDN)

**Purpose:** Surveillance, Research, Referral to Prevention/Intervention Services, General Birth Defect Prevention Education

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

**Program status:** Currently collecting data

**Start year:** 1994

**Earliest year of available data:** 1994

**Organizational location:** Department of Health (Division of Family Health and Preparedness, Bureau of Children with Special Health Care Needs)

**Population covered annually:** 48,226 for 2018

**Statewide:** Yes

**Current legislation or rule:** Birth Defects and Critical Congenital Heart Disease Reporting Rule (R398-5)

**Legislation year enacted:** 1999

#### Case Definition

**Outcomes covered:** Major structural and genetic defects identified by CDC and NBDPN.

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)

**Age:** 2 years based on mandatory reporting

**Residence:** Utah maternal residence, in and out of state births to state residents

#### Surveillance Methods

**Case ascertainment:** Combination of active and passive case ascertainment; population-based

**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, CCHD screening program, Autism Registry

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, Champions report live births delivered at their respective hospitals

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, Cardiac catheterization laboratories, Specialty outpatient clinics

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

**Other sources:** Physician reports, Midwives

#### 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 procedure codes, 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 infants in NICU or special care nursery, All prenatally diagnosed or suspected cases, All fetal death certificates, NICU reports, infant deaths are reviewed

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Auditory/hearing 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.), Illnesses/conditions, Family history

#### 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.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff using remote access from office (laptop, web-based, etc.)

**Database collection and storage:** Access

#### Data Analysis

**Data analysis software:** SAS, Access

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, Logical checks, duplicate check in tracking and surveillance module, case record form checked for completeness, timeliness through system

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention, International Clearinghouse for Birth Defects, Local studies

#### System Integration

**System links:** Link to other state registries/databases, Link to environmental databases, Link to Utah genealogic population database, Link to vital records

**System integration:** The database is linked with birth, death, and pulse oximetry screening data. Newborns having failed Pulse Oximetry Screening are integrated with UBDN.

#### Funding

**Funding source:** 7% General state funds, 66% MCH funds, 27% CDC grant

#### Other

**Web site:** <http://www.health.utah.gov/birthdefect>

**Surveillance reports on file:** [Http://ibis.health.utah.gov](http://ibis.health.utah.gov)

**Other comments:** IBIS indicators are online.

#### Contacts

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## **DATA TABLES**

## Utah 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	34 <i>1.8</i>	0 <i>0.0</i>	8 <i>2.0</i>	2 <i>2.1</i>	0 <i>0.0</i>	46 <i>1.9</i>	
Anophthalmia/microphthalmia	35 <i>1.8</i>	0 <i>0.0</i>	8 <i>2.0</i>	2 <i>2.1</i>	0 <i>0.0</i>	46 <i>1.9</i>	
Anotia/microtia	44 <i>2.3</i>	0 <i>0.0</i>	22 <i>5.6</i>	6 <i>6.2</i>	1 <i>4.0</i>	74 <i>3.0</i>	
Aortic valve stenosis	78 <i>4.1</i>	1 <i>3.0</i>	9 <i>2.3</i>	3 <i>3.1</i>	0 <i>0.0</i>	92 <i>3.7</i>	
Atrial septal defect	520 <i>27.5</i>	10 <i>30.1</i>	122 <i>31.1</i>	28 <i>28.9</i>	12 <i>48.4</i>	713 <i>28.7</i>	1
Atrioventricular septal defect (Endocardial cushion defect)	113 <i>6.0</i>	1 <i>3.0</i>	16 <i>4.1</i>	7 <i>7.2</i>	0 <i>0.0</i>	143 <i>5.8</i>	
Biliary atresia	17 <i>0.9</i>	1 <i>3.0</i>	1 <i>0.3</i>	3 <i>3.1</i>	1 <i>4.0</i>	24 <i>1.0</i>	
Bladder exstrophy	6 <i>0.3</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	25 <i>1.3</i>	1 <i>3.0</i>	3 <i>0.8</i>	0 <i>0.0</i>	1 <i>4.0</i>	31 <i>1.2</i>	
Cleft lip alone	91 <i>4.8</i>	1 <i>3.0</i>	19 <i>4.8</i>	9 <i>9.3</i>	0 <i>0.0</i>	126 <i>5.1</i>	
Cleft lip with cleft palate	140 <i>7.4</i>	2 <i>6.0</i>	27 <i>6.9</i>	2 <i>2.1</i>	3 <i>12.1</i>	177 <i>7.1</i>	
Cleft palate alone	133 <i>7.0</i>	0 <i>0.0</i>	41 <i>10.5</i>	3 <i>3.1</i>	1 <i>4.0</i>	186 <i>7.5</i>	
Cloacal exstrophy	1 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>0.0</i>	
Clubfoot	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	
Coarctation of the aorta	183 <i>9.7</i>	3 <i>9.0</i>	43 <i>11.0</i>	6 <i>6.2</i>	2 <i>8.1</i>	243 <i>9.8</i>	
Common truncus (truncus arteriosus)	15 <i>0.8</i>	0 <i>0.0</i>	5 <i>1.3</i>	0 <i>0.0</i>	1 <i>4.0</i>	22 <i>0.9</i>	
Congenital cataract	68 <i>3.6</i>	0 <i>0.0</i>	16 <i>4.1</i>	3 <i>3.1</i>	0 <i>0.0</i>	89 <i>3.6</i>	
Congenital posterior urethral valves	18 <i>1.9</i>	0 <i>0.0</i>	3 <i>1.5</i>	1 <i>2.0</i>	0 <i>0.0</i>	24 <i>1.9</i>	2
Craniosynostosis	229 <i>12.1</i>	1 <i>3.0</i>	43 <i>11.0</i>	0 <i>0.0</i>	2 <i>8.1</i>	281 <i>11.3</i>	
Deletion 22q11.2	26 <i>1.4</i>	0 <i>0.0</i>	7 <i>1.8</i>	1 <i>1.0</i>	1 <i>4.0</i>	35 <i>1.4</i>	
Diaphragmatic hernia	80 <i>4.2</i>	1 <i>3.0</i>	24 <i>6.1</i>	6 <i>6.2</i>	0 <i>0.0</i>	114 <i>4.6</i>	
Double outlet right ventricle	45 <i>2.4</i>	2 <i>6.0</i>	8 <i>2.0</i>	5 <i>5.2</i>	0 <i>0.0</i>	63 <i>2.5</i>	
Ebstein anomaly	20 <i>1.1</i>	0 <i>0.0</i>	6 <i>1.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	27 <i>1.1</i>	
Encephalocele	21 <i>1.1</i>	1 <i>3.0</i>	3 <i>0.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	26 <i>1.0</i>	
Esophageal atresia/tracheoesophageal fistula	63 <i>3.3</i>	1 <i>3.0</i>	14 <i>3.6</i>	3 <i>3.1</i>	1 <i>4.0</i>	86 <i>3.5</i>	
Gastroschisis	78 <i>4.1</i>	1 <i>3.0</i>	21 <i>5.4</i>	5 <i>5.2</i>	2 <i>8.1</i>	109 <i>4.4</i>	
Holoprosencephaly	41 <i>2.2</i>	2 <i>6.0</i>	7 <i>1.8</i>	1 <i>1.0</i>	1 <i>4.0</i>	52 <i>2.1</i>	
Hypoplastic left heart syndrome	71 <i>3.8</i>	1 <i>3.0</i>	16 <i>4.1</i>	2 <i>2.1</i>	1 <i>4.0</i>	97 <i>3.9</i>	
Hypospadias	736 <i>75.8</i>	12 <i>69.5</i>	63 <i>31.3</i>	23 <i>46.1</i>	8 <i>64.4</i>	863 <i>67.7</i>	2
Interrupted aortic arch	13 <i>0.7</i>	0 <i>0.0</i>	1 <i>0.3</i>	0 <i>0.0</i>	1 <i>4.0</i>	15 <i>0.6</i>	

**Utah**  
**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)	96 <i>5.1</i>	1 <i>3.0</i>	31 <i>7.9</i>	3 <i>3.1</i>	2 <i>8.1</i>	143 <i>5.8</i>	
Omphalocele	59 <i>3.1</i>	2 <i>6.0</i>	12 <i>3.1</i>	2 <i>2.1</i>	0 <i>0.0</i>	77 <i>3.1</i>	
Pulmonary valve atresia and stenosis	233 <i>12.3</i>	6 <i>18.1</i>	59 <i>15.1</i>	14 <i>14.4</i>	2 <i>8.1</i>	320 <i>12.9</i>	
Pulmonary valve atresia	24 <i>1.3</i>	0 <i>0.0</i>	7 <i>1.8</i>	4 <i>4.1</i>	0 <i>0.0</i>	35 <i>1.4</i>	
Rectal and large intestinal atresia/stenosis	80 <i>4.2</i>	1 <i>3.0</i>	15 <i>3.8</i>	3 <i>3.1</i>	2 <i>8.1</i>	105 <i>4.2</i>	
Renal agenesis/hypoplasia	91 <i>4.8</i>	2 <i>6.0</i>	21 <i>5.4</i>	8 <i>8.3</i>	1 <i>4.0</i>	129 <i>5.2</i>	
Single ventricle	7 <i>0.4</i>	0 <i>0.0</i>	1 <i>0.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	8 <i>0.3</i>	
Small intestinal atresia/stenosis	59 <i>3.1</i>	2 <i>6.0</i>	20 <i>5.1</i>	4 <i>4.1</i>	1 <i>4.0</i>	87 <i>3.5</i>	
Spina bifida without anencephalus	86 <i>4.5</i>	1 <i>3.0</i>	17 <i>4.3</i>	1 <i>1.0</i>	1 <i>4.0</i>	111 <i>4.5</i>	
Tetralogy of Fallot	61 <i>3.2</i>	1 <i>3.0</i>	17 <i>4.3</i>	4 <i>4.1</i>	2 <i>8.1</i>	89 <i>3.6</i>	
Total anomalous pulmonary venous connection	20 <i>1.1</i>	0 <i>0.0</i>	12 <i>3.1</i>	1 <i>1.0</i>	0 <i>0.0</i>	34 <i>1.4</i>	
Transposition of the great arteries (TGA)	63 <i>3.3</i>	1 <i>3.0</i>	11 <i>2.8</i>	3 <i>3.1</i>	1 <i>4.0</i>	80 <i>3.2</i>	
Dextro-transposition of great arteries (d-TGA)	55 <i>2.9</i>	0 <i>0.0</i>	10 <i>2.6</i>	3 <i>3.1</i>	1 <i>4.0</i>	70 <i>2.8</i>	
Tricuspid valve atresia and stenosis	23 <i>1.2</i>	0 <i>0.0</i>	6 <i>1.5</i>	1 <i>1.0</i>	0 <i>0.0</i>	30 <i>1.2</i>	
Tricuspid valve atresia	12 <i>0.6</i>	0 <i>0.0</i>	3 <i>0.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	15 <i>0.6</i>	
Trisomy 13	28 <i>1.5</i>	2 <i>6.0</i>	6 <i>1.5</i>	2 <i>2.1</i>	0 <i>0.0</i>	42 <i>1.7</i>	
Trisomy 18	59 <i>3.1</i>	4 <i>12.0</i>	14 <i>3.6</i>	7 <i>7.2</i>	1 <i>4.0</i>	89 <i>3.6</i>	
Trisomy 21 (Down syndrome)	330 <i>17.4</i>	8 <i>24.1</i>	85 <i>21.7</i>	19 <i>19.6</i>	10 <i>40.3</i>	467 <i>18.8</i>	
Turner syndrome	48 <i>5.2</i>	0 <i>0.0</i>	14 <i>7.3</i>	1 <i>2.1</i>	0 <i>0.0</i>	66 <i>5.5</i>	3
Ventricular septal defect	477 <i>25.2</i>	13 <i>39.1</i>	113 <i>28.8</i>	25 <i>25.8</i>	10 <i>40.3</i>	662 <i>26.7</i>	
<b>Total live births</b>	<b>189,236</b>	<b>3,321</b>	<b>39,191</b>	<b>9,689</b>	<b>2,481</b>	<b>248,215</b>	<b>4</b>
<b>Male live births</b>	<b>97,158</b>	<b>1,727</b>	<b>20,116</b>	<b>4,991</b>	<b>1,243</b>	<b>127,484</b>	
<b>Female live births</b>	<b>92,078</b>	<b>1,593</b>	<b>19,074</b>	<b>4,697</b>	<b>1,238</b>	<b>120,727</b>	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	105 <i>4.9</i>	4 <i>1.1</i>	109 <i>4.4</i>	
Trisomy 13	26 <i>1.2</i>	16 <i>4.5</i>	42 <i>1.7</i>	
Trisomy 18	47 <i>2.2</i>	42 <i>11.9</i>	89 <i>3.6</i>	
Trisomy 21 (Down syndrome)	233 <i>11.0</i>	234 <i>66.3</i>	467 <i>18.8</i>	
<b>Total live births</b>	<b>212,745</b>	<b>35,269</b>	<b>248,215</b>	<b>4</b>

**Notes**

1. Data for this condition exclude isolated secundum atrial septal defect beginning in 2014.
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. Prevalence 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.