Major Birth Defects Data from Population-based Birth Defects Surveillance Programs in the United States, 2016-2020

Intro

The first Congenital Malformations Surveillance Report was published by the National Birth Defects Prevention Network (NBDPN) in 1997. The NBDPN then began publishing state-specific counts and prevalence of birth defects and a directory of state-based birth defects surveillance programs on an annual basis in 2000. This information was first published in the journal Birth Defects Research Part A and later in the journal Birth Defects Research. Beginning in 2021 this same data will be published on a biennual basis on the NBDPN website (nbdpn.org).

Data Collection

The call for data for the 2023 report was distributed in March 2023 to population-based birth defects surveillance systems by the National Birth Defects Prevention Network (NBDPN) Surveillance Data Committee. Surveillance programs were provided with a data dictionary, and data collection tools that facilitated data collection.

Participating programs submitted data on case counts and live births occurring from January 1, 2016 to December 31, 2020. Case data was requested for the 47 major birth defects in Table 1 by the following maternal and infant covariates: maternal race/ethnicity, maternal age at delivery, year of delivery, and infant sex. Pregnancy outcome of the case was also submitted for select programs or birth defects. Similar covariates were collected for live birth denominator data with the exception of pregnancy outcome.

The values submitted for maternal race/ethnicity were stratified by the US. Census groups: non-Hispanic white, non-Hispanic black, Hispanic, non-Hispanic Asian/Pacific Islander, non-Hispanic American Indian/Alaska Native, and other/unknown. Maternal age at delivery was grouped into seven categories: <20, 20-24, 25-29, 30-34, 35-39, 40+ and unknown. For infant sex cases were classified as either male, female, or unknown. The categories used for pregnancy outcome were live births, fetal deaths, terminations, unspecified non-live births, and unknown. Data was submitted in either SAS or Microsoft Excel.

Birth defects surveillance programs also submitted information for the program directory regarding case definition, surveillance methods, case ascertainment, data collection procedures, data analysis, funding, and program contact information. Material for the directory was collected using a standardized form.

Data presentation

Program-specific data is presented in two tables a) counts and prevalences for the 47 major birth defects by the maternal race/ethnicity categories provided above and b) counts and prevalences for selected birth defects in the chromosomal and musculoskeletal organ systems by two maternal age categories (less than 35 years, and 35+ years). Prevalence for all birth defects in table 1 except Turner syndrome, congenital posterior urethral valves, and hypospadias is calculated as, the number of cases of each birth defect within each stratum (the numerator) divided by the total number of live births within each stratum (the denominator), multiplied by 10,000. For Turner syndrome female live births are used as the denominator in prevalence calculations, for congenital posterior urethral valves and hypospadias male live births are used as the denominator.

Data quality checks and data analysis were performed using SAS Version 9.4 (SAS Institute, Cary, NC). Due to variation in surveillance methodologies used by participating programs, footnotes are provided for each table indicating where programs may have used different definitions or inclusion/exclusion criteria than those specified by NBDPN. A more in-depth description of the case-ascertainment methodology, birth outcomes monitored, data sources used, and other sources of variation between surveillance systems can be found in the program directory. The prepared data tables and directory were approved by the birth defects surveillance programs in October 2023.

Table 1
Birth defects for the National Birth Defects Prevention Network (NBDPN) annual report by disease classification codes

Birth Defects	ICD-10-CM Codes	CDC/BPA Codes
Central Nervous System		
Anencephaly	Q00.0 – Q00.1	740.00 – 740.10
Spina bifida without anencephaly	Q05.0 – Q05.9, Q07.01, Q07.03 w/o Q00.0 – Q00.1	741.00 – 741.99 w/o 740.00 – 740.10
Encephalocele	Q01.0 – Q01.9	742.00 – 742.09
Holoprosencephaly	Q04.2	742.26
Eye		
Anophthalmia/microphthalmia	Q11.0 – Q11.2	743.00 – 743.10
Congenital cataract	Q12.0	743.32
Ear		
Anotia/microtia	Q16.0, Q17.2	744.01, 744.21
Cardiovascular		
Common truncus (truncus arteriosus or TA)	Q20.0	745.00 (excluding 745.01)
Transposition of the great arteries (TGA)	Q20.3, Q20.5	745.10 – 745.12, 745.18 – 745.19
Dextro-Transposition of great arteries (d-TGA) – for CCHD screening	Q20.3	745.10, 745.11, 745.18, 745.19
Tetralogy of Fallot (TOF)	Q21.3	745.20 – 745.21, 747.31
Ventricular septal defect	Q21.0	745.40 – 745.49 (excluding 745.487, 745.498)
Atrial septal defect	Q21.1	745.51 – 745.59
Atrioventricular septal defect (endocardial cushion defect)	Q21.2	745.60 – 745.69, 745.487
Pulmonary valve atresia and stenosis	Q22.0, Q22.1	746.00, 746.01
Pulmonary valve atresia – for CCHD screening	Q22.0	746.00
Tricuspid valve atresia and stenosis	Q22.4	746.100, 746.106 (excluding 746.105)
Tricuspid valve atresia– for CCHD screening	Q22.4	746.100
Ebstein anomaly	Q22.5	746.20
Aortic valve stenosis	Q23.0	746.30
Hypoplastic left heart syndrome	Q23.4	746.70
Coarctation of aorta	Q25.1	747.10 – 747.19

Birth Defects	ICD-10-CM Codes	CDC/BPA Codes
Total anomalous pulmonary venous connection (TAPVC)	Q26.2	747.42
Single ventricle	Q20.4	745.3
Interrupted aortic arch (IAA)	Prior to 10/1/2016: Q25.2, Q25.4 Post 10/1/2016: Q25.21	747.215 – 747.217, 747.285
Double outlet right ventricle (DORV)	Q20.1	745.13 – 745.15
Orofacial		
Cleft palate alone (without cleft lip)	Q35.1 – Q35.9	749.00 – 749.09
Cleft lip alone (without cleft palate)	Q36.0 – Q36.9	749.10 – 749.19
Cleft lip with cleft palate	Q37.0 – Q37.9	749.20 – 749.29
Choanal atresia	Q30.0	748.00
Gastrointestinal		
Esophageal atresia / tracheoesophageal fistula	Q39.0 – Q39.4	750.30 – 750.35
Rectal and large intestinal atresia/stenosis	Q42.0 – Q42.9	751.20 – 751.24
Biliary atresia	Q44.2 – Q44.3	751.65
Small intestinal atresia/stenosis	Q41.0 – Q41.9	751.10 – 751.19
Genitourinary		
Renal agenesis/hypoplasia	Q60.0 – Q60.6	753.00 – 753.01
Bladder exstrophy	Q64.10, Q64.19	753.50
Hypospadias	Q54.0 – Q54.9 (excluding Q54.4)	752.60 – 752.62 (excluding 752.61 and 752.621)
Congenital posterior urethral valves	Q64.2	753.60
Cloacal exstrophy	Q64.12	751.555
Musculoskeletal		
Gastroschisis	Q79.3	756.71
Omphalocele	Q79.2	756.70
Diaphragmatic hernia	Q79.0, Q79.1	756.60, 756.610 – 756.617
Limb deficiencies (reduction defects)	Q71.0 – Q71.9, Q72.0 – Q72.9, Q73.0 – Q73.8	755.20 – 755.49
Craniosynostosis	Q75.0	756.00 – 756.03
Clubfoot	Q66.0, Q66.89	754.50, 754.73 (excluding 754.735)
Chromosomal		
Trisomy 13	Q91.4 – Q91.7	758.10 – 758.19

Birth Defects	ICD-10-CM Codes	CDC/BPA Codes
Trisomy 21 (Down syndrome)	Q90.0 – Q90.9	758.00 – 758.09
Trisomy 18	Q91.0 – Q91.3	758.20 – 758.29
Turner syndrome	Q96.0 – Q96.9	758.60 – 758.69
Deletion 22 q11.2	Q93.81	758.37

Acknowledgments: State birth defects program staff provided the information for the directory. Their names can be found under the 'contact' section of each state profile. We would also like to acknowledge the 40 population-based birth defects programs contributing data to this report:

Alaska Birth Defects Registry; Arizona Birth Defects Monitoring Program; Arkansas Reproductive Health Monitoring System; California Birth Defects Monitoring Program; Colorado Responds to Children with Special Needs Section; Delaware Birth Defects Registry; Florida Birth Defects Registry; Metropolitan Atlanta Congenital Defects Program; Hawaii Birth Defects Program; Illinois Adverse Pregnancy Outcomes Reporting System; Indiana Birth Defects and Problems Registry; Iowa Registry for Congenital and Inherited Disorders; Kansas Birth Defects Program; Kentucky Birth Surveillance Registry; Louisiana Birth Defects Monitoring Network; Maine CDC Birth Defects Program; Maryland Birth Defects Reporting and Information System; Massachusetts Birth Defects Monitoring Program; Michigan Birth Defects Registry; Minnesota Birth Defects Information System; Missouri Birth Defect Surveillance System; Nevada Birth Outcomes Monitoring System; New Jersey Special Child Health Services Registry; New Mexico Birth Defects Prevention and Surveillance System; New York State Birth Defects Registry; North Carolina Birth Defects Monitoring Program; Oklahoma Birth Defect Registry; Oregon Birth Anomalies Surveillance System; Puerto Rico Birth Defects Surveillance and Prevention System; Rhode Island Birth Defects Program; South Carolina Birth Defects Program; Tennessee Birth Defects Surveillance System; Texas Birth Defects Epidemiology and Surveillance Branch; Utah Birth Defect Network; Vermont Birth Information Network; Virginia Congenital Anomalies and Reporting Education System; Washington State Birth Defects Surveillance System; West Virginia Birth Defects Surveillance System; Wisconsin Birth Defect Prevention and Surveillance System; and the U.S. Department of Defense Birth and Infant Health Research Program.

Data tables are available on pages 5-124.

Program directories are available on pages 125-179.

DATA TABLES

Alaska

Birth Defects Counts and Prevalence 2016 - 2020 (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	<6	0 ***0.0***	<6	<6	<6	11 ***2.1***	
Anophthalmia/microphthalmia	7 ***2.5***	0 ***0.0***	0 ***0.0***	<6	<6	13 ***2.5***	
Anotia/microtia	11 ***3.9***	<6	<6	<6	8 ***7.3***	28 ***5.5***	
Aortic valve stenosis	7 ***2.5***	0 ***0.0***	<6	<6	<6	14 ***2.7***	
Atrial septal defect	368 ***130.4***	28 ***129.2***	59 ***149.2***	70 ***148.7***	326 ***295.8***	882 ***172.1***	
Atrioventricular septal defect (Endocardial cushion defect)	11 ***3.9***	<6	<6	<6	<6	21 ***4.1***	
Biliary atresia	6 ***2.1***	<6	0 ***0.0***	<6	13 ***11.8***	23 ***4.5***	
Bladder exstrophy	<6	0 ***0.0***	<6	0 ***0.0***	0 ***0.0***	<6	
Choanal atresia	10 ***3.5***	<6	<6	<6	<6	16 ***3.1***	
Cleft lip alone	16 ***5.7***	<6	<6	<6	19 ***17.2***	43 ***8.4***	
Cleft lip with cleft palate	19 ***6.7***	<6	<6	6 ***12.7***	21 ***19.1***	50 ***9.8***	
Cleft palate alone	43 ***15.2***	<6	6 ***15.2***	6 ***12.7***	47 ***42.6***	106 ***20.7***	
Cloacal exstrophy	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	
Clubfoot	71 ***25.2***	<6	13 ***32.9***	18 ***38.2***	33 ***29.9***	143 ***27.9***	
Coarctation of the aorta	16 ***5.7***	0 ***0.0***	<6	<6	6 ***5.4***	27 ***5.3***	
Common truncus (truncus arteriosus)	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	<6	
Congenital cataract	14 ***5.0***	<6	<6	0 ***0.0***	<6	21 ***4.1***	
Congenital posterior urethral valves	7 ***5.9***	0 ***0.0***	<6	0 ***0.0***	<6	12 ***5.6***	1
Craniosynostosis	75 ***26.6***	7 ***32.3***	11 ***27.8***	9 ***19.1***	42 ***38.1***	146 ***28.5***	
Deletion 22q11.2	<6	0 ***0.0***	0 ***0.0***	<6	<6	8 ***2.0***	
Diaphragmatic hernia	6 ***2.1***	0 ***0.0***	0 ***0.0***	<6	11 ***10.0***	20 ***3.9***	
Double outlet right ventricle	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	<6	
Ebstein anomaly	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	
Encephalocele	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	<6	
Esophageal atresia/tracheoesophageal fistula	<6	<6	0 ***0.0***	<6	<6	10 ***2.4***	
Gastroschisis	13 ***4.6***	<6	<6	6 ***12.7***	11 ***10.0***	37 ***7.2***	
Holoprosencephaly	13 ***4.6***	<6	<6	7 ***14.9***	23 ***20.9***	46 ***9.0***	
Hypoplastic left heart syndrome	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	
Hypospadias	148 ***102.1***	13 ***118.8***	9 ***44.4***	19 ***78.2***	38 ***67.0***	231 ***87.6***	1
Interrupted aortic arch	<6	0 ***0.0***	0 ***0.0***	<6	<6	11 ***2.1***	
Limb deficiencies (reduction defects)	24 ***8.5***	<6	<6	6 ***12.7***	10 ***9.1***	47 ***9.2***	
Omphalocele	95 ***33.7***	26 ***119.9***	15 ***37.9***	12 ***25.5***	34 ***30.9***	184 ***35.9***	
Pulmonary valve atresia and stenosis	26 ***9.2***	<6	<6	<6	33 ***29.9***	71 ***13.9***	

Alaska

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Rectal and large intestinal atresia/stenosis	10 ***3.5***	0 ***0.0***	<6	<6	16 ***14.5***	31 ***6.0***	
Renal agenesis/hypoplasia	25 ***8.9***	<6	<6	<6	7 ***6.4***	42 ***8.2***	
Single ventricle	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	<6	
Small intestinal atresia/stenosis	9 ***3.2***	<6	<6	<6	16 ***14.5***	30 ***5.9***	
Spina bifida without anencephalus	11 ***3.9***	<6	<6	<6	6 ***5.4***	24 ***4.7***	
Tetralogy of Fallot	6 ***2.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	12 ***2.3***	
Total anomalous pulmonary venous connection	<6	0 ***0.0***	<6	<6	6 ***6.8***	9 ***2.2***	
Transposition of the great arteries (TGA)	<6	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	7 ***2.2***	
Tricuspid valve atresia and stenosis	0 ***0.0***	0 ***0.0***	0 ***0.0***	<6	<6	<6	
Trisomy 13	<6	0 ***0.0***	<6	0 ***0.0***	0 ***0.0***	<6	
Trisomy 18	<6	<6	0 ***0.0***	<6	0 ***0.0***	<6	
Turner syndrome	<6	<6	0 ***0.0***	<6	<6	7 ***3.5***	2
Ventricular septal defect	178 ***63.1***	7 ***32.3***	21 ***53.1***	19 ***40.4***	180 ***163.3***	416 ***81.2***	
Total live births	**28,215**	**2,168**	**3,955**	**4,706**	**11,020**	**51,248**	
Male live births	**14,495**	**1,094**	**2,028**	**2,431**	**5,673**	**26,359**	
Female live births	**11,165**	**867**	**1,553**	**1,857**	**4,301**	**20,168**	

Alaska

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	36 ***8.3***	<6	37 ***7.2***	
Trisomy 13	<6	0 ***0.0***	<6	
Trisomy 18	<6	<6	<6	
Total live births	**43,229**	**8,014**	**51,248**	

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. Prevalance is calculated per 10,000 female live births.

General comments

*Data for totals include unknown and/or other.

Arizona

Birth Defects Counts and Prevalence 2016 - 2020 (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	24	4	25	4	3	61	
	1.5	***1.9***	***1.4***	***2.6***	***1.5***	***1.5***	
Anophthalmia/microphthalmia	11	1	18	3	4	37	
	0.7	***0.5***	***1.0***	***2.0***	***2.0***	***0.9***	
Anotia/microtia	33	0	58	5	4	100	
	2.1	***0.0***	***3.3***	***3.3***	***2.0***	***2.5***	
Aortic valve stenosis	21	1	25	0	4	52	
	1.3	***0.5***	***1.4***	***0.0***	***2.0***	***1.3***	
Atrioventricular septal defect (Endocardial cushion defect)	94	10	93	4	16	220	
	5.9	***4.8***	***5.3***	***2.6***	***8.1***	***5.5***	
Biliary atresia	12	2	13	1	1	29	
	0.7	***1.0***	***0.7***	***0.7***	***0.5***	***0.7***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	19	2	16	0	1	38	
	1.2	***1.0***	***0.9***	***0.0***	***0.5***	***0.9***	
Cleft lip alone	47	5	67	3	14	136	
	2.9	***2.4***	***3.8***	***2.0***	***7.1***	***3.4***	
Cleft lip with cleft palate	105	8	129	7	39	290	
	6.5	***3.8***	***7.4***	***4.6***	***19.8***	***7.2***	
Cleft palate alone	96	8	122	8	16	253	
	6.0	***3.8***	***7.0***	***5.2***	***8.1***	***6.3***	
Coarctation of the aorta	81	6	88	2	7	189	
	5.0	***2.9***	***5.0***	***1.3***	***3.6***	***4.7***	
Common truncus (truncus arteriosus)	6	0	10	1	2	19	
	0.4	***0.0***	***0.6***	***0.7***	***1.0***	***0.5***	
Congenital cataract	9	1	11	0	4	25	
	0.6	***0.5***	***0.6***	***0.0***	***2.0***	***0.6***	
Diaphragmatic hernia	51	7	62	3	4	128	
	3.2	***3.3***	***3.5***	***2.0***	***2.0***	***3.2***	
Double outlet right ventricle	30	3	50	2	8	93	
	1.9	***1.4***	***2.8***	***1.3***	***4.1***	***2.3***	
Ebstein anomaly	19	0	19	1	1	40	
	1.2	***0.0***	***1.1***	***0.7***	***0.5***	***1.0***	
Encephalocele	13	5	18	0	3	39	
	0.8	***2.4***	***1.0***	***0.0***	***1.5***	***1.0***	
Esophageal atresia/tracheoesophageal fistula	43	0	38	3	6	91	
	2.7	***0.0***	***2.2***	***2.0***	***3.1***	***2.3***	
Gastroschisis	71	9	125	2	17	227	
	4.4	***4.3***	***7.1***	***1.3***	***8.6***	***5.6***	
Holoprosencephaly	17	3	12	1	5	38	
	1.1	***1.4***	***0.7***	***0.7***	***2.5***	***0.9***	
Hypoplastic left heart syndrome	42	5	48	1	6	102	
	2.6	***2.4***	***2.7***	***0.7***	***3.1***	***2.5***	
Interrupted aortic arch	9	0	12	2	2	25	
	0.6	***0.0***	***0.7***	***1.3***	***1.0***	***0.6***	
Limb deficiencies (reduction defects)	41	12	69	2	5	133	
	2.6	***5.7***	***3.9***	***1.3***	***2.5***	***3.3***	
Omphalocele	33	9	34	4	4	86	
	2.1	***4.3***	***1.9***	***2.6***	***2.0***	***2.1***	
Pulmonary valve atresia and stenosis	63	4	60	5	15	150	
	3.9	***1.9***	***3.4***	***3.3***	***7.6***	***3.7***	
Pulmonary valve atresia	28	2	28	2	12	73	
	1.7	***1.0***	***1.6***	***1.3***	***6.1***	***1.8***	
Single ventricle	6	3	7	0	0	16	
	0.4	***1.4***	***0.4***	***0.0***	***0.0***	***0.4***	
Spina bifida without anencephalus	41	7	68	2	10	131	
	2.6	***3.3***	***3.9***	***1.3***	***5.1***	***3.3***	
Tetralogy of Fallot	60	13	62	7	7	150	
	3.7	***6.2***	***3.5***	***4.6***	***3.6***	***3.7***	
Total anomalous pulmonary venous connection	16	2	25	3	16	62	
	1.0	***1.0***	***1.4***	***2.0***	***8.1***	***1.5***	
Transposition of the great arteries (TGA)	38	5	45	6	2	98	
	2.4	***2.4***	***2.6***	***3.9***	***1.0***	***2.4***	
Dextro-transposition of great arteries (d-TGA)	33	4	36	6	1	81	
	2.1	***1.9***	***2.1***	***3.9***	***0.5***	***2.0***	

Arizona
Birth Defects Counts and Prevalence 2016 - 2020 (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**
Tricuspid valve atresia and stenosis	5	0	24	1	5	35	
	0.3	***0.0***	***1.4***	***0.7***	***2.5***	***0.9***	
Tricuspid valve atresia	4	0	21	1	2	28	
	0.2	***0.0***	***1.2***	***0.7***	***1.0***	***0.7***	
Trisomy 13	30	3	18	2	1	55	
	1.9	***1.4***	***1.0***	***1.3***	***0.5***	***1.4***	
Trisomy 18	49	11	48	4	10	125	
	3.1	***5.2***	***2.7***	***2.6***	***5.1***	***3.1***	
Trisomy 21 (Down syndrome)	216	28	288	15	27	581	
	13.5	***13.3***	***16.4***	***9.8***	***13.7***	***14.4***	
Total live births	**160,565**	**21,029**	**175,455**	**15,280**	**19,666**	**402,571**	**2**

Arizona

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	207	11	227	
	6.1	***1.7***	***5.6***	
Trisomy 13	29	16	55	
	0.9	***2.5***	***1.4***	
Trisomy 18	57	57	125	
	1.7	***8.9***	***3.1***	
Trisomy 21 (Down syndrome)	259	307	581	
	7.6	***48.1***	***14.4***	
Total live births	**338,684**	**63,875**	**402,571**	**2**

Notes
1. Data for this condition begin mid-year 2019. Counts and prevalence may reflect under-reporting.
2. Data for total live births include unknown gender.

General comments
*Data for totals include unknown and/or other.
-Data for all conditions delivered from 2019-2020 are provisional.

Arkansas

Birth Defects Counts and Prevalence 2016 - 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	16	1	0	0	0	18	
	2.2	***0.5***	***0.0***	***0.0***	***0.0***	***1.6***	
Anophthalmia/microphthalmia	14	6	2	0	0	22	
	1.9	***2.8***	***1.7***	***0.0***	***0.0***	***2.0***	
Anotia/microtia	24	3	4	0	0	31	
	3.3	***1.4***	***3.3***	***0.0***	***0.0***	***2.8***	
Aortic valve stenosis	25	4	0	1	0	30	
	3.4	***1.8***	***0.0***	***2.7***	***0.0***	***2.7***	
Atrial septal defect	291	81	16	13	1	413	
	39.7	***37.4***	***13.2***	***35.6***	***14.7***	***36.7***	
Atrioventricular septal defect (Endocardial cushion defect)	69	12	3	2	0	86	
	9.4	***5.5***	***2.5***	***5.5***	***0.0***	***7.6***	
Biliary atresia	4	1	0	1	0	6	
	0.5	***0.5***	***0.0***	***2.7***	***0.0***	***0.5***	
Bladder exstrophy	2	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	8	2	1	0	0	11	
	1.1	***0.9***	***0.8***	***0.0***	***0.0***	***1.0***	
Cleft lip alone	39	5	1	0	0	45	
	5.3	***2.3***	***0.8***	***0.0***	***0.0***	***4.0***	
Cleft lip with cleft palate	67	9	1	3	0	80	
	9.2	***4.2***	***0.8***	***8.2***	***0.0***	***7.1***	
Cleft palate alone	65	4	0	0	1	72	
	8.9	***1.8***	***0.0***	***0.0***	***14.7***	***6.4***	
Cloacal exstrophy	1	0	1	0	0	2	
	0.1	***0.0***	***0.8***	***0.0***	***0.0***	***0.2***	
Clubfoot	149	33	9	4	2	200	
	20.3	***15.2***	***7.4***	***11.0***	***29.3***	***17.8***	
Coarctation of the aorta	43	6	4	1	0	54	
	5.9	***2.8***	***3.3***	***2.7***	***0.0***	***4.8***	
Common truncus (truncus arteriosus)	2	2	0	0	0	4	
	0.3	***0.9***	***0.0***	***0.0***	***0.0***	***0.4***	
Congenital cataract	30	8	2	1	0	41	
	4.1	***3.7***	***1.7***	***2.7***	***0.0***	***3.6***	
Congenital posterior urethral valves	10	4	1	0	0	15	1
	2.7	***3.7***	***1.6***	***0.0***	***0.0***	***2.6***	
Craniosynostosis	80	15	3	3	1	106	
	10.9	***6.9***	***2.5***	***8.2***	***14.7***	***9.4***	
Deletion 22q11.2	14	1	1	0	0	16	
	1.9	***0.5***	***0.8***	***0.0***	***0.0***	***1.4***	
Diaphragmatic hernia	38	5	1	3	0	47	
	5.2	***2.3***	***0.8***	***8.2***	***0.0***	***4.2***	
Double outlet right ventricle	17	6	0	0	0	23	
	2.3	***2.8***	***0.0***	***0.0***	***0.0***	***2.0***	
Ebstein anomaly	12	1	0	1	0	14	
	1.6	***0.5***	***0.0***	***2.7***	***0.0***	***1.2***	
Encephalocele	6	3	0	1	0	10	
	0.8	***1.4***	***0.0***	***2.7***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	25	2	0	2	0	29	
	3.4	***0.9***	***0.0***	***5.5***	***0.0***	***2.6***	
Gastroschisis	57	8	3	1	1	70	
	7.8	***3.7***	***2.5***	***2.7***	***14.7***	***6.2***	
Holoprosencephaly	8	1	1	0	0	10	
	1.1	***0.5***	***0.8***	***0.0***	***0.0***	***0.9***	
Hypoplastic left heart syndrome	31	3	1	2	0	37	
	4.2	***1.4***	***0.8***	***5.5***	***0.0***	***3.3***	
Hypospadias	424	61	6	5	1	504	1
	112.6	***55.9***	***9.7***	***26.9***	***29.0***	***87.5***	
Interrupted aortic arch	11	2	0	0	0	13	
	1.5	***0.9***	***0.0***	***0.0***	***0.0***	***1.2***	
Limb deficiencies (reduction defects)	32	11	2	1	2	49	
	4.4	***5.1***	***1.7***	***2.7***	***29.3***	***4.4***	
Omphalocele	19	6	0	0	1	26	
	2.6	***2.8***	***0.0***	***0.0***	***14.7***	***2.3***	
Pulmonary valve atresia and stenosis	87	29	6	4	0	129	
	11.9	***13.4***	***5.0***	***11.0***	***0.0***	***11.5***	

Arkansas

Birth Defects Counts and Prevalence 2016 - 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**
Pulmonary valve atresia	7	6	0	1	0	14	
	1.0	***2.8***	***0.0***	***2.7***	***0.0***	***1.2***	
Rectal and large intestinal atresia/stenosis	31	10	4	0	0	45	
	4.2	***4.6***	***3.3***	***0.0***	***0.0***	***4.0***	
Renal agenesis/hypoplasia	11	3	1	1	0	16	
	1.5	***1.4***	***0.8***	***2.7***	***0.0***	***1.4***	
Single ventricle	5	0	0	0	0	5	
	0.7	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Small intestinal atresia/stenosis	30	11	0	1	0	42	
	4.1	***5.1***	***0.0***	***2.7***	***0.0***	***3.7***	
Spina bifida without anencephalus	36	5	0	0	0	41	
	4.9	***2.3***	***0.0***	***0.0***	***0.0***	***3.6***	
Tetralogy of Fallot	42	13	1	2	0	59	
	5.7	***6.0***	***0.8***	***5.5***	***0.0***	***5.2***	
Total anomalous pulmonary venous connection	10	3	1	1	0	15	
	1.4	***1.4***	***0.8***	***2.7***	***0.0***	***1.3***	
Transposition of the great arteries (TGA)	29	6	2	0	0	39	
	4.0	***2.8***	***1.7***	***0.0***	***0.0***	***3.5***	
Dextro-transposition of great arteries (d-TGA)	27	5	2	0	0	34	
	3.7	***2.3***	***1.7***	***0.0***	***0.0***	***3.0***	
Tricuspid valve atresia and stenosis	8	0	0	0	0	8	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Tricuspid valve atresia	8	0	0	0	0	8	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Trisomy 13	3	0	0	0	0	3	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Trisomy 18	20	7	1	0	0	28	
	2.7	***3.2***	***0.8***	***0.0***	***0.0***	***2.5***	
Trisomy 21 (Down syndrome)	136	18	8	8	1	171	
	18.6	***8.3***	***6.6***	***21.9***	***14.7***	***15.2***	
Turner syndrome	7	2	0	0	0	10	2
	2.0	***1.9***	***0.0***	***0.0***	***0.0***	***1.8***	
Ventricular septal defect	500	94	42	24	3	671	
	68.3	***43.4***	***34.7***	***65.8***	***44.0***	***59.6***	
Total live births	**73,222**	**21,649**	**12,113**	**3,650**	**682**	**112,533**	
Male live births	**37,647**	**10,903**	**6,201**	**1,860**	**345**	**57,579**	
Female live births	**35,575**	**10,746**	**5,912**	**1,790**	**337**	**54,954**	

Arkansas

Birth Defects Counts and Prevalence 2016 - 2018 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	67	3	70	
	6.7	***2.5***	***6.2***	
Trisomy 13	3	0	3	
	0.3	***0.0***	***0.3***	
Trisomy 18	19	9	28	
	1.9	***7.6***	***2.5***	
Trisomy 21 (Down syndrome)	88	82	171	
	8.7	***69.4***	***15.2***	
Total live births	**100,597**	**11,817**	**112,533**	

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. Prevalance is calculated per 10,000 female live births.

General comments

*Data for totals include unknown and/or other.

California

Birth Defects Counts and Prevalence 2016 - 2020 (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	8	<5	42	7	<5	93	
	1.1		***2.3***	***2.8***		***3.1***	
Anophthalmia/microphthalmia	5	<5	31	<5	0	43	
	0.7		***1.7***		***0.0***	***1.4***	
Anotia/microtia	12	6	80	11	<5	114	
	1.7	***4.3***	***4.5***	***4.3***		***3.8***	
Aortic valve stenosis	23	0	50	<5	0	79	
	3.2	***0.0***	***2.8***		***0.0***	***2.6***	
Atrial septal defect	176	38	404	58	<5	701	1
	24.2	***27.2***	***22.5***	***22.9***		***23.3***	
Atrioventricular septal defect (Endocardial cushion defect)	47	8	102	15	<5	180	
	6.5	***5.7***	***5.7***	***5.9***		***6.0***	
Biliary atresia	<5	<5	16	<5	0	25	
			0.9		***0.0***	***0.8***	
Bladder exstrophy	<5	0	<5	0	0	8	
		0.0		***0.0***	***0.0***	***0.3***	
Choanal atresia	5	0	12	<5	0	20	
	0.7	***0.0***	***0.7***		***0.0***	***0.7***	
Cleft lip alone	25	<5	67	12	<5	114	
	3.4		***3.7***	***4.7***		***3.8***	
Cleft lip with cleft palate	69	8	152	17	0	259	
	9.5	***5.7***	***8.5***	***6.7***	***0.0***	***8.6***	
Cleft palate alone	46	5	89	16	0	166	
	6.3	***3.6***	***5.0***	***6.3***	***0.0***	***5.5***	
Cloacal exstrophy	0	0	<5	0	0	<5	
	0.0	***0.0***		***0.0***	***0.0***		
Coarctation of the aorta	44	6	89	9	0	155	
	6.1	***4.3***	***5.0***	***3.6***	***0.0***	***5.2***	
Common truncus (truncus arteriosus)	<5	<5	13	<5	0	18	
			0.7		***0.0***	***0.6***	
Congenital cataract	9	<5	31	<5	0	46	
	1.2		***1.7***		***0.0***	***1.5***	
Congenital posterior urethral valves	12	<5	16	<5	0	32	2
	3.2		***1.8***		***0.0***	***2.1***	
Craniosynostosis	34	0	79	<5	0	120	
	4.7	***0.0***	***4.4***		***0.0***	***4.0***	
Deletion 22q11.2	8	<5	29	0	0	42	
	1.1		***1.6***	***0.0***	***0.0***	***1.4***	
Diaphragmatic hernia	24	<5	67	6	0	110	
	3.3		***3.7***	***2.4***	***0.0***	***3.7***	
Double outlet right ventricle	18	8	55	8	0	95	
	2.5	***5.7***	***3.1***	***3.2***	***0.0***	***3.2***	
Ebstein anomaly	8	<5	23	<5	0	37	
	1.1		***1.3***		***0.0***	***1.2***	
Encephalocele	6	0	23	<5	0	37	
	0.8	***0.0***	***1.3***		***0.0***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	13	<5	27	<5	0	51	
	1.8		***1.5***		***0.0***	***1.7***	
Gastroschisis	38	<5	89	10	<5	152	
	5.2		***5.0***	***3.9***		***5.1***	
Holoprosencephaly	<5	<5	21	<5	0	34	
			1.2		***0.0***	***1.1***	
Hypoplastic left heart syndrome	12	5	40	<5	0	69	
	1.7	***3.6***	***2.2***		***0.0***	***2.3***	
Hypospadias	228	31	268	49	<5	602	2
	61.2	***43.2***	***29.4***	***37.4***		***39.2***	
Interrupted aortic arch	<5	<5	14	<5	0	21	
			0.8		***0.0***	***0.7***	
Limb deficiencies (reduction defects)	20	5	73	5	0	120	
	2.8	***3.6***	***4.1***	***2.0***	***0.0***	***4.0***	
Omphalocele	10	<5	35	<5	<5	64	
	1.4		***1.9***			***2.1***	
Pulmonary valve atresia	11	<5	26	<5	0	49	
	1.5		***1.4***		***0.0***	***1.6***	
Rectal and large intestinal atresia/stenosis	12	<5	48	<5	<5	78	
	1.7		***2.7***			***2.6***	

California

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Renal agenesis/hypoplasia	27	5	91	11	0	142	
	3.7	***3.6***	***5.1***	***4.3***	***0.0***	***4.7***	
Single ventricle	10	<5	25	<5	0	40	
	1.4		***1.4***		***0.0***	***1.3***	
Small intestinal atresia/stenosis	19	7	72	8	<5	108	
	2.6	***5.0***	***4.0***	***3.2***		***3.6***	
Spina bifida without anencephalus	21	<5	79	5	<5	121	
	2.9		***4.4***	***2.0***		***4.0***	
Tetralogy of Fallot	33	6	85	12	0	146	
	4.5	***4.3***	***4.7***	***4.7***	***0.0***	***4.9***	
Total anomalous pulmonary venous connection	9	0	39	8	0	59	
	1.2	***0.0***	***2.2***	***3.2***	***0.0***	***2.0***	
Dextro-transposition of great arteries (d-TGA)	16	<5	36	9	0	65	
	2.2		***2.0***	***3.6***	***0.0***	***2.2***	
Tricuspid valve atresia	<5	<5	22	<5	0	31	
			1.2		***0.0***	***1.0***	
Trisomy 13	8	<5	20	<5	0	43	
	1.1		***1.1***		***0.0***	***1.4***	
Trisomy 18	12	<5	42	6	0	83	
	1.7		***2.3***	***2.4***	***0.0***	***2.8***	
Trisomy 21 (Down syndrome)	93	14	321	26	<5	514	
	12.8	***10.0***	***17.9***	***10.3***		***17.1***	
Turner syndrome	6	<5	28	<5	0	52	3
	1.7		***3.2***		***0.0***	***3.5***	
Ventricular septal defect	184	38	580	62	10	902	1
	25.3	***27.2***	***32.3***	***24.5***	***60.2***	***30.0***	
Total live births	**72,595**	**13,980**	**179,715**	**25,323**	**1,662**	**300,442**	**4**
Male live births	**37,282**	**7,172**	**91,275**	**13,107**	**857**	**153,426**	
Female live births	**35,313**	**6,808**	**88,439**	**12,216**	**805**	**147,015**	

California

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	146	5	152	
	5.7	***1.1***	***5.1***	
Trisomy 13	23	19	43	
	0.9	***4.1***	***1.4***	
Trisomy 18	40	43	83	
	1.6	***9.3***	***2.8***	
Trisomy 21 (Down syndrome)	225	289	514	
	8.9	***62.4***	***17.1***	
Total live births	**254,050**	**46,351**	**300,442**	**4**

Notes

1. Data for this condition include cases with congestive heart failue, confirmation by catheterization or surgery, or, beginning in 2018, confirmation by echochardio gram when the case was 6 weeks of age and the case had a minimum gestational age of 37 weeks.
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.

Colorado
Birth Defects Counts and Prevalence 2016 - 2020 (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	7	<5	7	<5	0	38	
	0.4		***0.8***		***0.0***	***1.2***	
Anophthalmia/microphthalmia	22	<5	13	0	<5	45	
	1.2		***1.4***	***0.0***		***1.4***	
Anotia/microtia	50	<5	38	<5	<5	96	
	2.6		***4.2***			***3.0***	
Aortic valve stenosis	37	<5	22	<5	<5	68	
	1.9		***2.4***			***2.1***	
Atrial septal defect	2,068	218	1,026	120	42	3,569	
	108.9	***139.6***	***113.1***	***88.9***	***213.5***	***112.1***	
Atrioventricular septal defect (Endocardial cushion defect)	69	7	35	5	0	127	
	3.6	***4.5***	***3.9***	***3.7***	***0.0***	***4.0***	
Biliary atresia	41	12	26	<5	<5	88	
	2.2	***7.7***	***2.9***			***2.8***	
Bladder exstrophy	<5	0	<5	0	0	<5	
		0.0		***0.0***	***0.0***		
Choanal atresia	38	<5	22	0	<5	71	
	2.0		***2.4***	***0.0***		***2.2***	
Cleft lip alone	70	6	32	5	<5	120	
	3.7	***3.8***	***3.5***	***3.7***		***3.8***	
Cleft lip with cleft palate	99	6	68	6	<5	194	
	5.2	***3.8***	***7.5***	***4.4***		***6.1***	
Cleft palate alone	156	13	80	16	5	289	
	8.2	***8.3***	***8.8***	***11.9***	***25.4***	***9.1***	
Cloacal exstrophy	<5	0	<5	0	0	<5	
		0.0		***0.0***	***0.0***		
Clubfoot	380	33	168	20	6	643	
	20.0	***21.1***	***18.5***	***14.8***	***30.5***	***20.2***	
Coarctation of the aorta	153	12	67	6	7	253	
	8.1	***7.7***	***7.4***	***4.4***	***35.6***	***7.9***	
Common truncus (truncus arteriosus)	13	<5	7	0	0	24	
	0.7		***0.8***	***0.0***	***0.0***	***0.8***	
Congenital cataract	44	<5	21	0	0	70	
	2.3		***2.3***	***0.0***	***0.0***	***2.2***	
Congenital posterior urethral valves	28	9	13	<5	0	57	1
	2.9	***11.5***	***2.8***		***0.0***	***3.5***	
Deletion 22q11.2	29	<5	13	<5	<5	56	
	1.5		***1.4***			***1.8***	
Diaphragmatic hernia	79	<5	32	5	<5	130	
	4.2		***3.5***	***3.7***		***4.1***	
Double outlet right ventricle	30	<5	24	0	<5	65	
	1.6		***2.6***	***0.0***		***2.0***	
Ebstein anomaly	13	0	8	<5	0	22	
	0.7	***0.0***	***0.9***		***0.0***	***0.7***	
Encephalocele	16	<5	8	0	<5	31	
	0.8		***0.9***	***0.0***		***1.0***	
Esophageal atresia/tracheoesophageal fistula	70	5	26	<5	0	113	
	3.7	***3.2***	***2.9***		***0.0***	***3.5***	
Gastroschisis	47	<5	39	<5	7	107	
	2.5		***4.3***		***35.6***	***3.4***	
Holoprosencephaly	7	<5	<5	<5	0	20	
	0.4				***0.0***	***0.6***	
Hypoplastic left heart syndrome	58	5	25	<5	<5	102	
	3.1	***3.2***	***2.8***			***3.2***	
Hypospadias	1,303	104	292	69	11	1,856	1
	134.2	***132.4***	***63.2***	***99.2***	***106.5***	***114.2***	
Interrupted aortic arch	34	6	24	<5	0	73	
	1.8	***3.8***	***2.6***		***0.0***	***2.3***	
Limb deficiencies (reduction defects)	66	<5	31	<5	<5	122	
	3.5		***3.4***			***3.8***	
Omphalocele	27	8	10	0	<5	61	
	1.4	***5.1***	***1.1***	***0.0***		***1.9***	
Pulmonary valve atresia and stenosis	127	21	65	9	6	243	
	6.7	***13.4***	***7.2***	***6.7***	***30.5***	***7.6***	
Pulmonary valve atresia	33	6	22	<5	<5	70	
	1.7	***3.8***	***2.4***			***2.2***	

Colorado

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Rectal and large intestinal atresia/stenosis	87 ***4.6***	8 ***5.1***	51 ***5.6***	12 ***8.9***	<5	165 ***5.2***	
Renal agenesis/hypoplasia	121 ***6.4***	6 ***3.8***	61 ***6.7***	10 ***7.4***	<5	224 ***7.0***	
Single ventricle	12 ***0.6***	<5	8 ***0.9***	<5	0 ***0.0***	24 ***0.8***	
Small intestinal atresia/stenosis	81 ***4.3***	12 ***7.7***	43 ***4.7***	<5	<5	141 ***4.4***	
Spina bifida without anencephalus	39 ***2.1***	5 ***3.2***	25 ***2.8***	<5	<5	81 ***2.5***	
Tetralogy of Fallot	67 ***3.5***	<5	33 ***3.6***	<5	5 ***25.4***	120 ***3.8***	
Total anomalous pulmonary venous connection	13 ***0.7***	<5	20 ***2.2***	<5	0 ***0.0***	41 ***1.3***	
Transposition of the great arteries (TGA)	53 ***2.8***	9 ***5.8***	22 ***2.4***	<5	0 ***0.0***	92 ***2.9***	
Dextro-transposition of great arteries (d-TGA)	49 ***2.6***	7 ***4.5***	18 ***2.0***	<5	0 ***0.0***	82 ***2.6***	
Tricuspid valve atresia and stenosis	11 ***0.6***	<5	6 ***0.7***	<5	0 ***0.0***	21 ***0.7***	
Trisomy 13	11 ***0.6***	0 ***0.0***	10 ***1.1***	0 ***0.0***	0 ***0.0***	57 ***1.8***	
Trisomy 18	18 ***0.9***	<5	12 ***1.3***	0 ***0.0***	0 ***0.0***	110 ***3.5***	
Trisomy 21 (Down syndrome)	217 ***11.4***	26 ***16.6***	160 ***17.6***	12 ***8.9***	<5	606 ***19.0***	
Turner syndrome	39 ***4.2***	<5	14 ***3.1***	<5	<5	88 ***5.6***	2
Ventricular septal defect	912 ***48.0***	98 ***62.7***	502 ***55.3***	58 ***43.0***	35 ***177.9***	1,680 ***52.8***	
Total live births	**189,877**	**15,619**	**90,731**	**13,498**	**1,967**	**318,357**	**3**
Male live births	**97,107**	**7,855**	**46,178**	**6,956**	**1,033**	**162,559**	
Female live births	**92,764**	**7,764**	**44,550**	**6,540**	**934**	**155,786**	

Colorado

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	104	<5	107	
	4.1		***3.4***	
Trisomy 13	23	13	57	
	0.9	***2.0***	***1.8***	
Trisomy 18	24	36	110	
	1.0	***5.5***	***3.5***	
Trisomy 21 (Down syndrome)	224	232	606	
	8.9	***35.3***	***19.0***	
Total live births	**252,564**	**65,643**	**318,357**	**3**

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. Prevalance 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.

Delaware

Birth Defects Counts and Prevalence 2016 - 2020 (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	4	2	0	0	0	6	
	1.5	***1.4***	***0.0***	***0.0***	***0.0***	***1.1***	
Anophthalmia/microphthalmia	1	4	2	0	0	7	
	0.4	***2.8***	***2.3***	***0.0***	***0.0***	***1.3***	
Anotia/microtia	10	1	5	2	0	18	
	3.8	***0.7***	***5.8***	***6.1***	***0.0***	***3.4***	
Aortic valve stenosis	9	1	2	1	0	13	
	3.5	***0.7***	***2.3***	***3.0***	***0.0***	***2.4***	
Atrial septal defect	86	60	35	11	1	195	1
	33.0	***41.5***	***40.6***	***33.3***	***58.8***	***36.7***	
Atrioventricular septal defect (Endocardial cushion defect)	18	11	12	2	1	46	
	6.9	***7.6***	***13.9***	***6.1***	***58.8***	***8.7***	
Biliary atresia	1	2	0	1	0	5	
	0.4	***1.4***	***0.0***	***3.0***	***0.0***	***0.9***	
Bladder exstrophy	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Choanal atresia	3	3	1	0	0	7	
	1.2	***2.1***	***1.2***	***0.0***	***0.0***	***1.3***	
Cleft lip alone	6	2	2	1	0	12	
	2.3	***1.4***	***2.3***	***3.0***	***0.0***	***2.3***	
Cleft lip with cleft palate	14	1	6	0	0	21	
	5.4	***0.7***	***7.0***	***0.0***	***0.0***	***4.0***	
Cleft palate alone	18	9	3	1	0	32	
	6.9	***6.2***	***3.5***	***3.0***	***0.0***	***6.0***	
Cloacal exstrophy	1	0	0	0	0	1	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Clubfoot	41	17	7	1	0	67	
	15.8	***11.8***	***8.1***	***3.0***	***0.0***	***12.6***	
Coarctation of the aorta	8	2	3	1	0	14	
	3.1	***1.4***	***3.5***	***3.0***	***0.0***	***2.6***	
Common truncus (truncus arteriosus)	0	1	1	0	0	2	
	0.0	***0.7***	***1.2***	***0.0***	***0.0***	***0.4***	
Congenital cataract	11	2	0	2	0	15	
	4.2	***1.4***	***0.0***	***6.1***	***0.0***	***2.8***	
Congenital posterior urethral valves	3	5	1	0	0	9	2
	2.2	***6.8***	***2.3***	***0.0***	***0.0***	***3.3***	
Craniosynostosis	16	7	4	1	0	29	
	6.1	***4.8***	***4.6***	***3.0***	***0.0***	***5.5***	
Deletion 22q11.2	3	5	2	0	0	10	
	1.2	***3.5***	***2.3***	***0.0***	***0.0***	***1.9***	
Diaphragmatic hernia	3	4	2	1	0	10	
	1.2	***2.8***	***2.3***	***3.0***	***0.0***	***1.9***	
Double outlet right ventricle	5	3	4	1	0	13	
	1.9	***2.1***	***4.6***	***3.0***	***0.0***	***2.4***	
Ebstein anomaly	1	1	1	0	0	3	
	0.4	***0.7***	***1.2***	***0.0***	***0.0***	***0.6***	
Encephalocele	6	1	0	0	0	7	
	2.3	***0.7***	***0.0***	***0.0***	***0.0***	***1.3***	
Esophageal atresia/tracheoesophageal fistula	8	7	2	1	0	18	
	3.1	***4.8***	***2.3***	***3.0***	***0.0***	***3.4***	
Gastroschisis	6	4	2	0	0	13	
	2.3	***2.8***	***2.3***	***0.0***	***0.0***	***2.4***	
Holoprosencephaly	1	0	3	0	0	4	
	0.4	***0.0***	***3.5***	***0.0***	***0.0***	***0.8***	
Hypoplastic left heart syndrome	2	5	2	1	0	10	
	0.8	***3.5***	***2.3***	***3.0***	***0.0***	***1.9***	
Hypospadias	103	80	14	8	1	208	3
	76.4	***109.2***	***32.1***	***45.8***	***112.4***	***76.2***	
Interrupted aortic arch	0	1	0	0	0	1	
	0.0	***0.7***	***0.0***	***0.0***	***0.0***	***0.2***	
Limb deficiencies (reduction defects)	21	9	6	3	0	39	
	8.1	***6.2***	***7.0***	***9.1***	***0.0***	***7.3***	
Omphalocele	7	4	3	0	0	14	
	2.7	***2.8***	***3.5***	***0.0***	***0.0***	***2.6***	
Pulmonary valve atresia and stenosis	33	27	9	4	0	76	
	12.7	***18.7***	***10.4***	***12.1***	***0.0***	***14.3***	

Delaware

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	2	1	0	0	0	3	
	0.8	***0.7***	***0.0***	***0.0***	***0.0***	***0.6***	
Rectal and large intestinal atresia/stenosis	11	10	2	1	1	25	
	4.2	***6.9***	***2.3***	***3.0***	***58.8***	***4.7***	
Renal agenesis/hypoplasia	19	4	3	1	0	28	
	7.3	***2.8***	***3.5***	***3.0***	***0.0***	***5.3***	
Single ventricle	1	0	0	1	0	2	
	0.4	***0.0***	***0.0***	***3.0***	***0.0***	***0.4***	
Small intestinal atresia/stenosis	3	7	3	0	0	13	
	1.2	***4.8***	***3.5***	***0.0***	***0.0***	***2.4***	
Spina bifida without anencephalus	7	3	4	1	0	15	
	2.7	***2.1***	***4.6***	***3.0***	***0.0***	***2.8***	
Tetralogy of Fallot	10	8	5	2	0	25	
	3.8	***5.5***	***5.8***	***6.1***	***0.0***	***4.7***	
Total anomalous pulmonary venous connection	1	2	1	0	0	4	
	0.4	***1.4***	***1.2***	***0.0***	***0.0***	***0.8***	
Transposition of the great arteries (TGA)	10	2	1	1	0	14	
	3.8	***1.4***	***1.2***	***3.0***	***0.0***	***2.6***	
Dextro-transposition of great arteries (d-TGA)	10	2	0	1	0	13	
	3.8	***1.4***	***0.0***	***3.0***	***0.0***	***2.4***	
Tricuspid valve atresia and stenosis	1	2	0	0	0	3	
	0.4	***1.4***	***0.0***	***0.0***	***0.0***	***0.6***	
Tricuspid valve atresia	0	1	0	0	0	1	
	0.0	***0.7***	***0.0***	***0.0***	***0.0***	***0.2***	
Trisomy 13	2	1	3	0	0	6	
	0.8	***0.7***	***3.5***	***0.0***	***0.0***	***1.1***	
Trisomy 18	2	5	5	0	0	12	
	0.8	***3.5***	***5.8***	***0.0***	***0.0***	***2.3***	
Trisomy 21 (Down syndrome)	33	25	24	4	1	91	
	12.7	***17.3***	***27.8***	***12.1***	***58.8***	***17.1***	
Turner syndrome	2	1	2	0	0	5	4
	1.6	***1.4***	***4.7***	***0.0***	***0.0***	***1.9***	
Ventricular septal defect	196	95	57	15	1	366	5
	75.3	***65.7***	***66.1***	***45.5***	***58.8***	***69.0***	
Total live births	**26,031**	**14,453**	**8,619**	**3,300**	**170**	**53,075**	
Male live births	**13,479**	**7,328**	**4,361**	**1,747**	**89**	**27,281**	
Female live births	**12,552**	**7,125**	**4,258**	**1,553**	**81**	**25,794**	

Delaware

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	13	0	13	
	3.0	***0.0***	***2.4***	
Trisomy 13	4	2	6	
	0.9	***2.2***	***1.1***	
Trisomy 18	5	7	12	
	1.1	***7.6***	***2.3***	
Trisomy 21 (Down syndrome)	36	55	91	
	8.2	***59.5***	***17.1***	
Total live births	**43,827**	**9,248**	**53,075**	

Notes

1. Data for this condition include atrial septal fenestrations and exclude atrial septal defects that self-close (not present after a month).
2. 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.
3. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
4. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
5. Data for this condition include all sizes and types of ventricular septal defects (VSD), including resolved VSDs.

General comments

*Data for totals include unknown and/or other.
-Data for all chromosomal defects require a cytogenetics report.
-Data for all conditions may include possible/probable diagnoses. Possible/probable cases are only included if the defect was found prenatally and the fetus died without a confirmatory autopsy or there is evidence of the anomaly present, but no confirmed follow up.
-Data for all heart defects require an echocardiogram report.

Florida

Birth Defects Counts and Prevalence 2016 - 2020 (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	38	19	29	<5	0	91	
	0.8	***0.8***	***0.9***		***0.0***	***0.8***	
Anophthalmia/microphthalmia	35	40	31	5	0	118	
	0.8	***1.7***	***0.9***	***1.5***	***0.0***	***1.1***	
Anotia/microtia	65	22	65	<5	0	165	
	1.4	***0.9***	***2.0***		***0.0***	***1.5***	
Aortic valve stenosis	68	8	33	<5	0	119	
	1.5	***0.3***	***1.0***		***0.0***	***1.1***	
Atrial septal defect	4,625	3,052	4,056	331	14	12,453	
	101.4	***131.5***	***122.8***	***99.0***	***122.0***	***114.0***	
Atrioventricular septal defect (Endocardial cushion defect)	191	144	99	9	<5	462	1
	4.2	***6.2***	***3.0***	***2.7***		***4.2***	
Biliary atresia	94	135	78	11	0	329	
	2.1	***5.8***	***2.4***	***3.3***	***0.0***	***3.0***	
Bladder exstrophy	15	<5	<5	0	0	21	
	0.3			***0.0***	***0.0***	***0.2***	
Choanal atresia	87	28	44	6	0	169	
	1.9	***1.2***	***1.3***	***1.8***	***0.0***	***1.5***	
Cleft lip alone	162	28	54	7	0	259	
	3.6	***1.2***	***1.6***	***2.1***	***0.0***	***2.4***	
Cleft lip with cleft palate	259	88	152	16	<5	538	
	5.7	***3.8***	***4.6***	***4.8***		***4.9***	
Cleft palate alone	287	86	142	23	0	555	
	6.3	***3.7***	***4.3***	***6.9***	***0.0***	***5.1***	
Cloacal exstrophy	6	<5	<5	0	0	8	
	0.1			***0.0***	***0.0***	***0.1***	
Clubfoot	1,078	442	675	63	5	2,338	
	23.6	***19.0***	***20.4***	***18.8***	***43.6***	***21.4***	
Coarctation of the aorta	289	133	168	22	0	637	
	6.3	***5.7***	***5.1***	***6.6***	***0.0***	***5.8***	
Common truncus (truncus arteriosus)	13	17	19	<5	0	56	
	0.3	***0.7***	***0.6***		***0.0***	***0.5***	
Congenital cataract	61	35	41	<5	0	142	
	1.3	***1.5***	***1.2***		***0.0***	***1.3***	
Congenital posterior urethral valves	58	53	28	<5	0	149	2
	2.5	***4.5***	***1.7***		***0.0***	***2.7***	
Craniosynostosis	299	79	162	10	0	563	
	6.6	***3.4***	***4.9***	***3.0***	***0.0***	***5.2***	
Deletion 22q11.2	18	11	20	<5	0	53	
	0.4	***0.5***	***0.6***		***0.0***	***0.5***	
Diaphragmatic hernia	167	95	95	14	0	383	
	3.7	***4.1***	***2.9***	***4.2***	***0.0***	***3.5***	
Double outlet right ventricle	99	73	60	<5	0	240	
	2.2	***3.1***	***1.8***		***0.0***	***2.2***	
Ebstein anomaly	32	12	27	5	0	86	
	0.7	***0.5***	***0.8***	***1.5***	***0.0***	***0.8***	
Encephalocele	41	19	21	0	0	84	
	0.9	***0.8***	***0.6***	***0.0***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	123	47	93	10	0	288	
	2.7	***2.0***	***2.8***	***3.0***	***0.0***	***2.6***	
Gastroschisis	193	56	103	<5	0	368	
	4.2	***2.4***	***3.1***		***0.0***	***3.4***	
Holoprosencephaly	42	40	22	<5	0	112	
	0.9	***1.7***	***0.7***		***0.0***	***1.0***	
Hypoplastic left heart syndrome	162	112	84	8	0	379	
	3.6	***4.8***	***2.5***	***2.4***	***0.0***	***3.5***	
Hypospadias	2,029	757	929	120	<5	3,958	2
	86.8	***64.1***	***54.9***	***69.4***		***70.8***	
Interrupted aortic arch	26	16	18	<5	0	66	3
	0.6	***0.7***	***0.5***		***0.0***	***0.6***	
Limb deficiencies (reduction defects)	126	95	113	<5	0	349	
	2.8	***4.1***	***3.4***		***0.0***	***3.2***	
Omphalocele	89	85	58	<5	0	245	
	2.0	***3.7***	***1.8***		***0.0***	***2.2***	
Pulmonary valve atresia and stenosis	321	282	419	15	0	1,087	
	7.0	***12.2***	***12.7***	***4.5***	***0.0***	***9.9***	

Florida

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	17	15	16	<5	0	53	4
	0.4	***0.6***	***0.5***		***0.0***	***0.5***	
Rectal and large intestinal atresia/stenosis	172	93	134	13	0	426	
	3.8	***4.0***	***4.1***	***3.9***	***0.0***	***3.9***	
Renal agenesis/hypoplasia	276	151	182	19	0	653	
	6.1	***6.5***	***5.5***	***5.7***	***0.0***	***6.0***	
Single ventricle	57	51	35	<5	0	149	
	1.2	***2.2***	***1.1***		***0.0***	***1.4***	
Small intestinal atresia/stenosis	169	114	103	11	0	407	
	3.7	***4.9***	***3.1***	***3.3***	***0.0***	***3.7***	
Spina bifida without anencephalus	133	48	80	<5	0	271	
	2.9	***2.1***	***2.4***		***0.0***	***2.5***	
Tetralogy of Fallot	240	149	137	16	<5	563	5
	5.3	***6.4***	***4.1***	***4.8***		***5.2***	
Total anomalous pulmonary venous connection	30	18	38	<5	0	89	
	0.7	***0.8***	***1.2***		***0.0***	***0.8***	
Transposition of the great arteries (TGA)	147	52	85	6	0	300	
	3.2	***2.2***	***2.6***	***1.8***	***0.0***	***2.7***	
Dextro-transposition of great arteries (d-TGA)	134	51	82	6	0	282	
	2.9	***2.2***	***2.5***	***1.8***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	33	29	26	<5	0	91	6
	0.7	***1.2***	***0.8***		***0.0***	***0.8***	
Trisomy 13	32	46	15	5	0	106	
	0.7	***2.0***	***0.5***	***1.5***	***0.0***	***1.0***	
Trisomy 18	58	72	59	<5	0	201	
	1.3	***3.1***	***1.8***		***0.0***	***1.8***	
Trisomy 21 (Down syndrome)	564	356	411	34	<5	1,424	
	12.4	***15.3***	***12.4***	***10.2***		***13.0***	
Turner syndrome	62	15	39	6	0	125	7
	2.8	***1.3***	***2.4***	***3.7***	***0.0***	***2.3***	
Ventricular septal defect	2,757	1,447	2,170	168	8	6,743	8
	60.4	***62.4***	***65.7***	***50.3***	***69.7***	***61.7***	
Total live births	**456,183**	**232,075**	**330,315**	**33,430**	**1,148**	**1,092,491**	**9**
Male live births	**233,687**	**118,027**	**169,257**	**17,282**	**573**	**558,985**	
Female live births	**222,489**	**114,045**	**161,054**	**16,146**	**575**	**533,487**	

Florida

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	343	25	368	
	3.9	***1.2***	***3.4***	
Trisomy 13	55	51	106	
	0.6	***2.4***	***1.0***	
Trisomy 18	91	110	201	
	1.0	***5.3***	***1.8***	
Trisomy 21 (Down syndrome)	665	759	1,424	
	7.5	***36.3***	***13.0***	
Total live births	**883,273**	**209,149**	**1,092,491**	**9**

Notes

1. Data for this condition include canal type atrioventricular septal defect.
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 are based on code Q25.21.
4. Data for this condition exclude cases with a co-occurring ventricular septal defect.
5. Data for this condition include cases of pulmonary atresia that co-occurred with ventricular septal defect.
6. Data for this condition include congenital tricuspid stenosis.
7. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
8. Data for this condition include probable cases.
9. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.
-Data for all conditions include live births only.

Georgia (Metropolitan Atlanta Congenital Defects Program)

Birth Defects Counts and Prevalence 2016 - 2020 (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	<5	8	<5	<5	0	16	
		1.1			***0.0***	***0.9***	
Anophthalmia/microphthalmia	8	12	<5	0	0	22	
	1.8	***1.7***		***0.0***	***0.0***	***1.3***	
Anotia/microtia	9	9	21	<5	0	45	
	2.0	***1.2***	***6.7***		***0.0***	***2.6***	
Aortic valve stenosis	11	12	<5	5	0	30	
	2.5	***1.7***		***3.1***	***0.0***	***1.8***	
Atrial septal defect	106	209	83	35	0	442	
	23.7	***28.9***	***26.3***	***21.6***	***0.0***	***25.8***	
Atrioventricular septal defect (Endocardial cushion defect)	17	58	18	7	0	102	
	3.8	***8.0***	***5.7***	***4.3***	***0.0***	***6.0***	
Biliary atresia	<5	<5	5	<5	0	14	
			1.6		***0.0***	***0.8***	
Bladder exstrophy	0	<5	0	0	0	<5	
	0.0		***0.0***	***0.0***	***0.0***		
Choanal atresia	5	<5	<5	<5	0	14	
	1.1				***0.0***	***0.8***	
Cleft lip alone	11	14	6	5	0	40	
	2.5	***1.9***	***1.9***	***3.1***	***0.0***	***2.3***	
Cleft lip with cleft palate	22	33	19	7	0	82	
	4.9	***4.6***	***6.0***	***4.3***	***0.0***	***4.8***	
Cleft palate alone	29	28	20	18	0	97	
	6.5	***3.9***	***6.3***	***11.1***	***0.0***	***5.7***	
Cloacal exstrophy	0	<5	0	<5	0	<5	
	0.0		***0.0***		***0.0***		
Clubfoot	63	124	43	15	<5	259	
	14.1	***17.2***	***13.6***	***9.2***		***15.1***	
Coarctation of the aorta	29	35	11	12	0	89	
	6.5	***4.8***	***3.5***	***7.4***	***0.0***	***5.2***	
Common truncus (truncus arteriosus)	<5	<5	<5	0	0	7	
				0.0	***0.0***	***0.4***	
Congenital cataract	14	17	6	<5	0	41	
	3.1	***2.4***	***1.9***		***0.0***	***2.4***	
Congenital posterior urethral valves	<5	18	<5	6	0	32	1
		4.9		***7.2***	***0.0***	***3.7***	
Craniosynostosis	50	36	17	10	0	120	
	11.2	***5.0***	***5.4***	***6.2***	***0.0***	***7.0***	
Deletion 22q11.2	8	23	<5	<5	0	39	
	1.8	***3.2***			***0.0***	***2.3***	
Diaphragmatic hernia	9	17	11	<5	<5	41	
	2.0	***2.4***	***3.5***			***2.4***	
Double outlet right ventricle	7	23	9	<5	0	43	
	1.6	***3.2***	***2.9***		***0.0***	***2.5***	
Ebstein anomaly	<5	<5	<5	<5	0	10	
					0.0	***0.6***	
Encephalocele	<5	9	<5	<5	0	16	
		1.2			***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	12	21	7	<5	0	44	
	2.7	***2.9***	***2.2***		***0.0***	***2.6***	
Gastroschisis	10	15	12	0	0	42	
	2.2	***2.1***	***3.8***	***0.0***	***0.0***	***2.5***	
Holoprosencephaly	<5	15	<5	<5	0	23	
		2.1			***0.0***	***1.3***	
Hypoplastic left heart syndrome	10	20	<5	0	0	36	
	2.2	***2.8***		***0.0***	***0.0***	***2.1***	
Hypospadias	221	272	55	50	<5	636	1
	96.2	***74.7***	***34.3***	***59.7***		***73.0***	
Interrupted aortic arch	0	11	<5	<5	0	13	
	0.0	***1.5***			***0.0***	***0.8***	
Limb deficiencies (reduction defects)	19	42	12	<5	0	77	
	4.2	***5.8***	***3.8***		***0.0***	***4.5***	
Omphalocele	9	19	<5	<5	0	34	
	2.0	***2.6***			***0.0***	***2.0***	
Pulmonary valve atresia and stenosis	31	74	26	10	0	144	
	6.9	***10.2***	***8.3***	***6.2***	***0.0***	***8.4***	

Georgia (Metropolitan Atlanta Congenital Defects Program)

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	10	22	11	<5	0	48	
	2.2	***3.0***	***3.5***		***0.0***	***2.8***	
Rectal and large intestinal atresia/stenosis	14	34	16	11	0	78	
	3.1	***4.7***	***5.1***	***6.8***	***0.0***	***4.6***	
Renal agenesis/hypoplasia	34	31	16	8	0	98	
	7.6	***4.3***	***5.1***	***4.9***	***0.0***	***5.7***	
Single ventricle	<5	11	5	0	0	19	
		1.5	***1.6***	***0.0***	***0.0***	***1.1***	
Small intestinal atresia/stenosis	9	23	12	<5	0	48	
	2.0	***3.2***	***3.8***		***0.0***	***2.8***	
Spina bifida without anencephalus	13	16	13	<5	0	47	
	2.9	***2.2***	***4.1***		***0.0***	***2.7***	
Tetralogy of Fallot	35	60	19	12	0	128	
	7.8	***8.3***	***6.0***	***7.4***	***0.0***	***7.5***	
Total anomalous pulmonary venous connection	<5	12	5	0	0	20	
		1.7	***1.6***	***0.0***	***0.0***	***1.2***	
Transposition of the great arteries (TGA)	8	25	12	<5	0	47	
	1.8	***3.5***	***3.8***		***0.0***	***2.7***	
Dextro-transposition of great arteries (d-TGA)	5	20	9	<5	0	35	
	1.1	***2.8***	***2.9***		***0.0***	***2.0***	
Tricuspid valve atresia and stenosis	6	20	<5	0	0	30	
	1.3	***2.8***		***0.0***	***0.0***	***1.8***	
Tricuspid valve atresia	<5	6	<5	0	0	12	
		0.8		***0.0***	***0.0***	***0.7***	
Trisomy 13	5	14	<5	<5	0	26	
	1.1	***1.9***			***0.0***	***1.5***	
Trisomy 18	<5	21	5	<5	0	34	
		2.9	***1.6***		***0.0***	***2.0***	
Trisomy 21 (Down syndrome)	56	91	64	11	0	227	
	12.5	***12.6***	***20.3***	***6.8***	***0.0***	***13.2***	
Turner syndrome	6	8	<5	<5	0	17	2
	2.7	***2.2***			***0.0***	***2.0***	
Ventricular septal defect	338	330	244	98	<5	1,053	
	75.4	***45.7***	***77.4***	***60.4***		***61.4***	
Total live births	**44,807**	**72,251**	**31,505**	**16,233**	**96**	**171,397**	**3**
Male live births	**22,964**	**36,409**	**16,044**	**8,377**	**48**	**87,130**	
Female live births	**21,843**	**35,841**	**15,461**	**7,856**	**48**	**84,266**	

Georgia (Metropolitan Atlanta Congenital Defects Program)

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	41	<5	42	
	3.1		***2.5***	
Trisomy 13	12	11	26	
	0.9	***2.8***	***1.5***	
Trisomy 18	12	19	34	
	0.9	***4.9***	***2.0***	
Trisomy 21 (Down syndrome)	95	119	227	
	7.2	***30.7***	***13.2***	
Total live births	**132,624**	**38,753**	**171,397**	**3**

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. Prevalance 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.

-Data for all conditions may include cases where the year of delivery was unknown. When year of delivery was unknown year of last known prenatal test was used as a proxy.

Hawaii
Birth Defects Counts and Prevalence 2016 - 2017 (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	1	0	1	1	0	3	
	1.8	***0.0***	***18.9***	***0.4***	***0.0***	***1.0***	
Anophthalmia/microphthalmia	1	0	0	8	0	9	
	1.8	***0.0***	***0.0***	***3.4***	***0.0***	***2.9***	
Anotia/microtia	0	0	1	11	0	12	
	0.0	***0.0***	***18.9***	***4.6***	***0.0***	***3.9***	
Aortic valve stenosis	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.4***	***0.0***	***0.3***	
Atrial septal defect	5	0	1	21	0	27	
	9.1	***0.0***	***18.9***	***8.8***	***0.0***	***8.7***	
Atrioventricular septal defect (Endocardial cushion defect)	3	0	0	7	0	10	
	5.5	***0.0***	***0.0***	***2.9***	***0.0***	***3.2***	
Biliary atresia	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***0.6***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	1	0	0	0	0	1	
	1.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Cleft lip alone	0	0	0	7	0	7	
	0.0	***0.0***	***0.0***	***2.9***	***0.0***	***2.3***	
Cleft lip with cleft palate	1	0	0	24	0	25	
	1.8	***0.0***	***0.0***	***10.1***	***0.0***	***8.1***	
Cleft palate alone	1	1	1	18	1	22	
	1.8	***18.6***	***18.9***	***7.6***	***20.8***	***7.1***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	6	0	2	38	1	47	
	11.0	***0.0***	***37.9***	***15.9***	***20.8***	***15.2***	
Coarctation of the aorta	4	0	0	8	0	12	
	7.3	***0.0***	***0.0***	***3.4***	***0.0***	***3.9***	
Common truncus (truncus arteriosus)	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Congenital cataract	3	0	0	2	0	5	
	5.5	***0.0***	***0.0***	***0.8***	***0.0***	***1.6***	
Congenital posterior urethral valves	1	1	0	2	0	4	1
	3.5	***34.8***	***0.0***	***1.6***	***0.0***	***2.5***	
Craniosynostosis	4	0	0	4	0	8	
	7.3	***0.0***	***0.0***	***1.7***	***0.0***	***2.6***	
Deletion 22q11.2	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.4***	***0.0***	***0.3***	
Diaphragmatic hernia	2	0	0	7	0	9	
	3.7	***0.0***	***0.0***	***2.9***	***0.0***	***2.9***	
Double outlet right ventricle	2	0	0	5	0	7	
	3.7	***0.0***	***0.0***	***2.1***	***0.0***	***2.3***	
Ebstein anomaly	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***0.6***	
Encephalocele	1	0	0	1	0	2	
	1.8	***0.0***	***0.0***	***0.4***	***0.0***	***0.6***	
Esophageal atresia/tracheoesophageal fistula	2	0	0	3	0	5	
	3.7	***0.0***	***0.0***	***1.3***	***0.0***	***1.6***	
Gastroschisis	1	0	0	12	1	14	
	1.8	***0.0***	***0.0***	***5.0***	***20.8***	***4.5***	
Holoprosencephaly	0	0	0	3	0	3	
	0.0	***0.0***	***0.0***	***1.3***	***0.0***	***1.0***	
Hypoplastic left heart syndrome	1	0	0	2	0	3	
	1.8	***0.0***	***0.0***	***0.8***	***0.0***	***1.0***	
Hypospadias	18	3	0	57	3	81	1
	62.7	***104.5***	***0.0***	***45.5***	***128.8***	***50.0***	
Interrupted aortic arch	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Limb deficiencies (reduction defects)	0	0	1	7	0	8	
	0.0	***0.0***	***18.9***	***2.9***	***0.0***	***2.6***	
Omphalocele	2	0	1	5	0	8	
	3.7	***0.0***	***18.9***	***2.1***	***0.0***	***2.6***	
Pulmonary valve atresia and stenosis	4	1	3	16	0	24	
	7.3	***18.6***	***56.8***	***6.7***	***0.0***	***7.8***	

Hawaii

Birth Defects Counts and Prevalence 2016 - 2017 (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**
Pulmonary valve atresia	0	0	1	3	0	4	
	0.0	***0.0***	***18.9***	***1.3***	***0.0***	***1.3***	
Rectal and large intestinal atresia/stenosis	0	0	0	16	1	17	
	0.0	***0.0***	***0.0***	***6.7***	***20.8***	***5.5***	
Renal agenesis/hypoplasia	4	0	0	12	0	17	
	7.3	***0.0***	***0.0***	***5.0***	***0.0***	***5.5***	
Single ventricle	0	0	1	2	0	3	
	0.0	***0.0***	***18.9***	***0.8***	***0.0***	***1.0***	
Small intestinal atresia/stenosis	2	0	0	3	1	6	
	3.7	***0.0***	***0.0***	***1.3***	***20.8***	***1.9***	
Spina bifida without anencephalus	0	0	1	2	0	3	
	0.0	***0.0***	***18.9***	***0.8***	***0.0***	***1.0***	
Tetralogy of Fallot	1	0	0	7	0	8	
	1.8	***0.0***	***0.0***	***2.9***	***0.0***	***2.6***	
Total anomalous pulmonary venous connection	0	0	0	4	0	4	
	0.0	***0.0***	***0.0***	***1.7***	***0.0***	***1.3***	
Transposition of the great arteries (TGA)	0	0	1	3	0	4	
	0.0	***0.0***	***18.9***	***1.3***	***0.0***	***1.3***	
Dextro-transposition of great arteries (d-TGA)	0	0	1	2	0	3	
	0.0	***0.0***	***18.9***	***0.8***	***0.0***	***1.0***	
Tricuspid valve atresia and stenosis	0	0	2	3	0	5	
	0.0	***0.0***	***37.9***	***1.3***	***0.0***	***1.6***	
Tricuspid valve atresia	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***0.6***	
Trisomy 13	0	0	3	4	0	7	
	0.0	***0.0***	***56.8***	***1.7***	***0.0***	***2.3***	
Trisomy 18	1	0	2	11	0	14	
	1.8	***0.0***	***37.9***	***4.6***	***0.0***	***4.5***	
Trisomy 21 (Down syndrome)	9	0	3	36	1	49	
	16.4	***0.0***	***56.8***	***15.1***	***20.8***	***15.8***	
Turner syndrome	1	0	1	6	0	8	2
	3.8	***0.0***	***37.3***	***5.3***	***0.0***	***5.4***	
Ventricular septal defect	18	2	2	77	1	100	
	32.9	***37.1***	***37.9***	***32.3***	***20.8***	***32.3***	
Total live births	**5,473**	**539**	**528**	**23,837**	**480**	**30,955**	
Male live births	**2,873**	**287**	**260**	**12,514**	**233**	**16,214**	
Female live births	**2,600**	**252**	**268**	**11,323**	**247**	**14,741**	

Hawaii

Birth Defects Counts and Prevalence 2016 - 2017 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	14	0	14	
	5.9	***0.0***	***4.5***	
Trisomy 13	3	4	7	
	1.3	***5.7***	***2.3***	
Trisomy 18	7	7	14	
	2.9	***10.0***	***4.5***	
Trisomy 21 (Down syndrome)	16	33	49	
	6.7	***47.0***	***15.8***	
Total live births	**23,931**	**7,017**	**30,955**	

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. Prevalance is calculated per 10,000 female live births.

General comments

*Data for totals include unknown and/or other.
-Data for all conditions and for total live births exclude Tripler Army Medical Center (TAMC).
-Data for all conditions excludes possible/probable diagnoses.

Illinois

Birth Defects Counts and Prevalence 2016 - 2020 (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	45	12	20	3	0	81	
	1.2	***1.0***	***1.3***	***0.6***	***0.0***	***1.1***	
Anophthalmia/microphthalmia	85	32	41	11	0	169	
	2.2	***2.6***	***2.7***	***2.3***	***0.0***	***2.3***	
Anotia/microtia	65	16	56	15	0	152	
	1.7	***1.3***	***3.7***	***3.2***	***0.0***	***2.1***	
Aortic valve stenosis	131	34	47	5	0	217	
	3.4	***2.8***	***3.1***	***1.1***	***0.0***	***3.0***	
Atrial septal defect	1,376	552	577	189	1	2,703	
	36.0	***45.6***	***37.7***	***40.3***	***22.0***	***37.4***	
Atrioventricular septal defect (Endocardial cushion defect)	218	104	102	24	0	454	1
	5.7	***8.6***	***6.7***	***5.1***	***0.0***	***6.3***	
Biliary atresia	18	10	9	5	0	42	
	0.5	***0.8***	***0.6***	***1.1***	***0.0***	***0.6***	
Bladder exstrophy	8	5	3	1	0	17	
	0.2	***0.4***	***0.2***	***0.2***	***0.0***	***0.2***	
Choanal atresia	58	21	28	2	1	110	
	1.5	***1.7***	***1.8***	***0.4***	***22.0***	***1.5***	
Cleft lip alone	140	36	37	11	0	225	
	3.7	***3.0***	***2.4***	***2.3***	***0.0***	***3.1***	
Cleft lip with cleft palate	251	53	106	26	0	438	
	6.6	***4.4***	***6.9***	***5.5***	***0.0***	***6.1***	
Cleft palate alone	256	60	79	34	0	430	
	6.7	***5.0***	***5.2***	***7.3***	***0.0***	***6.0***	
Cloacal exstrophy	15	8	6	2	0	31	
	0.4	***0.7***	***0.4***	***0.4***	***0.0***	***0.4***	
Clubfoot	622	199	212	56	8	1,101	
	16.3	***16.4***	***13.8***	***11.9***	***176.2***	***15.2***	
Coarctation of the aorta	258	57	92	19	2	429	
	6.7	***4.7***	***6.0***	***4.1***	***44.1***	***5.9***	
Common truncus (truncus arteriosus)	23	9	7	2	0	41	
	0.6	***0.7***	***0.5***	***0.4***	***0.0***	***0.6***	
Congenital cataract	42	27	13	6	0	88	
	1.1	***2.2***	***0.8***	***1.3***	***0.0***	***1.2***	
Congenital posterior urethral valves	44	28	6	6	0	84	2
	2.2	***4.5***	***0.8***	***2.5***	***0.0***	***2.3***	
Craniosynostosis	235	31	109	14	1	390	
	6.1	***2.6***	***7.1***	***3.0***	***22.0***	***5.4***	
Deletion 22q11.2	38	24	12	1	0	75	
	1.0	***2.0***	***0.8***	***0.2***	***0.0***	***1.0***	
Diaphragmatic hernia	117	33	56	8	0	216	
	3.1	***2.7***	***3.7***	***1.7***	***0.0***	***3.0***	
Double outlet right ventricle	79	37	47	9	0	173	
	2.1	***3.1***	***3.1***	***1.9***	***0.0***	***2.4***	
Ebstein anomaly	31	9	20	3	0	63	
	0.8	***0.7***	***1.3***	***0.6***	***0.0***	***0.9***	
Encephalocele	30	14	18	5	0	69	
	0.8	***1.2***	***1.2***	***1.1***	***0.0***	***1.0***	
Esophageal atresia/tracheoesophageal fistula	120	28	40	11	0	199	
	3.1	***2.3***	***2.6***	***2.3***	***0.0***	***2.8***	
Gastroschisis	150	47	62	6	1	269	
	3.9	***3.9***	***4.0***	***1.3***	***22.0***	***3.7***	
Holoprosencephaly	41	18	23	4	0	87	
	1.1	***1.5***	***1.5***	***0.9***	***0.0***	***1.2***	
Hypoplastic left heart syndrome	122	52	40	9	0	223	
	3.2	***4.3***	***2.6***	***1.9***	***0.0***	***3.1***	
Hypospadias	1,647	491	334	168	9	2,651	2
	83.9	***79.5***	***43.0***	***69.8***	***400.0***	***71.8***	
Interrupted aortic arch	26	12	10	1	0	49	
	0.7	***1.0***	***0.7***	***0.2***	***0.0***	***0.7***	
Limb deficiencies (reduction defects)	189	90	58	17	1	357	
	4.9	***7.4***	***3.8***	***3.6***	***22.0***	***4.9***	
Omphalocele	82	29	32	12	0	156	
	2.1	***2.4***	***2.1***	***2.6***	***0.0***	***2.2***	
Pulmonary valve atresia and stenosis	305	118	134	36	0	593	
	8.0	***9.7***	***8.8***	***7.7***	***0.0***	***8.2***	

Illinois

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	25	13	15	4	0	57	
	0.7	***1.1***	***1.0***	***0.9***	***0.0***	***0.8***	
Rectal and large intestinal atresia/stenosis	178	61	80	29	1	350	
	4.7	***5.0***	***5.2***	***6.2***	***22.0***	***4.8***	
Renal agenesis/hypoplasia	367	151	168	45	2	733	
	9.6	***12.5***	***11.0***	***9.6***	***44.1***	***10.2***	
Single ventricle	28	9	12	1	0	50	
	0.7	***0.7***	***0.8***	***0.2***	***0.0***	***0.7***	
Small intestinal atresia/stenosis	126	54	60	18	0	260	
	3.3	***4.5***	***3.9***	***3.8***	***0.0***	***3.6***	
Spina bifida without anencephalus	137	37	63	11	0	249	
	3.6	***3.1***	***4.1***	***2.3***	***0.0***	***3.4***	
Tetralogy of Fallot	178	74	63	22	0	338	
	4.7	***6.1***	***4.1***	***4.7***	***0.0***	***4.7***	
Total anomalous pulmonary venous connection	36	19	30	9	0	94	
	0.9	***1.6***	***2.0***	***1.9***	***0.0***	***1.3***	
Transposition of the great arteries (TGA)	126	32	55	15	0	229	
	3.3	***2.6***	***3.6***	***3.2***	***0.0***	***3.2***	
Dextro-transposition of great arteries (d-TGA)	110	28	44	8	0	190	
	2.9	***2.3***	***2.9***	***1.7***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	40	29	21	2	0	92	
	1.0	***2.4***	***1.4***	***0.4***	***0.0***	***1.3***	
Tricuspid valve atresia	15	8	7	0	0	30	
	0.4	***0.7***	***0.5***	***0.0***	***0.0***	***0.4***	
Trisomy 13	42	22	21	4	1	90	
	1.1	***1.8***	***1.4***	***0.9***	***22.0***	***1.2***	
Trisomy 18	86	37	44	12	0	184	
	2.2	***3.1***	***2.9***	***2.6***	***0.0***	***2.5***	
Trisomy 21 (Down syndrome)	499	155	360	63	4	1,084	
	13.0	***12.8***	***23.5***	***13.4***	***88.1***	***15.0***	
Turner syndrome	56	16	13	6	1	93	3
	3.0	***2.7***	***1.7***	***2.6***	***43.7***	***2.6***	
Ventricular septal defect	2,095	626	1,006	284	10	4,028	4
	54.7	***51.7***	***65.7***	***60.6***	***220.3***	***55.8***	
Total live births	**382,675**	**121,031**	**153,103**	**46,885**	**454**	**722,134**	**5**
Male live births	**196,372**	**61,724**	**77,711**	**24,054**	**225**	**369,335**	
Female live births	**186,295**	**59,300**	**75,385**	**22,830**	**229**	**352,773**	

Illinois

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	258	11	269	
	4.5	***0.8***	***3.7***	
Trisomy 13	60	30	90	
	1.0	***2.1***	***1.2***	
Trisomy 18	79	105	184	
	1.4	***7.3***	***2.5***	
Trisomy 21 (Down syndrome)	528	555	1,084	
	9.1	***38.6***	***15.0***	
Total live births	**578,298**	**143,814**	**722,134**	**5**

Notes

1. Data for this condition include inlet ventricular septal defects including common atrioventricular canal type ventricular septal defect.
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 this condition exclude probable cases, and inlet ventricular septal defects including common atrioventricular canal type ventricular septal defects.
5. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

Indiana

Birth Defects Counts and Prevalence 2016 - 2020 (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	31	4	8	3	0	46	
	1.0	***0.8***	***3.4***	***2.6***	***0.0***	***1.2***	
Anophthalmia/microphthalmia	26	3	4	1	0	36	
	0.9	***0.6***	***1.7***	***0.9***	***0.0***	***0.9***	
Anotia/microtia	58	7	7	6	2	83	
	1.9	***1.5***	***2.9***	***5.2***	***46.9***	***2.1***	
Aortic valve stenosis	61	2	5	4	0	72	
	2.0	***0.4***	***2.1***	***3.5***	***0.0***	***1.8***	
Atrial septal defect	2,242	458	217	74	3	3,025	1
	73.9	***94.9***	***91.4***	***64.4***	***70.4***	***76.7***	
Atrioventricular septal defect (Endocardial cushion defect)	143	31	13	3	0	192	
	4.7	***6.4***	***5.5***	***2.6***	***0.0***	***4.9***	
Biliary atresia	18	10	6	1	0	36	
	0.6	***2.1***	***2.5***	***0.9***	***0.0***	***0.9***	
Bladder exstrophy	12	2	0	0	0	14	
	0.4	***0.4***	***0.0***	***0.0***	***0.0***	***0.4***	
Choanal atresia	44	2	1	1	0	48	
	1.5	***0.4***	***0.4***	***0.9***	***0.0***	***1.2***	
Cleft lip alone	117	7	9	2	1	139	
	3.9	***1.5***	***3.8***	***1.7***	***23.5***	***3.5***	
Cleft lip with cleft palate	217	17	33	7	0	277	
	7.2	***3.5***	***13.9***	***6.1***	***0.0***	***7.0***	
Cleft palate alone	287	22	15	3	1	330	
	9.5	***4.6***	***6.3***	***2.6***	***23.5***	***8.4***	
Cloacal exstrophy	8	2	0	0	0	10	
	0.3	***0.4***	***0.0***	***0.0***	***0.0***	***0.3***	
Clubfoot	482	77	40	12	0	620	
	15.9	***16.0***	***16.8***	***10.4***	***0.0***	***15.7***	
Coarctation of the aorta	189	18	18	7	0	234	
	6.2	***3.7***	***7.6***	***6.1***	***0.0***	***5.9***	
Common truncus (truncus arteriosus)	15	2	1	1	0	19	
	0.5	***0.4***	***0.4***	***0.9***	***0.0***	***0.5***	
Congenital cataract	27	7	6	2	0	42	
	0.9	***1.5***	***2.5***	***1.7***	***0.0***	***1.1***	
Congenital posterior urethral valves	41	6	1	4	0	52	2
	2.6	***2.5***	***0.8***	***6.7***	***0.0***	***2.6***	
Craniosynostosis	290	22	19	6	1	342	
	9.6	***4.6***	***8.0***	***5.2***	***23.5***	***8.7***	
Deletion 22q11.2	30	4	2	2	0	38	
	1.0	***0.8***	***0.8***	***1.7***	***0.0***	***1.0***	
Diaphragmatic hernia	111	21	12	4	0	149	
	3.7	***4.4***	***5.1***	***3.5***	***0.0***	***3.8***	
Double outlet right ventricle	78	17	11	1	0	107	
	2.6	***3.5***	***4.6***	***0.9***	***0.0***	***2.7***	
Ebstein anomaly	14	3	1	1	0	19	
	0.5	***0.6***	***0.4***	***0.9***	***0.0***	***0.5***	
Encephalocele	24	4	6	0	0	34	
	0.8	***0.8***	***2.5***	***0.0***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	92	9	5	1	0	110	
	3.0	***1.9***	***2.1***	***0.9***	***0.0***	***2.8***	
Gastroschisis	109	12	13	1	0	135	
	3.6	***2.5***	***5.5***	***0.9***	***0.0***	***3.4***	
Holoprosencephaly	32	8	5	1	0	46	
	1.1	***1.7***	***2.1***	***0.9***	***0.0***	***1.2***	
Hypoplastic left heart syndrome	76	7	5	1	0	91	
	2.5	***1.5***	***2.1***	***0.9***	***0.0***	***2.3***	
Hypospadias	1,328	189	61	48	2	1,639	2
	85.3	***77.2***	***50.5***	***80.5***	***99.0***	***81.1***	
Interrupted aortic arch	16	4	2	0	0	22	
	0.5	***0.8***	***0.8***	***0.0***	***0.0***	***0.6***	
Limb deficiencies (reduction defects)	103	10	13	1	0	127	
	3.4	***2.1***	***5.5***	***0.9***	***0.0***	***3.2***	
Omphalocele	65	17	4	3	0	90	
	2.1	***3.5***	***1.7***	***2.6***	***0.0***	***2.3***	
Pulmonary valve atresia and stenosis	274	46	45	9	1	375	
	9.0	***9.5***	***18.9***	***7.8***	***23.5***	***9.5***	

Indiana

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	25	2	8	1	0	36	
	0.8	***0.4***	***3.4***	***0.9***	***0.0***	***0.9***	
Rectal and large intestinal atresia/stenosis	147	20	15	4	0	189	
	4.8	***4.1***	***6.3***	***3.5***	***0.0***	***4.8***	
Renal agenesis/hypoplasia	189	24	22	7	0	245	
	6.2	***5.0***	***9.3***	***6.1***	***0.0***	***6.2***	
Single ventricle	29	4	6	0	0	39	
	1.0	***0.8***	***2.5***	***0.0***	***0.0***	***1.0***	
Small intestinal atresia/stenosis	120	18	4	10	0	153	
	4.0	***3.7***	***1.7***	***8.7***	***0.0***	***3.9***	
Spina bifida without anencephalus	93	12	18	2	0	126	
	3.1	***2.5***	***7.6***	***1.7***	***0.0***	***3.2***	
Tetralogy of Fallot	104	21	7	7	0	141	
	3.4	***4.4***	***2.9***	***6.1***	***0.0***	***3.6***	
Total anomalous pulmonary venous connection	37	6	4	1	0	49	
	1.2	***1.2***	***1.7***	***0.9***	***0.0***	***1.2***	
Transposition of the great arteries (TGA)	95	8	14	2	0	120	
	3.1	***1.7***	***5.9***	***1.7***	***0.0***	***3.0***	
Dextro-transposition of great arteries (d-TGA)	83	6	10	1	0	101	
	2.7	***1.2***	***4.2***	***0.9***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	14	3	4	1	0	22	
	0.5	***0.6***	***1.7***	***0.9***	***0.0***	***0.6***	
Trisomy 13	23	1	1	1	0	26	
	0.8	***0.2***	***0.4***	***0.9***	***0.0***	***0.7***	
Trisomy 18	42	16	6	2	0	68	
	1.4	***3.3***	***2.5***	***1.7***	***0.0***	***1.7***	
Trisomy 21 (Down syndrome)	405	62	55	22	0	549	
	13.4	***12.8***	***23.2***	***19.1***	***0.0***	***13.9***	
Turner syndrome	36	2	1	1	0	41	3
	2.4	***0.8***	***0.9***	***1.8***	***0.0***	***2.1***	
Ventricular septal defect	1,598	242	211	62	2	2,139	
	52.7	***50.1***	***88.8***	***54.0***	***46.9***	***54.2***	
Total live births	**303,369**	**48,266**	**23,753**	**11,491**	**426**	**394,432**	**4**
Male live births	**155,774**	**24,474**	**12,068**	**5,962**	**202**	**202,040**	
Female live births	**147,582**	**23,789**	**11,684**	**5,529**	**224**	**192,373**	

Indiana

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	135	0	135	
	3.9	***0.0***	***3.4***	
Trisomy 13	13	13	26	
	0.4	***2.6***	***0.7***	
Trisomy 18	32	36	68	
	0.9	***7.1***	***1.7***	
Trisomy 21 (Down syndrome)	274	275	549	
	8.0	***54.4***	***13.9***	
Total live births	**343,871**	**50,547**	**394,432**	**4**

Notes

1. Data for this condition underwent a change to case review protocols that affect probable cases. As a result case counts increased in 2016 and 2017.
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.
-Data for all conditions include probable cases.

Iowa
Birth Defects Counts and Prevalence 2016 - 2020 (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	15	0	3	0	0	53	
	1.0	***0.0***	***1.7***	***0.0***	***0.0***	***2.8***	
Anophthalmia/microphthalmia	22	1	3	2	1	32	
	1.5	***0.8***	***1.7***	***2.8***	***12.9***	***1.7***	
Anotia/microtia	42	0	10	5	1	60	
	2.9	***0.0***	***5.5***	***7.1***	***12.9***	***3.2***	
Aortic valve stenosis	44	0	3	1	0	51	
	3.0	***0.0***	***1.7***	***1.4***	***0.0***	***2.7***	
Atrial septal defect	320	44	40	19	3	445	
	21.8	***33.3***	***22.2***	***26.9***	***38.8***	***23.6***	
Atrioventricular septal defect (Endocardial cushion defect)	73	6	7	2	2	94	1
	5.0	***4.5***	***3.9***	***2.8***	***25.9***	***5.0***	
Biliary atresia	5	1	0	1	0	8	
	0.3	***0.8***	***0.0***	***1.4***	***0.0***	***0.4***	
Bladder exstrophy	4	0	1	1	0	6	
	0.3	***0.0***	***0.6***	***1.4***	***0.0***	***0.3***	
Choanal atresia	10	0	0	0	0	10	2
	0.7	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Cleft lip alone	62	3	6	1	0	75	
	4.2	***2.3***	***3.3***	***1.4***	***0.0***	***4.0***	
Cleft lip with cleft palate	101	6	16	5	1	150	
	6.9	***4.5***	***8.9***	***7.1***	***12.9***	***7.9***	
Cleft palate alone	103	13	9	4	0	132	3
	7.0	***9.9***	***5.0***	***5.7***	***0.0***	***7.0***	
Cloacal exstrophy	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	271	19	22	8	2	358	
	18.5	***14.4***	***12.2***	***11.3***	***25.9***	***19.0***	
Coarctation of the aorta	110	7	11	4	2	135	
	7.5	***5.3***	***6.1***	***5.7***	***25.9***	***7.1***	
Common truncus (truncus arteriosus)	7	0	3	0	0	11	
	0.5	***0.0***	***1.7***	***0.0***	***0.0***	***0.6***	
Congenital cataract	51	5	5	3	0	64	
	3.5	***3.8***	***2.8***	***4.2***	***0.0***	***3.4***	
Congenital posterior urethral valves	18	4	0	2	0	24	4
	2.4	***6.0***	***0.0***	***5.5***	***0.0***	***2.5***	
Craniosynostosis	93	0	5	3	1	104	
	6.3	***0.0***	***2.8***	***4.2***	***12.9***	***5.5***	
Deletion 22q11.2	24	1	2	0	0	28	
	1.6	***0.8***	***1.1***	***0.0***	***0.0***	***1.5***	
Diaphragmatic hernia	45	1	3	3	0	57	
	3.1	***0.8***	***1.7***	***4.2***	***0.0***	***3.0***	
Double outlet right ventricle	27	3	4	1	0	43	
	1.8	***2.3***	***2.2***	***1.4***	***0.0***	***2.3***	
Ebstein anomaly	12	1	2	0	0	15	
	0.8	***0.8***	***1.1***	***0.0***	***0.0***	***0.8***	
Encephalocele	11	1	2	0	0	22	
	0.8	***0.8***	***1.1***	***0.0***	***0.0***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	36	7	2	0	0	47	
	2.5	***5.3***	***1.1***	***0.0***	***0.0***	***2.5***	
Gastroschisis	43	2	3	1	0	53	
	2.9	***1.5***	***1.7***	***1.4***	***0.0***	***2.8***	
Holoprosencephaly	20	2	1	1	0	45	
	1.4	***1.5***	***0.6***	***1.4***	***0.0***	***2.4***	
Hypoplastic left heart syndrome	36	6	6	2	0	56	
	2.5	***4.5***	***3.3***	***2.8***	***0.0***	***3.0***	
Hypospadias	510	34	30	10	0	587	4
	68.1	***51.3***	***32.8***	***27.3***	***0.0***	***60.9***	
Interrupted aortic arch	9	1	2	0	0	14	
	0.6	***0.8***	***1.1***	***0.0***	***0.0***	***0.7***	
Limb deficiencies (reduction defects)	63	4	11	4	0	104	5
	4.3	***3.0***	***6.1***	***5.7***	***0.0***	***5.5***	
Omphalocele	27	3	3	1	1	55	
	1.8	***2.3***	***1.7***	***1.4***	***12.9***	***2.9***	
Pulmonary valve atresia and stenosis	140	18	8	9	0	176	
	9.5	***13.6***	***4.4***	***12.7***	***0.0***	***9.3***	

Iowa
Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	9	2	0	2	0	13	
	0.6	***1.5***	***0.0***	***2.8***	***0.0***	***0.7***	
Rectal and large intestinal atresia/stenosis	45	5	5	3	0	59	
	3.1	***3.8***	***2.8***	***4.2***	***0.0***	***3.1***	
Renal agenesis/hypoplasia	101	3	9	5	0	134	
	6.9	***2.3***	***5.0***	***7.1***	***0.0***	***7.1***	
Single ventricle	8	0	1	0	0	11	
	0.5	***0.0***	***0.6***	***0.0***	***0.0***	***0.6***	
Small intestinal atresia/stenosis	49	3	4	4	0	60	
	3.3	***2.3***	***2.2***	***5.7***	***0.0***	***3.2***	
Spina bifida without anencephalus	59	3	2	4	1	82	
	4.0	***2.3***	***1.1***	***5.7***	***12.9***	***4.3***	
Tetralogy of Fallot	51	9	2	2	0	68	
	3.5	***6.8***	***1.1***	***2.8***	***0.0***	***3.6***	
Total anomalous pulmonary venous connection	19	0	3	1	1	24	
	1.3	***0.0***	***1.7***	***1.4***	***12.9***	***1.3***	
Transposition of the great arteries (TGA)	43	0	6	0	1	54	
	2.9	***0.0***	***3.3***	***0.0***	***12.9***	***2.9***	
Dextro-transposition of great arteries (d-TGA)	36	0	6	0	1	46	
	2.5	***0.0***	***3.3***	***0.0***	***12.9***	***2.4***	
Tricuspid valve atresia and stenosis	30	6	5	4	0	47	
	2.0	***4.5***	***2.8***	***5.7***	***0.0***	***2.5***	
Tricuspid valve atresia	6	2	2	0	0	10	
	0.4	***1.5***	***1.1***	***0.0***	***0.0***	***0.5***	
Trisomy 13	18	1	0	0	0	37	
	1.2	***0.8***	***0.0***	***0.0***	***0.0***	***2.0***	
Trisomy 18	33	4	1	1	1	71	
	2.3	***3.0***	***0.6***	***1.4***	***12.9***	***3.8***	
Trisomy 21 (Down syndrome)	197	20	32	8	2	290	
	13.4	***15.2***	***17.7***	***11.3***	***25.9***	***15.4***	
Turner syndrome	13	0	3	2	0	36	6
	1.8	***0.0***	***3.4***	***5.9***	***0.0***	***3.9***	
Ventricular septal defect	769	70	90	30	5	999	7
	52.4	***53.0***	***49.9***	***42.5***	***64.7***	***52.9***	
Total live births	**146,658**	**13,196**	**18,047**	**7,063**	**773**	**188,907**	**8**
Male live births	**74,920**	**6,627**	**9,143**	**3,657**	**386**	**96,353**	
Female live births	**71,737**	**6,569**	**8,904**	**3,406**	**387**	**92,553**	

Iowa
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	52	1	53	
	3.2	***0.4***	***2.8***	
Trisomy 13	25	12	37	
	1.5	***4.6***	***2.0***	
Trisomy 18	35	36	71	
	2.1	***13.8***	***3.8***	
Trisomy 21 (Down syndrome)	144	146	290	
	8.8	***56.0***	***15.4***	
Total live births	**162,833**	**26,064**	**188,907**	**8**

Notes
1. Data for this condition include inlet ventricular septal defect.
2. Data for this condition exclude choanal stenosis.
3. Data for this condition exclude bifid uvula.
4. 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 exclude other specified and unspecified limb reductions.
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 exclude inlet ventricular septal defect.
8. Data for total live births include unknown gender.

General comments
*Data for totals include unknown and/or other.
-Data for all conditions exclude possible/probable cases.

Kansas

Birth Defects Counts and Prevalence 2016 - 2020 (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	17	<5	8	0	0	26	
	1.4		***2.7***	***0.0***	***0.0***	***1.5***	
Anophthalmia/microphthalmia	<5	0	0	<5	0	5	
		0.0	***0.0***		***0.0***	***0.3***	
Anotia/microtia	<5	0	11	0	0	15	
		0.0	***3.7***	***0.0***	***0.0***	***0.9***	
Aortic valve stenosis	11	<5	<5	<5	0	15	
	0.9				***0.0***	***0.9***	
Atrial septal defect	1,087	95	201	25	<5	1,469	
	90.7	***80.2***	***67.7***	***41.7***		***84.7***	
Atrioventricular septal defect (Endocardial cushion defect)	17	<5	7	<5	0	28	
	1.4		***2.4***		***0.0***	***1.6***	
Biliary atresia	18	0	<5	<5	0	23	
	1.5	***0.0***			***0.0***	***1.3***	
Bladder exstrophy	<5	0	<5	0	0	<5	
		0.0		***0.0***	***0.0***		
Choanal atresia	10	0	<5	0	0	14	
	0.8	***0.0***		***0.0***	***0.0***	***0.8***	
Cleft lip alone	79	7	23	<5	<5	116	
	6.6	***5.9***	***7.7***			***6.7***	
Cleft lip with cleft palate	35	<5	9	<5	0	49	
	2.9		***3.0***		***0.0***	***2.8***	
Cleft palate alone	78	<5	15	<5	0	98	
	6.5		***5.1***		***0.0***	***5.6***	
Clubfoot	101	9	21	5	<5	139	
	8.4	***7.6***	***7.1***	***8.3***		***8.0***	
Coarctation of the aorta	29	<5	8	0	0	40	
	2.4		***2.7***	***0.0***	***0.0***	***2.3***	
Common truncus (truncus arteriosus)	9	0	0	0	0	9	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Congenital cataract	16	0	<5	<5	0	20	
	1.3	***0.0***			***0.0***	***1.2***	
Congenital posterior urethral valves	5	0	<5	0	0	8	1
	0.8	***0.0***		***0.0***	***0.0***	***0.9***	
Craniosynostosis	113	7	17	<5	0	140	
	9.4	***5.9***	***5.7***		***0.0***	***8.1***	
Deletion 22q11.2	5	0	<5	0	0	7	
	0.4	***0.0***		***0.0***	***0.0***	***0.4***	
Diaphragmatic hernia	16	<5	8	0	0	25	
	1.3		***2.7***	***0.0***	***0.0***	***1.4***	
Double outlet right ventricle	<5	<5	0	0	0	<5	
			0.0	***0.0***	***0.0***		
Ebstein anomaly	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Encephalocele	11	<5	0	0	0	14	
	0.9		***0.0***	***0.0***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	18	<5	<5	<5	0	21	
	1.5				***0.0***	***1.2***	
Gastroschisis	35	<5	7	0	0	49	
	2.9		***2.4***	***0.0***	***0.0***	***2.8***	
Holoprosencephaly	<5	<5	<5	0	0	7	
				0.0	***0.0***	***0.4***	
Hypoplastic left heart syndrome	8	0	<5	0	0	10	
	0.7	***0.0***		***0.0***	***0.0***	***0.6***	
Hypospadias	225	29	36	5	<5	308	1
	36.6	***47.6***	***23.7***	***16.1***		***34.6***	
Interrupted aortic arch	5	0	0	0	0	5	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Limb deficiencies (reduction defects)	29	<5	<5	0	0	37	
	2.4			***0.0***	***0.0***	***2.1***	
Omphalocele	29	7	7	<5	0	50	
	2.4	***5.9***	***2.4***		***0.0***	***2.9***	
Pulmonary valve atresia and stenosis	46	<5	9	<5	0	61	
	3.8		***3.0***		***0.0***	***3.5***	
Rectal and large intestinal atresia/stenosis	16	<5	8	0	0	27	
	1.3		***2.7***	***0.0***	***0.0***	***1.6***	

Kansas

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Renal agenesis/hypoplasia	35	<5	7	<5	0	49	
	2.9		***2.4***		***0.0***	***2.8***	
Single ventricle	0	0	<5	0	0	<5	
	0.0	***0.0***		***0.0***	***0.0***		
Small intestinal atresia/stenosis	16	<5	<5	0	0	22	
	1.3			***0.0***	***0.0***	***1.3***	
Spina bifida without anencephalus	19	0	9	0	0	29	
	1.6	***0.0***	***3.0***	***0.0***	***0.0***	***1.7***	
Tetralogy of Fallot	18	<5	<5	0	0	22	
	1.5			***0.0***	***0.0***	***1.3***	
Total anomalous pulmonary venous connection	<5	0	<5	0	0	<5	
		0.0		***0.0***	***0.0***		
Transposition of the great arteries (TGA)	11	<5	<5	0	0	14	
	0.9			***0.0***	***0.0***	***0.8***	
Tricuspid valve atresia and stenosis	<5	0	<5	0	0	<5	
		0.0		***0.0***	***0.0***		
Trisomy 13	<5	0	<5	0	0	5	
		0.0		***0.0***	***0.0***	***0.3***	
Trisomy 18	14	<5	7	<5	0	26	
	1.2		***2.4***		***0.0***	***1.5***	
Trisomy 21 (Down syndrome)	145	10	52	9	<5	220	
	12.1	***8.4***	***17.5***	***15.0***		***12.7***	
Turner syndrome	12	<5	<5	0	0	20	2
	2.1			***0.0***	***0.0***	***2.4***	
Ventricular septal defect	283	15	59	7	<5	374	
	23.6	***12.7***	***19.9***	***11.7***		***21.6***	
Total live births	**119,884**	**11,842**	**29,689**	**5,990**	**714**	**173,529**	**3**
Male live births	**61,477**	**6,097**	**15,186**	**3,098**	**361**	**88,973**	
Female live births	**58,407**	**5,744**	**14,502**	**2,892**	**353**	**84,554**	

Kansas

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	47	<5	49	
	3.1		***2.8***	
Trisomy 13	<5	<5	5	
			0.3	
Trisomy 18	17	9	26	
	1.1	***3.8***	***1.5***	
Trisomy 21 (Down syndrome)	116	101	220	
	7.8	***42.2***	***12.7***	
Total live births	**149,564**	**23,956**	**173,529**	**3**

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. Prevalance 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.
-Data for all conditions include probable cases.

Kentucky
Birth Defects Counts and Prevalence 2016 - 2020 (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	40	8	6	3	0	59	
	1.9	***3.3***	***3.8***	***10.7***	***0.0***	***2.2***	
Anophthalmia/microphthalmia	20	1	1	0	0	24	
	0.9	***0.4***	***0.6***	***0.0***	***0.0***	***0.9***	
Anotia/microtia	26	1	4	0	0	32	
	1.2	***0.4***	***2.6***	***0.0***	***0.0***	***1.2***	
Aortic valve stenosis	20	1	1	0	0	24	
	0.9	***0.4***	***0.6***	***0.0***	***0.0***	***0.9***	
Atrial septal defect	6,414	1,395	539	155	7	8,910	
	300.1	***568.3***	***344.6***	***552.8***	***275.6***	***332.8***	
Atrioventricular septal defect (Endocardial cushion defect)	88	12	5	1	0	110	
	4.1	***4.9***	***3.2***	***3.6***	***0.0***	***4.1***	
Biliary atresia	14	5	2	4	0	25	
	0.7	***2.0***	***1.3***	***14.3***	***0.0***	***0.9***	
Bladder exstrophy	5	0	0	0	0	6	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	32	2	0	0	0	35	
	1.5	***0.8***	***0.0***	***0.0***	***0.0***	***1.3***	
Cleft lip alone	76	2	2	1	0	82	
	3.6	***0.8***	***1.3***	***3.6***	***0.0***	***3.1***	
Cleft lip with cleft palate	134	14	14	3	1	170	
	6.3	***5.7***	***9.0***	***10.7***	***39.4***	***6.3***	
Cleft palate alone	156	7	4	3	0	178	
	7.3	***2.9***	***2.6***	***10.7***	***0.0***	***6.6***	
Cloacal exstrophy	3	0	0	0	0	4	1
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	435	36	24	10	0	528	
	20.4	***14.7***	***15.3***	***35.7***	***0.0***	***19.7***	
Coarctation of the aorta	108	5	8	0	0	128	
	5.1	***2.0***	***5.1***	***0.0***	***0.0***	***4.8***	
Common truncus (truncus arteriosus)	14	1	2	0	0	18	
	0.7	***0.4***	***1.3***	***0.0***	***0.0***	***0.7***	
Congenital cataract	18	4	1	1	0	27	
	0.8	***1.6***	***0.6***	***3.6***	***0.0***	***1.0***	
Congenital posterior urethral valves	16	4	0	0	0	22	2
	1.5	***3.2***	***0.0***	***0.0***	***0.0***	***1.6***	
Deletion 22q11.2	16	5	2	0	0	24	
	0.7	***2.0***	***1.3***	***0.0***	***0.0***	***0.9***	
Diaphragmatic hernia	45	5	6	2	0	67	
	2.1	***2.0***	***3.8***	***7.1***	***0.0***	***2.5***	
Double outlet right ventricle	45	11	5	0	0	66	
	2.1	***4.5***	***3.2***	***0.0***	***0.0***	***2.5***	
Ebstein anomaly	12	0	0	1	0	15	
	0.6	***0.0***	***0.0***	***3.6***	***0.0***	***0.6***	
Encephalocele	20	2	1	0	0	25	
	0.9	***0.8***	***0.6***	***0.0***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	49	5	2	1	0	60	
	2.3	***2.0***	***1.3***	***3.6***	***0.0***	***2.2***	
Gastroschisis	97	9	3	0	0	113	
	4.5	***3.7***	***1.9***	***0.0***	***0.0***	***4.2***	
Holoprosencephaly	21	2	0	1	0	26	
	1.0	***0.8***	***0.0***	***3.6***	***0.0***	***1.0***	
Hypoplastic left heart syndrome	48	5	2	0	0	58	
	2.2	***2.0***	***1.3***	***0.0***	***0.0***	***2.2***	
Hypospadias	953	107	38	14	1	1,148	2
	86.7	***86.5***	***48.1***	***101.0***	***78.7***	***83.7***	
Interrupted aortic arch	8	2	0	0	0	10	
	0.4	***0.8***	***0.0***	***0.0***	***0.0***	***0.4***	
Limb deficiencies (reduction defects)	73	8	6	3	0	92	
	3.4	***3.3***	***3.8***	***10.7***	***0.0***	***3.4***	
Omphalocele	45	5	3	1	0	56	
	2.1	***2.0***	***1.9***	***3.6***	***0.0***	***2.1***	
Pulmonary valve atresia and stenosis	103	14	10	1	0	132	
	4.8	***5.7***	***6.4***	***3.6***	***0.0***	***4.9***	
Pulmonary valve atresia	9	3	2	0	0	14	
	0.4	***1.2***	***1.3***	***0.0***	***0.0***	***0.5***	

Kentucky
Birth Defects Counts and Prevalence 2016 - 2020 (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**
Rectal and large intestinal atresia/stenosis	103	8	6	1	0	126	
	4.8	***3.3***	***3.8***	***3.6***	***0.0***	***4.7***	
Renal agenesis/hypoplasia	107	17	13	5	0	146	
	5.0	***6.9***	***8.3***	***17.8***	***0.0***	***5.5***	
Single ventricle	3	0	0	0	0	3	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Small intestinal atresia/stenosis	57	9	9	2	0	79	
	2.7	***3.7***	***5.8***	***7.1***	***0.0***	***3.0***	
Spina bifida without anencephalus	74	4	6	0	0	90	
	3.5	***1.6***	***3.8***	***0.0***	***0.0***	***3.4***	
Tetralogy of Fallot	70	16	2	3	0	95	
	3.3	***6.5***	***1.3***	***10.7***	***0.0***	***3.5***	
Total anomalous pulmonary venous connection	25	3	2	1	0	32	
	1.2	***1.2***	***1.3***	***3.6***	***0.0***	***1.2***	
Transposition of the great arteries (TGA)	72	7	5	1	0	86	
	3.4	***2.9***	***3.2***	***3.6***	***0.0***	***3.2***	
Dextro-transposition of great arteries (d-TGA)	69	7	5	1	0	83	
	3.2	***2.9***	***3.2***	***3.6***	***0.0***	***3.1***	
Tricuspid valve atresia and stenosis	13	2	1	0	0	16	3
	0.6	***0.8***	***0.6***	***0.0***	***0.0***	***0.6***	
Trisomy 13	21	4	2	1	0	30	
	1.0	***1.6***	***1.3***	***3.6***	***0.0***	***1.1***	
Trisomy 18	53	11	3	0	0	67	
	2.5	***4.5***	***1.9***	***0.0***	***0.0***	***2.5***	
Trisomy 21 (Down syndrome)	240	21	23	7	0	317	
	11.2	***8.6***	***14.7***	***25.0***	***0.0***	***11.8***	
Turner syndrome	37	3	4	2	0	47	4
	3.6	***2.5***	***5.2***	***14.1***	***0.0***	***3.6***	
Ventricular septal defect	1,236	190	115	33	0	1,652	5
	57.8	***77.4***	***73.5***	***117.7***	***0.0***	***61.7***	
Total live births	**213,748**	**24,548**	**15,642**	**2,804**	**254**	**267,768**	**6**
Male live births	**109,856**	**12,367**	**7,893**	**1,386**	**127**	**137,133**	
Female live births	**103,885**	**12,180**	**7,749**	**1,418**	**127**	**130,627**	

Kentucky
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	105	5	113	
	4.6	***1.5***	***4.2***	
Trisomy 13	22	7	30	
	1.0	***2.2***	***1.1***	
Trisomy 18	37	30	67	
	1.6	***9.3***	***2.5***	
Trisomy 21 (Down syndrome)	172	129	317	
	7.6	***39.8***	***11.8***	
Total live births	**226,080**	**32,428**	**267,768**	**6**

Notes
1. Data for this condition begin 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 stenosis and hypoplasia.
4. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
5. Data for this condition exclude inlet ventricular septal defect (VSD) and common atrioventricular (AV) canal type VSD.
6. Data for total live births include unknown gender.

General comments
*Data for totals include unknown and/or other.

Louisiana

Birth Defects Counts and Prevalence 2016 - 2020 (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	24	12	<5	<5	<5	42	
	1.7	***1.1***				***1.5***	
Anophthalmia/microphthalmia	16	14	<5	0	<5	38	
	1.1	***1.3***		***0.0***		***1.3***	
Anotia/microtia	19	13	17	<5	0	51	
	1.3	***1.2***	***7.4***		***0.0***	***1.8***	
Aortic valve stenosis	28	6	6	<5	0	42	
	1.9	***0.6***	***2.6***		***0.0***	***1.5***	
Atrial septal defect	1,492	1,337	217	34	19	3,164	
	103.9	***124.3***	***94.4***	***67.3***	***150.0***	***110.4***	
Atrioventricular septal defect (Endocardial cushion defect)	114	99	20	<5	0	245	
	7.9	***9.2***	***8.7***		***0.0***	***8.6***	
Biliary atresia	8	12	<5	<5	0	23	
	0.6	***1.1***			***0.0***	***0.8***	
Bladder exstrophy	<5	<5	0	0	0	5	
			0.0	***0.0***	***0.0***	***0.2***	
Choanal atresia	22	<5	<5	<5	0	30	
	1.5				***0.0***	***1.0***	
Cleft lip alone	58	22	10	<5	0	96	
	4.0	***2.0***	***4.4***		***0.0***	***3.4***	
Cleft lip with cleft palate	103	47	21	<5	0	179	
	7.2	***4.4***	***9.1***		***0.0***	***6.2***	
Cleft palate alone	168	71	18	5	5	270	
	11.7	***6.6***	***7.8***	***9.9***	***39.5***	***9.4***	
Clubfoot	205	147	32	<5	0	392	
	14.3	***13.7***	***13.9***		***0.0***	***13.7***	
Coarctation of the aorta	88	49	7	<5	0	146	
	6.1	***4.6***	***3.0***		***0.0***	***5.1***	
Common truncus (truncus arteriosus)	11	<5	<5	0	0	16	
	0.8			***0.0***	***0.0***	***0.6***	
Congenital cataract	22	23	8	0	0	55	
	1.5	***2.1***	***3.5***	***0.0***	***0.0***	***1.9***	
Congenital posterior urethral valves	20	20	5	0	0	46	1
	2.7	***3.7***	***4.2***	***0.0***	***0.0***	***3.1***	
Craniosynostosis	160	76	21	<5	<5	267	
	11.1	***7.1***	***9.1***			***9.3***	
Deletion 22q11.2	29	16	<5	0	0	50	
	2.0	***1.5***		***0.0***	***0.0***	***1.7***	
Diaphragmatic hernia	40	22	9	<5	0	73	
	2.8	***2.0***	***3.9***		***0.0***	***2.5***	
Double outlet right ventricle	34	35	5	<5	0	78	
	2.4	***3.3***	***2.2***		***0.0***	***2.7***	
Ebstein anomaly	10	6	<5	<5	0	19	
	0.7	***0.6***			***0.0***	***0.7***	
Encephalocele	15	22	<5	0	0	40	
	1.0	***2.0***		***0.0***	***0.0***	***1.4***	
Esophageal atresia/tracheoesophageal fistula	23	24	<5	0	0	51	
	1.6	***2.2***		***0.0***	***0.0***	***1.8***	
Gastroschisis	49	30	<5	<5	0	87	
	3.4	***2.8***			***0.0***	***3.0***	
Holoprosencephaly	17	21	<5	0	0	44	
	1.2	***2.0***		***0.0***	***0.0***	***1.5***	
Hypoplastic left heart syndrome	38	19	<5	<5	<5	62	
	2.6	***1.8***				***2.2***	
Hypospadias	626	366	44	13	<5	1,079	1
	85.1	***67.0***	***37.4***	***49.9***		***73.8***	
Interrupted aortic arch	12	8	<5	0	0	22	
	0.8	***0.7***		***0.0***	***0.0***	***0.8***	
Limb deficiencies (reduction defects)	35	34	7	<5	0	80	
	2.4	***3.2***	***3.0***		***0.0***	***2.8***	
Omphalocele	31	27	<5	0	0	62	
	2.2	***2.5***		***0.0***	***0.0***	***2.2***	
Pulmonary valve atresia and stenosis	117	124	23	<5	<5	273	
	8.1	***11.5***	***10.0***			***9.5***	
Pulmonary valve atresia	7	9	<5	0	0	17	
	0.5	***0.8***		***0.0***	***0.0***	***0.6***	

Louisiana

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Rectal and large intestinal atresia/stenosis	62 ***4.3***	45 ***4.2***	9 ***3.9***	<5	<5	119 ***4.2***	
Renal agenesis/hypoplasia	89 ***6.2***	39 ***3.6***	13 ***5.7***	<5	<5	147 ***5.1***	
Single ventricle	8 ***0.6***	6 ***0.6***	<5	<5	0 ***0.0***	16 ***0.6***	
Small intestinal atresia/stenosis	65 ***4.5***	49 ***4.6***	10 ***4.4***	0 ***0.0***	0 ***0.0***	129 ***4.5***	
Spina bifida without anencephalus	45 ***3.1***	26 ***2.4***	11 ***4.8***	0 ***0.0***	0 ***0.0***	83 ***2.9***	
Tetralogy of Fallot	73 ***5.1***	44 ***4.1***	9 ***3.9***	<5	<5	133 ***4.6***	
Total anomalous pulmonary venous connection	14 ***1.0***	9 ***0.8***	<5	<5	0 ***0.0***	26 ***0.9***	
Transposition of the great arteries (TGA)	40 ***2.8***	22 ***2.0***	9 ***3.9***	<5	<5	75 ***2.6***	
Dextro-transposition of great arteries (d-TGA)	36 ***2.5***	19 ***1.8***	7 ***3.0***	<5	<5	66 ***2.3***	
Tricuspid valve atresia and stenosis	13 ***0.9***	7 ***0.7***	5 ***2.2***	0 ***0.0***	0 ***0.0***	25 ***0.9***	
Tricuspid valve atresia	11 ***0.8***	<5	<5	0 ***0.0***	0 ***0.0***	19 ***0.7***	
Trisomy 13	11 ***0.8***	12 ***1.1***	<5	0 ***0.0***	0 ***0.0***	25 ***0.9***	
Trisomy 18	25 ***1.7***	25 ***2.3***	9 ***3.9***	0 ***0.0***	0 ***0.0***	59 ***2.1***	
Trisomy 21 (Down syndrome)	175 ***12.2***	120 ***11.2***	41 ***17.8***	5 ***9.9***	<5	359 ***12.5***	
Turner syndrome	12 ***1.7***	11 ***2.1***	<5	0 ***0.0***	0 ***0.0***	24 ***1.7***	2
Ventricular septal defect	788 ***54.9***	511 ***47.5***	167 ***72.7***	26 ***51.4***	6 ***47.4***	1,523 ***53.1***	
Total live births	**143,625**	**107,533**	**22,977**	**5,054**	**1,267**	**286,549**	**3**
Male live births	**73,530**	**54,591**	**11,771**	**2,603**	**632**	**146,251**	
Female live births	**70,094**	**52,940**	**11,206**	**2,451**	**635**	**140,295**	

Louisiana

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	82	5	87	
	3.3	***1.4***	***3.0***	
Trisomy 13	20	5	25	
	0.8	***1.4***	***0.9***	
Trisomy 18	28	31	59	
	1.1	***8.6***	***2.1***	
Trisomy 21 (Down syndrome)	193	166	359	
	7.7	***46.0***	***12.5***	
Total live births	**250,439**	**36,110**	**286,549**	**3**

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. Prevalance 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.
-Data for all conditions include probable cases.

Maine

Birth Defects Counts and Prevalence 2016 - 2020 (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	6	0	0	0	0	7	1
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.2***	
Anophthalmia/microphthalmia	2	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Anotia/microtia	6	0	0	0	0	7	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.2***	
Aortic valve stenosis	6	2	0	0	0	8	
	1.1	***7.5***	***0.0***	***0.0***	***0.0***	***1.4***	
Atrial septal defect	80	10	0	1	0	114	
	15.1	***37.3***	***0.0***	***9.3***	***0.0***	***19.5***	
Atrioventricular septal defect (Endocardial cushion defect)	11	2	0	0	0	16	
	2.1	***7.5***	***0.0***	***0.0***	***0.0***	***2.7***	
Biliary atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Bladder exstrophy	3	0	0	0	0	3	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Choanal atresia	5	0	0	0	0	6	
	0.9	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	
Cleft lip alone	14	0	0	0	0	16	
	2.7	***0.0***	***0.0***	***0.0***	***0.0***	***2.7***	
Cleft lip with cleft palate	28	0	1	0	0	35	
	5.3	***0.0***	***8.8***	***0.0***	***0.0***	***6.0***	
Cleft palate alone	30	1	0	0	0	35	
	5.7	***3.7***	***0.0***	***0.0***	***0.0***	***6.0***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	40	0	0	1	0	56	
	7.6	***0.0***	***0.0***	***9.3***	***0.0***	***9.6***	
Coarctation of the aorta	17	1	0	0	0	19	
	3.2	***3.7***	***0.0***	***0.0***	***0.0***	***3.2***	
Common truncus (truncus arteriosus)	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Congenital cataract	3	0	0	0	0	3	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Congenital posterior urethral valves	1	0	0	0	0	1	2
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Craniosynostosis	3	2	0	0	0	7	
	0.6	***7.5***	***0.0***	***0.0***	***0.0***	***1.2***	
Deletion 22q11.2	2	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Diaphragmatic hernia	4	0	0	0	0	4	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Double outlet right ventricle	2	0	0	1	0	3	
	0.4	***0.0***	***0.0***	***9.3***	***0.0***	***0.5***	
Ebstein anomaly	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Encephalocele	2	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Esophageal atresia/tracheoesophageal fistula	6	0	0	0	0	7	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.2***	
Gastroschisis	11	1	0	0	0	15	
	2.1	***3.7***	***0.0***	***0.0***	***0.0***	***2.6***	
Holoprosencephaly	2	0	0	0	0	3	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Hypoplastic left heart syndrome	5	1	0	1	0	7	
	0.9	***3.7***	***0.0***	***9.3***	***0.0***	***1.2***	
Hypospadias	125	6	2	3	1	159	2
	46.6	***44.7***	***34.1***	***55.0***	***30.9***	***53.5***	
Interrupted aortic arch	4	0	0	0	0	4	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Limb deficiencies (reduction defects)	6	0	0	0	0	11	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.9***	
Omphalocele	10	0	0	0	0	10	
	1.9	***0.0***	***0.0***	***0.0***	***0.0***	***1.7***	
Pulmonary valve atresia and stenosis	8	0	0	0	0	10	
	1.5	***0.0***	***0.0***	***0.0***	***0.0***	***1.7***	

Maine

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Rectal and large intestinal atresia/stenosis	16	1	0	0	0	19	
	3.0	***3.7***	***0.0***	***0.0***	***0.0***	***3.2***	
Renal agenesis/hypoplasia	25	0	0	1	0	26	
	4.7	***0.0***	***0.0***	***9.3***	***0.0***	***4.4***	
Single ventricle	1	0	0	0	0	1	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Small intestinal atresia/stenosis	2	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Spina bifida without anencephalus	8	0	0	0	0	9	
	1.5	***0.0***	***0.0***	***0.0***	***0.0***	***1.5***	
Tetralogy of Fallot	18	0	1	0	0	19	
	3.4	***0.0***	***8.8***	***0.0***	***0.0***	***3.2***	
Total anomalous pulmonary venous connection	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Transposition of the great arteries (TGA)	7	1	0	1	0	9	
	1.3	***3.7***	***0.0***	***9.3***	***0.0***	***1.5***	
Tricuspid valve atresia and stenosis	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Tricuspid valve atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Trisomy 13	3	1	0	0	0	4	
	0.6	***3.7***	***0.0***	***0.0***	***0.0***	***0.7***	
Trisomy 18	7	0	1	0	0	8	
	1.3	***0.0***	***8.8***	***0.0***	***0.0***	***1.4***	
Trisomy 21 (Down syndrome)	50	5	1	0	0	62	
	9.5	***18.6***	***8.8***	***0.0***	***0.0***	***10.6***	
Turner syndrome	2	0	0	0	0	4	3
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.4***	
Ventricular septal defect	63	4	1	0	0	79	
	11.9	***14.9***	***8.8***	***0.0***	***0.0***	***13.5***	
Total live births	**52,807**	**2,681**	**1,138**	**1,076**	**619**	**58,589**	**4**
Male live births	**26,801**	**1,341**	**586**	**545**	**324**	**29,727**	
Female live births	**25,999**	**1,340**	**551**	**531**	**295**	**28,854**	

Maine

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	15	0	15	
	3.1	***0.0***	***2.6***	
Trisomy 13	0	4	4	
	0.0	***4.0***	***0.7***	
Trisomy 18	4	4	8	
	0.8	***4.0***	***1.4***	
Trisomy 21 (Down syndrome)	34	28	62	
	7.0	***27.8***	***10.6***	
Total live births	**48,523**	**10,061**	**58,589**	**4**

Notes

1. Data for this condition include probable cases.
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.

-In recent years, the number of unknown maternal race/ethnicity has increased in the Maine Birth Defects Registry. Use caution when using counts and rates based on maternal race/ethnicity.

Maryland

Birth Defects Counts and Prevalence 2016 - 2020 (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	3	0	0	0	10	
	0.1	***0.3***	***0.0***	***0.0***	***0.0***	***0.3***	
Anophthalmia/microphthalmia	1	1	0	0	0	5	
	0.1	***0.1***	***0.0***	***0.0***	***0.0***	***0.1***	
Anotia/microtia	0	0	1	1	0	16	
	0.0	***0.0***	***0.2***	***0.4***	***0.0***	***0.5***	
Aortic valve stenosis	3	1	0	0	0	10	
	0.2	***0.1***	***0.0***	***0.0***	***0.0***	***0.3***	
Atrial septal defect	105	137	3	3	2	428	
	7.0	***12.1***	***0.5***	***1.2***	***33.1***	***12.1***	
Atrioventricular septal defect (Endocardial cushion defect)	10	12	0	0	1	57	
	0.7	***1.1***	***0.0***	***0.0***	***16.6***	***1.6***	
Biliary atresia	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Bladder exstrophy	0	0	0	0	0	4	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Choanal atresia	2	1	0	0	0	6	
	0.1	***0.1***	***0.0***	***0.0***	***0.0***	***0.2***	
Cleft lip alone	18	10	1	1	0	79	
	1.2	***0.9***	***0.2***	***0.4***	***0.0***	***2.2***	
Cleft lip with cleft palate	24	5	1	0	0	73	
	1.6	***0.4***	***0.2***	***0.0***	***0.0***	***2.1***	
Cleft palate alone	43	17	4	4	0	155	
	2.9	***1.5***	***0.6***	***1.5***	***0.0***	***4.4***	
Cloacal exstrophy	1	0	0	0	0	2	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	65	28	8	5	0	251	
	4.3	***2.5***	***1.3***	***1.9***	***0.0***	***7.1***	
Coarctation of the aorta	20	15	1	1	0	76	
	1.3	***1.3***	***0.2***	***0.4***	***0.0***	***2.1***	
Common truncus (truncus arteriosus)	5	2	0	0	0	11	
	0.3	***0.2***	***0.0***	***0.0***	***0.0***	***0.3***	
Congenital cataract	0	2	0	0	0	6	
	0.0	***0.2***	***0.0***	***0.0***	***0.0***	***0.2***	
Congenital posterior urethral valves	2	5	0	0	0	14	1
	0.3	***0.9***	***0.0***	***0.0***	***0.0***	***0.8***	
Craniosynostosis	4	1	0	0	0	16	
	0.3	***0.1***	***0.0***	***0.0***	***0.0***	***0.5***	
Deletion 22q11.2	4	2	0	0	0	7	
	0.3	***0.2***	***0.0***	***0.0***	***0.0***	***0.2***	
Diaphragmatic hernia	12	7	0	0	0	71	
	0.8	***0.6***	***0.0***	***0.0***	***0.0***	***2.0***	
Double outlet right ventricle	8	8	0	1	0	51	
	0.5	***0.7***	***0.0***	***0.4***	***0.0***	***1.4***	
Ebstein anomaly	4	1	0	0	0	8	
	0.3	***0.1***	***0.0***	***0.0***	***0.0***	***0.2***	
Encephalocele	1	1	0	0	0	8	
	0.1	***0.1***	***0.0***	***0.0***	***0.0***	***0.2***	
Esophageal atresia/tracheoesophageal fistula	16	5	0	1	0	44	
	1.1	***0.4***	***0.0***	***0.4***	***0.0***	***1.2***	
Gastroschisis	19	9	0	0	0	59	
	1.3	***0.8***	***0.0***	***0.0***	***0.0***	***1.7***	
Holoprosencephaly	3	5	0	0	0	18	
	0.2	***0.4***	***0.0***	***0.0***	***0.0***	***0.5***	
Hypoplastic left heart syndrome	10	5	0	1	0	39	
	0.7	***0.4***	***0.0***	***0.4***	***0.0***	***1.1***	
Hypospadias	132	113	14	19	0	594	1
	17.1	***19.7***	***4.4***	***14.3***	***0.0***	***32.8***	
Interrupted aortic arch	22	26	1	1	0	97	
	1.5	***2.3***	***0.2***	***0.4***	***0.0***	***2.7***	
Limb deficiencies (reduction defects)	7	7	1	0	0	43	
	0.5	***0.6***	***0.2***	***0.0***	***0.0***	***1.2***	
Omphalocele	10	4	0	0	1	35	
	0.7	***0.4***	***0.0***	***0.0***	***16.6***	***1.0***	
Pulmonary valve atresia and stenosis	7	12	0	0	0	47	
	0.5	***1.1***	***0.0***	***0.0***	***0.0***	***1.3***	

Maryland

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	2	4	0	0	0	15	
	0.1	***0.4***	***0.0***	***0.0***	***0.0***	***0.4***	
Rectal and large intestinal atresia/stenosis	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Renal agenesis/hypoplasia	16	9	2	2	0	70	
	1.1	***0.8***	***0.3***	***0.8***	***0.0***	***2.0***	
Single ventricle	1	3	0	0	0	10	
	0.1	***0.3***	***0.0***	***0.0***	***0.0***	***0.3***	
Small intestinal atresia/stenosis	1	3	0	2	0	14	
	0.1	***0.3***	***0.0***	***0.8***	***0.0***	***0.4***	
Spina bifida without anencephalus	18	5	0	0	0	71	
	1.2	***0.4***	***0.0***	***0.0***	***0.0***	***2.0***	
Tetralogy of Fallot	28	16	1	4	0	92	
	1.9	***1.4***	***0.2***	***1.5***	***0.0***	***2.6***	
Total anomalous pulmonary venous connection	0	2	0	0	0	11	
	0.0	***0.2***	***0.0***	***0.0***	***0.0***	***0.3***	
Transposition of the great arteries (TGA)	18	5	0	0	0	47	
	1.2	***0.4***	***0.0***	***0.0***	***0.0***	***1.3***	
Dextro-transposition of great arteries (d-TGA)	15	5	0	0	0	40	
	1.0	***0.4***	***0.0***	***0.0***	***0.0***	***1.1***	
Tricuspid valve atresia and stenosis	2	3	0	0	0	13	
	0.1	***0.3***	***0.0***	***0.0***	***0.0***	***0.4***	
Trisomy 13	2	5	2	1	0	23	
	0.1	***0.4***	***0.3***	***0.4***	***0.0***	***0.6***	
Trisomy 18	14	14	2	1	1	79	
	0.9	***1.2***	***0.3***	***0.4***	***16.6***	***2.2***	
Trisomy 21 (Down syndrome)	75	56	19	6	1	310	
	5.0	***5.0***	***3.0***	***2.3***	***16.6***	***8.7***	
Turner syndrome	3	2	0	1	0	14	2
	0.4	***0.4***	***0.0***	***0.8***	***0.0***	***0.8***	
Ventricular septal defect	97	99	0	7	0	393	3
	6.4	***8.8***	***0.0***	***2.7***	***0.0***	***11.1***	
Total live births	**150,774**	**113,093**	**62,418**	**25,964**	**604**	**354,375**	**4**
Male live births	**77,292**	**57,358**	**31,851**	**13,265**	**293**	**180,837**	
Female live births	**73,480**	**55,728**	**30,564**	**12,698**	**311**	**173,525**	

Maryland

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	27	0	59	
	1.0	***0.0***	***1.7***	
Trisomy 13	10	7	23	
	0.4	***0.9***	***0.6***	
Trisomy 18	25	32	79	
	0.9	***4.0***	***2.2***	
Trisomy 21 (Down syndrome)	64	122	310	
	2.3	***15.2***	***8.7***	
Total live births	**274,160**	**80,197**	**354,375**	**4**

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. Prevalance is calculated per 10,000 female live births.
3. Data for this condition include probable cases.
4. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

Massachusetts

Birth Defects Counts and Prevalence 2016 - 2020 (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	56	16	19	16	0	116	
	2.8	***4.5***	***2.8***	***5.0***	***0.0***	***3.3***	
Anophthalmia/microphthalmia	21	3	8	6	0	42	
	1.0	***0.8***	***1.2***	***1.9***	***0.0***	***1.2***	
Anotia/microtia	38	5	27	10	0	83	
	1.9	***1.4***	***3.9***	***3.1***	***0.0***	***2.4***	
Aortic valve stenosis	40	5	9	3	0	59	
	2.0	***1.4***	***1.3***	***0.9***	***0.0***	***1.7***	
Atrial septal defect	519	120	203	71	6	942	
	25.9	***33.8***	***29.7***	***22.0***	***45.2***	***27.2***	
Atrioventricular septal defect (Endocardial cushion defect)	143	53	72	11	4	297	
	7.1	***14.9***	***10.5***	***3.4***	***30.1***	***8.6***	
Biliary atresia	13	1	5	0	0	19	
	0.6	***0.3***	***0.7***	***0.0***	***0.0***	***0.5***	
Bladder exstrophy	8	0	2	0	0	10	
	0.4	***0.0***	***0.3***	***0.0***	***0.0***	***0.3***	
Choanal atresia	10	1	4	2	2	20	
	0.5	***0.3***	***0.6***	***0.6***	***15.1***	***0.6***	
Cleft lip alone	59	4	18	15	1	102	
	2.9	***1.1***	***2.6***	***4.6***	***7.5***	***2.9***	
Cleft lip with cleft palate	83	16	34	16	1	155	
	4.1	***4.5***	***5.0***	***5.0***	***7.5***	***4.5***	
Cleft palate alone	116	19	36	18	1	201	
	5.8	***5.3***	***5.3***	***5.6***	***7.5***	***5.8***	
Cloacal exstrophy	7	1	5	1	0	14	
	0.3	***0.3***	***0.7***	***0.3***	***0.0***	***0.4***	
Clubfoot	374	53	138	23	4	610	1
	18.7	***14.9***	***20.2***	***7.1***	***30.1***	***17.6***	
Coarctation of the aorta	91	19	40	9	1	165	
	4.5	***5.3***	***5.8***	***2.8***	***7.5***	***4.8***	
Common truncus (truncus arteriosus)	15	2	1	4	0	24	
	0.7	***0.6***	***0.1***	***1.2***	***0.0***	***0.7***	
Congenital cataract	68	7	15	9	0	100	
	3.4	***2.0***	***2.2***	***2.8***	***0.0***	***2.9***	
Congenital posterior urethral valves	19	12	16	1	0	50	2
	1.9	***6.7***	***4.6***	***0.6***	***0.0***	***2.8***	
Craniosynostosis	140	8	30	11	1	197	
	7.0	***2.3***	***4.4***	***3.4***	***7.5***	***5.7***	
Deletion 22q11.2	37	7	18	6	1	71	
	1.8	***2.0***	***2.6***	***1.9***	***7.5***	***2.0***	
Diaphragmatic hernia	65	11	23	10	0	115	
	3.2	***3.1***	***3.4***	***3.1***	***0.0***	***3.3***	
Double outlet right ventricle	34	8	11	4	1	60	
	1.7	***2.3***	***1.6***	***1.2***	***7.5***	***1.7***	
Ebstein anomaly	15	1	5	1	0	25	
	0.7	***0.3***	***0.7***	***0.3***	***0.0***	***0.7***	
Encephalocele	23	8	7	2	0	42	
	1.1	***2.3***	***1.0***	***0.6***	***0.0***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	65	1	19	2	1	89	
	3.2	***0.3***	***2.8***	***0.6***	***7.5***	***2.6***	
Gastroschisis	48	7	31	5	1	96	
	2.4	***2.0***	***4.5***	***1.5***	***7.5***	***2.8***	
Holoprosencephaly	40	7	21	7	0	79	
	2.0	***2.0***	***3.1***	***2.2***	***0.0***	***2.3***	
Hypoplastic left heart syndrome	47	12	23	2	0	92	
	2.3	***3.4***	***3.4***	***0.6***	***0.0***	***2.7***	
Hypospadias	819	94	151	61	9	1,172	2
	79.9	***52.4***	***43.6***	***36.9***	***137.2***	***66.3***	
Interrupted aortic arch	8	5	5	1	0	19	
	0.4	***1.4***	***0.7***	***0.3***	***0.0***	***0.5***	
Limb deficiencies (reduction defects)	94	21	27	15	1	169	
	4.7	***5.9***	***3.9***	***4.6***	***7.5***	***4.9***	
Omphalocele	86	12	29	19	0	159	
	4.3	***3.4***	***4.2***	***5.9***	***0.0***	***4.6***	
Pulmonary valve atresia and stenosis	195	42	64	28	2	343	3
	9.7	***11.8***	***9.4***	***8.7***	***15.1***	***9.9***	

Massachusetts

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	29	3	5	9	1	48	3
	1.4	***0.8***	***0.7***	***2.8***	***7.5***	***1.4***	
Rectal and large intestinal atresia/stenosis	90	6	28	11	2	141	
	4.5	***1.7***	***4.1***	***3.4***	***15.1***	***4.1***	
Renal agenesis/hypoplasia	217	33	69	17	1	349	
	10.8	***9.3***	***10.1***	***5.3***	***7.5***	***10.1***	
Single ventricle	9	4	5	4	1	25	
	0.4	***1.1***	***0.7***	***1.2***	***7.5***	***0.7***	
Small intestinal atresia/stenosis	48	11	19	9	1	92	
	2.4	***3.1***	***2.8***	***2.8***	***7.5***	***2.7***	
Spina bifida without anencephalus	80	9	52	5	0	156	
	4.0	***2.5***	***7.6***	***1.5***	***0.0***	***4.5***	
Tetralogy of Fallot	98	23	36	18	1	191	
	4.9	***6.5***	***5.3***	***5.6***	***7.5***	***5.5***	
Total anomalous pulmonary venous connection	11	4	7	5	1	30	
	0.5	***1.1***	***1.0***	***1.5***	***7.5***	***0.9***	
Transposition of the great arteries (TGA)	53	12	19	12	0	99	
	2.6	***3.4***	***2.8***	***3.7***	***0.0***	***2.9***	
Dextro-transposition of great arteries (d-TGA)	43	10	11	10	0	76	
	2.1	***2.8***	***1.6***	***3.1***	***0.0***	***2.2***	
Tricuspid valve atresia and stenosis	13	1	4	1	0	19	
	0.6	***0.3***	***0.6***	***0.3***	***0.0***	***0.5***	
Tricuspid valve atresia	8	1	3	1	0	13	
	0.4	***0.3***	***0.4***	***0.3***	***0.0***	***0.4***	
Trisomy 13	92	15	25	15	0	167	
	4.6	***4.2***	***3.7***	***4.6***	***0.0***	***4.8***	
Trisomy 18	187	31	49	29	1	327	
	9.3	***8.7***	***7.2***	***9.0***	***7.5***	***9.4***	
Trisomy 21 (Down syndrome)	646	119	166	84	8	1,110	
	32.3	***33.5***	***24.3***	***26.0***	***60.2***	***32.0***	
Turner syndrome	186	33	62	23	1	318	4
	19.0	***18.8***	***18.4***	***14.6***	***14.9***	***18.7***	
Ventricular septal defect	618	87	221	96	1	1,053	
	30.9	***24.5***	***32.3***	***29.8***	***7.5***	***30.4***	
Total live births	**200,200**	**35,519**	**68,388**	**32,265**	**1,328**	**346,689**	**5**
Male live births	**102,492**	**17,934**	**34,623**	**16,540**	**656**	**176,807**	
Female live births	**97,707**	**17,585**	**33,764**	**15,725**	**672**	**169,880**	

Massachusetts

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	88	8	96	
	3.4	***0.9***	***2.8***	
Trisomy 13	71	96	167	
	2.8	***10.6***	***4.8***	
Trisomy 18	110	216	327	
	4.3	***23.8***	***9.4***	
Trisomy 21 (Down syndrome)	381	729	1,110	
	14.9	***80.2***	***32.0***	
Total live births	**255,736**	**90,942**	**346,689**	**5**

Notes

1. Data for this condition are limited to those who require casting or other treatment if the case is live birth.
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 cases of pulmonary valve atresia with a ventricular septal defect that were reviewed and determined not to be a variant of tetralogy of Fallot.
4. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
5. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.
-Data for all conditions exclude possible/probable cases.

Michigan
Birth Defects Counts and Prevalence 2016 - 2020 (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	47	5	2	4	0	61	
	1.3	***0.5***	***0.5***	***1.8***	***0.0***	***1.1***	
Anophthalmia/microphthalmia	83	23	3	4	1	140	
	2.2	***2.2***	***0.8***	***1.8***	***3.2***	***2.6***	
Anotia/microtia	100	19	16	9	1	179	
	2.7	***1.8***	***4.3***	***4.0***	***3.2***	***3.3***	
Aortic valve stenosis	113	20	7	5	3	170	
	3.1	***1.9***	***1.9***	***2.2***	***9.6***	***3.1***	
Atrial septal defect	6,717	2,657	666	319	55	11,264	
	181.5	***251.6***	***177.9***	***141.4***	***175.2***	***207.7***	
Atrioventricular septal defect (Endocardial cushion defect)	270	76	27	11	1	444	
	7.3	***7.2***	***7.2***	***4.9***	***3.2***	***8.2***	
Biliary atresia	54	30	10	2	0	107	
	1.5	***2.8***	***2.7***	***0.9***	***0.0***	***2.0***	
Choanal atresia	76	14	9	2	2	116	
	2.1	***1.3***	***2.4***	***0.9***	***6.4***	***2.1***	
Cleft lip alone	324	54	22	12	2	445	
	8.8	***5.1***	***5.9***	***5.3***	***6.4***	***8.2***	
Cleft lip with cleft palate	513	127	59	21	0	778	
	13.9	***12.0***	***15.8***	***9.3***	***0.0***	***14.3***	
Cleft palate alone	659	140	68	31	6	1,003	
	17.8	***13.3***	***18.2***	***13.7***	***19.1***	***18.5***	
Clubfoot	718	204	55	33	5	1,088	
	19.4	***19.3***	***14.7***	***14.6***	***15.9***	***20.1***	
Coarctation of the aorta	378	83	26	12	4	587	
	10.2	***7.9***	***6.9***	***5.3***	***12.7***	***10.8***	
Common truncus (truncus arteriosus)	37	10	9	2	0	69	
	1.0	***0.9***	***2.4***	***0.9***	***0.0***	***1.3***	
Congenital cataract	108	32	6	4	1	174	
	2.9	***3.0***	***1.6***	***1.8***	***3.2***	***3.2***	
Congenital posterior urethral valves	62	28	3	5	1	124	1
	3.3	***5.2***	***1.6***	***4.3***	***6.2***	***4.5***	
Craniosynostosis	935	188	81	57	3	1,369	
	25.3	***17.8***	***21.6***	***25.3***	***9.6***	***25.2***	
Diaphragmatic hernia	196	42	19	13	1	294	
	5.3	***4.0***	***5.1***	***5.8***	***3.2***	***5.4***	
Double outlet right ventricle	117	35	11	7	1	209	
	3.2	***3.3***	***2.9***	***3.1***	***3.2***	***3.9***	
Ebstein anomaly	23	7	1	1	1	36	
	0.6	***0.7***	***0.3***	***0.4***	***3.2***	***0.7***	
Encephalocele	63	20	6	1	0	94	
	1.7	***1.9***	***1.6***	***0.4***	***0.0***	***1.7***	
Esophageal atresia/tracheoesophageal fistula	183	25	5	11	0	251	
	4.9	***2.4***	***1.3***	***4.9***	***0.0***	***4.6***	
Gastroschisis	151	32	21	3	3	230	
	4.1	***3.0***	***5.6***	***1.3***	***9.6***	***4.2***	
Holoprosencephaly	14	14	2	2	0	41	
	0.4	***1.3***	***0.5***	***0.9***	***0.0***	***0.8***	
Hypoplastic left heart syndrome	173	38	16	7	6	283	
	4.7	***3.6***	***4.3***	***3.1***	***19.1***	***5.2***	
Hypospadias	2,459	545	115	89	10	3,388	1
	129.9	***101.7***	***60.1***	***77.2***	***62.0***	***122.3***	
Interrupted aortic arch	643	164	71	27	3	1,052	
	17.4	***15.5***	***19.0***	***12.0***	***9.6***	***19.4***	
Limb deficiencies (reduction defects)	325	116	23	11	1	514	
	8.8	***11.0***	***6.1***	***4.9***	***3.2***	***9.5***	
Omphalocele	95	141	11	7	0	270	
	2.6	***13.4***	***2.9***	***3.1***	***0.0***	***5.0***	
Pulmonary valve atresia and stenosis	535	177	44	18	3	873	
	14.5	***16.8***	***11.8***	***8.0***	***9.6***	***16.1***	
Rectal and large intestinal atresia/stenosis	234	38	19	9	0	330	
	6.3	***3.6***	***5.1***	***4.0***	***0.0***	***6.1***	
Renal agenesis/hypoplasia	357	103	24	13	3	554	
	9.6	***9.8***	***6.4***	***5.8***	***9.6***	***10.2***	
Single ventricle	93	36	10	6	1	173	
	2.5	***3.4***	***2.7***	***2.7***	***3.2***	***3.2***	

Michigan

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Small intestinal atresia/stenosis	144	56	17	5	0	240	
	3.9	***5.3***	***4.5***	***2.2***	***0.0***	***4.4***	
Spina bifida without anencephalus	293	40	48	14	0	450	
	7.9	***3.8***	***12.8***	***6.2***	***0.0***	***8.3***	
Tetralogy of Fallot	177	67	20	11	1	365	
	4.8	***6.3***	***5.3***	***4.9***	***3.2***	***6.7***	
Total anomalous pulmonary venous connection	41	12	8	2	0	77	
	1.1	***1.1***	***2.1***	***0.9***	***0.0***	***1.4***	
Transposition of the great arteries (TGA)	355	63	29	12	2	609	
	9.6	***6.0***	***7.7***	***5.3***	***6.4***	***11.2***	
Tricuspid valve atresia and stenosis	76	26	6	4	0	122	
	2.1	***2.5***	***1.6***	***1.8***	***0.0***	***2.2***	
Trisomy 13	26	9	5	2	0	45	
	0.7	***0.9***	***1.3***	***0.9***	***0.0***	***0.8***	
Trisomy 18	55	17	2	4	0	88	
	1.5	***1.6***	***0.5***	***1.8***	***0.0***	***1.6***	
Trisomy 21 (Down syndrome)	608	152	81	29	4	1,016	
	16.4	***14.4***	***21.6***	***12.9***	***12.7***	***18.7***	
Turner syndrome	113	14	2	6	2	139	2
	6.3	***2.7***	***1.1***	***5.4***	***13.1***	***5.2***	
Ventricular septal defect	2,260	654	218	117	12	3,651	
	61.1	***61.9***	***58.2***	***51.9***	***38.2***	***67.3***	
Total live births	**370,161**	**105,584**	**37,431**	**22,564**	**3,139**	**542,315**	**3**
Male live births	**189,372**	**53,569**	**19,132**	**11,524**	**1,613**	**276,986**	
Female live births	**180,781**	**52,007**	**18,298**	**11,039**	**1,526**	**265,311**	

Michigan

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	207	10	230	
	4.5	***1.2***	***4.2***	
Trisomy 13	31	11	45	
	0.7	***1.3***	***0.8***	
Trisomy 18	38	41	88	
	0.8	***5.0***	***1.6***	
Trisomy 21 (Down syndrome)	478	403	1,016	
	10.4	***48.9***	***18.7***	
Total live births	**459,819**	**82,407**	**542,315**	**3**

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. Prevalance 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.

-Data for all conditions include possible/probable diagnoses.

-Data for all conditions may differ from previous reports due to an upgrade in the Michigan Birth Defect Registry (MBDR) reporting process beginning with 2018 data.

Minnesota
Birth Defects Counts and Prevalence 2016 - 2020 (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	15	1	2	4	1	23	
	0.7	***0.2***	***0.8***	***1.5***	***1.9***	***0.7***	
Anophthalmia/microphthalmia	23	9	6	8	0	46	
	1.0	***2.1***	***2.4***	***3.0***	***0.0***	***1.4***	
Anotia/microtia	57	13	25	17	1	115	
	2.6	***3.1***	***10.2***	***6.3***	***1.9***	***3.6***	
Aortic valve stenosis	53	5	5	4	1	68	
	2.4	***1.2***	***2.0***	***1.5***	***1.9***	***2.1***	
Atrial septal defect	579	128	76	60	49	897	
	26.2	***30.1***	***30.9***	***22.3***	***91.1***	***27.8***	
Atrioventricular septal defect (Endocardial cushion defect)	121	30	4	8	4	167	1
	5.5	***7.1***	***1.6***	***3.0***	***7.4***	***5.2***	
Biliary atresia	8	3	2	2	0	15	
	0.4	***0.7***	***0.8***	***0.7***	***0.0***	***0.5***	
Bladder exstrophy	6	1	0	0	0	8	
	0.3	***0.2***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	37	0	0	1	1	39	
	1.7	***0.0***	***0.0***	***0.4***	***1.9***	***1.2***	
Cleft lip alone	63	10	10	12	4	100	
	2.8	***2.4***	***4.1***	***4.5***	***7.4***	***3.1***	
Cleft lip with cleft palate	127	20	17	17	5	187	
	5.7	***4.7***	***6.9***	***6.3***	***9.3***	***5.8***	
Cleft palate alone	162	20	14	30	7	236	
	7.3	***4.7***	***5.7***	***11.2***	***13.0***	***7.3***	
Cloacal exstrophy	4	0	1	1	0	7	
	0.2	***0.0***	***0.4***	***0.4***	***0.0***	***0.2***	
Clubfoot	350	65	24	26	9	476	
	15.8	***15.3***	***9.7***	***9.7***	***16.7***	***14.8***	
Coarctation of the aorta	123	26	12	11	4	177	
	5.6	***6.1***	***4.9***	***4.1***	***7.4***	***5.5***	
Common truncus (truncus arteriosus)	7	2	1	0	0	10	
	0.3	***0.5***	***0.4***	***0.0***	***0.0***	***0.3***	
Congenital cataract	55	25	9	9	1	100	
	2.5	***5.9***	***3.7***	***3.3***	***1.9***	***3.1***	
Congenital posterior urethral valves	27	15	0	1	1	44	2
	2.4	***6.9***	***0.0***	***0.7***	***3.7***	***2.7***	
Craniosynostosis	202	17	16	10	4	249	
	9.1	***4.0***	***6.5***	***3.7***	***7.4***	***7.7***	
Deletion 22q11.2	29	4	5	0	0	38	
	1.3	***0.9***	***2.0***	***0.0***	***0.0***	***1.2***	
Diaphragmatic hernia	66	11	7	4	2	90	
	3.0	***2.6***	***2.8***	***1.5***	***3.7***	***2.8***	
Double outlet right ventricle	44	14	4	7	1	70	
	2.0	***3.3***	***1.6***	***2.6***	***1.9***	***2.2***	
Ebstein anomaly	12	3	1	3	1	20	
	0.5	***0.7***	***0.4***	***1.1***	***1.9***	***0.6***	
Encephalocele	18	7	1	2	0	28	
	0.8	***1.6***	***0.4***	***0.7***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	63	6	5	4	3	81	
	2.8	***1.4***	***2.0***	***1.5***	***5.6***	***2.5***	
Gastroschisis	68	13	6	8	2	98	
	3.1	***3.1***	***2.4***	***3.0***	***3.7***	***3.0***	
Holoprosencephaly	8	6	2	3	0	19	
	0.4	***1.4***	***0.8***	***1.1***	***0.0***	***0.6***	
Hypoplastic left heart syndrome	44	9	4	2	1	60	
	2.0	***2.1***	***1.6***	***0.7***	***1.9***	***1.9***	
Hypospadias	796	184	40	43	11	1,079	2
	70.3	***84.9***	***31.9***	***31.2***	***40.8***	***65.5***	
Interrupted aortic arch	22	3	1	2	0	28	
	1.0	***0.7***	***0.4***	***0.7***	***0.0***	***0.9***	
Limb deficiencies (reduction defects)	83	17	16	6	3	125	
	3.8	***4.0***	***6.5***	***2.2***	***5.6***	***3.9***	
Omphalocele	42	16	3	4	1	67	
	1.9	***3.8***	***1.2***	***1.5***	***1.9***	***2.1***	
Pulmonary valve atresia and stenosis	307	68	38	23	6	446	
	13.9	***16.0***	***15.4***	***8.6***	***11.2***	***13.8***	

Minnesota

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	30	4	5	4	3	47	
	1.4	***0.9***	***2.0***	***1.5***	***5.6***	***1.5***	
Rectal and large intestinal atresia/stenosis	99	17	17	12	5	151	
	4.5	***4.0***	***6.9***	***4.5***	***9.3***	***4.7***	
Renal agenesis/hypoplasia	154	29	12	17	1	217	
	7.0	***6.8***	***4.9***	***6.3***	***1.9***	***6.7***	
Single ventricle	9	0	0	0	1	10	
	0.4	***0.0***	***0.0***	***0.0***	***1.9***	***0.3***	
Small intestinal atresia/stenosis	69	14	15	8	3	110	
	3.1	***3.3***	***6.1***	***3.0***	***5.6***	***3.4***	
Spina bifida without anencephalus	55	12	5	7	1	80	
	2.5	***2.8***	***2.0***	***2.6***	***1.9***	***2.5***	
Tetralogy of Fallot	109	13	5	9	4	140	
	4.9	***3.1***	***2.0***	***3.3***	***7.4***	***4.3***	
Total anomalous pulmonary venous connection	16	5	5	4	3	33	
	0.7	***1.2***	***2.0***	***1.5***	***5.6***	***1.0***	
Transposition of the great arteries (TGA)	87	12	3	3	5	111	
	3.9	***2.8***	***1.2***	***1.1***	***9.3***	***3.4***	
Dextro-transposition of great arteries (d-TGA)	77	9	3	3	4	96	
	3.5	***2.1***	***1.2***	***1.1***	***7.4***	***3.0***	
Tricuspid valve atresia and stenosis	29	10	3	2	1	45	
	1.3	***2.4***	***1.2***	***0.7***	***1.9***	***1.4***	
Tricuspid valve atresia	17	5	2	1	1	26	
	0.8	***1.2***	***0.8***	***0.4***	***1.9***	***0.8***	
Trisomy 13	13	10	1	4	0	28	
	0.6	***2.4***	***0.4***	***1.5***	***0.0***	***0.9***	
Trisomy 18	29	30	3	4	0	67	
	1.3	***7.1***	***1.2***	***1.5***	***0.0***	***2.1***	
Trisomy 21 (Down syndrome)	316	105	57	34	10	525	
	14.3	***24.7***	***23.2***	***12.6***	***18.6***	***16.3***	
Turner syndrome	25	5	1	5	1	38	3
	2.3	***2.4***	***0.8***	***3.8***	***3.7***	***2.4***	
Ventricular septal defect	1,566	286	189	139	55	2,248	4
	70.8	***67.2***	***76.8***	***51.7***	***102.2***	***69.7***	
Total live births	**221,333**	**42,538**	**24,616**	**26,894**	**5,381**	**322,504**	**5**
Male live births	**113,277**	**21,668**	**12,558**	**13,783**	**2,695**	**164,843**	
Female live births	**108,054**	**20,870**	**12,058**	**13,111**	**2,686**	**157,659**	

Minnesota

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	93	5	98	
	3.6	***0.8***	***3.0***	
Trisomy 13	15	13	28	
	0.6	***2.1***	***0.9***	
Trisomy 18	32	35	67	
	1.2	***5.7***	***2.1***	
Trisomy 21 (Down syndrome)	269	256	525	
	10.3	***41.5***	***16.3***	
Total live births	**260,842**	**61,656**	**322,504**	**5**

Notes

1. Data for this condition exclude inlet ventricular septal defect.
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 this condition include inlet ventricular septal defect.
5. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.
-Data for all conditions exclude possible/probable cases.

Missouri
Birth Defects Counts and Prevalence 2016 - 2020 (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	58	10	7	1	0	77	
	2.1	***1.8***	***3.2***	***1.0***	***0.0***	***2.1***	
Anophthalmia/microphthalmia	25	3	2	2	0	32	
	0.9	***0.5***	***0.9***	***1.9***	***0.0***	***0.9***	
Anotia/microtia	25	5	3	1	0	34	
	0.9	***0.9***	***1.4***	***1.0***	***0.0***	***0.9***	
Aortic valve stenosis	45	5	2	4	0	58	
	1.7	***0.9***	***0.9***	***3.8***	***0.0***	***1.6***	
Atrial septal defect	4,091	1,239	329	155	29	5,881	
	151.3	***219.9***	***152.6***	***147.3***	***199.6***	***161.9***	
Atrioventricular septal defect (Endocardial cushion defect)	140	31	9	2	0	185	1
	5.2	***5.5***	***4.2***	***1.9***	***0.0***	***5.1***	
Biliary atresia	81	44	7	6	1	142	
	3.0	***7.8***	***3.2***	***5.7***	***6.9***	***3.9***	
Bladder exstrophy	6	7	0	0	1	14	
	0.2	***1.2***	***0.0***	***0.0***	***6.9***	***0.4***	
Choanal atresia	58	5	4	1	1	69	
	2.1	***0.9***	***1.9***	***1.0***	***6.9***	***1.9***	
Cleft lip alone	107	18	7	3	2	138	
	4.0	***3.2***	***3.2***	***2.9***	***13.8***	***3.8***	
Cleft lip with cleft palate	204	22	14	1	1	243	
	7.5	***3.9***	***6.5***	***1.0***	***6.9***	***6.7***	
Cleft palate alone	227	42	17	7	3	297	
	8.4	***7.5***	***7.9***	***6.7***	***20.6***	***8.2***	
Cloacal exstrophy	2	3	0	0	0	5	
	0.1	***0.5***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	693	132	48	15	7	902	
	25.6	***23.4***	***22.3***	***14.3***	***48.2***	***24.8***	
Coarctation of the aorta	167	39	11	6	1	228	
	6.2	***6.9***	***5.1***	***5.7***	***6.9***	***6.3***	
Common truncus (truncus arteriosus)	20	2	1	0	0	23	
	0.7	***0.4***	***0.5***	***0.0***	***0.0***	***0.6***	
Congenital cataract	58	22	6	2	1	89	
	2.1	***3.9***	***2.8***	***1.9***	***6.9***	***2.4***	
Congenital posterior urethral valves	42	10	0	2	0	55	2
	3.0	***3.5***	***0.0***	***3.7***	***0.0***	***3.0***	
Craniosynostosis	319	40	18	12	1	393	
	11.8	***7.1***	***8.3***	***11.4***	***6.9***	***10.8***	
Deletion 22q11.2	26	11	4	0	0	42	
	1.0	***2.0***	***1.9***	***0.0***	***0.0***	***1.2***	
Diaphragmatic hernia	136	31	11	3	2	184	
	5.0	***5.5***	***5.1***	***2.9***	***13.8***	***5.1***	
Double outlet right ventricle	81	16	0	3	0	100	
	3.0	***2.8***	***0.0***	***2.9***	***0.0***	***2.8***	
Ebstein anomaly	33	4	2	0	1	40	
	1.2	***0.7***	***0.9***	***0.0***	***6.9***	***1.1***	
Encephalocele	36	7	2	0	0	45	
	1.3	***1.2***	***0.9***	***0.0***	***0.0***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	75	12	2	2	0	91	
	2.8	***2.1***	***0.9***	***1.9***	***0.0***	***2.5***	
Gastroschisis	127	28	14	0	3	172	
	4.7	***5.0***	***6.5***	***0.0***	***20.6***	***4.7***	
Holoprosencephaly	31	12	4	1	0	48	
	1.1	***2.1***	***1.9***	***1.0***	***0.0***	***1.3***	
Hypoplastic left heart syndrome	107	21	3	3	1	136	
	4.0	***3.7***	***1.4***	***2.9***	***6.9***	***3.7***	
Hypospadias	1,631	292	71	48	3	2,055	2
	117.3	***102.2***	***65.1***	***88.6***	***41.7***	***110.4***	
Interrupted aortic arch	43	9	3	1	1	58	
	1.6	***1.6***	***1.4***	***1.0***	***6.9***	***1.6***	
Limb deficiencies (reduction defects)	134	37	9	8	3	193	
	5.0	***6.6***	***4.2***	***7.6***	***20.6***	***5.3***	
Omphalocele	91	35	7	5	3	141	
	3.4	***6.2***	***3.2***	***4.8***	***20.6***	***3.9***	
Pulmonary valve atresia and stenosis	198	55	16	8	0	277	
	7.3	***9.8***	***7.4***	***7.6***	***0.0***	***7.6***	

Missouri

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	42	11	2	1	0	56	
	1.6	***2.0***	***0.9***	***1.0***	***0.0***	***1.5***	
Rectal and large intestinal atresia/stenosis	120	23	13	7	2	165	
	4.4	***4.1***	***6.0***	***6.7***	***13.8***	***4.5***	
Renal agenesis/hypoplasia	222	46	23	5	2	300	
	8.2	***8.2***	***10.7***	***4.8***	***13.8***	***8.3***	
Single ventricle	55	7	4	0	0	66	
	2.0	***1.2***	***1.9***	***0.0***	***0.0***	***1.8***	
Small intestinal atresia/stenosis	100	26	9	3	0	140	
	3.7	***4.6***	***4.2***	***2.9***	***0.0***	***3.9***	
Spina bifida without anencephalus	130	20	11	3	2	166	
	4.8	***3.6***	***5.1***	***2.9***	***13.8***	***4.6***	
Tetralogy of Fallot	132	31	4	6	0	174	
	4.9	***5.5***	***1.9***	***5.7***	***0.0***	***4.8***	
Total anomalous pulmonary venous connection	30	5	2	2	0	39	
	1.1	***0.9***	***0.9***	***1.9***	***0.0***	***1.1***	
Transposition of the great arteries (TGA)	109	15	8	1	0	134	
	4.0	***2.7***	***3.7***	***1.0***	***0.0***	***3.7***	
Dextro-transposition of great arteries (d-TGA)	101	12	7	1	0	122	
	3.7	***2.1***	***3.2***	***1.0***	***0.0***	***3.4***	
Tricuspid valve atresia and stenosis	24	4	3	0	0	32	3
	0.9	***0.7***	***1.4***	***0.0***	***0.0***	***0.9***	
Trisomy 13	23	5	2	2	0	32	
	0.9	***0.9***	***0.9***	***1.9***	***0.0***	***0.9***	
Trisomy 18	59	6	6	2	0	74	
	2.2	***1.1***	***2.8***	***1.9***	***0.0***	***2.0***	
Trisomy 21 (Down syndrome)	389	68	41	15	1	520	
	14.4	***12.1***	***19.0***	***14.3***	***6.9***	***14.3***	
Turner syndrome	46	7	4	2	0	61	4
	3.5	***2.5***	***3.8***	***3.9***	***0.0***	***3.4***	
Ventricular septal defect	1,374	291	110	46	5	1,840	5
	50.8	***51.7***	***51.0***	***43.7***	***34.4***	***50.7***	
Total live births	**270,437**	**56,338**	**21,561**	**10,520**	**1,453**	**363,273**	**6**
Male live births	**139,070**	**28,564**	**10,902**	**5,419**	**720**	**186,205**	
Female live births	**131,360**	**27,770**	**10,656**	**5,101**	**733**	**177,054**	

Missouri

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	165	7	172	
	5.3	***1.4***	***4.7***	
Trisomy 13	18	14	32	
	0.6	***2.8***	***0.9***	
Trisomy 18	38	36	74	
	1.2	***7.2***	***2.0***	
Trisomy 21 (Down syndrome)	291	229	520	
	9.3	***46.0***	***14.3***	
Total live births	**313,368**	**49,825**	**363,273**	**6**

Notes

1. Data for this condition include inlet ventricular septal defect (VSD), and common atrioventricular (AV) canal type VSD.
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 hypoplasia.
4. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
5. Data for this condition exclude probable cases.
6. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

Nevada

Birth Defects Counts and Prevalence 2016 - 2020 (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	4	0	1	3	0	8	
	0.6	***0.0***	***0.2***	***1.8***	***0.0***	***0.4***	
Anophthalmia/microphthalmia	7	6	8	2	0	23	
	1.0	***2.4***	***1.2***	***1.2***	***0.0***	***1.3***	
Anotia/microtia	9	2	11	5	0	27	
	1.3	***0.8***	***1.7***	***3.0***	***0.0***	***1.5***	
Aortic valve stenosis	7	2	8	2	0	19	
	1.0	***0.8***	***1.2***	***1.2***	***0.0***	***1.1***	
Atrial septal defect	5,404	2,127	4,636	1,454	102	13,821	
	796.1	***849.6***	***714.3***	***884.0***	***595.1***	***772.8***	
Atrioventricular septal defect (Endocardial cushion defect)	26	9	15	0	0	50	1
	3.8	***3.6***	***2.3***	***0.0***	***0.0***	***2.8***	
Biliary atresia	25	12	36	7	1	81	
	3.7	***4.8***	***5.5***	***4.3***	***5.8***	***4.5***	
Bladder exstrophy	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.6***	***0.0***	***0.1***	
Choanal atresia	12	2	5	1	0	20	
	1.8	***0.8***	***0.8***	***0.6***	***0.0***	***1.1***	
Cleft lip alone	22	6	13	6	0	48	
	3.2	***2.4***	***2.0***	***3.6***	***0.0***	***2.7***	
Cleft lip with cleft palate	35	9	39	9	1	95	
	5.2	***3.6***	***6.0***	***5.5***	***5.8***	***5.3***	
Cleft palate alone	42	11	40	10	2	105	
	6.2	***4.4***	***6.2***	***6.1***	***11.7***	***5.9***	
Clubfoot	124	31	100	31	3	292	
	18.3	***12.4***	***15.4***	***18.8***	***17.5***	***16.3***	
Coarctation of the aorta	40	10	31	5	1	87	
	5.9	***4.0***	***4.8***	***3.0***	***5.8***	***4.9***	
Common truncus (truncus arteriosus)	11	1	4	2	0	18	
	1.6	***0.4***	***0.6***	***1.2***	***0.0***	***1.0***	
Congenital cataract	4	2	6	1	0	13	
	0.6	***0.8***	***0.9***	***0.6***	***0.0***	***0.7***	
Congenital posterior urethral valves	6	2	4	1	0	13	2
	1.7	***1.6***	***1.2***	***1.2***	***0.0***	***1.4***	
Craniosynostosis	30	7	23	4	0	64	
	4.4	***2.8***	***3.5***	***2.4***	***0.0***	***3.6***	
Deletion 22q11.2	2	1	2	0	0	5	
	0.3	***0.4***	***0.3***	***0.0***	***0.0***	***0.3***	
Diaphragmatic hernia	11	15	18	4	1	51	
	1.6	***6.0***	***2.8***	***2.4***	***5.8***	***2.9***	
Double outlet right ventricle	8	4	14	1	0	27	
	1.2	***1.6***	***2.2***	***0.6***	***0.0***	***1.5***	
Ebstein anomaly	5	0	3	2	0	10	
	0.7	***0.0***	***0.5***	***1.2***	***0.0***	***0.6***	
Encephalocele	2	2	2	0	1	7	
	0.3	***0.8***	***0.3***	***0.0***	***5.8***	***0.4***	
Esophageal atresia/tracheoesophageal fistula	19	6	17	1	0	44	
	2.8	***2.4***	***2.6***	***0.6***	***0.0***	***2.5***	
Gastroschisis	23	7	37	6	0	74	
	3.4	***2.8***	***5.7***	***3.6***	***0.0***	***4.1***	
Holoprosencephaly	5	4	9	2	0	20	
	0.7	***1.6***	***1.4***	***1.2***	***0.0***	***1.1***	
Hypoplastic left heart syndrome	13	6	22	2	0	44	
	1.9	***2.4***	***3.4***	***1.2***	***0.0***	***2.5***	
Hypospadias	203	58	112	39	0	415	2
	58.2	***45.3***	***33.8***	***45.6***	***0.0***	***45.2***	
Interrupted aortic arch	15	6	13	1	0	35	
	2.2	***2.4***	***2.0***	***0.6***	***0.0***	***2.0***	
Limb deficiencies (reduction defects)	14	5	17	4	0	40	
	2.1	***2.0***	***2.6***	***2.4***	***0.0***	***2.2***	
Omphalocele	17	5	8	4	0	34	
	2.5	***2.0***	***1.2***	***2.4***	***0.0***	***1.9***	
Pulmonary valve atresia and stenosis	41	28	40	12	1	123	
	6.0	***11.2***	***6.2***	***7.3***	***5.8***	***6.9***	
Pulmonary valve atresia	4	0	2	2	1	9	
	0.6	***0.0***	***0.3***	***1.2***	***5.8***	***0.5***	

Nevada

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Rectal and large intestinal atresia/stenosis	31	9	24	5	0	69	
	4.6	***3.6***	***3.7***	***3.0***	***0.0***	***3.9***	
Renal agenesis/hypoplasia	29	18	36	5	1	90	
	4.3	***7.2***	***5.5***	***3.0***	***5.8***	***5.0***	
Single ventricle	2	4	9	1	0	16	
	0.3	***1.6***	***1.4***	***0.6***	***0.0***	***0.9***	
Small intestinal atresia/stenosis	19	7	34	5	0	66	
	2.8	***2.8***	***5.2***	***3.0***	***0.0***	***3.7***	
Spina bifida without anencephalus	10	4	23	2	0	39	
	1.5	***1.6***	***3.5***	***1.2***	***0.0***	***2.2***	
Tetralogy of Fallot	18	14	21	6	1	60	
	2.7	***5.6***	***3.2***	***3.6***	***5.8***	***3.4***	
Total anomalous pulmonary venous connection	5	1	9	1	1	17	
	0.7	***0.4***	***1.4***	***0.6***	***5.8***	***1.0***	
Transposition of the great arteries (TGA)	18	7	22	7	0	54	
	2.7	***2.8***	***3.4***	***4.3***	***0.0***	***3.0***	
Dextro-transposition of great arteries (d-TGA)	14	6	16	6	0	42	
	2.1	***2.4***	***2.5***	***3.6***	***0.0***	***2.3***	
Tricuspid valve atresia and stenosis	6	3	3	0	0	12	3
	0.9	***1.2***	***0.5***	***0.0***	***0.0***	***0.7***	
Tricuspid valve atresia	6	3	3	0	0	12	
	0.9	***1.2***	***0.5***	***0.0***	***0.0***	***0.7***	
Trisomy 13	5	7	3	1	0	16	
	0.7	***2.8***	***0.5***	***0.6***	***0.0***	***0.9***	
Trisomy 18	14	7	17	1	0	39	
	2.1	***2.8***	***2.6***	***0.6***	***0.0***	***2.2***	
Trisomy 21 (Down syndrome)	78	37	134	14	3	268	
	11.5	***14.8***	***20.6***	***8.5***	***17.5***	***15.0***	
Ventricular septal defect	606	217	648	124	16	1,620	
	89.3	***86.7***	***99.8***	***75.4***	***93.3***	***90.6***	
Total live births	**67,885**	**25,035**	**64,904**	**16,448**	**1,714**	**178,832**	
Male live births	**34,894**	**12,810**	**33,115**	**8,559**	**851**	**91,727**	

Nevada

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	68	6	74	
	4.7	***1.9***	***4.1***	
Trisomy 13	11	5	16	
	0.8	***1.6***	***0.9***	
Trisomy 18	16	23	39	
	1.1	***7.3***	***2.2***	
Trisomy 21 (Down syndrome)	113	155	268	
	7.8	***49.1***	***15.0***	
Total live births	**144,921**	**31,582**	**178,832**	

Notes

1. Data for this condition exclude inlet ventricular septal defect (VSD), including common atrioventricular (AV) canal type VSD.
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 tricuspid stenosis and hypoplasia.

General comments

*Data for totals include unknown and/or other.

New Hampshire
Birth Defects Counts and Prevalence 2018 - 2020 (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	0	0	0	0	0	<5	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***		
Anophthalmia/microphthalmia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Anotia/microtia	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Aortic valve stenosis	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Atrial septal defect	17	0	<5	0	0	18	
	5.6	***0.0***		***0.0***	***0.0***	***5.1***	
Atrioventricular septal defect (Endocardial cushion defect)	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Biliary atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	0	0	0	0	0	<5	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***		
Cleft lip alone	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Cleft lip with cleft palate	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Cleft palate alone	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	5	0	<5	0	0	7	
	1.7	***0.0***		***0.0***	***0.0***	***2.0***	
Coarctation of the aorta	<5	0	0	0	0	5	
		0.0	***0.0***	***0.0***	***0.0***	***1.4***	
Common truncus (truncus arteriosus)	0	0	0	0	0	<5	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***		
Congenital cataract	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Congenital posterior urethral valves	0	0	0	0	0	0	1
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Deletion 22q11.2	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Diaphragmatic hernia	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Double outlet right ventricle	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Ebstein anomaly	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Encephalocele	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Esophageal atresia/tracheoesophageal fistula	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Gastroschisis	0	0	0	0	0	<5	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***		
Holoprosencephaly	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Hypoplastic left heart syndrome	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Hypospadias	18	0	0	<5	0	22	1
	11.7	***0.0***	***0.0***		***0.0***	***12.2***	
Interrupted aortic arch	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Limb deficiencies (reduction defects)	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Omphalocele	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		
Pulmonary valve atresia and stenosis	11	0	0	0	0	11	
	3.6	***0.0***	***0.0***	***0.0***	***0.0***	***3.1***	
Pulmonary valve atresia	<5	0	0	0	0	<5	
		0.0	***0.0***	***0.0***	***0.0***		

New Hampshire

Birth Defects Counts and Prevalence 2018 - 2020 (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**
Rectal and large intestinal atresia/stenosis	<5	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	
Renal agenesis/hypoplasia	10 ***3.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	10 ***2.8***	
Single ventricle	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Small intestinal atresia/stenosis	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Spina bifida without anencephalus	<5	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	
Tetralogy of Fallot	<5	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	
Total anomalous pulmonary venous connection	<5	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	
Transposition of the great arteries (TGA)	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	
Dextro-transposition of great arteries (d-TGA)	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Tricuspid valve atresia and stenosis	<5	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	
Tricuspid valve atresia	<5	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	
Trisomy 13	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Trisomy 18	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Trisomy 21 (Down syndrome)	7 ***2.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	8 ***2.2***	
Turner syndrome	<5	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5	2
Ventricular septal defect	30 ***9.9***	0 ***0.0***	5 ***21.8***	0 ***0.0***	0 ***0.0***	40 ***11.2***	
Total live births	**30,250**	**702**	**2,294**	**1,312**	**28**	**35,585**	
Male live births	**15,405**	**340**	**1,171**	**677**	**11**	**18,106**	
Female live births	**14,845**	**362**	**1,123**	**635**	**17**	**17,479**	

New Hampshire

Birth Defects Counts and Prevalence 2018 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	0	0	<5	
	0.0	***0.0***		
Trisomy 13	0	0	0	
	0.0	***0.0***	***0.0***	
Trisomy 18	0	0	0	
	0.0	***0.0***	***0.0***	
Trisomy 21 (Down syndrome)	6	<5	8	
	2.1		***2.2***	
Total live births	**28,498**	**7,087**	**35,585**	

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. Prevalance is calculated per 10,000 female live births.

General comments
*Data for totals include unknown and/or other.
-Data for all conditions are based on confirmed cases.

New Jersey
Birth Defects Counts and Prevalence 2016 - 2020 (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	5	4	12	0	0	22	
	0.2	***0.6***	***0.9***	***0.0***	***0.0***	***0.4***	
Anophthalmia/microphthalmia	19	5	16	2	0	43	
	0.8	***0.7***	***1.2***	***0.3***	***0.0***	***0.8***	
Anotia/microtia	22	5	56	19	0	107	
	0.9	***0.7***	***4.1***	***3.3***	***0.0***	***2.1***	
Aortic valve stenosis	28	5	12	3	0	50	
	1.2	***0.7***	***0.9***	***0.5***	***0.0***	***1.0***	
Atrial septal defect	626	550	637	158	2	2,015	1
	26.7	***80.5***	***46.4***	***27.2***	***68.7***	***39.0***	
Atrioventricular septal defect (Endocardial cushion defect)	47	29	28	2	0	112	2
	2.0	***4.2***	***2.0***	***0.3***	***0.0***	***2.2***	
Biliary atresia	10	2	5	5	0	23	
	0.4	***0.3***	***0.4***	***0.9***	***0.0***	***0.4***	
Bladder exstrophy	2	1	0	1	0	4	
	0.1	***0.1***	***0.0***	***0.2***	***0.0***	***0.1***	
Choanal atresia	26	3	8	0	0	39	
	1.1	***0.4***	***0.6***	***0.0***	***0.0***	***0.8***	
Cleft lip alone	62	9	20	12	0	109	
	2.6	***1.3***	***1.5***	***2.1***	***0.0***	***2.1***	
Cleft lip with cleft palate	85	21	80	15	0	210	
	3.6	***3.1***	***5.8***	***2.6***	***0.0***	***4.1***	
Cleft palate alone	113	28	70	22	0	251	
	4.8	***4.1***	***5.1***	***3.8***	***0.0***	***4.9***	
Cloacal exstrophy	17	5	10	7	0	40	
	0.7	***0.7***	***0.7***	***1.2***	***0.0***	***0.8***	
Clubfoot	272	90	168	58	1	612	
	11.6	***13.2***	***12.2***	***10.0***	***34.4***	***11.9***	
Coarctation of the aorta	46	17	39	9	0	115	
	2.0	***2.5***	***2.8***	***1.6***	***0.0***	***2.2***	
Common truncus (truncus arteriosus)	8	1	7	0	0	16	
	0.3	***0.1***	***0.5***	***0.0***	***0.0***	***0.3***	
Congenital cataract	24	7	29	6	0	69	
	1.0	***1.0***	***2.1***	***1.0***	***0.0***	***1.3***	
Congenital posterior urethral valves	22	14	11	10	0	65	3
	1.8	***4.0***	***1.6***	***3.3***	***0.0***	***2.5***	
Craniosynostosis	125	31	91	21	0	281	
	5.3	***4.5***	***6.6***	***3.6***	***0.0***	***5.4***	
Deletion 22q11.2	9	2	1	0	0	14	
	0.4	***0.3***	***0.1***	***0.0***	***0.0***	***0.3***	
Diaphragmatic hernia	36	7	31	11	0	89	
	1.5	***1.0***	***2.3***	***1.9***	***0.0***	***1.7***	
Double outlet right ventricle	10	10	11	1	0	32	
	0.4	***1.5***	***0.8***	***0.2***	***0.0***	***0.6***	
Ebstein anomaly	9	1	5	2	0	18	
	0.4	***0.1***	***0.4***	***0.3***	***0.0***	***0.3***	
Encephalocele	4	3	5	0	0	12	
	0.2	***0.4***	***0.4***	***0.0***	***0.0***	***0.2***	
Esophageal atresia/tracheoesophageal fistula	60	18	26	6	0	114	
	2.6	***2.6***	***1.9***	***1.0***	***0.0***	***2.2***	
Gastroschisis	27	16	37	0	0	82	
	1.2	***2.3***	***2.7***	***0.0***	***0.0***	***1.6***	
Holoprosencephaly	28	12	31	7	0	81	
	1.2	***1.8***	***2.3***	***1.2***	***0.0***	***1.6***	
Hypoplastic left heart syndrome	29	14	14	5	0	64	
	1.2	***2.1***	***1.0***	***0.9***	***0.0***	***1.2***	
Hypospadias	1,176	261	378	188	0	2,066	3
	97.7	***75.3***	***54.0***	***62.2***	***0.0***	***78.0***	
Interrupted aortic arch	7	2	2	1	0	12	
	0.3	***0.3***	***0.1***	***0.2***	***0.0***	***0.2***	
Limb deficiencies (reduction defects)	53	22	37	10	0	124	
	2.3	***3.2***	***2.7***	***1.7***	***0.0***	***2.4***	
Omphalocele	13	26	16	6	0	66	
	0.6	***3.8***	***1.2***	***1.0***	***0.0***	***1.3***	
Pulmonary valve atresia and stenosis	110	89	111	25	0	356	
	4.7	***13.0***	***8.1***	***4.3***	***0.0***	***6.9***	

New Jersey
Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	6	3	8	2	0	20	
	0.3	***0.4***	***0.6***	***0.3***	***0.0***	***0.4***	
Rectal and large intestinal atresia/stenosis	48	19	50	22	0	145	
	2.0	***2.8***	***3.6***	***3.8***	***0.0***	***2.8***	
Renal agenesis/hypoplasia	141	32	82	26	0	292	
	6.0	***4.7***	***6.0***	***4.5***	***0.0***	***5.7***	
Single ventricle	3	1	5	1	0	11	
	0.1	***0.1***	***0.4***	***0.2***	***0.0***	***0.2***	
Small intestinal atresia/stenosis	48	18	55	9	0	133	
	2.0	***2.6***	***4.0***	***1.6***	***0.0***	***2.6***	
Spina bifida without anencephalus	19	11	29	11	0	79	
	0.8	***1.6***	***2.1***	***1.9***	***0.0***	***1.5***	
Tetralogy of Fallot	48	28	38	14	0	138	
	2.0	***4.1***	***2.8***	***2.4***	***0.0***	***2.7***	
Total anomalous pulmonary venous connection	17	5	15	5	0	42	
	0.7	***0.7***	***1.1***	***0.9***	***0.0***	***0.8***	
Transposition of the great arteries (TGA)	27	7	20	6	0	67	
	1.2	***1.0***	***1.5***	***1.0***	***0.0***	***1.3***	
Dextro-transposition of great arteries (d-TGA)	19	6	15	5	0	51	
	0.8	***0.9***	***1.1***	***0.9***	***0.0***	***1.0***	
Tricuspid valve atresia and stenosis	9	6	12	1	0	30	4
	0.4	***0.9***	***0.9***	***0.2***	***0.0***	***0.6***	
Trisomy 13	15	7	10	0	0	35	
	0.6	***1.0***	***0.7***	***0.0***	***0.0***	***0.7***	
Trisomy 18	11	7	24	2	0	45	
	0.5	***1.0***	***1.7***	***0.3***	***0.0***	***0.9***	
Trisomy 21 (Down syndrome)	193	79	238	24	0	557	
	8.2	***11.6***	***17.3***	***4.1***	***0.0***	***10.8***	
Turner syndrome	18	2	15	2	0	37	5
	1.6	***0.6***	***2.2***	***0.7***	***0.0***	***1.5***	
Ventricular septal defect	1,000	319	755	201	3	2,348	6
	42.6	***46.7***	***55.0***	***34.7***	***103.1***	***45.5***	
Total live births	**234,526**	**68,283**	**137,252**	**57,982**	**291**	**516,442**	**7**
Male live births	**120,410**	**34,644**	**70,008**	**30,230**	**152**	**264,815**	
Female live births	**114,113**	**33,636**	**67,240**	**27,750**	**139**	**251,615**	

New Jersey
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	77	5	82	
	2.0	***0.4***	***1.6***	
Trisomy 13	19	16	35	
	0.5	***1.2***	***0.7***	
Trisomy 18	17	28	45	
	0.4	***2.1***	***0.9***	
Trisomy 21 (Down syndrome)	217	328	557	
	5.6	***25.0***	***10.8***	
Total live births	**385,205**	**131,227**	**516,442**	**7**

Notes
1. Data for this condition include only live born cases with atrial septal defect. Patent foramen ovale are coded separately.
2. Data for this condition include only live born cases. Cases are coded based upon verbatim diagnosis provided by registering facility.
3. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
4. Data for this condition include only live born cases. Cases include hypoplasia.
5. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
6. Data for this condition include only live born cases with a confirmed diagnosis. Cases are coded based upon verbatim diagnosis provided by registering facility.
7. Data for total live births include unknown gender.

General comments
*Data for totals include unknown and/or other.

New Mexico
Birth Defects Counts and Prevalence 2016 - 2020 (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	3	0	6	1	4	14	
	1.0	***0.0***	***1.0***	***4.0***	***3.0***	***1.3***	
Anophthalmia/microphthalmia	4	0	7	0	4	15	
	1.3	***0.0***	***1.2***	***0.0***	***3.0***	***1.4***	
Anotia/microtia	7	0	38	1	16	62	
	2.3	***0.0***	***6.5***	***4.0***	***11.9***	***5.8***	
Aortic valve stenosis	3	0	3	0	1	7	
	1.0	***0.0***	***0.5***	***0.0***	***0.7***	***0.7***	
Atrial septal defect	914	77	1,843	80	468	3,390	
	306.0	***334.9***	***313.4***	***321.3***	***349.4***	***316.5***	
Atrioventricular septal defect (Endocardial cushion defect)	10	0	18	0	8	36	
	3.3	***0.0***	***3.1***	***0.0***	***6.0***	***3.4***	
Biliary atresia	7	2	18	0	8	35	
	2.3	***8.7***	***3.1***	***0.0***	***6.0***	***3.3***	
Bladder exstrophy	1	0	0	0	0	1	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Choanal atresia	9	1	6	0	1	17	
	3.0	***4.3***	***1.3***	***0.0***	***0.9***	***1.6***	
Cleft lip alone	14	0	23	4	8	49	
	4.7	***0.0***	***3.9***	***16.1***	***6.0***	***4.6***	
Cleft lip with cleft palate	30	1	49	3	31	114	
	10.0	***4.3***	***8.3***	***12.0***	***23.1***	***10.6***	
Cleft palate alone	36	4	48	3	14	105	
	12.1	***17.4***	***8.2***	***12.0***	***10.5***	***9.8***	
Clubfoot	62	4	172	8	28	275	
	20.8	***17.4***	***29.2***	***32.1***	***20.9***	***25.7***	
Coarctation of the aorta	25	1	54	1	13	94	
	8.4	***4.3***	***9.2***	***4.0***	***9.7***	***8.8***	
Common truncus (truncus arteriosus)	0	0	4	0	0	4	
	0.0	***0.0***	***0.7***	***0.0***	***0.0***	***0.4***	
Congenital cataract	0	0	1	0	2	3	
	0.0	***0.0***	***0.2***	***0.0***	***1.5***	***0.3***	
Congenital posterior urethral valves	6	1	7	0	0	14	1
	3.9	***8.5***	***2.3***	***0.0***	***0.0***	***2.6***	
Craniosynostosis	53	1	95	1	28	182	
	17.7	***4.3***	***16.2***	***4.0***	***20.9***	***17.0***	
Deletion 22q11.2	2	1	14	1	5	23	
	0.7	***4.3***	***2.4***	***4.0***	***3.7***	***2.1***	
Diaphragmatic hernia	15	0	24	1	9	49	
	5.0	***0.0***	***4.1***	***4.0***	***6.7***	***4.6***	
Double outlet right ventricle	7	0	11	0	4	22	
	2.3	***0.0***	***1.9***	***0.0***	***3.0***	***2.1***	
Ebstein anomaly	1	0	6	1	0	8	
	0.3	***0.0***	***1.0***	***4.0***	***0.0***	***0.7***	
Encephalocele	0	0	1	0	1	2	
	0.0	***0.0***	***0.2***	***0.0***	***0.7***	***0.2***	
Esophageal atresia/tracheoesophageal fistula	7	0	21	0	5	33	
	2.3	***0.0***	***3.6***	***0.0***	***3.7***	***3.1***	
Gastroschisis	20	0	40	3	17	81	
	6.7	***0.0***	***6.8***	***12.0***	***12.7***	***7.6***	
Holoprosencephaly	4	0	10	0	7	21	
	1.3	***0.0***	***1.7***	***0.0***	***5.2***	***2.0***	
Hypoplastic left heart syndrome	5	0	6	0	3	14	
	1.7	***0.0***	***1.0***	***0.0***	***2.2***	***1.3***	
Hypospadias	123	11	136	6	11	288	1
	80.5	***93.8***	***45.2***	***45.9***	***16.2***	***52.6***	
Interrupted aortic arch	7	1	11	0	1	20	
	2.3	***4.3***	***1.9***	***0.0***	***0.7***	***1.9***	
Limb deficiencies (reduction defects)	19	1	31	2	5	59	
	6.4	***4.3***	***5.3***	***8.0***	***3.7***	***5.5***	
Omphalocele	4	1	17	0	4	26	
	1.3	***4.3***	***2.9***	***0.0***	***3.0***	***2.4***	
Pulmonary valve atresia and stenosis	2	0	1	0	1	4	
	0.7	***0.0***	***0.2***	***0.0***	***0.7***	***0.4***	
Pulmonary valve atresia	5	0	3	0	5	13	
	1.7	***0.0***	***0.5***	***0.0***	***3.7***	***1.2***	

New Mexico
Birth Defects Counts and Prevalence 2016 - 2020 (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**
Rectal and large intestinal atresia/stenosis	12 ***4.0***	0 ***0.0***	28 ***4.8***	1 ***4.0***	6 ***4.5***	47 ***4.4***	
Renal agenesis/hypoplasia	24 ***8.0***	3 ***13.0***	34 ***5.8***	2 ***8.0***	14 ***10.5***	78 ***7.3***	
Single ventricle	3 ***1.0***	1 ***4.3***	5 ***0.9***	0 ***0.0***	3 ***2.2***	12 ***1.1***	
Small intestinal atresia/stenosis	21 ***7.0***	0 ***0.0***	19 ***3.2***	1 ***4.0***	7 ***5.2***	48 ***4.5***	
Spina bifida without anencephalus	12 ***4.0***	1 ***4.3***	23 ***3.9***	1 ***4.0***	7 ***5.2***	44 ***4.1***	
Tetralogy of Fallot	6 ***2.0***	0 ***0.0***	22 ***3.7***	1 ***4.0***	5 ***3.7***	34 ***3.2***	
Total anomalous pulmonary venous connection	2 ***0.7***	0 ***0.0***	2 ***0.3***	0 ***0.0***	6 ***4.5***	10 ***0.9***	
Transposition of the great arteries (TGA)	5 ***1.7***	1 ***4.3***	13 ***2.2***	1 ***4.0***	1 ***0.7***	21 ***2.0***	
Dextro-transposition of great arteries (d-TGA)	5 ***1.7***	1 ***4.3***	13 ***2.2***	1 ***4.0***	1 ***0.7***	21 ***2.0***	
Tricuspid valve atresia and stenosis	1 ***0.3***	0 ***0.0***	6 ***1.0***	0 ***0.0***	1 ***0.7***	8 ***0.7***	
Trisomy 13	1 ***0.3***	0 ***0.0***	6 ***1.0***	0 ***0.0***	0 ***0.0***	7 ***0.7***	
Trisomy 18	2 ***0.7***	0 ***0.0***	8 ***1.4***	1 ***4.0***	2 ***1.5***	14 ***1.3***	
Trisomy 21 (Down syndrome)	37 ***12.4***	3 ***13.0***	83 ***14.1***	4 ***16.1***	26 ***19.4***	153 ***14.3***	
Turner syndrome	3 ***2.1***	0 ***0.0***	12 ***4.2***	0 ***0.0***	3 ***4.6***	18 ***3.4***	2
Ventricular septal defect	176 ***58.9***	14 ***60.9***	380 ***64.6***	11 ***44.2***	146 ***109.0***	727 ***67.9***	
Total live births	**29,868**	**2,299**	**58,805**	**2,490**	**13,395**	**107,105**	
Male live births	**15,271**	**1,173**	**30,078**	**1,308**	**6,810**	**54,771**	
Female live births	**14,597**	**1,126**	**28,727**	**1,182**	**6,585**	**52,334**	

New Mexico
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	79	2	81	
	8.6	***1.3***	***7.6***	
Trisomy 13	6	1	7	
	0.7	***0.7***	***0.7***	
Trisomy 18	6	8	14	
	0.7	***5.4***	***1.3***	
Trisomy 21 (Down syndrome)	84	69	153	
	9.1	***46.5***	***14.3***	
Total live births	**92,266**	**14,839**	**107,105**	

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. Prevalance is calculated per 10,000 female live births.

General comments
*Data for totals include unknown and/or other.
-Data for all conditions delivered from 2018-2020 are provisional.

New York
Birth Defects Counts and Prevalence 2016 - 2020 (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	19	2	21	2	1	48	
	0.3	***0.1***	***0.8***	***0.2***	***5.4***	***0.4***	
Anophthalmia/microphthalmia	67	16	38	13	0	137	
	1.2	***1.0***	***1.5***	***1.0***	***0.0***	***1.2***	
Anotia/microtia	104	25	111	46	0	288	
	1.9	***1.5***	***4.3***	***3.6***	***0.0***	***2.5***	
Aortic valve stenosis	92	18	39	11	0	164	
	1.6	***1.1***	***1.5***	***0.9***	***0.0***	***1.4***	
Atrial septal defect	6,604	3,914	4,407	1,922	24	17,358	
	117.8	***239.5***	***169.9***	***151.6***	***130.2***	***152.0***	
Atrioventricular septal defect (Endocardial cushion defect)	233	141	167	44	1	604	
	4.2	***8.6***	***6.4***	***3.5***	***5.4***	***5.3***	
Biliary atresia	79	100	94	28	0	308	
	1.4	***6.1***	***3.6***	***2.2***	***0.0***	***2.7***	
Bladder exstrophy	14	6	4	2	0	27	
	0.2	***0.4***	***0.2***	***0.2***	***0.0***	***0.2***	
Choanal atresia	147	39	41	17	0	248	
	2.6	***2.4***	***1.6***	***1.3***	***0.0***	***2.2***	
Cleft lip alone	179	34	59	31	0	310	
	3.2	***2.1***	***2.3***	***2.4***	***0.0***	***2.7***	
Cleft lip with cleft palate	273	40	142	52	0	522	
	4.9	***2.4***	***5.5***	***4.1***	***0.0***	***4.6***	
Cleft palate alone	366	75	134	74	1	672	
	6.5	***4.6***	***5.2***	***5.8***	***5.4***	***5.9***	
Cloacal exstrophy	4	4	2	1	0	11	
	0.1	***0.2***	***0.1***	***0.1***	***0.0***	***0.1***	
Clubfoot	1,045	316	524	188	4	2,136	
	18.6	***19.3***	***20.2***	***14.8***	***21.7***	***18.7***	
Coarctation of the aorta	341	128	170	61	1	723	
	6.1	***7.8***	***6.6***	***4.8***	***5.4***	***6.3***	
Common truncus (truncus arteriosus)	29	10	16	2	0	60	
	0.5	***0.6***	***0.6***	***0.2***	***0.0***	***0.5***	
Congenital cataract	115	42	62	22	2	250	
	2.1	***2.6***	***2.4***	***1.7***	***10.9***	***2.2***	
Congenital posterior urethral valves	62	38	29	19	1	153	1
	2.2	***4.6***	***2.2***	***2.9***	***10.6***	***2.6***	
Craniosynostosis	681	202	400	105	1	1,416	
	12.2	***12.4***	***15.4***	***8.3***	***5.4***	***12.4***	
Deletion 22q11.2	86	51	46	24	0	214	
	1.5	***3.1***	***1.8***	***1.9***	***0.0***	***1.9***	
Diaphragmatic hernia	132	37	73	30	0	288	
	2.4	***2.3***	***2.8***	***2.4***	***0.0***	***2.5***	
Double outlet right ventricle	146	68	71	36	3	336	
	2.6	***4.2***	***2.7***	***2.8***	***16.3***	***2.9***	
Ebstein anomaly	44	9	33	10	0	98	
	0.8	***0.6***	***1.3***	***0.8***	***0.0***	***0.9***	
Encephalocele	36	20	27	13	1	102	
	0.6	***1.2***	***1.0***	***1.0***	***5.4***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	176	49	78	24	1	335	
	3.1	***3.0***	***3.0***	***1.9***	***5.4***	***2.9***	
Gastroschisis	116	31	76	5	1	242	
	2.1	***1.9***	***2.9***	***0.4***	***5.4***	***2.1***	
Holoprosencephaly	35	16	23	3	1	81	
	0.6	***1.0***	***0.9***	***0.2***	***5.4***	***0.7***	
Hypoplastic left heart syndrome	168	60	73	22	0	335	
	3.0	***3.7***	***2.8***	***1.7***	***0.0***	***2.9***	
Hypospadias	2,980	750	886	437	4	5,208	1
	103.7	***90.6***	***67.2***	***66.5***	***42.3***	***89.2***	
Interrupted aortic arch	31	12	14	4	0	64	
	0.6	***0.7***	***0.5***	***0.3***	***0.0***	***0.6***	
Limb deficiencies (reduction defects)	158	67	96	18	1	361	
	2.8	***4.1***	***3.7***	***1.4***	***5.4***	***3.2***	
Omphalocele	77	91	58	18	0	255	
	1.4	***5.6***	***2.2***	***1.4***	***0.0***	***2.2***	
Pulmonary valve atresia and stenosis	414	246	267	87	2	1,052	
	7.4	***15.1***	***10.3***	***6.9***	***10.9***	***9.2***	

New York

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	24	8	10	8	0	51	
	0.4	***0.5***	***0.4***	***0.6***	***0.0***	***0.4***	
Rectal and large intestinal atresia/stenosis	223	69	149	58	1	511	
	4.0	***4.2***	***5.7***	***4.6***	***5.4***	***4.5***	
Renal agenesis/hypoplasia	453	134	178	53	0	838	
	8.1	***8.2***	***6.9***	***4.2***	***0.0***	***7.3***	
Single ventricle	53	33	43	10	0	143	
	0.9	***2.0***	***1.7***	***0.8***	***0.0***	***1.3***	
Small intestinal atresia/stenosis	222	100	114	43	2	496	
	4.0	***6.1***	***4.4***	***3.4***	***10.9***	***4.3***	
Spina bifida without anencephalus	111	42	68	22	2	252	
	2.0	***2.6***	***2.6***	***1.7***	***10.9***	***2.2***	
Tetralogy of Fallot	297	105	141	73	0	635	
	5.3	***6.4***	***5.4***	***5.8***	***0.0***	***5.6***	
Total anomalous pulmonary venous connection	51	18	40	15	2	130	
	0.9	***1.1***	***1.5***	***1.2***	***10.9***	***1.1***	
Transposition of the great arteries (TGA)	106	25	33	12	0	191	
	1.9	***1.5***	***1.3***	***0.9***	***0.0***	***1.7***	
Dextro-transposition of great arteries (d-TGA)	104	25	28	12	0	182	
	1.9	***1.5***	***1.1***	***0.9***	***0.0***	***1.6***	
Tricuspid valve atresia and stenosis	64	33	40	11	0	149	
	1.1	***2.0***	***1.5***	***0.9***	***0.0***	***1.3***	
Tricuspid valve atresia	23	15	17	4	0	59	
	0.4	***0.9***	***0.7***	***0.3***	***0.0***	***0.5***	
Trisomy 13	31	14	13	6	0	67	
	0.6	***0.9***	***0.5***	***0.5***	***0.0***	***0.6***	
Trisomy 18	62	38	40	6	0	151	
	1.1	***2.3***	***1.5***	***0.5***	***0.0***	***1.3***	
Trisomy 21 (Down syndrome)	646	265	431	85	2	1,467	
	11.5	***16.2***	***16.6***	***6.7***	***10.9***	***12.8***	
Turner syndrome	52	24	41	9	0	129	2
	1.9	***3.0***	***3.2***	***1.5***	***0.0***	***2.3***	
Ventricular septal defect	3,346	1,029	1,816	676	7	7,056	
	59.7	***63.0***	***70.0***	***53.3***	***38.0***	***61.8***	
Total live births	**560,390**	**163,449**	**259,411**	**126,788**	**1,843**	**1,141,958**	**3**
Male live births	**287,358**	**82,794**	**131,890**	**65,721**	**946**	**584,163**	
Female live births	**273,025**	**80,650**	**127,516**	**61,065**	**897**	**557,771**	

New York
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	223	19	242	
	2.6	***0.7***	***2.1***	
Trisomy 13	35	32	67	
	0.4	***1.1***	***0.6***	
Trisomy 18	67	84	151	
	0.8	***3.0***	***1.3***	
Trisomy 21 (Down syndrome)	617	845	1,467	
	7.2	***30.1***	***12.8***	
Total live births	**861,528**	**280,405**	**1,141,958**	**3**

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. Prevalance 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.

North Carolina

Birth Defects Counts and Prevalence 2016 - 2020 (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	50	15	15	2	2	100	
	1.6	***1.0***	***1.6***	***0.8***	***2.5***	***1.7***	
Anophthalmia/microphthalmia	45	16	20	2	1	85	
	1.4	***1.1***	***2.1***	***0.8***	***1.3***	***1.4***	
Anotia/microtia	46	14	52	5	4	121	
	1.4	***1.0***	***5.5***	***1.9***	***5.1***	***2.0***	
Aortic valve stenosis	95	23	22	3	7	150	
	2.9	***1.6***	***2.3***	***1.1***	***8.9***	***2.5***	
Atrial septal defect	1,490	796	445	91	59	2,888	
	46.3	***55.4***	***47.5***	***34.7***	***75.1***	***48.5***	
Atrioventricular septal defect (Endocardial cushion defect)	217	131	54	15	5	422	
	6.7	***9.1***	***5.8***	***5.7***	***6.4***	***7.1***	
Biliary atresia	13	20	7	0	2	42	
	0.4	***1.4***	***0.7***	***0.0***	***2.5***	***0.7***	
Bladder exstrophy	10	3	0	1	0	15	
	0.3	***0.2***	***0.0***	***0.4***	***0.0***	***0.3***	
Choanal atresia	39	19	11	3	2	74	
	1.2	***1.3***	***1.2***	***1.1***	***2.5***	***1.2***	
Cleft lip alone	116	47	28	8	2	206	
	3.6	***3.3***	***3.0***	***3.1***	***2.5***	***3.5***	
Cleft lip with cleft palate	168	37	57	16	5	287	
	5.2	***2.6***	***6.1***	***6.1***	***6.4***	***4.8***	
Cleft palate alone	232	57	47	18	8	364	
	7.2	***4.0***	***5.0***	***6.9***	***10.2***	***6.1***	
Cloacal exstrophy	4	1	0	0	0	5	1
	0.1	***0.1***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	677	260	180	44	15	1,183	
	21.0	***18.1***	***19.2***	***16.8***	***19.1***	***19.9***	
Coarctation of the aorta	168	67	36	4	6	282	
	5.2	***4.7***	***3.8***	***1.5***	***7.6***	***4.7***	
Common truncus (truncus arteriosus)	16	11	12	0	1	40	
	0.5	***0.8***	***1.3***	***0.0***	***1.3***	***0.7***	
Congenital cataract	22	26	8	2	0	59	
	0.7	***1.8***	***0.9***	***0.8***	***0.0***	***1.0***	
Congenital posterior urethral valves	61	42	9	5	0	118	2
	3.7	***5.8***	***1.9***	***3.7***	***0.0***	***3.9***	
Craniosynostosis	212	41	58	8	5	325	
	6.6	***2.9***	***6.2***	***3.1***	***6.4***	***5.5***	
Deletion 22q11.2	26	15	18	1	1	61	
	0.8	***1.0***	***1.9***	***0.4***	***1.3***	***1.0***	
Diaphragmatic hernia	102	43	28	7	7	190	
	3.2	***3.0***	***3.0***	***2.7***	***8.9***	***3.2***	
Double outlet right ventricle	48	20	15	5	0	88	
	1.5	***1.4***	***1.6***	***1.9***	***0.0***	***1.5***	
Ebstein anomaly	23	6	8	1	1	39	
	0.7	***0.4***	***0.9***	***0.4***	***1.3***	***0.7***	
Encephalocele	26	16	4	0	1	51	
	0.8	***1.1***	***0.4***	***0.0***	***1.3***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	75	23	20	3	1	122	
	2.3	***1.6***	***2.1***	***1.1***	***1.3***	***2.0***	
Gastroschisis	136	38	43	9	6	237	
	4.2	***2.6***	***4.6***	***3.4***	***7.6***	***4.0***	
Holoprosencephaly	23	22	12	0	1	64	
	0.7	***1.5***	***1.3***	***0.0***	***1.3***	***1.1***	
Hypoplastic left heart syndrome	66	55	19	2	0	144	
	2.0	***3.8***	***2.0***	***0.8***	***0.0***	***2.4***	
Hypospadias	1,185	446	151	68	28	1,879	2
	71.7	***61.2***	***31.6***	***50.6***	***69.0***	***61.7***	
Interrupted aortic arch	18	15	9	1	0	44	
	0.6	***1.0***	***1.0***	***0.4***	***0.0***	***0.7***	
Limb deficiencies (reduction defects)	111	74	40	6	8	243	
	3.4	***5.2***	***4.3***	***2.3***	***10.2***	***4.1***	
Omphalocele	78	37	18	7	2	150	
	2.4	***2.6***	***1.9***	***2.7***	***2.5***	***2.5***	
Pulmonary valve atresia and stenosis	318	153	70	20	10	571	
	9.9	***10.7***	***7.5***	***7.6***	***12.7***	***9.6***	

North Carolina

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	50	38	18	5	2	113	
	1.6	***2.6***	***1.9***	***1.9***	***2.5***	***1.9***	
Rectal and large intestinal atresia/stenosis	130	43	31	11	2	218	
	4.0	***3.0***	***3.3***	***4.2***	***2.5***	***3.7***	
Renal agenesis/hypoplasia	216	96	52	13	6	389	
	6.7	***6.7***	***5.5***	***5.0***	***7.6***	***6.5***	
Single ventricle	22	13	7	2	0	44	
	0.7	***0.9***	***0.7***	***0.8***	***0.0***	***0.7***	
Small intestinal atresia/stenosis	99	55	32	3	6	195	
	3.1	***3.8***	***3.4***	***1.1***	***7.6***	***3.3***	
Spina bifida without anencephalus	109	31	33	6	3	185	
	3.4	***2.2***	***3.5***	***2.3***	***3.8***	***3.1***	
Tetralogy of Fallot	135	70	40	13	7	267	
	4.2	***4.9***	***4.3***	***5.0***	***8.9***	***4.5***	
Total anomalous pulmonary venous connection	35	21	18	2	1	77	
	1.1	***1.5***	***1.9***	***0.8***	***1.3***	***1.3***	
Transposition of the great arteries (TGA)	142	43	29	4	2	221	
	4.4	***3.0***	***3.1***	***1.5***	***2.5***	***3.7***	
Dextro-transposition of great arteries (d-TGA)	132	39	26	4	2	204	
	4.1	***2.7***	***2.8***	***1.5***	***2.5***	***3.4***	
Tricuspid valve atresia and stenosis	66	37	21	3	3	131	
	2.0	***2.6***	***2.2***	***1.1***	***3.8***	***2.2***	
Tricuspid valve atresia	52	33	17	3	2	108	
	1.6	***2.3***	***1.8***	***1.1***	***2.5***	***1.8***	
Trisomy 13	25	23	14	2	1	71	
	0.8	***1.6***	***1.5***	***0.8***	***1.3***	***1.2***	
Trisomy 18	70	41	32	5	2	173	
	2.2	***2.9***	***3.4***	***1.9***	***2.5***	***2.9***	
Trisomy 21 (Down syndrome)	375	159	205	28	12	817	
	11.6	***11.1***	***21.9***	***10.7***	***15.3***	***13.7***	
Turner syndrome	50	17	13	1	1	93	3
	3.2	***2.4***	***2.8***	***0.8***	***2.6***	***3.2***	
Ventricular septal defect	1,618	701	593	104	36	3,068	
	50.2	***48.8***	***63.3***	***39.7***	***45.8***	***51.5***	
Total live births	**322,117**	**143,595**	**93,725**	**26,222**	**7,858**	**595,301**	**4**
Male live births	**165,304**	**72,925**	**47,743**	**13,443**	**4,057**	**304,361**	
Female live births	**156,812**	**70,665**	**45,982**	**12,779**	**3,801**	**290,934**	

North Carolina

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	224	12	237	
	4.5	***1.2***	***4.0***	
Trisomy 13	45	25	71	
	0.9	***2.6***	***1.2***	
Trisomy 18	85	86	173	
	1.7	***8.9***	***2.9***	
Trisomy 21 (Down syndrome)	373	438	817	
	7.5	***45.4***	***13.7***	
Total live births	**498,879**	**96,407**	**595,301**	**4**

Notes

1. Data for this condition include persistent cloaca.
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.

Oklahoma
Birth Defects Counts and Prevalence 2016 - 2020 (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	27	5	11	4	6	53	
	1.8	***2.0***	***2.9***	***4.9***	***2.2***	***2.1***	
Anophthalmia/microphthalmia	29	4	10	1	6	50	
	1.9	***1.6***	***2.6***	***1.2***	***2.2***	***2.0***	
Anotia/microtia	22	1	16	6	6	52	
	1.5	***0.4***	***4.2***	***7.3***	***2.2***	***2.1***	
Aortic valve stenosis	46	1	8	1	10	67	
	3.0	***0.4***	***2.1***	***1.2***	***3.7***	***2.7***	
Atrial septal defect	363	60	91	17	53	586	
	24.0	***24.4***	***23.9***	***20.7***	***19.6***	***23.5***	
Atrioventricular septal defect (Endocardial cushion defect)	91	17	28	10	12	158	
	6.0	***6.9***	***7.4***	***12.2***	***4.4***	***6.3***	
Biliary atresia	10	4	4	1	4	23	
	0.7	***1.6***	***1.1***	***1.2***	***1.5***	***0.9***	
Bladder exstrophy	4	2	0	0	2	8	
	0.3	***0.8***	***0.0***	***0.0***	***0.7***	***0.3***	
Choanal atresia	43	2	3	1	6	56	
	2.8	***0.8***	***0.8***	***1.2***	***2.2***	***2.2***	
Cleft lip alone	56	8	10	1	8	83	
	3.7	***3.2***	***2.6***	***1.2***	***3.0***	***3.3***	
Cleft lip with cleft palate	119	12	28	7	20	186	
	7.9	***4.9***	***7.4***	***8.5***	***7.4***	***7.5***	
Cleft palate alone	131	12	20	5	24	194	
	8.6	***4.9***	***5.3***	***6.1***	***8.9***	***7.8***	
Cloacal exstrophy	1	0	0	0	1	2	
	0.1	***0.0***	***0.0***	***0.0***	***0.4***	***0.1***	
Clubfoot	296	51	80	19	44	492	
	19.5	***20.7***	***21.0***	***23.1***	***16.3***	***19.7***	
Coarctation of the aorta	125	15	24	3	25	192	
	8.3	***6.1***	***6.3***	***3.7***	***9.3***	***7.7***	
Common truncus (truncus arteriosus)	15	1	1	0	0	17	
	1.0	***0.4***	***0.3***	***0.0***	***0.0***	***0.7***	
Congenital cataract	26	1	5	1	6	39	
	1.7	***0.4***	***1.3***	***1.2***	***2.2***	***1.6***	
Congenital posterior urethral valves	20	5	3	1	3	33	1
	2.6	***4.0***	***1.5***	***2.4***	***2.2***	***2.6***	
Craniosynostosis	124	13	24	1	20	184	
	8.2	***5.3***	***6.3***	***1.2***	***7.4***	***7.4***	
Deletion 22q11.2	12	4	6	0	1	23	
	0.8	***1.6***	***1.6***	***0.0***	***0.4***	***0.9***	
Diaphragmatic hernia	53	10	13	6	9	91	
	3.5	***4.1***	***3.4***	***7.3***	***3.3***	***3.6***	
Double outlet right ventricle	49	6	17	4	10	86	
	3.2	***2.4***	***4.5***	***4.9***	***3.7***	***3.4***	
Ebstein anomaly	11	1	1	1	5	19	
	0.7	***0.4***	***0.3***	***1.2***	***1.9***	***0.8***	
Encephalocele	17	4	7	1	1	30	
	1.1	***1.6***	***1.8***	***1.2***	***0.4***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	46	5	6	0	5	62	
	3.0	***2.0***	***1.6***	***0.0***	***1.9***	***2.5***	
Gastroschisis	97	14	22	0	15	148	
	6.4	***5.7***	***5.8***	***0.0***	***5.6***	***5.9***	
Holoprosencephaly	19	9	5	0	4	37	
	1.3	***3.7***	***1.3***	***0.0***	***1.5***	***1.5***	
Hypoplastic left heart syndrome	48	6	10	0	9	74	
	3.2	***2.4***	***2.6***	***0.0***	***3.3***	***3.0***	
Hypospadias	353	63	48	14	65	543	1
	45.4	***50.2***	***24.7***	***33.3***	***47.0***	***42.5***	
Interrupted aortic arch	16	2	5	1	0	24	
	1.1	***0.8***	***1.3***	***1.2***	***0.0***	***1.0***	
Limb deficiencies (reduction defects)	75	14	12	5	25	131	
	5.0	***5.7***	***3.2***	***6.1***	***9.3***	***5.3***	
Omphalocele	37	7	10	1	5	61	
	2.4	***2.8***	***2.6***	***1.2***	***1.9***	***2.4***	
Pulmonary valve atresia and stenosis	126	17	42	9	29	223	
	8.3	***6.9***	***11.0***	***11.0***	***10.7***	***8.9***	

Oklahoma

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	30	5	9	2	3	49	
	2.0	***2.0***	***2.4***	***2.4***	***1.1***	***2.0***	
Rectal and large intestinal atresia/stenosis	96	9	34	7	18	164	
	6.3	***3.7***	***8.9***	***8.5***	***6.7***	***6.6***	
Renal agenesis/hypoplasia	128	16	30	9	19	202	
	8.5	***6.5***	***7.9***	***11.0***	***7.0***	***8.1***	
Single ventricle	8	1	3	1	1	14	
	0.5	***0.4***	***0.8***	***1.2***	***0.4***	***0.6***	
Small intestinal atresia/stenosis	43	7	16	2	11	79	
	2.8	***2.8***	***4.2***	***2.4***	***4.1***	***3.2***	
Spina bifida without anencephalus	70	3	16	5	6	101	
	4.6	***1.2***	***4.2***	***6.1***	***2.2***	***4.1***	
Tetralogy of Fallot	72	5	20	7	12	117	
	4.8	***2.0***	***5.3***	***8.5***	***4.4***	***4.7***	
Total anomalous pulmonary venous connection	20	6	6	4	3	39	
	1.3	***2.4***	***1.6***	***4.9***	***1.1***	***1.6***	
Transposition of the great arteries (TGA)	51	4	7	1	6	70	
	3.4	***1.6***	***1.8***	***1.2***	***2.2***	***2.8***	
Dextro-transposition of great arteries (d-TGA)	48	4	7	1	4	65	
	3.2	***1.6***	***1.8***	***1.2***	***1.5***	***2.6***	
Tricuspid valve atresia and stenosis	28	8	7	4	7	54	
	1.8	***3.2***	***1.8***	***4.9***	***2.6***	***2.2***	
Tricuspid valve atresia	19	4	3	1	4	31	
	1.3	***1.6***	***0.8***	***1.2***	***1.5***	***1.2***	
Trisomy 13	11	3	9	2	2	27	
	0.7	***1.2***	***2.4***	***2.4***	***0.7***	***1.1***	
Trisomy 18	38	13	12	2	2	67	
	2.5	***5.3***	***3.2***	***2.4***	***0.7***	***2.7***	
Trisomy 21 (Down syndrome)	175	29	61	13	26	305	
	11.6	***11.8***	***16.0***	***15.8***	***9.6***	***12.2***	
Turner syndrome	13	5	5	0	5	28	2
	1.8	***4.1***	***2.7***	***0.0***	***3.8***	***2.3***	
Ventricular septal defect	785	129	226	56	151	1,350	
	51.8	***52.4***	***59.4***	***68.2***	***55.9***	***54.1***	
Total live births	**151,464**	**24,631**	**38,027**	**8,209**	**27,005**	**249,382**	**3**
Male live births	**77,763**	**12,543**	**19,457**	**4,210**	**13,842**	**127,836**	
Female live births	**73,698**	**12,088**	**18,570**	**3,999**	**13,163**	**121,543**	

Oklahoma

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	145	3	148	
	6.6	***1.0***	***5.9***	
Trisomy 13	17	10	27	
	0.8	***3.5***	***1.1***	
Trisomy 18	35	32	67	
	1.6	***11.1***	***2.7***	
Trisomy 21 (Down syndrome)	162	142	305	
	7.3	***49.4***	***12.2***	
Total live births	**220,547**	**28,767**	**249,382**	**3**

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. Prevalance 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.

Oregon
Birth Defects Counts and Prevalence 2016 - 2020 (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	10	1	4	2	0	17	
	0.7	***1.6***	***1.0***	***1.4***	***0.0***	***0.8***	
Anophthalmia/microphthalmia	33	2	16	0	0	52	
	2.3	***3.1***	***4.0***	***0.0***	***0.0***	***2.5***	
Anotia/microtia	53	3	35	8	3	106	
	3.7	***4.7***	***8.8***	***5.7***	***10.9***	***5.1***	
Aortic valve stenosis	54	2	21	3	0	80	
	3.8	***3.1***	***5.3***	***2.1***	***0.0***	***3.8***	
Atrial septal defect	2,534	177	879	185	67	3,869	
	176.1	***276.3***	***221.6***	***131.6***	***242.4***	***185.4***	
Atrioventricular septal defect (Endocardial cushion defect)	102	3	38	7	0	150	
	7.1	***4.7***	***9.6***	***5.0***	***0.0***	***7.2***	
Biliary atresia	25	2	16	1	3	50	
	1.7	***3.1***	***4.0***	***0.7***	***10.9***	***2.4***	
Bladder exstrophy	3	0	1	0	0	4	
	0.2	***0.0***	***0.3***	***0.0***	***0.0***	***0.2***	
Choanal atresia	29	1	14	2	1	47	
	2.0	***1.6***	***3.5***	***1.4***	***3.6***	***2.3***	
Cleft lip alone	42	1	7	2	0	52	
	2.9	***1.6***	***1.8***	***1.4***	***0.0***	***2.5***	
Cleft lip with cleft palate	103	1	46	14	2	168	
	7.2	***1.6***	***11.6***	***10.0***	***7.2***	***8.1***	
Cleft palate alone	142	8	42	14	3	211	
	9.9	***12.5***	***10.6***	***10.0***	***10.9***	***10.1***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	395	18	108	26	10	564	
	27.5	***28.1***	***27.2***	***18.5***	***36.2***	***27.0***	
Coarctation of the aorta	116	5	36	11	2	172	
	8.1	***7.8***	***9.1***	***7.8***	***7.2***	***8.2***	
Common truncus (truncus arteriosus)	8	2	5	1	0	16	
	0.6	***3.1***	***1.3***	***0.7***	***0.0***	***0.8***	
Congenital cataract	53	2	13	3	1	72	
	3.7	***3.1***	***3.3***	***2.1***	***3.6***	***3.5***	
Congenital posterior urethral valves	14	1	4	2	0	22	1
	1.9	***3.0***	***2.0***	***2.8***	***0.0***	***2.1***	
Craniosynostosis	379	12	112	17	2	525	
	26.3	***18.7***	***28.2***	***12.1***	***7.2***	***25.2***	
Deletion 22q11.2	19	3	6	0	0	29	
	1.3	***4.7***	***1.5***	***0.0***	***0.0***	***1.4***	
Diaphragmatic hernia	53	4	23	5	2	88	
	3.7	***6.2***	***5.8***	***3.6***	***7.2***	***4.2***	
Double outlet right ventricle	20	2	15	6	1	45	
	1.4	***3.1***	***3.8***	***4.3***	***3.6***	***2.2***	
Ebstein anomaly	11	0	2	4	0	17	
	0.8	***0.0***	***0.5***	***2.8***	***0.0***	***0.8***	
Encephalocele	22	0	9	0	1	32	
	1.5	***0.0***	***2.3***	***0.0***	***3.6***	***1.5***	
Esophageal atresia/tracheoesophageal fistula	42	0	19	1	0	62	
	2.9	***0.0***	***4.8***	***0.7***	***0.0***	***3.0***	
Gastroschisis	52	4	25	1	4	89	
	3.6	***6.2***	***6.3***	***0.7***	***14.5***	***4.3***	
Holoprosencephaly	3	0	4	0	0	7	
	0.2	***0.0***	***1.0***	***0.0***	***0.0***	***0.3***	
Hypoplastic left heart syndrome	46	3	22	6	0	78	
	3.2	***4.7***	***5.5***	***4.3***	***0.0***	***3.7***	
Hypospadias	649	44	77	47	8	832	1
	87.9	***130.6***	***37.9***	***65.4***	***56.7***	***77.7***	
Interrupted aortic arch	43	3	12	0	2	60	
	3.0	***4.7***	***3.0***	***0.0***	***7.2***	***2.9***	
Limb deficiencies (reduction defects)	84	4	29	0	2	120	
	5.8	***6.2***	***7.3***	***0.0***	***7.2***	***5.8***	
Omphalocele	98	15	53	7	3	177	
	6.8	***23.4***	***13.4***	***5.0***	***10.9***	***8.5***	
Pulmonary valve atresia and stenosis	167	11	75	9	4	269	
	11.6	***17.2***	***18.9***	***6.4***	***14.5***	***12.9***	

Oregon

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	24	2	13	0	1	41	
	1.7	***3.1***	***3.3***	***0.0***	***3.6***	***2.0***	
Rectal and large intestinal atresia/stenosis	85	3	34	7	2	132	
	5.9	***4.7***	***8.6***	***5.0***	***7.2***	***6.3***	
Renal agenesis/hypoplasia	129	8	40	10	5	196	
	9.0	***12.5***	***10.1***	***7.1***	***18.1***	***9.4***	
Single ventricle	28	2	17	4	0	52	
	1.9	***3.1***	***4.3***	***2.8***	***0.0***	***2.5***	
Small intestinal atresia/stenosis	60	4	22	5	2	97	
	4.2	***6.2***	***5.5***	***3.6***	***7.2***	***4.6***	
Spina bifida without anencephalus	77	5	29	4	3	120	
	5.4	***7.8***	***7.3***	***2.8***	***10.9***	***5.8***	
Tetralogy of Fallot	56	7	29	4	2	99	
	3.9	***10.9***	***7.3***	***2.8***	***7.2***	***4.7***	
Total anomalous pulmonary venous connection	9	0	11	2	0	22	
	0.6	***0.0***	***2.8***	***1.4***	***0.0***	***1.1***	
Transposition of the great arteries (TGA)	64	1	15	3	1	86	
	4.4	***1.6***	***3.8***	***2.1***	***3.6***	***4.1***	
Dextro-transposition of great arteries (d-TGA)	61	1	14	3	1	82	
	4.2	***1.6***	***3.5***	***2.1***	***3.6***	***3.9***	
Tricuspid valve atresia and stenosis	25	3	8	1	1	38	
	1.7	***4.7***	***2.0***	***0.7***	***3.6***	***1.8***	
Trisomy 13	14	2	6	0	1	24	
	1.0	***3.1***	***1.5***	***0.0***	***3.6***	***1.2***	
Trisomy 18	21	1	8	2	2	34	
	1.5	***1.6***	***2.0***	***1.4***	***7.2***	***1.6***	
Trisomy 21 (Down syndrome)	199	10	84	15	3	320	
	13.8	***15.6***	***21.2***	***10.7***	***10.9***	***15.3***	
Turner syndrome	13	0	5	0	0	18	2
	1.9	***0.0***	***2.6***	***0.0***	***0.0***	***1.8***	
Ventricular septal defect	1,010	59	404	76	25	1,581	
	70.2	***92.1***	***101.8***	***54.0***	***90.4***	***75.8***	
Total live births	**143,866**	**6,405**	**39,669**	**14,063**	**2,764**	**208,659**	**3**
Male live births	**73,823**	**3,369**	**20,310**	**7,191**	**1,412**	**107,059**	
Female live births	**70,013**	**3,036**	**19,354**	**6,871**	**1,351**	**101,562**	

Oregon

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	87	2	89	
	5.2	***0.5***	***4.3***	
Trisomy 13	14	10	24	
	0.8	***2.4***	***1.2***	
Trisomy 18	18	16	34	
	1.1	***3.8***	***1.6***	
Trisomy 21 (Down syndrome)	164	156	320	
	9.8	***37.0***	***15.3***	
Total live births	**166,515**	**42,141**	**208,659**	**3**

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. Prevalance 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.

Puerto Rico
Birth Defects Counts and Prevalence 2016 - 2020 (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	0	0	8	0	0	36	
	0.0	***0.0***	***0.7***	***0.0***	***0.0***	***3.2***	
Anophthalmia/microphthalmia	1	0	13	0	0	17	
	3.9	***0.0***	***1.2***	***0.0***	***0.0***	***1.5***	
Anotia/microtia	1	0	22	0	0	24	
	3.9	***0.0***	***2.0***	***0.0***	***0.0***	***2.1***	
Aortic valve stenosis	0	0	14	0	0	14	
	0.0	***0.0***	***1.3***	***0.0***	***0.0***	***1.2***	
Atrial septal defect	5	2	264	0	0	274	
	19.6	***55.1***	***23.9***	***0.0***	***0.0***	***24.1***	
Atrioventricular septal defect (Endocardial cushion defect)	2	0	43	0	0	56	1
	7.8	***0.0***	***3.9***	***0.0***	***0.0***	***4.9***	
Bladder exstrophy	1	0	0	0	0	3	
	3.9	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Cleft lip alone	1	0	27	0	0	42	
	3.9	***0.0***	***2.4***	***0.0***	***0.0***	***3.7***	
Cleft lip with cleft palate	1	0	56	0	0	66	
	3.9	***0.0***	***5.1***	***0.0***	***0.0***	***5.8***	
Cleft palate alone	1	0	73	0	0	75	
	3.9	***0.0***	***6.6***	***0.0***	***0.0***	***6.6***	
Clubfoot	8	0	164	0	0	201	
	31.3	***0.0***	***14.8***	***0.0***	***0.0***	***17.7***	
Coarctation of the aorta	0	0	43	0	0	43	
	0.0	***0.0***	***3.9***	***0.0***	***0.0***	***3.8***	
Common truncus (truncus arteriosus)	0	0	7	0	0	8	
	0.0	***0.0***	***0.6***	***0.0***	***0.0***	***0.7***	
Congenital cataract	0	0	25	0	0	27	
	0.0	***0.0***	***2.3***	***0.0***	***0.0***	***2.4***	
Craniosynostosis	2	0	39	0	0	41	
	7.8	***0.0***	***3.5***	***0.0***	***0.0***	***3.6***	
Deletion 22q11.2	0	1	4	0	0	5	
	0.0	***27.5***	***0.4***	***0.0***	***0.0***	***0.4***	
Diaphragmatic hernia	0	0	24	0	0	39	
	0.0	***0.0***	***2.2***	***0.0***	***0.0***	***3.4***	
Double outlet right ventricle	1	0	22	0	0	27	
	3.9	***0.0***	***2.0***	***0.0***	***0.0***	***2.4***	
Ebstein anomaly	0	0	10	0	0	10	
	0.0	***0.0***	***0.9***	***0.0***	***0.0***	***0.9***	
Encephalocele	1	0	6	0	0	13	
	3.9	***0.0***	***0.5***	***0.0***	***0.0***	***1.1***	
Gastroschisis	1	0	51	0	0	64	
	3.9	***0.0***	***4.6***	***0.0***	***0.0***	***5.6***	
Holoprosencephaly	2	0	7	0	0	25	
	7.8	***0.0***	***0.6***	***0.0***	***0.0***	***2.2***	
Hypoplastic left heart syndrome	1	0	21	0	0	28	
	3.9	***0.0***	***1.9***	***0.0***	***0.0***	***2.5***	
Hypospadias	7	2	363	0	0	376	2
	54.7	***99.5***	***63.8***	***0.0***		***64.3***	
Interrupted aortic arch	1	0	9	0	0	10	
	3.9	***0.0***	***0.8***	***0.0***	***0.0***	***0.9***	
Limb deficiencies (reduction defects)	1	0	52	0	0	64	
	3.9	***0.0***	***4.7***	***0.0***	***0.0***	***5.6***	
Omphalocele	2	0	17	0	0	43	
	7.8	***0.0***	***1.5***	***0.0***	***0.0***	***3.8***	
Pulmonary valve atresia and stenosis	2	1	111	0	0	115	
	7.8	***27.5***	***10.0***	***0.0***	***0.0***	***10.1***	
Pulmonary valve atresia	0	0	7	0	0	7	
	0.0	***0.0***	***0.6***	***0.0***	***0.0***	***0.6***	
Single ventricle	0	0	4	0	0	4	
	0.0	***0.0***	***0.4***	***0.0***	***0.0***	***0.4***	
Spina bifida without anencephalus	4	0	27	0	0	45	
	15.7	***0.0***	***2.4***	***0.0***	***0.0***	***4.0***	
Tetralogy of Fallot	2	1	34	0	0	38	
	7.8	***27.5***	***3.1***	***0.0***	***0.0***	***3.3***	
Total anomalous pulmonary venous connection	2	0	11	0	0	13	
	7.8	***0.0***	***1.0***	***0.0***	***0.0***	***1.1***	

Puerto Rico

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Transposition of the great arteries (TGA)	3 ***11.8***	0 ***0.0***	29 ***2.6***	0 ***0.0***	0 ***0.0***	33 ***2.9***	
Dextro-transposition of great arteries (d-TGA)	1 ***3.9***	0 ***0.0***	17 ***1.5***	0 ***0.0***	0 ***0.0***	18 ***1.6***	
Tricuspid valve atresia and stenosis	0 ***0.0***	0 ***0.0***	13 ***1.2***	0 ***0.0***	0 ***0.0***	13 ***1.1***	
Tricuspid valve atresia	0 ***0.0***	0 ***0.0***	12 ***1.1***	0 ***0.0***	0 ***0.0***	12 ***1.1***	
Trisomy 13	0 ***0.0***	0 ***0.0***	5 ***0.5***	0 ***0.0***	0 ***0.0***	8 ***0.7***	
Trisomy 18	0 ***0.0***	0 ***0.0***	7 ***0.6***	0 ***0.0***	0 ***0.0***	14 ***1.2***	
Trisomy 21 (Down syndrome)	2 ***7.8***	1 ***27.5***	134 ***12.1***	0 ***0.0***	0 ***0.0***	145 ***12.7***	
Turner syndrome	0 ***0.0***	0 ***0.0***	5 ***0.9***	0 ***0.0***	0 ***0.0***	8 ***1.4***	3
Ventricular septal defect	4 ***15.7***	1 ***27.5***	379 ***34.3***	0 ***0.0***	0 ***0.0***	392 ***34.5***	4
Total live births	**2,552**	**363**	**110,500**	**149**	**3**	**113,746**	
Male live births	**1,280**	**201**	**56,854**	**79**	**0**	**58,509**	
Female live births	**1,272**	**162**	**53,646**	**70**	**3**	**55,237**	

Puerto Rico
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	64	0	64	
	6.4	***0.0***	***5.6***	
Trisomy 13	4	4	8	
	0.4	***3.0***	***0.7***	
Trisomy 18	7	7	14	
	0.7	***5.2***	***1.2***	
Trisomy 21 (Down syndrome)	75	70	145	
	7.5	***52.0***	***12.7***	
Total live births	**100,279**	**13,465**	**113,746**	

Notes
1. Data for this condition only include atrioventricular canal and atrioventricular septal defect (ASD) primum.
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 this condition exclude probable diagnosis and exclude inlet/posterior type ventricular septal defect only in the presence of atrioventricular canal.

General comments
*Data for totals include unknown and/or other.

Rhode Island

Birth Defects Counts and Prevalence 2016 - 2020 (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	3	0	1	0	0	6	
	1.0	***0.0***	***0.7***	***0.0***	***0.0***	***1.2***	
Anophthalmia/microphthalmia	3	1	1	0	0	6	
	1.0	***2.3***	***0.7***	***0.0***	***0.0***	***1.2***	
Anotia/microtia	8	0	6	1	0	15	
	2.7	***0.0***	***4.3***	***3.9***	***0.0***	***2.9***	
Aortic valve stenosis	3	1	2	0	0	7	
	1.0	***2.3***	***1.4***	***0.0***	***0.0***	***1.3***	
Atrial septal defect	65	9	42	4	0	135	
	22.3	***20.3***	***30.0***	***15.7***	***0.0***	***25.9***	
Atrioventricular septal defect (Endocardial cushion defect)	11	4	2	0	0	19	
	3.8	***9.0***	***1.4***	***0.0***	***0.0***	***3.6***	
Biliary atresia	3	0	0	0	0	3	
	1.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	2	0	3	0	0	5	
	0.7	***0.0***	***2.1***	***0.0***	***0.0***	***1.0***	
Cleft lip alone	9	1	4	0	0	14	
	3.1	***2.3***	***2.9***	***0.0***	***0.0***	***2.7***	
Cleft lip with cleft palate	8	0	9	2	0	21	
	2.7	***0.0***	***6.4***	***7.9***	***0.0***	***4.0***	
Cleft palate alone	9	3	11	0	0	24	
	3.1	***6.8***	***7.9***	***0.0***	***0.0***	***4.6***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	50	7	21	5	1	87	
	17.2	***15.8***	***15.0***	***19.7***	***35.8***	***16.7***	
Coarctation of the aorta	11	1	2	0	0	18	
	3.8	***2.3***	***1.4***	***0.0***	***0.0***	***3.5***	
Common truncus (truncus arteriosus)	0	1	0	0	0	1	
	0.0	***2.3***	***0.0***	***0.0***	***0.0***	***0.2***	
Congenital cataract	5	0	4	1	0	10	
	1.7	***0.0***	***2.9***	***3.9***	***0.0***	***1.9***	
Congenital posterior urethral valves	0	0	0	1	0	1	1
	0.0	***0.0***	***0.0***	***7.7***	***0.0***	***0.4***	
Craniosynostosis	3	0	3	0	0	7	
	1.0	***0.0***	***2.1***	***0.0***	***0.0***	***1.3***	
Deletion 22q11.2	1	0	0	0	0	3	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Diaphragmatic hernia	4	0	7	0	0	13	
	1.4	***0.0***	***5.0***	***0.0***	***0.0***	***2.5***	
Double outlet right ventricle	4	0	1	0	0	9	
	1.4	***0.0***	***0.7***	***0.0***	***0.0***	***1.7***	
Ebstein anomaly	1	0	0	0	0	1	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Encephalocele	1	0	0	0	0	1	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Esophageal atresia/tracheoesophageal fistula	9	0	2	0	0	11	
	3.1	***0.0***	***1.4***	***0.0***	***0.0***	***2.1***	
Gastroschisis	19	0	11	0	0	30	
	6.5	***0.0***	***7.9***	***0.0***	***0.0***	***5.8***	
Holoprosencephaly	1	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Hypoplastic left heart syndrome	2	1	4	1	0	10	
	0.7	***2.3***	***2.9***	***3.9***	***0.0***	***1.9***	
Hypospadias	124	30	41	5	2	217	1
	83.5	***139.0***	***58.1***	***38.7***	***129.9***	***82.2***	
Interrupted aortic arch	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Limb deficiencies (reduction defects)	8	1	4	1	0	16	
	2.7	***2.3***	***2.9***	***3.9***	***0.0***	***3.1***	
Omphalocele	3	0	6	0	0	10	
	1.0	***0.0***	***4.3***	***0.0***	***0.0***	***1.9***	
Pulmonary valve atresia and stenosis	13	5	7	3	0	33	
	4.5	***11.3***	***5.0***	***11.8***	***0.0***	***6.3***	

Rhode Island

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	6	2	4	1	0	15	
	2.1	***4.5***	***2.9***	***3.9***	***0.0***	***2.9***	
Rectal and large intestinal atresia/stenosis	8	0	7	1	0	16	
	2.7	***0.0***	***5.0***	***3.9***	***0.0***	***3.1***	
Renal agenesis/hypoplasia	14	1	3	0	0	19	
	4.8	***2.3***	***2.1***	***0.0***	***0.0***	***3.6***	
Single ventricle	1	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Small intestinal atresia/stenosis	10	4	3	1	0	18	
	3.4	***9.0***	***2.1***	***3.9***	***0.0***	***3.5***	
Spina bifida without anencephalus	5	0	7	0	0	13	
	1.7	***0.0***	***5.0***	***0.0***	***0.0***	***2.5***	
Tetralogy of Fallot	7	1	6	1	0	18	
	2.4	***2.3***	***4.3***	***3.9***	***0.0***	***3.5***	
Total anomalous pulmonary venous connection	2	0	2	0	0	4	
	0.7	***0.0***	***1.4***	***0.0***	***0.0***	***0.8***	
Transposition of the great arteries (TGA)	2	1	4	0	0	7	
	0.7	***2.3***	***2.9***	***0.0***	***0.0***	***1.3***	
Dextro-transposition of great arteries (d-TGA)	2	1	2	0	0	5	
	0.7	***2.3***	***1.4***	***0.0***	***0.0***	***1.0***	
Tricuspid valve atresia and stenosis	0	0	1	0	0	1	
	0.0	***0.0***	***0.7***	***0.0***	***0.0***	***0.2***	
Tricuspid valve atresia	0	0	1	0	0	1	
	0.0	***0.0***	***0.7***	***0.0***	***0.0***	***0.2***	
Trisomy 13	2	1	2	0	0	6	
	0.7	***2.3***	***1.4***	***0.0***	***0.0***	***1.2***	
Trisomy 18	9	1	8	0	0	25	
	3.1	***2.3***	***5.7***	***0.0***	***0.0***	***4.8***	
Trisomy 21 (Down syndrome)	47	14	27	3	0	109	
	16.1	***31.6***	***19.3***	***11.8***	***0.0***	***20.9***	
Turner syndrome	2	1	1	1	0	5	2
	1.4	***4.4***	***1.4***	***8.0***	***0.0***	***1.9***	
Ventricular septal defect	123	19	56	10	1	220	3
	42.3	***42.8***	***40.1***	***39.3***	***35.8***	***42.2***	
Total live births	**29,108**	**4,437**	**13,982**	**2,543**	**279**	**52,134**	**4**
Male live births	**14,853**	**2,159**	**7,051**	**1,292**	**154**	**26,410**	
Female live births	**14,255**	**2,277**	**6,931**	**1,252**	**125**	**25,723**	

Rhode Island

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	29	1	30	
	7.0	***0.9***	***5.8***	
Trisomy 13	3	3	6	
	0.7	***2.8***	***1.2***	
Trisomy 18	7	15	25	
	1.7	***14.0***	***4.8***	
Trisomy 21 (Down syndrome)	40	65	109	
	9.7	***60.5***	***20.9***	
Total live births	**41,381**	**10,752**	**52,134**	**4**

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. Prevalance is calculated per 10,000 female live births.
3. Data for this condition include probable cases.
4. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

South Carolina
Birth Defects Counts and Prevalence 2016 - 2020 (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	28	11	6	0	0	45	
	1.8	***1.4***	***2.3***	***0.0***	***0.0***	***1.7***	
Anophthalmia/microphthalmia	18	15	<5	<5	0	38	
	1.2	***1.9***			***0.0***	***1.4***	
Anotia/microtia	27	<5	10	<5	0	42	
	1.8		***3.8***		***0.0***	***1.6***	
Aortic valve stenosis	31	6	<5	0	0	40	
	2.0	***0.8***		***0.0***	***0.0***	***1.5***	
Atrioventricular septal defect (Endocardial cushion defect)	82	49	11	<5	0	146	1
	5.4	***6.2***	***4.2***		***0.0***	***5.5***	
Biliary atresia	7	<5	<5	<5	0	15	
	0.5				***0.0***	***0.6***	
Bladder exstrophy	5	<5	0	0	0	6	
	0.3		***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	12	10	<5	0	0	24	
	0.8	***1.3***		***0.0***	***0.0***	***0.9***	
Cleft lip alone	51	11	7	<5	<5	71	
	3.4	***1.4***	***2.7***			***2.7***	
Cleft lip with cleft palate	107	48	22	<5	<5	181	
	7.1	***6.0***	***8.4***			***6.9***	
Cleft palate alone	123	53	17	<5	<5	198	
	8.1	***6.7***	***6.5***			***7.5***	
Coarctation of the aorta	87	35	16	<5	<5	142	
	5.7	***4.4***	***6.1***			***5.4***	
Common truncus (truncus arteriosus)	16	<5	<5	<5	0	22	
	1.1				***0.0***	***0.8***	
Congenital cataract	10	22	5	<5	0	38	
	0.7	***2.8***	***1.9***		***0.0***	***1.4***	
Congenital posterior urethral valves	20	13	<5	0	<5	36	2
	2.6	***3.2***		***0.0***		***2.7***	
Craniosynostosis	117	24	10	6	<5	159	
	7.7	***3.0***	***3.8***	***10.9***		***6.0***	
Deletion 22q11.2	7	9	<5	<5	0	18	
	0.5	***1.1***			***0.0***	***0.7***	
Diaphragmatic hernia	60	24	6	<5	<5	93	
	4.0	***3.0***	***2.3***			***3.5***	
Double outlet right ventricle	30	33	7	0	<5	71	
	2.0	***4.2***	***2.7***	***0.0***		***2.7***	
Ebstein anomaly	<5	<5	<5	0	<5	9	
				0.0		***0.3***	
Encephalocele	11	18	0	<5	0	30	
	0.7	***2.3***	***0.0***		***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	37	13	9	0	<5	60	
	2.4	***1.6***	***3.4***	***0.0***		***2.3***	
Gastroschisis	56	34	12	<5	<5	104	
	3.7	***4.3***	***4.6***			***3.9***	
Holoprosencephaly	16	13	<5	0	<5	35	
	1.1	***1.6***		***0.0***		***1.3***	
Hypoplastic left heart syndrome	52	20	9	<5	0	83	
	3.4	***2.5***	***3.4***		***0.0***	***3.2***	
Interrupted aortic arch	85	31	12	<5	<5	130	
	5.6	***3.9***	***4.6***			***4.9***	
Limb deficiencies (reduction defects)	87	33	21	<5	0	142	
	5.7	***4.2***	***8.0***		***0.0***	***5.4***	
Omphalocele	46	30	<5	0	0	78	
	3.0	***3.8***		***0.0***	***0.0***	***3.0***	
Pulmonary valve atresia and stenosis	83	64	15	<5	5	168	
	5.5	***8.1***	***5.7***		***92.4***	***6.4***	
Pulmonary valve atresia	12	11	<5	0	<5	27	
	0.8	***1.4***		***0.0***		***1.0***	
Rectal and large intestinal atresia/stenosis	67	32	15	<5	<5	116	
	4.4	***4.0***	***5.7***			***4.4***	
Renal agenesis/hypoplasia	98	48	19	<5	<5	168	
	6.5	***6.0***	***7.2***			***6.4***	
Single ventricle	9	<5	<5	0	0	12	
	0.6			***0.0***	***0.0***	***0.5***	

South Carolina

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Small intestinal atresia/stenosis	65	29	16	<5	<5	112	
	4.3	***3.6***	***6.1***			***4.3***	
Spina bifida without anencephalus	46	25	11	<5	0	84	
	3.0	***3.1***	***4.2***		***0.0***	***3.2***	
Tetralogy of Fallot	72	47	12	<5	<5	135	
	4.8	***5.9***	***4.6***			***5.1***	
Total anomalous pulmonary venous connection	16	9	8	0	0	33	
	1.1	***1.1***	***3.0***	***0.0***	***0.0***	***1.3***	
Transposition of the great arteries (TGA)	46	21	<5	0	0	71	
	3.0	***2.6***		***0.0***	***0.0***	***2.7***	
Tricuspid valve atresia and stenosis	12	8	<5	0	<5	23	
	0.8	***1.0***		***0.0***		***0.9***	
Trisomy 13	25	11	<5	0	0	41	
	1.6	***1.4***		***0.0***	***0.0***	***1.6***	
Trisomy 18	47	19	14	<5	<5	83	
	3.1	***2.4***	***5.3***			***3.2***	
Trisomy 21 (Down syndrome)	216	87	57	11	<5	374	
	14.3	***10.9***	***21.7***	***20.1***		***14.2***	
Turner syndrome	10	7	5	0	<5	23	3
	3.5	***4.5***	***8.9***	***0.0***		***4.5***	
Ventricular septal defect	673	362	154	26	10	1,225	4
	44.4	***45.5***	***58.6***	***47.4***	***184.8***	***46.5***	
Total live births	**151,563**	**79,475**	**26,295**	**5,483**	**541**	**263,374**	**5**
Male live births	**78,305**	**40,127**	**13,167**	**2,839**	**288**	**134,734**	
Female live births	**28,928**	**15,561**	**5,614**	**1,032**	**80**	**51,218**	

South Carolina

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	102	<5	104	
	4.5		***3.9***	
Trisomy 13	29	11	41	
	1.3	***2.9***	***1.6***	
Trisomy 18	46	37	83	
	2.0	***9.9***	***3.2***	
Trisomy 21 (Down syndrome)	191	183	374	
	8.5	***48.8***	***14.2***	
Total live births	**225,799**	**37,533**	**263,374**	**5**

Notes

1. Data for this condition exclude inlet ventricular septal defect (VSD).
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 begin in 2019. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
4. Data for this condition include inlet ventricular septal defect (VSD) and common atrioventricular (AV) canal type VSD.
5. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.
-Data for all conditions exclude possible/probable cases.

Tennessee
Birth Defects Counts and Prevalence 2016 - 2020 (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	46	11	8	3	0	73	
	1.8	***1.4***	***2.0***	***3.2***	***0.0***	***1.8***	
Anophthalmia/microphthalmia	36	13	6	2	0	58	
	1.4	***1.7***	***1.5***	***2.1***	***0.0***	***1.4***	
Anotia/microtia	44	8	19	4	0	80	
	1.7	***1.0***	***4.7***	***4.2***	***0.0***	***2.0***	
Aortic valve stenosis	50	8	7	2	0	70	
	1.9	***1.0***	***1.7***	***2.1***	***0.0***	***1.7***	
Atrial septal defect	5,221	2,402	721	171	8	8,727	
	199.7	***305.7***	***178.5***	***180.2***	***190.5***	***217.3***	
Atrioventricular septal defect (Endocardial cushion defect)	175	62	28	4	0	273	1
	6.7	***7.9***	***6.9***	***4.2***	***0.0***	***6.8***	
Biliary atresia	123	56	19	9	0	213	
	4.7	***7.1***	***4.7***	***9.5***	***0.0***	***5.3***	
Bladder exstrophy	8	2	2	0	0	12	
	0.3	***0.3***	***0.5***	***0.0***	***0.0***	***0.3***	
Choanal atresia	63	16	14	1	0	96	
	2.4	***2.0***	***3.5***	***1.1***	***0.0***	***2.4***	
Cleft lip alone	91	13	11	6	0	130	
	3.5	***1.7***	***2.7***	***6.3***	***0.0***	***3.2***	
Cleft lip with cleft palate	220	38	35	6	1	307	
	8.4	***4.8***	***8.7***	***6.3***	***23.8***	***7.6***	
Cleft palate alone	237	37	21	6	0	311	
	9.1	***4.7***	***5.2***	***6.3***	***0.0***	***7.7***	
Cloacal exstrophy	4	0	1	0	0	5	
	0.2	***0.0***	***0.2***	***0.0***	***0.0***	***0.1***	
Clubfoot	681	201	91	9	2	1,018	
	26.0	***25.6***	***22.5***	***9.5***	***47.6***	***25.3***	
Coarctation of the aorta	207	67	37	6	0	327	
	7.9	***8.5***	***9.2***	***6.3***	***0.0***	***8.1***	
Common truncus (truncus arteriosus)	23	6	5	2	0	36	
	0.9	***0.8***	***1.2***	***2.1***	***0.0***	***0.9***	
Congenital cataract	74	20	9	0	0	104	
	2.8	***2.5***	***2.2***	***0.0***	***0.0***	***2.6***	
Congenital posterior urethral valves	38	21	2	4	0	66	2
	2.8	***5.3***	***1.0***	***8.2***	***0.0***	***3.2***	
Craniosynostosis	532	65	54	13	1	676	
	20.3	***8.3***	***13.4***	***13.7***	***23.8***	***16.8***	
Deletion 22q11.2	18	5	1	0	0	24	
	0.7	***0.6***	***0.2***	***0.0***	***0.0***	***0.6***	
Diaphragmatic hernia	104	35	17	4	0	166	
	4.0	***4.5***	***4.2***	***4.2***	***0.0***	***4.1***	
Double outlet right ventricle	84	27	17	4	0	136	
	3.2	***3.4***	***4.2***	***4.2***	***0.0***	***3.4***	
Ebstein anomaly	47	3	11	0	0	62	
	1.8	***0.4***	***2.7***	***0.0***	***0.0***	***1.5***	
Encephalocele	42	8	7	1	0	60	
	1.6	***1.0***	***1.7***	***1.1***	***0.0***	***1.5***	
Esophageal atresia/tracheoesophageal fistula	92	20	8	2	0	124	
	3.5	***2.5***	***2.0***	***2.1***	***0.0***	***3.1***	
Gastroschisis	110	30	18	3	1	169	
	4.2	***3.8***	***4.5***	***3.2***	***23.8***	***4.2***	
Holoprosencephaly	24	16	8	2	0	53	
	0.9	***2.0***	***2.0***	***2.1***	***0.0***	***1.3***	
Hypoplastic left heart syndrome	102	28	14	3	0	148	
	3.9	***3.6***	***3.5***	***3.2***	***0.0***	***3.7***	
Hypospadias	1,558	416	117	37	3	2,183	2
	116.3	***104.6***	***56.6***	***76.2***	***153.1***	***106.4***	
Interrupted aortic arch	35	18	8	0	0	63	
	1.3	***2.3***	***2.0***	***0.0***	***0.0***	***1.6***	
Limb deficiencies (reduction defects)	117	26	23	2	0	175	
	4.5	***3.3***	***5.7***	***2.1***	***0.0***	***4.4***	
Omphalocele	66	29	9	1	0	109	
	2.5	***3.7***	***2.2***	***1.1***	***0.0***	***2.7***	
Pulmonary valve atresia and stenosis	246	99	32	7	1	396	
	9.4	***12.6***	***7.9***	***7.4***	***23.8***	***9.9***	

Tennessee

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	25	4	4	1	0	35	
	1.0	***0.5***	***1.0***	***1.1***	***0.0***	***0.9***	
Rectal and large intestinal atresia/stenosis	131	37	33	6	0	210	
	5.0	***4.7***	***8.2***	***6.3***	***0.0***	***5.2***	
Renal agenesis/hypoplasia	202	46	31	5	0	291	
	7.7	***5.9***	***7.7***	***5.3***	***0.0***	***7.2***	
Single ventricle	40	12	7	2	0	63	
	1.5	***1.5***	***1.7***	***2.1***	***0.0***	***1.6***	
Small intestinal atresia/stenosis	125	46	17	1	0	197	
	4.8	***5.9***	***4.2***	***1.1***	***0.0***	***4.9***	
Spina bifida without anencephalus	131	22	18	7	0	181	
	5.0	***2.8***	***4.5***	***7.4***	***0.0***	***4.5***	
Tetralogy of Fallot	177	56	18	5	0	263	
	6.8	***7.1***	***4.5***	***5.3***	***0.0***	***6.5***	
Total anomalous pulmonary venous connection	27	4	15	0	0	47	
	1.0	***0.5***	***3.7***	***0.0***	***0.0***	***1.2***	
Transposition of the great arteries (TGA)	108	21	18	3	0	152	
	4.1	***2.7***	***4.5***	***3.2***	***0.0***	***3.8***	
Dextro-transposition of great arteries (d-TGA)	105	21	17	3	0	147	
	4.0	***2.7***	***4.2***	***3.2***	***0.0***	***3.7***	
Tricuspid valve atresia and stenosis	34	6	2	2	0	46	3
	1.3	***0.8***	***0.5***	***2.1***	***0.0***	***1.1***	
Trisomy 13	33	9	7	0	0	49	
	1.3	***1.1***	***1.7***	***0.0***	***0.0***	***1.2***	
Trisomy 18	49	19	18	1	0	90	
	1.9	***2.4***	***4.5***	***1.1***	***0.0***	***2.2***	
Trisomy 21 (Down syndrome)	375	94	89	13	0	588	
	14.3	***12.0***	***22.0***	***13.7***	***0.0***	***14.6***	
Turner syndrome	34	9	4	1	0	49	4
	2.7	***2.3***	***2.0***	***2.2***	***0.0***	***2.5***	
Ventricular septal defect	1,342	435	255	38	2	2,124	5
	51.3	***55.4***	***63.1***	***40.1***	***47.6***	***52.9***	
Total live births	**261,476**	**78,571**	**40,391**	**9,488**	**420**	**401,632**	**6**
Male live births	**133,923**	**39,755**	**20,672**	**4,855**	**196**	**205,159**	
Female live births	**127,552**	**38,811**	**19,718**	**4,633**	**224**	**196,466**	

Tennessee

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	159	10	169	
	4.6	***1.9***	***4.2***	
Trisomy 13	38	11	49	
	1.1	***2.1***	***1.2***	
Trisomy 18	50	40	90	
	1.4	***7.5***	***2.2***	
Trisomy 21 (Down syndrome)	319	268	588	
	9.2	***50.0***	***14.6***	
Total live births	**347,957**	**53,609**	**401,632**	**6**

Notes

1. Data for this condition include all cases with the code for atrioventricular septal defect (Q21.2) regardless of whether the case has inlet ventricular septal defect or common atrioventricular canal type VSD.
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 all cases with the code for congenital tricuspid stenosis (Q22.4) regardless of whether the case has tricuspid stenosis or hypoplasia.
4. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
5. Data for this condition include all cases with the code for ventricular septal defect (Q21.0) regardless of whether the case has inlet ventricular septal defect (VSD) or common atrioventricular canal type VSD.
6. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.
-Data for all conditions are based on infants diagnosed during the first year of life.

Texas

Birth Defects Counts and Prevalence 2016 - 2019 (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	89	45	200	13	0	370	
	1.8	***2.4***	***2.8***	***1.6***	***0.0***	***2.4***	
Anophthalmia/microphthalmia	128	51	254	18	0	462	
	2.5	***2.7***	***3.5***	***2.2***	***0.0***	***3.0***	
Anotia/microtia	137	38	433	32	0	653	
	2.7	***2.0***	***6.0***	***3.9***	***0.0***	***4.3***	
Aortic valve stenosis	134	26	168	15	0	348	
	2.7	***1.4***	***2.3***	***1.8***	***0.0***	***2.3***	
Atrial septal defect	4,015	1,792	7,255	476	27	13,785	
	79.9	***96.0***	***100.0***	***58.1***	***96.9***	***89.9***	
Atrioventricular septal defect (Endocardial cushion defect)	253	123	352	22	2	764	
	5.0	***6.6***	***4.9***	***2.7***	***7.2***	***5.0***	
Biliary atresia	25	22	48	7	0	106	
	0.5	***1.2***	***0.7***	***0.9***	***0.0***	***0.7***	
Bladder exstrophy	9	5	0	2	0	17	
	0.2	***0.3***	***0.0***	***0.2***	***0.0***	***0.1***	
Choanal atresia	65	25	96	6	1	194	1
	1.3	***1.3***	***1.3***	***0.7***	***3.6***	***1.3***	
Cleft lip alone	204	53	220	32	0	527	
	4.1	***2.8***	***3.0***	***3.9***	***0.0***	***3.4***	
Cleft lip with cleft palate	353	82	598	47	2	1,107	
	7.0	***4.4***	***8.2***	***5.7***	***7.2***	***7.2***	
Cleft palate alone	336	83	409	61	4	917	
	6.7	***4.4***	***5.6***	***7.4***	***14.4***	***6.0***	
Cloacal exstrophy	4	1	4	0	0	9	
	0.1	***0.1***	***0.1***	***0.0***	***0.0***	***0.1***	
Clubfoot	968	387	1,449	111	7	2,988	
	19.3	***20.7***	***20.0***	***13.5***	***25.1***	***19.5***	
Coarctation of the aorta	336	70	458	26	1	904	
	6.7	***3.8***	***6.3***	***3.2***	***3.6***	***5.9***	
Common truncus (truncus arteriosus)	24	15	56	3	0	100	
	0.5	***0.8***	***0.8***	***0.4***	***0.0***	***0.7***	
Congenital cataract	107	48	158	23	1	342	
	2.1	***2.6***	***2.2***	***2.8***	***3.6***	***2.2***	
Congenital posterior urethral valves	63	33	70	15	1	189	2
	2.4	***3.5***	***1.9***	***3.6***	***6.9***	***2.4***	
Craniosynostosis	441	67	477	36	2	1,041	
	8.8	***3.6***	***6.6***	***4.4***	***7.2***	***6.8***	
Deletion 22q11.2	62	28	96	5	0	196	
	1.2	***1.5***	***1.3***	***0.6***	***0.0***	***1.3***	
Diaphragmatic hernia	144	43	213	26	0	430	
	2.9	***2.3***	***2.9***	***3.2***	***0.0***	***2.8***	
Double outlet right ventricle	135	49	189	17	0	398	
	2.7	***2.6***	***2.6***	***2.1***	***0.0***	***2.6***	
Ebstein anomaly	45	5	78	8	0	139	
	0.9	***0.3***	***1.1***	***1.0***	***0.0***	***0.9***	
Encephalocele	40	33	78	2	1	163	
	0.8	***1.8***	***1.1***	***0.2***	***3.6***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	126	40	155	21	1	350	
	2.5	***2.1***	***2.1***	***2.6***	***3.6***	***2.3***	
Gastroschisis	256	59	371	12	1	717	
	5.1	***3.2***	***5.1***	***1.5***	***3.6***	***4.7***	
Holoprosencephaly	45	18	82	3	1	150	
	0.9	***1.0***	***1.1***	***0.4***	***3.6***	***1.0***	
Hypoplastic left heart syndrome	133	41	178	8	1	364	
	2.6	***2.2***	***2.5***	***1.0***	***3.6***	***2.4***	
Hypospadias	2,502	867	1,862	279	12	5,650	2
	97.2	***91.4***	***50.4***	***66.1***	***82.9***	***72.2***	
Interrupted aortic arch	35	20	59	2	0	118	
	0.7	***1.1***	***0.8***	***0.2***	***0.0***	***0.8***	
Limb deficiencies (reduction defects)	259	124	408	30	1	847	
	5.2	***6.6***	***5.6***	***3.7***	***3.6***	***5.5***	
Omphalocele	117	48	157	12	2	346	
	2.3	***2.6***	***2.2***	***1.5***	***7.2***	***2.3***	
Pulmonary valve atresia and stenosis	508	252	881	71	5	1,749	
	10.1	***13.5***	***12.1***	***8.7***	***18.0***	***11.4***	

Texas

Birth Defects Counts and Prevalence 2016 - 2019 (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**
Pulmonary valve atresia	64	26	103	15	0	209	3
	1.3	***1.4***	***1.4***	***1.8***	***0.0***	***1.4***	
Rectal and large intestinal atresia/stenosis	253	70	455	40	0	833	
	5.0	***3.8***	***6.3***	***4.9***	***0.0***	***5.4***	
Renal agenesis/hypoplasia	385	149	617	50	0	1,236	
	7.7	***8.0***	***8.5***	***6.1***	***0.0***	***8.1***	
Single ventricle	31	10	57	0	0	100	
	0.6	***0.5***	***0.8***	***0.0***	***0.0***	***0.7***	
Small intestinal atresia/stenosis	176	65	294	22	2	572	
	3.5	***3.5***	***4.1***	***2.7***	***7.2***	***3.7***	
Spina bifida without anencephalus	181	44	306	13	0	557	
	3.6	***2.4***	***4.2***	***1.6***	***0.0***	***3.6***	
Tetralogy of Fallot	255	117	377	43	1	810	4
	5.1	***6.3***	***5.2***	***5.2***	***3.6***	***5.3***	
Total anomalous pulmonary venous connection	56	22	139	14	1	233	
	1.1	***1.2***	***1.9***	***1.7***	***3.6***	***1.5***	
Transposition of the great arteries (TGA)	161	36	221	17	0	444	
	3.2	***1.9***	***3.0***	***2.1***	***0.0***	***2.9***	
Dextro-transposition of great arteries (d-TGA)	130	29	181	13	0	362	
	2.6	***1.6***	***2.5***	***1.6***	***0.0***	***2.4***	
Tricuspid valve atresia and stenosis	98	56	172	18	0	346	
	1.9	***3.0***	***2.4***	***2.2***	***0.0***	***2.3***	
Tricuspid valve atresia	31	12	61	6	0	110	
	0.6	***0.6***	***0.8***	***0.7***	***0.0***	***0.7***	
Trisomy 13	54	26	70	4	0	159	
	1.1	***1.4***	***1.0***	***0.5***	***0.0***	***1.0***	
Trisomy 18	95	53	190	12	1	367	
	1.9	***2.8***	***2.6***	***1.5***	***3.6***	***2.4***	
Trisomy 21 (Down syndrome)	613	255	1,288	84	7	2,292	
	12.2	***13.7***	***17.8***	***10.2***	***25.1***	***15.0***	
Turner syndrome	69	12	117	11	1	217	5
	2.8	***1.3***	***3.3***	***2.8***	***7.5***	***2.9***	
Ventricular septal defect	3,149	1,038	5,826	432	21	10,642	6
	62.7	***55.6***	***80.3***	***52.7***	***75.4***	***69.4***	
Total live births	**502,571**	**186,577**	**725,626**	**81,967**	**2,785**	**1,533,091**	
Male live births	**257,527**	**94,847**	**369,697**	**42,188**	**1,448**	**782,960**	
Female live births	**245,044**	**91,730**	**355,929**	**39,779**	**1,337**	**750,131**	

Texas

Birth Defects Counts and Prevalence 2016 - 2019 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	700	17	717	
	5.4	***0.7***	***4.7***	
Trisomy 13	98	60	159	
	0.8	***2.5***	***1.0***	
Trisomy 18	169	198	367	
	1.3	***8.3***	***2.4***	
Trisomy 21 (Down syndrome)	1,118	1,174	2,292	
	8.6	***49.0***	***15.0***	
Total live births	**1,293,555**	**239,454**	**1,533,091**	

Notes

1. Data for this condition may include stenosis.
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 exclude pulmonary valve atresia with co-occurring ventricular septal defect or tetralogy of Fallot.
4. Data for this condition include any pulmonary valve atresia with co-occurring ventricular septal defect.
5. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
6. Data for this condition include inlet ventricular septal defect.

General comments

*Data for totals include unknown and/or other.
-Data for all conditions exclude possible/probable cases.

Utah

Birth Defects Counts and Prevalence 2016 - 2020 (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	36	0	8	2	0	47	
	2.0	***0.0***	***2.0***	***2.1***	***0.0***	***2.0***	
Anophthalmia/microphthalmia	36	0	6	3	1	47	
	2.0	***0.0***	***1.5***	***3.2***	***4.5***	***2.0***	
Anotia/microtia	44	0	20	7	0	75	
	2.5	***0.0***	***5.0***	***7.4***	***0.0***	***3.1***	
Aortic valve stenosis	75	1	11	2	2	93	
	4.2	***2.8***	***2.8***	***2.1***	***9.1***	***3.9***	
Atrial septal defect	551	10	146	31	11	770	
	30.9	***27.8***	***36.7***	***33.0***	***49.9***	***32.2***	
Atrioventricular septal defect (Endocardial cushion defect)	101	2	8	6	0	120	
	5.7	***5.6***	***2.0***	***6.4***	***0.0***	***5.0***	
Biliary atresia	11	0	1	2	1	16	
	0.6	***0.0***	***0.3***	***2.1***	***4.5***	***0.7***	
Bladder exstrophy	3	0	0	0	0	3	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Choanal atresia	26	1	1	0	0	30	
	1.5	***2.8***	***0.3***	***0.0***	***0.0***	***1.3***	
Cleft lip alone	84	1	15	9	1	117	
	4.7	***2.8***	***3.8***	***9.6***	***4.5***	***4.9***	
Cleft lip with cleft palate	119	2	33	6	1	164	
	6.7	***5.6***	***8.3***	***6.4***	***4.5***	***6.9***	
Cleft palate alone	120	0	37	9	0	168	
	6.7	***0.0***	***9.3***	***9.6***	***0.0***	***7.0***	
Cloacal exstrophy	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Coarctation of the aorta	193	2	41	6	1	248	
	10.8	***5.6***	***10.3***	***6.4***	***4.5***	***10.4***	
Common truncus (truncus arteriosus)	14	0	1	0	1	17	
	0.8	***0.0***	***0.3***	***0.0***	***4.5***	***0.7***	
Congenital cataract	70	0	15	3	1	94	
	3.9	***0.0***	***3.8***	***3.2***	***4.5***	***3.9***	
Congenital posterior urethral valves	15	0	2	1	0	18	1
	1.6	***0.0***	***1.0***	***2.1***	***0.0***	***1.5***	
Craniosynostosis	229	1	36	5	3	278	
	12.8	***2.8***	***9.0***	***5.3***	***13.6***	***11.6***	
Deletion 22q11.2	28	1	5	1	2	37	
	1.6	***2.8***	***1.3***	***1.1***	***9.1***	***1.5***	
Diaphragmatic hernia	79	1	24	7	0	113	
	4.4	***2.8***	***6.0***	***7.4***	***0.0***	***4.7***	
Double outlet right ventricle	50	1	10	3	1	68	
	2.8	***2.8***	***2.5***	***3.2***	***4.5***	***2.8***	
Ebstein anomaly	17	1	6	0	0	25	
	1.0	***2.8***	***1.5***	***0.0***	***0.0***	***1.0***	
Encephalocele	15	1	1	1	0	18	
	0.8	***2.8***	***0.3***	***1.1***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	72	0	13	4	0	91	
	4.0	***0.0***	***3.3***	***4.3***	***0.0***	***3.8***	
Gastroschisis	67	0	19	5	1	95	
	3.8	***0.0***	***4.8***	***5.3***	***4.5***	***4.0***	
Holoprosencephaly	38	1	3	1	1	45	
	2.1	***2.8***	***0.8***	***1.1***	***4.5***	***1.9***	
Hypoplastic left heart syndrome	72	1	24	1	1	104	
	4.0	***2.8***	***6.0***	***1.1***	***4.5***	***4.4***	
Hypospadias	668	9	58	22	5	779	1
	72.9	***49.1***	***28.4***	***45.8***	***45.8***	***63.5***	
Interrupted aortic arch	9	0	1	1	1	12	
	0.5	***0.0***	***0.3***	***1.1***	***4.5***	***0.5***	
Limb deficiencies (reduction defects)	92	1	29	5	2	138	
	5.2	***2.8***	***7.3***	***5.3***	***9.1***	***5.8***	
Omphalocele	48	1	14	3	0	68	
	2.7	***2.8***	***3.5***	***3.2***	***0.0***	***2.8***	
Pulmonary valve atresia and stenosis	269	7	67	18	1	374	
	15.1	***19.5***	***16.8***	***19.1***	***4.5***	***15.7***	
Pulmonary valve atresia	20	0	9	3	0	32	
	1.1	***0.0***	***2.3***	***3.2***	***0.0***	***1.3***	

Utah

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Rectal and large intestinal atresia/stenosis	77 ***4.3***	0 ***0.0***	13 ***3.3***	5 ***5.3***	2 ***9.1***	100 ***4.2***	
Renal agenesis/hypoplasia	94 ***5.3***	1 ***2.8***	21 ***5.3***	8 ***8.5***	1 ***4.5***	130 ***5.4***	
Single ventricle	7 ***0.4***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	7 ***0.3***	
Small intestinal atresia/stenosis	59 ***3.3***	2 ***5.6***	23 ***5.8***	5 ***5.3***	2 ***9.1***	93 ***3.9***	
Spina bifida without anencephalus	79 ***4.4***	1 ***2.8***	19 ***4.8***	1 ***1.1***	0 ***0.0***	101 ***4.2***	
Tetralogy of Fallot	53 ***3.0***	0 ***0.0***	11 ***2.8***	4 ***4.3***	1 ***4.5***	74 ***3.1***	
Total anomalous pulmonary venous connection	23 ***1.3***	0 ***0.0***	9 ***2.3***	0 ***0.0***	0 ***0.0***	33 ***1.4***	
Transposition of the great arteries (TGA)	64 ***3.6***	0 ***0.0***	9 ***2.3***	2 ***2.1***	0 ***0.0***	77 ***3.2***	
Dextro-transposition of great arteries (d-TGA)	58 ***3.3***	0 ***0.0***	8 ***2.0***	2 ***2.1***	0 ***0.0***	70 ***2.9***	
Tricuspid valve atresia and stenosis	23 ***1.3***	0 ***0.0***	5 ***1.3***	1 ***1.1***	1 ***4.5***	31 ***1.3***	
Tricuspid valve atresia	11 ***0.6***	0 ***0.0***	4 ***1.0***	0 ***0.0***	1 ***4.5***	17 ***0.7***	
Trisomy 13	30 ***1.7***	2 ***5.6***	7 ***1.8***	2 ***2.1***	0 ***0.0***	44 ***1.8***	
Trisomy 18	56 ***3.1***	2 ***5.6***	14 ***3.5***	7 ***7.4***	1 ***4.5***	83 ***3.5***	
Trisomy 21 (Down syndrome)	300 ***16.8***	12 ***33.4***	79 ***19.9***	20 ***21.3***	8 ***36.3***	433 ***18.1***	
Turner syndrome	43 ***5.0***	1 ***5.7***	16 ***8.2***	2 ***4.4***	0 ***0.0***	64 ***5.5***	2
Ventricular septal defect	480 ***26.9***	13 ***36.2***	116 ***29.1***	28 ***29.8***	7 ***31.7***	669 ***28.0***	
Total live births	**178,273**	**3,592**	**39,797**	**9,401**	**2,206**	**238,831**	**3**
Male live births	**91,636**	**1,833**	**20,398**	**4,805**	**1,092**	**122,740**	
Female live births	**86,637**	**1,758**	**19,398**	**4,595**	**1,114**	**116,087**	

Utah

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	90	5	95	
	4.4	***1.4***	***4.0***	
Trisomy 13	26	18	44	
	1.3	***5.0***	***1.8***	
Trisomy 18	34	49	83	
	1.7	***13.7***	***3.5***	
Trisomy 21 (Down syndrome)	214	219	433	
	10.6	***61.3***	***18.1***	
Total live births	**202,698**	**35,736**	**238,831**	**3**

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. Prevalance 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.

Vermont

Birth Defects Counts and Prevalence 2016 - 2020 (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	1	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Anophthalmia/microphthalmia	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Anotia/microtia	3	0	0	0	0	3	
	1.2	***0.0***	***0.0***	***0.0***	***0.0***	***1.1***	
Aortic valve stenosis	9	0	1	0	0	12	
	3.6	***0.0***	***15.9***	***0.0***	***0.0***	***4.4***	
Atrial septal defect	253	6	6	8	1	291	
	102.4	***108.1***	***95.2***	***113.0***	***166.7***	***106.5***	
Atrioventricular septal defect (Endocardial cushion defect)	9	0	0	0	0	10	
	3.6	***0.0***	***0.0***	***0.0***	***0.0***	***3.7***	
Biliary atresia	1	0	0	0	0	1	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Bladder exstrophy	1	0	0	0	0	1	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Choanal atresia	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Cleft lip alone	11	0	1	0	0	12	
	4.5	***0.0***	***15.9***	***0.0***	***0.0***	***4.4***	
Cleft lip with cleft palate	5	0	0	0	0	8	
	2.0	***0.0***	***0.0***	***0.0***	***0.0***	***2.9***	
Cleft palate alone	12	0	1	2	0	16	
	4.9	***0.0***	***15.9***	***28.2***	***0.0***	***5.9***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	61	0	3	1	0	67	
	24.7	***0.0***	***47.6***	***14.1***	***0.0***	***24.5***	
Coarctation of the aorta	5	0	0	1	0	11	
	2.0	***0.0***	***0.0***	***14.1***	***0.0***	***4.0***	
Common truncus (truncus arteriosus)	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Congenital cataract	13	0	0	0	0	15	
	5.3	***0.0***	***0.0***	***0.0***	***0.0***	***5.5***	
Congenital posterior urethral valves	3	0	0	0	0	3	1
	2.4	***0.0***	***0.0***	***0.0***	***0.0***	***2.1***	
Craniosynostosis	13	0	0	0	0	13	
	5.3	***0.0***	***0.0***	***0.0***	***0.0***	***4.8***	
Deletion 22q11.2	1	0	0	0	0	3	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.1***	
Diaphragmatic hernia	5	0	0	0	0	8	
	2.0	***0.0***	***0.0***	***0.0***	***0.0***	***2.9***	
Double outlet right ventricle	3	0	0	0	0	5	
	1.2	***0.0***	***0.0***	***0.0***	***0.0***	***1.8***	
Ebstein anomaly	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Encephalocele	1	0	0	0	0	1	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Esophageal atresia/tracheoesophageal fistula	6	0	1	0	0	8	
	2.4	***0.0***	***15.9***	***0.0***	***0.0***	***2.9***	
Gastroschisis	11	0	0	0	0	11	2
	4.5	***0.0***	***0.0***	***0.0***	***0.0***	***4.0***	
Holoprosencephaly	1	0	0	0	0	2	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Hypoplastic left heart syndrome	2	0	0	0	0	5	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.8***	
Hypospadias	87	2	5	2	2	104	1
	69.1	***69.0***	***158.7***	***52.1***	***606.1***	***74.5***	
Interrupted aortic arch	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Limb deficiencies (reduction defects)	10	0	0	0	0	11	
	4.0	***0.0***	***0.0***	***0.0***	***0.0***	***4.0***	
Omphalocele	2	0	0	0	0	2	2
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Pulmonary valve atresia and stenosis	39	0	0	1	0	44	
	15.8	***0.0***	***0.0***	***14.1***	***0.0***	***16.1***	

Vermont

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	0	0	0	0	0	3	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***1.1***	
Rectal and large intestinal atresia/stenosis	24	1	0	0	0	27	
	9.7	***18.0***	***0.0***	***0.0***	***0.0***	***9.9***	
Renal agenesis/hypoplasia	14	0	0	0	0	15	
	5.7	***0.0***	***0.0***	***0.0***	***0.0***	***5.5***	
Single ventricle	0	0	0	0	0	1	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Small intestinal atresia/stenosis	14	0	0	0	0	14	
	5.7	***0.0***	***0.0***	***0.0***	***0.0***	***5.1***	
Spina bifida without anencephalus	6	0	0	0	0	7	
	2.4	***0.0***	***0.0***	***0.0***	***0.0***	***2.6***	
Tetralogy of Fallot	6	0	1	0	0	12	
	2.4	***0.0***	***15.9***	***0.0***	***0.0***	***4.4***	
Total anomalous pulmonary venous connection	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Transposition of the great arteries (TGA)	3	0	0	0	0	7	
	1.2	***0.0***	***0.0***	***0.0***	***0.0***	***2.6***	
Dextro-transposition of great arteries (d-TGA)	2	0	0	0	0	5	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.8***	
Tricuspid valve atresia and stenosis	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Tricuspid valve atresia	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Trisomy 13	0	0	0	0	0	2	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Trisomy 18	2	0	0	0	0	2	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Trisomy 21 (Down syndrome)	29	1	1	2	0	33	
	11.7	***18.0***	***15.9***	***28.2***	***0.0***	***12.1***	
Turner syndrome	2	0	0	0	0	2	3
	1.7	***0.0***	***0.0***	***0.0***	***0.0***	***1.5***	
Ventricular septal defect	154	4	0	6	0	177	
	62.3	***72.1***	***0.0***	***84.7***	***0.0***	***64.8***	
Total live births	**24,707**	**555**	**630**	**708**	**60**	**27,331**	
Male live births	**12,599**	**290**	**315**	**384**	**33**	**13,956**	
Female live births	**12,108**	**265**	**315**	**324**	**27**	**13,375**	

Vermont

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	11	0	11	2
	5.1	***0.0***	***4.0***	
Trisomy 13	1	1	2	
	0.5	***1.8***	***0.7***	
Trisomy 18	1	1	2	
	0.5	***1.8***	***0.7***	
Trisomy 21 (Down syndrome)	18	15	33	
	8.3	***26.6***	***12.1***	
Total live births	**21,699**	**5,632**	**27,331**	

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 are actively reviewed to differentiate between gastroschisis and omphalocele.
3. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.

General comments

*Data for totals include unknown and/or other.

-Data for all conditions represent births to Vermont residents, regardless of which state the birth occurred in. Non-resident births occurring in Vermont are excluded.

Virginia
Birth Defects Counts and Prevalence 2016 - 2020 (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	15	1	8	1	0	26	
	0.5	***0.1***	***1.1***	***0.3***	***0.0***	***0.5***	
Anophthalmia/microphthalmia	23	9	1	3	0	36	
	0.8	***0.9***	***0.1***	***0.8***	***0.0***	***0.7***	
Anotia/microtia	25	7	21	2	0	56	
	0.9	***0.7***	***2.9***	***0.5***	***0.0***	***1.1***	
Aortic valve stenosis	38	5	8	2	0	53	
	1.4	***0.5***	***1.1***	***0.5***	***0.0***	***1.1***	
Atrial septal defect	3,076	1,558	948	346	9	5,949	
	110.1	***150.7***	***132.2***	***92.0***	***107.5***	***120.5***	
Atrioventricular septal defect (Endocardial cushion defect)	116	38	42	8	0	204	
	4.2	***3.7***	***5.9***	***2.1***	***0.0***	***4.1***	
Biliary atresia	49	44	20	5	0	119	
	1.8	***4.3***	***2.8***	***1.3***	***0.0***	***2.4***	
Bladder exstrophy	2	1	2	0	0	5	
	0.1	***0.1***	***0.3***	***0.0***	***0.0***	***0.1***	
Choanal atresia	41	10	2	3	0	56	
	1.5	***1.0***	***0.3***	***0.8***	***0.0***	***1.1***	
Cleft lip alone	73	11	15	8	0	107	
	2.6	***1.1***	***2.1***	***2.1***	***0.0***	***2.2***	
Cleft lip with cleft palate	122	26	29	16	0	193	
	4.4	***2.5***	***4.0***	***4.3***	***0.0***	***3.9***	
Cleft palate alone	159	47	22	18	0	246	
	5.7	***4.5***	***3.1***	***4.8***	***0.0***	***5.0***	
Cloacal exstrophy	1	0	0	0	0	1	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	383	130	82	41	0	637	
	13.7	***12.6***	***11.4***	***10.9***	***0.0***	***12.9***	
Coarctation of the aorta	152	54	39	11	0	256	
	5.4	***5.2***	***5.4***	***2.9***	***0.0***	***5.2***	
Common truncus (truncus arteriosus)	14	5	0	0	0	19	1
	0.5	***0.5***	***0.0***	***0.0***	***0.0***	***0.4***	
Congenital cataract	25	18	7	6	0	56	
	0.9	***1.7***	***1.0***	***1.6***	***0.0***	***1.1***	
Congenital posterior urethral valves	28	14	2	2	0	46	2
	2.0	***2.7***	***0.5***	***1.0***	***0.0***	***1.8***	
Craniosynostosis	179	41	28	9	0	258	
	6.4	***4.0***	***3.9***	***2.4***	***0.0***	***5.2***	
Deletion 22q11.2	9	6	5	3	0	23	
	0.3	***0.6***	***0.7***	***0.8***	***0.0***	***0.5***	
Diaphragmatic hernia	57	31	19	4	0	111	
	2.0	***3.0***	***2.7***	***1.1***	***0.0***	***2.2***	
Double outlet right ventricle	48	36	19	11	0	115	
	1.7	***3.5***	***2.7***	***2.9***	***0.0***	***2.3***	
Ebstein anomaly	13	5	6	3	0	27	
	0.5	***0.5***	***0.8***	***0.8***	***0.0***	***0.5***	
Encephalocele	12	8	3	2	0	25	
	0.4	***0.8***	***0.4***	***0.5***	***0.0***	***0.5***	
Esophageal atresia/tracheoesophageal fistula	67	19	13	7	0	106	
	2.4	***1.8***	***1.8***	***1.9***	***0.0***	***2.1***	
Gastroschisis	73	17	17	3	0	111	
	2.6	***1.6***	***2.4***	***0.8***	***0.0***	***2.2***	
Holoprosencephaly	13	10	10	0	0	33	
	0.5	***1.0***	***1.4***	***0.0***	***0.0***	***0.7***	
Hypoplastic left heart syndrome	76	37	18	8	0	139	
	2.7	***3.6***	***2.5***	***2.1***	***0.0***	***2.8***	
Hypospadias	783	280	76	69	3	1,211	2
	54.7	***53.2***	***20.9***	***35.9***	***68.2***	***47.9***	
Interrupted aortic arch	34	19	6	3	0	63	3
	1.2	***1.8***	***0.8***	***0.8***	***0.0***	***1.3***	
Limb deficiencies (reduction defects)	60	30	13	7	0	110	
	2.1	***2.9***	***1.8***	***1.9***	***0.0***	***2.2***	
Omphalocele	38	55	8	7	0	108	
	1.4	***5.3***	***1.1***	***1.9***	***0.0***	***2.2***	
Pulmonary valve atresia and stenosis	117	65	35	15	0	233	4
	4.2	***6.3***	***4.9***	***4.0***	***0.0***	***4.7***	

Virginia

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	10	7	6	1	0	24	4
	0.4	***0.7***	***0.8***	***0.3***	***0.0***	***0.5***	
Rectal and large intestinal atresia/stenosis	104	63	28	14	0	209	
	3.7	***6.1***	***3.9***	***3.7***	***0.0***	***4.2***	
Renal agenesis/hypoplasia	113	56	34	10	0	213	
	4.0	***5.4***	***4.7***	***2.7***	***0.0***	***4.3***	
Single ventricle	43	19	13	7	0	82	
	1.5	***1.8***	***1.8***	***1.9***	***0.0***	***1.7***	
Small intestinal atresia/stenosis	79	38	31	12	0	160	
	2.8	***3.7***	***4.3***	***3.2***	***0.0***	***3.2***	
Spina bifida without anencephalus	48	16	18	10	0	92	
	1.7	***1.5***	***2.5***	***2.7***	***0.0***	***1.9***	
Tetralogy of Fallot	91	57	20	22	0	190	5
	3.3	***5.5***	***2.8***	***5.9***	***0.0***	***3.8***	
Total anomalous pulmonary venous connection	20	10	14	4	0	48	
	0.7	***1.0***	***2.0***	***1.1***	***0.0***	***1.0***	
Transposition of the great arteries (TGA)	82	33	29	13	0	157	
	2.9	***3.2***	***4.0***	***3.5***	***0.0***	***3.2***	
Dextro-transposition of great arteries (d-TGA)	71	31	27	13	0	142	
	2.5	***3.0***	***3.8***	***3.5***	***0.0***	***2.9***	
Tricuspid valve atresia and stenosis	29	17	9	1	0	56	
	1.0	***1.6***	***1.3***	***0.3***	***0.0***	***1.1***	
Trisomy 13	10	10	5	1	0	26	
	0.4	***1.0***	***0.7***	***0.3***	***0.0***	***0.5***	
Trisomy 18	34	16	10	3	0	63	
	1.2	***1.5***	***1.4***	***0.8***	***0.0***	***1.3***	
Trisomy 21 (Down syndrome)	349	95	135	22	1	605	
	12.5	***9.2***	***18.8***	***5.9***	***11.9***	***12.3***	
Turner syndrome	29	11	6	1	0	47	6
	2.1	***2.2***	***1.7***	***0.5***	***0.0***	***1.9***	
Ventricular septal defect	1,187	500	362	147	1	2,200	4
	42.5	***48.4***	***50.5***	***39.1***	***11.9***	***44.6***	
Total live births	**279,261**	**103,374**	**71,694**	**37,600**	**837**	**493,824**	**7**
Male live births	**143,266**	**52,642**	**36,447**	**19,241**	**440**	**252,590**	
Female live births	**135,985**	**50,726**	**35,240**	**18,357**	**397**	**241,209**	

Virginia
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	106	5	111	
	2.7	***0.5***	***2.2***	
Trisomy 13	14	12	26	
	0.4	***1.2***	***0.5***	
Trisomy 18	31	32	63	
	0.8	***3.2***	***1.3***	
Trisomy 21 (Down syndrome)	279	326	605	
	7.1	***32.6***	***12.3***	
Total live births	**393,781**	**99,899**	**493,824**	**7**

Notes
1. Data for this condition begin in 2017.
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 cases with the codes for atresia of aorta (Q25.2) or other congential malformations of aorta (Q25.4) until 02/02/2020. Starting on 02/03/2020 cases were identified using the code for interruption of aortic arch (Q25.21).
4. Data for this condition exclude cases with codes reported for tetralogy of Fallot (Q21.3) and cases with codes reported for pulmonary valve atresia with ventricular septal defect (both Q22.0 and Q21.0).
5. Data for this condition include cases with codes reported for tetralogy of Fallot (Q21.3) and cases with codes reported for pumonary valve atresia with ventricular septal defect (both Q22.0 and Q21.0).
6. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.
7. Data for total live births include unknown gender.

General comments
*Data for totals include unknown and/or other.
-Data for all conditions include possible/probable diagnoses.

Washington

Birth Defects Counts and Prevalence 2016 - 2020 (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	<10	<10	<10	<10	0 ***0.0***	14 ***0.3***	
Cleft lip alone	79 ***3.2***	<10	21 ***2.6***	<10	<10	119 ***2.8***	
Cleft lip with cleft palate	100 ***4.1***	<10	34 ***4.2***	15 ***3.1***	<10	174 ***4.0***	
Cleft palate alone	127 ***5.2***	<10	39 ***4.8***	22 ***4.5***	<10	212 ***4.9***	
Gastroschisis	68 ***2.8***	<10	39 ***4.8***	<10	<10	136 ***3.1***	
Hypospadias	679 ***54.6***	57 ***58.8***	110 ***26.7***	58 ***23.0***	<10	971 ***44.0***	1
Limb deficiencies (reduction defects)	50 ***2.1***	<10	10 ***1.2***	<10	<10	79 ***1.8***	
Omphalocele	46 ***1.9***	<10	10 ***1.2***	<10	<10	70 ***1.6***	
Spina bifida without anencephalus	52 ***2.1***	<10	24 ***3.0***	<10	<10	98 ***2.3***	
Trisomy 21 (Down syndrome)	264 ***10.8***	31 ***16.3***	150 ***18.6***	30 ***6.1***	<10	529 ***12.2***	
Total live births	**243,672**	**18,993**	**80,719**	**48,969**	**5,525**	**432,205**	**2**
Male live births	**124,291**	**9,693**	**41,162**	**25,216**	**2,755**	**220,679**	

Washington

Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	131	<10	136	
	3.8		***3.1***	
Trisomy 21 (Down syndrome)	235	293	529	
	6.9	***32.6***	***12.2***	
Total live births	**342,175**	**89,954**	**432,205**	**2**

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 total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

West Virginia

Birth Defects Counts and Prevalence 2016 - 2020 (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	14	2	0	0	0	17	
	1.7	***7.6***	***0.0***	***0.0***	***0.0***	***2.0***	
Anophthalmia/microphthalmia	4	0	0	0	0	4	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Anotia/microtia	8	1	0	0	0	9	
	1.0	***3.8***	***0.0***	***0.0***	***0.0***	***1.0***	
Aortic valve stenosis	11	0	0	0	0	11	
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Atrial septal defect	1,371	78	30	5	3	1,503	
	170.7	***295.9***	***174.9***	***68.7***	***256.4***	***174.0***	
Atrioventricular septal defect (Endocardial cushion defect)	13	1	0	0	0	14	
	1.6	***3.8***	***0.0***	***0.0***	***0.0***	***1.6***	
Biliary atresia	7	1	0	0	0	8	
	0.9	***3.8***	***0.0***	***0.0***	***0.0***	***0.9***	
Bladder exstrophy	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Choanal atresia	14	0	0	0	0	14	
	1.7	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Cleft lip alone	35	0	0	0	0	35	
	4.4	***0.0***	***0.0***	***0.0***	***0.0***	***4.1***	
Cleft lip with cleft palate	36	0	1	0	0	37	
	4.5	***0.0***	***5.8***	***0.0***	***0.0***	***4.3***	
Cleft palate alone	71	1	1	1	1	75	
	8.8	***3.8***	***5.8***	***13.7***	***85.5***	***8.7***	
Cloacal exstrophy	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	173	17	3	0	1	196	
	21.5	***64.5***	***17.5***	***0.0***	***85.5***	***22.7***	
Coarctation of the aorta	38	1	0	0	0	39	
	4.7	***3.8***	***0.0***	***0.0***	***0.0***	***4.5***	
Common truncus (truncus arteriosus)	1	0	0	0	1	2	
	0.1	***0.0***	***0.0***	***0.0***	***85.5***	***0.2***	
Congenital cataract	10	1	0	0	0	11	
	1.2	***3.8***	***0.0***	***0.0***	***0.0***	***1.3***	
Congenital posterior urethral valves	4	2	0	0	0	6	1
	1.0	***15.0***	***0.0***	***0.0***	***0.0***	***1.4***	
Craniosynostosis	63	1	1	1	0	66	
	7.8	***3.8***	***5.8***	***13.7***	***0.0***	***7.6***	
Deletion 22q11.2	4	0	0	0	0	4	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Diaphragmatic hernia	8	1	0	0	0	9	
	1.0	***3.8***	***0.0***	***0.0***	***0.0***	***1.0***	
Double outlet right ventricle	11	0	0	0	0	11	
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Ebstein anomaly	11	0	0	0	0	11	
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Encephalocele	14	1	1	0	0	16	
	1.7	***3.8***	***5.8***	***0.0***	***0.0***	***1.9***	
Esophageal atresia/tracheoesophageal fistula	22	0	0	0	0	22	
	2.7	***0.0***	***0.0***	***0.0***	***0.0***	***2.5***	
Gastroschisis	31	3	0	0	0	34	
	3.9	***11.4***	***0.0***	***0.0***	***0.0***	***3.9***	
Holoprosencephaly	11	0	0	0	0	11	
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Hypoplastic left heart syndrome	9	1	0	1	0	11	
	1.1	***3.8***	***0.0***	***13.7***	***0.0***	***1.3***	
Hypospadias	247	10	5	3	0	270	1
	60.0	***75.1***	***56.9***	***71.6***	***0.0***	***61.0***	
Interrupted aortic arch	8	0	0	0	1	9	
	1.0	***0.0***	***0.0***	***0.0***	***85.5***	***1.0***	
Limb deficiencies (reduction defects)	34	0	1	0	0	35	
	4.2	***0.0***	***5.8***	***0.0***	***0.0***	***4.1***	
Omphalocele	10	3	0	0	0	14	
	1.2	***11.4***	***0.0***	***0.0***	***0.0***	***1.6***	
Pulmonary valve atresia and stenosis	67	3	1	0	0	71	
	8.3	***11.4***	***5.8***	***0.0***	***0.0***	***8.2***	

West Virginia

Birth Defects Counts and Prevalence 2016 - 2020 (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**
Pulmonary valve atresia	11	0	1	0	0	12	
	1.4	***0.0***	***5.8***	***0.0***	***0.0***	***1.4***	
Rectal and large intestinal atresia/stenosis	40	1	0	0	0	42	
	5.0	***3.8***	***0.0***	***0.0***	***0.0***	***4.9***	
Renal agenesis/hypoplasia	59	0	0	0	0	59	
	7.3	***0.0***	***0.0***	***0.0***	***0.0***	***6.8***	
Single ventricle	13	1	0	0	0	14	
	1.6	***3.8***	***0.0***	***0.0***	***0.0***	***1.6***	
Small intestinal atresia/stenosis	22	2	1	0	0	25	
	2.7	***7.6***	***5.8***	***0.0***	***0.0***	***2.9***	
Spina bifida without anencephalus	23	0	0	0	0	24	
	2.9	***0.0***	***0.0***	***0.0***	***0.0***	***2.8***	
Tetralogy of Fallot	43	0	0	0	1	44	
	5.4	***0.0***	***0.0***	***0.0***	***85.5***	***5.1***	
Total anomalous pulmonary venous connection	5	0	0	0	0	5	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Transposition of the great arteries (TGA)	16	0	0	0	0	16	
	2.0	***0.0***	***0.0***	***0.0***	***0.0***	***1.9***	
Dextro-transposition of great arteries (d-TGA)	16	0	0	0	0	16	
	2.0	***0.0***	***0.0***	***0.0***	***0.0***	***1.9***	
Tricuspid valve atresia and stenosis	9	0	0	0	0	9	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	
Tricuspid valve atresia	9	0	0	0	0	9	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	
Trisomy 13	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Trisomy 18	14	1	0	0	0	15	
	1.7	***3.8***	***0.0***	***0.0***	***0.0***	***1.7***	
Trisomy 21 (Down syndrome)	72	4	2	1	0	81	
	9.0	***15.2***	***11.7***	***13.7***	***0.0***	***9.4***	
Turner syndrome	6	1	0	0	0	7	2
	1.5	***7.7***	***0.0***	***0.0***	***0.0***	***1.7***	
Ventricular septal defect	360	12	4	1	2	382	
	44.8	***45.5***	***23.3***	***13.7***	***170.9***	***44.2***	
Total live births	**80,320**	**2,636**	**1,715**	**728**	**117**	**86,369**	
Male live births	**41,156**	**1,331**	**878**	**419**	**60**	**44,239**	
Female live births	**39,165**	**1,304**	**836**	**394**	**58**	**42,130**	

West Virginia
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	33	1	34	
	4.3	***1.0***	***3.9***	
Trisomy 13	1	0	1	
	0.1	***0.0***	***0.1***	
Trisomy 18	11	4	15	
	1.4	***4.0***	***1.7***	
Trisomy 21 (Down syndrome)	56	25	81	
	7.3	***24.7***	***9.4***	
Total live births	**76,253**	**10,116**	**86,369**	

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. Prevalance is calculated per 10,000 female live births.

General comments
*Data for totals include unknown and/or other.
-Data for all conditions include probable cases.

Department of Defense
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	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	3	7	2	0	34	
	0.6	***0.4***	***0.9***	***0.7***	***0.0***	***0.6***	
Anophthalmia/microphthalmia	58	11	15	2	1	89	
	1.8	***1.4***	***2.0***	***0.7***	***1.3***	***1.7***	
Anotia/microtia	103	16	32	12	3	176	
	3.1	***2.1***	***4.3***	***4.4***	***3.9***	***3.3***	
Aortic valve stenosis	128	9	25	3	2	175	
	3.9	***1.2***	***3.3***	***1.1***	***2.6***	***3.3***	
Atrial septal defect	5,481	1,325	1,200	376	125	8,818	1
	165.4	***172.0***	***160.7***	***138.3***	***163.1***	***164.1***	
Atrioventricular septal defect (Endocardial cushion defect)	244	34	43	22	8	367	2
	7.4	***4.4***	***5.8***	***8.1***	***10.4***	***6.8***	
Biliary atresia	97	36	32	13	0	185	
	2.9	***4.7***	***4.3***	***4.8***	***0.0***	***3.4***	
Bladder exstrophy	5	3	1	0	0	10	
	0.2	***0.4***	***0.1***	***0.0***	***0.0***	***0.2***	
Choanal atresia	80	19	16	6	2	127	
	2.4	***2.5***	***2.1***	***2.2***	***2.6***	***2.4***	
Cleft lip alone	218	21	25	21	10	303	
	6.6	***2.7***	***3.3***	***7.7***	***13.0***	***5.6***	
Cleft lip with cleft palate	224	31	43	27	9	348	
	6.8	***4.0***	***5.8***	***9.9***	***11.7***	***6.5***	
Cleft palate alone	389	55	70	38	10	583	
	11.7	***7.1***	***9.4***	***14.0***	***13.0***	***10.8***	
Cloacal exstrophy	3	1	0	0	0	5	
	0.1	***0.1***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	935	176	197	49	18	1,424	
	28.2	***22.8***	***26.4***	***18.0***	***23.5***	***26.5***	
Coarctation of the aorta	320	65	68	14	12	497	
	9.7	***8.4***	***9.1***	***5.1***	***15.7***	***9.2***	
Common truncus (truncus arteriosus)	40	5	6	1	4	57	
	1.2	***0.6***	***0.8***	***0.4***	***5.2***	***1.1***	
Congenital cataract	117	33	26	7	1	193	
	3.5	***4.3***	***3.5***	***2.6***	***1.3***	***3.6***	
Congenital posterior urethral valves	54	17	7	3	0	83	3
	3.2	***4.3***	***1.8***	***2.1***	***0.0***	***3.0***	
Craniosynostosis	1,002	156	182	68	21	1,480	
	30.2	***20.3***	***24.4***	***25.0***	***27.4***	***27.5***	
Deletion 22q11.2	62	6	11	2	0	83	
	1.9	***0.8***	***1.5***	***0.7***	***0.0***	***1.5***	
Diaphragmatic hernia	110	29	32	12	6	193	
	3.3	***3.8***	***4.3***	***4.4***	***7.8***	***3.6***	
Double outlet right ventricle	92	21	22	7	5	154	
	2.8	***2.7***	***2.9***	***2.6***	***6.5***	***2.9***	
Ebstein anomaly	47	7	8	4	2	71	
	1.4	***0.9***	***1.1***	***1.5***	***2.6***	***1.3***	
Encephalocele	35	8	5	4	1	57	
	1.1	***1.0***	***0.7***	***1.5***	***1.3***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	102	19	18	6	1	150	
	3.1	***2.5***	***2.4***	***2.2***	***1.3***	***2.8***	
Gastroschisis	137	38	45	11	4	240	
	4.1	***4.9***	***6.0***	***4.0***	***5.2***	***4.5***	
Holoprosencephaly	24	12	4	1	0	43	
	0.7	***1.6***	***0.5***	***0.4***	***0.0***	***0.8***	
Hypoplastic left heart syndrome	146	25	29	7	5	222	
	4.4	***3.2***	***3.9***	***2.6***	***6.5***	***4.1***	
Hypospadias	2,000	432	331	122	38	3,031	3
	117.1	***109.5***	***86.6***	***86.2***	***98.4***	***109.6***	
Interrupted aortic arch	117	21	21	4	4	176	
	3.5	***2.7***	***2.8***	***1.5***	***5.2***	***3.3***	
Limb deficiencies (reduction defects)	201	53	37	11	1	312	
	6.1	***6.9***	***5.0***	***4.0***	***1.3***	***5.8***	
Omphalocele	61	18	11	4	0	97	4
	1.8	***2.3***	***1.5***	***1.5***	***0.0***	***1.8***	
Pulmonary valve atresia and stenosis	448	147	114	31	6	773	
	13.5	***19.1***	***15.3***	***11.4***	***7.8***	***14.4***	

Department of Defense
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	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**
Pulmonary valve atresia	22	4	7	4	0	39	
	0.7	***0.5***	***0.9***	***1.5***	***0.0***	***0.7***	
Rectal and large intestinal atresia/stenosis	160	32	49	12	7	274	
	4.8	***4.2***	***6.6***	***4.4***	***9.1***	***5.1***	
Renal agenesis/hypoplasia	265	57	50	22	7	414	
	8.0	***7.4***	***6.7***	***8.1***	***9.1***	***7.7***	
Single ventricle	91	13	16	5	2	132	
	2.7	***1.7***	***2.1***	***1.8***	***2.6***	***2.5***	
Small intestinal atresia/stenosis	146	38	37	17	1	243	
	4.4	***4.9***	***5.0***	***6.3***	***1.3***	***4.5***	
Spina bifida without anencephalus	161	18	27	5	4	218	
	4.9	***2.3***	***3.6***	***1.8***	***5.2***	***4.1***	
Tetralogy of Fallot	222	53	37	20	8	349	
	6.7	***6.9***	***5.0***	***7.4***	***10.4***	***6.5***	
Total anomalous pulmonary venous connection	40	4	11	2	1	59	
	1.2	***0.5***	***1.5***	***0.7***	***1.3***	***1.1***	
Transposition of the great arteries (TGA)	132	21	24	8	4	201	
	4.0	***2.7***	***3.2***	***2.9***	***5.2***	***3.7***	
Dextro-transposition of great arteries (d-TGA)	129	19	23	8	4	195	
	3.9	***2.5***	***3.1***	***2.9***	***5.2***	***3.6***	
Tricuspid valve atresia and stenosis	44	17	10	5	1	80	5
	1.3	***2.2***	***1.3***	***1.8***	***1.3***	***1.5***	
Trisomy 13	37	18	7	5	0	67	
	1.1	***2.3***	***0.9***	***1.8***	***0.0***	***1.2***	
Trisomy 18	63	17	16	7	0	105	
	1.9	***2.2***	***2.1***	***2.6***	***0.0***	***2.0***	
Trisomy 21 (Down syndrome)	495	97	97	36	9	755	
	14.9	***12.6***	***13.0***	***13.2***	***11.7***	***14.0***	
Turner syndrome	56	9	12	4	0	82	6
	3.5	***2.4***	***3.3***	***3.1***	***0.0***	***3.1***	
Ventricular septal defect	2,659	490	554	174	72	4,102	7
	80.2	***63.6***	***74.2***	***64.0***	***93.9***	***76.3***	
Total live births	**331,356**	**77,035**	**74,676**	**27,185**	**7,664**	**537,369**	
Male live births	**170,757**	**39,466**	**38,217**	**14,149**	**3,863**	**276,511**	
Female live births	**160,599**	**37,569**	**36,459**	**13,036**	**3,801**	**260,858**	

Department of Defense
Birth Defects Counts and Prevalence 2016 - 2020 (Prevalence per 10,000 Live Births)

	Maternal Age (Years)			
Defect	**Less than 35**	**35+**	**Total***	**Notes**
Gastroschisis	212	4	240	
	4.7	***0.6***	***4.5***	
Trisomy 13	38	24	67	
	0.8	***3.5***	***1.2***	
Trisomy 18	65	36	105	
	1.4	***5.3***	***2.0***	
Trisomy 21 (Down syndrome)	428	292	755	
	9.5	***43.0***	***14.0***	
Total live births	**449,599**	**67,905**	**537,369**	

Notes
1. Data for this condition include patent foramen ovale.
2. Data for this condition include inlet ventricular septal defect.
3. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
4. Data for this condition are based on the following criteria: one diagnosis from inpatient records during the first month of life.
5. Data for this condition include cases with tricuspid stenosis or hypoplasia.
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 inlet ventricular septal defect and probable ventricular septal defect.

General comments
*Data for totals include unknown and/or other.
-Data for all conditions are based on the following criteria unless otherwise specified: one diagnosis from institutional records, or two diagnoses from professional encounter records from different dates.
-Data for all conditions exclude infants that appear as multiples of same gender.
†Race/ethnicity for the Department of Defense Birth and Infant Health Research (BIHR) program is based on the military parent through whom the infant receives military health care benefits. This may be the infant's mother or father. The BIHR program does not account for multiple races.

PROGRAM DIRECTORY

Alabama

Alabama Birth Defects Surveillance Program (ABDSP)

Purpose: Data collection to analyze trends, promote awareness, and reduce infant mortality related to birth defects, and connect families to services
Partner: Hospitals, Office of Informatics & Data Analytics
Program status: Program has not started collecting data
Start year: Anticipated 2023
Earliest year of available data: N/A
Organizational location: Bureau of Clinical Laboratories (BCL)
Population covered annually: 58,000
Statewide: Yes
Current legislation or rule: The Notifiable Disease Administrative Code, Chapter 420-4-1, is in the process of adding birth defects to the AL notifiable diseases rule.

Case Definition
Outcomes covered: Major birth defects starting at 30 days of diagnosis
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: N/A
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without chart abstraction for case validation
Delivery hospitals: ECR
Pediatric & tertiary care hospitals: eCR
Other sources: Reports from health care providers

Case Ascertainment
Conditions warranting chart review in newborn period: Not applicable
Coding: ICD-10-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Tests and procedures, Birth defect diagnostic information

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: ALNBS (Alabama NEDSS Base System)

Data Analysis
Data analysis software: To be determined
Data use and analysis: Routine statistical monitoring, Baseline rates, Referral, Education/public awareness, Prevention projects

Funding
Funding source: 100% General state funds

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Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start year: 1996
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health)
Population covered annually: 9,500
Statewide: Yes
Current legislation or rule: 7 AAC 27.012
Legislation year enacted: 1996

Case Definition
Outcomes covered: Selected major birth defects based on ICD-10-CM code list
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Birth to third birthday
Residence: In and out of state births to Alaska residents

Surveillance Methods
Case ascertainment: Passive case-finding with limited case confirmation
Vital records: Birth certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Genetics clinics, specialty clinics (heart, cleft lip/palate, neurodevelopmental), Maternal Child Death Review (MCDR), public health nursing, Alaska Dept. of Behavioral Health (AKAIMS)
Delivery hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Pediatric & tertiary care hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Third party payers: Medicaid databases, Indian health services, Private health insurers
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Physician reports, Alaska Health Information Exchange, AK AIMS (Alaska Dept. of Behavioral Health)

Case Ascertainment
Conditions warranting chart review in newborn period: All Codes included in the current NBDPN list of birth defects listing (see: https://nbdpn.org/docs/Appendix_3_1_BirthDefectsDescriptions_2021MAR12_Rev.pdf) are sampled for review. Other collected conditions/codes will are sampled and reviewed based upon incoming requests and/or need.
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.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), 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.)
Database collection and storage: Access

Data Analysis
Data analysis software: R
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiological studies (using only program data), Needs assessment, Grant proposals, Education/public awareness

System Integration
System links: Link case finding data to final birth file
System integration: No.

Funding
Funding source: 20% General state funds, 80% MCH funds

Other
Web site:
https://health.alaska.gov/dph/wcfh/pages/mchepi/abdr/default.aspx
Surveillance reports on file:
Https://health.alaska.gov/dph/wcfh/Pages/mchepi/abdr/Data_Reports.aspx
Additional information on file:
1)https://health.alaska.gov/dph/wcfh/Documents/mchepi/abdr/Data%20Analysis%20Methods_v2.1.pdf
2)https://health.alaska.gov/dph/wcfh/Documents/mchepi/abdr/Data%20Collection%20Methods_v2.1.pdf

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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services
Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1986
Organizational location: Department of Health (Informatics/Business Intelligence Office)
Population covered annually: 87,000
Statewide: Yes
Current legislation or rule: Legislation enacted 1988; Rule effective 1991 Statute: 36-133; Rule: Arizona Administrative Code R9-4-Article 5
Legislation year enacted: 1988

Case Definition
Outcomes covered: Major birth defects, and those found to be significant in Arizona.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Any gestational age or weight if a fetal death certificate was issued), Elective terminations (If fetal death certificate was issued and medical records are available)
Age: Up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review, then the more precise diagnosis and information is used.
Residence: Arizona birth to an Arizona resident mother

Surveillance Methods
Case ascertainment: Active Case Finding, Passive case-finding with case confirmation
Vital records: Birth certificates, Death certificates, Fetal birth certificate, Hospital Discharge Database
Other state based registries: Newborn Screening pulse oximetry/CCHD screening results
Delivery hospitals: Disease index or discharge index, Mandated follow up forms submitted for failed CCHD screenings
Pediatric & tertiary care hospitals: Disease index or discharge index
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Midwifery Facilities, Physician reports

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 prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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
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, Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electonic file/report filled out by staff at ADHS
Database collection and storage: Access, Oracle

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, Clinical review, 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, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, We have provided data to environmental programs for their pages and databases

Funding
Funding source: 10% General state funds, 15% MCH funds, 73% CDC grant, 2% Other federal funding (non-CDC grants)

Other
Web site:
https://www.azdhs.gov/preparedness/public-health-statistics/prevention-month/index.php and
https://www.azdhs.gov/preparedness/public-health-statistics/birth-defects-monitoring/index.php
Surveillance reports on file: Annual Reports;
Additional information on file: Arizona Data/Fact Sheets; Resources
Other comments: To contact the ABDMP email abdmp@azdhs.gov

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Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Legislators
Program status: Currently collecting data
Start year: 1980
Earliest year of available data: 1980
Organizational location: Arkansas Children's Hospital
Population covered annually: 36,000
Statewide: Yes
Current legislation or rule: Acts 1985, No. 214
Legislation year enacted: 1985

Case Definition
Outcomes covered: Major congenital malformations, 740.000-759.990 (ICD10: Q00.0-Q99.9), plus select others outside this range in live birth, stillbirth, and terminations. All traceable stillbirths without birth defects are collected as well.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: Birth to second birthday
Residence: In and out of state births to Arkansas residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Stillbirth records
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Physician reports

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 prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: 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, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access, MS SQL Server

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, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link case finding data to final birth file
System integration: No.

Funding
Funding source: 100% General state funds

Other
Web site:
https://www.archildrens.org/research/research-programs-and-centers/arkansas-reproductive-health-monitoring-system/arhms

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California

California Birth Defects Monitoring Program (CBDMP)

Purpose: Surveillance, Research, Rapid response to emerging threats to pregnant women and their fetus/infants
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Universities, Additional California State Agencies
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: Department of Health (Genetic Disease Screening Program/ Center for Family Health/ California Department of Public Health)
Population covered annually: 130,000
Statewide: No, CBDMP currently monitors a ten-county subset of California births that are demographically similar to the state as a whole and whose birth defects rates and trends have been reflective of those throughout California. Furthermore, CBDMP has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.
Current legislation or rule: California Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1996
Legislation year enacted: 1982

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages, Casefind all and only report if co-occurring reportable defect indicated), Elective terminations (All gestational ages, Only if reportable defect indicated)
Age: One year
Residence: In-state births to residents of counties monitored by CBDMP

Surveillance Methods
Case ascertainment: Active Case Finding
Delivery hospitals: Disease index or discharge index
Pediatric & tertiary care hospitals: Disease index or discharge index
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic 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 chart with selected procedure codes, 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, Failure to thrive, 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-modified BPA codes, further modified for use in CA

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
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: SQL server

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, 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, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, link registry to final vital records birth, fetal death, death and birth cohort files

Funding
Funding source: 100% Other (Fee-based Special Funds)

Other
Web site:
https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/default.aspx
Surveillance reports on file: California-specific birth defect data available: select defect-specific data sheets, annual surveillance report, and county-level estimates
Additional information on file: Please send inquiries to gdspcbdmp@cdph.ca.gov

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Centers for Disease Control and Prevention (Metropolitan Atlanta Congenital Defects Program)

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Laboratories, Prenatal Diagnostic Providers
Program status: Currently collecting data
Start year: 1967
Earliest year of available data: 1968
Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities
Population covered annually: 35000
Statewide: No, Births to mothers residing within one of three central counties in the metropolitan Atlanta area of the state of Georgia

Case Definition
Outcomes covered: All major structural and genetic birth defects
Pregnancy outcome: Livebirths (>=20 weeks), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: Before 6 years of age
Residence: Births to mothers residing in one of three central metropolitan Atlanta counties

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Induction logs and miscarriage logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories

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), Infants with low birth weight or low gestation (Birth weight < 2500 grams and/or 20-36 weeks gestation), All stillborn infants, All elective abortions, All neonatal deaths, All infants in NICU or special care nursery, All infants with low APGAR scores, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codable defect
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, 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.), 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, SQL Server, SAS, Excel

Data Analysis
Data analysis software: SPSS, SAS, Access, Excel
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, 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, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Education/public awareness, Prevention projects, Survival analysis

System Integration
System links: Link case finding data to final birth file, National Death Index; Death and Fetal Death Records; Laboratory Records

Funding
Funding source: 100% Other (Intramural CDC funding)

Other
Web site: https://www.cdc.gov/ncbddd/birthdefects/research.html
Surveillance reports on file: MACDP 40th Anniversary Surveillance Report
Additional information on file: CDC/BPA Defect Code; Including prenatal diagnoses in BD monitoring
Other comments: The 40th Anniversary Surveillance Report was published:Correa A, Cragan JD, Kucik JE, et al. Reporting birth defects surveillance data 1968-2003. Birth Defects Research Part A. 2007;79(2):65-186.

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Colorado

Colorado Responds to Children with Special Needs Section (CRCSN)

Purpose: Surveillance
Partner: Local Health Departments, Universities
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Vital Statistics, Center for Health and Environmental Data (CHED))
Population covered annually: 63,455(2018)
Statewide: Yes
Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101.25-1.5-105
Legislation year enacted: 1985

Case Definition
Outcomes covered: Structural birth defects, fetal alcohol syndrome,selected genetic and metabolic disorders; muscular dystrophy;selected developmental disabilities; very low birth weight (less than 1500 grams);others with medical risk factors for developmental delay.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages, Less than 20 weeks gestation, 20 weeks gestation and greater)
Age: Up to the 5th birthday (up to 10th birthday for fetal alcohol syndrome)
Residence: Events occurring in-state- or out-of-state Colorado residents

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates, Fetal birth certificate
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Specialty outpatient clinics

Case Ascertainment
Coding: ICD-9-CM/ICD-10-CM, Program specific 'extended' code for added detail: 9CM and 10CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.)
Mother: Identification information (name, address, date-of-birth, etc.), Gravidity/parity, 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.), 99% of data are collected in electronic format
Database collection and storage: SQL-web based

Data Analysis
Data analysis software: SAS
Quality assurance: Timeliness, Records linkage and de-duplication
Data use and analysis: Environmental Studies

System Integration
System links: Link to other state registries/databases, Link to environmental databases

Funding
Funding source: 70% General state funds, 30% Service fees

Other
Web site: http://www.cdphe.state.co.us

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Connecticut

Connecticut Birth Defects Registry (CT BDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Reporting for MCH Block Grant
Partner: Local Health Departments, Hospitals, Advocacy Groups, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 37,000
Statewide: Yes
Current legislation or rule: Section 19a-53 (Formerly Sec. 19-21) of the general statutes was replaced (Effective October 1, 2017)
Legislation year enacted: 2017

Case Definition
Outcomes covered: All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71 (prior to ICD10 implementation still in the system although can no longer be selected). ICD10 codes include the entire Q series as well as some recommended by CDC in the provided crosswalk. Also Zika associated birth defects including those in ICD10 H series are included.
Pregnancy outcome: Livebirths (All gestational ages and birth weights, PDA = to 2500 gms birth weight)
Age: Up to one year after delivery for birth defects, but reported up to age 5
Residence: All in-state births are reported but reporting is done on in-state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, inpatient hospitalizations and emergency room visits
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Reports from health care professionals in newborn nurseries and NICUs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Reports from health care professionals in pediatric inpatient and outpatient services planned for future
Other sources: Midwifery Facilities, Physician reports, Mandatory reporting by health care providers and facilities; CYSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment
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, 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: 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 scanning of printed records
Database collection and storage: Web based database

Data Analysis
Data analysis software: SAS, Access, Excel
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Time trends, Epidemiological studies (using only program data), Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Provider education

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: We are integrated with Newborn Screening and Early Hearing and Detection Intervention Program. Vital Records electronically imports in Maven Newborn Screening System (NSS). This database is also linked to Childhood Lead Program, Children with Special Health Care Needs and Family Wellness Healthy Start.

Other
Web site:
https://portal.ct.gov/DPH/Family-Health/Birth-Defects-Registry/Connecticut-Birth-Defects-Registry
Surveillance reports on file: NBDPN annual reports, state profiles

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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. (20 weeks gestation and greater, In the absence of gestational age, greater than 350 grams), Elective terminations (20 weeks gestation and greater, In the absence of gestational age, greater than 350 grams)
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, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry
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, Laboratory logs, Cardiac catheterization laboratories, 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 elective abortions, All neonatal deaths, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, GI condition (e.g. intestinal blockage), 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, SAS, Excel
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
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), Identification of potential cases for other epidemiologic studies, Needs assessment, Education/public awareness

Funding

Funding source: 50% General state funds, 50% 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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Department of Defense

United States (US) Department of Defense (DoD) Birth and Infant Health Research (BIHR) Program (BIHR)

Purpose: Surveillance, Research
Partner: Hospitals, Universities, Other DoD Programs
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1998; data for formal analysis beginning with 2001
Organizational location: Deployment Health Research Department, Naval Health Research Center
Population covered annually: Approximately 100,000 per year
Statewide: No, National/Worldwide; includes all DoD beneficiaries
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum
Legislation year enacted: 1998

Case Definition
Outcomes covered: Outcomes include those birth defects listed in the case definition of the National Birth Defects Prevention Network. For a birth defect to be represented, the diagnosis must appear at least once in an inpatient record, or at least twice on two separate dates for outpatient encounters. Cases of omphalocele are limited to those diagnosed in an inpatient record in the first month of life. Same sex multiples are excluded from analysis.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Birth up to one year after delivery.
Residence: Worldwide; any birth to a US military beneficiary.

Surveillance Methods
Case ascertainment: Active Case Finding, Passive case-finding with case confirmation, Passive case-finding without case confirmation, Electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries at both civilian and military care facilities.
Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, All inpatient and outpatient encounters at both civilian and military care facilities are captured in standardized DoD data.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, All inpatient and outpatient encounters at both civilian and military care facilities are captured in standardized DoD data.
Third party payers: All inpatient and outpatient encounters at both civilian and military care facilities are captured in standardized DoD data.
Other sources: Validation of standardized electronic data performed by chart review of a random sample of births from military care 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, Validation of standardized electronic data performed by chart review of a random sample of births from military care facilities.
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM/ICD-10-CM, The BIHR program assesses outcomes through the first year of life.

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.), 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

Data Collection Methods and Storage
Data collection: Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, SAS

Data Analysis
Data analysis software: SAS
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, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Grant proposals, Prevention projects, Monitor birth defect outcomes following specific parental or gestational exposures of concern.

System Integration
System links: DoD databases
System integration: DoD databases

Funding
Funding source: 100% Other federal funding (non-CDC grants)

Other
Web site:
https://www.med.navy.mil/Naval-Medical-Research-Command/R-D-Commands/Naval-Health-Research-Center/Core-Research/Military-Population-Health/DOD-BIRTH-AND-INFANT-HEALTH-RESEARCH/
Surveillance reports on file: DoD/Health Affairs policy memorandum; annual reports

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District of Columbia

Program status: No surveillance program

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Florida

Florida Birth Defects Registry (FBDR)

Purpose: Surveillance, Research, Educate health care professionals, women of childbearing age and general public about birth defects.
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators, Federal and state agencies
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: Department of Health (Epidemiology/Environment), University
Population covered annually: 210,581 in 2020
Statewide: Yes
Current legislation or rule: Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added to the list in July 1999.
Legislation year enacted: 1999

Case Definition
Outcomes covered: Major structural malformations and genetic disorders
Pregnancy outcome: Livebirths (20 weeks gestation and greater)
Age: Until age 1
Residence: Florida

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation, FL has one CDC funded cooperative agreement which use active case ascertainment which is linked to the passive surveillance program.
Vital records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs
Delivery hospitals: Disease index or discharge index
Pediatric & tertiary care hospitals: Disease index or discharge index

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)
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, 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, 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 submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Dedicated server for birth defects data

Data Analysis
Data analysis software: SAS, SQL, dBASE
Quality assurance: Validity checks, Re-abstraction of cases, Comparison/verification between multiple data sources, 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, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Maternal linked file.
System integration: The department has created a maternally linked file beginning with 1998. The birth defects data has been included in this linked file.Birth defects data are displayed on the department's Environmental Public Health Tracking Program site (www.floridatracking.com) and the Florida Community Health Assessment Resource Tool Set (www.flhealthcharts.com)

Funding
Funding source: 75% General state funds, 25% CDC grant

Other
Web site:
http://www.floridahealth.gov/diseases-and-conditions/birth-defects/index.html
Surveillance reports on file: Publications, procedure manuals, electronic case ascertainment database and educational materials
Other comments: CDC/NCBDDD Cooperative Agreement for enhanced surveillance of selected birth defects, referral for services and prevention activities.

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Georgia

Georgia Birth Defects Registry (GBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 2018
Earliest year of available data: 2016-2017 for Zika-associated birth defects
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 126,001 live births in 2022.
Statewide: Yes
Current legislation or rule: Birth defects are reportable under State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2, which mandates the reporting of notifiable diseases and newborn hearing screening.
Legislation year enacted: Updated in 2003.

Case Definition
Outcomes covered: NBDPN core, recommended, and extended birth defects; Zika-associated birth defects per CDC guidelines, June 2017.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to six years of age, per Georgia law.
Residence: In- and out-of-state births to state residents.

Surveillance Methods
Case ascertainment: Active Case Finding, Passive case-finding with case confirmation, Passive case-finding without case confirmation, MACDP performs active case-finding and shares these data for inclusion into the Birth Defects Registry; 2016-2017 Zika-associated birth defects (ZABDs) have been confirmed; all other reported cases with a date of birth from January 1, 2020 and onward will be confirmed.
Vital records: Birth certificates, Death certificates, Fetal death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Zika Active Monitoring System, hospital line lists (Georgia Birth Defects Reporting and Information System (GBDRIS)), Early Hearing Detection and Intervention (EHDI) for hearing loss, early intervention services central intake (Children 1st, C1st). Program for CWSN refers to Children's Medical Services (CMS).
Delivery hospitals: Hospital line lists (GBDRIS)
Pediatric & tertiary care hospitals: Early intervention services central intake (Children 1st [C1st]); HL7 reporting from Children's Healthcare of Atlanta (CHOA), the largest pediatric health system in Georgia.
Other sources: Georgia Health Information Network (state HIE), Metropolitan Atlanta Congenital Defects Program (MACDP).

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 birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), ZABDs born during 2016-2017; 2020 and onward, all NBDPN conditions with <500 cases reported in a 12 month period (i.e., hypospadias, ASD, and VSD are not confirmed at this time).
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, 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, Pregnancy/delivery complications, Family history

Data Collection Methods and Storage
Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Cases can be reported directly by fax or submitted through an online case report form; case data may be identified through flags and free text on Vital Records and Newborn Screening records (NBS-CCHD and EHDI) or ascertained through passive reporting of line lists from select birthing hospitals (GBDRIS, CMS, MACDP) to our web-based SSH File Transfer Protocol (SFTP).
Database collection and storage: Oracle

Data Analysis
Data analysis software: SAS, Excel, Microsoft 365.
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness, As a part of Zika birth defect surveillance, all direct reports, electronic birth certificates, and passive line list cases were confirmed through medical record review and abstraction, and submitted to CDC-Zika Birth Defects Surveillance. Case confirmation will be employed for all NBDPN-reportable defects with a date of January 1, 2020 and onward. Records are reviewed for validity of reported defects. Quality assurance processes for validity and completeness will be automated once the web-based Birth Defects Registry (BDR) is active.
Data use and analysis: Public health program evaluation, Baseline rates, Monitoring outbreaks and cluster investigations, Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals

System Integration
System links: The BDR is linked to several internal surveillance and screening systems: Zika Active Monitoring System (lab and clinical data), which includes the Zika Pregnancy Registry (CDC initiative); Newborn Screening for critical congenital heart disease (CCHD) and Early Hearing Detection and Intervention (EHDI) for hearing loss; daily Vital Records feeds of electronic birth, death, and fetal death certificates; and early intervention services referrals (C1st) and usage (CMS) from providers.
System integration: In addition to the aforementioned internal and/or daily feeds, the BDR receives and matches cases from MACDP, GBDRIS, and CMS at regular intervals (e.g., monthly or quarterly basis). This registry has the capacity to identify and link cases from flagged Vital Records and internal screening sources, hospital line lists with reported birth defect cases, cases directly called in and manually entered into the online case report form, and those submitted regularly by external entities (e.g., MACDP).

Funding
Funding source: 32% MCH funds, 68% CDC grant

Other
Web site: https://dph.georgia.gov/birth-defects
Additional information on file: In Georgia, active surveillance is performed by the Metropolitan Atlanta Congenital Defects Program (MACDP) and is presently the data source for the NBDPN Annual Report. MACDP performs medical record abstraction for all birth defect cases born to mothers who reside within DeKalb, Fulton, and Gwinnett counties at the time of delivery. This catchment area constitutes roughly 27% of all live births in Georgia.
Other comments: The Georgia Department of Public Health (DPH) has constructed a web-based statewide BDR that will capture and link MACDP cases, in addition to those reported directly to DPH, flagged on Vital Records (e.g., electronic birth certificates), or submitted through regular hospital reporting. A procedure manual for the Georgia Birth Defects Registry is available on our website and contains the list of reportable conditions, a codebook for line list reporting, and media for reporting cases to the BDR. Providers interested in reporting birth defects should contact the Birth Defects Registry staff (birthdefects@dph.ga.gov) for more information.

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Hawaii

Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Early Childhood Prevention Programs, Iowa Registry for Congenital and Inherited Disorders
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1986
Organizational location: Department of Health (Children with Special Health Needs Branch)
Population covered annually: 19,000
Statewide: Yes
Current legislation or rule: Hawaii Revised Statutes - sec. 321-421 through 426Hawaii Revised Statutes - sec. 324-41 through 44
Legislation year enacted: 2002

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Up to one year after delivery
Residence: All in-state births

Surveillance Methods
Case ascertainment: Active Case Finding
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic 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 selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)
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, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
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, 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.), Family history

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

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes, Clinical review
Data use and analysis: Public health program evaluation, Rates by demographic and other variables, Epidemiological studies (using only program data)

Funding
Funding source: 100% Other (State Special Funds)

Other
Web site: http://health.hawaii.gov/genetics/programs/hbdhome/

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Idaho

Program status: No surveillance program

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Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Drug-testing laboratories; Departments of Human Services, Health and Family Services, Children and Family Services; Newborn Metabolic Screening Program, Specialized Care for Children, Illinois Maternal Child Health Program
Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 145,000
Statewide: Yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/)77 Illinois Administrative Code 840
Legislation year enacted: 1984; last amended 2022

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to 2 years after delivery
Residence: In and out of state births to state residents

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: Newborn metabolic screening program, Hospital discharge data
Delivery hospitals: Discharge summaries, Reporting from hospital nurseries
Pediatric & tertiary care hospitals: Reporting from hospital nurseries

Case Ascertainment
Conditions warranting chart review in newborn period: 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 prenatally diagnosed or suspected cases, Infants with selected defects noted on a death certificate (up to 2 years of age); any report to the program of a selected defect.
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care
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 submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Purpose-built system linked with Vital Record System

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, Data/hospital audits, Timeliness
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), Needs assessment, Service delivery, Referral, Grant proposals

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Cases are collected in a database that is a module of the Vital Record reporting system. Cases may be initiated from the birth certificate, by hospital staff or by APORS staff. Local community health agencies have access to cases in their jurisdiction for provision of case-management services. APORS cases are also included in the Illinois Healthcare and Family Services Enterprise Data Warehouse where they are available to Illinois' Department of Human Services, Department of Children and Family Services, and Department of Healthcare and Family Services staffs.

Funding
Funding source: 100% General state funds

Other
Web site: http://www.dph.illinois.gov/data-statistics/epidemiology/apors
Surveillance reports on file: Birth Defects and Other Adverse Pregnancy Outcomes in Illinois 2015-2019;Trends in the Prevalence of Birth Defects in Illinois and Chicago 2002-2018
Additional information on file: QC reports, fact sheets

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Indiana

Indiana Birth Defects and Problems Registry (IBDPR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Hospitals, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 2003 birth data is available in 2006
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 83,000
Statewide: Yes
Current legislation or rule: IC 16-38-4Rule 410 IAC 21-3
Legislation year enacted: 2001

Case Definition
Outcomes covered: Major birth defects, genetic disease, fetal alcohol syndrome, neonatal abstinence syndrome, pervasive developmental disorders, metabolic disorders, hearing loss, and congenital blood disorders.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Less than 20 weeks gestation, 20 weeks gestation and greater, We only capture if mom had a past stillbirth or spontaneous abortion, not for the current child. For spontaneous abortions we quantify it as less than 20 weeks gestation, and for stillbirth we quantify it as 20 weeks gestation or greater. Data is not delineated by birth outcome.)
Age: 0-3 for core, recommended, and extended conditions; up to 5 years for FAS; up to age 8 with Autism Spectrum Disorders
Residence: In- and out-of-state (as reported to IBDPR) births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation, case confirmation for hospital discharge data; w/o case confirmation for direct physician reporting
Vital records: Birth certificates, Death certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Developmental Disabilities Surveillance
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Midwifery Facilities, Physician reports

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)
Conditions warranting chart review beyond the newborn period: Developmental delay, Any infant with a codable defect
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, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Pregnancy/delivery complications
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: Oracle

Data Analysis
Data analysis software: SAS, SQL, Excel
Quality assurance: Double-checking of assigned codes, Data/hospital audits, Timeliness, Review by IBDPR staff, non-clinician
Data use and analysis: Routine statistical monitoring, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Needs assessment, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, The birth defects registry is linked to other program databases (see below).
System integration: The database is linked with birth, death, newborn hearing screening, newborn metabolic, and pulse oximetry screening data.

Funding
Funding source: 20% Service fees, 80% Genetic screening revenues

Other
Web site: www.birthdefects.in.gov
Surveillance reports on file: Progress Report to the Indiana Legislature

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Iowa

Iowa Registry for Congenital and Inherited Disorders (IRCID)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Prevention education programs
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Legislators
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: University
Population covered annually: 37,781 average live births per year (2016-2020)
Statewide: Yes
Current legislation or rule: Iowa Code 136A, Iowa Administrative Code 641-4.7
Legislation year enacted: 1986; Revised 2001, 2003, 2004, 2009, 2013

Case Definition
Outcomes covered: Major birth defects, muscular dystrophy, fetal deaths with and without birth defects, newborn screening disorders
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
Residence: Maternal residence in Iowa at time of delivery

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Death certificates, Fetal death certificates, Fetal Death Evaluation Protocol
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Developmental Disabilities Surveillance, Cancer registry, Iowa Perinatal Care Program
Delivery hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports.
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities
Other sources: Physician reports, Outpatient surgery facilities; IHA Discharge Data

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 elective abortions, All neonatal deaths, All infants in NICU or special care nursery, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, 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, 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.), Family history

Data Collection Methods and Storage
Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access, Oracle, PC Server, FileMaker Pro

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, 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, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link case finding data to final birth file, Link to environmental databases

Funding
Funding source: 100% General state funds

Other
Web site: http://www.public-health.uiowa.edu/ircid/

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Kansas

Kansas Birth Defects Program

Purpose: Surveillance
Partner: Hospitals, Environmental Agencies/Organizations, Universities
Program status: Interested in developing a surveillance program
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health, Vital Statistics)
Population covered annually: 34,697
Statewide: Yes
Current legislation or rule: K.S.A. 65-1,241 through 65-1,246
Legislation year enacted: 2004

Case Definition
Outcomes covered: The outcome data below are available from Office ofVital Statistics. Live births and stillbirths (fetal deaths) information areused as part of the Birth Defects Information System (BDIS). Thirteen anomalies (and 'other' congenital anomalies) are listed on the birth certificate and are reported, however, these are not linked to ICD-9 codes. In addition to major birth defects, low birth weight (<=1,200 grams), low Apgar scores (<=5 at five minutes), seizure or serious neurologic dysfunction, and significant birth injury [skeletal fracture(s), peripheral nerve injury, and/or soft tissue/solid organ hemorrhage which requires intervention] are also reported to BDIS.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition
Residence: In state and out of state births to Kansas residents and in-state births to out of state residents

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation
Vital records: Birth certificates, Stillbirth (fetal death) certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Reports
Pediatric & tertiary care hospitals: Reports
Other sources: Physician reports, Konza National Network

Case Ascertainment
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.), 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, 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 submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), In Kansas, birth defects (congenital anomalies) are collected through four data sources: live birth certificates, stillbirth (fetal death) certificates, Konza National Network and the congenital malformations and fetal alcohol syndrome reporting form. The live birth and stillbirth (fetal death) certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to Auris (the Birth Defects Information System). Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into Auris.
Database collection and storage: SQL Server

Data Analysis
Data analysis software: SAS
Quality assurance: Office of Vital Statistics conducts verification on live birth andstillbirth (fetal death) certificate data.
Data use and analysis: Baseline rates, Rates by demographic and other variables, Time trends, Grant proposals, Ad-hoc upon request (e.g. cluster investigations)

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Our program has a link with vital statistics records. The Birth Defects program uses the same data system (Auris) and shares information with Newborn Hearing Screening and Newborn Metabolic Screening program.

Funding
Funding source: 50% General state funds, 50% MCH funds

Other
Web site: www.kdhe.ks.gov/678/Birth-Defects-Program

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Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Genetic Clinics, Laboratories,
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 56,000
Statewide: Yes
Current legislation or rule: Kentucky Revised Statute 211.660 Kentucky birth surveillance registry - Department's authority to promulgate administrative regulations. Effective: July 15, 2002
Legislation year enacted: 1992

Case Definition
Outcomes covered: KBSR collects information concerning birth defects, stillbirths, and high-risk conditions for Kentucky residents birth to age five. Diagnoses include the following ICD-10 codes:• All congenital anomalies codes - Q00-Q99• Metabolic/storage disorders - D80-D82, E70-E72, E74-E83, E88, and all subcategories.• Teratogens (noxious influences) - P04.0-P04.9. • Zika Virus Disease - A92.5And any additional condition deemed necessary for public health surveillance.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (A fetal death of twenty (20) completed weeks' gestation or more, calculated from the date last normal menstrual period began to the date of delivery or in which the fetus weighs three hundred fifty (350) grams or more.)
Age: Up to 5 years of age
Residence: In and out of state births to state residents

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: Newborn CCHD Screening, NAS Public Health Reporting Registry
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, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic 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 prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, 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: Online database developed in-house

Data Analysis
Data analysis software: SAS
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, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Birth records from vitals statistics are linked with all cases in the KBSR database. Data from the state Newborn CCHD Screening database and the state Neonatal Abstinence Syndrome Reporting Registry are incorporated into KBSR.

Funding
Funding source: 90% MCH funds, 10% Other (some support from SSDI)

Other
Web site: https://chfs.ky.gov/agencies/dph/dmch/ecdb/Pages/kbsr.aspx
Surveillance reports on file: Birth Defect Specific Fact Sheets (English and Spanish) and Data Briefs; Contact of Partners; 10-Year Report

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Louisiana

Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start year: 2005
Earliest year of available data: 2005
Organizational location: Department of Health (Maternal and Child Health, LDH/OPH/CCPH/BFH/Title V CYSHCN Programs)
Population covered annually: 58,000
Statewide: Yes
Current legislation or rule: Law: LA R.S. 40:31.41 - 40:31.48, 2001. LDH Rule: LAC 48:V. Chapters 161 and 163
Legislation year enacted: 2001

Case Definition
Outcomes covered: Major structural birth defects and selected genetic conditions specified by NBDPN in core, recommended, and expanded lists including an additional list of interest to LBDMN.
Pregnancy outcome: Livebirths (greater than or equal to 20 weeks gestation or greater than or equal to 350 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Added Fetal Deaths for 2016 births)
Age: Up to third birthday
Residence: In and out of state births to state residents at the time of birth

Surveillance Methods
Case ascertainment: Active Case Finding, 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: Newborn hearing screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Third party payers: Medicaid databases
Other sources: Louisiana Hospital Inpatient Discharge Data (LAHIDD)

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)
Conditions warranting chart review beyond the newborn period: 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.), Family history

Data Collection Methods and Storage
Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Custom designed web-based database.

Data Analysis
Data analysis software: SAS, ArcGIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, 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, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Link case finding data to final death file
System integration: Integrated with Louisiana Electronic Event Registration System (LEERS) birth and death records and Louisiana Early Hearing Detection and Intervention (LA-EHDI) Program database.

Funding
Funding source: 100% Other (MCH Title V Block Grant CYSHCN portion; State Matching Funds;)

Other
Web site:
WWW.LDH.LA.GOV/LBDMNWWW.LDH.LA.GOV/LBDMN
Surveillance reports on file: Louisiana Morbidity Report, May-June 2009, Vol 20, No 3; Results from 2006-2008 Birth Defects Surveillance System; Presentations of analysis using 2006-2008 data concerning ASD Reporting; Cleft Lip/Palate and Hearing Loss; and Age and Racial Disparities

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Maine

Maine CDC Birth Defects Program (MBDP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Education
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, March of Dimes, Maine Tracking Network
Program status: Currently collecting data
Start year: 1999
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 12,000
Statewide: Yes
Current legislation or rule: 22 MRSA c. 1687
Legislation year enacted: 1999

Case Definition
Outcomes covered: Selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias and major heart defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Less than 20 weeks gestation, 20 weeks gestation and greater, Prenatally diagnosed at any gestation), Elective terminations (Prenatally diagnosed at any gestation)
Age: Through age 1
Residence: All in-state births to Maine residents

Surveillance Methods
Case ascertainment: Passive case ascertainment with active 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
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities
Other sources: Midwifery Facilities, Physician reports, Children with Special Health Needs

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 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 infants in NICU or special care nursery, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Cardiovascular condition, Any infant with a codable defect
Coding: lCD-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.), 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, 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 scanning of printed records
Database collection and storage: Oracle, Microsoft SQL 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, Baseline rates, Rates by demographic and other variables, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Newborn Hearing/ Newborn Bloodspot Screening Programs

Funding
Funding source: 100% MCH funds

Other
Web site:
http://www.maine.gov/dhhs/mecdc/population-health/mch/cshn/birth-defects/index.html

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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, Maternal and Child Health, 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 >=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.dhmh.maryland.gov/genetics/SitePages/bdris.aspx
Surveillance reports on file: All reports submitted to CDC

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Massachusetts

Massachusetts Birth Defects Monitoring Program (MBDMP)

Purpose: Surveillance, Research, Public health program evaluation, Assist community health assessments
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Maternal and Child Health Programs, State Lab
Program status: Currently collecting data
Start year: 1997
Earliest year of available data: 1999
Organizational location: Department of Public Health (Bureau of Family Health and Nutrition)
Population covered annually: 69,000
Statewide: Yes
Current legislation or rule: Massachusetts General Laws, Chapter 111, Section 67E in 1963. In 2002 the Massachusetts legislature amended this statute, expanding the birth defects monitoring program. In 2009 regulations for a Congenital Anomalies Registry, 105 CMR 302.000, were promulgated.
Legislation year enacted: 1963 (amended 2002, regulations 2009)

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (>= 20 weeks gestation or >= 350 grams), Elective terminations (Unspecified non-live births (elective terminations at any gestational age, spontaneous losses < 20 weeks and < 350 grams))
Age: 1 year
Residence: In- and out-of-state births to state residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Death certificates, Fetal death certificates
Delivery hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Physician reports if sent to us

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 prenatally diagnosed or suspected cases, Any birth certificate with a major birth defect box checked
Conditions warranting chart review beyond the newborn period: All infant deaths (excluding prematurity), Any infant with a codable defect
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, 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.), Family history

Data Collection Methods and Storage
Data collection: Electronic file/report abstracted by staff (laptop, web-based, etc.)
Database collection and storage: Microsoft Access

Data Analysis
Data analysis software: SAS, Microsoft Access, Microsoft Excel, Tableau
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, Data/hospital audits as needed
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Link case finding data to final fetal death file
System integration: Link birth defects data to MDPH Pregnancy to Early Life Longitudinal (PELL) data system.

Funding
Funding source: 11% General state funds, 60% MCH funds, 17% CDC grant, 12% Other federal funding (non-CDC grants)

Other
Web site: www.mass.gov/dph/birthdefects
Surveillance reports on file: Annual or bi-annual reports since 1999

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Michigan

Michigan Birth Defects Registry (MBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Prevalence and mortality statistics
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Outpatient Pediatrics clinics for HL7 reporting pilot, still in progress
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Epidemiology/Environment, Vital Statistics)
Population covered annually: 110,000
Statewide: Yes
Current legislation or rule: Public Act 236 of 1988
Legislation year enacted: 1988

Case Definition
Outcomes covered: Congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks or >400 grams)
Age: Up to two years after delivery except that reporting to age 12 for FASD beginning in 2013
Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

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, Cancer registry
Delivery hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Physician reports, Pediatric Dentistry

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)
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Ocular conditions, 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.)

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 scanning of printed records
Database collection and storage: FoxPro, SQL Server

Data Analysis
Data analysis software: SPSS, SAS, Access, Fox-pro, Excel
Quality assurance: Validity checks, Re-abstraction of cases, 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, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, CSHCS, WIC, NBS, MICR
System integration: No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

Funding
Funding source: 10% CDC grant, 90% Other (60% Vital Records Fees, 30% newborn screen revenue)

Other
Web site:
https://www.michigan.gov/mdhhs/0,5885,7-339-73970_2944_4670---,00.html
Additional information on file:
Https://www.michigan.gov/mdhhs/0,5885,7-339-71551_2945_5221-166655--,00.html

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Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: Surveillance, Research, Referral to Services, Targeted prevention to higher risk populations.
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 2005
Earliest year of available data: 2006
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 70,000
Statewide: Yes
Current legislation or rule: MS 144.2215-2219
Legislation year enacted: 2004

Case Definition
Outcomes covered: Pregnancy outcome: 1) Live birth; 2) Fetal death at => 20 wks in 2019 birth cohort Major structural and genetic defects diagnosed up to 1 year of age identified by CDC and NBDPN.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to 1 year after delivery
Residence: In-state and out of state births to state residents

Surveillance Methods
Case ascertainment: Active Case Finding
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, Newborn CCHD screening
Delivery hospitals: Disease index or discharge index, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Other sources: Any case reported by local public health agency

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 birth certificate with a birth defect box checked, All stillborn infants, Any chart with an ICD10 Q00-Q99 or an ICD 10(P, Z, O) indicating stillbirths; All deaths prior to age 2 with a birth defect indicated as cause of death on death certificates, starting with 2009 births; Fetal death reports shared by Vital Records
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, 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.), Family history

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.), Remote access to medical records for large volume reporting facilities/systems
Database collection and storage: Web-based department-wide integrated disease surveillance database. Maven platform by Consilience Software.

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects, Collaboration with Environmental Public Health Tracking Program

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Sharing of confirmed cases with key contacts at local public health agencies for service referral. LPH staff can log on to our birth defects database to view relevant case information. In 2012, LPH began entering follow up and service/program updates into BDIS.
System integration: The Birth Defects Information System (BDIS) is integrated with Newborn Hearing program, Newborn CCHD, and Heritable Conditions. The databases share a model on the same platform, but they are managed separately. (This platform, Maven by Consilience Software, is also used by many infectious disease surveillance systems in MN and access is limited by disease/user role.) Additional integration with the Newborn Congenital Cytomegalovirus Infection takes place in 2023 as universal newborn cCMV screening is implemented.

Funding
Funding source: 68% General state funds, 32% CDC grant

Other
Web site:
https://www.health.state.mn.us/people/childrenyouth/birthdefects/index.html

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Mississippi

Mississippi Birth Defects Surveillance Registry (MBDSR)

Purpose: Surveillance, Referral to Services
Partner: Local Health Departments, Hospitals, Advocacy Groups, Title V Children with Special Healthcare Needs
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health, Genetic Services Bureau)
Population covered annually: 38,000
Statewide: Yes
Current legislation or rule: Section 41-21-205 of the Mississippi Code of 1972
Legislation year enacted: 1997

Case Definition
Outcomes covered: The infant/fetus must have a reportable structural defect, newborn screening disorder, functional or metabolic disorder, genetically determined or a defect resulting from an environmental influence during embryonic or fetal life.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Birth to 21 years
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Physician reports

Case Ascertainment
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.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Demographic information (race/ethnicity, sex, etc.), 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 submitted by other agencies (hospitals, etc.)
Database collection and storage: New web based program (in development)

Data Analysis
Data analysis software: SAS, Excel
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, 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, Time trends, Epidemiological studies (using only program data), Referral, Education/public awareness

System Integration
System links: Link case finding data to final birth file

Funding
Funding source: 100% Genetic screening revenues

Other
Web site: www.HealthyMS.com

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Missouri

Missouri Birth Defect Surveillance System

Purpose: Surveillance, Research
Partner: Environmental Agencies/Organizations, Legislators
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1980
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 70,000
Statewide: Yes

Case Definition
Outcomes covered: ICD-9-codes 740-759, ICD-10 codes Q-codes, plus genetic, metabolic, and other disorders
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Fetal death certificates are only source of data)
Age: Up to one year after delivery
Residence: In- and out-of-state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation, Population-based
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics

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 birth certificate with a birth defect box checked, All stillborn infants
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, Infant complications
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, 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 submitted by other agencies (hospitals, etc.)
Database collection and storage: SAS

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Grant proposals, Education/public awareness

System Integration
System links: Link case finding data to final birth file

Funding
Funding source: 100% MCH funds

Other
Web site: http://health.mo.gov/data/birthdefectsregistry/index.php
Surveillance reports on file: MO Birth Defects Report 1996-2000

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

Program status: No surveillance program

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Nebraska

Nebraska Birth Defect Registry (NBDR)

Purpose: Surveillance, Research
Partner: Hospitals, Universities, Early Childhood Prevention Programs, Vital Statistics, Maternal Child Health
Program status: Currently collecting data
Start year: 1972
Earliest year of available data: 1973
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health, Vital Statistics)
Population covered annually: 26,000
Statewide: Yes
Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4(alternate citation: Public Health & Welfare [Codes] §71-645, §71-646, §71-647, §71-648, §71-649)
Legislation year enacted: 1972

Case Definition
Pregnancy outcome: Livebirths (=> 20 weeks, => 500 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (=> 20 weeks, => 500 grams)
Age: Up to one year after delivery
Residence: In state birth to state resident, out of state births to state residents when Out State Jurisdiction allows use of data

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates, Fetal death certificate
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Midwifery Facilities, Physician reports

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
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.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity
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: SQL

Data Analysis
Data analysis software: SAS, Reports from Netsmart
Quality assurance: Validity checks, 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, Grant proposals

System Integration
System links: Link to other state registries/databases
System integration: Births, Deaths, Fetal deaths

Funding
Funding source: 100% MCH funds

Other
Web site: http://dhhs.ne.gov/Pages/Vital-Records-Birth-Defects.aspx
Surveillance reports on file:
Http://dhhs.ne.gov/Pages/Vital-Statistics.aspx

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Nevada

Nevada Birth Outcomes Monitoring System (NBOMS)

Purpose: Surveillance, Research
Partner: Hospitals, Early Childhood Prevention Programs, Nevada Division of Public and Behavioral Health: Maternal, Child & Adolescent Health Program
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2005
Organizational location: Department of Health (Maternal and Child Health), Nevada Department of Health and Human Services, Office of Analytics for Nevada Division of Public and Behavioral Health
Population covered annually: 35,166
Statewide: Yes
Current legislation or rule: NRS 442.300 - 442.330 - Birth Defects Registry Legislation *** Regulation = NAC 442
Legislation year enacted: 1999

Case Definition
Outcomes covered: Major birth defects and genetic diseases
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: Birth to 7 years of age
Residence: In-state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation
Vital records: Birth certificates, Death certificates, Matched birth/death file, hospital medical records
Delivery hospitals: Disease index or discharge index, Discharge summaries
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

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
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.), 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: SAS files created from birth/hospital billing data and we keep the end results in SAS.
Database collection and storage: SAS

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Time trends, Epidemiological studies (using only program data), Needs assessment, Service delivery, Grant proposals, Education/public awareness, Prevention projects

Funding
Funding source: 100% MCH funds

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New Hampshire

New Hampshire Birth Conditions Program (NH BCP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start year: 2018
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 12,500
Statewide: Yes
Current legislation or rule: RSA 141:J, NH Administrative Rules He-P 3012
Legislation year enacted: 2008

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Birth to age 2
Residence: In-state birth to state resident

Surveillance Methods
Case ascertainment: Active Case Finding, Passive case-finding with case confirmation
Vital records: Birth certificates, Death certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Developmental Disabilities Surveillance
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Physician reports

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, All stillborn infants, All elective abortions, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, 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 submitted by other agencies (hospitals, etc.), Input into database from abstract paper
Database collection and storage: Proprietary system

Data Analysis
Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Monitoring outbreaks and cluster investigations, Referral

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

Funding
Funding source: 100% MCH funds

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New Jersey

Special Child Health Services Registry (SCHS Registry)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators, Neurodevelopmental Centers; Federally Qualified Health Care Centers; State Parent Advocacy Network; AAP NJ Chapter; all three (3) NJ MCH Consortia
Program status: Currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health (Division of Family Health Services/Special Child Health Services)
Population covered annually: ~100,000
Statewide: Yes
Current legislation or rule: NJSA 26:8-40.2 et seq., NJAC 8:20 - Amended: 1990, 1991, 1992, 2005, Readopted: 2010, Rule Amendments Adopted: 2009; Readopted: 2010
Legislation year enacted: 1983

Case Definition
Outcomes covered: All birth defects (structural, genetic, and biochemical), all Autism Spectrum Disorders, severe hyperbillirubinemia >25mg/dL, and failed pulse oximetry are mandated to be reported; all special needs and any condition which places a child at risk (e.g. prematurity, asthma, developmental delay) are also reported, but not mandated.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (15 week gestation and greater)
Age: Mandated reporting of birth defects diagnosed through age 5, voluntary reporting of birth defects diagnosed > age 6 and all children diagnosed with Special Needs conditions who are 22 years or younger. Autism mandated up to 22 years.
Residence: All NJ residents born in or out of state

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation, staff reach out to reporters to verify rule out diagnoses, pending diagnoses, and other questionable diagnoses
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal Death Certificate
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Autism Registry
Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, Quality assurance audits consisting of chart review of 3 month period -staff of BDR does not actively look at logs and discharge summaries but depends on staff of various hospitals and agencies to do same.
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Laboratory logs, quality assurance audit consisting of chart review of 3 month period
Third party payers: Universal billing database is used for quality assurance activities
Other sources: Midwifery Facilities, Physician reports, Special Child Health Services county-based Case Management Units, parents, medical examiners, Autism diagnosticians and treatment centers

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, Chart reviews are conducted on infants/children with mandated conditions that are in the 3 month audit window
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.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Prenatal diagnostic information
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.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records
Database collection and storage: SAS; PostgreSQL

Data Analysis
Data analysis software: SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness, Merge registry with birth certificate registry and the death certificate registry
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, link to hearing screening registry
System integration: Autism Registry is fully integrated. Newborns having failed Pulse Oximetry Screening are integrated with Registry. Newborn hearing screening registry provides direct report to the SCHS Registry. Metabolic screening program provides direct report to SCHS Registry. Special Child Health Services county-based Case Management Referral System is included in the Registry.

Funding
Funding source: 90% MCH funds, 10% CDC grant

Other
Web site: http://www.nj.gov/health/fhs/bdr/

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New Mexico

New Mexico Birth Defects Prevention and Surveillance System (NM BDPASS)

Purpose: Surveillance, Referral to Prevention/Intervention Services
Partner: Hospitals
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 21,000
Statewide: Yes
Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions must be reported to the New Mexico Department of Health's Epidemiology and Response Division. Specifically, the conditions must be reported to the Environmental Health Epidemiology Bureau.
Legislation year enacted: 2000

Case Definition
Outcomes covered: Since 2016, Q00-Q99 ICD-10 codes. Before that, 740.0-760.01 with emphasis on 12 birth defects that are nationally consistent data and measures for the Environmental Public Health Tracking Program.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Birth through age 4
Residence: Births to New Mexico residents occurring in New Mexico.

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation for selected defects
Vital records: Birth certificates, Death certificates, Fetal birth certificate
Delivery hospitals: Birthing hospital reports; Hospital Inpatient Discharge Database (HIDD)
Pediatric & tertiary care hospitals: specialty outpatient clinics, including neurosurgery, plastic surgery, pediatric surgical specialists, prenatal diagnostic providers
Third party payers: Children's Medical Services
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Cardiovascular conditions, renal agenesis/hypoplasia bilateral
Conditions warranting chart review beyond the newborn period: Cardiovascular condition
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.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage
Data collection: 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.)
Database collection and storage: Stata and SAS

Data Analysis
Data analysis software: SAS, Stata version 13.1
Quality assurance: Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Rates by demographic and other variables, Epidemiological studies (using only program data), Service delivery, Referral, Education/public awareness

Funding
Funding source: 100% CDC grant

Other
Web site:
https://nmtracking.org/epht-view/health/reproductive/BirthDefects.html
Additional information on file: The procedure manual requires updates. It can be shared once is finalized.
Other comments: The epidemiologist that just vacated the role will continue to support the program until a new employee is hired and trained. He is currently training the new Health Educator.

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New York

New York State Birth Defects Registry (NYS BDR)

Purpose: Surveillance, Research
Partner: Hospitals, Universities, CDC
Program status: Currently collecting data
Start year: 1982
Earliest year of available data: 1983
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: ~228,000
Statewide: Yes
Current legislation or rule: Public Health Law Article 2, Title II, Section 225(5)(t) and Article 2, Title I, Section 206(1)(j): Codes, Rules and Regulations, Chapter 1, State Sanitary Code, Part 22.3
Legislation year enacted: 1982

Case Definition
Outcomes covered: Major structural, functional or biochemical abnormality determined genetically or induced during gestation. A detailed list is available upon request.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages)
Age: As of 5/25/16: 10 years for heart defects, muscular dystrophy, genetic conditions, FAS; 2 years for all other defects
Residence: All children born in or residing in New York

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment; population-based
Vital records: Birth certificates
Other state based registries: NYS Dept. of Health statewide hospital discharge database
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Other specialty facilities: Cytogenetic laboratories

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
Conditions warranting chart review beyond the newborn period: 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.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
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 submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Oracle

Data Analysis
Data analysis software: SAS, Access
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, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals

Funding
Funding source: 11% General state funds, 11% MCH funds, 10% Other federal funding (non-CDC grants), 68% Other (State Superfund, Other)

Other
Web site: http://www.health.ny.gov/birthdefects
Surveillance reports on file: Reports for 1983 - 2008 births are available. Work on updating the surveillance reports is in progress.
Additional information on file: Counts of selected birth defects are provided on the NYS Environmental Public Health Tracking portal (Birth years 2000-2015 [updating soon]) and Health Data New York (birth years 1992-2020).

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North Carolina

N.C. Birth Defects Monitoring Program (NCBDMP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 1987
Earliest year of available data: 1989
Organizational location: Department of Health (State Center for Health Statistics)
Population covered annually: 120,000
Statewide: Yes
Current legislation or rule: NCGS 130A-131.16
Legislation year enacted: 1995

Case Definition
Outcomes covered: Major birth defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: 1 year
Residence: NC resident births, including out of state deliveries

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
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: Pulse oximetry screening records

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, All stillborn infants, All prenatally diagnosed or suspected cases, Failed newborn pulse oximetry screen
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, 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: 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.)
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, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Time-space cluster analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

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

Funding
Funding source: 60% General state funds, 5% MCH funds, 35% CDC grant

Other
Web site: https://schs.dph.ncdhhs.gov/units/bdmp/

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North Dakota

North Dakota Birth Defects Monitoring

Purpose: Surveillance, Referral to Prevention/Intervention Services
Partner: Special Health Services and Developmental Disabilities (Early intervention 0-3 years)
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 1994
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health, Vital Statistics), Developmental Disabilities
Population covered annually: 10,051-This data is for CY 2020. ---- Look up for 2022
Statewide: Yes
Current legislation or rule: North Dakota Century Code:1. 23-41-04. Birth report of child with special health care needs made to department.Within three days after the birth in this state of a child born with a visible congenital deformity, the licensed maternity hospital or home in which the child was born, or the legally qualified physician or other person in attendance at the birth of the child outside of a maternity hospital, shall furnish the department a report concerning the child with the information required by the department. 2. 23-41-05. Birth report of child with special health care needs - Use - Confidential. The information contained in the report furnished to the department under section 23-39-04 concerning a child with a visible congenital deformity may be used by the department for the care and treatment of the child pursuant to this chapter. The report is confidential and is solely for the use of the department in the performance of its duties. The report is not open to public inspection nor considered a public record.
Legislation year enacted: 1941

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: 12 months
Residence: In-state birth/s to state resident.

Surveillance Methods
Vital records: Birth certificates
Other state based registries: Programs for children with special needs
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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.)
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: MS Excel, SPSS, MAVEN

Data Analysis
Data analysis software: SPSS
Quality assurance: Validity checks, Double-checking of assigned codes
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Needs assessment, Education/public awareness, Due to agency reorganization and state mandates, the only monitoring occurring is the mandated birth defects reporting from the birth certificate and associated Child Find activities.

Funding
Funding source: 100% Other (State Systems Development Initiative (SSDI))

Other
Web site: https://www.hhs.nd.gov/health/data-statistics
Surveillance reports on file:

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Ohio

Ohio Connections for Children with Special Needs (OCCSN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, ODH Office of Health Preparedness, ODH Bureau of Infectious Diseases, ODH Violence and Prevention, Department of Developmental Disabilities, Department of Medicaid
Program status: Currently collecting data
Start year: 2006
Earliest year of available data: 2008
Organizational location: Department of Health (Data and Surveillance, Bureau of Child and Family Health)
Population covered annually: 129,000
Statewide: Yes
Current legislation or rule: Ohio Revised Code (ORC) 3705.30-3705.36 authorizes the department to implement a statewide birth defects information system and mandates hospital reporting (2000).Ohio Administrative Code (OAC) 3701-57-01 to 3701-57-04 specifies conditions to be reported and methods for reporting (2015).
Legislation year enacted: 2000

Case Definition
Outcomes covered: Major congenital anomalies as recommended by stakeholders in Ohio; Select genetic diseases; Neonatal Abstinence Syndrome; Fetal Alcohol Syndrome; 7 targets of newborn screening for critical congenital heart disease
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to 5 years of age
Residence: Ohio resident children up to 5 years of age

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation, Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn screening for CCHD data system - electronic birth certificate system
Delivery hospitals: Hospital medical records and other electronic administrative data sets
Pediatric & tertiary care hospitals: Discharge summaries, Laboratory logs, Hospital medical records and other electronic administrative data sets
Other sources: Genetics Clinic Data within some hospitals

Case Ascertainment
Conditions warranting chart review in newborn period: Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), ICD-10 codes or named congenital anomalyICD-10 codes or named congenital anomalies
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies
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 defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
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 submitted by other agencies (hospitals, etc.), Hospital reporters upload file to secure website for integration. Small volume hospitals can manually key data into secure user interface.
Database collection and storage: Data collected into Maternal and Child Health Integrated Data System (MCHIDS) and stored in SQL Server, Hue/Impala

Data Analysis
Data analysis software: SAS, MS Excel
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Clinical review, 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, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, OCCSN data system shares common demographic file with Vital Statistics and Genetics Program data systems.

Funding
Funding source: 100% MCH funds

Other
Web site:
https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/Birth-Defects/Reports
Surveillance reports on file: 2019 NBDPN Annual Report2019 OCCSN Annual Report
Additional information on file: OCCSN data system user guide for 1) reporting hospitals; 2) case confirmers

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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, 1994 Statewide
Organizational location: Department of Health (Screening and Special Services)
Population covered annually: 50,800 (ave 1994-2020)
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: 20% MCH funds, 80% Genetic screening revenues

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

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Oregon

Oregon Birth Anomalies Surveillance System (BASS)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 2013
Earliest year of available data: 2008
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 42,000
Statewide: Yes
Current legislation or rule: None

Case Definition
Outcomes covered: NBDPN core, recommended, and extended anomalies for surveillance, plus microcephaly and congenital hearing loss cases.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: 6 years and 0 months
Residence: Oregon resident births (in and out-of-state)

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates
Other state based registries: Newborn hearing screening program
Delivery hospitals: Hospital Discharge Data
Pediatric & tertiary care hospitals: Hospital Discharge Data
Third party payers: Medicaid databases
Other sources: Hospital Discharge Data

Case Ascertainment
Coding: ICD-9-CM/ICD-10-CM, ICD-10 for Death certificates

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data collection: Administrative data sets sharing with data use agreements in place: Birth Certificate, Death Certificate, Hospital Discharge Data and Medicaid claims
Database collection and storage: SPSS/FileMakerPro

Data Analysis
Data analysis software: SPSS, Access, Link Plus
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link case finding data to final birth file, Program work together with Oregon Environmental Public Health Tracking System but data are not linked

Funding
Funding source: 100% MCH funds

Other
Web site:
http://public.health.oregon.gov/HealthyPeopleFamilies/DataReports/Pages/birth-anomalies.aspx

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Pennsylvania

Pennsylvania Birth Defects Surveillance Program (PA-BDSP)

Purpose: Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Advocacy Groups, Community Nursing Services, Early Childhood Prevention Programs
Program status: Interested in developing a surveillance program
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health)
Population covered annually: 130730
Statewide: Yes

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages)
Age: 1 year
Residence: In-state birth to state resident

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates, Fetal birth certificate
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index

Case Ascertainment
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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.), 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, Pregnancy/delivery complications, Family history

Data Collection Methods and Storage
Data collection: Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Oracle

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes

System Integration
System links: Link case finding data to final birth file, hospital administrative data

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Puerto Rico

Puerto Rico Birth Defects Surveillance and Prevention System (PR-BDSPS)

Purpose: Surveillance, Referral to Services
Partner: Hospitals, Advocacy Groups, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Services for Children with Special Medical Needs Division)
Population covered annually: 20,000
Statewide: Yes
Current legislation or rule: Law #351- Birth Defects Surveillance System Law; 2004
Legislation year enacted: 2004

Case Definition
Outcomes covered: Selected birth defects covered: neural tube defects, microcephaly, holoprocencephaly, cleft lip and/or cleft palate, anotia, microtia, anophthalmia, microphthalmia, limb defects, talipes equinovarus, gastroschisis, omphalocele, craniosynostosis, diaphragmatic hernia, trisomy 13, 18 and 21, Tuner syndrome, 22q11.2 deletion syndrome, albinism, Jarcho-Levin syndrome, Prader Willi syndrome, major congenital heart defects, ambiguous genitalia, hypospadias , and bladder extrophy. Outcomes covered: live-births, stillbirths, terminations and spontaneous abortion.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Up to 6 years after delivery
Residence: In-state births to state residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories
Other sources: Physician reports

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 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 elective abortions, All neonatal deaths, All infants in NICU or special care nursery, All infants with low APGAR scores, All prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
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, 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: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, REDCap

Data Analysis
Data analysis software: SPSS, Excel
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding
Funding source: 100% MCH funds

Other
Web site: https://www.salud.gov.pr/CMS/204

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Rhode Island

Rhode Island Birth Defects Program (RIBDP)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Families
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2002
Organizational location: Department of Health (Center for Health Data and Analysis)
Population covered annually: 10,800
Statewide: Yes
Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws requires the development of a birth defects surveillance, reporting, and information system that will a) describe the occurrence of birth defects in children up to age five; b) detect trends of morbidity and mortality; and c) identify newborns and children with birth defects to intervene on a timely basis for treatment.
Legislation year enacted: 2003

Case Definition
Outcomes covered: All birth defects and genetic diseases
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Birth up to 5 years
Residence: RI maternal residence

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment
Vital records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, RI has an integrated child health information system called KIDSNET, which links data from 10 programs including: Newborn Developmental Risk Screening, Newborn Bloodspot Screening, Newborn Hearing Screening, Home Visiting, Immunization, etc.
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities
Other sources: Physician reports

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, All stillborn infants, All elective abortions, All infants in NICU or special care nursery, All prenatally diagnosed or suspected cases, Chart reviews are conducted for infants born at the regional perinatal center and the 4 other maternity hospitals who were identified with an ICD-9-CM code 740-759 and 760.71 or an ICD-10 Q code and other sentinel conditions
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, 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

Data Collection Methods and Storage
Data collection: 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.)
Database collection and storage: Access, Oracle

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, 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, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration
System links: Link to other state registries/databases, KIDSNET, hospital discharge data
System integration: Integrated into KIDSNET for web-based provider reporting

Funding
Funding source: 100% MCH funds

Other
Web site: www.health.ri.gov/programs/birthdefects
Surveillance reports on file: 2022 Rhode Island Birth Defects Data Book

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South Carolina

South Carolina Birth Defects Program (SCBDP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Education
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Greenwood Genetics Center (GGC)/genetic institution, March of Dimes, Cardiology groups
Program status: Currently collecting data
Start year: GGC began monitoring in 1992; transitioned to SC DHEC and expanded in 2006
Earliest year of available data: Full data available beginning in 2006
Organizational location: Department of Health (Division of Population Health Surveillance, Bureau of Maternal and Child Health)
Population covered annually: 56,668
Statewide: Yes
Current legislation or rule: Title 44-44-10, SC Birth Defects Act
Legislation year enacted: 2004

Case Definition
Outcomes covered: Central nervous system defects, eye and ear defects, cardiovascular defects, orofacial defects, gastrointestinal defects, genitourinary defects, musculoskeletal defects, and chromosomal defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (10 weeks or greater; all gestational ages for the data submitted in this report), Elective terminations (All gestational ages, 10 weeks or greater; all gestational ages for the data submitted in this report)
Age: Up to two years of age; program is expanding this age range for people with CHD to any age group
Residence: All SC residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital records: Birth certificates, Fetal birth certificate, The birth certificate data is NTD-specific
Other state based registries: Newborn hearing 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, Surgery logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Genetic institution

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 prenatally diagnosed or suspected cases, Elective abortions, prenatally diagnosed cases found through problem pregnancy codes, and select ICD-10/9 codes outside of that range
Conditions warranting chart review beyond the newborn period: Cardiovascular condition, Any infant with a codable defect
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

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.), Electronic scanning of printed records
Database collection and storage: Access, SQL Server

Data Analysis
Data analysis software: SAS, Access, Arc-GIS, Microsoft Excel
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, We look at comparison between multiple data sources for NTD only.
Data use and analysis: Routine statistical monitoring, 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, Legislative reports

System Integration
System links: Link case finding data to final birth file
System integration: SCBDP data is integrated with SC Vital Records.

Funding
Funding source: 55% General state funds, 10% MCH funds, 45% CDC grant

Other
Surveillance reports on file:
Https://scdhec.gov/sites/default/files/Library/CR-012491.pdf

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South Dakota

Program status: No surveillance program

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Tennessee

Tennessee Birth Defects Surveillance System (TNBDSS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators, Environmental Public Health Tracking program within the TN Department of Health
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 1999
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 80,326
Statewide: Yes
Current legislation or rule: TCA 68-5-506
Legislation year enacted: 2000

Case Definition
Outcomes covered: 47 major structural birth defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (350 grams or more, or in the absence of weight, 20 completed weeks of gestation or more)
Age: Up to 5 years old
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation, Passive case-finding without 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, Hospital Discharge Data System and Newborn Screening Pulse Oximetry
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: ICD-10-CM codes from 26 specific birth defects
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), Cardiovascular condition, Ocular conditions
Coding: 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: SAS, REDCap, and Birth defects internet case management system (iCMS)

Data Analysis
Data analysis software: SAS, Arc-GIS
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases
System integration: The Birth Defects case module is housed within the Newborn Screening internet case management system.

Funding
Funding source: 10% MCH funds, 90% CDC grant

Other
Web site:
https://www.tn.gov/health/health-program-areas/mch-cyshcn/tennessee-birth-defects-surveillance-system.html
Surveillance reports on file: Tennessee Birth Defects Data Report 2015-2019https://www.tn.gov/content/dam/tn/health/documents/FINAL%20Data%20Report%20Feb%206%202023.pdf

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Texas

Texas Birth Defects Epidemiology and Surveillance Branch (TBDES)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators, Researchers (NBDPN, NBDPS, ICBDSR)
Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 377,710 in 2019
Statewide: Yes
Current legislation or rule: Health and Safety Code, Title 2, Subtitle D, Section1, Chapter 87
Legislation year enacted: 1993

Case Definition
Outcomes covered: All major structural birth defects and fetal alcohol syndrome.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Up to one year after delivery and up to 6 years for FAS, special studies and childhood genetic disorders diagnosed after infancy.
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Active Case Finding, Population-based, includes entire state
Vital records: Fetal death certificates for delivery year 2009 to present
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Genetics, stillbirths and radiology logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, genetics, stillbirths and radiology logs
Other sources: Midwifery Facilities, Licensed birthing centers

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), Infants with low birth weight or low gestation (<34 weeks gestational age), All stillborn infants
Conditions warranting chart review beyond the newborn period: CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Any infant with a codable defect
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, 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.), 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: Oracle

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, Clinical review, Timeliness, Re-casefinding, re-review of medical records
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Link registry to vital records for demographic data, special projects linking to other files (Texas Health Data for geocodes, Newborn Screening data).

System Integration
System links: Link to other state registries/databases, Link to environmental databases, Statewide hospital discharge datasets

Funding
Funding source: 94% MCH funds, 6% CDC grant

Other
Web site: https://www.dshs.texas.gov/birthdefects/
Surveillance reports on file: See website for publication and surveillance reports

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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 (Department of Health and Human Services, Division of Family Health, Office of Children with Special Health Care Needs)
Population covered annually: 47,766 (2016-2020 for resident births)
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 neonatal deaths, 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, Cardiovascular condition, All infant deaths (excluding prematurity), 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, R
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, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link to environmental databases, Link to Utah genealogical population database
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: 5% General state funds, 55% MCH funds, 40% CDC grant

Other

Web site: familyhealth.utah.gov/cshcn/ubdn/
Surveillance reports on file: Http://ibis.health.utah.gov
Other comments: IBIS indicators are online.

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Vermont

Birth Information Network (BIN)

Purpose: Surveillance, Referral to Services
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Hospital Association
Program status: Currently collecting data
Start year: 2006
Earliest year of available data: 2006
Organizational location: Department of Health (Division of Health Statistics & Informatics)
Population covered annually: 6000
Statewide: Yes
Current legislation or rule: Act 32 (TITLE 18 VSA §5087)
Legislation year enacted: 2003

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 week gestation and greater or a birth weight of more than 400 grams)
Age: Up to one year after delivery
Residence: In and out of state births to state residents

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
Delivery hospitals: Discharge summaries, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Third party payers: Medicaid databases, Multi-payer claims database
Other specialty facilities: Cytogenetic laboratories
Other sources: Physician reports, Autopsy reports

Case Ascertainment
Conditions warranting chart review in newborn period: 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), Any chart with an ICD-10-CM code corresponding to a condition monitored by Vermont's registry.
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
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, 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, 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 submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records
Database collection and storage: Access

Data Analysis
Data analysis software: SPSS, Access, Excel
Quality assurance: Comparison/verification between multiple data sources, Clinical review, 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, Time trends, Observed vs. expected analyses, Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness

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

Funding
Funding source: 100% General state funds

Other
Web site:
https://www.healthvermont.gov/stats/registries/birth-information-network

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Virginia

Virginia Congenital Anomalies and Reporting Education System (VaCARES)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 2004
Organizational location: Department of Health (Office of Family Health Services, Division of Child and Family Health)
Population covered annually: 95,647
Statewide: Yes
Current legislation or rule: Code of Virginia, § 32.1-69.1https://law.lis.virginia.gov/vacodefull/title32.1/chapter2/article8.1/
Legislation year enacted: 1985

Case Definition
Outcomes covered: Major and non-major birth defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Up to 2 years of age
Residence: Any diagnoses occurring in-state

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries
Other specialty facilities: Genetic counseling/clinic genetic 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)
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.), 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, 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 submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Web-based reporting system is linked to electronic birth certificate and populates Oracle data tables

Data Analysis
Data analysis software: SAS
Data use and analysis: Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiological studies (using only program data), Needs assessment, Referral, Grant proposals, Education/public awareness

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: VaCARES is part of the Virginia Vital Events Screening and Tracking System, which also houses electronic birth certificate reporting and the Virginia Early Hearing Detection and Intervention tracking systems.

Funding
Funding source: 7% General state funds, 93% MCH funds

Other
Web site: https://www.vdh.virginia.gov/vacares/

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Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: Surveillance
Partner: Hospitals
Program status: Currently collecting data
Start year: 1986 (active), 1991 (passive)
Earliest year of available data: 1997
Organizational location: Department of Health (Office of Family & Community Health Improvement)
Population covered annually: 85,000 est
Statewide: Yes
Current legislation or rule: Notifiable Conditions: WAC 246-101
Legislation year enacted: 2000

Case Definition
Outcomes covered: Case definition for Washington State Birth Defects Surveillance System is based on ICD-10-CM diagnostic and procedure codes as they appear in the hospital medical records. Any child up to age one year, diagnosed or treated, with a reportable birth defect who was a Washington State resident at the time of birth, or at the time of treatment in a Washington facility is reportable. We receive the following data elements: Child's name, medical record number, date of birth, sex, admission date, zip code, discharge date, ICD-10-CM code for diagnosis, diagnosis, ICD code for procedure, and procedure.Currently required birth defects reporting includes - Anencephaly and similar anomalies, Spina Bifida, Cleft Palate, Cleft Lip, Cleft palate with cleft lip, Abnormalities of Abdominal Wall, Limb reduction defects, Hypospadias and Epispadias, Down Syndrome, Cerebral Palsy, Fetal Alcohol Syndrome/Alcohol related birth defects and Autism Spectrum Disorder.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: We ascertain cases through 1 year of age for structural defects
Residence: Resident births; children residing in-state

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates
Delivery hospitals: Disease index or discharge index
Pediatric & tertiary care hospitals: Disease index or discharge index

Case Ascertainment
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.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage
Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Case-finding log listing of all required data elements for each case are completed by Medical Records staff sometimes in conjunction with hospital Information Systems staff. Few facilities submit data through hard copies (fax) for cases. Most facilities report electronically through Secure File Transfer (SFT). A revised data system for BDSS is currently in development.
Database collection and storage: Web-based SQL server

Data Analysis
Data analysis software: SAS, Stata
Quality assurance: Validity checks
Data use and analysis: Routine statistical monitoring, Baseline rates

System Integration
System links: Link case finding data to final birth file

Funding
Funding source: 70% General state funds, 30% MCH funds

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West Virginia

West Virginia Birth Defects Surveillance System

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Hospitals, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 1989
Earliest year of available data: 1989
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 18,000
Statewide: Yes
Current legislation or rule: WV State Code 16-5-12a
Legislation year enacted: 1991; updated 2002

Case Definition
Outcomes covered: ICD-10 Codes Q00–Q07, Q10–Q18 , Q20–Q28 , Q30–Q34 , Q35–Q37, Q38–Q45, Q50–Q56 ,Q60–Q64, Q65–Q79, Q80–Q89, Q90–Q99
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: 0-6 years
Residence: In-state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without 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, Infant and Maternal Mortality Review Panel
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries
Other sources: Pediatric referrals

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), Infants with low birth weight or low gestation (<2500 grams or <37 weeks), All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: ICD-9-CM/ICD-10-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage
Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: Access
Quality assurance: Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, 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: 100% MCH funds

Other
Web site: http://wvdhhr.org/omcfh
Additional information on file: Legislative reports on file with State Legislative Library

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Wisconsin

Wisconsin Birth Defect Prevention and Surveillance System (WBDPSS)

Purpose: Surveillance, Research, Referral to Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 2004
Earliest year of available data: 2005
Organizational location: Department of Health (Maternal and Child Health, Department of Health Services, Division of Public Health, Bureau of Community Health Promotion, Family Health Section, Children and Youth with Special Health Care Needs Unit)
Population covered annually: average 64,000
Statewide: Yes
Current legislation or rule: State statute 253.12 Birth defect prevention and surveillance system. Enacted December 2000. The statute was updated September 2017 and was enacted on July 1, 2018. The original legislation required parent permission to submit identifiers to the registry. The 2017 updated removed that requirement and parents now opt out if they don't want identifiers included in the registry.Department of Health Services rules, Chapter DHS 116 Wisconsin Birth Defect Prevention and Surveillance System. Enacted April 2003.Requires all diagnosing and/or treating providers as well as pediatric specialty clinics to report cases to the registry. Hospitals may report but are not required to.
Legislation year enacted: 2000 and update enacted in 2018

Case Definition
Outcomes covered: A list of 64 specific birth defects are collected. The list was developed by the Scientific Committee of the Council on Birth Defect Prevention and Surveillance and is included as an appendix in the rules. Originally 87 conditions were being collected. However, the list was reviewed to ensure that all conditions met the criteria of birth defects to be collected in the state statute. Based on that review and comparison to the NBDPN recommended conditions to be collected the list was updated and approved by the Council January 2022.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to 2 years after delivery
Residence: All children diagnosed with and/or treated for a birth defect by a provider or specialty clinic in the state.

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation, Work with reporters who report batches from EMRs to assure reporting quality and allow manual case entry into the reporting system for reporters with fewer cases who prefer that method. There is also still a paper form, for those with just an occasional case who want to report that way. State statute does not allow active case finding but does allow follow up with reporter for clarification.
Vital records: Matched birth/death file, compare registry reports to vital records periodically for selected birth defects
Other sources: Physician reports, Physicians and Pediatric Specialty clinics who diagnose and/or treat birth defects are required to report.

Case Ascertainment
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.), Birth defect diagnostic information
Mother: 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 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.), Can submit one report on the website or upload multiple reports. A paper form is also available that is entered by state birth defects staff.
Database collection and storage: Oracle

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Prevention projects

System Integration
System links: Link case finding data to final birth file, Data linked to birth file to pull in any missing information that is available in the birth record.
System integration: Our registry is part of the Wisconsin Electronic Disease Surveillance System (WEDSS), which collects a variety of public health data, like HIV, Zika, and COVID. While it is a separate module within WEDSS, there are some benefits to being a part of this larger system and there is the option of linking to other data within WEDSS, if needed, in the future.

Funding
Funding source: 100% Other (revenue from birth certificate fees)

Other
Web site: https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm
Surveillance reports on file: Posted on the website

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Wyoming

Program status: No surveillance program

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