Major Birth Defects Data from Population-based Birth Defects Surveillance Programs in the United States, 2011-2015

The introduction, data collection procedure, and birth defects codes for the state-specific birth defects data are available in the article, "Population-based birth defects data in the United States, 2011-2015: A focus on eye and ear defects."

Additional information and program contacts on population-based birth defects surveillance programs are available on page S123-S177.

The state-specific birth defects tables were prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention and approved by the state programs in August 2018.

The 41 population-based birth defects programs contributing data include:

Alaska Birth Defects Registry; Arizona 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 Information System; 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; Mississippi Birth Defects Surveillance Registry; Missouri Birth Defects Surveillance System; Nebraska Birth Defect Registry; Nevada Birth Outcomes Monitoring System; New Jersey Special Child Health Services Registry; New Mexico Birth Defects Prevention and Surveillance System; New York State Congenital Malformations Registry; North Carolina Birth Defects Monitoring Program; Ohio Connections for Children with Special Needs; Oklahoma Birth Defects 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 Registry.

Alaska Birth Defects Counts and Prevalence 2011 - 2014 (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	<6	0	0	<6	<6		
Anophthalmia/microphthalmia	0 0.0	0 0.0	0.0 0 0.0	0.0 0 0.0	<6	<6		
Anotia/microtia	7 2.9	<6	<6	<6	9 8.3	19 4.2		
Aortic valve stenosis	0 <i>0.0</i>	0 0.0	0 0.0	<6	<6	8 1.8		
Atrial septal defect	312 129.9	32 196.2	51 161.2	73 175.4	264 243.2	780 171.1		
Atrioventricular septal defect (Endocardial cushion defect)	11 4.6	<6	0 0.0	<6	7 6.4	26 5.7		
Biliary atresia	<6	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	<6	<6		
Bladder exstrophy	<6	0 <i>0.0</i>	0 0.0	0 <i>0.0</i>	0 <i>0.0</i>	<6		
Choanal atresia	6 2.5	<6	0 0.0	<6	<6	12 2.6		
Cleft lip alone	24 10.0	0 <i>0.0</i>	<6	<6	19 <i>17.5</i>	55 12.1		
Cleft lip with cleft palate	22 9.2	<6	<6	<6	20 18.4	55 12.1		
Cleft palate alone	40 16.7	<6	<6	6 14.4	35 32.2	92 20.2		
Cloacal exstrophy	0 0.0	0 <i>0.0</i>	0 0.0	0	0 0.0	0 0.0		
Clubfoot	*	<6	*	*	↔	161 35.3		
Coarctation of the aorta	10 4.2	<6	<6	<6	6 5.5	23 5.0		
Common truncus (truncus arteriosus)	<6	<6	0 <i>0.0</i>	<6	<6	14 3.1		
Congenital cataract	*	0 <i>0.0</i>	0 0.0	<6	*	20 4.4		
Congenital posterior urethral valves	20 16.3	<6	<6	<6	<6	34 14.5	1	
Craniosynostosis	<6	0 <i>0.0</i>	0 0.0	<6	<6	8 1.8		
Deletion 22q11.2	<6	0 0.0	0 0.0	0 <i>0.0</i>	<6	6 1.3		
Diaphragmatic hernia	<6	0 0.0	<6	0 0.0	15 13.8	21 4.6		
Double outlet right ventricle	<6	0 0.0	0 <i>0.0</i>	<6	<6	8 1.8		
Ebstein anomaly	<6	0 0.0	0 0 0.0	0 <i>0.0</i>	<6	<6		
Encephalocele	<6	<i>0.0</i> <6	0.0 <6	0.0 <6	<6	10 2.2		
Esophageal atresia/tracheoesophageal	<6	0	0 0.0	0 <i>0.0</i>	*	13 2.9		
fistula Gastroschisis	16	0.0 0	0.0 <6	0.0 <6	17	38		
Holoprosencephaly	6. 7 21	0.0 7	<6	6	15.7 28	8.3 66		
Hypoplastic left heart syndrome	8. 7 <6	42.9 0	<6	14.4 <6	25.8 <6	14.5 7		
Hypospadias	164	0.0 7 82.4	20	12	51	1.5 266	1	
Interrupted aortic arch	<i>133.9</i> 12	82.4 <6	125.9 0	55.0 <6	91.0 13	<i>113.8</i> 33		
	5.0		0.0		12.0	7.2		

Alaska Birth Defects Counts and Prevalence 2011 - 2014 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	22	<6	<6	<6	15	45	
0 1 1 1	<i>9.2</i>			0	13.8	9.9	
Omphalocele	24	<6	<6	8 19.2	25	61	
Pulmonary valve atresia and stenosis	10.0 15	<6	<6	19.2 <6	23.0 29	13.4 57	
runnonary varve auesia and stenosis	6.2	<0	<0	$\triangleleft 0$	29 26.7	12.5	
Rectal and large intestinal	11	<6	<6	<6	16	37	
atresia/stenosis	4.6				14.7	8.1	
Renal agenesis/hypoplasia	15	<6	<6	<6	11	35	
	6.2				10.1	7.7	
Single ventricle	<6	0	<6	<6	<6	11	
		0.0	-			2.4	
Small intestinal atresia/stenosis	10	<6	0	<6	10	27	
Caine hiff de suidheast ea sao an h-bas	4.2	<6	0.0	<6	9.2	5.9 15	
Spina bifida without anencephalus	<6	<0	<6	<0	6 5.5	15 3.3	
Tetralogy of Fallot	13	<6	<6	<6	10	31	
retailingy of Fallot	5.4	~0	~0	~0	9.2	6.8	
Total anomalous pulmonary venous	<6	0	0	<6	<6	<6	
connection	-	0.0	0.0		-	-	
Transposition of the great arteries	9	0	<6	<6	<6	20	
(TGA)	3.7	0.0				4.4	
Tricuspid valve atresia and stenosis	<6	0	0	0	<6	<6	
		0.0	0.0	0.0			
Trisomy 13	<6	0	0	<6	0	<6	
	_	0.0	0.0		0.0		
Trisomy 18	<6	0	0	<6	<6	11	
		0.0	0.0		•	2.4	
Trisomy 21 (Down syndrome)	*	<6	*	*	*	74	
Turner syndrome	<6	0	0	0	<6	16.2 <6	2
Turner syndrome	<0	0.0	0.0	0.0	<0	<0	2
Ventricular septal defect	186	16	28	32	186	470	
venureular septar dereet	77.4	98.1	88.5	76.9	171.3	103.1	
Total live births	24,019	1,631	3,164	4,162	10,857	45,578	3
Male live births	12,252	849	1,589	2,180	5,603	23,384	
Female live births	11,767	782	1,575	1,982	5,254	22,192	

Alaska Birth Defects Counts and Prevalence 2011 - 2014 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	38	0	38					
	9.5	0.0	8.3					
Trisomy 13	<6	<6	<6					
Trisomy 18	*	<6	11 2.4					
Trisomy 21 (Down syndrome)	45	29	74					
	11.3	51.1	16.2					
Total live births	39,887	5,678	45,578	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. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

-<6 indicates cell size suppressed to protect confidentiality or to indicate a case count <6. A rhomboidal star (\diamondsuit) is used to protect confidentiality where case counts in at least one other column are less than 6.

Arizona Birth Defects Counts and Prevalence 2011 - 2015 (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	22	3	35	1	5	67	
	1.2	1.4	2.0	0.6	2.0	1.6	
Anophthalmia/microphthalmia	25 1.3	6 2.9	14 <i>0.8</i>	4 2.5	7 2.7	56 1.3	
Anotia/microtia	16	4	25	3	7	55	
	0.9	1.9	1.5	1.8	2.7	1.3	
Aortic valve stenosis	30	0	18	2	7	57	
Atrioventricular septal defect	1.6 68	0.0 10	1.1 56	1.2 4	2.7 8	<i>1.3</i> 147	1
(Endocardial cushion defect)	4.6	5.9	<i>4.1</i>	3.1	4.0	4.3	1
Biliary atresia	9	0	5	1	3	18	
DI 11 1 1	0.5	0.0	0.3	0.6	1.2	0.4	
Bladder exstrophy	6 0.3	0 0.0	2 0.1	0 0.0	0 <i>0.0</i>	8 0.2	
Choanal atresia	19	5	13	1	1	40	
	1.0	2.4	0.8	0.6	0.4	0.9	
Cleft lip alone	79	5	38	7	14	143	
Cleft lin with eleft nelete	4.2	2.4	2.2	4.3	5.5 31	3.3 271	
Cleft lip with cleft palate	126 6. 7	13 6.2	91 5.3	10 6.2	51 12.2	<i>6.3</i>	
Cleft palate alone	119	13	67	13	23	236	
-	6.3	6.2	3.9	8.0	9.0	5.5	
Coarctation of the aorta	88	10	67	2	14	181	
Common truncus (truncus arteriosus)	4.7 15	4.8 1	3.9 5	1.2 2	5.5 1	<i>4.2</i> 24	
continon truncus (truncus arteriosus)	0.8	0.5	0.3	1.2	0.4	24 0.6	
Congenital cataract	16	3	7	1	5	32	
	0.9	1.4	0.4	0.6	2.0	0.7	
Diaphragmatic hernia	53	4	44	5	9	115	
Double outlet right ventricle	2.8 31	1.9 6	2.6 38	3.1 5	3.5 10	2.7 90	
Double outlet light vehicle	2.1	3.5	2.8	3.9	5.0	2.6	
Ebstein anomaly	14	0	6	1	5	26	
	0.7	0.0	0.4	0.6	2.0	0.6	
Encephalocele	15 0.8	3 1.4	14 <i>0.8</i>	0 0.0	2 0.8	34 <i>0.8</i>	
Esophageal atresia/tracheoesophageal	44	3	38	4	6	9 6	
fistula	2.3	1.4	2.2	2.5	2.4	2.2	
Gastroschisis	112	18	123	8	37	298	
Uslamasanaanhaly	6.0 10	8.6 2	7.2 11	4.9 0	14.5 2	7.0 25	2
Holoprosencephaly	0.7	1.2	0.8	0.0	1.0	0.7	2
Hypoplastic left heart syndrome	46	9	28	3	6	92	
	2.5	4.3	1.6	1.8	2.4	2.2	
Interrupted aortic arch	12	3	8	1	2	26	2
Limb deficiencies (reduction defects)	0.8 51	1.8 11	0.6 37	0.8 3	1.0 12	0.8 114	
Lino denerencies (reduction derects)	2.7	5.2	2.2	1.8	4.7	2.7	
Omphalocele	56	7	32	4	2	101	
	3.0	3.3	1.9	2.5	0.8	2.4	
Pulmonary valve atresia and stenosis	120	14	88	9	23	255	
Pulmonary valve atresia	6.4 48	6. 7 9	5.1 37	5.5 5	9.0 11	6.0 110	
	2.6	4.3	2.2	3.1	4.3	2.6	
Single ventricle	17	2	16	0	1	36	
	0.9	1.0	0.9	0.0	0.4	0.8	
Spina bifida without anencephalus	65	5	48	4	13	136	
spina offica whiteat anoneephalas		21		25	51	37	
Tetralogy of Fallot	3.5 81	2.4 8	2.8 49	2.5 10	5.1 22	3.2 171	

Arizona Birth Defects Counts and Prevalence 2011 - 2015 (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			
Total anomalous pulmonary venous	22	3	38	4	4	71				
connection	1.2	1.4	2.2	2.5	1.6	1.7				
Transposition of the great arteries	75	8	53	3	4	143				
(TGA)	4.0	3.8	3.1	1.8	1.6	3.3				
Dextro-transposition of great arteries	52	2	34	3	2	93				
(d-TGA)	2.8	1.0	2.0	1.8	0.8	2.2				
Tricuspid valve atresia and stenosis	15	2	11	3	3	34				
	0.8	1.0	0.6	1.8	1.2	0.8				
Tricuspid valve atresia	14	2	11	3	3	33				
	0.7	1.0	0.6	1.8	1.2	0.8				
Trisomy 13	22	6	9	1	3	41				
-	1.2	2.9	0.5	0.6	1.2	1.0				
Trisomy 18	40	3	35	5	3	86				
	2.1	1.4	2.0	3.1	1.2	2.0				
Trisomy 21 (Down syndrome)	265	29	217	26	42	580				
· - /	14.1	13.8	12.7	16.0	16.5	13.6				
Total live births	187,608	21,006	171,012	16,236	25,508	427,533				

Arizona Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	291	7	298					
	7.9	1.2	7.0					
Trisomy 13	30	11	41					
-	0.8	1.8	1.0					
Trisomy 18	46	40	86					
	1.3	6.7	2.0					
Trisomy 21 (Down syndrome)	305	273	580					
• • • •	8.3	45.5	13.6					
Total live births	367,457	60,035	427,533					

Notes

1. Data for this condition begin mid-year 2011.

2. Data for this condition begin in 2012.

General comments

*Totals include unknown and/or other.

-Data for 2015 are provisional.

-Data for conditions exclude possible cases.

-Data for conditions exclude terminations.

-Stillborn cases are included in this report if there is a fetal death certificate, regardless of fetal weight or gestational age.

Colorado Birth Defects Counts and Prevalence 2011 - 2015 (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	4	14	0	0	40	Ttotes
A second de la sie (a sie se a la de starsie	0.8	2.8	1.6	0.0	0.0	1.2	
Anophthalmia/microphthalmia	36 1.8	1 0.7	22 2.5	2 1.7	1 4.8	68 2.1	
Anotia/microtia	22	1	43	4	0	87	
	1.1	0.7	<i>4.8</i>	3.3	0.0	2.7	
Aortic valve stenosis	66 3.3	3 2.1	26 2.9	2 1.7	0 0.0	102 <i>3.1</i>	
Atrial septal defect	2,369	235	1,173	152	35	4,290	
	116.8	163.0	130.9	125.7	166.6	130.9	
Atrioventricular septal defect (Endocardial cushion defect)	51 2.5	7 4.9	25 2.8	1 0.8	0 0.0	96 2.9	
Biliary atresia	26	0	12	0	1	47	
	1.3	0.0	1.3	0.0	4.8	1.4	
Bladder exstrophy	6 0.3	0 0.0	2 0.2	0 0.0	0 0.0	10 0.3	
Choanal atresia	38	1	17	1	0	61	
	1.9	0.7	1.9	0.8	0.0	1.9	
Cleft lip alone	81	7	38	4	0	138	
Cleft lip with cleft palate	4.0 150	4.9 7	4.2 78	3.3 6	0.0 2	4.2 259	
	7.4	4.9	8.7	5.0	9.5	7.9	
Cleft palate alone	175	8	70	19	3	298	
Cloacal exstrophy	8.6 116	5.5 16	7 .8 78	15.7 11	14.3 1	9.1 228	
Cloacal exsuopily	5.7	10	8.7	9.1	4.8	7.0	
Clubfoot	363	16	163	18	6	619	
	17.9	11.1	18.2	14.9	28.6	18.9	
Coarctation of the aorta	188 9.3	15 10.4	65 7.3	4 3.3	0 0.0	297 9.1	
Common truncus (truncus arteriosus)	17	0	6	0	0	26	
	0.8	0.0	0.7	0.0	0.0	0.8	
Congenital cataract	46 2.3	1 0.7	21 2.3	3 2.5	1 4.8	80 2.4	
Congenital posterior urethral valves	2.5	3	9	2.5	0	55	1
	2.7	4.1	2.0	3.3	0.0	3.3	
Deletion 22q11.2	24	3	15	0	0	46	
Diaphragmatic hernia	1.2 32	2.1 4	<i>1.7</i> 17	0.0 1	0.0 0	1.4 59	
	1.6	2.8	1.9	0.8	0.0	1.8	
Double outlet right ventricle	31	6	23	3	0	69	
Ebstein anomaly	1.5 16	4.2 0	2.6 3	2.5 2	0.0 0	2.1 25	
	0.8	0.0	0.3	ī.7	0.0	0.8	
Encephalocele	14	4	13	1	0	37	
Esophageal atresia/tracheoesophageal	0.7 91	2.8 2	1.5 37	0.8 5	0.0 0	<i>1.1</i> 148	
fistula	<i>4.5</i>	1.4	<i>4.1</i>	<i>4.1</i>	0.0	4.5	
Gastroschisis	74	6	46	2	3	145	
YY 1 1 1	3.6	4.2	5.1	1.7	14.3	4.4	
Holoprosencephaly	13 0.6	1 0.7	13 1.5	2 1.7	0 <i>0.0</i>	32 1.0	
Hypoplastic left heart syndrome	61	3	25	1	0	93	
	3.0	2.1	2.8	0.8	0.0	2.8	
Hypospadias	1,314 126.6	96 129.9	322 7 0.2	46 75.6	14 <i>130.2</i>	1,880 <i>112.1</i>	1
Interrupted aortic arch	42	9	22	2	0	81	
	2.1	6.2	2.5	1.7	0.0	2.5	
Limb deficiencies (reduction defects)	81	6	44	1	0	150	
	4.0	4.2	4.9	0.8	0.0	4.6	

Colorado Birth Defects Counts and Prevalence 2011 - 2015 (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
Omphalocele	37	2	18	2	1	82	
-	1.8	1.4	2.0	1.7	4.8	2.5	
Pulmonary valve atresia and stenosis	123	15	57	6	3	227	
-	6.1	10.4	6.4	5.0	14.3	6.9	
Pulmonary valve atresia	35	7	21	0	1	70	
	1.7	4.9	2.3	0.0	4.8	2.1	
Rectal and large intestinal	84	11	47	7	3	173	
atresia/stenosis	4.1	7.6	5.2	5.8	14.3	5.3	
Renal agenesis/hypoplasia	107	10	45	6	4	199	
	5.3	6.9	5.0	5.0	19.0	6.1	
Single ventricle	12	2	5	0	1	24	
-	0.6	1.4	0.6	0.0	4.8	0.7	
Small intestinal atresia/stenosis	93	7	61	7	1	176	
	4.6	4.9	6.8	5.8	4.8	5.4	
Spina bifida without anencephalus	58	3	38	2	1	115	
	2.9	2.1	4.2	1.7	4.8	3.5	
Tetralogy of Fallot	59	3	38	1	2	105	
	2.9	2.1	4.2	0.8	9.5	3.2	
Total anomalous pulmonary venous	18	1	17	2	0	40	
connection	0.9	0.7	1.9	1.7	0.0	1.2	
Transposition of the great arteries	49	3	19	5	0	78	
(TGA)	2.4	2.1	2.1	4.1	0.0	2.4	
Dextro-transposition of great arteries	39	3	17	5	0	65	
(d-TGA)	1.9	2.1	1.9	4.1	0.0	2.0	
Tricuspid valve atresia and stenosis	28	7	10	0	0	48	
	1.4	4.9	1.1	0.0	0.0	1.5	
Tricuspid valve atresia	25	7	10	0	0	45	
	1.2	4.9	1.1	0.0	0.0	1.4	
Trisomy 13	21	4	12	2	0	85	
2	1.0	2.8	1.3	1.7	0.0	2.6	
Trisomy 18	31	7	16	7	0	151	
5	1.5	4.9	1.8	5.8	0.0	4.6	
Trisomy 21 (Down syndrome)	254	30	187	13	3	739	
5 (5)	12.5	20.8	20.9	10.7	14.3	22.6	
Turner syndrome	25	4	17	2	0	76	2
5	2.5	5.7	3.9	3.3	0.0	4.8	
Ventricular septal defect	987	77	522	53	18	1,787	
	48.7	53.4	58.3	43.8	85.7	54.5	
Total live births	202,823	14,416	89,608	12,097	2,101	327,683	3
Male live births	103,791	7,392	45,877	6,084	1,075	167,681	
Female live births	99,028	7,023	43,729	6,012	1,026	159,994	

Colorado Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	133	6	145					
	4.9	1.0	4.4					
Trisomy 13	29	15	85					
-	1.1	2.6	2.6					
Trisomy 18	41	25	151					
	1.5	4.3	4.6					
Trisomy 21 (Down syndrome)	247	263	739					
	9.2	45.3	22.6					
Total live births	269,556	58,026	327,683	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. Total live births includes unknown gender.

General comments *Totals include unknown and/or other.

Delaware Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	Alaska Native, Non-Hispanic	Total*	Notes	
Anencephalus	3	2 1.4	0	0 <i>0.0</i>	0 <i>0.0</i>	5		
Anophthalmia/microphthalmia	1.1 3 1.1	1.4 5 3.5	0.0 3 4.3	0.0 0 0.0	0.0 0.0	1.0 11 2.1		
Anotia/microtia	11 3.9	4 2.8	9 12.9	2 7.3	0 0.0	26 5.0		
Aortic valve stenosis	5 1.8	1 0.7	3 4.3	1 3.7	0 0.0	10 1.9		
Atrial septal defect	1.8 82 29.2	38 27.0	4.5 30 43.1	3.7 7 25.6	0.0 0.0	1.9 160 30.5	1	
Atrioventricular septal defect (Endocardial cushion defect) Biliary atresia	14 5.0 1	13 9.2 1	6 8.6 0	0 0.0 0	0 0.0 0	34 6.5 4		
Bladder exstrophy	0.4 2	0.7 1	0.0 0	0.0 0	0.0 0	0.8 3		
Choanal atresia	0.7 2 0.7	0.7 3 2.1	0.0 1 1.4	0.0 0 0.0	0.0 0 0.0	0.6 6 1.1		
Cleft lip alone	9 3.2	1 0.7	5 7.2	1 3.7	0 0.0	1.1 16 3.1		
Cleft lip with cleft palate	18 6.4	8 5.7	5 7.2	2 7.3	0 <i>0.0</i>	35 6.7		
Cleft palate alone	21 7.5	10 7.1	6 8.6	0 0.0	0.0 0.0	37 7.1	2	
Cloacal exstrophy	1 0.4	1 0.7	0 0.0	0 0.0	0 0.0	2 0.4		
Clubfoot	43 15.3	19 <i>13.5</i>	12 17.2	4 14.6	0 <i>0.0</i>	81 15.5		
Coarctation of the aorta	24 8.6	6 <i>4.3</i>	5 7.2	4 14.6	0 0.0	39 7.4		
Common truncus (truncus arteriosus)	1 0.4	1 0.7	1 1.4	0 0.0	0 0.0	3 0.6		
Congenital cataract	6 2.1	1 0.7	1 1.4	2 7.3	0 <i>0.0</i>	10 1.9		
Congenital posterior urethral valves	3 2.1	5 7.0	0 <i>0.0</i>	1 7.0	0 <i>0.0</i>	9 3.4	3	
Craniosynostosis	17 6.1	6 4.3	1 1.4	0 <i>0.0</i>	0 0.0	25 4.8		
Deletion 22q11.2	6 2.1	1 0.7	0 <i>0.0</i>	0 0.0	0 0.0	7 1.3		
Diaphragmatic hernia	5 1.8	0 <i>0.0</i>	0 0.0	1 3.7	0 0.0	6 1.1		
Double outlet right ventricle	3 1.1	3 2.1	1 1.4	1 3.7	0 0.0	9 1.7		
Ebstein anomaly	2 0.9	0 <i>0.0</i>	0 0.0	0 0.0	0 0.0	2 0.5		
Encephalocele	1 0.4	3 2.1	1 1.4	0 <i>0.0</i>	0 <i>0.0</i>	5 1.0		
Esophageal atresia/tracheoesophageal fistula	5 1.8	1 0.7	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	6 1.1		
Gastroschisis	19 6.8	11 7.8	5 7.2	2 7.3	0 0.0	38 7.3		
Holoprosencephaly	1 0.4	4 2.8	3 4.3	0 0.0	0 0.0	8 1.5		
Hypoplastic left heart syndrome	10 3.6	2.0 2 1.4	3 4.3	0 0 0.0	0 0 0.0	1.5 15 2.9		
Hypospadias	145 101.6	52 7 2.8	14 4 0.1	14 97.6	0 0.0	228 85.7	4	
Interrupted aortic arch	0 0.0	0 0.0	1 2.3	0 0.0	0 0.0	1 0.3		

Delaware Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	22	13	5	3	0	43	
	7.8	9.2	7.2	11.0	0.0	8.2	
Omphalocele	3	7	3	0	0	13	
	1.1	5.0	4.3	0.0	0.0	2.5	
Pulmonary valve atresia and stenosis	34	29	7	0	1	73	
	12.1	20.6	10.1	0.0	91.7	13.9	
Pulmonary valve atresia	8	3 2.1	4	0	0	15 2.9	
Rectal and large intestinal	2.9 17	6	5.7 0	0.0 2	0.0 0	2.9 25	
atresia/stenosis	6.1	4.3	0.0	2 7.3	0.0	23 4.8	
Renal agenesis/hypoplasia	27	7	2	1	0.0	37	
Renar agenesis/nypopiasia	9.6	5.0	2.9	3.7	0.0	7.1	
Single ventricle	1	1	1	0	0	3	
Single venuiele	0.4	0.7	1.4	0.0	0.0	0.6	
Small intestinal atresia/stenosis	10	8	4	0	0	22	
	3.6	5.7	5.7	0.0	0.0	4.2	
Spina bifida without anencephalus	3	5	3	0	0	11	
	1.1	3.5	4.3	0.0	0.0	2.1	
Tetralogy of Fallot	12	7	1	1	0	21	
	4.3	5.0	1.4	3.7	0.0	4.0	
Total anomalous pulmonary venous	3	1	5	1	0	10	
connection	1.3	0.9	9.0	4.5	0.0	2.4	
Transposition of the great arteries	10	2	3	0	0	15	
(TGA)	3.6	1.4	4.3	0.0	0.0	2.9	
Dextro-transposition of great arteries	1	0	1	0	0	2	
(d-TGA)	0.4	0.0	1.4	0.0	0.0	0.4	
Tricuspid valve atresia and stenosis	2	3	1	1	0	7	
Tuiidli-	0.7	2.1	1.4	3.7	0.0	<i>1.3</i> 4	
Tricuspid valve atresia	2	1 0.7	0 0.0	1 3.7	0		
Trisomy 13	0. 7 5	0. / 3	0.0 1	3./ 1	0.0 0	0.8 10	
Thisonly 15	.s	3 2.1	1 1.4	3.7	0.0	10 1.9	
Trisomy 18	8	1	4	2	0.0	1.5	
Thisonly 16	2.9	0.7	5.7	7.3	0.0	2.9	
Trisomy 21 (Down syndrome)	40	16	16	5	0	78	
Theory 21 (Down Syndrome)	14.3	11.3	23.0	18.3	0.0	14.9	
Turner syndrome	4	0	1	0	0	6	5
5	2.9	0.0	2.9	0.0	0.0	2.3	
Ventricular septal defect	240	91	61	22	0	423	6
-	85.6	64.5	87.7	80.4	0.0	80.7	
Total live births	28,052	14,099	6,959	2,738	109	52,397	
Male live births	14,267	7,138	3,487	1,435	39	26,592	
Female live births	13,785	6,961	3,472	1,303	70	25,805	

Delaware Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	36	2	38					
	8.0	2.6	7.3					
Trisomy 13	8	2	10					
-	1.8	2.6	1.9					
Trisomy 18	3	12	15					
	0.7	15.8	2.9					
Trisomy 21 (Down syndrome)	41	37	78					
• • • •	9.2	48.7	14.9					
Total live births	44,801	7,596	52,397					

Notes

1. Data for this condition include atrial septal fenestrations and exclude atrial septal defects that self-close (not present after a month), which are considered patent foramen ovales.

2. Data for this condition include Pierre Robin anomalies with cleft palate.

3. Data for this condition 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.

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 include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.

6. Data for this condition include probable cases only if the defect was found prenatally and the fetus died without a confirmatory autopsy.

General comments

*Totals include unknown and/or other.

-All heart defects require an echocardiogram report.

-Fetal deaths and terminations are included if the fetus weighed 350 grams or higher or 20 weeks gestation or greater.

Florida Birth Defects Counts and Prevalence 2011 - 2015 (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	42	26	22	<5	0	92	
Anophthalmia/microphthalmia	0.9 48	1.1 29	0. 7 36	<5	0.0 0	0.9 116	
Anophulainia/merophulainia	1.0	1.2	1.2	<5	0.0	1.1	
Anotia/microtia	30	17	45	8	0	104	
Aortic valve stenosis	0.6 71	0.7 20	1.5 37	2.5 <5	0.0 0	1.0 136	
Aorue valve stenosis	1.5	0.8	1.2	<5	0.0	130 1.3	
Atrial septal defect	4,948	3,110	3,978	275	21	12,655	
	103.4	131.1	132.3	86.2	161.2	117.4	1
Atrioventricular septal defect (Endocardial cushion defect)	197 4.1	122 5.1	88 2.9	10 3.1	<5	432 4.0	1
Biliary atresia	44	32	17	7	0	102	
	0.9	1.3	0.6	2.2	0.0	0.9	
Bladder exstrophy	15	<5	<5	0	0	24	
Choanal atresia	<i>0.3</i> 102	37	60	0.0 <5	0.0 <5	<i>0.2</i> 209	
	2.1	1.6	2.0	C C	c .	1.9	
Cleft lip alone	150	36	53	<5	0	249	
Cleft lip with cleft palate	3.1 270	1.5 92	1.8 157	15	0.0 <5	2.3 549	
Cleft lip with cleft palate	5.6	92 3.9	5.2	4.7	< 3	5.1	
Cleft palate alone	280	81	135	27	<5	537	
	5.8	3.4	4.5	8.5	-	5.0	
Cloacal exstrophy	275 5. 7	148 6.2	180 6.0	10 3.1	<5	630 5.8	
Clubfoot	764	270	374	26	<5	1,471	
	16.0	11.4	12.4	8.2		13.7	
Coarctation of the aorta	387	143	161	15	0	726	
Common truncus (truncus arteriosus)	8.1 31	6.0 14	5.4 20	4. 7 <5	0.0 0	6. 7 69	
continon traneas (traneas archosus)	0.6	0.6	0.7	~5	0.0	0.6	
Congenital cataract	67	21	34	0	0	126	
Componited mostorion smothers welves	1.4 48	0.9 47	1.1 20	0.0 <5	0.0 0	<i>1.2</i> 116	2
Congenital posterior urethral valves	40 1.9	47 3.9	20 1.3	< 3	0.0	2.1	2
Craniosynostosis	30	7	20	0	0	58	
	0.6	0.3	0.7	0.0	0.0	0.5	
Deletion 22q11.2	16 0.3	6 0.3	<5	0 0.0	0 0.0	27 0.3	
Diaphragmatic hernia	141	71	90	9	<5	318	
	2.9	3.0	3.0	2.8		3.0	
Double outlet right ventricle	111	56	66	9	<5	254	
Ebstein anomaly	2.3 44	2.4 13	2.2 16	2.8 <5	0	2.4 78	
	0.9	0.5	0.5	~	0.0	0.7	
Encephalocele	37	21	22	<5	0	83	
Esophageal atresia/tracheoesophageal	0.8 113	0.9 60	0. 7 65	8	0.0 <5	0.8 252	
fistula	2.4	2.5	0.3 2.2	° 2.5	< 3	2.32 2.3	
Gastroschisis	275	60	125	10	<5	478	3
	5.7	2.5	4.2	3.1	0	4.4	
Holoprosencephaly	199 4.2	121 5.1	121 4.0	12 3.8	0 <i>0.0</i>	463 4.3	
Hypoplastic left heart syndrome	4.2 172	81	4.0 69	10	0	4.5 341	
	3.6	3.4	2.3	3.1	0.0	3.2	
Hypospadias	2,205	807	845	85	5	4,032	2
Interrupted aortic arch	89.5 44	67.0 24	54.9 31	<i>51.7</i> <5	7 3.1 0	73.0 107	
menupied dorde dien	0.9	1.0	1.0	~~	0.0	107 1.0	

Florida Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	178	83	100	12	<5	381	
	3.7	3.5	3.3	3.8		3.5	
Omphalocele	114	83	40	<5	0	243	3
	2.4	3.5	1.3		0.0	2.3	
Pulmonary valve atresia and stenosis	389	290	275	17	0	1,001	
	8.1	12.2	9.1	5.3	0.0	9.3	
Pulmonary valve atresia	61	37	38	<5	0	148	
N . 1 . 1	1.3	1.6	1.3	10	0.0	1.4	
Rectal and large intestinal	187	91	120	12	<5	426	
atresia/stenosis	3.9	3.8	4.0	3.8	-5	<i>4.0</i>	
Renal agenesis/hypoplasia	274	137	154	11	<5	592	
of 1	5.7	5.8	5.1	3.4	0	5.5	
Single ventricle	68	34	41	5	0	151	
Small intestinal atresia/stenosis	1.4	1.4	1.4	1.6	0.0 0	1.4	
Small intestinal atresia/stenosis	222	102	125	17	0.0	477	
Series hif do without on an aseholys	4.6 146	<i>4.3</i> 44	4.2 79	5.3 8	0.0	4.4 280	
Spina bifida without anencephalus	3.0	44 1.9	2.6	° 2.5	0.0	280 2.6	
Tetralogy of Fallot	3.0 247	115	2.0 124	2.5 12	0.0 <5	2.0 520	
Tetralogy of Fallot	5.2	4.8	124 4.1	3.8	< 3	320 4.8	
Total anomalous pulmonary venous	38	4.0 23	4.1 31		0	4.0 96	
connection	0.8	23 1.0	1.0	< 5	0.0	90 0.9	
Transposition of the great arteries	148	44	60	6	<5	266	
(TGA)	3.1	1.9	2.0	1.9	~5	2.5	
Dextro-transposition of great arteries	122	36	54	5	<5	225	
(d-TGA)	2.5	1.5	1.8	1.6	~5	2.1	
Tricuspid valve atresia and stenosis	48	29	22	<5	0	105	4
Theuspid valve allesia and stenosis	1.0	1.2	0.7	~0	0.0	1.0	-
Trisomy 13	52	29	24	0	0	106	
Theory To	1.1	1.2	0.8	0.0	0.0	1.0	
Trisomy 18	81	68	55	9	0	220	
Theory To	1.7	2.9	1.8	2.8	0.0	2.0	
Trisomy 21 (Down syndrome)	613	301	408	43	<5	1,413	
)	12.8	12.7	13.6	13.5		13.1	
Turner syndrome	44	12	31	<5	0	92	5
2	1.9	1.0	2.1		0.0	1.8	-
Ventricular septal defect	2,948	1,360	2,111	157	9	6,765	6
1	61.6	57.3	70.2	49.2	69.1	62.8	
Total live births	478,733	237,275	300,590	31,891	1,303	1,077,568	7
Male live births	246,326	120,390	154,032	16,443	684	552,176	
Female live births	232,406	116,882	146,558	15,447	619	525,384	

Florida Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	469	9	478	3				
	5.2	0.5	4.4					
Trisomy 13	74	32	106					
-	0.8	1.9	1.0					
Trisomy 18	107	113	220					
	1.2	6.6	2.0					
Trisomy 21 (Down syndrome)	706	707	1,413					
	7.8	41.5	13.1					
Total live births	907,089	170,408	1,077,568	7				

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 may differ from previous reports due to ICD-9-CM coding system changes.

4. Data for this condition include congenital tricuspid stenosis.

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 probable cases.

7. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

-Data for conditions only includes live births.

Georgia (Metropolitan Atlanta Congenital Defects Program) Birth Defects Counts and Prevalence 2011 - 2015 (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	15	10	1	0	51	Ttotes
Anophthalmia/microphthalmia	3.0 11	1.9 12	2.8 7	0. 7 0	0.0 0	2.7 32	
Anotia/microtia	2.1 7	1.5 5 0.6	1.9 10 2.8	0.0 4 2.7	0.0 0 0.0	1.7 28	
Aortic valve stenosis	1.3 16 3.0	0.6 4 0.5	2.8 7 1.9	2.7 0 0.0	0.0 0 0.0	1.5 29 1.5	
Atrial septal defect	74 14.0	175 22.2	44 12.2	16 10.8	0.0 0.0	341 17.8	
Atrioventricular septal defect (Endocardial cushion defect) Biliary atresia	33 6.2 2	57 7.2 1	13 3.6 2	3 2.0 0	0 <i>0.0</i> 1	119 6.2 9	
Bladder exstrophy	0.4 3	0.1 1 0.1	0.6 0	0.0 0 0.0	76.9 0 0.0	0.5 5 0.3	
Choanal atresia	0.6 3 0.6	0.1 8 1.0	0.0 4 1.1	0.0 0 0.0	0.0 0 0.0	0.3 15 0.8	
Cleft lip alone	24 4.5	1.0 14 1.8	1.1 11 3.1	6 4.1	0.0 0.0	56 2.9	
Cleft lip with cleft palate	27 5.1	32 4.1	21 5.8	10 6.8	0 0.0	106 5.5	
Cleft palate alone	26 4.9	28 3.6	14 3.9	11 7.4	0 <i>0.0</i>	86 4.5	
Cloacal exstrophy	0 <i>0.0</i>	1 0.1	0 0.0	1 0.7	0 <i>0.0</i>	2 0.1	
Clubfoot	63 11.9	114 <i>14.5</i>	34 9.5	16 10.8	1 7 6.9	249 13.0	
Coarctation of the aorta	43 8.1	39 5.0	19 5.3	6 4.1	0 0.0	114 6.0	
Common truncus (truncus arteriosus)	2 0.4	4 0.5	1 0.3	3 2.0	0 0.0	10 0.5	
Congenital cataract	2 0.4	13 1.7	2 0.6	3 2.0	0 0.0	25 1.3	
Congenital posterior urethral valves	4 1.5	19 4.8	7 3.8	2 2.7	0 0.0	37 3.8	1
Craniosynostosis	19 3.6	17 2.2 11	8 2.2 5	4 2.7	1 76.9	60 3.1	
Deletion 22q11.2 Diaphragmatic hernia	4 0.8 15	11 1.4 21	5 1.4 9	1 0.7 3	0 0.0 0	22 1.2 59	
Double outlet right ventricle	2.8 6	2. 7 21	2.5 9	2.0 4	0.0 0	<i>3.1</i> 45	
Ebstein anomaly	1.1 0	2.7 5	2.5 2	2.7 1	0.0 0	2.4 8	
Encephalocele	0.0 1	0.6 6	0.6 4	0. 7 2	0.0 0	0.4 15	
Esophageal atresia/tracheoesophageal	0.2 13	0.8 22	<i>1.1</i> 4	1.4 0	0.0 0	0.8 41	
fistula	2.5	2.8	1.1	0.0	0.0	2.1	
Gastroschisis	22 4.2	25 3.2	19 5.3	2 1.4	0 <i>0.0</i>	76 4.0	
Holoprosencephaly	11 2.1	15 1.9	6 1.7	2 1.4	0 0.0	41 2.1	
Hypoplastic left heart syndrome	16 3.0	19 2.4	8 2.2	4 2.7	0 0.0	51 2.7	
Hypospadias	204 7 5.4	256 64.2	55 30.1	36 47.8	1 149.3	626 64.5	1
Interrupted aortic arch	4 0.8	5 0.6	2 0.6	0 <i>0.0</i>	0 <i>0.0</i>	14 0. 7	

Georgia (Metropolitan Atlanta Congenital Defects Program) Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	15	31	13	2	0	70	
	2.8	3.9	3.6	1.4	0.0	3.7	
Omphalocele	9	31	8	4	0	65	
	1.7	3.9	2.2	2.7	0.0	3.4	
Pulmonary valve atresia and stenosis	44	58	26	10	0	156	
	8.3	7.4	7.2	6.8	0.0	8.2	
Pulmonary valve atresia	11	22	6	3	0	44	
	2.1	2.8	1.7	2.0	0.0	2.3	
Rectal and large intestinal	26 4.9	31 3.9	17 4.7	5 3.4	0	81 4.2	
atresia/stenosis	4.9 35	3.9 48	4. / 10	3.4 9	0.0 0	4. 2 114	
Renal agenesis/hypoplasia	55 6.6	48 6.1	2.8	9 6.1	0.0	6.0	
Single ventricle	2	7	5	2	0.0	18	
Single venuicie	2 0.4	0.9	, 1.4	2 1.4	0.0	0.9	
Small intestinal atresia/stenosis	18	27	7	0	0	56	
Sindii mestindi difesid/stenosis	3.4	3.4	1.9	0.0	0.0	2.9	
Spina bifida without anencephalus	23	23	8	3	0	65	
	4.3	2.9	2.2	2.0	0.0	3.4	
Tetralogy of Fallot	26	35	5	6	0	79	
	4.9	4.4	1.4	4.1	0.0	4.1	
Total anomalous pulmonary venous	6	6	7	5	0	25	
connection	1.1	0.8	1.9	3.4	0.0	1.3	
Transposition of the great arteries	19	14	10	1	1	54	
(TGA)	3.6	1.8	2.8	0.7	76.9	2.8	
Dextro-transposition of great arteries	18	11	7	1	1	47	
(d-TGA)	3.4	1.4	1.9	0.7	76.9	2.5	
Tricuspid valve atresia and stenosis	7	15	7	3	0	32	
	1.3	1.9	1.9	2.0	0.0	1.7	
Tricuspid valve atresia	6	4	2	3	0	15	
	1.1	0.5	0.6	2.0	0.0	0.8	
Trisomy 13	12	17	6	2	0	42	
	2.3	2.2	1.7	1.4	0.0	2.2	
Trisomy 18	16	29	9	5	0	74	
	3.0	3.7	2.5	3.4	0.0	3.9	
Trisomy 21 (Down syndrome)	89	102 12.9	64	18 12.2	0 0.0	311 16.3	
T	16.8		17.8				2
Turner syndrome	10 3.9	18 4.6	0 0.0	3 4.1	0 <i>0.0</i>	35 3.7	2
Ventricular septal defect	340	4.0 340	237	4.1 68	1	1.093	
venureulai septai delect	64.3	43.2	65.9	45.9	76.9	1,095 57.2	
Total live births	52,893	43.2 78,787	35,956	43.9 14,809	130	191,043	
Male live births	27,062	39,858	18,286	7,530	67	97,111	
Female live births	25,831	38,929	17,670	7,279	63	93,931	

Georgia (Metropolitan Atlanta Congenital Defects Program) Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	69	5	76				
	4.6	1.2	4.0				
Trisomy 13	27	15	42				
	1.8	3.7	2.2				
Trisomy 18	23	48	74				
	1.5	11.7	3.9				
Trisomy 21 (Down syndrome)	137	169	311				
• • • •	9.1	41.2	16.3				
Total live births	149,980	41,046	191,043				

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

*Totals include unknown and/or other.

-Cases for which the date of delivery was unknown are included in the year of their last known prenatal test.

-Data for conditions prior to 2012 include 5 counties, from 2012-2015 only 3 of the original 5 counties are included.

-Elective terminations include all gestational ages.

-Live births include gestational ages greater than or equal to 20 weeks.

-Stillbirths include gestational ages greater than or equal to 20 weeks.

Hawaii Birth Defects Counts and Prevalence 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity								
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	Alaska Native, Non-Hispanic	Total*	Notes		
Anencephalus	2 4.7	0 <i>0.0</i>	0 <i>0.0</i>	1 0.7	0 0.0	4 2.1			
Anotia/microtia	4.7 1 2.3	0.0 0.0	0.0 0 0.0	0.7 0 0.0	0.0 0.0	1 0.5			
Atrial septal defect	7 16.3	0 0.0	4 134.2	18 13.3	0 0.0	35 18.4			
Atrioventricular septal defect (Endocardial cushion defect)	1 2.3	0 <i>0.0</i>	1 33.6	3 2.2	0 <i>0.0</i>	5 2.6			
Biliary atresia	1 2.3	0 <i>0.0</i>	0 <i>0.0</i>	2 1.5	0 0.0	3 1.6			
Bladder exstrophy	1 2.3	0 0 0.0	0.0 0.0	0 0.0	0.0 0.0	1 0.5			
Choanal atresia	1 2.3	0 0.0	0 0.0	0 0.0	0 0.0	1 0.5			
Cleft lip alone	2 4.7	0 0.0	0 0.0	4 3.0	0 0.0	7 3.7			
Cleft lip with cleft palate	1 2.3	0 0.0	0 0.0	6 4.4	0 0.0	8 4.2			
Cleft palate alone	3 7.0	0 0.0	2 67.1	8 5.9	0 0.0	14 7.4			
Coarctation of the aorta	1 2.3	0 0.0	0 0.0	3 2.2	0 0.0	4 2.1			
Ebstein anomaly	0 0.0	0 0.0	0 <i>0.0</i>	1 0.7	0 <i>0.0</i>	1 0.5			
Encephalocele	0 0.0	0 0.0	0 0.0	2 1.5	0 <i>0.0</i>	2 1.1			
Esophageal atresia/tracheoesophageal fistula	1 2.3	0 <i>0.0</i>	0 <i>0.0</i>	3 2.2	0 0.0	5 2.6			
Gastroschisis	2 4. 7	0 0.0	0 <i>0.0</i>	9 6. 7	0 <i>0.0</i>	12 6.3			
Hypoplastic left heart syndrome	0 0.0	0 0.0	0 0.0	2 1.5	0 0.0	3 1.6			
Hypospadias	6 27.6	0 0.0	2 123.5	40 57.8	0 0.0	54 56.0	1		
Omphalocele	0 0.0	0 0.0	1 33.6	3 2.2	0 0.0	4 2.1			
Pulmonary valve atresia and stenosis	5 11.7	0 0.0	1 33.6	5 3.7	0 0.0	12 6.3			
Pulmonary valve atresia	0 <i>0.0</i>	0 0.0	0 <i>0.0</i>	2 1.5	0 0.0	2 1.1			
Rectal and large intestinal atresia/stenosis	3 7.0	0 <i>0.0</i>	0 0.0	8 5.9	0 <i>0.0</i>	12 6.3			
Renal agenesis/hypoplasia	1 2.3	0 0.0	0 <i>0.0</i>	6 4.4	0 <i>0.0</i>	8 <i>4.2</i>			
Spina bifida without anencephalus	0 <i>0.0</i>	0 0.0	0 0.0	1 0.7	0 0.0	1 0.5			
Tetralogy of Fallot	1 2.3	0 0.0	0 <i>0.0</i>	1 0.7	0 <i>0.0</i>	2 1.1			
Total anomalous pulmonary venous connection	0 0.0	0 0.0	0 0.0	2 1.5	0 0.0	2 1.1			
Transposition of the great arteries	0	1	1	6	0	8			
(TGA) Tricuspid valve atresia and stenosis	0.0 0 0.0	20.0 0	33.6 1	4.4 3 2.2	0.0 0	<i>4.2</i> 4 2.1			
Tricuspid valve atresia	0.0 0 0.0	0.0 0 0.0	33.6 1 22.6	2.2 3 2.2	0.0 0	2.1 4 2.1			
Trisomy 13	0.0 0 0.0	0.0 0 0.0	33.6 0 0 0	2.2 2 1.5	0.0 0 0.0	2.1 2			
Trisomy 18	0.0 3 7.0	0.0 0 0.0	0.0 1 22.6	1.5 6	0.0 0	1.1 14 7.4			
	7.0	0.0	33.6	4.4	0.0	7.4			

Hawaii Birth Defects Counts and Prevalence 2012 (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			
Trisomy 21 (Down syndrome)	5 11.7	0 0.0	2 67.1	14 10.3	0 0.0	27 14.2				
Turner syndrome	1	0	0	1	0	2	2			
Ventricular septal defect	4.7 8 18.7	0.0 0 0.0	0.0 4 134.2	1.5 29 21.4	0.0 0 0.0	2.1 50 26.3				
Total live births	4,282	501	298	13,532	237	18,985				
Male live births	2,172	251	162	6,918	113	9,642				
Female live births	2,110	250	136	6,614	124	9,343				

Hawaii Birth Defects Counts and Prevalence 2012 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	12	0	12				
	7.7	0.0	6.3				
Trisomy 13	1	1	2				
-	0.6	2.9	1.1				
Trisomy 18	8	7	15				
	5.2	20.6	7.9				
Trisomy 21 (Down syndrome)	13	16	29				
• • • •	8.4	47.2	15.3				
Total live births	15,497	3,392	18,985				

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

*Totals include unknown and/or other.

Illinois Birth Defects Counts and Prevalence 2011 - 2015 (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	59	20	41	9	0	132	
A second de a los is /second de a los is	1.3	1.5	3.0	1.9 5	0.0	1.7	
Anophthalmia/microphthalmia	81 1.8	26 2.0	48 3.5	5 1.0	2 34.6	162 2.0	
Anotia/microtia	63	13	75	7	0	158	
	1.4	1.0	5.4	1.5	0.0	2.0	
Aortic valve stenosis	72 1.6	19 1.4	35 2.5	8 1.7	0 <i>0.0</i>	134 1.7	
Atrial septal defect	1,226	433	564	152	8	2,389	
	26.8	<i>32.7</i>	<i>41.0</i>	31.8	138.4	<i>30.1</i>	1
Atrioventricular septal defect (Endocardial cushion defect)	213 4.7	78 5.9	84 6.1	17 3.6	0 <i>0.0</i>	393 5.0	I
Biliary atresia	9	6	6	5	0	26	
	0.2	0.5	0.4	1.0	0.0	0.3	
Bladder exstrophy	11 0.2	2 0.2	6 0.4	1 0.2	0 <i>0.0</i>	20 <i>0.3</i>	
Choanal atresia	52	17	23	2	0	94	
	1.1	1.3	1.7	0.4	0.0	1.2	
Cleft lip alone	143 <i>3.1</i>	39 2.9	43 <i>3.1</i>	15 3.1	2 34.6	243 <i>3.1</i>	
Cleft lip with cleft palate	219	62	126	22	1	430	
	4.8	4.7	9.1	4.6	17.3	5.4	
Cleft palate alone	255 5.6	58 4.4	92 6.7	22 4.6	2 34.6	429 5.4	
Cloacal exstrophy	12	3	4	1	0	20	
	0.3	0.2	0.3	0.2	0.0	0.3	
Clubfoot	436	137 <i>10.3</i>	191 <i>13.9</i>	37	2	804 10.1	
Coarctation of the aorta	9.5 199	41	86	7.8 18	34.6 1	345	
	4.4	3.1	6.2	3.8	17.3	4.3	
Common truncus (truncus arteriosus)	25	3	13	2	0	43	
Congenital cataract	0.5 41	0.2 28	0.9 16	0.4 4	0.0 0	0.5 89	
	0.9	2.1	1.2	0.8	0.0	1.1	
Congenital posterior urethral valves	36	19	12	3	0	70	2
Craniosynostosis	1.5 128	2.8 24	1.7 51	1.2 6	0.0 0	1.7 209	
	2.8	1.8	3.7	1.3	0.0	2.6	
Deletion 22q11.2	31	19	13	5	0	68	
Diaphragmatic hernia	0.7 134	<i>1.4</i> 31	0.9 53	1.0 10	0.0 1	0.9 230	
1 0	2.9	2.3	3.8	2.1	17.3	2.9	
Double outlet right ventricle	64	32	39	11	0	146	
Ebstein anomaly	1.4 26	2.4 6	2.8 18	2.3 3	0.0 0	1.8 53	
Losem anomary	0.6	0.5	1.3	0.6	0.0	0.7	
Encephalocele	24	15	17	2	0	58	
Esophageal atresia/tracheoesophageal	0.5 121	1.1 26	1.2 36	0.4 9	0.0 1	0. 7 193	
fistula	2.6	2.0	2.6	1.9	17.3	193 2.4	
Gastroschisis	153	70	90	5	0	318	
Ualamagan aga hali-	3.3	5.3	6.5	1.0	0.0	4.0	
Holoprosencephaly	31 0.7	20 1.5	30 2.2	3 0.6	2 34.6	86 1.1	
Hypoplastic left heart syndrome	80	33	33	9	1	157	
YY 1'	1.8	2.5	2.4	1.9	17.3	2.0	2
Hypospadias	1,514 64.5	377 56.0	258 36.8	114 46.5	12 408.2	2,275 56.0	2
Interrupted aortic arch	19	14	11	0	0	44	
	0.4	1.1	0.8	0.0	0.0	0.6	

Illinois Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes	
Limb deficiencies (reduction defects)	168	73	72	18	0	332		
``````	3.7	5.5	5.2	3.8	0.0	4.2		
Omphalocele	85	40	26	6	1	160		
	1.9	3.0	1.9	1.3	17.3	2.0		
Pulmonary valve atresia and stenosis	181	88	95	27	1	393		
	4.0	6.6	6.9	5.7	17.3	5.0		
Pulmonary valve atresia	12	9	8	1	0	30	3	
	0.3	0.7	0.6	0.2	0.0	0.4		
Rectal and large intestinal	166	52	71	10	2	301		
atresia/stenosis	3.6	3.9	5.2	2.1	34.6	3.8		
Renal agenesis/hypoplasia	286	113	123	33	0	556		
	6.3	8.5	8.9	6.9	0.0	7.0		
Single ventricle	22	12	12	3	0	49		
	0.5	0.9	0.9	0.6	0.0	0.6		
Small intestinal atresia/stenosis	106	36	57	12	1	212		
	2.3	2.7	4.1	2.5	17.3	2.7		
Spina bifida without anencephalus	142	42	61	11	0	256		
	3.1	3.2	4.4	2.3	0.0	3.2		
Tetralogy of Fallot	164	63	70	22	2	321		
	3.6	4.8	5.1	4.6	34.6	4.0		
Total anomalous pulmonary venous	30	11	27	5	0	73		
connection	0.7	0.8	2.0	1.0	0.0	0.9		
Transposition of the great arteries	131	30	46	9	0	216		
(TGA)	2.9	2.3	3.3	1.9	0.0	2.7		
Dextro-transposition of great arteries	109	26	35	7	0	177		
(d-TGA)	<b>2.4</b> 130	<b>2.0</b> 45	<b>2.5</b> 77	1.5 10	<b>0.0</b> 1	<b>2.2</b> 263	4	
Tricuspid valve atresia and stenosis						203 3.3	4	
Tricuspid valve atresia	<b>2.8</b> 22	3.4 9	<b>5.6</b> 14	<b>2.1</b> 2	17.3 0	3.3 47	5	
Theuspid valve allesia	0.5	9 0.7	1.0	<i>0.4</i>	0.0	<i>0.6</i>	5	
Trisomy 13	<b>0.3</b> 47	17	28	<b>0.4</b> 4	0.0	96		
Trisonly 15	1.0	1.3	2.0	0.8	0.0	1.2		
Trisomy 18	109	34	55	15	1	216		
Thisonly To	2.4	2.6	4.0	3.1	17.3	2.7		
Trisomy 21 (Down syndrome)	552	139	355	48	6	1,102		
Thisonly 21 (Down Syndrome)	12.1	10.5	25.8	10.1	103.8	13.9		
Turner syndrome	41	13	22	3	0	79	6	
	1.8	2.0	3.2	1.3	0.0	2.0	v	
Ventricular septal defect	1.899	516	901	214	11	3,542	7	
	41.5	38.9	65.4	44.8	190.3	44.6		
Total live births	457,112	132,599	137,727	47,738	578	793,927	8	
Male live births	234,573	67,367	70,016	24,494	294	406,108		
Female live births	222,528	65,223	67,705	23,244	284	387,793		

#### Illinois Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	301	17	318				
	5.7	1.6	4.0				
Trisomy 13	62	34	96				
-	1.2	3.2	1.2				
Trisomy 18	121	93	216				
	2.3	8.7	2.7				
Trisomy 21 (Down syndrome)	499	602	1,102				
• • • •	9.4	56.6	13.9				
Total live births	529,433	106,335	793,927	8			

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 exclude cases with tetralogy of Fallot or cases with a ventricular septal defect.

4. Data for this condition include tricuspid stenosis or hypoplasia.

5. Data for this condition exclude 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 exclude probable cases, and inlet ventricular septal defects including common atrioventricular canal type ventricular septal defects.

8. Total live births includes unknown gender.

#### **General comments**

*Totals include unknown and/or other.

-Data for conditions include live births from birth to age 2 years and fetal deaths (these include stillbirths of 20 weeks gestation or more, and miscarriages where the families chose to hold funerals).

# Indiana Birth Defects Counts and Prevalence 2011 - 2015 (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
Anophthalmia/microphthalmia	20	2	1	0	0	24	
Anotia/microtia	<b>0.6</b> 26	<b>0.4</b> 3	<b>0.3</b> 10	<b>0.0</b> 2	<b>0.0</b> 0	<b>0.6</b> 42	
Anoua/microua	0.8	.6	3.2	2.1	0.0	42 1.0	
Aortic valve stenosis	35	0	3	0	0	38	
Atrial septal defect	1.1 837	<b>0.0</b> 142	<b>1.0</b> 72	<b>0.0</b> 19	<b>0.0</b> 1	<b>0.9</b> 1,088	
Athai septai delect	857 26.4	<i>30.1</i>	23.3	19 19.8	1 24.2	1,088 26.1	
Atrioventricular septal defect	105	12	6	3	0	130	
(Endocardial cushion defect)	3.3	<b>2.5</b> 2	1.9 2	3.1	0.0	<i>3.1</i>	
Biliary atresia	15 0.5	2 0.4	3 1.0	0 <b>0.0</b>	0 <i>0.0</i>	21 0.5	
Choanal atresia	31	2	2	1	0	37	
	1.0	0.4	0.6	1.0	0.0	0.9	
Cleft lip alone	76 <b>2.4</b>	3 <b>0.6</b>	7 2.3	1 1.0	0 <b>0.0</b>	87 <b>2.1</b>	
Cleft lip with cleft palate	164	12	18	5	0	207	
	5.2	2.5	5.8	5.2	0.0	5.0	
Cleft palate alone	170	26	8	4	0	210	
Cloacal exstrophy	<b>5.4</b> 54	<b>5.5</b> 7	<b>2.6</b> 6	<b>4.2</b> 2	<b>0.0</b> 0	<b>5.0</b> 69	
cioucui existrophy	1.7	1.5	1.9	2.1	0.0	1.7	
Clubfoot	307	52	23	4	1	391	
Coarctation of the aorta	<b>9.7</b> 127	11.0 10	7.4	<b>4.2</b> 0	24.2 0	<b>9.4</b> 146	
Coarctation of the aorta	127 <b>4.0</b>	2.1	8 2.6	0.0	0.0	3.5	
Congenital cataract	14	4	2	1	0	22	
	0.4	0.8	0.6	1.0	0.0	0.5	
Congenital posterior urethral valves	21 1.3	8 <b>3.3</b>	2 1.3	0 <b>0.0</b>	0 <b>0.0</b>	31 <i>1.4</i>	1
Craniosynostosis	432	46	35	11	1	535	
	13.6	9.7	11.3	11.5	24.2	12.8	
Diaphragmatic hernia	74 2.3	9 <b>1.9</b>	6	1 1.0	0 <i>0.0</i>	93 2.2	
Double outlet right ventricle	2.3 47	6	<b>1.9</b> 0	1.0	0.0	2.2 58	
Bouble ouder light vehicle	1.5	1.3	0.0	1.0	0.0	1.4	
Ebstein anomaly	13	1	0	0	0	15	
Esophageal atresia/tracheoesophageal	<b>0.4</b> 56	<b>0.2</b> 3	<b>0.0</b> 4	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.4</b> 63	
fistula	1.8	.6	4 1.3	0.0	0.0	03 1.5	
Gastroschisis	94	12	11	2	0	123	
TT 1 1 1	3.0	2.5	3.6	2.1	0.0	3.0	
Holoprosencephaly	98 <b>3.1</b>	14 3.0	13 <i>4.2</i>	2 2.1	0 <b>0.0</b>	132 3.2	
Hypoplastic left heart syndrome	70	8	7	0	0	86	
	2.2	1.7	2.3	0.0	0.0	2.1	
Hypospadias	914 <b>56.1</b>	97 <b>40.4</b>	39 <b>24.</b> 7	17 <b>33.9</b>	0 <b>0.0</b>	1,086 <b>50.8</b>	1
Interrupted aortic arch	18	3	1	1	0	24	
-	0.6	0.6	0.3	1.0	0.0	0.6	
Limb deficiencies (reduction defects)	89	14	9	2	1	119	
Omphalocele	<b>2.8</b> 43	3.0 4	2.9 4	<b>2.1</b> 2	24.2 0	<b>2.9</b> 54	
omphaiooolo	43 1.4	<i>0.8</i>	4 1.3	2.1	0.0	1.3	
Pulmonary valve atresia and stenosis	197	26	20	3	0	254	
	6.2 22	5.5	6.5	3.1	0.0	6.1	
Pulmonary valve atresia	33 1.0	3 <b>0.6</b>	6 1.9	2 2.1	0 <b>0.0</b>	44 1.1	
Rectal and large intestinal	108	13	9	3	1	135	
atresia/stenosis	3.4	2.8	2.9	3.1	24.2	3.2	

# Indiana Birth Defects Counts and Prevalence 2011 - 2015 (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	109	19	7	2	0	139				
	3.4	4.0	2.3	2.1	0.0	3.3				
Single ventricle	17	4	0	1	0	25				
-	0.5	0.8	0.0	1.0	0.0	0.6				
Small intestinal atresia/stenosis	87	12	2	3	0	104				
	2.7	2.5	0.6	3.1	0.0	2.5				
Spina bifida without anencephalus	94	10	9	1	2	118				
· ·	3.0	2.1	2.9	1.0	48.4	2.8				
Tetralogy of Fallot	78	13	8	4	1	108				
	2.5	2.8	2.6	4.2	24.2	2.6				
Total anomalous pulmonary venous	22	2	3	0	0	27				
connection	0.7	0.4	1.0	0.0	0.0	0.6				
Transposition of the great arteries	53	6	4	1	0	66				
(TGA)	2.1	1.6	1.6	1.3	0.0	2.0				
Dextro-transposition of great arteries	51	5	4	2	0	64				
(d-TGA)	1.6	1.1	1.3	2.1	0.0	1.5				
Tricuspid valve atresia and stenosis	22	4	1	2	0	30				
-	0.7	0.8	0.3	2.1	0.0	0.7				
Trisomy 13	17	3	1	0	0	22				
•	0.5	0.6	0.3	0.0	0.0	0.5				
Trisomy 18	28	5	4	1	0	38				
	0.9	1.1	1.3	1.0	0.0	0.9				
Trisomy 21 (Down syndrome)	377	44	45	11	0	484				
• • • •	11.9	9.3	14.6	11.5	0.0	11.6				
Turner syndrome	23	2	0	0	0	25	2			
,	1.5	0.9	0.0	0.0	0.0	1.2				
Ventricular septal defect	962	131	102	22	1	1,252				
*	30.3	27.8	33.0	22.9	24.2	30.0				
Total live births	317,042	47,197	30,880	9,589	413	416,845				
Male live births	162,899	23,998	15,765	5,011	203	213,866				
Female live births	154,143	23,199	15,115	4,578	210	202,979				

#### Indiana Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)						
Defect	Less than 35	35+	Total*	Notes		
Gastroschisis	121	2	123			
	3.3	0.4	3.0			
Trisomy 13	21	1	22			
-	0.6	0.2	0.5			
Trisomy 18	23	15	38			
	0.6	3.2	0.9			
Trisomy 21 (Down syndrome)	310	174	484			
	8.4	37.0	11.6			
Total live births	369,753	47,045	416,845			

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

*Totals include unknown and/or other.

-Data for conditions are provisional.

-Data for conditions include probable cases.

#### Iowa Birth Defects Counts and Prevalence 2011 - 2015 (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	4	1	0	44	
Anophthalmia/microphthalmia	<b>1.9</b> 17	<b>4.1</b> 4	<b>2.5</b> 5	<b>1.6</b> 0	<b>0.0</b> 0	<b>2.3</b> 28	
	1.1	4.1	3.1	0.0	0.0	1.4	
Anotia/microtia	31 1.9	1 1.0	8 <b>4.9</b>	2 3.2	0 <b>0.0</b>	43 2.2	
Aortic valve stenosis	37	0	2	0	0	39	
	2.3	0.0	1.2	0.0	0.0	2.0	
Atrial septal defect	496 <i>31.2</i>	41 <b>41.</b> 7	50 <b>30.9</b>	10 <b>15.9</b>	0 <b>0.0</b>	603 <b>30.9</b>	
Atrioventricular septal defect	76	10	8	2	0	97	
(Endocardial cushion defect)	<b>4.8</b> 5	10.2 0	<b>4.9</b> 1	3.2 0	<b>0.0</b> 0	<b>5.0</b> 6	
Biliary atresia	<i>0.3</i>	0.0	1 0.6	0.0	0.0	0.3	
Bladder exstrophy	6	0	0	0	0	6	
Choanal atresia	<b>0.4</b> 18	<b>0.0</b> 1	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.0</b> 0	<i>0.3</i> 20	
Choanar auesia	1.1	1.0	0.6	0.0	0.0	20 1.0	
Cleft lip alone	63	3	10	2	1	80	
Cleft lip with cleft palate	<b>4.0</b> 93	3.1 6	<b>6.2</b> 8	3.2 5	11.3 0	<b>4.1</b> 113	
Clert ip will clert palate	5.8	6. <i>1</i>	6 4.9	7.9	0.0	5.8	
Cleft palate alone	119	5	10	4	0	139	
Cloacal exstrophy	<b>7.5</b> 0	<b>5.1</b> 0	<b>6.2</b> 0	<b>6.3</b> 0	0.0	7.1 0	
cloacal exstropily	0.0	0.0	0.0	0.0	0.0	0.0	
Clubfoot	254	15	27	6	1	309	
Coarctation of the aorta	<b>16.0</b> 103	15.3 0	<b>16.7</b> 6	<b>9.5</b> 0	11.3 0	<b>15.8</b> 109	
	6.5	0.0	3.7	0.0	0.0	5.6	
Common truncus (truncus arteriosus)	10	1	2	0	0	13	
Congenital cataract	<b>0.6</b> 67	1.0 4	1.2 7	0.0 1	<b>0.0</b> 1	0.7 81	
Congennal catalact	4.2	4.1	4.3	1.6	11.3	4.2	
Congenital posterior urethral valves	14	2	0	1	0	17	1
Craniosynostosis	1.7 98	<b>4.0</b> 5	<b>0.0</b> 10	3.0 2	<b>0.0</b> 0	<i>1.7</i> 117	
Clamosynosusis	6.2	5.1	6.2	3.2	0.0	6.0	
Deletion 22q11.2	28	4	1	1	0	34	
Diaphragmatic hernia	<b>1.8</b> 49	4.1 3	<b>0.6</b> 5	<b>1.6</b> 3	<b>0.0</b> 0	1.7 63	
1 0	3.1	3.1	3.1	4.8	0.0	3.2	
Double outlet right ventricle	24	4	7	2	0	39	
Ebstein anomaly	<i>1.5</i> 14	<b>4.1</b> 1	<i>4.3</i> 2	3.2 1	<b>0.0</b> 0	<b>2.0</b> 18	
	0.9	1.0	1.2	1.6	0.0	0.9	
Encephalocele	18	1	0	0	0	20	
Esophageal atresia/tracheoesophageal	1.1 48	1.0 1	0.0 3	<b>0.0</b> 2	<b>0.0</b> 0	<i>1.0</i> 54	
fistula	3.0	1.0	1.9	3.2	0.0	2.8	
Gastroschisis	85	7	14	1	1	108	
Holoprosencephaly	<b>5.3</b> 17	7.1 4	<b>8.6</b> 2	<b>1.6</b> 0	11.3 0	<b>5.5</b> 24	
	1.1	4.1	1.2	0.0	0.0	1.2	
Hypoplastic left heart syndrome	38	5	4	1	0	48	
Hypospadias	2.4 539	<b>5.1</b> 24	<b>2.5</b> 26	<b>1.6</b> 11	<b>0.0</b> 0	<b>2.5</b> 603	1
	66.0	47.7	32.2	33.5	0.0	60.4	
Interrupted aortic arch	13	0	0	0	0	13	
	0.8	0.0	0.0	0.0	0.0	0.7	

### Iowa Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	95	2	12	2	0	112	2
	6.0	2.0	7.4	3.2	0.0	5.7	
Omphalocele	37	3	6	1	0	51	
	2.3	3.1	3.7	1.6	0.0	2.6	
Pulmonary valve atresia and stenosis	176	17	17	7	0	218	
	11.1	17.3	10.5	11.1	0.0	11.2	
Pulmonary valve atresia	15	2	2	1	0	20	
	0.9	2.0	1.2	1.6	0.0	1.0	
Rectal and large intestinal	55 <b>3.5</b>	4 4.1	8 <b>4.9</b>	1	0	69 <b>3.5</b>	
atresia/stenosis Renal agenesis/hypoplasia	3.5 85	<b>4.1</b> 5	<b>4.9</b> 11	<b>1.6</b> 1	<b>0.0</b> 0	<b>5.5</b> 104	
Renar agenesis/nypopiasia	5.3	5.1	6.8	1 1.6	0.0	5.3	
Single ventricle	8	1	1	0	0	10	
Shigh venuleie	0.5	1.0	0.6	0.0	0.0	0.5	
Small intestinal atresia/stenosis	59	5	3	0	0	69	
Shan mestina aresia senosis	3.7	5.1	1.9	0.0	0.0	3.5	
Spina bifida without anencephalus	62	3	12	0	0	79	
1 1	3.9	3.1	7.4	0.0	0.0	4.0	
Tetralogy of Fallot	68	4	2	5	0	79	
	4.3	4.1	1.2	7.9	0.0	4.0	
Total anomalous pulmonary venous	8	1	4	1	0	14	
connection	0.5	1.0	2.5	1.6	0.0	0.7	
Transposition of the great arteries	41	4	5	1	0	51	
(TGA)	2.6	4.1	3.1	1.6	0.0	2.6	
Dextro-transposition of great arteries	36	4	4	1	0	45	
(d-TGA)	2.3	4.1	2.5	1.6	0.0	2.3	
Tricuspid valve atresia and stenosis	30	4	7	1	0	42	
	1.9	4.1	4.3	1.6	0.0	2.2	
Tricuspid valve atresia	6	1	1	1	0	9	
<b>T</b> : 10	0.4	1.0	0.6	1.6	0.0	0.5	
Trisomy 13	21	5	3	0	0	31	
T 10	1.3	5.1	1.9	0.0	0.0	1.6	
Trisomy 18	39 2.4	1 1.0	6 3.7	6 <b>9.5</b>	0	56 <b>2.9</b>	
Trisomy 21 (Down syndrome)	2.4 212	1.0 14	25	<b>9.5</b> 4	<b>0.0</b> 0	2.9 264	
risoniy 21 (Down Syndrome)	13.3	14 14.2	25 <b>15.4</b>	4 6.3	0.0	204 13.5	
Turner syndrome	37	1	5	0	0	44	3
rumer syndrome	<i>4.8</i>	2.1	6.2	0.0	0.0	4.6	5
Ventricular septal defect	802	37	73	20	3	943	
· ······	50.4	37.6	45.1	31.7	34.0	48.3	
Total live births	159,191	9,830	16,202	6,307	883	195,072	4
Male live births	81,728	5,027	8,076	3,284	464	99,915	
Female live births	77,462	4,803	8,126	3,023	419	95,156	

#### Iowa Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	107	1	108				
	6.2	0.5	5.5				
Trisomy 13	20	11	31				
-	1.2	5.0	1.6				
Trisomy 18	34	22	56				
	2.0	9.9	2.9				
Trisomy 21 (Down syndrome)	160	104	264				
• • • •	9.3	47.0	13.5				
Total live births	172,950	22,114	195,072	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 exclude other specified and unspecified limb reductions.

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

4. Total live births includes unknown gender.

#### **General comments**

*Totals include unknown and/or other.

-Data for conditions exclude probable/possible cases.

-Fetal deaths defined as 20 or more weeks gestation and/or 350 grams or greater.

-Terminations include all gestational ages. -Unspecified non-live births include spontaneous abortions.

# Kansas Birth Defects Counts and Prevalence 2011 - 2015 (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	34	<5	13	0	0	51	
A man betha lunia / union and tha lunia	2.5 <5	0	<b>4.2</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	2.7 <5	
Anophthalmia/microphthalmia	< 3	0.0	0.0	0.0	0.0	< 3	
Anotia/microtia	<5	0 <b>0.0</b>	<5	<5	0 <b>0.0</b>	<5	
Aortic valve stenosis	7	0	0	0	0	7	
Atrial septal defect	<b>0.5</b> 179	0.0 30	<b>0.0</b> 63	<b>0.0</b> 6	0.0 <5	<i>0.4</i> 304	
Autai septai delett	13.2	23.3	20.5	10.3	~5	16.0	
Atrioventricular septal defect	14	0	<5	0	0	17	
(Endocardial cushion defect)	1.0	0.0	-5	0.0	0.0	0.9	
Biliary atresia	0 <i>0.0</i>	<5	<5	<5	0 <b>0.0</b>	<5	
Choanal atresia	<5	0	<5	0	0	8	
		0.0	-	0.0	0.0	0.4	
Cleft lip alone	18 1.3	<5	5 1.6	<5	<5	28 1.5	
Cleft lip with cleft palate	1.5 19	0	1.0 11	0	<5	1.5 34	
	1.4	0.0	3.6	0.0	-	1.8	
Cleft palate alone	49	<5	19	<5	0	71	
Classel system by	3.6	<5	6.2 <5	0	0.0	3.7 22	
Cloacal exstrophy	16 1.2	< 3	<3	0.0	0 <b>0.0</b>	1.2	
Clubfoot	84	6	23	<5	0	124	
	6.2	4.7	7.5		0.0	6.5	
Coarctation of the aorta	15	0 <i>0.0</i>	<5	0 <b>0.0</b>	0	21 <i>1.1</i>	
Common truncus (truncus arteriosus)	1.1 5	0.0	0	0.0	<b>0.0</b> 0	5	
	0.4	0.0	0.0	0.0	0.0	0.3	
Congenital cataract	<5	0	<5	0	0	<5	
Congenital posterior urethral valves	<5	<b>0.0</b> 0	0	0.0	<b>0.0</b> 0	<5	1
Congenital posterior dicultar valves	<ul> <li>S</li> </ul>	0.0	0.0	0.0	0.0	< 3	1
Craniosynostosis	5	<5	<5	0	0	8	
	0.4			0.0	0.0	0.4	
Diaphragmatic hernia	24 1.8	0 <i>0.0</i>	13 4.2	0 <i>0.0</i>	0 <b>0.0</b>	40 <b>2.1</b>	
Double outlet right ventricle	<5	<5	4.2 <5	0.0	0	2.1 8	
				0.0	0.0	0.4	
Ebstein anomaly	<5	0	0	0	0	<5	
Encephalocele	<5	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<5	
Encephalocele	-5	0.0	0.0	0.0	0.0	~5	
Esophageal atresia/tracheoesophageal	12	<5	5	0	0	19	
fistula	0.9		1.6	0.0	0.0	1.0	
Gastroschisis	62 <b>4.6</b>	<5	20 6.5	0 <i>0.0</i>	<5	93 <b>4.9</b>	
Holoprosencephaly	28	<5	9	<5	0	43	
	2.1		2.9		0.0	2.3	
Hypoplastic left heart syndrome	<5	<5	<5	0	0	10	
Hypospadias	146	19	25	0.0 5	<b>0.0</b> 0	<b>0.5</b> 205	1
	21.1	28.9	16.0	17.0	0.0	203	1
Interrupted aortic arch	0	0	0	0	0	<5	
	0.0	0.0	0.0	0.0	0.0	47	
Limb deficiencies (reduction defects)	30 2.2	8 6.2	7 2.3	<5	0 <b>0.0</b>	47 2.5	
Omphalocele	18	<5	16	<5	0	39	
	1.3		5.2		0.0	2.1	

# Kansas Birth Defects Counts and Prevalence 2011 - 2015 (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 and stenosis	27	5	11	0	0	47	
	2.0	3.9	3.6	0.0	0.0	2.5	
Rectal and large intestinal	21	0	10	<5	0	32	
atresia/stenosis	1.6	0.0	3.3		0.0	1.7	
Renal agenesis/hypoplasia	17	0	6	0	0	25	
	1.3	0.0	2.0	0.0	0.0	1.3	
Single ventricle	0	0	<5	0	0	<5	
-	0.0	0.0		0.0	0.0		
Small intestinal atresia/stenosis	21	<5	7	<5	0	32	
	1.6		2.3		0.0	1.7	
Spina bifida without anencephalus	31	<5	13	<5	0	50	
	2.3		4.2		0.0	2.6	
Tetralogy of Fallot	13	0	6	<5	0	21	
	1.0	0.0	2.0		0.0	1.1	
Total anomalous pulmonary venous	<5	0	<5	0	0	7	
connection		0.0		0.0	0.0	0.4	
Transposition of the great arteries	<5	0	<5	<5	0	8	
(TGA)		0.0			0.0	0.4	
Tricuspid valve atresia and stenosis	<5	0	<5	0	0	5	
		0.0		0.0	0.0	0.3	
Trisomy 13	6	<5	<5	0	0	10	
	0.4			0.0	0.0	0.5	
Trisomy 18	15	<5	6	0	0	23	
	1.1		2.0	0.0	0.0	1.2	
Trisomy 21 (Down syndrome)	126	11	46	10	<5	205	
	9.3	8.6	15.0	17.2		10.8	
Turner syndrome	11	0	<5	0	0	13	2
	1.7	0.0		0.0	0.0	1.4	
Ventricular septal defect	146	11	77	8	<5	267	
	10.8	8.6	25.1	13.8		14.0	
Total live births	135,174	12,859	30,660	5,804	939	190,042	3
Male live births	69,136	6,575	15,630	2,934	470	97,094	
Female live births	66,038	6,284	15,029	2,870	469	92,947	

#### Kansas Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	89	<5	93				
	5.3		4.9				
Trisomy 13	5	5	10				
-	0.3	2.3	0.5				
Trisomy 18	13	10	23				
	0.8	4.6	1.2				
Trisomy 21 (Down syndrome)	117	88	205				
	6.9	40.9	10.8				
Total live births	168,495	21,541	190,042	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. Total live births includes unknown gender.

#### General comments

*Totals include unknown and/or other.

-Data for conditions include live births and fetal deaths/stillbirths.

-Data for conditions includes probable cases.

-Stillbirth means any complete expulsion or extraction from its mother of a human child the gestational age of which is not less than 20 completed weeks.

# Kentucky Birth Defects Counts and Prevalence 2011 - 2015 (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	1	0	0	0	59	
Anophthalmia/microphthalmia	<b>2.5</b> 16 <b>0.7</b>	0.4 3 1.3	0.0 1 0.7	0.0 0 0.0	<b>0.0</b> 0 <b>0.0</b>	<b>2.1</b> 22 <b>0.8</b>	
Anotia/microtia	10 0.4	0 0.0	5 3.7	1 3.9	0.0 0.0	16 <b>0.6</b>	
Aortic valve stenosis	42 1.8	1 0.4	2 1.5	0 <b>0.0</b>	0 <i>0.0</i>	47 1.7	
Atrial septal defect	6,011 263.7	1,096 4 <b>63.4</b>	1.5 253 186.2	133 519.9	8 301.9	7,879 283.9	
Atrioventricular septal defect (Endocardial cushion defect) Biliary atresia	88 <b>3.9</b> 9	13 5.5 1	2 1.5 0	1 <b>3.9</b> 0	0 <b>0.0</b> 0	114 <b>4.1</b> 14	
Bladder exstrophy	<b>0.4</b> 6	<b>0.4</b> 1	<b>0.0</b> 0	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.5</b> 8	
	0.3	0.4	0.0	<b>3.9</b> 0	0.0	0.3	
Choanal atresia	26 1.1	0 <i>0.0</i>	0 <i>0.0</i>	0.0	0 <b>0.0</b>	27 1.0	
Cleft lip alone	113 5.0	6 2.5	2 1.5	3 11.7	0 <b>0.0</b>	127 <b>4.6</b>	
Cleft lip with cleft palate	158 6.9	4 1.7	6 4.4	2 7.8	0 <b>0.0</b>	177 <b>6.4</b>	
Cleft palate alone	178 7.8	1.7 13 5.5	4.4 6 4.4	3 11.7	0.0 0.0	214 7.7	
Clubfoot	398 17.5	3.5 31 <i>13.1</i>	20 14.7	6 23.5	0.0 0.0	469 16.9	
Coarctation of the aorta	17.5 174 7.6	13.1 17 7.2	6	23.5 1 3.9	0.0 0.0	205 7.4	
Common truncus (truncus arteriosus)	21	3	4.4 0	0	0	26	
Congenital cataract	<b>0.9</b> 26	1.3 4	<b>0.0</b> 0	0.0 0	<b>0.0</b> 0	<b>0.9</b> 32	
Congenital posterior urethral valves	1.1 23 2.0	1.7 4 3.4	0.0 0 0.0	0.0 1 7.7	0.0 0 0.0	1.2 29 2.0	1
Deletion 22q11.2	5 0.2	0 0.0	0.0 0.0	0 <b>0.0</b>	0.0 0.0	5 0.2	
Diaphragmatic hernia	0.2 78 3.4	11 4.7	3 2.2	1 3.9	1 37.7	102 3.7	
Double outlet right ventricle	5.4 59 <b>2.6</b>	4.7 11 4.7	0 0.0	1 3.9	0 0.0	79 2.8	
Ebstein anomaly	2.0 21 0.9	2 0.8	1 0.7	0 0.0	0 0.0	2.0 25 0.9	
Encephalocele	26 1.1	4 1.7	2 1.5	0.0 0.0	0.0 0.0	34 1.2	
Esophageal atresia/tracheoesophageal	68	6	1	0	0	75	
fistula Gastroschisis	3.0 132	2.5 11	<b>0</b> .7 6	0.0 3	<b>0.0</b> 0	<b>2</b> .7 156	
Holoprosencephaly	<b>5.8</b> 115	<b>4.</b> 7 12	<b>4.4</b> 7	11.7 1	<b>0.0</b> 2	<b>5.6</b> 145	
Hypoplastic left heart syndrome	<b>5.0</b> 72	<b>5.1</b> 7	<b>5.2</b> 1	<b>3.9</b> 0	75.5 0	<b>5.2</b> 87	
Hypospadias	3.2 1,155	3.0 104	0.7 19	0.0 14	<b>0.0</b> 0	<i>3.1</i> 1,334	1
Interrupted aortic arch	<b>98.4</b> 12	<b>87.5</b> 3	<b>27.5</b> 0	<b>107.3</b> 0	<b>0.0</b> 0	<b>93.6</b> 16	
Limb deficiencies (reduction defects)	<b>0.5</b> 114	<b>1.3</b> 10	<b>0.0</b> 3	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.6</b> 135	
Omphalocele	<b>5.0</b> 49	<b>4.2</b> 2	<b>2.2</b> 3	<b>3.9</b> 0	<b>0.0</b> 0	<b>4.9</b> 55	
1	2.1	0.8	2.2	0.0	0.0	2.0	

# Kentucky Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity		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 and stenosis	163	24	5	2	0	207							
	7.2	10.1	3.7	7.8	0.0	7.5							
Pulmonary valve atresia	28	3	0	1	0	33							
-	1.2	1.3	0.0	3.9	0.0	1.2							
Rectal and large intestinal	114	11	9	4	3	146							
atresia/stenosis	5.0	4.7	6.6	15.6	113.2	5.3							
Renal agenesis/hypoplasia	121	12	7	4	1	156							
	5.3	5.1	5.2	15.6	37.7	5.6							
Single ventricle	12	3	0	0	0	18							
-	0.5	1.3	0.0	0.0	0.0	0.6							
Small intestinal atresia/stenosis	81	11	2	4	0	108							
	3.6	4.7	1.5	15.6	0.0	3.9							
Spina bifida without anencephalus	83	7	3	4	0	104							
	3.6	3.0	2.2	15.6	0.0	3.7							
Tetralogy of Fallot	96	14	2	1	0	122							
	4.2	5.9	1.5	3.9	0.0	4.4							
Total anomalous pulmonary venous	17	2	2	0	0	27							
connection	0.7	0.8	1.5	0.0	0.0	1.0							
Transposition of the great arteries	67	5	1	0	0	75							
(TGA)	2.9	2.1	0.7	0.0	0.0	2.7							
Dextro-transposition of great arteries	60	4	1	0	0	66							
(d-TGA)	2.6	1.7	0.7	0.0	0.0	2.4							
Tricuspid valve atresia and stenosis	23	1	0	0	0	24	2						
	1.0	0.4	0.0	0.0	0.0	0.9							
Trisomy 13	29	1	2	0	0	33							
	1.3	0.4	1.5	0.0	0.0	1.2							
Trisomy 18	49	12	2	2	0	68							
	2.1	5.1	1.5	7.8	0.0	2.4							
Trisomy 21 (Down syndrome)	309	39	25	6	0	426							
	13.6	16.5	18.4	23.5	0.0	15.3							
Turner syndrome	41	4	3	0	0	51	3						
	3.7	3.4	4.5	0.0	0.0	3.8							
Ventricular septal defect	1,302	143	66	18	2	1,621	4						
	57.1	60.5	48.6	70.4	75.5	58.4							
Total live births	227,938	23,652	13,588	2,558	265	277,569	5						
Male live births	117,336	11,881	6,905	1,305	124	142,504							
Female live births	110,585	11,770	6,682	1,253	141	135,046							

# Kentucky Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	150	4	156					
	6.2	1.4	5.6					
Trisomy 13	27	6	33					
-	1.1	2.1	1.2					
Trisomy 18	34	34	68					
	1.4	12.0	2.4					
Trisomy 21 (Down syndrome)	238	155	426					
	9.8	54.5	15.3					
Total live births	243,852	28,421	277,569	5				

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 cases with stenosis and hypoplasia.

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 inlet ventricular septal defect and common atrioventricular canal type ventricular sepatal defect.

5. Total live births includes unknown gender.

#### **General comments**

*Totals include unknown and/or other.

-Stillbirths are defined as a fetal death of 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 350 grams or more.

# Louisiana Birth Defects Counts and Prevalence 2011 - 2015 (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	9	<5	0	0	28	
Anophthalmia/microphthalmia	1.3 13 1.0	1.0 10 1.1	0 <b>0.0</b>	<b>0.0</b> <5	<b>0.0</b> <5	1.2 25 1.0	
Anotia/microtia	11 0.9	6 0.7	<5	0 <i>0.0</i>	<5	21 0.9	
Aortic valve stenosis	22 1.7	5 <b>0.6</b>	<5	0 <b>0.0</b>	0	28 1.2	
Atrial septal defect	723 57.1	655 7 <b>2.6</b>	90 <b>60.1</b>	18 44.6	0.0 9 70.5	1.2 1,523 63.2	
Atrioventricular septal defect (Endocardial cushion defect)	71 <b>5.6</b>	59 <b>6.5</b>	11 7.3	<5	0 <i>0.0</i>	148 <b>6.1</b>	
Biliary atresia	8 <b>0.6</b>	8 <b>0.9</b>	<5	<5	<5	20 <i>0.8</i>	
Bladder exstrophy	<5	<5	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	<5	
Choanal atresia	18 <i>1.4</i>	8 <b>0.9</b>	<5	<5	0 <b>0.0</b>	28 1.2	
Cleft lip alone	44 3.5	12 1.3	<5	<5	<5	60 2.5	
Cleft lip with cleft palate	67 <b>5.3</b>	45 <b>5.0</b>	10 6.7	<5	0 <b>0.0</b>	124 5.1	
Cleft palate alone	5.5 92 7.3	38 4.2	<b>0.</b> 7 12 <b>8.0</b>	<5	<b>0.0</b> <5	5.1 148 6.1	
Clubfoot	58 7.2	38 6.6	10 9.7	0 <b>0.0</b>	<5	108 7.0	
Coarctation of the aorta	68 5.4	35 3.9	9 6.0	<5	<5	118 4.9	
Common truncus (truncus arteriosus)	<5	6 1.1	<5	0 <i>0.0</i>	0 <i>0.0</i>	12 <b>0.8</b>	
Congenital cataract	16 <b>1.3</b>	1.1 15 1.7	0 <i>0.0</i>	<5	<5	33 1.4	
Congenital posterior urethral valves	36 5.5	28 6.2	<5	0 <i>0.0</i>	0 <i>0.0</i>	67 5.4	1
Craniosynostosis	56 11.2	22 6.2	0 <b>0.0</b>	<5	<5	82 <b>8.6</b>	
Deletion 22q11.2	15 1.5	10 1.4	<5	0 <b>0.0</b>	0 <b>0.0</b>	27 1.4	
Diaphragmatic hernia	25 <b>2.0</b>	21 2.3	6 <b>4.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	54 2.2	
Double outlet right ventricle	2.0 25 2.0	14 1.6	<5	0 0 0.0	0 0.0	45 1.9	
Ebstein anomaly	8 0.6	<5	<5	0 0.0	<5	14 <b>0.6</b>	
Encephalocele	9 0.7	5 <b>0.6</b>	0 <i>0.0</i>	0 <b>0.0</b>	0 <i>0.0</i>	16 0.7	
Esophageal atresia/tracheoesophageal fistula	28 2.2	22 2.4	<5	<5	0 <b>0.0</b>	57 2.4	
Gastroschisis	33 <b>2.6</b>	23 <b>2.6</b>	8 5.3	0 <i>0.0</i>	<5	66 2.7	
Holoprosencephaly	<5	6 1.2	<i>5.5</i> <5	0.0 0.0	0 <i>0.0</i>	2.7 9 0.6	
Hypoplastic left heart syndrome	25 2.0	24 2.7	<5	0 0.0	0 0.0	51 2.1	
Hypospadias	532 81.7	258 56.7	28 <i>37.0</i>	7 33.9	<5	840 68.3	1
Interrupted aortic arch	5 0.5	5 0.6	0 0.0	0 0.0	0 <i>0.0</i>	10 0.5	
Limb deficiencies (reduction defects)	47 3.7	30 3.3	5 3.3	0 <b>0.0</b>	<5	87 3.6	

# Louisiana Birth Defects Counts and Prevalence 2011 - 2015 (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
Omphalocele	17	24	0	0	<5	44	
	1.3	2.7	0.0	0.0		1.8	
Pulmonary valve atresia and stenosis	55	56	10	0	0	122	
	4.3	6.2	6.7	0.0	0.0	5.1	
Pulmonary valve atresia	<5	<5	<5	0 <i>0.0</i>	0 <b>0.0</b>	8 <b>0.6</b>	
Rectal and large intestinal	53	36	7	<5	0	98	
atresia/stenosis	4.2	4.0	4.7		0.0	4.1	
Renal agenesis/hypoplasia	53	34	<5	0	<5	92	
	4.2	3.8		0.0		3.8	
Single ventricle	<5	6	0	0	0	8	
		0.9	0.0	0.0	0.0	0.4	
Small intestinal atresia/stenosis	10	12	<5	0	0	26	
	2.0	3.4		0.0	0.0	2.7	
Spina bifida without anencephalus	44	27	5	0	<5	77	
	3.5	3.0	3.3	0.0	-	3.2	
Tetralogy of Fallot	45	51	11	<5	<5	114	
	3.6	5.7	7.3	0	0	4.7	
Total anomalous pulmonary venous	<5	<5	<5	0	0	<5	
connection	25	17	0	0.0	0.0	<b>5</b> 1	
Transposition of the great arteries	25	17	8	0	0	51	
(TGA)	2.0	1.9	5.3	0.0	0.0	2.1	
Dextro-transposition of great arteries	23	16	7	0	0	46	
(d-TGA)	1.8	<b>1.8</b> 9	4.7	0.0	0.0	1.9	
Tricuspid valve atresia and stenosis	14		<5	<5	0	27	
Taiananidan barataria	1.3	1.2 9	<5	0	<b>0.0</b> 0	<i>1.3</i> 25	
Tricuspid valve atresia	14 1.3	9 1.2	<3	0.0	0.0	25 1.2	
Trisoner 12	6	<b>1.</b> 2 7	<5		<5	1.2	
Trisomy 13	0.6	0.9	<5	0 <b>0.0</b>	< 3	0.8	
Trisomy 18	26	20	<5	0	0	<b>0.8</b> 49	
Theory To	2.1	2.2	<5	0.0	0.0	2.0	
Trisomy 21 (Down syndrome)	166	86	35	5	0	299	
Thisonly 21 (Down syndrome)	13.1	9.5	23.4	12.4	0.0	12.4	
Turner syndrome	8	6	<5	0	0	17	2
i anter synaronie	1.3	1.3	2	0.0	0.0	1.4	-
Ventricular septal defect	560	333	81	15	5	1.012	
······································	44.2	36.9	54.1	37.2	39.2	42.0	
Total live births	126,654	90,175	14,983	4,036	1,277	240,953	3
Male live births	65,141	45,502	7,564	2,062	673	122,942	
Female live births	61,511	44,672	7,419	1,974	604	118,008	

## Louisiana Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	65	<5	66					
	3.0		2.7					
Trisomy 13	12	<5	16					
	0.6		0.8					
Trisomy 18	39	10	49					
	1.8	4.3	2.0					
Trisomy 21 (Down syndrome)	196	103	299					
• • • •	9.0	43.9	12.4					
Total live births	217,475	23,478	240,953	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. Total live births includes unknown gender.

#### **General comments**

*Totals include unknown and/or other.

-Data for conditions from 2011 are final and include only live births to Louisiana residents that occurred in 41/54 birth hospitals and covered 71% of total births.

-Data for conditions from 2012 are final and include only live births to Louisiana residents that occurred in 35/57 birth hospitals and covered 67% of total births.

-Data for conditions from 2013 are final and include only live births to Louisiana residents that occurred in 46/55 birth hospitals and covered 92% of total births.

-Data for conditions from 2014 are final and include only live births to Louisiana residents that occurred in 45/53 birth hospitals and covered 93% of total births.

-Data for conditions from 2015 are provisional and include only live births to Louisiana residents that occurred in 22/52 birth hospitals and covered 53% of total births.

-Data for conditions include live births that had a birth weight of  $\geq 350$  grams or a gestational age  $\geq 20$  weeks.

-Data for conditions include probable cases.

# Maine Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

<b>Defect</b> Anencephalus Anophthalmia/microphthalmia Anotia/microtia	White, Non-Hispanic	Black,		Asian or Pacific	American Indian or		
Anencephalus Anophthalmia/microphthalmia		Non-Hispanic	Hispanic	Islander, Non-Hispanic	Alaska Native, Non-Hispanic	Total*	Notes
-	14	2	0	0	0	19	1
-	2.4 1	<b>9.3</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>3.0</b> 1	2
Anotia/microtia	0.3	0.0	0. <i>0</i>	0.0	0.0	0.3	-
	9 1.5	0 <b>0.0</b>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	10 <b>1.6</b>	
Aortic valve stenosis	2	0	0.0	0.0	0	2	2
	0.6	0.0	0.0	0.0	0.0	0.5	
Atrial septal defect	100 28.6	5 37.1	6 <b>96.3</b>	1 14.9	2 <b>49.3</b>	118 <b>31.0</b>	2
Atrioventricular septal defect	11	0	0	0	0	11	2
(Endocardial cushion defect)	3.1	0.0	0.0	0.0	0.0	2.9	
Biliary atresia	0 <i>0.0</i>	0 <b>0.0</b>	0 <i>0.0</i>	0 <b>0.0</b>	0 <b>0.0</b>	0 <i>0.0</i>	2
Bladder exstrophy	1	0	0.0	0.0	0	1	2
	0.3	0.0	0.0	0.0	0.0	0.3	
Choanal atresia	6 1.0	0 <b>0.0</b>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	6 <b>0.9</b>	3
Cleft lip alone	17	0	0.0	0.0	0	18	
-	2.9	0.0	0.0	0.0	0.0	2.8	
Cleft lip with cleft palate	34 5.8	1 4.7	0 <i>0.0</i>	0 <i>0.0</i>	1 15.6	37 <b>5.8</b>	
Cleft palate alone	34	<b>4.</b> /	2	1	2	42	
_	5.8	4.7	19.2	9.0	31.2	6.6	
Coarctation of the aorta	27 <b>4.6</b>	0	0 <i>0.0</i>	0	0 <i>0.0</i>	28	
Common truncus (truncus arteriosus)	<b>4.0</b> 1	<b>0.0</b> 0	0.0	<b>0.0</b> 0	0.0	<b>4.4</b> 1	
	0.2	0.0	0.0	0.0	0.0	0.2	
Congenital cataract	0	1	0	0	0	1	2
Diaphragmatic hernia	<b>0.0</b> 2	7.4 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.3</b> 2	2
	0.6	0.0	0.0	0.0	0.0	0.5	
Ebstein anomaly	1	0	0	0	0	1	2
Encephalocele	<b>0.3</b> 7	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 1	<b>0.0</b> 0	<b>0.3</b> 8	
	1.2	0.0	0. <i>0</i>	9.0	0.0	1.3	
Esophageal atresia/tracheoesophageal	13	0	0	0	0	14	2
fistula Gastroschisis	3.7 28	<b>0.0</b> 0	<b>0.0</b> 2	<b>0.0</b> 0	<b>0.0</b> 1	<b>3.</b> 7 32	
Sustrosenisis	<i>4.8</i>	0.0		0.0	15.6	5.0	
Hypoplastic left heart syndrome	17	2	0	0	0	21	
Hypospadias	<b>2.9</b> 186	<b>9.3</b> 5	<b>0.0</b> 2	<b>0.0</b> 3	<b>0.0</b> 2	<b>3.3</b> 210	5
rypospudius	61.8	43.9	- 36.6	<b>49.</b> 7	<b>59.</b> 7	<i>64.1</i>	5
Limb deficiencies (reduction defects)	20	0	0	0	0	23	
Omphalocele	<b>3.4</b> 10	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>3.6</b> 10	
Shiphaloeele	1.7	0.0	0.0	0.0	0.0	1.6	
Pulmonary valve atresia and stenosis	38	3	0	1	0	42	
Pulmonary valve atresia	<b>6.5</b> 7	<b>14.0</b> 2	<b>0.0</b> 0	<b>9.0</b> 0	<b>0.0</b> 0	<b>6.6</b> 9	
i unionary varve autora	1.2	2 9.3	0.0	0.0	0.0	, 1.4	
Rectal and large intestinal	17	0	0	1	0	19	2
atresia/stenosis	<b>4.9</b>	0.0	0.0	14.9 0	0.0	5.0 26	2
Renal agenesis/hypoplasia	24 <b>6.9</b>	1 7.4	1 16.1	0 <i>0.0</i>	0 <b>0.0</b>	26 <b>6.8</b>	2
Spina bifida without anencephalus	22	0	0	0	0	23	
	<b>3.8</b> 28	0.0	<b>0.0</b> 1	0.0	0.0	<b>3.6</b> 30	
Tetralogy of Fallot		0	1	0	0	411	

# Maine Birth Defects Counts and Prevalence 2011 - 2015 (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	16	1	1	1	0	19				
(TGA)	2.7	4.7	9.6	9.0	0.0	3.0				
Tricuspid valve atresia and stenosis	4	1	0	0	0	5				
	0.7	4.7	0.0	0.0	0.0	0.8				
Tricuspid valve atresia	4	0	0	0	0	4				
	0.7	0.0	0.0	0.0	0.0	0.6				
Trisomy 13	2	0	0	0	0	2	2			
	0.6	0.0	0.0	0.0	0.0	0.5				
Trisomy 18	7	0	0	0	0	7	2			
	2.0	0.0	0.0	0.0	0.0	1.8				
Trisomy 21 (Down syndrome)	66	4	2	2	2	81				
	11.3	18.7	19.2	18.0	31.2	12.7				
Ventricular septal defect	73	3	4	0	0	84	2			
	20.9	22.3	64.2	0.0	0.0	22.1				
Total live births	58,520	2,142	1,039	1,109	642	63,583				
Male live births	30,089	1,139	546	604	335	32,782				

## Maine Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	32	0	32				
	5.9	0.0	5.0				
Trisomy 13	2	0	2	2			
-	0.6	0.0	0.5				
Trisomy 18	5	2	7	2			
	1.5	3.6	1.8				
Trisomy 21 (Down syndrome)	49	29	81				
• • • •	9.0	32.5	12.7				
Total live births	54,662	8,921	63,583				

### Notes

Data for this condition include probable cases.
 Data for this condition begin in 2013.

3. Data for this condition begin in 2011.

4. Data for this condition end in 2011.

5. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.

#### General comments

*Totals include unknown and/or other.

-Fetal deaths are defined as those that occur at any gestational age.

# Maryland Birth Defects Counts and Prevalence 2011 - 2015 (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	7	7	0	0	39	
Anophthalmia/microphthalmia	<b>1.0</b> 1	<b>0.6</b> 3	1.3 1	<b>0.0</b> 0	<b>0.0</b> 0	<b>1.1</b> 11	1
-	0.1	0.4	0.3	0.0	0.0	0.5	1
Anotia/microtia	8 0.5	0 <b>0.0</b>	2 <b>0.4</b>	1 <b>0.4</b>	0 <b>0.0</b>	13 <b>0.4</b>	
Aortic valve stenosis	2	0	0.4	0.4	0	<b>0.4</b> 3	
	0.1	0.0	0.0	0.0	0.0	0.1	
Atrial septal defect	26 1.6	16 1.3	8 1.5	1 0.4	0 <b>0.0</b>	66 <b>1.8</b>	
Atrioventricular septal defect	8	6	0	0	0	20	
(Endocardial cushion defect)	0.5	0.5	0.0	0.0	0.0	0.5	
Biliary atresia	1 0.1	0 <b>0.0</b>	0 <i>0.0</i>	0 <b>0.0</b>	0 <b>0.0</b>	1 0.0	1
Bladder exstrophy	3	2	1	0	0	9	
Channel atom	0.2	0.2	0.2	0.0	0.0	0.2	1
Choanal atresia	7 <b>0.</b> 7	3 0.4	0 <i>0.0</i>	1 0.6	0 <b>0.0</b>	12 0.5	1
Cleft lip alone	36	7	8	4	0	69	
	2.2	0.6	1.5	1.5	0.0	1.9	
Cleft lip with cleft palate	46 <i>4.7</i>	14 2.0	11 3.3	2 1.2	0 <b>0.0</b>	87 <b>4.0</b>	1
Cleft palate alone	60	23	12	5	0	125	
c1 1 . 1	3.7	1.9	2.2	1.9	0.0	3.4	1
Cloacal exstrophy	3 0.3	5 0.7	1 0.3	0 <b>0.0</b>	0 <b>0.0</b>	10 0.5	1
Clubfoot	30	25	14	2	0	89	
	1.8	2.1	2.6	0.7	0.0	2.4	
Coarctation of the aorta	8 <i>0.8</i>	7 1.0	1 0.3	5 <b>3.1</b>	0 <b>0.0</b>	27 1.2	1
Common truncus (truncus arteriosus)	2	0	0	1	0	6	
	0.1	0.0	0.0	0.4	0.0	0.2	1
Congenital cataract	1 0.1	3 0.4	1 0.3	0 <b>0.0</b>	0 <b>0.0</b>	5 0.2	1
Congenital posterior urethral valves	1	1	0	0	0	2	2
	0.1	0.2	0.0	0.0	0.0	0.1	1
Craniosynostosis	0 <i>0.0</i>	0 <b>0.0</b>	0 <i>0.0</i>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	1
Deletion 22q11.2	0	0	0	0	0	0	1
Diamhua amatia hamia	<b>0.0</b> 15	0.0 14	<b>0.0</b> 2	<b>0.0</b> 2	<b>0.0</b> 0	<b>0.0</b> 45	
Diaphragmatic hernia	0.9	14 1.2	2 0.4	<i>0.7</i>	0.0	43 1.2	
Double outlet right ventricle	11	12	3	3	0	35	
Ebstein anomaly	<b>0.</b> 7 2	1.0 2	<b>0.6</b> 1	1.1 0	<b>0.0</b> 0	<b>1.0</b> 6	1
Eostem anomaly	<i>0.2</i>	0.3	0.3	0.0	0.0	0.3	1
Encephalocele	6	7	1	2	0	19	
Esophageal atresia/tracheoesophageal	<b>0.4</b> 22	<b>0.6</b> 10	<b>0.2</b> 3	<b>0.7</b> 3	<b>0.0</b> 0	<b>0.5</b> 48	
fistula	1.3	0.8	5 0.6	5 1.1	0.0	40 1.3	
Gastroschisis	24	16	3	1	0	57	
Holoprosencenholy	1.5	1.3 8	0.6	0.4	0.0	1.6	
Holoprosencephaly	8 0.5	8 <b>0.</b> 7	6 1.1	1 <i>0.4</i>	0 <b>0.0</b>	28 <b>0.8</b>	
Hypoplastic left heart syndrome	6	6	0	1	0	25	1
Hypognadias	<b>0.6</b>	<b>0.8</b> 196	<b>0.0</b> 74	<b>0.6</b> 28	<b>0.0</b> 0	<b>1.1</b> 738	2
Hypospadias	291 <b>34.6</b>	32.5	27.0	28 20.1	0.0	738 <b>39.6</b>	2
Interrupted aortic arch	3	3	0	1	0	10	1
	0.3	0.4	0.0	0.6	0.0	0.5	

# Maryland Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	34	38	15	3	1	113	
	2.1	3.2	2.8	1.1	14.2	3.1	
Omphalocele	8	8	0	0	1	28	
	0.5	0.7	0.0	0.0	14.2	0.8	
Pulmonary valve atresia and stenosis	7	8	1	2	0	29	1
	0.7	1.1	0.3	1.2	0.0	1.3	1
Pulmonary valve atresia	4 <i>0.4</i>	4 <b>0.6</b>	0 <b>0.0</b>	1 <b>0.6</b>	0 <i>0.0</i>	13 <i>0.6</i>	1
Rectal and large intestinal	22	17	9	5	0.0	64	
atresia/stenosis	1.3	1.4	1.7	1.9	0.0	1.8	
Renal agenesis/hypoplasia	1.5	13	6	3	0	51	
rtenar ageneous ny populata	1.0	1.1		1.1	0.0	1.4	
Single ventricle	1	2	0	1	0	5	
C	0.1	0.2	0.0	0.4	0.0	0.1	
Small intestinal atresia/stenosis	9	16	1	0	0	36	
	0.5	1.3	0.2	0.0	0.0	1.0	
Spina bifida without anencephalus	33	18	14	4	0	79	
	2.0	1.5	2.6	1.5	0.0	2.2	
Tetralogy of Fallot	40	14	3	4	1	77	
Total an amalana mulmanama yan ana	2.4	1.2 0	<b>0.6</b> 1	1.5 0	14.2 0	2.1	
Total anomalous pulmonary venous connection	2 0.1	0.0	0.2	0 0.0	0.0	7 <b>0.2</b>	
Transposition of the great arteries	4	1	0.2	0	0.0	6	1
(TGA)	0.4	0.1	0.0	0.0	0.0	0.3	1
Dextro-transposition of great arteries	2	1	0	0	0	4	
(d-TGA)	0.2	0.1	0.0	0.0	0.0	0.2	
Tricuspid valve atresia and stenosis	1	4	1	1	0	13	
	0.1	0.3	0.2	0.4	0.0	0.4	
Tricuspid valve atresia	1	4	1	1	0	13	
	0.1	0.3	0.2	0.4	0.0	0.4	
Trisomy 13	5	6	2	0	0	23	
<b>T</b> : 10	0.3	0.5	0.4	0.0	0.0	0.6	
Trisomy 18	10	16	8 1.5	0	0	49 <b>1.3</b>	
Trisomy 21 (Down syndrome)	<b>0.6</b> 114	1.3 88	1.5 64	<b>0.0</b> 11	<b>0.0</b> 0	1.5 359	
Thisonay 21 (Down syndrome)	6.9	⁸⁸ 7.4	11.9	4.1	0.0	9.8	
Turner syndrome	5	5	1	0	0	14	3
Tumer syndrome	0.6	0.9	0.4	0.0	0.0	0.8	5
Ventricular septal defect	51	62	11	5	0	173	
1	3.1	5.2	2.0	1.9	0.0	4.7	
Total live births	164,357	118,536	53,718	26,729	702	364,741	4
Male live births	84,215	60,322	27,420	13,939	125	186,455	
Female live births	80,140	58,212	26,298	13,071	127	178,282	

# Maryland Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	35	4	57				
	1.2	0.6	1.6				
Trisomy 13	7	11	23				
-	0.2	1.6	0.6				
Trisomy 18	23	21	49				
	0.8	3.0	1.3				
Trisomy 21 (Down syndrome)	164	153	359				
	5.6	21.9	9.8				
Total live births	294,745	69,933	364,741	4			

### Notes

1. Data for this condition begin in 2013.

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. Total live births includes unknown gender.

#### **General comments**

*Totals include unknown and/or other.

# Massachusetts Birth Defects Counts and Prevalence 2011 - 2015 (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 2.0	7 2.0	17 2.7	4	0 <b>0.0</b>	85	
Anophthalmia/microphthalmia	2.0 24 1.1	2.0 6 1.7	2.7 11 1.7	1.3 3 0.9	0.0 0.0	2.4 45 1.2	
Anotia/microtia	51 2.3	8 2.3	20 3.1	8 2.5	0.0 0.0	90 2.5	
Aortic valve stenosis	36 1.6	2 0.6	5 0.8	2 0.6	0 0.0	45 1.2	
Atrial septal defect	536 24.0	95 27.2	157 24.6	66 <b>20.8</b>	1 8.3	872 24.2	
Atrioventricular septal defect (Endocardial cushion defect)	119 5.3	37 10.6	55 <b>8.6</b>	15 4.7	0 0.0	233 6.5	
Biliary atresia	8 0.4	3 0.9	6 <b>0.9</b>	6 1.9	0 <b>0.0</b>	23 0.6	
Bladder exstrophy	7 0.3	1 0.3	1 0.2	0 0.0	0 <b>0.0</b>	9 0.2	
Choanal atresia	20 0.9	2 <b>0.6</b>	4 0.6	1 0.3	0 0.0	27 0.7	
Cleft lip alone	85 3.8	10 2.9	19 3.0	17 5.4	0 0.0	134 3.7	
Cleft lip with cleft palate	111 5.0	9 2.6	39 6.1	15 4.7	0 0.0	177 4.9	
Cleft palate alone	138 6.2	2.0 23 6.6	37 5.8	24 7.6	2 16.5	227 6.3	1
Cloacal exstrophy	9 0.4	0.0 0.0	3 0.5	0 0.0	0 0.0	12 0.3	
Clubfoot	345	42	84	32	3	525	2
Coarctation of the aorta	<b>15.5</b> 119	12.0 17	<i>13.2</i> 24	10.1 10	<b>24.8</b> 0	<b>14.6</b> 170	
Common truncus (truncus arteriosus)	5.3 8	<b>4.9</b> 3	3.8 3	3.2 1	<b>0.0</b> 0	<b>4.</b> 7 16	
Congenital cataract	0.4 65	<b>0.9</b> 9 <b>2.6</b>	<b>0.5</b> 26	0.3 3	0.0 0 0.0	0.4 104 2.9	
Congenital posterior urethral valves	<b>2.9</b> 21	8	4.1 7	<b>0.9</b> 7	0	47	3
Craniosynostosis	1.8 151	4.5 5	<b>2.1</b> 29	<i>4.3</i> 8 2.5	0.0 1	2.5 198	
Deletion 22q11.2	<b>6.8</b> 29	1.4 7 2.0	<b>4.5</b> 11	2.5 6	<b>8.3</b> 0	<b>5.5</b> 54	
Diaphragmatic hernia	<i>1.3</i> 71	<b>2.0</b> 10	1.7 20	1.9 8	<b>0.0</b> 1	1.5 110	
Double outlet right ventricle	<b>3.2</b> 37	<b>2.9</b> 6	<b>3.1</b> 16	<b>2.5</b> 8	<b>8.3</b> 0	<b>3.0</b> 68	
Ebstein anomaly	<b>1.7</b> 11	1.7 0	2.5 4	<b>2.5</b> 0	<b>0.0</b> 0	<b>1.9</b> 16	
Encephalocele	<b>0.5</b> 19	<b>0.0</b> 7	<b>0.6</b> 11	<b>0.0</b> 5	<b>0.0</b> 0	<b>0.4</b> 46	
Esophageal atresia/tracheoesophageal	<b>0.9</b> 76	<b>2.0</b> 9	<b>1.</b> 7 17	<b>1.6</b> 1	<b>0.0</b> 0	<i>1.3</i> 103	
fistula Gastroschisis	<b>3.4</b> 70	<b>2.6</b> 10	<b>2.</b> 7 30	<b>0.3</b> 8	<b>0.0</b> 1	<b>2.9</b> 123	
Holoprosencephaly	<b>3.1</b> 35	<b>2.9</b> 5	<b>4.</b> 7 19	2.5 4	<b>8.3</b> 0	<b>3.4</b> 67	
Hypoplastic left heart syndrome	1.6 51	<b>1.4</b> 10	3.0 15	<b>1.3</b> 7	<b>0.0</b> 0	1.9 88	
	2.3	2.9	2.4	2.2	0.0	2.4	4
Hypospadias	593 <b>51.9</b>	80 44.7	130 39.8	48 <b>29.5</b>	2 33.0	866 <b>46.9</b>	4
Interrupted aortic arch	8 <b>0.4</b>	3 0.9	1 0.2	0 <i>0.0</i>	0 <i>0.0</i>	12 <i>0.3</i>	

# Massachusetts Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	129	23	31	8	0	197	
. , , , , , , , , , , , , , , , , , , ,	5.8	6.6	4.9	2.5	0.0	5.5	
Omphalocele	95	4	30	12	0	149	
	4.3	1.1	4.7	3.8	0.0	4.1	
Pulmonary valve atresia and stenosis	188	49	50	16	2	309	
	8.4	14.0	7.8	5.1	16.5	8.6	
Pulmonary valve atresia	12	3	2	2	0	19	
D 4 1 11 14 41 1	0.5	0.9	0.3	0.6	0.0	0.5	
Rectal and large intestinal	88	10	25	9	0	139	
atresia/stenosis	<b>3.9</b> 106	<b>2.9</b> 14	<b>3.9</b> 14	<b>2.8</b> 11	<b>0.0</b> 1	<b>3.9</b> 156	5
Renal agenesis/hypoplasia	106 4.8	14 <b>4.0</b>	14 2.2	3.5	1 8.3	150 4.3	5
Single ventricle	10	1	3	1	0	<b>4.</b> 5	
Single venuele	0.4	0.3	0.5	0.3	0.0	0.4	
Small intestinal atresia/stenosis	58	11	20	7	0	98	
	2.6	3.1	3.1	2.2	0.0	2.7	
Spina bifida without anencephalus	103	9	28	7	0	153	
1 1	4.6	2.6	4.4	2.2	0.0	4.2	
Tetralogy of Fallot	118	16	26	14	1	179	6
	5.3	4.6	4.1	4.4	8.3	5.0	
Total anomalous pulmonary venous	9	3	7	9	0	28	
connection	0.4	0.9	1.1	2.8	0.0	0.8	
Transposition of the great arteries	70	11	22	8	0	114	
(TGA)	3.1	3.1	3.4	2.5	0.0	3.2	
Dextro-transposition of great arteries	59	11	19	8	0	100	
(d-TGA)	2.6	3.1	3.0	2.5	0.0	2.8	
Tricuspid valve atresia and stenosis	25	3	6	0	0	34	
Trimeril her store is	1.1	0.9	0.9	0.0	0.0	0.9	
Tricuspid valve atresia	16 0.7	3 0.9	4 0.6	0 <i>0.0</i>	0 <b>0.0</b>	23 <b>0.6</b>	
Trisomy 13	<b>0.</b> 7 75	<b>0.9</b> 6	<b>0.0</b> 12	6	0.0	<b>0.0</b> 115	
Thisonly 13	3.4	0 1.7	12 1.9	1.9	0.0	3.2	
Trisomy 18	151	24	42	26	0	271	
Thomy To	6.8	6.9	6.6	8.2	0.0	7.5	
Trisomy 21 (Down syndrome)	588	74	140	58	1	924	
, ( <u> </u>	26.4	21.2	21.9	18.3	8.3	25.6	
Turner syndrome	106	12	11	14	1	168	7
-	9.8	7.0	3.5	9.1	16.6	9.5	
Ventricular septal defect	533	87	186	81	4	898	8
	23.9	24.9	29.2	25.6	33.1	24.9	
Total live births	222,973	34,933	63,782	31,683	1,209	360,779	9
Male live births	114,268	17,881	32,623	16,255	606	184,811	
Female live births	108,702	17,050	31,158	15,428	603	175,962	

### Massachusetts Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	116	7	123				
	4.2	0.8	3.4				
Trisomy 13	45	70	115				
-	1.6	8.4	3.2				
Trisomy 18	97	174	271				
	3.5	20.9	7.5				
Trisomy 21 (Down syndrome)	339	585	924				
	12.2	70.4	25.6				
Total live births	277,653	83,117	360,779	9			

Notes

1. Data for this condition exclude isolated submucous cleft palate prior to 2014.

2. Data for this condition is limited to those who require casting or other treatment if the case is live birth.

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 exclude 1st degree and not otherwise specified prior to 2014. 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 isolated unilateral renal agenesis/hypoplasia prior to 2014.

6. Data for this condition include pulmonary atresia with ventricular septal defect.

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 exclude isolated muscular ventricular septal defect prior to 2014.

9. Total live births includes unknown gender.

#### **General comments**

*Totals include unknown and/or other.

-Data for conditions exclude possible/probable cases.

-Data for conditions include live births, stillbirths, and starting in 2011, unspecified non-live births.

-Stillbirths are defined as fetal deaths  $\geq 20$  weeks or  $\geq 350$  grams.

-Unspecified non-live births include elective terminations and early losses <20 weeks and <350 grams.

# Michigan Birth Defects Counts and Prevalence 2011 - 2015 (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	54	7	7	3	0	73	
Anophthalmia/microphthalmia	1.4 63	0.7 25 2.4	1.7 6 1.5	1.8 14 8.2	<b>0.0</b> 0	<b>1.3</b> 109 <b>1.9</b>	
Anotia/microtia	1.6 51 1.3	2.4 7 0.7	21 5.2	8.2 10 5.8	<b>0.0</b> 0 <b>0.0</b>	94 1.7	
Aortic valve stenosis	105	14	8	7	1	138	
Atrial septal defect	2.7 4,317 111.0	1.3 1,944 187.1	2.0 481 118.7	<b>4.1</b> 345 <b>201.</b> 7	4.5 40 179.2	<b>2.4</b> 7,282 <b>128.1</b>	
Atrioventricular septal defect (Endocardial cushion defect)	234 6.0	65 6.3	24 5.9	24 14.0	2 9.0	357 6.3	
Biliary atresia	36 <b>0.9</b>	22 <b>2.1</b>	7 1.7	11 <b>6.4</b>	1 4.5	79 1.4	
Bladder exstrophy	13 0.3	1 0.1	2 0.5	0 <b>0.0</b>	0 <b>0.0</b>	16 <b>0.3</b>	
Choanal atresia	77	35	8	8	1	132	
Cleft lip alone	<b>2.0</b> 76	<b>3.4</b> 16	2.0 3	<b>4.</b> 7 8	<b>4.5</b> 0	<b>2.3</b> 106	
Cleft lip with cleft palate	<b>2.0</b> 388	<b>1.5</b> 67	<b>0.</b> 7 42	<b>4.</b> 7 73	<b>0.0</b> 3	<b>1.9</b> 607	
Cleft palate alone	<b>10.0</b> 296	<b>6.4</b> 51	<b>10.4</b> 28	<b>42.</b> 7 44	<b>13.4</b> 2	<i>10.7</i> 434	
Cloacal exstrophy	7.6 1	<b>4.9</b> 0	<b>6.9</b> 0	25.7 0	<b>9.0</b> 0	7.6 1	
Clubfoot	<b>0.0</b> 619	<b>0.0</b> 229	<b>0.0</b> 63	<b>0.0</b> 68	<b>0.0</b> 6	<b>0.0</b> 1,011	
Coarctation of the aorta	<b>15.9</b> 312	<b>22.0</b> 87	<b>15.5</b> 33	<b>39.8</b> 31	<b>26.9</b> 2	<b>17.8</b> 475	
	8.0	8.4	8.1	18.1	9.0	8.4	
Common truncus (truncus arteriosus)	48 1.2	29 <b>2.8</b>	4 1.0	9 5.3	1 4.5	93 <b>1.6</b>	
Congenital cataract	90 2.3	26 2.5	8 2.0	11 <b>6.4</b>	0 <b>0.0</b>	138 2.4	
Congenital posterior urethral valves	50 2.5	21 <b>4.0</b>	6 2.9	4 4.5	0 <b>0.0</b>	82 <b>2.8</b>	1
Craniosynostosis	273 7.0	56 5.4	27 6.7	25 14.6	1 4.5	389 <b>6.8</b>	
Deletion 22q11.2	29 0.7	6 <b>0.6</b>	2 0.5	5 2.9	0 0.0	43 0.8	
Diaphragmatic hernia	126	34	21	9	1	201	
Double outlet right ventricle	<b>3.2</b> 89	<b>3.3</b> 43	<b>5.2</b> 16	<b>5.3</b> 13	<b>4.5</b> 0	<b>3.5</b> 163	
Ebstein anomaly	<b>2.3</b> 38	<b>4.1</b> 9	<b>3.9</b> 3	7.6 3	<b>0.0</b> 0	<b>2.9</b> 54	
Encephalocele	<b>1.0</b> 37	<b>0.9</b> 18	<b>0.</b> 7 7	<b>1.8</b> 6	<b>0.0</b> 0	<b>1.0</b> 72	
Esophageal atresia/tracheoesophageal	<i>1.0</i> 112	<i>1.7</i> 21	1.7 10	<b>3.5</b> 6	<b>0.0</b> 0	<i>1.3</i> 152	
fistula	2.9	2.0	2.5	3.5	0.0	2.7	
Gastroschisis	200 5.1	43 <i>4.1</i>	19 <b>4.</b> 7	10 5.8	1 4.5	277 <b>4.9</b>	
Holoprosencephaly	212 5.5	108 10.4	29 7.2	26 15.2	1 4.5	384 6.8	
Hypoplastic left heart syndrome	164 4.2	57 5.5	23 5.7	18 10.5	0 0.0	268 4.7	
Hypospadias	1,602	376	108	120	6	2,271	1
Interrupted aortic arch	<b>80.3</b> 99	71.3 33	<b>52.2</b> 7	<b>136.0</b> 16	<b>52.0</b> 1	7 <b>8.0</b> 159	
	2.5	3.2	1.7	9.4	4.5	2.8	

# Michigan Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	172	60	20	21	1	280	
	4.4	5.8	4.9	12.3	4.5	4.9	
Omphalocele	66	23	6	3	0	99	
	1.7	2.2	1.5	1.8	0.0	1.7	
Pulmonary valve atresia and stenosis	362	177	50	33	4	643	
	9.3	17.0	12.3	19.3	17.9	11.3	
Pulmonary valve atresia	93	37	16	8	0	162	
	2.4	3.6	3.9	4.7	0.0	2.9	
Rectal and large intestinal	183	54	26	29	0	300	
atresia/stenosis	4.7	5.2	6.4	17.0	0.0	5.3	
Renal agenesis/hypoplasia	256	80	23	22	3	393	
0.1 .1	6.6	7.7	5.7	12.9	13.4	6.9	
Single ventricle	52	34	15	6	0	111	
Small intestinal atresia/stenosis	<i>1.3</i> 176	<b>3.3</b> 66	3.7 14	3.5 11	<b>0.0</b> 0	<b>2.0</b> 273	
Sman mesunar aresia/stenosis	4.5	6.4	3.5	6.4	0.0	4.8	
Spina bifida without anencephalus	4.5 193	44	19	51	0.0	<b>4.0</b> 311	
Spina binda without ancheephalus	5.0	4.2	4.7	29.8	0.0	5.5	
Tetralogy of Fallot	218	4.2 74	23	35	1	357	
Tetralogy of Fallot	5.6	7.1	5.7	20.5	4.5	6.3	
Total anomalous pulmonary venous	56	14	8	6	0	86	
connection	1.4	1.3	2.0	3.5	0.0	1.5	
Transposition of the great arteries	167	50	24	18	0	264	
(TGA)	4.3	4.8	5.9	10.5	0.0	4.6	
Dextro-transposition of great arteries	55	13	2	7	0	79	
(d-TGA)	1.4	1.3	0.5	4.1	0.0	1.4	
Tricuspid valve atresia and stenosis	50	16	9	4	0	82	
•	1.3	1.5	2.2	2.3	0.0	1.4	
Tricuspid valve atresia	50	16	9	4	0	82	
	1.3	1.5	2.2	2.3	0.0	1.4	
Trisomy 13	21	16	4	5	0	47	
	0.5	1.5	1.0	2.9	0.0	0.8	
Trisomy 18	58	16	9	4	0	90	
	1.5	1.5	2.2	2.3	0.0	1.6	
Trisomy 21 (Down syndrome)	509	139	61	81	0	815	
	13.1	13.4	15.1	47.4	0.0	14.3	
Turner syndrome	0	0	0	0	0	0	2
	0.0	0.0	0.0	0.0	0.0	0.0	
Ventricular septal defect	1,812	562	230	172	16	2,856	
Total live births	46.6 388,897	<i>54.1</i> 103,918	56.8 40,518	<i>100.6</i> 17,102	71.7 2,232	50.2 568,365	3
Male live births	199,589	52,767	20,678	8,824	1,154	291,158	
Female live births	189,303	51,145	19,839	8,278	1,078	277,194	

# Michigan Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	268	9	277				
	5.4	1.2	4.9				
Trisomy 13	31	16	47				
-	0.6	2.1	0.8				
Trisomy 18	42	47	90				
	0.9	6.3	1.6				
Trisomy 21 (Down syndrome)	428	381	815				
	8.7	51.0	14.3				
Total live births	493,574	74,731	568,365	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. Total live births includes unknown gender.

General comments *Totals include unknown and/or other.

# Minnesota Birth Defects Counts and Prevalence 2011 - 2015 (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	3	4	6	0	13	
Anophthalmia/microphthalmia	0.0 6 0.9	1.2 8 3.2	3.7 2 1.9	3.3 2 1.1	<b>0.0</b> 0 <b>0.0</b>	1.1 18 1.5	
Anotia/microtia	10 1.6	5 2.0	1.9 14 13.0	8 4.5	3 22.7	41 3.4	
Aortic valve stenosis	21	4	0	1	0	26	
Atrial septal defect	3.3 133 20.6	<b>1.6</b> 60 <b>24.2</b>	0.0 24 22.3	0.6 46 25.6	0.0 5 37.9	2.2 271 22.5	
Atrioventricular septal defect (Endocardial cushion defect)	42 6.5	14 5.6	8 7.4	8 4.5	0 <b>0.0</b>	72 6.0	1
Biliary atresia	4 <i>0.6</i>	3 1.2	1 0.9	3 1.7	0 <b>0.0</b>	11 <b>0.9</b>	
Bladder exstrophy	2 0.3	1.2 1 0.4	0 0.0	0 0.0	0 0.0	3 0.2	
Choanal atresia	8 1.2	6 2.4	3 <b>2.8</b>	0 <i>0.0</i>	0 <b>0.0</b>	17 <b>1.4</b>	
Cleft lip alone	23 3.6	2.4 9 3.6	2.0 2 1.9	5 2.8	0.0 0.0	40 3.3	
Cleft lip with cleft palate	36	15	8	12	1	72	
Cleft palate alone	5.6 49 7.6	<b>6.0</b> 10 <b>4.0</b>	7.4 4 3.7	6.7 8 4.5	7.6 1 7.6	<b>6.0</b> 73 <b>6.1</b>	
Coarctation of the aorta	37 5.7	11 4.4	5 4.6	1 0.6	1 7.6	55 4.6	
Common truncus (truncus arteriosus)	4 0.6	1 0.4	1 0.9	2 1.1	0 0.0	8 0.7	
Congenital cataract	15 2.3	0.4 11 4.4	0.9 0.0	3 1.7	1 7.6	31 2.6	
Congenital posterior urethral valves	2.3 9 2.7	4.4 7 5.5	0.0 0.0	2 2.2	7.0 0 0.0	2.0 18 2.9	2
Diaphragmatic hernia	16 2.5	7 2.8	2 1.9	5 2.8	0 0.0	30 2.5	
Double outlet right ventricle	8 1.2	12 4.8	4 3.7	1 0.6	0 0.0	2.5 25 2.1	
Ebstein anomaly	4 0.6	1 0.4	0 0.0	1 0.6	0.0 0.0	6 0.5	
Encephalocele	5 0.8	3 1.2	1 0.9	3 1.7	1 7.6	14 1.2	
Esophageal atresia/tracheoesophageal	22	5	3	6	0	36	
fistula Gastroschisis	<b>3.4</b> 10	<b>2.0</b> 4	<b>2.8</b> 6	<b>3.3</b> 9	<b>0.0</b> 0	<b>3.0</b> 29	
Hypoplastic left heart syndrome	<b>1.6</b> 14	<b>1.6</b> 4	<b>5.6</b> 2	<b>5.0</b> 1	<b>0.0</b> 0	<b>2.4</b> 21	
Hypospadias	<b>2.2</b> 266	<b>1.6</b> 109	<b>1.9</b> 20	0.6 25	<b>0.0</b> 3	1.7 430	2
Limb deficiencies (reduction defects)	<b>80.8</b> 23	<b>85.</b> 7 8	<b>36.8</b> 2	27.4 8	<b>45.3</b> 1	<b>69.8</b> 43	3
Omphalocele	<b>3.6</b> 15	3.2 3	<b>1.9</b> 1	4.5 4	7.6 0	<b>3.6</b> 23	
Pulmonary valve atresia and stenosis	2.3 63	1.2 34	<b>0.9</b> 16	<b>2.2</b> 21	0.0 4 20.2	<b>1.9</b> 139	
Pulmonary valve atresia	<b>9.8</b> 3	<i>13.7</i> 4	<b>14.9</b> 0	11.7 4 2.2	<b>30.3</b> 0	11.5 11	
Rectal and large intestinal	0.5 22	<b>1.6</b> 13	0.0 5	2.2 8	<b>0.0</b> 0	<b>0.9</b> 48	
atresia/stenosis Renal agenesis/hypoplasia	<b>3.4</b> 33	<b>5.2</b> 13	<b>4.6</b> 4	<b>4.5</b> 7	<b>0.0</b> 0	<b>4.0</b> 58	
aBeneois ny Populoin	5.1	5.2	3.7	3.9	0.0	<u>4.8</u>	

# Minnesota Birth Defects Counts and Prevalence 2011 - 2015 (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
Single ventricle	0	3	0	2	0	5	
	0.0	1.2	0.0	1.1	0.0	0.4	
Spina bifida without anencephalus	18	10	2	3	0	35	
	2.8	4.0	1.9	1.7	0.0	2.9	
Tetralogy of Fallot	22	4	2	2	1	32	4
	3.4	1.6	1.9	1.1	7.6	2.7	
Total anomalous pulmonary venous	8	1	2	7	0	18	5
connection	2.1	0.6	3.2	6.3	0.0	2.5	
Transposition of the great arteries	13	6	3	2	1	25	
(TGA)	2.0	2.4	2.8	1.1	7.6	2.1	
Tricuspid valve atresia	2	5	1	3	0	11	
	0.3	2.0	0.9	1.7	0.0	0.9	
Trisomy 13	4	7	1	1	1	14	
	0.6	2.8	0.9	0.6	7.6	1.2	
Trisomy 18	9	9	0	5	0	23	
	1.4	3.6	0.0	2.8	0.0	1.9	
Trisomy 21 (Down syndrome)	121	47	24	24	1	218	
	18.8	18.9	22.3	13.4	7.6	18.1	
Ventricular septal defect	433	151	80	92	20	787	6
	67.2	60.9	74.4	51.3	151.4	65.3	
Total live births	64,409	24,807	10,753	17,938	1,321	120,534	7
Male live births	32,936	12,722	5,433	9,129	662	61,569	

## Minnesota Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	29	0	29				
	2.9	0.0	2.4				
Trisomy 13	7	7	14				
	0.7	3.1	1.2				
Trisomy 18	14	9	23				
	1.4	4.0	1.9				
Trisomy 21 (Down syndrome)	127	91	218				
	12.9	40.9	18.1				
Total live births	98,308	22,224	120,534	7			

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 exclude other specified reduction defect of lower limb, transverse reduction defect of lower limb not otherwise specified,

unspecified reduction defect of lower limb, and reduction defects of unspecified limb.

4. Data for this condition exclude pulmonary artery atresia with septal defect.

5. Data for this condition begin in 2013.

6. Data for this condition include inlet ventricular septal defect.

7. Total live births includes unknown gender.

#### **General comments**

*Totals include unknown and/or other.

-Data for conditions excludes probable and possible cases.

-Data for conditions include Hennepin and Ramsey Counties only.

# Mississippi Birth Defects Counts and Prevalence 2011 - 2015 (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	4	0	0	0	14	TUTES	
	1.0	0.5	0.0	0.0	0.0	0.7		
Anophthalmia/microphthalmia	9 <b>0.9</b>	13	1	1 4.2	1 8.5	26		
Anotia/microtia	12	<b>1.6</b> 11	<b>1.8</b> 0	4.2 0	8.5 2	1.3 25		
	1.2	1.3	0.0	0.0	17.1	1.3		
Aortic valve stenosis	21	7	1	0	1	31		
Atrial septal defect	<b>2.1</b> 1,983	<b>0.8</b> 2,419	<b>1.8</b> 154	<b>0.0</b> 37	<b>8.5</b> 94	<b>1.6</b> 4.856		
Autai septai delect	1,985 195.9	290.6	280.2	155.5	802.0	250.1		
Atrioventricular septal defect	67	57	4	0	0	132		
(Endocardial cushion defect)	6.6	6.8	7.3	0.0	0.0	6.8		
Biliary atresia	7 <b>0.</b> 7	14 1.7	0 <i>0.0</i>	0 <b>0.0</b>	0 <b>0.0</b>	21 1.1		
Bladder exstrophy	3	1.7	0.0	0.0	0	5		
	0.3	0.1	0.0	0.0	0.0	0.3		
Choanal atresia	12	12	1	0	0	25		
	1.2	1.4	1.8	0.0	0.0	1.3		
Cleft lip alone	33 <b>3.3</b>	9 1.1	1 1.8	0 <b>0.0</b>	1 8.5	44 2.3		
Cleft lip with cleft palate	74	47	1.0	6	2	138		
croit up mus croit parate	7.3	5.6	1.8	25.2	- 17.1	7.1		
Cleft palate alone	74	36	1	2	1	119		
C1 1 1 1	7.3	4.3	1.8	8.4	8.5	6.1		
Cloacal exstrophy	30 3.0	33 4.0	3 5.5	0 <b>0.0</b>	0 <b>0.0</b>	68 <b>3.5</b>		
Clubfoot	153	93	10	3	4	273		
	15.1	11.2	18.2	12.6	34.1	14.1		
Coarctation of the aorta	92	66	9	1	1	171		
	9.1	7.9	16.4	4.2	8.5	8.8		
Common truncus (truncus arteriosus)	12 1.2	11 1.3	0 <i>0.0</i>	0 <b>0.0</b>	0 <i>0.0</i>	23 1.2		
Congenital cataract	13	14	0	0	0	29		
	1.3	1.7	0.0	0.0	0.0	1.5		
Congenital posterior urethral valves	14	25	1	0	0	41	1	
Cronicatoria	2.7 45	<b>6.0</b> 20	<b>3.6</b> 3	0.0	<b>0.0</b> 1	<b>4.2</b> 73		
Craniosynostosis	43 4.4	20 2.4	5 5.5	0.0	8.5	7.5 3.8		
Deletion 22q11.2	4	8	0	0	0	12		
	0.4	1.0	0.0	0.0	0.0	0.6		
Diaphragmatic hernia	26	18	3	1	0	50		
Double outlet right ventricle	<b>2.6</b> 33	<b>2.2</b> 33	<b>5.5</b> 2	<b>4.2</b> 0	<b>0.0</b> 0	<b>2.6</b> 68		
Double outlet right vehicle	3.3	4.0	3.6	0.0	0.0	3.5		
Ebstein anomaly	10	6	0	0	0	17		
	1.0	0.7	0.0	0.0	0.0	0.9		
Encephalocele	13	12	0	0	3	28		
Esophageal atresia/tracheoesophageal	<i>1.3</i> 20	<b>1.4</b> 18	<b>0.0</b> 2	0.0 1	<b>25.6</b> 0	<b>1.4</b> 42		
fistula	2.0	2.2	- 3.6	4.2	0.0	2.2		
Gastroschisis	19	17	2	0	1	40		
	1.9	2.0	3.6	0.0	8.5	2.1		
Holoprosencephaly	41 <i>4.1</i>	36 <i>4.3</i>	8 14.6	1 4.2	2 17.1	89 <b>4.6</b>		
Hypoplastic left heart syndrome	<b>4.1</b> 55	<b>4.3</b> 34	14.0 3	4.2 0	17.1 0	<b>4.0</b> 93		
71 I	5.4	4.1	5.5	0.0	0.0	4.8		
Hypospadias	393	352	10	1	0	779	1	
Tutoment de stie e d	75.8	<i>84.3</i>	<i>36.1</i>	8.2	0.0	<b>79.1</b>		
Interrupted aortic arch	22 2.2	29 <b>3.5</b>	2 <b>3.6</b>	0 <i>0.0</i>	0 <i>0.0</i>	55 <b>2.8</b>		
	<i>4.4</i>	3.3	5.0	0.0	0.0	4.0		

# Mississippi Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	29	51	2	0	2	86	
	2.9	6.1	3.6	0.0	17.1	4.4	
Omphalocele	16	16	0	0	0	33	
-	1.6	1.9	0.0	0.0	0.0	1.7	
Pulmonary valve atresia and stenosis	135	144	6	1	1	293	
	13.3	17.3	10.9	4.2	8.5	15.1	
Rectal and large intestinal	50	28	4	1	0	84	
atresia/stenosis	4.9	3.4	7.3	4.2	0.0	4.3	
Renal agenesis/hypoplasia	59	35	0	1	2	99	
	5.8	4.2	0.0	4.2	17.1	5.1	
Single ventricle	22	29	1	0	0	53	
	2.2	3.5	1.8	0.0	0.0	2.7	
Small intestinal atresia/stenosis	15	28	2	0	1	46	
	1.5	3.4	3.6	0.0	8.5	2.4	
Spina bifida without anencephalus	57	35	2	2	2	100	
	5.6	4.2	3.6	8.4	17.1	5.1	
Tetralogy of Fallot	57	65	4	2	0	132	
	5.6	7.8	7.3	8.4	0.0	6.8	
Total anomalous pulmonary venous	8	14	1	0	0	23	
connection	0.8	1.7	1.8	0.0	0.0	1.2	
Transposition of the great arteries	39	23	3	2	0	68	
(TGA)	3.9	2.8	5.5	8.4	0.0	3.5	
Tricuspid valve atresia and stenosis	10	15	1	0	0	26	
	1.0	1.8	1.8	0.0	0.0	1.3	
Trisomy 13	5	7	0	0	0	12	
	0.5	0.8	0.0	0.0	0.0	0.6	
Trisomy 18	16	17	1	0	1	35	
	1.6	2.0	1.8	0.0	8.5	1.8	
Trisomy 21 (Down syndrome)	144	102	18	2	7	277	
	14.2	12.3	32.7	8.4	<b>59.</b> 7	14.3	
Turner syndrome	14	1	0	0	0	15	2
	2.8	0.2	0.0	0.0	0.0	1.6	
Ventricular septal defect	733	637	59	17	21	1,510	3
	72.4	76.5	107.3	71.4	179.2	77.8	
Total live births	101,203	83,238	5,497	2,380	1,172	194,187	
Male live births	51,854	41,742	2,769	1,226	571	98,520	
Female live births	49,349	41,496	2,728	1,154	601	95,667	

# Mississippi Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	34	3	40				
	1.9	1.9	2.1				
Trisomy 13	9	2	12				
-	0.5	1.2	0.6				
Trisomy 18	25	6	35				
	1.4	3.7	1.8				
Trisomy 21 (Down syndrome)	151	96	277				
	8.5	59.4	14.3				
Total live births	178,004	16,169	194,187				

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 exclude probable cases.

General comments *Totals include unknown and/or other.

# Missouri Birth Defects Counts and Prevalence 2011 - 2015 (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	37	7	6	0	0	50	
Anophthalmia/microphthalmia	1.3 28	1.3 1	3.0 2	<b>0.0</b> 1	<b>0.0</b> 0	<i>1.3</i> 33	
Anotia/microtia	1.0 13	0.2 5 0.9	1.0 8	1.1 2	0.0 0 0.0	0.9 28	
Aortic valve stenosis	0.5 36 1.3	0.9 3 0.6	4.0 5 2.5	<b>2.1</b> 0 <b>0.0</b>	0.0 0 0.0	0.7 45 1.2	
Atrial septal defect	1.5 3,968 141.0	1,092 202.8	2.3 272 135.5	115 123.5	6 7 <b>6.9</b>	5,648 149.9	
Atrioventricular septal defect (Endocardial cushion defect)	138 4.9	30 5.6	10 5.0	2 2.1	0 0.0	185 4.9	
Biliary atresia	23 0.8	10 1.9	5 2.5	3 3.2	0 <b>0.0</b>	42 1.1	
Bladder exstrophy	13 0.5	0 <b>0.0</b>	0	1 1.1	0 0.0	14 0.4	
Choanal atresia	56 2.0	13 2.4	4 2.0	1 1.1	0 <b>0.0</b>	75 2.0	
Cleft lip alone	150 5.3	22 4.1	8 4.0	3 3.2	1 12.8	192 5.1	
Cleft lip with cleft palate	196 7.0	31 5.8	13 6.5	4 4.3	1 12.8	258 6.8	
Cleft palate alone	173 6.1	21 3.9	17 8.5	3 3.2	0	215 5.7	
Cloacal exstrophy	190 6.7	54 10.0	13 6.5	5 5.4	0 <i>0.0</i>	273 7.2	
Clubfoot	503 17.9	80 14.9	23 11.5	18 19.3	1 12.8	649 17.2	
Coarctation of the aorta	202 7.2	24 4.5	18 9.0	3 3.2	0	249 6.6	
Common truncus (truncus arteriosus)	16 <b>0.6</b>	3 0.6	3 1.5	0 <b>0.0</b>	0 <b>0.0</b>	23 0.6	
Congenital cataract	34 1.2	6 1.1	1 0.5	1 1.1	0 <b>0.0</b>	44 1.2	
Congenital posterior urethral valves	34 2.4	14 5.1	1 1.0	1 2.1	0 <i>0.0</i>	52 2.7	1
Craniosynostosis	2 0.4	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	2 0.3	2
Deletion 22q11.2	17 <b>0.6</b>	2 <b>0.4</b>	1 0.5	1 1.1	0 <i>0.0</i>	21 <i>0.6</i>	
Diaphragmatic hernia	112 <b>4.0</b>	28 5.2	7 <b>3.5</b>	4 <i>4.3</i>	1 12.8	155 <b>4.1</b>	
Double outlet right ventricle	71 2.5	17 3.2	5 <b>2.5</b>	2 2.1	0 <i>0.0</i>	97 <b>2.6</b>	
Ebstein anomaly	20 0.7	1 0.2	3 1.5	0 <i>0.0</i>	0 <i>0.0</i>	27 <b>0.</b> 7	
Encephalocele	21 0.7	9 1.7	3 1.5	0 <i>0.0</i>	0 <i>0.0</i>	34 <i>0.9</i>	
Esophageal atresia/tracheoesophageal fistula	92 3.3	13 2.4	5 2.5	2 2.1	1 12.8	116 3.1	
Gastroschisis	153 5.4	29 5.4	14 7.0	2 2.1	0 0.0	202 5.4	
Holoprosencephaly	160 5.7	36 <b>6.</b> 7	17 8.5	4 4.3	0 0.0	221 5.9	
Hypoplastic left heart syndrome	90 3.2	18 3.3	4 2.0	0 <b>0.0</b>	0 0.0	113 3.0	
Hypospadias	1,175 <b>81.4</b>	239 <b>87.6</b>	38 37.2	37 7 <b>6.4</b>	6 150.4	1,538 7 <b>9.</b> 7	1
Interrupted aortic arch	24 <b>0.9</b>	4 <b>0.</b> 7	4 2.0	0 <b>0.0</b>	0 <i>0.0</i>	33 <i>0.9</i>	

# Missouri Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	110	17	7	4	0	142	110105
`````	3.9	3.2	3.5	4.3	0.0	3.8	
Omphalocele	66	16	5	1	0	92	
	2.3	3.0	2.5	1.1	0.0	2.4	
Pulmonary valve atresia and stenosis	232	59	18	8	1	330	
	8.2	11.0	9.0	8.6	12.8	8.8	
Pulmonary valve atresia	35	4	2	0	0	43	
	1.2	0.7	1.0	0.0	0.0	1.1	
Rectal and large intestinal	124	28	10	4	1	173	
atresia/stenosis	4.4	5.2	5.0	4.3	12.8	4.6	
Renal agenesis/hypoplasia	135 4.8	31 5.8	12 6.0	5 5.4	0 0.0	186 4.9	
Sin ala mantriala	4.8 34	5.8 6	6.0 3	5.4 1	0.0	4.9 46	
Single ventricle	54 1.2	0 1.1	5 1.5	1 1.1	0.0	40 1.2	
Small intestinal atresia/stenosis	1.2	28	1.5	4	0.0	1.2	
Sinan musunai aucsia/stenosis	3.9	5.2	5.0	4.3	0.0	4.2	
Spina bifida without anencephalus	64	8	2	0	0	75	
opina onica watout anoneephalas	2.3	1.5	- 1.0	0.0	0.0	2.0	
Tetralogy of Fallot	137	29	15	3	1	190	
	4.9	5.4	7.5	3.2	12.8	5.0	
Total anomalous pulmonary venous	31	5	3	0	0	41	
connection	1.1	0.9	1.5	0.0	0.0	1.1	
Transposition of the great arteries	122	13	7	3	0	148	
(TGA)	4.3	2.4	3.5	3.2	0.0	3.9	
Dextro-transposition of great arteries	105	10	4	2	0	123	
(d-TGA)	3.7	1.9	2.0	2.1	0.0	3.3	
Tricuspid valve atresia and stenosis	34	6	4	1	0	47	
	1.2	1.1	2.0	1.1	0.0	1.2	
Tricuspid valve atresia	34	6	4	1	0	47	
T : 12	1.2	1.1	2.0	1.1	0.0	1.2	
Trisomy 13	31	6	0	0	0	37	
T.:	1.1	1.1 9	0.0	0.0	0.0	1.0	
Trisomy 18	40 1.4	9 1.7	6 3.0	1 1.1	0 <i>0.0</i>	56 1.5	
Trisomy 21 (Down syndrome)	366	78	42	11	2	1.5 516	
Thisonly 21 (Down syndrome)	13.0	14.5	20.9	11.8	25.6	13.7	
Turner syndrome	26	2	2	0	0	30	3
rumer synarome	1.9	0.8	2.0	0.0	0.0	1.6	5
Ventricular septal defect	1,432	309	112	32	1	1,939	4
1	50.9	57.4	55.8	34.4	12.8	51.5	
Total live births	281,486	53,857	20,071	9,312	780	376,859	5
Male live births	144,390	27,288	10,206	4,843	399	193,044	
Female live births	137,090	26,566	9,865	4,469	381	183,806	

Missouri Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	196	6	202				
	5.9	1.4	5.4				
Trisomy 13	26	11	37				
-	0.8	2.6	1.0				
Trisomy 18	35	21	56				
	1.0	5.0	1.5				
Trisomy 21 (Down syndrome)	300	216	516				
	9.0	51.0	13.7				
Total live births	334,408	42,372	376,859	5			

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 only include 2015.

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.

5. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

-Fetal deaths are defined as more than 20 gestational weeks or 350 grams birth weight.

Nebraska Birth Defects Counts and Prevalence 2011 - 2015 (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	0	4	0	0	48	
Anophthalmia/microphthalmia	2.5 12 1.2	0.0 1 1.1	2.0 0 0.0	0.0 0 0.0	0.0 1 5.2	3.7 15 1.1	
Anotia/microtia	18 1.9	0 0.0	3 1.5	1 2.5	0 0.0	32 2.4	
Aortic valve stenosis	16 1.7	0 0.0	1 0.5	0 <i>0.0</i>	0 <i>0.0</i>	19 1.4	
Atrial septal defect	1.7 34 3.5	1 1.1	0.5 1 0.5	2 5.0	1 5.2	41 3.1	
Atrioventricular septal defect (Endocardial cushion defect) Biliary atresia	28 2.9 3 0.3	0 0.0 0 0.0	0 0.0 0 0.0	1 2.5 0 0.0	0 0.0 0 0.0	35 2.7 3 0.2	
Bladder exstrophy	6 0.6	1 1.1	0 <i>0.0</i>	0 0.0	0 <i>0.0</i>	7 0.5	
Choanal atresia	22 2.3	0 0.0	0 <i>0.0</i>	1 2.5	0 0.0	28 2.1	
Cleft lip alone	35 3.6	3 3.4	4 2.0	3 7.4	3 15.5	56 <i>4.3</i>	
Cleft lip with cleft palate	55 5. 7	2 2.2	2 1.0	6 14.9	2 10.3	80 6.1	
Cleft palate alone	47 4.9	2.2 2 2.2	3 1.5	2 5.0	1 5.2	63 4.8	
Cloacal exstrophy	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	0 0.0	
Clubfoot	152 15.8	11 12.3	11 5.6	3 7.4	4 20.7	204 15.5	
Coarctation of the aorta	72 7.5	1 1.1	4 2.0	1 2.5	0 0.0	91 6.9	
Common truncus (truncus arteriosus)	16 1.7	2 2.2	1 0.5	0 0.0	0 0.0	22 1.7	
Congenital cataract	17 1.8	0 0.0	3 1.5	2 5.0	0 0.0	25 1.9	
Congenital posterior urethral valves	1 0.2	1 2.2	0 0.0	0 0.0	0 0.0	2 0.3	1
Craniosynostosis	15 1.6	0 0.0	0 0.0	0 0.0	0 0.0	17 1.3	
Deletion 22q11.2	1 0.1	0 0.0	0 0.0	0 0.0	0 0.0	1 0.1	
Diaphragmatic hernia	16 1.7	3 3.4	2 1.0	1 2.5	1 5.2	27 2.1	
Double outlet right ventricle	17 1.8	2 2.2	2 1.0	1 2.5	2 10.3	30 <i>2.3</i>	
Ebstein anomaly	7 0. 7	0 <i>0.0</i>	0 <i>0.0</i>	0 0.0	1 5.2	10 <i>0.8</i>	
Encephalocele	9 0.9	1 1.1	0 0.0	1 2.5	1 5.2	14 1.1	
Esophageal atresia/tracheoesophageal fistula	33 3.4	2 2.2	2 1.0	0 0.0	0	41 3.1	
Gastroschisis	3.4 44 4.6	2.2 3 3.4	1.0 10 5.1	0.0 1 2.5	0.0 1 5.2	3.1 66 5.0	
Holoprosencephaly	4.6 2 0.2	1 1.1	0 0.0	2.5 2 5.0	5.2 1 5.2	8 0.6	
Hypoplastic left heart syndrome	0.2 34 3.5	1.1 5 5.6	0.0 0 0.0	0 0.0	3.2 2 10.3	46 3.5	
Hypospadias	422 85.1	3.0 35 7 8.1	18 18.0	3 14.8	0 0.0	525 77.9	1
Interrupted aortic arch	9 0.9	0 0.0	1 0.5	0 0.0	0 <i>0.0</i>	12 0.9	

Nebraska Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	60	5	3	1	0	76	
	6.2	5.6	1.5	2.5	0.0	5.8	
Omphalocele	24	5	2	1	0	35	
	2.5	5.6	1.0	2.5	0.0	2.7	
Pulmonary valve atresia and stenosis	71	4	3	2	2	92	
	7.4	4.5	1.5	5.0	10.3	7.0	
Pulmonary valve atresia	19	3	1	0	2	30	
	2.0	3.4	0.5	0.0	10.3	2.3	
Rectal and large intestinal	39	4	4	1	2	53	
atresia/stenosis	4.1 79	4.5 7	2.0 3	2.5 3	10.3 2	4.0	
Renal agenesis/hypoplasia	8.2	7.8	3 1.5	3 7.4	2 10.3	107 8.2	
Single ventricle	27	3	0	0	10.5	32	
Single ventricle	2.8	3.4	0.0	0.0	5.2	32 2.4	
Small intestinal atresia/stenosis	2.6	2	2	1	0	33	
Shah mesthal dresh/stehosis	2.7	2.2	1.0	2.5	0.0	2.5	
Spina bifida without anencephalus	135	3	15	0	3	183	
opina offica white an encorphanas	14.0	3.4	7.7	0.0	15.5	13.9	
Tetralogy of Fallot	33	3	1	3	0	44	
8,	3.4	3.4	0.5	7.4	0.0	3.4	
Total anomalous pulmonary venous	11	3	1	0	0	19	
connection	1.1	3.4	0.5	0.0	0.0	1.4	
Transposition of the great arteries	37	3	0	0	0	48	
(TGA)	3.8	3.4	0.0	0.0	0.0	3.7	
Dextro-transposition of great arteries	37	3	0	0	0	48	
(d-TGA)	3.8	3.4	0.0	0.0	0.0	3.7	
Tricuspid valve atresia and stenosis	15	3	0	0	0	21	
	1.6	3.4	0.0	0.0	0.0	1.6	
Trisomy 13	24	9	6	0	3	51	
	2.5	10.1	3.1	0.0	15.5	3.9	
Trisomy 18	114	12	6	6	0	150	
	11.9	13.4	3.1	14.9	0.0	11.4	
Trisomy 21 (Down syndrome)	519	12	42	33	6	699	
	54.0	13.4	21.4	81.8	31.0	53.3	_
Turner syndrome	10	0	0	0	0	13	2
Vontrioulon contol d-ft	2.1	0.0	0.0	0.0	0.0	2.0	
Ventricular septal defect	449 46. 7	25	37 18.9	12	3	626 47.7	
Total live births	40.7 96,161	27.9 8,947	19,582	29.7 4,035	<i>15.5</i> 1,937	<i>47.7</i> 131,223	
Male live births	49,575	4,483	10,021	2,023	978	67,365	
Female live births	46,586	4,464	9,561	2,012	959	63,858	

Nebraska Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	60	6	66				
	5.2	3.7	5.0				
Trisomy 13	36	15	51				
-	3.1	9.1	3.9				
Trisomy 18	90	60	150				
	7.8	36.5	11.4				
Trisomy 21 (Down syndrome)	444	255	699				
• • • •	38.7	155.3	53.3				
Total live births	114,801	16,416	131,223				

Notes 1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births. The second secon 2. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.

General comments

*Totals include unknown and/or other.

Nevada Birth Defects Counts and Prevalence 2011 - 2015 (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	0	3	0	0	6	
Anophthalmia/microphthalmia	<i>0.3</i> 4	0.0 3	0.5 7	0.0 2	0.0 0	0.3 18	
Anophulainia/merophulainia	0.5	1.5	1.1	2 1.4	0.0	1.0	
Anotia/microtia	5	0	3	1	0	11	
Aortic valve stenosis	0.7	0.0	0.5	0. 7 1	0.0 0	0.6 23	
Aortic valve stenosis	12 1.6	0 0.0	8 1.3	0.7	0.0	23 1.3	
Atrial septal defect	1,958	647	1,329	358	25	4,797	
	268.6	329.8	209.2	245.7	144.4	273.1	
Atrioventricular septal defect (Endocardial cushion defect)	13 1.8	6 3.1	8 1.3	1 0. 7	0 0.0	32 1.8	
Biliary atresia	7	2	3	1	0	16	
	1.0	1.0	0.5	0.7	0.0	0.9	
Bladder exstrophy	3	0 0.0	0	0	0	4	
Choanal atresia	0.4 6	0.0 1	0.0 4	0.0 1	0.0 0	<i>0.2</i> 14	
	0.8	0.5	0.6	0.7	0.0	0.8	
Cleft lip alone	22	3	7	6	0	40	
Cleft lip with cleft palate	3.0 47	1.5 16	1.1 45	4.1 2	0.0 2	2.3 124	
Cleft fip with cleft parate	47 6.4	8.2	43 7.1	2 1.4	11.6	7.1	
Cleft palate alone	34	5	19	4	2	72	
	4.7	2.5	3.0	2.7	11.6	4.1	
Cloacal exstrophy	24 3.3	8 4.1	13 2.0	3 2.1	0 0.0	51 2.9	
Clubfoot	104	23	2.0 75	8	1	2.9	
	14.3	11.7	11.8	5.5	5.8	13.0	
Coarctation of the aorta	42	7	32	5	0	92	
Common truncus (truncus arteriosus)	5.8 1	3.6 2	5.0 5	3.4 0	0.0 0	5.2 9	
common autous (autous arteriosus)	0.1	- 1.0	0.8	0.0	0.0	0.5	
Congenital cataract	5	3	4	1	0	14	
Conceptal posterior wrethral values	0.7 7	1.5 0	0.6 1	0. 7 0	0.0 0	0.8 8	1
Congenital posterior urethral valves	1.9	0.0	0.3	0.0	0.0	° 0.9	1
Craniosynostosis	64	13	24	4	0	118	
	8.8	6.6	3.8	2.7	0.0	6.7	
Deletion 22q11.2	0 <i>0.0</i>	0 0.0	0 <i>0.0</i>	0 0.0	0 0.0	1 <i>0.1</i>	
Diaphragmatic hernia	8	4	14	4	0	32	
1 0	1.1	2.0	2.2	2.7	0.0	1.8	
Double outlet right ventricle	8	2	6	0	0	18	
Ebstein anomaly	1.1 3	1.0 0	0.9 4	0.0 0	0.0 0	1.0 8	
	0.4	0.0	0.6	0.0	0.0	0.5	
Encephalocele	3	0	1	2	0	6	
	0.4	0.0	0.2	1.4	0.0	0.3	
Esophageal atresia/tracheoesophageal fistula	16 2.2	2 1.0	10 1.6	0 0.0	0 0.0	30 1.7	
Gastroschisis	21	8	18	4	0	57	
	2.9	4.1	2.8	2.7	0.0	3.2	
Holoprosencephaly	36 4.9	9 4.6	16 2.5	8	0 0.0	69 3.9	
Hypoplastic left heart syndrome	4.9 11	4.0 3	2.5 11	5.5 1	0.0	3.9 28	
	1.5	1.5	1.7	0.7	0.0	1.6	
Hypospadias	201	35	76	22	0	359	1
	53.5	34.9 2	23.4 6	29.1 3	0.0 0	39.8 26	
Interrupted aortic arch	9	/	0		0		

Nevada Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	18	4	12	2	0	39	
	2.5	2.0	1.9	1.4	0.0	2.2	
Omphalocele	5	1	7	2	0	20	
	0.7	0.5	1.1	1.4	0.0	1.1	
Pulmonary valve atresia and stenosis	68	26	39	3	3	149	
	9.3	13.3	6.1	2.1	17.3	8.5	
Rectal and large intestinal	27	1	22	1	0	55	
atresia/stenosis	3.7	0.5	3.5	0.7	0.0	3.1	
Renal agenesis/hypoplasia	26	7	19	5	3	64	
	3.6	3.6	3.0	3.4	17.3	3.6	
Single ventricle	2	2	2	0	0	6	
a 11	0.3	1.0	0.3	0.0	0.0	0.3	
Small intestinal atresia/stenosis	24	7	19	2	1	55	
Surias hift to suide out on our out obse	3.3	3.6	3.0	1.4	5.8	3.1 29	
Spina bifida without anencephalus	11	3	8	2	0		
T-4-1	<i>1.5</i> 17	1.5 1	<i>1.3</i> 23	1.4 3	0.0 1	<i>1.7</i> 49	
Tetralogy of Fallot	2.3	0.5				2.8	
Total an amalana mulmanami yan ana		0.5	3.6	2.1 0	5.8	2.8 9	
Total anomalous pulmonary venous	5 0. 7	0.0	2 0.3		0	9 0.5	
connection	<i>0.7</i> 12	5	0.3 5	0.0 1	0.0	0.5 24	
Transposition of the great arteries	12 1.6	2.5	5 0.8	0.7	0.0	24 1.4	
(TGA) Tricuspid valve atresia and stenosis	2	2.3	3	2	0.0	1.4 11	
Theuspid valve allesia and stenosis	2 0.3	2 1.0	<i>0.5</i>	2 1.4	0.0	0.6	
Trisomy 13	6	3	7	1.4	0.0	18	
Thisonly 15	0.8	1.5	1.1	0.7	0.0	1.0	
Trisomy 18	5	2	8	0.7	0.0	17	
Thisonly 18	0.7	1.0	1.3	0.0	0.0	1.0	
Trisomy 21 (Down syndrome)	69	15	93	9	2	204	
Thisonly 21 (Down Syndrome)	9.5	7.6	14.6	6.2	- 11.6	11.6	
Turner syndrome	5	3	5	1	0	15	2
Tunier Synaronie	1.4	3.1	1.6	1.4	0.0	1.8	2
Ventricular septal defect	372	83	331	61	8	936	3
	51.0	42.3	52.1	41.9	46.2	53.3	
Total live births	72,910	19,619	63,535	14,573	1,731	175,629	
Male live births	37,544	10,037	32,518	7,564	933	90,277	
Female live births	35,366	9,582	31,017	7,009	798	85,352	

Nevada Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	51	0	57				
	3.4	0.0	3.2				
Trisomy 13	8	6	18				
-	0.5	2.2	1.0				
Trisomy 18	9	6	17				
	0.6	2.2	1.0				
Trisomy 21 (Down syndrome)	93	75	204				
	6.3	27.6	11.6				
Total live births	148,274	27,134	175,629				

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 exculde cases that are less than 2500 grams birth weight or less than 36 weeks gestation.

General comments

*Totals include unknown and/or other.

-Data for 2014-15 was collected passively from hospital discharge data.

-Data for conditions exclude probable/possible diagnoses.

-Data for conditions include live births and resident births only.

New Jersey Birth Defects Counts and Prevalence 2011 - 2015 (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	3	6	0	0	19	110105
	0.4	0.4	0.4	0.0	0.0	0.4	
Anophthalmia/microphthalmia	10	7 0.9	9 0. 7	2	1 20.2	30	
Anotia/microtia	0.4 43	5	0. 7 67	0.3 12	0	0.6 127	
	1.8	0.7	4.9	2.1	0.0	2.5	
Aortic valve stenosis	18	5	14	2	0	40	
Atrial septal defect	0.8 564	0.7 553	1.0 599	0.3 166	0.0 3	0.8 1,929	
Autai septai delect	24.0	72.9	43.5	28.6	60.5	37.3	
Atrioventricular septal defect	61	29	42	5	0	139	
(Endocardial cushion defect)	2.6	3.8	3.1	0.9	0.0	2.7	
Biliary atresia	9 0.4	2 0.3	12 0.9	2 0.3	0 <i>0.0</i>	25 0.5	
Bladder exstrophy	0.4 3	0.5 0	0.9 3	1	0.0	<i>0.5</i> 8	
·F2	0.1	0.0	0.2	0.2	0.0	0.2	
Choanal atresia	30	4	18	1	0	53	
	1.3	0.5	1.3	0.2	0.0	1.0	
Cleft lip alone	78 3.3	24 <i>3.2</i>	66 4.8	15 2.6	0 <i>0.0</i>	186 3.6	
Cleft lip with cleft palate	66	16	55	12	0	151	
F F	2.8	2.1	4.0	2.1	0.0	2.9	
Cleft palate alone	161	29	93	40	0	331	
	6.8	3.8	6.8	6.9	0.0	6.4	
Cloacal exstrophy	41	14	34 2.5	11	0	107 2.1	
Clubfoot	1.7 240	1.8 95	2.5 161	1.9 50	0.0 1	2.1 560	
	10.2	12.5	11.7	8.6	20.2	10.8	
Coarctation of the aorta	85	21	59	11	0	186	
	3.6	2.8	4.3	1.9	0.0	3.6	
Common truncus (truncus arteriosus)	6 0.3	4 0.5	4 0.3	1 0.2	0 <i>0.0</i>	17 0.3	
Congenital cataract	22	18	30	11	0	0.3 86	
congenium enumer	0.9	2.4	2.2	1.9	0.0	1.7	
Congenital posterior urethral valves	24	19	18	8	0	72	1
	2.0	4.9	2.6	2.7	0.0	2.7	
Craniosynostosis	99 4.2	18 2.4	77 5.6	18 3.1	0 <i>0.0</i>	219 4.2	
Deletion 22q11.2	4.2	2.4 1	2	0	0	4. 2 7	
Detention 22411.2	0.2	0.1	<i>0.1</i>	0.0	0.0	0.1	
Diaphragmatic hernia	35	5	39	9	0	90	
	1.5	0.7	2.8	1.6	0.0	1.7	
Double outlet right ventricle	12 0.5	18 2.4	14 1.0	5 0.9	0 0.0	51 <i>1.0</i>	
Ebstein anomaly	9	2	6	3	0	20	
	0.4	0.3	0.4	0.5	0.0	0.4	
Encephalocele	2	4	4	1	0	12	
	0.1	0.5	0.3	0.2	0.0	0.2	
Esophageal atresia/tracheoesophageal fistula	59 2.5	14 1.8	29 2.1	11 1.9	0 0.0	119 2.3	
Gastroschisis	39	15	43	2	1	103	
	1.7	2.0	3.1	0.3	20.2	2.0	
Holoprosencephaly	92	49	68	13	0	226	
H 1 2 101 - 1	3.9	6.5	4.9	2.2	0.0	4.4	
Hypoplastic left heart syndrome	26 1.1	16 2.1	19 1.4	0 <i>0.0</i>	0 0.0	62 1.2	
Hypospadias	1,157	241	372	174	1	1,987	1
	96.0	62.7	53.4	58.3	39.4	75.4	
Interrupted aortic arch	11	8	9	0	0	28	
	0.5	1.1	0.7	0.0	0.0	0.5	

New Jersey Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	71	30	60	10	0	175	
	3.0	4.0	4.4	1.7	0.0	3.4	
Omphalocele	17	22	16	3	0	58	
	0.7	2.9	1.2	0.5	0.0	1.1	
Pulmonary valve atresia and stenosis	139	88	150	23	1	430	
	5.9	11.6	10.9	4.0	20.2	<i>8.3</i>	
Pulmonary valve atresia	13	10	18	0	0	49	
	0.6	1.3	1.3	0.0	0.0	0.9	
Rectal and large intestinal	55	24	53	19	0	160	
atresia/stenosis	2.3	3.2	3.9	3.3	0.0	3.1	
Renal agenesis/hypoplasia	140	30	65	23	0	263	
of 1	6.0	4.0	4.7	4.0	0.0	5.1	
Single ventricle	2	3	3	4	0	12	
Small intestinal atresia/stenosis	0.1	0.4	0.2	0.7	0.0 0	0.2 152	
Small intestinal airesia/stenosis	57 2.4	27 3.6	56	6	0.0	152 2.9	
Spina bifida without anencephalus	2.4 34	3.0 17	4.1 48	1.0 7	0.0	2.9 110	
spina binda without anencephalus		2.2	3.5	1.2	0.0	2.1	
Tetralogy of Fallot	1.4 73	30	50	1.2	0.0	2.1 181	
Tetralogy of Fallot	3.1	<i>4.0</i>	3.6	2.4	0.0	3.5	
Total anomalous pulmonary venous	8	8	18	7	0.0	43	
connection	0.3	<i>1.1</i>	1.3	1.2	0.0	0.8	
Transposition of the great arteries	35	12	28	3	0	82	
(TGA)	1.5	1.6	2.0	0.5	0.0	1.6	
Dextro-transposition of great arteries	17	6	12	2	0	40	
(d-TGA)	0.7	0.8	0.9	0.3	0.0	0.8	
Tricuspid valve atresia and stenosis	119	125	169	24	0	440	
•	5.1	16.5	12.3	4.1	0.0	8.5	
Tricuspid valve atresia	119	125	169	24	0	440	
	5.1	16.5	12.3	4.1	0.0	8.5	
Trisomy 13	9	5	12	0	0	27	
	0.4	0.7	0.9	0.0	0.0	0.5	
Trisomy 18	20	18	13	3	0	54	
	0.9	2.4	0.9	0.5	0.0	1.0	
Trisomy 21 (Down syndrome)	242	89	227	35	0	611	
_	10.3	11.7	16.5	6.0	0.0	11.8	
Turner syndrome	14	1	7	1	0	25	2
	1.2	0.3	1.0	0.4	0.0	1.0	2
Ventricular septal defect	1,246	408	834	252	3	2,809	3
Total live births	53.0 235,049	53.8 75,858	60.6 137,640	<i>43.4</i> 58,011	60.5 496	<i>54.4</i> 516,499	4
Male live births	120,520	38,449	69,688	29,854	254	263,643	
Female live births	114,528	37,405	67,950	28,157	242	252,849	

New Jersey Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	96	5	103				
	2.4	0.4	2.0				
Trisomy 13	16	11	27				
	0.4	1.0	0.5				
Trisomy 18	21	32	54				
	0.5	2.8	1.0				
Trisomy 21 (Down syndrome)	257	329	611				
	6.4	28.8	11.8				
Total live births	402,104	114,334	516,499	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 only include confirmed cases.

4. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

-Data for 2014 are provisional.

-Data for conditions include live births only.

New Mexico Birth Defects Counts and Prevalence 2011 - 2015 (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	0	15	1	4	27	
*	2.5	0.0	2.8	4.6	3.0	2.7	
Cleft lip alone	14	1	44	1	20	82	
-	4.0	4.0	6.6	3.6	12.0	6.6	
Cleft lip with cleft palate	19	2	48	1	18	90	
	5.5	7.9	7.2	3.6	10.8	7.2	
Cleft palate alone	34	3	33	0	13	84	
	9.8	11.9	4.9	0.0	7.8	6.7	
Common truncus (truncus arteriosus)	0	0	1	0	0	1	
	0.0	0.0	0.1	0.0	0.0	0.1	
Gastroschisis	11	2	48	0	14	75	
	3.2	7.9	7.2	0.0	8.4	6.0	
Hypoplastic left heart syndrome	4	1	7	1	3	16	
	1.2	4.0	1.0	3.6	1.8	1.3	
Hypospadias	117	8	106	6	12	252	1
	65. 7	63.0	31.3	41.8	14.2	39. 7	
Limb deficiencies (reduction defects)	25	0	47	1	12	86	
	7.2	0.0	7.0	3.6	7.2	6.9	
Renal agenesis/hypoplasia	3	0	19	0	3	25	
	0.9	0.0	2.8	0.0	1.8	2.0	
Spina bifida without anencephalus	19	2	37	0	12	71	
	5.5	7.9	5.5	0.0	7.2	5.7	
Tetralogy of Fallot	8	1	17	3	8	37	
	2.3	4.0	2.5	10.8	4.8	3.0	
Transposition of the great arteries	6	1	7	0	6	20	
(TGA)	1.7	4.0	1.0	0.0	3.6	1.6	
Trisomy 13	3	0	4	1	3	13	
	0.9	0.0	0.6	3.6	1.8	1.0	
Trisomy 18	4	0	8	2	4	30	
	1.2	0.0	1.2	7.2	2.4	2.4	
Trisomy 21 (Down syndrome)	41	4	89	1	21	169	
	11.8	15.9	13.3	3.6	12.6	13.6	
Total live births	34,601	2,517	66,821	2,773	16,702	124,564	
Male live births	17,811	1,270	33,826	1,434	8,440	63,400	

New Mexico Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	75	0	75				
	6.8	0.0	6.0				
Trisomy 13	7	4	13				
-	0.6	2.9	1.0				
Trisomy 18	10	8	30				
	0.9	5.7	2.4				
Trisomy 21 (Down syndrome)	95	63	169				
• • • •	8.6	45.1	13.6				
Total live births	110,580	13,984	124,564				

Notes 1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.

General comments

*Totals include unknown and/or other.

New York Birth Defects Counts and Prevalence 2011 - 2015 (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	4	5	1	0	31	
An amhthalmia (mianamhthalmia	0.3	0.2	0.2	0.1 9	0.0	0.3	
Anophthalmia/microphthalmia	56 1.0	24 1.3	41 1.5	9 0.8	0 0.0	141 <i>1.2</i>	
Anotia/microtia	65	21	71	28	1	201	
	1.1	1.2	2.5	2.5	5.0	1.7	
Aortic valve stenosis	98 1.7	21 1.2	44 1.6	9 0.8	0 <i>0.0</i>	178 1.5	
Atrial septal defect	2,960	1,921	2,151	697	6	8,267	
	51.6	106.2	7 6. 7	63.0	30.0	69.6	
Atrioventricular septal defect (Endocardial cushion defect)	214 3.7	132 7.3	140 5.0	40 3.6	2 10.0	558 4. 7	
Biliary atresia	57	25	41	22	0	155	
	1.0	1.4	1.5	2.0	0.0	1.3	
Bladder exstrophy	13 0.2	4 0.2	4 <i>0.1</i>	0 0.0	0 <i>0.0</i>	22 0.2	
Choanal atresia	113	27	53	9	0	218	
	2.0	1.5	1.9	0.8	0.0	1.8	
Cleft lip alone	185	33	55	36	2	328	
Cleft lip with cleft palate	3.2 283	1.8 58	2.0 127	3.3 56	10.0 3	2.8 567	
	4.9	3.2	4.5	5.1	15.0	4.8	
Cleft palate alone	399	71	143	98	0	752	
Clubfoot	7.0 965	3.9 268	5.1 433	8.9 152	0.0 3	6.3 1,924	
Chibioot	905 16.8	14.8	433 15.4	132 13.7	5 15.0	1,924 16.2	
Coarctation of the aorta	337	93	176	42	3	694	
	5.9	5.1	6.3	3.8	15.0	5.8	
Common truncus (truncus arteriosus)	36 <i>0.6</i>	10 0.6	11 0.4	4 0.4	0 0.0	67 0.6	
Congenital cataract	90	48	61	15	0	234	
-	1.6	2.7	2.2	1.4	0.0	2.0	·
Congenital posterior urethral valves	60 2.0	36 3.9	26 1.8	14 2.4	0 <i>0.0</i>	144 2.4	1
Craniosynostosis	432	87	235	2.4 66	2	2.4 880	
	7.5	4.8	8.4	6.0	10.0	7.4	
Deletion 22q11.2	9	6	5	2	0	22	
Diaphragmatic hernia	0.2 144	0.3 52	0.2 75	0.2 39	0.0 0	0.2 326	
Diapinaginatic nerma	2.5	2.9	2.7	3.5	0.0	2.7	
Double outlet right ventricle	82	36	66	19	0	217	
Ebstein anomaly	1.4 31	2.0 9	2.4 31	1.7 6	0.0 0	1.8 79	
Ebstein anomaly	0.5	0.5	<i>1.1</i>	0.5	0.0	0.7	
Encephalocele	36	22	16	11	0	92	
	0.6	1.2	0.6	1.0	0.0	0.8	
Esophageal atresia/tracheoesophageal fistula	137 2.4	36 2.0	55 2.0	23 2.1	1 5.0	267 2.2	
Gastroschisis	152	47	81	7	0	301	
	2.6	2.6	2.9	0.6	0.0	2.5	
Holoprosencephaly	39 0.7	17 0.9	10 0.4	2 0.2	1 5.0	75 0.6	
Hypoplastic left heart syndrome	142	48	0.4 68	10	1	280	
	2.5	2.7	2.4	0.9	5.0	2.4	
Hypospadias	2,986	769	1,028	383	9	5,442	1
Interrupted aortic arch	<i>101.2</i> 45	84.0 16	72.3 30	66. 7 10	89.5 0	89.6 105	
interrupted dorde dren	0.8	0.9	1.1	0.9	0.0	0.9	
Limb deficiencies (reduction defects)	162	64	78	15	0	334	
	2.8	3.5	2.8	1.4	0.0	2.8	

New York Birth Defects Counts and Prevalence 2011 - 2015 (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		
Omphalocele	87	25	31	9	0	158			
	1.5	1.4	1.1	0.8	0.0	1.3			
Pulmonary valve atresia and stenosis	437	200	288	100	1	1,081			
	7.6	11.1	10.3	9.0	5.0	9.1			
Pulmonary valve atresia	45	12	27	15	0	110			
	0.8	0.7	1.0	1.4	0.0	0.9			
Rectal and large intestinal	220	61	86	49	2	459			
atresia/stenosis	3.8	3.4	3.1	4.4	10.0	3.9			
Renal agenesis/hypoplasia	309	85	159	40	0	624			
	5.4	4.7	5.7	3.6	0.0	5.3			
Single ventricle	30	14	25	6	0	78			
	0.5	0.8	0.9	0.5	0.0	0.7			
Small intestinal atresia/stenosis	220	95	116	46	3	509			
	3.8	5.3	4.1	4.2	15.0	4.3			
Spina bifida without anencephalus	139	36	61	21	1	278			
	2.4	2.0	2.2	1.9	5.0	2.3			
Tetralogy of Fallot	289	105	129	99	2	656			
	5.0	5.8	4.6	8.9	10.0	5.5			
Total anomalous pulmonary venous	61	32	47	19	0	175			
connection	1.1	1.8	1.7	1.7	0.0	1.5			
Transposition of the great arteries	237	55	124	41	0	482			
(TGA)	4.1	3.0	4.4	3.7	0.0	4.1			
Dextro-transposition of great arteries	233	55	123	39	0	475			
(d-TGA)	4.1	3.0	4.4	3.5	0.0	4.0			
Tricuspid valve atresia and stenosis	71	30	33	18	1	165			
-	1.2	1.7	1.2	1.6	5.0	1.4			
Tricuspid valve atresia	58	26	22	15	1	131			
	1.0	1.4	0.8	1.4	5.0	1.1			
Trisomy 13	22	16	24	5	0	69			
	0.4	0.9	0.9	0.5	0.0	0.6			
Trisomy 18	60	37	47	8	0	159			
	1.0	2.0	1.7	0.7	0.0	1.3			
Trisomy 21 (Down syndrome)	723	277	378	102	3	1,583			
• • • •	12.6	15.3	13.5	9.2	15.0	13.3			
Turner syndrome	48	20	14	9	0	95	2		
-	1.7	2.2	1.0	1.7	0.0	1.6			
Ventricular septal defect	2,755	835	1,425	503	7	5,849			
	48.0	46.2	50.8	45.4	35.0	49.2			
Total live births	573,799	180,867	280,361	110,686	2,000	1,188,246			
Male live births	294,922	91,585	142,137	57,408	1,006	607,690			
Female live births	278,871	89,281	138,222	53,278	994	580,547			

New York Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	283	9	301				
	3.0	0.4	2.5				
Trisomy 13	34	32	69				
-	0.4	1.3	0.6				
Trisomy 18	72	81	159				
	0.8	3.2	1.3				
Trisomy 21 (Down syndrome)	697	771	1,583				
	7.4	30.9	13.3				
Total live births	938,899	249,280	1,188,246				

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

*Totals include unknown and/or other.

North Carolina Birth Defects Counts and Prevalence 2011 - 2015 (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	81	30	26	3	1	160	
A 14 1 1 / 1 14 1 1	2.4	2.1	2.9	1.3	1.2	2.7	
Anophthalmia/microphthalmia	57 1.7	16 <i>1.1</i>	11 1.2	4 1.7	1 1.2	91 1.5	
Anotia/microtia	40	9	38	6	2	95	
	1.2	0.6	4.2	2.6	2.5	1.6	
Aortic valve stenosis	86 2.6	23 1.6	14 1.6	2 0.9	1 1.2	127 2.1	
Atrial septal defect	1,793	865	444	97	56	3,261	
-	53.5	60.3	49.6	41.8	68.9	54.3	
Atrioventricular septal defect	197	101	52	7	6	371	
(Endocardial cushion defect) Biliary atresia	5.9 14	7.0 14	5.8 3	3.0 2	7.4 0	6.2 33	
Diffary duesia	0.4	1.0	0.3	<i>0.9</i>	0.0	0.5	
Bladder exstrophy	9	5	1	0	0	15	
C1 1 4 1	0.3	0.3	0.1	0.0	0.0	0.2	
Choanal atresia	49 1.5	12 0.8	13 1.5	2 0.9	0 0.0	76 1.3	
Cleft lip alone	135	44	25	5	4	218	
-	4.0	3.1	2.8	2.2	4.9	3.6	
Cleft lip with cleft palate	187	45	61	11	9	318	
Cleft palate alone	5.6 244	3.1 47	6.8 31	4. 7 10	<i>11.1</i> 4	5.3 337	
	7.3	3.3	3.5	4.3	4.9	5.6	
Cloacal exstrophy	10	8	1	0	0	19	
	0.3	0.6	0.1	0.0	0.0	0.3	
Clubfoot	661 19.7	268 18. 7	136 15.2	21 9.1	15 18.5	1,117 18.6	
Coarctation of the aorta	178	54	35	9	2	278	
	5.3	3.8	3.9	3.9	2.5	4.6	
Common truncus (truncus arteriosus)	22	5	7	4	1	40	
Congenital cataract	0.7 29	0.3 17	0.8 9	1.7 3	1.2 0	0.7 58	
Congenital catalact	0.9	1.2	, 1.0	1.3	0.0	1.0	
Congenital posterior urethral valves	67	31	13	0	5	119	1
	3.9	4.3	2.9	0.0	12.1	3.9	
Craniosynostosis	241 7.2	41 2.9	48 5.4	8 3.5	5 6.2	344 5.7	
Diaphragmatic hernia	96	45	29	5	1	181	
1 0	2.9	3.1	3.2	2.2	1.2	3.0	
Double outlet right ventricle	56	25	12	1	1	96	
Ebstein anomaly	<i>1.7</i> 21	1.7 8	1.3 3	0.4 0	1.2 3	1.6 35	
Losteni unomary	0.6	0.6	0.3	0.0	3.7	0.6	
Encephalocele	21	20	12	0	1	62	
	0.6	1.4	1.3	0.0	1.2	1.0	
Esophageal atresia/tracheoesophageal fistula	105 <i>3.1</i>	29 2.0	15 1.7	5 2.2	0 0.0	155 2.6	
Gastroschisis	162	47	36	3	7	2.0	
	4.8	3.3	4.0	1.3	8.6	4.3	
Holoprosencephaly	37	24	26	1	0	90	
Hypoplastic laft baset and drama	1.1	1.7	2.9 23	0.4 5	0.0	1.5	
Hypoplastic left heart syndrome	93 2.8	33 2.3	23 2.6	5 2.2	1 1.2	156 2.6	
Hypospadias	1,211	413	108	50	34	1,817	1
	70.4	56.8	23.8	42.3	82.1	59.2	
Interrupted aortic arch	26	15	4	3	1	50	
Limb deficiencies (reduction defects)	0.8 149	1.0 70	0.4 38	1.3 1	1.2 3	0.8 268	
Line denciencies (reduction defects)	149 4.4	4.9	38 4.2	0.4	3.7	208 4.5	
		•••		···			

North Carolina Birth Defects Counts and Prevalence 2011 - 2015 (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	
Omphalocele	73	63	19	3	2	172		
	2.2	4.4	2.1	1.3	2.5	2.9		
Pulmonary valve atresia and stenosis	281	153	71	15	12	536		
	8.4	10.7	7.9	6.5	14.8	8.9		
Pulmonary valve atresia	56	36	12	5	2	112		
	1.7	2.5	1.3	2.2	2.5	1.9		
Rectal and large intestinal	140	55	34	8	5	242		
atresia/stenosis	4.2	3.8	3.8	3.5	6.2	4.0		
Renal agenesis/hypoplasia	196	74	41	3	3	323		
	5.8	5.2	4.6	1.3	3.7	5.4		
Single ventricle	20	11	10	1	0	43		
	0.6	0.8	1.1	0.4	0.0	0.7		
Small intestinal atresia/stenosis	93	38	38	9	5	183		
	2.8	2.6	4.2	3.9	6.2	3.0		
Spina bifida without anencephalus	132	44	31	3	2	220		
	3.9	3.1	3.5	1.3	2.5	3.7		
Tetralogy of Fallot	146	77	34	12	2	272		
	4.4	5.4	3.8	5.2	2.5	4.5		
Total anomalous pulmonary venous	31	13	16	6	1	68		
connection	0.9	0.9	1.8	2.6	1.2	1.1		
Transposition of the great arteries	102	46	18	2	4	175		
(TGA)	3.0	3.2	2.0	0.9	4.9	2.9		
Dextro-transposition of great arteries	71	26	9	2	4	115		
(d-TGA)	2.1	1.8	1.0	0.9	4.9	1.9		
Tricuspid valve atresia and stenosis	83	51	22	6	5	169		
	2.5	3.6	2.5	2.6	6.2	2.8		
Tricuspid valve atresia	71	45	20	6	5	149		
	2.1	3.1	2.2	2.6	6.2	2.5		
Trisomy 13	30	34	22	3	1	97		
	0.9	2.4	2.5	1.3	1.2	1.6		
Trisomy 18	102	48	40	7	2	210		
	3.0	3.3	4.5	3.0	2.5	3.5		
Trisomy 21 (Down syndrome)	423	141	157	26	13	790		
	12.6	9.8	17.5	11.2	16.0	13.1		
Turner syndrome	41	7	8	1	1	66	2	
	2.5	1.0	1.8	0.9	2.5	2.2		
Ventricular septal defect	1,548	587	479	95	26	2,747		
	46.2	40.9	53.5	41.0	32.0	45.7		
Total live births	335,127	143,456	89,536	23,187	8,127	600,928	3	
Male live births	172,092	72,688	45,327	11,808	4,143	306,831		
Female live births	163,033	70,762	44,206	11,379	3,984	294,086		

North Carolina Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	253	7	260					
	4.9	0.8	4.3					
Trisomy 13	57	39	97					
-	1.1	4.7	1.6					
Trisomy 18	120	88	210					
	2.3	10.5	3.5					
Trisomy 21 (Down syndrome)	393	394	790					
	7.6	47.2	13.1					
Total live births	517,347	83,556	600,928	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. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

Ohio Birth Defects Counts and Prevalence 2011 - 2015 (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	25	1	3	0	0	30	
	0.5	0.1	0.9	0.0	0.0	0.4	
Anophthalmia/microphthalmia	57 1.1	17 1.5	1 0.3	2 1.0	0 0.0	78 1.1	
Anotia/microtia	15	2	1	2	1	21	
	0.3	0.2	0.3	1.0	8.7	0.3	
Aortic valve stenosis	19	2	1	0	0	22	
Atrial septal defect	0.4 615	0.2 138	0.3 29	0.0 23	0.0 3	0.3 820	
Athai septai delect	11.8	138	29 8.7	25 11.9	3 26.0	11.7	
Atrioventricular septal defect	61	15	3	1	0	80	
(Endocardial cushion defect)	1.2	1.3	0.9	0.5	0.0	1.1	
Biliary atresia	38	7 0.6	1 0.3	0	0	46	
Choanal atresia	0. 7 64	0.0 8	0.5 1	0.0 1	0.0 0	0.7 75	
	1.2	0.7	0.3	0.5	0.0	1.1	
Cleft lip alone	159	18	6	4	2	190	
	3.0	1.5	1.8	2.1	17.3	2.7	
Cleft lip with cleft palate	257 4.9	32 2.7	13 3.9	5 2.6	0 <i>0.0</i>	309 <i>4.4</i>	
Cleft palate alone	420	44	17	2.0	1	4.4 504	
creat parate areas	8.1	3.8	5.1	10.4	8.7	7.2	
Clubfoot	268	48	16	9	0	345	
	5.1	4.1	4.8	4.7	0.0	4.9	
Coarctation of the aorta	224	30 2.6	11	2	0	270 3.9	
Common truncus (truncus arteriosus)	4.3 32	2.0 4	3.3 2	1.0 2	0.0 0	3.9 40	
	0.6	0.3	- 0.6	- 1.0	0.0	0.6	
Congenital cataract	75	16	4	1	0	96	
	1.4	1.4	1.2	0.5	0.0	1.4	
Deletion 22q11.2	41 <i>0.8</i>	3 0.3	1 0.3	0 0.0	0 <i>0.0</i>	46 0. 7	
Diaphragmatic hernia	129	20	5	3	0	157	
	2.5	1.7	1.5	1.6	0.0	2.2	
Double outlet right ventricle	29	8	3	3	0	43	
F 1 1 1	0.6	0.7	0.9	1.6	0.0	0.6	
Encephalocele	20 <i>0.4</i>	8 0. 7	3 0.9	1 0.5	0 0.0	32 0.5	
Esophageal atresia/tracheoesophageal	94	16	3	3	0	117	
fistula	1.8	1.4	0.9	1.6	0.0	1.7	
Gastroschisis	106	21	9	1	1	142	
II - 1 - was soon a sub-she	2.0	1.8	2.7	0.5	8.7	2.0	
Holoprosencephaly	13 0.2	0 0.0	0 <i>0.0</i>	0 <i>0.0</i>	0 0.0	13 <i>0.2</i>	
Hypoplastic left heart syndrome	95	17	9	2	1	125	
	1.8	1.5	2.7	1.0	8.7	1.8	
Omphalocele	49	42	2	0	0	93	
Pulmonary valve atresia and stenosis	0.9 104	3.6	0.6	0.0	0.0 1	<i>1.3</i> 129	
Pulmonary valve alresia and stenosis	2.0	17 1.5	4 1.2	1 0.5	1 8.7	129 1.8	
Pulmonary valve atresia	49	8	1.2	0	1	61	
	0.9	0.7	0.3	0.0	8.7	0.9	
Rectal and large intestinal	124	14	8	8	1	155	
atresia/stenosis Renal agenesis/hypoplasia	2.4 248	1.2	2.4 12	4.2	8.7	2.2 312	
Kenai agenesis/nypopiasia	248 4.8	45 3.9	12 3.6	3 1.6	0 <i>0.0</i>	312 4.5	
Spina bifida without anencephalus	208	27	13	3	1	252	
	4.0	2.3	3.9	1.6	8.7	3.6	
Tetralogy of Fallot	168	27	11	1	0	211	
	3.2	2.3	3.3	0.5	0.0	3.0	

Ohio Birth Defects Counts and Prevalence 2011 - 2015 (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	
Total anomalous pulmonary venous	28	4	4	0	0	36		
connection	0.5	0.3	1.2	0.0	0.0	0.5		
Transposition of the great arteries	139	24	9	4	0	179		
(TGA)	2.7	2.1	2.7	2.1	0.0	2.6		
Dextro-transposition of great arteries	111	23	9	3	0	148		
(d-TGA)	2.1	2.0	2.7	1.6	0.0	2.1		
Tricuspid valve atresia and stenosis	33	11	1	1	1	47		
	0.6	0.9	0.3	0.5	8. 7	0.7		
Tricuspid valve atresia	33	11	1	1	1	47		
	0.6	0.9	0.3	0.5	8.7	0.7		
Trisomy 13	15	4	2	0	0	22		
	0.3	0.3	0.6	0.0	0.0	0.3		
Trisomy 18	36	5	2	1	1	45		
	0.7	0.4	0.6	0.5	8. 7	0.6		
Trisomy 21 (Down syndrome)	549	101	30	15	1	703		
	10.5	8.6	9.0	7.8	8.7	10.1		
Turner syndrome	49	5	4	3	0	62	1	
	1.9	0.9	2.4	3.2	0.0	1.8		
Ventricular septal defect	394	84	30	17	0	528		
	7.6	7.2	9.0	8.8	0.0	7.6		
Total live births	521,622	116,870	33,467	19,271	1,155	698,003	2	
Female live births	254,133	57,469	16,483	9,513	552	340,898		

Ohio Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	136	6	142					
	2.2	0.7	2.0					
Trisomy 13	17	5	22					
-	0.3	0.6	0.3					
Trisomy 18	29	16	45					
	0.5	1.8	0.6					
Trisomy 21 (Down syndrome)	389	314	703					
	6.4	36.1	10.1					
Total live births	610,871	87,046	698,003	2				

Notes
1. Data for this condition include female and unknown gender cases only. Prevalance is calculated per 10,000 female live births.

General comments

*Totals include unknown and/or other.

-Data for conditions include probable cases.

-Data for conditions include records linked to a birth certificate only.

Oklahoma Birth Defects Counts and Prevalence 2011 - 2015 (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	3	10	1	3	46	
Anophthalmia/microphthalmia	1.7 24 1.4	1.2 0 0.0	2.6 2 0.5	1.3 2 2.6	1.1 3 1.1	1.7 34 1.3	
Anotia/microtia	20 1.2	2 0.8	9 2.4	3 3.8	4 1.4	39 1.5	
Aortic valve stenosis	52 3.1	0 0.0	9 2.4	0 0.0	4	68 2.6	
Atrial septal defect	5.1 834 50.3	0.0 114 46.5	2.4 159 41.6	0.0 27 34.5	1.4 127 44.8	2.0 1,311 49.5	
Atrioventricular septal defect (Endocardial cushion defect)	82 4.9	13 5.3	20 5.2	3 3.8	7 2.5	132 5.0	
Biliary atresia	8 0.5	4 1.6	2 0.5	0 0.0	3 1.1	17 0.6	
Bladder exstrophy	5 0.3	0 0.0	1 0.3	0 0.0	1 0.4	7 0.3	
Choanal atresia	30 1.8	5 2.0	5 1.3	0 0.0	3 1.1	44 1.7	
Cleft lip alone	76 4.6	7 2.9	1.5 16 4.2	0 0.0	15 5.3	120 4.5	
Cleft lip with cleft palate	122 7.4	7 2.9	32 8.4	4 5.1	21 7.4	190 7 .2	
Cleft palate alone	129 7.8	8 3.3	23 6.0	8 10.2	18 6.4	200 7.6	
Cloacal exstrophy	0 0.0	0 0.0	0 0.0	0	0 0.0	0 0.0	
Clubfoot	285 17.2	21 8.6	63 16.5	10 12.8	50 17.6	451 17.0	
Coarctation of the aorta	89 5.4	6 2.4	15 3.9	1 1 1.3	17.0 17 6.0	136 5.1	
Common truncus (truncus arteriosus)	6 0.4	2.4 3 1.2	1 0.3	0 0.0	1 0.4	12 0.5	
Congenital cataract	21 1.3	2 0.8	3 0.8	2 2.6	1 0.4	33 1.2	
Congenital posterior urethral valves	16 1.9	5 4.0	0 0.0	0 0.0	2 1.4	28 2.1	1
Craniosynostosis	40 2.4	4 1.6	10 2.6	2 2.6	9 3.2	99 3.7	
Deletion 22q11.2	10 0.6	2 0.8	1 0.3	0 0.0	3 1.1	16 0.6	
Diaphragmatic hernia	48 2.9	5 2.0	21 5.5	2 2.6	10 3.5	88 3.3	
Double outlet right ventricle	31 1.9	6 2.4	4 1.0	2.6 2 2.6	6 2.1	5.5 51 1.9	
Ebstein anomaly	12 0.7	0 0.0	6 1.6	1 1.3	0 0.0	20 0.8	
Encephalocele	0.7 11 0.7	3 1.2	6 1.6	0 0.0	6 2.1	26 1.0	
Esophageal atresia/tracheoesophageal	45	1	7	2	5	62	
fistula Gastroschisis	2.7 84	0.4 7	1.8 13	2.6 2	1.8 7	2.3 117	
Holoprosencephaly	5.1 15	2.9 4	3.4 5	2.6 1	2.5 4	4.4 29	
Hypoplastic left heart syndrome	0.9 46	1.6 0	1.3 12	<i>1.3</i> 2	1.4 3	1.1 66	
Hypospadias	2.8 336	0.0 44	3.1 18	2.6 6	<i>1.1</i> 44	2.5 464	1
	39.4	35.2	9.2	15.3	30.4	34.2	1
Interrupted aortic arch	21 1.3	4 1.6	2 0.5	1 1.3	2 0.7	30 1.1	

Oklahoma Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	83	11	16	1	7	120	
	5.0	4.5	4.2	1.3	2.5	4.5	
Omphalocele	37	10	8	0	6	64	
	2.2	4.1	2.1	0.0	2.1	2.4	
Pulmonary valve atresia and stenosis	133	15	21	4	11	191	
	8.0	6.1	5.5	5.1	3.9	7.2	
Pulmonary valve atresia	19	3	7	2	3	36	
	1.1	1.2	1.8	2.6	1.1	1.4	
Rectal and large intestinal	84	11	20	7	14	142	
atresia/stenosis	5.1	4.5	5.2	8.9	4.9	5.4	
Renal agenesis/hypoplasia	95	11	20	1	14	150	
a: 1	5.7	4.5	5.2	1.3	4.9	5.7	
Single ventricle	10	1	3	0	0	16	
Small intestinal atresia/stenosis	0.6	0.4 7	0.8 10	0.0	0.0 5	0.6 95	
Small intestinal atresia/stenosis	63 3.8	2.9	10 2.6	1 1.3	5 1.8	95 3.6	
Spina bifida without anencephalus	5.8 60	3	2.0 12	1.5	1.8	3.0 89	
spina onida without anencephaius	3.6	, 1.2	3.1	1.3	3.5	3.4	
Tetralogy of Fallot	3.0 75	6	6	6	3.5 11	3.4 108	
Tetralogy of Fallot	<i>4.5</i>	2.4	1.6	7.7	3.9	4.1	
Total anomalous pulmonary venous	19	3	8	1	3	34	
connection	1.1	1.2	2.1	1.3	1.1	1.3	
Transposition of the great arteries	60	7	14	2	9	98	
(TGA)	3.6	2.9	3.7	2.6	3.2	3.7	
Dextro-transposition of great arteries	55	7	12	2	8	87	
(d-TGA)	3.3	2.9	3.1	2.6	2.8	3.3	
Tricuspid valve atresia and stenosis	25	4	5	1	1	39	
	1.5	1.6	1.3	1.3	0.4	1.5	
Tricuspid valve atresia	17	1	4	0	1	26	
	1.0	0.4	1.0	0.0	0.4	1.0	
Trisomy 13	11	3	3	1	1	20	
	0.7	1.2	0.8	1.3	0.4	0.8	
Trisomy 18	37	11	11	2	4	67	
	2.2	4.5	2.9	2.6	1.4	2.5	
Trisomy 21 (Down syndrome)	187	21	66	9	21	319	
	11.3	8.6	17.3	11.5	7.4	12.0	
Turner syndrome	20	1	3	0	4	31	2
	2.5	0.8	1.6	0.0	2.9	2.4	
Ventricular septal defect	960	102	200	36	111	1,481	
Total live births	57.9 165,795	41.6 24,537	<i>52.4</i> 38,185	46.0 7,829	39.2 28,336	55.9 264,761	3
Male live births	85,220	12,512	19,582	3,929	14,483	135,764	
Female live births	80,572	12,024	18,602	3,899	13,853	128,991	

Oklahoma Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	114	3	117					
	4.7	1.2	4.4					
Trisomy 13	16	4	20					
-	0.7	1.6	0.8					
Trisomy 18	42	25	67					
	1.7	10.2	2.5					
Trisomy 21 (Down syndrome)	191	123	319					
• • • •	8.0	50.0	12.0					
Total live births	240,053	24,580	264,761	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. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

-Fetal deaths are defined as baby born dead (without a heart rate), at or after 20th gestational week. Includes babies that died during labor.

-Terminations are defined as fetus terminated by parental choice prior to 37 weeks. When labor is induced to deliver a fetus who is dead prior to the onset of labor it is not considered an elective termination.

Oregon Birth Defects Counts and Prevalence 2011 - 2015 (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	6	0	0	18	
A nonhthalmia/miaranhthalmia	0.6 14	2.1 0	1.4 9	0.0 0	0.0 0	0.8 23	
Anophthalmia/microphthalmia	0.9	0.0	9 2.1	0.0	0.0	25 1.0	
Anotia/microtia	47	0	46	8	1	104	1
Aortic valve stenosis	3.0 84	0.0 2	10.9 24	6.4 3	4.0 2	4.6 118	
Aorue valve stellosis	5. <i>4</i>	4.2	5.7	<i>2.4</i>	2 8.0	5.3	
Atrial septal defect	2,554	124	925	156	76	4,027	
Atrioventricular septal defect	165.5 160	261.4 6	218.5 57	<i>125.3</i> 13	305.6 5	179.2 252	
(Endocardial cushion defect)	100 10.4	12.6	13.5	13 10.4	20.1	11.2	
Biliary atresia	15	2	3	2	0	24	
Bladder exstrophy	1.0 3	4.2 0	0.7 3	1.6 1	0.0 0	1.1 7	
Bladder exstrophy	<i>0.2</i>	0.0	.7	0.8	0.0	0.3	
Choanal atresia	45	2	10	4	0	63	
Claft lin along	2.9	4.2	2.4	3.2	0.0 1	2.8	
Cleft lip alone	24 1.6	1 2.1	12 2.8	3 2.4	1 4.0	47 2.1	
Cleft lip with cleft palate	143	2	41	11	2	209	
	9.3	4.2	9. 7	8.8	8.0	9.3	
Cleft palate alone	148 9.6	2 4.2	33 7 .8	9 7.2	2 8.0	203 9.0	
Cloacal exstrophy	120	2	44	4	1	177	
	7.8	4.2	10.4	3.2	4.0	7.9	
Clubfoot	404 26.2	12 25.3	97 22.9	22 17.7	2 8.0	554 24. 7	
Coarctation of the aorta	54	0	24	3	2	90	
	3.5	0.0	5.7	2.4	8.0	4.0	
Common truncus (truncus arteriosus)	19 1.2	2 4.2	8 1.9	0 0.0	0 <i>0.0</i>	29 1.3	
Congenital cataract	79	4	21	4	0	114	
	5.1	8.4	5.0	3.2	0.0	5.1	
Congenital posterior urethral valves	55 7.0	3 12.3	14 6.5	1 1.6	1 7.8	80 6.9	2
Deletion 22q11.2	19	0	2	0	2	25	
	1.2	0.0	0.5	0.0	8.0	1.1	
Diaphragmatic hernia	72	5 10.5	30	6	1	120	
Double outlet right ventricle	4.7 48	2	7.1 13	4.8 4	4.0 1	5.3 72	
-	3.1	4.2	3.1	3.2	4.0	3.2	
Ebstein anomaly	13	1	4 <i>0.9</i>	1	0	20 0.9	
Encephalocele	0.8 13	2.1 2	6	0.8 1	0.0 1	26	
-	0.8	4.2	1.4	0.8	4.0	1.2	
Esophageal atresia/tracheoesophageal	50	0	21	4	1	78	
fistula Gastroschisis	3.2 77	0.0 1	5.0 24	3.2 4	4.0 1	3.5 117	
	5.0	2.1	5.7	3.2	4.0	5.2	
Holoprosencephaly	106	8	45	10	1	182	
Hypoplastic left heart syndrome	6.9 73	16.9	10.6 22	8.0 3	4.0 1	8.1 103	
Trypoplastic fortheart synctome	4. 7	2.1	5.2	2.4	4.0	4.6	
Hypospadias	790	47	134	41	13	1,073	2
Interrupted aortic arch	99.8 71	192.6 2	62.2 19	64.5 2	101.3 1	93.2 99	
menupled aone alen	4.6	4.2	4.5	1.6	4.0	4.4	
Limb deficiencies (reduction defects)	134	2	37	4	3	191	
	8. 7	4.2	8. 7	3.2	12.1	8.5	

Oregon Birth Defects Counts and Prevalence 2011 - 2015 (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
Omphalocele	30	4	12	6	1	57	
	1.9	8.4	2.8	4.8	4.0	2.5	
Pulmonary valve atresia and stenosis	272	12	96	18	7	422	
-	17.6	25.3	22.7	14.5	28.1	18.8	
Pulmonary valve atresia	37	0	12	3	1	53	
	2.4	0.0	2.8	2.4	4.0	2.4	
Rectal and large intestinal	88	1	35	5	3	142	
atresia/stenosis	5.7	2.1	<i>8.3</i>	4.0	12.1	6.3	
Renal agenesis/hypoplasia	160	5	61	9	6	253	
	10.4	10.5	14.4	7.2	24.1	11.3	
Single ventricle	53	1	11	3	2	71	
0	3.4	2.1	2.6	2.4	8.0	3.2	
Small intestinal atresia/stenosis	63	2	30	4	2	107	
	4.1	4.2	7.1	3.2	8.0	4.8	
Spina bifida without anencephalus	119	3	35	4	5	174	
I I	7.7	6.3	8.3	3.2	20.1	7.7	
Tetralogy of Fallot	106	3	45	7	2	172	
	6.9	6.3	10.6	5.6	8.0	7.7	
Total anomalous pulmonary venous	24	0	12	1	0	40	
connection	1.6	0.0	2.8	0.8	0.0	1.8	
Transposition of the great arteries	77	1	22	6	3	116	
(TGA)	5.0	2.1	5.2	4.8	12.1	5.2	
Dextro-transposition of great arteries	66	1	20	5	1	99	
(d-TGA)	4.3	2.1	4.7	4.0	4.0	4.4	
Tricuspid valve atresia and stenosis	27	0	13	2	2	45	
	1.7	0.0	3.1	1.6	8.0	2.0	
Trisomy 13	14	1	5	0	0	20	
-	0.9	2.1	1.2	0.0	0.0	0.9	
Trisomy 18	13	1	15	3	0	32	
-	0.8	2.1	3.5	2.4	0.0	1.4	
Trisomy 21 (Down syndrome)	257	11	117	17	4	419	
	16.7	23.2	27.6	13.6	16.1	18.6	
Turner syndrome	15	2	3	1	1	22	3
-	2.0	8.7	1.4	1.6	8.3	2.0	
Ventricular septal defect	1,018	27	449	62	28	1,647	4
1.	66.0	56.9	106.1	49.8	112.6	73.3	
Total live births	154,299	4,744	42,325	12,455	2,487	224,727	5
Male live births	79,133	2,440	21,548	6,355	1,283	115,142	
Female live births	75,165	2,304	20,777	6,100	1,204	109,584	

Oregon Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	112	5	117				
	6.0	1.3	5.2				
Trisomy 13	13	7	20				
-	0.7	1.9	0.9				
Trisomy 18	18	14	32				
	1.0	3.8	1.4				
Trisomy 21 (Down syndrome)	244	175	419				
	13.0	47.0	18.6				
Total live births	187,452	37,264	224,727	5			

Notes

1. Data sources for this condition include the Incorporated Oregon Early Hearing Detection and Intervention (EHDI) program and the Oregon Birth Anomalies Surveillance System.

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 probable cases.

5. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

Puerto Rico Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	Hispanic	Total*	Notes					
Anencephalus	75	75						
Anophthalmia/microphthalmia	4.1 30	4.1 30						
	1.6	1.6						
Anotia/microtia	54	54						
Aortic valve stenosis	3.0 19	3.0 19						
	1.0	1.0						
Atrial septal defect	520	520 28.5						
Atrioventricular septal defect	28.5 102	102	1					
(Endocardial cushion defect)	5.6	5.6						
Bladder exstrophy	4 0.2	4 0.2						
Cleft lip alone	6 6	66						
	3.6	3.6						
Cleft lip with cleft palate	114 6.3	114 6.3						
Cleft palate alone	133	133						
-	7.3	7.3						
Clubfoot	370 20.3	370 20.3						
Coarctation of the aorta	47	47						
	2.6	2.6						
Common truncus (truncus arteriosus)	7 0.4	7 0.4						
Deletion 22q11.2	1	1						
	0.2	0.2						
Double outlet right ventricle	43 2.4	43 2.4						
Ebstein anomaly	2.4 15	15						
	0.8	0.8						
Encephalocele	21 1.2	21 1.2						
Gastroschisis	85	85						
	4.7	4.7						
Hypoplastic left heart syndrome	38 2.1	38 2.1						
Hypospadias	463	463	2					
• · · · • •	49.3	49.3						
Interrupted aortic arch	3 0.5	3 0.5						
Limb deficiencies (reduction defects)	124	124						
0 1 1 1	6.8	6.8						
Omphalocele	41 2.2	41 2.2						
Pulmonary valve atresia and stenosis	177	177						
Delesson and the store is	9. 7	9.7						
Pulmonary valve atresia	26 1.4	26 1.4						
Single ventricle	2	2						
	0.3	0.3						
Spina bifida without anencephalus	78 4.3	78 4.3						
Tetralogy of Fallot	71	71						
Total anomalous pulmonary venous	<i>3.9</i>	<i>3.9</i>						
connection	19 1.0	19 1.0						
Transposition of the great arteries	54	54						
(TGA)	3.0	3.0						
Dextro-transposition of great arteries (d-TGA)	15 0.8	15 0.8						
Tricuspid valve atresia and stenosis	15	15						
	0.8	0.8						

Puerto Rico Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	Hispanic	Total*	Notes				
Tricuspid valve atresia	15	15					
	0.8	0.8					
Trisomy 13	14	14					
	0.8	0.8					
Trisomy 18	45	45					
	2.5	2.5					
Trisomy 21 (Down syndrome)	204	204					
	11.2	11.2					
Turner syndrome	2	2	3				
	0.6	0.6					
Ventricular septal defect	501	501	4				
-	27.5	27.5					
Total live births	182,395	182,395					
Male live births	93,873	93,873					
Female live births	31,911	31,911					

Puerto Rico Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	84	1	85				
	5.1	0.6	4.7				
Trisomy 13	9	5	14				
-	0.5	3.0	0.8				
Trisomy 18	29	16	45				
	1.8	9.5	2.5				
Trisomy 21 (Down syndrome)	111	93	204				
• • • •	6.7	55.3	11.2				
Total live births	165,524	16,829	182,395				

Notes

1. Data for this condition only include atrioventricular canal.

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

*Totals include unknown and/or other.

-Fetal deaths include spontaneous abortions and stillbirths.

-There is no gestational age cut off for terminations.

Rhode Island Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

DefectNAnencephalus8Anophthalmia/microphthalmia2Anophthalmia/microphthalmia0Anotia/microtia0Aortic valve stenosis4Atrial septal defect7Atrioventricular septal defect4(Endocardial cushion defect)1Biliary atresia0Bladder exstrophy1Choanal atresia0Cleft lip alone13Atrib telft palate19	2.6 2.6 3.6 3.0 4 3.2 2 3.2 4 4.3 3.2 4 4.3 9 0.0 0 2.3 2.6 3.2 4 4.3 9 0.0 4.3 9 0.0 4.3 9 0.0 4.3 9 0.0 9 1.3 1.3 1.3 1.3 1.3 1.3 1.3 1.3 1.3 1.3	Black, Non-Hispanic 2 4.8 3 7.2 0 0.0 0 0.0 17 40.6 0 0.0 0 0.0 0 0.0 0 0.0 0 0.0 1 2.4	Hispanic 1 0.8 2 1.6 3 2.4 1 0.8 26 20.8 1 0.8 1 0.8 0 0.8 1 0.8 1 0.8 1 0.8 1 0.8 2 1.6 3 2.4 1 0.8 26 20 1.6 3 2.4 1 0.8 26 20 1.6 3 2.4 1 0.8 26 20 1.6 3 2.4 1 0.8 26 20 2.4 1 0.8 26 20 20 20 20 20 20 20 20 20 20	Asian or Pacific Islander, Non-Hispanic 0 0.0 0 0.0 0 0.0 0 0.0 1 4.1 0 0.0 0 0.0 1 4.1 0 0.0 0 0.0 0 0.0 0 0.0 0 0.0 0 0.0 0 0 0.0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	American Indian or Alaska Native, Non-Hispanic 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0 0	Total* 11 2.0 9 1.7 3 0.6 6 1.1 127 23.5 5 0.9 1 0.2	Notes
Anencephalus 8 Anophthalmia/microphthalmia 2 Anophthalmia/microphthalmia 0 Anotia/microtia 0 Aortic valve stenosis 4 Atrial septal defect 7 Atrioventricular septal defect 4 (Endocardial cushion defect) 1 Biliary atresia 0 Bladder exstrophy 1 Choanal atresia 2 Actel lip alone 13 4 4 Cleft lip with cleft palate 19	2.6 2.6 2.6 2.6 2.6 2.7 2.7 2.7 2.7 2.7 2.7 2.7 2.7 2.7 2.7	2 4.8 3 7.2 0 0.0 0 0.0 17 40.6 0 0.0 0 0.0 0 0.0 0 0.0 1 2.4	1 0.8 2 1.6 3 2.4 1 0.8 26 20.8 1 0.8 1 0.8 0 0.0	0 0.0 0 0.0 0 0 0.0 0 0.0 1 4.1 0 0.0 0 0.0 0 0.0 0 0 0 0 0 0	0 0.0 0 0.0 0 0.0 0 0.0 0 0.0 0	11 2.0 9 1.7 3 0.6 6 1.1 127 23.5 5 0.9 1	
Anophthalmia/microphthalmia 2 O O Anotia/microtia 0 O O Aortic valve stenosis 4 Atrial septal defect 77 Atrioventricular septal defect 2 Atrioventricular septal defect 4 (Endocardial cushion defect) 1 Biliary atresia 0 Bladder exstrophy 1 Choanal atresia 2 O Cleft lip alone 4 15	2. 2. 3. 4. 3. 2. 3.2. 4. 3. 2. 3.2. 4. 3. 2. 3.2. 4. 5.2.	3 7.2 0 0.0 0 0 0 0 0 0 0.0 0 0.0 0 0.0 0 0.0 1 2.4	2 1.6 3 2.4 1 0.8 26 20.8 1 0.8 1 0.8 0 0.0	0 0.0 0 0.0 0 0.0 1 4.1 0 0.0 0.0 0.0 0.0 0.0 0.0 0 0.0 0 0.0 0 0 0 0 0 0 0 0 0 0 0 0 0	0 0.0 0 0.0 0 0.0 2 57.1 0 0.0 0.0 0.0 0.0 0.0	9 1.7 3 0.6 6 1.1 127 23.5 5 0.9 1	
Anotia/microtia 0. Anotia/microtia 0 Aortic valve stenosis 4 Atrial septal defect 72 Atrioventricular septal defect 4 (Endocardial cushion defect) 1. Biliary atresia 0 Bladder exstrophy 1 Choanal atresia 2 Cleft lip alone 13 4. 19 Cleft lip with cleft palate 19	2.6 2.0 4.3 2.3 3.2 4.3 0.0 0.0 0.0 0.0 0.0 0.0 0.0 0	7.2 0 0.0 0 0.0 17 40.6 0 0 0 0.0 0 0.0 1 2.4	1.6 3 2.4 1 0.8 26 20.8 1 0.8 1 0.8 0 0.0	0.0 0 0.0 0 0.0 1 4.1 0 0.0 0.0 0.0 0.0 0 0.0 0 0 0 0 0 0 0 0 0 0 0 0 0	0.0 0 0.0 0 0.0 2 57.1 0 0.0 0 0.0	1.7 3 0.6 6 1.1 127 23.5 5 0.9 1	
0.Aortic valve stenosis41.Atrial septal defect72Atrioventricular septal defect4(Endocardial cushion defect)1.Biliary atresia00.Bladder exstrophy1.Choanal atresia2.Cleft lip alone1.4.Cleft lip with cleft palate1.	2.0 4 4 72 73.2 4 7.3 9 0.0 9 7.3 9 9.0 9.0 9.0 9.0 9.0 9.0 9.0 9.0 9.0 9	0.0 0 0.0 17 40.6 0 0.0 0 0.0 0.0 0.0 1 2.4	2.4 1 0.8 26 20.8 1 0.8 1 0.8 0 0.0	0.0 0 0.0 1 4.1 0 0.0 0 0.0 0 0 0 0 0 0 0 0 0 0 0 0 0	0.0 0 2 57.1 0 0.0 0 0.0	0.6 6 1.1 127 23.5 5 0.9 1	
Aortic valve stenosis 4 Atrial septal defect 72 Atrioventricular septal defect 4 (Endocardial cushion defect) 1 Biliary atresia 0 Bladder exstrophy 1 Choanal atresia 2 Cleft lip alone 13 4 2 4 2 4 3 4 3 4 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4 1 4	4.3 72 73.2 4.3 0.0 0.0 0.3 2.4 0.6 3 4.2	0 0.0 17 40.6 0 0.0 0 0.0 0.0 0.0 1 2.4	1 0.8 26 20.8 1 0.8 1 0.8 0 0 0.0	0 0.0 1 4.1 0 0.0 0 0.0 0 0 0 0 0 0 0 0 0 0 0 0 0	0 0.0 2 57.1 0 0.0 0 0.0	6 1.1 127 23.5 5 0.9 1	
I.Atrial septal defectZ2Atrioventricular septal defect4(Endocardial cushion defect)I.Biliary atresia0Bladder exstrophy10.Choanal atresia0.Cleft lip alone134.Cleft lip with cleft palate14	1.3 12 13.2 1.3 0.0 0.3 0.6 3 1.2	0.0 17 40.6 0 0.0 0 0.0 0.0 0.0 1 2.4	0.8 26 20.8 1 0.8 1 0.8 0 0 0.0	0.0 1 4.1 0 0.0 0 0.0 0 0 0 0	0.0 2 57.1 0 0.0 0 0.0	1.1 127 23.5 5 0.9 1	
22 Atrioventricular septal defect 4 (Endocardial cushion defect) 1 Biliary atresia 0 Bladder exstrophy 1 Choanal atresia 0 Cleft lip alone 13 4 4 Cleft lip with cleft palate 19	23.2 4 1.3 0.0 0.3 2 1.6 3 1.2	40.6 0 0.0 0 0.0 0 0.0 1 2.4	20.8 1 0.8 1 0.8 0 0.0	4.1 0 0.0 0 0.0 0	57.1 0 0.0 0 0.0 0.0	23.5 5 0.9 1	
Atrioventricular septal defect 4 (Endocardial cushion defect) 1. Biliary atresia 0 Bladder exstrophy 1 Choanal atresia 2 Cleft lip alone 12 4. Cleft lip with cleft palate	4.3)).0).3).6 3 1.2	0 0.0 0.0 0 0.0 1 2.4	1 0.8 1 0.8 0 0.0	0 0.0 0.0 0.0 0	0 0.0 0.0	5 0.9 1	
(Endocardial cushion defect) 1. Biliary atresia 0 0 0. Bladder exstrophy 1 0 0. Choanal atresia 2 0 0. Cleft lip alone 12 4. Cleft lip with cleft palate	2.3)).0).3).6 3 1.2	0.0 0 0.0 0 0.0 1 2.4	0.8 1 0.8 0 0.0	0.0 0 0.0 0	0.0 0 0.0	0.9 1	
Biliary atresia 0 Bladder exstrophy 1 0. 0. Choanal atresia 2 0. 0. Cleft lip alone 12 4. 19 Cleft lip with cleft palate 19	0.0 0.3 0.6 3 0.2	0.0 0 0.0 1 2.4	0.8 0 0.0	0.0 0	0.0		
Bladder exstrophy 1 0. Choanal atresia 2 0. Cleft lip alone 12 4. Cleft lip with cleft palate 19	2.3 2.6 3 1.2	0 0.0 1 2.4	0 0.0	0		02	
0. Choanal atresia 2 0. Cleft lip alone 12 4. Cleft lip with cleft palate 19	9.3 9.6 3 9.2	0.0 1 2.4	0.0				
Choanal atresia 2 Cleft lip alone 12 Cleft lip with cleft palate 19	2. 0.6 3 0.2	1 2.4		0.0	0.0	1 0.2	
Cleft lip alone 15 4. Cleft lip with cleft palate 19	3 9.2		1	0	0	5	
4. Cleft lip with cleft palate	.2	0	0.8	0.0	0.0	0.9	
Cleft lip with cleft palate 19		0 <i>0.0</i>	6 4.8	0 0.0	0 0.0	20 3.7	
	9	0	8	1	1	30	1
	5.1	0.0	6.4	4.1	28.6	5.6	
Cleft palate alone	.7 5.5	1 2.4	2	1	0	23	
Cloacal exstrophy 0		2.4 0	1.6 1	4.1 0	0.0	4.3 1	
	0.0	0.0	0.8	0.0	0.0	0.2	
	6	6	22	3	1	85	1
	4.8 0	14.3 0	17.6 5	12.2 0	28.6 0	<i>15.7</i> 16	
	.2	0.0	4.0	0.0	0.0	3.0	
Common truncus (truncus arteriosus) 2		0	0	0	0	2	
0. Congenital cataract 3).6	0.0 1	0.0 3	0.0 1	0.0 0	<i>0.4</i> 8	
	.0	1 2.4	5 2.4	1 4.1	0.0	。 1.5	
Congenital posterior urethral valves 4		1	1	0	0	7	2
	2.5	4.7	1.6	0.0	0.0	2.5	
Craniosynostosis 18	.8 5.8	1 2.4	2 1.6	3 12.2	0 0.0	25 4.6	
Deletion 22q11.2 0		0	0	0	0	0	
	.0	0.0	0.0	0.0	0.0	0.0	
Diaphragmatic hernia 7	2.3	0 <i>0.0</i>	3 2.4	1 4.1	0 0.0	11 2.0	
Double outlet right ventricle 2		0	1	1	0	4	
0.	0.6	0.0	0.8	4.1	0.0	0.7	
Ebstein anomaly 1		2	0	0	0	4	
Encephalocele 2).3	4.8 0	0.0 3	0.0 0	0.0 0	0. 7 7	
).6	0.0	2.4	0.0	0.0	1.3	
Esophageal atresia/tracheoesophageal 6		0	1	0	0	7	
	2.9 2	0.0 1	0.8 12	0.0 0	0.0 0	1.3 26	1
	2 8.9	2.4	9.6	0.0	0.0	20 4.8	1
Holoprosencephaly 0)	0	1	0	0	1	3
).0	0.0	0.8	0.0	0.0	<i>0.2</i>	
Hypoplastic left heart syndrome 4	.3	1 2.4	5 4.0	0 <i>0.0</i>	0 0.0	10 1.9	
Hypospadias 10	62	18	35	4	1	229	2
10	02.4	84.2	55.1	30.8	55.6	83.1	
Interrupted aortic arch).3	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 0.0	1 0.2	

Rhode Island Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	7	2	6	0	0	15	3
	2.3	4.8	4.8	0.0	0.0	2.8	
Omphalocele	5	1	3	1	0	11	
	1.6	2.4	2.4	4.1	0.0	2.0	
Pulmonary valve atresia and stenosis	16	1	6	5	0	30	
	5.2	2.4	4.8	20.3	0.0	5.6	
Pulmonary valve atresia	1	1	1	3	0	6	
Rectal and large intestinal	<i>0.3</i> 9	2.4	0.8 9	12.2	0.0	<i>1.1</i> 21	
atresia/stenosis	2.9	1 2.4	9 7.2	0 0.0	0 <i>0.0</i>	3.9	
Renal agenesis/hypoplasia	2.9 11	2.4 4	5	0	0.0	20	
Renal agenesis/hypoplasia	3.5	, 9.6	<i>4.0</i>	0.0	0.0	3.7	
Single ventricle	2	0	0	1	0	3	
Single venuleie	0.6	0.0	0.0	4.1	0.0	0.6	
Small intestinal atresia/stenosis	10	4	6	2	0	22	
	3.2	9.6	4.8	- 8.1	0.0	4.1	
Spina bifida without anencephalus	12	4	7	2	0	28	
1 1	3.9	9.6	5.6	8.1	0.0	5.2	
Tetralogy of Fallot	11	2	3	0	0	17	
	3.5	4.8	2.4	0.0	0.0	3.1	
Total anomalous pulmonary venous	4	0	0	0	0	5	
connection	1.3	0.0	0.0	0.0	0.0	0.9	
Transposition of the great arteries	5	0	1	1	0	14	
(TGA)	1.6	0.0	0.8	4.1	0.0	2.6	
Dextro-transposition of great arteries	2	0	0	1	0	3	
(d-TGA)	0.6	0.0	0.0	4.1	0.0	0.6	
Tricuspid valve atresia and stenosis	2	0	1	1	0	4	4
	0.6	0.0	0.8	4.1	0.0	0.7	
Tricuspid valve atresia	2	0	1	1	0	4	4
TT : 12	0.6	0.0	0.8	4.1	0.0	0.7	
Trisomy 13	7	2	3	0	0	12	
Tri	2.3	4.8	2.4	0.0	0.0 0	2.2 13	
Trisomy 18	6 1.9	3 7.2	3 2.4	0	0.0	13 2.4	
Trisomy 21 (Down syndrome)	36	8	2.4 16	0.0 0	1	2.4 69	
The syndrome (Down syndrome)	11.6	。 19.1	10 12.8	0.0	28.6	12.8	
Turner syndrome	2	0	0	0	0	3	5
Turner syndrome	1.3	0.0	0.0	0.0	0.0	1.1	5
Ventricular septal defect	162	27	40	8	0	244	6
and separation	52.2	64.5	32.0	32.5	0.0	45.2	v
Total live births	31,036	4,183	12,507	2,459	350	53,998	7
Male live births	15,817	2,139	6,354	1,299	180	27,566	
Female live births	15,218	2,043	6,153	1,164	170	26,429	

Rhode Island Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	26	0	26	1			
	5.8	0.0	4.8				
Trisomy 13	5	7	12				
-	1.1	7.4	2.2				
Trisomy 18	4	9	13				
	0.9	9.5	2.4				
Trisomy 21 (Down syndrome)	31	35	69				
• • • •	7.0	37.1	12.8				
Total live births	44,562	9,432	53,998	7			

Notes

1. Data for this condition include terminations in 2015.

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 terminations in 2014.

4. Data for this condition include probable cases in 2015.5. Data for this condition include stillbirths in 2014. 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 probable cases.

7. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

South Carolina Birth Defects Counts and Prevalence 2011 - 2015 (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	43	8	9	<5	0	73	
A second de la circa de la	2.6	0.9	3.9	0	0.0	2.5	
Anophthalmia/microphthalmia	16 <i>1.0</i>	15 1.7	<5	0 0.0	0 0.0	32 1.1	
Anotia/microtia	19	10	7	<5	0	38	
	1.1	1.1	3.0		0.0	1.3	
Aortic valve stenosis	16 <i>1.0</i>	5 0.6	<5	<5	0 <i>0.0</i>	25 0.9	
Atrial septal defect	122	0.0 79	25	7	0	242	1
	7.3	8.7	10.8	14.6	0.0	8.4	•
Atrioventricular septal defect	87	48	13	<5	0	155	
(Endocardial cushion defect)	5.2	5.3	5.6	0	0.0	5.4	
Biliary atresia	8 0.5	12 1.3	<5	0 0.0	0 0.0	24 0.8	
Bladder exstrophy	6	0	0	0	0	6	
	0.6	0.0	0.0	0.0	0.0	0.3	
Choanal atresia	22	14	0	0	0	36	
Claft lin along	<i>1.3</i> 44	1.5 20	0.0	0.0 <5	0.0 0	<i>1.3</i> 81	
Cleft lip alone	44 2.6	20 2.2	11 4. 7	< 3	0 0.0	81 2.8	
Cleft lip with cleft palate	92	35	13	6	0	148	
	5.5	3.9	5.6	12.5	0.0	5.2	
Cleft palate alone	97	30	9	<5	0	142	
Coarctation of the aorta	5.8	3.3	3.9 9	<5	0.0	4.9	
Coarctation of the aorta	96 5.8	37 4.1	9 3.9	<>>	<5	151 5.3	
Common truncus (truncus arteriosus)	13	6	<5	<5	0	24	
	0.8	0.7			0.0	0.8	
Congenital cataract	11	9	<5	0	<5	24	
Congenital posterior urethral valves	0.7 18	1.0 11	<5	0.0 0	0	0.8 38	2
Congenital posterior dreunal valves	2.1	2.4	<5	0.0	0.0	2.6	2
Diaphragmatic hernia	45	31	<5	<5	0	88	
	2.7	3.4			0.0	3.1	
Double outlet right ventricle	34	30	6	<5	0	73	
Ebstein anomaly	2.0 8	3.3 <5	2.6 <5	0	0.0 0	2.5 15	
Lostem anomary	。 0.5	< 3	<5	0.0	0.0	0.5	
Encephalocele	21	7	5	0	0	36	
-	1.3	0.8	2.2	0.0	0.0	1.3	
Esophageal atresia/tracheoesophageal	42	16	<5	<5	0	66	
Gastroschisis	2.5 89	1.8 26	8	0	0.0 0	2.3 131	
Gasuoscilisis	5.4	2.9	3.4	0.0	0.0	4.6	
Hypoplastic left heart syndrome	64	39	5	<5	0	116	
	3.8	4.3	2.2		0.0	4.0	-
Hypospadias	31	15	<5	<5	0	50	3
Interrupted aortic arch	3.6 6	3.3 9	0	<5	0.0 0	3.4 16	
interrupted dorite dien	0.4	1.0	0.0	~	0.0	0.6	
Limb deficiencies (reduction defects)	87	48	15	<5	0	168	4
	5.2	5.3	6.5		0.0	5.9	
Omphalocele	35	25	9	<5	<5	79 2 8	
Pulmonary valve atresia and stenosis	2.1 138	2.8 122	3.9 23	<5	<5	2.8 295	
- antonary varve areona and sentosis	8.3	13.5	9.9		2	10.3	
Pulmonary valve atresia	32	30	6	<5	0	71	
	1.9	3.3	2.6		0.0	2.5	
Rectal and large intestinal	61 3 7	38	<5	<5	0	107	
atresia/stenosis	3.7	4.2			0.0	3.7	

South Carolina Birth Defects Counts and Prevalence 2011 - 2015 (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	87	39	9	<5	0	144		
	5.2	4.3	3.9		0.0	5.0		
Single ventricle	<5	5	<5	<5	0	12		
		0.6			0.0	0.4		
Spina bifida without anencephalus	61	34	11	<5	0	118		
	3.7	3.8	4.7		0.0	4.1		
Tetralogy of Fallot	89	49	13	<5	0	159		
	5.4	5.4	5.6		0.0	5.5		
Total anomalous pulmonary venous	12	10	<5	<5	0	30	5	
connection	0.7	1.1			0.0	1.0		
Transposition of the great arteries	48	28	8	<5	0	86		
(TGA)	2.9	3.1	3.4		0.0	3.0		
Tricuspid valve atresia and stenosis	23	15	<5	0	0	42		
	1.4	1.7		0.0	0.0	1.5		
Trisomy 13	17	13	6	<5	0	42		
	1.0	1.4	2.6		0.0	1.5		
Trisomy 18	34	17	9	0	0	81		
	2.0	1.9	3.9	0.0	0.0	2.8		
Trisomy 21 (Down syndrome)	190	74	49	9	0	337		
	11.4	8.2	21.1	18.8	0.0	11.7		
Ventricular septal defect	640	306	118	23	0	1,130		
	38.5	33.9	50.7	47.9	0.0	39.4		
Total live births	166,285	90,326	23,255	4,800	942	286,946		
Male live births	85,126	45,914	11,887	2,516	479	146,598		

South Carolina Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)						
Defect	Less than 35	35+	Total*	Notes		
Gastroschisis	128	<5	131			
	5.1		4.6			
Trisomy 13	28	14	42			
-	1.1	4.1	1.5			
Trisomy 18	40	41	81			
	1.6	12.1	2.8			
Trisomy 21 (Down syndrome)	179	158	337			
• • • •	7.1	46.6	11.7			
Total live births	253,033	33,905	286,946			

Notes

1. Data for this condition are only collected when found with another reportable 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 only collected when found with another reportable defect. 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 begin in 2014.

5. Data for this condition begin in 2012.

General comments

*Totals include unknown and/or other.

-Data for conditions exclude probable and possible cases.

-Fetal deaths are only collected from inpatient hospitalizations.

-Terminations in South Carolina are not usually performed after 20 weeks gestation.

-Total births are resident births.

Tennessee Birth Defects Counts and Prevalence 2011 - 2015 (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	43	11	12	0	0	66	
Anophthalmia/microphthalmia	1.6 34 1.3	<i>1.3</i> 13	3.4 6 1.7	0.0 0 0.0	0.0 0	1.6 53	
Anotia/microtia	1.5 26 1.0	1.6 5 0.6	1.7 11 3.1	0.0 1 1.1	0.0 0 0.0	1.3 43 1.1	
Aortic valve stenosis	49 1.8	11 1.3	7 2.0	1 1.1	0 0.0	70 1.7	
Atrial septal defect	3,922 144.3	1,854 223.0	442 126.0	82 89.6	7 120.5	6,329 157.2	
Atrioventricular septal defect (Endocardial cushion defect)	148 5.4	51 6.1	17 4.8	6 6.6	1 17.2	224 5.6	
Biliary atresia	35 1.3	18 2.2	1 0.3	0 <i>0.0</i>	0 <i>0.0</i>	55 1.4	
Bladder exstrophy	5 0.2	2 0.2	2 0.6	0 <i>0.0</i>	0 <i>0.0</i>	9 0.2	
Choanal atresia	65 2.4	13 1.6	7 2.0	1 1.1	0 0.0	86 2.1	
Cleft lip alone	146 5. 4	21 2.5	15 4.3	3 3.3	1 17.2	186 4.6	
Cleft lip with cleft palate	194 7.1	28 3.4	30 8.6	6 6.6	0 0.0	258 6.4	
Cleft palate alone	244 9.0	40 4.8	31 8.8	3 3.3	1 17.2	319 7.9	
Cloacal exstrophy	185 6.8	153 18.4	25 7.1	4	2 34.4	371 9.2	
Clubfoot	507	121	66	4.4 6	0	703	
Coarctation of the aorta	18.6 243	14.6 60	18.8 31	6.6 5	0.0 1	17.5 343	
Common truncus (truncus arteriosus)	8.9 24	7.2 9	8.8 4	5.5 0	17.2 0	8.5 37 0.9	
Congenital cataract	0.9 62 2.3	1.1 17 2.0	1.1 8 2.3	0.0 2 2.2	0.0 0 0.0	89 2.2	
Congenital posterior urethral valves	2.3 38	20	3	1	0	62	1
Craniosynostosis	2.7 60	4.8 5	1.7 7	2.1 0	0.0 0	3.0 73	
Deletion 22q11.2	11.0 7	3.0 2	9.6 1	0.0 0	0.0 0	9.0 10	
Diaphragmatic hernia	<i>0.3</i> 105	0.2 37	<i>0.3</i> 13	0.0 3	0.0 0	0.2 158	
Double outlet right ventricle	3.9 77	4.4 38	3. 7 8	3.3 3	0.0 0	3.9 126	
Ebstein anomaly	2.8 47	4.6 12	2.3 6	3.3 4	0.0 0	3.1 69	
Encephalocele	1.7 28	1.4 16	<i>1.7</i> 4	4.4 0	0.0 0	1.7 48	
Esophageal atresia/tracheoesophageal	1.0 90	1.9 20	1.1 14	0.0 1	0.0 0	<i>1.2</i> 125	
fistula	3.3	2.4	4.0	1.1	0.0	3.1	
Gastroschisis	174 6.4	28 3.4	17 4.8	0 <i>0.0</i>	0 <i>0.0</i>	224 5.6	
Holoprosencephaly	189 7.0	54 6.5	21 6.0	5 5.5	1 17.2	270 6.7	
Hypoplastic left heart syndrome	98 3.6	36 <i>4.3</i>	13 3.7	1 1.1	1 17.2	151 3.8	
Hypospadias	1,641 117.5	422 100.5	89 50.0	32 67.6	3 100.0	2,198 106.8	1
Interrupted aortic arch	32 1.2	9 1.1	3 0.9	3 3.3	0 <i>0.0</i>	47 1.2	

Tennessee Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity							
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	109	36	13	3	0	161	
	4.0	4.3	3.7	3.3	0.0	4.0	
Omphalocele	62	31	8	2	0	103	
	2.3	3.7	2.3	2.2	0.0	2.6	
Pulmonary valve atresia and stenosis	252	96	37	4	0	390	
	9.3	11.5	10.5	4.4	0.0	9.7	
Pulmonary valve atresia	15	6	3	0	0	24	
Destal and lance intesting!	0.6	0.7	0.9	0.0 3	0.0	0.6 214	
Rectal and large intestinal atresia/stenosis	147 5.4	51 6.1	13 3.7	3 3.3	0 <i>0.0</i>	5.3	
Renal agenesis/hypoplasia	178	52	16	3	0	249	
ivenai agenesis/nypopiasia	6.5	52 6.3	4.6	3 3.3	0.0	6.2	
Single ventricle	43	15	5	1	0	65	
Shigle ventilele	1.6	1.8	1.4	1.1	0.0	1.6	
Small intestinal atresia/stenosis	136	47	22	3	1	210	
	5.0	5.7	6.3	3.3	17.2	5.2	
Spina bifida without anencephalus	120	33	21	1	0	176	
· ·	4.4	4.0	6.0	1.1	0.0	4.4	
Tetralogy of Fallot	155	54	11	4	0	224	
	5.7	6.5	3.1	4.4	0.0	5.6	
Total anomalous pulmonary venous	38	10	5	3	0	56	
connection	1.4	1.2	1.4	3.3	0.0	1.4	
Transposition of the great arteries	141	50	18	5	0	215	
(TGA)	5.2	6.0	5.1	5.5	0.0	5.3	
Dextro-transposition of great arteries	76	18	8	1	0	104	
(d-TGA)	2.8	2.2	2.3	1.1	0.0	2.6	
Tricuspid valve atresia and stenosis	33	17 2.0	7	0	0	57 1.4	
Tricuspid valve atresia	1.2 33	2.0 17	2.0 7	0.0	0.0 0	1.4 57	
Theuspid valve allesia		2.0	2.0	0.0	0.0	1.4	
Trisomy 13	24	12	2.0	2	0.0	40	
Thisonly 15	0.9	1.4	0.6	2.2	0.0	1.0	
Trisomy 18	35	18	7	0	0	61	
112011.9 10	1.3	2.2	2.0	0.0	0.0	1.5	
Trisomy 21 (Down syndrome)	404	105	75	11	2	598	
	14.9	12.6	21.4	12.0	34.4	14.9	
Turner syndrome	16	7	3	1	0	28	2
	1.2	1.7	1.7	2.3	0.0	1.4	
Ventricular septal defect	1,350	423	194	35	4	2,010	
Total live births	49.7 271,857	50.9 83,147	55.3 35,086	38.2 9,152	68.8 581	<i>49.9</i> 402,601	3
Male live births	139,611	42,007	17,799	4,731	300	205,836	
Female live births	132,243	41,140	17,285	4,421	281	196,758	

Tennessee Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	213	6	224					
	5.9	1.3	5.6					
Trisomy 13	31	9	40					
-	0.9	2.0	1.0					
Trisomy 18	45	16	61					
	1.3	3.6	1.5					
Trisomy 21 (Down syndrome)	340	247	598					
	9.5	55.5	14.9					
Total live births	358,013	44,514	402,601	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. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

-Data for conditions exclude terminations.

-Fetal deaths are defined as 350 grams or more, or 20 weeks gestation or more.

Texas Birth Defects Counts and Prevalence 2011 - 2015 (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	130	27	267	17	3	451	Notes
	1.9	1.2	2.9	1.8	8.4	2.3	
Anophthalmia/microphthalmia	165	47	297	21	0	539	
	2.5	2.1	3.2	2.3	0.0	2.8	
Anotia/microtia	147 2.2	36 1.6	491 5.3	19 2.1	2 5.6	699 3.6	
Aortic valve stenosis	181	27	258	14	2	3.0 484	
	2.7	1.2	2.8	1.5	5.6	2.5	
Atrial septal defect	5,395	1,973	8,455	605	21	16,661	
	80.4	88.1	90.8	65.7	58.5	85.5	
Atrioventricular septal defect	312	106	398	30	1	856	
(Endocardial cushion defect)	4.6 33	4. 7 17	4.3 62	3.3 12	2.8 1	4.4 129	
Biliary atresia	0.5	0.8	0.7	1.3	2.8	0.7	
Bladder exstrophy	19	5	9	2	0	35	
	0.3	0.2	0.1	0.2	0.0	0.2	
Choanal atresia	114	38	112	5	0	273	
	1.7	1.7	1.2	0.5	0.0	1.4	
Cleft lip alone	291	58	258	26	0	640	
Cleft lip with cleft palate	<i>4.3</i> 476	2.6 102	2.8 806	2.8 56	0.0 10	<i>3.3</i> 1,463	
Cleft lip with cleft palate	7.1	4.6	800 8.7	6.1	27.9	7.5	
Cleft palate alone	398	94	519	60	2	1,091	
1	5.9	4.2	5.6	6.5	5.6	5.6	
Cloacal exstrophy	1	0	4	0	0	5	
	0.0	0.0	0.0	0.0	0.0	0.0	
Clubfoot	1,195	375	1,592	101	6	3,313	
Coarctation of the aorta	17.8 405	16.8 95	<i>17.1</i> 507	11.0	16.7	17.0	
Coarctation of the aorta	403 6.0	93 4.2	5.4	41 <i>4.5</i>	1 2.8	1,062 5.4	
Common truncus (truncus arteriosus)	40	15	97	5	0	159	
	0.6	0.7	1.0	0.5	0.0	0.8	
Congenital cataract	131	45	170	8	0	356	
	2.0	2.0	1.8	0.9	0.0	1.8	
Congenital posterior urethral valves	73	33	60	15	0	183	1
Constitution and the site	2.1	2.9	1.3	3.1	0.0	1.8	
Craniosynostosis	536 8.0	73 3.3	569 6.1	24 2.6	1 2.8	1,216 6.2	
Deletion 22q11.2	48	22	78	6	2.0	159	
200000 224112	0.7	1.0	0.8	0.7	5.6	0.8	
Diaphragmatic hernia	183	47	266	17	0	515	
	2.7	2.1	2.9	1.8	0.0	2.6	
Double outlet right ventricle	81	36	146	14	0	279	
Ebstein anomaly	<i>1.2</i> 44	1.6 10	1.6 85	1.5 5	0.0 0	1.4 145	
Eostein anomaly	<i>0.7</i>	0.4	0.9	<i>0.5</i>	0.0	143 0.7	
Encephalocele	55	32	90	10	0	189	
	0.8	1.4	1.0	1.1	0.0	1.0	
Esophageal atresia/tracheoesophageal	175	56	203	14	0	453	
fistula	2.6	2.5	2.2	1.5	0.0	2.3	
Gastroschisis	352	86	629	19	2	1,100	
Holoprosencenholy	5.2 44	3.8	6.8	2.1	5.6	5.6	
Holoprosencephaly	44 0.7	16 0. 7	122 1.3	5 0.5	0 0.0	188 1.0	
Hypoplastic left heart syndrome	193	46	211	11	0	468	
· · · · · · · · · · · · · · · · · · ·	2.9	2.1	2.3	1.2	0.0	2.4	
Hypospadias	3,070	912	2,190	331	13	6,621	1
	89.2	80.1	46.1	69.4	71.4	66.4	
Interrupted aortic arch	36	24	61	5	0	128	
	0.5	1.1	0.7	0.5	0.0	0.7	

Texas Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity								
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes	
Limb deficiencies (reduction defects)	367	141	534	31	5	1,089		
	5.5	6.3	5.7	3.4	13.9	5.6		
Omphalocele	157	51	186	13	0	411		
	2.3	2.3	2.0	1.4	0.0	2.1		
Pulmonary valve atresia and stenosis	624	250	1,130	64	3	2,097		
	9.3	11.2	12.1	6.9	8.4	10.8		
Pulmonary valve atresia	109	37	200	15	2	365		
	1.6	1.7	2.1	1.6	5.6	1.9		
Rectal and large intestinal	317	103	532	38	2	1,010		
atresia/stenosis	4.7	4.6	5.7	4.1	5.6	5.2		
Renal agenesis/hypoplasia	428	148	609	69	1	1,275		
of 1	6.4	6.6	6.5	7.5	2.8	6.5		
Single ventricle	54	16	86	8	0	164		
Small intestinal atresia/stenosis	0.8 209	0. 7 89	0.9 328	0.9 18	0.0 2	0.8 653		
Small intestinal atresia/stenosis		89 4.0	328 3.5	18 2.0	2 5.6	055 3.3		
Spina bifida without anencephalus	3.1 233	4.0 61	3.5 412	2.0 14	5.0 1	3.3 735		
Spina binda without anencephalus	3.5	2.7	412 4.4	1.5	2.8	735 3.8		
Tetralogy of Fallot	312	115	4.4 437	47	4	933	2	
Tetralogy of Pallot	4.6	5.1	4. 7	5.1	11.1	<i>4.8</i>	2	
Total anomalous pulmonary venous	76	23	202	21	1	326		
connection	1.1	1.0	2.2	2.3	2.8	1.7		
Transposition of the great arteries	293	54	401	27	1	785		
(TGA)	4.4	2.4	4.3	2.9	2.8	4.0		
Dextro-transposition of great arteries	259	49	358	24	1	699		
(d-TGA)	3.9	2.2	3.8	2.6	2.8	3.6		
Tricuspid valve atresia and stenosis	131	43	191	16	2	388		
1	2.0	1.9	2.1	1.7	5.6	2.0		
Tricuspid valve atresia	59	23	63	8	1	156		
•	0.9	1.0	0.7	0.9	2.8	0.8		
Trisomy 13	75	31	99	10	0	219		
	1.1	1.4	1.1	1.1	0.0	1.1		
Trisomy 18	163	55	249	31	1	508		
	2.4	2.5	2.7	3.4	2.8	2.6		
Trisomy 21 (Down syndrome)	850	206	1,522	100	3	2,717		
	12.7	9.2	16.3	10.9	8.4	13.9		
Turner syndrome	92	15	116	13	0	237	3	
	2.8	1.4	2.5	2.9	0.0	2.5		
Ventricular septal defect	3,989	1,206	7,016	507	29	12,903	4	
Total live births	59. <i>4</i> 671,341	53.9 223,829	75.4 931,037	55.0 92,126	80.8 3,589	66.2 1,949,743		
Male live births	343,980	113,851	475,353	47,673	1,820	996,875		
Female live births	327,361	109,978	455,684	44,453	1,769	952,868		

Texas Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	1,074	26	1,100					
	6.4	1.0	5.6					
Trisomy 13	147	72	219					
	0.9	2.8	1.1					
Trisomy 18	256	252	508					
	1.5	9.7	2.6					
Trisomy 21 (Down syndrome)	1,402	1,315	2,717					
• • • •	8.3	50.7	13.9					
Total live births	1,690,121	259,515	1,949,743					

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 exclude co-occuring ventricular septal defect/tetralogy of Fallot.

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.

General comments

*Totals include unknown and/or other.

-Data for conditions exclude probable and possible cases.

-Fetal deaths are defined as spontaneous death of a conception product prior to the complete expulsion/extraction from its mother, regardless of gestational length. The labor onset may be natural/induced, the key is that the fetal death was spontaneous and not a result of an intended procedure.

Utah Birth Defects Counts and Prevalence 2011 - 2015 (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	30	1	13	0	0	47	rotes
	1.5	3.5	3.4	0.0	0.0	1.8	
Anophthalmia/microphthalmia	27 1.4	1 3.5	9 2.3	1 1.1	0 0.0	38 1.5	
Anotia/microtia	54	0	30	10	2	96	
	2.7	0.0	7.8	10.7	7.3	3.8	
Aortic valve stenosis	77 3.9	1 3.5	15 3.9	3 3.2	1 3.7	97 3.8	
Atrial septal defect	770	11	168	38	12	1,001	1
	38.7	38.5	43.8	40.6	44.1	39.2	
Atrioventricular septal defect (Endocardial cushion defect)	136 6.8	2 7.0	19 5.0	9 9.6	0 0.0	167 6.5	
Biliary atresia	14	1	3	2	0	20	
	0.7	3.5	0.8	2.1	0.0	0.8	
Bladder exstrophy	3 0.2	0 <i>0.0</i>	0 <i>0.0</i>	1 1.1	0 0.0	4 <i>0.2</i>	
Choanal atresia	29	0	6	0	1	36	
	1.5	0.0	1.6	0.0	3.7	1.4	
Cleft lip alone	113 5.7	4 <i>14.0</i>	16 4.2	7 7.5	0 0.0	141 5.5	
Cleft lip with cleft palate	157	3	27	2	4	194	
	7.9	10.5	7.0	2.1	14.7	7.6	
Cleft palate alone	151	3 10.5	27	5	3	190 7.4	
Cloacal exstrophy	7.6 5	0	7.0 0	5.3 1	11.0 0	6	
	0.3	0.0	0.0	1.1	0.0	0.2	
Clubfoot	0	0	0	0	0	0	
Coarctation of the aorta	0.0 205	0.0 4	0.0 35	0.0 3	<i>0.0</i> 4	0.0 251	
	10.3	14.0	9.1	3.2	14.7	9.8	
Common truncus (truncus arteriosus)	16	0	6	0	0	22	
Congenital cataract	0.8 53	0.0 0	1.6 15	0.0 2	0.0 0	0.9 70	
	2.7	0.0	3.9	2.1	0.0	2.7	
Congenital posterior urethral valves	31	1	5	0	0	37	2
Craniosynostosis	3.0 230	6. 7 3	2.6 50	0.0 2	0.0 6	2.8 292	
	11.6	10.5	13.0	2.1	22.0	11.4	
Deletion 22q11.2	27	1	7	3	2	40	
Diaphragmatic hernia	1.4 77	3.5 2	1.8 15	3.2 4	7.3 2	1.6 100	
	3.9	7.0	3.9	4.3	7.3	3.9	
Double outlet right ventricle	41	1	5	2	1	51	
Ebstein anomaly	2.1 25	3.5 0	1.3 8	2.1 0	3. 7 0	2.0 33	
	1.3	0.0	2.1	0.0	0.0	1.3	
Encephalocele	26	0	3	0	0	30	
Esophageal atresia/tracheoesophageal	1.3 58	0.0	0.8 9	0.0 2	0.0 2	1.2 72	
fistula	2.9	1 3.5	2.3	2.1	7.3	2.8	
Gastroschisis	79	1	20	0	1	103	
Uslamasanaanhalta	4.0	3.5	5.2	0.0	3.7	4.0	
Holoprosencephaly	30 1.5	1 3.5	10 2.6	0 <i>0.0</i>	0 0.0	41 1.6	
Hypoplastic left heart syndrome	60	3	8	4	1	77	
	3.0	10.5	2.1	4.3	3.7	3.0	2
Hypospadias	807 7 8.8	11 7 4.0	64 32. 7	27 56.4	6 43.4	921 7 0.1	2
Interrupted aortic arch	13	1	3	1	1	19	
	0.7	3.5	0.8	1.1	3.7	0.7	

Utah Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	128	2	26	2	1	162	
	6.4	7.0	6.8	2.1	3.7	6.3	
Omphalocele	61	1	11	2	2	78	
	3.1	3.5	2.9	2.1	7.3	3.1	
Pulmonary valve atresia and stenosis	268	6	56	10	4	345	
	13.5	21.0	14.6	10.7	14.7	13.5	
Pulmonary valve atresia	13 0.7	0 <i>0.0</i>	4 1.0	2 2.1	0 <i>0.0</i>	19 0. 7	
Rectal and large intestinal	85	2	12	2.1 5	0.0	104	
atresia/stenosis	65 4.3	7.0	3.1	5.3	0.0	4.1	
Renal agenesis/hypoplasia	89	2	16	6	3	116	
"Beneeve ut Lohnom	4.5	7.0	4.2	6.4	11.0	4.5	
Single ventricle	10	0	3	0	0	13	
e	0.5	0.0	0.8	0.0	0.0	0.5	
Small intestinal atresia/stenosis	62	2	19	3	0	86	
	3.1	7.0	5.0	3.2	0.0	3.4	
Spina bifida without anencephalus	81	2	12	1	1	100	
	4.1	7.0	3.1	1.1	3.7	3.9	
Tetralogy of Fallot	72	1	13	4	2	92	
T-4-1	3.6	3.5	3.4 11	4.3 2	7.3	3.6	
Total anomalous pulmonary venous connection	24 1.2	0 0.0	2.9	2 2.1	1 3.7	38 1.5	
Transposition of the great arteries	102	3	22	5	2	135	
(TGA)	5.1	10.5	5.7	5.3	7.3	5.3	
Dextro-transposition of great arteries	51	1	13	3	1	70	
(d-TGA)	2.6	3.5	3.4	3.2	3.7	2.7	
Tricuspid valve atresia and stenosis	20	0	7	0	0	27	
	1.0	0.0	1.8	0.0	0.0	1.1	
Tricuspid valve atresia	14	0	3	0	0	17	
	0.7	0.0	0.8	0.0	0.0	0.7	
Trisomy 13	28	1	8	3	0	42	
T: 10	1.4	3.5	2.1	3.2	0.0	1.6	
Trisomy 18	70	3 10.5	13 <i>3.4</i>	2 2.1	1	94 3.7	
Trisomy 21 (Down syndrome)	3.5 322	4	3.4 85	2.1	3. 7 6	3. 7 442	
mony 21 (Down synatome)	322 16.2	4 14.0	83 22.2	20 21.4	22.0	442 17.3	
Turner syndrome	49	0	10	0	0	60	3
	5.1	0.0	5.3	0.0	0.0	4.8	J.
Ventricular septal defect	503	8	125	19	8	669	4
	25.3	28.0	32.6	20.3	29.4	26.2	
Total live births	198,784	2,856	38,351	9,366	2,722	255,436	5
Male live births	102,402	1,487	19,588	4,784	1,381	131,343	
Female live births	96,381	1,369	18,763	4,582	1,341	124,092	

Utah Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	100	3	103				
	4.5	0.9	4.0				
Trisomy 13	25	17	42				
-	1.1	5.3	1.6				
Trisomy 18	67	27	94				
	3.0	8.5	3.7				
Trisomy 21 (Down syndrome)	221	221	442				
• • • •	9.9	69.5	17.3				
Total live births	223,605	31,808	255,436	5			

Notes

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

2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.

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

4. Data for this condition exclude inlet ventricular septal defect, and common atrioventricular canal type ventricular septal defect.

5. Total live births includes unknown gender.

General comments

*Totals include unknown and/or other.

-Stillbirths are based on >=20 weeks gestation.

-Terminations include any weeks' gestation.

Vermont Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity							
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	Alaska Native, Non-Hispanic	Total*	Notes	
Anencephalus	1	0	0	0	0	1		
Anotia/microtia	0.4 5 1.8	0.0 0 0.0	0.0 1 21.1	0.0 1 14.1	0.0 0 0.0	0.3 7 2.3		
Aortic valve stenosis	12 4.3	0 0.0	1 21.1	0 0.0	0 0.0	13 4.3		
Atrial septal defect	275 98.9	4 90.3	6 126.6	7 98.6	1 185.2	296 98.4		
Atrioventricular septal defect (Endocardial cushion defect)	16 5.8	0 <i>0.0</i>	0 0.0	1 14.1	0 <i>0.0</i>	17 5.6		
Bladder exstrophy	1 0.4	0 0.0	0 0.0	1 14.1	0 0.0	2 0.7		
Cleft lip alone	12 4.3	0 0.0	0 0.0	0 <i>0.0</i>	0 0.0	13 <i>4.3</i>		
Cleft lip with cleft palate	13 4.7	0 0.0	0 0.0	0 0.0	0 0.0	13 4.3		
Cleft palate alone	24 8.6	0 0.0	1 21.1	0 0.0	0 0.0	25 8.3		
Coarctation of the aorta	17 6.1	0 0.0	0 0.0	0 0.0	0 0.0	17 5.6		
Common truncus (truncus arteriosus)	2 0.7	0 0.0	1 21.1	0 0.0	0 0.0	3 1.0		
Diaphragmatic hernia	14 5.0	0 0.0	0 0.0	0 0.0	0 0.0	15 5.0		
Double outlet right ventricle	4 1.4	0 0.0	0 0.0	1 14.1	0 0.0	5 1.7		
Ebstein anomaly	3 1.1	0 0.0	0 0 0.0	0 0.0	0 0.0	3 1.0		
Encephalocele	1.1 1 0.4	0 0.0	0	0 0.0	0 0.0	1 0.3		
Esophageal atresia/tracheoesophageal fistula	6 2.2	0 0 0.0	1 21.1	1 1 14.1	0 0 0.0	8 2.7		
Gastroschisis	15 5.4	0 0.0	0 0.0	0 0.0	0 0.0	15 5.0		
Hypoplastic left heart syndrome	10 3.6	1 22.6	0.0 0.0	0.0 0.0	0.0 0.0	11 3.7		
Hypospadias	109 7 5. 7	3 128.8	1 39.8	0.0 0 0.0	0.0 0.0	114 72.9	1	
Limb deficiencies (reduction defects)	14	0	0	0	0	16		
Omphalocele	5.0 3	0.0 0	0.0 0	0.0 0	0.0 0	5.3 3		
Pulmonary valve atresia and stenosis	1.1 52	0.0 2	0.0 1	0.0 1	0.0 0	1.0 56		
Pulmonary valve atresia	18.7 5	45.1 2	21.1 0	<i>14.1</i> 0	0.0 0	18.6 7		
Rectal and large intestinal	1.8 17	45.1 0	0.0 0	0.0 0	0.0 0	2.3 17		
atresia/stenosis Renal agenesis/hypoplasia	6.1 15	0.0 0	0.0 0	0.0 1	0.0 0	5.6 16		
Small intestinal atresia/stenosis	5.4 8	0.0 0	0.0 0	14.1 1	0.0 0	5.3 9	2	
Spina bifida without anencephalus	2.9 7	0.0 0	0.0 0	<i>14.1</i> 0	0.0 0	3.0 7		
Tetralogy of Fallot	2.5 8	0.0 1	0.0 0	0.0 1	0.0 0	2.3 10		
Transposition of the great arteries	2.9	22.6 0	0.0 0	14.1	0.0 0	3.3 12		
(TGA) Dextro-transposition of great arteries	4.0 7	0.0 0	0.0 0	14.1 1	0.0 0	4.0 8		
(d-TGA)	2.5	0.0	0.0	14.1	0.0	2.7		

Vermont Birth Defects Counts and Prevalence 2011 - 2015 (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	0	0	0	5	
	1.8	0.0	0.0	0.0	0.0	1.7	
Tricuspid valve atresia	1	0	0	0	0	1	
	0.4	0.0	0.0	0.0	0.0	0.3	
Trisomy 13	0	0	0	0	0	0	
	0.0	0.0	0.0	0.0	0.0	0.0	
Trisomy 18	6	0	0	0	0	6	
·	2.2	0.0	0.0	0.0	0.0	2.0	
Trisomy 21 (Down syndrome)	29	1	1	1	0	32	
• • • •	10.4	22.6	21.1	14.1	0.0	10.6	
Ventricular septal defect	174	3	1	6	0	189	
-	62.6	67.7	21.1	84.5	0.0	62.8	
Total live births	27,798	443	474	710	54	30,093	3
Male live births	14,407	233	251	379	32	15,631	

Vermont Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	14	1	15					
	5.6	2.0	5.0					
Trisomy 13	0	0	0					
-	0.0	0.0	0.0					
Trisomy 18	3	3	6					
	1.2	5.9	2.0					
Trisomy 21 (Down syndrome)	19	13	32					
• • • •	7.6	25.8	10.6					
Total live births	25,044	5,045	30,093	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 only small intestinal atresia.

3. Total live births includes unknown gender.

General comments *Totals include unknown and/or other.

-Data for conditions include live births and fetal deaths.

-Fetal deaths are defined as 20 week gestation and greater or a birth weight of more than 400 grams.

Virginia Birth Defects Counts and Prevalence 2011 - 2015 (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	12	5	3	2	0	24	110103	
-	0.4	0.5	0.5	0.8	0.0	0.5		
Anophthalmia/microphthalmia	15	9	3	1	1	34		
Anotia/microtia	0.5 29	0.8 6	0.5 10	0.4 5	11.9 0	0. 7 52		
Anoua/microua	29 1.0	0. <i>6</i>	10 1.6	3 2.0	0.0	32 1.0		
Aortic valve stenosis	29	10	4	1	1	49		
	1.0	0.9	0.6	0.4	11.9	1.0		
Atrial septal defect	2,756	1,447	987	319	13	5,927		
	<i>96.1</i>	135.6	159.5	126.8	154.4	116.5		
Atrioventricular septal defect (Endocardial cushion defect)	123 4.3	63 5.9	21 3.4	3 1.2	4 47.5	230 4.5		
Biliary atresia	24	15	6	5	0	4. 3		
	0.8	1.4	1.0	2.0	0.0	1.0		
Bladder exstrophy	6	1	0	0	0	8		
	0.2	0.1	0.0	0.0	0.0	0.2		
Choanal atresia	32	14	4	3	0	58		
	1.1	1.3	0.6	1.2	0.0	1.1		
Cleft lip alone	83 2.9	20	15	11	0	134		
Cleft lip with cleft palate	189	1.9 36	2.4 39	4.4 22	0.0 0	2.6 305		
Cleft lip with cleft palate	6.6	3.4	6.3	8.7	0.0	6.0		
Cleft palate alone	231	46	33	14	1	339		
1	8.1	4.3	5.3	5.6	11.9	6.7		
Cloacal exstrophy	121	65	30	13	1	249		
	4.2	6.1	4.8	5.2	11.9	4.9		
Clubfoot	305	123	65	14	2	546		
	10.6	11.5	10.5	5.6	23.8	10.7		
Coarctation of the aorta	164 5.7	70 6.6	34 5.5	13 5.2	1 11.9	298 5.9		
Common truncus (truncus arteriosus)	21	0.0 7	3.5	1	0	3.9		
common autous (autous arteriosus)	0.7	0.7	0.5	0.4	0.0	0.7		
Congenital cataract	24	16	3	1	0	46		
-	0.8	1.5	0.5	0.4	0.0	0.9		
Congenital posterior urethral valves	21	19	6	1	0	53	1	
	1.4	3.5	1.9	0.8	0.0	2.0		
Craniosynostosis	35	8	4	1	0	49		
Deletion 22q11.2	1.2 9	0. 7 3	0.6 3	0.4 1	0.0 0	1.0 18		
Deletion 22q11.2	<i>0.3</i>	<i>0.3</i>	0.5	0.4	0.0	0.4		
Diaphragmatic hernia	67	30	15	4	0	129		
	2.3	2.8	2.4	1.6	0.0	2.5		
Double outlet right ventricle	50	28	11	8	1	103		
	1.7	2.6	1.8	3.2	11.9	2.0		
Ebstein anomaly	23	6	4	2	0	36		
Encephalocele	0.8	0.6	0.6	0.8	0.0	0.7		
Encephalocele	14 0.5	8 0. 7	4 0.6	0 <i>0.0</i>	0 0.0	26 0.5		
Esophageal atresia/tracheoesophageal	58	23	16	3	0	104		
fistula	2.0	2.2	2.6	1.2	0.0	2.0		
Gastroschisis	96	27	25	6	2	167		
	3.3	2.5	4.0	2.4	23.8	3.3		
Holoprosencephaly	114	69	24	9	2	225		
	4.0	6.5	3.9	3.6	23.8	4.4		
Hypoplastic left heart syndrome	59	33	12	10	2	119		
Humasmadias	2.1	3.1	<i>1.9</i>	4.0	23.8	2.3	1	
Hypospadias	901 61.3	343 63.3	109 34.4	49 37.8	5 118.8	1,494 57.4	1	
Interrupted aortic arch	23	15	4	0	2	45		
	0.8	1.4	0.6	<i>0.0</i>	23.8	0.9		

Virginia Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity									
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes		
Limb deficiencies (reduction defects)	102	36	11	7	0	169	110100		
`````	3.6	3.4	1.8	2.8	0.0	3.3			
Omphalocele	45	23	6	6	0	82			
	1.6	2.2	1.0	2.4	0.0	1.6			
Pulmonary valve atresia and stenosis	173	103	47	17	1	368			
	6.0	9.7	7.6	6.8	11.9	7.2			
Pulmonary valve atresia	2	1	3	0	0	6			
	0.1	0.1	0.5	0.0	0.0	0.1			
Rectal and large intestinal	94	49	25	12	0	196			
atresia/stenosis	3.3	4.6	4.0	4.8	0.0	<i>3.9</i>			
Renal agenesis/hypoplasia	130	40 3.7	28 <b>4.5</b>	6	0 <b>0.0</b>	218 <b>4.3</b>			
Single ventricle	4.5 35	3.7 18	4.5 8	2.4 2	0.0	<b>4.3</b> 68			
Single ventricle	35 1.2	18 1.7	8 1.3	2 0.8	0.0	08 1.3			
Small intestinal atresia/stenosis	1.2	44	22	8	0	201			
Sinan mesunai aresia/stenosis	3.7	4.1	3.6	3.2	0.0	4.0			
Spina bifida without anencephalus	72	45	26	7	0	165			
spina onica wanout anoneephanas	2.5	4.2	4.2	2.8	0.0	3.2			
Tetralogy of Fallot	134	77	19	14	2	264			
	4.7	7.2	3.1	5.6	23.8	5.2			
Total anomalous pulmonary venous	16	10	12	4	1	47			
connection	0.6	0.9	1.9	1.6	11.9	0.9			
Transposition of the great arteries	55	22	7	4	1	92			
(TGA)	1.9	2.1	1.1	1.6	11.9	1.8			
Dextro-transposition of great arteries	0	0	0	0	0	0			
(d-TGA)	0.0	0.0	0.0	0.0	0.0	0.0			
Tricuspid valve atresia and stenosis	37	15	9	4	0	68			
	1.3	1.4	1.5	1.6	0.0	1.3			
Tricuspid valve atresia	0	0	0	0	0	0			
T 12	0.0	0.0	0.0	0.0	0.0	0.0			
Trisomy 13	16	11 1.0	6 1.0	2	1 11.9	37 0.7			
Trisomy 18	<b>0.6</b> 38	20	6	<b>0.8</b> 2	0	<b>0.</b> 7 76			
Trisony 18	30 1.3	20 1.9	1.0	2 0.8	0.0	1.5			
Trisomy 21 (Down syndrome)	317	124	103	29	1	613			
monty 21 (Down Synatome)	11.1	124 11.6	103 16.6	11.5	1 11.9	12.0			
Turner syndrome	22	7	7	2	0	40	2		
	1.6	1.3	2.3	1.6	0.0	1.6	-		
Ventricular septal defect	1,206	539	314	109	6	2,323			
1	42.1	50.5	50.7	43.3	71.3	45.7			
Total live births	286,647	106,729	61,878	25,160	842	508,831			
Male live births	147,009	54,169	31,715	12,954	421	260,333			
Female live births	139,630	52,556	30,159	12,203	421	248,498			

# Virginia Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	161	4	167				
	3.8	0.4	3.3				
Trisomy 13	20	17	37				
-	0.5	1.9	0.7				
Trisomy 18	43	31	76				
	1.0	3.4	1.5				
Trisomy 21 (Down syndrome)	309	295	613				
• • • •	7.4	32.7	12.0				
Total live births	418,678	90,153	508,831				

Notes1. 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

*Totals include unknown and/or other.

# Washington Birth Defects Counts and Prevalence 2011 - 2015 (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	61 2.3	7 3.7	17 <b>2.1</b>	9 2.0	1 1.5	99 <b>2.3</b>				
Cleft palate alone	167 6.2	10 5.3	47 5.9	30 6.7	8 12.1	296 6.7				
Gastroschisis	110 4.1	9 <b>4.8</b>	39 <b>4.9</b>	9 2.0	8 12.1	196 4.5				
Hypospadias	870 62.4	63 40.4	109 27.0	105 45.4	17 49.2	1,261 54.4	1			
Limb deficiencies (reduction defects)	97 <b>3.6</b>	12 6.4	25 3.2	10 2.2	1 1.5	167 3.8				
Omphalocele	57 2.1	3 1.6	14 1.8	8 1.8	2 3.0	87 2.0				
Spina bifida without anencephalus	96 3.5	5 2.7	19 2.4	5 1.1	2 3.0	142 3.2	2			
Trisomy 21 (Down syndrome)	333 12.3	30 15.9	130 16.4	72 16.0	7 10.6	652 14.8				
Total live births	271,101	18,836	79,272	44,972	6,607	439,788				
Male live births	139,522	15,578	40,419	23,147	3,453	231,986				

# Washington Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	172	7	196				
	4.7	1.0	4.5				
Trisomy 21 (Down syndrome)	278	299	652				
• • • •	7.6	40.6	14.8				
Total live births	364,448	73,579	439,788				

**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 meningomylocele/spina bifida.

# General comments

*Totals include unknown and/or other.

-Data for conditions includes those with age less than or equal to 1 year.

-Data for condtions excludes cases from birth certificate only.

-Denominators are from the birth file.

# West Virginia Birth Defects Counts and Prevalence 2011 - 2015 (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	0	0	0	0	31		
Anophthalmia/microphthalmia	3.7 0 0.0	0.0 0 0.0	0.0 0 0.0	0.0 0 0.0	<b>0.0</b> 0 <b>0.0</b>	<b>3.4</b> 0 <b>0.0</b>		
Anotia/microtia	1 0.1	0 0.0	0 0.0	0 0.0	0 0.0	1 0.1		
Aortic valve stenosis	8	0	0	0	0	8		
Atrial septal defect	1.0 1,222 145.8	0.0 48 135.2	0.0 7 54.1	0.0 3 34.9	0.0 0 0.0	<b>0.9</b> 1,306 <b>144.1</b>		
Atrioventricular septal defect (Endocardial cushion defect)	23 2.7	1 2.8	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	24 <b>2.6</b>		
Biliary atresia	8 1.0	1 2.8	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	9 1.0		
Bladder exstrophy	1 0.1	0 0.0	0 0.0	0 <i>0.0</i>	0 0.0	1 0.1		
Choanal atresia	11 1.3	1 2.8	0 <i>0.0</i>	0 <b>0.0</b>	0 <b>0.0</b>	13 <i>1.4</i>		
Cleft lip alone	5 0.6	0 0.0	0 0.0	0 <b>0.0</b>	0 0.0	5 0.6		
Cleft lip with cleft palate	42 5.0	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	42 <b>4.6</b>		
Cleft palate alone	5.0 55 6.6	0.0 0 0.0	0.0 0 0.0	0.0 0.0	0.0 0.0	<b>4.0</b> 55 <b>6.1</b>		
Cloacal exstrophy	23 2.7	2 5.6	0	1 11.6	0 0.0	28 3.1		
Clubfoot	130 15.5	3 10.1	0 <b>0.0</b>	0 0.0	0 <b>0.0</b>	133 14.7		
Coarctation of the aorta	15.5 38 4.5	1 1 2.8	0.0 0 0.0	0.0 0 0.0	0.0 0.0	41 4.5		
Common truncus (truncus arteriosus)	51 6.1	2 5.6	0 0.0	1 11.6	0 0.0	54 6.0		
Congenital cataract	6 <b>0.</b> 7	0 <b>0.0</b>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	6 <b>0.</b> 7		
Congenital posterior urethral valves	5 1.2	0 <b>0.0</b>	0 <i>0.0</i>	1 21.3	0 <b>0.0</b>	6 1.3	1	
Craniosynostosis	1.2 159 <b>19.0</b>	7 19.7	0 0 0.0	0 0.0	0 0.0	1.5 168 18.5		
Deletion 22q11.2	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>		
Diaphragmatic hernia	23 2.7	1 2.8	0 0.0	0 <b>0.0</b>	0 0.0	24 2.6		
Double outlet right ventricle	17 2.0	0 0.0	0 0.0	0 <b>0.0</b>	0 0.0	19 2.1		
Ebstein anomaly	11 1.3	0 0.0	0 0.0	0 0.0	0 <b>0.0</b>	11 1.2		
Encephalocele	3 0.4	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	3 0.3		
Esophageal atresia/tracheoesophageal	13	0	0	0	0	15		
fistula Gastroschisis	<b>1.6</b> 12	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<i>1.7</i> 12	2	
Holoprosencephaly	<b>2.4</b> 36	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>2.2</b> 37		
Hypoplastic left heart syndrome	<b>4.3</b> 20	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>4.1</b> 20		
Hypospadias	2.4 227 53.0	0.0 5 27.1	0.0 1 14.2	0.0 0 0.0	<b>0.0</b> 0 <b>0.0</b>	<b>2.2</b> 235 <b>50.7</b>	1	
Interrupted aortic arch	5 0.6	0 0.0	14.2 0 0.0	0.0 0 0.0	0.0 0.0	50.7 5 0.6		
	0.0	0.0	0.0	0.0	0.0	0.0		

# West Virginia Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

		Maternal	Race/Ethnicity				
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes
Limb deficiencies (reduction defects)	15	1	0	0	0	17	
	1.8	2.8	0.0	0.0	0.0	1.9	
Omphalocele	8	0	0	0	0	8	2
Delan and the starting of the starting	1.6	0.0	0.0	0.0	0.0	1.5	
Pulmonary valve atresia and stenosis	54 <b>6.4</b>	1 2.8	0 <b>0.0</b>	0 <i>0.0</i>	0 <i>0.0</i>	56 <b>6.2</b>	
Pulmonary valve atresia	<b>0.4</b> 13	2.0 1	0	0.0	0.0	<b>0.</b> 2 14	
I unionary valve auesia	1.6	2.8	0.0	0.0	0.0	1.5	
Rectal and large intestinal	22	1	1	0	0	24	
atresia/stenosis	2.6	2.8	7.7	0.0	0.0	2.6	
Renal agenesis/hypoplasia	31	1	0	0	0	33	
	3.7	2.8	0.0	0.0	0.0	3.6	
Single ventricle	8	0	0	0	0	8	
	1.0	0.0	0.0	0.0	0.0	0.9	
Small intestinal atresia/stenosis	31	0	0	0	0	31	
	3.7	0.0	0.0	0.0	0.0	3.4	
Spina bifida without anencephalus	17	0	0	1	0	19	
	2.0	0.0	0.0	11.6	0.0	2.1	
Tetralogy of Fallot	38	1	1	0	0	40	
T.4.1	4.5	2.8	7.7	0.0	0.0	<i>4.4</i> 9	
Total anomalous pulmonary venous connection	9 1.1	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	0 <b>0.0</b>	9 1.0	
Transposition of the great arteries	24	0	0	0.0	0.0	26	
(TGA)	2.9	0.0	0.0	0.0	0.0	2.9	
Dextro-transposition of great arteries	21	0	0	0.0	0	23	
(d-TGA)	2.5	0.0	0.0	0.0	0.0	2.5	
Tricuspid valve atresia and stenosis	5	0	0	0	0	6	
1	0.6	0.0	0.0	0.0	0.0	0.7	
Tricuspid valve atresia	5	0	0	0	0	6	
	0.6	0.0	0.0	0.0	0.0	0.7	
Trisomy 13	4	0	0	0	0	4	
	0.5	0.0	0.0	0.0	0.0	0.4	
Trisomy 18	14	0	0	0	0	15	
	1.7	0.0	0.0	0.0	0.0	1.7	
Trisomy 21 (Down syndrome)	56	2	1	0	0	62	
Tram on our duomo	6.7	<b>5.6</b> 0	7.7 0	<b>0.0</b> 0	<b>0.0</b> 0	<b>6.8</b> 2	2
Turner syndrome	2 0.5	0.0	0 0.0	0 0.0	0.0	2 0.5	3
Ventricular septal defect	306	10	0	3	0	326	
venureulai septai deleet	36.5	28.2	0.0	3 34.9	0.0	36.0	
Total live births	83,799	3,551	1,293	859	118	90,622	
Male live births	42,827	1,844	702	470	63	46,369	
Female live births	40,972	1,707	591	389	55	44,253	

# West Virginia Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	11	1	12	2			
	2.3	1.8	2.2				
Trisomy 13	3	1	4				
	0.4	1.1	0.4				
Trisomy 18	9	6	15				
	1.1	6.6	1.7				
Trisomy 21 (Down syndrome)	41	21	62				
• • • •	5.0	23.2	6.8				
Total live births	81,545	9,067	90,622				

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 begin in 2013.

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

General comments *Totals include unknown and/or other.

-Data for conditions include probable cases.

# Wisconsin Birth Defects Counts and Prevalence 2011 - 2015 (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	9	3	1	1	0	14	
Anophthalmia/microphthalmia	0.4 7 0.3	1.0 1 0.3	0.3 1 0.3	0.7 0 0.0	<b>0.0</b> 0 <b>0.0</b>	<b>0.4</b> 9 <b>0.3</b>	
Anotia/microtia	13 0.6	1 0.3	6 1.9	1 0.7	2 5.7	24 0.8	
Aortic valve stenosis	15 0.7	2 <b>0.6</b>	1 0.3	1 0.7	2 5.7	21 <b>0.</b> 7	
Atrial septal defect	0.7 1,197 52.9	162 51.9	0.3 149 47.2	73 49.5	35 99.0	1,649 52.4	
Atrioventricular septal defect (Endocardial cushion defect)	41 <i>1.8</i>	8 2.6	7 2.2	5 3.4	0 <i>0.0</i>	63 <b>2.0</b>	
Biliary atresia	1 <i>0.1</i>	1 0.8	1 0.8	0 <i>0.0</i>	0 <i>0.0</i>	3 <i>0.2</i>	
Bladder exstrophy	5 0.2	0 <i>0.0</i>	1 0.3	0 <i>0.0</i>	0 <i>0.0</i>	7 0.2	
Choanal atresia	20 <b>0.9</b>	3 1.0	6 <b>1.9</b>	1 0.7	1 2.8	32 1.0	
Cleft lip alone	72 <b>3.2</b>	6 1.9	7 2.2	5 <b>3.4</b>	2 5.7	93 <b>3.0</b>	
Cleft lip with cleft palate	47 2.1	11 3.5	9 <b>2.9</b>	1 0.7	2 5.7	70 2.2	
Cleft palate alone	113 5.0	7 2.2	13 4.1	11 7.5	5 14.1	156 5.0	
Cloacal exstrophy	92 4.1	11 3.5	15 4.8	8 5.4	1 2.8	129 4.1	
Clubfoot	375 16.6	47 15.1	45 14.3	11 7.5	5 14.1	496 15.8	
Coarctation of the aorta	85 3.8	10 3.2	9 2.9	3 2.0	3 8.5	111 3.5	
Common truncus (truncus arteriosus)	3.8 7 0.3	1 0.3	1 0.3	0 0.0	0.3 1 2.8	10 0.3	
Congenital cataract	0.5 15 0.7	2 0.6	4 1.3	0 0 0.0	1 2.8	22 0.7	
Congenital posterior urethral valves	20 1.7	5 3.1	1.5 1 0.6	1 1.3	1 5.5	28 1.7	1
Deletion 22q11.2	5 0.3	0 0.0	0.0 0.0	0 0.0	0 0.0	5 0.2	
Diaphragmatic hernia	55 2.4	4 1.3	3 1.0	2 1.4	2 5.7	66 2.1	
Double outlet right ventricle	2.4 23 1.0	4 1.3	1	0	0	29	
Ebstein anomaly	14	0	<b>0.3</b> 0	0.0 0	<b>0.0</b> 0	<b>0.9</b> 15 <b>0.5</b>	
Encephalocele	<b>0.6</b> 10	0.0 3	0.0 3	0.0 2	0.0 0	21	
Esophageal atresia/tracheoesophageal	<b>0.4</b> 53	1.0 7 2.2	1.0 3	1.4 4 2.7	<b>0.0</b> 0	<b>0</b> .7 69	
fistula Gastroschisis	2.3 94	2.2 9	<b>1.0</b> 20	2.7	0.0 3	<b>2.2</b> 137	
Holoprosencephaly	<b>4.2</b> 58	<b>2.9</b> 13	6.3 8	3.4 6	<b>8.5</b> 1	<b>4.4</b> 91	
Hypoplastic left heart syndrome	<b>2.6</b> 37	4.2 5	2.5 4	<b>4.1</b> 2	2.8 3	<b>2.9</b> 51	
Hypospadias	<b>1.6</b> 884 76.2	<b>1.6</b> 89 55 0	1.3 66	1.4 27 25 2	8.5 7 29 2	<b>1.6</b> 1,097	1
Interrupted aortic arch	76.3 6 0.3	55.9 2 0.8	41.1 0 0.0	35.2 2 1.7	38.3 1 3.5	68.1 11 0.4	
Limb deficiencies (reduction defects)	69	0.0 8 2.6	8 2.5	1.7 5 3.4	1 2.8	93 3.0	
	3.1	2.0	4.3	3.4	4.0	3.0	

# Wisconsin Birth Defects Counts and Prevalence 2011 - 2015 (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
Omphalocele	39	5	3	2	0	49	
	1.7	1.6	1.0	1.4	0.0	1.6	
Pulmonary valve atresia and stenosis	100	12	12	4	4	135	
	4.4	3.8	3.8	2.7	11.3	4.3	
Pulmonary valve atresia	10	0	1	1	0	12	
	0.4	0.0	0.3	0.7	0.0	0.4	
Rectal and large intestinal	72	7	9	12	2	106	
atresia/stenosis	3.2	2.2	2.9	8.1	5.7	3.4	
Renal agenesis/hypoplasia	131	15	7	7	0	162	
	5.8	4.8	2.2	4.7	0.0	5.1	
Single ventricle	1	0	1	0	1	3	
	0.1	0.0	0.5	0.0	4.6	0.2	
Small intestinal atresia/stenosis	65	7	10	4	1	87	
	2.9	2.2	3.2	2.7	2.8	2.8	
Spina bifida without anencephalus	56	8	12	2	1	79	
T ( 1 ) C T 11 (	2.5	2.6	3.8	1.4	2.8	2.5	
Tetralogy of Fallot	56	9	9	3	0	80	
T-4-1	<b>2.5</b> 7	2.9	<b>2.9</b> 2	2.0	<b>0.0</b> 3	<b>2.5</b> 13	
Total anomalous pulmonary venous	0.4	0 <b>0.0</b>		1			
connection	<b>0.4</b> 60	<i>0.0</i> 8	<b>0.8</b> 5	<b>0.8</b> 3	10.5 0	<b>0.5</b> 81	
Transposition of the great arteries	2.7	° 2.6	, 1.6	3 2.0	0.0	2.6	
(TGA) Dextro-transposition of great arteries	32	2.0 4	1.0 4	2.0	0.0	<b>2.0</b> 46	
(d-TGA)	32 1.4	4 1.3	4 1.3	2 1.4	0.0	1.5	
Tricuspid valve atresia and stenosis	1.4	1.5	2	0	0.0	1.5	
Theuspid valve allesia and stenosis	0.8	0.4	2 0.8	0.0	0.0	0.7	
Tricuspid valve atresia	14	1	2	0	0.0	17	
Theuspid valve allesia	0.8	0.4	2 0.8	0.0	0.0	0.7	
Trisomy 13	16	2	4	1	0.0	24	
Thisonly 15	0.7	0.6	1.3	0.7	0.0	0.8	
Trisomy 18	35	5	5	3	0	51	
Thisonly 18	1.5	1.6	1.6	2.0	0.0	1.6	
Trisomy 21 (Down syndrome)	248	27	43	19	2	342	
Theory 21 (Down Synatome)	11.0	8.7	13.6	12.9	5.7	10.9	
Turner syndrome	15	0	5	2	0	22	2
	1.7	0.0	4.0	3.5	0.0	1.8	-
Ventricular septal defect	590	76	118	37	14	847	
1	26.1	24.4	37.4	25.1	39.6	26.9	
Total live births	226,229	31,189	31,562	14,747	3,537	314,632	3
Male live births	115,816	15,920	16,050	7,678	1,830	161,138	
Female live births	88,285	12,278	12,479	5,648	1,348	122,863	

# Wisconsin Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)							
Defect	Less than 35	35+	Total*	Notes			
Gastroschisis	136	1	137				
	5.0	0.2	4.4				
Trisomy 13	12	12	24				
-	0.4	2.8	0.8				
Trisomy 18	25	26	51				
	0.9	6.2	1.6				
Trisomy 21 (Down syndrome)	178	164	342				
• • • •	6.5	38.9	10.9				
Total live births	272,498	42,133	314,632	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. Total live births includes unknown gender.

# General comments

*Totals include unknown and/or other.

# Department of Defense Birth Defects Counts and Prevalence 2011 - 2015 (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	26	1	4	1	2	34	110005	
	0.7	0.1	0.5	0.3	2.0	<b>0.6</b> 94		
Anophthalmia/microphthalmia	52 1.3	21 <b>2.6</b>	12 1.6	7 2.4	1 1.0	94 1.6		
Anotia/microtia	97	10	32	14	3	158		
Aortic valve stenosis	2.4 129	<i>1.2</i> 21	<b>4.4</b> 13	<b>4.8</b> 3	<b>3.0</b> 4	<b>2.6</b> 173		
Aortic valve stenosis	3.2	2.1 2.6	13 1.8	5 1.0	4 4.0	2.9		
Atrial septal defect	4,747	1,035	873	277	87	7,171	1	
A triavantriaular contal defect	<b>119.1</b> 228	<b>129.1</b> 60	<b>120.0</b> 36	<b>95.9</b>	<b>87.3</b> 3	<i>118.5</i> 345	2	
Atrioventricular septal defect (Endocardial cushion defect)	5.7	7.5	30 <b>4.9</b>	13 <b>4.5</b>	5 3.0	545 5.7	2	
Biliary atresia	43	23	9	4	1	81		
Die dates erretus alter	1.1	2.9	1.2	1.4	1.0	<i>1.3</i> 29		
Bladder exstrophy	25 <b>0.6</b>	3 0.4	0 <i>0.0</i>	0 <b>0.0</b>	0 <b>0.0</b>	29 0.5		
Choanal atresia	103	19	21	6	4	157		
	2.6	2.4	2.9	2.1	4.0	2.6		
Cleft lip alone	278 7.0	31 <b>3.9</b>	32 <b>4.4</b>	24 <b>8.3</b>	5 <b>5.0</b>	376 <b>6.2</b>		
Cleft lip with cleft palate	309	37	52	31	9	446		
	7.8	4.6	7.1	10.7	9.0	7.4		
Cleft palate alone	465	57	80	34	11	658		
Cloacal exstrophy	11.7 322	7.1 72	11.0 52	11.8 16	11.0 5	<b>10.9</b> 479		
	8.1	9.0	7.1	5.5	5.0	7.9		
Clubfoot	875	166	137	48	13	1,264		
Coarctation of the aorta	22.0 454	<b>20.</b> 7 80	<b>18.8</b> 52	16.6 18	<i>13.0</i> 13	<b>20.9</b> 631		
	11.4	10.0	7.1	6.2	13.0	10.4		
Common truncus (truncus arteriosus)	97	12	12	5	1	131		
Congenital cataract	2.4 128	1.5 41	<b>1.6</b> 27	1.7 8	<i>1.0</i> 4	2.2 216		
Congenital catalact	3.2	5.1	3.7	° 2.8	4.0	3.6		
Congenital posterior urethral valves	78	18	7	4	2	113	3	
Curvita como esta sis	3.8	4.4	<i>1.9</i>	2.7	3.9	3.6		
Craniosynostosis	141 3.5	22 2.7	21 2.9	4 1.4	2 2.0	195 3.2		
Deletion 22q11.2	52	10	5	1	2	70		
	1.3	1.2	0.7	0.3	2.0	1.2		
Diaphragmatic hernia	184 <b>4.6</b>	48 <b>6.0</b>	37 <b>5.1</b>	14 <b>4.8</b>	5 5.0	296 <b>4.9</b>		
Double outlet right ventricle	138	36	19	8	1	206		
_	3.5	4.5	2.6	2.8	1.0	3.4		
Ebstein anomaly	63 <b>1.6</b>	10 1.2	8 1.1	5 1.7	2 2.0	90 1.5		
Encephalocele	53	8	1.1 9	1.7	2.0 1	73		
	1.3	1.0	1.2	0.3	1.0	1.2		
Esophageal atresia/tracheoesophageal	119	20	17	6	2	166		
fistula Gastroschisis	<b>3.0</b> 227	<b>2.5</b> 32	<b>2.3</b> 57	<b>2.1</b> 15	<b>2.0</b> 8	2.7 346		
	5.7	4.0	7.8	5.2	8.0	5.7		
Holoprosencephaly	269	47	32	13	8	383		
Hypoplastic left heart syndrome	<b>6.8</b> 178	<b>5.9</b> 40	<b>4.4</b> 14	<b>4.5</b> 9	<b>8.0</b> 2	<b>6.3</b> 247		
	4.5	5.0	1.9	3.1	2.0	4.1		
Hypospadias	2,444	469	304	140	58	3,484	3	
Interrupted aortic arch	<i>119.0</i> 102	<b>114.6</b> 21	<b>81.5</b> 15	<b>94.0</b> 7	<i>113.4</i> 3	<i>111.9</i> 149		
menupuu aone aten	2.6	2.6	13 2.1	2.4	3.0	2.5		

# Department of Defense Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Race/Ethnicity									
Defect	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic	Total*	Notes		
Limb deficiencies (reduction defects)	212	43	40	9	4	315			
	5.3	5.4	5.5	3.1	4.0	5.2			
Omphalocele	82	23	8	4	0	121			
	2.1	2.9	1.1	1.4	0.0	2.0			
Pulmonary valve atresia and stenosis	548	163	120	39	15	907			
	13.8	20.3	16.5	13.5	15.1	15.0			
Pulmonary valve atresia	35	13	9	4	0	62			
	0.9	1.6	1.2	1.4	0.0	1.0			
Rectal and large intestinal	241 6.0	39 <b>4.9</b>	43 5.9	22 7.6	4 4.0	354 <b>5.9</b>			
atresia/stenosis Renal agenesis/hypoplasia	281	<b>4.9</b> 60	43	20	3	<b>3.9</b> 412			
Kenai agenesis/hypopiasia	7.1	00 7.5	<b>5.9</b>	20 6.9	3.0	<b>6.8</b>			
Single ventricle	118	30	15	8	1	175			
Single ventricle	3.0	3.7	2.1	2.8	1.0	2.9			
Small intestinal atresia/stenosis	212	54	29	14	5	320			
	5.3	6.7	4.0	4.8	5.0	5.3			
Spina bifida without anencephalus	194	22	35	7	4	268			
-1	4.9	2.7	4.8	2.4	4.0	4.4			
Tetralogy of Fallot	269	49	42	29	5	401			
	6.8	6.1	5.8	10.0	5.0	6.6			
Total anomalous pulmonary venous	47	9	14	4	2	79			
connection	1.2	1.1	1.9	1.4	2.0	1.3			
Transposition of the great arteries	169	25	19	10	1	227			
(TGA)	4.2	3.1	2.6	3.5	1.0	3.8			
Dextro-transposition of great arteries	153	23	19	10	1	209			
(d-TGA)	3.8	2.9	2.6	3.5	1.0	3.5			
Tricuspid valve atresia and stenosis	66	18	12	3	0	101	4		
	1.7	2.2	1.6	1.0	0.0	1.7			
Trisomy 13	38	13	8	4	0	64			
	1.0	1.6	1.1	1.4	0.0	1.1			
Trisomy 18 Trisomy 21 (Down syndrome)	69	24	9	2	1	110			
	1.7	3.0	1.2	0.7	1.0	1.8			
	587 <b>14.7</b>	113 <b>14.1</b>	91 12.5	32 11.1	14 <b>14.0</b>	851 <b>14.1</b>			
Turner syndrome	43	14.1 7	12.5			70	5		
	43 2.2	1.8	3.1	6 <b>4.3</b>	2 <b>4.1</b>	70 2.4	5		
Ventricular septal defect	2,888	532	482	<b>4.3</b> 162	60	4,210	6		
	72.5	66.4	<b>66.3</b>	56.1	60.2	<b>69.6</b>	0		
Total live births	398,464	80,169	72,729	28,877	9,965	605,057			
Male live births	205,419	40,930	37,316	14,895	5,115	311,319			
Female live births	193,045	39,239	35,413	13,982	4,850	293,738			

# **Department of Defense** Birth Defects Counts and Prevalence 2011 - 2015 (Prevalence per 10,000 Live Births)

Maternal Age (Years)								
Defect	Less than 35	35+	Total*	Notes				
Gastroschisis	305	6	346					
	5.8	1.0	5.7					
Trisomy 13	38	25	64					
	0.7	4.2	1.1					
Trisomy 18	67	38	110					
	1.3	6.4	1.8					
Trisomy 21 (Down syndrome)	519	297	851					
	9.9	50.0	14.1					
Total live births	524,466	59,364	605,057					

# 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 include cases with tricuspid stenosis or 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 inlet ventricular septal defect and probable ventricular septal defect.

# **General comments**

*Totals include unknown and/or other.

-Criteria for a case: One diagnosis from institutional records, or 2 diagnoses from professional encounter records.

-Data for conditions exclude infants that appear as multiples of same gender are excluded from analysis.

-Data for conditions include live births only.

-Race/ethnicity for the Department of Defense Birth and Infant Health Registry is based on the military parent through whom the infant receives military health care benefits. This may be the infant's mother or father.

# STATE BIRTH DEFECTS SURVEILLANCE

# **PROGRAM DIRECTORY**

Updated September 2018

Prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Acknowledgement: State birth defects program directors provided the information for the directory. Their names can be found under the 'contact' section of each state profile.

# STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

# Alabama

#### Alabama Zika Birth Defects Surveillance Program (AZBDSP)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
 Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Centers for Disease Control and Prevention, Bureau of Communicable Disease
 Program status: Currently collecting data
 Start year: 2016

Earliest year of available data: 2016

*Organizational location:* Department of Health (Maternal and Child Health)

**Population covered annually:** 60,000 **Statewide:** Yes

*Current legislation or rule:* The Notifiable Disease Administrative Code, Chapter 420-4-1, establishes the authority for Zika virus surveillance to include Zika related birth defect surveillance. A new rule is in the process of being established to provide authority to create an Alabama Birth Defects Registry.

#### Case Definition

Outcomes covered: Zika related birth defects

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages) **Age:** Up to 24 months of age for infants that meet eligibility criteria **Residence:** State residents

#### Surveillance Methods

*Case ascertainment:* Passive case-finding with case confirmation *Vital records:* Reported by Communicable Disease *Other sources:* Calls from health care providers

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** Infants born to mother's at risk for Zika virus transmission that are approved for Zika testing, and infants born with Zika related birth defects that are reported to the program.

# 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**

Database collection and storage: Access, National Electronic Disease Surveillance System

### <u>Data Analysis</u>

Data analysis software: SAS Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Service delivery, Referral, Prevention projects

**Funding** 

Funding source: 100% CDC grant

<u>Contacts</u> Rachael Montgomery, BSN, RN Alabama Department of Public Health 201 Monroe Street Montgomery, Alabama 36104 *Phone:* 334-206-5955 *Fax:* 334-206-3791 *Email:* rachael.montgomery@adph.state.al.us

Janice Smiley, MSN Alabama Department of Public Health 201 Monroe Street Montgomery, Alabama 36104 *Phone:* 334-206-2928 Fax: 334-206-2983 *Email:* janice.smiley@adph.state.al.us

#### 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: 11,000 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 sixth 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 **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: http://www.nbdpn.org/docs/Appendix_3_1_BirthDefectsDescriptions201 5.pdf) are sampled for review. Other collected conditions/codes will are sampled and reviewed based upon incoming requests and/or need. The current report is based only on reported ICD codes. for adjusted estimates please visit

http://www.dhss.alaska.gov/dph/wcfh/Pages/mchepi/abdr/Data_Reports.a spx for condition specific reports

Coding: 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:* 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, Timeliness

Data use and analysis: Routine statistical monitoring, Rates by demographic and other variables, Time trends, 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

# <u>Other</u>

Web site:

http://www.dhss.alaska.gov/dph/wcfh/Pages/mchepi/abdr/default.aspx *Surveillance reports on file:* 

 $http://www.dhss.alaska.gov/dph/wcfh/Pages/mchepi/abdr/Data_Reports.aspx$ 

# Additional information on file:

1)http://www.dhss.alaska.gov/dph/wcfh/Documents/mchepi/abdr/Prevale nce_Estimates/SurveillanceNotes_v1.pdf 2)http://www.dhss.alaska.gov/dph/wcfh/Documents/mchepi/abdr/Prevale nce_Estimates/DataCollectionMethods_v1.pdf

# **Contacts**

Alaska Birth Defects Registry Alaska Dept. of Health and Social Services MCH-Epidemiology *Phone:* 907-269-8097 *Email:* hssbirthdefreg@alaska.gov

#### 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 (Public Health Statistics) *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

**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

*Vital records:* Birth certificates, Fetal birth certificate, Hospital Discharge Database

Delivery hospitals: Disease index or discharge index

**Pediatric & tertiary care hospitals:** Disease index or discharge index **Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities **Other sources:** Miduifery Equilities

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 prenatal 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 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 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, Observed vs. expected analyses, Epidemiologic 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

# <u>Funding</u>

Funding source: 3% General state funds, 9% MCH funds, 44% CDC grant, 44.44% Other (CDC Zika grant)

# Other

Web site: http://azdhs.gov/phs/phstats/bdr/index.htm and azhealth.gov/birth-defects 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

# Contacts

Dianna Contreras Arizona Department of Health Services 150 North 18th Avenue, Suite 550 Phoenix, AZ 85007 *Phone:* 602-542-7335 *Fax:* 602-542-7447 *Email:* dianna.contreras@azdhs.gov

Timothy J. Flood, MD Arizona Department of Health Services 150 North 18th Avenue, Suite 550 Phoenix, AZ 85007 *Phone:* 602-542-7331 *Fax:* 602-542-7447 *Email:* floodt@azdhs.gov

#### 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: 40,000 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, plus select others outside this range

**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 second birthday

Residence: In and out of state births to Arkansas residents

#### Surveillance Methods

*Case ascertainment:* Active Case Finding *Vital records:* Birth certificates

**Delivery hospitals:** Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.

**Pediatric & tertiary care hospitals:** Disease index or discharge index, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 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 prenatal 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

*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, Access, STATA

**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, Epidemiologic 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 case finding data to final birth file System integration: No.

#### Funding

Funding source: 100% General state funds

#### **Other**

Web site: http://arbirthdefectsresearch.uams.edu/ Surveillance reports on file: Online data query system available through the Arkansas Department of Health:http://www.healthy.arkansas.gov/programsServices/healthStatistic s/Pages/Statistics.aspx

# <u>Contacts</u>

Elizabeth Sellars, MD ARHMS, Section of Birth Defect Research, AR Children's Research Institute 13 Children's Way, Slot 512-22 Little Rock, AR 72202 *Phone:* 501-364-2966 *Fax:* 501-364-1564 *Email:* EASellars@uams.edu

Xiaoyi (Joy) Shan, Ph.D ARHMS, AR Children's Research Institute 13 Children's Way, Slot 512-40 Little Rock, AR 72202 *Phone:* 501-364-5034 *Fax:* 501-364-5107 *Email:* xshan@uams.edu

#### California

### California Birth Defects Monitoring Program (CBDMP)

Purpose: Surveillance, Research

Partner: Local Health Departments, Hospitals, Universities 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), 70,000 *Statewide:* No, CBDMP currently monitors a sampling 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), Elective terminations (All gestational ages) **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, 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

*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

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 elective abortions, All neonatal deaths, All prenatal 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 BPA codes but modified for use in California

# 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

*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, Validity checks are done on all abstracts

*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, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic 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 case finding data to final birth file, Hospital discharge. CBDMP links case finding data to final vital statistics fetal death files

#### <u>Funding</u>

Funding source: 100% Other (CBDMP Special Fund)

# <u>Other</u>

#### Web site:

https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/default.asp x

Surveillance reports on file: Birth defect fact sheets and California regional birth defect data available on the website. Additional information on file: Please send inquiries to gdspcbdmp@cdph.ca.gov

# **Contacts**

Valorie Eckert, MPH California Birth Defects Monitoring Program/Genetic Disease Screening ProgramCalifornia Department of Public Health 1615 Capitol Avenue Sacramento, CA 95814 *Phone:* 916-341-6674 *Fax:* 916-341-6499 *Email:* Valorie.Eckert@cdph.ca.gov

Barbara Warmerdam California Birth Defects Monitoring Program/Genetic Disease Screening ProgramCalifornia Department of Public Health 1615 Capitol Avenue Sacramento, CA 95814 *Phone:* 916-341-6677 *Fax:* 916-341-6499 *Email:* Barbara.Warmerdam@cdph.ca.gov

# 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, 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), 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 prenatal 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

#### Data Analysis

Data analysis software: SPSS, SAS, Access

*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, Epidemiologic 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:* http://www.cdc.gov/ncbddd/bd/macdp.htm *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.

# **Contacts**

Janet D. Cragan, MD, MPH Centers for Disease Control and Prevention 1600 Clifton Rd., MS E-86 Atlanta, GA 30333 *Phone:* 404-498-3807 *Fax:* 770-488-3263 *Email:* JCragan@cdc.gov

Birth Defects Research 110: S1-S177 (2018)

#### Colorado

#### Colorado Responds to Children with Special Needs Section (CRCSN)

*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

**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:* 64,386(2017)

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 with 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

Third party payers: Medicaid databases

Other specialty facilities: Cytogenetic laboratories Other sources: Physician reports

# Case Ascertainment

*Conditions warranting chart review in newborn period:* Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Selected chart reviews for prenatal to age 3 (28 conditions), minimal active case ascertainment data sources *Coding:* 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:* 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.), 99% of data are collected in electronic format *Database collection and storage:* SQL-web based

Data Analysis

*Data analysis software:* Epi-Info, SAS, Access, Arcview (GIS software) ; Maptitude, SaTScan, Centrus

*Quality assurance:* Re-abstraction of cases, Comparison/verification between multiple data sources, Timeliness, Records linkage and de-duplication

*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, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Environmental Studies

# 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: 26% General state funds, 31% Service fees, 43% CDC grant

#### <u>Other</u>

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

# **Contacts**

Margaret Frances Ruttenber, MSPH Colorado Respond to Children with Special Need Section 4300 Cherry Creek Drive, South Denver, Colorado 80246-1530 *Phone:* 303-692-2636 *Fax:* 303-691-7930 *Email:* margaret.ruttenber@state.co.us

Carol Stanton, MBA Colorado Respond to Children with Special Need Section 4300 Cherry Creek Drive, South Denver, Colorado 80246-1530 *Phone:* 303-692-2621 *Fax:* 303-691-7930 *Email:* carol.stanton@state.co.us

# 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, Environmental Agencies/Organizations, 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

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, All Zika associated birth defects as identified by the USBDS are currently rapid ascertainment (within 12 hours of being entered) and referred to the CT DPH Infectious Disease program for follow-up to see if a Zika association is connected.

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, Developmental Disabilities Surveillance

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

Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease) 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, 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: 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, Mainframe, Web based database

#### Data Analysis

Data analysis software: SAS, Access, Arc GIS Quality assurance: Validity checks, 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, Observed vs. expected analyses, Epidemiologic 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 the newborn metabolic and early hearing and detection intervention program. Vital Records imports into the Maven Newborn Screening System (NSS). This database also links with the Lead program and the Children and Youth with Special Health Care Needs program.

# Funding

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

Ot<u>her</u> Web site: http://www.ct.gov/dph/birthdefectsregistry Surveillance reports on file: NBDPN annual reports, state profiles

# **Contacts**

Karin C Davis, BS Public Health **Connecticut Department of Public Health** 410 Capitol Avenue, MS #11MAT Hartford, CT 6134 Phone: (860) 509-7499 Fax: (860) 509-7720 Email: karin.davis@ct.gov

### Delaware

# Delaware Birth Defects Registry (DBDR)

Purpose: Surveillance

Partner: Local Health Departments, Hospitals, Early Childhood
Prevention Programs, 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: 12,000
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 diseases, and infant morality.

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 week gestation and greater or greater than 350 grams.), Elective terminations (20 week gestation and greater or 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, Matched birth/death file

*Other state based registries:* Programs for children with special needs, Newborn hearing screening program, Newborn screening program, Cancer registry, AIDS/HIV registry

*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, Surgery logs, High risk pregnancy logs

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

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

Other sources: Midwifery Facilities

#### Case Ascertainment

**Conditions warranting chart review in newborn period:** Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases

*Conditions warranting chart review beyond the newborn period:* Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codable defect *Coding:* CDC coding system based on BPA, ICD-9-CM/ICD-10-CM

#### Data Collected

*Infant/fetus:* Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information *Mother:* Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

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

#### Data Collection Methods and Storage

*Data collection:* 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: Redcap

# 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, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data)

#### System Integration

System links: Link to Newborn Bloodspot and Hearing Screening.

#### **Funding**

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

# <u>Other</u>

**Web site:** http://dhss.delaware.gov/dhss/dph/chca/dphbdr1.html **Surveillance reports on file:** Analysis of the 2007 Delaware Birth Defects Registry:

 $http://dhss.\bar{d}elaware.gov/dhss/dph/chca/files/birthdefectsregistryreport200\ 7.pdf$ 

#### **Contacts**

Dana R Thompson, MPHChristiana Care Health System4735 Ogletown Stanton RoadNewark, DE 19718Phone: 302-733-5032Fax: 302-733-5044Email: Dana.Thompson@ChristianaCare.org

Purpose: Surveillance, Referral to Services Partner: Hospitals, Help Me Grow Program status: Currently collecting data Start year: 2017 Earliest year of available data: 2015 Organizational location: Department of Health (Center for Policy, Planning, and Evaluation) Population covered annually: 9300 Statewide: Yes Current legislation or rule: TBD

#### Case Definition

*Outcomes covered:* Any birth defect will be collected with focus on major birth defects

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater) **Age:** 2 years

Residence: In-state resident at birth or time of report

#### 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 *Pediatric & tertiary care hospitals:* Disease index or discharge index

Other sources: Physician reports

#### <u>Case Ascertainment</u> 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:* REDCap

#### Data Analysis

Data analysis software: SAS

*Quality assurance:* Validity checks, Comparison/verification between multiple data sources

*Data use and analysis:* Routine statistical monitoring, Baseline rates, Observed vs. expected analyses, Education/public awareness

<u>System Integration</u> System links: Link case finding data to final birth file

 Contacts

 Sarah Warner, MPH

 DC Health, Center for Policy, Planning, and Evaluation

 899 North Capitol Street, NE 6th Floor

 Washington, DC 20002

 Phone: 202-442-5843

 Fax: 202-442-8060

 Email: sarah.warner@dc.gov

Preetha Iyengar, MD DC Health, Center for Policy, Planning, and Evaluation 899 North Capitol Street, NE 6th Floor Washington, DC 20002 *Phone:* 202-442-8141 *Fax:* 202-442-8060 *Email:* preetha.iyengar@dc.gov

#### 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: 224,273 in 2015

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 week 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-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, Epidemiologic 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

# <u>Other</u>

Web site: www.fbdr.org

Surveillance reports on file: Publications, procedure manauals, electronic case ascertaintment dababase and educational materials Other comments: CDC/NCBDDD Cooperative Agreement for enhanced surveillance of selected birth defects, referral for services and prevention activities.

#### **Contacts**

Heather R. Lake-Burger, MS/MPH Florida Department of Health 4052 Bald Cypress Way, Bin A24 Tallahassee, FL 32399-1712 *Phone:* 850-245-4444, ext. 2828 *Fax:* 850-245-8250 *Email:* Heather.Lake-Burger@flhealth.gov

Melissa Murray-Jordan, MPH Florida Department of Health 4052 Bald Cypress Way, Bin A24 Tallahassee, FL 32399-1712 *Phone:* 850-245-4577 *Fax:* 850-245-8250 *Email:* Melissa.Jordan@flhealth.goMelissa.Jordan@flhealth.goV

### 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, Legislators

Program status: Program has not started collecting data

Start year: 2017

Organizational location: Department of Health

(Epidemiology/Environment)

*Population covered annually:* 129,940 live births in 2016. *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 mandate the reporting of notifiable diseases and newborn hearing screening, and Chapters 290-5-24 of the Rules of Department of Human Resources, which regulate the reporting of notifiable diseases and metabolic disorders.

Legislation year enacted: Updated in 2003.

# Case Definition

*Outcomes covered:* NBDPN core and recommended 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), Elective terminations (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:* Passive case-finding without case confirmation *Vital records:* Birth certificates, Death certificates, Fetal death certificates *Other state based registries:* Newborn hearing screening program, Newborn metabolic screening program, Zika Active Monitoring System, GBDRIS

*Delivery hospitals:* Hospital Discharge Data from Georgia hospitals. *Pediatric & tertiary care hospitals:* Hospital Discharge Data from Georgia hospitals.

*Other sources:* Metropolitan Atlanta Congenital Defects Program (MACDP)

#### Case Ascertainment

*Conditions warranting chart review in newborn period:* Zika-associated birth defects

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, 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.), Cases can be called/faxed in directly, identified through passive reporting of line lists from select birthing hospitals to our web-based reporting platform, or identified through flags on electronic birth certificates.

Database collection and storage: Oracle

# Data Analysis

Data analysis software: SAS, Microsoft Excel 2013.

**Quality assurance:** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness, As a part of Zika birth defects surveillance, we confirm all electronic birth certificates and passive line list cases through medical record review and abstraction. We will automate the quality assurance processes once the web-based birth defects registry is active.

*Data use and analysis:* Routine statistical monitoring, Public health program evaluation, Monitoring outbreaks and cluster investigations, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals

#### System Integration

*System links:* Zika Active Monitoring System (lab and clinical data); Zika Pregnancy Registry (CDC initiative)

System integration: We are in the process of building a registry for our web-based reporting platform. This registry will have the capacity to identify and link cases from flagged electronic birth certificates, hospital line lists with reported birth defect cases, cases directly called in and manually entered into the registry, and those submitted by MACDP. Subsequently, we aim to match children identified with intervention referral services (e.g. Children's Medical Services, CMS).

# **Funding**

Funding source: 100% CDC grant

# <u>Other</u>

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, or Gwinett 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) is working toward statewide reporting in 2018. We are constructing a web-based statewide birth defects registry 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 will be available upon completion of the development of the Registry. Providers interested in reporting birth defects should contact the Birth Defects Registry staff (birthdefects@dph.ga.gov) for more information.

# **Contacts**

Jerusha E. Barton, MPH Epidemiology Section, Georgia Department of Public Health 2 Peachtree St., NW, Suite 14-133 Atlanta, GA 30303 *Phone:* 404-463-0782 *Fax:* 404-463-1416 *Email:* jerusha.barton@dph.ga.gov

J. Michael Bryan, PhD, MPH Epidemiology Section, Georgia Department of Public Health 2 Peachtree St., NW, Suite 14-293 Atlanta, GA 30303 *Phone:* 404-657-2578 *Fax:* 404-463-1416 *Email:* michael.bryan@dph.ga.gov

# Hawaii

# Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance, Referral to Services

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

**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: Epidemiologic studies (using only program data)

# **Funding**

*Funding source:* 30% CDC grant, 70% Other (State of Hawaii Birth Defects Special Fund)

### <u>Other</u>

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

<u>Contacts</u> Jonathan B. Kimura, MSCP Hawaii Birth Defects Program, Hawaii State Department of Health 741 Sunset Avenue Honolulu, Hawaii 96816 *Phone:* 808-733-9065 *Fax:* 808-733-9068 *Email:* jonathan.kimura@doh.hawaii.gov

Sylvia Mann, MS, CGC Genomics Section, Hawaii State Department of Health 741 Sunset Avenue Honolulu, Hawaii 96816 *Phone:* 808-733-9063 *Fax:* 808-733-9068 *Email:* sylvia@hawaiigenetics.org

# Idaho

Program status: No surveillance program

<u>Contacts</u> Pam Harder Idaho Dept of Health & Welfare 450 West State Street Boise, ID 83720 *Phone:* 208 334-6658 *Fax:* 208-334-4946 *Email:* pam.harder@dhw.idaho.gov

Jacquie Watson Childrens Special Health Program, Idaho Department of Health and Welfare 450 West State Street Boise, ID 83720 *Phone:* 208-334-5963 *Fax:* 208-334-4946 *Email:* jacquie.watson@dhw.idaho.gov

#### 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 Program status: Currently collecting data Start year: 1986 Earliest year of available data: 1989 Organizational location: Department of Health (Epidemiology/Environment) Population covered annually: 155,000 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 2008

#### **Case Definition**

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, or the family chose to hold a funeral) 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 hearing screening program, Newborn metabolic screening program, Hospital discharge data Delivery hospitals: Discharge summaries, Reporting from all hospital nurseries

Pediatric & tertiary care hospitals: Discharge summaries, Reporting from all 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 prenatal diagnosed or suspected cases, APORS collects and refers cases of neonatal deaths, infants with gestational age less than 31 weeks, infants with prenatal drug exposure (excluding marijuana), serious congenital infections, endocrine, metabolic and immune disorders, hemoglobinopathies, coagulation defects, leukemia, intrauterine growth restriction, seizures, conditions leading to more than 72 hours on a ventilator, and selected other conditions. Only charts of infants identified with selected birth defects are reviewed.

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 filled out by staff at facility (laptop, web-based, 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, Epidemiologic 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

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: 52% General state funds, 42% CDC grant

### 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 2005-2009Trends in the Prevalence of Birth Defects in Illinois and Chicago 2002-2014

Additional information on file: QC reports, fact sheets

**Contacts** Jane Fornoff, MA, MSC, DPhil **Illinois Department of Public Health** 535 W Jefferson St, Fl 3 Springfield, IL 62761 Phone: 217-785-7133 Fax: 217-524-1770 Email: jane.fornoff@illinois.gov

Teifu Shen, Shen Illinois Department of Public Health 535 W Jefferson St, Fl 3 Springfield, IL 62761 Phone: 217-785-1873 Fax: 217-524-1770 Email: teifu.shen@illinois.gov

#### Indiana

#### Indiana Birth Defects & Problems Registry (IBDPR)

*Purpose:* Surveillance, Per statute research and referrals should be completed, however, due to limitations those processes are currently on hold.

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: 85,000

Statewide: Yes Current legislation or rule: IC 16-38-4-7Rule 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, congenital blood disorders, and certain eye 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.) **Age:** Up to 5 years (FAS); all individuals with Autism Spectrum

Disorders; up to 3 years for all other birth defects

**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, Matched birth/death file

*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:* Any infant with a codable defect

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

# 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

Quality assurance: Data/hospital audits

*Data use and analysis:* Due to systemic limitations and lack of confidence, birth defect data is not currently used for programmatic needs. Following a data system rebuild, we strive to perform biosurveillance and population health awareness activities, individual patient referrals to services, and drive programmatic decisions regarding perinatal health and infant mortality.

### 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). However, data sharing is limited to demographics.

*System integration:* The database is linked with birth, death, newborn hearing screening, newborn metabolic and pulse oximetry screening data.

# <u>Funding</u>

Funding source: 20% Service fees, 80% CDC grant

# **Other**

Web site: www.birthdefects.in.gov Surveillance reports on file: Indiana's IBDPR Rule (410 IAC 21-3), Progress Report to the Indiana Legislature, and most recent statistics from IBDPR

Other comments: Our website is being updated

<u>Contacts</u> Allison Forkner, MPH Indiana State Department of Health 2 North Meridian Street, 2E Indianapolis, IN 46204 *Phone:* 317-233-7848 *Fax:* 317-234-2995 *Email:* AForkner@isdh.in.gov

Megan Griffie, PhD, MS Indiana State Department of Health 2 North Meridian St, 2E Indianapolis, IN 46204 *Phone:* 317-233-1231 *Fax:* 317-234-2995 *Email:* MGriffie@isdh.IN.gov

# STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

#### 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:* 39,014 average live births per year (2011-2015)

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 prenatal 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, Epidemiologic 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

#### <u>Other</u>

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

<u>Contacts</u> Paul A. Romitti, Ph.D. Iowa Registry for Congenital and Inherited Disorders UI Research Park 201 IREH Iowa City, IA 52242-5000 *Phone:* 319-384-1549 *Fax:* 319-353-4095 *Email:* paul-romitti@uiowa.edu

Carrie J. Fall, B.A.S. Iowa Registry for Congenital and Inherited Disorders UI Research Park 201 IREH Iowa City, IA 52242-5000 *Phone:* 319-335-4511 *Fax:* 319-335-4030 *Email:* carrie-fall@uiowa.edu

#### 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:* 38,048

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 of Vital Statistics. Live births and stillbirths (fetal deaths) information are used 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 without 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, Kansas Health Information Network

#### Case Ascertainment

*Conditions warranting chart review in newborn period:* Currently only Zika virus related birth defects *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.), 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, Kansas Health Information 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 and stillbirth (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 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:** 25% MCH funds, 75% Other (CDC-RFA-DD16-1605: "Surveillance, intervention, and referral to services activities for infants with microcephaly and other adverse outcomes linked with the Zika virus.")

#### <u>Other</u>

Web site: http://www.kdheks.gov/bfh/birth_defects.htm

# **Contacts**

Jamie S. Kim, MPH Kansas Department of Health and Environment 1000 SW Jackson, Suite 220 Topeka, Kansas 66612-1274 *Phone:* 785-296-6467 *Fax:* 785-296-6553 *Email:* Jamie.Kim@ks.gov

Heather Smith, MPH Kansas Department of Health and Environment 1000 SW Jackson, Suite 220 Topeka, Kansas 66612-1274 *Phone:* 785-296-4747 *Fax:* 785-296-6553 *Email:* Heather.Smith@ks.gov

#### Kentucky

#### Kentucky Birth Surveillance Registry (KBSR)

*Purpose:* Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services *Partner:* Local Health Departments, Hospitals, 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:* 2002

#### 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-9 codes:• All congenital anomalies codes - 740-759• Dwarfism not elsewhere classified - 259.4.• Metabolic/storage disorders - 270-279, Excluding codes 274, 276 and 278.• Hereditary hemolytic anemia - 282.• Neurologic disorders of brain and spinal cord - 334-335.• Cerebral palsy - 343.• Teratogens (noxious influences) - 760.7 and all subcategories, from 760.70 to 760.79.• Infant of diabetic mother - 775.0.• Failure to thrive - 783.4.• Small for gestational age - 764.0• Neonatal Abstinence Syndrome – 760.79• Fetal Alcohol Syndrome – 760.71

**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

*Delivery hospitals:* Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics

*Pediatric & tertiary care hospitals:* Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Laboratory logs, Specialty outpatient clinics

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 prenatal diagnosed or suspected cases

*Conditions warranting chart review beyond the newborn period:* Any infant with a codable defect

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 *Faher:* 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, Monitoring outbreaks and cluster investigations, Time trends, Epidemiologic 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 surveillance system are incorporated into KBSR.

# **Funding**

Funding source: 100% CDC grant

# 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

### <u>Contacts</u>

Monica L Clouse, MPH Kentucky Department for Public Health 275 E Main St Frankfort, KY 40601 *Phone:* 502-564-4830 *Email:* monica.clouse@ky.gov

# 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 (LDH/OPH/CCPH/BFH/Title V CYSHCN Programs)
Population covered annually: 62,000
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 including CDC recommended conditions associated with Congenital Zika Syndrome.

**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) **Age:** Up to third birthday except for Zika which is up to 12 months **Residence:** In and out of state births to state residents

#### 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

*Delivery hospitals:* Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts

**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), Any chart with selected ICD-10 Q00-Q99 codes, N13.1-N13.4; E78.71-E78.72; H90.0-91.9 *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.), complexity, and the set of the s

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 built 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, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, 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 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 GrantState Matching Funds)

# <u>Other</u>

Web site: www.dhh.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; 2013 Annual NBDPN Data Report; Presentations of analysis using 2006-2008 data concerning ASD Reporting; Cleft Lip/Palate and Hearing Loss;

# **Contacts**

Dionka C Pierce, MPH LDH/OPH/CCPH/BFH/CSHS/LBDMNRoom 2060 1450 Poydras St., Ste 1950 New Orleans, LA 70112 *Phone:* 504-568-5629 *Fax:* 504-568-7529 *Email:* Dionka.Pierce@la.gov

Julie A Johnston, BS LDH/OPH/CCPH/BFH/LBDMN PO BOX 60630 New Orleans, LA 70160-0630 Phone: 225-342-2017 Email: Julie.Johnston@la.gov

#### 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 (Division of Population Health/MCH Unit/CSHN)
 Population covered annually: 12,593

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 prenatal diagnosed or suspected cases

*Conditions warranting chart review beyond the newborn period:* Cardiovascular condition, Any infant with a codable defect *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.), 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

#### <u>Data Analysis</u>

Data analysis software: SAS, Stat-exact

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, Epidemiologic 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-def ects/index.html

<u>Contacts</u> Patricia Williams Department of Health & Human Services 11 State House Station, 286 Water St. 7th floor Augusta, ME 4333 *Phone:* 207-287-4802 *Fax:* 207-287-5355 *Email:* Patricia.Williams@maine.gov

Diane Haberman, MSW, LCSW Department of Health & Human Services 11 State House Station, 286 Water St. 7th floor Augusta, ME 4333 *Phone:* 207-287-8424 *Fax:* 207-287-5355 *Email:* Diane.Haberman@maine.gov

# Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

Purpose: Surveillance, Referral to Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1984
Organizational location: Department of Health (Epidemiology/Environment, Prevention and Health Promotion Administration)
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, Beginning active case finding July 2018.

*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-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

# <u>Other</u>

Web site: http://phpa.dhmh.maryland.gov/genetics/SitePages/bdris.aspx Surveillance reports on file: All reports submitted to CDC

<u>Contacts</u> Monika Piccardi, RN, BSN Maryland Dept. of Health 201 W. Preston Street, Room 423 N Baltimore, MD 21201 *Phone:* 410-767-6737 *Fax:* 443-333-7956 *Email:* monika.piccardi@maryland.gov

Jed Miller, MD Maryland Dept. of Health 201 W. Preston Street, Room 423 Baltimore, MD 21201 *Phone:* 410-767-5642 *Fax:* 443-333-7956 *Email:* Jed.miller1@maryland.gov

# 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: 72,000

# 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), 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, Matched birth/death file, Fetal death certificate

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.),

Other sources: Accepting physician reports 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 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:* All infant deaths (excluding prematurity), Any infant with a codable defect *Coding:* CDC coding system based on BPA, ICD=9=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:** Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.) **Database collection and storage:** Microsoft (MS) Access

#### Data Analysis

**Data analysis software:** SAS, MS Access, MS 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, Epidemiologic studies (using 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 and final fetal death file. System integration: Link birth defects data to MDPH Pregnancy to Early Life Longitudinal (PELL) data system.

# Funding

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

#### . .

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

# **Contacts**

Mahsa M. Yazdy, PhD, MPHMassachusetts Department of Public Health, Bureau of FamilyHealth and Nutrition250 Washington Street, 5th floorBoston, MA 2108Phone: 617-624-6045Fax: 617-624-5574Email: mahsa.yazdy@state.ma.us

Cathleen A. Higgins, BA Massachusetts Department of Public Health, Bureau of Family Health and Nutrition 250 Washington Street, 5th floor Boston, MA 2108 *Phone:* 617-624-5510 *Fax:* 617-624-5574 *Email:* cathleen.higgins@state.ma.us

# 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, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Outpatient Pediatrics clinics for HL7 reporting pilot 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: 115,000

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 without case confirmation *Vital records:* Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, Fetal deaths since 2004 only

*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 specially 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:* 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.) *Database collection and storage:* FoxPro

# 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, Epidemiologic 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

*System integration:* No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

# <u>Funding</u>

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

#### <u>Other</u> Web site:

http://www.michigan.gov/mdch/0,1607,7-132-2944_4670---,00.html Additional information on file: Http://www.michigan.gov/mdch/0,1607,7-132-2945_5221-16665--,00.ht ml

# **Contacts**

Georgetta Alverson Michigan Birth Defects Registry 333 S. Grand Ave. Lansing, MI 48933 *Phone:* 517-335-8855 *Fax:* 517-335-8711 *Email:* alversong@michigan.gov

Lorrie Kay Simmons, RHIT Michigan Department of Community Health 333 S. Grand Ave. Lansing, MI 48933 *Phone:* 517-335-9197 *Fax:* 517-335-8711 *Email:* simmonsI@michigan.gov

#### 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:* No, Currently covering about 97% of live births in MN. Statewide surveillance is expected to be completed by the end of 2018. Coverage is complete for smaller regions of the state. Prevalence estimates from 2006-2010 are available for the two largest counties in Minnesota, Hennepin and Ramsey counties, which account for just over 40% of MN births.

*Current legislation or rule:* MS 144.2215-2219 *Legislation year enacted:* 2004

# Case Definition

*Outcomes covered:* 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) *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

*Other state based registries:* 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:* Statewide de-identified hospital discharge dataset; 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, Any chart with an ICD10 Q00-Q99; All deaths prior to age 2 with a birth defect indicated as cause of death on death certificates, starting with 2009 births *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.), etc.)

*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 in some reporting facilities

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, Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, 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 the 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 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 CCHD Screening program takes place in 2017 as universal newborn CCHD screening is implemented.

# **Funding**

Funding source: 90% General state funds, 10% CDC grant

#### <u>Other</u> Web site:

http://www.health.state.mn.us/divs/cfh/program/cyshn/bdmaintro.cfm

<u>Contacts</u> Sook Ja Cho, PhD, MPH, BSN Minnesota Department of Health 85 East 7th Place, PO Box 64882 St. Paul, MN 55164 *Phone:* 651-201-4931 *Fax:* 651-201-3590 *Email:* sook.ja.cho@state.mn.us

Barbara Frohnert, MPH Minnesota Department of Health 85 East 7th Place, PO Box 64882 St. Paul, MN 55164 *Phone:* 651-201-5953 *Fax:* 651-201-3590 *Email:* barbara.frohnert@state.mn.us

# Mississippi

# Mississippi Birth Defects Surveillance Registry

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, Active case-finding for Zika related birth defects

*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

*Conditions warranting chart review in newborn period:* Zika related birth defects

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.), 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:* Access, New web based program (in development)

# Data Analysis

Data analysis software: SPSS, SAS, Access Quality assurance: Validity checks, 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, Epidemiologic studies (using only program data), Referral, Education/public awareness

# System Integration

*System links:* Link case finding data to final birth file, Newborn Screening ProgramNewborn screening program database and Early Hearing program database

# Funding

Funding source: 100% Genetic screening revenues

# Other

Web site: www.HealthyMS.com

#### **Contacts**

Alyce L. Stewart, DrPH, MPH, MCHESMississippi State Department of Health570 East Woodrow Wilson AveJackson, Mississippi 39215-1700Phone: 601 576-7619Fax: 601 576-7498Email: alyce.stewart@msdh.ms.gov

Ninglong Han, MS Mississippi State Department of Health 570 East Woodrow Wilson Ave Jackson, Mississippi 39215-1700 Phone: 601 576-8165 Fax: 601 576-8168 Email: ninglong.han@msdh.ms.gov

# 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: 76,000 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 summariesPediatric logs *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, Missouri is currently using CDC/NCBDD grant to abstract birth defects *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, Prenatal care, Pregnancy/delivery complications, Barnly 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

# <u>Data Analysis</u>

# Data analysis software: SAS

*Quality assurance:* Validity checksDouble-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, Education/public awareness

#### System Integration

System links: Link case finding data to final birth file

#### Funding

Funding source: 100% MCH funds

#### <u>Other</u>

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

#### **Contacts**

Loise Wambuguh, PhD Missouri Dept of Health, Bureau of Vital Statistics

#### PO Box 570, 920 Wildwood Drive Jefferson City, MO 65102 Phone: 573-751-6343 Fax: 573-526-4102 Email: loise.wambuguh@health.mo.gov

Elizabeth McCarthy, MS Missouri Dept of Health, Bureau of Vital Statistics PO Box 570, 920 Wildwood Drive Jefferson City, MO 65102 *Phone:* 573-751-6078 *Fax:* 573-526-4102 *Email:* Elizabeth.McCarthy@health.mo.gov

# Montana

### Montana Birth Outcomes Monitoring System (MBOMS)

Program status: No surveillance program Start year: 1999 Earliest year of available data: 2000 Organizational location: Department of Health (Maternal and Child Health) Population covered annually: 12,000 Current legislation or rule: None

# Case Definition

Outcomes covered: Major structural birth defects, chromosomal anomalies specified in the CDC 45 reportables for births occurring in calendar years 200 through 2004. Registry suspended beginning with calendar year 2005 births due to loss of CDC funding.

<u>Contacts</u> Rachel Donahoe Montana Dept. of Public Health and Human Services PO Box 202951 Helena, MT 59620 Phone: 406-444-3617 Fax: 406-444-2750 Email: rdonahoe@mt.gov

#### 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 (Vital Statistics, Office of Epidemiology and Informatics)
Population covered annually: 27,000
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 birth certificate with a birth defect box checked *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.), 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

#### <u>Data Analysis</u>

**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

#### <u>Other</u> Web site:

http://dhhs.ne.gov/publichealth/Pages/vitalrecords_partners.aspx Surveillance reports on file: Http://dhhs.ne.gov/publichealth/Pages/ced_vs.aspx

Fax: 402-742-2388

<u>Contacts</u> Ming Qu NE Department of Health & Human Services 301 Centennial Mall South Lincoln, NE 68509 *Phone:* 402-471-0566 Fax: 402-471-1371 *Email:* Ming.Qu@nebraska.gov

Nila Irwin NE Department of Health & Human Services 1033 O St Suite 130 Lincoln, NE 68509

Phone: 402-471-0354

Email: Nila.Irwin@nebraska.gov

#### Nevada

#### Nevada Birth Outcomes Monitoring System (NBOMS)

Purpose: Surveillance, Research

*Partner:* Hospitals, Early Childhood Prevention Programs, Legislators, Nevada Bureau of Child, Family & Community Wellness, Nevada Division of Public and Behavioral Health *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:* 35,658

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 (Other gestational birth age and/or birth weight criterion), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (20 weeks gestation and greater)

Age: Birth to 7 years of age **Residence:** In-state births

# Surveillance Methods

*Case ascertainment:* 2011-2013 data combination of active & passive, Population-based, Hospital-based. 2014 and subsequent data passive data collection (hospital discharge data).

*Vital records:* Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, hospital medical records, diagnostic/laboratory reports

*Other state based registries:* Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry

*Delivery hospitals:* Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

Other specialty facilities: Genetic counseling/clinic 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 birth certificate with a birth defect box checked *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, Any infant with a codable defect *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.), Illnesses/conditions,

Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history *Father:* Identification information (name, address, date-of-birth, etc.),

*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, 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:** 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, Epidemiologic 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

# <u>Funding</u>

Funding source: 70% MCH funds, 30% CDC grant

# <u>Other</u>

Surveillance reports on file: Http://dpbh.nv.gov/Programs/NBOMS/dta/Publications/Nevada_Birth_O utcomes_Monitoring_System_%28NBOMS%29_-_Publications/

# Contacts

Jie Zhang, MS Nevada Birth Outcomes Monitoring System, Office of Public Health Informatics and Epidemiology (OPHIE), Division of Public and Behavioral Health, Department of Health and Human Services 4126 Technology Way, Suite 200 Carson City, NV 89706 *Phone:* 775-684-5933 *Email:* jzhang@health.nv.gov

Kyra Morgan, MS

Director's Office, Nevada Department of Health and Human Services 4126 Technology Way, Suite 200 Carson City, NV 89706 *Phone:* 775-684-4161 *Email:* kmorgan@health.nv.gov

# **New Hampshire**

#### New Hampshire Zika Birth Conditions Program

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Universities, Legislators
Program status: Currently collecting data
Start year: 2016 Zika only
Earliest year of available data: 2016 Zika only
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

*Outcomes covered:* Zika related birth defects *Pregnancy outcome:* Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages) *Age:* Up to one year after delivery *Residence:* In-state birth to state resident

#### Surveillance Methods

Case ascertainment: Active Case Finding Vital records: Birth certificates, Death certificates Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Developmental Disabilities Surveillance, Bureau of Infectious Disease Control 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, Postmortem/pathology logs, Surgery logs, Laboratory logs, Specialty outpatient clinics **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, All stillborn infants

*Conditions warranting chart review beyond the newborn period:* CNS condition (e.g. seizure) *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:* Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history *Father:* Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions

# Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff Database collection and storage: None at this time

#### Data Analysis

Data analysis software: SPSS Quality assurance: Double-checking of assigned codes, Comparison/verification between multiple data sources Data use and analysis: Monitoring outbreaks and cluster investigations, Referral

# Funding

Funding source: 100% CDC grant

#### **Contacts**

Suzann Beauregard, Registered Nurse Maternal and Child Health Section, Division of Public Health Services, New Hampshire Department of Health and Human Services 29 Hazen Drive Concord, NH 3301 *Phone:* 603-271-4521 *Email:* Suzann.Beauregard@dhhs.nh.gov

Paulette Valliere, MPH Maternal and Child Health Section, Division of Public Health Services, New Hampshire Department of Health and Human Services 29 Hazen Drive Concord, NH 3301 *Phone:* 603-271-4587 *Email:* Paulette.Valliere@dhhs.nh.gov

### 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 (Family Health Services/Special Child Health and Early Intervention Services) Population covered annually: 103,000

# Statewide: Yes

Current legislation or rule: NJSA 26:8-40.2 et seq., NJAC 8:20 -Ammended: 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, and severe hyperbillirubinemia >25, are required 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 required.

Pregnancy outcome: Livebirths (All gestational ages and birth weights) 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: combination of active & passive, Population-based, with annual audits

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, Autism Registry

Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, Quality assurance visit 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 visit 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-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 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: Mainframe, 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, Epidemiologic 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. Autism Registry is included in the 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

# <u>Other</u>

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

# Contacts

Mary M. Knapp, MSN, RN New Jersey Department of Health, Special Child Health and Early Intervention Services, Early Identification & Monitoring Program PO Box 364 Trenton, NJ 8625 Phone: 609-292-5676 Fax: 609-292-8235 Email: Mary.Knapp@doh.nj.gov

# 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: 28,000

# 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:** 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., 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

*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.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information

*Mother:* Identification information (name, address, date-of-birth, etc.), Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, 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:** Stata, version 13.1

#### Data Analysis

Data analysis software: 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

# Funding

Funding source: 100% CDC grant

# <u>Other</u>

Web site:

https://nmtracking.org/en/health_effects/birthdefects/about_birthdefects/

Contacts

Heidi R Krapfl, MSNM Department of Health, Epidemiology and Response Division1190 St. Francis Drive, Suite N1304Santa Fe, NM 87505Phone: 505-476-3577Fax: 505-827-0013Email: heidi.krapfl@state.nm.us

# **New York**

New York State Congenital Malformations Registry (CMR)

Purpose: Surveillance, Research, Public health education
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: 240,000
Statewide: Yes
Current legislation or rule: Public Health Law Article 2, Title II, Section

*Current legislation or rule:* Public Health Law Article 2, 1itle 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. (20 weeks gestation and greater), Elective terminations (All gestational ages, Applies to active surveillance studies)

*Age:* As of 5/25/16: 10 years for heart defects, muscular dystrophy, genetic conditions, FAS; 2 years for all other defects

**Residence:** In-state and out-of-state births to state residents; in-state births to non-residents; all children born in or residing in New York

# Surveillance Methods

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

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, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, MFM practices in regions where active surveillance is conducted.

*Pediatric & tertiary care hospitals:* Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, 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, All stillborn infants, All prenatal diagnosed or suspected cases, Ascertainment of stillbirths and prenatally diagnosed cases applies to special studies

Conditions warranting chart review beyond the newborn period: Any infant with a codable defect

*Coding:* CDC coding system based on BPA, ICD-9-CM prior to 1992; both ICD-9-CM and ICD-10-CM from September 2015; Only ICD-10-CM from 2016

# **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.), Illnesses/conditions *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, 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, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness

# **Funding**

*Funding source:* 14% General state funds, 8% MCH funds, 9% CDC grant, 69% Other (State Superfund, Other)

# **Other**

Web site: http://www.health.ny.gov/birthdefects Surveillance reports on file: Reports for 1983 - 2008 births

# **Contacts**

Michele Herdt, PhD New York State Department of Health Empire State Plaza, Corning Tower, Room 1203 Albany, NY 12237 Phone: 518-402-7996 Fax: 518-402-7959 Email: michele.herdt@health.ny.gov

Marilyn L. Browne, PhD

New York State Department of Health Empire State Plaza, Corning Tower, Room 1203 Albany, NY 12237 *Phone:* 518-402-7990 *Fax:* 518-402-7959 *Email:* marilyn.browne@health.ny.gov

# 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, Communicable disease programs; State Laboratory for Public Health 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: 121,000 Statewide: Yes Current legislation or rule: NCGS 130A-131 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, 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: Positive pulse oximetry screening database

# 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 prenatal 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, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Epidemiologic 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 case finding data to final birth file, Link to environmental databases, Early Intervention Program

#### Other

Web site: http://www.schs.state.nc.us/units/bdmp/

# **Contacts**

Nina E. Forestieri, MPH State Center for Health Statistics 222 N. Dawson St. Raleigh, NC 27603 Phone: 919-733-4728 Fax: 919-733-8485 Email: nina.forestieri@dhhs.nc.gov

Jennifer Stock State Center for Health Statistics 222 N. Dawson St. Raleigh, NC 27603 Phone: 919-733-4728 Fax: 919-733-8485 Email: jennifer.stock@dhhs.nc.gov

# North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

Purpose: Surveillance

Partner: Advocacy Groups, Division of Special Health Services. Program status: Currently collecting data Start year: 2002

#### Earliest year of available data: 1994

*Organizational location:* Department of Health (Maternal and Child Health, Vital Statistics, Office of the State Epidemiologist.) *Population covered annually:* 10,738-This data is for CY 2017. *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 (Other gestational birth age and/or birth weight criterion), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: 12 months or within the year of birth.

Residence: In-state birth/s to state resident.

# 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 Pediatric & tertiary care hospitals: Specialty outpatient clinics 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)

Coding: ICD-10-CM

# Data Collected

*Infant/fetus:* 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:* 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, Excel and SPSS

#### Data Analysis

#### Data analysis software: SPSS, Access

Quality assurance: Validity checks, 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, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

#### Funding

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

# <u>Other</u>

Web site: http://www.ndhealth.gov/cshs/ Surveillance reports on file: North Dakota Birth Defects Monitoring System Summary Report 2001-2005North Dakota Birth Defects Monitoring System Summary Report 1995-1999

# **Contacts**

Devaiah Muthappa Muccatira, MS Office of the State Epidemiologist 600 East Boulevard Avenue, Dept.301 Bismarck, North Dakota 58505-200 Phone: 701-328-4963 Fax: 701-328-1645 Email: dmuccatira@nd.gov

Tamara Lynn Lelm, RN, MPH Division of Special Health Services, North Dakota Department of Health 600 East Boulevard Avenue, Dept.301 Bismarck, North Dakota 58505-200 Phone: 701-328-4814 Fax: 701-328-1645 Email: tlelm@nd.gov

#### 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, Ohio Collaborative to Prevent Infant Mortality, ODH Office of Health Preparedness, ODH Bureau of Infectious Diseases

Program status: Currently collecting data

Start year: 2006

Earliest year of available data: 2008

*Organizational location:* Department of Health (Maternal and Child Health)

Population covered annually: 138,000

# 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; Zika-related birth defects; 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, Active case finding for Zika-related birth defects until April, 2018; passive case-finding with diagnostic validation for certain disorders; Passive case finding only for all other disorders

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 *Coding:* 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: SQL server

#### <u>Data Analysis</u>

Data analysis software: SAS, Access, 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, Observed vs. expected analyses, 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.

#### <u>Funding</u>

Funding source: 100% MCH funds

#### <u>Other</u> Web site:

http://www.odh.ohio.gov/odhprograms/cmh/bdefects/birthdefects1.aspx Surveillance reports on file: 2012 Annual Report Additional information on file: OCCSN data system user guide for 1) reporting hospitals; 2) case abstractors; and 3) Hospital contacts for Zika-related birth defects

**Contacts** 

Kirstan Duckett, MPH Ohio Department of Health 246 N. High Street Columbus, OH 43215 *Phone:* 614-728-2427 *Fax:* 614-564-2504 *Email:* Kirstan.Duckett@odh.ohio.gov

Anna Starr, BS Ohio Department of Health 246 N. High Street Columbus, OH 43215 *Phone:* 614-995-5333 *Fax:* 614-564-2504 *Email:* Anna.Starr@odh.ohio.gov

#### Oklahoma

#### Oklahoma Birth Defect 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

*Organizational location:* Department of Health (Screening and Special Services)

**Population covered annually:** 53,000 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

*Other state based registries:* 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 prenatal 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 Database collection and storage: Access

#### <u>Data Analysis</u>

Data analysis software: SAS, Access, ArcGIS 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, Referral, Education/public awareness, Prevention projects

# System Integration

System links: Link to other state registries/databases

#### **Funding**

Funding source: 57% MCH funds, 43% CDC grant

#### Other Web site:

https://www.ok.gov/health/Community_&_Family_Health/Screening_&_ Special_Services/Oklahoma_Birth_Defects_Registry/index.html *Surveillance reports on file:* Yes

# **Contacts**

Lisa R Caton, MS, RN Oklahoma State Department of Health 1000 NE 10th St, Room 709 Oklahoma City, OK 73117 *Phone:* 405-271-6617 *Fax:* 405-271-4892 *Email:* lisarc@health.ok.gov

Linsay Denson, MS, RDMS Oklahoma State Department of Health 1000 NE 10th St, Room 710 Oklahoma City, OK 73117 *Phone:* 405-271-6617 *Fax:* 405-271-4892 *Email:* LindsayXD@health.ok.gov

# Oregon

# Oregon Birth Anomalies Surveillance System (BASS)

# Purpose: Surveillance

Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, 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: 45,000 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-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.), *Father:* Identification information (name, address, date-of-birth, etc.),

# Data Collection Methods and Storage

Demographic information (race/ethnicity, sex, etc.)

**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:** Access, SQL/SPSS

#### 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, Grant proposals, Education/public awareness

#### System Integration

System links: Oregon Environmental Public Health Tracking System

# Funding

Funding source: 50% MCH funds, 50% CDC grant

# <u>Other</u>

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

**Contacts** 

Vivian Siu, MPH, MURP Maternal and Child Health Section, Center for Prevention and Health Promotion, Oregon Public Health Division. Oregon Health Authority 800 NE Oregon St, Suite 825 Portland, OR 97232 Phone: 971-673-0244 Email: vivian.w.siu@state.or.us

Suzanne B Zane, DVM, MPH Maternal and Child Health Section, Center for Prevention and Health Promotion, Oregon Public Health Division. Oregon Health Authority 800 NE Oregon St, Suite 850 Portland, OR 97232 *Phone:* 971-673-0559 *Email:* suzanne.zane@state.or.us

#### Pennsylvania

### Pennsylvania Birth Defects Surveillance Program (PA-BDSP)

 Purpose:
 Surveillance of Zika-related birth defects only

 Partner:
 Local Health Departments, Hospitals, Environmental

 Agencies/Organizations, Advocacy Groups, Universities, Early

 Childhood Prevention Programs

 Program status:
 Currently collecting data

 Start year:
 2017

 Earliest year of available data:
 2016 (Zika-related birth defects only)

 Organizational location:
 Department of Health

 (Epidemiology/Environment)
 Population covered annually:

 Population covered annually:
 117,895

 Statewide:
 No, Excludes Philadelphia City/County

 Current legislation or rule:
 None

# Case Definition

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (After 18 weeks gestation) **Age:** 1 year **Residence:** In-state birth to state resident

<u>Surveillance Methods</u>

Case ascertainment: Passive case-finding with case confirmation Vital records: Birth certificates, Death certificates, Fetal birth certificate 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:* ICD-10 CM code for Zika-related birth defects

Conditions warranting chart review beyond the newborn period: Any infant with a codable defect 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

#### **Data Collection Methods and Storage**

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

#### <u>Data Analysis</u>

Data analysis software: SAS Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Timeliness Data use and analysis: Baseline rates, CDC cooperative agreement

<u>System Integration</u> System links: Link case finding data to final birth file

<u>Funding</u> Funding source: 100% CDC grant

<u>Contacts</u> Sharon Watkins, PhD PA Department of Health, Bureau of Epidemiology 625 Forster Street, Health & Welfare Bldg. 9th Floor East Harrisburg, PA 17120 *Phone:* 717-787-3350 *Email:* shawatkins@pa.gov

# Puerto Rico

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

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Community Nursing Services, 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: 30,000
Statewide: Yes
Current legislation or rule: Law #351
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, 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. Birth Defects potentially related to Zika virus covered: congenital hearing loss ( unilateral or bilateral) congenital hip dislocation with associated brain anomalies, arthrogryposis, eye anomalies( coloboma; congenital cataract; chorioretinal atrophy, scarring and pigmentary changes; intraocular calcifications; optic nerve abnormalities) and brain abnormalities with and without microcephaly( intracranial calcifications; cerebral/cortical atrophy; abnormal cortical gyral patterns; corpus callosum abnormalities; porencephaly; hydranencephaly; fetal brain disruption sequence; other mayor brain abnormalities).

**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:** 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 *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

*Third party payers:* Medicaid databases, Health Maintenance organizations (HMOs)

*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 neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases

*Conditions warranting chart review beyond the newborn period:* Facial dysmorphism or abnormal facies, Cardiovascular condition, Ocular conditions, Auditory/hearing 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 *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, Access, 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: 51.4% MCH funds, 48.6% CDC grant

<u>Contacts</u> Carla P Espinet, MPH Puerto Rico Department of Health PO Box 70184 San Juan, PR 936 *Phone:* 787-765-2929 x4571 *Email:* carlaespinet@salud.pr.gov

Miguel Valencia, MD Puerto Rico Department of Health PO Box 70184 San Juan, PR 936 *Phone:* 787-765-2929 x4572 *Email:* mvalencia@salud.pr.gov

# **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: Voc

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 prenatal 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-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, Epidemiologic 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

# <u>Funding</u>

Funding source: 5% General state funds, 10% MCH funds, 85% CDC grant

# <u>Other</u>

Web site: www.health.ri.gov/programs/birthdefects Surveillance reports on file: 2016 Rhode Island Birth Defects Data Book

# **Contacts**

Samara Viner-Brown, MS Rhode Island Department of Health 3 Capitol HI Providence, RI 2908 *Phone:* (401)222-5122 *Email:* samara.vinerbrown@health.ri.gov

Kristen St. John, MPH Rhode Island Department of Health 3 Capitol HI Providence, RI 2908 *Phone:* (401)222-5123 *Email:* Kristen.stjohn@health.ri.gov

# South Carolina

South Carolina Birth Defects Program (SCBDP)

**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, Greenwood Genetics Center (GGC) *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 (Health Improvement and Equity)

Population covered annually: 58,135

Statewide: Yes

*Current legislation or rule:* A281, R308, H4115 *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. (All gestational ages), Elective terminations (All gestational ages) **Age:** Up to two years of age **Residence:** In-state births to state residents

# Surveillance Methods

Case ascertainment: Active Case Finding

*Vital records:* Birth certificates, The birth certificate data is NTD-specific *Other state based registries:* First Sound (EHDI) sends a report of cases of hearing loss

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries

Other sources: NTD reports from a few geneticists

# 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 prenatal diagnosed or suspected cases, inpatient 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: Any infant with a codable defect 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.), 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

# Data Collection Methods and Storage

**Data collection:** Electronic file/report filled out by staff at facility (laptop, web-based, 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, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects

#### 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: 60% General state funds, 10% MCH funds, 30% CDC grant

# <u>Other</u>

Web site:

http://www.scdhec.gov/Health/FamilyPlanning/DataStaticsonPregnancyBabyHealth/BirthDefects/

# **Contacts**

Vinita Oberoi Leedom, MPH, CIC SC Department of Health and Environmental Control 2100 Bull Street Columbia, SC 29201 *Phone:* 803-898-0771 *Fax:* 803-898-3236 *Email:* leedomvo@dhec.sc.gov

Katherine Craigue Zielke, MPH, RN SC Department of Health and Environmental Control 2100 Bull Street Columbia, SC 29201 *Phone:* 803-898-2379 *Fax:* 803-898-3236 *Email:* zielkekc@dhec.sc.gov

# South Dakota

Program status: No surveillance program

ContactsLinda AhrendtSD Dept Health600 E. Capitol Ave.Pierre, SD 57501Phone: 605-773-3361Fax: 605-773-5683Email: linda.ahrendt@state.sd.us.us

# 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
 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: 80,559
 Statewide: Yes
 Current legislation or rule: TCA 68-5-506
 Legislation year enacted: 2000

# Case Definition

*Outcomes covered:* 46 major structural birth defects *Pregnancy outcome:* Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Prior to July 1st 2010: 500 grams or more, or in the absence of weight, 22 completed weeks of gestation or more; July 1st 2010 and later: 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: Newborn hearing screening program, Newborn metabolic screening program, Hospital Discharge Data System 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, Specialty outpatient clinics Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics

Other sources: Midwifery Facilities

# Case Ascertainment

Conditions warranting chart review in newborn period: ICD-10 codes from 23 Zika-related birth defects

*Conditions warranting chart review beyond the newborn period:* CNS condition (e.g. seizure), Auditory/hearing 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.), etc.), etc., and the set of the

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 and REDCap

### 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 **Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), 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

# Funding

Funding source: 100% CDC grant

# <u>Other</u>

Web site: www.tn.gov/health Surveillance reports on file: Tennessee Birth Defects Registry Report 2009-2013

#### **Contacts**

Katherine Lolley, MPH, CPH Tennessee Dept. of Health 710 James Robertson Parkway, 7th Floor Nashville, TN 37243 *Phone:* 615-253-4145 *Fax:* 615-532-7189 *Email:* Katherine.Lolley@tn.gov

Carolina Clark, MD, MPH Tennessee Dept. of Health 710 James Robertson Parkway, 8th Floor Nashville, TN 37243 *Phone:* 615-532-6936 *Fax:* 615-532-7189 *Email:* Carolina.Clark@tn.gov

# Texas

Texas Birth Defects Epidemiology and Surveillance Branch (TBDES)

**Purpose:** Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services

*Partner:* Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, 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:* 403,439 in 2015

Statewide: Yes

*Current legislation or rule:* Health and Safety Code, Title 2, Subtitle D, Section 1, 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

# <u>Data Analysis</u>

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, Epidemiologic 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: 26% General state funds, 73% MCH funds, 1% CDC grant

# <u>Other</u>

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

**Contacts** 

Mark A Canfield, PhD Birth Defects Epidemiology and Surveillance Branch P.O. Box 149347, Mail Code 1964 Austin, TX 78714-9347 *Phone:* 512-776-7232 *Fax:* 512-776-7330 *Email:* Mark.Canfield@dshs.texas.gov

Adrienne T Hoyt, M.S., M.P.H., M.A.L.A., M.A.L.S. Birth Defects Epidemiology and Surveillance Branch P.O. Box 149347, Mail Code 1964 Austin, TX 78714-9347 *Phone:* 512-776-6381 *Fax:* 512-776-7330 *Email:* adrienne.hoyt@dshs.texas.gov

# 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 (CSHCN) Population covered annually: 50,000

Statewide: Yes

*Current legislation or rule:* Birth Defect Rule (R398-5) *Legislation year enacted:* 1999

# Case Definition

*Outcomes covered:* All major structural birth defects and Zika associated birth defects.

**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

#### 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, ICU/NICU logs or charts, Specialty outpatient clinics, Champions report live births delivered at their respective hospitals

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

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

Other sources: Physician reports, Lay midwives

# Case Ascertainment

**Conditions warranting chart review in newborn period:** Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any chart with selected procedure codes, Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, All fetal death certificates, NICU reports, infant deaths are reviewed **Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, 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.), Illnesses/conditions, Family history

# Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff using remote access from office (laptop, web-based, etc.) Database collection and storage: Access

Data Analysis

Data analysis software: SAS, Access

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

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

# **System Integration**

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

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

# Funding

Funding source: 80% MCH funds, 20% CDC grant

#### <u>Other</u>

Web site: http://www.health.utah.gov/birthdefect Surveillance reports on file: Http://ibis.health.utah.gov Other comments: IBIS indicators are online.

# <u>Contacts</u>

Amy E Nance, MPH Utah Birth Defect Network 44 N Mario Capecchi Drive, PO Box 144699 Salt Lake City, UT 84114 *Phone:* 801-883-4661 *Fax:* 801-323-1578 *Email:* aenance@utah.gov

#### 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 Surveillance / Statistics)

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-9-CM or 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-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.)

Database collection and storage: Access

#### <u>Data Analysis</u>

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, 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: 5% General state funds, 95% CDC grant

# <u>Other</u>

Web site:

http://www.healthvermont.gov/health-statistics-vital-records/registries/bir th-information-network

**Contacts** Brennan Martin, MPH Vermont Department of Health

P.O. Box 70, 108 Cherry Street Burlington, VT 5402 Phone: 802-863-7611 Fax: 802-865-7701 Email: brennan.martin@vermont.gov

Peggy Brozicevic, B.A. Vermont Department of Health P.O. Box 70, 108 Cherry Street Burlington, VT 5402 Phone: 802-863-7298 Fax: 802-865-7701 Email: peggy.brozicevic@vermont.gov

# 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: 101,000
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-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, Epidemiologic 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: 34% MCH funds, 5% Genetic screening revenues, 61% CDC grant

# <u>Other</u>

Web site: http://www.vdh.virginia.gov/livewell/programs/vacares/

<u>Contacts</u> Jennifer Olsen Macdonald, MPH, BSN, RN Virginia Department of Health 109 Governor Street Richmond, VA 23219 *Phone:* (804) 864-7729 *Email:* jennifer.macdonald@vdh.virginia.gov

Colin Benusa, MPH Virginia Department of Health 109 Governor Street Richmond, VA 23219 *Phone:* 804-864-7767 *Email:* colin.benusa@vdh.virginia.gov

#### Washington

# Washington State Birth Defects Surveillance System (BDSS)

Purpose: Surveillance

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Universities Program status: Currently collecting data Start year: 1986 (active), 1991 (passive) Earliest year of available data: 1987 Organizational location: Department of Health (Office of Family & Community Health Improvement) Population covered annually: 90,000 est Statewide: Yes Current legislation or rule: Notifiable Conditions: WAC 246-101 Legislation year enacted: 2000

#### Case Definition

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

*Age:* We ascertain cases through 1 year of age for structural defects and to age 10 for FAS/FAE, Cerebral Palsy and Autism

Residence: Resident births; children born, diagnosed, or treated in-state

# Surveillance Methods

*Case ascertainment:* Passive case-finding without case confirmation *Vital records:* Birth certificates, Fetal birth certificate *Delivery hospitals:* Disease index or discharge index *Pediatric & tertiary care hospitals:* Disease index or discharge index

<u>Case Ascertainment</u> 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 *Mother:* Identification information (name, address, date-of-birth, etc.) *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 submitted by other agencies (hospitals, etc.), Case-finding Log listing of all data elements required for each case are completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff. Several facilities submit print-outs from data query of internal system of discharge data. Minimal use of diskette or other forms of electronic data transfer. A web-based reporting system 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, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses

# System Integration

System links: Link case finding data to final birth file

**Funding** 

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

ContactsKevin Beck, MAWashington Dept. of HealthPO Box 47835Olympia, WA 98504-7835Phone: 360-236-3492Fax: 360-236-2323Email: kevin.beck@doh.wa.gov

Teresa Vollan, MPH Washington Dept. of Health; Maternal and Child Health; CSHCN PO Box 47835 Olympia, WA 98504-7835 *Phone:* 360-236-3581 *Fax:* 360-236-2323 *Email:* teresa.vollan@doh.wa.gov

# 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) Boundation concerned annually, 20,000

**Population covered annually:** 20,000

Statewide: Yes

*Current legislation or rule:* WV State Code 16-5-12a *Legislation year enacted:* 1991; updated 2002

# Case Definition

*Outcomes covered:* ICD-9-CM codes 740-759, 760, 764, 765, 766 with transition to ICD-10

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (20 weeks gestation and greater) **Age:** 0-6 years

Residence: In and out of 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, Elective termination certificates *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 of children not identified on birth certificate

# 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 elective abortions, 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, 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: 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.)

# 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

### <u>Data Analysis</u>

#### 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, Epidemiologic 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

# <u>Funding</u>

Funding source: 100% MCH funds

# <u>Other</u>

Web site: http://wvdhhr.org/omcfh

<u>Contacts</u> Kathy Cummons, MSW Research, Evaluation and Planning Division 350 Capitol St. Room 427 Charleston, WV 25301 *Phone:* 304-558-5388 *Fax:* 304-558-3510 *Email:* kathy.g.cummons@wv.gov

Melissa A. Baker, MA Office of Maternal, Child and Family Health 350 Capitol St. Room 427 Charleston, WV 25301 *Phone:* 304-356-4438 *Fax:* 304-558-3510 *Email:* melissa.a.baker@wv.gov

#### 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) *Population covered annually:* average 69,000 *Statewide:* Yes

*Current legislation or rule:* State statute 253.12 Birth defect prevention and surveillance system. Enacted December 2000.Department of Health Services rules, Chapter DHS 116 Wisconsin Birth Defect Prevention and Surveillance System. Enacted April 2003. *Legislation year enacted:* 2000

# Case Definition

*Outcomes covered:* A list of 87 specific birth defects are collected. The list may be viewed on our website at

https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm. It is an appendix to the reporting form DPH 40054. 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.

**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 born in and/or receiving services 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

Vital records: Matched birth/death file, compare registry reports to vital records periodically for selected birth defects

# Case Ascertainment

*Coding:* ICD-10-CM, State assigned codes assigned to all conditions collected. Reporters combine ICD-9-CM or ICD-10 with text searches to derive defects that share an ICD code.

# 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.) *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.), 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, Rates by demographic and other variables, Time trends, Observed vs. expected analyses, Referral, Grant proposals, Prevention projects

# **Funding**

Funding source: 100% Other (birth certificate fees)

#### <u>Other</u>

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

# **Contacts**

 Peggy Helm-Quest, MSEd, MHSA

 Wisconsin Department of Health Services, Division of Public Health

 1 W Wilson St

 Madison, WI 53703

 Phone: 608-267-2945

 Fax: 608-267-3824

 Email: Peggy.HelmQuest@wi.gov

# Wyoming

Program status: Interested in developing a surveillance program

 Contacts

 Amy Spieker, MPH

 Wyoming Department of Health

 6101 Yellowstone Rd, Ste 420

 Cheyenne, WY 82002

 Phone: 307-777-5769

 Fax: 307-777-8687

 Email: amy.spieker@wyo.gov

Ashley Busacker, PhD CDC/WDH 6101 Yellowstone Rd, Ste 510 Cheyenne, WY 82002 *Phone:* 307-777-6936 *Email:* ashley.busacker@wyo.gov

#### **Department of Defense**

United States Department of Defense (DoD) Birth and Infant Health Research (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. 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 active case ascertainment and chart review of a random sample of births from military 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 active case ascertainment and chart review of a random sample of births from military healthcare facilities

# Conditions warranting chart review beyond the newborn period: Any infant with a codable defect

Coding: ICD-10-CM, The BIHR program assesses outcomes through the first year of life. Infants born on or after October 1, 2014 concluded their first year of life after the transition from ICD-9-CM to ICD-10-CM coding on October 1, 2015. For these infants, the Registry employed ICD-10-CM coding to assess outcomes for the final months of their assessment period.

# 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

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, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, 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)

# <u>Other</u>

Web site: http://www.med.navy.mil/sites/nhrc/research/mph/Pages/Reproductive-H ealth.aspx Surveillance reports on file: DoD/Health Affairs policy memorandum; annual reports

# **Contacts**

Ava Marie S. Conlin, DO, MPH Deployment Health Research Department, Dept 164, Naval Health **Research Center** 140 Sylvester Road San Diego, CA 92106-3521 Phone: 619-553-9255 Fax: 619-767-4806 Email: avamarie.s.conlin.ctr@mail.mil

Gia R. Gumbs, MPH DoD Birth and Infant Health Registry 140 Sylvester Road San Diego, CA 92106-3521 Phone: 619-553-9255 Fax: 619-767-4806 Email: gia.r.gumbs.ctr@mail.mil