Major Birth Defects Data from Population-based Birth Defects Surveillance Programs in the United States, 2005-2009

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

This report contains data from 41 population-based birth defects programs. These include: Alaska Birth Defects Registry; Arkansas Reproductive Health Monitoring System; Arizona Birth Defects Monitoring Program; California Birth Defects Monitoring Program; Colorado Responds To Children With Special Needs; Connecticut Birth Defects Registry; Delaware Birth Defects Surveillance Project; Florida Birth Defects Registry; Metropolitan Atlanta Congenital Defects Program; Hawaii Birth Defects Program; Iowa Registry For Congenital and Inherited Disorders; Illinois Adverse Pregnancy Outcomes Reporting System; Indiana Birth Defects & Problems Registry; Kentucky Birth Surveillance Registry; Louisiana Birth Defects Monitoring Network; Massachusetts Center For Birth Defects Research And Prevention; Maryland Birth Defects Reporting and Information System; Maine Birth Defects Program; Michigan Birth Defects Registry; Minnesota Birth Defects Information System; Mississippi Birth Defects Registry; Missouri Birth Defects Surveillance System; North Carolina Birth Defects Monitoring Program; North Dakota Birth Defects Monitoring System; Nebraska Birth Defects Registry; New Hampshire Birth Conditions Program; New Jersey Special Child Health Services Registry; Nevada Birth Outcomes Monitoring System; New York State Congenital Malformations Registry; Ohio Connections For Children With Special Needs; Oklahoma Birth Defects Registry; Puerto Rico Birth Defects Surveillance and Prevention System; Rhode Island Birth Defects Program; South Carolina Birth Defects Program; Tennessee Birth Defects Registry; Texas Birth Defects Epidemiology and Surveillance Branch; Utah Birth Defect Network; Virginia Congenital Anomalies Reporting And Education System; Wisconsin Birth Defects Registry; West Virginia Congenital Abnormalities Registry, Education And Surveillance System; and the United States Department of Defense Birth and Infant Health Registry

Additional information and program contacts on population-based birth defects surveillance programs are available on page S121.

Alaska

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	<6 .	. .	. .	. .	<6 .	<6 .	
Aniridia	0 ***0.0***	. .	. .	. .	<6 .	<6 .	
Anophthalmia/microphthalmia	6 ***1.8***	. .	. .	. .	7 ***5.0***	15 ***2.7***	
Anotia/microtia	9 ***2.7***	. .	. .	. .	8 ***5.7***	18 ***3.3***	
Aortic valve stenosis	<6 .	. .	. .	. .	0 ***0.0***	<6 .	
Atrial septal defect	401 ***119.9***	. .	. .	. .	315 ***224.9***	814 ***148.6***	
Atrioventricular septal defect (endocardial cushion defect)	18 ***5.4***	. .	. .	. .	12 ***8.6***	34 ***6.2***	
Biliary atresia	<6 .	. .	. .	. .	12 ***8.6***	16 ***2.9***	
Bladder exstrophy	<6 .	. .	. .	. .	<6 .	6 ***1.1***	
Choanal atresia	7 ***2.1***	. .	. .	. .	<6 .	12 ***2.2***	
Cleft lip with and without cleft palate	51 ***15.3***	. .	. .	. .	55 ***39.3***	118 ***21.5***	
Cleft palate without cleft lip	23 ***6.9***	. .	. .	. .	52 ***37.1***	84 ***15.3***	
Coarctation of aorta	18 ***5.4***	. .	. .	. .	6 ***4.3***	25 ***4.6***	
Common truncus	7 ***2.1***	. .	. .	. .	<6 .	12 ***2.2***	
Congenital cataract	11 ***3.3***	. .	. .	. .	16 ***11.4***	30 ***5.5***	
Congenital hip dislocation	67 ***20.0***	. .	. .	. .	29 ***20.7***	106 ***19.3***	
Diaphragmatic hernia	11 ***3.3***	. .	. .	. .	21 ***15.0***	36 ***6.6***	
Down syndrome (Trisomy 21)	43 ***12.9***	. .	. .	. .	30 ***21.4***	87 ***15.9***	
Ebstein anomaly	<6 .	. .	. .	. .	<6 .	<6 .	
Encephalocele	10 ***3.0***	. .	. .	. .	13 ***9.3***	24 ***4.4***	
Epispadias	<6 .	. .	. .	. .	<6 .	6 ***1.1***	
Esophageal atresia/tracheoesophageal fistula	9 ***2.7***	. .	. .	. .	6 ***4.3***	16 ***2.9***	
Hirschsprung disease (congenital megacolon)	19 ***5.7***	. .	. .	. .	12 ***8.6***	36 ***6.6***	
Hydrocephalus without spina bifida	27 ***8.1***	. .	. .	. .	19 ***13.6***	59 ***10.8***	
Hypoplastic left heart syndrome	10 ***3.0***	. .	. .	. .	<6 .	14 ***2.6***	
Hypospadias*	203 ***128.9***	. .	. .	. .	45 ***62.1***	297 ***129.1***	
Microcephalus	53 ***15.9***	. .	. .	. .	45 ***32.1***	107 ***19.5***	
Obstructive genitourinary defect	191 ***57.1***	. .	. .	. .	62 ***44.3***	284 ***51.8***	
Patent ductus arteriosus	265 ***79.3***	. .	. .	. .	168 ***119.9***	506 ***92.3***	1
Pulmonary valve atresia and stenosis	38 ***11.4***	. .	. .	. .	36 ***25.7***	80 ***14.6***	
Pyloric stenosis	68 ***20.3***	. .	. .	. .	65 ***46.4***	143 ***26.1***	
Rectal and large intestinal atresia/stenosis	29 ***8.7***	. .	. .	. .	19 ***13.6***	52 ***9.5***	

Alaska

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Reduction deformity, lower limbs	26	.	.	.	17	49	
	7.8	**.**	**.**	**.**	***12.1***	***8.9***	
Reduction deformity, upper limbs	11	.	.	.	8	24	
	3.3	**.**	**.**	**.**	***5.7***	***4.4***	
Renal agenesis/hypoplasia	28	.	.	.	8	44	
	8.4	**.**	**.**	**.**	***5.7***	***8.0***	
Spina bifida without anencephalus	18	.	.	.	16	35	
	5.4	**.**	**.**	**.**	***11.4***	***6.4***	
Tetralogy of Fallot	13	.	.	.	14	30	
	3.9	**.**	**.**	**.**	***10.0***	***5.5***	
Total anomalous pulmonary venous return (TAPVR)	<6	.	.	.	<6	11	
	.	**.**	**.**	**.**	**.**	***2.0***	
Transposition of great arteries - All	12	.	.	.	11	24	
	3.6	**.**	**.**	**.**	***7.9***	***4.4***	
Tricuspid valve atresia and stenosis	6	.	.	.	<6	9	
	1.8	**.**	**.**	**.**	**.**	***1.6***	
Trisomy 13 (Patau syndrome)	6	.	.	.	<6	8	
	1.8	**.**	**.**	**.**	**.**	***1.5***	
Trisomy 18 (Edwards syndrome)	<6	.	.	.	<6	12	
	.	**.**	**.**	**.**	**.**	***2.2***	
Ventricular septal defect	246	.	.	.	270	559	2
	73.6	**.**	**.**	**.**	***192.7***	***102.0***	
Total Live Births	**33432**	**.**	**.**	**.**	**14009**	**54796**	
Total Male Live Births	**15754**	**.**	**.**	**.**	**7244**	**22998**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Alaska

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	51 ***13.7***	36 ***52.5***	87 ***15.9***	
Trisomy 13 (Patau syndrome)	<6 .	<6 .	8 ***1.5***	
Trisomy 18 (Edwards syndrome)	<6 .	<6 .	12 ***2.2***	
Total Live Births	**37354**	**6859**	**54796**	

**Total includes unknown maternal age

Notes
1.Patent ductus arteriosus - only birth weight =>2500 grams Infants.
2.Ventricular septal defect - The ABDR is a passive surevillance system. Reports are not submitted as 'probable'. The ABDR does not conduct case verification on these reports.

General comments
-Alaska conducts surveillance for FAS using FASSNET methodology. Contact the program for data on FAS and FASD.
-Cases matched to Alaska birth certificates only; birth cohort 2002-2006 for major anomalies only
-Data was indicated by race for non-hispanic White and non-hispanic AK Native only. Live birth numbers were queried from VS data sets and not from published VS data as VS does not publish break downs on these two races with indicated ethnicity.
-The ABDR does not collect data on still births or terminations; live birth information only.
-The ABDR does not collect or provide infomation on amniotic bands.
-The ABDR does not provide data to any other state agency for the purpose of further metabolic and/or medical testing.
-The ABDR does not provide numbers for cells with <6 cases.
-The Alaska Birth Defects Registry collected data during all years of this birth cohort
-The Alaska Birth Defects Registry does not provide data on individual years within the birth cohort. Only Totals by Race and Age are presented with individual year data
-The Alaska Birth Defects Registry uses the ICD-9 coding system.

Arizona

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	21	4	41	1	4	73	
	1.0	***2.1***	***1.9***	***0.7***	***1.3***	***1.5***	
Aniridia	1	0	2	0	0	3	
	0.0	***0.0***	***0.1***	***0.0***	***0.0***	***0.1***	
Anophthalmia/microphthalmia	10	1	28	1	2	44	
	0.5	***0.5***	***1.3***	***0.7***	***0.6***	***0.9***	
Anotia/microtia	15	0	37	3	10	65	
	0.7	***0.0***	***1.7***	***2.0***	***3.2***	***1.3***	
Aortic valve stenosis	37	2	42	2	6	89	
	1.8	***1.1***	***2.0***	***1.3***	***1.9***	***1.8***	
Biliary atresia	2	2	6	0	2	12	
	0.1	***1.1***	***0.3***	***0.0***	***0.6***	***0.2***	
Bladder exstrophy	3	0	6	0	0	9	
	0.1	***0.0***	***0.3***	***0.0***	***0.0***	***0.2***	
Choanal atresia	20	1	17	0	2	42	
	1.0	***0.5***	***0.8***	***0.0***	***0.6***	***0.9***	
Cleft lip with and without cleft palate	202	13	239	16	72	549	
	9.8	***7.0***	***11.1***	***10.5***	***23.3***	***11.2***	
Cleft palate without cleft lip	114	7	148	14	20	310	
	5.5	***3.8***	***6.9***	***9.2***	***6.5***	***6.3***	
Coarctation of aorta	109	4	90	6	12	225	
	5.3	***2.1***	***4.2***	***3.9***	***3.9***	***4.6***	
Common truncus	11	1	11	1	1	26	
	0.5	***0.5***	***0.5***	***0.7***	***0.3***	***0.5***	
Congenital cataract	8	1	19	0	3	33	
	0.4	***0.5***	***0.9***	***0.0***	***1.0***	***0.7***	
Diaphragmatic hernia	38	3	44	2	11	100	
	1.8	***1.6***	***2.0***	***1.3***	***3.6***	***2.0***	
Down syndrome (Trisomy 21)	248	18	280	16	37	608	
	12.1	***9.7***	***13.0***	***10.5***	***12.0***	***12.4***	
Ebstein anomaly	15	0	13	2	5	36	
	0.7	***0.0***	***0.6***	***1.3***	***1.6***	***0.7***	
Encephalocele	10	2	17	2	3	34	
	0.5	***1.1***	***0.8***	***1.3***	***1.0***	***0.7***	
Esophageal atresia/tracheoesophageal fistula	43	2	41	0	6	92	
	2.1	***1.1***	***1.9***	***0.0***	***1.9***	***1.9***	
Gastroschisis	91	5	132	3	25	265	
	4.4	***2.7***	***6.1***	***2.0***	***8.1***	***5.4***	
Hirschsprung disease (congenital megacolon)	31	6	23	1	1	64	
	1.5	***3.2***	***1.1***	***0.7***	***0.3***	***1.3***	
Hypoplastic left heart syndrome	65	6	51	3	9	136	
	3.2	***3.2***	***2.4***	***2.0***	***2.9***	***2.8***	
Omphalocele	33	3	37	6	3	84	
	1.6	***1.6***	***1.7***	***3.9***	***1.0***	***1.7***	
Pulmonary valve atresia and stenosis	80	6	115	6	18	230	
	3.9	***3.2***	***5.3***	***3.9***	***5.8***	***4.7***	
Pulmonary valve atresia	36	4	50	3	11	107	
	1.8	***2.1***	***2.3***	***2.0***	***3.6***	***2.2***	
Reduction deformity, lower limbs	10	7	25	1	3	47	
	0.5	***3.8***	***1.2***	***0.7***	***1.0***	***1.0***	
Reduction deformity, upper limbs	34	5	56	2	10	111	
	1.7	***2.7***	***2.6***	***1.3***	***3.2***	***2.3***	
Spina bifida without anencephalus	64	7	81	4	11	173	
	3.1	***3.8***	***3.8***	***2.6***	***3.6***	***3.5***	
Tetralogy of Fallot	79	7	97	5	19	212	
	3.8	***3.8***	***4.5***	***3.3***	***6.1***	***4.3***	
Transposition of great arteries - All	53	5	42	3	2	108	
	2.6	***2.7***	***2.0***	***2.0***	***0.6***	***2.2***	
dextro-Transposition of great arteries (d-TGA)	50	5	34	3	2	97	
	2.4	***2.7***	***1.6***	***2.0***	***0.6***	***2.0***	
Trisomy 13 (Patau syndrome)	15	4	26	5	3	54	
	0.7	***2.1***	***1.2***	***3.3***	***1.0***	***1.1***	

Arizona

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Trisomy 18 (Edwards syndrome)	37	4	40	5	10	97	
	1.8	***2.1***	***1.9***	***3.3***	***3.2***	***2.0***	
Total Live Births	**205619**	**18626**	**214999**	**15253**	**30914**	**491930**	

**Total includes unknown race

Arizona

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	340 ***7.9***	268 ***43.3***	608 ***12.4***	
Trisomy 13 (Patau syndrome)	41 ***1.0***	12 ***1.9***	54 ***1.1***	
Trisomy 18 (Edwards syndrome)	63 ***1.5***	33 ***5.3***	97 ***2.0***	
Total Live Births	**429859**	**61931**	**491930**	

**Total includes unknown maternal age

General comments

-In this data submission, ABDMP adhered to the requested race/Hispanic categories. However, for traditional in-state reports ABDMP categorizes Whites as Hispanic or non-Hispanic, and for other races (i.e. Black, Asian, and American Indian) retains the single race code regardless of their Hispanic designation.

Arkansas

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Amniotic bands	26	11	1	1	0	39	
	1.9	***2.8***	***0.5***	***2.4***	***0.0***	***1.9***	
Anencephalus	46	6	11	0	0	63	
	3.4	***1.5***	***5.1***	***0.0***	***0.0***	***3.1***	
Aniridia	2	1	1	0	0	4	
	0.1	***0.3***	***0.5***	***0.0***	***0.0***	***0.2***	
Anophthalmia/microphthalmia	25	7	3	0	2	37	
	1.8	***1.8***	***1.4***	***0.0***	***18.0***	***1.8***	
Anotia/microtia	22	3	15	1	0	41	
	1.6	***0.8***	***7.0***	***2.4***	***0.0***	***2.0***	
Aortic valve stenosis	47	5	3	0	0	55	
	3.5	***1.3***	***1.4***	***0.0***	***0.0***	***2.7***	
Atrial septal defect	401	93	52	14	5	565	
	29.5	***23.9***	***24.3***	***33.1***	***44.9***	***28.0***	
Atrioventricular septal defect (endocardial cushion defect)	92	24	9	2	0	127	
	6.8	***6.2***	***4.2***	***4.7***	***0.0***	***6.3***	
Biliary atresia	5	5	0	0	0	10	
	0.4	***1.3***	***0.0***	***0.0***	***0.0***	***0.5***	
Bladder exstrophy	4	0	0	0	0	4	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	8	3	0	0	1	12	
	0.6	***0.8***	***0.0***	***0.0***	***9.0***	***0.6***	
Cleft lip with and without cleft palate	173	31	19	2	0	225	
	12.7	***8.0***	***8.9***	***4.7***	***0.0***	***11.2***	
Cleft palate without cleft lip	108	20	11	1	1	141	
	7.9	***5.1***	***5.1***	***2.4***	***9.0***	***7.0***	
Coarctation of aorta	102	20	8	1	0	131	
	7.5	***5.1***	***3.7***	***2.4***	***0.0***	***6.5***	
Common truncus	9	3	2	1	0	15	
	0.7	***0.8***	***0.9***	***2.4***	***0.0***	***0.7***	
Congenital cataract	52	16	7	1	1	77	
	3.8	***4.1***	***3.3***	***2.4***	***9.0***	***3.8***	
Congenital hip dislocation	17	3	3	1	0	24	
	1.3	***0.8***	***1.4***	***2.4***	***0.0***	***1.2***	
Diaphragmatic hernia	47	8	6	0	0	61	
	3.5	***2.1***	***2.8***	***0.0***	***0.0***	***3.0***	
Down syndrome (Trisomy 21)	170	27	39	6	0	242	
	12.5	***6.9***	***18.2***	***14.2***	***0.0***	***12.0***	
Ebstein anomaly	8	2	3	0	1	14	
	0.6	***0.5***	***1.4***	***0.0***	***9.0***	***0.7***	
Encephalocele	15	9	4	1	0	29	
	1.1	***2.3***	***1.9***	***2.4***	***0.0***	***1.4***	
Epispadias	10	1	1	0	0	12	
	0.7	***0.3***	***0.5***	***0.0***	***0.0***	***0.6***	
Esophageal atresia/tracheoesophageal fistula	42	6	5	3	0	56	
	3.1	***1.5***	***2.3***	***7.1***	***0.0***	***2.8***	
Fetus or newborn affected by maternal alcohol use	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Gastroschisis	91	14	8	1	2	116	
	6.7	***3.6***	***3.7***	***2.4***	***18.0***	***5.7***	
Hirschsprung disease (congenital megacolon)	41	11	2	1	0	55	
	3.0	***2.8***	***0.9***	***2.4***	***0.0***	***2.7***	
Hydrocephalus without spina bifida	69	21	12	2	0	104	
	5.1	***5.4***	***5.6***	***4.7***	***0.0***	***5.2***	
Hypoplastic left heart syndrome	54	13	2	0	1	70	
	4.0	***3.3***	***0.9***	***0.0***	***9.0***	***3.5***	
Hypospadias*	630	131	29	7	5	802	
	90.0	***66.6***	***26.8***	***32.3***	***90.4***	***77.7***	
Microcephalus	22	12	6	4	1	45	
	1.6	***3.1***	***2.8***	***9.5***	***9.0***	***2.2***	
Obstructive genitourinary defect	253	63	46	5	1	368	
	18.6	***16.2***	***21.5***	***11.8***	***9.0***	***18.2***	
Omphalocele	29	16	3	0	0	48	
	2.1	***4.1***	***1.4***	***0.0***	***0.0***	***2.4***	

Arkansas

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	88	26	15	3	3	135	
	6.5	***6.7***	***7.0***	***7.1***	***27.0***	***6.7***	
Pulmonary valve atresia and stenosis	186	56	24	9	1	276	
	13.7	***14.4***	***11.2***	***21.3***	***9.0***	***13.7***	
Pulmonary valve atresia	9	3	1	1	0	14	
	0.7	***0.8***	***0.5***	***2.4***	***0.0***	***0.7***	
Pyloric stenosis	269	34	60	2	3	368	
	19.8	***8.7***	***28.0***	***4.7***	***27.0***	***18.2***	
Rectal and large intestinal atresia/stenosis	95	28	25	6	1	155	
	7.0	***7.2***	***11.7***	***14.2***	***9.0***	***7.7***	
Reduction deformity, lower limbs	37	16	4	0	0	57	
	2.7	***4.1***	***1.9***	***0.0***	***0.0***	***2.8***	
Reduction deformity, upper limbs	61	15	12	4	0	92	
	4.5	***3.9***	***5.6***	***9.5***	***0.0***	***4.6***	
Renal agenesis/hypoplasia	27	12	8	0	0	47	
	2.0	***3.1***	***3.7***	***0.0***	***0.0***	***2.3***	
Spina bifida without anencephalus	72	6	13	0	0	91	
	5.3	***1.5***	***6.1***	***0.0***	***0.0***	***4.5***	
Tetralogy of Fallot	64	15	7	1	0	87	
	4.7	***3.9***	***3.3***	***2.4***	***0.0***	***4.3***	
Total anomalous pulmonary venous return (TAPVR)	13	5	2	1	1	22	
	1.0	***1.3***	***0.9***	***2.4***	***9.0***	***1.1***	
Transposition of great arteries - All	66	11	6	1	0	84	
	4.9	***2.8***	***2.8***	***2.4***	***0.0***	***4.2***	
dextro-Transposition of great arteries (d-TGA)	60	10	5	1	0	76	
	4.4	***2.6***	***2.3***	***2.4***	***0.0***	***3.8***	
Tricuspid valve atresia	6	3	4	0	0	13	
	0.4	***0.8***	***1.9***	***0.0***	***0.0***	***0.6***	
Trisomy 13 (Patau syndrome)	14	4	2	0	0	20	
	1.0	***1.0***	***0.9***	***0.0***	***0.0***	***1.0***	
Trisomy 18 (Edwards syndrome)	37	14	1	0	0	52	
	2.7	***3.6***	***0.5***	***0.0***	***0.0***	***2.6***	
Ventricular septal defect	856	158	159	25	5	1203	
	63.0	***40.6***	***74.2***	***59.1***	***44.9***	***59.6***	
Total Live Births	**135927**	**38898**	**21430**	**4228**	**1113**	**201763**	
Total Male Live Births	**69974**	**19684**	**10822**	**2166**	**553**	**103282**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Arkansas

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	142 ***7.6***	99 ***63.5***	242 ***12.0***	
Trisomy 13 (Patau syndrome)	14 ***0.8***	6 ***3.8***	20 ***1.0***	
Trisomy 18 (Edwards syndrome)	30 ***1.6***	22 ***14.1***	52 ***2.6***	
Total Live Births	**186100**	**15602**	**201763**	

**Total includes unknown maternal age

General comments

-Stillborns include fetal losses at any gestational age and subjects where outcome is unknown.

California

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total***	Notes
Amniotic bands	13 ***1.4***	* .	24 ***1.1***	* .	* .	47 ***1.4***	
Anencephalus	13 ***1.4***	* .	53 ***2.5***	* .	0 ***0.0***	98 ***2.8***	
Anophthalmia/microphthalmia	6 ***0.7***	* .	17 ***0.8***	* .	0 ***0.0***	27 ***0.8***	
Anotia/microtia	11 ***1.2***	* .	87 ***4.1***	9 ***5.6***	* .	115 ***3.3***	
Aortic valve stenosis	20 ***2.2***	* .	41 ***2.0***	* .	* .	68 ***2.0***	
Atrial septal defect	123 ***13.7***	28 ***17.9***	351 ***16.7***	28 ***17.5***	5 ***19.1***	550 ***15.9***	1
Atrioventricular septal defect (endocardial cushion defect)	45 ***5.0***	14 ***9.0***	91 ***4.3***	8 ***5.0***	* .	166 ***4.8***	
Biliary atresia	6 ***0.7***	0 ***0.0***	8 ***0.4***	* .	* .	18 ***0.5***	
Bladder exstrophy	* .	0 ***0.0***	* .	0 ***0.0***	0 ***0.0***	5 ***0.1***	
Choanal atresia	* .	0 ***0.0***	* .	0 ***0.0***	0 ***0.0***	8 ***0.2***	
Cleft lip with and without cleft palate	83 ***9.2***	* .	215 ***10.3***	20 ***12.5***	* .	350 ***10.1***	
Cleft palate without cleft lip	37 ***4.1***	* .	108 ***5.1***	9 ***5.6***	* .	169 ***4.9***	2
Coarctation of aorta	47 ***5.2***	8 ***5.1***	94 ***4.5***	* .	* .	168 ***4.9***	
Common truncus	* .	* .	7 ***0.3***	0 ***0.0***	0 ***0.0***	10 ***0.3***	
Congenital cataract	12 ***1.3***	* .	19 ***0.9***	* .	0 ***0.0***	36 ***1.0***	
Diaphragmatic hernia	25 ***2.8***	* .	51 ***2.4***	* .	* .	86 ***2.5***	
Down syndrome (Trisomy 21)	104 ***11.6***	19 ***12.2***	313 ***14.9***	* .	* .	488 ***14.1***	
Ebstein anomaly	7 ***0.8***	0 ***0.0***	13 ***0.6***	* .	0 ***0.0***	24 ***0.7***	
Encephalocele	* .	* .	20 ***1.0***	* .	* .	32 ***0.9***	
Esophageal atresia/tracheoesophageal fistula	12 ***1.3***	* .	29 ***1.4***	* .	* .	48 ***1.4***	3
Fetus or newborn affected by maternal alcohol use	* .	0 ***0.0***	* .	* .	0 ***0.0***	* .	
Gastroschisis	46 ***5.1***	6 ***3.8***	115 ***5.5***	14 ***8.8***	0 ***0.0***	187 ***5.4***	
Hydrocephalus without spina bifida	27 ***3.0***	7 ***4.5***	66 ***3.1***	* .	* .	110 ***3.2***	
Hypoplastic left heart syndrome	20 ***2.2***	* .	47 ***2.2***	5 ***3.1***	* .	81 ***2.3***	
Hypospadias**	68 ***14.7***	11 ***13.7***	78 ***7.3***	6 ***7.3***	* .	172 ***9.7***	4
Omphalocele	7 ***0.8***	* .	26 ***1.2***	* .	0 ***0.0***	46 ***1.3***	
Pulmonary valve atresia and stenosis	52 ***5.8***	9 ***5.8***	108 ***5.1***	15 ***9.4***	* .	190 ***5.5***	
Rectal and large intestinal atresia/stenosis	30 ***3.3***	* .	81 ***3.9***	12 ***7.5***	* .	142 ***4.1***	5
Reduction deformity, lower limbs	13 ***1.4***	* .	25 ***1.2***	* .	* .	46 ***1.3***	
Reduction deformity, upper limbs	25 ***2.8***	7 ***4.5***	59 ***2.8***	7 ***4.4***	* .	104 ***3.0***	
Renal agenesis/hypoplasia	11 ***1.2***	0 ***0.0***	32 ***1.5***	5 ***3.1***	* .	50 ***1.4***	6
Spina bifida without anencephalus	25 ***2.8***	* .	93 ***4.4***	* .	0 ***0.0***	142 ***4.1***	

California

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total*** **	**Notes**
Tetralogy of Fallot	27	*	66	5	0	102	
	3.0	**.**	***3.1***	***3.1***	***0.0***	***3.0***	
Total anomalous pulmonary venous return (TAPVR)	9	0	35	*	0	47	
	1.0	***0.0***	***1.7***	**.**	***0.0***	***1.4***	
dextro-Transposition of great arteries (d-TGA)	21	*	34	*	0	61	
	2.3	**.**	***1.6***	**.**	***0.0***	***1.8***	
Tricuspid valve atresia	9	0	14	*	*	25	
	1.0	***0.0***	***0.7***	**.**	**.**	***0.7***	
Trisomy 13 (Patau syndrome)	7	*	21	*	0	43	
	0.8	**.**	***1.0***	**.**	***0.0***	***1.2***	
Trisomy 18 (Edwards syndrome)	16	5	52	*	*	101	
	1.8	***3.2***	***2.5***	**.**	**.**	***2.9***	
Total Live Births	**89951**	**15616**	**209751**	**15999**	**2614**	**345349**	
Total Male Live Births	**46356**	**8026**	**106684**	**8234**	**1339**	**176557**	

*Cell size suppressed to protect confidentiality or to indicate case count <5
**Hypospadias: prevalence per 10,000 male live births
***Total includes unknown race

California

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total*** **	**Notes**
Down syndrome (Trisomy 21)	254 ***8.3***	222 ***58.7***	488 ***14.1***	
Trisomy 13 (Patau syndrome)	24 ***0.8***	11 ***2.9***	43 ***1.2***	
Trisomy 18 (Edwards syndrome)	44 ***1.4***	42 ***11.1***	101 ***2.9***	
Total Live Births	**307458**	**37847**	**345349**	

***Total includes unknown maternal age

Notes
1.ASD: 1) only cases confirmed by physician review or echo or cath or surgery or autopsy are included; 2) if the ASD is a component of another major heart malformation, it is not counted
2.Submucous cleft and bifid uvula are not included in this report.
3.Isolated tracheoesophageal fistula is not included in this report.
4.Hypospadias case counts include only 2nd and 3rd degree.
5.Anal stenosis is not included in this report.
6.Unilateral renal agenesis/hypoplasia is not included in this report.

General comments
-Cases with chromosomal defects other than trisomy 13, 18 and 21 are not included in this report.
-Cases with single gene disorders are not included in this report.
-Stillbirth > = 20 wks is included for all defect types.

Colorado

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	24 ***1.2***	0 ***0.0***	22 ***2.0***	2 ***1.7***	1 ***4.1***	52 ***1.5***	1
Aniridia	6 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	6 ***0.2***	
Anophthalmia/microphthalmia	26 ***1.3***	1 ***0.7***	17 ***1.5***	0 ***0.0***	0 ***0.0***	48 ***1.4***	
Anotia/microtia	46 ***2.2***	6 ***3.9***	48 ***4.4***	2 ***1.7***	0 ***0.0***	104 ***3.0***	
Aortic valve stenosis	83 ***4.0***	3 ***2.0***	31 ***2.8***	0 ***0.0***	1 ***4.1***	118 ***3.4***	
Atrial septal defect	1908 ***91.9***	211 ***138.3***	1107 ***100.7***	113 ***97.6***	18 ***73.1***	3394 ***97.2***	
Atrioventricular septal defect (endocardial cushion defect)	76 ***3.7***	8 ***5.2***	38 ***3.5***	6 ***5.2***	1 ***4.1***	131 ***3.8***	2
Biliary atresia	23 ***1.1***	1 ***0.7***	10 ***0.9***	0 ***0.0***	0 ***0.0***	34 ***1.0***	
Bladder exstrophy	6 ***0.3***	0 ***0.0***	3 ***0.3***	0 ***0.0***	1 ***4.1***	10 ***0.3***	
Choanal atresia	35 ***1.7***	5 ***3.3***	19 ***1.7***	1 ***0.9***	1 ***4.1***	64 ***1.8***	
Cleft lip with and without cleft palate	225 ***10.8***	12 ***7.9***	146 ***13.3***	6 ***5.2***	5 ***20.3***	405 ***11.6***	
Cleft palate without cleft lip	170 ***8.2***	10 ***6.6***	94 ***8.6***	6 ***5.2***	4 ***16.2***	289 ***8.3***	
Coarctation of aorta	192 ***9.3***	11 ***7.2***	86 ***7.8***	3 ***2.6***	1 ***4.1***	296 ***8.5***	
Common truncus	12 ***0.6***	0 ***0.0***	5 ***0.5***	0 ***0.0***	0 ***0.0***	19 ***0.5***	
Congenital cataract	44 ***2.1***	3 ***2.0***	22 ***2.0***	1 ***0.9***	0 ***0.0***	71 ***2.0***	
Congenital hip dislocation	307 ***14.8***	11 ***7.2***	149 ***13.6***	13 ***11.2***	3 ***12.2***	489 ***14.0***	
Diaphragmatic hernia	82 ***4.0***	6 ***3.9***	36 ***3.3***	5 ***4.3***	0 ***0.0***	137 ***3.9***	
Down syndrome (Trisomy 21)	293 ***14.1***	28 ***18.4***	171 ***15.6***	15 ***13.0***	1 ***4.1***	743 ***21.3***	
Ebstein anomaly	15 ***0.7***	0 ***0.0***	9 ***0.8***	3 ***2.6***	0 ***0.0***	27 ***0.8***	
Encephalocele	14 ***0.7***	3 ***2.0***	13 ***1.2***	1 ***0.9***	0 ***0.0***	36 ***1.0***	
Epispadias	27 ***1.3***	2 ***1.3***	14 ***1.3***	0 ***0.0***	0 ***0.0***	43 ***1.2***	
Esophageal atresia/tracheoesophageal fistula	90 ***4.3***	7 ***4.6***	35 ***3.2***	3 ***2.6***	1 ***4.1***	138 ***4.0***	
Gastroschisis	74 ***3.6***	4 ***2.6***	74 ***6.7***	2 ***1.7***	3 ***12.2***	162 ***4.6***	3
Hirschsprung disease (congenital megacolon)	55 ***2.6***	6 ***3.9***	18 ***1.6***	2 ***1.7***	0 ***0.0***	82 ***2.3***	
Hydrocephalus without spina bifida	140 ***6.7***	18 ***11.8***	104 ***9.5***	6 ***5.2***	3 ***12.2***	280 ***8.0***	
Hypoplastic left heart syndrome	58 ***2.8***	4 ***2.6***	27 ***2.5***	0 ***0.0***	0 ***0.0***	90 ***2.6***	
Hypospadias*	1513 ***141.9***	105 ***134.4***	393 ***69.7***	55 ***93.3***	12 ***98.6***	2095 ***117.0***	
Microcephalus	144 ***6.9***	18 ***11.8***	120 ***10.9***	5 ***4.3***	2 ***8.1***	294 ***8.4***	
Obstructive genitourinary defect	845 ***40.7***	63 ***41.3***	416 ***37.9***	59 ***50.9***	11 ***44.7***	1417 ***40.6***	
Omphalocele	37 ***1.8***	6 ***3.9***	21 ***1.9***	1 ***0.9***	0 ***0.0***	79 ***2.3***	4
Patent ductus arteriosus	814 ***39.2***	82 ***53.8***	451 ***41.0***	48 ***41.5***	11 ***44.7***	1414 ***40.5***	5
Pulmonary valve atresia and stenosis	161 ***7.8***	21 ***13.8***	108 ***9.8***	8 ***6.9***	1 ***4.1***	302 ***8.7***	

Colorado

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia	36	7	30	2	0	76	
	1.7	***4.6***	***2.7***	***1.7***	***0.0***	***2.2***	
Pyloric stenosis	277	15	188	4	4	489	
	13.3	***9.8***	***17.1***	***3.5***	***16.2***	***14.0***	
Rectal and large intestinal atresia/stenosis	116	7	80	6	2	219	
	5.6	***4.6***	***7.3***	***5.2***	***8.1***	***6.3***	
Reduction deformity, lower limbs	37	2	11	1	1	55	
	1.8	***1.3***	***1.0***	***0.9***	***4.1***	***1.6***	
Reduction deformity, upper limbs	56	4	34	1	1	107	
	2.7	***2.6***	***3.1***	***0.9***	***4.1***	***3.1***	
Renal agenesis/hypoplasia	115	9	48	2	1	193	
	5.5	***5.9***	***4.4***	***1.7***	***4.1***	***5.5***	
Spina bifida without anencephalus	68	2	42	2	1	121	6
	3.3	***1.3***	***3.8***	***1.7***	***4.1***	***3.5***	
Tetralogy of Fallot	86	9	42	9	0	146	
	4.1	***5.9***	***3.8***	***7.8***	***0.0***	***4.2***	
Total anomalous pulmonary venous return (TAPVR)	15	1	21	2	0	41	
	0.7	***0.7***	***1.9***	***1.7***	***0.0***	***1.2***	
Transposition of great arteries - All	59	6	34	3	1	107	
	2.8	***3.9***	***3.1***	***2.6***	***4.1***	***3.1***	
dextro-Transposition of great arteries (d-TGA)	39	3	17	2	0	64	
	1.9	***2.0***	***1.5***	***1.7***	***0.0***	***1.8***	
Tricuspid valve atresia and stenosis	25	5	22	2	0	56	7
	1.2	***3.3***	***2.0***	***1.7***	***0.0***	***1.6***	
Trisomy 13 (Patau syndrome)	27	1	6	0	2	94	
	1.3	***0.7***	***0.5***	***0.0***	***8.1***	***2.7***	
Trisomy 18 (Edwards syndrome)	39	3	29	3	0	163	
	1.9	***2.0***	***2.6***	***2.6***	***0.0***	***4.7***	
Ventricular septal defect	921	75	543	39	10	1614	8
	44.4	***49.2***	***49.4***	***33.7***	***40.6***	***46.2***	
Total Live Births	**207564**	**15254**	**109893**	**11580**	**2463**	**349062**	
Total Male Live Births	**106639**	**7810**	**56394**	**5896**	**1217**	**179134**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Colorado

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	300 ***10.2***	395 ***72.1***	743 ***21.3***	
Trisomy 13 (Patau syndrome)	41 ***1.4***	45 ***8.2***	94 ***2.7***	
Trisomy 18 (Edwards syndrome)	68 ***2.3***	78 ***14.2***	163 ***4.7***	
Total Live Births	**294218**	**54818**	**349062**	

**Total includes unknown maternal age

Notes
1.Anencephalus: live births and fetal deaths any gestational age
2.Atrioventricular septal defect:Cannot include Inlet VSD
3.Gastroschisis: medical record review
4.Omphalocele: medical record review
5.Patent ductus arteriosus: birth weight greater than or equal to 2500 grams
6.Spina bifidia without anencephalus: live birth and fetal deaths any gestational age
7.Tricuspid valve atresia and stenosis:Tricuspid stenosis and hypoplasia included
8.Ventricular septal defects: includes probable cases

General comments
-Contact State Program directly in regards to fetal alcohol syndrome
-CDPHE disclaims responsibility for any analysis, interpretations, or conclusions

Connecticut

Birth Defects Counts and Prevalence 2005-2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Anencephalus	27	3	5	1	0	36	
	2.7	***1.5***	***1.5***	***1.1***	***0.0***	***2.2***	
Anophthalmia/microphthalmia	2	1	4	0	0	7	
	0.2	***0.5***	***1.2***	***0.0***	***0.0***	***0.4***	
Anotia/microtia	8	1	4	0	0	13	
	0.8	***0.5***	***1.2***	***0.0***	***0.0***	***0.8***	
Aortic valve stenosis	7	0	2	0	0	9	
	0.7	***0.0***	***0.6***	***0.0***	***0.0***	***0.5***	
Atrial septal defect	463	144	172	47	0	837	
	46.8	***72.5***	***50.7***	***52.5***	***0.0***	***50.6***	
Atrioventricular septal defect (endocardial cushion defect)	33	9	9	2	0	53	
	3.3	***4.5***	***2.7***	***2.2***	***0.0***	***3.2***	
Biliary atresia	4	4	4	2	0	14	
	0.4	***2.0***	***1.2***	***2.2***	***0.0***	***0.8***	
Bladder exstrophy	3	1	3	0	0	7	
	0.3	***0.5***	***0.9***	***0.0***	***0.0***	***0.4***	
Choanal atresia	15	3	7	1	0	26	
	1.5	***1.5***	***2.1***	***1.1***	***0.0***	***1.6***	
Cleft lip with and without cleft palate	65	15	30	5	0	115	
	6.6	***7.5***	***8.8***	***5.6***	***0.0***	***6.9***	
Cleft palate without cleft lip	56	6	14	6	0	82	
	5.7	***3.0***	***4.1***	***6.7***	***0.0***	***5.0***	
Coarctation of aorta	40	9	19	2	0	71	
	4.0	***4.5***	***5.6***	***2.2***	***0.0***	***4.3***	
Common truncus	4	1	0	2	0	7	
	0.4	***0.5***	***0.0***	***2.2***	***0.0***	***0.4***	
Congenital cataract	6	3	7	2	0	19	
	0.6	***1.5***	***2.1***	***2.2***	***0.0***	***1.1***	
Congenital hip dislocation	82	7	30	8	0	128	
	8.3	***3.5***	***8.8***	***8.9***	***0.0***	***7.7***	
Diaphragmatic hernia	25	6	11	3	0	46	
	2.5	***3.0***	***3.2***	***3.4***	***0.0***	***2.8***	
Down syndrome (Trisomy 21)	146	28	40	6	0	222	
	14.8	***14.1***	***11.8***	***6.7***	***0.0***	***13.4***	
Ebstein anomaly	5	2	6	0	0	13	
	0.5	***1.0***	***1.8***	***0.0***	***0.0***	***0.8***	
Encephalocele	6	0	7	0	0	13	
	0.6	***0.0***	***2.1***	***0.0***	***0.0***	***0.8***	
Epispadias	6	4	12	2	0	24	
	0.6	***2.0***	***3.5***	***2.2***	***0.0***	***1.5***	
Esophageal atresia/tracheoesophageal fistula	32	5	8	2	0	47	
	3.2	***2.5***	***2.4***	***2.2***	***0.0***	***2.8***	
Fetus or newborn affected by maternal alcohol use	12	7	4	0	0	25	
	1.2	***3.5***	***1.2***	***0.0***	***0.0***	***1.5***	
Gastroschisis	56	12	29	3	0	101	
	5.7	***6.0***	***8.6***	***3.4***	***0.0***	***6.1***	
Hirschsprung disease (congenital megacolon)	22	11	11	2	0	48	
	2.2	***5.5***	***3.2***	***2.2***	***0.0***	***2.9***	
Hydrocephalus without spina bifida	44	16	22	3	0	85	
	4.4	***8.1***	***6.5***	***3.4***	***0.0***	***5.1***	
Hypoplastic left heart syndrome	16	3	11	0	0	30	
	1.6	***1.5***	***3.2***	***0.0***	***0.0***	***1.8***	
Hypospadias*	420	64	75	26	0	591	
	83.1	***62.8***	***43.1***	***56.6***	***0.0***	***69.8***	
Microcephalus	29	16	19	2	0	66	
	2.9	***8.1***	***5.6***	***2.2***	***0.0***	***4.0***	
Obstructive genitourinary defect	29	5	13	4	0	51	
	2.9	***2.5***	***3.8***	***4.5***	***0.0***	***3.1***	
Omphalocele	9	0	4	0	0	13	
	0.9	***0.0***	***1.2***	***0.0***	***0.0***	***0.8***	
Patent ductus arteriosus	381	123	153	41	0	704	
	38.5	***61.9***	***45.1***	***45.8***	***0.0***	***42.5***	

Connecticut

Birth Defects Counts and Prevalence 2005-2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	56	21	26	1	0	109	
	5.7	***10.6***	***7.7***	***1.1***	***0.0***	***6.6***	
Pyloric stenosis	235	33	128	12	0	411	
	23.7	***16.6***	***37.8***	***13.4***	***0.0***	***24.8***	
Rectal and large intestinal atresia/stenosis	29	9	15	1	0	55	
	2.9	***4.5***	***4.4***	***1.1***	***0.0***	***3.3***	
Reduction deformity, lower limbs	12	3	3	2	0	21	
	1.2	***1.5***	***0.9***	***2.2***	***0.0***	***1.3***	
Reduction deformity, upper limbs	20	4	5	2	0	32	
	2.0	***2.0***	***1.5***	***2.2***	***0.0***	***1.9***	
Renal agenesis/hypoplasia	53	7	22	2	0	84	
	5.4	***3.5***	***6.5***	***2.2***	***0.0***	***5.1***	
Spina bifida without anencephalus	16	2	7	1	0	27	
	1.6	***1.0***	***2.1***	***1.1***	***0.0***	***1.6***	
Tetralogy of Fallot	56	11	21	5	0	95	
	5.7	***5.5***	***6.2***	***5.6***	***0.0***	***5.7***	
Transposition of great arteries - All	40	7	21	4	0	72	
	4.0	***3.5***	***6.2***	***4.5***	***0.0***	***4.4***	
Tricuspid valve atresia and stenosis	7	0	2	0	0	9	
	0.7	***0.0***	***0.6***	***0.0***	***0.0***	***0.5***	
Trisomy 13 (Patau syndrome)	5	2	2	0	0	9	
	0.5	***1.0***	***0.6***	***0.0***	***0.0***	***0.5***	
Trisomy 18 (Edwards syndrome)	7	2	3	2	0	14	
	0.7	***1.0***	***0.9***	***2.2***	***0.0***	***0.8***	
Ventricular septal defect	472	102	136	85	2	806	
	47.7	***51.3***	***40.1***	***94.9***	***24.7***	***48.7***	
Total Live Births	**98952**	**19871**	**33905**	**8953**	**811**	**165496**	
Total Male Live Births	**50548**	**10184**	**17414**	**4590**	**432**	**84665**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Connecticut

Trisomy Counts and Prevalence by Maternal Age 2005-2008 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	111 ***8.5***	110 ***31.2***	222 ***13.4***	
Trisomy 13 (Patau syndrome)	4 ***0.3***	5 ***1.4***	9 ***0.5***	
Trisomy 18 (Edwards syndrome)	9 ***0.7***	5 ***1.4***	14 ***0.8***	
Total Live Births	**130250**	**35240**	**165496**	

**Total includes unknown maternal age

General comments
-Coding system used is ICD-9

Delaware

Birth Defects Counts and Prevalence 2007-2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	1 *0.8*	2 *3.1*	1 *2.7*	0 *0.0*	0 *0.0*	4 *1.6*	
Anencephalus	1 *0.8*	1 *1.6*	1 *2.7*	0 *0.0*	0 *0.0*	4 *1.6*	
Aniridia	1 *0.8*	0 *0.0*	1 *2.7*	0 *0.0*	0 *0.0*	2 *0.8*	
Anophthalmia/microphthalmia	0 *0.0*	0 *0.0*	0 *0.0*	1 *9.5*	0 *0.0*	1 *0.4*	
Anotia/microtia	3 *2.3*	1 *1.6*	6 *16.0*	0 *0.0*	0 *0.0*	10 *4.1*	
Aortic valve stenosis	5 *3.9*	0 *0.0*	0 *0.0*	1 *9.5*	0 *0.0*	6 *2.5*	1
Atrial septal defect	31 *23.9*	13 *20.2*	10 *26.7*	0 *0.0*	0 *0.0*	54 *22.3*	2
Atrioventricular septal defect (endocardial cushion defect)	8 *6.2*	3 *4.7*	2 *5.3*	0 *0.0*	0 *0.0*	13 *5.4*	
Biliary atresia	1 *0.8*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	1 *0.4*	
Bladder exstrophy	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	
Choanal atresia	1 *0.8*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	1 *0.4*	
Cleft lip with and without cleft palate	9 *6.9*	3 *4.7*	3 *8.0*	1 *9.5*	0 *0.0*	17 *7.0*	
Cleft palate without cleft lip	11 *8.5*	3 *4.7*	4 *10.7*	2 *18.9*	0 *0.0*	20 *8.2*	3
Coarctation of aorta	2 *1.5*	2 *3.1*	0 *0.0*	0 *0.0*	0 *0.0*	4 *1.6*	
Common truncus	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	
Congenital cataract	4 *3.1*	0 *0.0*	2 *5.3*	1 *9.5*	0 *0.0*	7 *2.9*	
Congenital hip dislocation	48 *37.1*	4 *6.2*	7 *18.7*	2 *18.9*	0 *0.0*	62 *25.6*	
Diaphragmatic hernia	2 *1.5*	0 *0.0*	1 *2.7*	0 *0.0*	0 *0.0*	3 *1.2*	
Down syndrome (Trisomy 21)	21 *16.2*	6 *9.3*	3 *8.0*	2 *18.9*	0 *0.0*	32 *13.2*	
Ebstein anomaly	1 *0.8*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	1 *0.4*	
Encephalocele	2 *1.5*	2 *3.1*	0 *0.0*	0 *0.0*	0 *0.0*	4 *1.6*	
Epispadias	1 *0.8*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	2 *0.8*	
Esophageal atresia/tracheoesophageal fistula	2 *1.5*	0 *0.0*	1 *2.7*	0 *0.0*	0 *0.0*	3 *1.2*	
Fetus or newborn affected by maternal alcohol use	1 *0.8*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	1 *0.4*	
Gastroschisis	11 *8.5*	1 *1.6*	3 *8.0*	0 *0.0*	0 *0.0*	15 *6.2*	
Hirschsprung disease (congenital megacolon)	1 *0.8*	1 *1.6*	2 *5.3*	0 *0.0*	0 *0.0*	4 *1.6*	
Hydrocephalus without spina bifida	7 *5.4*	1 *1.6*	1 *2.7*	0 *0.0*	0 *0.0*	10 *4.1*	4
Hypoplastic left heart syndrome	4 *3.1*	3 *4.7*	4 *10.7*	0 *0.0*	0 *0.0*	11 *4.5*	
Hypospadias*	51 *77.0*	25 *76.7*	5 *26.7*	3 *53.2*	1 *625.0*	87 *70.4*	
Microcephalus	9 *6.9*	10 *15.5*	2 *5.3*	2 *18.9*	1 *303.0*	25 *10.3*	5
Obstructive genitourinary defect	123 *94.9*	36 *55.9*	27 *72.0*	13 *123.0*	0 *0.0*	200 *82.4*	6
Omphalocele	1 *0.8*	3 *4.7*	0 *0.0*	0 *0.0*	0 *0.0*	4 *1.6*	

Delaware

Birth Defects Counts and Prevalence 2007-2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	11 ***8.5***	12 ***18.6***	3 ***8.0***	0 ***0.0***	0 ***0.0***	26 ***10.7***	7
Pulmonary valve atresia and stenosis	22 ***17.0***	12 ***18.6***	1 ***2.7***	1 ***9.5***	0 ***0.0***	36 ***14.8***	8
Pulmonary valve atresia	1 ***0.8***	1 ***1.6***	1 ***2.7***	0 ***0.0***	0 ***0.0***	3 ***1.2***	8
Pyloric stenosis	12 ***9.3***	2 ***3.1***	7 ***18.7***	2 ***18.9***	0 ***0.0***	24 ***9.9***	
Rectal and large intestinal atresia/stenosis	9 ***6.9***	2 ***3.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	12 ***4.9***	
Reduction deformity, lower limbs	0 ***0.0***	2 ***3.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***0.8***	
Reduction deformity, upper limbs	5 ***3.9***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	5 ***2.1***	
Renal agenesis/hypoplasia	8 ***6.2***	5 ***7.8***	2 ***5.3***	1 ***9.5***	0 ***0.0***	16 ***6.6***	
Spina bifida without anencephalus	3 ***2.3***	3 ***4.7***	1 ***2.7***	0 ***0.0***	0 ***0.0***	8 ***3.3***	9
Tetralogy of Fallot	9 ***6.9***	2 ***3.1***	2 ***5.3***	2 ***18.9***	0 ***0.0***	15 ***6.2***	10
Total anomalous pulmonary venous return (TAPVR)	1 ***0.8***	1 ***1.6***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***0.8***	
Transposition of great arteries - All	3 ***2.3***	1 ***1.6***	3 ***8.0***	0 ***0.0***	0 ***0.0***	7 ***2.9***	
dextro-Transposition of great arteries (d-TGA)	3 ***2.3***	1 ***1.6***	3 ***8.0***	0 ***0.0***	0 ***0.0***	7 ***2.9***	
Tricuspid valve atresia	0 ***0.0***	1 ***1.6***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.4***	
Trisomy 13 (Patau syndrome)	0 ***0.0***	1 ***1.6***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.4***	
Trisomy 18 (Edwards syndrome)	2 ***1.5***	2 ***3.1***	1 ***2.7***	1 ***9.5***	0 ***0.0***	6 ***2.5***	
Ventricular septal defect	97 ***74.9***	41 ***63.7***	34 ***90.7***	2 ***18.9***	1 ***303.0***	177 ***73.0***	11
Total Live Births	**12955**	**6440**	**3749**	**1057**	**33**	**24260**	
Total Male Live Births	**6624**	**3260**	**1875**	**564**	**16**	**12353**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Delaware

Trisomy Counts and Prevalence by Maternal Age 2007-2008 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	17 ***8.1***	13 ***38.9***	32 ***13.2***	
Trisomy 13 (Patau syndrome)	1 ***0.5***	0 ***0.0***	1 ***0.4***	
Trisomy 18 (Edwards syndrome)	2 ***1.0***	4 ***12.0***	6 ***2.5***	
Total Live Births	**20922**	**3338**	**24260**	

**Total includes unknown maternal age

Notes
1.Trivial or limited are not included.
2.Atrial septal fenestrations are reported as an atrial septal defect (ASD). ASDs that self-close (not present after a month) are considered Patent Foramen Ovales (PFO). PFOs are not counted.
3.Pierre Robin sequence defects are included as a cleft palate.
4.Benign external hydrocephalus or hydrocephalus due to a secondary cause are not included.
5.Head circumference must be less than the 5th percentile.
6.All obstructive and non-obstructive genitourinary defects (i.e., all hydronephrosis and other types of kidney dilation) are included as well as all resolved defects.
7.The newborn must weigh 2500 grams or greater and the PDA must be present at one month of age.
8.Peripheral, branch, trivial, or limited are not included.
9.Spina bifida occulta is not included.
10.A ventricular septal defect with an overriding aorta is counted as Tetralogy of Fallot.
11.All sizes and types of ventricular septal defects are included and all resolved VSDs are included.

General comments
-2007 Maternal Fetal Medicine cases were derived from cytogenetic lists and fetal therapy lists. 2008 Maternal Fetal Medicine cases were derived from all possible defect cases handled by MFM.
-All chromosomal defects require a cytogenetics report.
-All defects found prenatally must be confirmed postnatally or through cytogenetic testing.
-All heart defects require an echocardiogram report.
-Coding System used was CDC/BPA.
-Registry does not distinguish spontaneous terminations from elective terminations. Stillbirths, miscarriages, and terminations are all currently reported together.
-Registry was not collecting data in 2005 and 2006. Registry data from 2009 is currently being vetted.

Florida

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Anencephalus	29	14	8	1	1	59	1
	0.6	***0.6***	***0.2***	***0.3***	***4.0***	***0.5***	
Aniridia	3	3	2	0	0	8	
	0.1	***0.1***	***0.1***	***0.0***	***0.0***	***0.1***	
Anophthalmia/microphthalmia	53	33	18	1	0	106	
	1.0	***1.3***	***0.5***	***0.3***	***0.0***	***0.9***	
Anotia/microtia	37	7	31	3	1	80	
	0.7	***0.3***	***0.9***	***1.0***	***4.0***	***0.7***	
Aortic valve stenosis	115	25	34	4	0	180	
	2.2	***1.0***	***1.0***	***1.3***	***0.0***	***1.6***	
Atrioventricular septal defect (endocardial cushion defect)	207	111	111	10	0	448	2
	4.0	***4.5***	***3.3***	***3.2***	***0.0***	***3.9***	
Biliary atresia	41	40	28	2	1	115	
	0.8	***1.6***	***0.8***	***0.6***	***4.0***	***1.0***	
Bladder exstrophy	17	12	7	0	0	36	
	0.3	***0.5***	***0.2***	***0.0***	***0.0***	***0.3***	
Choanal atresia	91	31	42	3	0	170	
	1.8	***1.3***	***1.3***	***1.0***	***0.0***	***1.5***	
Cleft lip with and without cleft palate	505	126	239	27	1	907	
	9.8	***5.1***	***7.2***	***8.6***	***4.0***	***7.9***	
Cleft palate without cleft lip	335	113	165	16	1	635	
	6.5	***4.6***	***5.0***	***5.1***	***4.0***	***5.5***	
Coarctation of aorta	402	135	190	12	3	759	
	7.8	***5.5***	***5.7***	***3.8***	***12.1***	***6.6***	
Common truncus	54	15	21	2	0	92	
	1.0	***0.6***	***0.6***	***0.6***	***0.0***	***0.8***	
Congenital cataract	74	38	29	3	0	145	
	1.4	***1.5***	***0.9***	***1.0***	***0.0***	***1.3***	
Congenital hip dislocation	486	107	288	31	4	926	
	9.4	***4.4***	***8.7***	***9.9***	***16.1***	***8.0***	
Diaphragmatic hernia	174	85	79	6	0	355	
	3.4	***3.5***	***2.4***	***1.9***	***0.0***	***3.1***	
Down syndrome (Trisomy 21)	694	307	434	33	3	1496	1
	13.5	***12.5***	***13.1***	***10.5***	***12.1***	***13.0***	
Ebstein anomaly	38	13	14	2	1	68	
	0.7	***0.5***	***0.4***	***0.6***	***4.0***	***0.6***	
Encephalocele	38	39	33	2	1	115	
	0.7	***1.6***	***1.0***	***0.6***	***4.0***	***1.0***	
Epispadias	77	20	22	1	0	123	
	1.5	***0.8***	***0.7***	***0.3***	***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	116	48	70	2	0	239	
	2.3	***2.0***	***2.1***	***0.6***	***0.0***	***2.1***	
Gastroschisis	304	72	104	7	0	491	3
	5.9	***2.9***	***3.1***	***2.2***	***0.0***	***4.3***	
Hirschsprung disease (congenital megacolon)	144	96	63	3	1	313	
	2.8	***3.9***	***1.9***	***1.0***	***4.0***	***2.7***	
Hydrocephalus without spina bifida	320	295	197	23	1	850	
	6.2	***12.0***	***5.9***	***7.3***	***4.0***	***7.4***	
Hypoplastic left heart syndrome	174	94	73	5	0	351	
	3.4	***3.8***	***2.2***	***1.6***	***0.0***	***3.1***	
Hypospadias*	2208	764	787	89	3	3935	
	83.8	***60.9***	***46.3***	***55.0***	***23.3***	***66.9***	
Microcephalus	294	187	189	7	3	690	
	5.7	***7.6***	***5.7***	***2.2***	***12.1***	***6.0***	
Obstructive genitourinary defect	1846	673	1382	109	6	4103	
	35.9	***27.4***	***41.6***	***34.7***	***24.2***	***35.7***	
Pulmonary valve atresia and stenosis	519	334	288	17	5	1181	
	10.1	***13.6***	***8.7***	***5.4***	***20.1***	***10.3***	
Pulmonary valve atresia	81	42	39	7	1	172	
	1.6	***1.7***	***1.2***	***2.2***	***4.0***	***1.5***	
Pyloric stenosis	1944	423	774	18	1	3206	
	37.8	***17.2***	***23.3***	***5.7***	***4.0***	***27.9***	
Rectal and large intestinal atresia/stenosis	234	117	115	13	0	490	
	4.5	***4.8***	***3.5***	***4.1***	***0.0***	***4.3***	

Florida

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Reduction deformity, lower limbs	76	44	45	3	0	170	
	1.5	***1.8***	***1.4***	***1.0***	***0.0***	***1.5***	
Reduction deformity, upper limbs	125	49	52	3	0	231	
	2.4	***2.0***	***1.6***	***1.0***	***0.0***	***2.0***	
Renal agenesis/hypoplasia	230	101	109	9	1	461	
	4.5	***4.1***	***3.3***	***2.9***	***4.0***	***4.0***	
Spina bifida without anencephalus	152	75	97	2	0	329	1
	3.0	***3.1***	***2.9***	***0.6***	***0.0***	***2.9***	
Tetralogy of Fallot	286	128	126	14	1	566	
	5.6	***5.2***	***3.8***	***4.5***	***4.0***	***4.9***	
Total anomalous pulmonary venous return (TAPVR)	38	25	27	6	0	98	
	0.7	***1.0***	***0.8***	***1.9***	***0.0***	***0.9***	
Transposition of great arteries - All	266	119	151	8	0	551	
	5.2	***4.8***	***4.5***	***2.5***	***0.0***	***4.8***	
dextro-Transposition of great arteries (d-TGA)	163	40	79	3	0	290	
	3.2	***1.6***	***2.4***	***1.0***	***0.0***	***2.5***	
Tricuspid valve atresia and stenosis	74	29	33	3	0	141	2
	1.4	***1.2***	***1.0***	***1.0***	***0.0***	***1.2***	
Trisomy 13 (Patau syndrome)	44	30	24	0	0	100	1
	0.9	***1.2***	***0.7***	***0.0***	***0.0***	***0.9***	
Trisomy 18 (Edwards syndrome)	75	54	53	4	0	189	1
	1.5	***2.2***	***1.6***	***1.3***	***0.0***	***1.6***	
Ventricular septal defect	2796	1267	1923	126	9	6210	2
	54.3	***51.5***	***57.9***	***40.1***	***36.2***	***54.0***	
Total Live Births	**514599**	**245888**	**331910**	**31389**	**2483**	**1150397**	
Total Male Live Births	**263432**	**125364**	**170036**	**16192**	**1289**	**588624**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Florida

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	783 ***8.0***	713 ***42.5***	1496 ***13.0***	1
Trisomy 13 (Patau syndrome)	71 ***0.7***	29 ***1.7***	100 ***0.9***	1
Trisomy 18 (Edwards syndrome)	109 ***1.1***	80 ***4.8***	189 ***1.6***	1
Total Live Births	**982505**	**167823**	**1150397**	

**Total includes unknown maternal age

Notes
1.FL reports live births only
2.Includes probable cases
3.Cases of Gastroschisis were differentiated from omphalocele by using 54.71 procedure code

General comments
-The Florida Birth Defect Registry is a passive population based surveillance system. In 2008, the data linkage methodology was modified to improve case ascertainment. In 2009, the linking methodology was again modified with the addition of Infant Death Certificate as a data source and the elimination of three data sources from the department's Children's Medical Services program. These modifications may affect the observed counts and rates.

Georgia

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	8	23	5	2	0	38	
	1.0	***2.2***	***0.8***	***1.2***	***0.0***	***1.4***	
Anencephalus	14	28	21	4	0	74	
	1.7	***2.7***	***3.3***	***2.4***	***0.0***	***2.7***	
Aniridia	2	2	1	0	0	7	
	0.2	***0.2***	***0.2***	***0.0***	***0.0***	***0.3***	
Anophthalmia/microphthalmia	6	18	8	3	0	38	
	0.7	***1.7***	***1.3***	***1.8***	***0.0***	***1.4***	
Anotia/microtia	4	15	13	2	0	37	
	0.5	***1.4***	***2.1***	***1.2***	***0.0***	***1.4***	
Aortic valve stenosis	20	23	7	2	0	54	
	2.5	***2.2***	***1.1***	***1.2***	***0.0***	***2.0***	
Atrial septal defect	247	283	164	27	2	749	
	30.6	***27.1***	***26.1***	***16.3***	***66.0***	***27.5***	
Atrioventricular septal defect (endocardial cushion defect)	49	82	27	3	1	174	
	6.1	***7.8***	***4.3***	***1.8***	***33.0***	***6.4***	
Biliary atresia	3	16	2	0	0	23	
	0.4	***1.5***	***0.3***	***0.0***	***0.0***	***0.8***	
Bladder exstrophy	1	2	0	0	0	3	
	0.1	***0.2***	***0.0***	***0.0***	***0.0***	***0.1***	
Choanal atresia	12	11	2	1	0	27	
	1.5	***1.1***	***0.3***	***0.6***	***0.0***	***1.0***	
Cleft lip with and without cleft palate	78	89	65	9	6	257	
	9.7	***8.5***	***10.3***	***5.4***	***198.0***	***9.4***	
Cleft palate without cleft lip	42	56	42	4	2	152	
	5.2	***5.4***	***6.7***	***2.4***	***66.0***	***5.6***	
Coarctation of aorta	51	45	25	3	0	134	
	6.3	***4.3***	***4.0***	***1.8***	***0.0***	***4.9***	
Common truncus	10	17	3	2	0	35	
	1.2	***1.6***	***0.5***	***1.2***	***0.0***	***1.3***	
Congenital cataract	16	11	8	1	0	36	
	2.0	***1.1***	***1.3***	***0.6***	***0.0***	***1.3***	
Congenital hip dislocation	89	21	46	3	1	173	
	11.0	***2.0***	***7.3***	***1.8***	***33.0***	***6.4***	
Diaphragmatic hernia	23	20	25	2	1	81	
	2.8	***1.9***	***4.0***	***1.2***	***33.0***	***3.0***	
Down syndrome (Trisomy 21)	152	146	109	18	1	456	
	18.8	***14.0***	***17.4***	***10.9***	***33.0***	***16.7***	
Ebstein anomaly	8	4	9	0	0	22	
	1.0	***0.4***	***1.4***	***0.0***	***0.0***	***0.8***	
Encephalocele	0	18	3	5	1	30	
	0.0	***1.7***	***0.5***	***3.0***	***33.0***	***1.1***	
Epispadias	4	5	1	0	0	10	
	0.5	***0.5***	***0.2***	***0.0***	***0.0***	***0.4***	
Esophageal atresia/tracheoesophageal fistula	26	20	10	0	0	57	
	3.2	***1.9***	***1.6***	***0.0***	***0.0***	***2.1***	
Fetus or newborn affected by maternal alcohol use	4	6	1	0	0	11	
	0.5	***0.6***	***0.2***	***0.0***	***0.0***	***0.4***	
Gastroschisis	28	51	32	5	0	122	
	3.5	***4.9***	***5.1***	***3.0***	***0.0***	***4.5***	
Hirschsprung disease (congenital megacolon)	13	38	3	0	1	55	
	1.6	***3.6***	***0.5***	***0.0***	***33.0***	***2.0***	
Hydrocephalus without spina bifida	62	114	41	12	4	264	
	7.7	***10.9***	***6.5***	***7.2***	***132.0***	***9.7***	
Hypoplastic left heart syndrome	16	18	11	2	0	51	
	2.0	***1.7***	***1.8***	***1.2***	***0.0***	***1.9***	
Hypospadias*	355	306	69	21	2	783	
	85.0	***57.0***	***21.2***	***24.1***	***120.5***	***55.7***	
Microcephalus	28	78	27	2	1	143	
	3.5	***7.5***	***4.3***	***1.2***	***33.0***	***5.3***	
Obstructive genitourinary defect	404	334	248	32	12	1098	
	50.0	***31.9***	***39.5***	***19.3***	***396.0***	***40.3***	
Omphalocele	16	34	14	1	0	72	
	2.0	***3.3***	***2.2***	***0.6***	***0.0***	***2.6***	

Georgia

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	272	255	187	22	7	768	1
	33.7	***24.4***	***29.8***	***13.3***	***231.0***	***28.2***	
Pulmonary valve atresia and stenosis	49	85	39	12	1	195	
	6.1	***8.1***	***6.2***	***7.2***	***33.0***	***7.2***	
Pulmonary valve atresia	9	23	12	3	0	50	
	1.1	***2.2***	***1.9***	***1.8***	***0.0***	***1.8***	
Pyloric stenosis	138	64	111	8	0	339	
	17.1	***6.1***	***17.7***	***4.8***	***0.0***	***12.5***	
Rectal and large intestinal atresia/stenosis	24	36	35	8	0	111	
	3.0	***3.4***	***5.6***	***4.8***	***0.0***	***4.1***	
Reduction deformity, lower limbs	15	22	12	0	0	52	
	1.9	***2.1***	***1.9***	***0.0***	***0.0***	***1.9***	
Reduction deformity, upper limbs	14	32	14	1	0	69	
	1.7	***3.1***	***2.2***	***0.6***	***0.0***	***2.5***	
Renal agenesis/hypoplasia	49	49	26	2	1	135	
	6.1	***4.7***	***4.1***	***1.2***	***33.0***	***5.0***	
Spina bifida without anencephalus	37	38	28	3	0	115	
	4.6	***3.6***	***4.5***	***1.8***	***0.0***	***4.2***	
Tetralogy of Fallot	37	50	15	7	0	117	
	4.6	***4.8***	***2.4***	***4.2***	***0.0***	***4.3***	
Total anomalous pulmonary venous return (TAPVR)	7	9	10	2	0	29	
	0.9	***0.9***	***1.6***	***1.2***	***0.0***	***1.1***	
Transposition of great arteries - All	28	32	15	4	0	82	
	3.5	***3.1***	***2.4***	***2.4***	***0.0***	***3.0***	
dextro-Transposition of great arteries (d-TGA)	26	26	12	4	0	71	
	3.2	***2.5***	***1.9***	***2.4***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	10	26	9	2	0	54	
	1.2	***2.5***	***1.4***	***1.2***	***0.0***	***2.0***	
Tricuspid valve atresia	6	21	6	2	0	36	
	0.7	***2.0***	***1.0***	***1.2***	***0.0***	***1.3***	
Trisomy 13 (Patau syndrome)	11	21	2	0	0	41	
	1.4	***2.0***	***0.3***	***0.0***	***0.0***	***1.5***	
Trisomy 18 (Edwards syndrome)	31	33	13	8	0	105	
	3.8	***3.2***	***2.1***	***4.8***	***0.0***	***3.9***	
Ventricular septal defect	546	437	368	40	7	1456	
	67.6	***41.8***	***58.6***	***24.1***	***231.0***	***53.5***	
Total Live Births	**80810**	**104606**	**62812**	**16583**	**303**	**272284**	
Total Male Live Births	**41765**	**53672**	**32506**	**8718**	**166**	**140500**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Georgia

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	234 ***10.4***	220 ***45.7***	456 ***16.7***	
Trisomy 13 (Patau syndrome)	25 ***1.1***	16 ***3.3***	41 ***1.5***	
Trisomy 18 (Edwards syndrome)	36 ***1.6***	68 ***14.1***	105 ***3.9***	
Total Live Births	**224092**	**48192**	**272284**	

**Total includes unknown maternal age

Notes
1.Cases included if gestational age =>36 weeks at birth and PDA is present at or beyond 6 weeks of age, or if PDA is present with other heart defects regardless of gestational age at birth.

General comments
-All totals include definite and probable/possible diagnoses.
-All totals include live births and stillbirths >= 20 weeks, elective terminations at any gestational age, and prenatal diagnoses with undocumented outcome at any gestational age.
-All totals include prenatal diagonses.
-NCHS bridged race data were not available. Multiple-race individuals are included in the totals only.

Hawaii

Birth Defects Counts and Prevalence 2005 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Amniotic bands	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***0.6***	
Anencephalus	1	0	0	3	0	7	
	2.8	***0.0***	***0.0***	***2.5***	***0.0***	***3.9***	
Aniridia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Anophthalmia/microphthalmia	1	0	0	0	0	1	
	2.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Anotia/microtia	2	0	0	7	0	9	
	5.7	***0.0***	***0.0***	***5.8***	***0.0***	***5.0***	
Aortic valve stenosis	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Atrial septal defect	24	23	4	163	2	228	
	67.8	***562.3***	***481.9***	***134.1***	***74.1***	***127.2***	
Atrioventricular septal defect (endocardial cushion defect)	1	0	0	3	0	4	
	2.8	***0.0***	***0.0***	***2.5***	***0.0***	***2.2***	
Biliary atresia	0	0	1	1	0	2	
	0.0	***0.0***	***120.5***	***0.8***	***0.0***	***1.1***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Cleft lip with and without cleft palate	3	1	0	15	0	22	
	8.5	***24.4***	***0.0***	***12.3***	***0.0***	***12.3***	
Cleft palate without cleft lip	2	0	0	13	0	16	
	5.7	***0.0***	***0.0***	***10.7***	***0.0***	***8.9***	
Coarctation of aorta	0	1	0	1	0	3	
	0.0	***24.4***	***0.0***	***0.8***	***0.0***	***1.7***	
Common truncus	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***1.6***	***0.0***	***1.1***	
Congenital cataract	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***0.6***	
Congenital hip dislocation	3	0	0	6	0	10	
	8.5	***0.0***	***0.0***	***4.9***	***0.0***	***5.6***	
Diaphragmatic hernia	0	0	0	1	0	2	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***1.1***	
Down syndrome (Trisomy 21)	3	1	0	12	0	16	
	8.5	***24.4***	***0.0***	***9.9***	***0.0***	***8.9***	
Ebstein anomaly	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***0.6***	
Encephalocele	0	1	0	2	0	3	
	0.0	***24.4***	***0.0***	***1.6***	***0.0***	***1.7***	
Epispadias	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Esophageal atresia/tracheoesophageal fistula	1	0	0	2	0	3	
	2.8	***0.0***	***0.0***	***1.6***	***0.0***	***1.7***	
Fetus or newborn affected by maternal alcohol use	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.8***	***0.0***	***0.6***	
Gastroschisis	0	3	0	6	0	9	1
	0.0	***73.3***	***0.0***	***4.9***	***0.0***	***5.0***	
Hirschsprung disease (congenital megacolon)	1	2	0	2	0	5	
	2.8	***48.9***	***0.0***	***1.6***	***0.0***	***2.8***	
Hydrocephalus without spina bifida	2	0	0	4	0	7	
	5.7	***0.0***	***0.0***	***3.3***	***0.0***	***3.9***	
Hypoplastic left heart syndrome	1	0	0	2	0	3	
	2.8	***0.0***	***0.0***	***1.6***	***0.0***	***1.7***	
Hypospadias*	4	2	0	26	0	35	
	29.4	***57.5***	***0.0***	***39.0***	***0.0***	***37.7***	
Microcephalus	0	2	0	6	0	9	
	0.0	***48.9***	***0.0***	***4.9***	***0.0***	***5.0***	
Obstructive genitourinary defect	7	5	1	31	0	48	
	19.8	***122.2***	***120.5***	***25.5***	***0.0***	***26.8***	
Omphalocele	1	0	0	2	0	4	1
	2.8	***0.0***	***0.0***	***1.6***	***0.0***	***2.2***	

Hawaii

Birth Defects Counts and Prevalence 2005 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	30 ***84.8***	20 ***489.0***	4 ***481.9***	153 ***125.8***	2 ***74.1***	224 ***125.0***	2
Pulmonary valve atresia and stenosis	8 ***22.6***	7 ***171.1***	1 ***120.5***	27 ***22.2***	0 ***0.0***	46 ***25.7***	
Pyloric stenosis	1 ***2.8***	0 ***0.0***	0 ***0.0***	3 ***2.5***	0 ***0.0***	8 ***4.5***	
Rectal and large intestinal atresia/stenosis	1 ***2.8***	1 ***24.4***	0 ***0.0***	6 ***4.9***	0 ***0.0***	8 ***4.5***	
Reduction deformity, lower limbs	1 ***2.8***	0 ***0.0***	0 ***0.0***	1 ***0.8***	0 ***0.0***	2 ***1.1***	
Reduction deformity, upper limbs	3 ***8.5***	0 ***0.0***	0 ***0.0***	2 ***1.6***	0 ***0.0***	5 ***2.8***	
Renal agenesis/hypoplasia	1 ***2.8***	1 ***24.4***	0 ***0.0***	3 ***2.5***	0 ***0.0***	7 ***3.9***	
Spina bifida without anencephalus	3 ***8.5***	0 ***0.0***	0 ***0.0***	3 ***2.5***	0 ***0.0***	6 ***3.3***	
Tetralogy of Fallot	0 ***0.0***	2 ***48.9***	0 ***0.0***	2 ***1.6***	0 ***0.0***	4 ***2.2***	
Total anomalous pulmonary venous return (TAPVR)	1 ***2.8***	1 ***24.4***	0 ***0.0***	1 ***0.8***	0 ***0.0***	3 ***1.7***	
Transposition of great arteries - All	1 ***2.8***	0 ***0.0***	0 ***0.0***	5 ***4.1***	0 ***0.0***	7 ***3.9***	
Tricuspid valve atresia and stenosis	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Trisomy 13 (Patau syndrome)	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Trisomy 18 (Edwards syndrome)	1 ***2.8***	0 ***0.0***	0 ***0.0***	2 ***1.6***	0 ***0.0***	3 ***1.7***	
Ventricular septal defect	5 ***14.1***	6 ***146.7***	1 ***120.5***	58 ***47.7***	0 ***0.0***	77 ***43.0***	3
Total Live Births	**3539**	**409**	**83**	**12158**	**270**	**17922**	
Total Male Live Births	**1361**	**348**	**27**	**6673**	**142**	**9275**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Hawaii

Trisomy Counts and Prevalence by Maternal Age 2005 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	7 ***4.7***	9 ***28.5***	16 ***8.9***	
Trisomy 13 (Patau syndrome)	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Trisomy 18 (Edwards syndrome)	2 ***1.4***	1 ***3.2***	3 ***1.7***	
Total Live Births	**14762**	**3159**	**17922**	

**Total includes unknown maternal age

Notes
1.Omphalocele and Gastroschisis are reported separately as distinguished from active case ascertainment and by CDC/BPA codes.
2.Patent ductus arteriosus: Infants that weigh <2500 grams are excluded.
3.Ventricular septal defect: probable cases are included.

General comments
-2006-2009 data were not included in this report; however as of 2011, active case ascertainment is in progress for these years.
-Data includes stillbirths >/= 20 weeks gestational age.
-No major methodological changes to report during the period of 2005. Data collection completed by staff filling out an electronic file/report on laptop at facility.
-Pregnancies electively terminated after prenatal diagnosis are included in surveillance data regardless of the gestational age at which they were terminated.

Illinois

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	40	19	17	3	0	81	
	0.9	***1.2***	***0.8***	***0.6***	***0.0***	***0.9***	
Anencephalus	57	23	41	9	0	132	
	1.2	***1.5***	***1.9***	***1.9***	***0.0***	***1.5***	
Aniridia	2	0	0	1	0	3	
	0.0	***0.0***	***0.0***	***0.2***	***0.0***	***0.0***	
Anophthalmia/microphthalmia	51	14	27	5	0	100	
	1.1	***0.9***	***1.3***	***1.1***	***0.0***	***1.1***	
Anotia/microtia	43	11	59	5	0	121	
	0.9	***0.7***	***2.7***	***1.1***	***0.0***	***1.4***	
Aortic valve stenosis	73	9	14	3	0	101	
	1.6	***0.6***	***0.7***	***0.6***	***0.0***	***1.1***	
Atrial septal defect	1141	448	480	63	0	2177	
	24.3	***29.2***	***22.3***	***13.3***	***0.0***	***24.5***	
Atrioventricular septal defect (endocardial cushion defect)	213	83	67	6	0	371	
	4.5	***5.4***	***3.1***	***1.3***	***0.0***	***4.2***	
Biliary atresia	5	4	6	0	0	15	
	0.1	***0.3***	***0.3***	***0.0***	***0.0***	***0.2***	
Bladder exstrophy	15	3	4	0	0	22	
	0.3	***0.2***	***0.2***	***0.0***	***0.0***	***0.2***	
Choanal atresia	44	17	20	4	0	87	
	0.9	***1.1***	***0.9***	***0.8***	***0.0***	***1.0***	
Cleft lip with and without cleft palate	394	99	225	33	1	764	
	8.4	***6.4***	***10.5***	***6.9***	***8.5***	***8.6***	
Cleft palate without cleft lip	243	43	100	20	0	414	
	5.2	***2.8***	***4.7***	***4.2***	***0.0***	***4.7***	
Coarctation of aorta	140	33	57	5	0	240	
	3.0	***2.1***	***2.7***	***1.1***	***0.0***	***2.7***	
Common truncus	18	8	7	1	0	35	
	0.4	***0.5***	***0.3***	***0.2***	***0.0***	***0.4***	
Congenital cataract	29	19	15	1	0	65	
	0.6	***1.2***	***0.7***	***0.2***	***0.0***	***0.7***	
Congenital hip dislocation	192	14	73	9	0	294	
	4.1	***0.9***	***3.4***	***1.9***	***0.0***	***3.3***	
Diaphragmatic hernia	100	40	53	8	1	208	
	2.1	***2.6***	***2.5***	***1.7***	***8.5***	***2.3***	
Down syndrome (Trisomy 21)	594	157	334	39	3	1150	
	12.7	***10.2***	***15.5***	***8.2***	***25.4***	***13.0***	
Ebstein anomaly	24	3	18	0	0	46	
	0.5	***0.2***	***0.8***	***0.0***	***0.0***	***0.5***	
Encephalocele	22	19	20	3	0	65	
	0.5	***1.2***	***0.9***	***0.6***	***0.0***	***0.7***	
Epispadias	52	21	16	1	0	90	
	1.1	***1.4***	***0.7***	***0.2***	***0.0***	***1.0***	
Esophageal atresia/tracheoesophageal fistula	109	30	35	6	0	183	
	2.3	***2.0***	***1.6***	***1.3***	***0.0***	***2.1***	
Fetus or newborn affected by maternal alcohol use	8	11	3	0	0	23	
	0.2	***0.7***	***0.1***	***0.0***	***0.0***	***0.3***	
Gastroschisis	153	67	119	5	0	349	
	3.3	***4.4***	***5.5***	***1.1***	***0.0***	***3.9***	
Hirschsprung disease (congenital megacolon)	46	26	12	4	0	90	
	1.0	***1.7***	***0.6***	***0.8***	***0.0***	***1.0***	
Hydrocephalus without spina bifida	279	183	168	14	3	659	
	6.0	***11.9***	***7.8***	***2.9***	***25.4***	***7.4***	
Hypoplastic left heart syndrome	86	31	40	4	0	166	
	1.8	***2.0***	***1.9***	***0.8***	***0.0***	***1.9***	
Hypospadias*	1434	372	284	68	0	2208	
	40.1	***27.6***	***14.9***	***27.9***	***0.0***	***31.1***	
Microcephalus	164	141	90	10	0	410	
	3.5	***9.2***	***4.2***	***2.1***	***0.0***	***4.6***	
Obstructive genitourinary defect	1177	304	507	104	0	2135	
	25.1	***19.8***	***23.6***	***21.9***	***0.0***	***24.1***	
Omphalocele	72	26	33	1	0	135	
	1.5	***1.7***	***1.5***	***0.2***	***0.0***	***1.5***	

Illinois

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	1023	335	427	66	0	1891	1
	21.8	***21.8***	***19.9***	***13.9***	***0.0***	***21.3***	
Pulmonary valve atresia and stenosis	136	52	43	7	0	244	
	2.9	***3.4***	***2.0***	***1.5***	***0.0***	***2.7***	
Pulmonary valve atresia	22	7	8	2	0	40	
	0.5	***0.5***	***0.4***	***0.4***	***0.0***	***0.5***	
Pyloric stenosis	28	4	8	0	0	40	
	0.6	***0.3***	***0.4***	***0.0***	***0.0***	***0.5***	
Rectal and large intestinal atresia/stenosis	152	55	79	19	1	312	
	3.2	***3.6***	***3.7***	***4.0***	***8.5***	***3.5***	
Reduction deformity, lower limbs	78	24	22	4	2	133	
	1.7	***1.6***	***1.0***	***0.8***	***16.9***	***1.5***	
Reduction deformity, upper limbs	136	49	49	8	2	249	
	2.9	***3.2***	***2.3***	***1.7***	***16.9***	***2.8***	
Renal agenesis/hypoplasia	207	58	90	11	0	373	
	4.4	***3.8***	***4.2***	***2.3***	***0.0***	***4.2***	
Spina bifida without anencephalus	130	34	65	6	4	243	
	2.8	***2.2***	***3.0***	***1.3***	***33.8***	***2.7***	
Tetralogy of Fallot	130	61	55	17	0	271	
	2.8	***4.0***	***2.6***	***3.6***	***0.0***	***3.1***	
Total anomalous pulmonary venous return (TAPVR)	22	8	20	5	0	56	
	0.5	***0.5***	***0.9***	***1.1***	***0.0***	***0.6***	
Transposition of great arteries - All	137	35	51	12	0	243	
	2.9	***2.3***	***2.4***	***2.5***	***0.0***	***2.7***	
dextro-Transposition of great arteries (d-TGA)	72	18	25	5	0	124	
	1.5	***1.2***	***1.2***	***1.1***	***0.0***	***1.4***	
Tricuspid valve atresia and stenosis	67	28	34	4	0	135	
	1.4	***1.8***	***1.6***	***0.8***	***0.0***	***1.5***	
Tricuspid valve atresia	63	26	25	4	0	120	
	1.3	***1.7***	***1.2***	***0.8***	***0.0***	***1.4***	
Trisomy 13 (Patau syndrome)	59	18	22	1	2	104	
	1.3	***1.2***	***1.0***	***0.2***	***16.9***	***1.2***	
Trisomy 18 (Edwards syndrome)	102	41	43	6	4	198	
	2.2	***2.7***	***2.0***	***1.3***	***33.8***	***2.2***	
Ventricular septal defect	1752	454	858	102	0	3228	
	37.4	***29.6***	***39.9***	***21.5***	***0.0***	***36.4***	
Total Live Births	**468624**	**153630**	**214912**	**47544**	**1183**	**887616**	
Total Male Live Births	**358043**	**134849**	**190622**	**24383**	**602**	**709479**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Illinois

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	541 ***7.2***	583 ***42.3***	1150 ***13.0***	
Trisomy 13 (Patau syndrome)	62 ***0.8***	30 ***2.2***	104 ***1.2***	
Trisomy 18 (Edwards syndrome)	70 ***0.9***	84 ***6.1***	198 ***2.2***	
Total Live Births	**749761**	**137749**	**887616**	

**Total includes unknown maternal age

Notes
1.Only includes cases where the birth weight >=2500g

General comments
-Illinois is under court order that strictly limits the data that can be collected about a termination. The birth defect registry is therefore unable to obtain birth defect information
-In 2009, Illinois reduced the number of charts that were reviewed for birth defects, dropping primarily children with very low-birth weights and no reported associated birth defects

Indiana

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	11	2	1	1	0	16	1
	0.3	***0.4***	***0.3***	***1.1***	***0.0***	***0.4***	
Aniridia	11	2	1	0	0	14	
	0.3	***0.4***	***0.3***	***0.0***	***0.0***	***0.3***	
Anophthalmia/microphthalmia	19	2	3	1	0	27	
	0.6	***0.4***	***0.8***	***1.1***	***0.0***	***0.6***	
Anotia/microtia	29	2	3	0	0	35	
	0.9	***0.4***	***0.8***	***0.0***	***0.0***	***0.8***	
Aortic valve stenosis	49	4	2	0	0	57	
	1.5	***0.7***	***0.5***	***0.0***	***0.0***	***1.3***	
Atrial septal defect	1161	168	96	35	2	1491	2
	36.2	***30.6***	***25.0***	***37.5***	***24.0***	***34.1***	
Atrioventricular septal defect (endocardial cushion defect)	112	11	10	4	1	140	3
	4.4	***2.5***	***3.1***	***5.8***	***14.1***	***4.0***	
Biliary atresia	19	8	4	1	0	32	
	0.6	***1.5***	***1.0***	***1.1***	***0.0***	***0.7***	
Bladder exstrophy	13	1	0	0	0	15	
	0.4	***0.2***	***0.0***	***0.0***	***0.0***	***0.3***	
Choanal atresia	46	3	5	0	0	56	
	1.4	***0.5***	***1.3***	***0.0***	***0.0***	***1.3***	
Cleft lip with and without cleft palate	289	24	39	11	1	371	
	9.0	***4.4***	***10.2***	***11.8***	***12.0***	***8.5***	
Cleft palate without cleft lip	235	23	10	4	0	278	
	7.3	***4.2***	***2.6***	***4.3***	***0.0***	***6.4***	
Coarctation of aorta	193	18	24	4	0	244	
	6.0	***3.3***	***6.2***	***4.3***	***0.0***	***5.6***	
Common truncus	12	1	1	1	0	15	
	0.4	***0.2***	***0.3***	***1.1***	***0.0***	***0.3***	
Congenital cataract	20	5	0	1	0	28	
	0.6	***0.9***	***0.0***	***1.1***	***0.0***	***0.6***	
Congenital hip dislocation	243	13	24	4	0	289	
	7.6	***2.4***	***6.2***	***4.3***	***0.0***	***6.6***	
Diaphragmatic hernia	86	12	14	1	0	115	
	2.7	***2.2***	***3.6***	***1.1***	***0.0***	***2.6***	
Down syndrome (Trisomy 21)	399	40	62	13	1	524	
	12.5	***7.3***	***16.1***	***13.9***	***12.0***	***12.0***	
Ebstein anomaly	22	1	2	1	0	26	
	0.7	***0.2***	***0.5***	***1.1***	***0.0***	***0.6***	
Encephalocele	22	1	4	0	0	27	
	0.7	***0.2***	***1.0***	***0.0***	***0.0***	***0.6***	
Epispadias	27	8	1	1	0	37	4
	0.8	***1.5***	***0.3***	***1.1***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	87	8	12	1	1	109	
	2.7	***1.5***	***3.1***	***1.1***	***12.0***	***2.5***	
Fetus or newborn affected by maternal alcohol use	105	24	7	13	0	153	
	3.3	***4.4***	***1.8***	***13.9***	***0.0***	***3.5***	
Gastroschisis	142	19	20	2	0	188	5
	4.4	***3.5***	***5.2***	***2.1***	***0.0***	***4.3***	
Hirschsprung disease (congenital megacolon)	66	12	9	1	0	92	
	2.1	***2.2***	***2.3***	***1.1***	***0.0***	***2.1***	
Hydrocephalus without spina bifida	374	64	26	8	1	480	
	11.7	***11.7***	***6.8***	***8.6***	***12.0***	***11.0***	
Hypoplastic left heart syndrome	56	9	8	2	0	76	
	1.7	***1.6***	***2.1***	***2.1***	***0.0***	***1.7***	
Hypospadias*	1151	124	42	15	1	1351	4
	70.2	***45.4***	***21.6***	***30.9***	***25.3***	***60.5***	
Microcephalus	300	58	34	16	1	416	
	9.4	***10.6***	***8.9***	***17.2***	***12.0***	***9.5***	
Obstructive genitourinary defect	768	91	76	19	1	971	
	24.0	***16.6***	***19.8***	***20.4***	***12.0***	***22.2***	
Omphalocele	19	7	3	0	0	29	5
	0.6	***1.3***	***0.8***	***0.0***	***0.0***	***0.7***	
Patent ductus arteriosus	504	129	56	16	2	718	6
	15.7	***23.5***	***14.6***	***17.2***	***24.0***	***16.4***	

Indiana

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	242	41	19	7	1	315	
	7.6	***7.5***	***4.9***	***7.5***	***12.0***	***7.2***	
Pyloric stenosis	882	68	96	6	4	1075	
	27.5	***12.4***	***25.0***	***6.4***	***48.1***	***24.6***	
Rectal and large intestinal atresia/stenosis	151	13	18	5	1	189	
	4.7	***2.4***	***4.7***	***5.4***	***12.0***	***4.3***	
Reduction deformity, lower limbs	44	10	9	1	0	65	
	1.4	***1.8***	***2.3***	***1.1***	***0.0***	***1.5***	
Reduction deformity, upper limbs	75	8	13	1	0	97	
	2.3	***1.5***	***3.4***	***1.1***	***0.0***	***2.2***	
Renal agenesis/hypoplasia	106	9	15	1	1	133	
	3.3	***1.6***	***3.9***	***1.1***	***12.0***	***3.0***	
Spina bifida without anencephalus	143	15	21	1	0	183	7
	4.5	***2.7***	***5.5***	***1.1***	***0.0***	***4.2***	
Tetralogy of Fallot	96	14	14	2	0	129	
	3.0	***2.6***	***3.6***	***2.1***	***0.0***	***3.0***	
Total anomalous pulmonary venous return (TAPVR)	21	4	3	0	0	29	
	0.7	***0.7***	***0.8***	***0.0***	***0.0***	***0.7***	
Transposition of great arteries - All	149	20	14	0	0	190	8
	4.7	***3.6***	***3.6***	***0.0***	***0.0***	***4.4***	
Tricuspid valve atresia and stenosis	26	4	4	0	0	34	9
	0.8	***0.7***	***1.0***	***0.0***	***0.0***	***0.8***	
Trisomy 13 (Patau syndrome)	13	3	5	0	0	22	
	0.4	***0.5***	***1.3***	***0.0***	***0.0***	***0.5***	
Trisomy 18 (Edwards syndrome)	35	10	1	0	1	49	
	1.1	***1.8***	***0.3***	***0.0***	***12.0***	***1.1***	
Ventricular septal defect	1312	136	134	42	0	1648	10
	40.9	***24.8***	***34.9***	***45.0***	***0.0***	***37.7***	
Total Live Births	**320405**	**54843**	**38409**	**9325**	**832**	**436733**	
Total Male Live Births	**163976**	**27314**	**19413**	**4852**	**396**	**223437**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Indiana

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	346	178	524	
	8.7	***47.6***	***12.0***	
Trisomy 13 (Patau syndrome)	19	3	22	
	0.5	***0.8***	***0.5***	
Trisomy 18 (Edwards syndrome)	36	13	49	
	0.9	***3.5***	***1.1***	
Total Live Births	**399093**	**37428**	**436733**	

**Total includes unknown maternal age

Notes

1.Ancephalus: Indiana does not collect or report information on stillbirths or terminations. Data reported is based on livebirths (2005-2009).
2.Atrial septal defect: A more stringent classification was recently adopted. This classification was only applied to 2005 data.
3.Atrioventricular septal defect: Data does not distinguish BPA code 745.487 (2005-2009).
4.Prior to July 2009, all children reported with either hypospadias or epispadias were reviewed for a combined disorder of 'hypospadias/epispadias.' Since that time our system was modified and children are currently reviewed for hypospadius and epispadias separately.
5.Indiana utilizes BPA codes to differentiate gastroschisis from omphalocele.
6.Patent ductus arterious: Data reported for children who were gestational age e 36 weeks at birth and whose PDA was last noted at e 6 weeks of age (2005-2009). Unable to exclude < 2500 grams infants.
7.Spina bifida with anencephalus: Indiana does not collect or report information on stillbirths or terminations. Data reported is based on livebirths (2005-2009).
8.Transposition of great arteries: Data includes entire coding range of 745.10 - 745.19 (2005-2009).
9.Tricuspid valve atresia and stenosis: Data does not distinguish BPA codes 746.105 or 746.106 (2005-2009).
10.Ventricular septal defect: Data does not distinguish BPA code 745.487 (2005-2009). Probable cases included.

General comments

-Birth defects rates based on fewer than 20 cases are unstable.
-Case ascertainment in Indiana is a combination of passive ascertainment by electronic submission of hospital discharge information and active ascertainment through chart auditing of 45 targeted conditions identified trhough hospital discharge ICD-9-CM codes.
-Data includes children whose conditions were classified with a status of either 'confirmed' or 'probable' based on the abstracted information.
-Report based on data as of 08/16/2012. As additional information is constantly entering the system, updated data for birth years 2006-2009 will be submitted, along with 2010 data, in the next report.
-The IBDPR changed how maternal residency was defined in 2012

Iowa

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	19 ***1.1***	4 ***4.9***	1 ***0.6***	1 ***2.1***	0 ***0.0***	26 ***1.3***	
Anencephalus	49 ***2.9***	3 ***3.7***	7 ***4.3***	1 ***2.1***	0 ***0.0***	63 ***3.1***	
Aniridia	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Anophthalmia/microphthalmia	36 ***2.1***	4 ***4.9***	7 ***4.3***	2 ***4.2***	1 ***9.8***	50 ***2.5***	
Anotia/microtia	31 ***1.8***	1 ***1.2***	7 ***4.3***	0 ***0.0***	0 ***0.0***	40 ***2.0***	
Aortic valve stenosis	56 ***3.3***	2 ***2.5***	0 ***0.0***	1 ***2.1***	2 ***19.6***	61 ***3.0***	
Atrial septal defect	522 ***30.9***	34 ***41.7***	38 ***23.3***	9 ***19.0***	6 ***58.7***	611 ***30.5***	
Atrioventricular septal defect (endocardial cushion defect)	117 ***6.9***	7 ***8.6***	11 ***6.7***	3 ***6.3***	0 ***0.0***	138 ***6.9***	
Biliary atresia	7 ***0.4***	1 ***1.2***	0 ***0.0***	0 ***0.0***	0 ***0.0***	8 ***0.4***	
Bladder exstrophy	8 ***0.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	8 ***0.4***	
Choanal atresia	33 ***2.0***	1 ***1.2***	2 ***1.2***	1 ***2.1***	0 ***0.0***	37 ***1.8***	
Cleft lip with and without cleft palate	180 ***10.7***	8 ***9.8***	17 ***10.4***	5 ***10.6***	2 ***19.6***	212 ***10.6***	
Cleft palate without cleft lip	111 ***6.6***	3 ***3.7***	13 ***8.0***	2 ***4.2***	1 ***9.8***	130 ***6.5***	
Coarctation of aorta	91 ***5.4***	3 ***3.7***	4 ***2.5***	1 ***2.1***	1 ***9.8***	100 ***5.0***	
Common truncus	12 ***0.7***	0 ***0.0***	0 ***0.0***	1 ***2.1***	0 ***0.0***	13 ***0.6***	
Congenital cataract	41 ***2.4***	1 ***1.2***	5 ***3.1***	2 ***4.2***	1 ***9.8***	50 ***2.5***	
Congenital hip dislocation	107 ***6.3***	4 ***4.9***	7 ***4.3***	3 ***6.3***	0 ***0.0***	121 ***6.0***	
Diaphragmatic hernia	21 ***1.2***	1 ***1.2***	1 ***0.6***	0 ***0.0***	0 ***0.0***	23 ***1.1***	
Down syndrome (Trisomy 21)	243 ***14.4***	5 ***6.1***	41 ***25.1***	9 ***19.0***	0 ***0.0***	303 ***15.1***	
Ebstein anomaly	14 ***0.8***	0 ***0.0***	1 ***0.6***	1 ***2.1***	0 ***0.0***	16 ***0.8***	
Encephalocele	20 ***1.2***	1 ***1.2***	1 ***0.6***	0 ***0.0***	0 ***0.0***	23 ***1.1***	
Epispadias	9 ***0.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	9 ***0.4***	
Esophageal atresia/tracheoesophageal fistula	30 ***1.8***	0 ***0.0***	2 ***1.2***	2 ***4.2***	0 ***0.0***	34 ***1.7***	
Fetus or newborn affected by maternal alcohol use	8 ***0.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	9 ***0.4***	
Gastroschisis	68 ***4.0***	4 ***4.9***	12 ***7.4***	3 ***6.3***	3 ***29.3***	90 ***4.5***	
Hirschsprung disease (congenital megacolon)	29 ***1.7***	3 ***3.7***	3 ***1.8***	0 ***0.0***	1 ***9.8***	36 ***1.8***	
Hydrocephalus without spina bifida	190 ***11.2***	11 ***13.5***	15 ***9.2***	8 ***16.9***	1 ***9.8***	227 ***11.3***	
Hypoplastic left heart syndrome	39 ***2.3***	1 ***1.2***	3 ***1.8***	0 ***0.0***	0 ***0.0***	43 ***2.1***	
Hypospadias*	404 ***46.6***	18 ***43.6***	22 ***26.3***	7 ***29.2***	1 ***18.8***	452 ***44.0***	
Microcephalus	181 ***10.7***	15 ***18.4***	18 ***11.0***	3 ***6.3***	1 ***9.8***	219 ***10.9***	
Obstructive genitourinary defect	461 ***27.3***	22 ***27.0***	51 ***31.2***	12 ***25.3***	2 ***19.6***	550 ***27.4***	
Omphalocele	51 ***3.0***	2 ***2.5***	1 ***0.6***	1 ***2.1***	0 ***0.0***	55 ***2.7***	

Iowa

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	465	15	57	14	4	557	
	27.5	***18.4***	***34.9***	***29.6***	***39.1***	***27.8***	
Pulmonary valve atresia and stenosis	196	9	11	6	2	225	
	11.6	***11.1***	***6.7***	***12.7***	***19.6***	***11.2***	
Pulmonary valve atresia	22	2	1	1	0	26	
	1.3	***2.5***	***0.6***	***2.1***	***0.0***	***1.3***	
Pyloric stenosis	435	14	36	1	4	491	
	25.7	***17.2***	***22.1***	***2.1***	***39.1***	***24.5***	
Rectal and large intestinal atresia/stenosis	77	4	15	3	0	99	
	4.6	***4.9***	***9.2***	***6.3***	***0.0***	***4.9***	
Reduction deformity, lower limbs	33	5	3	2	0	43	
	2.0	***6.1***	***1.8***	***4.2***	***0.0***	***2.1***	
Reduction deformity, upper limbs	70	8	10	2	1	91	
	4.1	***9.8***	***6.1***	***4.2***	***9.8***	***4.5***	
Renal agenesis/hypoplasia	125	6	9	5	0	146	
	7.4	***7.4***	***5.5***	***10.6***	***0.0***	***7.3***	
Spina bifida without anencephalus	76	7	13	2	1	99	
	4.5	***8.6***	***8.0***	***4.2***	***9.8***	***4.9***	
Tetralogy of Fallot	68	2	10	1	0	82	
	4.0	***2.5***	***6.1***	***2.1***	***0.0***	***4.1***	
Total anomalous pulmonary venous return (TAPVR)	21	0	2	0	1	24	
	1.2	***0.0***	***1.2***	***0.0***	***9.8***	***1.2***	
Transposition of great arteries - All	57	2	3	2	0	64	
	3.4	***2.5***	***1.8***	***4.2***	***0.0***	***3.2***	
dextro-Transposition of great arteries (d-TGA)	47	1	3	2	0	53	
	2.8	***1.2***	***1.8***	***4.2***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	41	1	3	0	1	47	
	2.4	***1.2***	***1.8***	***0.0***	***9.8***	***2.3***	
Tricuspid valve atresia	20	1	2	0	1	24	
	1.2	***1.2***	***1.2***	***0.0***	***9.8***	***1.2***	
Trisomy 13 (Patau syndrome)	30	1	3	1	0	35	
	1.8	***1.2***	***1.8***	***2.1***	***0.0***	***1.7***	
Trisomy 18 (Edwards syndrome)	51	3	6	1	0	61	
	3.0	***3.7***	***3.7***	***2.1***	***0.0***	***3.0***	
Ventricular septal defect	923	35	85	18	8	1071	
	54.6	***43.0***	***52.1***	***38.0***	***78.2***	***53.4***	
Total Live Births	**169001**	**8144**	**16324**	**4734**	**1023**	**200585**	
Total Male Live Births	**86711**	**4133**	**8353**	**2395**	**533**	**102811**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Iowa

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	165 ***9.2***	137 ***63.0***	303 ***15.1***	
Trisomy 13 (Patau syndrome)	24 ***1.3***	11 ***5.1***	35 ***1.7***	
Trisomy 18 (Edwards syndrome)	33 ***1.8***	28 ***12.9***	61 ***3.0***	
Total Live Births	**178826**	**21748**	**200585**	

**Total includes unknown maternal age

Kentucky

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Anencephalus	42 ***1.8***	<5 ***.***	5 ***3.6***	0 ***0.0***	0 ***0.0***	51 ***1.8***	
Aniridia	<5 ***.***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	<5 ***.***	
Anophthalmia/microphthalmia	12 ***0.5***	<5 ***.***	0 ***0.0***	0 ***0.0***	0 ***0.0***	14 ***0.5***	
Anotia/microtia	9 ***0.4***	<5 ***.***	6 ***4.3***	<5 ***.***	0 ***0.0***	17 ***0.6***	
Aortic valve stenosis	32 ***1.3***	5 ***1.9***	<5 ***.***	<5 ***.***	0 ***0.0***	40 ***1.4***	
Atrial septal defect	3614 ***152.1***	825 ***317.4***	188 ***135.0***	48 ***124.0***	5 ***139.7***	4821 ***170.3***	1
Atrioventricular septal defect (endocardial cushion defect)	79 ***3.3***	13 ***5.0***	<5 ***.***	<5 ***.***	0 ***0.0***	98 ***3.5***	
Biliary atresia	14 ***0.6***	<5 ***.***	<5 ***.***	0 ***0.0***	0 ***0.0***	17 ***0.6***	
Bladder exstrophy	<5 ***.***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	5 ***0.2***	
Choanal atresia	24 ***1.0***	<5 ***.***	<5 ***.***	0 ***0.0***	0 ***0.0***	29 ***1.0***	
Cleft lip with and without cleft palate	246 ***10.4***	19 ***7.3***	15 ***10.8***	<5 ***.***	0 ***0.0***	295 ***10.4***	
Cleft palate without cleft lip	119 ***5.0***	10 ***3.8***	<5 ***.***	<5 ***.***	0 ***0.0***	139 ***4.9***	
Coarctation of aorta	142 ***6.0***	13 ***5.0***	5 ***3.6***	<5 ***.***	0 ***0.0***	161 ***5.7***	
Common truncus	9 ***0.4***	<5 ***.***	<5 ***.***	0 ***0.0***	0 ***0.0***	12 ***0.4***	
Congenital cataract	17 ***0.7***	<5 ***.***	<5 ***.***	0 ***0.0***	0 ***0.0***	20 ***0.7***	
Congenital hip dislocation	181 ***7.6***	9 ***3.5***	8 ***5.7***	<5 ***.***	0 ***0.0***	209 ***7.4***	
Diaphragmatic hernia	56 ***2.4***	7 ***2.7***	<5 ***.***	0 ***0.0***	0 ***0.0***	68 ***2.4***	
Down syndrome (Trisomy 21)	280 ***11.8***	32 ***12.3***	23 ***16.5***	8 ***20.7***	0 ***0.0***	356 ***12.6***	
Ebstein anomaly	15 ***0.6***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	15 ***0.5***	
Encephalocele	11 ***0.5***	0 ***0.0***	<5 ***.***	0 ***0.0***	0 ***0.0***	12 ***0.4***	
Epispadias	19 ***1.4***	<5 ***.***	0 ***0.0***	0 ***0.0***	0 ***0.0***	23 ***1.4***	
Esophageal atresia/tracheoesophageal fistula	56 ***2.4***	5 ***1.9***	<5 ***.***	<5 ***.***	0 ***0.0***	67 ***2.4***	
Fetus or newborn affected by maternal alcohol use	20 ***0.8***	13 ***5.0***	<5 ***.***	0 ***0.0***	0 ***0.0***	41 ***1.4***	
Gastroschisis	83 ***3.5***	7 ***2.7***	7 ***5.0***	0 ***0.0***	0 ***0.0***	106 ***3.7***	
Hirschsprung disease (congenital megacolon)	49 ***2.1***	13 ***5.0***	<5 ***.***	<5 ***.***	0 ***0.0***	69 ***2.4***	
Hydrocephalus without spina bifida	125 ***5.3***	10 ***3.8***	<5 ***.***	<5 ***.***	<5 ***.***	141 ***5.0***	
Hypoplastic left heart syndrome	58 ***2.4***	9 ***3.5***	6 ***4.3***	0 ***0.0***	0 ***0.0***	77 ***2.7***	
Hypospadias*	918 ***75.4***	98 ***74.2***	30 ***42.4***	<5 ***.***	<5 ***.***	1157 ***79.9***	
Microcephalus	75 ***3.2***	16 ***6.2***	<5 ***.***	0 ***0.0***	0 ***0.0***	94 ***3.3***	
Obstructive genitourinary defect	477 ***20.1***	46 ***17.7***	34 ***24.4***	8 ***20.7***	<5 ***.***	580 ***20.5***	
Omphalocele	23 ***1.0***	6 ***2.3***	<5 ***.***	0 ***0.0***	0 ***0.0***	33 ***1.2***	

Kentucky
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	1661	356	92	19	<5	2150	2
	69.9	***137.0***	***66.1***	***49.1***	**.**	***75.9***	
Pulmonary valve atresia and stenosis	181	19	7	<5	0	209	
	7.6	***7.3***	***5.0***	**.**	***0.0***	***7.4***	
Pyloric stenosis	876	42	22	<5	<5	952	
	36.9	***16.2***	***15.8***	**.**	**.**	***33.6***	
Rectal and large intestinal atresia/stenosis	122	20	7	5	0	161	
	5.1	***7.7***	***5.0***	***12.9***	***0.0***	***5.7***	
Reduction deformity, lower limbs	37	<5	<5	0	0	47	
	1.6	**.**	**.**	***0.0***	***0.0***	***1.7***	
Reduction deformity, upper limbs	43	<5	<5	<5	<5	51	
	1.8	**.**	**.**	**.**	**.**	***1.8***	
Renal agenesis/hypoplasia	87	8	<5	<5	0	102	
	3.7	***3.1***	**.**	**.**	***0.0***	***3.6***	
Spina bifida without anencephalus	86	11	<5	0	0	101	
	3.6	***4.2***	**.**	***0.0***	***0.0***	***3.6***	
Tetralogy of Fallot	80	9	<5	0	0	92	
	3.4	***3.5***	**.**	***0.0***	***0.0***	***3.2***	
Total anomalous pulmonary venous return (TAPVR)	7	0	0	0	0	7	
	1.5	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Transposition of great arteries - All	89	10	5	<5	0	108	
	3.7	***3.8***	***3.6***	**.**	***0.0***	***3.8***	
Tricuspid valve atresia and stenosis	22	<5	<5	<5	0	26	
	0.9	**.**	**.**	**.**	***0.0***	***0.9***	
Trisomy 13 (Patau syndrome)	19	0	<5	0	0	25	
	0.8	***0.0***	**.**	***0.0***	***0.0***	***0.9***	
Trisomy 18 (Edwards syndrome)	34	6	<5	0	0	50	
	1.4	***2.3***	**.**	***0.0***	***0.0***	***1.8***	
Ventricular septal defect	1041	142	63	15	0	1309	3
	43.8	***54.6***	***45.2***	***38.7***	***0.0***	***46.2***	
Total Live Births	**237656**	**25992**	**13924**	**3872**	**358**	**283168**	
Total Male Live Births	**121695**	**13215**	**7070**	**2008**	**187**	**144867**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Kentucky

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	213 ***8.3***	135 ***49.5***	356 ***12.6***	
Trisomy 13 (Patau syndrome)	18 ***0.7***	6 ***2.2***	25 ***0.9***	
Trisomy 18 (Edwards syndrome)	33 ***1.3***	11 ***4.0***	50 ***1.8***	
Total Live Births	**255588**	**27252**	**283168**	

**Total includes unknown maternal age

Notes
1.Atrial septal defect: Probable cases are included
2.Patent ductus arteriosus: includes only babies over 2500 g
3.Ventricular septal defect: Probable cases are included

General comments
-2007-2009 data is preliminary
-Although some terminations are issued stillbirth certificates, we do not collect data about terminations
-Use ICD-9 codes

Louisiana

Birth Defects Counts and Prevalence 2005-2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	8 *1.1*	6 *1.1*	<5 *.*	0 *0.0*	0 *0.0*	15 *1.1*	
Anencephalus	10 *1.1*	8 *1.2*	0 *0.0*	0 *0.0*	0 *0.0*	18 *1.1*	
Aniridia	0 *0.0*	<5 *.*	0 *0.0*	0 *0.0*	0 *0.0*	<5 *.*	
Anophthalmia/microphthalmia	9 *1.0*	6 *0.9*	0 *0.0*	0 *0.0*	0 *0.0*	15 *0.9*	
Anotia/microtia	9 *1.0*	0 *0.0*	<5 *.*	0 *0.0*	0 *0.0*	12 *0.7*	
Aortic valve stenosis	19 *2.2*	11 *1.6*	0 *0.0*	<5 *.*	0 *0.0*	31 *1.8*	
Atrial septal defect	494 *56.5*	371 *53.7*	42 *51.0*	19 *59.4*	5 *72.3*	933 *55.1*	
Atrioventricular septal defect (endocardial cushion defect)	63 *7.2*	32 *4.6*	<5 *.*	5 *15.6*	0 *0.0*	104 *6.1*	
Biliary atresia	11 *1.3*	8 *1.2*	<5 *.*	<5 *.*	0 *0.0*	22 *1.3*	
Bladder exstrophy	5 *0.6*	<5 *.*	<5 *.*	0 *0.0*	<5 *.*	10 *0.6*	
Choanal atresia	14 *1.6*	8 *1.2*	<5 *.*	0 *0.0*	0 *0.0*	25 *1.5*	
Cleft lip with and without cleft palate	84 *9.6*	46 *6.7*	13 *15.8*	<5 *.*	<5 *.*	147 *8.7*	
Cleft palate without cleft lip	73 *8.3*	35 *5.1*	6 *7.3*	<5 *.*	0 *0.0*	116 *6.9*	
Coarctation of aorta	38 *4.3*	28 *4.1*	5 *6.1*	<5 *.*	0 *0.0*	72 *4.3*	
Common truncus	12 *1.4*	5 *0.7*	0 *0.0*	<5 *.*	0 *0.0*	18 *1.1*	
Congenital cataract	11 *1.3*	12 *1.7*	<5 *.*	0 *0.0*	0 *0.0*	24 *1.4*	
Congenital hip dislocation	62 *7.1*	20 *2.9*	<5 *.*	<5 *.*	<5 *.*	88 *5.2*	
Diaphragmatic hernia	27 *3.1*	12 *1.7*	5 *6.1*	0 *0.0*	0 *0.0*	44 *2.6*	
Down syndrome (Trisomy 21)	136 *15.5*	60 *8.7*	10 *12.1*	11 *34.4*	<5 *.*	218 *12.9*	
Ebstein anomaly	7 *1.0*	5 *0.9*	<5 *.*	0 *0.0*	0 *0.0*	13 *1.0*	
Encephalocele	7 *0.8*	10 *1.4*	<5 *.*	0 *0.0*	0 *0.0*	18 *1.1*	
Epispadias	12 *1.4*	8 *1.2*	0 *0.0*	0 *0.0*	0 *0.0*	20 *1.2*	
Esophageal atresia/tracheoesophageal fistula	22 *2.5*	15 *2.2*	<5 *.*	<5 *.*	0 *0.0*	40 *2.4*	
Fetus or newborn affected by maternal alcohol use	9 *1.3*	13 *2.4*	<5 *.*	0 *0.0*	<5 *.*	24 *1.8*	
Gastroschisis	55 *6.3*	22 *3.2*	0 *0.0*	0 *0.0*	0 *0.0*	77 *4.5*	
Hirschsprung disease (congenital megacolon)	27 *3.1*	23 *3.3*	<5 *.*	0 *0.0*	0 *0.0*	51 *3.0*	
Hydrocephalus without spina bifida	46 *5.3*	52 *7.5*	5 *6.1*	<5 *.*	<5 *.*	107 *6.3*	
Hypoplastic left heart syndrome	12 *1.4*	12 *1.7*	<5 *.*	0 *0.0*	<5 *.*	27 *1.6*	
Hypospadias*	344 *76.8*	189 *53.8*	11 *26.2*	<5 *.*	<5 *.*	551 *63.8*	
Microcephalus	72 *8.2*	99 *14.3*	6 *7.3*	<5 *.*	0 *0.0*	179 *10.6*	
Obstructive genitourinary defect	257 *29.4*	153 *22.1*	17 *20.6*	5 *15.6*	<5 *.*	435 *25.7*	
Omphalocele	12 *1.4*	16 *2.3*	<5 *.*	0 *0.0*	<5 *.*	31 *1.8*	

Louisiana

Birth Defects Counts and Prevalence 2005-2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	343	212	23	9	<5	588	1
	39.2	***30.7***	***27.9***	***28.2***	**.**	***34.7***	
Pulmonary valve atresia and stenosis	74	54	<5	<5	0	135	
	8.5	***7.8***	**.**	**.**	***0.0***	***8.0***	
Pulmonary valve atresia	13	8	0	0	0	21	
	1.5	***1.2***	***0.0***	***0.0***	***0.0***	***1.2***	
Pyloric stenosis	148	42	12	<5	<5	207	
	16.9	***6.1***	***14.6***	**.**	**.**	***12.2***	
Rectal and large intestinal atresia/stenosis	42	25	<5	<5	<5	74	
	4.8	***3.6***	**.**	**.**	**.**	***4.4***	
Reduction deformity, lower limbs	12	15	<5	0	0	29	
	1.4	***2.2***	**.**	***0.0***	***0.0***	***1.7***	
Reduction deformity, upper limbs	19	19	<5	0	0	41	
	2.2	***2.7***	**.**	***0.0***	***0.0***	***2.4***	
Renal agenesis/hypoplasia	47	33	<5	0	0	82	
	5.4	***4.8***	**.**	***0.0***	***0.0***	***4.8***	
Spina bifida without anencephalus	35	14	<5	<5	0	53	
	4.0	***2.0***	**.**	**.**	***0.0***	***3.1***	
Tetralogy of Fallot	44	27	<5	0	0	74	
	5.0	***3.9***	**.**	***0.0***	***0.0***	***4.4***	
Transposition of great arteries - All	41	19	<5	<5	<5	63	
	4.7	***2.7***	**.**	**.**	**.**	***3.7***	
dextro-Transposition of great arteries (d-TGA)	37	18	<5	<5	<5	58	
	4.2	***2.6***	**.**	**.**	**.**	***3.4***	
Tricuspid valve atresia and stenosis	<5	11	<5	<5	0	17	
	.	***1.6***	**.**	**.**	***0.0***	***1.0***	
Tricuspid valve atresia	<5	9	<5	<5	0	15	
	.	***1.3***	**.**	**.**	***0.0***	***0.9***	
Trisomy 13 (Patau syndrome)	<5	<5	<5	0	0	9	
	.	**.**	**.**	***0.0***	***0.0***	***0.7***	
Trisomy 18 (Edwards syndrome)	17	6	<5	<5	0	27	
	1.9	***0.9***	**.**	**.**	***0.0***	***1.6***	
Ventricular septal defect	505	287	39	15	<5	852	
	57.7	***41.5***	***47.4***	***46.9***	**.**	***50.3***	
Total Live Births	**70886**	**54755**	**6989**	**2525**	**588**	**136201**	
Total Male Live Births	**44771**	**35126**	**4196**	**1654**	**331**	**86377**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Louisiana

Trisomy Counts and Prevalence by Maternal Age 2005-2008 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	117	101	218	
	7.6	***62.0***	***12.9***	
Trisomy 13 (Patau syndrome)	7	<5	9	
	0.6	**.**	***0.7***	
Trisomy 18 (Edwards syndrome)	18	9	27	
	1.2	***5.5***	***1.6***	
Total Live Births	**152990**	**16280**	**169283**	

**Total includes unknown maternal age

Notes
1.Includes only if weight =>2500 grams or gestational age >=36 wks, however, unable to define if defect lasted at >= 6 wks of age

General comments
-2005-2006 birth data include only live births to Louisiana residents at birth that occurred in regions Greater New Orleans, Baton Rouge, Lake Charles and Shreveport
-2005-2006 birth defects data include only live births to Louisiana residents at birth that occurred in Greater New Orleans, Baton Rouge, Lake Charles and Shreveport areas.
-2007 birth defects data include only live births to Louisiana residents at birth that occurred in Greater New Orleans, Baton Rouge, Lafayette, Lake Charles and Shreveport areas
-2007-2009 birth data include only live births to Louisiana residents at birth that occurred in regions Greater New Orleans, Baton Rouge, Lafayette, Lake Charles and Shreveport
-2008 birth defects data are provisional and include only live births to Louisiana residents that occurred in Greater New Orleans, Baton Rouge, Lafayette, Lake Charles and Shreveport
-2009 birth defects data are not available
-All probable cases are included
-BPA codes are used to define the birth defects
-Hurricane Katrina disrupted the active surveillance in Louisiana and may have created several types of selection bias.
-Louisiana is an active surveillance state that began identifying births in 2005. Birth defects surveillance has not been conducted among terminations and still births yet
-The 2009 cohort will not be complete until 12/31/2012 because the LA case definition includes children up to their third birthday.

Maine

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	6	0	0	0	0	7	
	0.9	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	
Cleft lip with and without cleft palate	54	0	0	2	1	59	
	8.5	***0.0***	***0.0***	***18.0***	***17.8***	***8.7***	
Cleft palate without cleft lip	54	0	0	0	0	54	
	8.5	***0.0***	***0.0***	***0.0***	***0.0***	***8.0***	
Coarctation of aorta	30	0	0	0	0	30	
	4.7	***0.0***	***0.0***	***0.0***	***0.0***	***4.4***	
Common truncus	6	0	0	0	0	6	
	0.9	***0.0***	***0.0***	***0.0***	***0.0***	***0.9***	
Down syndrome (Trisomy 21)	76	1	3	0	1	86	
	12.0	***6.2***	***30.3***	***0.0***	***17.8***	***12.7***	
Encephalocele	1	0	1	0	0	2	
	0.2	***0.0***	***10.1***	***0.0***	***0.0***	***0.3***	
Gastroschisis	38	0	0	1	0	39	1
	6.0	***0.0***	***0.0***	***9.0***	***0.0***	***5.8***	
Hypoplastic left heart syndrome	19	0	0	0	0	19	
	3.0	***0.0***	***0.0***	***0.0***	***0.0***	***2.8***	
Hypospadias*	73	2	2	1	0	78	2
	58.2	***51.9***	***97.6***	***43.1***	***0.0***	***57.6***	
Omphalocele	15	0	0	0	0	16	3
	2.4	***0.0***	***0.0***	***0.0***	***0.0***	***2.4***	
Pulmonary valve atresia	3	0	0	0	0	3	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Reduction deformity, lower limbs	2	0	0	0	0	2	2
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Reduction deformity, upper limbs	2	0	0	0	1	3	2
	0.8	***0.0***	***0.0***	***0.0***	***41.5***	***1.1***	
Spina bifida without anencephalus	22	1	0	0	0	23	
	3.5	***6.2***	***0.0***	***0.0***	***0.0***	***3.4***	
Tetralogy of Fallot	21	0	1	0	0	22	4
	3.3	***0.0***	***10.1***	***0.0***	***0.0***	***3.2***	
Transposition of great arteries - All	30	1	0	0	1	32	
	4.7	***6.2***	***0.0***	***0.0***	***17.8***	***4.7***	
dextro-Transposition of great arteries (d-TGA)	21	1	0	0	0	22	
	3.3	***6.2***	***0.0***	***0.0***	***0.0***	***3.2***	
Tricuspid valve atresia and stenosis	2	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Total Live Births	**63264**	**1601**	**990**	**1112**	**562**	**67735**	
Total Male Live Births (2008-2009)	**12534**	**385**	**205**	**232**	**131**	**13536**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Maine

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	46 ***7.9***	40 ***42.3***	86 ***12.7***	
Total Live Births	**58283**	**9451**	**67735**	

**Total includes unknown maternal age

Notes

1.Gastroschisis is coded 756.73. Cases are also abstracted to determine diagnosis
2.Surveillance for this condition began with 2008 births
3.Omphalocele is coded 756.72. Cases are also abstracted to determine diagnosis
4.Includes pulmonary atresia with septal defect

Maryland
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	3 ***0.3***	3 ***0.4***	1 ***0.3***	1 ***0.7***	0 ***0.0***	8 ***0.3***	
Anencephalus	71 ***4.0***	32 ***2.5***	12 ***2.4***	4 ***1.6***	0 ***0.0***	130 ***3.4***	
Aniridia	1 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.1***	
Anophthalmia/microphthalmia	3 ***0.2***	7 ***0.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	10 ***0.3***	
Anotia/microtia	11 ***0.6***	2 ***0.2***	9 ***1.8***	2 ***0.8***	0 ***0.0***	24 ***0.6***	
Aortic valve stenosis	3 ***0.3***	0 ***0.0***	1 ***0.3***	0 ***0.0***	0 ***0.0***	4 ***0.2***	
Atrial septal defect	28 ***1.6***	29 ***2.3***	12 ***2.4***	4 ***1.6***	0 ***0.0***	73 ***1.9***	
Atrioventricular septal defect (endocardial cushion defect)	28 ***1.6***	23 ***1.8***	4 ***0.8***	1 ***0.4***	0 ***0.0***	56 ***1.5***	
Biliary atresia	0 ***0.0***	2 ***0.4***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***0.1***	
Bladder exstrophy	9 ***0.6***	1 ***0.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	11 ***0.4***	
Choanal atresia	0 ***0.0***	2 ***0.2***	4 ***1.0***	0 ***0.0***	0 ***0.0***	6 ***0.2***	
Cleft lip with and without cleft palate	179 ***10.0***	61 ***4.8***	49 ***9.9***	15 ***6.0***	1 ***12.4***	310 ***8.1***	
Cleft palate without cleft lip	87 ***4.9***	25 ***2.0***	3 ***0.6***	4 ***1.6***	0 ***0.0***	120 ***3.1***	
Coarctation of aorta	13 ***0.7***	7 ***0.5***	1 ***0.2***	3 ***1.2***	0 ***0.0***	24 ***0.6***	
Common truncus	1 ***0.1***	2 ***0.3***	1 ***0.3***	0 ***0.0***	0 ***0.0***	4 ***0.2***	
Congenital cataract	3 ***0.2***	1 ***0.1***	0 ***0.0***	1 ***0.5***	0 ***0.0***	5 ***0.2***	
Congenital hip dislocation	35 ***2.0***	8 ***0.6***	7 ***1.4***	2 ***0.8***	0 ***0.0***	52 ***1.4***	
Diaphragmatic hernia	29 ***1.6***	18 ***1.4***	5 ***1.0***	2 ***0.8***	0 ***0.0***	54 ***1.4***	
Down syndrome (Trisomy 21)	213 ***11.9***	126 ***9.9***	42 ***8.5***	30 ***11.9***	1 ***12.4***	429 ***11.2***	
Ebstein anomaly	7 ***0.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	7 ***0.2***	
Encephalocele	14 ***0.8***	6 ***0.5***	1 ***0.2***	0 ***0.0***	0 ***0.0***	22 ***0.6***	
Epispadias	5 ***0.3***	1 ***0.1***	2 ***0.5***	2 ***1.0***	0 ***0.0***	10 ***0.3***	
Esophageal atresia/tracheoesophageal fistula	29 ***1.6***	22 ***1.7***	6 ***1.2***	1 ***0.4***	0 ***0.0***	60 ***1.6***	
Fetus or newborn affected by maternal alcohol use	0 ***0.0***	0 ***0.0***	1 ***1.2***	0 ***0.0***	0 ***0.0***	1 ***0.1***	
Hirschsprung disease (congenital megacolon)	5 ***0.3***	3 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	8 ***0.3***	
Hydrocephalus without spina bifida	73 ***4.1***	57 ***4.5***	16 ***3.2***	6 ***2.4***	0 ***0.0***	155 ***4.1***	
Hypoplastic left heart syndrome	22 ***1.2***	11 ***0.9***	1 ***0.2***	4 ***1.6***	0 ***0.0***	39 ***1.0***	
Hypospadias*	423 ***46.0***	243 ***37.6***	46 ***18.2***	31 ***23.7***	. *** .***	758 ***38.8***	
Microcephalus	7 ***0.4***	11 ***0.9***	6 ***1.2***	0 ***0.0***	0 ***0.0***	24 ***0.6***	
Obstructive genitourinary defect	13 ***0.9***	5 ***0.5***	0 ***0.0***	1 ***0.5***	0 ***0.0***	19 ***0.6***	
Patent ductus arteriosus	22 ***1.2***	15 ***1.2***	5 ***1.0***	2 ***0.8***	0 ***0.0***	44 ***1.2***	1
Pulmonary valve atresia and stenosis	7 ***0.5***	5 ***0.5***	0 ***0.0***	2 ***1.0***	0 ***0.0***	14 ***0.5***	

Maryland

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia	3	1	0	0	0	4	
	0.4	***0.2***	***0.0***	***0.0***	***0.0***	***0.3***	
Pyloric stenosis	2	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Rectal and large intestinal atresia/stenosis	36	22	6	4	0	68	
	2.0	***1.7***	***1.2***	***1.6***	***0.0***	***1.8***	
Reduction deformity, lower limbs	35	23	4	1	0	64	
	2.0	***1.8***	***0.8***	***0.4***	***0.0***	***1.7***	
Reduction deformity, upper limbs	51	34	12	4	0	103	
	2.8	***2.7***	***2.4***	***1.6***	***0.0***	***2.7***	
Renal agenesis/hypoplasia	60	36	6	6	0	111	
	3.3	***2.8***	***1.2***	***2.4***	***0.0***	***2.9***	
Spina bifida without anencephalus	67	27	18	5	0	119	
	3.7	***2.1***	***3.6***	***2.0***	***0.0***	***3.1***	
Tetralogy of Fallot	20	18	3	5	0	46	
	1.1	***1.4***	***0.6***	***2.0***	***0.0***	***1.2***	
Transposition of great arteries - All	26	14	5	5	0	51	
	1.4	***1.1***	***1.0***	***2.0***	***0.0***	***1.3***	
dextro-Transposition of great arteries (d-TGA)	7	5	4	1	0	18	
	0.5	***0.5***	***1.0***	***0.5***	***0.0***	***0.6***	
Trisomy 13 (Patau syndrome)	23	13	2	3	0	42	
	1.3	***1.0***	***0.4***	***1.2***	***0.0***	***1.1***	
Trisomy 18 (Edwards syndrome)	69	22	15	6	0	119	
	3.8	***1.7***	***3.0***	***2.4***	***0.0***	***3.1***	
Ventricular septal defect	39	33	7	10	0	89	2
	2.7	***3.2***	***1.8***	***5.2***	***0.0***	***2.9***	
Total Live Births	**179338**	**127578**	**49402**	**25178**	**809**	**382305**	
Total Male Live Births	**92040**	**64568**	**25241**	**13105**	**.**	**195508**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Maryland

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	203	225	429	
	6.5	***31.7***	***11.2***	
Trisomy 13 (Patau syndrome)	22	20	42	
	0.7	***2.8***	***1.1***	
Trisomy 18 (Edwards syndrome)	49	69	119	
	1.6	***9.7***	***3.1***	
Total Live Births	**311626**	**70967**	**382634**	

**Total includes unknown maternal age

Notes
1.Weight greater than or equal to 2500 grams
2.Includes probable cases

General comments
-Critical Congenital Heart Defect - Data is based on hospital reporting and can not be validated through Vital Statistics as there is no requirement to specify the cardiac defect on the birth certificate.
-Hispanic: Includes all births to mothers of Hispanic origin of any race.
-The total number of births data was receieved from Vital Statistics
-The total number of male live births is not available for American Indian/Alaskan Native category
-Total births: Includes races categorized as 'other' .
-White(Total), Black, American Indian, Asian or Pacific Islander: Race and Hispanic origin are reported separately on the birth certificate. Data for persons of Hispanic origin are included in the data for each race group according to the mother' s reported race.

Massachusetts

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	17 ***0.7***	6 ***1.8***	10 ***1.9***	1 ***0.4***	1 ***12.3***	36 ***0.9***	
Anencephalus	14 ***0.5***	2 ***0.6***	5 ***0.9***	2 ***0.7***	0 ***0.0***	25 ***0.6***	
Aniridia	0 ***0.0***	0 ***0.0***	1 ***0.2***	1 ***0.4***	0 ***0.0***	2 ***0.1***	
Anophthalmia/microphthalmia	18 ***0.7***	12 ***3.7***	9 ***1.7***	2 ***0.7***	0 ***0.0***	41 ***1.1***	
Anotia/microtia	43 ***1.6***	3 ***0.9***	13 ***2.4***	10 ***3.5***	0 ***0.0***	69 ***1.8***	
Aortic valve stenosis	47 ***1.8***	8 ***2.5***	8 ***1.5***	1 ***0.4***	0 ***0.0***	65 ***1.7***	
Atrial septal defect	495 ***19.0***	79 ***24.2***	93 ***17.4***	44 ***15.5***	3 ***36.8***	732 ***19.0***	
Atrioventricular septal defect (endocardial cushion defect)	135 ***5.2***	26 ***8.0***	21 ***3.9***	5 ***1.8***	0 ***0.0***	194 ***5.0***	
Biliary atresia	12 ***0.5***	1 ***0.3***	2 ***0.4***	5 ***1.8***	1 ***12.3***	21 ***0.5***	
Bladder exstrophy	4 ***0.2***	0 ***0.0***	1 ***0.2***	0 ***0.0***	0 ***0.0***	5 ***0.1***	1
Choanal atresia	23 ***0.9***	1 ***0.3***	3 ***0.6***	0 ***0.0***	0 ***0.0***	29 ***0.8***	
Cleft lip with and without cleft palate	220 ***8.4***	17 ***5.2***	42 ***7.8***	25 ***8.8***	0 ***0.0***	307 ***8.0***	
Cleft palate without cleft lip	164 ***6.3***	11 ***3.4***	28 ***5.2***	6 ***2.1***	0 ***0.0***	215 ***5.6***	
Coarctation of aorta	126 ***4.8***	10 ***3.1***	19 ***3.5***	5 ***1.8***	1 ***12.3***	166 ***4.3***	
Common truncus	12 ***0.5***	1 ***0.3***	2 ***0.4***	0 ***0.0***	1 ***12.3***	16 ***0.4***	
Congenital cataract	65 ***2.5***	13 ***4.0***	16 ***3.0***	3 ***1.1***	0 ***0.0***	100 ***2.6***	
Diaphragmatic hernia	69 ***2.6***	10 ***3.1***	8 ***1.5***	5 ***1.8***	1 ***12.3***	100 ***2.6***	
Down syndrome (Trisomy 21)	307 ***11.8***	57 ***17.5***	80 ***14.9***	25 ***8.8***	3 ***36.8***	487 ***12.7***	
Ebstein anomaly	10 ***0.4***	1 ***0.3***	2 ***0.4***	0 ***0.0***	0 ***0.0***	13 ***0.3***	
Encephalocele	5 ***0.2***	0 ***0.0***	1 ***0.2***	0 ***0.0***	0 ***0.0***	7 ***0.2***	
Esophageal atresia/tracheoesophageal fistula	74 ***2.8***	5 ***1.5***	13 ***2.4***	2 ***0.7***	1 ***12.3***	98 ***2.5***	
Gastroschisis	79 ***3.0***	14 ***4.3***	26 ***4.9***	4 ***1.4***	0 ***0.0***	132 ***3.4***	
Hirschsprung disease (congenital megacolon)	58 ***2.2***	3 ***0.9***	12 ***2.2***	7 ***2.5***	1 ***12.3***	83 ***2.2***	
Hydrocephalus without spina bifida	64 ***2.5***	24 ***7.4***	26 ***4.9***	4 ***1.4***	0 ***0.0***	122 ***3.2***	
Hypoplastic left heart syndrome	42 ***1.6***	4 ***1.2***	9 ***1.7***	2 ***0.7***	0 ***0.0***	59 ***1.5***	
Hypospadias*	361 ***27.1***	44 ***26.4***	39 ***14.2***	28 ***19.1***	1 ***24.4***	482 ***24.5***	2
Microcephalus	48 ***1.8***	10 ***3.1***	13 ***2.4***	1 ***0.4***	1 ***12.3***	74 ***1.9***	3
Obstructive genitourinary defect	360 ***13.8***	42 ***12.9***	97 ***18.1***	42 ***14.8***	0 ***0.0***	556 ***14.5***	
Omphalocele	27 ***1.0***	7 ***2.1***	9 ***1.7***	2 ***0.7***	0 ***0.0***	47 ***1.2***	
Patent ductus arteriosus	432 ***16.6***	81 ***24.8***	85 ***15.9***	42 ***14.8***	3 ***36.8***	667 ***17.3***	4
Pulmonary valve atresia and stenosis	166 ***6.4***	27 ***8.3***	40 ***7.5***	13 ***4.6***	0 ***0.0***	253 ***6.6***	
Pulmonary valve atresia	16 ***0.6***	2 ***0.6***	4 ***0.7***	0 ***0.0***	0 ***0.0***	23 ***0.6***	

Massachusetts
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Rectal and large intestinal atresia/stenosis	72	6	20	13	1	117	
	2.8	***1.8***	***3.7***	***4.6***	***12.3***	***3.0***	
Reduction deformity, lower limbs	28	6	14	3	0	52	
	1.1	***1.8***	***2.6***	***1.1***	***0.0***	***1.4***	
Reduction deformity, upper limbs	63	6	26	5	1	104	
	2.4	***1.8***	***4.9***	***1.8***	***12.3***	***2.7***	
Renal agenesis/hypoplasia	7	5	2	1	0	17	5
	0.3	***1.5***	***0.4***	***0.4***	***0.0***	***0.4***	
Spina bifida without anencephalus	40	5	11	4	0	64	
	1.5	***1.5***	***2.1***	***1.4***	***0.0***	***1.7***	
Tetralogy of Fallot	104	21	31	15	0	178	
	4.0	***6.4***	***5.8***	***5.3***	***0.0***	***4.6***	
Total anomalous pulmonary venous return (TAPVR)	22	3	4	5	0	34	
	0.8	***0.9***	***0.7***	***1.8***	***0.0***	***0.9***	
Transposition of great arteries - All	92	10	13	4	1	124	
	3.5	***3.1***	***2.4***	***1.4***	***12.3***	***3.2***	
dextro-Transposition of great arteries (d-TGA)	80	7	13	4	1	109	
	3.1	***2.1***	***2.4***	***1.4***	***12.3***	***2.8***	
Tricuspid valve atresia	17	2	2	0	0	23	
	0.7	***0.6***	***0.4***	***0.0***	***0.0***	***0.6***	
Trisomy 13 (Patau syndrome)	19	4	4	0	0	27	
	0.7	***1.2***	***0.7***	***0.0***	***0.0***	***0.7***	
Trisomy 18 (Edwards syndrome)	29	12	13	7	0	63	
	1.1	***3.7***	***2.4***	***2.5***	***0.0***	***1.6***	
Ventricular septal defect	476	69	105	56	0	727	6
	18.3	***21.2***	***19.6***	***19.7***	***0.0***	***18.9***	
Total Live Births	**260777**	**32623**	**53524**	**28389**	**815**	**384688**	
Total Male Live Births	**133441**	**16682**	**27423**	**14688**	**409**	**197041**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Massachusetts

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	217 ***7.3***	270 ***30.4***	487 ***12.7***	
Trisomy 13 (Patau syndrome)	14 ***0.5***	13 ***1.5***	27 ***0.7***	
Trisomy 18 (Edwards syndrome)	28 ***0.9***	35 ***3.9***	63 ***1.6***	
Total Live Births	**295932**	**88756**	**384688**	

**Total includes unknown maternal age

Notes
1.Excludes isolated diagnosis without surgical intervention and secondary diagnosis without postnatal confirmation.
2.Excludes 1st degree and NOS.
3.Defined as head circumference 2 std dev below normal.
4.Wt <=2500 gms is excluded. We use a decision tree for coding PDA: never code if on PGE or <36 wks GA. If >=6 weeks code. If <6 wks code if treated with indocin, ligated or surgically closed or associated with other codable defect.
5.Excludes isolated unilateral renal agenesis/hypoplasia.
6.Excludes isolated muscular VSDs.

General comments
-2009 data are provisional.
-Coding system is CDC/BPA.
-Differences in numbers from previous publications are the result of updated files.
-Possible/probable cases are excluded.
-Source for race and Hispanic ethnicity is vital records.
-Stillbirths are included, terminations are not included.

Michigan
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Anencephalus	75	12	2	3	1	104	
	1.7	***1.1***	***0.4***	***1.5***	***3.3***	***1.7***	
Aniridia	11	3	0	0	0	14	
	0.3	***0.3***	***0.0***	***0.0***	***0.0***	***0.2***	
Anophthalmia/microphthalmia	66	23	3	3	0	102	
	1.5	***2.1***	***0.7***	***1.5***	***0.0***	***1.6***	
Anotia/microtia	49	6	5	4	0	67	
	1.1	***0.5***	***1.1***	***2.0***	***0.0***	***1.1***	
Aortic valve stenosis	116	10	9	8	0	161	
	2.7	***0.9***	***2.0***	***3.9***	***0.0***	***2.6***	
Atrial septal defect	3898	1285	250	150	27	5807	
	89.6	***116.2***	***55.1***	***73.7***	***88.3***	***93.8***	
Atrioventricular septal defect (endocardial cushion defect)	240	67	14	11	0	361	
	5.5	***6.1***	***3.1***	***5.4***	***0.0***	***5.8***	
Biliary atresia	36	21	1	5	0	67	
	0.8	***1.9***	***0.2***	***2.5***	***0.0***	***1.1***	
Bladder exstrophy	14	1	0	1	1	20	
	0.3	***0.1***	***0.0***	***0.5***	***3.3***	***0.3***	
Choanal atresia	69	16	3	3	0	93	
	1.6	***1.4***	***0.7***	***1.5***	***0.0***	***1.5***	
Cleft lip with and without cleft palate	505	70	19	24	3	650	
	11.6	***6.3***	***4.2***	***11.8***	***9.8***	***10.5***	
Cleft palate without cleft lip	304	50	13	11	3	397	
	7.0	***4.5***	***2.9***	***5.4***	***9.8***	***6.4***	
Coarctation of aorta	290	71	21	12	2	445	
	6.7	***6.4***	***4.6***	***5.9***	***6.5***	***7.2***	
Common truncus	52	20	5	3	0	88	
	1.2	***1.8***	***1.1***	***1.5***	***0.0***	***1.4***	
Congenital cataract	95	18	3	5	2	132	
	2.2	***1.6***	***0.7***	***2.5***	***6.5***	***2.1***	
Congenital hip dislocation	554	57	22	20	0	671	
	12.7	***5.2***	***4.9***	***9.8***	***0.0***	***10.8***	
Diaphragmatic hernia	160	31	8	6	1	221	
	3.7	***2.8***	***1.8***	***2.9***	***3.3***	***3.6***	
Down syndrome (Trisomy 21)	577	129	42	26	3	815	
	13.3	***11.7***	***9.3***	***12.8***	***9.8***	***13.2***	
Ebstein anomaly	33	9	2	3	0	53	
	0.8	***0.8***	***0.4***	***1.5***	***0.0***	***0.9***	
Encephalocele	42	19	6	0	0	68	
	1.0	***1.7***	***1.3***	***0.0***	***0.0***	***1.1***	
Epispadias	39	11	0	0	0	52	
	0.9	***1.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	127	22	6	6	0	173	
	2.9	***2.0***	***1.3***	***2.9***	***0.0***	***2.8***	
Fetus or newborn affected by maternal alcohol use	33	22	1	1	0	57	
	0.8	***2.0***	***0.2***	***0.5***	***0.0***	***0.9***	
Gastroschisis	288	71	18	3	5	400	1
	6.6	***6.4***	***4.0***	***1.5***	***16.3***	***6.5***	
Hirschsprung disease (congenital megacolon)	107	45	4	5	1	176	
	2.5	***4.1***	***0.9***	***2.5***	***3.3***	***2.8***	
Hydrocephalus without spina bifida	389	152	21	18	9	622	
	8.9	***13.7***	***4.6***	***8.8***	***29.4***	***10.0***	
Hypoplastic left heart syndrome	186	58	9	7	1	296	
	4.3	***5.2***	***2.0***	***3.4***	***3.3***	***4.8***	
Hypospadias*	1431	295	47	49	10	1882	
	64.1	***52.4***	***20.2***	***46.4***	***64.7***	***59.3***	
Microcephalus	385	131	30	22	2	594	
	8.8	***11.8***	***6.6***	***10.8***	***6.5***	***9.6***	
Obstructive genitourinary defect	1013	202	64	35	7	1363	
	23.3	***18.3***	***14.1***	***17.2***	***22.9***	***22.0***	
Omphalocele	0	0	0	0	0	0	1
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Patent ductus arteriosus	1360	480	112	50	9	2031	
	31.3	***43.4***	***24.7***	***24.6***	***29.4***	***32.8***	

Michigan

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	460	178	30	27	4	732	
	10.6	***16.1***	***6.6***	***13.3***	***13.1***	***11.8***	
Pulmonary valve atresia	93	39	9	6	2	161	
	2.1	***3.5***	***2.0***	***2.9***	***6.5***	***2.6***	
Pyloric stenosis	843	93	65	16	5	1065	
	19.4	***8.4***	***14.3***	***7.9***	***16.3***	***17.2***	
Rectal and large intestinal atresia/stenosis	210	48	14	12	2	315	
	4.8	***4.3***	***3.1***	***5.9***	***6.5***	***5.1***	
Reduction deformity, lower limbs	83	29	7	1	2	128	
	1.9	***2.6***	***1.5***	***0.5***	***6.5***	***2.1***	
Reduction deformity, upper limbs	111	24	9	2	2	152	
	2.6	***2.2***	***2.0***	***1.0***	***6.5***	***2.5***	
Renal agenesis/hypoplasia	233	67	15	14	4	350	
	5.4	***6.1***	***3.3***	***6.9***	***13.1***	***5.7***	
Spina bifida without anencephalus	235	42	14	16	2	339	
	5.4	***3.8***	***3.1***	***7.9***	***6.5***	***5.5***	
Tetralogy of Fallot	226	73	16	11	1	386	
	5.2	***6.6***	***3.5***	***5.4***	***3.3***	***6.2***	
Total anomalous pulmonary venous return (TAPVR)	46	24	4	5	3	94	
	1.1	***2.2***	***0.9***	***2.5***	***9.8***	***1.5***	
Transposition of great arteries - All	260	58	8	13	5	407	
	6.0	***5.2***	***1.8***	***6.4***	***16.3***	***6.6***	
dextro-Transposition of great arteries (d-TGA)	180	29	3	8	3	256	
	4.1	***2.6***	***0.7***	***3.9***	***9.8***	***4.1***	
Tricuspid valve atresia and stenosis	63	18	2	3	1	98	
	1.4	***1.6***	***0.4***	***1.5***	***3.3***	***1.6***	
Trisomy 13 (Patau syndrome)	32	14	5	2	0	56	
	0.7	***1.3***	***1.1***	***1.0***	***0.0***	***0.9***	
Trisomy 18 (Edwards syndrome)	55	24	3	3	0	86	
	1.3	***2.2***	***0.7***	***1.5***	***0.0***	***1.4***	
Ventricular septal defect	1919	486	95	86	11	2760	2
	44.1	***44.0***	***20.9***	***42.2***	***36.0***	***44.6***	
Total Live Births	**435184**	**110569**	**45356**	**20365**	**3059**	**619332**	
Total Male Live Births	**223154**	**56291**	**23221**	**10570**	**1545**	**317259**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Michigan

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	448 ***8.3***	334 ***40.7***	815 ***13.2***	
Trisomy 13 (Patau syndrome)	41 ***0.8***	12 ***1.5***	56 ***0.9***	
Trisomy 18 (Edwards syndrome)	51 ***0.9***	34 ***4.1***	86 ***1.4***	
Total Live Births	**537132**	**82140**	**619332**	

**Total includes unknown maternal age

Notes
1.ICD-9 coding - 1st available for 2010 data
2.Include all reported with this code - may include probable cases

Minnesota

Birth Defects Counts and Prevalence 2006-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Anencephalus	1 ***0.2***	1 ***0.6***	2 ***1.7***	2 ***1.8***	1 ***8.7***	7 ***0.7***	
Aniridia	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.9***	0 ***0.0***	1 ***0.1***	
Anophthalmia/microphthalmia	4 ***0.8***	2 ***1.1***	1 ***0.9***	0 ***0.0***	0 ***0.0***	7 ***0.7***	
Anotia/microtia	4 ***0.8***	1 ***0.6***	3 ***2.6***	0 ***0.0***	0 ***0.0***	9 ***0.9***	
Aortic valve stenosis	3 ***0.6***	1 ***0.6***	1 ***0.9***	1 ***0.9***	0 ***0.0***	6 ***0.6***	
Atrial septal defect	73 ***14.2***	45 ***25.7***	20 ***17.3***	23 ***20.3***	1 ***8.7***	171 ***17.7***	
Atrioventricular septal defect (endocardial cushion defect)	26 ***5.0***	7 ***4.0***	4 ***3.5***	6 ***5.3***	0 ***0.0***	46 ***4.7***	
Biliary atresia	4 ***0.8***	0 ***0.0***	0 ***0.0***	1 ***0.9***	0 ***0.0***	6 ***0.6***	
Bladder exstrophy	1 ***0.2***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.1***	
Choanal atresia	4 ***0.8***	3 ***1.7***	3 ***2.6***	0 ***0.0***	0 ***0.0***	10 ***1.0***	
Cleft lip with and without cleft palate	50 ***9.7***	14 ***8.0***	15 ***13.0***	10 ***8.8***	3 ***26.2***	97 ***10.0***	
Cleft palate without cleft lip	38 ***7.4***	6 ***3.4***	11 ***9.5***	4 ***3.5***	1 ***8.7***	65 ***6.7***	
Coarctation of aorta	27 ***5.2***	11 ***6.3***	4 ***3.5***	5 ***4.4***	0 ***0.0***	49 ***5.1***	
Common truncus	3 ***0.6***	1 ***0.6***	1 ***0.9***	0 ***0.0***	0 ***0.0***	5 ***0.5***	
Congenital cataract	6 ***1.2***	1 ***0.6***	1 ***0.9***	1 ***0.9***	0 ***0.0***	11 ***1.1***	
Congenital hip dislocation	20 ***3.9***	7 ***4.0***	4 ***3.5***	0 ***0.0***	1 ***8.7***	36 ***3.7***	
Diaphragmatic hernia	18 ***3.5***	0 ***0.0***	4 ***3.5***	3 ***2.6***	0 ***0.0***	26 ***2.7***	
Down syndrome (Trisomy 21)	66 ***12.8***	34 ***19.4***	16 ***13.9***	10 ***8.8***	2 ***17.4***	141 ***14.6***	
Ebstein anomaly	1 ***0.2***	0 ***0.0***	1 ***0.9***	0 ***0.0***	0 ***0.0***	2 ***0.2***	
Encephalocele	1 ***0.2***	2 ***1.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	3 ***0.3***	
Epispadias	5 ***1.0***	1 ***0.6***	0 ***0.0***	0 ***0.0***	0 ***0.0***	6 ***0.6***	
Esophageal atresia/tracheoesophageal fistula	19 ***3.7***	4 ***2.3***	2 ***1.7***	1 ***0.9***	0 ***0.0***	28 ***2.9***	
Gastroschisis	14 ***2.7***	6 ***3.4***	7 ***6.1***	10 ***8.8***	1 ***8.7***	40 ***4.1***	
Hirschsprung disease (congenital megacolon)	8 ***1.6***	3 ***1.7***	2 ***1.7***	1 ***0.9***	0 ***0.0***	15 ***1.5***	
Hydrocephalus without spina bifida	14 ***2.7***	6 ***3.4***	3 ***2.6***	0 ***0.0***	0 ***0.0***	23 ***2.4***	
Hypoplastic left heart syndrome	15 ***2.9***	3 ***1.7***	3 ***2.6***	0 ***0.0***	0 ***0.0***	23 ***2.4***	
Hypospadias*	138 ***52.5***	46 ***51.6***	15 ***25.6***	11 ***18.8***	0 ***0.0***	225 ***45.6***	
Microcephalus	10 ***1.9***	16 ***9.1***	8 ***6.9***	6 ***5.3***	0 ***0.0***	43 ***4.4***	
Obstructive genitourinary defect	149 ***28.9***	49 ***28.0***	36 ***31.2***	21 ***18.5***	0 ***0.0***	273 ***28.2***	
Omphalocele	5 ***1.0***	5 ***2.9***	3 ***2.6***	0 ***0.0***	0 ***0.0***	13 ***1.3***	
Patent ductus arteriosus	77 ***14.9***	43 ***24.6***	22 ***19.1***	13 ***11.5***	1 ***8.7***	165 ***17.0***	
Pulmonary valve atresia and stenosis	25 ***4.8***	8 ***4.6***	9 ***7.8***	7 ***6.2***	1 ***8.7***	55 ***5.7***	

Minnesota
Birth Defects Counts and Prevalence 2006-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia	4	2	1	3	0	10	
	0.8	***1.1***	***0.9***	***2.6***	***0.0***	***1.0***	
Pyloric stenosis	113	13	20	3	7	167	
	21.9	***7.4***	***17.3***	***2.6***	***61.0***	***17.2***	
Rectal and large intestinal atresia/stenosis	15	7	5	2	0	30	
	2.9	***4.0***	***4.3***	***1.8***	***0.0***	***3.1***	
Reduction deformity, lower limbs	2	4	1	0	0	8	
	0.4	***2.3***	***0.9***	***0.0***	***0.0***	***0.8***	
Reduction deformity, upper limbs	5	4	2	4	0	16	
	1.0	***2.3***	***1.7***	***3.5***	***0.0***	***1.7***	
Renal agenesis/hypoplasia	15	4	7	3	0	34	
	2.9	***2.3***	***6.1***	***2.6***	***0.0***	***3.5***	
Spina bifida without anencephalus	19	3	3	1	1	28	
	3.7	***1.7***	***2.6***	***0.9***	***8.7***	***2.9***	
Tetralogy of Fallot	28	7	1	6	0	43	
	5.4	***4.0***	***0.9***	***5.3***	***0.0***	***4.4***	
Transposition of great arteries - All	21	7	3	7	0	39	
	4.1	***4.0***	***2.6***	***6.2***	***0.0***	***4.0***	
dextro-Transposition of great arteries (d-TGA)	20	7	3	7	0	38	
	3.9	***4.0***	***2.6***	***6.2***	***0.0***	***3.9***	
Tricuspid valve atresia	3	3	0	1	0	7	
	0.6	***1.7***	***0.0***	***0.9***	***0.0***	***0.7***	
Trisomy 13 (Patau syndrome)	2	4	3	0	0	9	
	0.4	***2.3***	***2.6***	***0.0***	***0.0***	***0.9***	
Trisomy 18 (Edwards syndrome)	11	5	1	2	0	19	
	2.1	***2.9***	***0.9***	***1.8***	***0.0***	***2.0***	
Ventricular septal defect	148	70	53	22	6	314	
	28.7	***40.0***	***45.9***	***19.4***	***52.3***	***32.4***	
Total Live Births	**51574**	**17508**	**11542**	**11349**	**1147**	**96859**	
Total Male Live Births	**26303**	**8919**	**5850**	**5858**	**570**	**49385**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Minnesota

Trisomy Counts and Prevalence by Maternal Age 2006-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	37 ***4.7***	61 ***35.6***	141 ***14.6***	
Trisomy 13 (Patau syndrome)	5 ***0.6***	3 ***1.8***	9 ***0.9***	
Trisomy 18 (Edwards syndrome)	8 ***1.0***	6 ***3.5***	19 ***2.0***	
Total Live Births	**79223**	**17135**	**96859**	

**Total includes unknown maternal age

General comments
-All data include confirmed cases only
-All data include live births only
-Data are for Hennepin and Ramsey Counties only
-Minnesota uses BPA codes

Mississippi

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	4	6	0	0	0	10	
	0.4	***0.6***	***0.0***	***0.0***	***0.0***	***0.4***	
Aniridia	1	1	0	0	0	2	
	0.1	***0.1***	***0.0***	***0.0***	***0.0***	***0.1***	
Anophthalmia/microphthalmia	6	6	0	0	0	12	
	0.5	***0.6***	***0.0***	***0.0***	***0.0***	***0.5***	
Anotia/microtia	11	7	1	0	0	20	
	1.0	***0.7***	***1.4***	***0.0***	***0.0***	***0.9***	
Aortic valve stenosis	16	8	0	0	0	25	
	1.4	***0.8***	***0.0***	***0.0***	***0.0***	***1.1***	
Atrial septal defect	470	624	17	10	21	1164	
	42.0	***62.7***	***23.3***	***43.3***	***136.1***	***52.3***	
Atrioventricular septal defect (endocardial cushion defect)	27	40	3	1	0	72	
	2.4	***4.0***	***4.1***	***4.3***	***0.0***	***3.2***	
Biliary atresia	5	6	1	0	2	14	
	0.4	***0.6***	***1.4***	***0.0***	***13.0***	***0.6***	
Bladder exstrophy	3	1	0	0	0	4	
	0.3	***0.1***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	2	1	0	0	1	4	
	0.2	***0.1***	***0.0***	***0.0***	***6.5***	***0.2***	
Cleft lip with and without cleft palate	73	54	5	5	3	145	
	6.5	***5.4***	***6.9***	***21.6***	***19.4***	***6.5***	
Cleft palate without cleft lip	47	34	2	3	0	86	
	4.2	***3.4***	***2.7***	***13.0***	***0.0***	***3.9***	
Coarctation of aorta	40	17	3	0	0	60	
	3.6	***1.7***	***4.1***	***0.0***	***0.0***	***2.7***	
Common truncus	4	5	0	0	0	9	
	0.4	***0.5***	***0.0***	***0.0***	***0.0***	***0.4***	
Congenital cataract	4	6	0	0	0	10	
	0.4	***0.6***	***0.0***	***0.0***	***0.0***	***0.4***	
Congenital hip dislocation	21	16	1	2	0	41	
	1.9	***1.6***	***1.4***	***8.7***	***0.0***	***1.8***	
Diaphragmatic hernia	15	23	4	0	0	42	
	1.3	***2.3***	***5.5***	***0.0***	***0.0***	***1.9***	
Down syndrome (Trisomy 21)	94	65	7	0	1	172	
	8.4	***6.5***	***9.6***	***0.0***	***6.5***	***7.7***	
Ebstein anomaly	8	9	1	0	0	18	
	0.7	***0.9***	***1.4***	***0.0***	***0.0***	***0.8***	
Encephalocele	5	4	1	0	0	10	
	0.4	***0.4***	***1.4***	***0.0***	***0.0***	***0.4***	
Epispadias	1	3	0	0	0	4	
	0.1	***0.3***	***0.0***	***0.0***	***0.0***	***0.2***	
Esophageal atresia/tracheoesophageal fistula	21	16	0	0	2	40	
	1.9	***1.6***	***0.0***	***0.0***	***13.0***	***1.8***	
Fetus or newborn affected by maternal alcohol use	15	15	0	0	0	31	
	1.3	***1.5***	***0.0***	***0.0***	***0.0***	***1.4***	
Hirschsprung disease (congenital megacolon)	26	33	0	1	0	62	
	2.3	***3.3***	***0.0***	***4.3***	***0.0***	***2.8***	
Hydrocephalus without spina bifida	67	86	4	0	2	165	
	6.0	***8.6***	***5.5***	***0.0***	***13.0***	***7.4***	
Hypoplastic left heart syndrome	31	22	0	0	0	54	
	2.8	***2.2***	***0.0***	***0.0***	***0.0***	***2.4***	
Hypospadias*	167	235	3	1	1	413	
	29.1	***46.3***	***8.0***	***8.6***	***12.7***	***36.3***	
Microcephalus	90	207	2	1	5	310	
	8.0	***20.8***	***2.7***	***4.3***	***32.4***	***13.9***	
Obstructive genitourinary defect	150	147	4	3	1	307	
	13.4	***14.8***	***5.5***	***13.0***	***6.5***	***13.8***	
Patent ductus arteriosus	186	220	14	5	9	441	1
	16.6	***22.1***	***19.2***	***21.6***	***58.3***	***19.8***	
Pulmonary valve atresia and stenosis	62	102	3	1	1	170	
	5.5	***10.3***	***4.1***	***4.3***	***6.5***	***7.6***	
Pyloric stenosis	144	62	5	1	1	216	
	12.9	***6.2***	***6.9***	***4.3***	***6.5***	***9.7***	

Mississippi

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Rectal and large intestinal atresia/stenosis	25	27	2	1	1	57	
	2.2	***2.7***	***2.7***	***4.3***	***6.5***	***2.6***	
Reduction deformity, lower limbs	11	12	0	0	0	23	
	1.0	***1.2***	***0.0***	***0.0***	***0.0***	***1.0***	
Reduction deformity, upper limbs	15	9	1	1	0	28	
	1.3	***0.9***	***1.4***	***4.3***	***0.0***	***1.3***	
Renal agenesis/hypoplasia	23	22	1	0	0	46	
	2.1	***2.2***	***1.4***	***0.0***	***0.0***	***2.1***	
Spina bifida without anencephalus	39	14	1	1	1	57	
	3.5	***1.4***	***1.4***	***4.3***	***6.5***	***2.6***	
Tetralogy of Fallot	56	49	2	2	1	111	
	5.0	***4.9***	***2.7***	***8.7***	***6.5***	***5.0***	
Transposition of great arteries - All	35	44	2	1	0	83	
	3.1	***4.4***	***2.7***	***4.3***	***0.0***	***3.7***	
Tricuspid valve atresia and stenosis	17	22	1	1	0	43	
	1.5	***2.2***	***1.4***	***4.3***	***0.0***	***1.9***	
Trisomy 13 (Patau syndrome)	6	7	0	1	0	14	
	0.5	***0.7***	***0.0***	***4.3***	***0.0***	***0.6***	
Trisomy 18 (Edwards syndrome)	9	12	1	0	0	23	
	0.8	***1.2***	***1.4***	***0.0***	***0.0***	***1.0***	
Ventricular septal defect	332	315	20	4	10	696	2
	29.7	***31.7***	***27.4***	***17.3***	***64.8***	***31.3***	
Total Live Births	**111867**	**99477**	**7297**	**2311**	**1543**	**222541**	
Total Male Live Births	**57373**	**50705**	**3745**	**1169**	**785**	**113802**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Mississippi

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	122 ***5.9***	50 ***30.1***	172 ***7.7***	
Trisomy 13 (Patau syndrome)	13 ***0.6***	1 ***0.6***	14 ***0.6***	
Trisomy 18 (Edwards syndrome)	19 ***0.9***	4 ***2.4***	23 ***1.0***	
Total Live Births	**205902**	**16619**	**222541**	

**Total includes unknown maternal age

Notes
1.Cases with =>2500 grams Birth Weights are included for Patent ductus arteriosus.
2.Mississippi does not indicate probable causes

General comments
-Mississippi uses the ICD-9 coding system.

Missouri

Birth Defects Counts and Prevalence 2005-2007 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	39	5	6	1	0	51	
	2.1	***1.4***	***4.4***	***1.8***	***0.0***	***2.1***	
Anophthalmia/microphthalmia	34	11	1	0	0	46	
	1.8	***3.0***	***0.7***	***0.0***	***0.0***	***1.9***	
Atrial septal defect	2011	528	140	65	16	2770	
	109.0	***145.9***	***103.8***	***117.5***	***140.6***	***114.6***	
Cleft lip with and without cleft palate	245	18	20	6	2	293	
	13.3	***5.0***	***14.8***	***10.8***	***17.6***	***12.1***	
Cleft palate without cleft lip	143	18	11	0	1	173	
	7.8	***5.0***	***8.2***	***0.0***	***8.8***	***7.2***	
Coarctation of aorta	158	29	6	1	1	196	
	8.6	***8.0***	***4.4***	***1.8***	***8.8***	***8.1***	
Common truncus	21	1	0	0	0	22	
	1.1	***0.3***	***0.0***	***0.0***	***0.0***	***0.9***	
Congenital cataract	69	10	3	1	0	83	
	3.7	***2.8***	***2.2***	***1.8***	***0.0***	***3.4***	
Diaphragmatic hernia	97	17	5	4	0	124	
	5.3	***4.7***	***3.7***	***7.2***	***0.0***	***5.1***	
Down syndrome (Trisomy 21)	304	39	31	15	3	392	
	16.5	***10.8***	***23.0***	***27.1***	***26.4***	***16.2***	
Hydrocephalus without spina bifida	173	51	15	3	1	243	
	9.4	***14.1***	***11.1***	***5.4***	***8.8***	***10.1***	
Hypoplastic left heart syndrome	69	11	2	0	0	85	
	3.7	***3.0***	***1.5***	***0.0***	***0.0***	***3.5***	
Microcephalus	113	33	8	2	0	156	
	6.1	***9.1***	***5.9***	***3.6***	***0.0***	***6.5***	
Obstructive genitourinary defect	448	53	42	14	4	563	
	24.3	***14.6***	***31.1***	***25.3***	***35.1***	***23.3***	
Patent ductus arteriosus	1009	206	69	25	5	1316	
	54.7	***56.9***	***51.2***	***45.2***	***43.9***	***54.4***	
Pyloric stenosis	611	54	36	2	4	713	
	33.1	***14.9***	***26.7***	***3.6***	***35.1***	***29.5***	
Rectal and large intestinal atresia/stenosis	116	15	10	2	1	144	
	6.3	***4.1***	***7.4***	***3.6***	***8.8***	***6.0***	
Reduction deformity, lower limbs	45	7	0	2	0	54	
	2.4	***1.9***	***0.0***	***3.6***	***0.0***	***2.2***	
Reduction deformity, upper limbs	56	9	1	1	0	67	
	3.0	***2.5***	***0.7***	***1.8***	***0.0***	***2.8***	
Renal agenesis/hypoplasia	111	9	6	2	2	130	
	6.0	***2.5***	***4.4***	***3.6***	***17.6***	***5.4***	
Spina bifida without anencephalus	96	9	5	1	0	111	
	5.2	***2.5***	***3.7***	***1.8***	***0.0***	***4.6***	
Tetralogy of Fallot	97	18	5	2	0	122	
	5.3	***5.0***	***3.7***	***3.6***	***0.0***	***5.0***	
Transposition of great arteries - All	108	19	1	3	0	133	
	5.9	***5.2***	***0.7***	***5.4***	***0.0***	***5.5***	
Trisomy 13 (Patau syndrome)	19	6	6	2	0	33	
	1.0	***1.7***	***4.4***	***3.6***	***0.0***	***1.4***	
Trisomy 18 (Edwards syndrome)	36	11	6	1	0	54	
	2.0	***3.0***	***4.4***	***1.8***	***0.0***	***2.2***	
Ventricular septal defect	857	164	62	20	3	1110	
	46.5	***45.3***	***46.0***	***36.1***	***26.4***	***45.9***	
Total Live Births	**184411**	**36197**	**13485**	**5533**	**1138**	**241783**	

Missouri

Trisomy Counts and Prevalence by Maternal Age 2005-2007 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	245 ***11.3***	147 ***57.5***	392 ***16.2***	
Trisomy 13 (Patau syndrome)	25 ***1.2***	8 ***3.1***	33 ***1.4***	
Trisomy 18 (Edwards syndrome)	29 ***1.3***	25 ***9.8***	54 ***2.2***	
Total Live Births	**216216**	**25548**	**241783**	

**Total includes unknown maternal age

General comments

-Missouri has a passive surveillance system and uses ICD-9 codes to identify birth defect cases.

-Our surveillance systems uses information from the following files to ascertain cases: birth certificates, death certificates, fetal death certificates, newborn inpatient abstract system, pediatric in- and outpatient abstracts

Nebraska

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Amniotic bands	8	0	0	0	0	8	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Anencephalus	33	2	8	0	1	44	1
	3.1	***2.3***	***3.8***	***0.0***	***4.3***	***3.1***	
Aniridia	1	1	0	0	0	2	
	0.1	***1.2***	***0.0***	***0.0***	***0.0***	***0.1***	
Anophthalmia/microphthalmia	9	0	2	0	0	12	
	0.9	***0.0***	***1.0***	***0.0***	***0.0***	***0.9***	
Anotia/microtia	15	1	14	2	0	32	
	1.4	***1.2***	***6.7***	***6.4***	***0.0***	***2.3***	
Aortic valve stenosis	23	1	2	0	1	27	
	2.2	***1.2***	***1.0***	***0.0***	***4.3***	***1.9***	
Atrial septal defect	230	26	40	6	3	311	
	22.0	***30.2***	***19.2***	***19.3***	***12.9***	***22.2***	
Atrioventricular septal defect (endocardial cushion defect)	20	1	2	0	0	23	
	1.9	***1.2***	***1.0***	***0.0***	***0.0***	***1.6***	
Biliary atresia	8	2	4	0	0	14	
	0.8	***2.3***	***1.9***	***0.0***	***0.0***	***1.0***	
Bladder exstrophy	4	0	0	0	0	4	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Choanal atresia	20	2	3	0	0	25	
	1.9	***2.3***	***1.4***	***0.0***	***0.0***	***1.8***	
Cleft lip with and without cleft palate	113	4	23	2	6	152	
	10.8	***4.7***	***11.1***	***6.4***	***25.9***	***10.9***	
Cleft palate without cleft lip	58	4	11	2	1	83	
	5.5	***4.7***	***5.3***	***6.4***	***4.3***	***5.9***	
Coarctation of aorta	70	0	8	1	0	81	
	6.7	***0.0***	***3.8***	***3.2***	***0.0***	***5.8***	
Common truncus	5	0	1	0	1	7	
	0.5	***0.0***	***0.5***	***0.0***	***4.3***	***0.5***	
Congenital cataract	29	1	3	1	1	35	
	2.8	***1.2***	***1.4***	***3.2***	***4.3***	***2.5***	
Congenital hip dislocation	93	1	16	4	3	118	
	8.9	***1.2***	***7.7***	***12.9***	***12.9***	***8.4***	
Diaphragmatic hernia	27	1	6	0	0	34	
	2.6	***1.2***	***2.9***	***0.0***	***0.0***	***2.4***	
Down syndrome (Trisomy 21)	160	10	36	4	1	215	
	15.3	***11.6***	***17.3***	***12.9***	***4.3***	***15.4***	
Ebstein anomaly	9	0	3	0	0	12	
	0.9	***0.0***	***1.4***	***0.0***	***0.0***	***0.9***	
Encephalocele	4	2	4	1	0	12	
	0.4	***2.3***	***1.9***	***3.2***	***0.0***	***0.9***	
Epispadias	5	0	0	1	0	6	
	0.5	***0.0***	***0.0***	***3.2***	***0.0***	***0.4***	
Esophageal atresia/tracheoesophageal fistula	14	1	7	0	0	22	
	1.3	***1.2***	***3.4***	***0.0***	***0.0***	***1.6***	
Fetus or newborn affected by maternal alcohol use	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Gastroschisis	45	1	10	1	5	64	
	4.3	***1.2***	***4.8***	***3.2***	***21.6***	***4.6***	
Hirschsprung disease (congenital megacolon)	27	1	6	3	1	38	
	2.6	***1.2***	***2.9***	***9.7***	***4.3***	***2.7***	
Hydrocephalus without spina bifida	73	4	15	2	1	98	
	7.0	***4.7***	***7.2***	***6.4***	***4.3***	***7.0***	
Hypoplastic left heart syndrome	41	0	6	0	0	49	
	3.9	***0.0***	***2.9***	***0.0***	***0.0***	***3.5***	
Hypospadias*	365	25	33	7	2	444	
	68.1	***56.8***	***30.8***	***43.9***	***16.3***	***61.9***	
Microcephalus	57	8	21	2	2	93	
	5.4	***9.3***	***10.1***	***6.4***	***8.6***	***6.6***	
Omphalocele	27	2	5	1	0	36	
	2.6	***2.3***	***2.4***	***3.2***	***0.0***	***2.6***	
Patent ductus arteriosus	230	22	43	5	1	307	
	22.0	***25.6***	***20.7***	***16.1***	***4.3***	***21.9***	

Nebraska

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	65	8	6	0	0	81	
	6.2	***9.3***	***2.9***	***0.0***	***0.0***	***5.8***	
Pulmonary valve atresia	13	1	4	0	1	19	
	1.2	***1.2***	***1.9***	***0.0***	***4.3***	***1.4***	
Pyloric stenosis	201	4	30	3	1	241	
	19.2	***4.7***	***14.4***	***9.7***	***4.3***	***17.2***	
Rectal and large intestinal atresia/stenosis	64	2	13	4	1	86	
	6.1	***2.3***	***6.3***	***12.9***	***4.3***	***6.1***	
Reduction deformity, lower limbs	20	2	0	0	0	22	
	1.9	***2.3***	***0.0***	***0.0***	***0.0***	***1.6***	
Reduction deformity, upper limbs	35	4	8	0	0	48	
	3.3	***4.7***	***3.8***	***0.0***	***0.0***	***3.4***	
Renal agenesis/hypoplasia	48	2	9	1	0	62	
	4.6	***2.3***	***4.3***	***3.2***	***0.0***	***4.4***	
Spina bifida without anencephalus	92	10	11	1	0	114	
	8.8	***11.6***	***5.3***	***3.2***	***0.0***	***8.1***	
Tetralogy of Fallot	35	1	6	0	1	44	
	3.3	***1.2***	***2.9***	***0.0***	***4.3***	***3.1***	
Total anomalous pulmonary venous return (TAPVR)	6	0	7	0	0	13	
	0.6	***0.0***	***3.4***	***0.0***	***0.0***	***0.9***	
Transposition of great arteries - All	53	2	5	0	0	61	
	5.1	***2.3***	***2.4***	***0.0***	***0.0***	***4.4***	
dextro-Transposition of great arteries (d-TGA)	50	1	5	0	0	57	
	4.8	***1.2***	***2.4***	***0.0***	***0.0***	***4.1***	
Tricuspid valve atresia	8	1	1	0	1	13	
	0.8	***1.2***	***0.5***	***0.0***	***4.3***	***0.9***	
Trisomy 13 (Patau syndrome)	14	2	7	0	0	24	
	1.3	***2.3***	***3.4***	***0.0***	***0.0***	***1.7***	
Trisomy 18 (Edwards syndrome)	27	5	3	0	1	37	
	2.6	***5.8***	***1.4***	***0.0***	***4.3***	***2.6***	
Ventricular septal defect	404	22	83	7	6	535	
	38.6	***25.6***	***39.9***	***22.5***	***25.9***	***38.2***	
Total Live Births	**104763**	**8597**	**20794**	**3107**	**2317**	**139995**	
Total Male Live Births	**53571**	**4405**	**10712**	**1593**	**1224**	**71711**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Nebraska

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	128 ***10.8***	87 ***41.2***	215 ***15.4***	
Trisomy 13 (Patau syndrome)	20 ***1.7***	4 ***1.9***	24 ***1.7***	
Trisomy 18 (Edwards syndrome)	22 ***1.9***	15 ***7.1***	37 ***2.6***	
Total Live Births	**118877**	**21105**	**139995**	

**Total includes unknown maternal age

Notes
1.Includes probable cases

General comments
-2009 data are complete

Nevada

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	0 ***0.0***	0 ***0.0***	8 ***1.1***	0 ***0.0***	0 ***0.0***	8 ***0.4***	
Aniridia	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Anophthalmia/microphthalmia	7 ***0.8***	2 ***1.2***	8 ***1.1***	0 ***0.0***	0 ***0.0***	17 ***0.9***	
Anotia/microtia	5 ***0.6***	0 ***0.0***	1 ***0.1***	0 ***0.0***	0 ***0.0***	6 ***0.3***	
Aortic valve stenosis	22 ***2.7***	2 ***1.2***	14 ***1.9***	2 ***1.3***	0 ***0.0***	41 ***2.1***	
Atrial septal defect	512 ***61.9***	178 ***104.7***	513 ***68.0***	105 ***69.1***	12 ***51.3***	1347 ***68.9***	
Atrioventricular septal defect (endocardial cushion defect)	23 ***2.8***	3 ***1.8***	28 ***3.7***	1 ***0.7***	0 ***0.0***	56 ***2.9***	
Biliary atresia	6 ***0.7***	1 ***0.6***	2 ***0.3***	4 ***2.6***	0 ***0.0***	13 ***0.7***	
Bladder exstrophy	5 ***0.6***	0 ***0.0***	1 ***0.1***	0 ***0.0***	0 ***0.0***	6 ***0.3***	
Choanal atresia	7 ***0.8***	1 ***0.6***	13 ***1.7***	0 ***0.0***	0 ***0.0***	22 ***1.1***	
Cleft lip with and without cleft palate	76 ***9.2***	12 ***7.1***	78 ***10.3***	9 ***5.9***	3 ***12.8***	182 ***9.3***	
Cleft palate without cleft lip	32 ***3.9***	4 ***2.4***	33 ***4.4***	3 ***2.0***	0 ***0.0***	77 ***3.9***	
Coarctation of aorta	53 ***6.4***	7 ***4.1***	43 ***5.7***	10 ***6.6***	1 ***4.3***	118 ***6.0***	
Common truncus	7 ***0.8***	0 ***0.0***	9 ***1.2***	2 ***1.3***	0 ***0.0***	18 ***0.9***	
Congenital cataract	2 ***0.2***	2 ***1.2***	7 ***0.9***	0 ***0.0***	0 ***0.0***	12 ***0.6***	
Congenital hip dislocation	51 ***6.2***	11 ***6.5***	38 ***5.0***	5 ***3.3***	1 ***4.3***	113 ***5.8***	
Diaphragmatic hernia	28 ***3.4***	2 ***1.2***	19 ***2.5***	3 ***2.0***	0 ***0.0***	53 ***2.7***	
Down syndrome (Trisomy 21)	94 ***11.4***	22 ***12.9***	132 ***17.5***	19 ***12.5***	1 ***4.3***	271 ***13.9***	
Ebstein anomaly	9 ***1.1***	0 ***0.0***	9 ***1.2***	1 ***0.7***	0 ***0.0***	19 ***1.0***	
Encephalocele	4 ***0.5***	4 ***2.4***	3 ***0.4***	0 ***0.0***	0 ***0.0***	12 ***0.6***	
Epispadias	4 ***0.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	4 ***0.2***	
Esophageal atresia/tracheoesophageal fistula	18 ***2.2***	6 ***3.5***	14 ***1.9***	4 ***2.6***	0 ***0.0***	43 ***2.2***	
Fetus or newborn affected by maternal alcohol use	19 ***2.3***	8 ***4.7***	3 ***0.4***	2 ***1.3***	1 ***4.3***	34 ***1.7***	
Hirschsprung disease (congenital megacolon)	14 ***1.7***	13 ***7.6***	9 ***1.2***	3 ***2.0***	0 ***0.0***	40 ***2.0***	
Hydrocephalus without spina bifida	45 ***5.4***	19 ***11.2***	53 ***7.0***	5 ***3.3***	1 ***4.3***	126 ***6.4***	
Hypoplastic left heart syndrome	12 ***1.5***	5 ***2.9***	23 ***3.0***	2 ***1.3***	0 ***0.0***	44 ***2.3***	
Hypospadias*	214 ***50.1***	37 ***42.6***	92 ***24.0***	15 ***19.2***	5 ***43.6***	375 ***37.5***	
Microcephalus	31 ***3.7***	9 ***5.3***	26 ***3.4***	1 ***0.7***	0 ***0.0***	70 ***3.6***	
Obstructive genitourinary defect	249 ***30.1***	26 ***15.3***	205 ***27.2***	36 ***23.7***	6 ***25.7***	533 ***27.3***	
Patent ductus arteriosus	457 ***55.2***	154 ***90.5***	460 ***61.0***	93 ***61.2***	9 ***38.5***	1196 ***61.2***	1
Pulmonary valve atresia and stenosis	74 ***8.9***	21 ***12.3***	66 ***8.7***	14 ***9.2***	2 ***8.6***	183 ***9.4***	
Pulmonary valve atresia	14 ***1.7***	3 ***1.8***	11 ***1.5***	5 ***3.3***	0 ***0.0***	33 ***1.7***	

Nevada

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pyloric stenosis	147	15	130	5	4	321	
	17.8	***8.8***	***17.2***	***3.3***	***17.1***	***16.4***	
Rectal and large intestinal atresia/stenosis	23	9	27	7	0	71	
	2.8	***5.3***	***3.6***	***4.6***	***0.0***	***3.6***	
Reduction deformity, lower limbs	7	4	13	0	0	24	
	0.8	***2.4***	***1.7***	***0.0***	***0.0***	***1.2***	
Reduction deformity, upper limbs	15	3	16	0	1	35	
	1.8	***1.8***	***2.1***	***0.0***	***4.3***	***1.8***	
Renal agenesis/hypoplasia	32	9	21	9	0	75	
	3.9	***5.3***	***2.8***	***5.9***	***0.0***	***3.8***	
Spina bifida without anencephalus	9	5	21	0	0	37	
	1.1	***2.9***	***2.8***	***0.0***	***0.0***	***1.9***	
Tetralogy of Fallot	56	11	40	2	1	113	
	6.8	***6.5***	***5.3***	***1.3***	***4.3***	***5.8***	
Total anomalous pulmonary venous return (TAPVR)	7	0	9	1	0	17	
	0.8	***0.0***	***1.2***	***0.7***	***0.0***	***0.9***	
Transposition of great arteries - All	39	6	34	1	1	85	
	4.7	***3.5***	***4.5***	***0.7***	***4.3***	***4.3***	
dextro-Transposition of great arteries (d-TGA)	18	3	13	0	1	38	
	2.2	***1.8***	***1.7***	***0.0***	***4.3***	***1.9***	
Tricuspid valve atresia and stenosis	8	6	8	1	1	25	
	1.0	***3.5***	***1.1***	***0.7***	***4.3***	***1.3***	
Trisomy 13 (Patau syndrome)	4	1	4	0	0	10	
	0.5	***0.6***	***0.5***	***0.0***	***0.0***	***0.5***	
Trisomy 18 (Edwards syndrome)	8	3	16	2	0	29	
	1.0	***1.8***	***2.1***	***1.3***	***0.0***	***1.5***	
Ventricular septal defect	345	59	383	45	12	861	2
	41.7	***34.7***	***50.8***	***29.6***	***51.3***	***44.1***	
Total Live Births	**82731**	**17008**	**75436**	**15205**	**2338**	**195437**	
Total Male Live Births	**42714**	**8686**	**38335**	**7825**	**1147**	**100089**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Nevada

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	121 ***7.2***	119 ***45.2***	271 ***13.9***	
Trisomy 13 (Patau syndrome)	6 ***0.4***	2 ***0.8***	10 ***0.5***	
Trisomy 18 (Edwards syndrome)	16 ***0.9***	10 ***3.8***	29 ***1.5***	
Total Live Births	**169082**	**26313**	**195437**	

**Total includes unknown maternal age

Notes
1.Includes birth weight => 2500 grams
2.Ventricular septal defect: excluded if <2500 grams birth weight or < 36 weeks gestation. Probable cases excluded.

General comments
-Data are reported for live births and Nevada resident births only.
-Nevada uses ICD-9 Coding system.
-Probable/possible diagnoses are excluded.

New Hampshire

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Amniotic bands	2	0	0	0	0	4	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Anencephalus	2	0	0	1	0	6	
	0.3	***0.0***	***0.0***	***4.0***	***0.0***	***0.9***	
Aniridia	2	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Anophthalmia/microphthalmia	3	1	0	0	0	5	
	0.5	***9.3***	***0.0***	***0.0***	***0.0***	***0.7***	
Anotia/microtia	9	0	0	1	0	10	
	1.4	***0.0***	***0.0***	***4.0***	***0.0***	***1.4***	
Aortic valve stenosis	8	0	0	0	0	10	
	1.3	***0.0***	***0.0***	***0.0***	***0.0***	***1.4***	
Atrial septal defect	59	1	3	4	0	91	
	9.3	***9.3***	***37.5***	***16.2***	***0.0***	***13.0***	
Atrioventricular septal defect (endocardial cushion defect)	14	1	0	1	0	26	
	2.2	***9.3***	***0.0***	***4.0***	***0.0***	***3.7***	
Biliary atresia	2	0	0	0	0	4	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	1	0	0	0	0	2	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Cleft lip with and without cleft palate	32	0	1	2	0	54	
	5.1	***0.0***	***12.5***	***8.1***	***0.0***	*7.7*	
Cleft palate without cleft lip	28	0	0	2	1	46	
	4.4	***0.0***	***0.0***	***8.1***	***79.4***	***6.6***	
Coarctation of aorta	16	0	0	0	0	23	
	2.5	***0.0***	***0.0***	***0.0***	***0.0***	***3.3***	
Common truncus	3	0	0	0	0	5	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Congenital cataract	5	1	0	0	0	8	
	0.8	***9.3***	***0.0***	***0.0***	***0.0***	***1.1***	
Congenital hip dislocation	33	0	2	0	0	44	
	5.2	***0.0***	***25.0***	***0.0***	***0.0***	***6.3***	
Diaphragmatic hernia	9	0	0	3	0	15	
	1.4	***0.0***	***0.0***	***12.1***	***0.0***	***2.1***	
Down syndrome (Trisomy 21)	46	1	1	4	1	75	
	7.3	***9.3***	***12.5***	***16.2***	***79.4***	***10.7***	
Ebstein anomaly	1	0	0	0	0	5	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Encephalocele	2	0	0	0	0	4	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Epispadias	5	0	0	0	0	6	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	10	0	0	0	0	14	
	1.6	***0.0***	***0.0***	***0.0***	***0.0***	***2.0***	
Fetus or newborn affected by maternal alcohol use	2	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Gastroschisis	15	0	1	0	0	18	1
	2.4	***0.0***	***12.5***	***0.0***	***0.0***	***2.6***	
Hirschsprung disease (congenital megacolon)	5	0	2	0	0	9	
	0.8	***0.0***	***25.0***	***0.0***	***0.0***	***1.3***	
Hydrocephalus without spina bifida	7	0	0	0	0	11	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Hypoplastic left heart syndrome	6	1	1	0	1	16	
	0.9	***9.3***	***12.5***	***0.0***	***79.4***	***2.3***	
Hypospadias*	197	2	4	6	0	250	
	60.8	***35.5***	***102.3***	***47.5***	***0.0***	***69.6***	
Microcephalus	27	2	1	1	0	38	
	4.3	***18.6***	***12.5***	***4.0***	***0.0***	***5.4***	
Obstructive genitourinary defect	131	4	9	5	0	212	
	20.7	***37.2***	***112.5***	***20.2***	***0.0***	***30.3***	
Omphalocele	5	0	1	0	0	12	1
	0.8	***0.0***	***12.5***	***0.0***	***0.0***	***1.7***	

New Hampshire

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	22	3	0	1	0	32	2
	3.5	***27.9***	***0.0***	***4.0***	***0.0***	***4.6***	
Pulmonary valve atresia and stenosis	31	2	1	1	0	53	
	4.9	***18.6***	***12.5***	***4.0***	***0.0***	***7.6***	
Pyloric stenosis	117	0	3	2	0	163	
	18.5	***0.0***	***37.5***	***8.1***	***0.0***	***23.3***	
Rectal and large intestinal atresia/stenosis	16	0	2	0	0	23	
	2.5	***0.0***	***25.0***	***0.0***	***0.0***	***3.3***	
Reduction deformity, lower limbs	3	0	0	0	0	5	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Reduction deformity, upper limbs	12	0	1	0	0	20	
	1.9	***0.0***	***12.5***	***0.0***	***0.0***	***2.9***	
Renal agenesis/hypoplasia	33	0	3	0	0	47	
	5.2	***0.0***	***37.5***	***0.0***	***0.0***	***6.7***	
Spina bifida without anencephalus	7	0	1	0	0	13	
	1.1	***0.0***	***12.5***	***0.0***	***0.0***	***1.9***	
Tetralogy of Fallot	14	1	2	2	0	32	
	2.2	***9.3***	***25.0***	***8.1***	***0.0***	***4.6***	
Transposition of great arteries - All	7	0	0	0	0	16	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***2.3***	
Tricuspid valve atresia and stenosis	0	0	0	0	0	2	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Trisomy 13 (Patau syndrome)	2	0	0	0	0	5	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Trisomy 18 (Edwards syndrome)	6	0	0	0	0	13	
	0.9	***0.0***	***0.0***	***0.0***	***0.0***	***1.9***	
Ventricular septal defect	102	2	3	3	0	152	3
	16.1	***18.6***	***37.5***	***12.1***	***0.0***	***21.7***	
Total Live Births	**63183**	**1074**	**800**	**2473**	**126**	**70082**	
Total Male Live Births	**32386**	**563**	**391**	**1262**	**54**	**35905**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

New Hampshire

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	46 ***8.0***	24 ***19.3***	75 ***10.7***	
Trisomy 13 (Patau syndrome)	2 ***0.3***	1 ***0.8***	5 ***0.7***	
Trisomy 18 (Edwards syndrome)	6 ***1.0***	7 ***5.6***	13 ***1.9***	
Total Live Births	**57567**	**12433**	**70082**	

**Total includes unknown maternal age

Notes
1.ICD-9 code data and active medical record abstraction used for all gastroschisis and omphalocele cases
2.Includes weight =>2500 grams only
3.Probable cases not included

General comments
-Data for all birth conditions includes data ascertained during calendar years 2004 through 2009 for NH resident mothers.
-Data for live births was obtained from the New Hampshire Department of State, Division of Vital Records Administration, Web Query Tool. Data may vary from year to year due to the process of continuing acquisition of birth certificate information, particularly from NH residents that give birth out of state.
-Data includes live births from birth to age 2 years, stillbirths and terminations.
-Data is for confirmed cases only, following medical chart review and use of the NBDPN Guidelines.
-For gastroschisis and omphalocele, cases are distinguished using active medical chart review.

New Jersey
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Amniotic bands	14	9	18	1	0	44	1
	0.5	***1.1***	***1.3***	***0.2***	***0.0***	***0.8***	
Anencephalus	5	4	10	0	0	19	
	0.2	***0.5***	***0.7***	***0.0***	***0.0***	***0.3***	
Aniridia	9	1	3	0	0	14	
	0.3	***0.1***	***0.2***	***0.0***	***0.0***	***0.2***	
Anophthalmia/microphthalmia	19	11	23	4	0	57	
	0.7	***1.3***	***1.6***	***0.7***	***0.0***	***1.0***	
Anotia/microtia	43	11	68	11	0	140	
	1.6	***1.3***	***4.8***	***2.0***	***0.0***	***2.5***	
Aortic valve stenosis	25	5	16	2	0	51	
	1.0	***0.6***	***1.1***	***0.4***	***0.0***	***0.9***	
Atrial septal defect	647	435	532	145	5	1803	2
	24.6	***51.9***	***37.2***	***27.0***	***81.2***	***32.0***	
Atrioventricular septal defect (endocardial cushion defect)	84	27	35	11	1	163	
	3.2	***3.2***	***2.4***	***2.0***	***16.2***	***2.9***	
Biliary atresia	8	8	10	4	0	31	
	0.3	***1.0***	***0.7***	***0.7***	***0.0***	***0.6***	
Bladder exstrophy	2	2	3	0	0	7	
	0.1	***0.2***	***0.2***	***0.0***	***0.0***	***0.1***	
Choanal atresia	38	17	28	5	0	90	
	1.4	***2.0***	***2.0***	***0.9***	***0.0***	***1.6***	
Cleft lip with and without cleft palate	196	47	132	51	1	441	
	7.4	***5.6***	***9.2***	***9.5***	***16.2***	***7.8***	
Cleft palate without cleft lip	159	38	103	38	0	348	
	6.0	***4.5***	***7.2***	***7.1***	***0.0***	***6.2***	
Coarctation of aorta	91	29	53	15	0	197	
	3.5	***3.5***	***3.7***	***2.8***	***0.0***	***3.5***	
Common truncus	10	2	15	2	0	29	
	0.4	***0.2***	***1.0***	***0.4***	***0.0***	***0.5***	
Congenital cataract	39	16	40	5	0	102	
	1.5	***1.9***	***2.8***	***0.9***	***0.0***	***1.8***	
Congenital hip dislocation	140	18	67	26	1	260	
	5.3	***2.1***	***4.7***	***4.8***	***16.2***	***4.6***	
Diaphragmatic hernia	34	9	25	10	0	81	
	1.3	***1.1***	***1.7***	***1.9***	***0.0***	***1.4***	
Down syndrome (Trisomy 21)	300	100	205	44	2	671	
	11.4	***11.9***	***14.3***	***8.2***	***32.5***	***11.9***	
Ebstein anomaly	15	5	12	1	0	33	
	0.6	***0.6***	***0.8***	***0.2***	***0.0***	***0.6***	
Encephalocele	13	5	8	4	0	31	
	0.5	***0.6***	***0.6***	***0.7***	***0.0***	***0.6***	
Epispadias	62	15	27	8	1	116	
	2.4	***1.8***	***1.9***	***1.5***	***16.2***	***2.1***	
Esophageal atresia/tracheoesophageal fistula	65	13	33	2	0	116	
	2.5	***1.6***	***2.3***	***0.4***	***0.0***	***2.1***	
Fetus or newborn affected by maternal alcohol use	11	14	0	0	1	27	
	0.4	***1.7***	***0.0***	***0.0***	***16.2***	***0.5***	
Gastroschisis	49	21	48	7	1	127	3
	1.9	***2.5***	***3.4***	***1.3***	***16.2***	***2.3***	
Hirschsprung disease (congenital megacolon)	45	23	24	8	0	103	
	1.7	***2.7***	***1.7***	***1.5***	***0.0***	***1.8***	
Hydrocephalus without spina bifida	66	54	88	8	0	224	
	2.5	***6.4***	***6.2***	***1.5***	***0.0***	***4.0***	
Hypoplastic left heart syndrome	36	15	33	4	0	93	
	1.4	***1.8***	***2.3***	***0.7***	***0.0***	***1.7***	
Hypospadias*	1418	317	359	163	6	2314	
	105.1	***74.1***	***49.2***	***59.4***	***183.5***	***80.4***	
Microcephalus	131	76	128	35	0	378	
	5.0	***9.1***	***9.0***	***6.5***	***0.0***	***6.7***	
Obstructive genitourinary defect	1237	272	596	204	5	2352	
	47.0	***32.4***	***41.7***	***38.0***	***81.2***	***41.8***	
Omphalocele	21	24	14	4	0	65	3
	0.8	***2.9***	***1.0***	***0.7***	***0.0***	***1.2***	

New Jersey
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	1775	828	1086	334	6	4075	
	67.5	***98.8***	***76.0***	***62.2***	***97.4***	***72.4***	
Pulmonary valve atresia and stenosis	246	112	120	32	0	523	
	9.3	***13.4***	***8.4***	***6.0***	***0.0***	***9.3***	
Pulmonary valve atresia	18	13	15	3	0	53	
	0.7	***1.6***	***1.0***	***0.6***	***0.0***	***0.9***	
Pyloric stenosis	493	73	279	30	0	907	
	18.7	***8.7***	***19.5***	***5.6***	***0.0***	***16.1***	
Rectal and large intestinal atresia/stenosis	75	19	58	20	1	175	
	2.9	***2.3***	***4.1***	***3.7***	***16.2***	***3.1***	
Reduction deformity, lower limbs	45	34	32	9	0	124	
	1.7	***4.1***	***2.2***	***1.7***	***0.0***	***2.2***	
Reduction deformity, upper limbs	57	32	52	16	0	166	
	2.2	***3.8***	***3.6***	***3.0***	***0.0***	***3.0***	
Renal agenesis/hypoplasia	140	30	63	13	1	254	
	5.3	***3.6***	***4.4***	***2.4***	***16.2***	***4.5***	
Spina bifida without anencephalus	75	17	52	5	1	153	
	2.9	***2.0***	***3.6***	***0.9***	***16.2***	***2.7***	
Tetralogy of Fallot	78	49	48	17	0	201	
	3.0	***5.8***	***3.4***	***3.2***	***0.0***	***3.6***	
Total anomalous pulmonary venous return (TAPVR)	19	10	16	2	0	47	
	0.7	***1.2***	***1.1***	***0.4***	***0.0***	***0.8***	
Transposition of great arteries - All	72	34	51	15	0	180	
	2.7	***4.1***	***3.6***	***2.8***	***0.0***	***3.2***	
dextro-Transposition of great arteries (d-TGA)	49	12	29	10	0	104	
	1.9	***1.4***	***2.0***	***1.9***	***0.0***	***1.8***	
Tricuspid valve atresia and stenosis	18	16	18	3	0	56	
	0.7	***1.9***	***1.3***	***0.6***	***0.0***	***1.0***	
Trisomy 13 (Patau syndrome)	8	2	7	1	0	19	
	0.3	***0.2***	***0.5***	***0.2***	***0.0***	***0.3***	
Trisomy 18 (Edwards syndrome)	23	14	16	5	0	58	
	0.9	***1.7***	***1.1***	***0.9***	***0.0***	***1.0***	
Ventricular septal defect	1694	481	942	268	4	3433	4
	64.4	***57.4***	***65.9***	***49.9***	***64.9***	***61.0***	
Total Live Births	**263116**	**83832**	**142918**	**53714**	**616**	**562582**	
Total Male Live Births	**134977**	**42766**	**72928**	**27450**	**327**	**287933**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

New Jersey

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	285 ***6.5***	350 ***28.8***	671 ***11.9***	
Trisomy 13 (Patau syndrome)	9 ***0.2***	10 ***0.8***	19 ***0.3***	
Trisomy 18 (Edwards syndrome)	25 ***0.6***	33 ***2.7***	58 ***1.0***	
Total Live Births	**441248**	**121318**	**562582**	

**Total includes unknown maternal age

Notes
1.Used codes 658.80 and 762.80.
2.ASD only, PFO coded separately.
3.Gastroschisis coded 756.79, Omphalocele coded 756.78.
4.Only confirmed cases included.

General comments
-Hybrid system; passive with audit, uses ICD9-CM codes
-Live births only

New York
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Amniotic bands	25	10	19	1	0	55	
	0.4	***0.5***	***0.7***	***0.1***	***0.0***	***0.5***	
Anencephalus	19	10	20	2	0	52	
	0.3	***0.5***	***0.7***	***0.2***	***0.0***	***0.4***	
Aniridia	10	1	7	1	0	19	
	0.2	***0.0***	***0.2***	***0.1***	***0.0***	***0.2***	
Anophthalmia/microphthalmia	68	25	50	12	0	157	
	1.1	***1.2***	***1.7***	***1.1***	***0.0***	***1.3***	
Anotia/microtia	53	7	45	8	1	116	
	0.9	***0.3***	***1.6***	***0.7***	***4.3***	***0.9***	
Aortic valve stenosis	139	29	40	9	0	220	
	2.3	***1.4***	***1.4***	***0.8***	***0.0***	***1.8***	
Atrial septal defect	2218	1462	1316	491	10	5592	
	37.0	***72.4***	***45.5***	***45.7***	***43.3***	***45.8***	
Atrioventricular septal defect (endocardial cushion defect)	243	119	102	36	1	512	
	4.1	***5.9***	***3.5***	***3.3***	***4.3***	***4.2***	
Biliary atresia	43	37	39	19	0	140	
	0.7	***1.8***	***1.3***	***1.8***	***0.0***	***1.1***	
Bladder exstrophy	18	3	1	0	0	22	
	0.3	***0.1***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	129	41	47	6	0	225	
	2.2	***2.0***	***1.6***	***0.6***	***0.0***	***1.8***	
Cleft lip with and without cleft palate	484	93	231	73	4	908	
	8.1	***4.6***	***8.0***	***6.8***	***17.3***	***7.4***	
Cleft palate without cleft lip	366	93	141	67	1	681	
	6.1	***4.6***	***4.9***	***6.2***	***4.3***	***5.6***	
Coarctation of aorta	328	110	150	47	1	648	
	5.5	***5.5***	***5.2***	***4.4***	***4.3***	***5.3***	
Common truncus	38	21	12	6	0	78	
	0.6	***1.0***	***0.4***	***0.6***	***0.0***	***0.6***	
Congenital cataract	102	56	58	14	0	234	
	1.7	***2.8***	***2.0***	***1.3***	***0.0***	***1.9***	
Congenital hip dislocation	595	76	282	82	1	1050	
	9.9	***3.8***	***9.7***	***7.6***	***4.3***	***8.6***	
Diaphragmatic hernia	161	40	59	23	1	292	
	2.7	***2.0***	***2.0***	***2.1***	***4.3***	***2.4***	
Down syndrome (Trisomy 21)	761	266	365	75	1	1498	
	12.7	***13.2***	***12.6***	***7.0***	***4.3***	***12.3***	
Ebstein anomaly	37	15	21	5	0	80	
	0.6	***0.7***	***0.7***	***0.5***	***0.0***	***0.7***	
Encephalocele	42	20	21	8	0	93	
	0.7	***1.0***	***0.7***	***0.7***	***0.0***	***0.8***	
Epispadias	94	52	45	5	0	200	
	1.6	***2.6***	***1.6***	***0.5***	***0.0***	***1.6***	
Esophageal atresia/tracheoesophageal fistula	185	39	68	19	0	319	
	3.1	***1.9***	***2.4***	***1.8***	***0.0***	***2.6***	
Fetus or newborn affected by maternal alcohol use	29	24	13	0	0	67	
	0.5	***1.2***	***0.4***	***0.0***	***0.0***	***0.5***	
Gastroschisis	164	51	86	5	4	314	
	2.7	***2.5***	***3.0***	***0.5***	***17.3***	***2.6***	
Hirschsprung disease (congenital megacolon)	168	83	60	23	0	341	
	2.8	***4.1***	***2.1***	***2.1***	***0.0***	***2.8***	
Hydrocephalus without spina bifida	415	229	251	67	3	979	
	6.9	***11.3***	***8.7***	***6.2***	***13.0***	***8.0***	
Hypoplastic left heart syndrome	180	51	74	16	3	329	
	3.0	***2.5***	***2.6***	***1.5***	***13.0***	***2.7***	
Hypospadias*	2970	657	709	264	8	4685	
	96.7	***63.9***	***47.9***	***47.5***	***71.2***	***74.8***	
Microcephalus	297	184	215	43	3	759	
	5.0	***9.1***	***7.4***	***4.0***	***13.0***	***6.2***	
Obstructive genitourinary defect	2491	649	1112	497	12	4836	
	41.6	***32.2***	***38.4***	***46.2***	***52.0***	***39.6***	
Omphalocele	70	36	29	12	3	153	
	1.2	***1.8***	***1.0***	***1.1***	***13.0***	***1.3***	

New York
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	1708	959	665	292	14	3711	
	28.5	***47.5***	***23.0***	***27.2***	***60.7***	***30.4***	
Pulmonary valve atresia and stenosis	503	241	237	85	3	1091	
	8.4	***11.9***	***8.2***	***7.9***	***13.0***	***8.9***	
Pulmonary valve atresia	40	17	30	4	0	92	
	0.7	***0.8***	***1.0***	***0.4***	***0.0***	***0.8***	
Pyloric stenosis	1563	264	833	123	10	2825	
	26.1	***13.1***	***28.8***	***11.4***	***43.3***	***23.1***	
Rectal and large intestinal atresia/stenosis	251	74	139	32	1	509	
	4.2	***3.7***	***4.8***	***3.0***	***4.3***	***4.2***	
Reduction deformity, lower limbs	52	23	15	10	1	104	
	0.9	***1.1***	***0.5***	***0.9***	***4.3***	***0.9***	
Reduction deformity, upper limbs	149	37	53	10	1	254	
	2.5	***1.8***	***1.8***	***0.9***	***4.3***	***2.1***	
Renal agenesis/hypoplasia	305	90	105	26	2	541	
	5.1	***4.5***	***3.6***	***2.4***	***8.7***	***4.4***	
Spina bifida without anencephalus	134	46	63	21	1	269	
	2.2	***2.3***	***2.2***	***2.0***	***4.3***	***2.2***	
Tetralogy of Fallot	282	118	104	61	1	579	
	4.7	***5.8***	***3.6***	***5.7***	***4.3***	***4.7***	
Total anomalous pulmonary venous return (TAPVR)	47	18	40	11	0	118	
	0.8	***0.9***	***1.4***	***1.0***	***0.0***	***1.0***	
Transposition of great arteries - All	185	48	68	20	0	328	
	3.1	***2.4***	***2.4***	***1.9***	***0.0***	***2.7***	
dextro-Transposition of great arteries (d-TGA)	175	48	68	18	0	316	
	2.9	***2.4***	***2.4***	***1.7***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	62	42	44	17	0	168	
	1.0	***2.1***	***1.5***	***1.6***	***0.0***	***1.4***	
Tricuspid valve atresia	35	18	19	7	0	80	
	0.6	***0.9***	***0.7***	***0.7***	***0.0***	***0.7***	
Trisomy 13 (Patau syndrome)	50	20	28	6	0	104	
	0.8	***1.0***	***1.0***	***0.6***	***0.0***	***0.9***	
Trisomy 18 (Edwards syndrome)	58	38	38	6	0	145	
	1.0	***1.9***	***1.3***	***0.6***	***0.0***	***1.2***	
Ventricular septal defect	2790	837	1329	403	12	5470	
	46.6	***41.5***	***45.9***	***37.5***	***52.0***	***44.8***	
Total Live Births	**598723**	**201832**	**289265**	**107492**	**2307**	**1221543**	
Total Male Live Births	**307169**	**102881**	**147869**	**55574**	**1124**	**625949**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

New York

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	696 ***7.1***	802 ***33.3***	1498 ***12.3***	
Trisomy 13 (Patau syndrome)	72 ***0.7***	32 ***1.3***	104 ***0.9***	
Trisomy 18 (Edwards syndrome)	63 ***0.6***	82 ***3.4***	145 ***1.2***	
Total Live Births	**980378**	**240937**	**1221543**	

**Total includes unknown maternal age

General comments
-2009 data are provisional
-NY only ascertains birth defects among live births

North Carolina

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	48	24	15	3	4	95	
	1.3	*1.6*	*1.4*	*1.6*	*4.5*	*1.5*	
Anencephalus	78	30	40	6	3	170	
	2.2	*2.0*	*3.9*	*3.1*	*3.4*	*2.7*	
Aniridia	2	5	1	0	0	8	
	0.1	*0.3*	*0.1*	*0.0*	*0.0*	*0.1*	
Anophthalmia/microphthalmia	59	29	21	3	1	113	
	1.7	*1.9*	*2.0*	*1.6*	*1.1*	*1.8*	
Anotia/microtia	57	19	42	5	5	129	
	1.6	*1.3*	*4.1*	*2.6*	*5.7*	*2.0*	
Aortic valve stenosis	92	31	24	2	6	155	
	2.6	*2.1*	*2.3*	*1.0*	*6.8*	*2.4*	
Atrial septal defect	1338	773	365	59	54	2598	
	37.6	*51.6*	*35.2*	*30.7*	*61.4*	*40.6*	
Atrioventricular septal defect (endocardial cushion defect)	197	97	51	8	4	359	
	5.5	*6.5*	*4.9*	*4.2*	*4.5*	*5.6*	
Biliary atresia	23	20	9	0	2	54	
	0.6	*1.3*	*0.9*	*0.0*	*2.3*	*0.8*	
Bladder exstrophy	9	6	2	0	0	17	
	0.3	*0.4*	*0.2*	*0.0*	*0.0*	*0.3*	
Choanal atresia	49	16	17	0	1	83	
	1.4	*1.1*	*1.6*	*0.0*	*1.1*	*1.3*	
Cleft lip with and without cleft palate	345	98	93	19	13	569	
	9.7	*6.5*	*9.0*	*9.9*	*14.8*	*8.9*	
Cleft palate without cleft lip	258	64	49	18	7	396	
	7.2	*4.3*	*4.7*	*9.4*	*8.0*	*6.2*	
Coarctation of aorta	203	62	45	10	7	328	
	5.7	*4.1*	*4.3*	*5.2*	*8.0*	*5.1*	
Common truncus	34	13	6	2	1	56	
	1.0	*0.9*	*0.6*	*1.0*	*1.1*	*0.9*	
Congenital cataract	48	27	9	2	2	88	
	1.3	*1.8*	*0.9*	*1.0*	*2.3*	*1.4*	
Diaphragmatic hernia	93	35	30	6	4	169	
	2.6	*2.3*	*2.9*	*3.1*	*4.5*	*2.6*	
Down syndrome (Trisomy 21)	436	158	137	24	13	774	
	12.2	*10.6*	*13.2*	*12.5*	*14.8*	*12.1*	
Ebstein anomaly	28	8	13	5	1	55	
	0.8	*0.5*	*1.3*	*2.6*	*1.1*	*0.9*	
Encephalocele	40	21	21	2	2	86	
	1.1	*1.4*	*2.0*	*1.0*	*2.3*	*1.3*	
Epispadias	29	20	4	0	0	53	
	0.8	*1.3*	*0.4*	*0.0*	*0.0*	*0.8*	
Esophageal atresia/tracheoesophageal fistula	96	29	20	3	3	151	
	2.7	*1.9*	*1.9*	*1.6*	*3.4*	*2.4*	
Gastroschisis	145	60	39	6	7	260	
	4.1	*4.0*	*3.8*	*3.1*	*8.0*	*4.1*	
Hirschsprung disease (congenital megacolon)	79	60	14	3	1	157	
	2.2	*4.0*	*1.4*	*1.6*	*1.1*	*2.5*	
Hydrocephalus without spina bifida	324	187	98	13	11	637	
	9.1	*12.5*	*9.5*	*6.8*	*12.5*	*10.0*	
Hypoplastic left heart syndrome	105	32	26	3	2	169	
	2.9	*2.1*	*2.5*	*1.6*	*2.3*	*2.6*	
Hypospadias*	1191	409	114	40	31	1786	
	65.1	*53.7*	*21.5*	*40.2*	*69.4*	*54.5*	
Microcephalus	140	117	40	8	3	308	
	3.9	*7.8*	*3.9*	*4.2*	*3.4*	*4.8*	
Obstructive genitourinary defect	1179	458	314	63	30	2049	
	33.1	*30.6*	*30.3*	*32.8*	*34.1*	*32.1*	
Omphalocele	65	34	16	8	0	123	
	1.8	*2.3*	*1.5*	*4.2*	*0.0*	*1.9*	
Patent ductus arteriosus	1144	520	365	56	36	2124	
	32.1	*34.7*	*35.2*	*29.2*	*40.9*	*33.2*	
Pulmonary valve atresia and stenosis	242	150	87	13	7	500	
	6.8	*10.0*	*8.4*	*6.8*	*8.0*	*7.8*	

North Carolina

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia	42	34	19	4	1	100	
	1.2	***2.3***	***1.8***	***2.1***	***1.1***	***1.6***	
Pyloric stenosis	720	96	181	10	29	1037	
	20.2	***6.4***	***17.5***	***5.2***	***33.0***	***16.2***	
Rectal and large intestinal atresia/stenosis	150	53	52	5	5	266	
	4.2	***3.5***	***5.0***	***2.6***	***5.7***	***4.2***	
Reduction deformity, lower limbs	53	33	21	2	5	115	
	1.5	***2.2***	***2.0***	***1.0***	***5.7***	***1.8***	
Reduction deformity, upper limbs	122	58	38	3	6	228	
	3.4	***3.9***	***3.7***	***1.6***	***6.8***	***3.6***	
Renal agenesis/hypoplasia	236	104	69	10	7	429	
	6.6	***6.9***	***6.7***	***5.2***	***8.0***	***6.7***	
Spina bifida without anencephalus	153	40	55	9	2	262	
	4.3	***2.7***	***5.3***	***4.7***	***2.3***	***4.1***	
Tetralogy of Fallot	138	70	30	9	7	256	
	3.9	***4.7***	***2.9***	***4.7***	***8.0***	***4.0***	
Total anomalous pulmonary venous return (TAPVR)	36	16	22	5	2	81	
	1.0	***1.1***	***2.1***	***2.6***	***2.3***	***1.3***	
Transposition of great arteries - All	111	36	32	5	3	187	
	3.1	***2.4***	***3.1***	***2.6***	***3.4***	***2.9***	
dextro-Transposition of great arteries (d-TGA)	96	33	26	3	2	160	
	2.7	***2.2***	***2.5***	***1.6***	***2.3***	***2.5***	
Tricuspid valve atresia and stenosis	63	39	20	1	3	126	
	1.8	***2.6***	***1.9***	***0.5***	***3.4***	***2.0***	
Tricuspid valve atresia	52	37	17	1	2	109	
	1.5	***2.5***	***1.6***	***0.5***	***2.3***	***1.7***	
Trisomy 13 (Patau syndrome)	38	23	15	2	1	80	
	1.1	***1.5***	***1.4***	***1.0***	***1.1***	***1.3***	
Trisomy 18 (Edwards syndrome)	93	37	26	10	2	171	
	2.6	***2.5***	***2.5***	***5.2***	***2.3***	***2.7***	
Ventricular septal defect	1421	595	525	58	41	2645	
	39.9	***39.8***	***50.7***	***30.2***	***46.6***	***41.4***	
Total Live Births	**356226**	**149674**	**103644**	**19192**	**8794**	**639115**	
Total Male Live Births	**182972**	**76191**	**53034**	**9952**	**4467**	**327419**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

North Carolina

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	451 ***8.1***	320 ***39.6***	774 ***12.1***	
Trisomy 13 (Patau syndrome)	57 ***1.0***	23 ***2.8***	80 ***1.3***	
Trisomy 18 (Edwards syndrome)	98 ***1.8***	71 ***8.8***	171 ***2.7***	
Total Live Births	**558240**	**80843**	**639115**	

**Total includes unknown maternal age

North Dakota

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Amniotic bands	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Anencephalus	12 ***3.4***	1 ***14.8***	0 ***0.0***	0 ***0.0***	1 ***2.1***	14 ***3.2***	
Aniridia	1 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.2***	
Anophthalmia/microphthalmia	1 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.2***	
Anotia/microtia	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***4.1***	2 ***0.5***	
Aortic valve stenosis	9 ***2.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	3 ***6.2***	12 ***2.7***	
Atrial septal defect	215 ***60.6***	10 ***148.1***	0 ***0.0***	2 ***35.3***	76 ***156.2***	307 ***70.2***	
Atrioventricular septal defect (endocardial cushion defect)	7 ***2.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	4 ***8.2***	12 ***2.7***	1
Biliary atresia	2 ***0.6***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***2.1***	3 ***0.7***	
Bladder exstrophy	1 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.2***	
Choanal atresia	3 ***0.8***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	3 ***0.7***	
Cleft lip with and without cleft palate	39 ***11.0***	1 ***14.8***	0 ***0.0***	0 ***0.0***	9 ***18.5***	50 ***11.4***	
Cleft palate without cleft lip	52 ***14.7***	0 ***0.0***	0 ***0.0***	1 ***17.7***	7 ***14.4***	60 ***13.7***	
Coarctation of aorta	11 ***3.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	11 ***2.5***	
Common truncus	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***4.1***	2 ***0.5***	
Congenital cataract	7 ***2.0***	1 ***14.8***	0 ***0.0***	0 ***0.0***	1 ***2.1***	9 ***2.1***	
Congenital hip dislocation	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	
Diaphragmatic hernia	9 ***2.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	3 ***6.2***	12 ***2.7***	
Down syndrome (Trisomy 21)	30 ***8.5***	0 ***0.0***	0 ***0.0***	1 ***17.7***	1 ***2.1***	35 ***8.0***	
Ebstein anomaly	6 ***1.7***	1 ***14.8***	0 ***0.0***	0 ***0.0***	1 ***2.1***	8 ***1.8***	
Encephalocele	1 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***2.1***	2 ***0.5***	
Esophageal atresia/tracheoesophageal fistula	16 ***4.5***	1 ***14.8***	0 ***0.0***	0 ***0.0***	1 ***2.1***	18 ***4.1***	
Fetus or newborn affected by maternal alcohol use	3 ***0.8***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***4.1***	5 ***1.1***	
Hirschsprung disease (congenital megacolon)	7 ***2.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	3 ***6.2***	10 ***2.3***	
Hydrocephalus without spina bifida	17 ***4.8***	2 ***29.6***	0 ***0.0***	0 ***0.0***	4 ***8.2***	24 ***5.5***	
Hypoplastic left heart syndrome	12 ***3.4***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***2.1***	13 ***3.0***	
Hypospadias*	47 ***26.0***	1 ***27.9***	0 ***0.0***	0 ***0.0***	6 ***22.4***	54 ***24.3***	2
Microcephalus	16 ***4.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***2.1***	18 ***4.1***	
Obstructive genitourinary defect	4 ***1.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	4 ***0.9***	
Patent ductus arteriosus	158 ***44.6***	5 ***74.1***	0 ***0.0***	2 ***35.3***	43 ***88.4***	212 ***48.5***	3
Pulmonary valve atresia and stenosis	45 ***12.7***	0 ***0.0***	0 ***0.0***	0 ***0.0***	16 ***32.9***	62 ***14.2***	
Pulmonary valve atresia	7 ***2.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***4.1***	9 ***2.1***	

North Dakota

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pyloric stenosis	76	3	0	0	20	99	
	21.4	***44.4***	***0.0***	***0.0***	***41.1***	***22.6***	
Rectal and large intestinal atresia/stenosis	16	1	0	0	4	21	
	4.5	***14.8***	***0.0***	***0.0***	***8.2***	***4.8***	
Reduction deformity, lower limbs	4	0	0	0	2	6	
	1.1	***0.0***	***0.0***	***0.0***	***4.1***	***1.4***	
Reduction deformity, upper limbs	2	0	0	0	1	3	
	0.6	***0.0***	***0.0***	***0.0***	***2.1***	***0.7***	
Renal agenesis/hypoplasia	13	0	0	0	4	17	
	3.7	***0.0***	***0.0***	***0.0***	***8.2***	***3.9***	
Spina bifida without anencephalus	21	0	0	0	6	27	
	5.9	***0.0***	***0.0***	***0.0***	***12.3***	***6.2***	
Tetralogy of Fallot	17	0	0	0	7	24	
	4.8	***0.0***	***0.0***	***0.0***	***14.4***	***5.5***	
Total anomalous pulmonary venous return (TAPVR)	0	0	0	0	1	1	
	0.0	***0.0***	***0.0***	***0.0***	***2.1***	***0.2***	
Transposition of great arteries - All	17	0	0	0	0	17	
	4.8	***0.0***	***0.0***	***0.0***	***0.0***	***3.9***	
dextro-Transposition of great arteries (d-TGA)	9	0	0	0	0	9	
	2.5	***0.0***	***0.0***	***0.0***	***0.0***	***2.1***	
Tricuspid valve atresia and stenosis	5	0	0	0	0	5	4
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.1***	
Tricuspid valve atresia	5	0	0	0	0	5	
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.1***	
Trisomy 13 (Patau syndrome)	2	1	0	0	0	3	5
	2.9	***78.7***	***0.0***	***0.0***	***0.0***	***3.6***	
Trisomy 18 (Edwards syndrome)	3	0	0	0	1	4	6
	0.8	***0.0***	***0.0***	***0.0***	***2.1***	***0.9***	
Ventricular septal defect	131	2	0	0	38	177	7
	36.9	***29.6***	***0.0***	***0.0***	***78.1***	***40.5***	
Total Live Births	**35465**	**675**	**1606**	**566**	**4866**	**43716**	
Total Male Live Births	**18102**	**358**	**678**	**167**	**2678**	**22249**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

North Dakota

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	25 ***6.4***	10 ***22.4***	35 ***8.0***	
Trisomy 13 (Patau syndrome)	2 ***2.7***	1 ***11.8***	3 ***3.6***	5
Trisomy 18 (Edwards syndrome)	3 ***0.8***	1 ***2.2***	4 ***0.9***	6
Total Live Births	**39247**	**4469**	**43716**	

**Total includes unknown maternal age

Notes

1.State uses ICD-9 code 745.60. .61, .69 for confirmed diagnosis.We cannot distinguish 745.487 CDC/BPA codes.
2.The state uses ICD-9 codes and cannot distinguish these two conditions (Epispadias, Hypospadias) often unless reported.
3.Infants< 2500 grams are unable to be excluded.
4.State uses ICD-9 code 746.1 for confirmed diagnosis.We cannot distinguish 746.105 and 746.106 CDC/BPA codes.
5.Trisomy 13 was collected in the birth certificates up to the year 2005. Data for Trisomy 13 are for the year 2005 only. Trisomy 13 is not being colleted in the new electronic birth certificates from the year 2006 onwards.
6.Trisomy 18 was collected in the birth certificates up to the year 2005. Data for Trisomy 18 are for the years 2005 through 2009. Trisomy 18 is not being collected in the new electronic birth certificates from the year 2006 onwards.
7.State uses ICD-9 code 745.4 for confirmed diagnosis.We cannot distinguish 745.487 and 745.498 CDC/BPA codes.

General comments

-Fetal Death or birth resulting in stillbirth means death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy. The death is indicated by the fact that after such expulsion or extraction the fetus does not breathe or show any evidence of life such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles. North Dakota does not require reporting of this event before 20 weeks of gestation. Although collection is attempted, reporting is poor.
-North Dakota Vital Statistics implemented electronic registration of births from 2006 onwards.
-The North Dakota Birth Defects Monitoring System master registry is translated to ICD-9 using ICD-10 codes from birth certificates.
-There was no major methodological changes in the registry for the year 2011.

Ohio

Birth Defects Counts and Prevalence 2008 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Cleft lip with and without cleft palate	119 ***10.5***	14 ***5.6***	5 ***7.3***	3 ***9.6***	0 ***0.0***	141 ***9.5***	1
Cleft palate without cleft lip	94 ***8.3***	19 ***7.7***	3 ***4.4***	2 ***6.4***	0 ***0.0***	118 ***7.9***	2
Spina bifida without anencephalus	39 ***3.4***	3 ***1.2***	3 ***4.4***	0 ***0.0***	0 ***0.0***	45 ***3.0***	3
Total Live Births	**113542**	**24818**	**6887**	**3129**	**216**	**148592**	

**Total includes unknown race

Notes

1.Cleft lip with and without cleft palate: Data pulled on 14JUL2011.
2.Cleft palate without cleft lip: Includes one late reported case after lock-down of birth records. Data pulled on 14JUL2011.
3.Spina bifida: Livebirths only. Includes one late reported case after lock-down of birth records. Data pulled on 05JUL2011.

Oklahoma

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	16	4	1	1	3	25	
	1.1	*1.9*	*0.3*	*2.1*	*1.2*	*0.9*	
Anencephalus	47	4	4	2	6	63	
	3.2	*1.9*	*1.2*	*4.1*	*2.4*	*2.3*	
Aniridia	8	1	1	0	0	11	
	0.5	*0.5*	*0.3*	*0.0*	*0.0*	*0.4*	
Anophthalmia/microphthalmia	25	5	5	1	8	44	
	1.7	*2.4*	*1.4*	*2.1*	*3.1*	*1.6*	
Anotia/microtia	32	2	11	2	5	52	
	2.2	*1.0*	*3.2*	*4.1*	*2.0*	*1.9*	
Aortic valve stenosis	70	5	4	0	9	88	
	4.8	*2.4*	*1.2*	*0.0*	*3.5*	*3.3*	
Atrial septal defect	1185	195	160	20	251	1827	
	80.4	*94.3*	*46.0*	*41.2*	*98.5*	*68.0*	
Atrioventricular septal defect (endocardial cushion defect)	87	8	7	1	15	118	
	5.9	*3.9*	*2.0*	*2.1*	*5.9*	*4.4*	
Biliary atresia	10	1	2	0	2	15	
	0.7	*0.5*	*0.6*	*0.0*	*0.8*	*0.6*	
Bladder exstrophy	8	1	0	0	2	11	
	0.5	*0.5*	*0.0*	*0.0*	*0.8*	*0.4*	
Choanal atresia	30	4	4	1	5	44	
	2.0	*1.9*	*1.2*	*2.1*	*2.0*	*1.6*	
Cleft lip with and without cleft palate	154	13	15	1	25	208	
	10.5	*6.3*	*4.3*	*2.1*	*9.8*	*7.7*	
Cleft palate without cleft lip	241	18	34	8	45	348	
	16.4	*8.7*	*9.8*	*16.5*	*17.7*	*13.0*	
Coarctation of aorta	93	15	9	4	14	136	
	6.3	*7.3*	*2.6*	*8.2*	*5.5*	*5.1*	
Common truncus	21	2	1	1	3	28	
	1.4	*1.0*	*0.3*	*2.1*	*1.2*	*1.0*	
Congenital cataract	42	6	1	1	4	54	
	2.9	*2.9*	*0.3*	*2.1*	*1.6*	*2.0*	
Congenital hip dislocation	83	5	16	4	12	121	
	5.6	*2.4*	*4.6*	*8.2*	*4.7*	*4.5*	
Diaphragmatic hernia	76	6	13	1	8	104	
	5.2	*2.9*	*3.7*	*2.1*	*3.1*	*3.9*	
Down syndrome (Trisomy 21)	206	20	59	6	26	319	
	14.0	*9.7*	*17.0*	*12.4*	*10.2*	*11.9*	
Ebstein anomaly	14	0	1	0	4	19	
	1.0	*0.0*	*0.3*	*0.0*	*1.6*	*0.7*	
Encephalocele	18	4	3	1	2	29	
	1.2	*1.9*	*0.9*	*2.1*	*0.8*	*1.1*	
Epispadias	12	2	0	0	0	14	
	0.8	*1.0*	*0.0*	*0.0*	*0.0*	*0.5*	
Esophageal atresia/tracheoesophageal fistula	58	9	5	1	9	82	
	3.9	*4.4*	*1.4*	*2.1*	*3.5*	*3.1*	
Fetus or newborn affected by maternal alcohol use	3	1	0	0	2	6	
	0.2	*0.5*	*0.0*	*0.0*	*0.8*	*0.2*	
Gastroschisis	115	10	16	3	29	173	
	7.8	*4.8*	*4.6*	*6.2*	*11.4*	*6.4*	
Hirschsprung disease (congenital megacolon)	31	4	2	1	6	44	
	2.1	*1.9*	*0.6*	*2.1*	*2.4*	*1.6*	
Hydrocephalus without spina bifida	119	23	15	1	21	182	
	8.1	*11.1*	*4.3*	*2.1*	*8.2*	*6.8*	
Hypoplastic left heart syndrome	40	3	2	2	7	54	
	2.7	*1.5*	*0.6*	*4.1*	*2.7*	*2.0*	
Hypospadias*	434	47	14	7	49	552	
	57.6	*44.3*	*7.9*	*28.2*	*37.8*	*40.2*	
Microcephalus	126	25	18	2	26	202	
	8.6	*12.1*	*5.2*	*4.1*	*10.2*	*7.5*	
Obstructive genitourinary defect	731	84	125	24	93	1064	
	49.6	*40.6*	*36.0*	*49.4*	*36.5*	*39.6*	
Omphalocele	48	10	8	0	5	71	
	3.3	*4.8*	*2.3*	*0.0*	*2.0*	*2.6*	

Oklahoma

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Pulmonary valve atresia and stenosis	116	18	17	2	20	174	
	7.9	***8.7***	***4.9***	***4.1***	***7.8***	***6.5***	
Pulmonary valve atresia	16	4	4	1	3	28	
	1.1	***1.9***	***1.2***	***2.1***	***1.2***	***1.0***	
Pyloric stenosis	769	40	108	6	146	1074	
	52.2	***19.3***	***31.1***	***12.4***	***57.3***	***40.0***	
Rectal and large intestinal atresia/stenosis	122	19	15	2	17	175	
	8.3	***9.2***	***4.3***	***4.1***	***6.7***	***6.5***	
Reduction deformity, lower limbs	464	58	82	9	60	676	
	31.5	***28.1***	***23.6***	***18.5***	***23.5***	***25.2***	
Reduction deformity, upper limbs	71	11	8	1	14	106	
	4.8	***5.3***	***2.3***	***2.1***	***5.5***	***3.9***	
Renal agenesis/hypoplasia	110	13	16	3	11	155	
	7.5	***6.3***	***4.6***	***6.2***	***4.3***	***5.8***	
Spina bifida without anencephalus	91	8	6	0	10	116	
	6.2	***3.9***	***1.7***	***0.0***	***3.9***	***4.3***	
Tetralogy of Fallot	76	14	14	0	17	121	
	5.2	***6.8***	***4.0***	***0.0***	***6.7***	***4.5***	
Total anomalous pulmonary venous return (TAPVR)	26	5	7	0	8	46	
	1.8	***2.4***	***2.0***	***0.0***	***3.1***	***1.7***	
Transposition of great arteries - All	51	4	7	2	10	74	
	3.5	***1.9***	***2.0***	***4.1***	***3.9***	***2.8***	
dextro-Transposition of great arteries (d-TGA)	45	4	6	2	10	67	
	3.1	***1.9***	***1.7***	***4.1***	***3.9***	***2.5***	
Tricuspid valve atresia and stenosis	19	4	4	0	1	28	
	1.3	***1.9***	***1.2***	***0.0***	***0.4***	***1.0***	
Tricuspid valve atresia	16	4	3	0	1	24	
	1.1	***1.9***	***0.9***	***0.0***	***0.4***	***0.9***	
Trisomy 13 (Patau syndrome)	20	4	0	1	7	32	
	1.4	***1.9***	***0.0***	***2.1***	***2.7***	***1.2***	
Trisomy 18 (Edwards syndrome)	40	8	2	1	5	56	
	2.7	***3.9***	***0.6***	***2.1***	***2.0***	***2.1***	
Ventricular septal defect	947	136	165	24	156	1432	
	64.3	***65.8***	***47.5***	***49.4***	***61.2***	***53.3***	
Total Live Births	**147354**	**20674**	**34758**	**4854**	**25480**	**268661**	
Total Male Live Births	**75408**	**10600**	**17732**	**2484**	**12969**	**137407**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Oklahoma

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	175 ***7.1***	144 ***64.6***	319 ***11.9***	
Trisomy 13 (Patau syndrome)	25 ***1.0***	7 ***3.1***	32 ***1.2***	
Trisomy 18 (Edwards syndrome)	39 ***1.6***	17 ***7.6***	56 ***2.1***	
Total Live Births	**246360**	**22283**	**268661**	

**Total includes unknown maternal age

Puerto Rico

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Anencephalus	.	.	95	.	.	95	
	.	.	***4.0***	.	.	***4.0***	
Anophthalmia/microphthalmia	.	.	16	.	.	16	1
	.	.	***1.8***	.	.	***1.8***	
Anotia/microtia	.	.	29	.	.	29	2
	.	.	***3.2***	.	.	***3.2***	
Aortic valve stenosis	.	.	46	.	.	46	
	.	.	***1.9***	.	.	***1.9***	
Atrial septal defect	.	.	534	.	.	534	3
	.	.	***22.6***	.	.	***22.6***	
Atrioventricular septal defect (endocardial cushion defect)	.	.	99	.	.	99	4
	.	.	***4.2***	.	.	***4.2***	
Bladder exstrophy	.	.	0	.	.	0	5
	.	.	***0.0***	.	.	***0.0***	
Cleft lip with and without cleft palate	.	.	227	.	.	227	
	.	.	***9.6***	.	.	***9.6***	
Cleft palate without cleft lip	.	.	151	.	.	151	
	.	.	***6.4***	.	.	***6.4***	
Coarctation of aorta	.	.	97	.	.	97	
	.	.	***4.1***	.	.	***4.1***	
Common truncus	.	.	19	.	.	19	
	.	.	***0.8***	.	.	***0.8***	
Down syndrome (Trisomy 21)	.	.	355	.	.	355	
	.	.	***15.0***	.	.	***15.0***	
Ebstein anomaly	.	.	23	.	.	23	
	.	.	***1.0***	.	.	***1.0***	
Encephalocele	.	.	35	.	.	35	
	.	.	***1.5***	.	.	***1.5***	
Epispadias	.	.	6	.	.	6	6
	.	.	***0.4***	.	.	***0.4***	
Gastroschisis	.	.	114	.	.	114	7
	.	.	***4.8***	.	.	***4.8***	
Hypoplastic left heart syndrome	.	.	55	.	.	55	
	.	.	***2.3***	.	.	***2.3***	
Hypospadias*	.	.	218	.	.	218	8
	.	.	***30.9***	.	.	***30.9***	
Omphalocele	.	.	59	.	.	59	7
	.	.	***2.5***	.	.	***2.5***	
Patent ductus arteriosus	.	.	640	.	.	640	9
	.	.	***27.0***	.	.	***27.0***	
Pulmonary valve atresia and stenosis	.	.	251	.	.	251	
	.	.	***10.6***	.	.	***10.6***	
Pulmonary valve atresia	.	.	27	.	.	27	
	.	.	***1.1***	.	.	***1.1***	
Reduction deformity, lower limbs	.	.	35	.	.	35	
	.	.	***1.5***	.	.	***1.5***	
Reduction deformity, upper limbs	.	.	82	.	.	82	
	.	.	***3.5***	.	.	***3.5***	
Spina bifida without anencephalus	.	.	103	.	.	103	
	.	.	***4.4***	.	.	***4.4***	
Tetralogy of Fallot	.	.	88	.	.	88	
	.	.	***3.7***	.	.	***3.7***	
Total anomalous pulmonary venous return (TAPVR)	.	.	14	.	.	14	
	.	.	***0.6***	.	.	***0.6***	
Transposition of great arteries - All	.	.	63	.	.	63	10
	.	.	***2.7***	.	.	***2.7***	
dextro-Transposition of great arteries (d-TGA)	.	.	59	.	.	59	
	.	.	***2.5***	.	.	***2.5***	
Tricuspid valve atresia	.	.	34	.	.	34	
	.	.	***1.4***	.	.	***1.4***	
Trisomy 13 (Patau syndrome)	.	.	39	.	.	39	
	.	.	***1.6***	.	.	***1.6***	
Trisomy 18 (Edwards syndrome)	.	.	90	.	.	90	
	.	.	***3.8***	.	.	***3.8***	

Puerto Rico

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Ventricular septal defect	.	.	560	.	.	560	11
	.	**.**	***23.7***	**.**	**.**	***23.7***	
Total Live Births	**.**	**.**	**236699**	**.**	**.**	**236699**	
Total Male Live Births (2007-2009)	**.**	**.**	**70552**	**.**	**.**	**70552**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Puerto Rico

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	209	146	355	
	9.6	***74.7***	***15.0***	
Trisomy 13 (Patau syndrome)	27	12	39	
	1.2	***6.1***	***1.6***	
Trisomy 18 (Edwards syndrome)	54	36	90	
	2.5	***18.4***	***3.8***	
Total Live Births	**217092**	**19545**	**236699**	

**Total includes unknown maternal age

Notes
1.Anophtalmia/microphtalmia: Only include data for 2008-2009.
2.Anotia/microtia: Only include data for 2008-2009
3.Excludes PFO
4.Only includes AV Canal.
5.Bladder exstrophy: Only include data for 2008-2009
6.Epispadias: Only include data for 2007-2009
7.We used clinical diagnosis to distinguish gastroschisis and omphalocele.
8.Hypospadias: Only include data for 2007-2009
9.Unable to exclude infants with defect last noted at <6 wks of age.
10.Excludes 745.11 (DORV)
11.Excludes probable cases. We can't distinguish inlet VSD from other VSD. However we exclude inlet/posterior type VSD in the presence of AV Canal.

General comments
-Probable/possible diagnoses were not included.
-The coding system used was ICD 9 CM
-We include stillbirths and terminations (no gestational age cut off) in our counts.

Rhode Island

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	2 *0.5*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	2 *0.3*	
Anencephalus	3 *0.8*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	3 *0.5*	
Aniridia	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	
Anophthalmia/microphthalmia	2 *0.5*	1 *2.0*	2 *1.6*	0 *0.0*	0 *0.0*	5 *0.8*	
Anotia/microtia	1 *0.3*	0 *0.0*	3 *2.4*	0 *0.0*	1 *17.7*	5 *0.8*	
Aortic valve stenosis	2 *0.5*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	2 *0.3*	
Atrial septal defect	142 *37.7*	26 *51.6*	50 *39.5*	5 *18.5*	4 *70.8*	230 *37.9*	
Atrioventricular septal defect (endocardial cushion defect)	8 *2.1*	2 *4.0*	1 *0.8*	0 *0.0*	0 *0.0*	11 *1.8*	
Biliary atresia	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	
Bladder exstrophy	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	
Choanal atresia	2 *0.5*	2 *4.0*	0 *0.0*	0 *0.0*	0 *0.0*	4 *0.7*	
Cleft lip with and without cleft palate	32 *8.5*	1 *2.0*	9 *7.1*	2 *7.4*	0 *0.0*	45 *7.4*	
Cleft palate without cleft lip	28 *7.4*	1 *2.0*	7 *5.5*	3 *11.1*	1 *17.7*	40 *6.6*	
Coarctation of aorta	7 *1.9*	2 *4.0*	3 *2.4*	2 *7.4*	0 *0.0*	15 *2.5*	
Common truncus	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	
Congenital cataract	1 *0.3*	1 *2.0*	1 *0.8*	0 *0.0*	0 *0.0*	3 *0.5*	
Congenital hip dislocation	33 *8.8*	3 *6.0*	7 *5.5*	0 *0.0*	0 *0.0*	43 *7.1*	
Diaphragmatic hernia	9 *2.4*	1 *2.0*	5 *4.0*	1 *3.7*	0 *0.0*	16 *2.6*	
Down syndrome (Trisomy 21)	56 *14.9*	5 *9.9*	13 *10.3*	3 *11.1*	0 *0.0*	83 *13.7*	
Ebstein anomaly	2 *0.5*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	2 *0.3*	
Encephalocele	2 *0.5*	0 *0.0*	0 *0.0*	0 *0.0*	0 *0.0*	2 *0.3*	
Epispadias	10 *2.7*	1 *2.0*	0 *0.0*	0 *0.0*	0 *0.0*	11 *1.8*	
Esophageal atresia/tracheoesophageal fistula	7 *1.9*	1 *2.0*	6 *4.7*	0 *0.0*	0 *0.0*	16 *2.6*	
Fetus or newborn affected by maternal alcohol use	4 *1.1*	4 *7.9*	2 *1.6*	0 *0.0*	0 *0.0*	11 *1.8*	
Gastroschisis	11 *2.9*	5 *9.9*	12 *9.5*	1 *3.7*	1 *17.7*	30 *4.9*	
Hirschsprung disease (congenital megacolon)	7 *1.9*	2 *4.0*	0 *0.0*	0 *0.0*	0 *0.0*	10 *1.6*	
Hydrocephalus without spina bifida	14 *3.7*	4 *7.9*	3 *2.4*	2 *7.4*	1 *17.7*	26 *4.3*	
Hypoplastic left heart syndrome	3 *0.8*	1 *2.0*	1 *0.8*	1 *3.7*	0 *0.0*	7 *1.2*	
Hypospadias*	148 *76.1*	19 *73.7*	39 *61.3*	3 *22.0*	0 *0.0*	211 *67.8*	
Microcephalus	11 *2.9*	1 *2.0*	2 *1.6*	2 *7.4*	0 *0.0*	17 *2.8*	
Obstructive genitourinary defect	97 *25.8*	20 *39.7*	30 *23.7*	6 *22.2*	1 *17.7*	156 *25.7*	
Omphalocele	6 *1.6*	1 *2.0*	2 *1.6*	0 *0.0*	0 *0.0*	9 *1.5*	

Rhode Island

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	136	25	49	7	1	219	
	36.1	***49.6***	***38.7***	***25.9***	***17.7***	***36.1***	
Pulmonary valve atresia and stenosis	28	2	13	2	1	49	
	7.4	***4.0***	***10.3***	***7.4***	***17.7***	***8.1***	
Pulmonary valve atresia	5	0	2	0	1	8	
	1.3	***0.0***	***1.6***	***0.0***	***17.7***	***1.3***	
Pyloric stenosis	2	0	1	0	0	3	
	0.5	***0.0***	***0.8***	***0.0***	***0.0***	***0.5***	
Rectal and large intestinal atresia/stenosis	13	4	4	1	0	22	
	3.5	***7.9***	***3.2***	***3.7***	***0.0***	***3.6***	
Reduction deformity, lower limbs	7	0	2	0	0	9	
	1.9	***0.0***	***1.6***	***0.0***	***0.0***	***1.5***	
Reduction deformity, upper limbs	6	1	1	0	0	8	
	1.6	***2.0***	***0.8***	***0.0***	***0.0***	***1.3***	
Renal agenesis/hypoplasia	4	3	1	0	0	8	
	1.1	***6.0***	***0.8***	***0.0***	***0.0***	***1.3***	
Spina bifida without anencephalus	8	2	5	0	0	15	
	2.1	***4.0***	***4.0***	***0.0***	***0.0***	***2.5***	
Tetralogy of Fallot	13	3	8	0	0	26	
	3.5	***6.0***	***6.3***	***0.0***	***0.0***	***4.3***	
Total anomalous pulmonary venous return (TAPVR)	2	0	3	0	0	5	
	0.5	***0.0***	***2.4***	***0.0***	***0.0***	***0.8***	
Transposition of great arteries - All	7	1	4	2	0	14	
	1.9	***2.0***	***3.2***	***7.4***	***0.0***	***2.3***	
dextro-Transposition of great arteries (d-TGA)	5	1	4	1	0	11	
	1.3	***2.0***	***3.2***	***3.7***	***0.0***	***1.8***	
Tricuspid valve atresia	1	1	1	0	1	4	
	0.3	***2.0***	***0.8***	***0.0***	***17.7***	***0.7***	
Trisomy 13 (Patau syndrome)	0	2	2	1	0	6	
	0.0	***4.0***	***1.6***	***3.7***	***0.0***	***1.0***	
Trisomy 18 (Edwards syndrome)	7	2	2	0	0	12	
	1.9	***4.0***	***1.6***	***0.0***	***0.0***	***2.0***	
Ventricular septal defect	141	14	42	12	1	215	
	37.5	***27.8***	***33.2***	***44.4***	***17.7***	***35.4***	
Total Live Births	**37623**	**5036**	**12652**	**2703**	**565**	**60715**	
Total Male Live Births	**19460**	**2579**	**6367**	**1361**	**286**	**31137**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Rhode Island

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	38 ***7.6***	41 ***37.9***	83 ***13.7***	
Trisomy 13 (Patau syndrome)	2 ***0.4***	4 ***3.7***	6 ***1.0***	
Trisomy 18 (Edwards syndrome)	5 ***1.0***	7 ***6.5***	12 ***2.0***	
Total Live Births	**49906**	**10809**	**60715**	

**Total includes unknown maternal age

General comments
-Includes specialty clinic data from 2009
-Prenatal ascertainment of cases begins in 2009

South Carolina

Birth Defects Counts and Prevalence 2006-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	27 ***2.0***	19 ***2.3***	14 ***5.8***	0 ***0.0***	0 ***0.0***	61 ***2.4***	
Aniridia	2 ***0.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***0.1***	
Anophthalmia/microphthalmia	6 ***0.4***	3 ***0.4***	1 ***0.4***	0 ***0.0***	0 ***0.0***	10 ***0.4***	
Anotia/microtia	3 ***0.2***	2 ***0.2***	0 ***0.0***	1 ***2.5***	0 ***0.0***	6 ***0.2***	
Aortic valve stenosis	11 ***0.8***	4 ***0.5***	4 ***1.7***	1 ***2.5***	0 ***0.0***	22 ***0.9***	
Atrial septal defect	226 ***22.0***	152 ***24.7***	53 ***28.8***	7 ***23.6***	0 ***0.0***	445 ***23.8***	1
Atrioventricular septal defect (endocardial cushion defect)	58 ***4.2***	52 ***6.4***	8 ***3.3***	0 ***0.0***	0 ***0.0***	120 ***4.8***	
Biliary atresia	5 ***0.4***	4 ***0.5***	0 ***0.0***	0 ***0.0***	0 ***0.0***	9 ***0.4***	
Bladder exstrophy	0 ***0.0***	2 ***0.2***	0 ***0.0***	0 ***0.0***	0 ***0.0***	2 ***0.1***	
Choanal atresia	7 ***0.5***	6 ***0.7***	3 ***1.2***	0 ***0.0***	0 ***0.0***	16 ***0.6***	
Cleft lip with and without cleft palate	109 ***8.0***	41 ***5.0***	21 ***8.7***	5 ***12.5***	2 ***20.0***	185 ***7.5***	
Cleft palate without cleft lip	60 ***4.4***	44 ***5.4***	10 ***4.2***	1 ***2.5***	0 ***0.0***	116 ***4.7***	
Coarctation of aorta	58 ***4.2***	21 ***2.6***	8 ***3.3***	2 ***5.0***	0 ***0.0***	90 ***3.6***	
Common truncus	12 ***0.9***	3 ***0.4***	1 ***0.4***	0 ***0.0***	1 ***10.0***	17 ***0.7***	
Congenital cataract	9 ***0.7***	3 ***0.4***	2 ***0.8***	0 ***0.0***	0 ***0.0***	14 ***0.6***	
Congenital hip dislocation	47 ***3.4***	8 ***1.0***	14 ***5.8***	1 ***2.5***	0 ***0.0***	70 ***2.8***	
Diaphragmatic hernia	32 ***2.3***	12 ***1.5***	7 ***2.9***	0 ***0.0***	0 ***0.0***	52 ***2.1***	
Down syndrome (Trisomy 21)	66 ***9.5***	35 ***8.6***	18 ***15.2***	3 ***14.4***	0 ***0.0***	124 ***9.9***	2
Ebstein anomaly	8 ***0.6***	3 ***0.4***	1 ***0.4***	2 ***5.0***	0 ***0.0***	14 ***0.6***	
Encephalocele	14 ***1.0***	8 ***1.0***	8 ***3.3***	1 ***2.5***	0 ***0.0***	31 ***1.3***	
Esophageal atresia/tracheoesophageal fistula	8 ***0.6***	4 ***0.5***	1 ***0.4***	0 ***0.0***	0 ***0.0***	13 ***0.5***	
Gastroschisis	6 ***0.4***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	6 ***0.2***	
Hirschsprung disease (congenital megacolon)	18 ***1.3***	8 ***1.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	26 ***1.0***	
Hydrocephalus without spina bifida	63 ***4.6***	44 ***5.4***	10 ***4.2***	1 ***2.5***	0 ***0.0***	118 ***4.8***	
Hypoplastic left heart syndrome	32 ***2.3***	22 ***2.7***	9 ***3.7***	1 ***2.5***	0 ***0.0***	64 ***2.6***	
Microcephalus	37 ***2.7***	43 ***5.3***	18 ***7.5***	2 ***5.0***	0 ***0.0***	103 ***4.2***	
Obstructive genitourinary defect	89 ***6.5***	42 ***5.2***	22 ***9.2***	1 ***2.5***	0 ***0.0***	159 ***6.4***	
Omphalocele	1 ***0.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.0***	
Patent ductus arteriosus	196 ***19.1***	179 ***29.0***	51 ***27.7***	6 ***20.3***	1 ***14.0***	441 ***23.6***	3
Pulmonary valve atresia and stenosis	69 ***5.0***	48 ***5.9***	15 ***6.2***	0 ***0.0***	1 ***10.0***	135 ***5.5***	
Pulmonary valve atresia	11 ***0.8***	10 ***1.2***	4 ***1.7***	0 ***0.0***	0 ***0.0***	25 ***1.0***	
Pyloric stenosis	70 ***6.8***	25 ***4.1***	20 ***10.8***	1 ***3.4***	1 ***14.0***	119 ***6.4***	4

South Carolina

Birth Defects Counts and Prevalence 2006-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Rectal and large intestinal atresia/stenosis	24	9	2	1	1	37	
	1.8	***1.1***	***0.8***	***2.5***	***10.0***	***1.5***	
Reduction deformity, lower limbs	25	16	5	0	0	46	
	1.8	***2.0***	***2.1***	***0.0***	***0.0***	***1.9***	
Reduction deformity, upper limbs	29	19	12	0	1	61	
	2.1	***2.3***	***5.0***	***0.0***	***10.0***	***2.5***	
Renal agenesis/hypoplasia	34	20	6	0	0	60	
	2.5	***2.5***	***2.5***	***0.0***	***0.0***	***2.4***	
Spina bifida without anencephalus	49	17	6	1	0	73	
	3.6	***2.1***	***2.5***	***2.5***	***0.0***	***2.9***	
Tetralogy of Fallot	45	39	12	1	0	99	
	3.3	***4.8***	***5.0***	***2.5***	***0.0***	***4.0***	
Transposition of great arteries - All	66	28	8	1	1	106	
	4.8	***3.4***	***3.3***	***2.5***	***10.0***	***4.3***	
dextro-Transposition of great arteries (d-TGA)	39	11	3	0	1	55	
	2.8	***1.4***	***1.2***	***0.0***	***10.0***	***2.2***	
Tricuspid valve atresia and stenosis	8	8	5	0	0	21	
	0.6	***1.0***	***2.1***	***0.0***	***0.0***	***0.8***	
Trisomy 13 (Patau syndrome)	7	6	1	0	0	15	5
	1.0	***1.5***	***0.8***	***0.0***	***0.0***	***1.2***	
Trisomy 18 (Edwards syndrome)	15	8	4	0	0	27	6
	2.2	***2.0***	***3.4***	***0.0***	***0.0***	***2.2***	
Ventricular septal defect	420	251	121	9	2	811	
	30.7	***30.8***	***50.4***	***22.5***	***20.0***	***32.7***	
Total Live Births	**136903**	**81439**	**24022**	**3998**	**999**	**250776**	

**Total includes unknown race

South Carolina

Trisomy Counts and Prevalence by Maternal Age 2006-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	64 ***5.8***	60 ***44.6***	124 ***9.9***	2
Trisomy 13 (Patau syndrome)	12 ***1.1***	3 ***2.2***	15 ***1.2***	5
Trisomy 18 (Edwards syndrome)	17 ***1.5***	10 ***7.4***	27 ***2.2***	6
Total Live Births	**111204**	**13447**	**124654**	

**Total includes unknown maternal age

Notes
1.Atrial Septal Defect was dropped beginning in 2009
2.Down Syndrome was collected beginning in 2008
3.Patent Ductus Arteriosus was dropped beginning in 2009
4.Pyloric Stenosis was dropped beginning in 2009
5.Trisomy 13 was collected beginning in 2008
6.Trisomy 18 was collected beginning in 2008

Tennessee

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	35	11	8	0	0	56	
	1.2	***1.3***	***2.1***	***0.0***	***0.0***	***1.3***	
Aniridia	7	0	0	0	0	7	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Anophthalmia/microphthalmia	20	16	3	1	0	41	
	0.7	***1.8***	***0.8***	***1.2***	***0.0***	***1.0***	
Anotia/microtia	18	2	7	1	0	28	
	0.6	***0.2***	***1.8***	***1.2***	***0.0***	***0.7***	
Aortic valve stenosis	71	5	8	0	0	85	
	2.5	***0.6***	***2.1***	***0.0***	***0.0***	***2.0***	
Atrial septal defect	2450	1133	274	47	1	3921	
	86.3	***130.3***	***71.0***	***58.4***	***16.0***	***93.3***	
Atrioventricular septal defect (endocardial cushion defect)	123	34	10	1	0	168	1
	4.3	***3.9***	***2.6***	***1.2***	***0.0***	***4.0***	
Biliary atresia	18	7	3	3	0	31	
	0.6	***0.8***	***0.8***	***3.7***	***0.0***	***0.7***	
Bladder exstrophy	18	4	0	0	0	22	
	0.6	***0.5***	***0.0***	***0.0***	***0.0***	***0.5***	
Choanal atresia	59	11	3	0	1	74	
	2.1	***1.3***	***0.8***	***0.0***	***16.0***	***1.8***	
Cleft lip with and without cleft palate	372	60	35	1	2	473	
	13.1	***6.9***	***9.1***	***1.2***	***32.1***	***11.3***	
Cleft palate without cleft lip	244	46	20	8	2	320	
	8.6	***5.3***	***5.2***	***9.9***	***32.1***	***7.6***	
Coarctation of aorta	200	49	27	1	0	277	
	7.0	***5.6***	***7.0***	***1.2***	***0.0***	***6.6***	
Common truncus	37	3	3	1	0	44	
	1.3	***0.3***	***0.8***	***1.2***	***0.0***	***1.0***	
Congenital cataract	74	20	4	5	0	103	
	2.6	***2.3***	***1.0***	***6.2***	***0.0***	***2.5***	
Congenital hip dislocation	246	39	27	3	0	315	
	8.7	***4.5***	***7.0***	***3.7***	***0.0***	***7.5***	
Diaphragmatic hernia	106	29	14	4	0	153	
	3.7	***3.3***	***3.6***	***5.0***	***0.0***	***3.6***	
Down syndrome (Trisomy 21)	420	112	60	9	0	605	
	14.8	***12.9***	***15.5***	***11.2***	***0.0***	***14.4***	
Ebstein anomaly	24	7	4	1	0	36	
	0.8	***0.8***	***1.0***	***1.2***	***0.0***	***0.9***	
Encephalocele	35	10	11	0	0	56	
	1.2	***1.1***	***2.8***	***0.0***	***0.0***	***1.3***	
Epispadias	44	10	2	0	0	56	
	1.5	***1.1***	***0.5***	***0.0***	***0.0***	***1.3***	
Esophageal atresia/tracheoesophageal fistula	81	13	9	0	0	103	
	2.9	***1.5***	***2.3***	***0.0***	***0.0***	***2.5***	
Fetus or newborn affected by maternal alcohol use	55	33	0	0	0	88	
	1.9	***3.8***	***0.0***	***0.0***	***0.0***	***2.1***	
Gastroschisis	178	23	19	4	0	224	2
	6.3	***2.6***	***4.9***	***5.0***	***0.0***	***5.3***	
Hirschsprung disease (congenital megacolon)	79	43	8	0	0	131	
	2.8	***4.9***	***2.1***	***0.0***	***0.0***	***3.1***	
Hydrocephalus without spina bifida	176	85	37	3	0	303	
	6.2	***9.8***	***9.6***	***3.7***	***0.0***	***7.2***	
Hypoplastic left heart syndrome	91	34	13	0	0	138	
	3.2	***3.9***	***3.4***	***0.0***	***0.0***	***3.3***	
Hypospadias*	1694	489	66	22	2	2281	
	116.5	***110.6***	***33.6***	***53.3***	***63.9***	***106.2***	
Microcephalus	308	117	44	5	0	477	
	10.8	***13.5***	***11.4***	***6.2***	***0.0***	***11.3***	
Obstructive genitourinary defect	896	176	87	23	1	1186	
	31.6	***20.2***	***22.5***	***28.6***	***16.0***	***28.2***	
Omphalocele	79	37	11	0	0	127	3
	2.8	***4.3***	***2.8***	***0.0***	***0.0***	***3.0***	
Patent ductus arteriosus	1582	693	214	33	1	2529	4
	55.7	***79.7***	***55.4***	***41.0***	***16.0***	***60.2***	

Tennessee

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	307	103	29	5	2	447	
	10.8	***11.8***	***7.5***	***6.2***	***32.1***	***10.6***	
Pulmonary valve atresia	44	17	8	0	0	70	
	1.5	***2.0***	***2.1***	***0.0***	***0.0***	***1.7***	
Pyloric stenosis	1401	230	183	10	1	1829	
	49.4	***26.4***	***47.4***	***12.4***	***16.0***	***43.5***	
Rectal and large intestinal atresia/stenosis	171	47	24	3	0	247	
	6.0	***5.4***	***6.2***	***3.7***	***0.0***	***5.9***	
Reduction deformity, lower limbs	53	25	7	2	0	88	
	1.9	***2.9***	***1.8***	***2.5***	***0.0***	***2.1***	
Reduction deformity, upper limbs	56	20	12	2	0	91	
	2.0	***2.3***	***3.1***	***2.5***	***0.0***	***2.2***	
Renal agenesis/hypoplasia	140	51	19	4	0	214	
	4.9	***5.9***	***4.9***	***5.0***	***0.0***	***5.1***	
Spina bifida without anencephalus	121	29	29	1	0	181	
	4.3	***3.3***	***7.5***	***1.2***	***0.0***	***4.3***	
Tetralogy of Fallot	177	52	19	5	0	253	
	6.2	***6.0***	***4.9***	***6.2***	***0.0***	***6.0***	
Transposition of great arteries - All	182	54	24	4	0	265	5
	6.4	***6.2***	***6.2***	***5.0***	***0.0***	***6.3***	
dextro-Transposition of great arteries (d-TGA)	67	19	8	3	0	97	
	2.4	***2.2***	***2.1***	***3.7***	***0.0***	***2.3***	
Tricuspid valve atresia and stenosis	40	7	1	0	0	49	6
	1.4	***0.8***	***0.3***	***0.0***	***0.0***	***1.2***	
Tricuspid valve atresia	40	7	1	0	0	49	6
	1.4	***0.8***	***0.3***	***0.0***	***0.0***	***1.2***	
Trisomy 13 (Patau syndrome)	17	13	3	1	0	34	
	0.6	***1.5***	***0.8***	***1.2***	***0.0***	***0.8***	
Trisomy 18 (Edwards syndrome)	46	13	9	0	0	68	
	1.6	***1.5***	***2.3***	***0.0***	***0.0***	***1.6***	
Ventricular septal defect	1341	386	182	21	1	1937	7
	47.2	***44.4***	***47.1***	***26.1***	***16.0***	***46.1***	
Total Live Births	**283873**	**86969**	**38615**	**8043**	**624**	**420278**	
Total Male Live Births	**145385**	**44223**	**19659**	**4131**	**313**	**214748**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Tennessee

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	355 ***9.4***	250 ***58.6***	605 ***14.4***	
Trisomy 13 (Patau syndrome)	25 ***0.7***	9 ***2.1***	34 ***0.8***	
Trisomy 18 (Edwards syndrome)	46 ***1.2***	22 ***5.2***	68 ***1.6***	
Total Live Births	**377393**	**42668**	**420278**	

**Total includes unknown maternal age

Notes
1.TN does not use the new CDC/BPA codes and cannot distinguish 745.487 from other VSD.
2.ICD-9 Procedure Code = 54.71
3.ICD-9 Procedure Code not equal to 54.71
4.Birthweight = 2500 grams.
5.TN does not use the new CDC/BPA codes: information includes the entire range.
6.TN does not use the new CDC/BPA codes and cases with 746.106 are included within this category
7.Includes probable cases. TN does not use the new CDC/BPA codes and cannot distinguish 745.487.

Texas

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	57	25	66	4	1	154	
	0.8	***1.1***	***0.7***	***0.6***	***2.8***	***0.8***	
Anencephalus	134	43	301	14	1	503	
	1.9	***1.9***	***3.0***	***1.9***	***2.8***	***2.5***	
Aniridia	8	2	9	1	0	20	
	0.1	***0.1***	***0.1***	***0.1***	***0.0***	***0.1***	
Anophthalmia/microphthalmia	211	56	343	16	4	635	
	3.1	***2.5***	***3.4***	***2.2***	***11.1***	***3.2***	
Anotia/microtia	132	34	475	25	5	673	
	1.9	***1.5***	***4.8***	***3.5***	***13.9***	***3.4***	
Aortic valve stenosis	180	34	229	10	1	460	
	2.6	***1.5***	***2.3***	***1.4***	***2.8***	***2.3***	
Atrial septal defect	4425	1565	6505	349	24	12938	
	64.3	***69.3***	***65.2***	***48.2***	***66.7***	***64.7***	
Atrioventricular septal defect (endocardial cushion defect)	348	109	400	15	1	876	
	5.1	***4.8***	***4.0***	***2.1***	***2.8***	***4.4***	
Biliary atresia	43	12	83	7	2	148	
	0.6	***0.5***	***0.8***	***1.0***	***5.6***	***0.7***	
Bladder exstrophy	17	2	8	2	0	29	
	0.2	***0.1***	***0.1***	***0.3***	***0.0***	***0.1***	
Choanal atresia	97	28	119	10	0	255	
	1.4	***1.2***	***1.2***	***1.4***	***0.0***	***1.3***	
Cleft lip with and without cleft palate	747	155	1144	68	6	2131	
	10.8	***6.9***	***11.5***	***9.4***	***16.7***	***10.7***	
Cleft palate without cleft lip	481	105	583	47	0	1223	
	7.0	***4.7***	***5.8***	***6.5***	***0.0***	***6.1***	
Coarctation of aorta	396	82	527	25	3	1040	
	5.8	***3.6***	***5.3***	***3.5***	***8.3***	***5.2***	
Common truncus	50	14	75	4	0	143	
	0.7	***0.6***	***0.8***	***0.6***	***0.0***	***0.7***	
Congenital cataract	146	57	182	8	0	397	
	2.1	***2.5***	***1.8***	***1.1***	***0.0***	***2.0***	
Congenital hip dislocation	343	48	447	35	1	881	
	5.0	***2.1***	***4.5***	***4.8***	***2.8***	***4.4***	
Diaphragmatic hernia	204	51	290	14	2	564	
	3.0	***2.3***	***2.9***	***1.9***	***5.6***	***2.8***	
Down syndrome (Trisomy 21)	856	221	1510	77	4	2691	
	12.4	***9.8***	***15.1***	***10.6***	***11.1***	***13.5***	
Ebstein anomaly	42	5	70	7	0	124	
	0.6	***0.2***	***0.7***	***1.0***	***0.0***	***0.6***	
Encephalocele	51	24	112	3	0	196	
	0.7	***1.1***	***1.1***	***0.4***	***0.0***	***1.0***	
Epispadias	79	25	71	8	0	183	
	1.1	***1.1***	***0.7***	***1.1***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	168	32	200	12	2	417	
	2.4	***1.4***	***2.0***	***1.7***	***5.6***	***2.1***	
Fetus or newborn affected by maternal alcohol use	15	10	14	1	0	40	
	0.2	***0.4***	***0.1***	***0.1***	***0.0***	***0.2***	
Gastroschisis	410	92	634	18	2	1161	
	6.0	***4.1***	***6.4***	***2.5***	***5.6***	***5.8***	
Hirschsprung disease (congenital megacolon)	121	58	87	14	2	285	
	1.8	***2.6***	***0.9***	***1.9***	***5.6***	***1.4***	
Hydrocephalus without spina bifida	485	161	732	20	2	1410	
	7.0	***7.1***	***7.3***	***2.8***	***5.6***	***7.1***	
Hypoplastic left heart syndrome	166	52	191	8	1	419	
	2.4	***2.3***	***1.9***	***1.1***	***2.8***	***2.1***	
Hypospadias*	2899	784	1947	196	14	5866	
	81.9	***68.2***	***38.3***	***52.8***	***74.9***	***57.4***	
Microcephalus	639	341	1162	71	7	2236	
	9.3	***15.1***	***11.6***	***9.8***	***19.4***	***11.2***	
Obstructive genitourinary defect	3144	714	4705	328	15	8963	
	45.7	***31.6***	***47.1***	***45.3***	***41.7***	***44.8***	
Omphalocele	137	55	195	10	2	408	
	2.0	***2.4***	***2.0***	***1.4***	***5.6***	***2.0***	

Texas

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Patent ductus arteriosus	3702	1211	6129	353	16	11478	1
	53.8	***53.6***	***61.4***	***48.7***	***44.5***	***57.4***	
Pulmonary valve atresia and stenosis	624	241	1066	41	5	1984	
	9.1	***10.7***	***10.7***	***5.7***	***13.9***	***9.9***	
Pulmonary valve atresia	87	31	163	6	0	289	2
	1.3	***1.4***	***1.6***	***0.8***	***0.0***	***1.4***	
Pyloric stenosis	1522	194	2167	31	6	3932	
	22.1	***8.6***	***21.7***	***4.3***	***16.7***	***19.7***	
Rectal and large intestinal atresia/stenosis	368	99	564	32	3	1078	
	5.3	***4.4***	***5.7***	***4.4***	***8.3***	***5.4***	
Reduction deformity, lower limbs	151	62	178	8	0	401	
	2.2	***2.7***	***1.8***	***1.1***	***0.0***	***2.0***	
Reduction deformity, upper limbs	304	97	393	19	7	822	
	4.4	***4.3***	***3.9***	***2.6***	***19.4***	***4.1***	
Renal agenesis/hypoplasia	396	127	614	28	4	1176	
	5.8	***5.6***	***6.2***	***3.9***	***11.1***	***5.9***	
Spina bifida without anencephalus	238	57	415	8	2	726	
	3.5	***2.5***	***4.2***	***1.1***	***5.6***	***3.6***	
Tetralogy of Fallot	273	109	362	35	3	792	
	4.0	***4.8***	***3.6***	***4.8***	***8.3***	***4.0***	
Total anomalous pulmonary venous return (TAPVR)	93	20	229	10	1	355	
	1.4	***0.9***	***2.3***	***1.4***	***2.8***	***1.8***	
Transposition of great arteries - All	269	63	352	27	2	714	3
	3.9	***2.8***	***3.5***	***3.7***	***5.6***	***3.6***	
dextro-Transposition of great arteries (d-TGA)	256	64	353	26	2	703	4
	3.7	***2.8***	***3.5***	***3.6***	***5.6***	***3.5***	
Tricuspid valve atresia and stenosis	109	49	192	14	0	367	
	1.6	***2.2***	***1.9***	***1.9***	***0.0***	***1.8***	
Tricuspid valve atresia	50	22	75	7	0	155	
	0.7	***1.0***	***0.8***	***1.0***	***0.0***	***0.8***	
Trisomy 13 (Patau syndrome)	75	29	109	10	0	225	
	1.1	***1.3***	***1.1***	***1.4***	***0.0***	***1.1***	
Trisomy 18 (Edwards syndrome)	186	66	260	23	1	544	
	2.7	***2.9***	***2.6***	***3.2***	***2.8***	***2.7***	
Ventricular septal defect	3906	1065	6899	338	19	12289	5
	56.7	***47.2***	***69.1***	***46.6***	***52.8***	***61.5***	
Total Live Births	**688672**	**225737**	**997993**	**72455**	**3599**	**1999140**	
Total Male Live Births	**353805**	**114886**	**508998**	**37139**	**1868**	**1022134**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Texas

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	1521	1170	2691	
	8.6	***50.5***	***13.5***	
Trisomy 13 (Patau syndrome)	160	65	225	
	0.9	***2.8***	***1.1***	
Trisomy 18 (Edwards syndrome)	298	246	544	
	1.7	***10.6***	***2.7***	
Total Live Births	**1767472**	**231538**	**1999140**	

**Total includes unknown maternal age

Notes

1.Patent ductus arteriosus: In Texas, coding of patent ductus arteriosus (PDA) is based on the following criteria. PDA is never coded if the infant was less than 36 weeks gestation and less than 12 weeks of age at diagnosis, or if the infant was on prostaglandin. If the infant was greater than or equal to 36 weeks gestation and less than 12 weeks of age at diagnosis, PDA is coded only if there is another reportable defect present, or if there was a medical/surgical intervention for this problem. PDA is always coded if the infant is greater than or equal to 12 weeks of age at diagnosis, unless the infant was on prostaglandin.
2.Pulmonary valve atresia for CCHD: Excludes TOF.
3.Transposition of the great arteries: As Texas does not use the new CDC BPA codes and the exclusion criteria has '745.180', those defects of 'double outlet right ventricle' which we have coded into 745.180 will not be counted in this defect.
4.Transposition of the great arteries for CCHD: Data are provisional.
5.Ventricular Septal Defect: We are unable to distinguish inlet VSD from other types of VSD.

General comments

-Our case definition includes livebirths, stillbirths, and terminations at any length of gestation and any birthweight.
-Texas only reports confirmed and definite diagnoses for any defect reported. Possible/probable cases are not given.
-Texas uses the CDC/BPA coding system, but does not use the new CDC/BPA codes.

Utah

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Amniotic bands	24 ***1.1***	0 ***0.0***	4 ***0.9***	0 ***0.0***	0 ***0.0***	29 ***1.1***	
Anencephalus	58 ***2.8***	1 ***4.1***	11 ***2.5***	1 ***1.2***	1 ***3.0***	74 ***2.7***	
Aniridia	1 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***0.0***	
Anophthalmia/microphthalmia	10 ***0.5***	0 ***0.0***	4 ***0.9***	0 ***0.0***	0 ***0.0***	14 ***0.5***	
Anotia/microtia	50 ***2.4***	0 ***0.0***	21 ***4.9***	0 ***0.0***	0 ***0.0***	71 ***2.6***	
Aortic valve stenosis	103 ***4.9***	0 ***0.0***	20 ***4.6***	7 ***8.1***	2 ***5.9***	132 ***4.9***	
Atrial septal defect	772 ***36.9***	14 ***57.7***	171 ***39.6***	39 ***45.4***	16 ***47.3***	1017 ***37.7***	
Atrioventricular septal defect (endocardial cushion defect)	116 ***5.5***	2 ***8.2***	25 ***5.8***	5 ***5.8***	2 ***5.9***	150 ***5.6***	
Biliary atresia	13 ***0.6***	2 ***8.2***	2 ***0.5***	0 ***0.0***	0 ***0.0***	17 ***0.6***	
Bladder exstrophy	4 ***0.2***	0 ***0.0***	0 ***0.0***	1 ***1.2***	0 ***0.0***	5 ***0.2***	
Choanal atresia	17 ***0.8***	0 ***0.0***	2 ***0.5***	0 ***0.0***	0 ***0.0***	19 ***0.7***	
Cleft lip with and without cleft palate	297 ***14.2***	4 ***16.5***	41 ***9.5***	5 ***5.8***	3 ***8.9***	354 ***13.1***	
Cleft palate without cleft lip	141 ***6.7***	0 ***0.0***	23 ***5.3***	11 ***12.8***	6 ***17.7***	182 ***6.8***	
Coarctation of aorta	209 ***10.0***	4 ***16.5***	32 ***7.4***	4 ***4.7***	2 ***5.9***	252 ***9.4***	
Common truncus	16 ***0.8***	0 ***0.0***	1 ***0.2***	0 ***0.0***	0 ***0.0***	17 ***0.6***	
Congenital cataract	66 ***3.2***	1 ***4.1***	7 ***1.6***	0 ***0.0***	1 ***3.0***	75 ***2.8***	
Diaphragmatic hernia	34 ***1.6***	0 ***0.0***	6 ***1.4***	1 ***1.2***	3 ***8.9***	44 ***1.6***	
Down syndrome (Trisomy 21)	281 ***13.4***	6 ***24.7***	84 ***19.5***	10 ***11.6***	4 ***11.8***	394 ***14.6***	
Ebstein anomaly	24 ***1.1***	0 ***0.0***	1 ***0.2***	0 ***0.0***	1 ***3.0***	27 ***1.0***	
Encephalocele	18 ***0.9***	0 ***0.0***	6 ***1.4***	0 ***0.0***	1 ***3.0***	26 ***1.0***	
Epispadias	1 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***3.0***	3 ***0.1***	
Esophageal atresia/tracheoesophageal fistula	56 ***2.7***	0 ***0.0***	18 ***4.2***	4 ***4.7***	1 ***3.0***	80 ***3.0***	
Gastroschisis	93 ***4.4***	4 ***16.5***	27 ***6.3***	12 ***14.0***	5 ***14.8***	141 ***5.2***	
Hirschsprung disease (congenital megacolon)	37 ***1.8***	0 ***0.0***	2 ***0.5***	7 ***8.1***	0 ***0.0***	46 ***1.7***	
Hydrocephalus without spina bifida	93 ***4.4***	5 ***20.6***	13 ***3.0***	2 ***2.3***	1 ***3.0***	114 ***4.2***	
Hypoplastic left heart syndrome	81 ***3.9***	2 ***8.2***	12 ***2.8***	2 ***2.3***	0 ***0.0***	97 ***3.6***	
Hypospadias*	810 ***75.1***	14 ***110.8***	45 ***20.6***	19 ***42.2***	6 ***34.9***	902 ***65.1***	
Microcephalus	132 ***6.3***	2 ***8.2***	35 ***8.1***	3 ***3.5***	4 ***11.8***	176 ***6.5***	
Obstructive genitourinary defect	146 ***7.0***	2 ***8.2***	20 ***4.6***	3 ***3.5***	0 ***0.0***	172 ***6.4***	
Omphalocele	59 ***2.8***	3 ***12.4***	10 ***2.3***	2 ***2.3***	0 ***0.0***	75 ***2.8***	
Pulmonary valve atresia and stenosis	299 ***14.3***	5 ***20.6***	53 ***12.3***	17 ***19.8***	4 ***11.8***	381 ***14.1***	
Pulmonary valve atresia	24 ***1.1***	0 ***0.0***	7 ***1.6***	4 ***4.7***	0 ***0.0***	37 ***1.4***	

Utah

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pyloric stenosis	317	1	81	6	4	411	
	15.1	***4.1***	***18.8***	***7.0***	***11.8***	***15.2***	
Rectal and large intestinal atresia/stenosis	84	2	20	2	2	110	
	4.0	***8.2***	***4.6***	***2.3***	***5.9***	***4.1***	
Reduction deformity, lower limbs	36	1	6	5	0	48	
	1.7	***4.1***	***1.4***	***5.8***	***0.0***	***1.8***	
Reduction deformity, upper limbs	112	0	30	5	1	150	
	5.3	***0.0***	***7.0***	***5.8***	***3.0***	***5.6***	
Renal agenesis/hypoplasia	68	2	17	3	0	91	
	3.2	***8.2***	***3.9***	***3.5***	***0.0***	***3.4***	
Spina bifida without anencephalus	93	1	18	1	2	115	
	4.4	***4.1***	***4.2***	***1.2***	***5.9***	***4.3***	
Tetralogy of Fallot	68	2	16	5	2	94	
	3.2	***8.2***	***3.7***	***5.8***	***5.9***	***3.5***	
Total anomalous pulmonary venous return (TAPVR)	21	0	7	2	2	32	
	1.0	***0.0***	***1.6***	***2.3***	***5.9***	***1.2***	
Transposition of great arteries - All	89	2	22	4	1	120	
	4.2	***8.2***	***5.1***	***4.7***	***3.0***	***4.5***	
dextro-Transposition of great arteries (d-TGA)	50	0	8	2	0	60	
	2.4	***0.0***	***1.9***	***2.3***	***0.0***	***2.2***	
Tricuspid valve atresia	22	0	6	3	0	31	
	1.1	***0.0***	***1.4***	***3.5***	***0.0***	***1.2***	
Trisomy 13 (Patau syndrome)	36	2	18	1	0	57	
	1.7	***8.2***	***4.2***	***1.2***	***0.0***	***2.1***	
Trisomy 18 (Edwards syndrome)	71	4	16	2	1	96	
	3.4	***16.5***	***3.7***	***2.3***	***3.0***	***3.6***	
Ventricular septal defect	470	14	111	18	10	625	
	22.4	***57.7***	***25.7***	***20.9***	***29.6***	***23.2***	
Total Live Births	**209441**	**2426**	**43141**	**8597**	**3381**	**269509**	
Total Male Live Births	**107861**	**1264**	**21890**	**4505**	**1718**	**138538**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Utah

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	223 ***9.1***	171 ***68.0***	394 ***14.6***	
Trisomy 13 (Patau syndrome)	38 ***1.6***	19 ***7.6***	57 ***2.1***	
Trisomy 18 (Edwards syndrome)	57 ***2.3***	39 ***15.5***	96 ***3.6***	
Total Live Births	**244335**	**25161**	**269509**	

**Total includes unknown maternal age

Virginia

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Anencephalus	28	3	10	6	0	53	
	0.9	***0.3***	***1.4***	***1.7***	***0.0***	***1.0***	
Aniridia	6	0	1	0	0	8	
	0.2	***0.0***	***0.1***	***0.0***	***0.0***	***0.2***	
Anophthalmia/microphthalmia	19	5	4	1	0	34	
	0.6	***0.4***	***0.6***	***0.3***	***0.0***	***0.6***	
Anotia/microtia	19	9	10	3	0	49	
	0.6	***0.8***	***1.4***	***0.8***	***0.0***	***0.9***	
Aortic valve stenosis	53	5	7	3	0	88	
	1.7	***0.4***	***1.0***	***0.8***	***0.0***	***1.7***	
Atrial septal defect	2627	1034	797	481	5	5854	
	86.1	***90.3***	***113.5***	***133.2***	***65.8***	***110.3***	
Atrioventricular septal defect (endocardial cushion defect)	105	55	13	8	0	201	
	3.4	***4.8***	***1.9***	***2.2***	***0.0***	***3.8***	
Biliary atresia	23	7	1	3	0	41	
	0.8	***0.6***	***0.1***	***0.8***	***0.0***	***0.8***	
Bladder exstrophy	11	2	0	1	0	16	
	0.4	***0.2***	***0.0***	***0.3***	***0.0***	***0.3***	
Choanal atresia	53	12	6	2	0	91	
	1.7	***1.0***	***0.9***	***0.6***	***0.0***	***1.7***	
Cleft lip with and without cleft palate	292	44	57	27	0	489	
	9.6	***3.8***	***8.1***	***7.5***	***0.0***	***9.2***	
Cleft palate without cleft lip	221	38	27	33	0	365	
	7.2	***3.3***	***3.8***	***9.1***	***0.0***	***6.9***	
Coarctation of aorta	161	32	20	11	0	281	
	5.3	***2.8***	***2.8***	***3.0***	***0.0***	***5.3***	
Common truncus	15	8	5	5	0	35	
	0.5	***0.7***	***0.7***	***1.4***	***0.0***	***0.7***	
Congenital cataract	27	18	5	3	0	60	
	0.9	***1.6***	***0.7***	***0.8***	***0.0***	***1.1***	
Congenital hip dislocation	190	20	35	19	1	297	
	6.2	***1.7***	***5.0***	***5.3***	***13.2***	***5.6***	
Diaphragmatic hernia	73	38	18	3	0	146	
	2.4	***3.3***	***2.6***	***0.8***	***0.0***	***2.7***	
Down syndrome (Trisomy 21)	344	112	100	38	1	683	
	11.3	***9.8***	***14.2***	***10.5***	***13.2***	***12.9***	
Ebstein anomaly	20	9	4	5	0	45	
	0.7	***0.8***	***0.6***	***1.4***	***0.0***	***0.8***	
Encephalocele	12	4	4	2	0	26	
	0.4	***0.3***	***0.6***	***0.6***	***0.0***	***0.5***	
Epispadias	35	12	4	2	0	57	
	1.1	***1.0***	***0.6***	***0.6***	***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	80	28	9	3	0	137	
	2.6	***2.4***	***1.3***	***0.8***	***0.0***	***2.6***	
Fetus or newborn affected by maternal alcohol use	17	20	2	0	0	45	
	0.6	***1.7***	***0.3***	***0.0***	***0.0***	***0.8***	
Gastroschisis	4	1	2	0	0	7	
	0.1	***0.1***	***0.3***	***0.0***	***0.0***	***0.1***	
Hirschsprung disease (congenital megacolon)	70	28	7	6	0	123	
	2.3	***2.4***	***1.0***	***1.7***	***0.0***	***2.3***	
Hydrocephalus without spina bifida	141	75	30	12	0	306	
	4.6	***6.6***	***4.3***	***3.3***	***0.0***	***5.8***	
Hypoplastic left heart syndrome	57	19	11	3	0	103	
	1.9	***1.7***	***1.6***	***0.8***	***0.0***	***1.9***	
Hypospadias*	954	260	92	75	1	1504	
	60.9	***44.9***	***25.5***	***40.5***	***27.9***	***55.3***	
Microcephalus	129	50	37	19	0	278	
	4.2	***4.4***	***5.3***	***5.3***	***0.0***	***5.2***	
Obstructive genitourinary defect	729	152	114	98	0	1216	
	23.9	***13.3***	***16.2***	***27.1***	***0.0***	***22.9***	
Omphalocele	2	2	1	0	0	6	
	0.1	***0.2***	***0.1***	***0.0***	***0.0***	***0.1***	
Patent ductus arteriosus	3085	1613	836	484	5	6839	
	101.1	***140.9***	***119.0***	***134.1***	***65.8***	***128.8***	

Virginia

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	279	137	72	57	0	663	
	9.1	***12.0***	***10.3***	***15.8***	***0.0***	***12.5***	
Pulmonary valve atresia	26	16	8	5	0	63	
	0.9	***1.4***	***1.1***	***1.4***	***0.0***	***1.2***	
Pyloric stenosis	521	96	72	15	3	772	
	17.1	***8.4***	***10.3***	***4.2***	***39.5***	***14.5***	
Rectal and large intestinal atresia/stenosis	124	33	22	6	0	210	
	4.1	***2.9***	***3.1***	***1.7***	***0.0***	***4.0***	
Reduction deformity, lower limbs	37	17	3	3	1	67	
	1.2	***1.5***	***0.4***	***0.8***	***13.2***	***1.3***	
Reduction deformity, upper limbs	81	24	12	5	0	132	
	2.7	***2.1***	***1.7***	***1.4***	***0.0***	***2.5***	
Renal agenesis/hypoplasia	93	28	16	6	0	162	
	3.0	***2.4***	***2.3***	***1.7***	***0.0***	***3.1***	
Spina bifida without anencephalus	119	45	27	4	0	241	
	3.9	***3.9***	***3.8***	***1.1***	***0.0***	***4.5***	
Tetralogy of Fallot	113	49	23	16	1	233	
	3.7	***4.3***	***3.3***	***4.4***	***13.2***	***4.4***	
Transposition of great arteries - All	164	40	24	14	0	288	
	5.4	***3.5***	***3.4***	***3.9***	***0.0***	***5.4***	
dextro-Transposition of great arteries (d-TGA)	78	14	10	6	0	125	
	2.6	***1.2***	***1.4***	***1.7***	***0.0***	***2.4***	
Tricuspid valve atresia and stenosis	24	12	4	5	0	55	
	0.8	***1.0***	***0.6***	***1.4***	***0.0***	***1.0***	
Trisomy 13 (Patau syndrome)	18	5	9	1	0	40	
	0.6	***0.4***	***1.3***	***0.3***	***0.0***	***0.8***	
Trisomy 18 (Edwards syndrome)	39	13	6	8	0	76	
	1.3	***1.1***	***0.9***	***2.2***	***0.0***	***1.4***	
Ventricular septal defect	1374	378	356	177	3	2685	
	45.0	***33.0***	***50.7***	***49.0***	***39.5***	***50.6***	
Total Live Births	**305140**	**114481**	**70231**	**36102**	**760**	**530936**	
Total Male Live Births	**156663**	**57923**	**36118**	**18518**	**359**	**271762**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Virginia

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	312 ***7.0***	286 ***33.0***	683 ***12.9***	
Trisomy 13 (Patau syndrome)	22 ***0.5***	11 ***1.3***	40 ***0.8***	
Trisomy 18 (Edwards syndrome)	35 ***0.8***	31 ***3.6***	76 ***1.4***	
Total Live Births	**443714**	**86753**	**530936**	

**Total includes unknown maternal age

West Virginia

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Anencephalus	16	0	0	0	0	17	
	1.7	***0.0***	***0.0***	***0.0***	***0.0***	***1.7***	
Aniridia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Anophthalmia/microphthalmia	3	0	0	0	0	3	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Anotia/microtia	5	0	0	0	0	5	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Aortic valve stenosis	9	0	0	0	0	11	
	1.0	***0.0***	***0.0***	***0.0***	***0.0***	***1.1***	
Atrial septal defect	614	12	2	3	0	753	
	66.1	***33.8***	***17.1***	***34.6***	***0.0***	***75.8***	
Atrioventricular septal defect (endocardial cushion defect)	21	0	0	0	0	23	
	2.3	***0.0***	***0.0***	***0.0***	***0.0***	***2.3***	
Biliary atresia	3	0	0	0	0	3	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Bladder exstrophy	2	0	0	0	0	2	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	2	0	0	0	0	5	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Cleft lip with and without cleft palate	32	1	0	1	0	35	
	3.4	***2.8***	***0.0***	***11.5***	***0.0***	***3.5***	
Cleft palate without cleft lip	50	1	0	1	0	52	
	5.4	***2.8***	***0.0***	***11.5***	***0.0***	***5.2***	
Coarctation of aorta	22	1	0	0	0	25	
	2.4	***2.8***	***0.0***	***0.0***	***0.0***	***2.5***	
Common truncus	36	1	0	0	0	37	
	3.9	***2.8***	***0.0***	***0.0***	***0.0***	***3.7***	
Congenital cataract	3	0	0	0	0	3	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Congenital hip dislocation	11	0	0	0	0	13	
	1.2	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Diaphragmatic hernia	15	1	0	0	0	17	
	1.6	***2.8***	***0.0***	***0.0***	***0.0***	***1.7***	
Down syndrome (Trisomy 21)	56	2	0	0	0	72	
	6.0	***5.6***	***0.0***	***0.0***	***0.0***	***7.3***	
Ebstein anomaly	6	0	0	0	0	6	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Encephalocele	4	0	0	0	0	5	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Epispadias	4	0	0	0	0	5	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Esophageal atresia/tracheoesophageal fistula	10	0	0	0	0	14	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.4***	
Fetus or newborn affected by maternal alcohol use	14	0	0	0	0	16	
	1.5	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Hirschsprung disease (congenital megacolon)	10	2	0	0	0	15	
	1.1	***5.6***	***0.0***	***0.0***	***0.0***	***1.5***	
Hydrocephalus without spina bifida	24	0	0	0	0	28	
	2.6	***0.0***	***0.0***	***0.0***	***0.0***	***2.8***	
Hypoplastic left heart syndrome	13	1	0	0	0	17	
	1.4	***2.8***	***0.0***	***0.0***	***0.0***	***1.7***	
Hypospadias*	165	5	0	0	0	198	
	35.5	***27.7***	***0.0***	***0.0***	***0.0***	***39.9***	
Microcephalus	22	1	0	0	0	30	
	2.4	***2.8***	***0.0***	***0.0***	***0.0***	***3.0***	
Obstructive genitourinary defect	62	1	1	0	0	66	
	6.7	***2.8***	***8.6***	***0.0***	***0.0***	***6.6***	
Patent ductus arteriosus	201	9	0	0	0	211	1
	21.6	***25.4***	***0.0***	***0.0***	***0.0***	***21.2***	
Pulmonary valve atresia and stenosis	27	0	0	0	0	30	
	2.9	***0.0***	***0.0***	***0.0***	***0.0***	***3.0***	
Pulmonary valve atresia	6	0	0	0	0	10	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	

West Virginia

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pyloric stenosis	70	1	0	0	0	79	
	7.5	***2.8***	***0.0***	***0.0***	***0.0***	***8.0***	
Rectal and large intestinal atresia/stenosis	22	1	1	0	0	27	
	2.4	***2.8***	***8.6***	***0.0***	***0.0***	***2.7***	
Reduction deformity, lower limbs	8	0	0	0	0	8	
	0.9	***0.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Reduction deformity, upper limbs	11	1	0	0	0	12	
	1.2	***2.8***	***0.0***	***0.0***	***0.0***	***1.2***	
Renal agenesis/hypoplasia	26	0	0	0	0	30	
	2.8	***0.0***	***0.0***	***0.0***	***0.0***	***3.0***	
Spina bifida without anencephalus	33	0	0	0	0	33	
	3.6	***0.0***	***0.0***	***0.0***	***0.0***	***3.3***	
Tetralogy of Fallot	28	1	1	0	0	36	
	3.0	***2.8***	***8.6***	***0.0***	***0.0***	***3.6***	
Total anomalous pulmonary venous return (TAPVR)	3	0	0	0	0	6	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Transposition of great arteries - All	24	0	0	0	0	32	
	2.6	***0.0***	***0.0***	***0.0***	***0.0***	***3.2***	
dextro-Transposition of great arteries (d-TGA)	10	0	0	0	0	15	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.5***	
Tricuspid valve atresia and stenosis	7	0	0	0	0	13	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Trisomy 13 (Patau syndrome)	6	0	0	0	0	10	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	
Trisomy 18 (Edwards syndrome)	10	0	0	0	0	11	
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.1***	
Ventricular septal defect	194	3	0	1	0	227	
	20.9	***8.5***	***0.0***	***11.5***	***0.0***	***22.9***	
Total Live Births	**92855**	**3550**	**1167**	**867**	**119**	**99295**	
Total Male Live Births	**46430**	**1807**	**581**	**466**	**51**	**49662**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

West Virginia

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	46 ***5.0***	17 ***22.5***	72 ***7.3***	
Trisomy 13 (Patau syndrome)	8 ***0.9***	1 ***1.3***	10 ***1.0***	
Trisomy 18 (Edwards syndrome)	7 ***0.8***	3 ***4.0***	11 ***1.1***	
Total Live Births	**91735**	**7559**	**99295**	

**Total includes unknown maternal age

Notes
1.Includes only births =>2500 grams or =>36 wks gestation.

General comments
-Birth defects defined by ICD-9 coding.
-No metholologic changes during this period.
-Probable cases are included.
-Stillbirths and terminations per birth defect are not collected.

Wisconsin

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Anencephalus	37 ***1.5***	5 ***1.4***	8 ***2.4***	3 ***2.2***	0 ***0.0***	56 ***1.7***	
Aniridia	2 ***0.1***	3 ***0.9***	0 ***0.0***	0 ***0.0***	0 ***0.0***	5 ***0.1***	
Anophthalmia/microphthalmia	14 ***0.6***	5 ***1.4***	1 ***0.3***	1 ***0.7***	0 ***0.0***	21 ***0.6***	
Anotia/microtia	18 ***0.7***	1 ***0.3***	12 ***3.6***	0 ***0.0***	0 ***0.0***	31 ***0.9***	
Aortic valve stenosis	18 ***0.7***	0 ***0.0***	1 ***0.3***	1 ***0.7***	1 ***1.9***	21 ***0.6***	
Atrial septal defect	933 ***37.1***	131 ***37.6***	115 ***34.5***	35 ***25.2***	43 ***80.0***	1257 ***37.0***	
Atrioventricular septal defect (endocardial cushion defect)	47 ***1.9***	7 ***2.0***	3 ***0.9***	1 ***0.7***	0 ***0.0***	58 ***1.7***	
Biliary atresia	3 ***0.1***	0 ***0.0***	0 ***0.0***	0 ***0.0***	1 ***1.9***	4 ***0.1***	
Bladder exstrophy	7 ***0.3***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	7 ***0.2***	
Choanal atresia	36 ***1.4***	2 ***0.6***	6 ***1.8***	1 ***0.7***	0 ***0.0***	45 ***1.3***	
Cleft lip with and without cleft palate	232 ***9.2***	26 ***7.5***	31 ***9.3***	8 ***5.8***	8 ***14.9***	305 ***9.0***	
Cleft palate without cleft lip	161 ***6.4***	13 ***3.7***	14 ***4.2***	7 ***5.0***	3 ***5.6***	199 ***5.9***	
Coarctation of aorta	44 ***1.7***	7 ***2.0***	8 ***2.4***	1 ***0.7***	0 ***0.0***	60 ***1.8***	
Common truncus	16 ***0.6***	2 ***0.6***	3 ***0.9***	0 ***0.0***	0 ***0.0***	21 ***0.6***	
Congenital cataract	23 ***0.9***	4 ***1.1***	1 ***0.3***	0 ***0.0***	0 ***0.0***	28 ***0.8***	
Congenital hip dislocation	177 ***7.0***	4 ***1.1***	20 ***6.0***	4 ***2.9***	0 ***0.0***	205 ***6.0***	
Diaphragmatic hernia	41 ***1.6***	7 ***2.0***	9 ***2.7***	1 ***0.7***	1 ***1.9***	59 ***1.7***	
Down syndrome (Trisomy 21)	311 ***12.4***	29 ***8.3***	58 ***17.4***	27 ***19.5***	6 ***11.2***	431 ***12.7***	
Ebstein anomaly	5 ***0.2***	0 ***0.0***	2 ***0.6***	1 ***0.7***	1 ***1.9***	9 ***0.3***	
Encephalocele	10 ***0.4***	2 ***0.6***	0 ***0.0***	1 ***0.7***	1 ***1.9***	14 ***0.4***	
Epispadias	22 ***0.9***	6 ***1.7***	2 ***0.6***	1 ***0.7***	0 ***0.0***	31 ***0.9***	
Esophageal atresia/tracheoesophageal fistula	55 ***2.2***	5 ***1.4***	4 ***1.2***	2 ***1.4***	0 ***0.0***	66 ***1.9***	
Fetus or newborn affected by maternal alcohol use	20 ***0.8***	8 ***2.3***	3 ***0.9***	0 ***0.0***	3 ***5.6***	34 ***1.0***	
Hirschsprung disease (congenital megacolon)	12 ***0.5***	4 ***1.1***	2 ***0.6***	2 ***1.4***	0 ***0.0***	20 ***0.6***	
Hydrocephalus without spina bifida	80 ***3.2***	23 ***6.6***	13 ***3.9***	3 ***2.2***	0 ***0.0***	119 ***3.5***	
Hypoplastic left heart syndrome	44 ***1.7***	13 ***3.7***	3 ***0.9***	2 ***1.4***	0 ***0.0***	62 ***1.8***	
Hypospadias*	973 ***75.3***	123 ***70.1***	58 ***34.1***	13 ***18.4***	11 ***40.6***	1180 ***68.0***	
Microcephalus	33 ***1.3***	8 ***2.3***	6 ***1.8***	2 ***1.4***	0 ***0.0***	49 ***1.4***	
Obstructive genitourinary defect	487 ***19.3***	39 ***11.2***	37 ***11.1***	26 ***18.7***	13 ***24.2***	602 ***17.7***	
Patent ductus arteriosus	697 ***27.7***	115 ***33.0***	100 ***30.0***	30 ***21.6***	24 ***44.7***	966 ***28.5***	
Pulmonary valve atresia and stenosis	71 ***2.8***	18 ***5.2***	12 ***3.6***	5 ***3.6***	4 ***7.4***	110 ***3.2***	
Pulmonary valve atresia	8 ***0.3***	1 ***0.3***	2 ***0.6***	1 ***0.7***	0 ***0.0***	12 ***0.4***	

Wisconsin

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Pyloric stenosis	3	0	0	0	0	3	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Rectal and large intestinal atresia/stenosis	86	6	9	3	1	105	
	3.4	***1.7***	***2.7***	***2.2***	***1.9***	***3.1***	
Reduction deformity, lower limbs	29	4	4	2	0	39	
	1.2	***1.1***	***1.2***	***1.4***	***0.0***	***1.1***	
Reduction deformity, upper limbs	65	10	9	4	3	91	
	2.6	***2.9***	***2.7***	***2.9***	***5.6***	***2.7***	
Renal agenesis/hypoplasia	89	6	9	5	1	110	
	3.5	***1.7***	***2.7***	***3.6***	***1.9***	***3.2***	
Spina bifida without anencephalus	78	10	9	2	1	100	
	3.1	***2.9***	***2.7***	***1.4***	***1.9***	***2.9***	
Tetralogy of Fallot	54	13	11	2	1	81	
	2.1	***3.7***	***3.3***	***1.4***	***1.9***	***2.4***	
Total anomalous pulmonary venous return (TAPVR)	4	0	1	0	0	5	
	0.2	***0.0***	***0.3***	***0.0***	***0.0***	***0.1***	
Transposition of great arteries - All	46	5	12	1	1	65	
	1.8	***1.4***	***3.6***	***0.7***	***1.9***	***1.9***	
dextro-Transposition of great arteries (d-TGA)	33	2	5	1	1	42	
	1.3	***0.6***	***1.5***	***0.7***	***1.9***	***1.2***	
Tricuspid valve atresia and stenosis	15	4	2	1	0	22	
	0.6	***1.1***	***0.6***	***0.7***	***0.0***	***0.6***	
Tricuspid valve atresia	1	0	1	0	0	2	
	0.0	***0.0***	***0.3***	***0.0***	***0.0***	***0.1***	
Trisomy 13 (Patau syndrome)	20	2	3	1	0	26	
	0.8	***0.6***	***0.9***	***0.7***	***0.0***	***0.8***	
Trisomy 18 (Edwards syndrome)	57	6	7	1	0	72	
	2.3	***1.7***	***2.1***	***0.7***	***0.0***	***2.1***	
Ventricular septal defect	627	56	115	35	21	854	1
	24.9	***16.1***	***34.5***	***25.2***	***39.1***	***25.2***	
Total Live Births	**251798**	**34819**	**33317**	**13874**	**5373**	**339341**	
Total Male Live Births	**129258**	**17551**	**16984**	**7062**	**2708**	**173652**	

*Hypospadias: prevalence per 10,000 male live births
**Total includes unknown race

Wisconsin

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	220	206	426	
	7.5	***46.6***	***12.6***	
Trisomy 13 (Patau syndrome)	17	4	21	
	0.6	***0.9***	***0.6***	
Trisomy 18 (Edwards syndrome)	23	16	39	
	0.8	***3.6***	***1.1***	
Total Live Births	**295093**	**44200**	**339341**	

**Total includes unknown maternal age

Notes
1.Hospital practice in coding is not known.

General comments
-Anencephaly, Spina Bifida, Down Syndrome, Trisomy 13, and Trisomy 18 data include livebirths and stillbirths (although trisomy data in the maternal age table include only livebirths). Data for all other defects include only livebirths.
-As in the past, Wisconsin used its linked birth-hospital discharge records. Live births that were not linked to a newborn discharge record are not included. Since the discharge records are only available from Wisconsin hospitals, only Wisconsin resident births occurring in Wisconsin hospitals are included.
-Questions? richard.miller@wisconsin.gov
-The discharge records include a primary diagnosis and up to eight other diagnoses; all were scanned for the conditions. The diagnoses are ICD-9 coded.

Department of Defense

Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	Non-Hispanic White	Non-Hispanic Black or African	Hispanic	Asian or Pacific Islander	American Indian or Alaskan Native	Total**	Notes
Anencephalus	20 ***0.6***	8 ***1.0***	6 ***1.0***	3 ***1.2***	0 ***0.0***	38 ***0.7***	1
Aniridia	8 ***0.2***	0 ***0.0***	0 ***0.0***	0 ***0.0***	0 ***0.0***	8 ***0.1***	
Anophthalmia/microphthalmia	65 ***1.8***	22 ***2.7***	11 ***1.8***	5 ***2.0***	2 ***2.0***	106 ***1.9***	
Anotia/microtia	72 ***2.0***	11 ***1.4***	14 ***2.3***	4 ***1.6***	3 ***3.0***	104 ***1.9***	
Aortic valve stenosis	150 ***4.2***	15 ***1.9***	16 ***2.6***	7 ***2.9***	5 ***4.9***	194 ***3.5***	
Atrial septal defect	2860 ***79.1***	696 ***86.1***	472 ***76.8***	163 ***66.4***	64 ***63.3***	4332 ***78.7***	2
Atrioventricular septal defect (endocardial cushion defect)	202 ***5.6***	65 ***8.0***	40 ***6.5***	9 ***3.7***	4 ***4.0***	326 ***5.9***	3
Biliary atresia	40 ***1.1***	9 ***1.1***	7 ***1.1***	2 ***0.8***	0 ***0.0***	58 ***1.1***	
Bladder exstrophy	16 ***0.4***	2 ***0.2***	2 ***0.3***	1 ***0.4***	0 ***0.0***	21 ***0.4***	
Choanal atresia	111 ***3.1***	17 ***2.1***	13 ***2.1***	3 ***1.2***	1 ***1.0***	147 ***2.7***	
Cleft lip with and without cleft palate	465 ***12.9***	57 ***7.1***	60 ***9.8***	27 ***11.0***	6 ***5.9***	625 ***11.4***	
Cleft palate without cleft lip	436 ***12.1***	54 ***6.7***	69 ***11.2***	23 ***9.4***	5 ***4.9***	599 ***10.9***	
Coarctation of aorta	328 ***9.1***	66 ***8.2***	52 ***8.5***	15 ***6.1***	9 ***8.9***	476 ***8.6***	
Common truncus	77 ***2.1***	13 ***1.6***	13 ***2.1***	5 ***2.0***	3 ***3.0***	111 ***2.0***	
Congenital cataract	114 ***3.2***	26 ***3.2***	29 ***4.7***	8 ***3.3***	1 ***1.0***	180 ***3.3***	
Congenital hip dislocation	751 ***20.8***	82 ***10.1***	111 ***18.1***	39 ***15.9***	25 ***24.7***	1024 ***18.6***	
Diaphragmatic hernia	162 ***4.5***	33 ***4.1***	23 ***3.7***	10 ***4.1***	1 ***1.0***	230 ***4.2***	
Down syndrome (Trisomy 21)	531 ***14.7***	111 ***13.7***	90 ***14.6***	35 ***14.3***	8 ***7.9***	786 ***14.3***	1
Ebstein anomaly	39 ***1.1***	9 ***1.1***	5 ***0.8***	3 ***1.2***	3 ***3.0***	62 ***1.1***	
Encephalocele	41 ***1.1***	11 ***1.4***	13 ***2.1***	4 ***1.6***	4 ***4.0***	74 ***1.3***	
Epispadias*	51 ***2.7***	15 ***3.7***	7 ***2.2***	2 ***1.6***	1 ***1.9***	77 ***2.7***	
Esophageal atresia/tracheoesophageal fistula	95 ***2.6***	19 ***2.4***	13 ***2.1***	5 ***2.0***	1 ***1.0***	135 ***2.5***	
Fetus or newborn affected by maternal alcohol use	26 ***0.7***	6 ***0.7***	2 ***0.3***	0 ***0.0***	0 ***0.0***	36 ***0.7***	
Hirschsprung disease (congenital megacolon)	151 ***4.2***	36 ***4.5***	26 ***4.2***	13 ***5.3***	7 ***6.9***	245 ***4.4***	
Hydrocephalus without spina bifida	376 ***10.4***	99 ***12.3***	46 ***7.5***	16 ***6.5***	11 ***10.9***	556 ***10.1***	
Hypoplastic left heart syndrome	165 ***4.6***	43 ***5.3***	27 ***4.4***	9 ***3.7***	7 ***6.9***	257 ***4.7***	
Hypospadias*	1918 ***103.0***	384 ***93.5***	213 ***67.7***	120 ***95.0***	39 ***75.2***	2739 ***96.8***	
Microcephalus	366 ***10.1***	95 ***11.8***	48 ***7.8***	31 ***12.6***	7 ***6.9***	555 ***10.1***	
Obstructive genitourinary defect	1531 ***42.4***	257 ***31.8***	268 ***43.6***	96 ***39.1***	45 ***44.5***	2231 ***40.5***	
Pulmonary valve atresia and stenosis	670 ***18.5***	212 ***26.2***	110 ***17.9***	36 ***14.7***	22 ***21.7***	1071 ***19.5***	
Pulmonary valve atresia	88 ***2.4***	24 ***3.0***	16 ***2.6***	7 ***2.9***	3 ***3.0***	142 ***2.6***	
Pyloric stenosis	1020 ***28.2***	91 ***11.3***	145 ***23.6***	28 ***11.4***	37 ***36.6***	1344 ***24.4***	

Department of Defense
Birth Defects Counts and Prevalence 2005-2009 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**Non-Hispanic White**	**Non-Hispanic Black or African**	**Hispanic**	**Asian or Pacific Islander**	**American Indian or Alaskan Native**	**Total****	**Notes**
Rectal and large intestinal atresia/stenosis	220	36	24	20	3	309	
	6.1	***4.5***	***3.9***	***8.1***	***3.0***	***5.6***	
Reduction deformity, lower limbs	92	24	9	4	4	136	
	2.5	***3.0***	***1.5***	***1.6***	***4.0***	***2.5***	
Reduction deformity, upper limbs	116	16	21	8	2	164	
	3.2	***2.0***	***3.4***	***3.3***	***2.0***	***3.0***	
Renal agenesis/hypoplasia	206	20	33	11	6	282	
	5.7	***2.5***	***5.4***	***4.5***	***5.9***	***5.1***	
Spina bifida without anencephalus	181	24	26	8	6	254	1
	5.0	***3.0***	***4.2***	***3.3***	***5.9***	***4.6***	
Tetralogy of Fallot	223	48	36	23	9	345	
	6.2	***5.9***	***5.9***	***9.4***	***8.9***	***6.3***	
Total anomalous pulmonary venous return (TAPVR)	50	13	13	5	0	85	
	1.4	***1.6***	***2.1***	***2.0***	***0.0***	***1.5***	
Transposition of great arteries - All	212	37	37	17	3	310	
	5.9	***4.6***	***6.0***	***6.9***	***3.0***	***5.6***	
dextro-Transposition of great arteries (d-TGA)	138	23	19	14	2	199	
	3.8	***2.8***	***3.1***	***5.7***	***2.0***	***3.6***	
Tricuspid valve atresia and stenosis	54	15	3	1	1	76	
	1.5	***1.9***	***0.5***	***0.4***	***1.0***	***1.4***	
Trisomy 13 (Patau syndrome)	48	17	7	1	0	75	1
	1.3	***2.1***	***1.1***	***0.4***	***0.0***	***1.4***	
Trisomy 18 (Edwards syndrome)	68	11	13	5	0	98	1
	1.9	***1.4***	***2.1***	***2.0***	***0.0***	***1.8***	
Ventricular septal defect	2680	475	432	149	71	3882	4
	74.2	***58.8***	***70.3***	***60.7***	***70.2***	***70.5***	
Total Live Births	**361422**	**80801**	**61447**	**24552**	**10116**	**550562**	
Total Male Live Births	**186253**	**41071**	**31446**	**12636**	**5184**	**282914**	

*Hypospadias and Epispadias: prevalence per 10,000 male live births
**Total includes unknown race

Department of Defense

Trisomy Counts and Prevalence by Maternal Age 2005-2009 (Prevalence per 10,000 Live Births)

	Age			
Defect	**Less than 35**	**35 and greater**	**Total****	**Notes**
Down syndrome (Trisomy 21)	505 ***10.5***	254 ***50.7***	786 ***14.3***	1
Trisomy 13 (Patau syndrome)	58 ***1.2***	15 ***3.0***	75 ***1.4***	1
Trisomy 18 (Edwards syndrome)	58 ***1.2***	36 ***7.2***	98 ***1.8***	1
Total Live Births	**480438**	**50143**	**550562**	

**Total includes unknown maternal age

Notes
1.DoD Registry only captures livebirths
2.DoD Registry relies on ICD-9-CM codes and cannot differentiate PFO
3.DoD Registry relies on ICD-9-CM codes and cannot distinguish 745.487
4.All ICD-9-CM coded cases that meet DoD Registry case criteria are included. DoD Registry relies on ICD-9-CM codes and cannot distinguish 745.487

General comments
-Criteria for a case: One diagnosis from institutional records, or 2 diagnoses from professional encounter records
-Infants that appear as multiples of same gender are excluded from analysis
-Race/Ethnicity for the DoD Birth and Infant Health Registry is based on the military parent through whom the infant receives military health care benefits. This may be the infants' mother or father.

STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Updated September 2012

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.

Alabama

Program status: No surveillance program

Contacts

Cindy Ashley, RN, BSN
Alabama Newborn Screening Program
201 Monroe Street
Montgomery, Alabama, 36104
Phone: **334-206-2971** ***Fax***: **334-206-3791**
E-mail: **Cindy.Ashley@adph.state.al.us**

Rachel Montgomery, RN, BSN
Alabama Newborn Screening Program
201 Monroe Street
Montgomery, Alabama, 36104
Phone: 334-206-5955 ***Fax***: 334-206-3063
E-mail: Rachel.Montgomery.adph.state.al.us

Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 1996
Earliest year of available data: 1996
Organizational location: Department of Health and Social Services, Division of Public Health, Section of Women's, Children's and Family Health
Population covered annually: 11,000
Statewide: Yes
Current legislation or rule: 7 AAC 27.012
Legislation year enacted: 1996

Case Definition

Outcomes covered: ICD-9 Codes 237.7, 243, 255.2, 270, 271, 277, 279, 282, 284.0, 331, 334, 335, 343, 359, 362.74, 389, 740-760, 760.71
Pregnancy outcome: Live Births (all gestational ages and birth weights)
Age: Birth to age six
Residence: In and out of state births to Alaska residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based, Passive case ascertainment with case verification of selected conditions including FAS and NTDs
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), MIMR (FIMR), public health nursing
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-9 code.
Pediatric & tertiary care hospitals: Disease index or discharge index, 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.
Third party payers: Medicaid databases, Indian health services
Other specialty facilities: Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9 code of 760.71 and other birth defects as selected for review by the ABDR Program Manager.
Coding: 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.), Birth defect diagnostic information

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 storage/management: Access

Data Analysis

Data analysis software: Epi-Info, SPSS, SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link case finding data to final birth file

Funding

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

Other

Web site: www.epi.alaska.gov/mchepi/ABDR
Surveillance reports on file: See website

Contacts

Jennifer A. Bisson
State of Alaska, Division of Public Health
3601 C Street, Suite 358
Anchorage, AK, 99503
Phone: **907-269-8097**
E-mail: **jennifer.bisson@alaska.gov**

Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1986
Organizational location: Department of Health (Bureau of Public Health Statistics/Office of Health Registries)
Population covered annually: 87,053 live births in AZ to AZ residents, 2010
Statewide: Yes
Current legislation or rule:
Statute- www.azleg.state.az.us/ars/36/00133.htm
Rule- www.azsos.gov/public_services/Title_09/9-04.htm Effective 1991.
Legislation year enacted: 1988

Case Definition
Outcomes covered: Major birth defects and genetic diseases, as defined by the BPA/MACDP codes. Covered conditions vary by year of birth.
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, stillbirths with a fetal death certificate can be of any gestational age or weight), Terminations are not included in the electronic database.
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 (which occurs 2-3 years after the child's birth or fetal death), then the more precise diagnosis is used.
Residence: Cases are born in Arizona and have an Arizona abstract indicating mother's residence in AZ

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based, 1986-2004: 44 categories; 2005-2009: 31 categories; 2010+: 32 categories of defects.
Vital Records: Birth certificates, Fetal death certificates
Other state based registries: Programs for children with special needs
Delivery hospitals: Disease index or discharge index, Discharge summaries, Mother's chart for stillborns
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Mother's chart for stillborns
Third party payers: Indian Health Service
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart within a narrowed list of ICD9-CM codes between 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, Some prenatally diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, 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, Maternal risk factors, 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
Database storage/management: Access, Oracle

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
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

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

Funding
Funding Source: 14.5% general state funds, 16.5% MCH funds, and 69% CDC Cooperative grant funds

Other
Web site: http://www.azdhs.gov/phs/phstats/bdr/index.htm
Surveillance reports on file: Same as Above

Contacts
Timothy J. Flood, M.D.
Arizona Department of Health Services
150 North 18th Ave., Ste. 550
Phoenix, AZ, 85007
Phone: **602-542-7331** ***Fax***: **602-364-0082**
E-mail: **floodt@azdhs.gov**

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

Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

Purpose: Surveillance, Research, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1980
Earliest year of available data: 1980
Organizational location: University, Arkansas Children's Hospital
Population covered annually: 41,000
Statewide: Yes
Current legislation or rule: Senate Bill Act 214
Legislation year enacted: 1985

Case Definition
Outcomes covered: Major structural birth defects
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective Terminations (all gestational ages)
Age: Two years after delivery
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, All stillborn infants
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: Locally modified BPA/CDC and NBDPS coding system

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, 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 storage/management: Access

Data Analysis
Data analysis software: SAS, Access, STATA
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 investigation, 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, Prevention projects

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

Funding
Funding Source: 100% General state funds

Other
Web site: http://arbirthdefectsresearch.uams.edu/

Contacts
Bridget S. Mosley, MPH
Arkansas Reproductive Health Monitoring System
13 Children's Way, Slot 512-40
Little Rock, AR, 72202
Phone: **501-364-8951** ***Fax***: **501-364-5050**
E-mail: **MosleyBridgetS@uams.edu**

Charlotte A. Hobbs, MD, PhD
UAMS College of Medicine; Arkansas Center for Birth Defects Research and Prevention
13 Children's Way, Slot 512-40
Little Rock, AR, 72202
Phone: 501-364-5000 *Fax*: 501-364-5107
E-mail: HobbsCharlotte@uams.edu

California

California Birth Defects Monitoring Program (CBDMP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: Department of Health (California Department of Public Health: Maternal, Child, Adolescent Health Division, Center for Family Health)
Population covered annually: 70,000
Statewide: No, The Program 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, the Program has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.
Current legislation or rule: Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1996.
Legislation year enacted: 1982

Case Definition

Outcomes covered: Serious structural birth defects, primarily encompassed within ICD codes 740-759
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater), Terminations (less than 20 week gestation, 20 weeks gestation and greater)
Age: One year
Residence: In-state births to residents of 1 of 8 counties; does not include births in military hospitals.

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based
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
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, Terminations, All prenatal diagnosed or suspected cases, apgar 0-0
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., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codable defect
Coding: CDC BPA coding system 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, 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 storage/management: SQL Server 2008 R2

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, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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, Service delivery, 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 birth and fetal death files

Funding

Funding Source: 69% California Birth Defects Monitoring Fund, 31% Other federal funding (non-CDC grants)

Other

Web site: www.cdph.ca.gov/programs/CBDMP
Comments: Please send inquiries to mchinet@cdph.ca.gov.

Contacts

Barbara Warmerdam
California Birth Defects Monitoring Program,
Maternal, Child and Adolescent Health Program
California Department of Public Health
1615 Capitol Avenue, MS 8304
Sacramento, CA, 95814
Phone: **916-341-6677** ***Fax***: **916-650-0455**
E-mail: **Barbara.Warmerdam@cdph.ca.gov**

Shabbir Ahmad, DVM, MS, PhD
Maternal, Child, and Adolescent Health Program
California Department of Public Health
1615 Capitol Ave, MS 8304
Sacramento, CA, 95814
Phone: 916-650-0300 *Fax*: 916-650-0305
E-mail: Shabbir.Ahmad@cdph.ca.gov

Colorado

Colorado Responds To Children with Special Needs: Colorado (CRCSN)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 66,346 (2010)
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: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (less than 20 week gestation, 20 weeks gestation and greater, less than 20 week limited to selected post-mortem pathology sites)
Age: Up to the 3rd birthday (up to the 10th birthday for fetal alcohol syndrome)
Residence: Events occurring in-state or out-of-state to Colorado residents

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics, selected postmortem pathology sites
Pediatric & tertiary care hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics, selected postmortem pathology sites
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Other sources: Physician reports, selected sites for fetal alcohol syndrome and muscular dystrophy

Case Ascertainment
Conditions warranting chart review in newborn period: Selected chart reviews for prenatal to age 3: for statistical trends monitoring (20 conditions - categories); selected death and fetal deaths; fetal alcohol syndrome (to age 10); active case ascertainment data sources (postmortem pathology and specialty clinics); quality control (selected procedures); and others as needed.
Coding: ICD-9-CM, extended code utilized to describe syndromes, further detail of a condition, and to specify status

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, Pregnancy/delivery complications, Maternal risk factors
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 storage/management: Access, Conversion to SQL Server

Data Analysis
Data analysis software: SAS, Access, ArcView (GIS software), Maptitude, SaTScan
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness, ongoing quality control procedures for problematic conditions and situations; 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 investigation, 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, Referral, Grant proposals, Education/public awareness, Prevention projects, environmental studies

System Integration
System links: Link to other state registries/databases, Ongoing match to vital records files (birth, death, fetal death)

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

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

Contacts
Margaret Frances Ruttenber, MSPH
Colorado Responds to Children with Special Needs
4300 Cherry Creek Drive, South
Denver, CO, 80246-1530
Phone: **303-692-2636** ***Fax***: **303-782-0904**
E-mail: **margaret.ruttenber@state.co.us**

Carol Stanton, MBA
CRCSN
4300 Cherry Creek Dr, South
Denver, CO, 80246-1530
Phone: 303-692-2621 *Fax*: 303-782-0904
E-mail: carol.stanton@state.co.us

Connecticut

Connecticut Birth Defects Registry (CTBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, reporting for MCH Block Grant
Partner: Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, CT Council on Genomics
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: 43,000
Statewide: Yes
Current legislation or rule: Sec. 19a-56a. (Formerly Sec. 10a-132b), Birth defects surveillance program; Sec. 19a-54. (Formerly Sec. 19-21a),Registration of physically handicapped children; Sec. 19a-53. (Formerly Sec. 19-21), Reports of physical defects of children.
Legislation year enacted: Sec. 10a-132b: 1991; Sec. 19-21a: 1949 Sec. 19-21: 1949.

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
Pregnancy outcome: Live Births (all gestational ages and birth weights, PDA ≥ to 2500 gms birth weight)
Age: Up to one year after delivery for birth defects
Residence: In state births to state residents

Surveillance Methods
Case ascertainment: Passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, inpatient hospitalizations and emergency room visits
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Reports from health care professionals in newborn nurseries and NICUs.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Reports from health care professionals in pediatric inpatient and outpatient services planned for future.
Midwifery facilities: Midwifery facilities
Other sources: Physician reports, Mandatory reporting by health care providers and facilities; CSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment
Coding: ICD-9-CM, test written in 'other' field categories

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, Maternal risk factors, 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 storage/management: Access, Oracle

Data Analysis
Data analysis software: SAS, Access, STATA, 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 investigation, Time trends, Time-space cluster analyses, Capture-recapture analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Provider education

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

Funding
Funding Source: 100% MCH funds

Other
Web site: http://www.ct.gov/dph/birthdefectsregistry

Contacts
Karin Davis, B.S.
Connecticut Department of Public Health, Family Health Division
410 Capitol Avenue, MS #11MAT
Hartford, CT, 06134
Phone: **860-509-7499** ***Fax***: **860-509-7720**
E-mail: **Karin.Davis@ct.gov**

Delaware

Delaware Birth Defects Surveillance Project

Purpose: Surveillance, Referral to Prevention/Intervention
Partner: Hospitals, Early Childhood Prevention Programs
Program status: Currently collecting data
Start year: 2007
Earliest year of available data: 2007, 2008, 2009
Organizational location: Department of Health and Social Services, Division of Public Health, Family Health Services
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: Birth Defects Registry - Selected birth defects for passive surveillance, developmental disabilities if due to a birth defect, selected metabolic defects, genetic diseases, infant mortality, congenital infections, Autism
Pregnancy outcome: Live Births (any gestation for live birth, greater than 20 weeks for fetal death), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Birth to 5 years
Residence: In-state and out-of-state birth to state resident, and in-state birth to state non-resident.

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, hospital discharge records/data
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry
Delivery hospitals: Disease index or discharge index, Discharge summaries, Postmortem/pathology logs, High risk pregnancy
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Midwifery facilities: Midwifery facilities
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.)
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, 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, Failure to thrive, Development delay, Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: ICD-9-CM, six-digit modified BPA/ICD-9 codes

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, Maternal risk factors
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 submitted by other agencies (hospitals, etc.)
Database storage/management: Natus Medical Inc.

Data Analysis

Data analysis software: Natus Medical Inc.
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Clinical review, none at this time
Data use and analysis: Only became active in early 2010 with review of calendar year 2007

System Integration

System links: Link to Newborn Bloodspot and Hearing Screening
System integration: Initial check into Newborn Bloodspot Screening records with a link which pulls info to Birth Defects Registry from Newborn Bloodspot Screening case management system.

Funding

Funding Source: Genetic screening revenues, Title V MCH Block grant

Contacts

Leah Jones Woodall, MPA
DE Division of Public Health
417 Federal Street
Dover, DE, 19901
Phone: **(302) 744-4825** ***Fax***: **(302) 739-3313**
E-mail: **leah.woodall@state.de.us**

Kristin Maiden, PhD
Christiana Care Health System
4735 Ogletown Stanton Rd
Newark, DE, 19718
Phone: (302)733-5032
E-mail: kmaiden@christianacare.org

District of Columbia

District of Columbia Birth Defects Surveillance and Prevention Program (DC BDSPP)

Purpose: Research, Referral to Services, Referral to Prevention/Intervention
Partner: Hospitals
Program status: Interested in developing a surveillance program

Surveillance Methods
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Data Collected
Mother: Maternal risk factors

Contacts

Karen Watts, BSN, MPA, MBA, RNC, FAHM, PMP
Department of Health, Community Health Administration
899 North Capitol Street, NE 3rd Floor, Washington, DC, 20002
Phone: **202-442-9405** ***Fax***: **202-671-0849**
E-mail: **karenp.watts@dc.gov**

Sandra A. Davis, MPH
Department of Health, Community Health Administration
899 North Capitol Street, NE 3rd Floor, Washington, DC, 20002
Phone: 2024785820 *Fax*: 2026710854
E-mail: sandraa.davis@dc.gov

Florida

Florida Birth Defects Registry (FBDR)

Purpose: Surveillance, Research, Referral to Prevention/Intervention, educate health care professionals, women of childbearing age and general public about birth defects.
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, 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: 213,234 in 2011
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 selected genetic disorders
Pregnancy outcome: Live Births
Age: Until age 1
Residence: Florida

Surveillance Methods
Case ascertainment: Passive case ascertainment, Population based, FL has two CDC funded cooperative agreements 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
Coding: 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, Maternal risk factors
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 storage/management: Access, Dedicated server for birth defects data.

Data Analysis
Data analysis software: SPSS, SAS, Access, SQL, dBASE
Quality assurance: Validity checks, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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, 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.

Other
Web site: www.fbdr.org
Surveillance reports on file: Publications, procedure manuals, electronic case ascertaintment dababase and educational materials
Comments: CDC/NCBDDD Cooperative Agreement for enhanced surveillance of selected birth defects, referral for services and prevention activities. CDC/NCEH Cooperative Agreement for Environmental Public Health Tracking for active surveillance of selected birth defects and analysis of environmental data and birth defects.

Contacts
Jane A. Correia, B.S.
Florida Department of Health
4052 Bald Cypress Way, Bin A08,
Tallahassee, FL, 32399-1712
Phone: **850-245-4444, ext. 2198** ***Fax***: **850-922-8473**
E-mail: **Jane_Correia@doh.state.fl.us**

Sharon M. Watkins, PhD
Florida Department of Health
4052 Bald Cypress Way, Bin A08
Tallahassee, FL, 32399-1712
Phone: 850-245-4444 ext. 3939 *Fax*: 850-922-8473
E-mail: Sharon_Watkins@doh.state.fl.us

Georgia

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Universities, Hospitals, Advocacy Groups, 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: 50,000
Statewide: No, Births to mothers residing within one of five central counties in the metropolitan Atlanta area of the state of Georgia
Current legislation or rule: State Laws Official Georgia Code Annotated (OCGA) 31-12-2

Case Definition
Outcomes covered: Major structural or genetic birth defects
Pregnancy outcome: Live Births (≥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 five central metropolitan Atlanta counties

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal death certificates
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, induction logs and miscarriage logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (birth weight < 2500 grams and/or 20-36 weeks gestation), All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, 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, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), 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

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 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 storage/management: SQL Server

Data Analysis
Data analysis software: SPSS, SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, 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 investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Education/public awareness, Prevention projects, survival analysis

System Integration
System links: Link case finding data to final birth file, National Death Index, Birth certificates, Death certificates, Fetal death certificates, Laboratory Records

Funding
Funding Source: 100% CDC funded

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
Comments: The 40th Anniversary Surveilance 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. Copies are available upon request from: JCragan@cdc.gov

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***: **404-498-3040**
E-mail: **JCragan@cdc.gov**

Pamela Costa, MPH
Centers for Disease Control and Prevention
1600 Clifton Rd., MS E-86
Atlanta, GA, 30333
Phone: 404-498-3488 *Fax*: 404-498-3040
E-mail: PCosta@cdc.gov

Georgia

Georgia Birth Defects Reporting and Information System (GBDRIS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 2003
Earliest year of available data: 2005
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 138,000
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 290-5-3-.02 and 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: Major birth defects, genetic diseases, FAS and CP
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective Terminations (all gestational ages)
Age: Up to 18 years of age
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case ascertainment
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance
Delivery hospitals: Disease index or discharge index, Discharge summaries
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other specialty facilities: Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease)
Coding: 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.), Birth defect diagnostic information
Mother: 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 storage/management: Access

Data Analysis
Data analysis software: SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Public health program evaluation, Service delivery

System Integration
System integration: We are working to integrate it with our child health data system that contains birth, genetics and intervention referrals.

Other
Web site: http://health.state.ga.us/epi/mch/birthdefects/gbdris/index.asp
Comments: In Georgia, please note that other surveillance is performed by MACDP and that is where the numbers for your report come from.

Contacts
Brendan Noggle, MPH
GA Division of Public Health, MCH Program
2 Peachtree St., NW, Suite 11-463
Atlanta, GA, 30303
Phone: **404-463-2191** ***Fax***: **404-657-7517**
E-mail: **rbnoggle@dhr.state.ga.us**

Katherine Kahn, MPH
GA Division of Public Health, MCH Program
2 Peachtree St., NW, Suite 14-482
Atlanta, GA, 30303
Phone: 404-657-2602 *Fax*: 404-657-7517
E-mail: kekahn@dhr.state.ga.us

Hawaii

Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance, Research, Report incidences and trends, develop preventive strategies, develop a statewide registry
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Hawaii Health Data Warehouse
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: 18,913 (average over past 3 years)
Statewide: Yes
Current legislation or rule: HRS §321.421 to 426; HRS §321.41 to 44
Legislation year enacted: 2002

Case Definition

Outcomes covered: All outcomes identified on the ICD-9 and CDC/BPA codes for the NBDPN Annual Report to CDC as well as other adverse neonatal conditions such as congenital infections, fetal alcohol syndrome, and specific chromosomal syndromes
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective Terminations (all gestational ages, elective medical terminations that were carried out because a screening test or diagnostic procedure documented that the fetus was severely impaired with a birth defect, and the parents elected not to bring the baby to term)
Age: Up to one year after delivery, except for Fetal Alcohol Syndrome, which can be diagnosed at any age.
Residence: All in-state Hawaii births (resident and non-resident).

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based, Hospital based
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, Prenatal summaries
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Laboratory logs
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases, Medical terminations and spontaneous abortions where fetus was diagnosed with a birth defect, and parents elected not to bring baby to term, or mother spontaneously aborted.
Conditions warranting chart review beyond the newborn period: All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, 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, Maternal risk factors, 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: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Access, SQL Server 2000

Data Analysis

Data analysis software: Access, SQL Server 2000
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, Time trends, Epidemiologic studies (using only program data), Needs assessment, Grant proposals, Education/public awareness, Prevention projects, State Surveillance Data Report

Funding

Funding Source: 100% Birth Defects Special Fund (state fund from marriage license fee)

Other

Web site: http://hawaii.gov/health/family-child-health/genetics/hbdhome.html
Surveillance reports on file: Thirteen HBDP Statewide Surveillance Data Reports: (1) 1989-1991, (2) 1988-1993, (3) 1988-1994, (4) 1988-1995, (5) 1987-1996, (6) 1986-1997, (7) 1986-1998, (8) 1986-1999, (9) 1986-2000, (10) 1986-2001, (11) 1986-2002, (12) 1986-2003, (13) 1986-2005.
Additional information on file: Hawai'i Statutory Authority; HBDP Publications; HBDP Case finding list; HBDP BPA Codes

Contacts

Patricia L. Heu, M.D., M.P.H.
Children with Special Health Needs Branch, Hawaii State Department of Health
741 Sunset Avenue
Honolulu, HI, 96816
Phone: **808-733-9058** ***Fax***: **808-733-9068**
E-mail: **patricia.heu@doh.hawaii.gov**

Sylvia M. Au, M.S.
Children with Special Health Needs Branch, Hawaii State Department of Health
741 Sunset Avenue
Honolulu, HI, 96816
Phone: 808-733-9063 *Fax*: 808-733-9068
E-mail: sylvia@hawaiigenetics.org

Idaho

Program status: No surveillance program in Idaho

Contacts

Pam Harder
Idaho Dept of Health & Welfare
450 West State Street, Boise, ID, 83720
Phone: **208-334-6658** ***Fax:*** **208-334-4946**
E-mail: **harperp@dhw.idaho.gov**

Jacquie Watson
Children's Special Health Program
Idaho Department of Health and Welfare
450 West State Street, Boise, ID, 83720
Phone: 208-334-5963 *Fax*: 208-334-4946
E-mail: watsonj1@dhw.idaho.gov

Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Hospitals, Early Childhood Prevention Programs, State agency serving children with special healthcare needs
Program status: Currently collecting data
Start year: 1986
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 170,000
Statewide: Yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525)
Legislation year enacted: 1985

Case Definition

Outcomes covered: ICD-9-CM Codes 740.0 through 759.9; infants positive for controlled substances; very low birth weight (< 1500g); fetal death; death during the newborn hospital stay; serious congenital infections; congenital endocrine, metabolic or immune disorders; congenital blood disorders; other conditions such as retinopathy of prematurity, intrauterine growth retardation, FAS
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to 2 years of age
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based, Hospital based
Vital Records: Birth certificates, Fetal death certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, hospitals mandated to identify newborn cases and report to IDPH
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, hospitals mandated to report newborns discharged from any of the NICU or specialty units

Case Ascertainment

Conditions warranting chart review in newborn period: Charts of children identified by APORS with major structural birth defects or Trisomy 13, 18 or 21 are reviewed. Prior to 2008, any chart with ICD9-CM code 740-759, or with selected conditions outside that range were reviewed.
Conditions warranting chart review beyond the newborn period: Charts of children identified by APORS with major structural birth defects or Trisomy 13, 18 or 21 are reviewed. Prior to 2008, any chart with ICD9-CM code 740-759, or with selected conditions outside that range were reviewed.
Coding: Modified CDC/BPA coding system

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: 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 storage/management: Access, Mainframe

Data Analysis

Data analysis software: SAS, Access, Arc Map, JoinPoint & SaTScan
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 investigation, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, Public Use Data Set

System Integration

System links: Link case finding data to final birth file
System integration: The APORS program data is incorporated into a data warehouse at the Illinois Department of Healthcare and Family Services

Funding

Funding Source: 63% General state funds, 37% CDC grant

Other

Web site: www.idph.state.il.us/about/epi/apors.htm
Surveillance reports on file: Surveillance reports are available on-line -- visit website listed above, as are public use data sets.

Contacts

Jane Fornoff, PhD
Illinois Department of Public Health
535 West Jefferson St, 3rd Floor, Springfield, IL, 62761
Phone: **217-785-7133** ***Fax***: **217-524-1770**
E-mail: **jane.fornoff@illinois.gov**

Tiefu Shen, MD, PhD
Illinois Department of Public Health
535 West Jefferson St, 3rd Floor, Springfield, IL, 62761
Phone: 217-785-1873 *Fax*: 217-524-1770
E-mail: tiefu.shen@illinois.gov

Indiana

Indiana Birth Defects & Problems Registry (IBDPR)

Purpose: Surveillance, Research, Referral to Services
Partner: Universities, Hospitals, Early Childhood Prevention Programs, 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 (Epidemiology/Environment), Department of Health (Maternal and Child Health), Department of Health (State Health Data Center)
Population covered annually: 89,000
Statewide: Yes
Current legislation or rule: IC 16-38-4-7, Rule 410 IAC 21-3
Legislation year enacted: 2001

Case Definition

Outcomes covered: ICD-9-CM Codes 740-759.9, Fetal Alcohol Spectrum Disorder (760.71), Pervasive Developmental Disorder (299.0), fetal deaths, metabolic disorders & hearing loss from newborn screening, selected neoplasms, congenital blood disorders, and certain eye disorders.
Pregnancy outcome: Live Births (all gestational ages and birth weights)
Age: Up to 5 years (FAS, autism); 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: Combination of active and passive case ascertainment, Hospital based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Chart audits of 45 targeted birth defects
Pediatric & tertiary care hospitals: Disease index or discharge index, Chart audits of 45 targeted birth defects
Other specialty facilities: Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM, and 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, Maternal risk factors, 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.), Electronic file/report submitted by other agencies (hospitals, etc.), ISDH Chart Auditors submit hospital chart audit information electronically through use of a laptop and a web-based portal to the Indiana State Department of Health Repository, which stores and integrates the data.
Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, Oracle and ArcView GIS
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, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Needs assessment

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: The database is linked with birth, death, newborn hearing screening, and newborn metabolic screening data.

Funding

Funding Source: 20% MCH funds, 80% from the IBDPR fund obtained through birth certificate sales

Other

Web site: www.birthdefects.in.gov

Contacts

Malorie Hensley, MS
Indiana State Department of Health
2 North Meridian Street, 7F
Indianapolis, IN, 46204
Phone: **317-233-7019** ***Fax***: **317-234-2995**
E-mail: **MHensley@isdh.IN.gov**

Robert Bowman, MS, MA, MS
Indiana State Department of Health
2 North Meridian Street, 7F
Indianapolis, IN, 46204
Phone: 317-233-1231 *Fax*: 317-234-2995
E-mail: BobBowman@isdh.IN.gov

Iowa

Iowa Registry for Congenital and Inherited Disorders (IRCID)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Prevention education programs
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1983
Organizational location: University
Population covered annually: 37,831 average 10 year
Statewide: Yes
Current legislation or rule: Iowa Code 136A, Iowa Administrative Code 641-4.7
Legislation year enacted: 1986; Revised 2001, 2003, 2004, 2009

Case Definition
Outcomes covered: Major birth defects, Duchenne/Becker muscular dystrophy, fetal deaths with and without birth defects, newborn screening disorders
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective Terminations (all gestational ages)
Age: 1 year
Residence: Maternal residence in Iowa at time of delivery

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal death certificates, Stillbirth Evaluation Protocol
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Iowa Perinatal Care 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.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities
Other sources: Physician reports, Outpatient surgery facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases, muscular dystrophy
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), 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

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, Maternal risk factors, 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 storage/management: Access, Oracle, PC server

Data Analysis
Data analysis software: SPSS, SAS, Access, Oracle
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 investigation, 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, 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. For specific studies, data may be linked with environmental databases or other state databases.

Funding
Funding Source: 35% General state funds, 65% CDC grant

Contacts
Paul A. Romitti, Ph.D.
Iowa Registry for Congenital and Inherited Disorders
UI Research Park 100 BVC Room W245-G
Iowa City, IA, 52242-5000
Phone: **319-384-1549** ***Fax***: **319-353-8711**
E-mail: **paul-romitti@uiowa.edu**

Kansas

Birth Defects Information System (BDIS)

Purpose: Registry
Partner: Hospitals
Program status: Interested in developing a surveillance program
Start year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Maternal and Child Health), Department of Health (Vital Statistics)
Population covered annually: 40,439 (Year 2010)
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 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 and low Apgar scores are also reported to BDIS.
Pregnancy outcome: Live births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (greater than 350 grams)
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 ascertainment, Population based
Vital Records: Birth certificates, Fetal death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Other sources: Physician reports

Case Ascertainment

Coding: 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.)
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: 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.), In Kansas, birth defects (congenital anomalies) are collected through three data sources: birth certificates, fetal death certificates, and the congenital malformations and fetal alcohol syndrome reporting form. The birth certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to BDIS. Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into BDIS.
Database storage/management: SQL Server

Data Analysis

Data analysis software: SAS
Quality assurance: Comparison/verification between multiple data sources, Office of Vital Statistics conducts verification on birth certificate data.
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Grant proposals, ad-hoc upon request

System Integration

System links: Link to other state registries/databases
System integration: Our program has a link with vital statistics records. BDIS uses the same data system (WebBFH) and shares information with Children and Youth with Special Health Care Needs Program.

Funding

Funding Source: 100% MCH funds

Contacts

Jamie S. Kim, MPH
Kansas Department of Health & Environment
1000 SW Jackson, Suite 220
Topeka, KS, 66612-1274
Phone: **785-296-6467** ***Fax***: **785-296-6553**
E-mail: **jkim@kdheks.gov**

Jamey. Kendall, RN, BSN
Kansas Department of Health & Environment
1000 SW Jackson, Suite 220
Topeka, KS, 66612-1274
Phone: 785-291-3363 *Fax*: 785-296-6553
E-mail: jkendall@kdheks.gov

Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention, Prevention of birth defects
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1996
Earliest year of available data: 1998
Organizational location: Department of Health (Maternal and Child Health), Department for Public Health, Division of Maternal and Child Health, Early Childhood Development Branch
Population covered annually: 56,000
Statewide: Yes
Current legislation or rule: KRS 211.651-211.670
Legislation year enacted: 1992

Case Definition
Outcomes covered: Major birth defects, genetic diseases, fetal mortality
Pregnancy outcome: Live Births (all gestational ages and birth weights) Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 20 weeks or 350 gms)
Age: Up to fifth birthday
Residence: All in-state births; out of state births to state residents

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, medical laboratory reporting mandated; outpatient reporting voluntary
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), ICU/NICU logs or charts, Specialty outpatient clinics, laboratory records
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, laboratory records
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Other sources: Physician reports, local health departments

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), 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, CNS condition (e.g., seizure), Cardiovascular condition, Any infant with a codable defect
Coding: ICD-9-CM, ICD-10 for Vital Statistics death data

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, Maternal risk factors, 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.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access

Data Analysis
Data analysis software: SAS, Access, Link Plus
Quality assurance: 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 investigation, 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, IRB-approved research projects

System Integration
System links: Link case finding data to final birth file
System integration: True positives identified by newborn screening are integrated into the KBSR database.

Funding
Funding Source: 30% General state funds, 70% CDC grant

Other
Web site: http://chfs.ky.gov/dph/ach/ecd/kbsr.htm

Contacts
Sandy G. Fawbush, RN, BSN
Kentucky Department for Public Health
275 East Main Street, HS 2WC
Frankfort, KY, 40621
Phone: **502-564-3756 x3563** ***Fax***: **502-564-8389**
E-mail: **sandy.fawbush@ky.gov**

Troi J Cunningham, RN
Kentucky Department for Public Health
275 East Main Street, HS 2WC
Frankfort, KY, 40621
Phone: 502-564-3756 x3779 *Fax*: 502-564-8389
E-mail: troi.cunningham@ky.gov

Louisiana

Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Centers for Disease Control and Prevention, Louisiana State University HSC School of Medicine, Hospitals, Louisiana Environmental Public Health Tracking Program, Early Childhood Prevention Programs, Louisiana Public Health Institute, Louisiana Center for Health Statistics and Vital Records, March of Dimes, Louisiana Maternal and Child Health Program, Louisiana Genetic Diseases Program, Louisiana Hearing, Speech, and Vision Program, and Louisiana Medicaid Office.
Program status: Currently collecting data
Start year: 2005
Earliest year of available data: 2005
Organizational location: Department of Health and Hospitals (Title V Children and Youth with Special Health Care Needs Programs)
Population covered annually: Approx. 62,000 live births (2011)
Statewide: No
Current legislation or rule: Law: LA R.S. 40:31.41 - 40:31.48, 2001. DHH Rule: LAC 48:V.Chapters 161 and 163
Legislation year enacted: 2001

Case Definition
Outcomes covered: Major structural birth defects and selected genetic diseases
Pregnancy outcome: Live Births (≥ 20 weeks or ≥ 350 grams)
Age: Birth through three years old
Residence: In- and out-of-state births to state residents

Surveillance Methods
Case ascertainment: Active surveillance, Population based
Vital Records: Birth certificates, Matched birth/death file
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

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a selected list of ICD9-CM codes 740-759; 760.71; 762.8
Conditions warranting chart review beyond the newborn period: Any child up to three years of age with a selected birth defects code
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected
Live births/children up to 3 years of age: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgar score, etc.), Tests and procedures, and 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, Maternal risk factors, 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 scanning of printed records, Hand-written, printed forms phased out in 2011.
Database storage/management: Access, Excel, and InfoPath/SharePoint

Data Analysis
Data analysis software: SAS and GIS (Arc View)
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, Time trends, Education/public awareness, Prevention projects

System Integration
System links: Link case finding data to birth records, child death records, hospital inpatient discharge data, and Medicaid data up to three years of age

Funding
Funding Source: 28% CDC grant, 72% Title V Block Grant funds

Other
Web site: http://new.dhh.louisiana.gov/index.cfm/page/771
Surveillance reports on file: Louisiana Morbidity Report
Additional information on file: Advisory Board Documentation
Comments:
Web-based birth defects database integrated with Louisiana Electronic Event Registration System (LEERS) is under development;
LBDMN Advisory Board:
http://wwwprd.doa.louisiana.gov/boardsandcommissions/viewBoard.cfm?board=192

Contacts
Dionka C. Pierce, MPH, Interim Program Manager
DHH / OPH / CSHS
1450 Poydras St., Ste 1950
New Orleans, LA, 70112
***Phone*: 504-568-5055** ***Fax*: 504-568-7529**
***E-mail*: Dionka.Pierce@la.gov**

Susan Berry, MD, MPH
DHH / OPH / CSHS
1450 Poydras St., Ste 1950
New Orleans, LA, 70112
Phone: 504-568-5055 *Fax*: 504-568-7529
E-mail: Susan.Berry@LA.gov

Maine

Maine CDC Birth Defects Program (MBDP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Education
Partner: Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, March of Dimes
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: 12,814
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: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, prenatally diagnosed at any gestation), Elective Terminations (prenatally diagnosed at any gestation)
Age: Through age one
Residence: All in-state births to Maine residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based, Passive case ascertainment with active case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal 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, Laboratory logs, Specialty outpatient clinics
Midwifery facilities: Midwifery facilities
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities, Maternal serum screening facilities
Other sources: Physician reports, Children with Special Health Needs

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, 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: Cardiovascular condition, 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, Maternal risk factors, 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 storage/management: Oracle, Citrix, University of Maine/Center for Excellence in Developmental Disabilities ChildLINK database system electronic abstraction record/hospital case reports/electronic submission of hospital discharge data. On-line hospital case report form.

Data Analysis

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, Baseline rates, Rates by demographic and other variables, 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: 85% MCH funds, 15% Maine Environmental Public Health Tracking grant

Other

Web site: http://www.maine.gov/dhhs/boh/cshn/birth_defects/index.html

Contacts

Toni G. Wall, MPA
Department of Health & Human Services
11 State House Station, 286 Water St.-7th floor
Augusta, ME, 04333
Phone: **207-287-5350** ***Fax***: **207-287-5355**
E-mail: **toni.g.wall@maine.gov**

Diane C. Haberman, MSW, LCSW
Department of Health & Human Services
11 State House Station, 286 Water St. 7th floor
Augusta, ME, 04333
Phone: 207-287-8424 *Fax*: 207-287-5355
E-mail: Diane.Haberman@maine.gov

Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

Purpose: Surveillance, Research, Referral to Services
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1983
Earliest year of available data: 1984
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (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: Live Births (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 (all gestational ages; 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 ascertainment, Population based, Multiple-Source
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates
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: Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form
Pediatric & tertiary care hospitals: ICU/NICU logs or charts, primary source: sentinel birth defects hospital report form
Midwifery facilities: Midwifery facilities
Other specialty facilities: Genetic counseling/clinical genetics facilities, Maternal serum screening facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All fetal death certificates
Coding: 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, 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, Maternal risk factors, 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, Printed abstract/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access, Mainframe, Visual dBASE, SAS, ASCII files

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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: In the process of linkage with other state registries/databases

Funding

Funding Source: 100% General state funds

Contacts

Debra Harper-Hill
Maryland Dept. of Health & Mental Hygiene
201 W. Preston Street, Room 423
Baltimore, MD, 21201
Phone: **410-767-6625** ***Fax***: **443-333-7956**
E-mail: **Debra.HarperHill@maryland.gov**

Donna X. Harris
Maryland Dept. of Health & Mental Hygiene
201 W. Preston Street, Room 423
Baltimore, MD, 21201
Phone: 410-767-5642 *Fax*: 443-333-7956
E-mail: Donna.Harris@maryland.gov

Massachusetts

Birth Defects Monitoring Program, Massachusetts Center for Birth Defects Research and Prevention, Massachusetts Department of Public Health (MBDMP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 1997
Earliest year of available data: 1999 for statewide data
Organizational location: Department of Public Health (Bureau of Family Health and Nutrition)
Population covered annually: 75,000
Statewide: Yes
Current legislation or rule: Massachusetts General Laws, Chapter 111, Section 67E. In 2002 the Massachusetts Legislature amended this statute, expanding the birth defects monitoring program. Regulations (105 CMR 302.000) were promulgated on February 6, 2009.
Legislation year enacted: 1963

Case Definition
Outcomes covered: Major structural birth defects and chromosomal anomalies of medical, surgical or cosmetic significance
Pregnancy outcome: Live Births (all gestational ages and birth weights) Fetal deaths - stillbirths, spontaneous abortions, etc. (reportable fetal deaths: ≥20 weeks gestation or ≥350 grams)
Age: Up to one year
Residence: In and out-of-state births to state residents

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Delivery hospitals: Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs
Pediatric & tertiary care hospitals: Disease index or discharge index, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), 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, Maternal risk factors, 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, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records, Data from printed Confidential Reporting and Abstracting Form is entered into electronic surveillance database.
Database storage/management: Access

Data Analysis
Data analysis software: SAS, Access, Excel
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 investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects, 1) selected cases from surveillance are eligible for CDCs National Birth Defects Prevention Study 2) Down syndrome and cardiovascular defects used for CDC grant to determine prevalence, disparities, and cost of these defects; 3) contributed data to other surveillance research projects

System Integration
System links: 1) Link case finding data to final birth file, 2) Link case finding data to final fetal death file, 3) Massachusetts Pregnancy to Early Life Longitudinal (PELL) Linkage Project

Funding
Funding Source: 28% General state funds, 72% MCH funds

Other
Web site: http://www.mass.gov/dph/birthdefects
Surveillance reports on file: go to http://www.mass.gov/dph/birthdefects to view or download annual surveillance reports.

Contacts
Marlene Anderka, ScD, MPH
Massachusetts Department of Public Health
5th Floor, 250 Washington Street
Boston, MA, 02108-4619
Phone: **617-624-6045** ***Fax***: **617-624-5574**
E-mail: **marlene.anderka@state.ma.us**

Cathy Higgins, BA
Massachusetts Department of Public Health
5th Floor, 250 Washington Street
Boston, MA, 02108-4619
Phone: 617-624-5510 *Fax*: 617-624-5574
E-mail: cathleen.higgins@state.ma.us

Michigan

Michigan Birth Defects Registry (MBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Prevalence and mortality statistics
Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 112,000
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: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks or >400 grams)
Age: Up to two years after delivery
Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

Surveillance Methods

Case ascertainment: Passive case ascertainment, Combination of active and passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, 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, AIDS/HIV registry
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, CSHCS
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), 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, CNS condition (e.g., seizure), GI condition (e.g., recurrent 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-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, Maternal risk factors
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 storage/management: FoxPro

Data Analysis

Data analysis software: SPSS, 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, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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.

Funding

Funding Source: 20% CDC grant, 80% Vital Records Fees

Other

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.html

Contacts

Glenn Edward Copeland, MBA
Michigan Birth Defects Registry
201 Townsend
Lansing, MI, 48913
Phone: **517-335-8677** ***Fax***: **517-335-8711**
E-mail: **CopelandG@Michigan.gov**

Lorrie Simmons, RHIT
Michigan Dept. of Community Health
201 Townsend.
Lansing, MI, 48913
Phone: 517-335-9197 *Fax*: 517-335-8711
E-mail: Simmonsl@Michigan.gov

Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 2005
Earliest year of available data: 2006
Organizational location: Department of Health (Division of Community and Family Health)
Population covered annually: 73,000
Statewide: No, The statewide surveillance system will be phased in over a number of years. Data is currently being collected in the two largest counties in Minnesota Hennepin and Ramsey counties). These two counties account for approximately 50 percent of the births.
Current legislation or rule: MS 144.2215-2219
Legislation year enacted: 2004

Case Definition
Outcomes covered: Major "reported birth defects" as defined by CDC and ICD-9 codes up to 1 year of age
Pregnancy outcome: Live Births (all gestational ages and birth weights)
Age: Up to 1 year after delivery
Residence: In-state data

Surveillance Methods
Case ascertainment: Active case ascertainment, Combination of active and passive case ascertainment, Population based, Hospital based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics
Third party payers: Medicaid databases

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: 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, Maternal risk factors, 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.), laptops encrypted and data loaded into web-based database
Database storage/management: Web-based department-wide integrated disease surveillance database

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, physician review as needed;
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, collaboration with Environmental Public Health Tracking Program, phased-in statewide system expansion beginning in 2010; Many of these listed above will be used when full data sets are available

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Program plans to integrate with Newborn Screening/Hearing and collaborate with other regional programs.

Funding
Funding Source: 85% General state funds, 15% CDC grant

Other
Web site: http://www.health.state.mn.us/divs/eh/birthdefects
Surveillance reports on file: Annual reports: 2005-2009
Additional information on file: Folic Acid Guidelines for physicians

Contacts
Barbara Frohnert, MPH
Minnesota Department of Health
85 East 7th Place
St. Paul, MN, 55164
Phone: **651-201-5953** ***Fax***: **651-201-3590**
E-mail: **Barbara.Frohnert@state.mn.us**

Kristin Oehlke, MS, CGC
Minnesota Department of Health
85 East 7th Place
St. Paul, MN, 55164
Phone: 651-201-3648 *Fax*: 651-201-3590
E-mail: kristin.oehlke@state.mn.us

Mississippi

Mississippi Birth Defects Surveillance Registry (BDRS)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Title V Children with Special Health Care Needs
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health), Department of Health (Genetic Services Bureau)
Population covered annually: 42,000
Statewide: Yes
Current legislation or rule: Section 41-21-205 of the Mississippi Code of 1972
Legislation year enacted: 1997

Case Definition
Outcomes covered: Live births and reportable fetal deaths with birth defects (fetal death of 20 completed weeks of gestation or more, or a weight of 350 grams or more) shall be reported.
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, or 350 grams or more)
Age: Birth to 21 years
Residence: In state and out of state births to residents

Surveillance Methods
Case ascertainment: Passive case ascertainment, Population based
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
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment
Coding: 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.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

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

Data Analysis
Data analysis software: SPSS, SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Needs assessment, Education/public awareness

Funding
Funding Source: 100% Genetic screening revenues

Other
Web site: www.healthyms.com
Surveillance reports on file: Birth Defects Surveillance Report 2000-2007

Contacts
Beryl Polk, PhD
Mississippi State Dept. of Health
570 E. Woodrow Wilson Ave, Suite 200
Jackson, MS, 39215-1700
Phone: **601-576-7619** ***Fax***: **601-576-7498**
E-mail: **beryl.polk@msdh.state.ms.us**

Patricia Terry, MS
Mississippi State Dept. of Health
570 E. Woodrow Wilson Ave, Suite 200
Jackson, MS, 39215-1700
Phone: 601-576-7619 *Fax*: 601-576-7498
E-mail: patricia.terry@msdh.state.ms.us

Missouri

Missouri Birth Defects 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: 79,000
Statewide: Yes

Case Definition
Outcomes covered: ICD9 codes 740-759, plus genetic, metabolic, and other disorders
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, 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 ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates
Delivery hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics

Case Ascertainment
Coding: ICD-9-CM, ICD-10

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, Maternal risk factors
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 storage/management: SAS

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

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

Funding
Funding Source: 100% MCH funds

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

Contacts
Ray Shell, BS
Missouri Dept of Health, Bureau of Vital Statistics
920 Wildwood Dr.
Jefferson City, Missouri, 65109
***Phone*: 573-751-6343** ***Fax*: 573-526-4102**
***E-mail*: ray.shell@health.mo.gov**

Montana

Montana Birth Outcomes Monitoring System (MBOMS)

Purpose: Surveillance, Referral to Services
Partner: Private practice physicians
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 2000 through 2004. Registry suspended beginning with calendar year 2006 births due to loss of CDC funding.
Pregnancy outcome: 20 weeks and greater

Funding
Funding Source: No funding available since 8/26/2005

Other
Comments: Due to lack of funding, Montana is no longer performing active surveillance. Informal active/passive surveillance continues and linkages between ascertainment and services are in place and supported. Data and program linkages exist between newborn hearing screening, birth certificates, and newborn screening.

Contacts
MaryLynn Donnelly, RN
Children's Special Health Services
Mt. Dept.of Public Hlth and Human Services, PO Box 202951
Helena, MT, 59620-2951
***Phone*: 406-444-3620** ***Fax*: 406-444-2750**
***E-mail*: mdonnelly@mt.gov**

Nebraska

Nebraska Birth Defects Registry

Purpose: Surveillance, We are in the process of exploring our policy on expanding the use of the birth defects data
Partner: Hospitals, Early Childhood Prevention Programs, Nebraska Department of Health and Human Services, Vital Statistics and MCH
Program status: Currently collecting data
Start year: 1973
Earliest year of available data: 1973
Organizational location: Department of Health (Vital Statistics), Department of Health (Nebraska Department of Health and Human Services, Public Health, Office of Health Statistics)
Population covered annually: Statewide, 27,000 births annually
Statewide: Yes
Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health and Welfare [Codes] §71-645, §71-646, §71-647, §71-648, §71-649)
Legislation year enacted: 1972

Case Definition

Outcomes covered: All birth defects, exclusions according to CDC exclusion list
Pregnancy outcome: Live Births (Greater than 20 weeks and greater than 500 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Birth to 1 year
Residence: In-state and out-of-state birth to state resident.

Surveillance Methods

Case ascertainment: Passive case ascertainment
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
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
Other specialty facilities: Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation, 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, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: CDC coding system based on BPA

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: 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.), Defects taken from paper copies of birth certificates submitted to the Vital Statistics Office.
Database storage/management: Netsmart

Data Analysis

Data analysis software: SAS, Reports from Netsmart.
Quality assurance: Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Case finding, data coding and entry.
Data use and analysis: Baseline rates, Monitoring outbreaks and cluster investigation, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Incidence rates, trend analysis, birth defect registry.

System Integration

System links: Netsmart.
System integration: Integrated with births, fetal deaths, deaths and hearing screening.

Funding

Funding Source: 100% MCH funds

Other

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

Contacts

Nila Irwin
Nebraska Department of Health and Human Services
1033 O Street, Suite 130
Lincoln, Nebraska, 68509-5026
***Phone*: 402-471-0354** ***Fax*: 402-742-2388**
***E-mail*: Nila.Irwin@nebraska.gov**

Nevada

Nevada Birth Outcomes Monitoring System (NBOMS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Hospitals, Early Childhood Prevention Programs, Legislators, Bureau of Child, Family, & Community Wellness
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 2005
Organizational location: Department of Health (Maternal and Child Health), State Health Division, Office of Health Statistics and Surveillance, Bureau of Health Statistics, Planning, Epidemiology and Response
Population covered annually: Nearly 40,000
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: Live Births (20 weeks of gestation and greater with all birth weights), 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: Combination of active and passive case ascertainment, Population based, Hospital based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, hospital medical records, diagnostic/laboratory reports
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Cancer 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/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, 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, Development delay, CNS condition (e.g., seizure), GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, Any infant with a codable defect
Coding: 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.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, 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
Database storage/management: Access

Data Analysis

Data analysis software: SPSS, 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 investigation, 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

System Integration

System links: Link to other state registries/databases, Birth registry data is manually linked to birth defect data, but the actual databases are not linked.

Funding

Funding Source: 100% MCH Block Grant

Other

Surveillance reports on file:
http://health.nv.gov/PUBLICATIONS/OHSS/2009_NBOMS_Annual_Report.pdf

Contacts

Prasanjit Chakma, MPH
NV Birth Outcomes Monitoring System, Office of Health Statistics&Surveillance, BHSPER
3811 W. Charleston Blvd., Ste. 205
Las Vegas, NV, 89102
Phone: **702-486 9855** ***Fax***: **702-486 0490**
E-mail: **pchakma@health.nv.gov**

Brad Towle, MA, MPA
Office of Health Statistics and Surveillance (OHSS), Bureau of Health Statistics, Planning, Epidemiology and Response (BHSP&ER)
4150 Technology Way, Suite 200
Carson City, Nevada, 89706
Phone: 775-684-4243
E-mail: btowle@health.nv.gov

New Hampshire

New Hampshire Birth Conditions Program (NHBCP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 2003
Earliest year of available data: 2003
Organizational location: Department of Health (Maternal and Child Health), Department of Health (Bureau of Special Medical Services: Bureau of Nutrition and Health Promotion, Department of Environmental Services Bureau of Environmental Health), University
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: all major birth defects and genetic diseases recommended by the CDC/NBDPN
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective Terminations (all gestational ages)
Age: Currently collecting birth to age 2
Residence: All New Hampshire residents, those born in-state as well as out of state

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Fetal death certificates, Elective termination certificates, hospital ICD-9 codes for admissions, discharges and transports, fetal pathology reviews at Dartmouth Hitchcock Medical Center
Other state based registries: Programs for children with special needs, Newborn hearing screening program
Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, medical records abstraction of charts of selected ICD 9 Codes
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, cytogenetics laboratory, perinatal pathology logs, Medical Genetics Clinic files, molecular genetics laboratory, Prenatal Diagnosis Program files
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., 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, elective terminations that have confirmed birth conditions by autopsy or confirmed by clinical assessment
Conditions warranting chart review beyond the newborn period: 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.), 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, Maternal risk factors, Family history
Father: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database storage/management: Oracle, AURIS, a web-based reporting system currently utilized by the NH DHHS Newborn Hearing Screening Program, has added a module to the currently operating system to meet the birth defects tracking requirements.

Data Analysis

Data analysis software: SPSS, Access
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, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Observed vs. expected analyses, Epidemiologic studies (using only program data), Service delivery, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases
System integration: Integrated into the NH DHHS Newborn Hearing Screening Program registry, a state-wide universal hearing program for all NH infants. This system also receives weekly uploads from the State's Vital Records system that is then linked with the birth conditions and newborn screening data. In addition, in 2011 the NH Birth Conditions Program database was linked with the Title V program database with data on children receiving Special Medical Services in NH.

Funding

Funding Source: 100% CDC grant

Other

Web site: www.nhbcp.org

Contacts

John B. Moeschler, MD, MS
Division of Genetics and Child Development, Dept. of PediatricsDartmouth Hitchcock Medical Center
1 Medical Center Drive
Lebanon, NH, 03756
Phone: **603-653-6053** ***Fax***: **603-650-8268**
E-mail: **john.b.moeschler@hitchcock.org**

Stephanie D. Miller, RN, MSN, MPH
NH Birth Conditions Program - Dartmouth Medical School
1 Medical Center Drive
Lebanon, NH, 03756
Phone: 603-653-3163 *Fax*: 603-653-0712
E-mail: stephanie.d.miller@hitchcock.org

New Jersey

Special Child Health Services Registry (SCHS REGISTRY)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Neurodevelopmental Centers; Federally Qualified Health Care Centers
Program status: Currently collecting data
Start year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health - Special Child, Adult, and Early Intervention Services
Population covered annually: 110,000
Statewide: Yes
Current legislation or rule: NJSA 26:8-40.20 et seq., NJAC 8:20 - Amended: 1990, 1991, 1992, 2005, Readopted: 2010, Rule Amendments Adopted: 2009; Re-adopted 2010
Legislation year enacted: 1983

Case Definition

Outcomes covered: All birth defects (structural, genetic, and biochemical), all Autism Spectrum Disorders, and severe hyperbilirubinemia, are required to be reported; all special needs and any condition which places a child at risk (prematurity, asthma, cancer, developmental delay) are also reported but not required.
Pregnancy outcome: Live Births (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
Residence: All NJ residents, in and out of state

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based
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, 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, quality assurance visit consisting of chart review of 3 month period
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, quality assurance visit consisting of chart review of 3 month period
Midwifery facilities: Midwifery facilities
Third party payers: Universal Billing database is used for Quality Assurance activities
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Other sources: 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 a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, All neonatal deaths, all death certificates for < 3 year of age
Conditions warranting chart review beyond the newborn period: GI condition (e.g., recurrent blockage), GU condition (e.g., recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codable defect
Coding: 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.), 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.), implementation of a web-based reporting ongoing since July 1, 2009
Database storage/management: Mainframe, SAS; SQL

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 investigation, 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: Newborn hearing screening registry provides direct report to SCHS Registry. Metabolic screening program provides direct report to SCHS Registry. Autism Registry is included in the Registry.

Funding

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

Contacts

Leslie M. Beres-Sochka, MS, Hyg
SCHEIS, New Jersey Department of Health
PO Box 364, Trenton, NJ, 08625-0364
Phone: **609-292-5676** ***Fax***: **609-633-7820**
E-mail: **Leslie.Beres-Sochka@doh.state.nj.us**

Mary M. Knapp, MSN
New Jersey Department of Health
PO Box 364, Trenton, NJ, 08625-0364
Phone: 609-292-5676 *Fax*: 609-633-7820
E-mail: mary.knapp@doh.state.nj.us

New Mexico

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

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Private providers
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Maternal and Child Health)
Population covered annually: 30,000
Statewide: Yes
Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions are updated by the Office of Epidemiology. This did not involve legislation, only a change in regulations.
Legislation year enacted: January 1, 2000

Case Definition

Outcomes covered: 740-760.71, Currently focused on major birth defects of interest to Environmental Public Health Tracking.
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective Terminations (all gestational ages)
Age: Birth through age 4 years
Residence: Births to New Mexico residents.

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Disease index or discharge index, medical chart review
Pediatric & tertiary care hospitals: Disease index or discharge index, Specialty outpatient clinics, specialty outpatient clinics, including neurosurgery, plastic surgery, pediatric surgical specialists, prenatal diagnostic providers
Third party payers: Medicaid databases, Health maintenance organization (HMOs), Indian health services, Children's Medical Services (CMS)
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Chart reviews only done to clarify birth defect diagnosis identified through other means, e.g., nonspecific diagnosis such as 749
Coding: CDC coding system based on BPA, ICD-9-CM, ICD10 for deaths

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.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Stata

Data Analysis

Data analysis software: Stata
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 investigation, Grant proposals, Education/public awareness, Prevention projects

System Integration

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

Funding

Funding Source: 100% CDC grant; At this point, the only funding for birth defects surveillance is from Environmental Public Health Tracking grant. We are actively seeking resources to support this effort.

Other

Web site:
https://nmtracking.unm.edu/health_effects/birthdefects/about_birthdefects

Contacts

Heidi Krapfl, MS
NM Department of Health
1190 St. Francis Drive, Suite N1304
Santa Fe, NM 87502
Phone: **505-476-3577** ***Fax***: **505-827-0013**
E-mail: **heidi.krapfl@state.nm.us**

New York

New York State Congenital Malformations Registry (CMR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Community outreach and education
Partner: Universities, Hospitals, Early Childhood Prevention Programs, March of Dimes
Program status: Currently collecting data
Start year: 1982
Earliest year of available data: 1983
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 250,000 - 300,000
Statewide: Yes
Current legislation or rule: Public Health Law Art. 2, Title, II, Sect 225(5)(t) and Art. 2 Title I, sect 206(1)(j): Codes, Rules and Regulations,Chap 1, State Sanitary Code, part 22.3
Legislation year enacted: 1982

Case Definition

Outcomes covered: Major malformations - a detailed list is available upon request
Pregnancy outcome: Live Births (all gestational ages and birth weights)
Age: 2 years
Residence: In-state and out-of-state birth to state resident; in-state birth to nonresident; all children born in or residing in New York, up to age 2

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, 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, Specialty outpatient clinics
Other specialty facilities: Cytogenetic laboratories
Other sources: Physician reports, Cytogenetic laboratories

Case Ascertainment

Conditions warranting chart review in newborn period: Charts with major malformations - a detailed list is available upon request
Conditions warranting chart review beyond the newborn period: 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, 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.)
Database storage/management: Access, Sybase

Data Analysis

Data analysis software: SAS, Access, JAVA
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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 to other state registries/databases, Link case finding data to final birth file, Link to environmental databases

Funding

Funding Source: 13.6% General state funds, 10.2% MCH funds, 3.4% Genetic screening revenues, 50.2% CDC grant, 13.3% Other federal funding (non-CDC grants), 9.3% State Superfund

Other

Web site:
http://www.health.state.ny.us/diseases/congenital_malformations/cmrhome.htm
Surveillance reports on file: Reports for 1983-2007

Contacts

Charlotte M. Druschel, MD, MPH
New York Department of Health
Empire State Plaza - Corning Tower, Room 1203
Albany, NY 12237
Phone: **518-402-7771** ***Fax***: **518-402-7769**
E-mail: **cmd05@health.state.ny.us**

Ying Wang, PhD, MPH
New York Department of Health
Empire State Plaza - Corning Tower, Room 1203
Albany, NY 12237
Phone: 518-402-7716 *Fax*: 518-402-7723
E-mail: wxy01@health.state.ny.us

North Carolina

North Carolina Birth Defects Monitoring Program (NCBDMP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Education, Advocacy
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators
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: 122,000
Statewide: Yes
Current legislation or rule: NCGS 130A-131
Legislation year enacted: 1995

Case Definition
Outcomes covered: Major birth defects
Pregnancy outcome: Live Births (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 one year after delivery
Residence: NC resident births, in-state and out-of-state occurrence

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates
Other state based registries: Programs for children with special needs
Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any birth certificate with a birth defect box checked, 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, 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, Maternal risk factors, 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 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 storage/management: Access, Mainframe, SAS

Data Analysis
Data analysis software: SAS, Access, Various software for spatial analyses
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 investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects, advocacy

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Vital Statistics, Medicaid Paid Claims, MCH Program Data

Funding
Funding Source: 80% General state funds, 20% CDC grant

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

Contacts
Robert E. Meyer, PhD
North Carolina Center for Health Statistics
1908 Mail Service Center
Raleigh, NC, 27699-1908
Phone: **919.733.4728** ***Fax***: **919.715.4489**
E-mail: **robert.meyer@dhhs.nc.gov**

Jennifer Stock
North Carolina Center for Health Statistics
1908 Mail Service Center
Raleigh, NC, 27699-1908
Phone: 919.715.0263 *Fax*: 919.715.4489
E-mail: Jennifer.stock@dhhs.nc.gov

North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

Purpose: Surveillance
Partner: Universities, March of Dimes
Program status: Currently collecting data
Start year: 2002
Earliest year of available data: 1994
Organizational location: Department of Health (Vital Statistics), Department of Health (Maternal and Child Health), Department of Health (Children's Special Health Services)
Population covered annually: 9234
Statewide: Yes
Current legislation or rule: North Dakota Century code 23-41
Legislation year enacted: 1941

Case Definition

Outcomes covered: Selected birth defects (NTDs, congenital heart defects, cleft lip and palate, chromosomal anomalies) and other risk factors that may lead to health and developmental problems
Pregnancy outcome: Live Births (all gestational ages and birth weights, numbers collected and reported via Vital Records), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, numbers collected and reported via Vital Records), Elective Terminations (less than 20 week gestation, 20 weeks gestation and greater, numbers collected and reported via Vital Records)
Age: Newborn period
Residence: In-state resident births and out of state birth receiving services in ND

Surveillance Methods

Case ascertainment: Passive case ascertainment
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry, FAS
Delivery hospitals: Birth certificate completion
Pediatric & tertiary care hospitals: Specialty outpatient clinics
Third party payers: Medicaid databases
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked
Coding: ICD-9-CM, ICD 10

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, Maternal risk factors, 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 storage/management: Access, Mainframe, DB2, SPSS, Excel

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, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System Integration

System links: Link case finding data to final birth file
System integration: The program/system/registry is integrated with birth, death, fetal death, Medicaid claims payment and Children with Special Healthcare Needs databases.

Funding

Funding Source: 100% from the State System Development Initiative (SSDI) Grant

Other

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

Contacts

Devaiah Muthappa Muccatira, MS
ND Department of Health, Childrens Special Health Services Division
600 East Boulevard Avenue, Dept. 301
Bismarck, ND, 58505-0200
Phone: **701-328-4963** ***Fax***: **701-328-1645**
E-mail: **dmuccatira@nd.gov**

Tamara Lynn Gallup-Millner, RN, MPA
ND Department of Health, Childrens Special Health Services Division
600 East Boulevard Avenue, Dept. 301
Bismarck, ND, 58505-0200
Phone: 701-328-4814 *Fax*: 701-328-1645
E-mail: tgallupmillner@nd.gov

Ohio

Ohio Connections for Children with Special Needs (OCCSN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Title V CSHCN, Ohio Hospital Association
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: 145,000
Statewide: Yes
Current legislation or rule: Ohio Revised Code (ORC) 3705.30 - 3705.36, signed into law in July, 2000. "The Director of Health shall establish and, if funds for this purpose are available, implement a statewide birth defects information system for the collection of information concerning congenital anomalies, stillbirths, and abnormal conditions of newborns." Ohio Administrative Code (OAC) 3701-57-01 to 3701-57-04.revised 2010
Legislation year enacted: 2000

Case Definition
Outcomes covered: Major birth defects recommended by NBDPN, disorders on state newborn bloodspot panel, disorders related to infant hearing loss
Pregnancy outcome: Live Births (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 children 0 to 5 years of age seen for medical care at a hospital in Ohio; all in and out of state births and fetal deaths to state residents

Surveillance Methods
Case ascertainment: Passive case ascertainment, and passive case ascertainment with follow-up for certain disorders.
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates (20 weeks gestation and greater)
Other state based registries: Programs for children with special needs, Newborn metabolic screening program, Title V CSHCN Program data, Genetics Program Data System, Part C Early Intervention System Data, Newborn Bloodspot Screening Data
Delivery hospitals: Hospital data for medical records and billing
Pediatric & tertiary care hospitals: Hospital data for medical records and billing
Other specialty facilities: Genetic counseling/clinical genetics facilities

Case Ascertainment
Conditions warranting chart review in newborn period: Any birth certificate with a birth defect box checked, ICD-9-CM, ICD-10 (death certificates), or named congenital anomaly
Coding: ICD-9-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.)

Data Collection Methods and Storage
Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.), Reporting hospitals upload CSV flat file to secure website for integration. Low volume reporters can manually key data into user interface on secure internet site.
Database storage/management: SQL 2008 server. External system data methods and storage: ODBC connection with SAS. SAS import of other data sets and merge export of cohort line lists to MS Excel (follow-up)

Data Analysis
Data analysis software: SAS, MS Excel, FRIL
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, Observed vs. expected analyses, Epidemiologic studies (using only program data), Referral, Grant proposals, Education/public awareness, Prevention projects, IRB approved research projects

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

Funding
Funding Source: 25% Genetic screening revenues, 75% CDC grant

Other
Web site:
http://www.odh.ohio.gov/odhPrograms/cmh/bdefects/birthdefects1.aspx

Contacts
Anna Starr, BS
Ohio Department of Health
246 N. High Street
Columbus, OH, 43216-0118
Phone: **614-995-5333** ***Fax***: **614-728-9163**
E-mail: **Anna.Starr@odh.ohio.gov**

Norma Ryan, PhD
Ohio Dept. of Health
246 N. High Street
Columbus, OH, 43215
Phone: 614-752-9523 *Fax*: 614-564-2504
E-mail: Norma.Ryan@odh.ohio.gov

Richard Thomas, MPH
Birth Defects Epidemiologist
Ohio Department of Health
Center for Public Health Statistics & Informatics
246 N. High Street
Columbus, Ohio 43215
Phone: 614-466-0269
E-mail: Richard.Thomas@odh.ohio.gov

Oklahoma

Oklahoma Birth Defects Registry (OBDR)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators, Cytogenetics/ & Medical Genetics
Program status: Currently collecting data
Start year: 1992; statewide 1994
Earliest year of available data: 1992; 1994 statewide
Organizational location: Department of Health (Prevention and Preparedness)
Population covered annually: 55,000
Statewide: Yes
Current legislation or rule: 63 O.S. Section 1-550.2
Legislation year enacted: 1992

Case Definition

Outcomes covered: Modified 6-digit ICD-9-CM codes for birth defects and genetic diseases (CDC/BPA)
Pregnancy outcome: Live Births (≥ 20 weeks gestation), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective Terminations (20 weeks gestation and greater)
Age: 2 years
Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Other state based registries: 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, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics
Midwifery facilities: Midwifery facilities
Third party payers: Indian health services, military hospitals delivering babies
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code
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.), 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, Maternal risk factors, 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
Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access, ArcView GIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Timeliness, editing of all completed abstracts
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, program quality assurance

Funding

Funding Source: 13% General state funds, 57% MC funds, 30% CDC grant

Other

Web site:
http://www.ok.gov/health/Child_and_Family_Health/Screening,_and_Special_Services/

Contacts

Sharon Vaz, MS
Oklahoma State Department of Health; Screening and Special Services
1000 NE 10th Street, Room 709
Oklahoma City, OK, 73117-1299
Phone: **405-271-6617** ***Fax***: **405-271-4892**
E-mail: **SharonAV@health.ok.gov**

Oregon

Birth Anomalies Registry (BAR)

Purpose: Surveillance
Partner: Environmental Agencies/Organizations, Advocacy Groups, Legislators
Program status: Program has not started collecting data yet
Start year: 2012?
Earliest year of available data: 2010?
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 49,000
Statewide: Yes
Current legislation or rule: None

Case Definition
Outcomes covered: EPHT-12 (Anencephalus, Spina bifida without anencephalus, Transposition of great arteries, Tetralogy of Fallot, Hypoplastic left heart syndrome, Cleft lip with and without cleft palate, Cleft palate without cleft lip, Upper limb defect, Lower limb defect, Gastroschisis, Down syndrome, Hypospadias)
Pregnancy outcome: Live Births (all gestational ages and birth weights)
Age: 0-1 now
Residence: In-state births to state residents?

Surveillance Methods
Case ascertainment: Link birth certificate to hospital discharge dataset
Vital Records: Birth certificates
Delivery hospitals: Discharge summaries, Dataset of all state hospital discharges
Pediatric & tertiary care hospitals: Discharge summaries

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

Data Analysis
Data use and analysis: Routine statistical monitoring

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

Funding
Funding Source: 20% MCH funds, 80% EPHT

Contacts
Kenneth D. Rosenberg, MD, MPH
Oregon Public Health Division
800 NE Oregon Street, Suite 850
Portland, OR, 97232
Phone: **971-673-0237** ***Fax***: **971-673-0240**
E-mail: **ken.d.rosenberg@state.or.us**

Pennsylvania

Pennsylvania Birth Defects Surveillance Database

Program status: No surveillance program

Contacts
Ronald A. Tringali, PhD
PA Department of Health, Bureau of Epidemiology
933 Health & Welfare Building, Commonwealth Avenue & Forster Street
Harrisburg, PA, 17120
Phone: **(717) 787-3350** ***Fax***: **(717) 772-6975**
E-mail: **rtringali@pa.gov**

Puerto Rico

Puerto Rico Birth Defects Surveillance and Prevention System (PRBDSS)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 45,000
Statewide: Yes
Current legislation or rule: Yes, Law 351
Legislation year enacted: September 16th, 2004

Case Definition
Outcomes covered: Selected birth defects - neural tube defects, cleft lip and/or cleft palate, talipes equinovarus, limb defects, ventral wall defects, ambiguous genitalia, trisomy 13, 18 and 21, albinism, congenital heart defects, hipos/epispadias, Jarcho-Levin syndrome, anotia, microtia, anophthalmia, microphthalmia and bladder extrophy.
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages), Elective Terminations (all gestational ages)
Age: Up to 6 years after delivery
Residence: In-state birth to state residents

Surveillance Methods
Case ascertainment: Active case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs
Third party payers: Medicaid databases, Health maintenance organization (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 a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, 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, Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: 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, 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.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access

Data Analysis
Data analysis software: SPSS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, 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 investigation, Time trends, Time-space cluster 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

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

Other
Web site: http://www.salud.gov.pr
Surveillance reports on file: PR Birth Defects Databook 2012

Contacts
Mónica R. Castellano Vega, MS
Puerto Rico Birth Defects Surveillance and Prevention System, PR Department of Health
PO Box 70184
San Juan, PR, 00936
Phone: **787-765-2929 X-4571** ***Fax***: **787-764-4259**
E-mail: **mocastellano@salud.gov.pr**

Rhode Island

Rhode Island Birth Defects Program

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention
Partner: Universities, Hospitals, Community Nursing Services, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, families
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 1997
Organizational location: Department of Health (Center for Health Data and Analysis)
Population covered annually: 11,000
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: Major birth defects and genetic diseases
Pregnancy outcome: Live Births (all gestational ages and birth weights), Elective Terminations (20 weeks gestation and greater)
Age: Birth-4 years
Residence: RI residents

Surveillance Methods

Case ascertainment: Active 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 9 programs including: Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting and Vital Records
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 genetics facilities, Maternal serum screening facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Chart reviews are conducted for infants born at the regional perinatal center and 3 community hospitals (represents 90% of newborns with birth defects) who were identified with an ICD-9 code 740-759 and other sentinel conditions
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: 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, Maternal risk factors, 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 storage/management: 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, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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 to KIDSNET (Newborn Developmental Risk Screening; Universal Newborn Hearing; Newborn Bloodspot Screening; Early Intervention; Immunization; Lead Poisoning; WIC; Home Visiting; and Vital Records); hospital discharge database
System integration: Integrated into KIDSNET for web-based provider reporting

Funding

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

Other

Web site: http://www.health.ri.gov/family/birthdefects/index.php
Surveillance reports on file: 2010 Rhode Island Birth Defects Data Book
Comments: Chart reviews are also conducted for ICD-9-CM codes 740-759 and other sentinel conditions after the newborn period from sources such as, genetics counseling and testing centers.

Contacts

Samara Viner-Brown, MS
Rhode Island Department of Health
3 Capitol Hill, Room 407
Providence, RI, 02908-5097
Phone: **401-222-5122** ***Fax***: **401-222-4415**
E-mail: **Samara.Viner-Brown@health.ri.gov**

William Arias, MPH
Rhode Island Department of Health
3 Capitol Hill, Room 407
Providence, RI, 02908
Phone: 401-222-7930 *Fax*: 401-222-4415
E-mail: william.arias@health.ri.gov

South Carolina

South Carolina Birth Defects Program (SCBDP)

Purpose: Surveillance, Research, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Greenwood Genetic 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: Via GGC, for 3 categories of defects, since 1993
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 60,682
Statewide: Yes
Current legislation or rule: A281,R308,H4115
Legislation year enacted: 2004

Case Definition
Outcomes covered: Neural tube defects, cardiovascular defects, musculoskeletal defects, orofacial clefts
Pregnancy outcome: Live Births (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: Currently monitoring in-state births to persons residing in South Carolina

Surveillance Methods
Case ascertainment: Active case ascertainment
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Elective termination certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, Autopsy
Delivery hospitals: Disease index or discharge index, Discharge summaries, Postmortem/pathology logs, ICD-9 codes
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICD-9 codes
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), birth certificate with neural tube defect box checked, All stillborn infants, All elective abortions, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: 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

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 storage/management: Access

Data Analysis
Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, 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 case finding data to final birth file, Link to environmental databases, SC Vital Records
System integration: SC Vital Records

Funding
Funding Source: 100% General state funds

Contacts
Brenda Martin, MN
SC Birth Defects Program, SC Dept of Health & Environmental Control
1751 Calhoun St.
Columbia, SC, 29201
Phone: **803-898-3780** ***Fax***: **803-898-2065**
E-mail: **martinby@dhec.sc.gov**

Kimberly Jenkins, BSN
SC DHEC
1751 Calhoun Street
Columbia, SC, 29201
Phone: 803-360-1039 *Fax*: 803-898-2065
E-mail: jenkinka@dhec.sc.gov

South Dakota

Program status: No surveillance program

Contacts
Darlene Bergeleen, BS, RN
SD Dept Health
600 E. Capitol Ave.
Pierre, SD, 57501
Phone: **605-773-3737** ***Fax***: **605-773-5683**
E-mail: **darlene.bergeleen@state.sd.us**

Tennessee

Tennessee Birth Defects Registry (TBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Local Health Departments, Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 2000
Earliest year of available data: 1999
Organizational location: Department of Health (Division of Policy, Planning & Analysis)
Population covered annually: 85,000
Statewide: Yes
Current legislation or rule: TCA 68-5-506
Legislation year enacted: 2000

Case Definition

Outcomes covered: 45 major structural birth defects
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (500 grams or more, or in the absence of weight, 22 completed weeks of gestation or more)
Age: Up to one year after delivery
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based, Hospital based, Active medical record reviews at five regional perinatal center hospitals.
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates
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, 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, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., congenital heart disease, musculoskeletal defects, Chromosomal anomalies), All stillborn infants, ICD-9-CM code 760.71
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: 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, Maternal risk factors
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 storage/management: Access, SQL Server

Data Analysis

Data analysis software: SAS, Access, SQL Server, Arc-GIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Education/public awareness, Prevention projects

System Integration

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

Funding

Funding Source: 100% General state funds

Other

Web site: http://hit.state.tn.us/Reports.aspx
Surveillance reports on file: Tennessee Birth Defects Registry 2004-2008

Contacts

David J. Law, Ph.D.
TN Dept. of Health - PPA
425 Fifth Avenue North, 6th Flr.
Nashville, TN, 37247
Phone: **615-253-4702** ***Fax***: **615-253-1688**
E-mail: **david.law@tn.gov**

Texas

Texas Birth Defects Epidemiology and Surveillance Branch (TBDES)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Universities, Hospitals, Advocacy Groups
Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 401,599 in 2009
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: Live Births (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 - FAS up to 6 years
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based
Vital Records: We are now using fetal death certificates (2009+) to aid in 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, genetics logs, stillbirth logs, 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 logs, radiology logs
Midwifery facilities: Midwifery facilities
Other sources: Licensed birthing centers, reference labs

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Infants with low birth weight or low gestation (<34 weeks GA), All stillborn infants
Conditions warranting chart review beyond the newborn period: CNS condition (e.g., seizure), GI condition (e.g., recurrent 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 diagnostic information, Pregnancy/delivery complications, Family history, Prenatal care
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
Database storage/management: SQL Server migrating to Oracle in Fall 2012.

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness, Re-casefinding, Re-review of medical records
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, Link to environmental databases, link registry to vital records for demographic data, special projects linking to other files (Texas Health Data for geocodes, Newborn Screening data)

Funding

Funding Source: 46% General state funds, 54% MCH funds * Note: does not include CDC-funded Texas Birth Defects Research Center funds

Other

Web site: www.dshs.state.tx.us/birthdefects/
Comments: In order to maintain efficiency with increasing workloads; we stopped the routine review and abstraction of mother's medical records (we still occasionally abstract specific information from the mother's record when it's needed and can't be found elsewhere) and that change only applies to live born cases (we still routinely review and abstract information from mother's medical records for other pregnancy outcomes).

Contacts

Mark A. Canfield, PhD
Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services
P.O. Box 149347, Mail code 1964
Austin, TX, 78714-9347
Phone: **512-776-7232** ***Fax***: **512-776-7330**
E-mail: **mark.canfield@dshs.state.tx.us**

Lisa K. Marengo, MS
Birth Defects Epidemiology and Surveillance Branch
Texas Department of State Health Services
P.O. Box 149347, Mail code 1964
Austin, TX, 78714-9347
Phone: 512-776-6657 *Fax*: 512-776-7330
E-mail: lisa.marengo@dshs.state.tx.us

Utah

Utah Birth Defect Network (UBDN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention, Education
Partner: Universities, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Legislators
Program status: Currently collecting data
Start year: 1994
Earliest year of available data: 1994
Organizational location: Department of Health (CSHCN), University of Utah
Population covered annually: 55,000
Statewide: Yes
Current legislation or rule: Birth Defect Rule (R398-5)
Legislation year enacted: 1999

Case Definition

Outcomes covered: Major structural malformations; newborn metabolic conditions; stillbirths
Pregnancy outcome: Live Births (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: Maternal residence in Utah at time of delivery

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Fetal birth certificate
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, 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, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Midwifery facilities: Midwifery facilities
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetics facilities
Other sources: Physician reports, lay midwives

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, all fetal deaths 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, Maternal risk factors, 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.)
Database storage/management: Access

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, Logical checks, Duplicate check in tracking and surveillance module, Case record form checked for completeness, Timeliness through system, Manual review of subset of surveillance module case data compared to case record form.
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

System Integration

System links: Link to environmental databases, Link to Utah genealogic population database

Funding

Funding Source: 82% General state funds, 18% Other federal funding (non-CDC grants), CDC-EHTP

Other

Web site: http://www.health.utah.gov/birthdefect/
Surveillance reports on file: http://ibis.health.utah.gov/
Additional information on file: Scientific Collaboration Protocol
Comments: IBIS indicators for specific birth defects are on-line.

Contacts

Marcia Lynn Feldkamp, PhD
Utah Birth Defect Network
44 N Mario Capecchi Drive, P.O. Box 144699
Salt Lake City, UT, 84114-4699
Phone: **801-584-8490** ***Fax***: **801-883-4668**
E-mail: **Marcia.feldkamp@hsc.utah.edu**

Amy E. Nance, MPH
Utah Birth Defect Network
44 N Mario Capecchi Drive, P.O. Box 144699
Salt Lake City, UT, 84114-4699
Phone: 801-883-4661 *Fax*: 801-883-4668
E-mail: aenance@utah.gov

Vermont

Birth Information Network (BIN)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention, Prevention education
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups, Vermont Department of Financial Regulation, VT Association of Hospitals and Health Systems.
Program status: Currently collecting data
Start year: 2006
Earliest year of available data: 2006
Organizational location: Department of Health (Statistics)
Population covered annually: 6,500
Statewide: Yes
Current legislation or rule: Act 32 (TITLE 18 VSA §5087)
Legislation year enacted: 2003

Case Definition

Outcomes covered: Major birth defects and genetic diseases, very low birth weight (less than 1500 grams), hearing loss
Pregnancy outcome: Live Births (all gestational ages and birth weights)
Age: Up to one year after delivery
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Discharge summaries, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Third party payers: Medicaid databases
Other sources: Physician reports from offices and clinics associated with Tertiary Care Hospital, Autopsy reports from Office of the Chief Medical Examiner

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM

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, Maternal risk factors
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 storage/management: Access

Data Analysis

Data analysis software: SPSS, Access, Excel
Quality assurance: Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Monitoring outbreaks and cluster investigation, Observed vs. expected analyses, Referral, Grant proposals, Prevention projects, Education/public awareness

System Integration

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

Funding

Funding Source: 100% CDC grant

Contacts

Peggy Brozicevic
Vermont Department of Health
P.O. Box 70, 108 Cherry Street
Burlington, VT, 05402
Phone: **802-863-7298** ***Fax***: **802-865-7701**
E-mail: **peggy.brozicevic@state.vt.us**

Brennan Martin
Vermont Department of Health
P.O. Box 70, 108 Cherry Street
Burlington, VT, 05402
Phone: 802-863-7611 *Fax*: 802-865-7701
E-mail: brennan.martin@state.vt.us

Virginia

Virginia Congenital Anomalies Reporting and Education System (VACARES)

Purpose: Surveillance, Research, Referral to Services
Partner: Universities, Hospitals, Children with Special Health Care Needs, Care Connection for Children Network
Program status: Currently collecting data
Start year: 1985
Earliest year of available data: 1987
Organizational location: Department of Health (Division of Child and Family Health, Child Health Programs, Genetics and Newborn Screening)
Population covered annually: 101,202
Statewide: Yes
Current legislation or rule: Health Law 32.1-69.1,-69.1:1,-69.2
Legislation year enacted: 1985, ammended 1986, 1988, 2006

Case Definition

Outcomes covered: Major birth defects and genetic diseases
Pregnancy outcome: Live Births (all gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (all gestational ages, only for the Neural tube defect and Trisomy cases requested)
Age: Below 24 months of age
Residence: All in state births; Out of state births hospitalized in state up to 24 months of age with reportable birth defect

Surveillance Methods

Case ascertainment: Passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery hospitals: Discharge summaries, Medical records abstracts codes from charts
Pediatric & tertiary care hospitals: Discharge summaries
Other specialty facilities: Genetic counseling/clinical genetics facilities

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All neonatal deaths, Chart review done by the coders in Health Information Management
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM, ICD-10 for death certificate

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 submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Oracle

Data Analysis

Data analysis software: SAS, Access
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, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases
System integration: Virginia birth defects registry data (VaCARES) are reported by hospitals to the state health department via the Virginia Infant Screening and Infant Tracking System (VISITS II), which is a Web-based integrated data tracking and management system. VISITS II is a component of the Virginia Vital Events and Screening Tracking System (VVESTS), which also includes the Virginia electronic birth certificate and Virginia Early Hearing Detection and Intervention Program databases.

Funding

Funding Source: 100% MCH funds

Other

Web site: http://www.vahealth.org/gns/vaCares.htm
Surveillance reports on file: Virginia Congenital Anomalies Reporting and Education System: Birth Defect Surveillance Data 1989-1998 available on Web site.
Additional information on file: Family Brochure and Parent Fact Sheets (English and Spanish) available on Web site.

Contacts

Kathleen Moline, BSN, MA
Division of Child and Family Health, Office of Family Health Services, Virginia Department of Health
109 Governor Street, 8th Floor
Richmond, VA, 23219
Phone: **804-864-7712** ***Fax***: **804-864-7721**
E-mail: **kathleen.moline@vdh.virginia.gov**

Joanne Boise
Division of Child and Family Health, Virginia Department of Health
109 Governor Street, 8th Floor
Richmond, VA, 23219
Phone: 804-864-7688 *Fax*: 804-864-7721
E-mail: Joanne.boise@vdh.virginia.gov

Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: Surveillance, Referral to Services
Partner: Universities, Hospitals, Environmental Agencies/Organizations
Program status: Currently collecting data
Start year: 1986- Active and 1991- Passive
Earliest year of available data: 1987
Organizational location: Department of Health (Office of Healthy Communities, Surveillance & Evaluation)
Population covered annually: 90,000
Statewide: Yes
Current legislation or rule: Notifiable Conditions: WAC 246-101
Legislation year enacted: 2000

Case Definition

Outcomes covered: From 1987 to 1991 (active surveillance), and from 1991 to the 2000 (passive surveillance), the cases reportable to the Birth Defects Registry included those with ICD-9-CM codes 740-759, selected primary cancers, selected metabolic conditions, and FAS/FAE. Since the adoption of the Notifiable Conditions law in 2000, conditions subject to mandatory reporting are neural tube defects, orofacial clefts, limb deficiencies, abdominal wall defects, hypospadias/epispadias and Down Syndrome. FAS/FAE, Cerebral Palsy and Autism are designated as reportable with systems being established to ascertain cases outside the hospital setting.
Pregnancy outcome: Live Births (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 ten for FAS/FAE, Cerebral Palsy and Autism.
Residence: Resident births; children born, diagnosed or treated in-state

Surveillance Methods

Case ascertainment: Passive case ascertainment
Vital Records: Birth certificates, Fetal death certificates
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
Other sources: University-based FAS/FAE and Autism specialty centers

Case Ascertainment

Coding: ICD-9-CM, ICD-9-CM, FAS/FAE coding scheme will be utilized in data collection and case description for FAS/FAE cases

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.), Casefinding 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 storage/management: Web-based SQL server

Data Analysis

Data analysis software: SAS, Stata
Quality assurance: Validity checks, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Baseline rates, Monitoring outbreaks and cluster investigation, Time trends, Observed vs. expected analyses, Education/public awareness

System Integration

System links: Link case finding data to final birth file, CSHCN program participant file

Funding

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

Contacts

Kevin Mark Beck, MA
Washington Dept. of Health; Office of Healthy Communities, Surveillance & Evaluation
P.O. Box 47835
Olympia, WA, 98504-7835
Phone: **360-236-3492** ***Fax***: **360-236-2323**
E-mail: **kevin.beck@doh.wa.gov**

Katie Hutchinson, PhD, MSPH
Washington Dept. of Health; Office of Healthy Communities, Surveillance & Evaluation
P.O. Box 47835
Olympia, WA
Phone: 360-236-3546 *Fax*: 360-236-2323
E-mail: katie.hutchinson@doh.wa.gov

West Virginia

West Virginia Birth Defects Surveillance System Congenital Abnormalities Registry, Education and Surveillance System (CARESS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention
Partner: Universities, Hospitals, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 1989
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment), Department of Health (Vital Statistics), Department of Health (Maternal and Child Health)
Population covered annually: 21,000
Statewide: Yes
Current legislation or rule: State Statute Section 16-5-12a
Legislation year enacted: 1991Legislation updated: 2002

Case Definition
Outcomes covered: Congenital anomalies of ICD-9 codes 740-759, 760, 764, 765, 766
Pregnancy outcome: Live Births (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 ascertainment, monthly reports sent from birthing facilities across the state and reproductive outcome forms submitted by facilities and individual physicians
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificates, Elective termination certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Development Disabilities Surveillance, Cancer registry, AIDS/HIV registry, SIDS/SUID
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, Pediatric logs, Specialty outpatient clinics, physicians complete reproductive outcomes forms for those diagnosed after delivery
Other specialty facilities: Genetic counseling/clinical genetics facilities
Other sources: Physician reports, pediatric referrals of children diagnosed after delivery and discharge

Case Ascertainment
Conditions warranting chart review in newborn period: Any chart with a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (e.g., abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (less than 2500 grams or less than 37 weeks), All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Development delay, CNS condition (e.g., seizure), GI condition (e.g., recurrent 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-9-CM, ICD-10-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, 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 submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database storage/management: Access

Data Analysis
Data analysis software: Access
Quality assurance: Validity checks, 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, Plans continue to link several programs housed in the Office of Maternal, Child and Family Health.

Funding
Funding Source: Title V Block Grant funds

Other
Web site: http://www.wvdhhr.org/caress/

Contacts
Kathryn G. Cummons, MSW
Research, Evaluation and Planning
350 Capitol St.
Charleston, WV, 25301
Phone: **304-558-5388** ***Fax***: **304-558-3510**
E-mail: **kathy.g.cummons@wv.gov**

Melissa A. Baker, MA
OMCFH
350 Capitol St.
Charleston, WV, 25301
Phone: 304-356-4438 *Fax*: 304-558-3510
E-mail: melissa.a.baker@wv.gov

Wisconsin

Wisconsin Birth Defects Registry (WBDR)

Purpose: Surveillance, Research, Referral to Services
Partner: Local Health Departments, Universities, Hospitals, Environmental Agencies/Organizations, Early Childhood Prevention Programs, Advocacy Groups
Program status: Currently collecting data
Start year: 2004
Earliest year of available data: 2004
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: ~69,000
Statewide: Yes
Current legislation or rule: Wisconsin Statutes 253.12
Rules: ***HFS 116***--Took effect April 1, 2003
Legislation year enacted: 2000

Case Definition
Outcomes covered: Structural malformations, deformations, disruptions, or dysplasias; genetic, inherited, or biochemical diseases.
Pregnancy outcome: Live Births (20 weeks gestational age or greater), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Birth to 2 years
Residence: Statute mandates reporting of birth defects diagnosed or treated in Wisconsin regardless of residence status

Surveillance Methods
Case ascertainment: Passive case ascertainment, Population based
Delivery hospitals: Case reports from nursery managers
Pediatric & tertiary care hospitals: case reports from pediatric specialty clinics
Midwifery facilities: Midwifery facilities
Third party payers: Health maintenance organization (HMOs)
Other specialty facilities: Genetic counseling/clinical genetics facilities
Other sources: Physician reports

Case Ascertainment
Coding: Wisconsin codes assigned to a specific list of birth defects crosswalked to ICD-9-CM where possible

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

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Organizations can report by uploading multiple records from their electronic patient records system to the WBDR secure website.
Database storage/management: Oracle

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, Rates by demographic and other variables, Monitoring outbreaks and cluster investigation, 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, Prevention projects

System Integration
System links: Legislation currently prohibits data linkage.

Funding
Funding Source: MCH Block grant - staffing and Birth Record/Certificate fees - Registry/Program

Other
Web site: https://phin.wisconsin.gov/wbdr/index.html
Surveillance reports on file:
http://www.dhs.wisconsin.gov/health/children/birthdefects/index.htm
Comments: We have stopped printing reports as of 2008 and instead post them to our website.

Contacts
Elizabeth Oftedahl, MPH
Division of Public Health, Department of Health and Family Services
1 West Wilson, PO Box 2659
Madison, WI, 53701
Phone: **608-261-9304** ***Fax***: **608-267-3824**
E-mail: **Elizabeth.Oftedahl@dhs.wisconsin.gov**

Peggy Helm-Quest, MSEd, MHA, CHES
Division of Public Health, Department of Health and Family Services
1 West Wilson, PO Box 2659
Madison, WI, 53701
Phone: 608-267-2945 *Fax*: 608-267-382
E-mail: Peggy.HelmQuest@dhs.wisconsin.gov

Wyoming

Program status: Interested in developing a surveillance program
Wyoming plans to have birth defects surveillance data in 2012.

Contacts
Amy Spieker, MPH
Wyoming Department of Health
6101 Yellowstone Rd, Ste 420
Cheyenne, WY, 82002
Phone: **307-777-5769** ***Fax***: **307-777-8687**
E-mail: **amy.spieker@wyo.gov**

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

US Department of Defense

United States Department of Defense (DoD) Birth and Infant Health Registry

Purpose: Surveillance, Research
Partner: Universities, Hospitals, Other DoD Programs
Program status: Currently collecting data
Start year: 1998
Earliest year of available data: 1998
Organizational location: Deployment Health Research Department, Naval Health Research Center, San Diego, CA
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: Live Births (all gestational ages and birth weights)
Age: Birth to 1 year
Residence: Worldwide; any birth to a US military beneficiary.

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based, electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries.
Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, all inpatient and outpatient encounters 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 are captured in standardized DoD data.
Third party payers: All inpatient and outpatient encounters 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 a ICD9-CM code 740-759, Any chart with a selected list of ICD9-CM codes outside 740-759, 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-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.), 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 storage/management: 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, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Prevention projects

System Integration

System links: DoD databases
System integration: DoD databases

Funding

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

Other

Web site: http://www.med.navy.mil/sites/nhrc/Pages/Department164.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: **619-767-4489** ***Fax***: **619-767-4806**
E-mail: **ava.conlin@med.navy.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
E-mail: NHRC-birthregistry@med.navy.mil