

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Alabama (selected counties) and US

Defects	Alabama [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	5	2.41	1,009	2.51
Spina bifida without anencephalus	6	3.04	1,477	3.68
Cardiovascular				
Transposition of great arteries	5	2.83	1,901	4.73
Tetralogy of Fallot	7	3.67	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	11	5.56	1,748	4.36
Hypoplastic left heart syndrome	3	1.57	975	2.43
Orofacial				
Cleft lip with and without cleft palate	18	9.54	4,209	10.47
Cleft palate without cleft lip	16	8.60	2,567	6.39
Musculoskeletal				
Upper limb defect	8	4.30	1,521	3.79
Lower limb defect	4	1.89	763	1.90
Gastroschisis	4	1.89	1,497	3.73
Chromosomal				
Down syndrome	24	12.79	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Alabama's Birth Defect Surveillance System

The Alabama Birth Defects Surveillance and Prevention Program (ABDSPP) has conducted population based active surveillance since 1998. Currently, the surveillance area covers 22 counties (approximately 32% of the state's births). We are unique in that we are a voluntary system. The surveillance is sustained by partnerships with state public and mental health and mental retardation agencies and support from a major university.

Program information:

Wladimir Wertelecki, MD
Alabama Birth Defects Surveillance and Prevention Program
E-mail: wwertele@usouthal.edu

Peg Hilliard, BSN
Alabama Birth Defects Surveillance and Prevention Program
E-mail: philliard@usouthal.edu

Website: www.usouthal.edu/genetics/index/html

How birth defects data are used in Alabama

The data collected is used to produce yearly reports on the prevalence of birth defects, and to provide data to national and international birth defects projects on the causes of birth defects and their prevention. The surveillance also links families to early intervention and health care services and conducts educational programs for professionals and the community.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Alaska and US

Defects	Alaska [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	0	0	1,009	2.51
Spina bifida without anencephalus	4	3.96	1,477	3.68
Cardiovascular				
Transposition of great arteries	5	5.15	1,901	4.73
Tetralogy of Fallot	7	7.13	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	5	5.35	1,748	4.36
Hypoplastic left heart syndrome	3	3.37	975	2.43
Orofacial				
Cleft lip with and without cleft palate	16	16.04	4,209	10.47
Cleft palate without cleft lip	15	14.66	2,567	6.39
Musculoskeletal				
Upper limb defect	2	1.58	1,521	3.79
Lower limb defect	4	4.16	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	17	17.23	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Program information:

Sandra Collins, MPH
 Alaska Birth Defects Registry (ABDR)
 E-mail: Sandra.Collins@alaska.gov
 Website: www.epi.alaska.gov/mcheppi/ABDR

Alaska's Birth Defect Surveillance System

Since 1996 the Alaska Birth Defects Registry (ABDR) has monitored the statewide prevalence of birth defects. Alaska uses passive surveillance methodology. Medical providers identify birth defects for children up to the age of six years and report them to the registry. Reportable birth defects in Alaska include all major congenital anomalies as well as fetal alcohol spectrum disorders (FASD) for which we routinely conduct case verification studies.

How birth defects data are used in Alaska

The ABDR has monitored over 130,000 births and has information on approximately 30,000 children born with birth defects. Data are used to provide counts and prevalence estimates for birth defects occurring in Alaska. This data is used by agencies statewide to target prevention messages, interventions and health care services; define populations at increased risk for birth defects; and identify clusters of conditions that may be related to environmental exposures. Data is published periodically and is posted on our website.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Arizona and US

Defects	Arizona		US [†]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	16 [†]	1.78	1,009	2.51
Spina bifida without anencephalus	34 [†]	3.84	1,477	3.68
Cardiovascular				
Transposition of great arteries	34 [§]	3.73	1,901	4.73
Tetralogy of Fallot	33 [§]	3.67	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	33 [§]	3.67	1,748	4.36
Hypoplastic left heart syndrome	15 [§]	1.59	975	2.43
Orofacial				
Cleft lip with and without cleft palate	96 [†]	10.86	4,209	10.47
Cleft palate without cleft lip	54 [†]	6.11	2,567	6.39
Musculoskeletal				
Upper limb defect	24 [§]	2.58	1,521	3.79
Lower limb defect	9 [§]	0.99	763	1.90
Gastroschisis	34 [†]	3.87	1,497	3.73
Chromosomal				
Down syndrome	73 [†]	8.28	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2004

[§] estimates based on pooled data from birth years 2003-2004

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Arizona's Birth Defect Monitoring Program

Since 1986 the Arizona program has monitored the prevalence of major birth defects among Arizona infants in all 15 counties. Arizona Department of Health Services staff obtain this information by visiting all Arizona hospitals and selected clinics. A rapid reporting system provides current information on neural tube defects, cleft lip/palate, and gastroschisis within 6 months of birth. Duplicate records are merged and the data used to generate summary reports. The program operates through state funds and federal grant monies.

How birth defects data are used in Arizona

Data are used for birth defects prevention activities and improving access to health services through partnerships, publications, dissemination of reports, community awareness, and educational activities. The program monitors the state trend of spina bifida, which is often preventable by consuming the vitamin folic acid before conception. The goal of the rapid reporting system is to provide families of living children with information and resources for follow-up medical and social services.

Program information:

Timothy J. Flood, MD
Arizona Birth Defects Monitoring Program (ABDMP)
E-mail: floodt@azdhs.gov

Viral G. Joshi, MPH
Arizona Birth Defects Monitoring Program (ABDMP)
E-mail: viral.joshi@azdhs.gov

Website: <http://www.azdhs.gov/phs/phstats/bdr/index.htm>

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Arkansas and US

Defects	Arkansas [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	12	3.16	1,009	2.51
Spina bifida without anencephalus	15	4.01	1,477	3.68
Cardiovascular				
Transposition of great arteries	22	5.70	1,901	4.73
Tetralogy of Fallot	12	3.22	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	10	2.74	1,748	4.36
Hypoplastic left heart syndrome	10	2.64	975	2.43
Orofacial				
Cleft lip with and without cleft palate	47	12.39	4,209	10.47
Cleft palate without cleft lip	24	6.33	2,567	6.39
Musculoskeletal				
Upper limb defect	14	3.69	1,521	3.79
Lower limb defect	9	2.43	763	1.90
Gastroschisis	21	5.64	1,497	3.73
Chromosomal				
Down syndrome	46	11.92	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Program information:

Bridget S. Mosley, MPH
 Arkansas Reproductive Health Monitoring System
 E-mail: MosleyBridgetS@uams.edu

Charlotte A. Hobbs, MD, PhD
 Arkansas Center for Birth Defects Research and Prevention
 E-mail : HobbsCharlotte@uams.edu

Website: <http://arbirthdefectsresearch.uams.edu/>

Arkansas’s Birth Defect Surveillance System

Since 1980, the Arkansas Reproductive Health Monitoring System (ARHMS) has monitored the occurrence of birth defects within the state. Using state-wide, active surveillance methods, ARHMS gathers information on more than 200 adverse birth conditions affecting Arkansas residents. Rates of these conditions are computed for the state and closely monitored by public health professionals. ARHMS responds to community and individual requests regarding information on birth defects. ARHMS serves as a lead agency on birth defect prevention activities, including folic acid education among the healthcare provider and childbearing populations.

How birth defects data are used in Arkansas

Data derived from ARHMS allow researchers to identify trends and patterns in the prevalence of birth defects in the state. These ARHMS data provide the basis of the research studies investigating the causes of birth defects. ARHMS data also serve as a tool to evaluate the impact of prevention programs.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Colorado and US

Defects	Colorado [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	9	1.32	1,009	2.51
Spina bifida without anencephalus	23	3.42	1,477	3.68
Cardiovascular				
Transposition of great arteries	27	3.95	1,901	4.73
Tetralogy of Fallot	25	3.62	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	29	4.30	1,748	4.36
Hypoplastic left heart syndrome	23	3.36	975	2.43
Orofacial				
Cleft lip with and without cleft palate	83	12.10	4,209	10.47
Cleft palate without cleft lip	65	9.44	2,567	6.39
Musculoskeletal				
Upper limb defect	26	3.80	1,521	3.79
Lower limb defect	13	1.96	763	1.90
Gastroschisis	30	4.36	1,497	3.73
Chromosomal				
Down syndrome	139	20.34	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Program information:

Margaret Frances Ruttenber, MSPH
 Colorado Responds to Children with Special Needs
 E-mail: margaret.ruttenber@state.co.us

Carol Stanton, MBA
 Colorado Responds to Children with Special Needs
 E-mail: carol.stanton@state.co.us

Website: <http://www.cdphe.state.co.us>

Colorado's Birth Defect Surveillance System

Case ascertainment: combination of active and passive case ascertainment

Vital records: birth certificates, death certificates, and 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.

How birth defects data are used in Colorado

Routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, monitoring outbreaks and cluster investigation, time trends, capture-recapture analysis, observed vs. expected analysis, epidemiologic studies.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Connecticut and US

Defects	Connecticut [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	<1	0.12	1,009	2.51
Spina bifida without anencephalus	12	2.89	1,477	3.68
Cardiovascular				
Transposition of great arteries	16	3.66	1,901	4.73
Tetralogy of Fallot	17	4.07	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	13	3.07	1,748	4.36
Hypoplastic left heart syndrome	8	1.77	975	2.43
Orofacial				
Cleft lip with and without cleft palate	21	5.02	4,209	10.47
Cleft palate without cleft lip	21	4.96	2,567	6.39
Musculoskeletal				
Upper limb defect	5	1.18	1,521	3.79
Lower limb defect	2	0.47	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	58	13.57	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2004

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Connecticut’s Birth Defect Surveillance System

The Connecticut Birth Defects Registry collects information on birth defects through various sources of data, including reporting from birth hospitals across the state, vital records, and hospital discharge data. The surveillance activities will provide useful statistical information to health care professionals, researchers, and policy makers. Reporting of birth defects to the Registry is mandatory under the Connecticut State Statutes Sec. 19a-53, 19a-54 and 19a-56a.

How birth defects data are used in Connecticut

The mission of the Connecticut Birth Defects Registry is to:

1. Maintain statewide surveillance through collecting information on birth defect incidence in Connecticut;
2. Monitor trends and patterns in birth defect statistics;
3. Conduct research studies to identify risk factors for birth defects; and
4. Promote education activities for the prevention of birth defects.

Program information:

Karin Davis, BS
 Connecticut Birth Defects Registry (CTBDR)
 E-mail: Karin.Davis@ct.gov

Website:
<http://www.ct.gov/dph/cwp/view.asp?a=3138&pm=1&Q=396758>

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Florida and US

Defects	Florida [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	10	0.45	1,009	2.51
Spina bifida without anencephalus	68	3.21	1,477	3.68
Cardiovascular				
Transposition of great arteries	96	4.52	1,901	4.73
Tetralogy of Fallot	114	5.36	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	90	4.24	1,748	4.36
Hypoplastic left heart syndrome	59	2.76	975	2.43
Orofacial				
Cleft lip with and without cleft palate	178	8.35	4,209	10.47
Cleft palate without cleft lip	109	5.10	2,567	6.39
Musculoskeletal				
Upper limb defect	37	1.73	1,521	3.79
Lower limb defect	28	1.33	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	283	13.29	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Florida's Birth Defect Surveillance System

Since 1999, The Florida Birth Defects Registry has monitored the prevalence of birth defects in Florida. The Registry is a statewide, population-based passive surveillance program with information on more than 55,000 infants born with serious birth defects. The registry was established to identify and describe the patterns of birth defects in Florida and to respond to community concerns about possible environmental associations.

How birth defects data are used in Florida

Through multiple sources of information, the Registry monitors all births in Florida to identify risk factors, develop prevention and intervention programs, investigate causes, promote scientific research and collaboration and assist families with referral to services. Registry data on the occurrence of neural tube defects was used to obtain funding for the purchase of multi-vitamins containing folic acid for distribution to minority and underserved women.

Program information:

Jane A. Correia, BS
 Florida Birth Defects Registry (FBDR)
 E-mail: Jane_Correia@doh.state.fl.us

Sharon Watkins, PhD
 Florida Birth Defects Registry (FBDR)
 E-mail: Sharon_Watkins@doh.state.fl.us

Website: www.fbdr.org

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Georgia (metropolitan Atlanta 5-county area) and US

Defects	Georgia [†] (metro-Atlanta area)		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	11	2.19	1,009	2.51
Spina bifida without anencephalus	20	3.94	1,477	3.68
Cardiovascular				
Transposition of great arteries	26	5.11	1,901	4.73
Tetralogy of Fallot	22	4.25	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	23	4.57	1,748	4.36
Hypoplastic left heart syndrome	12	2.34	975	2.43
Orofacial				
Cleft lip with and without cleft palate	45	8.89	4,209	10.47
Cleft palate without cleft lip	31	6.09	2,567	6.39
Musculoskeletal				
Upper limb defect	15	3.69	1,521	3.79
Lower limb defect	6	1.22	763	1.90
Gastroschisis	15	3.18	1,497	3.73
Chromosomal				
Down syndrome	74	14.48	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005 in 5-county area of metropolitan Atlanta

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Georgia's Birth Defect Surveillance systems

For over 40 years, the Metropolitan Atlanta Congenital Defects Program (MACDP) has monitored the prevalence of birth defects in 5 central counties in the metropolitan Atlanta area and served as a model for other state birth defect surveillance systems. The Georgia Birth Defects Reporting and Information System (GBDRIS) was recently established by the Georgia Division of Public Health to provide information on the rates and patterns of birth defects across the state.

How birth defects data are used in Georgia

MACDP has monitored over 1.1 million births and has information on over 41,000 children born with birth defects. MACDP data are used to observe unusual patterns and to detect changes in the occurrence of birth defects. These data provide the basis for research studies into the cause of birth defects and also serve to evaluate the impact of prevention programs. MACDP also partners with the GBDRIS which provides referrals to programs and health services for at-risk children.

Program information:

Janet Cragan, MD, MPH
 Metropolitan Atlanta Congenital Defects Program
 E-mail: macdp@cdc.gov
 Website: <http://www.cdc.gov/ncbddd/bd/macdp.htm>

Katherine Kahn, MPH
 Georgia Division of Public Health
 E-mail: kckahn@dhr.state.ga.us
 Website: <http://health.state.ga.us/epi/mch/birthdefects/gbdris/index.asp>

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Hawaii and US

Defects	Hawaii [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	6	3.26	1,009	2.51
Spina bifida without anencephalus	5	3.03	1,477	3.68
Cardiovascular				
Transposition of great arteries	9	4.83	1,901	4.73
Tetralogy of Fallot	6	3.37	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	3	1.80	1,748	4.36
Hypoplastic left heart syndrome	1	0.56	975	2.43
Orofacial				
Cleft lip with and without cleft palate	17	9.78	4,209	10.47
Cleft palate without cleft lip	11	6.07	2,567	6.39
Musculoskeletal				
Upper limb defect	4	2.47	1,521	3.79
Lower limb defect	2	1.35	763	1.90
Gastroschisis	8	4.49	1,497	3.73
Chromosomal				
Down syndrome	22	12.58	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Hawaii's Birth Defect Surveillance System

Since 1988, the Hawaii Birth Defects Program (HBDP) has been an accurate, complete, and timely source of statewide data on infants with specific birth defects and pregnancies resulting in adverse reproductive outcomes. It annually finds and collects demographic, diagnostic, and health risk information on 800 to 1,000 infants diagnosed with a birth defect. HBDP is now a program in the Hawaii State Department of Health.

How birth defects data are used in Hawaii

HBDP is established by state law to: 1) collect surveillance information on birth defects and other adverse reproductive outcomes; 2) report the incidence, trends, and causes of birth defects and other adverse reproductive outcomes; 3) report information for the development of prevention strategies to reduce the incidence of birth defects and other adverse reproductive outcomes; and 4) develop strategies to improve the access of children with birth defects to health and early intervention services. (H.R.S. §321-422).

Program information:

Hawaii Birth Defects Program
 Children with Special Health Needs Branch
 Hawaii State Department of Health

E-mail: hbdp.coordinator@doh.hawaii.gov

Website: <http://hawaii.gov/health/family-child-health/genetics/hbdhome.html>

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Idaho and US

Defects	Idaho [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Idaho's Birth Defect Surveillance System

Idaho updated their birth certificate in 2004 to reflect the changes made to the U.S. standard birth certificate. Idaho does not have a birth defect registry.

Program information:

Pam Harder
 Children's Special Health Program
 E-mail: harderp@dhw.idaho.gov

Mitch Scoggins
 Children's Special Health Program
 E-mail: scogginm@dhw.idaho.gov

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Illinois and US

Defects	Illinois [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	31	1.69	1,009	2.51
Spina bifida without anencephalus	52	2.86	1,477	3.68
Cardiovascular				
Transposition of great arteries	66	3.63	1,901	4.73
Tetralogy of Fallot	51	2.84	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	60	3.30	1,748	4.36
Hypoplastic left heart syndrome	33	1.81	975	2.43
Orofacial				
Cleft lip with and without cleft palate	140	7.74	4,209	10.47
Cleft palate without cleft lip	86	4.77	2,567	6.39
Musculoskeletal				
Upper limb defect	60	3.29	1,521	3.79
Lower limb defect	30	1.64	763	1.90
Gastroschisis	38	2.12	1,497	3.73
Chromosomal				
Down syndrome	234	12.91	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Illinois's Birth Defect Surveillance System

The Illinois Department of Public Health's (IDPH) Adverse Pregnancy Outcomes Reporting System (APORS) is a statewide system, established in 1986. Information is collected about children with birth defects, very-low birth weights, fetal or neonatal death, prenatal exposure to controlled substances, serious infections, disorders and conditions. This information includes demographic and medical data on infants and their mothers, as well as diagnostic and treatment information.

How birth defects data are used in Illinois

APORS' purpose is twofold. First, families of infants reported to APORS are contacted by local health department nurses to offer a series of home visits and assistance. Infants with some conditions are referred to other IDPH programs for additional follow-up. Second, the collected information is used for public health surveillance of birth defects and other adverse pregnancy outcomes to monitor the status of these conditions for reporting, policy development and research.

Program information:

Trish Wilson, MPA
 Adverse Pregnancy Outcomes Reporting System (APORS)
 E-mail: trish.wilson@illinois.gov

Jane Fornoff, D. Phil.
 Adverse Pregnancy Outcomes Reporting System (APORS)
 E-mail: jane.fornoff@illinois.gov

Web-site: www.idph.state.il.us/about/epi/apors.htm

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Indiana and US

Defects	Indiana [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	4	0.42	1,009	2.51
Spina bifida without anencephalus	34	3.95	1,477	3.68
Cardiovascular				
Transposition of great arteries	40	4.61	1,901	4.73
Tetralogy of Fallot	28	3.22	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	37	4.22	1,748	4.36
Hypoplastic left heart syndrome	17	2.00	975	2.43
Orofacial				
Cleft lip with and without cleft palate	77	8.90	4,209	10.47
Cleft palate without cleft lip	55	6.37	2,567	6.39
Musculoskeletal				
Upper limb defect	19	2.19	1,521	3.79
Lower limb defect	9	1.07	763	1.90
Gastroschisis	25	2.84	1,497	3.73
Chromosomal				
Down syndrome	93	10.75	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2003-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Indiana's Birth Defect Surveillance System

The Indiana Birth Defects and Problems Registry (IBDPR) is a population-based surveillance system that seeks to promote fetal, infant, and child health. The purpose of the Registry is to prevent birth defects and childhood developmental disabilities and to enhance the quality of life of affected Indiana residents. The 1986 Indiana General Assembly enacted a law to establish the registry. In 2001, the law was amended to allow additional data sources to be used to improve the quality of the data. IBDPR data is currently available for children born beginning in 2003.

Program information:

Courtney B. Eddy, MT (ASCP), MS
 Indiana State Department of Health
 E-mail: Ceddy@isdh.in.gov

Robert R. Bowman, MS, MA, MS
 Indiana State Department of Health
 E-mail: bobbowman@isdh.in.gov

Website: www.birthdefects.in.gov

How birth defects data are used in Indiana

Data from the Indiana Birth Problems Registry is used to detect trends in birth defects and suggest areas for further study; to identify epidemiological factors associated with birth defects; to address community concerns about the environmental effects on birth outcomes; to evaluate education, screening, and prevention programs; and to establish efficient referral systems that provide special services for the children with identified birth defects and their families.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Iowa and US

Defects	Iowa [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	11	2.78	1,009	2.51
Spina bifida without anencephalus	20	5.13	1,477	3.68
Cardiovascular				
Transposition of great arteries	20	5.29	1,901	4.73
Tetralogy of Fallot	14	3.61	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	25	6.55	1,748	4.36
Hypoplastic left heart syndrome	9	2.41	975	2.43
Orofacial				
Cleft lip with and without cleft palate	48	12.46	4,209	10.47
Cleft palate without cleft lip	29	7.70	2,567	6.39
Musculoskeletal				
Upper limb defect	21	5.39	1,521	3.79
Lower limb defect	11	2.78	763	1.90
Gastroschisis	19	4.98	1,497	3.73
Chromosomal				
Down syndrome	62	16.13	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Iowa's Birth Defect Surveillance System

The mission of the Iowa Registry for Congenital and Inherited Disorders is to:

- maintain statewide surveillance for collecting information on selected congenital and inherited disorders in Iowa,
- monitor annual trends in occurrence and mortality of these disorders, and
- provide data for research studies and educational activities for the prevention and treatment of these disorders.

How birth defects data are used in Iowa

Since 1983, the Iowa Registry for Congenital and Inherited Disorders has worked to advance the health of Iowa children by monitoring the entire state for congenital and inherited disorders. By providing data for research studies and educational programs, the Registry works for the prevention and treatment of these disorders. The Registry also provides important information to state policy makers and public health professionals.

Program information:

Paul A. Romitti, PhD
 Iowa Registry for Congenital and Inherited Disorders
 E-mail: paul-romitti@uiowa.edu

Bradley D. McDowell, PhD
 Iowa Registry for Congenital and Inherited Disorders
 E-mail: bradley-mcdowell@uiowa.edu

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Kansas and US

Defects	Kansas [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	8	2.04	1,009	2.51
Spina bifida without anencephalus	10	2.53	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	35	8.57	4,209	10.47
Cleft palate without cleft lip	13	3.18	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	15	3.59	1,497	3.73
Chromosomal				
Down syndrome	36	8.73	5,132	12.78

* per 10,000 live births

† estimates based on reported Kansas resident birth data from birth years 2005-2007

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Kansas’s Birth Defect Surveillance System

Congenital anomalies have been reported on the Kansas birth certificate since 1979. Kansas has conducted limited surveillance activities under congenital malformations reporting under Kansas administrative regulations (KAR 28-1-4) since 1982 with fetal alcohol syndrome added in 1986. In 2004, Kansas statutes annotated (KSA 65-1241 through 65-1246) provided statutory reporting of all patients under 5 years of age with a primary diagnosis of a congenital anomaly or abnormal condition and establishing a birth defects surveillance system. No funding was appropriated to implement the new law.

How birth defects data are used in Kansas

Congenital anomalies reported through two data sources (birth certificates and the birth defects prevention program reporting form) have been used to provide baseline rates of morbidity and mortality from different congenital defects, monitor secular and temporal trends, and identify unusual changes in disease patterns. Birth defect export files (live and still birth) from the Vital Statistics Integrated Information System have been utilized for notifying of the availability of services and supports through Children with Special Health Care Needs, early intervention, and other programs.

Program information:

Jamie S. Kim, MPH
 Bureau of Family Health
 Kansas Department of Health and Environment
 E-mail: jkim@kdehs.gov

Garry Kelley, MS
 Bureau of Family Health
 Kansas Department of Health and Environment
 E-mail: gkelley@kdehs.gov

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Kentucky and US

Defects	Kentucky [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	12	2.15	1,009	2.51
Spina bifida without anencephalus	23	4.12	1,477	3.68
Cardiovascular				
Transposition of great arteries	19	3.40	1,901	4.73
Tetralogy of Fallot	23	4.03	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	22	3.94	1,748	4.36
Hypoplastic left heart syndrome	13	2.24	975	2.43
Orofacial				
Cleft lip with and without cleft palate	9	1.61	4,209	10.47
Cleft palate without cleft lip	24	4.20	2,567	6.39
Musculoskeletal				
Upper limb defect	16	2.77	1,521	3.79
Lower limb defect	8	1.52	763	1.90
Gastroschisis	12	2.15	1,497	3.73
Chromosomal				
Down syndrome	77	13.78	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2004-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Kentucky's Birth Defect Surveillance System

For over 10 years, the Kentucky Birth Surveillance Registry (KBSR) has monitored the prevalence of birth defects statewide. KBSR has served as a model for other states as both passive and active surveillance are performed in order to obtain accurate data as well as linking hospital discharge with vital records. KBSR was developed as a collaborative effort with the March of Dimes, the Kentucky Hospital Association, the KBSR Advisory Committee, and various advocacy organizations. KBSR collects information on inpatients from acute care hospitals and birthing centers as required by law. Medical laboratories licensed in KY are also required to report data.

How birth defects data are used in Kentucky

KBSR has information on approximately 90,000 children born with birth defects since 1998. KBSR has submitted data for studies by the World Health Organization, Centers for Disease Control and Prevention, National Birth Defects Prevention Network and local agencies such as the Down Syndrome Association for evaluating service needs across the state.

Program information:

Sandy G. Fawbush, RN
 Kentucky Birth Surveillance Registry (KBSR)
 E-mail: sandy.fawbush@ky.gov

Troi J Cunningham, RN
 Kentucky Birth Surveillance Registry (KBSR)
 E-mail: troi.cunningham@ky.gov

Website: <http://chfs.ky.gov/dph/ach/eecd/kbsr.htm>

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Louisiana and US

Defects	Louisiana		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Program information:

Kay Webster, MPH
 Louisiana Birth Defects Monitoring Network (LBDMN)
 E-mail: kwebster@dhh.la.gov

Website: <http://www.dhh.louisiana.gov/offices/?ID=261>

Louisiana's Birth Defect Surveillance System

The Louisiana Birth Defects Monitoring Network (LBDMN) is a relatively new program that initiated data collection in 2005. LBDMN currently tracks birth defects in 37 parishes (covering an estimated 70% of yearly births); statewide data are not yet available. Gradual expansion to statewide coverage is planned over the next few years, subject to the availability of adequate funding.

How birth defects data are used in Louisiana

LBDMN provides information on locally available medical, educational and social services to families whose children are included in the birth defects registry. When statewide data are available, LBDMN will be able to provide rates of the conditions listed above. LBDMN data will also be used to detect changes over time and study unusual patterns in the occurrence of birth defects (i.e. "clusters"). Most importantly, statewide data can be used to identify high-risk populations and to target birth defects prevention programs to these groups as needed.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Maine and US

Defects	Maine ⁺		US [‡]	
	Annual no. of cases	Birth prevalence**	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	7	1.00	1,009	2.51
Spina bifida without anencephalus	14	2.00	1,477	3.68
Cardiovascular				
Transposition of great arteries	24	3.42	1,901	4.73
Tetralogy of Fallot	22	3.14	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	17	2.42	975	2.43
Orofacial				
Cleft lip with and without cleft palate	50	7.13	4,209	10.47
Cleft palate without cleft lip	44	6.27	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	27	3.85	1,497	3.73
Chromosomal				
Down syndrome	60	8.55	5,132	12.78

*per 10,000 live births

**per 10,000 live births to Maine residents

+ estimates based on pooled data from birth years 2003-2007

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Maine's Birth Defect Surveillance System

The Maine Birth Defects Program was established in 1999. Rules were officially adopted in April 2003 at which time data collection began. The Maine Birth Defects Program is currently collecting data on 22 birth defects which include major heart defects, cleft lip, palate and lip and palate, reduction deformities of upper and lower limbs, hypospadias and Down Syndrome. The program is working towards electronic submission from all data sources.

How birth defects data are used in Maine

Maine Birth Defects Program uses the data collected to assess the full impact of birth defects on Maine children and their families, to improve access to specialty services for families and locate resources for emotional and economic support, to monitor trends related to the prevalence of selected birth defects in Maine and to educate provider and the general public on prevention strategies to decrease the incidence of birth defects in Maine.

Program information:

Maine Birth Defects Program

Toni G. Wall, MPA

E-mail: toni.g.wall@maine.gov

Diane C. Haberman, MSW, LCSW

E-mail: Diane.Haberman@maine.gov

Website:

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

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Maryland and US

Defects	Maryland [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	19	2.73	1,009	2.51
Spina bifida without anencephalus	25	3.62	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	34	4.84	4,209	10.47
Cleft palate without cleft lip	20	2.87	2,567	6.39
Musculoskeletal				
Upper limb defect	27	3.91	1,521	3.79
Lower limb defect	18	2.55	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	94	13.52	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2004

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Program information:

Susan R. Panny, MD
 Maryland Birth Defects Reporting and Information System
 E-mail: PannyS@dhmh.state.md.us

Anne D. Terry, RN (BSN), BS, MA
 Maryland Birth Defects Reporting and Information System
 E-mail: terrya@dhmh.state.md.us

Maryland’s Birth Defect Surveillance System

Since 1984 Maryland’s Birth Defects Reporting and Information System (BDRIS) has monitored the 12 sentinel birth defects designated by the World Health Organization (WHO). During the Maryland legislative session of 2008, the mandate for surveillance of birth defects was expanded to all birth defects documented as present or suspected at delivery or live birth of an infant. BDRIS is a passive surveillance system residing in a newly developed and launched MS Access dedicated database. Birth defects data is verified through electronic matching with the Vital Statistics Administration’s birth certificate and fetal death certificate records. Any additional cases are added. The BDRIS program is staffed and operated by a nurse consultant

How birth defects data are used in Maryland

BDRIS is able to populate surveys for needs assessments, access to care, and outreach through regional mapping of the distribution of selected birth defects. BDRIS has a working partnership with the Environment Public Health Tracking System (EPHT). BDRIS data is available for stakeholders towards planning, policy deliberations and resource allocation.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Massachusetts and US

Defects	Massachusetts [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	4	0.53	1,009	2.51
Spina bifida without anencephalus	13	1.61	1,477	3.68
Cardiovascular				
Transposition of great arteries	32	4.03	1,901	4.73
Tetralogy of Fallot	38	4.84	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	41	5.19	1,748	4.36
Hypoplastic left heart syndrome	10	1.31	975	2.43
Orofacial				
Cleft lip with and without cleft palate	60	7.50	4,209	10.47
Cleft palate without cleft lip	47	5.89	2,567	6.39
Musculoskeletal				
Upper limb defect	22	2.82	1,521	3.79
Lower limb defect	10	1.23	763	1.90
Gastroschisis	21	2.64	1,497	3.73
Chromosomal				
Down syndrome	99	12.42	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Program information:

Marlene Anderka, ScD, MPH
 Massachusetts Birth Defects Monitoring Program
 E-mail: marlene.anderka@state.ma.us

Cathy Higgins, BA
 Massachusetts Birth Defects Monitoring Program
 E-mail: cathleen.higgins@state.ma.us

Website: www.mass.gov/birthdefectscenter

Massachusetts's Birth Defect Surveillance System

The Massachusetts Birth Defects Monitoring Program (BDMP) is a state-wide, population-based program that collects data on infants (liveborn or stillborn) diagnosed with a birth defect. Based in the Massachusetts Department of Public Health, monitoring activities are mandated by state law and delineated by state regulations. Covering approximately 77,000 births per year, the Massachusetts BDMP produces data reports, maintains a website, and collaborates with researchers and public health colleagues on research, data requests and environmental investigations.

How birth defects data are used in Massachusetts

The Massachusetts BDMP collects data in order to: identify trends; search for causative factors linked with birth defects; address community concerns about birth defects; provide information and referral to families of children with birth defects; and measure the success of screening and prevention efforts.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Michigan and US

Defects	Michigan [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	16	1.23	1,009	2.51
Spina bifida without anencephalus	62	4.71	1,477	3.68
Cardiovascular				
Transposition of great arteries	66	5.03	1,901	4.73
Tetralogy of Fallot	68	5.17	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	65	4.98	1,748	4.36
Hypoplastic left heart syndrome	57	4.33	975	2.43
Orofacial				
Cleft lip with and without cleft palate	137	10.44	4,209	10.47
Cleft palate without cleft lip	71	5.38	2,567	6.39
Musculoskeletal				
Upper limb defect	29	2.21	1,521	3.79
Lower limb defect	26	1.98	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	170	12.98	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Michigan’s Birth Defect Registry (MBDR)

Michigan has been conducting surveillance of birth defects since 1992 under the authority of the Michigan law (MCL 333.5717) which established the registry as a statewide surveillance system. The registry is operated by the Division for Vital and Health Statistics within the Michigan Department of Community Health. Conditions included in the registry include congenital anomalies, chromosomal disorders, metabolic disorders, certain infectious diseases and fetal exposures. The registry relies upon the collaborative efforts of Michigan hospitals, cytogenetic laboratories, genetic counselors and others.

Program information:

Glenn Edward Copeland, MBA
 Michigan Birth Defects Registry
 E-mail: CopelandG@Michigan.gov

Lorrie Simmons, RHIT
 Michigan Birth Defects Registry
 E-mail: SimmonsL@Michigan.gov

How birth defects data are used in Michigan

MBDR has information on over 200,000 children born with birth defects. These data are used to provide information on the frequency and trends in birth defects and to monitor the mortality experience of these children. The data also provide the basis for research studies into the cause of birth defects. The information is also used to assist service programs in evaluating the availability of services to families of children with birth defects.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Minnesota and US

Defects	Minnesota		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Program information:

Myron Falken, PhD, MPH
 Minnesota Birth Defects Information System
 E-mail: myron.falken@health.state.mn.us

Daniel Symonik, PhD
 Minnesota Birth Defects Information System
 E-mail: daniel.symonik@health.state.mn.us

Minnesota's Birth Defect Surveillance System

The Birth Defects Program began active surveillance data collection in mid-2005. The program gathers data about babies diagnosed within the first year of life with ICD-CM9 codes 740 -760. Data will be available in 2009 for babies born in Hennepin and Ramsey counties in Minnesota (about 50% of state births).

How birth defects data are used in Minnesota

Birth defects data are used to:

- Monitor prevalence trends of birth defects to detect emerging health concerns and identify affected populations,
- Ensure appropriate services are provided to affected families,
- Prevent birth defects through targeted education,
- Educate physicians and the public regarding birth defects, and
- Stimulate research on risk factors, treatment, prevention, and the cure of birth defects.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Defects	Mississippi [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	3	0.70	1,009	2.51
Spina bifida without anencephalus	12	2.80	1,477	3.68
Cardiovascular				
Transposition of great arteries	13	3.04	1,901	4.73
Tetralogy of Fallot	20	4.67	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	5	1.17	1,748	4.36
Hypoplastic left heart syndrome	6	1.40	975	2.43
Orofacial				
Cleft lip with and without cleft palate	43	10.04	4,209	10.47
Cleft palate without cleft lip	27	6.31	2,567	6.39
Musculoskeletal				
Upper limb defect	8	1.87	1,521	3.79
Lower limb defect	1	0.23	763	1.90
Gastroschisis	38	8.88	1,497	3.73
Chromosomal				
Down syndrome	23	5.37	5,132	12.78

Selected birth defects counts and birth prevalence, Mississippi and US

* per 10,000 live births

† estimates based on data from birth year 2004

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Mississippi’s Birth Defect Surveillance System

The Birth Defects Surveillance registry is housed in the Office of Child and Adolescent Health, Division of Genetic Services. Section 41-21-205 of the Mississippi Code established a birth defects surveillance registry in the Mississippi State Department of Health. Effective January 2000, all hospitals, clinics, and other health facilities that serve patients from birth to 21 years of age began reporting to the Mississippi Birth Defects Surveillance Registry.

How birth defects data are used in Mississippi

The data reported to the Mississippi Birth Defects Surveillance Registry is monitored regularly and systematically, for changes in incidence or other unusual patterns suggesting preventable causes. The data is used to ensure that children identified with birth defects are placed in a system of care.

Program information:

Beryl Polk, PhD
Mississippi Birth Defects Registry
E-mail: bpolk@msdh.state.ms.us

Pat Terry, BSW
Mississippi Birth Defects Registry
E-mail: pterry@msdh.state.ms.us

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Montana and US

Defects	Montana		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Montana's Birth Defect Surveillance System

Due to lack of funding, Montana suspended its birth defects surveillance system in 2005

Program information:

Linda S. Beischel, CLSp(MB), CLSup
 Children's Special Health Services
 Family and Community Health Bureau
 Department of Public Health and Human Services
 E-mail: lbeischel@mt.gov

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Nevada (2005-2007) and US

Defects	Nevada		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	8	0.68	1,009	2.51
Spina bifida without anencephalus	25	2.13	1,477	3.68
Cardiovascular				
Transposition of great arteries	54	4.59	1,901	4.73
Tetralogy of Fallot	78	6.63	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	29	2.47	975	2.43
Orofacial				
Cleft lip with and without cleft palate	113	9.61	4,209	10.47
Cleft palate without cleft lip	50	4.25	2,567	6.39
Musculoskeletal				
Upper limb defect	15	1.28	1,521	3.79
Lower limb defect	16	1.36	763	1.90
Gastroschisis	62	5.27	1,497	3.73
Chromosomal				
Down syndrome	176	14.97	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Nevada's Birth Defect Surveillance System

It is a statewide population based surveillance system, collecting data on major birth defects and genetic diseases following ICD-9CM codes, covering all live births and still births with 20 weeks and greater gestational age. Collection of maternal substance abused babies is also carried out side by side. Program started from 2005; complete data is available from 2005 to 2007. Number of births covered in 2007 is 40,703. Prevalence rate of major birth defects is 3.95 in 2005 through 2007. Currently, collecting data for the year 2008. Program is totally funded by the State through collection of service fees.

Program information:

Brad Towle, MA, MPA
 Nevada Birth Defects Registry
 E-mail: btowle@health.nv.gov

Prasanjit Chakma, MBBS, MPH
 Nevada Birth Defects Registry
 E-mail: pchakma@health.nv.gov

How birth defects data are used in Nevada

Date is used for routine statistical monitoring, public health program evaluation, tracking of birth defects incidence and prevalence, referral for services, and determination of prevention strategies.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Defects	New Hampshire [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	1	1.04	1,009	2.51
Spina bifida without anencephalus	0	0	1,477	3.68
Cardiovascular				
Transposition of great arteries	2	1.82	1,901	4.73
Tetralogy of Fallot	7	5.73	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	6	4.43	1,748	4.36
Hypoplastic left heart syndrome	4	2.87	975	2.43
Orofacial				
Cleft lip with and without cleft palate	11	8.34	4,209	10.47
Cleft palate without cleft lip	10	7.82	2,567	6.39
Musculoskeletal				
Upper limb defect	2	1.30	1,521	3.79
Lower limb defect	1	1.04	763	1.90
Gastroschisis	4	2.87	1,497	3.73
Chromosomal				
Down syndrome	21	16.16	5,132	12.78

Selected birth defects counts and birth prevalence, New Hampshire and US

* per 10,000 live births

† estimates based on pooled data from birth years 2003-2005

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

New Hampshire’s Birth Defect Surveillance System

The NH Birth Conditions Program (NHBCP) is a public health surveillance program that has been collecting state-wide data since 2003. The mission of the program is to: monitor 45 birth conditions in New Hampshire; develop birth conditions prevention strategies; support epidemiological research into the causes and public health impact of birth conditions; improve the ability of families to have access to intervention programs and services for infants and children with birth conditions; and to educate the community, health care providers, and service agencies regarding birth conditions.

How birth defects data are used in New Hampshire

From 2003 - 2006, over 1100 birth conditions were identified in babies born in New Hampshire with an overall annual prevalence of approximate 2% of all births. Knowledge of the occurrence of birth conditions in New Hampshire will help to monitor the occurrence of these conditions, target prevention activities and educate families about the services that are available to them.

Better tracking of when and where birth conditions occur and potential links to environmental factors will provide critical information that may help prevent birth conditions in the future.

Program information:

John B. Moeschler, MD, MS
 New Hampshire Birth Conditions Program
 E-mail: john.b.moeschler@hitchcock.org

Stephanie D. Miller, RN, MSN, MPH
 New Hampshire Birth Conditions Program
 E-mail: stephanie.d.miller@hitchcock.org

Website: www.nhbcp.org

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, New Jersey and US

Defects	New Jersey [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	5	0.42	1,009	2.51
Spina bifida without anencephalus	23	1.97	1,477	3.68
Cardiovascular				
Transposition of great arteries	43	3.76	1,901	4.73
Tetralogy of Fallot	46	4.02	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	30	2.58	1,748	4.36
Hypoplastic left heart syndrome	18	1.58	975	2.43
Orofacial				
Cleft lip with and without cleft palate	80	6.94	4,209	10.47
Cleft palate without cleft lip	64	5.57	2,567	6.39
Musculoskeletal				
Upper limb defect	34	2.94	1,521	3.79
Lower limb defect	20	1.71	763	1.90
Gastroschisis	24	2.09	1,497	3.73
Chromosomal				
Down syndrome	140	12.22	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

New Jersey's Birth Defect Surveillance System

This is the oldest such program in the country. Since 1928, the New Jersey Special Child Health Services (SCHS) Registry has registered children having birth defects and other special needs conditions. State law requires the reporting of children diagnosed with congenital defects through age five to the SCHS Registry. The Registry has confidential records of all birth defects that occur in New Jersey in order to conduct thorough and complete epidemiologic surveys of birth defects and to plan for and provide services to children with birth defects and their families.

Program information:

Leslie M. Beres-Sochka, MS Hyg, CPM
 Special Child Health Services Registry
 E-mail: Leslie.Beres-Sochka@doh.state.nj.us

Mary M. Knapp, MSN
 Special Child Health Services Registry
 E-mail: mary.knapp@doh.state.nj.us

How birth defects data are used in New Jersey

New Jersey has monitored nearly 3 million births since 1985 and has information on over 200,000 children either born with birth defects or diagnosed with special needs conditions. SCHS data are used to report incidence of birth defects in New Jersey. The New Jersey SCHS Registry serves as a national model for linking registered children and their families to various services. Families are directly linked with local county-based case management units; coordination includes health, educational, financial, and social services.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Defects	New Mexico		US [†]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	12 [†]	4.44	1,009	2.51
Spina bifida without anencephalus	15 [†]	5.63	1,477	3.68
Cardiovascular				
Transposition of great arteries	4 [§]	1.44	1,901	4.73
Tetralogy of Fallot	3 [§]	1.26	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	3 [§]	1.26	975	2.43
Orofacial				
Cleft lip with and without cleft palate	35 [†]	13.03	4,209	10.47
Cleft palate without cleft lip	18 [†]	6.59	2,567	6.39
Musculoskeletal				
Upper limb defect	7 [§]	2.52	1,521	3.79
Lower limb defect	5 [§]	1.80	763	1.90
Gastroschisis	17 [†]	6.14	1,497	3.73
Chromosomal				
Down syndrome	28 [§]	9.91	5,132	12.78

Selected birth defects counts and birth prevalence, New Mexico and US

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[§] estimates based on pooled data from birth years 2004-2005

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

New Mexico’s Birth Defect Surveillance System

There are over 29,000 births per year in New Mexico. Since 1995, the New Mexico Birth Defects Prevention and Surveillance System (BDPASS) at the New Mexico Department of Health has monitored birth defects among infants born to residents of New Mexico. Babies born with birth defects have a greater chance of illness and long term disability than babies without birth defects. By identifying these children early in their life, we have the opportunity to assure that they receive the medical care and early intervention services to allow them to be productive adults and fulfill their potential.

Program information:

Maggi Gallaher, MD, MPH
 New Mexico Department of Health
 Birth Defects Prevention And Surveillance System
 E-mail: maggi.gallaher@state.nm.us

How birth defects data are used in New Mexico

Birth defects data are used to:

- Monitor the prevalence of birth defects in the state and to identify clusters that should be investigated,
- Target prevention activities,
- Assess the impact of screening and prevention activities, and
- Link children to necessary services such as case management for those that have complex medical needs and early intervention services to support the child’s development.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, New York and US

Defects	New York [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	10	0.42	1,009	2.51
Spina bifida without anencephalus	51	2.06	1,477	3.68
Cardiovascular				
Transposition of great arteries	106	4.24	1,901	4.73
Tetralogy of Fallot	117	4.69	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	68	2.71	1,748	4.36
Hypoplastic left heart syndrome	56	2.26	975	2.43
Orofacial				
Cleft lip with and without cleft palate	174	6.99	4,209	10.47
Cleft palate without cleft lip	144	5.76	2,567	6.39
Musculoskeletal				
Upper limb defect	40	1.61	1,521	3.79
Lower limb defect	24	0.98	763	1.90
Gastroschisis	47	1.89	1,497	3.73
Chromosomal				
Down syndrome	299	11.98	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

New York's Birth Defect Surveillance System

The New York State Department of Health Congenital Malformations Registry (CMR) is one of the largest statewide, population-based birth defects registries in the nation. The CMR was established by enactment of Part 22 of the State Sanitary Code in 1981. Reporting to the registry began in October 1982. Hospitals and physicians are required to report children up to two years of age diagnosed with a malformation. Case reports are received electronically on the Internet using the Health Provider Network, a secure system for electronically collecting and distributing health related data.

How birth defects data are used in New York

The birth defects data are used for routine statistical monitoring of birth defects in New York, generating annual report that summarizes birth defects by type, by organ system, and by county, and provide basis for research studies in searching for causes of birth defects. The CMR data are also used to link children with services in their home communities such as Early Intervention Program, to ensure that families of children identified in the Registry can find available resources and support groups.

Program information:

New York State Congenital Malformations Registry

Charlotte M Druschel, MD, MPH
E-mail: cmd05@health.state.ny.us

Ying Wang, PhD, MPH
E-mail: wxy01@health.state.ny.us

Website:
www.health.state.ny.us/diseases/congenital_malformations/cmhome.htm

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Defects	North Carolina [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	28	2.36	1,009	2.51
Spina bifida without anencephalus	50	4.21	1,477	3.68
Cardiovascular				
Transposition of great arteries	54	4.54	1,901	4.73
Tetralogy of Fallot	52	4.34	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	58	4.83	1,748	4.36
Hypoplastic left heart syndrome	31	2.63	975	2.43
Orofacial				
Cleft lip with and without cleft palate	107	9.00	4,209	10.47
Cleft palate without cleft lip	66	5.50	2,567	6.39
Musculoskeletal				
Upper limb defect	37	3.10	1,521	3.79
Lower limb defect	19	1.58	763	1.90
Gastroschisis	44	3.70	1,497	3.73
Chromosomal				
Down syndrome	155	12.98	5,132	12.78

Selected birth defects counts and birth prevalence, North Carolina and US

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

North Carolina’s Birth Defect Surveillance System

The N.C. Birth Defects Monitoring Program (NCBDMP) is a statewide surveillance system that tracks the occurrence of birth defects among all North Carolina infants. The NCBDMP is located in the State Center for Health Statistics in the N.C. Division of Public Health. The program monitors over 130,000 births each year among nearly 100 hospitals and medical facilities statewide. The NCBDMP works with a number of partners to improve the health status of all infants and children in North Carolina.

How birth defects data are used in North Carolina

Information collected by the NCBDMP is used in many ways, including: monitoring geographic patterns and trends over time, evaluating the effectiveness of services and interventions, improving access to services for affected families, providing statistical data to various audiences, and engaging in research aimed at understanding the causes of birth defects and identifying potential new opportunities for prevention.

Program information for the N.C. Birth Defects Monitoring Program:

Robert E. Meyer, PhD
E-mail: robert.meyer@ncmail.net

Katie Harmsen
E-mail: katie.harmsen@ncmail.net

Jennifer Stock
E-mail jennifer.stock@ncmail.net

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Defects	North Dakota [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	2	2.50	1,009	2.51
Spina bifida without anencephalus	5	5.76	1,477	3.68
Cardiovascular				
Transposition of great arteries	4	4.76	1,901	4.73
Tetralogy of Fallot	4	4.51	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	2	3.00	1,748	4.36
Hypoplastic left heart syndrome	3	3.50	975	2.43
Orofacial				
Cleft lip with and without cleft palate	8	10.01	4,209	10.47
Cleft palate without cleft lip	9	10.76	2,567	6.39
Musculoskeletal				
Upper limb defect	<1	0.75	1,521	3.79
Lower limb defect	<1	0.50	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	6	8.01	5,132	12.78

Selected birth defects counts and birth prevalence, North Dakota and US

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

North Dakota’s Birth Defect Surveillance System

The North Dakota Birth Defects Monitoring System was established in 2003 as a means of identifying and collecting information about babies born with certain birth defects in North Dakota. The North Dakota Birth Defects Monitoring program is a passive surveillance system. Data are collected and linked from three secondary data sources. Because of the low numbers of both resident births and occurrences of individual birth defects in North Dakota, rates for each birth defect are averaged over five consecutive years to improve statistical stability of the data.

Program information:

Devaiah Muthappa Muccatira, MS
 North Dakota Birth Defects Monitoring System
 E-mail: dmuccatira@nd.gov

Tamara Lynn Gallup-Millner, RN, MPA
 North Dakota Birth Defects Monitoring System
 E-mail: tgallupmillner@nd.gov

Website: <http://www.health.state.nd.us/cshs/docs/birth-defects-report.pdf>

How birth defects data are used in North Dakota

Data from the North Dakota Birth Defects Monitoring System is used to: 1) report incidence and prevalence of birth defects, 2) increase awareness of birth defects and identified risk factors, 3) help researchers and health-care providers learn more about preventing future problems, and 4) assure that children born with birth defects have access to needed health-care and other services.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Ohio and US

Defects	Ohio		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Ohio initiated statewide reporting of birth defects data in 2007. Birth defects data are not currently available for public use at this time.

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Ohio’s Birth Defect Surveillance System

Ohio initiated statewide reporting of birth defects to the Ohio Connections for Children with Special Health Care Needs (OCCSN) system in 2007. Over 165 hospitals report children from birth to 5 years of age per state legislation. The goals of the system are to develop a comprehensive system that includes collecting data on children with birth defects; ensuring that children with birth defects are referred to public health programs to improve their health outcomes; and educating the public and health professionals about birth defects.

How birth defects data are used in Ohio

OCCSN will utilize birth defects data to determine the burden of birth defects in Ohio and provide data to further research for birth defects causes and prevention. Ohio is currently pilot testing a referral mechanism whereby children reported to OCCSN will be cross-checked with Ohio’s Part C early intervention and CSHCN data systems. If the child is not known to these programs, a referral is made. A training curriculum for early intervention staff and public health nurses was established and continues to be presented regularly with positive feedback.

Program information:

James Bryant, MD
Ohio Connections For Children With Special Needs
E-mail: James.Bryant@odh.ohio.gov

Anna E. Starr, BS
Ohio Connections For Children With Special Needs
E-mail: Anna.Starr@odh.ohio.gov

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Oklahoma and US

Defects	Oklahoma [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	13	2.56	1,009	2.51
Spina bifida without anencephalus	19	3.74	1,477	3.68
Cardiovascular				
Transposition of great arteries	27	5.31	1,901	4.73
Tetralogy of Fallot	21	4.13	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	24	4.76	1,748	4.36
Hypoplastic left heart syndrome	13	2.60	975	2.43
Orofacial				
Cleft lip with and without cleft palate	68	13.34	4,209	10.47
Cleft palate without cleft lip	41	8.07	2,567	6.39
Musculoskeletal				
Upper limb defect	20	3.86	1,521	3.79
Lower limb defect	10	2.01	763	1.90
Gastroschisis	31	6.06	1,497	3.73
Chromosomal				
Down syndrome	67	13.10	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Oklahoma's Birth Defect Surveillance System

The Oklahoma Birth Defects Registry (OBDR) began operation in 1992, in Oklahoma County. In 1993, Tulsa and Cleveland Counties were added. Statewide surveillance of birth defects was established in 1994. The mission of the OBDR is to provide statewide surveillance of birth defects to reduce the prevalence of birth defects through prevention education, monitoring trends and analyzing data.

How birth defects data are used in Oklahoma

The OBDR has several prevention efforts to reduce birth defects in Oklahoma: folic acid education for women of childbearing age; recurrence prevention of neural tube defects (spina bifida and anencephaly); and preconception training for health care workers. Data is analyzed to monitor trends, identify changes or clustering of birth defects, evaluate potential effects of environmental contaminants and provide geospatial analysis. The OBDR conducted a statewide needs assessment of birth defects and is utilizing the information to establish a system of referral for families of children with birth defects to programs and services.

Program information:

Kay A. Pearson, MS
 Oklahoma Birth Defects Registry
 E-mail: kayp@health.ok.gov

Web site:
http://www.ok.gov/health/Child_and_Family_Health/Screening_Special_Services_and_Sooner_Start/Oklahoma_Birth_Defects_Registry_/index.html

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Oregon and US

Defects	Oregon		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Oregon Birth Defect Surveillance

Oregon does not have a birth defects surveillance system.

Program information:

Kenneth D. Rosenberg, MD, MPH
 Oregon Public Health Division
 E-mail: ken.d.rosenberg@state.or.us

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Pennsylvania and US

Defects	Pennsylvania [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	28	3.25	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	141	9.79	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2003

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Pennsylvania's Birth Defect Surveillance System

Pennsylvania currently does not have a birth defects surveillance system in place.

How birth defects data are used in Pennsylvania

The Genetic Services Section supports vendors to provide access to comprehensive genetic services, screening, counseling, and referral services to ensure that eligible, low-income individuals and families seeking information about the occurrence, or risk of occurrence, of a genetic condition or birth defect are provided. Supported vendors include: seven comprehensive genetic screening centers, three major metabolic screening and treatment centers, and four Family Health Councils.

Program information:

Ronald A. Tringali, PhD
 PA Department of Health, Bureau of Epidemiology
 E-mail: rtringali@state.pa.us

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Puerto Rico and US

Defects	Puerto Rico		US [†]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	17 [†]	3.25	1,009	2.51
Spina bifida without anencephalus	23 [†]	4.43	1,477	3.68
Cardiovascular				
Transposition of great arteries	18 [§]	3.54	1,901	4.73
Tetralogy of Fallot	18 [§]	3.54	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	21 [§]	4.06	1,748	4.36
Hypoplastic left heart syndrome	10 [§]	1.90	975	2.43
Orofacial				
Cleft lip with and without cleft palate	42 [†]	8.10	4,209	10.47
Cleft palate without cleft lip	30 [†]	5.81	2,567	6.39
Musculoskeletal				
Upper limb defect	10 [†]	1.94	1,521	3.79
Lower limb defect	7 [†]	1.26	763	1.90
Gastroschisis	17 [†]	3.25	1,497	3.73
Chromosomal				
Down syndrome	59 [†]	11.20	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[§] estimates based on pooled data from birth years 2003-2005

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Puerto Rico's Birth Defect Surveillance System

The Puerto Rico Birth Defects Surveillance System (BDSS) was established in 1995. It is an active, population based, surveillance system for 48 birth defects. The program has a current legislation enacted in September 2004. The BDSS also has a Birth Defects Prevention Campaign which also partners with other Agencies to promote birth defects prevention messages Island wide.

Program information:

Diana Valencia, MSc.
 Puerto Rico Birth Defects Surveillance System
 E-mail: dvalencia@salud.gov.pr

Laureane Alvelo-Maldonado, MSc.
 Puerto Rico Birth Defects Surveillance System
 E-mail: lalvelo@salud.gov.pr

We site: <http://www.salud.gov.pr>

How birth defects data are used in Puerto Rico

BDSS data is monitored to identify time trends, and to detect changes in the occurrence of birth defects. An annual basis data book is prepared and distributed to health professionals interested in the field. The BDSS provides referrals to programs and health services for at risk children. These data also serve to evaluate the impact of the Birth Defects Prevention Campaign.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Rhode Island and US

Defects	Rhode Island [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	1	0.82	1,009	2.51
Spina bifida without anencephalus	4	3.27	1,477	3.68
Cardiovascular				
Transposition of great arteries	2	1.64	1,901	4.73
Tetralogy of Fallot	8	6.55	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	2	1.64	1,748	4.36
Hypoplastic left heart syndrome	1	0.82	975	2.43
Orofacial				
Cleft lip with and without cleft palate	10	8.18	4,209	10.47
Cleft palate without cleft lip	11	9.00	2,567	6.39
Musculoskeletal				
Upper limb defect	4	3.27	1,521	3.79
Lower limb defect	1	0.82	763	1.90
Gastroschisis	10	8.18	1,497	3.73
Chromosomal				
Down syndrome	21	17.19	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth year 2005

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Rhode Island's Birth Defect Surveillance System

The Rhode Island Birth Defects Program (RIBDP) describes the occurrence of birth defects in children up to age five; detects trends of morbidity and mortality; and helps assure children with birth defects receive services and treatment on a timely basis. Housed within the Rhode Island Department of Health's Center for Health Data and Analysis, the RIBDP collects data and service information from multiple sources including hospital discharge data, specialty clinics, and primary care providers.

How birth defects data are used in Rhode Island

Data collected by the RIBDP are utilized to determine the prevalence of birth defects and to identify trends related to specific conditions, maternal and/or child demographics, and other factors. Case ascertainment data are linked to Rhode Island's integrated child health information system, KIDSNET, to identify whether children have received preventive and other appropriate services. The RIBDP works closely with pediatric practices and parent consultants to determine whether families of children with birth defects receive appropriate services and program referrals.

Program information:

Samara Viner-Brown, MS
Rhode Island Birth Defects Surveillance Program
E-mail: Samara.Viner-Brown@health.ri.gov

William Arias, MPH
Rhode Island Birth Defects Surveillance Program
E-mail: william.arias@health.ri.gov

Website:
<http://www.health.ri.gov/family/birthdefects/index.php>

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, South Carolina and US

Defects	South Carolina [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	19	3.32	1,009	2.51
Spina bifida without anencephalus	22	3.90	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,429	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

* Data reported is from Greenwood Genetic Center, prior to SC Birth Defects Program start-up in 2006.

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

South Carolina's Birth Defect Surveillance System

The SC Birth Defects Program began in July 2006 after passage of the SC Birth Defects Act which mandated active surveillance of major structural birth defects identified prenatally through age two. Birth defects monitoring was transitioned from Greenwood Genetic Center to SC Department of Health & Environmental Control. In the first 1 ½ years central nervous system, cardiovascular, musculoskeletal and orofacial defects were monitored. In January 2008 all birth defects recommended by the CDC/NBDPN were added for surveillance. Nurse Abstractors collect comprehensive data on mother and infant from inpatient facilities statewide. Data is collected in a web-based electronic data system that is integrated with the state's vital record system. The program is guided by the SC Birth Defects Advisory Council.

How birth defects data are used in South Carolina

To determine rates and trends of birth defects; to promote effective referral of infants/families for appropriate services; to develop public health strategies for prevention of birth defects; to conduct research on the causes, distribution and prevention of birth defects.

Program information:

Lyn Phillips, LISW
 South Carolina Birth Defects Program
 E-mail: philliej@dhec.sc.gov

Kirk Shull, BS
 South Carolina Birth Defects Program
 E-mail: shullka@dhec.sc.gov

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, South Dakota and US

Defects	South Dakota		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

South Dakota's Birth Defect Surveillance System

South Dakota does not have a birth defects registry at this time.

Program information:

Kayla Tinker, BS-RN
 SD Department of Health
 E-mail: kayla.tinker@state.sd.us

How birth defects data are used in South Dakota

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Tennessee and US

Defects	Tennessee [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	14	1.72	1,009	2.51
Spina bifida without anencephalus	32	4.09	1,477	3.68
Cardiovascular				
Transposition of great arteries	45	5.69	1,901	4.73
Tetralogy of Fallot	40	5.03	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	28	3.56	1,748	4.36
Hypoplastic left heart syndrome	25	3.11	975	2.43
Orofacial				
Cleft lip with and without cleft palate	91	11.44	4,209	10.47
Cleft palate without cleft lip	59	7.43	2,567	6.39
Musculoskeletal				
Upper limb defect	17	2.15	1,521	3.79
Lower limb defect	10	1.26	763	1.90
Gastroschisis	38	4.75	1,497	3.73
Chromosomal				
Down syndrome	102	12.91	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Tennessee's Birth Defect Surveillance System

The Tennessee Birth Defects Registry (TBDR) collects prevalence information for 44 birth defects by abstracting data from the Hospital Discharge Data System (HDDS), and the Birth, Death and Fetal Death Statistical Data Systems. The TBDR also abstracts individual medical records to assess the accuracy of the TBDR data system. This includes information for all of Tennessee's 95 counties dating back to 1999. The most recent year of available data is 2005. These activities are performed in accordance to state law TCA 68-5-506.

Program information:

David J. Law, Ph.D.
Tennessee Birth Defects Registry
E-mail: david.law@tn.gov

John B. Daley, MS
Tennessee Birth Defects Registry
E-mail: john.daley@tn.gov

How birth defects data are used in Tennessee

TBDR data is used to provide annual information on birth defects prevalence and trends. These data also provide the basis to identify possible associations between birth defects and environmental hazards or other causes of birth defects, and to evaluate and guide birth defect prevention initiatives. The TBDR has shared information with public interest groups such as the March of Dimes, Tennessee Perinatal Association, Tennessee Folic Acid Foundation, CDC and NBDPN.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Texas and US

Defects	Texas [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	93	2.48	1,009	2.51
Spina bifida without anencephalus	135	3.58	1,477	3.68
Cardiovascular				
Transposition of great arteries	181	4.81	1,901	4.73
Tetralogy of Fallot	132	3.50	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	152	4.04	1,748	4.36
Hypoplastic left heart syndrome	78	2.06	975	2.43
Orofacial				
Cleft lip with and without cleft palate	413	10.97	4,209	10.47
Cleft palate without cleft lip	216	5.74	2,567	6.39
Musculoskeletal				
Reduction deformity, upper limbs	150	4.00	1,521	3.79
Reduction deformity, lower limbs	72	1.92	763	1.90
Gastroschisis	170	4.52	1,497	3.73
Chromosomal				
Down syndrome	478	12.71	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to prevent serious defects of the baby's brain and spinal cord.

Texas's Birth Defects Surveillance System

The Texas Birth Defects Registry was established in 1994 as the result of an unusual cluster of anencephaly in Brownsville. Since then, Texas has maintained an active, population-based surveillance system, which became statewide in 1999. An active surveillance approach, where staff routinely visit all hospitals to identify cases of birth defects, is considered the gold standard. More than 14,000 Texas babies are born each year with one or more major structural malformations. Birth defects are the second leading cause of infant deaths and the fourth leading cause of death among 1-14 year-olds in Texas.

Program information:

Mark A. Canfield, PhD
 Birth Defects Epidemiology and Surveillance Branch
 E-mail: Mark.Canfield@dshs.state.tx.us

Lisa K. Marengo, MS
 Birth Defects Epidemiology and Surveillance Branch
 E-mail: Lisa.Marengo@dshs.state.tx.us

Website: www.dshs.state.tx.us/birthdefects/

How birth defects data are used in Texas

The Texas Birth Defects Registry monitors all births in Texas (> 380,000 each year) to identify and describe the patterns of birth defects in Texas. The Registry collaborates with researchers in finding causes of birth defects and ultimately working towards prevention. Children identified through the Registry are referred to appropriate services.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Utah and US

Defects	Utah [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	12	2.33	1,009	2.51
Spina bifida without anencephalus	21	4.22	1,477	3.68
Cardiovascular				
Transposition of great arteries	22	4.46	1,901	4.73
Tetralogy of Fallot	18	3.61	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	27	5.50	1,748	4.36
Hypoplastic left heart syndrome	18	3.65	975	2.43
Orofacial				
Cleft lip with and without cleft palate	66	13.29	4,209	10.47
Cleft palate without cleft lip	38	7.63	2,567	6.39
Musculoskeletal				
Upper limb defect	32	6.34	1,521	3.79
Lower limb defect	9	1.77	763	1.90
Gastroschisis	26	5.30	1,497	3.73
Chromosomal				
Down syndrome	78	15.74	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Utah’s Birth Defect Surveillance System

The Utah Birth Defect Network (UBDN) is a state wide population based birth defect surveillance system. The UBDN began by monitoring neural tube defects in 1994. Select defects were added each year until all major structural malformations were being tracked in 1999. Multiple sources of ascertainment are maintained to insure accuracy and completeness of data.

How birth defects data are used in Utah

The UBDN has monitored over 650,000 births. Data has been collected on over 11,000 children born in Utah with major structural birth defects. These data are used to: detect and respond to birth defect epidemics in Utah; identify potential risk factors; plan, establish and evaluate primary prevention activities; and to identify potential participants for specific birth defect studies. The UBDN also provides information to concerned parents and their healthcare providers regarding their child’s birth defect.

Program information:

Miland Ned Palmer, MPH, RHIA
 Utah Birth Defect Network
 E-mail: mpalmer@utah.gov

Marcia Lynn Feldkamp, PhD, PA, MSPH
 Utah Birth Defect Network
 E-mail: marcia.feldkamp@hsc.utah.edu

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Vermont and US

Defects	Vermont		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	--	--	1,009	2.51
Spina bifida without anencephalus	--	--	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	--	--	4,209	10.47
Cleft palate without cleft lip	--	--	2,567	6.39
Musculoskeletal				
Upper limb defect	--	--	1,521	3.79
Lower limb defect	--	--	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	--	--	5,132	12.78

* per 10,000 live births

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Vermont's Birth Defect Surveillance System

Vermont's Birth Information Network began data collection with 2006 births. In early 2010 information based on three years of data will be pooled to provide Vermont-specific prevalence rates.

How birth defects data are used in Vermont

The Vermont Birth Information Network provides referrals to families of infants with birth defects. The data will also be used to provide accurate counts of children with birth defects to ensure that adequate services are available; to find ways to prevent or reduce the impact of birth defects; to improve overall health services; to evaluate prevention activities; and to document possible links between environmental and chemical exposure with birth defects of Vermont's infants and children.

Program information:

Peggy Brozicevic
 Birth Information Network (BIN)
 E-mail: pbrozic@vdh.state.vt.us

John Burley
 Birth Information Network (BIN)
 E-mail: jburley@vdh.state.vt.us

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Virginia and US

Defects	Virginia [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	3	0.34	1,009	2.51
Spina bifida without anencephalus	40	3.95	1,477	3.68
Cardiovascular				
Transposition of great arteries	50	4.93	1,901	4.73
Tetralogy of Fallot	51	4.99	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	42	4.11	1,748	4.36
Hypoplastic left heart syndrome	26	2.53	975	2.43
Orofacial				
Cleft lip with and without cleft palate	104	10.26	4,209	10.47
Cleft palate without cleft lip	76	7.54	2,567	6.39
Musculoskeletal				
Upper limb defect	18	1.80	1,521	3.79
Lower limb defect	13	1.32	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	120	11.86	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Program information:

Sharon K. Williams, MS, RN
 Virginia Congenital Anomalies Reporting & Education System
 E-mail: Sharonk.Williams@vdh.virginia.gov

Nancy C. Ford, MPH, RN
 Virginia Congenital Anomalies Reporting & Education System
 E-mail: nancy.ford@vdh.virginia.gov

Virginia's Birth Defect Surveillance System

Virginia Congenital Anomaly Reporting and Education System (VaCARES) has collected state-wide birth defect data since 1987. VaCARES is a web-based system that identifies more than 4,000 Virginia infants born with birth defects each year. In addition to birth defect data collected from birthing, pediatric and tertiary care hospitals, VaCARES also ascertains cases from the 3 regional genetic centers. System improvements scheduled for completion in calendar year 2009 will support VaCARES within the same system as the Electronic Birth Certificate. This linkage ensures more comprehensive reporting of affected children.

How birth defects data are used in Virginia

Data is used to provide routine statistical monitoring, public health program evaluation, baseline rates, rates by demographic and other variables, as well as other data related activities. VaCARES data is also used to provide families with defect specific educational material and service related resource information for children and families affected by birth defects.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Washington and US

Defects	Washington [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	5	0.65	1,009	2.51
Spina bifida without anencephalus	17	2.12	1,477	3.68
Cardiovascular				
Transposition of great arteries	--	--	1,901	4.73
Tetralogy of Fallot	--	--	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate	91	11.11	4,209	10.47
Cleft palate without cleft lip	47	5.80	2,567	6.39
Musculoskeletal				
Upper limb defect	16	1.92	1,521	3.79
Lower limb defect	9	1.14	763	1.90
Gastroschisis**	45	5.25	1,497	3.73
Chromosomal				
Down syndrome	107	13.07	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2003-2005 (passive case ascertainment)

** estimates based on pooled data from birth years 2005-2006 (active case ascertainment)

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby’s brain and spinal cord.

Washington’s Birth Defect Surveillance System

The Washington State Birth Defects Surveillance System (BDSS) began in 1986 as a state-wide active surveillance system. Since 1992, the system has been a passive surveillance system that relies on hospitals to report cases of children with birth defects. The BDSS currently monitors the prevalence of nine conditions: anencephaly, spina bifida, cleft lip with and without cleft palate, cleft palate alone, hypospadias/epispadias, limb reduction defects, gastroschisis, omphalocele, and Down syndrome.

How birth defects data are used in Washington

An estimated 2500 to 3400 children are born with birth defects in Washington each year. The Washington BDSS monitors the magnitude and trends in birth defects over time. The data are used to evaluate unusual occurrences in reported birth defects and have been utilized in recent birth defect cluster investigations. The BDSS also works with other programs to increase the awareness of birth defects in Washington State.

Program information:

Kevin Beck, MA
 Washington State Birth Defects Surveillance System
 E-mail: kevin.beck@doh.wa.gov

Katie Hutchinson, PhD, MSPH
 Washington State Birth Defects Surveillance System
 E-mail: katie.hutchinson@doh.wa.gov

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, West Virginia and US

Defects	West Virginia [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	2	1.30	1,009	2.51
Spina bifida without anencephalus	7	3.89	1,477	3.68
Cardiovascular				
Transposition of great arteries	7	3.67	1,901	4.73
Tetralogy of Fallot	8	4.32	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	6	3.03	1,748	4.36
Hypoplastic left heart syndrome	3	1.73	975	2.43
Orofacial				
Cleft lip with and without cleft palate	4	1.95	4,209	10.47
Cleft palate without cleft lip	8	4.54	2,567	6.39
Musculoskeletal				
Upper limb defect	1	0.54	1,521	3.79
Lower limb defect	1	0.54	763	1.90
Gastroschisis	--	--	1,497	3.73
Chromosomal				
Down syndrome	21	11.35	5,132	12.78

* per 10,000 live births

† estimates based on pooled data from birth years 2001-2005

‡ estimates based on pooled data from birth years 1999-2001

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Program information:

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

Kathryn G. Cummons, MSW

E-mail: kathycummons@wvdhhr.org

Melissa A. Baker, MA

E-mail: melissabaker@wvdhhr.org

Website: <http://www.wvdhhr.org/caress/>

West Virginia's Birth Defect Surveillance System

West Virginia birth defects system is a passive system housed within the Office of Maternal, Child and Family Health of the Bureau for Public Health in the Department of Health and Human Resources. The system collects birth defects data from all birthing facilities across the state and monitors the prevalence.

How birth defects data are used in West Virginia

West Virginia birth defects data are used to detect trends and patterns in the occurrence of birth defects in the state. These data are used for research, evaluation and prevention activities. WV CARESS also partners with Children Special Health Care Needs Systems Point of Entry, also housed in the Office of Maternal, Child and Family Health, to ensure parents of infants identified with birth defects are aware of services available to them and their families.

About 1 out of every 33 babies is born with a major birth defect.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Wisconsin and US

Defects	Wisconsin [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	10	1.53	1,009	2.51
Spina bifida without anencephalus	17	2.60	1,477	3.68
Cardiovascular				
Transposition of great arteries	11	1.74	1,901	4.73
Tetralogy of Fallot	12	1.89	1,574	3.92
Atrioventricular septal defect (also known as endocardial cushion defect)	9	1.40	1,748	4.36
Hypoplastic left heart syndrome	10	1.50	975	2.43
Orofacial				
Cleft lip with and without cleft palate	60	9.13	4,209	10.47
Cleft palate without cleft lip	41	6.29	2,567	6.39
Musculoskeletal				
Upper limb defect	19	2.93	1,521	3.79
Lower limb defect	8	1.28	763	1.90
Gastroschisis	39	5.99	1,497	3.73
Chromosomal				
Down syndrome	70	10.69	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Wisconsin's Birth Defect Surveillance System

Wisconsin has operated a passive registry, the Wisconsin Birth Defects Registry (WBDR), housed in the Maternal and Child Health section in the Division of Public Health, since 2003 following passage of legislation and administrative rules requiring the establishment of a registry and an advisory council. The WBDR is a secure web-based system that allows for both entry of an individual report and uploading of multiple reports from an electronic patient records system. The WBDR also accepts paper reports. Wisconsin leads one or more prevention projects each year and partially funds a stillbirth project that reports identified birth defects to the WBDR.

How birth defects data are used in Wisconsin

Wisconsin has about 72,000 births a year. Birth certificate data is used for comparison purposes and for outreach to underreporting areas. Researchers also request and receive WBDR data for research purposes most recently on cleft lip/palate. Five Regional Centers for CYSHCN use birth defects data for outreach to families and referral and follow-up activities.

Program information:

Elizabeth Oftedahl, MPH
 Wisconsin Birth Defects Registry
 E-mail: Elizabeth.Oftedahl@dhs.wisconsin.gov

Peggy Helm-Quest, MEd, MHA, CHES
 Wisconsin Birth Defects Registry
 E-mail: Peggy.HelmQuest@dhs.wisconsin.gov

Website: <https://wbdr.han.wisc.edu/index.html>

Approximately 1 baby out of every 216 is born with a major birth defect in Wyoming.

Birth defects cause one in five deaths among infants less than a year old.

Birth defects lead to \$2.5 billion per year in hospital costs alone in the U.S.

Selected birth defects counts and birth prevalence, Wyoming and US

Defects	Wyoming [†]		US [‡]	
	Annual no. of cases	Birth prevalence*	Annual no. of cases	Birth prevalence*
Central nervous system				
Anencephalus	2	0.60	1,009	2.51
Spina bifida without anencephalus	10	2.99	1,477	3.68
Cardiovascular				
Transposition of great arteries [§]	--	--	1,901	4.73
Tetralogy of Fallot [§]	--	--	1,574	3.92
Atrioventricular septal defect [§] (also known as endocardial cushion defect)	--	--	1,748	4.36
Hypoplastic left heart syndrome [§]	--	--	975	2.43
Orofacial				
Cleft lip with and without cleft palate [§]	--	--	4,209	10.47
Cleft palate without cleft lip [§]	--	--	2,567	6.39
Cleft lip/palate	48	14.37	--	--
Musculoskeletal				
Upper limb defect	20	5.99	1,521	3.79
Lower limb defect	41	12.28	763	1.90
Gastroschisis	9	2.69	1,497	3.73
Chromosomal				
Down syndrome	18	5.39	5,132	12.78

* per 10,000 live births

[†] estimates based on pooled data from birth years 2001-2005

[‡] estimates based on pooled data from birth years 1999-2001

[§] data not collected to this level of specificity

-- No data available

Note: Due to variability in the methods used by state birth defects surveillance systems and differences in populations and risk factors, state prevalence estimates may not be directly comparable with national estimates or those of other states.

Preventing birth defects

- The causes of about 70% of birth defects are unknown.
- Many birth defects happen during early pregnancy, often before a woman knows she is pregnant.
- Addressing health risks and behaviors before pregnancy can reduce the risk of poor birth outcomes, including some birth defects.
- All women who could become pregnant should take 400 micrograms of folic acid every day to help prevent serious defects of the baby's brain and spinal cord.

Wyoming's Birth Defect Surveillance System

Currently the state of Wyoming does not perform birth defects surveillance. In 2009 the Wyoming Health Department, Community and Public Health Division will be developing a statewide plan for birth defects surveillance. The statewide plan will establish a passive birth defects surveillance system to be initiated in 2010.

Program information:

Angela Crotsenberg, MS.
Wyoming Department of Health
E-mail angi.crotsenberg@health.wyo.gov

Christopher Hill, MPH, CPH
Wyoming Department of Health
E-mail christopher.hill1@health.wyo.gov