Metropolitan Atlanta Congenital Defects Program

Monitoring babies since 1967

2002

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

It is with great pride that we bring to you this 2002 Report on the Metropolitan Atlanta Congenital Defect Program (MACDP). For over 30 years, the Centers for Disease Control and Prevention has developed valuable partnerships throughout the metropolitan Atlanta area to create and maintain MACDP, a birth defects monitoring program that is a model for other programs around the Nation. This report reflects the ongoing excellence of the research and monitoring program and the dedication of our staff at the National Center on Birth Defects and Developmental Disabilities, CDC, and our colleagues in metropolitan Atlanta.

Birth defects continue to be the leading cause of infant mortality. For birth defect prevention strategies to be effective, they need a strong monitoring program. In Georgia, MACDP serves this purpose, and we are proud that the State was awarded an "A" by the Trust for America's Health in their recent review of state-based birth defect surveillance programs. We are also proud of the wealth of data that MACDP provides for researchers who work to uncover more causes of birth defects.

We hope that this report is useful in your efforts to prevent birth defects, and we thank you for your work on this critical public health issue. In working together and sharing information and ideas, we move one step closer to ensuring the health of all babies.

Sincerely,

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Director
National Center on Birth Defects and
Developmental Disabilities
Centers for Disease Control and Prevention

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MACDP

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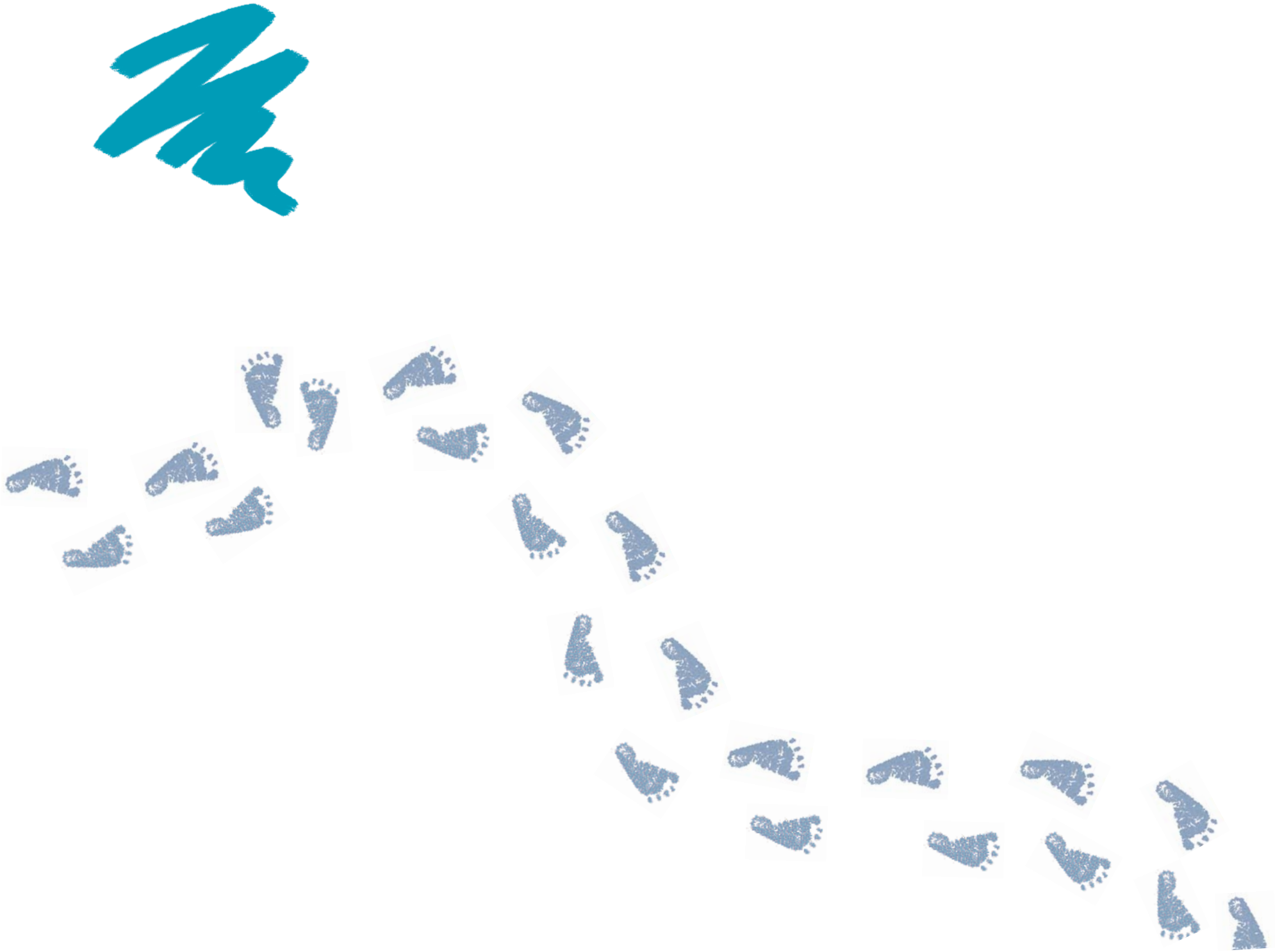
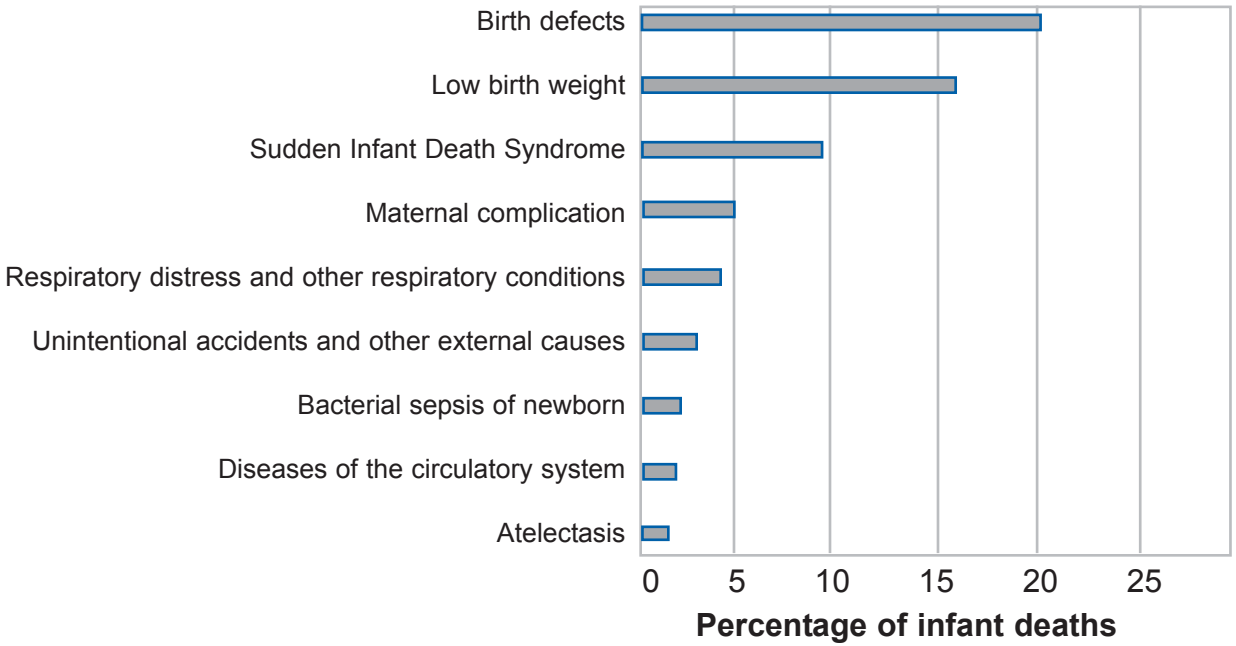


Impact of Birth Defects

Birth defects are the leading cause of infant mortality in the United States, accounting for 20% of all infant deaths. Of about 120,000 U.S. babies born each year with a birth defect, nearly 6,000 die during their first year of life. In addition, birth defects are the fifth leading cause of years of potential life lost and contribute substantially to childhood morbidity and long-term disability. Birth defects also account for 30% of all pediatric hospital admissions. Annual costs for birth defect-related conditions are nearly $2 billion.

Because the causes of about 70% of all birth defects are unknown, there continues to be concern about whether environmental pollutants cause birth defects, developmental disabilities, or other adverse reproductive outcomes. There are additional questions about whether various occupational hazards, genetic and dietary factors, medications, and personal behaviors cause or contribute to birth defects.

Leading Causes of Infant Mortality
United States, 1999



Source: National Vital Statistics Report, 1999

History of MACDP

The Metropolitan Atlanta Congenital Defects Program (MACDP) was established in 1967 by the Centers for Disease Control and Prevention with Emory University and the Georgia Mental Health Institute as the nation's first population-based active ascertainment birth defects surveillance program, which means the CDC does not wait for defects to be reported by hospitals, but rather goes to the hospitals and clinics to monitor records for all births.

For over 30 years, MACDP has served multiple purposes which include monitoring the incidence of birth defects, serving as a data source for a variety of epidemiologic studies, developing and evaluating intervention and prevention strategies, and providing data for health policy decisions.

MACDP also acts as the model for many state-based programs and as a resource for the development of uniform methods and approaches to birth defect surveillance.

An effective surveillance system is an important tool to:

- Detect trends and birth defect clusters
- Identify risk factors for birth defects
- Guide and assess the progress of prevention
- Have the ability to coordinate with special health care delivery services
- Educate and advocate

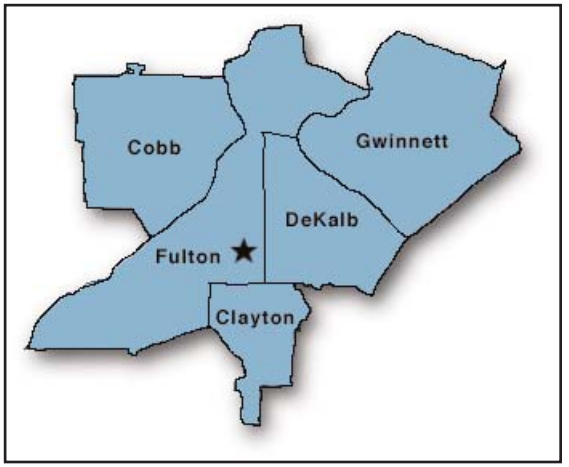
MACDP serves as a training ground for a large number of professionals active in birth defects epidemiology, including CDC Epidemic Intelligence Service Officers, visiting scientists, fellows, preventive medicine residents, and medical and public health students. Such training serves to build professional capacity in birth defects epidemiology in state health departments, federal agencies, universities, and private industry.

MACDP also serves as the source of case data for one of eight centers participating in the National Birth Defects Prevention Study (NBDPS). The NBDPS is one of the largest case-control studies ever conducted to evaluate the role of environmental and genetic factors in the occurrence of birth defects.

Methods

The MACDP monitors all major birth defects among infants and fetuses of 20 weeks or more gestation. A birth defect is defined by MACDP as a structural or chromosomal anomaly present at birth and recognized before six years of age.

The surveillance system covers five counties in the metropolitan Atlanta area (Clayton, Cobb, DeKalb, Fulton, and Gwinnett) with an estimated population of 2.9 million and an estimated 50,000 annual births.



MACDP Case Definition

- Child whose mother is a resident of five-county metropolitan Atlanta area at the time of birth
- Child with a birth defect on list of standard diagnoses
- Child with a birth defect diagnosed by the child s sixth birthday
- Live or stillborn infant with a gestational age greater than or equal to 20 weeks.

Birth defects are reportable diseases in Georgia. CDC is authorized by the Division of Public Health, Georgia Department of Human Resources to collect data on birth defects in Atlanta.

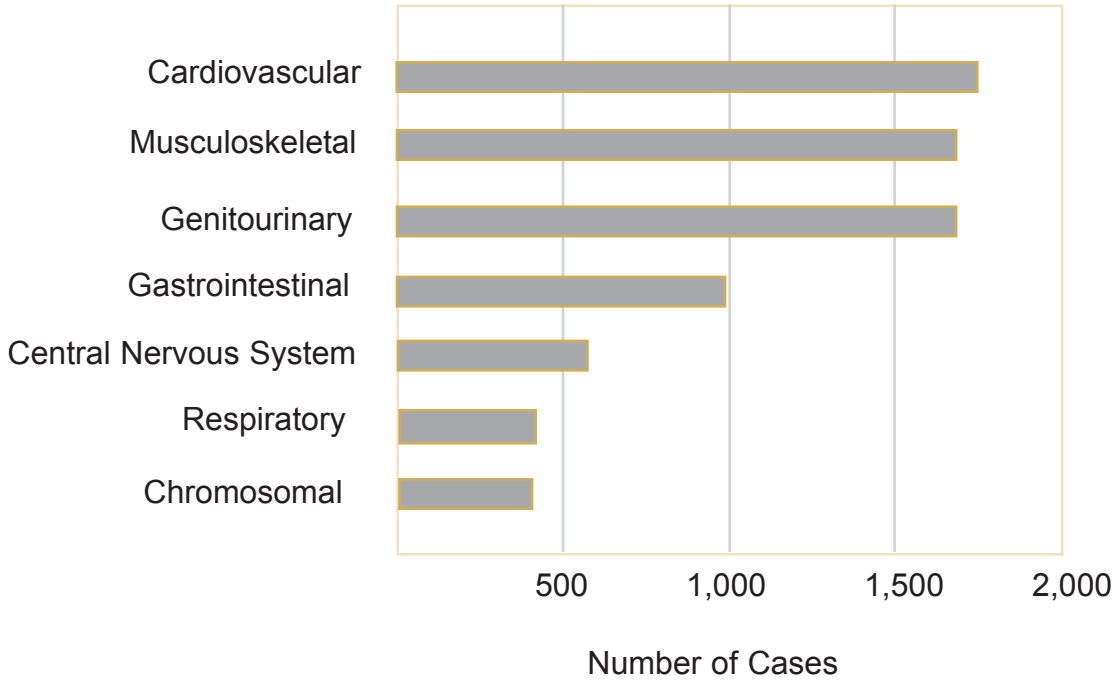
Babies and children born with birth defects are identified by a systematic review of hospital records for all births to residents of the five-county metropolitan area in, or infant referrals to, the area's approximate 18 hospitals and through vital records maintained by the State of Georgia. The highest level of confidentiality is maintained for all identifying information. The data are protected by the Privacy Act of 1974 and by an Assurance of Confidentiality that is granted by the Director of the CDC. Approval was granted to MACDP by CDC's Institutional Review Board in 1998.

Birth Defects in Metropolitan Atlanta

In the five-county metropolitan Atlanta area during 1996-1999, over 7,000 babies, 3.3% of all births, were born with a major birth defect.

In recent years, the ability to diagnose defects prenatally before 20 weeks of gestation has developed dramatically. Although MACDP began a monitoring system for these prenatal defects in 1994, the data in this report are limited to rates for infants and fetuses greater than or equal to 20 weeks gestational age.

Number of Selected Birth Defects Diagnosed by Organ System, Metropolitan Atlanta, 1996 - 1999



Rates of Selected Birth Defects in Metropolitan Atlanta

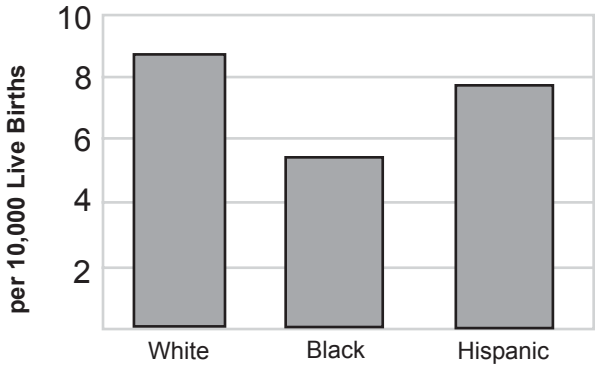
Rates are per 10,000 live births

		1996	1997	1998	1999
Central Nervous System	Spina bifida	3.4	4.2	4.7	1.1
	Anencephaly	2.2	1.9	2.4	2.6
	Encephalocele	1.7	1.4	1.1	1.9
Cardiovascular	Atrial septal defects	24.4	27.5	27.1	21.7
	Ventricular septal defects	33.5	34.0	35.8	41.7
	Pulmonary valve anomalies	7.6	7.0	6.0	5.7
	Coarctation of aorta	4.6	4.4	6.0	5.1
	Aortic valve anomalies	3.2	2.6	1.8	2.3
	Transposition of Great Arteries	6.1	4.2	4.5	4.9
	Tetralogy of Fallot	5.6	3.3	4.2	4.3
	Hypoplastic left heart syndrome	2.9	3.0	2.9	2.8
Orofacial	Cleft lip with and without cleft palate	9.8	7.2	10.9	8.5
	Cleft palate	7.3	4.4	6.2	7.4
Musculoskeletal	Clubfoot	16.4	14.7	19.1	16.6
	Reduction defect of upper limb	4.2	3.3	4.0	3.2
	Reduction defect of lower limb	2.2	1.9	1.6	1.3
Chromosomal	Down syndrome	12.7	11.2	12.9	13.8
	Trisomy 18	2.0	2.8	2.7	3.6
	Trisomy 13	1.0	2.1	1.3	1.5
	22q11.2 deletion	1.5	2.2	1.6	1.5
Eye	Cataract	2.9	2.1	1.6	1.3
	Anophthalmos and microphthalmos	3.4	3.0	2.4	2.1
Genitourinary	Hypospadias	36.4	33.8	29.6	37.0
	Anomalies of renal pelvis and ureter	6.4	3.5	3.3	5.5
	Ambiguous genitalia	0.2	0.9	2.0	0.9

Neural Tube Defects

Neural tube defects (NTDs) are congenital malformations of the central nervous system (i.e., the brain and spinal cord) in which the neural tube, which is the foundation of the central nervous system, fails to close properly in the first 28 days following conception. NTDs result in physical and neurological impairments, which are often disabling and in some cases fatal. Those surviving with an NTD face enormous financial and emotional burdens in addition to the life long physical disabilities.

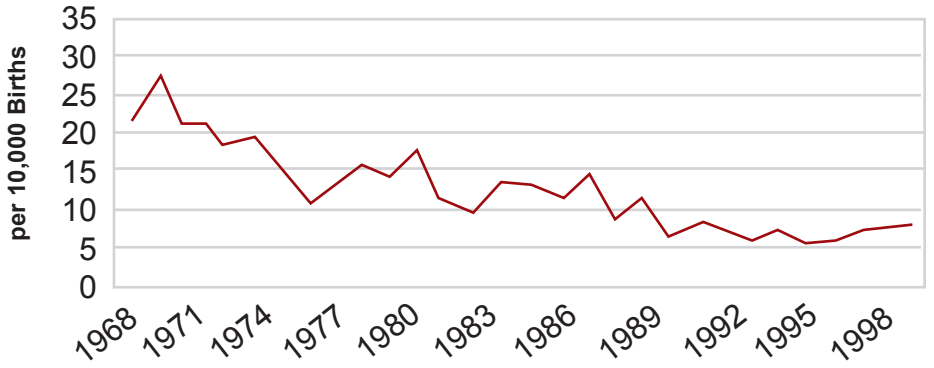
NTD Rates by Race/Ethnicity, 1996 - 1999



An inadequate intake or metabolism of folate can be a risk factor for NTDs. If all women of childbearing age consumed 400 micrograms of folic acid every day, rates of children born with an NTD would drop by 50%-70%. Because NTDs form in the first 28 days following conception, before most women know they are pregnant, it is critical for women to to start getting enough folic acid before becoming pregnant. The U.S. Public Health Service recommends that all women of child bearing age who are capable of becoming pregnant consume 400 micrograms of synthetic folic acid daily either through supplements, such as a multivitamin, or through food fortified with folic acid.

NTD rates in the metropolitan Atlanta area have fallen steadily over the last 30 years; however, there continues to be a racial disparity in the birth prevalence of NTDs.

NTD Rates in Metropolitan Atlanta



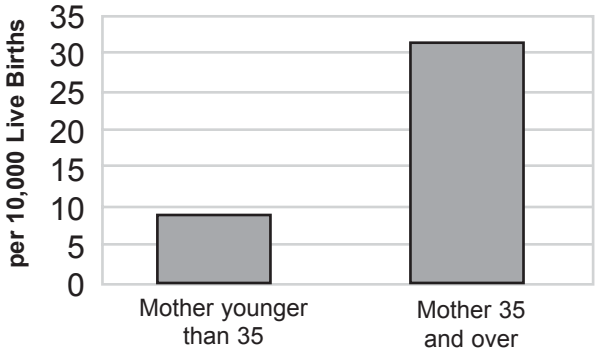
Down Syndrome

Of the 100 children born in the Atlanta area in 1999 with a chromosomal disorder, over half of those were born with Trisomy 21, or Down syndrome. A person typically has 23 pairs of chromosomes, but babies with Down syndrome are born with an extra chromosome number 21.

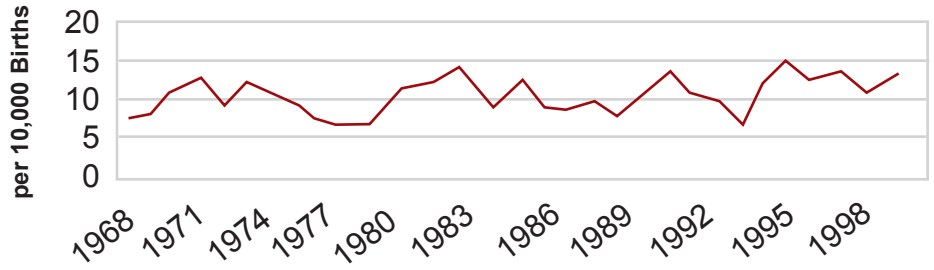
Although all the risk factors for Down syndrome are not yet known, maternal age at the time of pregnancy can be a risk factor. The most dramatic increase in risk comes with a maternal age of 35 or older. In the Atlanta area, the differences in the rate are three times higher for women over the age of 34. Concern is increased because of the growing percentage of women who are giving birth over the age of 35. Between 1990 and 1999, that percentage increased from 10% to 15%.

Chromosomal disorders such as Down syndrome can be diagnosed postnatally through blood tests and prenatally through a diagnostic test such as an amniocentesis, which tests cells in the fluid surrounding the fetus. There are many clinical signs of Down syndrome including a variety of physical characteristics and cognitive delays.

Down Syndrome Rates by Maternal Age, Metropolitan Atlanta, 1996-99



Down Syndrome Rates in Metropolitan Atlanta



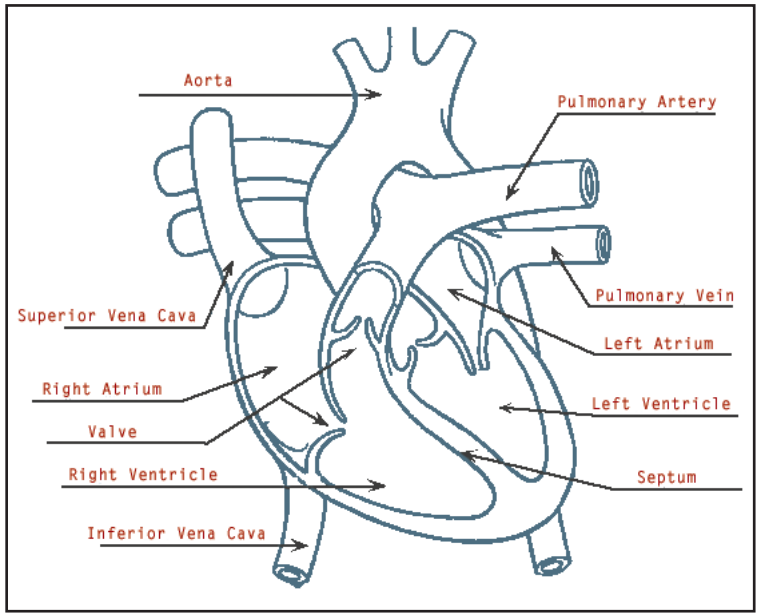
Congenital Heart Defects

Congenital abnormalities of the heart affect more infants born in Georgia than any other type of birth defect. One of every 120 babies born in the metropolitan Atlanta area are born with a congenital heart defect.

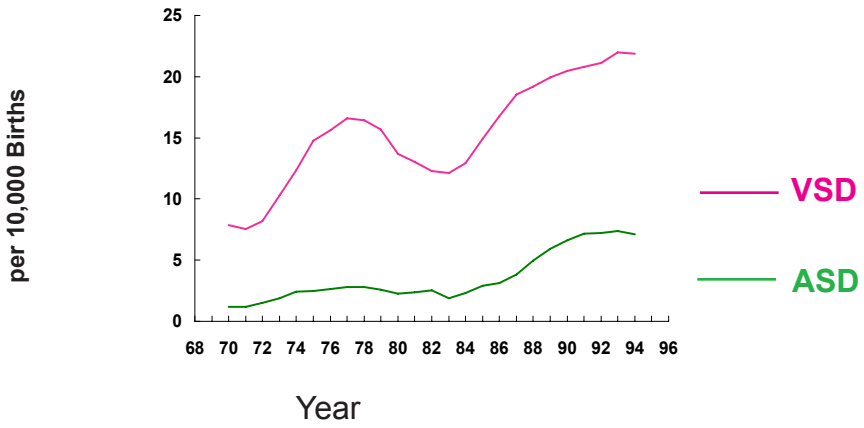
While many defects are not considered severe, defects of the heart are responsible for more infant deaths than any other birth defect. In many cases, the intensive treatment during the first years to correct the abnormality is followed by a lifetime of costly care.

The two most common types of heart defects are ventricular septal defect (VSD) and atrial septal defect (ASD). In both cases, a hole in the wall between the heart chambers disrupts the flow of blood and oxygen to the body. In some cases, clinical symptoms result that need to be corrected surgically. The severity and necessity of treatment are dependent on the size of the opening.

Rates for VSD and ASD have risen in recent years mainly due to more widespread use of sophisticated technology to detect these defects.



Rates of VSD and ASD in metropolitan Atlanta from 1968-1999



Though less common, other heart conditions such as Tetralogy of Fallot and transposition of the great arteries are much more serious and complex to treat. Approximately four to five children per 10,000 are affected by each of these defects.

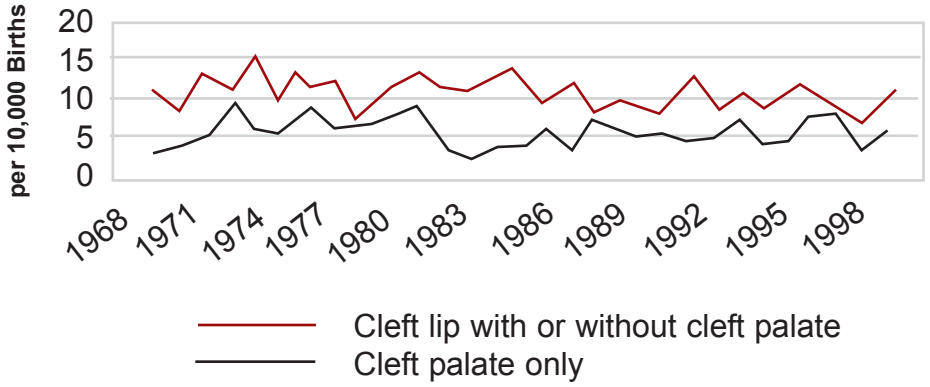
In most cases, it is not known what causes congenital heart defects, however a condition like Down syndrome may affect multiple organs in the body including the heart. Other possible risk factors are viral infections, genetics (i.e., a family member with a congenital heart defect), maternal consumption of alcohol, maternal diabetes, some prescribed medications, and some recreational drugs.

Orofacial Clefts

Clefts of the lip and palate occur when structures of the mouth fail to develop properly. These defects typically occur early in fetal development between four and ten weeks after conception. Cleft lip and palate may occur separately or together. A cleft lip involves the space between the upper lip and the nostrils, and clefts of the palate may occur in the front of the palate, which involves underlying bone, or in the back area involving soft tissue. Infants born with a cleft typically undergo surgery and receive speech therapy and orthodontia care.

Orofacial clefts affect about one of every 680 metropolitan Atlanta children. The estimated prevalence was 14.7 per 10,000 live births from 1996-1999. The cause of clefts is still not known, but studies indicate that both genetic and environmental factors may play a role. Current research is examing each of these as well as any potential relationships between the two.

Rates of Cleft Lip and Palate in Metropolitan Atlanta



Studies using MACDP data have shown that multivitamin use may reduce the risk of some facial clefts. CDC researchers noted a 48% reduction in cleft lip with and without cleft palate among births to mothers who began taking a multivitamin by the first month following conception.

Research Projects & Publications

In addition to serving as a surveillance system, MACDP also provides invaluable data to ongoing research efforts to identify risk factors for birth defects. Below are a few brief examples of some of the past and current projects using data from MACDP.

Surveillance Studies

Congenital heart defects are a leading cause of morbidity and mortality among infants and are associated with enormous health care costs. In an effort to better understand current prevalence rates and distribution of congenital heart defects, MACDP data were used to provide a recent estimate of the burden of these anomalies, evaluate past and recent temporal trends, and assess whether these trends varied by race.

Pediatrics 107(3):E32 (2001)

Identifying Risk Factors

There is considerable evidence that genes and the environment interact to produce adverse effects in pregnancy outcomes. Using data from MACDP, researchers at the CDC unveiled a relationship between a gene-environment interaction and clubfoot. It is widely accepted that family history of clubfoot is a significant risk factor for this congenital malformation. This study showed that maternal smoking along with a family history of clubfoot increased the risk by far more than what would be expected.

American Journal of Epidemiology 152:658-65 (2000)

Researchers found that the pregnancy weight of the mother may affect the likelihood of having a child with a heart defect. In a study of over 1,000 Atlanta-area women who gave birth to a live infant with a major heart defect, women who were overweight were more likely to give birth to a child with a major heart defect than average weight women. Women who were underweight were less likely to have a child born with a major heart defect than average weight women. Taking a mulitivitamin at the time of conception reduced the risk for average and underweight women but did not do so for overweight women.

Epidemiology 12:439-446 (2001)

Multivitamin use is known to prevent neural tube defects and research suggests micronutrients may help prevent other types of birth defects. A case-control study examining cases of orofacial clefts, identified from the MACDP registry, found that there was 48% reduction in the risk for cleft lip with cleft palate among mothers who used multivitamins during the first month of pregnancy. No such protection was found among mothers who began vitamin use during or after the second month of pregnancy. This suggests that, like folic acid use to prevent neural tube defects, supplement usage is only beneficial before many women know they are pregnant. A similar reduction of risk for cleft palate alone was not observed, but the lack of such evidence may be due to the small number of cases with cleft palate only in the study.

Teratology 63:79-86 (2001)

Survival Studies

A recent study investigated the survival of a cohort of liveborn infants with spina bifida from 1979 to 1994 in the metropolitan Atlanta area and attempted to identify selected risk factors associated with their survival. The MACDP provided a unique look at survival rates by virtue of its population-based data and actively ascertained cases. The study revealed that survival among infants born with spina bifida has steadily improved. Survival was significantly poorer when lesions were in the upper part of the spine compared with low lesions and survival was also poorer with those infants with low birthweight.

Paediatric Perinatal Epidemiology 15(4):374-8 (2001)

Steps to a Healthy Pregnancy

Preconception

It is important to plan for your baby's health before you are pregnant. Consult your health-care provider to discuss preconception and prenatal care. If you think you may already be pregnant, see your health-care provider as soon as possible.

Take folic acid daily both before pregnancy and during the first few months. Consumption of 400 micrograms of folic acid can reduce the risk of birth defects of the brain and spine, but only if taken before and during the first weeks of development.

Tell your health-care provider about any history of problems with pregnancy or birth defects in your family.

Eat a healthy diet! It is best to be within 15 pounds of your ideal weight before pregnancy, if possible. Being overweight or underweight during pregnancy may lead to problems. Consult your health-care provider before making changes in your diet.

Get all needed vaccines before you become pregnant. Consult your health-care provider for guidelines about the use of vaccines during pregnancy.

During your pregnancy

Take iron supplements during your pregnancy, as prescribed by your health-care provider, to reduce the risk of anemia.

Exercise during pregnancy can benefit both you and your baby by lessening discomfort and fatigue, providing a sense of well-being, and speeding recovery after delivery. Always check with your health-care provider before beginning any kind of exercise, especially during pregnancy.

Make sure that medical conditions such as diabetes, epilepsy, and high blood pressure are treated and kept under control both before and during pregnancy. Some medications may need to be changed or adjusted during pregnancy.

Consult your health-care provider about any prescription or over-the-counter drugs you are taking or may consider taking during pregnancy. Over-the-counter cough and cold remedies may contain alcohol or other ingredients that should be avoided during pregnancy.

Avoid X rays while pregnant or when planning a pregnancy. If you must have dental work or diagnostic tests, tell your dentist or physician that you are pregnant so that extra care can be taken.

Avoid using alcohol and cigarettes while pregnant. There is no safe amount of alcohol a woman can drink while pregnant. Fetal alcohol syndrome, a disorder characterized by growth retardation, facial abnormalities, and central nervous system dysfunction, is caused by heavy alcohol use during pregnancy. Even small amounts of alcohol can cause learning and behavior problems in a child who was fetally exposed. Cigarette smoking during pregnancy has been associated with low birth weight, infertility, miscarriage, tubal pregnancy, infant mortality, and childhood morbidity. Secondary smoke may be harmful to a mother and her developing baby.

Avoid exposure to toxic chemicals such as cleaning solvents, lead, mercury, some insecticides, paint, and paint fumes.

Please consult your doctor on any issue regarding your pregnancy.

Sources of additional information *

National Center on Birth Defects and Developmental Disabilities
http://www.cdc.gov/ncbddd/
Phone: (770) 488-7150

CDC Office of Genomics and Disease Prevention
http://www.cdc.gov/genetics/default.htm

Children's Health Network -
Congenital Heart Disease Information & Resources
http://www.tchin.org
Phone: (215) 493-3068

International Clearinghouse for Birth Defects Monitoring Systems
www.icbd.org

March of Dimes, Georgia
http://www.marchofdimesga.com
Phone:(404)350-9800

National Birth Defects Prevention Network
http://www.nbdpn.org/

National Down Syndrome Society
http://www.ndss.org

National Organization for Rare Disorders
http://www.rarediseases.org

Forum on Child and Family Statistics
www.childstats.gov

National Society of Genetic Counselors
www.ngc.org

SMILES
http://www.cleft.org/

* These resources are provided solely as a service to our users. These links do not constitute an endorsement of these organizations or their programs by the CDC or the federal government, and none should be inferred. CDC is not responsible for the content of the individual organization Web pages found at these sites.

Acknowledgments

The MACDP and the National Center on Birth Defects and Developmental Disabilities would like to thank all the participating hospitals and clinics for their invaluable assistance in the gathering of birth defect data. It is this partnership that helps create the premier birth defects surveillance system in the country.

Atlanta Medical Center
Children's Healthcare of Atlanta at Egleston
Children's Healthcare of Atlanta at Scottish Rite
Crawford Long Hospital
DeKalb Medical Center
Emory Dunwoody Medical Center
Emory Eastside Medical Center
Emory Genetics Laboratory
Emory Parkway Medical Center
Grady Memorial/Hughes Spalding Children's Hospital
Gwinnett Medical Center
Genzyme Genetics
North Fulton Regional Hospital
Northside Hospital
Piedmont Hospital
Sibley Heart Center at Children’s Healthcare of Atlanta
South Fulton Medical Center
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WellStar Cobb Hospital
WellStar Kennestone Hospital

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