Arkansas Center For Birth Defects Research and Prevention

Arkansas Reproductive Health Monitoring System

Surveillance Data, 1993 — 1997

May 2000
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The Impact of Birth Defects

Birth defects are the leading cause of infant deaths and the fifth leading cause of potential years of life lost in the United States, where approximately 120,000 infants are born with major birth defects every year. Many of these infants require major surgery and prolonged hospitalizations. A single birth defect may require hundreds of thousands of dollars in health care and therapy costs. These costs are much higher if missed work time and family stress are included.

The Arkansas Center for Birth Defects Research and Prevention

In October 1997, the Arkansas Center for Birth Defects Research and Prevention (Arkansas Center) was established through a grant from the Centers for Disease Control and Prevention (CDC). Other Centers for Birth Defects Research and Prevention associated with state surveillance systems are located in California, Georgia, Iowa, Massachusetts, New Jersey, New York, and Texas.

The mission of the Arkansas Center is to reduce the prevalence of birth defects in Arkansas and the nation, as well as to reduce the economic, social, and psychological impact of birth defects at state and national levels. Goals of the Center include improving the Arkansas Reproductive Health Monitoring System (ARHMS), Arkansas’ statewide birth defects registry and using surveillance data to conduct research into the causes of birth defects, and to develop programs to help prevent birth defects.

The major research project being conducted by all of the Centers for Birth Defects Research and Prevention is the National Birth Defects Prevention Study. The purpose of this study is to gather information about environmental and genetic risk factors for 30 major structural birth defects. This project involves interviewing mothers of children with and without birth defects and obtaining cheek cell samples from the children and their parents. Interviews contribute information about environmental exposures where cheek cell samples provide genetic information. Each Center is responsible for completing interviews with 300 mothers of children with birth defects and 100 mothers of children without birth defects each year. When this study is completed, it will be one of the largest sources of information about factors that may increase the
risk for, or protect against, birth defects. Some of the information the Arkansas Center has collected for this study is described in the section about congenital heart defects located on page 11 of this report.

In addition to the National Birth Defects Prevention Study, the Arkansas Center has several local research projects, including:

- Studying the relationship of maternal micronutrient intake and genetic susceptibilities to congenital heart defects and neural tube defects
- Investigating the relationship of folate metabolism with Down syndrome
- Working with the United States Department of Agriculture’s Lower Mississippi Delta Nutrition Intervention Research Initiative to investigate folic acid knowledge and intake among women of the Lower Mississippi River Delta
- Collaborating with the Iowa Center for Birth Defects Research and Prevention to study the molecular epidemiology of cleft lip and palate
- Working with researchers from Emory University to determine risk factors for Down syndrome

The Arkansas Center is also involved in birth defects prevention activities such as the Arkansas Folic Acid Coalition. Folic acid helps to prevent neural tube defects (NTDs), serious birth defects of the brain and spinal cord. This coalition encourages women of childbearing age to take folic acid before they become pregnant. Additionally, the Arkansas Center is working with women who have had a previous NTD-affected pregnancy to educate them about the benefits of folic acid and to identify and overcome any barriers that may keep them from taking this vitamin.

The third goal of the Center is to improve Arkansas' existing birth defects registry, ARHMS. We are in the process of evaluating the surveillance system to improve its efficiency. We are also working to identify cases of birth defects more rapidly, and to disseminate information from the system more frequently.
The Arkansas Reproductive Health Monitoring System

The Arkansas Reproductive Health Monitoring System is the state’s program for the surveillance of birth defects. The main purpose of ARHMS is to count the number of birth defects that occur in Arkansas each year and to monitor trends in their occurrence. ARHMS is an active birth defects registry, and staff visit all hospitals throughout the state to obtain information about pregnancies that have been affected by birth defects. ARHMS includes all children who are born with a major structural birth defect and diagnosed before age two. Complete information about the case must be obtained within five years of the end of the pregnancy. All data are abstracted from hospital medical records and only diagnoses that are confirmed by a physician are included in the registry.

ARHMS is important to the health of Arkansans because it may be used to identify trends in the prevalence of birth defects and provide the basis for studies of their causes. Trends and clusters or groups of birth defects may be caused by factors such as demographic changes or the introduction of a new teratogen, which is a substance that causes birth defects.

A recent report from the Pew Environmental Health Commission at the Johns Hopkins University School of Public Health emphasized the need for birth defects surveillance across the United States. The report, entitled “Healthy from the Start: Why America Needs a Better System to Track and Understand Birth Defects and the Environment,” emphasized the fact that only about 20 percent of birth defects have known causes, while the causes of the majority await further research. However, there is increasing evidence that environmental factors, including diet, personal behavior and exposure to toxic substances and pollutants, may play an important role in the development of birth defects and related conditions.

ARHMS provides Arkansas with a starting point from which to formulate and test theories about the potential exposures and risk factors mentioned in the Pew Commission’s report. This research will lead to a better understanding of birth defects in Arkansas and help us target intervention programs to specific areas and populations in the state.

Birth Defects in Arkansas

All of the rates of birth defects included in this report are calculated as the number of defects per 10,000 live births. There are almost 37,000 births in Arkansas each year. As reported last year, congenital heart defects are the most common type of birth defects in Arkansas and the United States. Of particular interest is that the total number of cases of the neural tube defects (NTDs) spina bifida and anencephaly, decreased in Arkansas from 56 in 1996 to 39 in 1997. The prevalence of these NTDs for 1997 was 10 per 10,000 live births, a decrease from a prevalence of 15 per 10,000 live births in 1996. A section of this report is devoted to NTDs.

Additional sections of this report will focus on other prevalent birth defects in Arkansas, including Down syndrome and congenital heart defects, the importance of good nutrition during pregnancy, and the association between infectious diseases and birth defects.
## Prevalence of Selected Birth Defects in Arkansas

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* Excludes patent foramen ovale
Down Syndrome

Humans usually have 23 pairs of chromosomes, structures made of DNA that contain the individual's genetic information. Down syndrome is a common genetic birth defect that is caused by the presence of an extra chromosome 21. The presence of this extra chromosome is associated with a combination of clinical problems, including moderate to severe mental retardation. Down syndrome also increases the risk for congenital heart defects, gastrointestinal malformations and childhood leukemia.

The prevalence of Down syndrome at birth in the United States is approximately 9 per 10,000 live births. The prevalence of Down syndrome in Arkansas, 11.6 per 10,000 live births, is slightly higher than the national rate.

As is the case with many birth defects, we do not know all of the factors that may cause Down syndrome. Maternal age is the most studied risk factor for Down syndrome, and research has shown that the most dramatic increase in Down syndrome risk occurs after age 35. This difference can be seen in the table showing the prevalence of Down syndrome by maternal age in Arkansas. Studies show that the rate of Down syndrome is similar across all ethnic groups.

Recent research by Dr. S. Jill James, a scientist associated with the Arkansas Center and a researcher at the National Center for Toxicological Research suggests that a mother may have a higher risk of having a Down syndrome-affected pregnancy if she has certain genes that affect the way she metabolizes folic acid.

The average lifetime cost of Down syndrome, including medical and non-medical costs, is approximately $451,000. Early intervention programs may help to reduce some of the medical, emotional, and social costs associated with Down syndrome.

Intervention strategies for individuals with Down syndrome should be approached from a developmental perspective. Children with Down syndrome often do not demonstrate an even pattern of cognitive development. Strengths are frequently noted in adaptive and social intelligence, while speech and language skills may be comparatively delayed. This unevenness in development demonstrates the need for early and individual assessment of the child's strengths and weaknesses with emphasis on utilizing strengths and compensating for weaker skills.
Early intervention includes such services as screening infants for medical problems, providing nutritional meals to young children in low income family settings, and helping babies to develop important developmental skills. Early intervention benefits children, families, and society. Children who receive early intervention show significant improvement in development and learning. Early intervention helps improve the family’s self-esteem and enables the family to be their child’s best advocate. Appropriate early intervention may reduce the need for more costly special education programs when the child enters school. 

![Down Syndrome by Mother’s Age, Arkansas, 1993-1997](image1)

![Down Syndrome by Race, Arkansas](image2)
Limb Reduction Defects

Babies with limb reduction defects are born missing tissue or bone from one or more of the limbs. These birth defects can range in severity from problems with the hands or feet such as missing or webbed fingers and toes to the complete absence of one or more arms or legs. The best known cause of these defects is the drug thalidomide, which was used in the 1960’s to treat nausea during pregnancy. The drug was never approved for this purpose in the United States. The United States Food and Drug Administration (FDA) has recently approved the drug for limited use to treat a severe inflammatory condition in patients with Hansen’s Disease, also known as leprosy. Strict regulations have been imposed by the FDA, including limiting prescribers to only those registered with the program, pregnancy tests for women before and during treatment, and the use of at least two forms of reliable contraception simultaneously during treatment.* Since the limited approval of thalidomide, surveillance for limb reduction defects has become especially important.

While thalidomide is the best known cause of limb reduction defects, it is not the only risk factor. A mother who smokes cigarettes while she is pregnant may increase her baby’s risk of being born with a limb reduction defect.8;9 This risk seems to be especially high if the baby has a rare form of a gene called MSX1, which is involved in limb formation. If the baby has the rare form of this gene and the mother smokes, the risk of a limb reduction defect may increase up to 4.8 times.10

The accompanying tables show the prevalence of limb reduction defects in Arkansas. Overall, in the years 1993 through 1997, limb reductions were slightly more common in women over age 35, although the rate for this group did not exceed 4.5 per 10,000 live births. These data also showed a higher risk of upper limb reduction defects in Caucasians than in African-Americans. These findings have not been reported previously, and we will continue to observe whether this association persists over time.

*For further information on the use of thalidomide in Hansen’s Disease patients and thalidomide regulations please visit the FDA web site at www.fda.gov
As with other birth defects, adequate nutrition before pregnancy is vitally important to the prevention of limb reduction defects. Multivitamin supplementation before pregnancy may reduce the chance that the baby will have a limb defect. Limb development begins at the end of the 4th week following fertilization, usually before a woman thinks that she may be pregnant. This is just one of the many reasons why it is important for women of childbearing age to take a multivitamin supplement before pregnancy.
Spina bifida and anencephaly are major defects of the central nervous system (CNS). These defects are called neural tube defects (NTDs). They are caused by incomplete closure of the neural tube, which is the embryonic structure that later becomes the brain and the spine.

Spina bifida is caused by a defective closure of the encasement of the spinal cord. Spina bifida causes physical disabilities that vary with the location of the defect, which determines the severity. Anencephaly is the absence of the skull, with the cerebral hemispheres of the brain severely reduced or missing entirely.

Arkansas data from 1993 through 1997 indicate that NTDs are more prevalent in Caucasians than they are in African-Americans. This association has been shown in other populations as well. People of Hispanic origin are at highest risk for NTDs.¹²;¹³

As is the case with most birth defects, the origin of NTDs is multifactorial. Genetic factors do play a role in NTD risk.¹⁴-¹⁶ Rare forms of certain genes that are involved in the way that the body uses the vitamin folic acid have been shown to increase a woman’s risk of having a pregnancy affected by an NTD. The influence of these genetic factors may sometimes be reduced by changes in diet, including increasing intake of the vitamin folic acid. Women consuming a diet with adequate levels of the vitamin folic acid have a lower risk of having an NTD-affected pregnancy than women with deficient levels of folic acid.

Other risk factors for NTDs include maternal obesity and diabetes.¹⁷-²⁰ Women with these conditions should consult a physician prior to pregnancy, if possible, or as soon as pregnancy is confirmed.

* This chart does not include cases with mixed parentage or of races other than African-American and Caucasian due to difficulties in determining the denominators for these groups.
Congenital heart defects comprise the largest group of congenital anomalies. They affect approximately 4 of every 1,000 births in the United States each year. These defects are multifactorial in origin. More than one factor may contribute to the chance that a baby will have a heart defect. The risk of having a congenital heart defect is often genetic. For instance, if a baby has a chromosomal anomaly such as Down syndrome, the risk of that baby also having a congenital heart defect is much greater than for an infant without Down syndrome.

There are many maternal factors that increase the risk of having a pregnancy affected by a congenital heart defect. Mothers with diabetes that are not treated adequately are more likely to have a baby with a congenital heart defect. Also, if the mother does not take prenatal vitamins, the risk of a heart defect is increased. Several studies have shown that if a mother takes a multivitamin containing folic acid before and during pregnancy she can reduce the risk of these defects.\(^{21,22}\)

Because congenital heart defects affect so many children and families each year, it is important that more research be conducted into the causes of these conditions. The Arkansas Center is helping in this effort by participating in the National Birth Defects Prevention Study. The table below lists some categories of heart defects that are included in this study, and the prevalence of these defects in Arkansas in 1998. The Arkansas Center is also working to develop local studies to investigate the association of maternal micronutrient intake and congenital heart defects for children in Arkansas.

### Congenital Heart Defects in Arkansas, 1998

<table>
<thead>
<tr>
<th>Defect</th>
<th>Total Number</th>
<th>Prevalence per 10,000 Live Births</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conotruncal Heart Defects</td>
<td>25</td>
<td>6.8</td>
</tr>
<tr>
<td>Obstructive Heart Defects</td>
<td>39</td>
<td>10.6</td>
</tr>
<tr>
<td>Septal Heart Defects</td>
<td>188</td>
<td>51.0</td>
</tr>
<tr>
<td><strong>Total, 1998</strong></td>
<td><strong>252</strong></td>
<td><strong>68.4</strong></td>
</tr>
</tbody>
</table>
Infectious Diseases and Birth Defects

Infections that are transmitted from the mother to the baby during pregnancy may result in disabilities and deaths in infants and children. This transmission may occur if the mother has only recently been infected, or if she has a chronic infection. It is important that a woman who is thinking of becoming pregnant be tested for certain infections, and be vaccinated against others before becoming pregnant.

Cytomegalovirus and Toxoplasmosis

Cytomegalovirus (CMV) and toxoplasmosis are two infectious agents that may only cause mild illness in people with healthy immune systems. However, if a pregnant woman is infected by these agents it may have adverse effects for the infant that she is carrying.

Cytomegalovirus is the leading infectious cause of brain damage and hearing loss in children. Between 30,000 and 35,000 infants infected with CMV are born in the United States each year. Although CMV may cause only mild symptoms in the mother, it may cause mental retardation and growth and hearing problems in the infant, and some infants severely affected by CMV will die.

Toxoplasmosis is a disease caused by a parasite that can be transmitted to humans from animals. Like CMV, toxoplasmosis infection is usually mild or asymptomatic in adults but can cause vision and hearing problems or mental retardation in an infant if the mother becomes infected during pregnancy. Toxoplasmosis can be prevented by handling raw meat correctly, cooking meat thoroughly, and avoiding contact with cat feces. If a pregnant woman is at risk of infection, early testing and treatment can reduce the risk of transmission to the baby.
Rubella

Rubella, sometimes called German Measles, is a viral infection that can impart severe consequences for a pregnancy. If a woman contracts rubella early in her pregnancy, particularly in the first 16 weeks, it can lead to miscarriage, stillbirth, or birth defects. The pattern of birth defects caused by rubella during pregnancy is called Congenital Rubella Syndrome (CRS). Characteristics of CRS include central nervous system, cardiovascular, vision, and hearing defects. Luckily, rubella is a vaccine-preventable disease and can be prevented if a woman is vaccinated before she becomes pregnant. Most United States citizens are vaccinated before they begin school, but it is especially important for women from countries without a rubella vaccination program to be immunized.

Sexually Transmitted Diseases

Sexually transmitted diseases (STDs) may be asymptomatic but they do pose a risk to the fetus that an infected woman is carrying. Herpes simplex virus has two important sub-types: type 1 usually causes cold sores around the mouth, while type 2 usually is responsible for genital herpes. A baby might become infected with the virus during delivery if the mother was having her first episode of genital herpes, or in the rare circumstance of high viral production in a subsequent episode. The presence of the virus may also increase chances of premature birth or miscarriage. Syphilis is another STD that can cause problems for the baby if the mother is infected. Transmission from the mother to the fetus can cause nervous system and musculoskeletal problems, and rarely death. Chlamydia causes conjunctivitis and respiratory infections in the infant and may increase a woman’s risk of having an ectopic pregnancy.
Nutrition and Pregnancy

A diet high in vitamins and minerals is essential for a healthy pregnancy. The best sources of daily nutrients are readily available foods such as fresh fruits and vegetables. The United States Department of Agriculture’s Food Pyramid is an excellent dietary guide (See Figure next page). Additionally, the evaluation of a pregnant woman’s dietary pattern by a licensed/registered dietitian or other health care professional may help to identify beneficial dietary changes and realistic ways to implement them into a daily routine.²⁸ The Nutrition Services Section at the Arkansas Department of Health (ADH) counsels low-income and nutritionally at-risk childbearing women through various services, including the Special Supplemental Nutrition Program for Women, Infants and Children (WIC). These services are available to all women through clinics that are located in every county in the state. WIC is designed to have an impact on a child’s development during the most crucial stages of his or her growth: (1) prenatally, (2) during infancy and (3) in early childhood. WIC achieves its goals by providing food and nutrition counseling for childbearing women, infants, and children, and increasing the participant’s access to other health services.

Unfortunately many women do not receive sufficient amounts of vitamins and minerals from the foods that they eat, and this has been shown to be true for the vitamin folic acid. Therefore, the Institute of Medicine recommends that, in addition to eating a varied diet, women capable of becoming pregnant also take a supplement containing 400 micrograms of folic acid for the prevention of neural tube defects.²⁹ Foods high in folate include orange juice, green leafy vegetables, liver, and dried beans. Folic acid can be found in fortified breakfast cereals and in vitamin supplements.
The USDA Food Pyramid consists of 5 serving groups: (1) milk (2) meat (3) vegetable (4) fruit and (5) grains.

In the figure above, the Food Guide shows the daily serving amounts needed by pregnant women.

**The ADH Nutrition Services suggests the following for pregnant women:**

- Eat Right
- Eat fruits and vegetables daily
- Eat regular meals, avoid skipping meals
- Choose healthy snacks instead of candy, chips, or soft drinks
- Healthy snack examples: yogurt, fruit, fruit juices, milk, cheese and crackers and peanut butter and crackers
- Eat iron-rich foods every day
- Iron-rich foods examples: cereals fortified with iron, beef, chicken, fish, whole wheat bread, enriched bread, rice, pasta, dried beans and peas, and greens and spinach
- Drink water several times a day
- Pregnant women should consult their health care provider before changing their diet and exercise program
Steps to Prevent Birth Defects

A healthy lifestyle before pregnancy will help expectant mothers manage the day-to-day stress of pregnancy, labor and delivery. With extra preparation, the expectant mother can be sure that she is not exposing her baby or herself to harmful situations. The American College of Obstetricians and Gynecologists recommends that women with the ability to become pregnant and expectant mothers should take the following measures to reduce the risk of birth defects and improve the health of the fetus.32

- Have a medical checkup before conceiving. During this visit, the doctor will discuss the patient’s medical history, contraceptive use, previous pregnancies and her daily activities.

- Consult a physician about health problems such as high blood pressure before and during the pregnancy. These conditions will need to be supervised by a doctor. For instance, expectant mothers with diabetes are two or three times more likely to give birth to a child with severe birth defects. A woman can increase her chances of having a healthy baby with a proper diet, exercise, and blood sugar level maintenance before and during her pregnancy.

- Keep immunizations and vaccines current. If a woman is vaccinated before becoming pregnant, she will be protecting herself and her unborn children. A woman should be immunized approximately 3 months before trying to have a baby. Consult a physician for additional information.
- Obtain a healthy weight before becoming pregnant.
- Eat a nutritious diet that includes fruits and vegetables and is also low in fat and high in fiber. Consult a physician for additional information.
- Take 0.4 mg of folic acid before and during pregnancy. Folate is available in a variety of foods and also in multivitamin supplements.
- Avoid the use of alcohol, illicit drugs, and tobacco products. These substances are associated with birth defects and they can hurt mothers and their unborn children.
- Avoid any exposure to toxic substances such as chemicals and lead that are used in paints.
- Avoid any non-essential exposures to x-rays. If a medical or dental x-ray is needed, mothers-to-be should inform their medical professionals about their condition. In many cases, measures can be taken to protect the unborn child.
- Exercise moderately before and during pregnancy. Consult a physician before starting an exercise program.
Birth Defects on the World Wide Web

March of Dimes
http://www.modimes.org
This web site presents information on this non-profit organization’s fight against birth defects. Sections include research, local support, public affairs and a health library.

Arkansas Folic Acid Coalition
http://www.aristotle.net/~folic acid
This page features information about the Coalition, whose purpose is to educate Arkansans about the importance of folic acid in the prevention of neural tube defects. Sections include Arkansas statistics, a list of foods containing folate, press releases and an overview of the coalition.

National Birth Defects Prevention Network (NBDPN)
http://www.nbdpn.org
This web site focuses on current birth defects surveillance, research, and prevention in the United States. Sections include NBDPN news, other birth defects news and information, related web site links, newsletters and publications.

Children’s Health Information Network
Congenital Heart Disease Information and Resources
http://www.tchin.org
This web site provides resources and information to families of children with acquired and congenital heart disease, adults with congenital heart defects, and the health care professionals who care for these individuals. Sections include available support groups, educational materials, and Internet links designed for families, adults with congenital heart disease, and health care professionals.

SMILES
http://www.cleft.org
This web site features a cleft lip and palate support group called SMILES. The group is comprised of families whose children have or have had cleft lip, cleft palate and craniofacial deformities. Sections include an overview of cleft lip and cleft palate management, language and speech development, genetics and patient care after cleft palate repairs.

The Pediatric Database
http://www.icondata.com/health/pedbase/pedlynx.htm
This site provides an alphabetical list of over 550 childhood illnesses including genetic diseases and birth defects. Database information has been obtained through several sources including pediatric textbooks, journal articles, and review articles.
International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS)
http://www.icbd.org
This web site focuses on current birth defects research throughout the world. Sections include birth defects prevention, reports and papers, and birth defects web site links.

Directory of Genetic Support Groups Sites
http://members.aol.com/dnacutter/sgroup.htm
This web site lists national genetic support groups in alphabetical order by condition. It also features Internet links to other national support group directories and informational sites.

University of Kansas Medical Center Medical Genetics
http://www.kumc.edu/gec/support
An alphabetical list of birth defects and genetic conditions for individuals, educators, and health care professionals is included in this web site. Sections include national and international organizations, specific categories and conditions, genetic counselors and clinical geneticists, support groups and Internet links for children teenagers and young adults.

Family Village
http://www.familyvillage.wisc.edu/index.html
This web site furnishes resources, information, and Internet communication opportunities for persons with cognitive and other disabilities, for their families and for the professionals who provide services and support to these individuals. Sections include health issues, adaptive recreational activities, technology and products, and disability-related media.

The information and resources listed here are intended for educational use only. The information provided through this section should not be used for diagnosing or treating a health problem or a disease. It is not a substitute for professional care.
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