



Iowa



With sincere gratitude, I bring to your attention the Iowa Birth Defects Registry's annual report for the year 2002. This report demonstrates the Registry's commitment to surveillance, research, and education for all Iowans dedicated to birth defect prevention and adaptive health initiatives.

Overall this is a model program that demonstrates how epidemiologic information can be implemented with multi-level results. At the national level, the Registry participates as an exemplary program to help measure progress in birth defects prevention. Statewide, health care providers and various support agencies utilize the Registry's information. Perhaps the more penetrating role is executed at the local level and includes the educational activities the Registry can provide for the families of Iowa.

It is most relevant to cite a series of national health objectives entitled "Healthy People 2010" created by the U.S. Department of Health and Human Services in January, 2000. Complimentary to this plan, the Iowa Department of Public Health has established strategic initiatives, Healthy Iowans 2010, to promote "Healthy Iowans living in a healthy environment". Examples of the many important objectives include decreasing the infant mortality rate and providing preventive care services and specialized care for at-risk populations. Given the Iowa Birth Defects Registry's integral role for the past nineteen years, it gives me great pleasure to promote this program as a means to monitor trends of disease decline within infant populations which may guide health promotion and disease prevention efforts.

I applaud the Registry's ongoing efforts to play an important role in monitoring factors that may contribute to birth defects in one of Iowa's biggest investments in the future—Iowa infants.

Sincerely,

Stephen C. Gleason, D.O.,

Director

Iowa Department of Public Health

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e welcome the Iowa Birth Defects Registry's annual report for 2002 as we forge an effective partnership dedicated to improving the health of young Iowans. The University is committed to collaborative efforts with the Registry and the Iowa Department of Public Health to execute research that is consistent with the strategic initiatives of the Healthy Iowans 2010 plan. The University also recognizes the important roles of the Registry to identify, collect, and analyze critical data for agencies to implement these health initiatives.



A strong, state-wide monitoring system is critical for birth defects prevention. We are proud to say that the Registry has served as an archetype for other registries around the country. The Registry has many responsibilities, serving families at the national, state, and community levels and responding to emerging issues across these different populations.

The University will continue to support the Registry's commitment to surveillance, research, and education. We are all invested in facilitating educational opportunities that will promote the well-being of Iowa's youth and future generations.



A handwritten signature in dark ink that reads "Mary Sue Coleman".

Mary Sue Coleman, Ph.D.,  
President  
The University of Iowa

A handwritten signature in dark ink that reads "David Skorton".

David J. Skorton, M.D.,  
Vice President for Research  
The University of Iowa



## About the Registry

### Location

The Iowa Birth Defects Registry is located within the College of Public Health at the University of Iowa. The Registry conducts active surveillance to identify information about birth defects that occur in pregnancies of state residents. Active surveillance entails the use of field staff who collect birth defect information from reviewing medical records in hospitals and clinics both in Iowa and in neighboring states that serve Iowa residents.

### Mission

The mission of the Iowa Birth Defects Registry is to: 1) Maintain statewide surveillance for collecting information on birth defect occurrence in Iowa; 2) Monitor annual trends in birth defect occurrence and mortality; 3) Conduct research studies to identify genetic and environmental risk factors for birth defects; and 4) Promote educational activities for the prevention of birth defects.

### Surveillance

The Iowa Birth Defects Registry has collected information for over 32,000 children with major birth defects identified from more than 650,000 Iowa pregnancies. This information has been used by health care providers and educators to provide treatment and support services, and by researchers to study risk factors for birth defects and to evaluate treatments for birth defects.

### Research

The Iowa Birth Defects Registry has conducted several research projects to study risk factors for birth defects. These projects typically include mailed or telephone surveys of women who have experienced a pregnancy affected by a birth defect, and, for comparison, those women who have not experienced a pregnancy affected by a birth defect.

Examples of birth defects studied by the Registry include Down syndrome, heart defects, neural tube defects, and cleft lip and cleft palate.

### Education

The Iowa Birth Defects Registry also participates in educational programs designed to help prevent the occurrence and recurrence of birth defects. Registry faculty and staff annually present lectures around the state and promote community awareness to students, families, health care workers, and multiple agencies. Awareness training is a cornerstone of our educational program.

### Confidentiality

Information collected by the Registry is kept confidential using computer security measures and locked files and offices. All staff are required to sign a pledge to maintain the confidentiality of all information collected. These individuals are also reminded that their pledge remains in effect after the conclusion of their employment.

Confidentiality is rigorously maintained so that the rights and welfare of the patients and families are not compromised.

### Recognition

The Iowa Birth Defects Registry has received national recognition for its role in birth defects surveillance, research, and education. The Registry has been recognized nationally for leading other registries in surveillance activities and analytic programs. In 1996, the Registry was one of only eight registries to receive an award from the Centers for Disease Control and Prevention to establish a "Center for Excellence in the Research and Prevention of Birth Defects". More recently, the Registry has served as an advisor to the World Health Organization regarding birth defects surveillance and research.

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THROUGH THE JOINT  
EFFORTS OF THE  
UNIVERSITY OF  
IOWA, THE IOWA  
DEPARTMENT OF  
PUBLIC HEALTH  
AND THE IOWA  
DEPARTMENT OF  
HUMAN SERVICES.

# Surveillance

Public health surveillance involves the monitoring of disease, injuries or conditions to identify the frequency of their occurrence, to investigate potential risk factors, to plan for and to evaluate the effectiveness of intervention programs and to provide referrals to appropriate care for affected individuals. Early on, birth defects surveillance programs were established in response to: clusters of birth defects, such as the high number of skeletal defects associated with a mother's use of the morning-sickness medication, thalidomide; or concerns over environmental pollutants, such as the impact of contamination from toxic waste sites on the occurrence of birth defects. More recently, birth defects surveillance programs have been established to permit health officials to implement and evaluate intervention programs and to estimate the need for special health care services. Often, birth defect surveillance programs, such as the Iowa Birth Defects Registry, attempt to provide a comprehensive monitoring program through surveillance, research and education efforts.

## Birth Defects Surveillance-United States

The Centers for Disease Control and Prevention (CDC) recognizes three types of birth defect surveillance systems, each rated differently for completeness of patient ascertainment:

**Vital Records:** Use of birth and fetal death certificates provided by the state's Department of Health (Rating: Poor)

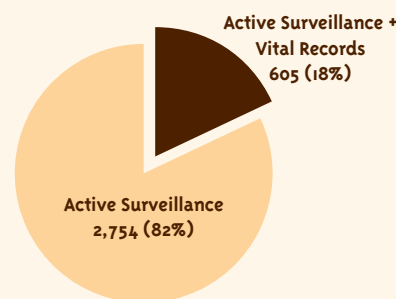
**Passive Reporting:** Use of medical reports submitted by staff from hospitals, clinics, or other facilities (Rating: Fair-Good)

**Active System:** Use of trained personnel who systematically review records in hospitals, clinics, or other facilities (Rating: Excellent)

Source: Centers for Disease Control and Prevention

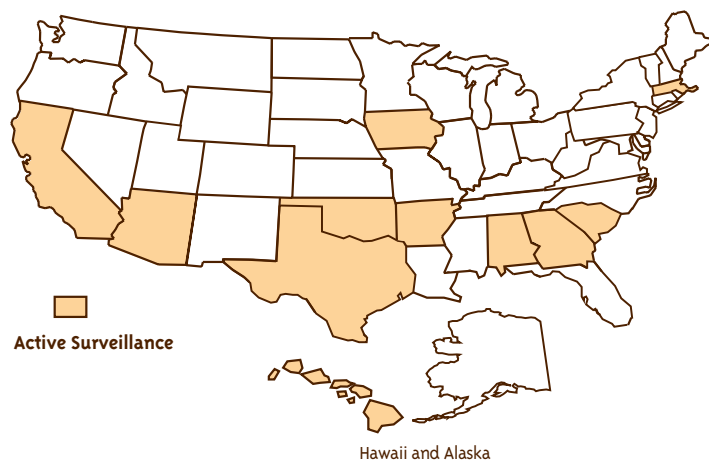
For the years 1998 and 1999, a record review of 3,359 infants identified by the Iowa Birth Defects Registry's active surveillance system showed that vital records would have identified only 605 or 18% of these infants. Therefore, for these years, if the Registry relied on vital records only for birth defect surveillance, on average, four out of every five infants diagnosed with a birth defect would not have been identified.

## Iowa Birth Defects Ascertainment, 1998-1999



Although active surveillance systems may provide the most comprehensive surveillance for birth defects, they also are most costly to maintain. In the U.S., there are only eleven states that have birth defect registries that meet the criteria for an active surveillance system. As shown on the map below, the Iowa Birth Defects Registry is the only active surveillance system in the Midwest.

## Birth Defect Surveillance-United States



# Definitions of Birth Defects

A BIRTH DEFECT IS A CONDITION OF POSSIBLE GENETIC AND/OR ENVIRONMENTAL ORIGIN THAT MAY IMPACT A CHILD'S DEVELOPMENT OR HEALTH.

The term "defect" refers to abnormal development related to body structure, body function, body metabolism, or an error in body chemistry. Typically a defect is present at birth (congenital), but there may be a recognizable defect diagnosed during pregnancy (prenatal) or following birth (postnatal).

Birth defects can have many causes including genetic mutations, chromosomal abnormalities, environmental exposures, nutrition, and/or random events in the prenatal period. Many defects are thought to be a combination of these factors. Examples of two major categories of birth defects include structural and metabolic defects.

Structural defects typically involve a body part that is missing or malformed. These types of defects have both genetic and environmental causes. Examples of structural defects include heart defects, spina bifida, and oral and facial clefts. Other terms often used for these types of defects include anomalies, malformations, and deformities.

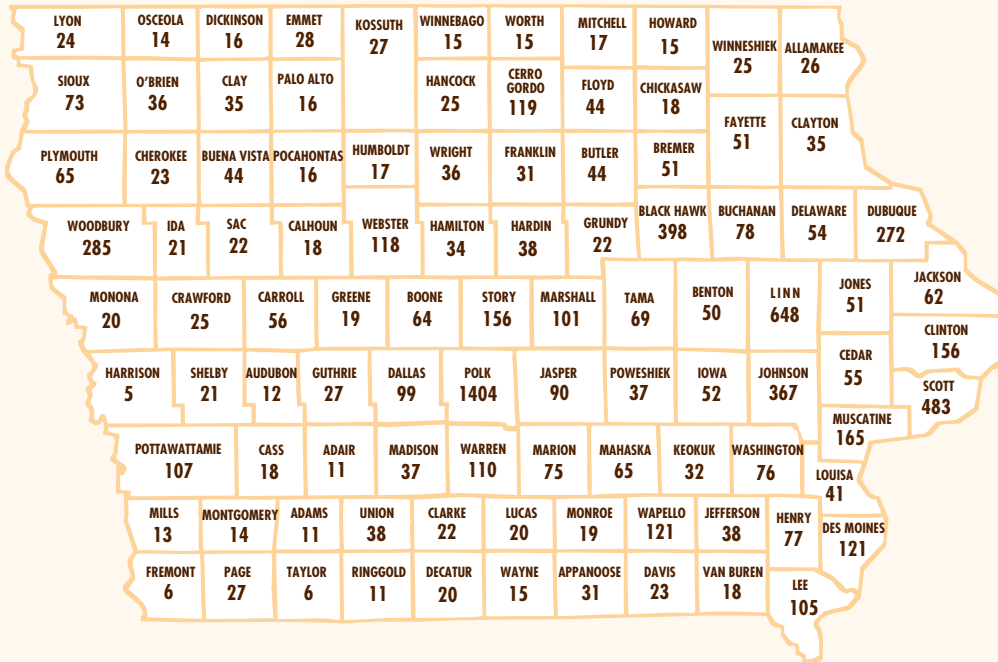
Metabolic defects often involve the inability of cells to produce a protein in the correct amount to regulate the chemistry of the body. High sugar levels in persons with diabetes is an example of a metabolic defect in adults. In infants, phenylketonuria or PKU is one example of this type of defect. Excess phenylalanine in the body is toxic to the central nervous system. Early detection of PKU can prevent brain damage in affected infants.

## Birth Defect Rates in Iowa, 1995-1999

Type of Birth Defect	Rate per 1,000 Live Births
Brain/Spinal Cord	4.3
Congenital Infection	0.4
Congenital Tumors	2.9
Digestive	4.7
Ear	4.7
Eye	3.5
Genital/Urinary	10.0
Heart	12.3
Muscle/Skeletal	13.5
Oral/Facial	5.5
Respiratory	1.2
Skin	3.5
Syndromes	3.7
Other*	1.2

\* Includes blood, hormonal, and metabolic conditions

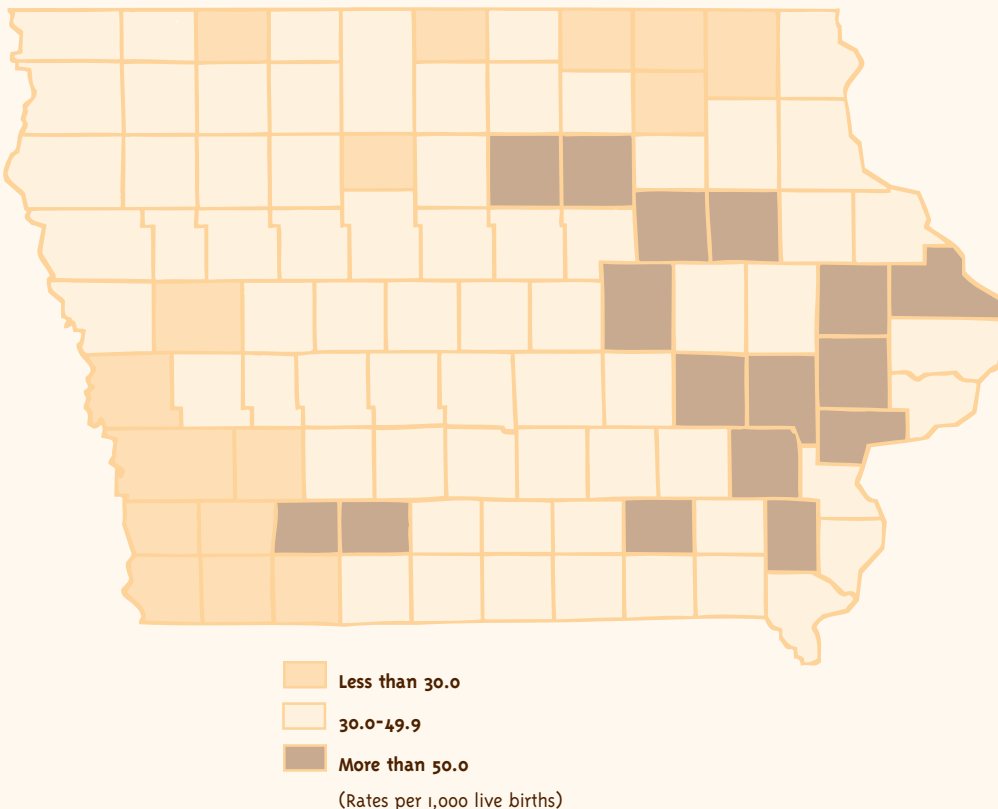
### Number of Deliveries Affected by Birth Defects in Iowa, 1995-1999



This map shows the number of deliveries in Iowa affected by one or more reportable birth defects by mother's county of residence for the period 1995-1999.

When examining this map, note that numbers in some counties may be higher due to 1) greater population in certain counties and 2) greater numbers of reproductive-aged individuals (15-44) in such counties.

### Rate of Deliveries Affected by Birth Defects in Iowa, 1995-1999



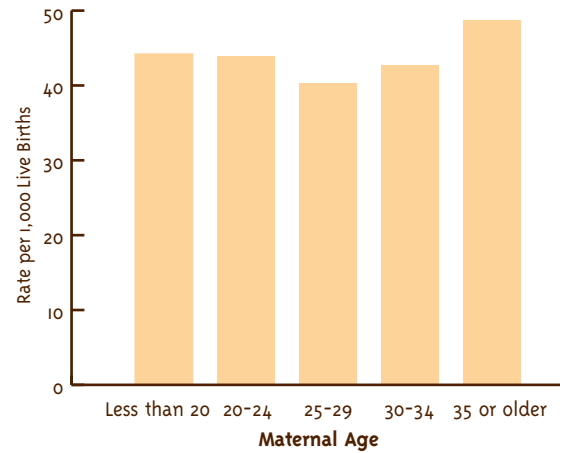
This map shows the rate of deliveries in Iowa affected by one or more reportable birth defects by mother's county of residence for the period 1995-1999.

For all counties combined, the average rate of occurrence of birth defects for this time period was 43.1/1,000 live births.



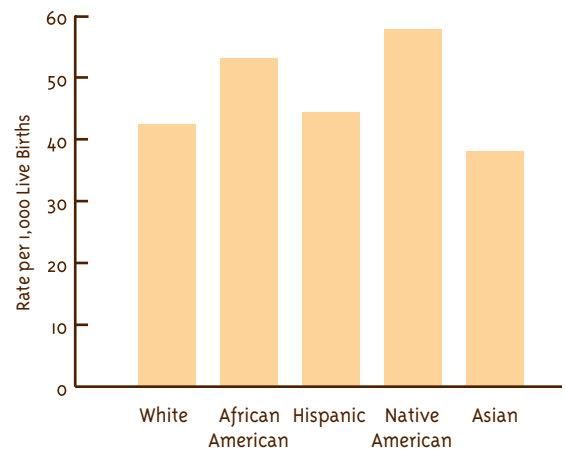
This chart shows birth defect rates by maternal age for the period 1995-1999. Rates were found to be lowest for mothers 25 to 29 years of age and highest for mothers 35 years of age or older. The higher rate found for older mothers may be due in part to the increased occurrence of certain syndromes, such as Down syndrome.

**Birth Defect Rates in Iowa by Maternal Age, 1995-1999**



This chart shows birth defect rates by maternal race/ethnicity for the period 1995-1999. Rates were found to be lowest for Asian mothers and highest for African-American and Native American mothers. Differences in rates may be due to mothers' health behaviors, access to health care, or other factors.

**Birth Defect Rates in Iowa by Maternal Race/Ethnicity, 1995-1999**



# Congenital Hydrocephalus



## What is it?

The term hydrocephalus is derived from two words (hydro = water, and cephalus = head). Hydrocephalus has been defined as a condition in which too much cerebrospinal fluid (CSF) accumulates within the spaces surrounding the brain and increases the pressure within the skull. The brain is partly composed of cavities called ventricles, which are filled with CSF.

## How is it detected?

Hydrocephalus affects about one in every 500-1,000 children born in the U.S.

Infants with hydrocephalus may have profound enlargement of the skull because the immature skull is not yet fused (joined together) and can therefore expand to accommodate the excess fluid.

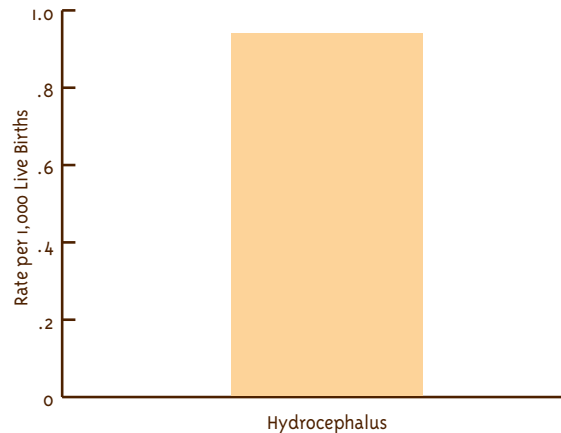
Symptoms associated with hydrocephalus can include vomiting, sleepiness, irritability and downward deviation of the baby's eyes.

Older children can show symptoms of increased pressure caused by the enlarged ventricles. These may include nausea, vomiting, headaches, double vision, poor balance, poor coordination, or thinking changes such as difficulties with concentration or memory. Some of these symptoms are obvious, while other symptoms are more subtle in nature.

## Diagnosis

Hydrocephalus is diagnosed by a combination of history, physical examination, and specialized tests. A neurological examination, usually by a neurosurgeon, will help determine how severe the hydrocephalus is. Testing such as ultrasound, computed tomography (CT) scan, or magnetic resonance imaging (MRI) may be ordered to provide information as to the type of the hydrocephalus and possible causes.

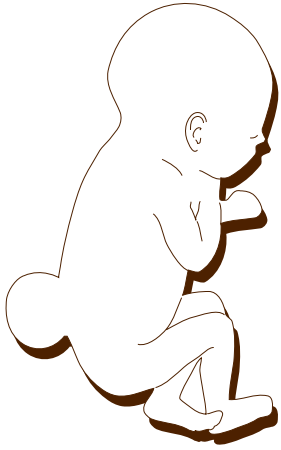
Occurrence of Hydrocephalus  
Iowa Rate 1995-1999



## What are the risk factors?

Most cases of hydrocephalus are the result of mechanical obstruction or blockage. Obstruction of CSF flow can be caused by infection, hemorrhage, brain injury, brain tumor, or a birth defect. With each of these causes of hydrocephalus, one or more ventricles becomes enlarged as the CSF accumulates.

The most common defect or lesion causing congenital hydrocephalus is aqueductal stenosis or atresia, which is a narrowing or blockage between the third and fourth ventricles of the brain. Hydrocephalus may occur alone or with other defects such as spina bifida. Causes which can be identified in certain genetic syndromes with hydrocephalus include chromosome abnormalities and gene defects. However, in many cases of hydrocephalus, the cause is unknown.



## Neural Tube Defects

### What are they?

Neural tube defects are a group of disorders caused by failure of development of the structures which form and enclose the brain and spinal cord. These conditions are among the most common birth defects, affecting about 1 in 1,000 infants born in Iowa, or about 40 cases per year. Approximately half of these defects are openings in the spine, called spina bifida, which lead to a loss of sensation and muscle control below the opening. In the remainder of cases, the top of the brain and the skull do not develop. This condition, called anencephaly, leads to death of the infant.

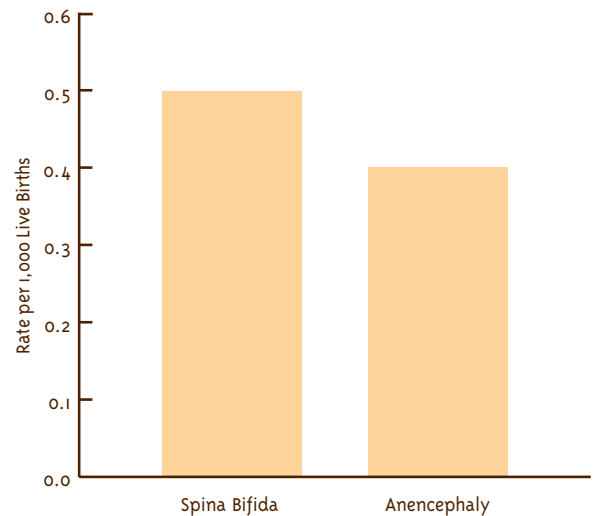
### How are they detected?

A protein called alpha-fetoprotein (AFP) is made in the fetal liver. When a fetus has an open neural tube defect, this protein leaks through the defect and becomes elevated in the bloodstream of the mother. Roughly 85% of neural tube defects can be detected by measuring AFP in the mother's blood stream between 15 and 20 weeks of pregnancy. If the AFP is elevated and the fetus has a neural tube defect, an ultrasound can usually determine the location and extent of the defect.

### What are the risk factors?

An insufficient level of folic acid is a risk factor for neural tube defects. Women who take a multivitamin containing folic acid every day can decrease their chance of having a child with a neural tube defect by about 50%. The risk is also decreased somewhat in women who eat a diet with higher levels of folic acid. The neural tube usually closes within 28 days after conception, often before a woman is aware that she is pregnant. For this reason, it is important that folic acid be taken before beginning a pregnancy.

Neural Tube Defects  
Iowa Rates 1995-1999



## Folic Acid

Investigations over the past twenty to thirty years have demonstrated that folic acid, a B vitamin, is critical for the normal development of a human fetus. The primary benefit of adequate intake of folic acid is a reduction of a category of birth defects known as neural tube defects. These defects represent a failure of normal closure of the spinal canal (spina bifida) or failure of the top portion of the skull and brain to develop (anencephaly). Folic acid is vital for rapid cell division, essential to make tissues and organs in the fetus. More research is needed to understand specifically how folic acid works.

If a woman has delivered a child with a neural tube defect, the risk this will happen in a subsequent pregnancy is about 3%. In this circumstance, a prescription for folic acid will be given to the mother. She will be instructed to take a relatively large dose of folic acid daily 1 to 2 months prior to any subsequent attempt to conceive another child and through the months of the pregnancy.

A major public health effort is underway to educate the population about the benefits of adequate consumption of folic acid. The U.S. Public Health Service has recommended that all women of reproductive age consume 0.4 milligrams of folic acid daily. To help insure that more women are adequately supplemented, the Food and Drug Administration has fortified grain products with increased folic acid. A healthy diet which emphasizes fresh fruits, green leafy vegetables (e.g., spinach), orange juice, enriched whole grain foods and fortified cereals will allow some women to achieve the recommended daily intake of folic acid.

Many women, however, will remain undersupplemented. While fortification offers some protection, this strategy is not optimal unless used in combination with a vitamin supplement. The current recommendation, therefore, is to consume a healthy diet rich in folic acid, but to also take a multivitamin daily which contains 0.4 milligrams of folic acid. If every woman of childbearing age in the United States followed this recommendation, it is estimated that the incidence of neural tube defects would be decreased by at least 50%.

Other health benefits may also be associated with the daily consumption of adequate folic acid, such as the decrease of abnormalities in the development of the heart, limbs, urinary tract, lip and palate. However, more studies need to be done to know definitively whether folic acid will decrease these defects, as has been the case for neural tube defects.

There are also studies which show that some of the more serious health problems which affect adults, such as heart attacks and strokes, may occur less frequently in individuals who consume the recommended daily dose of 0.4 milligrams of folic acid. More research is needed to clarify the effects of folic acid in the prevention of these types of diseases, but the message is clear regarding the potential benefits related to consuming folic acid starting in the teen years and continuing throughout life.



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## Neural Tube Defects Studies

**Dr. Roger Williamson** has received funding from the Centers for Disease Control (CDC) for a 3-year project to rapidly identify cases of neural tube defects (NTDs) for prompt referral for care and counseling. The personnel associated with this grant have relied heavily upon Iowa Birth Defects Registry staff to assist in identification of these cases. Another goal of the project has been an attempt to reduce the incidence of NTDs in Iowa. This has involved a major effort to educate the population and health care professionals about the benefits of consuming adequate amounts of folic acid. The most effective organization for dissemination of information has been the Iowa Folic Acid Council, representing a partnership among the Iowa Chapter of the March of Dimes, the Iowa Department of Public Health, The University of Iowa, and the Iowa Birth Defects Registry. Dr. Williamson's project will rely upon data collected by the Registry in subsequent years to determine the effectiveness of efforts to reduce the occurrence of NTDs.

**Dr. Dimitri Trembath**, a physician in Dr. Jeff Murray's laboratory, has conducted an investigation to determine why some individuals seem more susceptible to having a child with a neural tube defect. Since we know that folic acid can prevent many neural tube defects, one theory that Dr. Trembath tested was that genes involved in the use of this vitamin might vary in their effectiveness from person to person. It is already known that individuals respond in different ways to environmental exposures or medications, such as alcohol, tobacco smoke, chemotherapy, and anti-convulsant medicines. These differences are based on the body's ability to break down some of the chemicals contained in these drugs or medications, and they vary from person to person on an inherited basis.



Dr. Trembath's study looked at individuals with neural tube defects in Iowa, Nebraska, and Minnesota to show that some genes involved in folic acid metabolism appear to have different genetic variations in individuals at higher risk for NTDs. He found suggestive evidence that at least one of these genes may play a role in the variability observed in individual susceptibility, and these studies are now being further extended through collaboration with Dr. Donald Van Dyke and his colleagues in the Department of Pediatrics. Future studies will look at more individuals and additional genes involved in folic acid metabolism.

## Research Projects

The Iowa Birth Defects Registry annually participates in a number of additional research projects. A brief description of some of these projects is presented below:

### Iowa Child Health Study

*Funding Agency:* National Institutes of Health

This is a population-based study to investigate genetic and environmental risk factors for cleft lip and/or cleft palate (CL/P). Iowa women with a pregnancy affected by a CL/P and women with an unaffected pregnancy are asked to report information on family history, medical history, nutrition, lifestyle, and occupation to study environmental factors that may contribute to the development of CL/P. Biologic samples are collected from families to study genetic factors that may contribute to CL/P.

### National Birth Defects Prevention Study

*Funding Agency:* Centers for Disease Control and Prevention

This is a population-based study to investigate genetic and environmental risk factors for 31 major birth defects. This study is a combined effort of the Iowa registry and registries in seven other states. Women with a pregnancy affected by one or more of the 31 defects and women with an unaffected pregnancy are interviewed about their health, diet and lifestyle during their pregnancies. Biologic samples are also collected from each family to study genetic factors that may contribute to birth defects.

### National Down Syndrome Project

*Funding Agency:* National Institutes of Health

This is a population-based study to investigate genetic and environmental risk factors for Down syndrome. This study is a combined effort of the Iowa registry and registries in five other states. Iowa women who give birth to an infant affected with Down syndrome and women with an unaffected birth are interviewed about their health, diet and lifestyle during pregnancy. Biologic samples are collected from each family to better understand genetic factors that may contribute to Down syndrome.

## Select Publications

**Burns TL, Sheffield VC, Beck JS, Hockey RRB, & Lauer RM.** (2002). Evidence for a genetic locus involved in non-syndromic atrioventricular canal and ventricular septal defects on chromosome 1 using transmission disequilibrium analysis. (in press).

**Kepler-Noreuil KM.** (2001). OEIS Complex (Omphalocele-Exstrophy-Imperforate Anus-Spinal Defects): A review of 14 cases. *American Journal of Medical Genetics* 99: 271-279.

**Kepler-Noreuil KM, Welch J, Major H, Qiau Q, Epstein C, Patil S.** (2002). Atypical Down syndrome phenotype with severe developmental delay, hypertension, and seizures in a child with translocation Trisomy 21. *Developmental Medicine and Child Neurology* 44: 64-67.

**Kim YJ, Williamson RA, Murray JC, Andrews J, Pietscher JJ, Peraud PJ, Merrill DC.** (2001). Genetic susceptibility to preeclampsia: roles of cytosine-thymine substitution at nucleotide 677 of the gene for methylenetetrahydrofolate reductase, 68-base pair insertion at nucleotide 844 of the gene for cystathionine beta-synthase, and factor V Leiden mutation. *American Journal of Obstetrics and Gynecology* 184: 1211-1217.

**Peleg D, Nelson GM, Williamson RA, Widness JA.** (2001). Expanded Mobius syndrome. *Pediatric Neurology* 24: 306-309.

**Romitti, PA, Lidral AC, Munger RG, Daack-Hirsch S, Burns TL, Murray JC.** (1999). Candidate genes for nonsyndromic cleft lip and palate and maternal smoking and alcohol consumption: evaluation of genotype-environment interactions from a population-based case-control study of orofacial clefts. *Teratology* 59: 39-50.

**Trembath D, Sherbondy AL, VanDyke DC, Shaw GM, Todoroff K, Lammer EJ, Finnell RH, Marker S, Lerner G, Murray JC.** (1999). Analysis of select folate pathway genes, PAX3, and human T in a Midwestern neural tube defect population. *Teratology* 59: 331-341.

**Yoon PW, Rasmussen SA, Lynberg MC, Moore CA, Anderka M, Carmichael SL, Costa P, Druschel C, Hobbs CA, Romitti PA, Langlois P, Edmonds LD** and the National Birth Defects Prevention Study. (2001). The National Birth Defects Prevention Study. *Public Health Reports* 116 (suppl): 32-40.

## Registry Spotlight



**Dr. Kim Keppler-Noreuil**, Associate Director of the Iowa Birth Defects Registry, fulfills a tripartite role for the state of Iowa in teaching, pediatric clinical care, and research activities as a clinical geneticist.

Since 1996, Dr. Keppler-Noreuil has held a faculty position at the University of Iowa Health Care in the Division of Medical Genetics.

In her role as Clinical Geneticist/Reviewer for the Registry, she has been part of a collaborative network studying birth defects. Her research interests involve the clinical delineation of multiple malformation syndromes. Dr. Keppler-Noreuil's research performance has been recognized by her receipt of grants that investigated the genetic etiology of birth defects, risk factors for specific birth defects, and the expansion of genetic services in Iowa.

Dr. Keppler-Noreuil and the Registry recently received a March of Dimes grant to evaluate multiple factors affecting patients' utilization of genetic services in Iowa. Dr. Keppler-Noreuil stated that ... "the information gained will help in the development of strategies to enhance these necessary services...". These research projects compliment her duties with the Medical Genetics Service at University of Iowa Health Care and with the Regional Genetic Consultation Clinics. She recently completed a 15-month pilot study evaluating the effectiveness of telemedicine facilities as a new means for delivery of genetics services.

Dr. Keppler-Noreuil provides an invaluable link to expanding the Registry's mission through education, care, and research.



**Ms. Rhonda J. Hosler** has been a Field Representative for the Iowa Birth Defects Registry since 1997. As a Field Representative, her responsibilities include collecting information on all children born with

birth defects in the Des Moines area and transmitting that data to the Registry's central offices in Iowa City. Her work involves a great deal of travel to a number of hospitals and medical facilities, including surgery centers, newborn nurseries, neonatal intensive care units, pathology laboratories and medical records departments.

Ms. Hosler enjoys the variety of her work environments and values her professional relationships with a diverse group of medical personnel. She also appreciates the individuality of each case she abstracts. "What I enjoy most about the job is feeling like I make a difference with those children born with birth defects and their families, by the information I'm able to provide to the Registry."

Ms. Hosler is a Certified Coding Specialist. Prior to joining the Registry, she worked as a coder-abstractor for Iowa Lutheran Hospital for ten years.

The essential functions of Ms. Hosler's job help the Registry serve as a model for other registries around the nation.

## Registry Spotlight:

### March of Dimes Organization



For many Iowans, the March of Dimes is synonymous with the phrase, "Saving Babies". What many Iowans may not know is that for over 60 years, this organization has created an unparalleled concert between the scientific community and families.

The primary mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality. March of Dimes demonstrates this mission through many quality programs encompassing education, research, and community services. The state of Iowa continuously benefits from research grants that fund both research programs and community/health agencies delivering clinical care to families. In the year 2000, \$799,300 was given to the state of Iowa for research and program grants, and a full \$.85/\$1.00 spent supported programs that help prevent and treat birth defects. These programs cover a variety of topics such as investigating genetic factors that impact birth defects, studying causes of premature births, identifying environmental factors influencing birth defects, working with social programs helping expectant mothers/families to obtain prenatal care, and funding children's programs or hospitals.

The March of Dimes has guided Iowa with legislative campaigns to promote women's and infants' health in the political arena. More recently there have been efforts to expand Iowa's health insurance program to cover children from low income families and income-eligible pregnant women. The Iowa General Assembly created the Healthy and Well Kids in Iowa (*hawk-i*) health insurance program for children whose families are uninsured. The March of Dimes advocates for expansion of this provision given the organization's estimate of 45,000 uninsured children in Iowa.

In conjunction with *hawk-i* funding, March of Dimes (MOD)-Iowa State Chapter has promoted the Registry among its priorities for 2001/2002. MOD has actively lobbied for funds to be appropriated annually to continue to support the Registry's essential functions in Iowa. In turn, the Registry promotes legislative action for women and children by attending the MOD Lobby Day at the State Capitol.

The March of Dimes shares the Registry's commitment to give back to the community. This agency demonstrates cooperation of the private sector as an active partner in vigorous pursuit to improve the quality of life in Iowans and Iowa's future generations. Iowa state chapter offices are located in Sioux City, Des Moines, Cedar Rapids, Dubuque, and Davenport. For more information about the March of Dimes programs or calendar of events, visit their website: [www.modimes.org](http://www.modimes.org) or call 1-800-456-9115.



## *Giving Back to the Community*



### **Families**

The primary benefit of surveillance is to promote adaptive health strategies and care for Iowa families impacted by birth defects. Each family member may experience the long term consequences of these defects, and the Registry is committed to increasing awareness, executing research, and providing resources for those families seeking education or referral.

One of the goals of our educational services includes awareness training for family members. This includes the circulation of clinical information about specific birth defects, strategies to monitor the impact of birth defects, behavioral management strategies, and/or referral to specific health care professionals, agencies, or academic centers.

Consistent with this goal is the linkage of educational services or the provision of a networking role so families are aware of community support services. For example, specific referrals to statewide services such as the Regional Genetic Consultation Service help families to receive comprehensive genetic health care services and genetics education.

### **State-Wide Awareness**

Every year the Registry provides outreach education that parallels national campaigns supported by the Centers for Disease Control and Prevention and the National Birth Defects Prevention Network.

These activities are demonstrated by initiating lectures to students, health care professionals, families, and/or community organizations. Some of these lectures address concerns about environmental effects on birth defects in addition to genetic influences.

The Registry also promotes community involvement through locally sponsored activities such as the Environmental Health Science Institute research camp for rural youth, Children's Miracle Network, and the Iowa Chapter of the March of Dimes. Public awareness may be initiated with press releases, articles, or educational campaigns in which educational materials are disseminated throughout communities. Residents in each of Iowa's 99 counties have been reached through the combination of our surveillance, research, or educational activities.

## *Professional Roles at the National Level*

The Registry has established a long-term goal to implement longitudinal research that can be used at all levels of interest, from the Iowa family to communities across Iowa, as well as, national groups such as the National Birth Defects Prevention Network.

It is critical that the Registry provide accurate, timely data on birth defects and continue to play a primary research role in many projects in order to elucidate the roles of environment and genetics impacting birth defects. Our Registry has been recognized by the Centers for Disease Control and Prevention as a birth defects registry for other states to model. Currently the Registry is one of only eight state registries participating in a national study to evaluate the causes of 31 major birth defects. In addition, the Iowa Registry is one of six state registries to participate in a national research project exploring factors related to Down syndrome.

The Registry is also active in educational and consulting roles. Registry staff participate on many national committees dedicated to research and educational endeavors all working towards understanding and treating birth defects.

The Registry will continue to examine the quality and the availability of data to all interested groups. This is also relevant in order to provide accurate conclusions that foster public program planning, direct program management and public health policy, and to expand and evaluate these actions through service evaluations or continued surveillance. In the future the Registry plans to examine economic factors and psychosocial impact of birth defects.



Dr. Jeff Murray (right), Chair, Iowa Birth Defects Registry Executive Committee, with Dr. Francis Collins (left), National Institutes of Health, and U.S. Senator Tom Harkin (center) following Dr. Murray's testimony to the Senate Appropriation Committee for the Human Genome Project and birth defects research.



Dr. Paul Romitti (right), Director, Iowa Birth Defects Registry, with (left to right) Dr. Lowell Sever, University of Texas, Mr. Larry Edmonds, Centers for Disease Control and Prevention, and Dr. Victor Boulyjenkov, World Health Organization at the World Health Organization Meeting on Craniofacial Anomalies.



## Websites: For More Information

The Registry encourages readers to review these sites and discuss these topics in further detail with their medical providers. The Registry is not responsible for the quality of information provided at these sites.

### Iowa

#### **Iowa Birth Defects Registry**

[www.public-health.uiowa.edu/birthdefects](http://www.public-health.uiowa.edu/birthdefects)

#### **University of Iowa and University of Iowa Health Care**

[www.craniofacialcenter.uiowa.edu](http://www.craniofacialcenter.uiowa.edu)

[www.medicine.uiowa.edu/otolaryngology/clinic/cleftpalate/index.html](http://www.medicine.uiowa.edu/otolaryngology/clinic/cleftpalate/index.html)

[www.medicine.uiowa.edu](http://www.medicine.uiowa.edu)

[www.public-health.uiowa.edu](http://www.public-health.uiowa.edu)

[www.uihealthcare.com/depts/indexfull.html](http://www.uihealthcare.com/depts/indexfull.html)

[www.uihealthcare.com/depts/med/pediatrics/welcome/index.html](http://www.uihealthcare.com/depts/med/pediatrics/welcome/index.html)

[www.uihealthcare.com/news/news/2000/09/0925marchdimes.html](http://www.uihealthcare.com/news/news/2000/09/0925marchdimes.html)

[www.uihealthcare.com/topics/childhealthdevelopment/catchil.html](http://www.uihealthcare.com/topics/childhealthdevelopment/catchil.html)

[www.uihealthcare.com/topics/pregnancyandchildbirth/catpreg.html](http://www.uihealthcare.com/topics/pregnancyandchildbirth/catpreg.html)

[www.uihealthcare.com/topics/geneticsbirthdefects/catgene.html](http://www.uihealthcare.com/topics/geneticsbirthdefects/catgene.html)

#### **Children's Miracle Network: IOWA**

[www.uihealthcare.com/depts/childrensmiraclenetwork/index.html](http://www.uihealthcare.com/depts/childrensmiraclenetwork/index.html)

#### **Virtual Hospital**

[www.vh.org](http://www.vh.org)

#### **Iowa Department of Public Health**

[www.idph.state.ia.us](http://www.idph.state.ia.us)

#### **Iowa Department of Public Health: Division of Family and Community Health**

[www.idph.state.ia.us/fch.htm](http://www.idph.state.ia.us/fch.htm)

#### **State Department of Education: Special Education**

[www.state.ia.us/educate](http://www.state.ia.us/educate)

#### **State Agency for the Visually Impaired**

[www.blind.state.ia.us](http://www.blind.state.ia.us)

#### **Programs for Children Who Are Deaf or Hard of Hearing**

[www.state.ia.us/government/dhr](http://www.state.ia.us/government/dhr)

#### **Autism Society of Iowa**

[www.autismia.org](http://www.autismia.org)

#### **Brain Injury Association of Iowa**

[www.biaia.org](http://www.biaia.org)

#### **Epilepsy Foundation**

[www.efa.org](http://www.efa.org)

#### **Arc of Iowa (Persons with Mental Retardation)**

[www.thearc.org](http://www.thearc.org)

#### **Spina Bifida**

[www.sbaa.org](http://www.sbaa.org)

#### **Technology-Related Assistance**

[www.uiowa.edu/infotech](http://www.uiowa.edu/infotech)

#### **Iowa Compass (information and referral services)**

[www.medicine.uiowa.edu/iowacompass](http://www.medicine.uiowa.edu/iowacompass)

### United States

#### **Alliance of Genetic Support Groups**

[www.geneticalliance.org](http://www.geneticalliance.org)

#### **American Academy of Pediatrics**

[www.aap.org](http://www.aap.org)

#### **Centers for Disease Control and Prevention**

[www.cdc.gov/nceh](http://www.cdc.gov/nceh)

#### **Child Statistics**

[www.childstats.gov](http://www.childstats.gov)

#### **Cleft Palate Support, Research and Prevention**

[www.cleft.net](http://www.cleft.net)

#### **GeneClinics**

[www.geneclinics.org](http://www.geneclinics.org)

#### **HuGE Net**

[www.cdc.gov/genetics/hugenet](http://www.cdc.gov/genetics/hugenet)

#### **International Clearinghouse for Birth Defects Monitoring Systems**

[www.icbd.org](http://www.icbd.org)

#### **National Association for the Education of Young Children**

[www.naeyc.org](http://www.naeyc.org)

#### **KidNeeds.com (information and resource center)**

[www.kidneeds.com](http://www.kidneeds.com)

**March of Dimes**  
www.modimes.org

**National Birth Defects Prevention Network**  
www.nbdpn.org

**National Center for Biotechnology  
Information Online**  
Mendelian Inheritance in Man (OMIM)  
www.ncbi.nlm.nih.gov/Omim

**National Institutes of Health**  
www.nih.gov

**National Organization for Rare Disorders**  
www.rarediseases.org

**National Society of Genetic Counselors**  
www.nsgc.org

**Organization for Teratology Information Services**  
www.otispregnancy.org

**Pediatric Database**  
www.icondata.com/health/pedbase/pedlynx.htm

**Phenylketonuria Organization**  
www.pkunews.org

**Teratology Society**  
www.teratology.org

**The Birth Defects Foundation**  
www.birthdefects.co.uk

**Birth Defect Research for Children, Inc.**  
www.birthdefects.org

**Birth Defects Prevention Legislation Committee**  
www.birthdefectsprevention.org

**National Organization on Fetal Alcohol Syndrome**  
www.nofas.org

**National Information Center for Children and  
Youth with Disabilities**  
www.nichcy.org

**Family Village: Information Center (sponsored in  
part by U. of Wisconsin)**  
www.familyvillage.wisc.edu/index.htmlx  
(click on library)

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Iowa Cancer Registry  
University Hygenic Laboratory

- Iowa Birth Defects Advisory Committee
- Iowa Department of Public Health
- Iowa Regional Genetic Consultation Service
- March of Dimes Birth Defects Foundation

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- Centers for Disease Control and Prevention
- Children's Miracle Network
- Craniofacial Anomalies Research Center
- National Institutes of Health

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