Iowa Registry for Congenital and Inherited Disorders

2009 Report

Iowa Registry for Congenital and Inherited Disorders Personnel

Director
Paul A. Romitti, Ph.D.

Clinical Director for Birth Defects
Kim Keppler-Noreuil, M.D.

Clinical Director for Neuromuscular Disorders
Katherine Mathews, M.D.

Clinical Directors for Stillbirths
Roger Williamson, M.D.
Kristi Borowski, M.D.

Program Manager
Kristine Hardin, M.S.

Clinical Editors
Sue Gorton, B.S.N., R.N., R.H.I.T.
Carrie Stephan, M.A., R.N.

Programming Staff
Bill Budelier, M.S.
Florence Foo, M.A.

Surveillance Field Staff
Carrie Fall, B.A.S., R.H.I.T.
Patricia Ganzer Holland
Jacquelyn Loesche, P.A.
Evelyn Redtree, M.S.
Patricia Steen, A.S., R.H.I.T.
Ann Vogt, R.N.

Internal Advisory Committee
James Torner, Ph.D., Chair
Trudy Burns, M.P.H., Ph.D.
Jane Borst, R.N., M.A.
Jeffrey Murray, M.D.
Roger Williamson, M.D., M.S.

Center for Congenital and Inherited Disorders, Iowa Department of Public Health
Kimberly Piper, R.N.C., B.S., C.P.H.

Dear members of the Legislature, health care professionals, and concerned citizens of Iowa:

We are happy to provide you with the 2009 report of the Iowa Registry for Congenital and Inherited Disorders (IRCID). The IRCID has conducted state-wide surveillance for birth defects since 1983, and state-wide surveillance for Duchenne/Becker muscular dystrophy and stillbirths, since 2002 and 2005, respectively. In 2009, the IRCID began surveillance for selected newborn screening disorders.

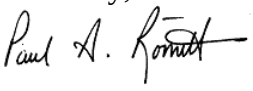
Nationally, the IRCID is the only active state-wide surveillance program for birth defects in the Midwest and serves as a model program for other states. IRCID staff members are active members of the National Birth Defects Prevention Network (NBDPN), an organization of individuals and programs that conduct birth defect monitoring, research, and prevention.

The IRCID is also a key partner with the Iowa Center of Excellence for Birth Defects Research and Prevention, which is a collaborative enterprise between the College of Public Health, Carver College of Medicine, and the College of Pharmacy at The University of Iowa. Its other partners include the Iowa Department of Public Health, the Iowa Chapter of the March of Dimes, and The University of Iowa Center for Health Effects of Environmental Contamination.

Additionally, the IRCID is a key partner with the Iowa site for the Muscular Dystrophy Surveillance, Tracking, and Research Network, which is a collaborative enterprise between the College of Public Health and Carver College of Medicine at The University of Iowa. Other partners include the Iowa Department of Public Health and the Muscular Dystrophy Association of Iowa.

Our strong state-wide program to monitor congenital and inherited disorders is a valuable resource for the state of Iowa. While taking care to preserve the privacy of families affected by these disorders, the IRCID provides important information to state policy makers and public health professionals. Not only does it provide irreplaceable information, it allows for important research on the causes, prevention, and treatment of such disorders. We are pleased to perform this important work on behalf of the citizens of Iowa.

Sincerely,



Paul A. Romitti, Ph.D.
Director and Associate Professor of Epidemiology

In the United States, the Centers for Disease Control and Prevention (CDC) recognize three types of surveillance systems; each is 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 to Good)
- Active System: Use of trained personnel who systematically review records in hospitals, clinics, or other facilities (Rating: Excellent)

The IRCID conducts active surveillance to identify information about congenital and inherited disorders that occur in Iowa and to Iowa residents. The IRCID has collected information for over 46,000 children with various birth defects. This information has been used by health care providers and educators to provide treatment and support services. It is also used by researchers to study risk factors for birth defects and to evaluate treatments for birth defects. The IRCID also conducts surveillance for Duchenne/Becker muscular dystrophy and has identified nearly 100 children with this neuromuscular disease. In addition, the IRCID is collaborating with the Metropolitan Atlanta Congenital Defects Program to develop approaches to active surveillance for stillbirths.

Surveillance for Birth Defects

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

The IRCID has traditionally focused on structural birth defects, which typically involve a body part that is missing or malformed. Examples include heart defects, spina bifida, and cleft lip and palate. Starting with 2003 deliveries, the IRCID adopted the recommendations of the National Birth Defects Prevention Network (NBDPN) to focus on a core set of 45 defects (see Table 1). Prior to this change, the IRCID included many 'minor' conditions, so this change represents a reduction in the number of conditions that it monitors.

Table 1
Prevalence for birth defects in Iowa, 2002-2006 deliveries

Condition	Total	Prevalence Rate[†]
Brain/Spinal Cord		
Anencephalus	58	2.99
Encephalocele	16	0.83
Hydrocephalus without spina bifida	197	10.16
Microcephalus	193	9.95
Spina bifida without anencephalus	95	4.90
Eye		
Aniridia	1	0.05
Anophthalmia/microphthalmia	56	2.89
Congenital cataract	47	2.42
Ear		
Anotia/microtia	35	1.80
Heart		
Aortic valve stenosis	75	3.87
Atrial septal defect	591	30.48
Coarctation of aorta	88	4.54
Common truncus	19	0.98
Ebstein's anomaly	17	0.88
Endocardial cushion defect	151	7.79
Hypoplastic left heart syndrome	41	2.11
Patent ductus arteriosus	545	28.10
Pulmonary valve atresia and stenosis	192	9.90
Tetralogy of Fallot	88	4.54
Transposition of great arteries	66	3.40
Tricuspid valve atresia and stenosis	23	1.19
Ventricular septal defect	977	50.38

[†] Prevalence per 10,000 live births.
Continued on next page…

Table 1 (continued from previous page)

Condition	Total	Prevalence Rate[†]
Oral/Facial		
Choanal atresia	37	1.91
Cleft lip with and without cleft palate	248	12.79
Cleft palate without cleft lip	155	7.99
Digestive		
Biliary atresia	10	.52
Esophageal atresia / tracheoesophageal fistula	41	2.11
Hirshsprung's disease (congenital megacolon)	39	2.01
Pyloric stenosis	578	29.80
Rectal and large intestinal atresia/stenosis	95	4.90
Genital/Urinary		
Bladder exstrophy	11	0.57
Hypospadias and Epispadias [*]	185	[**]18.58
Obstructive genitourinary defect	528	27.23
Renal agenesis/hypoplasia	143	7.37
Muscle/Skeletal		
Congenital hip dislocation	174	8.97
Diaphragmatic hernia	16	0.83
Gastroschisis	94	4.85
Omphalocele	53	2.73
Reduction deformity, lower limbs	43	2.22
Reduction deformity, upper limbs	89	4.59
Syndromes		
Down syndrome (Trisomy 21)	329	16.96
Edwards syndrome (Trisomy 18)	54	2.78
Patau syndrome (Trisomy 13)	30	1.55
Other		
Amniotic bands	18	0.93
Fetus or newborn affected by maternal alcohol use	8	0.41

[†] Prevalence rates per 10,000 live births.
[*] Includes epispadias and/or second or third degree hypospadias. Excludes hypospadias NOS and first degree hypospadias.
[**] Prevalence per 10,000 male live births.

Birth Defects Research

Approximately 1 in 33 newborns are affected by a major birth defect, making such conditions disturbingly common. These conditions come with personal and monetary costs, both for the families of these children and for society. Nearly 20% of all infant deaths are caused by birth defects. Hospitalizations associated with such conditions are longer than hospitalizations for other conditions. More than $8 billion is required to provide lifetime care for the children born with birth defects each year.

Because the causes of up to 70% of birth defects are unknown, research is a critical part of any strategy to prevent these conditions. For this reason, in 1996 the United States Congress directed the CDC to establish regional "centers of excellence" in birth defect research and prevention. Furthermore, interest in fostering collaboration among state birth defect programs led to the formation of the National Birth Defects Prevention Network in 1998.

National Birth Defects Prevention Network

The National Birth Defects Prevention Network (NBDPN) is a nationwide association of birth defect programs and individuals. The IRCID is an active member of the NBDPN and participates in many of its projects. For example, the NBDPN provides a set of guidelines to help birth defect registries around the country organize their work in a consistent manner. The NBDPN also provides educational materials to birth defect abstractors, as well as informational resources to promote Birth Defects Prevention Month each January. Another goal of the NBDPN is to encourage scientific collaboration among birth defect programs. The IRCID is currently participating in NBDPN projects for biliary atresia, neural tube defects, pyloric stenosis, and ventral wall defects.

<u>2009 NBDPN Publications Using IRCID Data</u>

National Birth Defects Prevention Network (NBDPN). (2009) Population-based birth defects surveillance data from selected states, 2002-2006. *Birth Defects Res A Clin Mol Teratol* 85:939-1004.

Parker SE, Mai CT, Strickland MJ, Olney RS, Rickard R, Marengo L, Wang Y, Shahrukh Hashmi S, Meyer RE for the National Birth Defects Prevention Network. (2009) Multistate study of the epidemiology of clubfoot. *Birth Defects Res A Clin Mol Teratol* 85:897-904.

Iowa Center of Excellence for Birth Defects Research and Prevention

The Iowa Center of Excellence for Birth Defects Research and Prevention was one of eight charter centers established by the CDC to study genetic and environmental (broadly defined) risk factors for birth defects. Iowa Center investigators participate in local (state-wide) projects as well as the National Birth Defects Prevention Study (NBDPS). The NBDPS is a population-based study that investigates genetic and environmental risk factors for over 30 major birth

defects. As a partner with the Iowa Center, the IRCID identifies children with NBDPS-eligible birth defects and secures permission from mothers and guardians to share information with researchers. Women with a pregnancy affected by one or more of the 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 these birth defects. Presently, over 35,000 interviews have been completed nationwide, and biologic samples have been collected from more than 19,333 families.

Over 200 research projects are currently underway nation-wide as part of the NBDPS. Some of them examine risk factors such as maternal nutrition. Others examine gene and environment interactions. Still others examine maternal behavior during pregnancy. For example, the Iowa Center recently led a project that examined the role of maternal caffeine consumption during pregnancy on the development of neural tube defects.

The research performed by Iowa investigators has the potential to positively affect the lives of Iowans. Current studies by Iowa investigators are focused on the relationships between birth defects and agricultural chemicals, cigarette smoking, alcohol consumption, medications, and compounds in drinking water.

2009 Iowa Center Publications Using IRCID Data
(Names listed in bold designate Iowa investigators)

Kancherla V, Romitti PA, **Damiano PC, Tyler MC**, Druschel CM, Robbins JM, Kizelnik-Freilich S. (2009) Maternal reports of satisfaction with care and outcomes for children with microtia. *Plast Recontr Surg* 123:149e-150e

The University of Iowa and the Iowa Department of Public Health. 2009 Iowa Health Fact Book. Iowa City, IA: The University of Iowa College of Public Health. July 2009.

Wong-Gibbons DL, Kancherla V, Romitti PA, **Tyler MC, Damiano PC**, Druschel CM, Robbins JM, Kizelnik-Freilich S, Burnett W. (2009) Maternal reports of satisfaction with care and outcomes for children with craniosynostosis. *J Craniofac Surg* 20:138-142.

2009 NBDPS Publications Using IRCID Data
(Names listed in bold designate Iowa investigators)

Browne ML, Rasmussen SA, Hoyt AT, Waller DK, Druschel CM, Caton AR, Canfield MA, Lin AE, Carmichael SL, **Romitti PA**, and the National Birth Defects Prevention Study. (2009) Maternal thyroid disease, thyroid medication use and selected birth defects in the National Birth Defects Prevention Study. *Birth Defects Res Part A Clin Mol Teratol* 85:621-628

Canfield MA, Ramadhani TA, Shaw GM, Carmichael SL, Waller DK, Mosley B, Royle MH, Olney RS, and the National Birth Defects Prevention Study. (2009) Anencephaly and spina bifida among Hispanics: maternal, socio-demographic, and acculturation factors in the National Birth Defects Prevention Study. *Birth Defects Res A Clin Mol Teratol* 85: 637-646.

Carmichael SL, Ma C, Werler MM, Olney RS, Shaw GM and the National Birth Defects Prevention Study. (2009) Maternal corticosteroid use and hypospadias. *J Pediatr* 155: 39-44.

Carmichael SL, Yang W, Correa A, Olney RS, Shaw GM, and the National Birth Defects Prevention Study. (2009) Hypospadias and intake of nutrients related to one-carbon metabolism. *J Urol* 181: 315-321

Caton A, Bell EM, Druschel C, Werler MM, McNutt LA, Browne ML, **Romitti PA**, Mitchell AA, Lin AE, Olney RS, Correa A and the National Birth Defects Prevention Study. (2009) Antihypertensive medication use and cardiovascular malformations in the National Birth Defects Prevention Study. *Hypertension* 54:63-70.

Cogswell ME, Bitsko RH, Anderka M, Caton AR, Feldkamp ML, **Hockett Sherlock SM**, Meyer RE, Ramadhani T, Robbins JM, Shaw GM, Mathews TJ, Royle M, Reefhuis J, and the National Birth Defects Prevention Study. (2009) Control selection and participation in an ongoing, population-based, case-control study of birth defects: the National Birth Defects Prevention Study. *Am J Epidemiol* 170: 975-985.

Collier SA, Browne ML, Rasmussen SA, Honein MA, and the National Birth Defects Prevention Study. (2009) Maternal caffeine intake during pregnancy and orofacial clefts. *Birth Defects Res A Clin Mol Teratol* 85: 842-849.

Collier S, Rasmussen SA, Feldkamp ML, Honein MA, and the National Birth Defects Prevention Study. (2009) Prevalence of self-reported infection during pregnancy among control mothers in the National Birth Defects Prevention Study. *Birth Defects Res A Clin Mol Teratol* 85: 193-201.

Crider KS, Cleves MA, Reefhuis J, Berry RJ, Hobbs CA, Hu DJ. (2009) Antibacterial medication use during pregnancy and risk of birth defects: National Birth Defects Prevention Study. *Arch Pediatr Adolesc Med* 163: 978-985

Damiano P, Tyler M, Romitti PA, Druschel C, Austin AA, Burnett W, Kizelnik-Freilich S, Robbins JM. (2009) Demographic characteristics, care and outcomes for children with oral clefts in three states using participants from the National Birth Defects Prevention Study. *Cleft Palate Craniofac J* 46:575-582.

Ethen M, Ramadhani T, Scheuerle A, Canfield M, Wyszynski D, Druschel C, **Romitti PA**, and the National Birth Defects Prevention Study. (2009) Alcohol consumption by women before and during pregnancy. *Mat Child Health J* 13(2):274-285.

Gallaway MS, Waller DK, Canfield MA, Scheuerle A, and the National Birth Defects Prevention Study. (2009) The association between use of spermicides or male condoms and major structural birth defects. *Contraception* 80: 422-429.

Genisca AE, Frias JL, Broussard CS, Honein MA, Lammer EJ, Moore CA, Shaw GM, **Murray JC**, Yang W, Rasmussen SA, and the National Birth Defects Prevention Study. (2009) Orofacial clefts in the National Birth Defects Prevention Study, 1997-2004. *Am J Med Genet A* 149A: 1149-1158.

Gilboa SM, Strickland MJ, Olshan AF, Werler MM, Correa A, and the National Birth Defects Prevention Study. (2009) Use of antihistamine medications during early pregnancy and isolated major malformations. *Birth Defects Res A Clin Mol Teratol* 85: 137-150.

Johnson CY, Honein MA, Hobbs CA, Rasmussen SA, and the National Birth Defects Prevention Study. (2009) Prenatal diagnosis of orofacial clefts, National Birth Defects Prevention Study, 1998-2004. *Prenat Diagn* 29: 833-839.

Langlois PH, Ramadhani TA, Royle M, Robbins JM, Scheuerle AE, Wyzynski DF. (2009) Birth defects and military service since 1990. *Mil Med* 174: 170-176.

Mac Bird T, Robbins JM, Druschel C, Cleves MA, Yang S, Hobbs CA, and the National Birth Defects Prevention Study. (2009) Demographic and environmental risk factors for gastroschisis and omphalocele in the National Birth Defects Prevention Study. *J Pediatr Surg* 44: 1546-1551.

MacLehose RF, Olshan AF, Herring AH, Honein MA, Shaw GM, **Romitti PA**, and the National Birth Defects Prevention Study. (2009) Bayesian methods for misclassification correction: an example from birth defects epidemiology. *Epidemiology* 20:27-35.

Miller EA, Manning SE, Rasmussen SA, Reefhuis J, Honein MA, and the National Birth Defects Prevention Study. (2009) Maternal exposure to tobacco smoke, alcohol and caffeine and risk of anorectal atresia: National Birth Defects Prevention Study 1997-2003. *Paediatr Perinat Epidemiol* 23: 9-17.

Mosley BS, Cleves MA, Siega-Riz AM, Shaw GM, Canfield MA, Waller DK, Werler MM, Hobbs CA, and the National Birth Defects Prevention Study. (2009) Neural tube defects and maternal folate intake among pregnancies conceived after folic acid fortification in the United States. *Am J Epidemiol* 169: 9-17.

Ramadhani T, Short V, Canfield MA, Waller DK, Correa A, Royle M, Scheuerle A, and the National Birth Defects Prevention Study (NBDPS). (2009) Are birth defects among Hispanics related to maternal nativity or number of years lived in the United States? *Birth Defects Res A Clin Mol Teratol* 85: 755-763.

Reefhuis J, Honein MA, Schieve LA, Correa A, Hobbs CA, Rasmussen SA, and the National Birth Defects Prevention Study. (2009) Assisted reproductive technology (ART) and major structural birth defects in the United States. *Hum Reprod* 24: 360-366.

Robitaille J, Carmichael SL, Shaw GM, Olney RS, and the National Birth Defects Prevention Study. (2009) Maternal nutrient intake and risks for transverse and longitudinal limb deficiencies: data from the National Birth Defects Prevention Study, 1997-2003. *Birth Defects Res A Clin Mol Teratol* 85: 773-9.

Schmidt RJ, Romitti PA, **Burns TL, Murray JC**, Druschel C, Browne M, Olney RS, and the National Birth Defects Prevention Study. (2009) Maternal caffeine consumption and neural tube defects. *Birth Defects Res Part A Clin Mol Teratol* 85:879-889

Siega-Riz AM, Herring AH, Olshan AF, Smith J, Moore C, and the National Birth Defects Prevention Study. (2009) The joint effects of maternal prepregnancy body mass index and age on the risk of gastroschisis. *Paediatr Perinat Epidemiol* 23: 51-57.

van Gelder M, Reefhuis J, Caton A, Werler M, Druschel C, Roeleveld N, and the National Birth Defects Prevention Study. (2009) Maternal periconceptional illicit drug use and the risk of congenital malformations in offspring. *Epidemiology* 20: 60-66.

Werler MM, Bosco JL, Shapira SK and the National Birth Defects Prevention Study. (2009) Maternal vasoactive exposures, amniotic bands, and terminal transverse limb defects. *Birth Defects Res A Clin Mol Teratol* 85: 52-57.

Werler MM, Mitchell AA, Moore CA, Honein MA and the National Birth Defects Prevention Study. (2009) Is there epidemiologic evidence to support vascular disruption as a pathogenesis of gastroschisis? *Am J Med Genet A* 149A: 1399-1406.

National Down Syndrome Project

The National Down Syndrome Project (NDSP) is a population-based study to investigate genetic and environmental risk factors for Down syndrome. This study is led by investigators at Emory University and is a combined effort of the Iowa Center and programs in five other states. Iowa women who gave birth to an infant affected with Down syndrome and women with an unaffected birth were interviewed about their health, diet, and lifestyle during pregnancy and biologic samples were collected from each family.

2009 NDSP Publications Using IRCID Data
(Names listed in bold designate Iowa investigators)

Freeman SB, Druschel CM, Hobbs CA, **Romitti PA**, Royle MH, Torfs CP, Sherman SL. (2009) Congenital gastrointestinal defects in Down Syndrome: a report from the National Down Syndrome Project. *Clin Genet* 75:180-184.

Allen EG, Freeman SB, Druschel C, Hobbs CA, O'Leary LA, **Romitti PA**, Royle MH, Torfs CP, Sherman SL. (2009) Maternal age and risk for trisomy 21 assessed by the origin of chromosome nondisjunction: a report from the Atlanta and National Down Syndrome Projects. *Hum Genet* 125:41-52

Muscular Dystrophy Research

Muscular dystrophy refers to a group of genetic diseases that cause progressive muscle weakness. The most common form of muscular dystrophy affecting children is Duchenne/Becker muscular dystrophy (DBMD). Duchenne muscular dystrophy is the name that historically refers to the most severe form of this disorder. DBMD usually presents with weakness in early childhood. Weakness is progressive and children lose the ability to walk in late childhood. In the severe form, death occurs in young adulthood.

DBMD is caused by mutations in the dystrophin gene on the X chromosome. Approximately 1 in 3,500 boys have DBMD. Girls rarely have the disease, but they can be carriers of the gene mutation. Approximately one-third of boys with Duchenne muscular dystrophy did not inherit the disorder.

The Muscular Dystrophy Surveillance Tracking and Research Network

MD STARnet, the Muscular Dystrophy Surveillance, Tracking and Research Network, is a program currently active in six states. Its goal is to identify all people with childhood-onset Duchenne/Becker muscular dystrophies (DBMD). On behalf of the MD STARnet, the IRCID is undertaking surveillance of Iowans born since 1982 with DBMD. This surveillance consists of identification and ongoing medical chart review.

<u>2009 MD STARnet Publications Using IRCID Data</u>

Cunniff C, Andrews J, Meaney FJ, **Mathews KD**, Matthews D, Ciafaloni E, Miller TM, Bodensteiner JB, Miller LA, James KA, Druschel CM, **Romitti PA**, Pandya MS. (2009) Mutation analysis in population-based sample of boys with Duchenne or Becker muscular dystrophy. *J Child Neurol* 24:425-430.

Ciafaloni E, Fox D, Pandya S, Westfield C, **Puzhankara S**, **Romitti PA**, **Mathews K**, Miller T, Matthews D, Miller L, Cunniff C, Druschel C, Moxley R, and the MD STARnet. Delayed Diagnosis in Duchenne Muscular Dystrophy: Data from the Muscular Dystrophy Surveillance, Tracking, and Research Network. *J Pediatr* [Epub ahead of print 2009 Apr 23]

Romitti P, **Puzhankara S**, **Mathews K**, **Zamba G**, Cunniff C, Andrews J, Matthews D, James K, Miller L, Druschel C, Fox D, Pandya S, Ciafaloni E, Adams M, Mandel D, Ouyang L, Constantin C, Costa P. (2009) Prevalence of Duchenne/Becker muscular dystrophy among males aged 5-24 years – four states, 2007. *MMWR Morb Mortal Wkly Rep* 58:1119-1122.

Romitti P, **Puzhankara S, Mathews K**, **Zamba G**, Cunniff C, Andrews J, Matthews D, James K, Miller L, Druschel C, Fox D, Pandya S, Ciafaloni E, Adams M, Mandel D, Ouyang L, Constantin C, Costa P. (2009) Prevalence of Duchenne/Becker muscular dystrophy among males aged 5-24 years – four states, 2007. *JAMA* 302:2539-2546 (reprint)

Acknowledgements

We gratefully acknowledge the assistance of the following collaborating Iowa agencies and organizations:

The University of Iowa

- Members of the internal advisory committee for the Iowa Registry for Congenital and Inherited Disorders
- Center for Health Effects of Environmental Contamination
- College of Liberal Arts
- Carver College of Medicine
- College of Nursing
- College of Public Health
- Craniofacial Anomalies Research Center
- Governmental Relations Office
- Hygienic Laboratory
- Iowa Cancer Registry

Iowa Department of Public Health and the members of the Center for Congenital and Inherited Disorders Advisory Committee
Iowa Regional Genetic Consultation Service
Iowa Board of Regents
March of Dimes Birth Defects Foundation
KID Coalition
ASK Resource Center

Registry surveillance activities are funded by:
State of Iowa through a special appropriation to the Board of Regents
State of Iowa through a fee on issuance of birth certificates
Centers for Disease Control and Prevention

Registry research activities are funded by:
Centers for Disease Control and Prevention
National Institutes of Health

Registry educational activities are funded by:
Centers for Disease Control and Prevention
National Institutes of Health

Development and publication of this report was supported by funds appropriated by the Iowa General Assembly to the State Board of Regents.

Contact Information

Iowa Registry for Congenital and Inherited Disorders
UI Research Park & BioVentures Center
N215 Oakdale Hall
Iowa City, IA 52242-5000

Phone: 319-335-4107
Fax: 319-335-4030

E-mail: ircid@uiowa.edu

www: http://www.public-health.uiowa.edu/ircid

The Iowa Registry for Congenital and Inherited Disorders is a collaborative program of the University of Iowa's College of Public Health and the Iowa Department of Public Health.