# Iowa Registry for Congenital and Inherited Disorders

**2016 Report**

The Iowa Registry for Congenital and Inherited Disorders (IRCID) continues to be a national leader in surveillance of congenital and inherited disorders and serves as a model program for other states. 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 55,000 children with various birth defects. This information is 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 140 children with this neuromuscular disease. More recently, we have expanded our surveillance of muscular dystrophies to include seven additional muscular dystrophies – Congenital, Distal, Emery-Dreifuss, Fascioscapulohumeral, Limb-Girdle, Myotonic, and Oculopharyngeal. Additionally, the IRCID has collaborated with the Metropolitan Atlanta Congenital Defects Program to develop approaches to conduct active surveillance for stillbirths and also newborn screening disorders. Most recently, the IRCID has partnered with the CDC to conduct rapid, active statewide surveillance of microcephaly and other birth defects that may be related to Zika virus exposure among pregnant women.

The surveillance and research efforts of the IRCID and its partners provide 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. We are pleased to perform this important work on behalf of the citizens of Iowa.

## Surveillance for Birth Defects

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

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. Since 2003, the IRCID adopted the recommendations of the National Birth Defects Prevention Network (NBDPN) to focus largely on a core set of birth 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 (per 10,000 live births) for birth defects in Iowa, 2009-2013 deliveries.**

| Birth Defect | Total | Prevalence* |
|---|---|---|
| **Brain/Spinal Cord** | | |
| Anencephalus | 52 | 2 |
| Encephalocele | 17 | 0.9 |
| Holoprosencephaly | 33 | 1.7 |
| Microcephalus | 154 | 7.9 |
| Spina bifida without anencephalus | 80 | 4.1 |
| **Eye** | | |
| Anophthalmia/microphthalmia | 33 | 1.7 |
| Congenital cataract | 74 | 3.8 |
| **Ear** | | |
| Anotia/microtia | 42 | 2.2 |
| **Heart** | | |
| Aortic valve stenosis | 54 | 2.8 |
| Atrial septal defect | 605 | 31.2 |
| Atrioventricular septal defect | 121 | 6.2 |
| Coarctation of aorta | 109 | 5.6 |
| Common truncus | 7 | 0.4 |
| Double outlet right ventricle | 46 | 2.4 |
| Ebstein's anomaly | 15 | 0.8 |
| Hypoplastic left heart syndrome | 55 | 2.8 |
| Interrupted aortic arch | 10 | 0.5 |
| Pulmonary valve atresia and stenosis | 258 | 13.3 |
| Single ventricle | 12 | 0.6 |
| Tetralogy of Fallot | 74 | 3.8 |
| Total anomalous pulmonary venous return | 18 | 0.9 |
| Transposition of great arteries | 58 | 3.0 |
| Tricuspid valve atresia and stenosis | 42 | 2.2 |
| Ventricular septal defect | 1053 | 54.3 |
| **Oral/Facial** | | |
| Choanal atresia | 28 | 1.4 |
| Cleft lip only | 71 | 3.7 |
| Cleft lip with cleft palate | 111 | 5.7 |
| Cleft palate without cleft lip | 139 | 7.2 |

**Table 1 (continued from previous page)**

| Birth Defect | Total | Prevalence* |
|---|---|---|
| **Gastro-Intestinal** | | |
| Biliary atresia | 9 | 0.5 |
| Esophageal atresia/tracheoesophageal fistula | 57 | 2.9 |
| Hirschsprung's disease (congenital megacolon) | 33 | 1.7 |
| Pyloric stenosis | 412 | 21.2 |
| Rectal and large intestinal atresia/stenosis | 87 | 4.5 |
| Small intestinal atresia and stenosis | 69 | 3.6 |
| **Genital/Urinary** | | |
| Bladder exstrophy | 7 | 0.4 |
| Cloacal exstrophy | < 5 | -- |
| Congenital posterior urethral valves | 23 | 1.2 |
| †Hypospadias | 577 | ‡58.3 |
| Renal agenesis/hypoplasia | 108 | 5.6 |
| **Muscle/Skeletal** | | |
| Clubfoot | 320 | 16.5 |
| Craniosynostosis | 139 | 7.2 |
| Diaphragmatic hernia | 55 | 2.8 |
| Gastroschisis | 120 | 6.2 |
| Limb deficiencies (reduction defects) | 117 | 6.0 |
| Omphalocele | 48 | 2.5 |
| **Syndromes/Chromosomes** | | |
| Down syndrome (Trisomy 21) | 235 | 12.0 |
| Edwards syndrome (Trisomy 18) | 69 | 3.5 |
| Patau syndrome (Trisomy 13) | 30 | 1.5 |
| Turner syndrome^ | 49 | ^5.2 |

*Prevalence per 10,000 live births.
†Includes first, second, and third degree hypospadias.
‡Prevalence per 10,000 male live births.
^Prevalence per 10,000 female live births.

## Birth Defect Research

Approximately 1 in 33 newborns is 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. As such, in 1996 the United States Congress directed the CDC to establish regional "centers of excellence" in birth defect research and prevention. Further, 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 congenital diaphragmatic hernia, gastroschisis, microcephaly, and pyloric stenosis.

### *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 participated in local (state-wide) projects as well as the National Birth Defects Prevention Study (NBDPS). The NBDPS was a population-based study that investigated genetic and environmental risk factors for over 30 major birth defects. As a partner with the Iowa Center, the IRCID identified children with NBDPS-eligible birth defects and secured permission from mothers to share information with researchers. Women with a pregnancy affected by one or more of the defects and women with an unaffected pregnancy were interviewed about their health, diet, and lifestyle during their pregnancies. Biological specimens were also requested from each family to study genetic factors that may contribute to these birth defects. Over 43,000 interviews were completed nationwide, and biological specimens have been collected from more than 25,000 families.

Over 300 research projects are currently underway nation-wide as part of the NBDPS. Some of these projects examine risk factors, such as maternal nutrition. Others examine gene and environment interaction effects. Still others examine maternal behavior during pregnancy.

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, as well as genetic risk factors and their interactions with these exposures.

**2016 Iowa Center Publication Using IRCID Data** (Names listed in bold designate Iowa investigators)

Leslie EJ, Liu H, Carlson JC, Shaffer JR, Feingold E, **Wehby G,** Laurie CA, Jain D, Laurie CC, Doheny KF, McHenry T, Resick J, Sanchez C, Jacobs J, Emanuele B, Vieira AR, Neiswanger K, Standley J, Czeizel AE, Deleyiannis F, Christensen K, Munger RG, Lie RT, Wilcox A, **Romitti PA**, Field LL, Padilla CD, Cutionqco-de la Paz EM, **Lidral AC**, Valencia-Ramirez LC, Lopez-Palacio AM, Valencia DR, Arcos-Burgos M, Castilla EE, Mereb JC, Poletta FA, Orioli IM, Carvalho FM, Hecht JT, Blanton SH, Buxo CJ, **Butali A**, Mossey PA, Adeyemo WL, James O, Braimah RO, Aregbesola BS, Eshete MA, Deribew M, Koruyucu M, Seymen F, Ma L, de Salamance JE, Weinberg SM, **Moreno L,** Cornell RA, **Murray JC,** Marazita ML. (2016) A genome-wide association study of nonsyndromic cleft palate identifies an etiologic missense variant in GRHL3. Am J Hum Genet 98:744-754. PMID: 27018472 doi: 10.1016/j.ajhg.2016.02.014

Leslie EJ, Carlson JC, Shaffer JR, Feingold E, **Wehby G,** Laurie CA, Jain D, Laurie CC, Doheny KF, McHenry T, Resick J, Sanchez C, Jacobs J, Emanuele B, Vieira AR, Neiswanger K, **Lidral AC**, Valencia-Ramirez LC, Lopez-Palacio AM, Valencia DR, Arcos-Burgos M, Czeizel AE, Field LL, Padilla CD, Cutiongco-de la Paz EM, Deleyiannis F, Christensen K, Munger RG, Lie RT, Wilcox A, **Romitti PA**, Castilla EE, Mereb JC, Poletta FA, Orioli IM, Carvalho FM, Hecht JT, Blanton SH, Buxó CJ, **Butali A**, Mossey PA, Adeyemo WL, James O, Braimah RO, Aregbesola BS, Eshete MA, Abate F, Koruyucu M, Seymen F, Ma L, de Salamanca JE, Weinberg SM, **Moreno L, Murray JC,** Marazita ML. (2016) A multi-ethnic genome-wide association study identifies novel loci for nonsyndromic cleft lip with or without cleft palate on 2p24.2, 17q23 and 19q13. Hum Mol Genet 25:2862-2872. PMID: 27033726 doi: 10.1093/hmg/ddw104

Ye X, Guilmatre A, Reva B, Peter I, Heuzé Y, Richtsmeier JT, Fox DJ, **Goedken RJ,** Jabs EW, **Romitti PA**. (2016) Mutation screening of candidate genes in patients with nonsyndromic sagittal craniosynostosis. Plast Reconstr Surg 137:952-961. PMID: 26910679 doi: 10.1097/01.prs.0000479978.75545.ee

**2016 NBDPN Publication Using IRCID Data** (Names listed in bold designate Iowa investigators)

Cragan JD, Isenburg JL, Parker SE, Alverson CJ, Meyer RE, Stallings EB, Kirby RS, Lupo PJ, Liu JS, Seagroves A, Ethen MK, Cho SJ, Evans MA, Liberman RF, Fornoff J, Browne ML, Rutkowski RE, Nance AE, Anderka M, Fox DJ, Steele A, Copeland G, **Romitti PA**, Mai CT for the National Birth Defects Prevention Network. (2016) Population-based microcephaly surveillance in the United States, 2009-2013: an analysis of potential factors contributing to variation. Birth Defects Res A Clin Mol Teratol 106:972-982. PMID: 27891783 doi: 10.1002/bdra.23587

Jones AM, Isenburg J, Salemi JL, Arnold KE, Mai CT, Aggarwal D, Arias W, Carrino GE, Ferrell E, Folorunso O, Ibe B, Kirby RS, Krapfl HR, Marengo LK, Mosley BS, Nance AE, **Romitti PA**, Spadafino J, Stock J, Honein MA. (2016) Increasing Prevalence of Gastroschisis - 14 States, 1995-2012. MMWR Morb Mortal Wkly Rep 65:23-26. PMID: 26796490 doi: 10.15585/mmwr.mm6502a2

**2016 NBDPS Publications Using IRCID Data** (Names listed in bold designate Iowa investigators)

DeRoo LA, Wilcox AJ, Lie RT, **Romitti PA**, Pedersen DA, Munger RG, **Moreno Uribe LM, Wehby GL**. (2016) Maternal alcohol binge-drinking in the first trimester and the risk of orofacial clefts in offspring: a large population-based pooling study. Eur J Epidemiol 31:1021-1034. PMID: 27350158 doi: 10.1007/s10654-016-0171-5

Howley MM, Carter TC, Browne ML, **Romitti PA**, Cunniff CM, Druschel CM for the National Birth Defects Prevention Study. (2016) Fluconazole use and birth defects in the National Birth Defects Prevention Study. Am J Obstet Gynecol 214:657.e1-657.e9. PMID: 26640069 doi: 10.1016/j.ajog.2015.11.022

Hoyt A, Canfield MA, **Romitti PA**, Botto LD, Anderka MT, Krikov SV, Tarpey MK, Feldkamp ML. (2016) Associations between maternal periconceptional exposure to secondhand tobacco smoke and major birth defects. Amer J Obstet Gynecol 215:613.e1-11. PMID: 27443814 doi: 10.1016/j.ajog.2016.07.022

**Kummet CM, Moreno LM,** Wilcox AJ, **Romitti PA**, DeRoo LA, Munger RG, Lie RT, **Wehby GL**. (2016) Passive smoke exposure as a risk factor for oral clefts – a large international population-based study. Am J Epidemiol 183:834-841. PMID: 27045073 doi: 10.1093/aje/kwv279

Kutbi H, **Wehby GL, Moreno Uribe LM, Romitti PA**, Carmichael S, Shaw GM, Olshan AF, DeRoo L, Rasmussen SA, **Murray JC,** Wilcox A, Lie RT, Munger RG. (2016) Maternal underweight and obesity and risk of orofacial clefts in a large international consortium of population-based studies. Int J Epidemiol :1-10. [Epub ahead of print] PMID: 27215617 doi: 10.1093/ije/dyw035

Lee LJ, Symasnki E, Lupo PJ, Tinker SC, Razzaghi H, Pompeii LA, Hoyt AT, Canfield MA, Chan W, and the National Birth Defects Prevention Study. (2016) Data linkage between the national birth defects prevention study and the occupational information network (O*NET) to assess workplace physical activity, sedentary behaviors, and emotional stressors during pregnancy. Am J Ind Med 59:137-149. PMID: 26681357 doi: 10.1002/ajim.22548

Li M, Li J, He Z, Lu Q, Witte JS, Macleod SL, Hobbs CA, Cleves MA, and the National Birth Defects Prevention Study. (2016) Testing allele transmission of an SNP set using a family-based generalized genetic random field method. Genet Epidemiol 40:341-351. PMID: 27061818 doi: 10.1002/gepi.21970

Lim H, Beasley CW, Whitehead LW, Emery RJ, Agopian AJ, Langlois PH, Waller DK, and the National Birth Defects Prevention Study. (2016) Maternal exposure to radiographic exams and major structural birth defects. Birth Defects Res A Clin Mol Teratol 106:563-572 PMID: 27001904 doi: 10.1002/bdra.23496

O'Brien JL, Langlois PH, Lawson CC, Scheuerle A, Rocheleau CM, Waters MA, Symanski E, **Romitti PA**, Agopian AJ, Lupo PJ, and the National Birth Defects Prevention Study. (2016) Maternal occupational exposure to polycyclic aromatic hydrocarbons and craniosynostosis among offspring in the national birth defects prevention study. Birth Defects Res A Clin Mol Teratol 106:55-60. PMID: 26033890 doi: 10.1002/bdra.23389

Pettigrew S, Bell EM, Van Zutphen A, Rocheleau CM, Shaw GM, **Romitti PA**, Olshan A, Lupo PJ, Soim AS, **Makelarski JA,** Michalski A, Sanderson WT. (2016) Paternal and joint parental occupational pesticide exposure and spina bifida in the National Birth Defects Prevention Study, 1997-2002. Birth Defects Res A Clin Mol Teratol 106:963-971. PMID: 27891778 doi: 10.1002/bdra.23551

Razzaghi H, Tinker SC, Herring AH, Howards PP, Waller DK, Johnson CY, and the National Birth Defects Prevention Study. (2016) Impact of missing data for body mass index in an epidemiologic study. Matern Child Health J 20:1497-1505. PMID: 27029540 doi: 10.1007/s10995-016-1948-6

Vuong AM, Shinde MU, Brender JD, Shipp EM, Huber JC Jr., Sharkey JR, McDonald TJ, Werler MM, Kelley KE, Griesenbeck JS, Langlois PH, Canfield MA, and the National Birth Defects Prevention Study. (2016) Prenatal exposure to nitrosatable drugs, dietary intake of nitrates, and preterm birth. Am J Epidemiol 183:634-642. PMID: 26953287 doi: 10.1093/aje/kwv250

Wadhwa EL, Ma C, Shaw GM, Carmichael SL, and the National Birth Defects Prevention Study. (2016) Gastroschisis and maternal intake of phytoestrogens. Am J Med Gen A 170:2078-2082. PMID: 27232448 doi: 10.1002/ajmg.a.37659

Warren JL, Stingone JA, Herring AH, Luben TJ, Fuentes M, Aylsworth AS, Langlois PH, Botto LD, Correa A, Olshan AF, and the National Birth Defects Prevention Study. (2016) Bayesian multinomial probit modeling of daily windows of susceptibility for maternal PM2.5 exposure and congenital heart defects. Stat Med 35:2786-2801. PMID: 26853919 doi: 10.1002/sim.6891

## Surveillance for Microcephaly and Other Birth Defects Related to Zika Virus Exposure

Congenital microcephaly (MC) is a serious birth defect characterized by an abnormally small head size in affected infants compared to infants of the same sex and gestational age. A recent, dramatic increase in MC in infants in Brazil has been linked to pregnant women infected with Zika virus. This virus is transmitted most commonly through the bite of infected mosquitoes. Unlike its often mild presentation in infected adults, Zika virus exposure poses a serious risk to an unborn fetus. With the potentially devastating effects of fetal exposure to Zika virus, more timely surveillance is needed for monitoring birth defects that may be related to Zika virus exposure among pregnant women. To advance statewide surveillance of MC and other birth defects that may be related to Zika virus exposure among pregnancy women, the IRCID created a rapid response team comprised of experienced surveillance professionals. In Iowa, our team is partnering with the Center for Acute Disease Epidemiology at the Iowa Department of Public Health and the State Hygienic Laboratory of Iowa. Along with rapid surveillance, our team will connect affected infants and families to health and social services, examine health and developmental outcomes of infants born to women with a positive or inconclusive Zika virus test result during pregnancy, and participate in centralized national projects led by the CDC for effective translation of our surveillance data into public health action.

## Surveillance for Muscular Dystrophy

Muscular dystrophies (MDs) are a group of genetic progressive muscle diseases affecting an estimated 33 per 100,000 individuals and characterized by worsening muscle weakness. Historically, types of MDs were diagnosed by known changes in muscle and clinical presentation; more recently, diagnosis is determined largely by genetic analysis. Ages at symptom onset of MDs can range from birth through late adulthood. In children, Duchenne is the most common childhood MD, followed by the congenital MDs. In adults, myotonic dystrophy is the most common MD, followed by facioscapulohumeral MD.

### *Muscular Dystrophy Surveillance Tracking and Research Network (MD STARnet)*

The MD STAR*net* is a surveillance program currently active in six states. The goals of the MD STAR*net* are to define and describe the MD population in the United States, define and describe healthcare needs and outcomes for individuals living with MD, and collect information to guide MD care, treatment, and

policy. On behalf of the MD STAR*net*, the IRCID is conducting surveillance of Iowans diagnosed with one of nine MDs (Table 2). This surveillance consists of identification and ongoing medical chart review.

**Table 2. Number of patients identified with a muscular dystrophy among Iowa residents, 2004-2016**

| Phase of Surveillance/Muscular Dystrophy | Number of Patients |
|---|---|
| Phase I* | |
| Duchenne or Becker | 140 |
| Phase II† | |
| Becker | 52 |
| Congenital | 24 |
| Distal | 5 |
| Duchenne | 105 |
| Emery-Dreifuss | 12 |
| Fascioscapulohumeral | 81 |
| Limb-Girdle | 66 |
| Myotonic | 253 |
| Oculopharyngeal | 17 |

*Patient born on or after January 1, 1982 through December 31, 2011.
†Patient with MD diagnosis and health encounter from January 1, 2007 through December 31, 2011.

## Muscular Dystrophy Research

**2016 MD STAR*net* Publications Using IRCID Data** (Names listed in bold designate Iowa investigators)

Andrews JG, Soim A, Pandya S, Westfield CP, Ciafaloni E, Fox DJ, Birnkrant DJ, Cunniff CM, Sheehan DW; Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STAR*net*). (2016) Respiratory care received by individuals with Duchenne muscular dystrophy from 2000 to 2011. Respir Care 61:1349-1359. PMID: 27507176 doi: 10.4187/respcare.04676

Ciafaloni E, Kumar A, **Liu K**, Pandya S, Westfield C, Fox DJ, **Caspers Conway KM**, Cunniff C, **Mathews K**, West N, **Romitti PA**, McDermott MP. (2016) Age at onset of first signs or symptoms predicts age at loss of ambulation in Duchenne and Becker muscular dystrophy: Data from the MD STAR*net*. J Pediatr Rehabil Med 9:5-11. PMID: 26966795 doi: 10.3233/PRM-160361

Lamb MM, West NA, Ouyang L, Yang M, Weitzenkamp D, James K, Ciafaloni E, Pandya S, DiGuiseppi C; Muscular Dystrophy Surveillance, Research, and Tracking Network (MD STAR*net*). (2016) Corticosteroid treatment and growth patterns in ambulatory males with Duchenne muscular dystrophy. J Pediatr 173:207-213.e3. PMID: 27039228 doi: 10.1016/j.jpeds.2016.02.067

Pandya SK, Campbell KA, Andrews JG, Meaney FJ, Ciafaloni E. (2016) Health services received by individuals with Duchenne/Becker muscular dystrophy. Muscle Nerve 53:191-197. PMID: 26044770 doi: 10.1002/mus.24727

Pandya S, Andrews J, Campbell K, Meaney FJ. (2016) Rehabilitative technology use among individuals with Duchenne/Becker muscular dystrophy. J Pediatr Rehabil Med 9:45-53. PMID: 26966800 doi: 10.3233/PRM-160356

**Iowa Registry for Congenital and Inherited Disorders Personnel**

**Director**
Paul A Romitti, PhD

**Clinical Directors for Birth Defects**
Daniel Bonthius, MD, PhD
Amy Calhoun, MD
Thomas Scholz, MD

**Clinical Director for Neuromuscular Disorders**
Katherine Mathews, MD

**Clinical Directors for Stillbirths**
Patricia Kirby, MBBCh, M Med, MRCPath, FRCPath

**Clinical Editor**
Kim Martin, RNC

**Data Manager**
Lowell "Bill" McKirgan, MA

**Surveillance Field Staff**
Leanna Darnold, BA, MT, CIC
Patricia Ganzer Holland

**Center for Congenital and Inherited Disorders, Iowa Department of Public Health**
Kimberly Piper, RNC, BS, CPH



*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.*

## Acknowledgements

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

The University of Iowa
- Center for Health Effects of Environmental Contamination
- Carver College of Medicine
- College of Public Health
- Governmental Relations Office
- 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
State Hygienic Laboratory of Iowa
KID Coalition
ASK Resource Center

**IRCID 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

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

**IRCID educational activities are funded by:**
Centers for Disease Control and Prevention

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
100 IREH, Room 201
Iowa City, IA 52242-5000
Phone: 319-335-4107
Fax: 319-335-4030
E-mail: ircid@uiowa.edu
Website: http://www.public-health.uiowa.edu/ircid