

## Iowa

## Iowa Registry for Congenital and Inherited Disorders (IRCID)

**Purpose:** Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Prevention education programs  
**Partner:** Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Legislators  
**Program status:** Currently collecting data  
**Start year:** 1983  
**Earliest year of available data:** 1983  
**Organizational location:** University  
**Population covered annually:** 39,223 average live births per year (2014-2017)  
**Statewide:** Yes  
**Current legislation or rule:** Iowa Code 136A, Iowa Administrative Code 641-4.7  
**Legislation year enacted:** 1986; Revised 2001, 2003, 2004, 2009, 2013

**Case Definition**

**Outcomes covered:** Major birth defects, muscular dystrophy, fetal deaths with and without birth defects, newborn screening disorders  
**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)  
**Age:** 2 years  
**Residence:** Maternal residence in Iowa at time of delivery

**Surveillance Methods**

**Case ascertainment:** Active Case Finding  
**Vital records:** Birth certificates, Death certificates, Fetal death certificates, Fetal Death Evaluation Protocol  
**Other state based registries:** Programs for children with special needs, Newborn hearing screening program, Developmental Disabilities Surveillance, Cancer registry, Iowa Perinatal Care Program  
**Delivery hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports.  
**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports.  
**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities  
**Other sources:** Physician reports, Outpatient surgery facilities; IHA Discharge Data

**Case Ascertainment**

**Conditions warranting chart review in newborn period:** Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any chart with selected procedure codes, Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All elective abortions, All neonatal deaths, All infants in NICU or special care nursery, All prenatally diagnosed or suspected cases

**Conditions warranting chart review beyond the newborn period:** Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

**Coding:** CDC coding system based on BPA, ICD-9-CM/ICD-10-CM

**Data Collected**

**Infant/fetus:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information  
**Mother:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history  
**Father:** Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

**Data Collection Methods and Storage**

**Data collection:** Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

**Database collection and storage:** Access, Oracle, PC Server, FileMaker Pro

**Data Analysis**

**Data analysis software:** SAS

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

**System Integration**

**System links:** Link case finding data to final birth file, Link to environmental databases

**Funding**

**Funding source:** 100% General state funds

**Other**

**Web site:** <http://www.public-health.uiowa.edu/ircid/>

**Contacts**

**Paul A. Romitti, Ph.D.**

Iowa Registry for Congenital and Inherited Disorders

UI Research Park 201 IREH

Iowa City, IA 52242-5000

Phone: 319-384-1549

Fax: 319-353-4095

Email: [paul-romitti@uiowa.edu](mailto:paul-romitti@uiowa.edu)

Carrie J. Fall, B.A.S.

Iowa Registry for Congenital and Inherited Disorders

UI Research Park 201 IREH

Iowa City, IA 52242-5000

Phone: 319-335-4511

Fax: 319-335-4030

Email: [carrie-fall@uiowa.edu](mailto:carrie-fall@uiowa.edu)

## **DATA TABLES**

**Iowa**  
**Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)**

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Anencephalus	17 <i>1.4</i>	2 <i>2.1</i>	3 <i>2.2</i>	1 <i>1.8</i>	0 <i>0.0</i>	37 <i>2.4</i>	
Anophthalmia/microphthalmia	17 <i>1.4</i>	4 <i>4.2</i>	4 <i>2.9</i>	2 <i>3.5</i>	0 <i>0.0</i>	29 <i>1.8</i>	
Anotia/microtia	42 <i>3.4</i>	0 <i>0.0</i>	9 <i>6.5</i>	3 <i>5.3</i>	0 <i>0.0</i>	55 <i>3.5</i>	
Aortic valve stenosis	36 <i>2.9</i>	0 <i>0.0</i>	3 <i>2.2</i>	1 <i>1.8</i>	0 <i>0.0</i>	41 <i>2.6</i>	
Atrial septal defect	342 <i>27.3</i>	38 <i>39.9</i>	31 <i>22.5</i>	11 <i>19.4</i>	2 <i>28.9</i>	435 <i>27.7</i>	
Atrioventricular septal defect (Endocardial cushion defect)	55 <i>4.4</i>	8 <i>8.4</i>	7 <i>5.1</i>	3 <i>5.3</i>	1 <i>14.5</i>	75 <i>4.8</i>	
Biliary atresia	5 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>1.8</i>	0 <i>0.0</i>	7 <i>0.4</i>	
Bladder exstrophy	6 <i>0.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>1.8</i>	0 <i>0.0</i>	7 <i>0.4</i>	
Choanal atresia	7 <i>0.6</i>	1 <i>1.0</i>	1 <i>0.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>0.6</i>	1
Cleft lip alone	48 <i>3.8</i>	5 <i>5.2</i>	8 <i>5.8</i>	2 <i>3.5</i>	1 <i>14.5</i>	66 <i>4.2</i>	
Cleft lip with cleft palate	91 <i>7.3</i>	5 <i>5.2</i>	7 <i>5.1</i>	3 <i>5.3</i>	0 <i>0.0</i>	115 <i>7.3</i>	
Cleft palate alone	89 <i>7.1</i>	11 <i>11.5</i>	4 <i>2.9</i>	2 <i>3.5</i>	0 <i>0.0</i>	109 <i>6.9</i>	
Cloacal exstrophy	1 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>0.1</i>	
Clubfoot	225 <i>18.0</i>	17 <i>17.8</i>	23 <i>16.7</i>	5 <i>8.8</i>	2 <i>28.9</i>	282 <i>18.0</i>	
Coarctation of the aorta	96 <i>7.7</i>	3 <i>3.1</i>	4 <i>2.9</i>	3 <i>5.3</i>	0 <i>0.0</i>	106 <i>6.8</i>	
Common truncus (truncus arteriosus)	9 <i>0.7</i>	1 <i>1.0</i>	3 <i>2.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	13 <i>0.8</i>	
Congenital cataract	51 <i>4.1</i>	6 <i>6.3</i>	4 <i>2.9</i>	1 <i>1.8</i>	0 <i>0.0</i>	62 <i>4.0</i>	
Congenital posterior urethral valves	11 <i>1.7</i>	1 <i>2.1</i>	0 <i>0.0</i>	1 <i>3.4</i>	0 <i>0.0</i>	13 <i>1.6</i>	2
Craniosynostosis	78 <i>6.2</i>	1 <i>1.0</i>	5 <i>3.6</i>	3 <i>5.3</i>	1 <i>14.5</i>	90 <i>5.7</i>	
Deletion 22q11.2	19 <i>1.5</i>	3 <i>3.1</i>	1 <i>0.7</i>	1 <i>1.8</i>	1 <i>14.5</i>	25 <i>1.6</i>	
Diaphragmatic hernia	33 <i>2.6</i>	1 <i>1.0</i>	5 <i>3.6</i>	2 <i>3.5</i>	0 <i>0.0</i>	44 <i>2.8</i>	
Double outlet right ventricle	21 <i>1.7</i>	2 <i>2.1</i>	5 <i>3.6</i>	2 <i>3.5</i>	0 <i>0.0</i>	31 <i>2.0</i>	
Ebstein anomaly	13 <i>1.0</i>	1 <i>1.0</i>	3 <i>2.2</i>	1 <i>1.8</i>	0 <i>0.0</i>	18 <i>1.1</i>	
Encephalocele	14 <i>1.1</i>	0 <i>0.0</i>	2 <i>1.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	18 <i>1.1</i>	
Esophageal atresia/tracheoesophageal fistula	31 <i>2.5</i>	2 <i>2.1</i>	2 <i>1.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	35 <i>2.2</i>	
Gastroschisis	57 <i>4.6</i>	4 <i>4.2</i>	3 <i>2.2</i>	1 <i>1.8</i>	0 <i>0.0</i>	67 <i>4.3</i>	
Holoprosencephaly	16 <i>1.3</i>	1 <i>1.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	27 <i>1.7</i>	
Hypoplastic left heart syndrome	37 <i>3.0</i>	4 <i>4.2</i>	1 <i>0.7</i>	1 <i>1.8</i>	0 <i>0.0</i>	46 <i>2.9</i>	
Hypospadias	438 <i>68.3</i>	33 <i>69.9</i>	24 <i>34.2</i>	11 <i>37.2</i>	0 <i>0.0</i>	508 <i>63.2</i>	2
Interrupted aortic arch	9 <i>0.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	9 <i>0.6</i>	

**Iowa**  
**Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)**

Defect	Maternal Race/Ethnicity					Total*	Notes
	White, Non-Hispanic	Black, Non-Hispanic	Hispanic	Asian or Pacific Islander, Non-Hispanic	American Indian or Alaska Native, Non-Hispanic		
Limb deficiencies (reduction defects)	63 <i>5.0</i>	4 <i>4.2</i>	9 <i>6.5</i>	3 <i>5.3</i>	0 <i>0.0</i>	84 <i>5.4</i>	3
Omphalocele	31 <i>2.5</i>	2 <i>2.1</i>	3 <i>2.2</i>	2 <i>3.5</i>	1 <i>14.5</i>	44 <i>2.8</i>	
Pulmonary valve atresia and stenosis	131 <i>10.5</i>	15 <i>15.7</i>	12 <i>8.7</i>	3 <i>5.3</i>	0 <i>0.0</i>	161 <i>10.3</i>	
Pulmonary valve atresia	3 <i>0.2</i>	2 <i>2.1</i>	0 <i>0.0</i>	1 <i>1.8</i>	0 <i>0.0</i>	6 <i>0.4</i>	
Rectal and large intestinal atresia/stenosis	39 <i>3.1</i>	3 <i>3.1</i>	6 <i>4.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	49 <i>3.1</i>	
Renal agenesis/hypoplasia	82 <i>6.6</i>	3 <i>3.1</i>	9 <i>6.5</i>	1 <i>1.8</i>	0 <i>0.0</i>	100 <i>6.4</i>	
Single ventricle	5 <i>0.4</i>	0 <i>0.0</i>	1 <i>0.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	6 <i>0.4</i>	
Small intestinal atresia/stenosis	49 <i>3.9</i>	5 <i>5.2</i>	2 <i>1.5</i>	2 <i>3.5</i>	0 <i>0.0</i>	59 <i>3.8</i>	
Spina bifida without anencephalus	61 <i>4.9</i>	4 <i>4.2</i>	4 <i>2.9</i>	1 <i>1.8</i>	0 <i>0.0</i>	76 <i>4.8</i>	
Tetralogy of Fallot	45 <i>3.6</i>	5 <i>5.2</i>	3 <i>2.2</i>	1 <i>1.8</i>	1 <i>14.5</i>	55 <i>3.5</i>	
Total anomalous pulmonary venous connection	10 <i>0.8</i>	1 <i>1.0</i>	4 <i>2.9</i>	1 <i>1.8</i>	0 <i>0.0</i>	16 <i>1.0</i>	
Transposition of the great arteries (TGA)	39 <i>3.1</i>	1 <i>1.0</i>	5 <i>3.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	47 <i>3.0</i>	
Dextro-transposition of great arteries (d-TGA)	34 <i>2.7</i>	1 <i>1.0</i>	5 <i>3.6</i>	0 <i>0.0</i>	0 <i>0.0</i>	42 <i>2.7</i>	
Tricuspid valve atresia and stenosis	30 <i>2.4</i>	6 <i>6.3</i>	6 <i>4.4</i>	1 <i>1.8</i>	0 <i>0.0</i>	43 <i>2.7</i>	
Tricuspid valve atresia	8 <i>0.6</i>	1 <i>1.0</i>	0 <i>0.0</i>	1 <i>1.8</i>	0 <i>0.0</i>	10 <i>0.6</i>	
Trisomy 13	21 <i>1.7</i>	3 <i>3.1</i>	2 <i>1.5</i>	0 <i>0.0</i>	0 <i>0.0</i>	33 <i>2.1</i>	
Trisomy 18	33 <i>2.6</i>	2 <i>2.1</i>	5 <i>3.6</i>	5 <i>8.8</i>	1 <i>14.5</i>	57 <i>3.6</i>	
Trisomy 21 (Down syndrome)	182 <i>14.6</i>	17 <i>17.8</i>	26 <i>18.9</i>	6 <i>10.6</i>	1 <i>14.5</i>	237 <i>15.1</i>	
Turner syndrome	23 <i>3.8</i>	1 <i>2.1</i>	4 <i>5.9</i>	2 <i>7.4</i>	0 <i>0.0</i>	35 <i>4.6</i>	4
Ventricular septal defect	707 <i>56.5</i>	60 <i>62.9</i>	69 <i>50.2</i>	24 <i>42.4</i>	2 <i>28.9</i>	878 <i>56.0</i>	
<b>Total live births</b>	<b>125,069</b>	<b>9,535</b>	<b>13,751</b>	<b>5,667</b>	<b>692</b>	<b>156,891</b>	<b>5</b>
<b>Male live births</b>	<b>64,157</b>	<b>4,719</b>	<b>7,011</b>	<b>2,958</b>	<b>360</b>	<b>80,319</b>	
<b>Female live births</b>	<b>60,911</b>	<b>4,816</b>	<b>6,740</b>	<b>2,709</b>	<b>332</b>	<b>76,571</b>	

**Iowa**  
**Birth Defects Counts and Prevalence 2014 - 2017 (Prevalence per 10,000 Live Births)**

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	66 <i>4.8</i>	1 <i>0.5</i>	67 <i>4.3</i>	
Trisomy 13	21 <i>1.5</i>	12 <i>6.0</i>	33 <i>2.1</i>	
Trisomy 18	35 <i>2.6</i>	22 <i>11.1</i>	57 <i>3.6</i>	
Trisomy 21 (Down syndrome)	129 <i>9.4</i>	108 <i>54.4</i>	237 <i>15.1</i>	
<b>Total live births</b>	<b>137,018</b>	<b>19,867</b>	<b>156,891</b>	<b>5</b>

**Notes**

1. Data for this condition excludes choanal stenosis.
2. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
3. Data for this condition excludes other specified and unspecified limb reductions.
4. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
5. Data for total live births include unknown gender.

**General comments**

\*Data for totals include unknown and/or other.

-Data for all conditions excludes probable/possible cases.