

Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services

Partner: Local Health Departments, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Drug-testing laboratories; Departments of Human Services, Health and Family Services, Children and Family Services; Newborn Metabolic Screening Program, Specialized Care for Children

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1989

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 150,000

Statewide: Yes

Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/77 Illinois Administrative Code 840)

Legislation year enacted: 1984; last amended 2008

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)

Age: Up to 2 years after delivery

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation

Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate

Other state based registries: Newborn metabolic screening program, Hospital discharge data

Delivery hospitals: Discharge summaries, Reporting from hospital nurseries

Pediatric & tertiary care hospitals: Reporting from hospital nurseries

Case Ascertainment

Conditions warranting chart review in newborn period: 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 prenatally diagnosed or suspected cases, Infants with selected defects noted on a death certificate (up to 2 years of age); any report to the program of a selected defect.

Conditions warranting chart review beyond the newborn period: Any infant with a codable defect

Coding: CDC coding system based on BPA

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, Prenatal care

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Access, Purpose-built system linked with Vital Record System

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file

System integration: Cases are collected in a database that is a module of the Vital Record reporting system. Cases may be initiated from the birth certificate, by hospital staff or by APORS staff. Local community health agencies have access to cases in their jurisdiction for provision of case-management services. APORS cases are also included in the Illinois Healthcare and Family Services Enterprise Data Warehouse where they are available to Illinois' Department of Human Services, Department of Children and Family Services, and Department of Healthcare and Family Services staffs.

Funding

Funding source: 100% General state funds

Other

Web site: <http://www.dph.illinois.gov/data-statistics/epidemiology/apors>
Surveillance reports on file: Birth Defects and Other Adverse Pregnancy Outcomes in Illinois 2014-2018; Trends in the Prevalence of Birth Defects in Illinois and Chicago 2002-2018

Additional information on file: QC reports, fact sheets

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DATA TABLES

Illinois
Birth Defects Counts and Prevalence 2014 - 2018 (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 Alaska Native, Non-Hispanic		
Anencephalus	49 <i>1.2</i>	18 <i>1.4</i>	30 <i>1.9</i>	7 <i>1.4</i>	0 <i>0.0</i>	106 <i>1.4</i>	
Anophthalmia/microphthalmia	87 <i>2.1</i>	35 <i>2.7</i>	58 <i>3.6</i>	10 <i>2.1</i>	2 <i>39.4</i>	192 <i>2.5</i>	
Anotia/microtia	68 <i>1.7</i>	16 <i>1.2</i>	72 <i>4.4</i>	11 <i>2.3</i>	0 <i>0.0</i>	167 <i>2.2</i>	
Aortic valve stenosis	124 <i>3.0</i>	38 <i>3.0</i>	43 <i>2.7</i>	7 <i>1.4</i>	0 <i>0.0</i>	212 <i>2.8</i>	
Atrial septal defect	1,128 <i>27.7</i>	460 <i>35.8</i>	538 <i>33.2</i>	157 <i>32.3</i>	4 <i>78.9</i>	2,295 <i>30.0</i>	
Atrioventricular septal defect (Endocardial cushion defect)	208 <i>5.1</i>	91 <i>7.1</i>	94 <i>5.8</i>	22 <i>4.5</i>	0 <i>0.0</i>	416 <i>5.4</i>	1
Biliary atresia	17 <i>0.4</i>	7 <i>0.5</i>	5 <i>0.3</i>	8 <i>1.6</i>	0 <i>0.0</i>	37 <i>0.5</i>	
Bladder exstrophy	11 <i>0.3</i>	3 <i>0.2</i>	2 <i>0.1</i>	1 <i>0.2</i>	0 <i>0.0</i>	17 <i>0.2</i>	
Choanal atresia	49 <i>1.2</i>	19 <i>1.5</i>	30 <i>1.9</i>	2 <i>0.4</i>	1 <i>19.7</i>	101 <i>1.3</i>	
Cleft lip alone	140 <i>3.4</i>	36 <i>2.8</i>	46 <i>2.8</i>	10 <i>2.1</i>	1 <i>19.7</i>	235 <i>3.1</i>	
Cleft lip with cleft palate	255 <i>6.3</i>	65 <i>5.1</i>	131 <i>8.1</i>	21 <i>4.3</i>	0 <i>0.0</i>	473 <i>6.2</i>	
Cleft palate alone	291 <i>7.1</i>	65 <i>5.1</i>	80 <i>4.9</i>	39 <i>8.0</i>	2 <i>39.4</i>	477 <i>6.2</i>	
Cloacal exstrophy	13 <i>0.3</i>	4 <i>0.3</i>	7 <i>0.4</i>	2 <i>0.4</i>	0 <i>0.0</i>	26 <i>0.3</i>	
Clubfoot	613 <i>15.0</i>	213 <i>16.6</i>	236 <i>14.6</i>	64 <i>13.2</i>	8 <i>157.8</i>	1,137 <i>14.9</i>	
Coarctation of the aorta	263 <i>6.5</i>	50 <i>3.9</i>	96 <i>5.9</i>	19 <i>3.9</i>	2 <i>39.4</i>	430 <i>5.6</i>	
Common truncus (truncus arteriosus)	22 <i>0.5</i>	6 <i>0.5</i>	9 <i>0.6</i>	2 <i>0.4</i>	0 <i>0.0</i>	39 <i>0.5</i>	
Congenital cataract	55 <i>1.3</i>	32 <i>2.5</i>	22 <i>1.4</i>	8 <i>1.6</i>	0 <i>0.0</i>	117 <i>1.5</i>	
Congenital posterior urethral valves	54 <i>2.6</i>	27 <i>4.1</i>	10 <i>1.2</i>	6 <i>2.4</i>	0 <i>0.0</i>	97 <i>2.5</i>	2
Craniosynostosis	253 <i>6.2</i>	38 <i>3.0</i>	114 <i>7.0</i>	16 <i>3.3</i>	1 <i>19.7</i>	422 <i>5.5</i>	
Deletion 22q11.2	43 <i>1.1</i>	25 <i>1.9</i>	13 <i>0.8</i>	4 <i>0.8</i>	0 <i>0.0</i>	85 <i>1.1</i>	
Diaphragmatic hernia	131 <i>3.2</i>	28 <i>2.2</i>	69 <i>4.3</i>	9 <i>1.9</i>	0 <i>0.0</i>	237 <i>3.1</i>	
Double outlet right ventricle	79 <i>1.9</i>	35 <i>2.7</i>	46 <i>2.8</i>	11 <i>2.3</i>	0 <i>0.0</i>	171 <i>2.2</i>	
Ebstein anomaly	21 <i>0.5</i>	9 <i>0.7</i>	22 <i>1.4</i>	2 <i>0.4</i>	0 <i>0.0</i>	54 <i>0.7</i>	
Encephalocele	29 <i>0.7</i>	12 <i>0.9</i>	21 <i>1.3</i>	4 <i>0.8</i>	0 <i>0.0</i>	67 <i>0.9</i>	
Esophageal atresia/tracheoesophageal fistula	114 <i>2.8</i>	25 <i>1.9</i>	42 <i>2.6</i>	14 <i>2.9</i>	1 <i>19.7</i>	196 <i>2.6</i>	
Gastroschisis	145 <i>3.6</i>	60 <i>4.7</i>	67 <i>4.1</i>	7 <i>1.4</i>	1 <i>19.7</i>	280 <i>3.7</i>	
Holoprosencephaly	35 <i>0.9</i>	24 <i>1.9</i>	31 <i>1.9</i>	2 <i>0.4</i>	0 <i>0.0</i>	92 <i>1.2</i>	
Hypoplastic left heart syndrome	115 <i>2.8</i>	49 <i>3.8</i>	43 <i>2.7</i>	7 <i>1.4</i>	0 <i>0.0</i>	215 <i>2.8</i>	
Hypospadias	1,647 <i>78.7</i>	483 <i>73.7</i>	322 <i>39.1</i>	159 <i>64.1</i>	15 <i>600.0</i>	2,627 <i>67.1</i>	2
Interrupted aortic arch	29 <i>0.7</i>	13 <i>1.0</i>	13 <i>0.8</i>	0 <i>0.0</i>	0 <i>0.0</i>	55 <i>0.7</i>	

Illinois
Birth Defects Counts and Prevalence 2014 - 2018 (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)	189 <i>4.6</i>	82 <i>6.4</i>	64 <i>3.9</i>	20 <i>4.1</i>	0 <i>0.0</i>	357 <i>4.7</i>	
Omphalocele	78 <i>1.9</i>	41 <i>3.2</i>	31 <i>1.9</i>	8 <i>1.6</i>	0 <i>0.0</i>	159 <i>2.1</i>	
Pulmonary valve atresia and stenosis	285 <i>7.0</i>	124 <i>9.7</i>	137 <i>8.5</i>	46 <i>9.5</i>	1 <i>19.7</i>	594 <i>7.8</i>	
Pulmonary valve atresia	18 <i>0.4</i>	17 <i>1.3</i>	14 <i>0.9</i>	4 <i>0.8</i>	0 <i>0.0</i>	53 <i>0.7</i>	
Rectal and large intestinal atresia/stenosis	158 <i>3.9</i>	55 <i>4.3</i>	85 <i>5.2</i>	22 <i>4.5</i>	1 <i>19.7</i>	322 <i>4.2</i>	
Renal agenesis/hypoplasia	347 <i>8.5</i>	135 <i>10.5</i>	155 <i>9.6</i>	43 <i>8.9</i>	1 <i>19.7</i>	681 <i>8.9</i>	
Single ventricle	22 <i>0.5</i>	6 <i>0.5</i>	14 <i>0.9</i>	1 <i>0.2</i>	0 <i>0.0</i>	43 <i>0.6</i>	
Small intestinal atresia/stenosis	124 <i>3.0</i>	48 <i>3.7</i>	63 <i>3.9</i>	19 <i>3.9</i>	0 <i>0.0</i>	255 <i>3.3</i>	
Spina bifida without anencephalus	141 <i>3.5</i>	41 <i>3.2</i>	57 <i>3.5</i>	14 <i>2.9</i>	0 <i>0.0</i>	253 <i>3.3</i>	
Tetralogy of Fallot	187 <i>4.6</i>	73 <i>5.7</i>	68 <i>4.2</i>	26 <i>5.4</i>	1 <i>19.7</i>	356 <i>4.7</i>	
Total anomalous pulmonary venous connection	36 <i>0.9</i>	23 <i>1.8</i>	36 <i>2.2</i>	7 <i>1.4</i>	0 <i>0.0</i>	102 <i>1.3</i>	
Transposition of the great arteries (TGA)	136 <i>3.3</i>	29 <i>2.3</i>	55 <i>3.4</i>	11 <i>2.3</i>	0 <i>0.0</i>	232 <i>3.0</i>	
Dextro-transposition of great arteries (d-TGA)	116 <i>2.8</i>	25 <i>1.9</i>	38 <i>2.3</i>	6 <i>1.2</i>	0 <i>0.0</i>	185 <i>2.4</i>	
Tricuspid valve atresia and stenosis	38 <i>0.9</i>	28 <i>2.2</i>	22 <i>1.4</i>	4 <i>0.8</i>	0 <i>0.0</i>	92 <i>1.2</i>	
Tricuspid valve atresia	15 <i>0.4</i>	8 <i>0.6</i>	12 <i>0.7</i>	1 <i>0.2</i>	0 <i>0.0</i>	36 <i>0.5</i>	
Trisomy 13	44 <i>1.1</i>	23 <i>1.8</i>	26 <i>1.6</i>	2 <i>0.4</i>	0 <i>0.0</i>	95 <i>1.2</i>	
Trisomy 18	105 <i>2.6</i>	38 <i>3.0</i>	41 <i>2.5</i>	16 <i>3.3</i>	0 <i>0.0</i>	202 <i>2.6</i>	
Trisomy 21 (Down syndrome)	504 <i>12.4</i>	159 <i>12.4</i>	375 <i>23.1</i>	58 <i>11.9</i>	6 <i>118.3</i>	1,102 <i>14.4</i>	
Turner syndrome	55 <i>2.8</i>	14 <i>2.2</i>	18 <i>2.3</i>	2 <i>0.8</i>	1 <i>38.9</i>	90 <i>2.4</i>	3
Ventricular septal defect	2,138 <i>52.5</i>	645 <i>50.2</i>	1,030 <i>63.6</i>	282 <i>58.0</i>	11 <i>217.0</i>	4,108 <i>53.7</i>	4
Total live births	407,521	128,430	162,034	48,580	507	765,308	5
Male live births	209,193	65,509	82,359	24,818	250	391,456	
Female live births	198,318	62,912	79,666	23,761	257	373,821	

Illinois**Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)**

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	265 <i>4.3</i>	15 <i>1.1</i>	280 <i>3.7</i>	
Trisomy 13	62 <i>1.0</i>	33 <i>2.3</i>	95 <i>1.2</i>	
Trisomy 18	98 <i>1.6</i>	104 <i>7.3</i>	202 <i>2.6</i>	
Trisomy 21 (Down syndrome)	540 <i>8.7</i>	561 <i>39.4</i>	1,102 <i>14.4</i>	
Total live births	622,897	142,381	765,308	5

Notes

1. Data for this condition include inlet ventricular septal defects including common atrioventricular canal type ventricular septal defect.
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 include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
4. Data for this condition exclude probable cases, and inlet ventricular septal defects including common atrioventricular canal type ventricular septal defects.
5. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

-Data for all conditions include live births from birth to age 2 years and fetal deaths (these include stillbirths of 20 weeks gestation or more, and miscarriages where the families chose to hold funerals).