

Ohio

Ohio Connections for Children with Special Needs (OCCSN)

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

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, ODH Office of Health Preparedness, ODH Bureau of Infectious Diseases, ODH Violence and Prevention, Department of Developmental Disabilities, OMNI, ASTHO, Department of Medicaid

Program status: Currently collecting data

Start year: 2006

Earliest year of available data: 2008

Organizational location: Department of Health (Maternal and Child Health)

Population covered annually: 135,000

Statewide: Yes

Current legislation or rule: Ohio Revised Code (ORC) 3705.30-3705.36 authorizes the department to implement a statewide birth defects information system and mandates hospital reporting (2000). Ohio Administrative Code (OAC) 3701-57-01 to 3701-57-04 specifies conditions to be reported and methods for reporting (2015).

Legislation year enacted: 2000

Case Definition

Outcomes covered: Major congenital anomalies as recommended by stakeholders in Ohio; Neonatal Abstinence Syndrome; 7 targets of newborn screening for critical congenital heart disease

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

Age: Up to 5 years of age

Residence: Ohio resident children up to 5 years of age

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation

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

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn screening for CCHD data system - electronic birth certificate system

Delivery hospitals: Hospital medical records and other electronic administrative data sets

Pediatric & tertiary care hospitals: Discharge summaries, Laboratory logs, Hospital medical records and other electronic administrative data sets

Other sources: Genetics Clinic Data within some hospitals

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), ICD-10 codes or named congenital anomaly ICD-10 codes or named congenital anomalies

Coding: 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 defect diagnostic information

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

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

Data Collection Methods and Storage

Data collection: Electronic file/report submitted by other agencies (hospitals, etc.), Hospital reporters upload file to secure website for integration. Small volume hospitals can manually key data into secure user interface.

Database collection and storage: SQL server

Data Analysis

Data analysis software: SAS, Access, MS Excel

Quality assurance: Validity checks, 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, Observed vs. expected analyses, Referral, Grant proposals, Education/public awareness, Prevention projects

System Integration

System links: Link to other state registries/databases, OCCSN data system shares common demographic file with Vital Statistics and Genetics Program data systems.

Funding

Funding source: 100% MCH funds

Other

Web site:

<https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/Birth-Defects/Reports>

Surveillance reports on file: 2019 NBDPN Annual Report 2019 OCCSN Annual Report

Additional information on file: OCCSN data system user guide for 1) reporting hospitals; 2) case confirmers

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DATA TABLES

Ohio
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		
Anencephalus	42 <i>0.8</i>	8 <i>0.7</i>	8 <i>2.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	60 <i>0.9</i>	
Anophthalmia/microphthalmia	74 <i>2.5</i>	14 <i>2.0</i>	5 <i>2.2</i>	4 <i>2.9</i>	0 <i>0.0</i>	98 <i>2.4</i>	1
Anotia/microtia	3 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>0.7</i>	0 <i>0.0</i>	4 <i>0.1</i>	1
Aortic valve stenosis	133 <i>2.6</i>	15 <i>1.3</i>	8 <i>2.2</i>	1 <i>0.4</i>	2 <i>18.3</i>	163 <i>2.4</i>	
Atrial septal defect	2,568 <i>123.2</i>	723 <i>153.0</i>	175 <i>125.4</i>	87 <i>104.8</i>	9 <i>194.0</i>	3,603 <i>128.4</i>	2
Atrioventricular septal defect (Endocardial cushion defect)	135 <i>6.5</i>	27 <i>5.7</i>	8 <i>5.7</i>	0 <i>0.0</i>	0 <i>0.0</i>	173 <i>6.2</i>	2
Biliary atresia	130 <i>2.6</i>	63 <i>5.3</i>	17 <i>4.7</i>	5 <i>2.2</i>	0 <i>0.0</i>	218 <i>3.1</i>	
Choanal atresia	161 <i>3.2</i>	28 <i>2.4</i>	7 <i>1.9</i>	6 <i>2.7</i>	0 <i>0.0</i>	205 <i>3.0</i>	
Cleft lip alone	140 <i>2.7</i>	14 <i>1.2</i>	6 <i>1.6</i>	6 <i>2.7</i>	2 <i>18.3</i>	172 <i>2.5</i>	
Cleft lip with cleft palate	280 <i>5.5</i>	46 <i>3.9</i>	18 <i>4.9</i>	14 <i>6.3</i>	0 <i>0.0</i>	363 <i>5.2</i>	
Cleft palate alone	486 <i>9.5</i>	55 <i>4.6</i>	28 <i>7.7</i>	14 <i>6.3</i>	2 <i>18.3</i>	590 <i>8.5</i>	
Clubfoot	583 <i>19.4</i>	106 <i>14.8</i>	37 <i>16.5</i>	25 <i>17.9</i>	0 <i>0.0</i>	764 <i>18.5</i>	1
Coarctation of the aorta	496 <i>9.7</i>	90 <i>7.6</i>	20 <i>5.5</i>	12 <i>5.4</i>	2 <i>18.3</i>	628 <i>9.1</i>	
Common truncus (truncus arteriosus)	49 <i>1.0</i>	12 <i>1.0</i>	6 <i>1.6</i>	4 <i>1.8</i>	1 <i>9.2</i>	73 <i>1.1</i>	
Congenital cataract	108 <i>3.6</i>	36 <i>5.0</i>	11 <i>4.9</i>	6 <i>4.3</i>	0 <i>0.0</i>	162 <i>3.9</i>	1
Deletion 22q11.2	100 <i>2.0</i>	18 <i>1.5</i>	7 <i>1.9</i>	2 <i>0.9</i>	0 <i>0.0</i>	127 <i>1.8</i>	
Diaphragmatic hernia	375 <i>7.4</i>	86 <i>7.2</i>	24 <i>6.6</i>	12 <i>5.4</i>	1 <i>9.2</i>	504 <i>7.3</i>	
Double outlet right ventricle	49 <i>2.4</i>	13 <i>2.8</i>	8 <i>5.7</i>	3 <i>3.6</i>	0 <i>0.0</i>	73 <i>2.6</i>	2
Encephalocele	62 <i>2.1</i>	11 <i>1.5</i>	5 <i>2.2</i>	2 <i>1.4</i>	0 <i>0.0</i>	84 <i>2.0</i>	1
Esophageal atresia/tracheoesophageal fistula	326 <i>6.4</i>	46 <i>3.9</i>	17 <i>4.7</i>	12 <i>5.4</i>	0 <i>0.0</i>	403 <i>5.8</i>	
Gastroschisis	304 <i>6.0</i>	57 <i>4.8</i>	25 <i>6.9</i>	1 <i>0.4</i>	2 <i>18.3</i>	404 <i>5.8</i>	
Holoprosencephaly	35 <i>1.2</i>	5 <i>0.7</i>	1 <i>0.4</i>	2 <i>1.4</i>	0 <i>0.0</i>	45 <i>1.1</i>	1
Hypoplastic left heart syndrome	232 <i>4.6</i>	50 <i>4.2</i>	18 <i>4.9</i>	6 <i>2.7</i>	1 <i>9.2</i>	314 <i>4.5</i>	
Omphalocele	153 <i>3.0</i>	81 <i>6.8</i>	6 <i>1.6</i>	2 <i>0.9</i>	0 <i>0.0</i>	242 <i>3.5</i>	
Pulmonary valve atresia and stenosis	48 <i>2.3</i>	10 <i>2.1</i>	3 <i>2.2</i>	0 <i>0.0</i>	0 <i>0.0</i>	61 <i>2.2</i>	2
Pulmonary valve atresia	28 <i>0.5</i>	7 <i>0.6</i>	3 <i>0.8</i>	2 <i>0.9</i>	0 <i>0.0</i>	40 <i>0.6</i>	
Rectal and large intestinal atresia/stenosis	398 <i>7.8</i>	75 <i>6.3</i>	34 <i>9.3</i>	18 <i>8.1</i>	1 <i>9.2</i>	532 <i>7.7</i>	
Renal agenesis/hypoplasia	642 <i>12.6</i>	157 <i>13.2</i>	41 <i>11.3</i>	18 <i>8.1</i>	0 <i>0.0</i>	874 <i>12.6</i>	
Spina bifida without anencephalus	800 <i>15.7</i>	95 <i>8.0</i>	37 <i>10.2</i>	12 <i>5.4</i>	0 <i>0.0</i>	951 <i>13.7</i>	
Tetralogy of Fallot	131 <i>2.6</i>	47 <i>4.0</i>	7 <i>1.9</i>	9 <i>4.0</i>	0 <i>0.0</i>	198 <i>2.9</i>	

Ohio
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		
Total anomalous pulmonary venous connection	75 <i>1.5</i>	9 <i>0.8</i>	8 <i>2.2</i>	3 <i>1.3</i>	0 <i>0.0</i>	97 <i>1.4</i>	
Transposition of the great arteries (TGA)	320 <i>6.3</i>	65 <i>5.5</i>	28 <i>7.7</i>	7 <i>3.1</i>	0 <i>0.0</i>	423 <i>6.1</i>	
Dextro-transposition of great arteries (d-TGA)	196 <i>3.8</i>	41 <i>3.4</i>	12 <i>3.3</i>	6 <i>2.7</i>	0 <i>0.0</i>	256 <i>3.7</i>	
Tricuspid valve atresia and stenosis	85 <i>1.7</i>	23 <i>1.9</i>	1 <i>0.3</i>	2 <i>0.9</i>	0 <i>0.0</i>	112 <i>1.6</i>	
Trisomy 13	32 <i>0.6</i>	18 <i>1.5</i>	6 <i>1.6</i>	1 <i>0.4</i>	0 <i>0.0</i>	60 <i>0.9</i>	
Trisomy 18	93 <i>1.8</i>	29 <i>2.4</i>	4 <i>1.1</i>	1 <i>0.4</i>	3 <i>27.5</i>	132 <i>1.9</i>	
Trisomy 21 (Down syndrome)	987 <i>19.4</i>	197 <i>16.6</i>	80 <i>22.0</i>	35 <i>15.7</i>	2 <i>18.3</i>	1,313 <i>19.0</i>	
Turner syndrome	110 <i>4.4</i>	9 <i>1.5</i>	15 <i>8.4</i>	6 <i>5.5</i>	0 <i>0.0</i>	142 <i>4.2</i>	3
Ventricular septal defect	353 <i>16.9</i>	88 <i>18.6</i>	32 <i>22.9</i>	12 <i>14.5</i>	0 <i>0.0</i>	492 <i>17.5</i>	2
Total live births	509,555	118,871	36,399	22,260	1,091	692,695	4
Female live births	248,689	58,324	17,870	10,888	520	338,534	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	382	13	404	
	<i>6.4</i>	<i>1.4</i>	<i>5.8</i>	
Trisomy 13	44	15	60	
	<i>0.7</i>	<i>1.6</i>	<i>0.9</i>	
Trisomy 18	84	47	132	
	<i>1.4</i>	<i>5.0</i>	<i>1.9</i>	
Trisomy 21 (Down syndrome)	753	557	1,313	
	<i>12.6</i>	<i>59.3</i>	<i>19.0</i>	
Total live births	598,612	93,955	692,695	4

Notes

1. Data for this condition begin in 2016.
2. Data for this condition end in 2015.
3. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
4. Data for total live births include unknown gender.

General comments

- *Data for totals include unknown and/or other.
- Data for conditions include probable cases.