Ohio Connections for Children with Special Needs

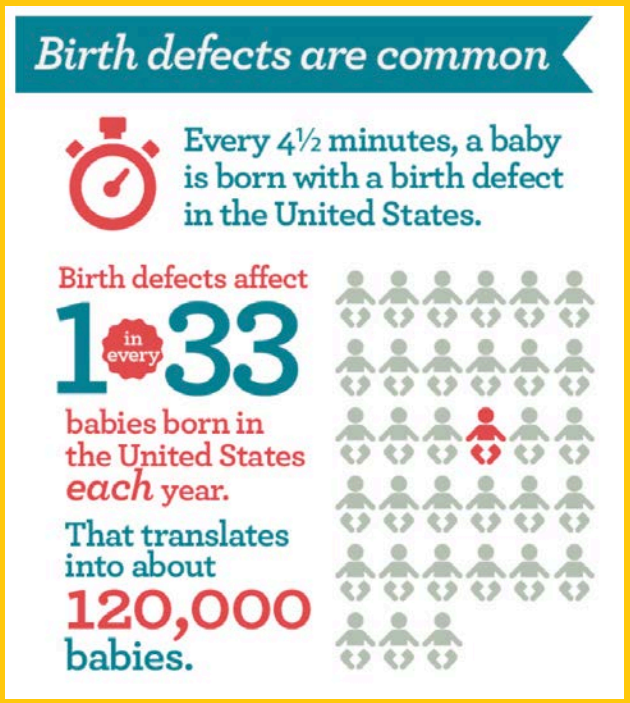
Ohio | Department of Health

2019 Annual Report

Overview

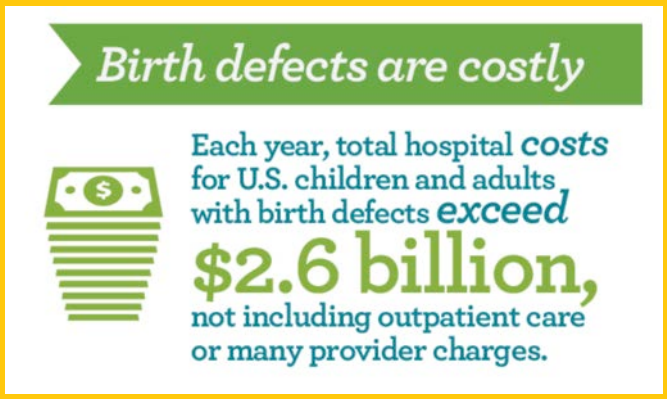
One in 33 children is born with a birth defect. Birth defects, or congenital anomalies, are the second leading cause of infant mortality, accounting for approximately 19% of infant deaths in Ohio. For those who survive, birth defects are a major cause of morbidity and mortality throughout childhood. Ohio Connections for Children with Special Needs (OCCSN) is Ohio's statewide population-based birth defects surveillance program. The Ohio Revised Code 3705.30 authorizes the state director of health to require hospitals, physicians, and freestanding birthing centers to report children from birth to 5 years of age with certain reportable birth defects to the Ohio Department of Health (ODH).

Collection of birth defect data is important for public health action, including facilitating referrals to services such as early intervention and targeting prevention strategies. The OCCSN program includes activities in four major areas: surveillance of birth defects, analysis of surveillance data, referrals to early intervention services, and awareness and prevention activities.



Reportable Conditions and Reporting Methods

The OCCSN data system utilizes passive case ascertainment whereby hospitals report data to the online database after a child has an encounter at that facility. Genetic counselors at the eight state-funded genetic centers across the state conduct case reviews on selected children with birth defects to provide data validation. Approximately 130 hospitals, including birthing and children's hospitals, report cases to ODH through the OCCSN data system. For certain confirmed birth defects in children under 3, family contact information is sent via automatic email to ODH's Help Me Grow Central Coordination for referral to early intervention services.



2012-2016 Surveillance Data

Data reported include suspected cases.
Data include only cases linked to an Ohio birth certificate.

Congenital Anomaly	Ohio Cases 2012-2016[1]	Ohio Rate Per 10,000 Live Births 2012-2016[1]	National Passive Surveillance Rate Per 10,000 Live Births 2010-2014[2,3]
Central Nervous			
Anencephaly	74	1.1	1.32
Spina bifida without anencephaly	367	5.3	3.52
Encephalocele	105	1.5	0.84
Cardiovascular			
Common truncus	74	1.1	1.01
Transposition of the great arteries	312	4.5	3.07
Tetralogy of Fallot	363	5.2	4.17
Pulmonary valve atresia	187	2.7	1.65
Tricuspid valve atresia and stenosis	118	1.7	1.10
Aortic valve stenosis	193	2.8	—
Hypoplastic left heart syndrome	307	4.4	2.72
Coarctation of aorta	656	9.4	8.25
Total anomalous pulmonary venous return	65	0.9	0.93
Orofacial			
Choanal atresia	185	2.7	—
Cleft palate alone	731	10.5	5.83
Cleft lip alone	216	3.1	3.41
Cleft lip with cleft palate	471	6.7	5.78
Gastrointestinal			
Esophageal atresia/ tracheoesophageal fistula	235	3.4	2.52
Rectal and large intestinal atresia/stenosis	399	5.7	4.32
Hirschsprung's disease	302	4.3	—
Biliary atresia	126	1.8	—
Genitourinary			
Renal agenesis/ hypoplasia	625	9.0	—
Musculoskeletal			
Diaphragmatic hernia	397	5.7	2.95
Gastroschisis	366	5.2	4.80
Omphalocele	242	3.5	2.04

Congenital anomaly	Ohio cases 2012-2016[1]	Ohio rate per 10,000 live births 2012-2016[1]	National passive surveillance rate per 10,000 live births 2010-2014[2,3]
Chromosomal			
Deletion 22q11.2	99	1.4	—
Trisomy 13 (Patau syndrome)	55	0.8	0.97
Trisomy 18 (Edwards syndrome)	116	1.7	1.96
Trisomy 21 (Down syndrome)	1,009	14.5	13.69
Turner syndrome[4]	82	2.4	—
Single Gene Disorders			
Neurofibromatosis, type 1	232	3.3	—
Tuberous sclerosis	74	1.1	—
Osteogenesis imperfecta	93	1.3	—
Other			
Fetal alcohol syndrome[5]	226	3.2	—

[1]Ohio data sources: MCHIDS OCCSN database and Vital Statistics birth occurrence files.
[2]National passive surveillance data source: Mai CT, Isenburg JL, Canfield MA, et al. National population-based estimates for major birth defects, 2010–2014. Birth Defects Research. 2019;1–16. https://doi.org/10.1002/bdr2.1589.
[3]National and statewide comparisons may differ in case definitions, may cover different time periods, and may differ in data sources by state. Caution should be exercised when making these comparisons.
[4] Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
[5] Fetal alcohol syndrome cases include cases that did not link to an Ohio birth certificate.

Referrals to Services

Early identification and intervention services, family peer support, and community connections improve children's and families' lives and enrich our communities. OCCSN facilitates referrals to services to ensure families are informed of early intervention and support services available. The OCCSN system automatically generates referrals to Help Me Grow Central Coordination for children under age 3 who have been confirmed through case review. Parents are then contacted with information about programs and services available in the county where they reside. Parents may decide if they wish to receive services.

Help Me Grow (HMG) Referrals from OCCSN

Year	Referrals to Central Coordination	All Applicable Program Referrals Made*	Attempts to Contact Unsuccessful	Family Not Interested in Ongoing HMG Services
2016	251	109	111	31
2017	249	100	114	35
Total	**500**	**209**	**225**	**66**

*Parent must consent to having an early intervention (EI) referral.
Data provided by DODD, Nov. 13, 2019.

Birth Defects Data Projects

Birth defects surveillance data can be used to detect trends, identify potential risk factors, and plan primary prevention activities. The OCCSN program shares state-level data with the Centers for Disease Control and Prevention (CDC) and National Birth Defects Prevention Network to be published annually in the journal Birth Defects Research. In addition to the state-level data, a data brief pools states' data to examine special topics in an annual article in the journal. Ohio data was included in the data briefs on eye and ear defects in 2018[1] and gastroschisis and omphalocele in 2019.[2] OCCSN data also contributes to the study of emerging threats. The 2016 Zika virus outbreak highlighted the need for birth defects surveillance activities to rapidly assess the impact of the virus on infants. Using state surveillance data, the CDC found that 15% of pregnant women with confirmed Zika virus infection in the first trimester had babies with Zika-associated birth defects.[3] Another emerging threat is the opioid epidemic. In 2018, the CDC began utilizing birth defects surveillance data to identify potential links between opioid use and birth defects. Ohio contributed birth defects surveillance data to a study that found an association between opioid prescribing rates and higher incidence of the birth defect gastroschisis.[4]

[1] https://doi.org/10.1002/bdr2.1413
[2] https://doi.org/10.1002/bdr2.1607
[3] http://dx.doi.org/10.15585/mmwr.mm6613e1
[4] http://dx.doi.org/10.15585/mmwr.mm6802a2

Awareness and Prevention

The causes of many birth defects are unknown, and many happen during early pregnancy, often before a woman knows she is pregnant. Steps can be taken to increase the chances of having a healthy pregnancy, but even when steps are taken, birth defects still occur among families of every race, ethnicity, health history, and economic status. Steps for a healthy pregnancy include taking a daily vitamin with folic acid before and during pregnancy, adopting healthy behaviors before and during pregnancy, managing chronic conditions, and stopping alcohol or drug use during pregnancy.

While we refer to congenital anomalies as birth defects, persons affected are not defective. In addition, while we communicate opportunities to prevent birth defects, it is also important to communicate that we can all encourage children with birth defects to meet their full potential and lead important roles in our communities without limits.

The OCCSN program aims to increase awareness partnerships, and policy opportunities. Data can inform prevention and intervention efforts, as well as contribute to critical studies of birth defects. Birth defects prevention strategies often overlap with intervention programs aimed at women and infant health, and partnerships with those programs can increase the reach for both programs. Policy opportunities include changes to funding and program administration to include birth defects prevention in standard practice.

For additional information about the OCCSN program, visit https://odh.ohio.gov/wps/portal/gov/odh/know-our-programs/birth-defects *or contact us at* bcmh.occsn@odh.ohio.gov.