

Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: Surveillance, Research, Referral to Services, Targeted prevention to higher risk populations.

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 2005

Earliest year of available data: 2006

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

Population covered annually: 70,000

Statewide: Yes

Current legislation or rule: MS 144.2215-2219

Legislation year enacted: 2004

Case Definition

Outcomes covered: Pregnancy outcome: 1) Live birth; 2) Fetal death at => 20 wks in 2019 birth cohort Major structural and genetic defects diagnosed up to 1 year of age identified by CDC and NBDPN.

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

Age: Up to 1 year after delivery

Residence: In-state and out of state births to state residents

Surveillance Methods

Case ascertainment: Active Case Finding

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

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Newborn CCHD screening

Delivery hospitals: Disease index or discharge index, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Other sources: Statewide de-identified hospital discharge dataset; Any case reported by local public health agency

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 birth certificate with a birth defect box checked, All stillborn infants, Any chart with an ICD10 Q00-Q99 or an ICD 10(P, Z, O) indicating stillbirths; All deaths prior to age 2 with a birth defect indicated as cause of death on death certificates, starting with 2009 births; Fetal death reports shared by Vital Records

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, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, etc.), Family history

Data Collection Methods and Storage

Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Remote access to medical records for large volume reporting facilities/systems

Database collection and storage: Web-based department-wide integrated disease surveillance database. Maven platform by Consilience Software.

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, Data/hospital audits, 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, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Education/public awareness, Prevention projects, Collaboration with Environmental Public Health Tracking Program

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Sharing of confirmed cases with key contacts at local public health agencies for service referral. LPH staff can log on to our the birth defects database to view relevant case information. In 2012, LPH began entering follow up and service/program updates into BDIS.

System integration: The Birth Defects Information System (BDIS) is integrated with Newborn Hearing program and Heritable Conditions. The databases share a model on the same platform, but they are managed separately. (This platform, Maven by Consilience Software, is also used by many infectious disease surveillance systems in MN and access is limited by disease/user role.) Additional integration with the Newborn CCHD Screening program takes place in 2017 as universal newborn CCHD screening is implemented.

Funding

Funding source: 76% General state funds, 24% CDC grant

Other

Web site:

<https://www.health.state.mn.us/people/childreneyouth/birthdefects/index.html>

Contacts

Sook Ja Cho, PhD, MPH, BSN
Minnesota Department of Health
85 East 7th Place, PO Box 64882
St. Paul, MN 55164

Phone: 651-201-4931 Fax: 651-201-3590

Email: sook.ja.cho@state.mn.us

Barbara Frohnert, MPH
Minnesota Department of Health
85 East 7th Place, PO Box 64882
St. Paul, MN 55164

Phone: 651-201-5953 Fax: 651-201-3590

Email: barbara.frohnert@state.mn.us

DATA TABLES

Minnesota
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	17 <i>0.7</i>	2 <i>0.5</i>	3 <i>1.3</i>	7 <i>2.6</i>	1 <i>1.8</i>	30 <i>0.9</i>	
Anophthalmia/microphthalmia	30 <i>1.3</i>	11 <i>2.7</i>	3 <i>1.3</i>	6 <i>2.2</i>	1 <i>1.8</i>	51 <i>1.5</i>	
Anotia/microtia	50 <i>2.2</i>	10 <i>2.5</i>	23 <i>9.7</i>	15 <i>5.5</i>	2 <i>3.5</i>	101 <i>3.0</i>	
Aortic valve stenosis	62 <i>2.7</i>	4 <i>1.0</i>	5 <i>2.1</i>	3 <i>1.1</i>	1 <i>1.8</i>	75 <i>2.3</i>	
Atrial septal defect	597 <i>25.7</i>	94 <i>23.1</i>	61 <i>25.7</i>	52 <i>19.0</i>	49 <i>86.2</i>	859 <i>25.9</i>	
Atrioventricular septal defect (Endocardial cushion defect)	134 <i>5.8</i>	23 <i>5.6</i>	5 <i>2.1</i>	12 <i>4.4</i>	2 <i>3.5</i>	176 <i>5.3</i>	1
Biliary atresia	7 <i>0.3</i>	1 <i>0.2</i>	2 <i>0.8</i>	4 <i>1.5</i>	0 <i>0.0</i>	14 <i>0.4</i>	
Bladder exstrophy	4 <i>0.2</i>	2 <i>0.5</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	7 <i>0.2</i>	
Choanal atresia	33 <i>1.4</i>	3 <i>0.7</i>	2 <i>0.8</i>	0 <i>0.0</i>	1 <i>1.8</i>	39 <i>1.2</i>	
Cleft lip alone	73 <i>3.1</i>	8 <i>2.0</i>	5 <i>2.1</i>	10 <i>3.7</i>	5 <i>8.8</i>	101 <i>3.0</i>	
Cleft lip with cleft palate	139 <i>6.0</i>	19 <i>4.7</i>	16 <i>6.8</i>	18 <i>6.6</i>	4 <i>7.0</i>	197 <i>5.9</i>	
Cleft palate alone	166 <i>7.1</i>	20 <i>4.9</i>	14 <i>5.9</i>	24 <i>8.8</i>	8 <i>14.1</i>	233 <i>7.0</i>	
Cloacal exstrophy	2 <i>0.1</i>	0 <i>0.0</i>	0 <i>0.0</i>	1 <i>0.5</i>	0 <i>0.0</i>	3 <i>0.1</i>	2
Clubfoot	258 <i>14.0</i>	59 <i>17.8</i>	22 <i>11.5</i>	18 <i>8.2</i>	7 <i>15.6</i>	366 <i>13.8</i>	2
Coarctation of the aorta	134 <i>5.8</i>	26 <i>6.4</i>	9 <i>3.8</i>	7 <i>2.6</i>	2 <i>3.5</i>	180 <i>5.4</i>	
Common truncus (truncus arteriosus)	14 <i>0.6</i>	3 <i>0.7</i>	2 <i>0.8</i>	1 <i>0.4</i>	0 <i>0.0</i>	20 <i>0.6</i>	
Congenital cataract	63 <i>2.7</i>	26 <i>6.4</i>	5 <i>2.1</i>	7 <i>2.6</i>	1 <i>1.8</i>	103 <i>3.1</i>	
Congenital posterior urethral valves	23 <i>1.9</i>	12 <i>5.8</i>	1 <i>0.8</i>	3 <i>2.2</i>	0 <i>0.0</i>	39 <i>2.3</i>	3
Craniosynostosis	160 <i>8.7</i>	11 <i>3.3</i>	15 <i>7.8</i>	9 <i>4.1</i>	5 <i>11.1</i>	200 <i>7.6</i>	2
Deletion 22q11.2	27 <i>1.5</i>	3 <i>0.9</i>	4 <i>2.1</i>	1 <i>0.5</i>	0 <i>0.0</i>	35 <i>1.3</i>	2
Diaphragmatic hernia	68 <i>2.9</i>	12 <i>2.9</i>	13 <i>5.5</i>	5 <i>1.8</i>	2 <i>3.5</i>	100 <i>3.0</i>	
Double outlet right ventricle	45 <i>1.9</i>	15 <i>3.7</i>	4 <i>1.7</i>	6 <i>2.2</i>	0 <i>0.0</i>	70 <i>2.1</i>	
Ebstein anomaly	15 <i>0.6</i>	1 <i>0.2</i>	1 <i>0.4</i>	2 <i>0.7</i>	0 <i>0.0</i>	19 <i>0.6</i>	
Encephalocele	15 <i>0.6</i>	7 <i>1.7</i>	0 <i>0.0</i>	1 <i>0.4</i>	0 <i>0.0</i>	24 <i>0.7</i>	
Esophageal atresia/tracheoesophageal fistula	71 <i>3.1</i>	4 <i>1.0</i>	6 <i>2.5</i>	7 <i>2.6</i>	3 <i>5.3</i>	92 <i>2.8</i>	
Gastroschisis	74 <i>3.2</i>	10 <i>2.5</i>	6 <i>2.5</i>	6 <i>2.2</i>	2 <i>3.5</i>	98 <i>3.0</i>	
Holoprosencephaly	6 <i>0.3</i>	4 <i>1.2</i>	2 <i>1.0</i>	0 <i>0.0</i>	0 <i>0.0</i>	12 <i>0.5</i>	2
Hypoplastic left heart syndrome	51 <i>2.2</i>	6 <i>1.5</i>	6 <i>2.5</i>	2 <i>0.7</i>	0 <i>0.0</i>	65 <i>2.0</i>	
Hypospadias	904 <i>76.1</i>	199 <i>95.7</i>	42 <i>34.9</i>	48 <i>34.6</i>	14 <i>48.9</i>	1,216 <i>71.7</i>	3
Interrupted aortic arch	12 <i>0.7</i>	2 <i>0.6</i>	1 <i>0.5</i>	1 <i>0.5</i>	0 <i>0.0</i>	16 <i>0.6</i>	2

Minnesota
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)	89 <i>3.8</i>	12 <i>2.9</i>	12 <i>5.1</i>	4 <i>1.5</i>	2 <i>3.5</i>	120 <i>3.6</i>	
Omphalocele	42 <i>1.8</i>	10 <i>2.5</i>	3 <i>1.3</i>	5 <i>1.8</i>	1 <i>1.8</i>	61 <i>1.8</i>	
Pulmonary valve atresia and stenosis	309 <i>13.3</i>	67 <i>16.4</i>	33 <i>13.9</i>	27 <i>9.9</i>	7 <i>12.3</i>	445 <i>13.4</i>	
Pulmonary valve atresia	26 <i>1.1</i>	7 <i>1.7</i>	3 <i>1.3</i>	6 <i>2.2</i>	2 <i>3.5</i>	44 <i>1.3</i>	
Rectal and large intestinal atresia/stenosis	90 <i>3.9</i>	18 <i>4.4</i>	21 <i>8.9</i>	9 <i>3.3</i>	6 <i>10.6</i>	144 <i>4.3</i>	
Renal agenesis/hypoplasia	151 <i>6.5</i>	24 <i>5.9</i>	12 <i>5.1</i>	17 <i>6.2</i>	2 <i>3.5</i>	210 <i>6.3</i>	
Single ventricle	13 <i>0.6</i>	3 <i>0.7</i>	0 <i>0.0</i>	1 <i>0.4</i>	1 <i>1.8</i>	18 <i>0.5</i>	
Small intestinal atresia/stenosis	57 <i>3.1</i>	11 <i>3.3</i>	9 <i>4.7</i>	5 <i>2.3</i>	0 <i>0.0</i>	82 <i>3.1</i>	2
Spina bifida without anencephalus	70 <i>3.0</i>	13 <i>3.2</i>	4 <i>1.7</i>	9 <i>3.3</i>	0 <i>0.0</i>	96 <i>2.9</i>	
Tetralogy of Fallot	108 <i>4.7</i>	12 <i>2.9</i>	4 <i>1.7</i>	11 <i>4.0</i>	3 <i>5.3</i>	139 <i>4.2</i>	
Total anomalous pulmonary venous connection	23 <i>1.0</i>	5 <i>1.2</i>	8 <i>3.4</i>	9 <i>3.3</i>	2 <i>3.5</i>	47 <i>1.4</i>	
Transposition of the great arteries (TGA)	78 <i>3.4</i>	10 <i>2.5</i>	3 <i>1.3</i>	2 <i>0.7</i>	4 <i>7.0</i>	97 <i>2.9</i>	
Dextro-transposition of great arteries (d-TGA)	67 <i>2.9</i>	6 <i>1.5</i>	3 <i>1.3</i>	2 <i>0.7</i>	3 <i>5.3</i>	81 <i>2.4</i>	
Tricuspid valve atresia and stenosis	24 <i>1.0</i>	7 <i>1.7</i>	1 <i>0.4</i>	3 <i>1.1</i>	0 <i>0.0</i>	35 <i>1.1</i>	
Tricuspid valve atresia	14 <i>0.6</i>	3 <i>0.7</i>	1 <i>0.4</i>	3 <i>1.1</i>	0 <i>0.0</i>	21 <i>0.6</i>	
Trisomy 13	17 <i>0.7</i>	8 <i>2.0</i>	0 <i>0.0</i>	5 <i>1.8</i>	1 <i>1.8</i>	31 <i>0.9</i>	
Trisomy 18	28 <i>1.2</i>	27 <i>6.6</i>	3 <i>1.3</i>	4 <i>1.5</i>	0 <i>0.0</i>	63 <i>1.9</i>	
Trisomy 21 (Down syndrome)	347 <i>14.9</i>	85 <i>20.8</i>	43 <i>18.2</i>	35 <i>12.8</i>	6 <i>10.6</i>	518 <i>15.6</i>	
Turner syndrome	21 <i>2.3</i>	5 <i>3.1</i>	1 <i>1.1</i>	4 <i>3.7</i>	0 <i>0.0</i>	31 <i>2.4</i>	4
Ventricular septal defect	1,586 <i>68.3</i>	252 <i>61.8</i>	165 <i>69.6</i>	146 <i>53.5</i>	53 <i>93.2</i>	2,219 <i>66.9</i>	5
Total live births	232,183	40,773	23,690	27,307	5,684	331,901	6
Male live births	118,762	20,787	12,047	13,865	2,862	169,481	
Female live births	89,964	16,268	9,336	10,668	2,215	129,336	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	94 <i>3.4</i>	4 <i>0.7</i>	98 <i>3.0</i>	
Trisomy 13	15 <i>0.5</i>	16 <i>2.8</i>	31 <i>0.9</i>	
Trisomy 18	33 <i>1.2</i>	30 <i>5.2</i>	63 <i>1.9</i>	
Trisomy 21 (Down syndrome)	277 <i>10.1</i>	241 <i>41.5</i>	518 <i>15.6</i>	
Total live births	273,813	58,081	331,901	6

Notes

1. Data for this condition exclude inlet ventricular septal defect.
2. Data for this condition begin in 2015.
3. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
4. Data for this condition begin in 2015. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
5. Data for this condition include inlet ventricular septal defect.
6. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

-Data for conditions exclude probable and possible cases.