

New York

New York State Birth Defects Registry (NYS BDR)

Purpose: Surveillance, Research

Partner: Hospitals, Universities, CDC

Program status: Currently collecting data

Start year: 1982

Earliest year of available data: 1983

Organizational location: Department of Health
(Epidemiology/Environment)

Population covered annually: ~232,000

Statewide: Yes

Current legislation or rule: Public Health Law Article 2, Title II, Section 225(5)(t) and Article 2, Title I, Section 206(1)(j): Codes, Rules and Regulations, Chapter 1, State Sanitary Code, Part 22.3

Legislation year enacted: 1982

Case Definition

Outcomes covered: Major structural, functional or biochemical abnormality determined genetically or induced during gestation. A detailed list is available upon request.

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

Age: As of 5/25/16: 10 years for heart defects, muscular dystrophy, genetic conditions, FAS; 2 years for all other defects

Residence: All children born in or residing in New York

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment; population-based

Vital records: Birth certificates

Other state based registries: NYS Dept. of Health statewide hospital discharge database

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics

Other specialty facilities: Cytogenetic laboratories

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

Conditions warranting chart review beyond the newborn period: 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.), 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: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Access, Oracle

Data Analysis

Data analysis software: SAS, Access

Quality assurance: Validity checks, 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, Monitoring outbreaks and cluster investigations, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals

Funding

Funding source: 11% General state funds, 11% MCH funds, 10% Other federal funding (non-CDC grants), 68% Other (State Superfund, Other)

Other

Web site: <http://www.health.ny.gov/birthdefects>

Surveillance reports on file: Reports for 1983 - 2008 births are available. Work on a new report covering birth years 2009-2015 is under way.

Additional information on file: Counts of selected birth defects are provided on the NYS Environmental Public Health Tracking portal (Birth years 2000-2015) and Health Data New York (birth years 1992-2015).

Contacts

Michele L Herdt, PhD, MPH

New York State Department of Health

Empire State Plaza, Corning Tower, Room 1203

Albany, NY 12237

Phone: 518-402-7996

Fax: 518-402-7959

Email: Michele.Herd@health.ny.gov

Amanda St. Louis, MSPH

New York State Department of Health

Empire State Plaza, Corning Tower, Room 1203

Albany, NY 12237

Phone: 518-402-7958

Fax: 518-402-7959

Email: Amanda.St.Louis@health.ny.gov

DATA TABLES

New York
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	22 <i>0.4</i>	3 <i>0.2</i>	16 <i>0.6</i>	4 <i>0.3</i>	1 <i>5.3</i>	48 <i>0.4</i>	
Anophthalmia/microphthalmia	60 <i>1.0</i>	20 <i>1.2</i>	46 <i>1.7</i>	15 <i>1.1</i>	0 <i>0.0</i>	143 <i>1.2</i>	
Anotia/microtia	95 <i>1.6</i>	23 <i>1.3</i>	109 <i>4.0</i>	37 <i>2.8</i>	0 <i>0.0</i>	264 <i>2.2</i>	
Aortic valve stenosis	100 <i>1.7</i>	13 <i>0.8</i>	37 <i>1.4</i>	14 <i>1.1</i>	0 <i>0.0</i>	166 <i>1.4</i>	
Atrial septal defect	5,166 <i>89.6</i>	2,898 <i>168.3</i>	3,370 <i>123.7</i>	1,550 <i>116.8</i>	14 <i>74.0</i>	13,326 <i>112.3</i>	
Atrioventricular septal defect (Endocardial cushion defect)	216 <i>3.7</i>	134 <i>7.8</i>	150 <i>5.5</i>	39 <i>2.9</i>	1 <i>5.3</i>	553 <i>4.7</i>	
Biliary atresia	76 <i>1.3</i>	79 <i>4.6</i>	83 <i>3.0</i>	25 <i>1.9</i>	0 <i>0.0</i>	270 <i>2.3</i>	
Bladder exstrophy	17 <i>0.3</i>	6 <i>0.3</i>	4 <i>0.1</i>	2 <i>0.2</i>	0 <i>0.0</i>	29 <i>0.2</i>	
Choanal atresia	138 <i>2.4</i>	30 <i>1.7</i>	46 <i>1.7</i>	22 <i>1.7</i>	0 <i>0.0</i>	243 <i>2.0</i>	
Cleft lip alone	190 <i>3.3</i>	29 <i>1.7</i>	58 <i>2.1</i>	35 <i>2.6</i>	0 <i>0.0</i>	317 <i>2.7</i>	
Cleft lip with cleft palate	292 <i>5.1</i>	43 <i>2.5</i>	145 <i>5.3</i>	61 <i>4.6</i>	2 <i>10.6</i>	559 <i>4.7</i>	
Cleft palate alone	379 <i>6.6</i>	65 <i>3.8</i>	152 <i>5.6</i>	77 <i>5.8</i>	1 <i>5.3</i>	697 <i>5.9</i>	
Cloacal exstrophy	4 <i>0.1</i>	5 <i>0.3</i>	2 <i>0.1</i>	1 <i>0.1</i>	0 <i>0.0</i>	12 <i>0.1</i>	
Clubfoot	1,080 <i>18.7</i>	291 <i>16.9</i>	503 <i>18.5</i>	180 <i>13.6</i>	5 <i>26.4</i>	2,109 <i>17.8</i>	
Coarctation of the aorta	363 <i>6.3</i>	129 <i>7.5</i>	203 <i>7.5</i>	62 <i>4.7</i>	1 <i>5.3</i>	774 <i>6.5</i>	
Common truncus (truncus arteriosus)	27 <i>0.5</i>	9 <i>0.5</i>	15 <i>0.6</i>	3 <i>0.2</i>	0 <i>0.0</i>	58 <i>0.5</i>	
Congenital cataract	121 <i>2.1</i>	50 <i>2.9</i>	72 <i>2.6</i>	25 <i>1.9</i>	1 <i>5.3</i>	277 <i>2.3</i>	
Congenital posterior urethral valves	66 <i>2.2</i>	34 <i>3.9</i>	28 <i>2.0</i>	16 <i>2.3</i>	0 <i>0.0</i>	146 <i>2.4</i>	1
Craniosynostosis	604 <i>10.5</i>	167 <i>9.7</i>	348 <i>12.8</i>	78 <i>5.9</i>	3 <i>15.9</i>	1,218 <i>10.3</i>	
Deletion 22q11.2	87 <i>1.5</i>	46 <i>2.7</i>	47 <i>1.7</i>	19 <i>1.4</i>	0 <i>0.0</i>	203 <i>1.7</i>	
Diaphragmatic hernia	135 <i>2.3</i>	40 <i>2.3</i>	70 <i>2.6</i>	24 <i>1.8</i>	0 <i>0.0</i>	285 <i>2.4</i>	
Double outlet right ventricle	155 <i>2.7</i>	57 <i>3.3</i>	82 <i>3.0</i>	32 <i>2.4</i>	3 <i>15.9</i>	337 <i>2.8</i>	
Ebstein anomaly	44 <i>0.8</i>	8 <i>0.5</i>	30 <i>1.1</i>	11 <i>0.8</i>	0 <i>0.0</i>	95 <i>0.8</i>	
Encephalocele	34 <i>0.6</i>	24 <i>1.4</i>	28 <i>1.0</i>	15 <i>1.1</i>	1 <i>5.3</i>	107 <i>0.9</i>	
Esophageal atresia/tracheoesophageal fistula	165 <i>2.9</i>	47 <i>2.7</i>	70 <i>2.6</i>	25 <i>1.9</i>	0 <i>0.0</i>	315 <i>2.7</i>	
Gastroschisis	131 <i>2.3</i>	40 <i>2.3</i>	79 <i>2.9</i>	8 <i>0.6</i>	1 <i>5.3</i>	270 <i>2.3</i>	
Holoprosencephaly	24 <i>0.4</i>	11 <i>0.6</i>	14 <i>0.5</i>	3 <i>0.2</i>	1 <i>5.3</i>	57 <i>0.5</i>	
Hypoplastic left heart syndrome	178 <i>3.1</i>	63 <i>3.7</i>	82 <i>3.0</i>	17 <i>1.3</i>	2 <i>10.6</i>	355 <i>3.0</i>	
Hypospadias	3,269 <i>110.5</i>	769 <i>88.2</i>	922 <i>66.7</i>	444 <i>64.5</i>	7 <i>74.0</i>	5,562 <i>91.6</i>	1
Interrupted aortic arch	42 <i>0.7</i>	14 <i>0.8</i>	21 <i>0.8</i>	4 <i>0.3</i>	0 <i>0.0</i>	82 <i>0.7</i>	

New York
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)	150 <i>2.6</i>	69 <i>4.0</i>	106 <i>3.9</i>	20 <i>1.5</i>	0 <i>0.0</i>	366 <i>3.1</i>	
Omphalocele	79 <i>1.4</i>	80 <i>4.6</i>	48 <i>1.8</i>	12 <i>0.9</i>	0 <i>0.0</i>	228 <i>1.9</i>	
Pulmonary valve atresia and stenosis	397 <i>6.9</i>	209 <i>12.1</i>	263 <i>9.7</i>	93 <i>7.0</i>	0 <i>0.0</i>	1,000 <i>8.4</i>	
Pulmonary valve atresia	29 <i>0.5</i>	8 <i>0.5</i>	22 <i>0.8</i>	14 <i>1.1</i>	0 <i>0.0</i>	74 <i>0.6</i>	
Rectal and large intestinal atresia/stenosis	242 <i>4.2</i>	69 <i>4.0</i>	124 <i>4.6</i>	62 <i>4.7</i>	1 <i>5.3</i>	506 <i>4.3</i>	
Renal agenesis/hypoplasia	415 <i>7.2</i>	125 <i>7.3</i>	175 <i>6.4</i>	60 <i>4.5</i>	0 <i>0.0</i>	793 <i>6.7</i>	
Single ventricle	57 <i>1.0</i>	32 <i>1.9</i>	40 <i>1.5</i>	14 <i>1.1</i>	1 <i>5.3</i>	149 <i>1.3</i>	
Small intestinal atresia/stenosis	209 <i>3.6</i>	106 <i>6.2</i>	109 <i>4.0</i>	49 <i>3.7</i>	3 <i>15.9</i>	488 <i>4.1</i>	
Spina bifida without anencephalus	117 <i>2.0</i>	43 <i>2.5</i>	66 <i>2.4</i>	23 <i>1.7</i>	0 <i>0.0</i>	257 <i>2.2</i>	
Tetralogy of Fallot	312 <i>5.4</i>	116 <i>6.7</i>	143 <i>5.3</i>	74 <i>5.6</i>	1 <i>5.3</i>	662 <i>5.6</i>	
Total anomalous pulmonary venous connection	62 <i>1.1</i>	27 <i>1.6</i>	51 <i>1.9</i>	17 <i>1.3</i>	0 <i>0.0</i>	160 <i>1.3</i>	
Transposition of the great arteries (TGA)	124 <i>2.2</i>	24 <i>1.4</i>	40 <i>1.5</i>	15 <i>1.1</i>	0 <i>0.0</i>	212 <i>1.8</i>	
Dextro-transposition of great arteries (d-TGA)	121 <i>2.1</i>	24 <i>1.4</i>	38 <i>1.4</i>	15 <i>1.1</i>	0 <i>0.0</i>	206 <i>1.7</i>	
Tricuspid valve atresia and stenosis	55 <i>1.0</i>	29 <i>1.7</i>	41 <i>1.5</i>	9 <i>0.7</i>	1 <i>5.3</i>	136 <i>1.1</i>	
Tricuspid valve atresia	21 <i>0.4</i>	18 <i>1.0</i>	14 <i>0.5</i>	3 <i>0.2</i>	0 <i>0.0</i>	57 <i>0.5</i>	
Trisomy 13	30 <i>0.5</i>	13 <i>0.8</i>	16 <i>0.6</i>	9 <i>0.7</i>	0 <i>0.0</i>	72 <i>0.6</i>	
Trisomy 18	67 <i>1.2</i>	38 <i>2.2</i>	40 <i>1.5</i>	7 <i>0.5</i>	0 <i>0.0</i>	157 <i>1.3</i>	
Trisomy 21 (Down syndrome)	671 <i>11.6</i>	274 <i>15.9</i>	436 <i>16.0</i>	95 <i>7.2</i>	1 <i>5.3</i>	1,516 <i>12.8</i>	
Turner syndrome	52 <i>1.9</i>	31 <i>3.6</i>	29 <i>2.2</i>	10 <i>1.6</i>	0 <i>0.0</i>	124 <i>2.1</i>	2
Ventricular septal defect	3,235 <i>56.1</i>	965 <i>56.0</i>	1,741 <i>63.9</i>	659 <i>49.7</i>	7 <i>37.0</i>	6,757 <i>56.9</i>	
Total live births	576,326	172,231	272,362	132,709	1,892	1,187,108	3
Male live births	295,847	87,145	138,230	68,812	946	607,314	
Female live births	280,472	85,080	134,128	63,895	946	579,773	

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

Defect	Maternal Age (Years)		Total*	Notes
	Less than 35	35+		
Gastroschisis	256 <i>2.8</i>	14 <i>0.5</i>	270 <i>2.3</i>	
Trisomy 13	37 <i>0.4</i>	35 <i>1.3</i>	72 <i>0.6</i>	
Trisomy 18	71 <i>0.8</i>	86 <i>3.1</i>	157 <i>1.3</i>	
Trisomy 21 (Down syndrome)	669 <i>7.3</i>	847 <i>30.8</i>	1,516 <i>12.8</i>	
Total live births	911,785	275,287	1,187,108	3

Notes

1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.
2. Data for this condition include female and unknown gender cases only. Prevalence is calculated per 10,000 female live births.
3. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.