

Pennsylvania

Pennsylvania Birth Defects Surveillance Program (PA-BDSP)

Purpose: Surveillance of Zika-related birth defects only

Partner: Local Health Departments, Advocacy Groups

Program status: No surveillance program

Start year: 2017

Earliest year of available data: 2016 (Zika-related birth defects only)

Organizational location: Department of Health
(Epidemiology/Environment)

Population covered annually: 114440 (2016) and 113048 (2017)

Statewide: No, Excludes Philadelphia County

Current legislation or rule: Emerging threat (Zika)

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages, 18 or more weeks gestation)

Age: 1 year

Residence: In-state birth to state resident

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation

Vital records: Birth certificates, Death certificates, Fetal birth certificate

Delivery hospitals: Disease index or discharge index

Pediatric & tertiary care hospitals: Disease index or discharge index

Case Ascertainment

Conditions warranting chart review in newborn period: ICD-10 CM codes for Zika-related birth defects or stillbirths \geq 18 weeks gestational age

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

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 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

Data Collection Methods and Storage

Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)

Database collection and storage: REDCap Cloud

Data Analysis

Data analysis software: SAS

Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Timeliness

Data use and analysis: Baseline rates

System Integration

System links: Link case finding data to final birth file, hospital administrative data

Contacts

Sharon Watkins, PhD

PA Department of Health, Bureau of Epidemiology

625 Forster Street, Health & Welfare Bldg, 9th Floor East

Harrisburg, PA 17120

Phone: 717-787-3350

Email: shawatkins@pa.gov

DATA TABLES

Pennsylvania
Birth Defects Counts and Prevalence 2016 - 2017 (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	18 <i>1.1</i>	4 <i>1.9</i>	3 <i>1.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	29 <i>1.3</i>	1
Anophthalmia/microphthalmia	16 <i>0.9</i>	1 <i>0.5</i>	1 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	18 <i>0.8</i>	
Congenital cataract	22 <i>1.3</i>	4 <i>1.9</i>	1 <i>0.4</i>	0 <i>0.0</i>	0 <i>0.0</i>	27 <i>1.2</i>	
Encephalocele	11 <i>0.7</i>	0 <i>0.0</i>	3 <i>1.3</i>	0 <i>0.0</i>	0 <i>0.0</i>	14 <i>0.6</i>	
Holoprosencephaly	11 <i>0.7</i>	1 <i>0.5</i>	2 <i>0.9</i>	0 <i>0.0</i>	0 <i>0.0</i>	15 <i>0.7</i>	2
Spina bifida without anencephalus	60 <i>3.6</i>	2 <i>1.0</i>	8 <i>3.5</i>	2 <i>2.2</i>	0 <i>0.0</i>	73 <i>3.2</i>	3
Total live births	168,807	20,736	22,726	9,060	271	227,488	4

Notes

1. Data for this condition include iniencephaly.
2. Data for this condition include arhinencephaly.
3. Data for this condition excludes cases with co-occurring iniencephaly.
4. Data for total live births include unknown gender.

General comments

*Data for totals include unknown and/or other.

-Data for conditions exclude Philadelphia county and are restricted to birth outcomes to Pennsylvania residents that occurred in 70/120 facilities (88% of catchment area live births).

-Data for conditions exclude probable and possible cases.

-Data for denominator exclude Philadelphia county and are not restricted to facilities contacted.