

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).

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