

Georgia
Georgia Birth Defects Registry (GBDR)

Purpose: Surveillance, Research, Referral to Services

Partner: Local Health Departments, Hospitals, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 2018

Earliest year of available data: 2016-2017 for Zika-associated birth defects

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 126,250 live births in 2019.

Statewide: Yes

Current legislation or rule: Birth defects are reportable under State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2, which mandates the reporting of notifiable diseases and newborn hearing screening.

Legislation year enacted: Updated in 2003.

Case Definition

Outcomes covered: NBDPN core, recommended, and extended birth defects; Zika-associated birth defects per CDC guidelines, June 2017.

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

Age: Up to six years of age, per Georgia law.

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

Surveillance Methods

Case ascertainment: Active Case Finding, Passive case-finding with case confirmation, Passive case-finding without case confirmation, MACDP performs active case-finding and shares these data for inclusion into the Birth Defects Registry; 2016-2017 Zika-associated birth defects (ZABDs) have been confirmed; all other reported cases with a date of birth from January 1, 2020 and onward will be confirmed.

Vital records: Birth certificates, Death certificates, Fetal death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Zika Active Monitoring System, hospital line lists (Georgia Birth Defects Reporting and Information System (GBDRIS)), Early Hearing Detection and Intervention (EHDI) for hearing loss, early intervention services central intake (Children 1st, C1st). Program for CWSN refers to Children's Medical Services (CMS).

Delivery hospitals: Hospital line lists (GBDRIS)

Pediatric & tertiary care hospitals: Early intervention services central intake (Children 1st [C1st]).

Other sources: Georgia Health Information Network (state HIE), Metropolitan Atlanta Congenital Defects Program (MACDP).

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, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), ZABDs born during 2016-2017; 2020 and onward, all NBDPN conditions with <500 cases reported in a 12 month period (i.e., hypospadias, ASD, and VSD are not confirmed at this time).

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, Pregnancy/delivery complications, Family history

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.), Cases can be reported directly by fax or submitted through an online case report form; case data may be identified through flags and free text on vital records and Newborn Screening records (NBS-CCHD and EHDI) or ascertained through passive reporting of line lists from select birthing hospitals (GBDRIS, CMS, MACDP) to our web-based SSH File Transfer Protocol (SFTP).

Database collection and storage: Oracle

Data Analysis

Data analysis software: SAS, Microsoft Excel 2013.

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness, As a part of Zika birth defect surveillance, all direct reports, electronic birth certificates, and passive line list cases were confirmed through medical record review and abstraction, and submitted to CDC-Zika Birth Defects Surveillance. Case confirmation will be employed for all NBDPN-reportable defects with a date of January 1, 2020 and onward. Records are reviewed for validity of reported defects. Quality assurance processes for validity and completeness will be automated once the web-based Birth Defects Registry (BDR) is active.

Data use and analysis: Public health program evaluation, Monitoring outbreaks and cluster investigations, Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals

System Integration

System links: The BDR is linked to several internal surveillance and screening systems: Zika Active Monitoring System (lab and clinical data), which includes the Zika Pregnancy Registry (CDC initiative); Newborn Screening for critical congenital heart disease (CCHD) and Early Hearing Detection and Intervention for hearing loss; daily vital records feeds of electronic birth, death, and fetal death certificates; and early intervention services referrals (C1st) and usage (CMS) from providers.

System integration: We are nearing completion of our web-based reporting platform. In addition to the aforementioned internal and/or daily feeds, the BDR receives and matches cases from MACDP, GBDRIS, and CMS at regular intervals (e.g., monthly or quarterly basis). This registry will have the capacity to identify and link cases from flagged vital records and internal screening sources, hospital line lists with reported birth defect cases, cases directly called in and manually entered into the online case report form, and those submitted regularly by external entities (e.g., MACDP).

Funding

Funding source: 32% MCH funds, 68% CDC grant

Other

Web site: <https://dph.georgia.gov/birth-defects>

Additional information on file: In Georgia, active surveillance is performed by the Metropolitan Atlanta Congenital Defects Program (MACDP) and is presently the data source for the NBDPN Annual Report. MACDP performs medical record abstraction for all birth defect cases born to mothers

Other comments: The Georgia Department of Public Health (DPH) is working toward statewide reporting in 2021. We have constructed a web-based statewide BDR that will capture and link MACDP cases, in addition to those reported directly to DPH, flagged on vital records (e.g

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