

Centers for Disease Control and Prevention (Metropolitan Atlanta Congenital Defects Program)

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: Surveillance, Research

Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Laboratories, Prenatal Diagnostic Providers

Program status: Currently collecting data

Start year: 1967

Earliest year of available data: 1968

Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities

Population covered annually: 35000

Statewide: No, Births to mothers residing within one of three central counties in the metropolitan Atlanta area of the state of Georgia

Case Definition

Outcomes covered: All major structural and genetic birth defects

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

Age: Before 6 years of age

Residence: Births to mothers residing in one of three central metropolitan Atlanta counties

Surveillance Methods

Case ascertainment: Active Case Finding

Vital records: Birth certificates

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Induction logs and miscarriage logs

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

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), 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 birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Infants with low birth weight or low gestation (Birth weight < 2500 grams and/or 20-36 weeks gestation), All stillborn infants, All elective abortions, All neonatal deaths, All infants in NICU or special care nursery, All infants with low APGAR scores, All prenatally diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codable defect

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.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

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

Database collection and storage: Access, SQL Server, SAS, Excel

Data Analysis

Data analysis software: SPSS, SAS, Access, Excel

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, 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, Time-space cluster analyses, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Education/public awareness, Prevention projects, Survival analysis

System Integration

System links: Link case finding data to final birth file, National Death Index; Death and Fetal Death Records; Laboratory Records

Funding

Funding source: 100% Other (Intramural CDC funding)

Other

Web site: <https://www.cdc.gov/ncbddd/birthdefects/macdp.html>

Surveillance reports on file: MACDP 40th Anniversary Surveillance Report

Additional information on file: CDC/BPA Defect Code; Including prenatal diagnoses in BD monitoring

Other comments: The 40th Anniversary Surveillance Report was published: Correa A, Cragan JD, Kucik JE, et al. Reporting birth defects surveillance data 1968-2003. Birth Defects Research Part A. 2007;79(2):65-186.

Contacts

Janet D. Cragan, MD, MPH

Centers for Disease Control and Prevention

4770 Buford Hwy., MS S106-3

Atlanta, GA 30341-3717

Phone: 404-498-3807

Fax: 770-488-3263

Email: JCragan@cdc.gov

Laura J Pabst, MPH

Centers for Disease Control and Prevention

4770 Buford Hwy., MS S106-3

Atlanta, GA 30341-3717

Phone: 404-639-6082

Fax: 770-488-3263

Email: LNW9@cdc.gov