

## Puerto Rico

### *Puerto Rico Birth Defects Surveillance and Prevention System (PR-BDSPS)*

**Purpose:** Surveillance, Referral to Services, Referral to Prevention/Intervention Services

**Partner:** Local Health Departments, Hospitals, Advocacy Groups, Early Childhood Prevention Programs

**Program status:** Currently collecting data

**Start year:** 1995

**Earliest year of available data:** 1995

**Organizational location:** Department of Health (Services for Children with Special Medical Needs Division)

**Population covered annually:** 23,000

**Statewide:** Yes

**Current legislation or rule:** Law #351

**Legislation year enacted:** 2004

#### Case Definition

**Outcomes covered:** Selected birth defects covered: neural tube defects, microcephaly, holoprocencephaly, cleft lip and/or cleft palate, anotia, microtia, anophthalmia, microphthalmia, limb defects, talipes equinovarus, gastroschisis, omphalocele, craniosynostosis, diaphragmatic hernia, trisomy 13, 18 and 21, Turner syndrome, 22q11.2 deletion syndrome, albinism, Jarcho-Levin syndrome, Prader Willi syndrome, major congenital heart defects, ambiguous genitalia, hypospadias, and bladder extrophy. Outcomes covered: live-births, stillbirths, terminations and spontaneous abortion.

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

**Age:** Up to 6 years after delivery

**Residence:** In-state births to state residents

#### Surveillance Methods

**Case ascertainment:** Active Case Finding

**Vital records:** Birth certificates, Death certificates

**Other state based registries:** Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

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

**Pediatric & tertiary care hospitals:** Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories

**Other sources:** Physician reports

#### 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), 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, Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, 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

**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 filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.)

**Database collection and storage:** Access, REDCap

#### Data Analysis

**Data analysis software:** SPSS, Excel

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness

**Data use and analysis:** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

#### Funding

**Funding source:** 67.2% MCH funds, 32.7% CDC grant

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