**South Carolina**

*South Carolina Birth Defects Program (SCBDP)*

***Purpose:*** Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Education
***Partner:*** Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Greenwood Genetics Center (GGC)/genetic institution, March of Dimes, Cardiology groups
***Program status:*** Currently collecting data
***Start year:*** GGC began monitoring in 1992; transitioned to SC DHEC and expanded in 2006
***Earliest year of available data:*** Full data available beginning in 2006
***Organizational location:*** Department of Health (Bureau of Population Helth Data Analytics and Informatics)
***Population covered annually:*** 56,668
***Statewide:*** Yes
***Current legislation or rule:*** Title 44-44-10, SC Birth Defects Act
***Legislation year enacted:*** 2004

***Case Definition***
***Outcomes covered:*** Central nervous system defects, eye and ear defects, cardiovascular defects, orofacial defects, gastrointestinal defects, genitourinary defects, musculoskeletal defects, and chromosomal defects
***Pregnancy outcome:*** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (10 weeks or greater; all gestational ages for the data submitted in this report), Elective terminations (All gestational ages, 10 weeks or greater; all gestational ages for the data submitted in this report)
***Age:*** Up to two years of age; program is expanding this age range for people with CHD to any age group
***Residence:*** All SC residents

***Surveillance Methods***
***Case ascertainment:*** Active Case Finding
***Vital records:*** Birth certificates, Fetal birth certificate, The birth certificate data is NTD-specific
***Other state based registries:*** Newborn hearing screening program
***Delivery hospitals:*** Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
***Pediatric & tertiary care hospitals:*** Disease index or discharge index, Discharge summaries, Surgery logs, Specialty outpatient clinics
***Other specialty facilities:*** Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
***Other sources:*** Genetic institution

***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 defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All elective abortions, All prenatally diagnosed or suspected cases, Elective abortions, prenatally diagnosed cases found through problem pregnancy codes, and select ICD-10/9 codes outside of that range
***Conditions warranting chart review beyond the newborn period:*** Cardiovascular condition, 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, 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.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records
***Database collection and storage:*** Access, SQL Server

***Data Analysis***
***Data analysis software:*** SAS, Access, Arc-GIS, Microsoft Excel
***Quality assurance:*** Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, We look at comparison between multiple data sources for NTD only. The program is trying to hire a geneticist for more assistance.
***Data use and analysis:*** Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Legislative reports

***System Integration***
***System links:*** Link case finding data to final birth file
***System integration:*** SCBDP data is integrated with SC Vital Records.

***Funding***
***Funding source:*** 55% General state funds, 10% MCH funds, 45% CDC grant

***Other***
***Surveillance reports on file:***
Https://scdhec.gov/sites/default/files/Library/CR-012491.pdf

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# DATA TABLES

# South Carolina

## Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

| | Maternal Race/Ethnicity | | | | | | |
|---|---|---|---|---|---|---|---|
| **Defect** | **White, Non-Hispanic** | **Black, Non-Hispanic** | **Hispanic** | **Asian or Pacific Islander, Non-Hispanic** | **American Indian or Alaska Native, Non-Hispanic** | **Total*** | **Notes** |
| Anencephalus | 36 | 12 | 7 | <5 | 0 | 59 | |
| | ***2.2*** | ***1.4*** | ***2.8*** | | ***0.0*** | ***2.1*** | |
| Anophthalmia/microphthalmia | 15 | 16 | 0 | <5 | 0 | 33 | |
| | ***0.9*** | ***1.8*** | ***0.0*** | | ***0.0*** | ***1.2*** | |
| Anotia/microtia | 22 | 6 | 11 | <5 | <5 | 42 | |
| | ***1.3*** | ***0.7*** | ***4.5*** | | | ***1.5*** | |
| Aortic valve stenosis | 23 | 6 | <5 | <5 | 0 | 33 | |
| | ***1.4*** | ***0.7*** | | | ***0.0*** | ***1.2*** | |
| Atrioventricular septal defect (Endocardial cushion defect) | 77 | 50 | 10 | <5 | 0 | 141 | |
| | ***4.6*** | ***5.7*** | ***4.1*** | | ***0.0*** | ***4.9*** | |
| Biliary atresia | 12 | 7 | <5 | 0 | 0 | 22 | |
| | ***0.7*** | ***0.8*** | | ***0.0*** | ***0.0*** | ***0.8*** | |
| Bladder exstrophy | 7 | <5 | 0 | 0 | 0 | 8 | |
| | ***0.4*** | | ***0.0*** | ***0.0*** | ***0.0*** | ***0.3*** | |
| Choanal atresia | 13 | 13 | 0 | 0 | 0 | 26 | |
| | ***0.8*** | ***1.5*** | ***0.0*** | ***0.0*** | ***0.0*** | ***0.9*** | |
| Cleft lip alone | 55 | 15 | 8 | <5 | <5 | 83 | |
| | ***3.3*** | ***1.7*** | ***3.2*** | | | ***2.9*** | |
| Cleft lip with cleft palate | 111 | 46 | 17 | <5 | <5 | 179 | |
| | ***6.7*** | ***5.2*** | ***6.9*** | | | ***6.2*** | |
| Cleft palate alone | 97 | 40 | 8 | <5 | 0 | 151 | |
| | ***5.8*** | ***4.6*** | ***3.2*** | | ***0.0*** | ***5.3*** | |
| Cloacal exstrophy | <5 | <5 | <5 | 0 | 0 | <5 | |
| | | | | ***0.0*** | ***0.0*** | | |
| Coarctation of the aorta | 85 | 35 | 10 | <5 | <5 | 136 | |
| | ***5.1*** | ***4.0*** | ***4.1*** | | | ***4.7*** | |
| Common truncus (truncus arteriosus) | 13 | <5 | <5 | <5 | <5 | 25 | |
| | ***0.8*** | | | | | ***0.9*** | |
| Congenital cataract | 10 | 18 | <5 | <5 | <5 | 34 | |
| | ***0.6*** | ***2.1*** | | | | ***1.2*** | |
| Congenital posterior urethral valves | 18 | 11 | <5 | <5 | 0 | 33 | 1 |
| | ***2.1*** | ***2.5*** | | | ***0.0*** | ***2.3*** | |
| Craniosynostosis | 58 | 14 | 5 | <5 | <5 | 82 | |
| | ***3.5*** | ***1.6*** | ***2.0*** | | | ***2.9*** | |
| Deletion 22q11.2 | 5 | 7 | <5 | 0 | 0 | 13 | |
| | ***0.3*** | ***0.8*** | | ***0.0*** | ***0.0*** | ***0.5*** | |
| Diaphragmatic hernia | 55 | 27 | 8 | <5 | 0 | 95 | |
| | ***3.3*** | ***3.1*** | ***3.2*** | | ***0.0*** | ***3.3*** | |
| Double outlet right ventricle | 28 | 31 | 9 | <5 | <5 | 71 | |
| | ***1.7*** | ***3.5*** | ***3.6*** | | | ***2.5*** | |
| Ebstein anomaly | <5 | <5 | 0 | 0 | <5 | 9 | |
| | | | ***0.0*** | ***0.0*** | | ***0.3*** | |
| Encephalocele | 23 | 14 | <5 | <5 | 0 | 40 | |
| | ***1.4*** | ***1.6*** | | | ***0.0*** | ***1.4*** | |
| Esophageal atresia/tracheoesophageal fistula | 35 | 20 | <5 | 0 | <5 | 62 | |
| | ***2.1*** | ***2.3*** | | ***0.0*** | | ***2.2*** | |
| Gastroschisis | 69 | 29 | 7 | <5 | <5 | 111 | |
| | ***4.1*** | ***3.3*** | ***2.8*** | | | ***3.9*** | |
| Holoprosencephaly | 37 | 27 | 6 | 0 | <5 | 72 | |
| | ***2.2*** | ***3.1*** | ***2.4*** | ***0.0*** | | ***2.5*** | |
| Hypoplastic left heart syndrome | 57 | 27 | 6 | <5 | 0 | 95 | |
| | ***3.4*** | ***3.1*** | ***2.4*** | | ***0.0*** | ***3.3*** | |
| Interrupted aortic arch | 18 | 12 | <5 | <5 | 0 | 33 | |
| | ***1.1*** | ***1.4*** | | | ***0.0*** | ***1.2*** | |
| Limb deficiencies (reduction defects) | 63 | 28 | 13 | <5 | 0 | 109 | |
| | ***3.8*** | ***3.2*** | ***5.3*** | | ***0.0*** | ***3.8*** | |
| Omphalocele | 40 | 35 | 6 | <5 | 0 | 85 | |
| | ***2.4*** | ***4.0*** | ***2.4*** | | ***0.0*** | ***3.0*** | |
| Pulmonary valve atresia and stenosis | 78 | 70 | 10 | <5 | <5 | 162 | |
| | ***4.7*** | ***8.0*** | ***4.1*** | | | ***5.6*** | |

## South Carolina

**Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)**

| | Maternal Race/Ethnicity | | | | | | |
|---|---|---|---|---|---|---|---|
| **Defect** | **White, Non-Hispanic** | **Black, Non-Hispanic** | **Hispanic** | **Asian or Pacific Islander, Non-Hispanic** | **American Indian or Alaska Native, Non-Hispanic** | **Total*** | **Notes** |
| Pulmonary valve atresia | 9 | 14 | <5 | <5 | <5 | 29 | |
| | ***0.5*** | ***1.6*** | | | | ***1.0*** | |
| Rectal and large intestinal atresia/stenosis | 61 | 32 | 12 | <5 | 0 | 108 | |
| | ***3.7*** | ***3.7*** | ***4.9*** | | ***0.0*** | ***3.8*** | |
| Renal agenesis/hypoplasia | 107 | 44 | 14 | <5 | <5 | 169 | |
| | ***6.4*** | ***5.0*** | ***5.7*** | | | ***5.9*** | |
| Single ventricle | 10 | 8 | <5 | <5 | 0 | 21 | |
| | ***0.6*** | ***0.9*** | | | ***0.0*** | ***0.7*** | |
| Small intestinal atresia/stenosis | 34 | 15 | 8 | 0 | 0 | 58 | |
| | ***2.0*** | ***1.7*** | ***3.2*** | ***0.0*** | ***0.0*** | ***2.0*** | |
| Spina bifida without anencephalus | 51 | 29 | 12 | <5 | 0 | 95 | |
| | ***3.1*** | ***3.3*** | ***4.9*** | | ***0.0*** | ***3.3*** | |
| Tetralogy of Fallot | 83 | 51 | 9 | 5 | <5 | 151 | |
| | ***5.0*** | ***5.8*** | ***3.6*** | ***8.9*** | | ***5.3*** | |
| Total anomalous pulmonary venous connection | 17 | 11 | <5 | <5 | 0 | 33 | |
| | ***1.0*** | ***1.3*** | | | ***0.0*** | ***1.2*** | |
| Transposition of the great arteries (TGA) | 49 | 22 | 5 | <5 | 0 | 77 | |
| | ***2.9*** | ***2.5*** | ***2.0*** | | ***0.0*** | ***2.7*** | |
| Dextro-transposition of great arteries (d-TGA) | 47 | 22 | <5 | 0 | 0 | 73 | |
| | ***2.8*** | ***2.5*** | | ***0.0*** | ***0.0*** | ***2.5*** | |
| Tricuspid valve atresia and stenosis | 13 | 12 | <5 | <5 | <5 | 30 | |
| | ***0.8*** | ***1.4*** | | | | ***1.0*** | |
| Trisomy 13 | 23 | 18 | <5 | <5 | 0 | 44 | |
| | ***1.4*** | ***2.1*** | | | ***0.0*** | ***1.5*** | |
| Trisomy 18 | 49 | 26 | 19 | <5 | <5 | 103 | |
| | ***2.9*** | ***3.0*** | ***7.7*** | | | ***3.6*** | |
| Trisomy 21 (Down syndrome) | 198 | 86 | 50 | 14 | <5 | 354 | |
| | ***11.9*** | ***9.8*** | ***20.3*** | ***24.9*** | | ***12.3*** | |
| Ventricular septal defect | 625 | 310 | 110 | 29 | 6 | 1,088 | |
| | ***37.5*** | ***35.4*** | ***44.6*** | ***51.6*** | ***82.8*** | ***37.9*** | |
| **Total live births** | **166,679** | **87,654** | **24,671** | **5,625** | **725** | **286,801** | |
| **Male live births** | **85,834** | **44,337** | **12,434** | **2,921** | **379** | **146,652** | |

## South Carolina

### Birth Defects Counts and Prevalence 2014 - 2018 (Prevalence per 10,000 Live Births)

| | Maternal Age (Years) | | | |
|---|---|---|---|---|
| **Defect** | **Less than 35** | **35+** | **Total*** | **Notes** |
| Gastroschisis | 108 | <5 | 111 | |
| | ***4.4*** | | ***3.9*** | |
| Trisomy 13 | 29 | 15 | 44 | |
| | ***1.2*** | ***3.9*** | ***1.5*** | |
| Trisomy 18 | 52 | 51 | 103 | |
| | ***2.1*** | ***13.2*** | ***3.6*** | |
| Trisomy 21 (Down syndrome) | 177 | 177 | 354 | |
| | ***7.1*** | ***45.9*** | ***12.3*** | |
| **Total live births** | **248,215** | **38,578** | **286,801** | |

**Notes**
1. Data for this condition include male and unknown gender cases only. Prevalence is calculated per 10,000 male live births.

**General comments**
*Data for totals include unknown and/or other.
-Data for conditions exclude probable and possible cases.