## South Carolina

### Birth Defects Surveillance System

<table>
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<tr>
<th>State</th>
<th>Statute/Rule</th>
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<th>Data Sharing</th>
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<tr>
<td>SC</td>
<td>STATUTE: SCCL, Title 44, Chapter 44</td>
<td>SECTION 44-44-30. South Carolina Birth Defects Program established; public health monitoring and referral. (A) There is established the South Carolina Birth Defects Program within the Department of Health and Environmental Control to promote increased understanding of birth defects, prevent and reduce birth defects, and assist families with children who have birth defects. (B) As part of this program, the department shall conduct public health monitoring, make appropriate referrals and provide other interventions related to birth defects. Information obtained pursuant to this subsection must be used for: (1) public health and epidemiology purposes in which incidence, distribution, causes,</td>
<td>44-44-80. Access to health and medical records; confidentiality. All hospitals, health providers, birth centers, clinics, medical records departments, third party payors, laboratories, universities, and other sources of birth defects information shall provide access to all health or medical records for the purpose of surveillance and identification of birth defects in accordance with procedures promulgated by the department in regulation. This access is protected by state and federal law concerning birth defects monitoring, and confidentiality must be maintained by the department in accordance with Section 44-44-140. Individually identifiable data may not be made available to</td>
<td>44-44-60. Utilization of data. The Birth Defects Program shall concentrate on public health surveillance and monitoring birth defects. Data may be made available to persons or institutions outside the program for education, research, provision of services, and other purposes in accordance with program procedures. 44-44-100. Use and disclosure of birth defects data. Birth defects data</td>
<td>NO</td>
<td>NO</td>
</tr>
</tbody>
</table>

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Updated August 2012. All state statutes and department rules originally accessed online July/Aug 2008.
Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature.
| SECTION 44-44-70. Maintenance of central database; case ascertainment. The department shall maintain a central database for the gathering of data from hospitalizations, specialty clinics, births, pregnancies, stillbirths, and pediatric deaths through age two, throughout the State, including border regions. The department shall establish procedures for active birth defect case ascertainment. The data system must be maintained to be accurate, timely, and dynamic, and the department shall institute procedures to make this system more accessible for education and research purposes. This information must be released in aggregate form only without identifying information; (2) referral for service and treatment purposes so that referrals of the individual child and family may be facilitated for optimal care... |

| 61-114, Section C—6. Monitoring may be used and disclosed for the purposes of scientific research concerning causation, prevention strategies, epidemiological analysis, environmental and geographic study, and other purposes authorized by the department. |

| 44-44-110. Providing data to the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention... |

| SECTION 44-44-140. (A) All birth defects information collected by the department in the birth defects program is confidential and must be used solely for the purposes provided in this chapter... (C) An entity required to provide information to the department pursuant to Section 44-44-80 is not subject to liability for providing access and information or use and disclosure of protected health information. This access and reporting may not be considered a waiver, breach, or violation of a confidential relationship. |

| 44-44-110. Data may be provided to the National Center for Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention to enhance scientific, epidemiological, and investigative efforts and studies. |
The department may expand the age range for data collection as resources become available and if the department determines the additional data collection would benefit the program.

**61-114 South Carolina Birth Defects Program**

Section C: Public Health Surveillance and Monitoring of Birth Defects

1. The Department shall conduct statewide monitoring of all major structural birth defects using active surveillance methods to ascertain cases. This monitoring may be both prenatal and postnatal (up to two years of age) and shall include live births and fetal deaths occurring in South Carolina. South Carolina Birth Defects Program Nurse Abstractors will conduct active surveillance at all hospitals in South Carolina that provide obstetrical or pediatric care for case identification and

a. Upon request, the Department shall have access to all records of parent(s), child, and siblings if necessary, for the purpose of identifying birth defects, including vital records, hospital medical records, physician office medical records, specialty clinic records, and discharge data, in order to identify birth defect cases. The Department shall verify the cases through records review and may include review by a physician geneticist.

b. For the purpose of surveillance and identification of birth defects, all laboratories, universities, and other sources of birth defects information shall provide the Department access to all health, medical, or other records, upon request.

c. Access to all records described herein may be granted in hard copy or electronically.

The department shall maintain confidentiality in regard to:

- (3) epidemiological study and reporting;
- (4) research uses;

**61-114...Section F: Confidentiality**

These records will be kept confidential and used and released pursuant to the provisions of S.C. Code Ann. Section 44-44-140 only.
abstraction. Hospitals and other medical facilities will provide, upon request, access to medical records containing ICD-9-CM diagnostic code categories in the range of birth defects codes recommended by the Centers for Disease Control (CDC) and the National Birth Defects Prevention Network (NBDPN) for surveillance. The categories of ICD-9-CM codes for birth defects includes, but is not limited to, the following:

a. Central nervous system disorders
b. Eye and ear disorders
c. Cardiovascular disorders
d. Orofacial disorders
e. Gastrointestinal disorders
f. Genitourinary disorders
g. Musculoskeletal disorders
h. Chromosomal disorders
i. Other disorders to include Fetal Alcohol Syndrome and Amniotic bands
j. ICD-9-CM codes regarding known or suspected fetal

Section D: Data Usage

1. Unless otherwise provided by law, all reports generated by the Department containing birth defects data will be publicly disclosed in aggregate form only. No identifying information will be publicly released by the Department.

2. Birth defect data may be used by the Department, its agents, partners and contractors, to facilitate optimal treatment services for affected children and families.

3. Any entity or person wishing to conduct research using this data must comply with the Department’s procedures, including review by the Institutional Review Board (IRB).

4. The Department may negotiate and enter into agreements and contracts with state and federal agencies,
abnormality affecting management of mother.

2. The birth defects surveillance system will be implemented by phasing in additional birth defect categories until all CDC recommended types of birth defects are monitored.

3. Birth defects case abstraction information will include demographic data on the child, mother and father, if available.

4. The Department shall maintain a central database of all birth defects data gathered from hospitals, specialty clinics and other facilities, regarding births, pregnancies, stillbirths, and pediatric deaths through age two, throughout the state, including border regions.

5. The Department may enter into agreements with other states, universities, genetic centers and other parties, as appropriate, in order to facilitate operation of the program. These agreements and contracts may include the release of identifying data to enable the other entity to offer families assistance for prevention of recurrence of birth defects.

61-114 …Section E: Referral

1. The Department may contact a family whose child is identified as having a structural birth defect either directly or through the child's health care provider in order to offer services. Family acceptance of referrals is voluntary. Referrals shall be made in accordance with the Department guidelines and recommendations.

2. South Carolina Birth Defects Program nurse abstractors will conduct surveillance activities, to...
include review of medical records for documentation of physician, social work or discharge planner referral for follow-up of children with birth defects. When there is no documented evidence of follow-up, South Carolina Birth Defects Program staff may access other appropriate health and developmental systems or organizations for referral for early intervention, such as Babynet. Babynet will provide regular feedback, as requested, to South Carolina Birth Defects Program on status of birth defects cases referred.