## North Carolina

### Birth Defects Surveillance System

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<td>NC</td>
<td>STATUTE: NCGS Chapter 130A, Article 5, Part 7</td>
<td>§130A–131.16. Birth defects monitoring program established; definitions. (a) The Birth Defects Monitoring Program is established within the State Center for Health and Environmental Statistics. The Birth Defects Monitoring Program shall compile, tabulate, and publish information related to the incidence and prevention of birth defects. (b) As used in this Part, unless the context clearly requires otherwise, the term: (1) &quot;Birth defect&quot; means any physical, functional, or chemical abnormality present at birth that is of possible genetic or prenatal origin… [emphasis added]</td>
<td>§130A–131.16. ...(c) Physicians and persons in charge of licensed medical facilities shall, upon request, permit staff of the Program to examine, review, and obtain a copy of any medical record in their possession or under their control that pertains to a diagnosed or suspected birth defect, including the records of the mother. (d) A physician or person in charge of a licensed medical facility who permits examination, review, or copying of medical records pursuant to this section shall be immune from civil or criminal liability that might otherwise be incurred or imposed for providing</td>
<td>§130A–131.17. Confidentiality of information; research. (a)…The Director of the State Center for Health and Environmental Statistics may also authorize access to this information to persons engaged in demographic, epidemiological, or other similar scientific studies related to health. The Commission shall adopt rules that establish strict criteria for the use of monitoring Program information for scientific research. All persons given</td>
<td>NO</td>
<td>NO</td>
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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. www.cchfreedom.org
### .0101 GENERAL

(a) This Section implements G.S. 130A, Article 5, Part 7 entitled Birth Defects. The legislation establishes a Birth Defects Monitoring Program within the State Center for Health Statistics. The purpose of the monitoring program is to compile, tabulate and publish information related to the incidence and prevention of birth defects.

(b) All scientific research proposed to be conducted by persons other than authorized Program staff using the information from the Program, shall first be reviewed and approved by the Director of the State Center for Health and Environmental Statistics and an appropriate committee for the protection of human subjects which is approved by the United States Department of Health and Human Services pursuant to Part 46 of Title 45 of the Code of Federal Regulations. Satisfaction of the terms of the Commission's rules for data access shall entitle authorized access to Program information shall agree, in writing, to maintain confidentiality.

### 10A NCAC 47C .0104 SURVEILLANCE OF BIRTH DEFECTS; CENTRAL REGISTRY

(a) The monitoring program shall operate statewide. (b) In order for information on a child to be included in the monitoring program's central registry, the following conditions must be met:

1. The state of birth or the mother's state of residence at the time of birth must have been in North Carolina; and
2. The child must have a birth defect or other specified access to these medical records based upon invasion of privacy or breach of physician-patient confidentiality.

(b) All scientific research proposed to be conducted by persons other than authorized Program staff using the information from the Program, shall first be reviewed and approved by the Director of the State Center for Health and Environmental Statistics and an appropriate committee for the protection of human subjects which is approved by the United States Department of Health and Human Services pursuant to Part 46 of Title 45 of the Code of Federal Regulations. Satisfaction of the terms of the Commission's rules for data access shall entitle authorized access to Program information shall agree, in writing, to maintain confidentiality.
perinatal condition that can adversely affect his or her health and development. 

(c) The central registry shall include birth defects occurring in a fetal death, miscarriage, or pregnancy termination.

(d) The coding scheme used by the monitoring program to classify birth defects shall be based on a medically recognized system, such as ICD-9-CM or the CDC/BPA system used by the Centers for Disease Control and Prevention in the Metropolitan Atlanta Congenital Defects Program, as described in the report titled "Metropolitan Atlanta Congenital Defects Program Procedure Manual," dated June, 1993.

(e) Nothing in this section prohibits the Program from publishing statistical compilations relating to birth defects that do not in any way identify individual patients.