## Tennessee

### Birth Defects Surveillance System

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<td>TN</td>
<td>STATUTE: T.C. Title 68, Chapter 5, Part 5</td>
<td>68-5-506. Creation of birth defects registry — Advisory committee — Confidentiality — Penalty for unauthorized disclosure of confidential information.</td>
<td>68-5-506. ...(e)(2) The department shall maintain an accurate record of all persons who are given access to the information in the registry. The record shall include: (A) The name of the persons authorizing access; (B) The name, title, and organizational affiliation of persons given access;</td>
<td>68-5-506. (d) The staff of the registry shall use the information collected pursuant to this section and information available from other reporting systems and health providers to conduct studies to investigate the causes of birth defects, and to determine and evaluate measures designed to prevent their occurrence. The department's investigation shall not be limited to geographic,</td>
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interferes with normal growth or development;
(2) To provide, on at least an annual basis, information on the incidence, prevalence and trends of birth defects;
(3) To provide information to determine whether environmental hazards are associated with birth defects;
(4) To provide information as to other possible causes of birth defects;
(5) To evaluate the current prevention initiatives undertaken by the state, and to give guidance for improvement of these initiatives or for the addition of new prevention strategies; and
(6) To provide a case referral element whereby the families of children born with birth defects are provided information on public services available to them and their children.

(b)(1) There is established a birth defects registry in the department of health...

(3) The department shall maintain a system for the collection of information necessary to accomplish the outlined purposes of this section. For purposes related to the registry, the department shall have access to any medical record that pertains to a diagnosed or suspected birth defect, including the records of the mother. Providers acting pursuant to this section shall not be liable for the release of medical records as authorized by this section.

(C) The dates of access;
(D) The specific purpose for which the information is to be used; and
(E) The results of the independent research.

(3) Nothing in this section shall prohibit the publishing of statistical compilations relating to birth defects or poor reproductive outcomes that do not in any way identify individual sources of information.

(e)(1) All information collected and analyzed pursuant to this section shall be confidential insofar as the identity of the individual patient is concerned and shall be used solely for the purposes provided in this section; provided, that the commissioner may provide access to those scientists approved by the advisory committee who are engaged in demographic, epidemiological or other similar research.

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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)
The department shall develop and disseminate information about the birth defects registry to the participating perinatal centers that will be made available to the family, that explains and describes the purpose and process of the registry and how confidentiality will be protected. The commissioner, with guidance from the advisory committee, shall promulgate by rule a mechanism for the active verification of reports through the use of multiple sources.

(4) The registry shall collect information on birth defects, whether they occur as live births, stillbirths, or fetal deaths.

(5) The registry shall collect information on birth defects diagnosed in children up to five (5) years of age.

(6) The registry shall be implemented as a pilot project to include reporting by any of the five (5) designated perinatal centers choosing to be included in the pilot project. Perinatal centers participating in the pilot project shall report to the birth defects registry as required by the commissioner.

(c) The department, with guidance from the advisory committee, shall establish a program in the registry for referring families of children born with birth defects or the mothers of children lost to birth defects to available appropriate state resources. In order for a family of a child with a birth defect to

| studies related to health, and who agree, in writing as non-state employees, to be identified and coded while maintaining confidentiality as described in this section and to the centers for disease control (CDC) for inclusion in the National Birth Defects Registry.

“*The TBDR shares birth defect statistics and related information with other stat agencies and public interest groups such as the March of Dimes, the Tennessee Perinatal Association, the Tennessee Folic Acid Council and..."
participate in the referral program established by this subsection (c), the child's parents or legal guardian must contact the department and request to be included in the program.

“The TBDR gathers data from hospital discharge reports and vital records (birth, fetal death, and infant death certificates) to ascertain birth defect information for infants born to Tennessee resident. Gathering data from archival data systems such as these is sometimes called a passive surveillance approach. The TBDR also employs an active surveillance approach reviewing and abstracting medical records of infants identified with specific birth defects… - “Tennessee Birth Defects 2002 – 2006,” Tennessee Birth Defects Registry (2010). Tennessee Department of Health.”