## Connecticut

### Birth Defects Surveillance System

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<td>CT</td>
<td>STATUTE: Sec. 19a–56a and 56b.</td>
<td>Sec. 19a-56a. (Formerly Sec. 10a-132b). Birth defects surveillance program. Collection of birth defects data. Advisory committee. …There is established a birth defects surveillance program, within available funds, in the Department of Public Health. The program shall monitor the frequency, distribution and type of birth defects occurring in Connecticut on an annual basis. The Commissioner of Public Health shall establish a system for the collection of information concerning birth defects and other adverse reproductive outcomes.</td>
<td>19a-36-A1. Definitions. (dd.) “Reportable disease” means a communicable disease, disease outbreak, or other condition of public health significance required to be reported to the department and local health directors.</td>
<td>Sec. 19a-56b. (Formerly Sec. 10a-132d). Confidentiality of birth defects information. Access. Access to such information shall be limited to the Department of Public Health and persons with a valid scientific interest and qualifications as determined by the Commissioner of Public Health, provided the</td>
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<td>GENERAL RULE: 19a-36-A1 to 19a-36-A9</td>
<td>Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children. Each person licensed to practice medicine, surgery, midwifery, chiropractic, naturopathic, podiatry or nursing or to use any other means or agencies to treat, prescribe for, heal or otherwise alleviate deformity, ailment, disease or any other form of human ills, who has professional knowledge that any child under five years of age has any physical defect shall,</td>
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within forty-eight hours from the time of acquiring such knowledge, mail to the Department of Public Health a report, stating the name and address of the child, the name and address of the child's parents or guardians, the nature of the physical defect and such other information as may reasonably be required by the department. The department shall prepare and furnish suitable blanks in duplicate for such reports, shall keep each report on file for at least six years from the receipt thereof and shall furnish a copy thereof to the State Board of Education within ten days.

“CT Birth Defects Registry” is the primary source of birth defects/adverse birth outcomes in CT. The registry actively collects data through the newborn screening program and contains approximately 200 records (annual reporting unknown) since its inception in October 2002. The registry includes the following demographic information obtained from medical records: patient name, birth mother’s name and date of birth, address, state file number, race, ethnicity, gender, and date of birth (see Database File Layout pgs 17 – 19 of inventory for detailed database contents). Aggregate data is available when generated; internal data requests written request to database manager (no patient identifiers); external requests IRB/HIC request (no patient identifying information in hospital discharge records. Such identifying information shall be used solely for purposes of the program. The commissioner may require general acute care hospitals to make available to the department the medical records of patients diagnosed with birth defects or other adverse reproductive outcomes for the purposes of research and verification of data.

department and such persons are engaged in demographic, epidemiologic or other similar studies related to health and agree, in writing, to maintain confidentiality as prescribed in this section.
identifiers).” -