# Connecticut

## Newborn Genetic Testing & Surveillance System

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<td>STATUTE: Title 19a Chapter 368a RULE: Public Health Code Section 19-13-D41 (under revision)</td>
<td>19a-55. Newborn infant health screening. Tests Required. Fees. Regulations. (a) The administrative officer or other person in charge of each institution caring for newborn infants shall cause to have administered to every such infant in its care an HIV-related test, as defined in section 19a-581, a test for phenylketonuria and other metabolic diseases, hypothyroidism, galactosemia, sickle cell disease, maple syrup urine disease, homocystinuria, biotinidase deficiency, congenital adrenal hyperplasia and such other tests for inborn errors of metabolism as shall be prescribed by the Department of Public Health. The tests shall be administered as soon after birth as is medically appropriate…</td>
<td>19a-55. Newborn infant health screening. … (c) The provisions of this section shall not apply to any infant whose parents object to the test or treatment as being in conflict with their religious tenets and practice. Sec. 19-13-D42. Objection of parents to test If the parents of an infant object</td>
<td>19a-25-3. Disclosure of identifiable health data (a) The department shall not disclose identifiable health data unless:…(2) The disclosure is to health care providers, the local director of health, the department, another state or public health agency, including those in other states and the federal government, or other persons when deemed necessary by the department in its sole discretion for disease prevention and control pursuant to section 19a-215 of the Connecticut General Statutes or for the purpose of reducing morbidity and mortality from any cause or condition, except that every effort shall be made to limit the disclosure of identifiable health data to the...</td>
<td>NO</td>
<td>YES</td>
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The Commissioner of Public Health shall (1) administer the newborn screening program, (2) direct persons identified through the screening program to appropriate specialty centers for treatments, consistent with any applicable confidentiality requirements, and (3) set the fees to be charged to institutions to cover all expenses of the comprehensive screening program including testing, tracking and treatment. ...The commissioner shall adopt regulations, in accordance with chapter 54, to implement the provisions of this section.

Sec. 19-13-D41. (UNDER REVISION) Tests of infants for phenylketonuria and metabolic errors. Unless the parents object, the administrator or other person in charge of any institution providing medical care of infants twenty-eight days or less of age shall cause to be taken from each such infant a blood specimen or specimens in writing to a test for phenylketonuria and other inborn errors of metabolism, as being in conflict with their religious tenets and practice, such fact shall be reported to the state department of health and a statement on a form provided by the state department of health signed by the parents shall be made a part of the infant's hospital record.

minimal amount necessary to accomplish the public health purpose; (3) The disclosure is to an individual, organization, governmental entity in this or another state or to the federal government, provided the department determines that:

(A) Based upon a written application and such other information as required by the department to be submitted by the requesting individual, organization or governmental entity the data will be used solely for bona fide medical and scientific research;

(B) The disclosure of data to the requesting individual, organization or governmental entity is required for the medical or scientific research proposed;

(C) The requesting individual, organization, or governmental entity has entered into a written agreement satisfactory to the
satisfactory for tests for phenylketonuria and other inborn errors of metabolism, subject to the following conditions:

(a) Materials for the collection of specimens shall be of a type furnished by or acceptable to the state department of health;

(b) Specimens shall not be collected until at least twenty-four hours after the first milk feeding of the infant unless discharged sooner, in which case specimens shall be taken not earlier than three hours before discharge;

(c) Specimens shall be submitted to the laboratory division of the state department of health, or to a laboratory approved for the purpose by the state department of health, within forty-eight hours after collection;

(d) Laboratory tests shall be

department agreeing to protect such data in accordance with the requirements of this section and not permit disclosure without prior approval of the department; and

(D) The requesting individual, organization or governmental entity, upon request of the department or after a specified date or event, returns or destroys all identifiable health data provided by the department and copies thereof in any form.
made according to methods approved by the state department of health;

(e) Information accompanying each specimen shall be sufficient to identify for future reference the infant from whom taken;

(f) Results of tests shall be transmitted to the state department of public health within twenty-four hours after test on forms provided for the purpose;

(g) Records of tests shall clearly indicate the tests performed and the results thereof and shall be maintained for a period of five years.