### North Dakota

#### Newborn Genetic Testing & Surveillance System

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<th>State</th>
<th>Statute/Rule</th>
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<td>ND</td>
<td>STATUTE: NDCC Title 25, Chpt 25-17 RULE: Chapter 33-06-16</td>
<td><strong>25-17-03. Treatment for positive diagnosis - Registry of cases.</strong> The state department of health shall: 1. Follow up with attending physicians cases with positive tests for metabolic diseases in order to determine the exact diagnosis. 2. Refer every diagnosed case of a metabolic disease to a qualified health care provider for necessary treatment. 3. Maintain a registry of cases of metabolic and genetic diseases…</td>
<td><strong>25-17-04. Testing and reporting requirements.</strong> The physician attending a newborn child, or the birth attendant in the case of an out-of-hospital birth, shall provide the parents with written information regarding the nature of the proposed testing and then cause that newborn child</td>
<td><strong>23-01-03.1. Newborn metabolic and genetic disease screening tests.</strong> The health council may authorize the use of newborn metabolic and genetic disease screening tests, as provided for in chapter 25-17, for research purposes. The council shall adopt rules to ensure that the results are used for legitimate research purposes and to ensure that the confidentiality of the newborns and their families is protected.</td>
<td>NO</td>
<td>YES</td>
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**Definitions....3.**
"Metabolic disease" and “genetic disease” means a disease as designated by rule of the state health council for which early identification and timely intervention will lead to a significant reduction in mortality, morbidity, and associated disabilities.

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**State Title V Block Grant Narrative, State: ND Application Year: 2007:** “Birth certificate and newborn screening files have been linked since 1996. This linkage has helped identify the characteristics of infants not screened as well as assess the characteristics of women who breastfeed to be subjected to testing for metabolic and genetic diseases, in the manner prescribed by the state department of health. A physician attending a patient with a metabolic disease or genetic disease, or both, shall report the case to the state department of health. The testing requirements of this section do not apply if the parents of a newborn child object to or organizations, for the purpose of reducing the morbidity or mortality from any cause or condition of health is confidential and must be used solely for the purposes of medical or scientific research.

**33-06-16-05. Research and testing materials.** Information and testing materials generated by the newborn screening program under North Dakota Century Code chapter 25-17 are strictly confidential information subject to North Dakota Century Code chapter 23-01.3 and section 23-01-15.

1. Access to information or testing materials may be obtained only as follows: …c. Information and testing materials may be disclosed to a person engaged in a bona fide research project concerning medical, psychological, or sociological issues provided all of the following conditions are met: …

2. Retention and destruction of information and testing materials.

   a. Information and testing materials provided to the university of North Dakota school of medicine and health sciences may be retained indefinitely or destroyed according to this subsection. [emphasis added]

   b. Information and testing materials may be destroyed by any available means that
c. Information and testing materials may be destroyed based upon the following schedule:

(1) Information and testing materials created less than ten years before the present date may be destroyed only with the state health officer’s prior written approval.
(2) After ten years, information and testing materials may be destroyed without prior approval.