### Oklahoma

#### Newborn Genetic Testing & Surveillance System

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<td>OK</td>
<td>STATUTE: OSC, Title 63, Chapter 1, Article 5. OSC, Title 36, Chapter 3, Article 6. RULE: OAC Title 310, Chapter 550</td>
<td>§63-1-533. Phenylketonuria, related inborn metabolic disorders and other genetic or biochemical disorders – Educational and newborn screening programs. A. The State Board of Health shall provide, pursuant to the provisions of Section 1-534 of this title as technologies and funds become available, an intensive educational and newborn screening program among physicians, hospitals, public health nurses, and the public concerning phenylketonuria, related inborn metabolic disorders, and other genetic or biochemical disorders for which:</td>
<td>63-1-534. Tests. …provided that the provisions of this section shall not apply to any infant whose parents object thereto on the grounds that such examination conflicts with their religious tenets and practices.</td>
<td>OAC 310:550-3-1. Testing of newborns (a) All newborns in Oklahoma shall be tested by a Certified Newborn Screening Laboratory for phenylketonuria, congenital hypothyroidism, galactosemia, sickle cell diseases, cystic fibrosis, congenital adrenal hyperplasia, medium-chain acyl coenzyme A dehydrogenase deficiency (MCAD) and after October 1, 2007,</td>
<td>NO</td>
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1. Newborn screening will provide early treatment and management opportunities that might not be available without screening; and
2. Treatment and management will prevent mental retardation and/or reduce infant morbidity and mortality. …

63-1-534. Tests. The State Board of Health shall make such rules and regulations pertaining to such tests as accepted medical practice shall indicate, and is authorized to make such testing mandatory if sufficient evidence exists that the public has been negligent in accepting such practice and if the Board considers it in the public interest to do so.

OAC 310:550-3-1. Testing of newborns
(a) …a parent or guardian may refuse screening of their newborn on the grounds that such examination conflicts with their religious tenets and practices

upon completion of validation studies and establishment of short-term follow-up services, infants shall be screened for biotinidase deficiency, amino acid disorders, fatty acid oxidation disorders, and organic acid disorders detectable via the Department's laboratory technology utilized in newborn screening and approved by the Commissioner of Health… [emphasis added]

OAC 310:550-19-1. Physician Reporting
(c) These reports shall be confidential and may be utilized only for the purpose of ensuring service delivery, program administration, data analysis, and evaluation.
The State Board of Health is hereby authorized to set up laboratory facilities and use existing facilities for the performance of examinations and tests for the detection of these diseases and make a reasonable charge therefore; provided, however, that no child shall be denied such laboratory work or tests because of the inability of its parents or guardian to pay therefor. Provided, further, that the State Board of Health may approve other laboratories for the performance of such examinations and tests for the detection of such diseases and make a reasonable charge therefore; provided that the provisions of this section shall not apply to any infant whose parents object thereto on the grounds that such examination conflicts with their religious tenets and practices.

(b) A parent or guardian who refuses the newborn screening blood test of their newborn on the grounds that their newborn's medical record with a copy of the Newborn Screening Program Parent Refusal Form placed in the newborn's medical record shall also indicate in writing this refusal utilizing the Newborn Screening Program Parent Refusal Form as illustrated in Appendix C of this Chapter. This signed refusal form shall be placed in the newborn's medical record with a copy sent to the Newborn Screening Program Coordinator.

A. This section shall be known and may be cited as the "genetic Research Studies Nondisclosure Act."
B. "genetic research study or studies" shall mean those genetic research studies approved by an institutional review board, including blood that arise from surgery, other diagnostic or therapeutic steps, or autopsy.
C. All stored tissues, including blood, that arise from surgery, other diagnostic or therapeutic steps, or autopsy may be disclosed for genetic or other research studies if informed consent has been obtained. Informed consent may be included in a section of the consent for treatment, admission to a hospital, or permission for an autopsy and no other consent shall be required.
OAC 310:550-1-1. Purpose
Under 63 O.S., Sections 1-533 and 1-534 the following rules and regulations are established concerning the screening of all infants born in Oklahoma…

OAC 310:550-19-1. Physician Reporting
a) If confirmatory or follow-up testing is not performed by the Newborn Screening Laboratory or through a contract laboratory designated by the Newborn Screening Program, the infant's physician must report to the Newborn Screening Program Coordinator the results within 7 days after the completion of the medical evaluation, using the Department's Newborn Screening Report Form as illustrated in Appendix B of this Chapter. A copy of the confirmatory test results must accompany the report form...

F. It shall be permissible to publish or otherwise use the results of genetic research studies for research or educational purposes if no individual subject is identified. **If specific informed consent** from the individual has been obtained, the individual may be identified. (eff. Nov. 1, 1999) [emphasis added]