## Missouri Newborn Genetic Testing & Surveillance System

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<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Genetic Testing and Surveillance System</th>
<th>Exemption</th>
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<th>Consent Required?</th>
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<td>MO</td>
<td>STATUTE: M.R.S. Title XII, Chapter 191  RULE: Title 19, Division 25,</td>
<td>Genetics program to be established by department--rules authorized--procedure. 191.315. 1. The department is hereby designated as administrator of a comprehensive genetics program which will provide genetic diagnosis, counseling, treatment, education and research…</td>
<td>191.331. 4. The provisions of this section shall not apply if the parents of such child object to the tests or examinations provided in this section on the grounds that such tests or examinations conflict with their religious tenets and practices.</td>
<td>191.323. The department may… (3) Conduct or support scientific research concerning the causes, mortality, methods of treatment, prevention and cure of genetic diseases which are considered to be of major importance to the problems of genetic disease and birth defects in Missouri, in cooperation with</td>
<td>NO</td>
<td>YES</td>
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Genetic diagnostic and counseling services to be established --outreach centers, duties--referral for abortion, procedure, requirements.

191.320. The department may contract with tertiary genetic centers to … initiate and conduct investigations of the causes, mortality, methods of treatment, prevention and cure of genetic disorders and related birth defects.

5. As provided in subsection 4 of this section, the parents of any child who fail to have such test or examination administered after notice of the requirement for such test or examination shall be required to document in writing such refusal. All physicians, certified nurse midwives, public health nurses and administrators of ambulatory surgical centers or hospitals shall provide to the parents or guardians a written packet of educational information developed and supplied by the department of health and senior services describing the type of specimen, how it is obtained, the nature of diseases being screened, and the consequences of treatment and nontreatment. The attending physician, certified nurse midwife, public health facility, ambulatory surgical center or hospital shall obtain the written refusal and make such refusal part of the medical record of the infant.

9. The department shall have authority over the use, retention, and disposal of biological specimens and all related information collected in connection with newborn screening tests conducted under subsection 1 of this section. The use of such specimens and related information shall only be made for other public and private agencies, except as provided in section 188.037, RSMo;

191.331.... 9. The department shall have authority over the use, retention, and disposal of biological specimens and all related information collected in connection with newborn screening tests conducted under subsection 1 of this section. The use of such specimens and related information shall only be made for
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<th>Powers and duties of department of health and senior services in prevention and treatment of genetic diseases and birth defects. 191.323. The department may:…(4) Maintain a central registry to collect and store data to facilitate the compiling of statistical information on the causes, treatment, prevention and cure of genetic diseases. Identifying information shall remain confidential pursuant to the provisions of section 191.315. Information will be reported to the Missouri board of health and other health care agencies so that it may be used for the prevention and treatment of genetic diseases and birth defects;…</th>
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<td>25-36.010 Testing for Metabolic and Disorders…(4) Parents who object to testing on religious grounds shall state those objections in writing. The written objection shall be filed with the attending physician, certified nurse midwife, public health facility, ambulatory surgical center or hospital. Upon receipt, the attending physician, certified nurse midwife, public health facility, ambulatory surgical center or hospital shall send a copy of the written objection to the Department of Health and Senior Services, Bureau of Genetics and Healthy Childhood, PO Box 570, Jefferson City, MO 65102-0570</td>
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<td>public health purposes and shall comply with all applicable provisions of federal law. The department may charge a reasonable fee for the use of such specimens for public health research and preparing and supplying specimens for research proposals approved by the department.</td>
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### Infants to be tested for metabolic and genetic diseases--reports -- exceptions--refusal to test--fee for screening test, department may impose by rule, use of fees--formula provided by department, when--assistance available, when.

#### 191.331

1. Every infant who is born in this state shall be tested for phenylketonuria and such other metabolic or genetic diseases as are prescribed by the department. The test used by the department shall be dictated by accepted medical practice and such tests shall be of the types approved by the department. All newborn screening tests required by the department shall be performed by the department of health and senior services laboratories…

2. All testing results and personal information obtained from any individual, or from specimens from any individual, shall be held confidential and be considered a confidential medical record, except for such information as the individual, parent or guardian consents to be released; but the individual must first be fully informed of the scope of the information requests to be released, of the risks, benefits and purposes for such release, and of the identity of those to whom the information will be released. Statistical data compiled without reference to the identity of any individual shall not be declared confidential.

3. Notwithstanding any other provision of law to the contrary the department may release the results of newborn screening tests to a child’s health care professional.

4. The specimen shall be retained for five years after initial submission to the department. After five years, the specimen shall be destroyed. Unless otherwise directed under this section, a biological specimen may be released for purposes of anonymous scientific study…

5. A biological specimen released for anonymous study under this section shall not contain information that may be used to determine the identity of the donor.
2. All physicians, certified nurse midwives, public health nurses and administrators of ambulatory surgical centers or hospitals shall report to the department all diagnosed cases of phenylketonuria and other metabolic or genetic diseases as designated by the department. The department shall prescribe and furnish all necessary reporting forms...

191.317. ...2 ... At the time of collection, the parent or legal guardian of the child from whom a biological specimen was obtained may direct the department to:

1. Return a biological specimen that remains after all screening tests have been performed;
2. Destroy a biological specimen in a scientifically acceptable manner after all screening tests required under section 191.331 or rule promulgated thereunder have been performed; or
3. Store a biological specimen but not release the biological specimen for anonymous scientific study.