Rules of
Department of Health
and Senior Services
Division 25—State Public Health Laboratory
Chapter 36—Testing for Metabolic Diseases

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Purpose: State law requires that all infants be tested for metabolic and genetic disorders as prescribed by the Department of Health and Senior Services. This rule establishes the metabolic and genetic disorders that each infant shall be tested for and the collection and submission procedures to be used by health care providers in sending specimens to the State Public Health Laboratory. This rule also establishes the fee for newborn screening.

1) As used in this rule—
   (A) Newborn screening means the testing of infants for metabolic and genetic disorders pursuant to sections 191.331 and 191.332, RSMo; and
   (B) Submitter(s) means a person or persons responsible for collecting specimens under section 191.331, RSMo, for newborn screening tests.

2) Submitters shall collect specimens on the newborn screening collection forms purchased from the Department of Health and Senior Services. The submitter of the specimen shall provide all information requested on the specimen collection form.

3) Specimens shall be collected in accordance with instructions on the specimen collection form. The timing of specimen collection shall be determined by the conditions specified in subsections (3)(A) through (C) below. All specimens shall be sent within twenty-four (24) hours of collection to the State Public Health Laboratory in Jefferson City.

   (A) A specimen shall be taken from all infants before being discharged from the hospital or birthing facility regardless of age. A specimen collected between twenty-four (24) and forty-eight (48) hours of life is considered optimum for newborn screening. A second, or repeat, specimen shall be required within fourteen (14) days of life if the initial specimen was collected before twenty-four (24) hours of life.

   (B) Initial specimens from ill or premature infants shall be collected before a blood transfusion or between twenty-four (24) to forty-eight (48) hours of life. All ill or premature infants shall have a repeat screen collected between seven (7) to fourteen (14) days of life.

   (C) If an infant has been transferred from one hospital to another, the records shall clearly indicate if a specimen for newborn screening was collected and submitted. If no specimen was collected, the hospital the infant is transferred to shall collect a specimen and submit it within forty-eight (48) hours of the transfer.

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.

5) The health care provider caring for an infant with an abnormal high-risk test report from newborn screening shall report a definitive diagnosis within thirty (30) days of the date of diagnosis for that infant to the appropriate newborn screening follow-up center as contracted by the Department of Health and Senior Services. The department shall prescribe and furnish all necessary reporting forms for this purpose.

6) Effective January 30, 2008, a fee of up to sixty-five dollars ($65) shall be charged for each specimen collection form used to obtain a newborn screening blood specimen. If the State Public Health Laboratory determines a submitted blood specimen to be unsatisfactory for testing, then a replacement specimen collection form will be made available without the fee being imposed. The Department of Health and Senior Services may collect the fee from any entity or individual described in 191.331.1, RSMo.
