# Kentucky

## Newborn Genetic Testing & Surveillance System

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<td>KY</td>
<td>STATUTE: KRS 214.155</td>
<td><strong>214.155</strong> Screening and tests for heritable disorders for newborns and infants -- Information provided to parent or guardian -- Application for federal grants -- Section cited as James William Lazzaro and Madison Leigh Heflin Newborn Screening Act. (1) The Cabinet for Health and Family Services shall operate a newborn screening program for heritable disorders that includes but is not limited to procedures for conducting initial newborn screening tests on infants twenty-eight (28) days or less of age and definitive diagnostic evaluations provided by a state university-based specialty clinic for infants whose initial screening tests resulted in a positive test…(2)…The listing of tests for heritable disorders to be performed shall include all conditions consistent with the recommendations of the American College of Medical Genetics (3) Each health care provider of newborn care shall provide an infant’s parent or guardian with information</td>
<td><strong>214.155 (4)</strong> Nothing in this section shall be construed to require the testing of any child whose parents are members of a nationally recognized and established church or religious denomination, the teachings of which are opposed to medical tests, and who object in writing to the</td>
<td>Title XVII, Chapter 194A Cabinet for Health and Family Services: 194A.060 Confidentiality of records and reports. (1) The secretary shall develop and promulgate administrative regulations that protect the confidential nature of all records and reports of the cabinet that directly or indirectly identify a client or patient or former client or patient of the cabinet and that insure that these records are not</td>
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### 902 KAR 4:030. Newborn Screening Program. …Section 4. Specimen Collection.

1. Capillary blood specimens required in Section 3 of this administrative regulation shall be obtained by a heel stick. Blood from the heel stick shall be applied directly to filter paper specimen card. All circles shall be saturated completely using a drop of blood per circle on a filter paper specimen card. The specimen collector shall provide, on the filter paper specimen card, information requested by the laboratory.

2. The cabinet shall share pertinent information from within the agency’s records on clients, current and former clients, recipients, and patients as may be permitted by federal and state confidentiality statutes and regulations governing release of data with other public, quasi-public, and private agencies involved in providing services to current or former clients or patients.

3. Hospitals or facilities shall report all written refusals, in accordance with RS 214.155(4), to the program within seven (7) days.

4. Disclosure may be permitted under state or federal law.

5. The person identified or the guardian, if any, shall give consent; or

6. The institution or health care provider shall arrange for appropriate and timely follow-ups to the newborn screening tests, including but not limited to additional diagnoses, evaluation, and treatment when indicated.

7. A parent or guardian shall be provided information by the institution or health care provider of newborn care about the availability and costs of screening tests not specified in subsection (2) of this section. The parent or guardian shall be responsible for costs relating to additional screening tests performed under this subsection.
(2) The capillary blood specimen shall be air dried for three (3) hours and then shall be mailed or sent to the laboratory within twenty-four (24) hours of collection of the specimen or the next business day in which mail or delivery service is available.

(3) Submitters send submit blood specimens to the Cabinet for Health and Family Services, Department for Public Health, Division of Laboratory Services, P.O. Box 2010, Frankfort, Kentucky 40602.

(4) Specimens processed or tracked under the newborn screening program shall be limited to specimens on infants less than six (6) months of age. Subject to confidentiality agreements as permitted by federal and state law if those agencies demonstrate a direct, tangible, and legitimate interest in the records. In all instance, the individual’s right to privacy is to be respected.