## Colorado

### Newborn Genetic Testing & Surveillance System

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<td>STATUTES: Title 25, Article 4</td>
<td>25-4-802. Tests for metabolic defects. (1) It is the duty of either the chief medical staff officer or other person in charge of each institution caring for newborn infants… to cause to be obtained from every such infant a specimen of the type designated by the state board of health, which specimen shall be forwarded to the department of public health and environment or other laboratory approved by it for testing for phenylketonuria and testing for such other metabolic defects which may be prescribed from time to time by the state</td>
<td>25-4-1002. Legislative declaration. (1) The general assembly hereby finds and declares that: (a) State policy regarding newborn screening and genetic counseling and education should be made with full public knowledge, in light of expert opinion, and should be constantly reviewed to consider changing medical knowledge and ensure full public protection;(b) Participation of persons in genetic counseling programs in this state should be</td>
<td>25-4-1003. (2)(e) All information gathered by the department of public health and environment, or by other agencies, entities, and individuals conducting programs and projects on newborn screening and genetic counseling and education, other than statistical information and information which the individual allows to be released through his informed consent, shall be confidential. Public and private access to individual patient data shall be limited to data compiled without the individual's name;</td>
<td>NO</td>
<td>YES</td>
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*Updated August 2012. All state statutes and department rules originally accessed online July/Aug 2008. Statute/Rule data not inclusive. For comprehensive or updated language, access complete statute and rules online, at local library or through the state legislature.*

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board of health to be conducted with respect to such specimen.

**25-4-803. Rules and regulations.**
*(1)* The state board of health shall promulgate rules and regulations concerning the obtaining of samples or specimens from newborn infants required for the tests prescribed by the state board of health for the handling and delivery of the same and for the testing and examination thereof to detect phenylketonuria or other metabolic disorders found likely to cause mental retardation.

*(2)* The department of public health and environment shall furnish all physicians, public health nurses, hospitals, maternity homes, county

| wholly voluntary | and that all information obtained from persons involved in such programs or in newborn screening programs in the state should be held strictly confidential. |

[emphasis added]

**25-4-804. Exceptions.**
Nothing in the provisions of this part 8 shall be construed to require the testing or medical treatment for the minor child of any person who is a member of a well-recognized church or religious denomination and whose religious convictions in accordance with the tenets or principles of his church or religious denomination are against medical liability. *(5)* …any research facility may use the information derived from genetic testing for scientific research purposes so long as the identity of any individual to whom the information pertains is not disclosed to any third party; except that the individual's identity may be disclosed to the individual's physician if the individual consents to such disclosure in writing.

**25-1-122. Named reporting of certain diseases and conditions - access to medical records - confidentiality of reports and records.**

*(1)* With respect to investigations of epidemic and communicable diseases, morbidity and mortality, cancer in connection with the statewide cancer registry, environmental and chronic diseases, sexually transmitted infections, tuberculosis, and rabies and mammal bites, the board has the...
departments of social services, and the state department of human services available medical information concerning the nature and effects of phenylketonuria and other metabolic disorders and defects found likely to cause mental retardation.

25-4-1001. Short title. This part 10 shall be known and may be cited as the “Newborn Screening and Genetic Counseling and Education Act.”

25-4-1003. Powers and duties of executive director - newborn screening programs - genetic counseling and education programs – rules. (b) Promulgate rules, regulations, and standards for the provision of newborn screening programs and treatment for disease or physical defects.

25-4-1005. Exceptions. Nothing in the provisions of this part 10 shall be construed to require the testing or medical treatment for the minor child of any person or of any person who is a member of a well-recognized church or religious denomination and whose religious convictions in accordance with the tenets or principles of his church or religious denomination are against medical treatment for disease or physical defects or has a personal objection to the administration of such tests or treatment.

authority to require reporting, without patient consent, of occurrences of those diseases and conditions by any person…

(3) Any report or disclosure made in good faith pursuant to subsection (1) or (2) of this section shall not constitute libel or slander or a violation of any right of privacy or privileged communication.

(4) … Such reports and records shall not be released, shared with any agency or institution, or made public, upon subpoena, search warrant, discovery proceedings, or otherwise, except under any of the following circumstances:

(a) Release may be made of medical and epidemiological information in a manner such that no individual person can be identified;

(b) Release may be made of medical and epidemiological
genetic counseling and education programs;

25-4-1004. Newborn screening.
...(b) On or after April 1, 1989, all infants born in the state of Colorado shall be tested for the following conditions: Phenylketonuria, hypothyroidism, abnormal hemoglobins, galactosemia, cystic fibrosis, biotinidase deficiency, and such other conditions as the board of health may determine meet the criteria set forth in paragraph (c) of this subsection (1).
Appropriate specimens for such testing shall be forwarded by the hospital in which the child is born to the laboratory operated or designated by the department of public health and environment for such purposes....The information to the extent necessary for the treatment, control, investigation, and prevention of diseases and conditions dangerous to the public health; except that every effort shall be made to limit disclosure of personal identifying information to the minimal amount necessary to accomplish the public health purpose;...
results of the testing shall be forwarded directly to the physician or other primary health care provider for the provision of such information to the parent or parents of the child. The results of any testing or follow-up testing pursuant to section 25-4-1004.5 may be sent to the immunization tracking system authorized by section 25-4-2403 and accessed by the physician or other primary health care provider. [emphasis added]

(c) The board of health shall…determine whether or not to test infants for conditions which are not specifically enumerated in this subsection.

25-4-1006. Cash funds…(2)
Notwithstanding any
provision of this section to the contrary, for the fiscal year beginning July 1, 1988, the state treasurer shall transfer to the general fund out of any unappropriated moneys in the newborn screening and genetic counseling cash funds the sum of five hundred thousand dollars.

5 CCR 1005-4…1.4 Testing and Reporting:…The [Colorado Department of Public Health and Environment] Laboratory shall report as follows:…1.4.4 The submitting agency that originated the specimen shall forward the Newborn Screening results to the health care provider responsible for the newborn’s care…