# Vermont

## Newborn Genetic Testing & Surveillance System

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<td>VT</td>
<td>STATUTE: Title 18, Chapter 3, Section 115 (Chronic Disease) Rule: CVR 13-140-057</td>
<td><strong>Newborn Screening Regulations Website:</strong> “These regulations are made under the Department of Health’s statutory responsibility and authority to develop an early case-finding program, in cooperation with the medical profession, concerning chronic diseases.” <a href="http://healthvermont.gov/regs/newborn_screening_reg.aspx">http://healthvermont.gov/regs/newborn_screening_reg.aspx</a> <strong>§ 115. Chronic diseases; study; program</strong> (a) The department of health may, in the discretion of the commissioner, accept for treatment children suffering from chronic diseases such as cystic fibrosis and severe hemophilia. (b) The state board of health is authorized to: (1) Study the prevalence of chronic disease, (2) Make such morbidity studies as may be necessary to evaluate the over-all problem of chronic disease, (3) <strong>Develop an early case-finding program, in cooperation with the medical profession,</strong> (4) Develop and carry</td>
<td>CVR 13-140-057 III B. Screening tests shall be performed on newborn infants, except that after being informed of the reasons for the tests, the parents, guardians, or custodians may refuse in writing to have the tests performed. The written objection shall be sent to the Vermont Department of</td>
<td>Chapter 217 § 9332. Genetic testing; limitations…(b) A person may be required to undergo genetic testing in connection with insurance subject to the limitations imposed under section 9334 of this title or if otherwise required by law for the following reasons: …(2) To determine the presence of metabolic disorders in a newborn by testing conducted pursuant to newborn screening and protocols. ……(d) Except for the provisions of subsection (b) of this section, no genetic testing shall be</td>
<td>NO</td>
<td>YES</td>
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on an educational program as to the causes, prevention and alleviation of chronic disease, (5) Integrate this program with that of the state rehabilitation center where possible, by seeking the early referral of persons with chronic disease, who are capable of being rehabilitated… [emphasis added]

§ 9332. Genetic testing: limitations
…(b) A person may be required to undergo genetic testing in connection with insurance subject to the limitations imposed under section 9334 of this title or if otherwise required by law for the following reasons: …(2) To determine the presence of metabolic disorders in a newborn by testing conducted pursuant to newborn screening and protocols. … (c) Samples collected pursuant to subdivisions (1), (2), (3) or (4) of subsection (b) of this section or collected voluntarily pursuant to an agreement shall not be utilized for any purpose in connection with the state DNA data bank, the state DNA database and CODIS unless specifically authorized by subchapter 4 of chapter 113 of Title 20.

CVR 13-140-057 I. Authority and
Health, Vermont Newborn Screening Program.

performed on any individual or body parts of any individual nor shall any bodily materials be released for purposes of genetic testing without the prior written authorization and informed consent of the individual to be tested except for medical research where the identity of the subject is unknown or, if the research shall be conducted with anonymized medical information where individual identifiers are encrypted or encoded and the identity of the individual is not disclosed, or if the identity of the individual is known, where standards of protection are equal to those contained in regulations promulgated by the federal Office for
| Purpose. These regulations are made under the Department of Health's statutory responsibility and authority to develop an early case-finding program, in cooperation with the medical profession, concerning chronic diseases. |
| Protection from Research Risk (OPRR). [all emphasis added] |

**II. DEFINITIONS**

Newborn Screening Program: The Vermont Department of Health's program to assure that infants born in the state are tested for certain metabolic diseases for which early identification and treatment will prevent mental retardation and/or death, and, for those affected, to assure timely initiation of treatment services.

Newborn Screening Test: A laboratory procedure capable of detecting the possible presence of one of the diseases specified in section III.A.

Screening: The presumptive identification of unrecognized disease or defect by the application of tests, examinations, or other procedures which can be applied rapidly.