## Maine

### Newborn Genetic Testing & Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Genetic Testing and Surveillance System</th>
<th>Exemption</th>
<th>Research Authority</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>ME</td>
<td>STATUTE: Title 22, Subtitle 2, Part 3, Chapter 261-A M.R.S. §1532 to 1533</td>
<td>§1532. Detection of serious conditions. The department shall require hospitals, birthing centers and other birthing services to test newborn infants, or to cause them to be tested, by means of blood spot screening for the presence of treatable congenital, genetic or metabolic conditions that may be expected to result in subsequent cognitive disabilities, serious illness or death. The department shall adopt rules to define this requirement and the approved testing methods, materials, procedure and testing sequences. Reports and records of those making these tests may be required to be submitted to the department in accordance with departmental rules. The department may, on request, offer consultation, training and evaluation services to those testing facilities. The department shall</td>
<td>§1532. …The requirement in this section that a newborn infant be tested for the presence of treatable congenital, genetic or metabolic conditions that may be expected to result in subsequent cognitive disability does not apply to a child if the parents of that child object on the grounds that the test conflicts with their religious tenets and practices.</td>
<td>Chapter 283: 12.0 FILTER PAPER STORAGE AND USE</td>
<td>NO</td>
<td>YES</td>
</tr>
</tbody>
</table>

Copyright © Citizens’ Council for Health Freedom August 2013

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. www.cchfreedom.org
| adopt rules according to which it shall in a timely fashion refer newborn infants with confirmed treatable congenital, genetic or metabolic conditions to the Child Development Services System as defined in Title 20-A, section 7001, subsection 1-A. The department shall also adopt rules according to which it shall in a timely fashion refer a newborn infant to the Child Development Services System if at least 6 months have passed since an initial positive test result of a treatable congenital, genetic or metabolic condition without the specific nature of the condition having been confirmed. The department and the Department of Education shall execute an interagency agreement to facilitate all referrals in this section. In accordance with the interagency agreement, the Department of Education shall offer a single point of contact for the Department of Health and Human Services to use in making referrals. Also in accordance with the interagency agreement, the Chapter 283: PARENTAL REFUSAL OF THE SCREENING TESTS 

| 9.0 In the instance of parental refusal of the screening tests on religious grounds, the parental refusal shall be stated in writing and made a part of the infant’s medical record. 

| 9.1 The administrator of hospitals and birthing centers, and principal birthing attendants shall ensure that the Maine Newborn Screening Program, Maine Department of Health and Human Services is notified in writing of the parental refusal within 5 days of the infant’s birth. 

| 12.5 The information…is used to identify infants at risk of birth defects in order to develop programs to prevent and detect such defects. 

| 12.6 Unless the person or his/her legal authorized representative specifically prohibits such use in writing, the blood specimen and information obtained during the testing process becomes the property of the State and may be used for program evaluation or research…

Copyright © Citizens’ Council for Health Freedom August 2013
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. www.cchfreedom.org
agreement, the Child Development Services System may make direct contact with the families who are referred. The referrals may take place electronically. For purposes of quality assurance and improvement, the Child Development Services System shall supply to the department aggregate data at least annually on the number of children referred to the Child Development Services System under this section who are found eligible for early intervention services and on the number of children found not eligible for early intervention services. In addition, the department shall supply data at least annually to the Child Development Services System on how many children in the newborn blood spot screening program as established by rule of the department under section 1533, subsection 2, paragraph G were screened and how many were found to have a disorder…

| 12.7 Filter paper specimens may be released for research or testing with identifiers intact with specific written request or consent of a parent/guardian; for anonymous research without consent as approved by the Department with input from the program advisory committee; or for program evaluation or planning without consent. |  |  |

Copyright © Citizens’ Council for Health Freedom August 2013
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.