# Maine

## Birth Defects Surveillance System

<table>
<thead>
<tr>
<th>State</th>
<th>Statute/Rule</th>
<th>Language Specific to Surveillance System</th>
<th>Data Sharing</th>
<th>Research Authority</th>
<th>Consent Required?</th>
<th>Dissent Allowed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>ME</td>
<td>STATUTE: M.R.S. Title 22, Subt 6 Chpt 1687 (§8941 to §8945) RULE: 10-144, Chapter 280</td>
<td>§8941. Birth Defects Program. There is established, within the Bureau of Health, the Birth Defects Program, referred to in this chapter as the &quot;program,&quot; to identify and investigate birth defects in children. The program shall identify and research birth defects in children and maintain a central registry of cases of birth defects. &lt;br&gt;&lt;br&gt;§8943. Central registry. The department shall establish and maintain a central registry for cases of birth defects to accomplish the purposes of this chapter and facilitate research on birth defects. The submission of information to and distribution of information from the central registry are subject to the requirements of this chapter and other provisions of law. &lt;br&gt;&lt;br&gt;§8943. The department shall adopt rules according to which it will in a timely fashion refer to the Child Development Services System children with confirmed birth defects who may be eligible for early intervention. The department and the Department of Education shall execute an interagency agreement to facilitate the referrals under 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 §8943. The department shall establish and maintain a central registry for cases of birth defects to accomplish the purposes of this chapter and facilitate research on birth defects.</td>
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<td>NO</td>
<td>YES</td>
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</table>
Information that directly or indirectly identifies individual persons contained within the registry is confidential and must be distributed from the registry in accordance with rules adopted by the department. …

§8943. Central registry. …For a child whose parent or legal guardian objects on the basis of sincerely held religious belief, the department may not require the reporting of information about that child to the central registry or enter into the central registry information regarding birth defects of that child. [2007, c. 450, Pt. A, §9 (AMD).]

Chapter 280. RULES RELATING TO THE MAINE BIRTH DEFECTS PROGRAM. …9.0 PARENTAL OBJECTION TO PARTICIPATION…9.3 In the event of documented parental objection to participation in the Birth Services to use in making referrals. Also in accordance with the interagency 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 under this section who were 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 defects in order to determine the nature and extent of disease or known or suspected causes of the birth defects, to improve access to services and to formulate and evaluate control measures to protect the public health. Persons requested to provide information and access to health care and other records for the purposes of an investigation or inspection under this section shall provide information and access.

Chapter 280…7.4 Institutional Review Board approval is required for any research plan which involves either the use or release of any information contained

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<table>
<thead>
<tr>
<th>Defects Program, based upon sincerely held religious beliefs, the Program shall not collect or gather any medical records relating to birth defects of the fetus, newborn or infant.</th>
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<tr>
<td>annually to the Child Development Services System on how many children had data entered into the registry.</td>
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<td>in the Birth Defects Program…</td>
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7.5 In the event a proposed research plan involves contacting family members, written consent of the parent or guardian of any infant or fetus will be required as a predicate for use or release of any information from the Birth Defects Program.