Rhode Island

Birth Defects Surveillance System

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<tr>
<th>State</th>
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<tr>
<td>RI</td>
<td>STATUTE: RGL Title 23, Chapter 23-13.3 RULE: R23-13.3, Sections 1.0 to 7.0</td>
<td>§ 23-13.3-1 Preamble to birth defects surveillance and information system. – Whereas birth defects are a major cause of infants deaths and childhood disabilities; and whereas early recognition and response to birth defects often prevents more serious effects; and whereas the epidemiological patterns of specific birth defects may provide keys to improved birth outcomes. An active birth defects surveillance and information system is essential to developing programs and disseminating information that can reduce birth defects and infant mortality. An active birth defects surveillance and information system serves to: <strong>(a)</strong> Describe occurrence of birth defects in the newborn and children up to five; <strong>(b)</strong> Detect</td>
<td>§ 23-13.3-3 (g) The department shall not require the reporting of information or entering of information into the birth defects surveillance and information system regarding birth defects of a child whose parents or legal guardian objects. <strong>(h)</strong> Parents and/or guardians shall have the right to prohibit the release of individually identifiable information on their children from the birth defects surveillance and information system; and shall have the right to prohibit being contacted by the Birth Defects Surveillance Program. <strong>(i)</strong> The department shall provide timely notification to parents and/or</td>
<td>§ 23-13.3-3 …(c) The birth defects surveillance and information system shall maintain comprehensive records of all reports submitted pursuant to this section. These reports shall be confidential in accordance with chapter 37.3 of title 5 and subject to the restrictions on release incorporated in</td>
<td>NO</td>
<td>YES – however no mention of dissent or dissent form found on DOH website.</td>
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trends of morbidity and mortality, stimulate epidemiological research diminish the impact of birth defects and infant mortality; (c) Identify newborns and children with birth defects to intervene on a timely basis for treatment.

§ 23-13.3-3 Statewide birth defects surveillance and information system. – (a) The director shall establish and implement not later than one year after passage of this act a statewide birth defects reporting, surveillance and information system for the collection of information concerning birth defects of newborns and spontaneous fetal deaths. The director shall establish the types of birth defects to be reported, reporting requirements and confidentiality standards. (b) The director shall require the reporting of birth defects and the submission of any specified additional information on cases necessary and appropriate for the recognition of birth defects and to guardians of their rights under subsections (g) and (h).

**Section 3.0 Reportable Defects…Rights of Parents/Legal Guardians.**

3.11 There shall be written documentation of a parent/guardian’s prohibition of the release of their child’s individually identifiable information from the birth defects surveillance and information system. Written documentation shall include, but not be limited to: (1) a parent/guardian’s signature maintained on file by the Department, health care facility, clinical laboratory, or health care practitioner; or (2) a note regarding the prohibition of release of information entered into the child’s medical record by the attending health care practitioner.

§ 23-13.3-3 …(d) The department shall maintain a public listing of any that chapter. Provided, however: (1) any such information shall be available only for the purposes of this chapter; and (2) any data requested for demographic or epidemiological studies shall be provided in a format without individually identifiable information.

**Section 5.0 Confidentiality…Ownership and Publication of Data.**

5.2 All individual
conduct epidemiological surveys of birth defects.

**Section 3.0 Reportable Defects**

3.5 Such data and information shall be abstracted from medical charts and other sources of patient information by personnel possessing, at a minimum, a basic working knowledge of medical terminology, human anatomy, and physiology.

“The Rhode Island Birth Defects Program (RIBDP) has been using hospital discharge data to identify babies born with birth defects because it is the only data set that captures diagnoses coded by the International Classification of Disease (ICD) system. …A higher number of babies with birth defects have been identified using the hospital discharge database than the birth certificate.” (“Birth Defects Data Book 2008, Rhode Island Department of Health”)

nondepartmental employees who are given access to identifiable information in the surveillance and information system. The listing shall include: the name of the person authorizing access; the name, title and organizational affiliation of each person given access; the date of access; and the specific purpose for which the information was used.

“The RIBDP is linked to Rhode Island’s integrated child health information system, KIDSNET, to determine whether children with birth defects have received appropriate preventive and program services.” (“Birth Defects Data Book 2008, Rhode Island Department of Health”)

records and aggregate data including abstract report forms relating to the Rhode Island Birth Defects Registry are the property of the Department…

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