### RHODE ISLAND

**Birth Defects Surveillance System**

<table>
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<tr>
<th>State</th>
<th>Statute/Rule</th>
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<th>Research Authority</th>
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<tr>
<td>RI</td>
<td>STATUTE: RGL Title 23, Chapter 23-13.3</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: (a) Describe occurrence of birth defects in the newborn and children up to five; (b) Detect 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.</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. (h) 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. (i) The department shall provide timely notification to parents and/or guardians of their rights under subsections (g) and (h).</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 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.</td>
<td>NO</td>
<td>YES – however no mention of dissent or dissent form found on DOH website.</td>
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§ 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 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”)

§ 23-13.3-3 …(d) The department shall maintain a public listing of any 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 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”)
## Cancer Surveillance System

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<td>RI</td>
<td>STATUTE: RGL Title 23 Chapter 23-12 RGL Title 5, Chapter 5-37 RULE: R-23-12-CA</td>
<td>23-12-4 Central cancer registry – Reports. – (a) The state director of health may enter into a contract with a non-profit organization to establish a registry to record certain cases of malignant disease that occur in residents of the state, and any appropriate information concerning these cases that it shall deem necessary and appropriate in order to conduct epidemiologic surveys of cancer and to apply appropriate preventive and control measures. (b) The state director of health shall require the reporting of certain cases of malignant disease and the submission of any specified additional information on reported cases or control populations that he or she deems necessary and appropriate for the recognition, prevention, or control of certain cases of malignant diseases. (c) The central cancer registry 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 that chapter. (d) The state director of health shall conduct those activities to prevent and control cancer among the residents of the state that he or she shall deem necessary and appropriate and as are indicated from the findings of the central cancer registry.</td>
<td>Section 2.0 Administration of the Rhode Island Cancer Registry. 2.1 All new cases of malignant disease as defined in section 1.5 (above) diagnosed on and after 1 October 1986 in Rhode Island and all new cases of benign neoplasm of the brain or central nervous system as defined in section 1.2 (above) diagnosed on and after January 1, 1998 shall be reportable in accordance with the statutory and regulatory provision herein. Section 2.2 Pursuant to section 23-12-4 of the Acts, the Director may enter into a contract with a non-profit organization to be responsible to the Rhode Island Cancer Registry for the Collection and recording of all new cases of malignant disease or benign neoplasm of the brain or central nervous system diagnosed in health care facilities and/or by health care providers in Rhode Island. Section 3.2.2 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…5.1 To ensure the accuracy of the data and the completeness of reporting, the Registrar is authorized to review periodically patients’ medical records and all other sources of patient information, including but not limited to, pathology reports or logs, cytology reports or logs, disease indexes, operating room logs, or radiation therapy logs, as may be necessary to substantiate the accuracy of the data and the completeness of reporting. Section 6.1.1 The mutual exchange of cancer related data with neighboring states pursuant to reciprocal contracts for said purpose shall also be subject to the aforementioned statutory provisions on confidentiality.</td>
<td>Section 6.0 Confidentiality. 6.1 The Rhode Island Cancer Registry shall maintain comprehensive records of all reports of cases of malignant disease or benign neoplasm of the brain or central nervous system submitted pursuant to the provisions of the Acts and the rules and regulations herein. Such reports shall be confidential in accordance with Chapter 5-37.3 of the General Laws of Rhode Island, as amended, and subject to the restrictions on release incorporated therein. [see below] Section 7.0 Ownership and Publication of Data. 7.1 All individual records and aggregate data relating to the Rhode Island Cancer Registry are the property of the Rhode Island Department of Health. The use of confidential records and aggregate data by any person shall be subject to the approval of the Director in accordance with applicable federal and state law, rules and regulations regarding confidentiality and public access to data. § 5-37.3-1 Short Title This chapter may be cited as the “Confidentiality of Health Care Information Act.” § 5-37.3-4—Limitations on and permitted disclosures. (a) Except as provided in subsection (b) of this section or as specifically provided by the law, a patient’s confidential health care information shall not be released or transferred without the written consent of the patient or his or her authorized representative, on a consent form meeting the requirements of subsection (d) of this section.</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. www.cchfreedom.org
(e) Nothing in this section shall be construed to compel any individual to submit to medical or department examination or supervision.

(f) The department shall make rules and regulations that are necessary to implement the provisions of this section pursuant to chapter 35 of title 42.

(b) No consent for release or transfer of confidential health care information shall be required in the following situations:… (3) To qualified personnel for the purpose of conducting scientific research, management audits, financial audits, program evaluations, actuarial, insurance underwriting, or similar studies; provided, that personnel shall not identify, directly or indirectly, any individual patient in any report of that research, audit, or evaluation, or otherwise disclose patient identities in any manner;… (18) To the central cancer registry… [emphasis added]
Newborn Genetic Testing & Surveillance System

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<td>RI</td>
<td>STATUTE: RGL Title 23, Chapter 23-13</td>
<td>§ 23-13-14 Newborn screening program. – (a) The physician attending a newborn child shall cause that child to be subject to newborn screening tests for metabolic, endocrine, and hemoglobinopathy disorders, and other conditions for which there is a medical benefit to the early detection and treatment of the disorder, and an assessment for developmental risk. The department of health shall make rules and regulations pertaining to screenings, diagnostic, and treatment services as accepted medical practice shall indicate. … (b) In addition, the department of health is authorized to establish by rule and regulation a reasonable fee structure for the newborn screening and disease control program, which includes but is not limited to screening, diagnostic, and treatment services. The program shall be a covered benefit and be reimbursable by all health insurers, as defined in § 27-38.2-2(1), providing health insurance coverage in Rhode Island except for supplemental policies which only provide coverage for specific diseases, hospital indemnity Medicare supplements, or other supplemental policies. The department of human services shall pay for the program where the patient is eligible for medical assistance under the provisions of chapter 8 of title 40. The charges for the program shall be borne by the hospitals or other health-care facilities where births occur in the absence of a third-party payor. Nothing in this section shall preclude the hospital or health care facility from billing the patient directly.</td>
<td>§ 23-13-14 (a) …The provisions of this section shall not apply if the parents of the child object to the tests on the grounds that those tests conflict with their religious tenets and practices.</td>
<td>§ 5-37.3-1 Short Title This chapter may be cited as the “Confidentiality of Health Care Information Act.” § 5-37.3-4—Limitations on and permitted disclosures. (a) Except as provided in subsection (b) of this section or as specifically provided by the law, a patient's confidential health care information shall not be released or transferred without the written consent of the patient or his or her authorized representative, on a consent form meeting the requirements of subsection (d) of this section. (b) No consent for release or transfer of confidential health care information shall be required in the following situations: …(3) To qualified personnel for the purpose of conducting scientific research, management audits, financial audits, program evaluations, actuarial, insurance underwriting, or similar studies; provided, that personnel shall not identify, directly or indirectly, any individual patient in any report of that research, audit, or evaluation, or otherwise disclose patient identities in any manner;…(9) To public health authorities in order to carry out their functions as described in this title and titles 21 and 23, and rules promulgated under those titles. These functions include, but are not restricted to, investigations into the causes of disease, the control of public health hazards, enforcement of sanitary laws, investigation of reportable diseases, certification and licensure of health professionals and facilities, review of health care such as that required by the federal government and other governmental agencies;</td>
<td>NO</td>
<td>YES</td>
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Section 2.0 Newborn Metabolic, Endocrine and Hemoglobinopathy Screening Program.

2.2 The Department shall provide specimen collection testing kits to health care facilities where births are known to occur and to physicians and midwives attending newborns in locations other than health care facilities. The specimen collection testing kits shall contain instructions for the collection and submission of specimens to the laboratory contracted by the Department.

2.3 Laboratories performing newborn **disease** screening tests shall be approved by the Director to perform the tests cited in section 2.1 and as required herein.

2.3.1 All reports of newborn disease screening tests performed by a laboratory shall be submitted to the attending physician and the Department and shall include actual value and reference ranges used for each disorder.
Vaccination Surveillance System

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<td>RI</td>
<td>NO SPECIFIC LAW OR RULE (DOH claimed authority in 23-1-1 per CCHC survey)</td>
<td>§ 23-1-1 General functions of department. – The department of health shall take cognizance of the interests of life and health among the peoples of the state; shall make investigations into the causes of disease, the prevalence of epidemics and endemics among the people, the sources of mortality, the effect of localities, employments and all other conditions and circumstances on the public health, and do all in its power to ascertain the causes and the best means for the prevention and control of diseases or conditions detrimental to the public health, and adopt proper and expedient measures to prevent and control diseases and conditions detrimental to the public health in the state. It shall publish and circulate, from time to time, information that the director may deem to be important and useful for diffusion among the people of the state, and shall investigate and give advice in relation to those subjects relating to public health that may be referred to it by the general assembly or by the governor when the general assembly is not in session, or when requested by any city or town. The department shall adopt and promulgate rules and regulations that it deems necessary, not inconsistent with law, to carry out the purposes of this section; provided, however, that the department shall not require all nonprofit volunteer ambulance, rescue service, and volunteer fire departments to have two (2) or more certified emergency medical technicians manning ambulances or rescue vehicles. [emphasis added] Chapter 5-37.3 Confidentiality of Health Care Communications and Information.</td>
<td>“KIDSNET protects the information in the system very carefully. KIDSNET follows these practices to assure confidentiality: “Confidentiality Agreements from Authorized Users. Before getting access to KIDSNET, authorized users must sign statements of confidentiality that are in line with the Access to Public Records, Rhode Island General Laws § 38-2-2(d)(1)(1-19). Each authorized practice or authorized agency must also sign a KIDSNET User Agreement with the Department of Health that says they will follow the Confidentiality of Health Care Information Act, Rhode Island General Laws § 5-37.3 and recognize that any use of this information for purposes other than those specifically stated in the KIDSNET User Agreement is a violation of the law and subject to penalties. Compliance with the Privacy Rule. KIDSNET complies with HIPAA (Health Information Portability and Accountability Act) Privacy Rule, 45 Code of Federal Regulations, CFR § 164.512. The Privacy Rule allows healthcare professionals to share protected health information with a public health authority (such as the Department of Health) for “preventing or controlling disease, injury or disability.” - <a href="http://www.health.ri.gov/family/kidsnet/confidentiality.php">http://www.health.ri.gov/family/kidsnet/confidentiality.php</a> 12/17/08</td>
<td>NO</td>
<td>NO</td>
<td></td>
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</table>
§ 5-37.3-4 Limitations on and permitted disclosures. –
(a) Except as provided in subsection (b) of this section or as specifically provided by the law, a patient's confidential health care information shall not be released or transferred without the written consent of the patient or his or her authorized representative, on a consent form meeting the requirements of subsection (d) of this section. A copy of any notice used pursuant to subsection (d) of this section, and of any signed consent shall, upon request, be provided to the patient prior to his or her signing a consent form. Any and all managed care entities and managed care contractors writing policies in the state shall be prohibited from providing any information related to enrollees which is personal in nature and could reasonably lead to identification of an individual and is not essential for the compilation of statistical data related to enrollees, to any international, national, regional, or local medical information data base. This provision shall not restrict or prohibit the transfer of information to the department of health to carry out its statutory duties and responsibilities.

(2) Any person who violates the provisions of this section may be liable for actual and punitive damages. (3) The court may award a reasonable attorney's fee at its discretion to the prevailing party in any civil action under this section. (4) Any person who knowingly and intentionally violates the provisions of this section shall, upon conviction, be fined not more than five thousand ($5,000) dollars for each violation, or imprisoned not more than six (6) months for each violation, or both (5) Any contract or agreement which purports to waive the provisions of this section shall be declared null and void as against public policy.

(b) No consent for release or transfer of confidential health care information shall be required in the following situations: (1) To a physician, dentist, or other medical personnel who believes, in good faith, that the information is necessary for diagnosis or treatment of that individual in a medical or dental emergency; . . . (24) To a probate court of competent jurisdiction, petitioner, respondent, and/or their attorneys, when the information is contained within a decision-making assessment tool which conforms to the provisions of § 33-15-47. . . . [NOTE: 24 exemptions!]
(d) Consent forms for the release or transfer of confidential health care information shall contain, or in the course of an application or claim for insurance be accompanied by a notice containing, the following information in a clear and conspicuous manner:

1. A statement of the need for and proposed uses of that information;
2. A statement that all information is to be released or clearly indicating the extent of the information to be released; and
3. A statement that the consent for release or transfer of information may be withdrawn at any future time and is subject to revocation, except where an authorization is executed in connection with an application for a life or health insurance policy in which case the authorization expires two (2) years from the issue date of the insurance policy, and when signed in connection with a claim for benefits under any insurance policy the authorization shall be valid during the pendency of that claim. Any revocation shall be transmitted in writing.

(e) Except as specifically provided by law, an individual's confidential health care information shall not be given, sold, transferred, or in any way relayed to any other person not specified in the consent form or notice meeting the requirements of subsection (d) of this section without first obtaining the individual's additional written consent on a form stating the need for the proposed new use of this information or the need for its transfer to another person.

(f) Nothing contained in this chapter shall be construed to limit the permitted disclosure of confidential health care information and communications described in subsection (b) of this section.