Rhode Island

Newborn Genetic Testing & Surveillance System

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| RI    | STATUTE: RGL Title 23, Chapter 23-13  
RGL Title 5, Chapter 5-37  
RULE: R23-13 (METAB & HRG) | § 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…. | § 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. | § 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. | NO | YES |
… (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.

2.1 The physician and/or midwife attending a newborn child shall cause said child to be subject to screening tests for the conditions listed below. Provided, however, if parents of a newborn child object thereto, on the grounds that such tests conflict with their religious tenets and practices pursuant to section 23-13-14 of the Act, such tests shall not be performed.

(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;…
| R23-13 Section 1.0 Definitions. 1.6 | (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; |
| “Newborn disease” means conditions that have their origin in mutational events that alter the genetic constitution of an individual and/or disrupts normal functions through some other disease mechanism. …1.9 “The Programs”, as used herein, means the Rhode Island Newborn Metabolic, Endocrine, and Hemoglobinopathy Screening Program and the Newborn Hearing Loss Screening Program. |
| 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.