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STATE OF RHODE ISLAND

IN GENERAL ASSEMBLY

JANUARY SESSION, A.D. 2025

A N A C T

RELATING TO HEALTH AND SAFETY -- MATERNAL AND CHILD HEALTH SERVICES  
FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Introduced By: Senators Gallo, DiMario, Lauria, and Mack

Date Introduced: March 07, 2025

Referred To: Senate Health & Human Services

(Dept. of Health)

It is enacted by the General Assembly as follows:

1           SECTION 1. Section 23-13-14 of the General Laws in Chapter 23-13 entitled "Maternal  
2   and Child Health Services for Children with Special Health Care Needs" is hereby amended to read  
3   as follows:

4           **23-13-14. Newborn screening program.**

5           (a) The physician, midwife, nurse practitioner, or physician assistant attending a newborn  
6   child shall cause that child to be subject to newborn screening tests for metabolic, endocrine, and  
7   hemoglobinopathy disorders, and other conditions for which there is a medical benefit to the early  
8   detection and treatment of the disorder, and an assessment for developmental risk. The department  
9   of health shall make rules and regulations pertaining to screenings, diagnostic, and treatment  
10   services as accepted medical practice shall indicate. The rules and regulations shall include, at a  
11   minimum, newborn screening tests for all disorders and conditions for which there is a medical  
12   benefit to the early detection and treatment of the disorder or condition listed in the current version  
13   of the federal Recommended Uniform Screening Panel (RUSP) issued by the Secretary of the U.S.  
14   Department of Health and Human Services, and shall include newborn screening tests for all new  
15   disorders or conditions for which there is a medical benefit to the early detection and treatment of  
16   the disorder or condition added to the federal RUSP within two (2) years after the disorder or  
17   condition is added; provided, if the director of health determines in writing that it is not practicable  
18   to include a new disorder or condition within two (2) years, the time period may be extended for

1 the shortest amount of time necessary, as determined by the director. The provisions of this section  
2 shall not apply if the parents of the child object to the tests on the grounds that those tests conflict  
3 with their religious tenets and practices.

4 (b) In addition, the department of health is authorized to establish by rule and regulation a  
5 reasonable fee structure for the newborn screening and disease control program, which includes  
6 but is not limited to, screening, diagnostic, and treatment services. The program shall be a covered  
7 benefit and be reimbursable by all health insurers, as defined in § 27-38.2-2, providing health  
8 insurance coverage in Rhode Island except for supplemental policies that only provide coverage  
9 for specific diseases, hospital indemnity Medicare supplements, or other supplemental policies.  
10 The department of human services shall pay for the program where the patient is eligible for  
11 medical assistance under the provisions of chapter 8 of title 40. The charges for the program shall  
12 be borne by the hospitals or other healthcare facilities where births occur in the absence of a third-  
13 party payor. Nothing in this section shall preclude the hospital or healthcare facility from billing  
14 the patient directly. The department of health is authorized to promulgate, by rule and regulation,  
15 requirements for the storage, access, and use of residual newborn screening specimens and classify  
16 data as protected health information. All personally identifiable information including records,  
17 correspondence, and documents specific to individual newborns and newborn screening specimens  
18 shall be used solely for purposes of the newborn screening program, such as medical intervention  
19 and counseling. Access to de-identified information shall be limited to the department and persons  
20 with a valid scientific interest and qualification as determined by the department, provided the  
21 department and such persons are engaged in demographic, epidemiologic or other similar studies  
22 related to health and agree, in writing, to maintain the confidentiality of such information as  
23 prescribed in the federal Health Insurance Portability and Accountability Act of 1996 and chapter  
24 37.3 of title 5 (“Confidentiality of health care information Act”). Newborn screening specimens  
25 and newborn screening program information, records, reports, statements, notes, memoranda or  
26 other data shall not be subjected to subpoena or discovery, nor shall it be admissible as evidence in  
27 any action of any kind in any court or before any other tribunal, board, agency or person.

28 (c) There is created within the general fund a restricted receipt account to be known as the  
29 “newborn screening account” to implement the provisions of §§ 23-13-13 and 23-13-14. All funds  
30 received pursuant to §§ 23-13-13 and 23-13-14 shall be deposited in the account. Funding dedicated  
31 exclusively to implement the provisions of §§ 23-13-13 and 23-13-14 and received by the  
32 department of health from sources other than those identified in §§ 23-13-13 and 23-13-14 may  
33 also be deposited in the newborn screening account. The general treasurer is authorized and directed  
34 to draw his or her orders on the account upon receipt of properly authenticated vouchers from the

1 department of health.

2 SECTION 2. This act shall take effect upon passage.

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EXPLANATION  
BY THE LEGISLATIVE COUNCIL  
OF  
A N A C T  
RELATING TO HEALTH AND SAFETY -- MATERNAL AND CHILD HEALTH SERVICES  
FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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1           This act would authorize a midwife, nurse practitioner or physician assistant attending a  
2 newborn child to cause that child to be subject to newborn screening tests for metabolic, endocrine,  
3 and hemoglobinopathy disorders, and other conditions for which there is a medical benefit to the  
4 early detection and treatment of the disorder, and an assessment for developmental risk. It would  
5 also authorize the department of health to promulgate rules and regulations requirements for the  
6 storage, access, and use of residual newborn screening specimens and classify data as protected  
7 health information.

8           This act would take effect upon passage.

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