

GENERAL ASSEMBLY OF NORTH CAROLINA
SESSION 2021

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HOUSE BILL 736
Committee Substitute Favorable 5/11/21

Short Title: Timely Updates to Newborn Screening Program.

(Public)

Sponsors:

Referred to:

May 3, 2021

1 A BILL TO BE ENTITLED
2 AN ACT REQUIRING THAT NEW CONDITIONS LISTED ON THE RECOMMENDED
3 UNIFORM SCREENING PANEL (RUSP) BE ADDED TO NORTH CAROLINA'S
4 NEWBORN SCREENING PROGRAM WITHIN THREE YEARS AFTER BEING
5 ADDED TO THE RUSP AND TO REQUIRE THE DEPARTMENT OF HEALTH AND
6 HUMAN SERVICES TO PROVIDE REPORTS ON ADDING RUSP CONDITIONS TO
7 THE NEWBORN SCREENING PROGRAM.

8 The General Assembly of North Carolina enacts:

9 **SECTION 1.** G.S. 130A-125(b) reads as rewritten:

10 "(b) The Commission shall adopt rules necessary to implement the Newborn Screening
11 Program. The rules shall include, but shall not be limited to, the conditions for which screening
12 is required. The Commission shall amend the rules as necessary to ensure that each condition
13 listed on the Recommended Uniform Screening Panel developed by the Secretary of the United
14 States Department of Health and Human Services and the Advisory Committee on Heritable
15 Disorders of Newborns and Children (the RUSP) is included in the Newborn Screening Program,
16 Program within three years after being added to the RUSP, except that the Commission is exempt
17 from rule making with respect to adding screening tests for Pompe disease,
18 Mucopolysaccharidosis Type I (MPS I), and X-Linked Adrenoleukodystrophy (X-ALD). The
19 Department of Health and Human Services shall provide a report to the Joint Legislative
20 Oversight Committee on Health and Human Services 18 months after a condition is added to the
21 RUSP. When a delay adding an RUSP-identified condition to the Newborn Screening Program
22 exceeds three years, the Department shall provide a report on the status and reasons for the delay
23 to the Joint Legislative Oversight Committee on Health and Human Services every six months
24 following the three-year delay. Screening is not required when the parents or the guardian of the
25 infant object to such screening. If the parents or guardian object to the screening, the objection
26 shall be presented in writing to the physician or other person responsible for administering the
27 test, who shall place the written objection in the infant's medical record."

28 **SECTION 2.** This act becomes effective January 1, 2022.

