



# House of Representatives

General Assembly

**File No. 86**

February Session, 2024

Substitute House Bill No. 5321

*House of Representatives, March 21, 2024*

The Committee on Public Health reported through REP. MCCARTHY VAHEY of the 133rd Dist., Chairperson of the Committee on the part of the House, that the substitute bill ought to pass.

## ***AN ACT REQUIRING NEWBORN SCREENING FOR DUCHENNE MUSCULAR DYSTROPHY.***

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Subsection (c) of section 19a-55 of the 2024 supplement to  
2 the general statutes is repealed and the following is substituted in lieu  
3 thereof (*Effective from passage*):

4 (c) The Commissioner of Public Health shall publish a list of all the  
5 abnormal conditions for which the department screens newborns under  
6 the newborn screening program, which shall include, but need not be  
7 limited to, testing for (1) amino acid disorders, including  
8 phenylketonuria, organic acid disorders, fatty acid oxidation disorders,  
9 including, but not limited to, long-chain 3-hydroxyacyl CoA  
10 dehydrogenase (L-CHAD) and medium-chain acyl-CoA  
11 dehydrogenase (MCAD), hypothyroidism, galactosemia, sickle cell  
12 disease, maple syrup urine disease, homocystinuria, biotinidase  
13 deficiency, congenital adrenal hyperplasia, severe combined

14 immunodeficiency disease, adrenoleukodystrophy, spinal muscular  
15 atrophy and any other disorder included on the recommended uniform  
16 screening panel pursuant to 42 USC 300b-10, as amended from time to  
17 time, and as prescribed by the Commissioner of Public Health, [and] (2)  
18 on and after July 1, 2025, cytomegalovirus, and (3) on and after July 1,  
19 2027, Duchenne muscular dystrophy.

This act shall take effect as follows and shall amend the following sections:		
Section 1	<i>from passage</i>	19a-55(c)

**PH**      *Joint Favorable Subst.*

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*The following Fiscal Impact Statement and Bill Analysis are prepared for the benefit of the members of the General Assembly, solely for purposes of information, summarization and explanation and do not represent the intent of the General Assembly or either chamber thereof for any purpose. In general, fiscal impacts are based upon a variety of informational sources, including the analyst's professional knowledge. Whenever applicable, agency data is consulted as part of the analysis, however final products do not necessarily reflect an assessment from any specific department.*

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### **OFA Fiscal Note**

**State Impact:** In the out years

**Municipal Impact:** None

### **Explanation**

The bill, which requires that, starting 7/1/27, all newborns be tested for Duchenne Muscular Dystrophy (DMD) as part of the Department of Public Health's newborn screening program for genetic and metabolic disorders, results in a cost to the department, and to the Office of the State Comptroller - Fringe Benefits, in the out years.

### **The Out Years**

It is anticipated that the Department of Public Health would incur costs of approximately \$376,572 in FY 27 and \$358,597 in FY 28,<sup>1</sup> and the Office of the State Comptroller - Fringe Benefits would incur costs of approximately \$66,365 in FY 27 and \$69,724 in FY 28, to test newborns for DMD. Positions and other expenses are anticipated a full fiscal year ahead of the implementation deadline to validate the testing method before it goes live. The fiscal impact identified for the out years would continue into the future subject to inflation.

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<sup>1</sup>Costs reflect wages and compensation for a Microbiologist 2 or Chemist 2 needed to perform DMD screening and one Health Program Assistant 1 to assist with reporting results, for each year's birth cohort (approximately 38,000 newborns per year), as well as other expenses related to the purchase of ancillary supplies and reagents.

**OLR Bill Analysis**

sHB 5321

***AN ACT REQUIRING NEWBORN SCREENING FOR DUCHENNE MUSCULAR DYSTROPHY.*****SUMMARY**

Starting July 1, 2027, this bill requires all newborns to be tested for Duchenne Muscular Dystrophy (DMD) as part of the Department of Public Health's newborn screening program for genetic and metabolic disorders.

Under existing law, the newborn screening program requires health care institutions, licensed nurse-midwives, and midwives to perform newborn screenings using blood spot specimens between 24 and 48 hours after the infant's birth, except under limited conditions (e.g., it is medically contraindicated or a parent objects on religious grounds).

EFFECTIVE DATE: Upon passage

**BACKGROUND*****Duchenne Muscular Dystrophy***

DMD is one of the most severe forms of muscular dystrophy characterized by progressive muscle degeneration and weakness. It usually presents between ages two and three and primarily affects males.

**COMMITTEE ACTION**

Public Health Committee

Joint Favorable Substitute

Yea 37 Nay 0 (03/11/2024)