House of Representatives

General Assembly

File No. 84

January Session, 2025

House Bill No. 6919

House of Representatives, March 12, 2025

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 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:

Section 1. Subsection (c) of section 19a-55 of the general statutes is repealed and the following is substituted in lieu thereof (*Effective July 1, 2025*):

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

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

This act shall take effect as follows and shall amend the following sections:		
Section 1	*July 1, 2025*	19a-55(c)

PH *Joint Favorable*

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.

OFA Fiscal Note

State Impact:

Agency Affected	Fund-Effect	FY 26 $	FY 27 $	FY 28 $
Public Health, Dept.	GF - Cost	None	337,000	319,000
State Comptroller - Fringe Benefits[1]	GF - Cost	None	56,000	56,000
Public Health, Dept.	GF - Potential Revenue Gain	None	See Below	See Below

Note: GF=General Fund

Municipal Impact: None

Explanation

The bill adds Duchenne Muscular Dystrophy (DMD) to the state's newborn screening panel. This will result in a cost to the Department of Public Health's (DPH's) existing Newborn Screening Program of approximately $337,000 in FY 27 and $319,000 in FY 28 (and annually thereafter), and an estimated annual cost to the Office of State Comptroller for associated fringe benefits of $56,000 beginning in FY 27. It is anticipated that DPH will initiate implementation of the programmatic expansion during FY 27, to validate testing methods and prepare for universal testing starting July 1, 2027.

The costs to DPH reflect the need for two new positions, with a total Personal Services annual cost of $137,000: (1) a Chemist 2 to perform this

[1]The fringe benefit costs for most state employees are budgeted centrally in accounts administered by the Comptroller. The estimated active employee fringe benefit cost associated with most personnel changes is 40.71% of payroll in FY 26.

new laboratory screening on each year's birth cohort, at an annual salary of $73,000, and (2) a Health Program Assistant 1 to facilitate the new screening process, at an annual salary of $64,000. Fringe benefits costs for these positions are $30,000 and $26,000, respectively.

Additional costs to DPH are anticipated to total $200,000 in FY 27 and $182,000 in FY 28 (and annually thereafter).[2] The expected FY 27 costs, which continue with inflation into the out years (except where noted), are: (1) DMD testing kits ($150,000), (2) ancillary laboratory supplies and are reagents ($18,000), (3) education materials regarding DMD symptoms, diagnosis and treatment to be distributed to every gynecologist, obstetrician and pediatrician in the state for provision to their pregnant and postpartum patients ($7,000), and (4) a one-time FY 27 expense for Laboratory Information Management System software upgrades ($25,000).

It is uncertain at this time whether any offsetting revenue will be generated due to passage of this bill. DPH is currently authorized to collect a fee of at least $98 per child from hospitals submitting samples for newborn testing. The exact fee (currently $113) is set at the discretion of the commissioner, subject to the Secretary of the Office of Policy and Management's approval. If the agency elects to increase the fee to cover the costs of DMD testing, a corresponding General Fund revenue gain, which may be significant in magnitude, would occur.

The Out Years

The DMD program is nominated for inclusion on the federal Recommended Uniform Screening Panel (RUSP), which is a list of disorders that the Secretary of Health and Human Services recommends for states to screen as part of their Newborn Screening Program. If added, future DMD screening costs may be eligible for a federal NBS Propel grant from the Health Resources and Services Administration.

[2]FY 28 other expenses cost reflects an estimated 4% increase in product prices annually, resulting in increased costs for DMD testing kits ($6,000) and ancillary supplies and reagents ($1,000).

If DMD screening is not added to the RUSP, the annualized ongoing fiscal impact identified above would continue into the future subject to inflation.

OLR Bill Analysis

HB 6919

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: July 1, 2025

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
Yea 32 Nay 0 (03/05/2025)