

Department of Legislative Services
 Maryland General Assembly
 2009 Session

FISCAL AND POLICY NOTE

House Bill 180 (Delegate Nathan-Pulliam, *et al.*)
 Health and Government Operations

Hereditary and Congenital Disorders - Newborn Screening

This bill prohibits the Statewide System for Newborn Screening from providing an exemption from screening for any severe hereditary and congenital disorder, *unless* there is no proven effective treatment for a particular hereditary and congenital disorder. The Department of Health and Mental Hygiene (DHMH) has to establish a list of hereditary and congenital disorders covered under the system for which there are effective treatments.

Fiscal Summary

State Effect: General fund expenditures increase by \$790,000 in FY 2010 only to purchase one additional mass spectrometer and to hire an outside vendor to develop new software to test for varying groups of disorders. The costs are related to one-time purchases, so future year expenditures are not affected by the bill. Revenues are not affected.

(in dollars)	FY 2010	FY 2011	FY 2012	FY 2013	FY 2014
Revenues	\$0	\$0	\$0	\$0	\$0
GF Expenditure	790,000	0	0	0	0
Net Effect	(\$790,000)	\$0	\$0	\$0	\$0

Note:() = decrease; GF = general funds; FF = federal funds; SF = special funds; - = indeterminate effect

Local Effect: None.

Small Business Effect: None.

Analysis

Current Law/Background: Chapter 256 of 2008 codified a statewide system for screening all newborn infants in the State for hereditary and congenital disorders. Parents or guardians have the option to withdraw a newborn from screening.

Chapter 256 also required DHMH to submit a report addressing whether a statewide system for screening newborn infants for hereditary and congenital disorders should be applied to all newborn infants in the State. DHMH submitted its report on January 5, 2009. In the report, DHMH concluded that a coordinated statewide hereditary screening system should be applied to all newborn infants unless an infant's parents or guardians object.

All states except Nebraska allow parents to refuse newborn screening for one reason or another. Massachusetts, in addition to allowing parents to refuse all screening on the basis of religious beliefs, offers parents the option of having their baby tested for an optional set of conditions in addition to the routine screening tests. Routine tests are for disorders that are believed to be treatable.

According to DHMH, less than 0.02% of families refuse screening nationally, and even fewer in Maryland, about two to five infants (0.004%) per year. DHMH advises that it screens for approximately 50 disorders. If a parent opts out of screening, no screening tests are performed.

State Fiscal Effect: DHMH advises that its mass spectrometers currently run at capacity to meet the required 72-hour turn around time for normal screening results. DHMH further advises that allowing parents to choose a certain number of optional tests in addition to the tests for disorders required by DHMH will prevent the lab from running large batches of tests through the same mass spectrometer at one time, which will decrease testing efficiency. In addition, DHMH advises that its current software does not have the flexibility to choose varying groups of tests to be performed; rather, it is designed to identify all 50 disorders at once. Therefore, general fund expenditures increase by \$790,000 in fiscal 2010 to purchase one new mass spectrometer (\$450,000) to ensure the 72-hour turn around time for test results can continue to be met, and to hire an outside vendor (\$340,000) to develop software that can identify and process different groups of tests rather than all 50. Since fiscal 2010 costs are one-time purchases, future year expenditures are not affected by the bill. DHMH can revise the bloodspot collection forms and parental educational materials, and establish the list of disorders for which there are effective treatments with existing resources.

Additional Information

Prior Introductions: None.

Cross File: SB 160 (Senator Kelley, *et al.*) - Finance.

Information Source(s): New England Newborn Screening Program, Department of Health and Mental Hygiene, Department of Legislative Services

Fiscal Note History: First Reader - February 18, 2009
mcp/mwc

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