

Department of Legislative Services
 Maryland General Assembly
 2018 Session

FISCAL AND POLICY NOTE
First Reader

House Bill 1414 (Delegates A. Washington and Healey)
 Health and Government Operations

**Sickle–Cell Trait Screening, Treatment, Education, and Public Awareness
 (Journey’s Law)**

This bill requires the Maryland Department of Health (MDH), in collaboration with the Statewide Steering Committee on Services for Adults with Sickle Cell Disease and local health planning agencies, to develop a specified public awareness campaign related to sickle cell trait screening. The bill also specifies that the steering committee must work in conjunction with members of the medical community when seeking grant funding to develop, implement, and lead a State comprehensive education and treatment program for adults with sickle cell disease.

Fiscal Summary

State Effect: General fund expenditures increase by *at least* \$100,000 in FY 2019 to develop the required public awareness campaign as discussed below. MDH can reconvene the steering committee with existing resources. Revenues are not affected.

(in dollars)	FY 2019	FY 2020	FY 2021	FY 2022	FY 2023
Revenues	\$0	\$0	\$0	\$0	\$0
GF Expenditure	100,000	0	0	0	0
Net Effect	(\$100,000)	\$0	\$0	\$0	\$0

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

Local Effect: Local health planning agencies can participate in the development of the public awareness campaign with existing resources. Revenues are not affected.

Small Business Effect: None.

Analysis

Bill Summary: The public awareness campaign must address the importance of (1) an individual knowing the individual's sickle cell trait status; (2) an individual receiving screening for the sickle cell trait; and (3) an individual who carries the sickle cell trait receiving counseling.

Current Law/Background: Chapter 435 of 2007 established the Statewide Steering Committee for Adults with Sickle Cell Disease to establish institutional and community partnerships and a statewide network of stakeholders who care for individuals with sickle cell disease (SCD). The steering committee is also charged with educating individuals with SCD, the public, and health care providers about options for care of SCD in Maryland. The steering committee must seek grant funding to (1) develop and establish a case management system for adults with SCD; (2) establish an adult SCD day infusion center; (3) develop, implement, and lead a State comprehensive education and treatment program for adults with SCD; and (4) develop and implement a health care provider awareness and education campaign to increase provider awareness of health care disparities, community dynamics, cultural practice, behavioral and psychosocial issues, and the use of standardized treatment and emergency room protocols. The Prevention and Health Promotion Administration (PHPA) within MDH advises that the steering committee last met in 2008.

Sickle cell trait is not a disease but refers to an individual's genetic makeup and whether they have inherited a specific gene for hemoglobin. People with sickle cell trait inherit one gene for hemoglobin S (sickle hemoglobin) from one parent and one gene for hemoglobin A (the normal hemoglobin) from the other parent. If both parents have sickle cell trait (one normal hemoglobin gene and one sickle hemoglobin gene), there is a one in four chance that their child will have SCD (two sickle hemoglobin genes). One in 10 African Americans has sickle cell trait. People of other nationalities also have sickle cell trait, but it is less common.

[According to the U.S. Centers for Disease Control and Prevention](#), SCD affects approximately 100,000 Americans. SCD is particularly common among those whose ancestors came from sub-Saharan Africa, and the disease occurs among about 1 of every 365 Black or African American births. In Maryland, all newborn babies are screened for SCD. Maryland has the lowest death rate in the United States among children with SCD.

State Expenditures: General fund expenditures increase by *at least* \$100,000 in fiscal 2019 to develop the public awareness campaign required under the bill. This reflects the cost of hiring a consultant to develop and distribute the campaign materials in consultation with the committee and local health planning agencies. This analysis assumes that all expenditures related to the public awareness campaign occur during fiscal 2019. PHPA advises that it can reconvene the steering committee with existing resources.

Additional Information

Prior Introductions: None.

Cross File: None.

Information Source(s): Maryland Department of Health; Maryland Association of County Health Officers; U.S. Centers for Disease Control and Prevention; Department of Legislative Services

Fiscal Note History: First Reader - March 8, 2018
mm/jc

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