

Department of Legislative Services  
 Maryland General Assembly  
 2020 Session

FISCAL AND POLICY NOTE  
 Third Reader

House Bill 1079

(Delegate Acevero, *et al.*)

Health and Government Operations

Education, Health, and Environmental Affairs

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 Steering Committee on Services for Adults with Sickle Cell Disease and local health planning agencies to develop a public awareness campaign on the importance of an individual (1) knowing their sickle cell trait status; (2) receiving screening for the sickle cell trait; and (3) receiving counseling if they carry the sickle cell trait.

Fiscal Summary

**State Effect:** General fund expenditures increase by *at least* \$100,000 in FY 2021 to develop the required public awareness campaign as discussed below. Revenues are not affected.

(in dollars)	FY 2021	FY 2022	FY 2023	FY 2024	FY 2025
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

**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.

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 the 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 the sickle cell trait. People of other nationalities also have sickle cell trait, but it is less common.

Chapter 452 of 2019 altered the membership of the Statewide Steering Committee on Services for Adults with Sickle Cell Disease and expanded the intent of the Sickle Cell Anemia Subtitle within the Health-General Article to include providing resources for detecting SCD and supporting individuals with SCD. Chapter 452 also authorized MDH, in consultation with the steering committee, to provide specified services related to SCD in the State.

### *Sickle Cell Anemia*

Sickle cell anemia is a severe hereditary form of anemia in which a mutated form of hemoglobin distorts the red blood cells into a crescent shape at low oxygen levels. The sickle cells die early, which causes a constant shortage of red blood cells. When the cells travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious problems such as infection, acute chest syndrome, and stroke.

[According to the U.S. Centers for Disease Control and Prevention \(CDC\)](#), sickle cell anemia affects approximately 100,000 Americans. Sickle cell anemia 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.

Symptoms and complications are different for each person and can range from mild to severe. Treatment options are different for each person depending on the symptoms. CDC recommends that people with SCD should drink 8 to 10 glasses of water every day and eat healthy food. They should also not get too hot, too cold, or too tired, especially during physical activity.

#### *Sickle Cell Testing in Maryland*

MDH advises that the Laboratories Administration, Newborn & Childhood Screening Division provides congenital and hereditary screening for approximately 55 known serious medical disorders. The screening includes sickle cell trait and disease testing and identifies newborns that are “at risk” for potential disorders. Information is also provided on whether additional diagnostic testing is required.

MDH further advises that the Newborn & Childhood Screening Division historically provided testing services for sickle cell in adults. However, testing for adults ended in December 2018, as the laboratory only received approximately one sample per quarter. Notwithstanding, sickle cell test results are currently maintained by the State Public Health Laboratory. Reports are provided to the submitters of the request and can be provided to third parties such as local health departments upon written request and with the submitter’s express authorization.

**State Expenditures:** General fund expenditures increase by *at least* \$100,000 in fiscal 2021 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 health awareness campaign occur during fiscal 2021.

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## Additional Information

**Prior Introductions:** HB 1414 of 2018, a similar bill, received a hearing in the House Health and Government Operations Committee, but no further action was taken.

**Designated Cross File:** None.

**Information Source(s):** Maryland Association of County Health Officers; Maryland Department of Health; Department of Legislative Services

**Fiscal Note History:** First Reader - February 24, 2020  
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