

Department of Legislative Services
Maryland General Assembly
2022 Session

FISCAL AND POLICY NOTE
First Reader

House Bill 1176
(Delegate McComas)
Health and Government Operations

Public Health - Sickle Cell Disease Registry - Establishment

This bill requires the Maryland Department of Health (MDH) to establish and maintain a registry of individuals diagnosed with sickle cell disease (SCD). The purpose of the registry is to serve as a single repository of accurate, complete records to aid in promoting the siting of hematologist offices and health care facilities that provide infusion therapy in areas of the State with high populations of individuals with SCD. The registry must include any other information regarding individuals diagnosed with SCD that MDH considers necessary and appropriate. A health care provider who serves individuals with SCD must provide specified information to MDH in the form and manner required. To the extent authorized by law, MDH must periodically publish information identifying areas with high populations of individuals with SCD, which may include information published in a map.

Fiscal Summary

State Effect: MDH general fund expenditures increase by \$43,200 in FY 2023 for staff to establish and maintain the SCD registry. Future years reflect annualization and ongoing operating costs. Revenues are not affected.

(in dollars)	FY 2023	FY 2024	FY 2025	FY 2026	FY 2027
Revenues	\$0	\$0	\$0	\$0	\$0
GF Expenditure	43,200	48,800	50,200	51,600	53,100
Net Effect	(\$43,200)	(\$48,800)	(\$50,200)	(\$51,600)	(\$53,100)

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

Local Effect: None.

Small Business Effect: Minimal.

Analysis

Bill Summary: MDH must establish a process and guidelines for (1) obtaining information regarding an individual diagnosed with SCD from health care facilities for use in the registry and (2) ensuring that the registry and the process of obtaining information for the registry comply with specified privacy laws.

MDH may use any available sources of data for the registry or as a part of the process and guidelines, including (1) data from the State-designated health information exchange; (2) census-tract level data; and (3) information collected from vital records.

Current Law: In Maryland, all newborn babies are screened for SCD. MDH advises that the Laboratories Administration, Newborn and Childhood Screening Division provides congenital and hereditary screening for approximately 58 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 and Childhood Screening Division historically provided testing services for SCD in adults. However, testing for adults ended in December 2018, as the laboratory only received approximately one sample per quarter, and it was no longer cost effective to continue screening for sickle cell in adults.

On determination of the presence of sickle cell anemia, MDH must (1) notify the physician of record or the institution where the child is born, and the parents or guardian of the infant; (2) provide the parents or guardian of the infant and the physician of record with educational materials; and (3) offer referral for genetic counseling. Within two months after a positive finding of sickle cell anemia, a confirmatory test must be administered, and the results must be reported to MDH.

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 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.

Chapter 452 of 2019 altered the membership of the steering committee 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.

In general, a hereditary and congenital disorders program must treat all information gathered during the course of the program as a confidential medical record. However, this requirement does not prevent the disclosure of information if the individual or, if the individual is a minor or disabled person, a parent or guardian of the person (1) is informed of the scope of information to be released and the purpose of the release and (2) consents to the release.

State Expenditures: MDH advises that the Prevention and Health Promotion Administration (PHPA) will be responsible for the establishment and maintenance of the SCD registry. PHPA does not currently have staff to absorb the additional duties required under the bill. Therefore, MDH general fund expenditures increase by \$43,195 in fiscal 2023, which accounts for the bill's October 1, 2022 effective date. This estimate reflects the cost of hiring one part-time (50%) employee to establish and maintain the SCD registry and periodically publish specified information. It includes a salary, fringe benefits, one-time start-up costs, and ongoing operating expenses.

Position	0.5
Salary and Fringe Benefits	\$36,249
Operating Expenses	<u>6,946</u>
Total FY 2023 State Expenditures	\$43,195

Future year expenditures reflect a full salary with annual increases and employee turnover as well as annual increases in ongoing operating expenses.

Small Business Effect: Small business health care providers for patients with SCD must report specified information to MDH.

Additional Comments: MDH advises that there are approximately 4,000 individuals in the State with SCD.

Additional Information

Prior Introductions: None.

Designated Cross File: SB 859 (Senator Watson) - Finance.

Information Source(s): Maryland Department of Health; Department of Legislative Services

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