HB 1188

Department of Legislative Services

Maryland General Assembly
2022 Session

FISCAL AND POLICY NOTE
Enrolled

House Bill 1188 (Delegate Patterson, *et al.*)
Health and Government Operations Finance

Public Health - Sickle Cell Disease

This bill renames the Statewide Steering Committee on Services for Adults with Sickle Cell Disease to be the Statewide Steering Committee on Sickle Cell Disease. The Maryland Department of Health (MDH), in consultation with the steering committee, must establish and implement a system of providing information on the sickle cell trait (SCT) or the thalassemia trait to an individual who has either trait or, for a minor, the individual's family. The information must include how the traits impact health and are passed from a parent to a child. MDH must maintain a list of online resources for health care practitioners to improve their understanding and clinical treatment of individuals with sickle cell disease (SCD) or the SCT, as specified. By April 1, 2023, MDH must establish a plan to update its website to reflect the information, including a timeline. By December 1, 2022, the steering committee must study and make recommendations on specified issues and submit a report to the General Assembly. **The bill takes effect July 1, 2022.**

Fiscal Summary

State Effect: MDH general fund expenditures increase by $36,700 in FY 2023 only for contractual staff. Revenues are not affected.

(in dollars)	FY 2023	FY 2024	FY 2025	FY 2026	FY 2027
Revenues	$0	$0	$0	$0	$0
GF Expenditure	36,700	0	0	0	0
Net Effect	($36,700)	$0	$0	$0	$0

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: The steering committee, in conjunction with MDH and other relevant stakeholders, must study and make recommendations on:

- how to enhance access to services for individuals with SCD with a focus on areas of the State where there is a statistically high number of individuals with SCD and areas where there is a lack of providers with expertise in treating SCD;
- whether to establish a SCD registry and, if recommended, the process and guidelines for establishing a registry, obtaining information, connecting with the State-designated exchange, and protecting data privacy;
- how to enhance the coordination of health care services for individuals with SCD who are transitioning from pediatric to adult health care in the State, including the identification of available resources for these individuals; and
- how to engage with community-based health fairs and other community-sponsored events in areas with a statistically high number of individuals with SCD to provide outreach and education on living with SCD and how to access health care services.

Current Law: In Maryland, all newborn babies are screened for SCD. MDH advises that the Laboratories Administration, Newborn & Childhood Screening Division provides congenital and hereditary screening for approximately 58 known serious medical disorders. The screening includes SCT, sickle beta thalassemia, and disease testing and identifies newborns that are "at risk" for potential disorders. Information is also provided on whether additional diagnostic testing is required.

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 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.

On determination of the presence of sickle beta thalassemia, which indicates the presence of thalassemia, a laboratory must notify the appropriate health care provider, who often refers the newborn to a hematologist. Additional testing can confirm the type of thalassemia abnormality present. MDH advises that there is no current requirement for a health care provider to notify parents or guardians of a newborn's thalassemia trait status, or to provide the parent with educational materials.

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Chapter 435 of 2007 established the Statewide Steering Committee on Services 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.

Chapter 452 of 2019 authorizes MDH, in consultation with the steering committee, to provide services relating to SCD, including (1) educational programs on SCD for individuals, families, caregivers, health care providers, and others affected by the disease; (2) social services support to individuals with SCD; (3) testing; (4) genetic counseling; (5) assistance with any available reimbursement for medical expenses related to SCD; (6) education and counseling services after the receipt of SCT test results from the State's newborn screening program; and (7) any other programs or services that are necessary to decrease the use of acute care services by individuals who have SCD.

State Expenditures: The Prevention and Health Promotion Administration (PHPA) will be responsible for the establishment of a program to provide information on the thalassemia trait, to gather information about SCD and the SCT for health care practitioners to be included on MDH's website, and to establish a plan and timeline for updating the department's website. PHPA does not currently have staff to absorb these additional duties. Therefore, MDH general fund expenditures increase by $36,744 in fiscal 2023, which accounts for the bill's July 1, 2022 effective date. This estimate reflects the cost of hiring one part-time (50%) contractual employee to establish the thalassemia trait information program, gather information to be included on the MDH website, and to assist the steering committee with completing the required report. It includes a salary, fringe benefits, one-time start-up costs, and ongoing operating expenses**.**

Position	0.5
Salary and Fringe Benefits	$29,003
Operating Expenses	7,741
Total FY 2023 State GF Expenditures	**$36,744**

This estimate does not include any health insurance costs that could be incurred for specified contractual employees under the State's implementation of the federal Patient Protection and Affordable Care Act. The contractual position terminates at the end of fiscal 2023.

Additional Comments: SCD and thalassemia are hereditary genetic disorders caused by errors in the genes for hemoglobin. Sickle cell anemia is a severe form of anemia in which a mutated form of hemoglobin distorts the red blood cells into a crescent shape at low

oxygen levels. People who inherit one sickle cell gene and one normal gene have SCT. People with SCT usually do not have symptoms of SCD, but they can pass the trait on to their children. Additionally, there are a few, uncommon health problems that may be related to SCT. Thalassemia is caused when the body doesn't make enough hemoglobin. People with thalassemia may have mild or severe anemia. A person who has a thalassemia trait may not have any symptoms at all or may have only mild anemia. Thalassemia traits are passed from parents to children. The type of thalassemia a person has depends on how many and what type of thalassemia traits a person has inherited from their parents.

Additional Information

Prior Introductions: None.

Designated Cross File: None.

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

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