HOUSE BILL 1119

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By: Delegate Acevero

Introduced and read first time: February 5, 2021 Assigned to: Health and Government Operations

A BILL ENTITLED

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2	Public Health - Sickle Cell Trait - Public Awareness
3	(Journey's Law)
4	FOR the purpose of requiring the Maryland Department of Health, in collaboration with
5	the Statewide Steering Committee on Services for Adults with Sickle Cell Disease
6	and local health planning agencies, to develop a public awareness campaign on the
7	importance of an individual knowing certain information and receiving a certain
8	screening and, under certain circumstances, certain counseling; and generally
9	relating to public awareness for individuals with the sickle cell trait.
10	BY repealing and reenacting, with amendments,
11	Article – Health – General
12	Section 18–506
13	Annotated Code of Maryland
14	(2019 Replacement Volume and 2020 Supplement)
15	Preamble

WHEREAS, Sickle cell disease is the most common inherited blood disorder in the United States, affecting approximately 100,000 Americans; and

WHEREAS, More than 3,000,000 people in the United States have the sickle cell trait, and many who do are unaware of their status; and

WHEREAS, In 2010, the total number of babies born with the sickle cell trait was estimated to have exceeded 60,000, and the total United States incidence estimate was 15.5 cases per 1,000 births; and

WHEREAS, African Americans, with a rate of 1 in 12 carrying the sickle cell trait, and Hispanic Americans, with a rate of 1 in 100 carrying the sickle cell trait, are most at risk for carrying the sickle cell trait; and



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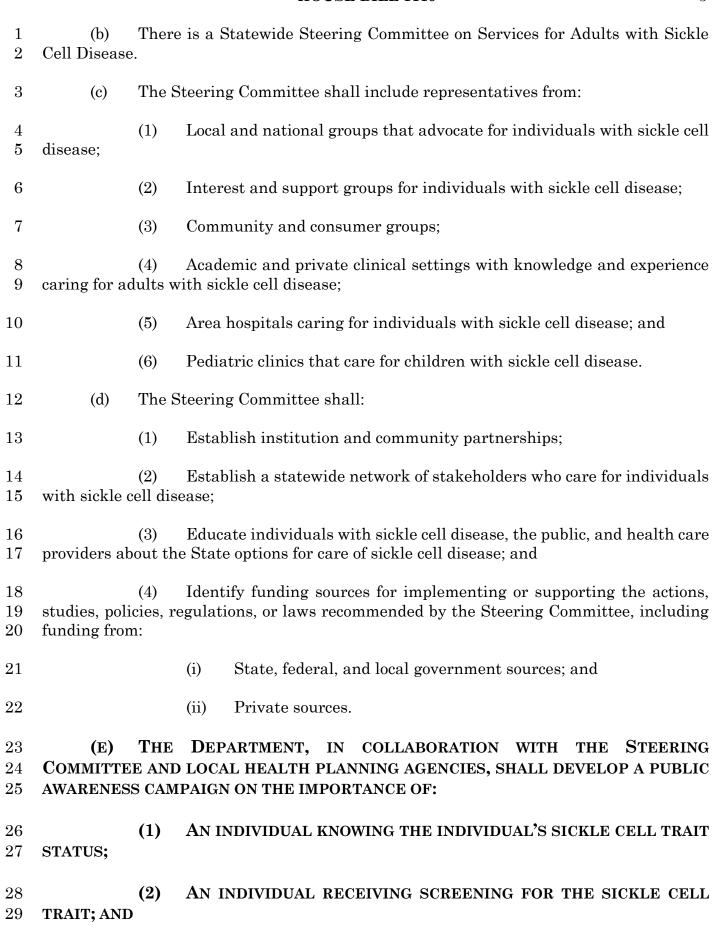
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1	WHEREAS, The trait has been found in individuals of African, Asian, European, and
2	Middle Eastern origin; and

- WHEREAS, Individuals who have the sickle cell trait have a 1 in 2 chance of passing on the abnormal sickle cell gene to future offspring and, if their spouses also have the trait, a 1 in 4 chance of having children with sickle cell disease; and
- WHEREAS, Individuals with the sickle cell trait have the same life expectancy as the general population, but are at risk for certain conditions, including blood in the urine, kidney cancer, complications with trauma to the eye, spleen tissue death at high altitudes, and false positives on A1C type 2 diabetes tests; and
- WHEREAS, According to a 2007 study in the American Journal of Medical Genetics, despite a universal requirement of screening for the sickle cell trait in every state, most states lack a protocol for disseminating the results, and parents are notified only 37% of the time; and
- WHEREAS, The limited research regarding the communication of sickle cell trait test results to parents demonstrates that there is a high prevalence of misleading information being communicated to new parents; and
- WHEREAS, No studies have examined whether information on sickle cell trait test results is being accurately communicated to an individual, whether by a family member or health care provider, prior to the individual becoming a parent; and
- WHEREAS, The General Assembly recognizes the importance of ensuring that Marylanders can make informed health decisions when they are aware of their sickle cell trait status; and
- WHEREAS, The General Assembly recognizes the ongoing challenges in addressing health outcomes among people with the sickle cell trait and sickle cell disease; and
- WHEREAS, The General Assembly commits to ensuring support for research that expands our understanding of the sickle cell trait, its implications, and the associated health risks; now, therefore,
- SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:

30 Article - Health - General

- 31 18–506.
- 32 (a) In this section, "Steering Committee" means the Statewide Steering 33 Committee on Services for Adults with Sickle Cell Disease.



- 1 (3) An individual who carries the sickle cell trait 2 receiving counseling.
- 3 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect
- 4 October 1, 2021.