

HOUSE BILL 1079

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HB 1414/18 – HGO

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By: **Delegates Acevero, Washington, Anderson, B. Barnes, Boyce, Bridges, Carr, Charkoudian, Charles, Conaway, Crutchfield, Cullison, D.M. Davis, W. Fisher, Forbes, Fraser-Hidalgo, Gilchrist, Harrison, Haynes, Henson, Ivey, C. Jackson, M. Jackson, Kerr, Korman, R. Lewis, Lierman, Lopez, Love, Moon, Mosby, Palakovich Carr, Patterson, Qi, Queen, Rogers, Sample-Hughes, Smith, Stewart, Turner, Valentino-Smith, Wells, Wilkins, ~~and Williams~~ Williams, Pendergrass, Pena-Melnyk, Reilly, Kelly, Bagnall, Chisholm, Morgan, Hill, Krebs, Rosenberg, Bhandari, Kipke, K. Young, Szeliga, Barron, Johnson, and Saab**

Introduced and read first time: February 6, 2020
Assigned to: Health and Government Operations

Committee Report: Favorable with amendments
House action: Adopted
Read second time: March 6, 2020

CHAPTER _____

1 AN ACT concerning

2 **Sickle Cell Trait Screening, Treatment, Education, and Public Awareness**
3 **(Journey's Law)**

4 FOR the purpose of requiring the Statewide Steering Committee on Services for Adults
5 with Sickle Cell Disease, to work in conjunction with members of the medical
6 community in leading a certain comprehensive education and treatment program for
7 which the Steering Committee is required to seek grant funding; requiring the
8 Maryland Department of Health, in conjunction with local health departments and
9 the Steering Committee, to develop a certain public awareness campaign; and
10 generally relating to screening, treatment, education, and public awareness for
11 individuals with the sickle cell trait.

12 BY repealing and reenacting, with amendments,
13 Article – Health – General
14 Section 18–506
15 Annotated Code of Maryland
16 (2019 Replacement Volume)

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.

Underlining indicates amendments to bill.

~~Strike out~~ indicates matter stricken from the bill by amendment or deleted from the law by amendment.



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

WHEREAS, The trait has been found in individuals of African, Asian, European, and 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

1 health outcomes among people with the sickle cell trait and sickle cell disease; and

2 WHEREAS, The General Assembly commits to ensuring support for research that
3 expands our understanding of the sickle cell trait, its implications, and the associated
4 health risks; now, therefore,

5 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND,
6 That the Laws of Maryland read as follows:

7 **Article – Health – General**

8 18–506.

9 (a) In this section, “Steering Committee” means the Statewide Steering
10 Committee on Services for Adults with Sickle Cell Disease.

11 (b) There is a Statewide Steering Committee on Services for Adults with Sickle
12 Cell Disease.

13 (c) The Steering Committee shall include representatives from:

14 (1) Local and national groups that advocate for individuals with sickle cell
15 disease;

16 (2) Interest and support groups for individuals with sickle cell disease;

17 (3) Community and consumer groups;

18 (4) Academic and private clinical settings with knowledge and experience
19 caring for adults with sickle cell disease;

20 (5) Area hospitals caring for individuals with sickle cell disease; and

21 (6) Pediatric clinics that care for children with sickle cell disease.

22 (d) The Steering Committee shall:

23 (1) Establish institution and community partnerships;

24 (2) Establish a statewide network of stakeholders who care for individuals
25 with sickle cell disease;

26 (3) Educate individuals with sickle cell disease, the public, and health care
27 providers about the State options for care of sickle cell disease; and

(4) Identify funding sources for implementing or supporting the actions, studies, policies, regulations, or laws recommended by the Steering Committee, including funding from:

(i) State, federal, and local government sources; and

(ii) Private sources.

(E) THE DEPARTMENT, IN COLLABORATION WITH THE STEERING COMMITTEE AND LOCAL HEALTH PLANNING AGENCIES, SHALL DEVELOP A PUBLIC AWARENESS CAMPAIGN ON 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.

SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect October 1, 2020.

Approved:

Governor.

Speaker of the House of Delegates.

President of the Senate.