

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**

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

A BILL ENTITLED

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)

17 Preamble

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

20 WHEREAS, More than 3,000,000 people in the United States have the sickle cell

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.
[Brackets] indicate matter deleted from existing law.



1 trait, and many who do are unaware of their status; and

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

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

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

10 WHEREAS, Individuals who have the sickle cell trait have a 1 in 2 chance of passing
11 on the abnormal sickle cell gene to future offspring and, if their spouses also have the trait,
12 a 1 in 4 chance of having children with sickle cell disease; and

13 WHEREAS, Individuals with the sickle cell trait have the same life expectancy as
14 the general population, but are at risk for certain conditions, including blood in the urine,
15 kidney cancer, complications with trauma to the eye, spleen tissue death at high altitudes,
16 and false positives on A1C type 2 diabetes tests; and

17 WHEREAS, According to a 2007 study in the American Journal of Medical Genetics,
18 despite a universal requirement of screening for the sickle cell trait in every state, most
19 states lack a protocol for disseminating the results, and parents are notified only 37% of
20 the time; and

21 WHEREAS, The limited research regarding the communication of sickle cell trait
22 test results to parents demonstrates that there is a high prevalence of misleading
23 information being communicated to new parents; and

24 WHEREAS, No studies have examined whether information on sickle cell trait test
25 results is being accurately communicated to an individual, whether by a family member or
26 health care provider, prior to the individual becoming a parent; and

27 WHEREAS, The General Assembly recognizes the importance of ensuring that
28 Marylanders can make informed health decisions when they are aware of their sickle cell
29 trait status; and

30 WHEREAS, The General Assembly recognizes the ongoing challenges in addressing
31 health outcomes among people with the sickle cell trait and sickle cell disease; and

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

35 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND,

1 That the Laws of Maryland read as follows:

2 **Article – Health – General**

3 18–506.

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

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

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

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

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

12 (3) Community and consumer groups;

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

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

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

17 (d) The Steering Committee shall:

18 (1) Establish institution and community partnerships;

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

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

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

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

27 (ii) Private sources.

28 **(E) THE DEPARTMENT, IN COLLABORATION WITH THE STEERING**

1 COMMITTEE AND LOCAL HEALTH PLANNING AGENCIES, SHALL DEVELOP A PUBLIC
2 AWARENESS CAMPAIGN ON THE IMPORTANCE OF:

3 (1) AN INDIVIDUAL KNOWING THE INDIVIDUAL'S SICKLE CELL TRAIT
4 STATUS;

5 (2) AN INDIVIDUAL RECEIVING SCREENING FOR THE SICKLE CELL
6 TRAIT; AND

7 (3) AN INDIVIDUAL WHO CARRIES THE SICKLE CELL TRAIT
8 RECEIVING COUNSELING.

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