

# HOUSE BILL 1119

J1

1lr2161

---

By: **Delegate Acevero**

Introduced and read first time: February 5, 2021

Assigned to: Health and Government Operations

---

## A BILL ENTITLED

1 AN ACT concerning

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

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

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

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

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

---

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



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

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

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

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

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

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

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

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

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

28 SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND,  
29 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 (b) There is a Statewide Steering Committee on Services for Adults with Sickle  
2 Cell Disease.

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

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

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

7 (3) Community and consumer groups;

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

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

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

12 (d) The Steering Committee shall:

13 (1) Establish institution and community partnerships;

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

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

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

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

22 (ii) Private sources.

23 **(E) THE DEPARTMENT, IN COLLABORATION WITH THE STEERING**  
24 **COMMITTEE AND LOCAL HEALTH PLANNING AGENCIES, SHALL DEVELOP A PUBLIC**  
25 **AWARENESS CAMPAIGN ON THE IMPORTANCE OF:**

26 **(1) AN INDIVIDUAL KNOWING THE INDIVIDUAL'S SICKLE CELL TRAIT**  
27 **STATUS;**

28 **(2) AN INDIVIDUAL RECEIVING SCREENING FOR THE SICKLE CELL**  
29 **TRAIT; AND**

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.