

# HOUSE BILL 761

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By: **Delegates Patterson, D. Barnes, Brooks, Carey, Charles, D.M. Davis, Fennell, W. Fisher, Harrison, Healey, Hill, Ivey, Jackson, Proctor, Queen, Sample-Hughes, Turner, and Valentino-Smith**

Introduced and read first time: February 8, 2019

Assigned to: Health and Government Operations

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## A BILL ENTITLED

1 AN ACT concerning

2 **Health – Sickle Cell Disease – Steering Committee, Services, Testing, and**  
3 **Funding**  
4 **(Sickle Cell Treatment Act of 2019)**

5 FOR the purpose of altering the intent of certain provisions of law regarding sickle cell  
6 anemia to include the provision of certain resources; altering the representatives  
7 required to be included on the Statewide Steering Committee on Services for Adults  
8 with Sickle Cell Disease; altering the duties of the Steering Committee; requiring  
9 the Maryland Department of Health to provide certain services relating to sickle cell  
10 disease in consultation with the Steering Committee; requiring the Department to  
11 provide certain services through community-based organizations to the extent  
12 practicable; requiring a local health department to provide sickle cell disease testing  
13 and counseling at no cost to any individual referred by certain health care providers;  
14 requiring a local health department to notify an individual if certain testing is  
15 positive for sickle cell disease; requiring the Maryland Public Health Laboratory,  
16 under certain circumstances, to provide an individual's sickle cell screening test  
17 results to a local health department or entity contracting with the local health  
18 department providing certain services to the individual; and generally relating to  
19 sickle cell disease.

20 BY repealing and reenacting, with amendments,  
21 Article – Health – General  
22 Section 18–501 and 18–506  
23 Annotated Code of Maryland  
24 (2015 Replacement Volume and 2018 Supplement)

25 BY adding to  
26 Article – Health – General  
27 Section 18–507 and 18–508

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EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 Annotated Code of Maryland  
2 (2015 Replacement Volume and 2018 Supplement)

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

5 **Article – Health – General**

6 18–501.

7 The intent of this subtitle is:

8 (1) To educate parents and physicians regarding homozygous sickle cell  
9 anemia; [and]

10 (2) To monitor each affected infant’s health in that regard; AND

11 **(3) TO PROVIDE RESOURCES FOR DETECTING SICKLE CELL DISEASE**  
12 **AND SUPPORTING INDIVIDUALS WITH SICKLE CELL DISEASE.**

13 18–506.

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

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

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

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

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

22 [(3) The Genetic Alliance;

23 (4) Faith–based organizations;]

24 [(5)] **(3)** Community and consumer groups;

25 [(6)] **(4)** Academic and private clinical settings with knowledge and  
26 experience caring for adults with sickle cell disease;

27 [(7)] **(5)** Area hospitals caring for individuals with sickle cell disease; and

1            ~~[(8)] (6)~~        Pediatric clinics that care for children with sickle cell disease.

2            (d)        The Steering Committee shall:

3                    (1)        Establish institution and community partnerships;

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

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

8                    [(4)        Seek grant funding to:

9                            (i)        Develop and establish a case management system for adults with  
10 sickle cell disease;

11                            (ii)       Establish an adult sickle cell disease day infusion center;

12                            (iii)       Develop, implement, and lead a State comprehensive education  
13 and treatment program for adults with sickle cell disease; and

14                            (iv)       Develop and implement a health care provider awareness and  
15 education campaign to increase provider awareness of health disparities, community  
16 dynamics, cultural practice, behavioral and psychosocial issues, and the use of  
17 standardized treatment and emergency room protocols.]

18                    **(4)        IDENTIFY FUNDING SOURCES FOR IMPLEMENTING OR**  
19 **SUPPORTING THE ACTIONS, STUDIES, POLICIES, REGULATIONS, OR LAWS**  
20 **RECOMMENDED BY THE STEERING COMMITTEE, INCLUDING FUNDING FROM:**

21                            **(I)        STATE, FEDERAL, AND LOCAL GOVERNMENT SOURCES; AND**

22                            **(II)       PRIVATE SOURCES.**

23 **18-507.**

24                    **(A)        THE DEPARTMENT SHALL, IN CONSULTATION WITH THE STATEWIDE**  
25 **STEERING COMMITTEE ON SERVICES FOR ADULTS WITH SICKLE CELL DISEASE,**  
26 **PROVIDE SERVICES RELATING TO SICKLE CELL DISEASE, INCLUDING:**

27                            **(1)        EDUCATIONAL PROGRAMS ON SICKLE CELL DISEASE FOR**  
28 **INDIVIDUALS AFFECTED BY THE DISEASE, INCLUDING:**

29                            **(I)        INDIVIDUALS WITH SICKLE CELL DISEASE;**

- 1 (II) FAMILIES OF INDIVIDUALS WITH SICKLE CELL DISEASE;  
2 (III) CAREGIVERS OF INDIVIDUALS WITH SICKLE CELL DISEASE;  
3 (IV) EMPLOYEES AT PRIMARY AND SECONDARY SCHOOLS; AND  
4 (V) HEALTH CARE PROVIDERS;

5 (2) SOCIAL SERVICES SUPPORT TO INDIVIDUALS WITH SICKLE CELL  
6 DISEASE, INCLUDING SUPPORT FROM SOCIAL WORKERS AND COMMUNITY HEALTH  
7 WORKERS TO PROVIDE INFORMATION ON SERVICES THAT MAY BE AVAILABLE TO  
8 THE INDIVIDUAL;

9 (3) TESTING;

10 (4) GENETIC COUNSELING;

11 (5) BY ESTABLISHING SICKLE CELL DISEASE INFUSION CENTERS IN  
12 THE STATE;

13 (6) ASSISTANCE WITH ANY AVAILABLE REIMBURSEMENT FOR  
14 MEDICAL EXPENSES RELATED TO SICKLE CELL DISEASE;

15 (7) EDUCATION AND COUNSELING SERVICES AFTER THE RECEIPT OF  
16 SICKLE CELL TRAIT TEST RESULTS FROM THE STATE'S NEWBORN SCREENING  
17 PROGRAM; AND

18 (8) ANY OTHER PROGRAMS OR SERVICES THAT ARE NECESSARY TO  
19 DECREASE THE USE OF ACUTE CARE SERVICES BY INDIVIDUALS WHO HAVE SICKLE  
20 CELL DISEASE.

21 (B) THE DEPARTMENT SHALL PROVIDE THE SERVICES IN SUBSECTION (A)  
22 OF THIS SECTION THROUGH COMMUNITY-BASED ORGANIZATIONS TO THE EXTENT  
23 PRACTICABLE.

24 18-508.

25 (A) (1) A LOCAL HEALTH DEPARTMENT SHALL PROVIDE SICKLE CELL  
26 DISEASE TESTING AND COUNSELING AT NO COST TO ANY INDIVIDUAL WHO IS  
27 REFERRED BY:

28 (I) A PHYSICIAN LICENSED TO PRACTICE MEDICINE IN THE

1 STATE;

2 (II) A PHYSICIAN ASSISTANT LICENSED UNDER TITLE 15 OF THE  
3 HEALTH OCCUPATIONS ARTICLE; OR

4 (III) A NURSE PRACTITIONER LICENSED TO PRACTICE  
5 REGISTERED NURSING IN THE STATE WHO IS CERTIFIED AS A NURSE PRACTITIONER  
6 BY THE STATE BOARD OF NURSING UNDER TITLE 8 OF THE HEALTH OCCUPATIONS  
7 ARTICLE.

8 (2) A LOCAL HEALTH DEPARTMENT SHALL NOTIFY AN INDIVIDUAL IF  
9 ANY TESTING CONDUCTED BY THE DEPARTMENT IS POSITIVE FOR SICKLE CELL  
10 DISEASE.

11 (B) THE MARYLAND PUBLIC HEALTH LABORATORY SHALL PROVIDE AN  
12 INDIVIDUAL'S SICKLE CELL SCREENING TEST RESULTS TO ANY LOCAL HEALTH  
13 DEPARTMENT OR ENTITY CONTRACTING WITH THE LOCAL HEALTH DEPARTMENT  
14 THAT IS PROVIDING SICKLE CELL SERVICES TO THE INDIVIDUAL UNDER  
15 SUBSECTION (A) OF THIS SECTION:

16 (1) ON REQUEST; AND

17 (2) WITH THE INDIVIDUAL'S AUTHORIZATION.

18 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect June  
19 1, 2019.