

HOUSE BILL 761

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9lr2762
CF SB 600

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~~ Valentino Smith, Pendergrass, Pena-Melnyk, Bagnall, Barron, Bhandari, Carr, Chisholm, Cullison, Johnson, Kelly, Kerr, Kipke, Krebs, R. Lewis, Metzgar, Morgan, Rosenberg, Saab, Szeliga, and K. Young

Introduced and read first time: February 8, 2019

Assigned to: Health and Government Operations

Committee Report: Favorable with amendments

House action: Adopted

Read second time: March 13, 2019

CHAPTER _____

1 AN ACT concerning

2 **Health – Sickle Cell Disease – Steering Committee, and 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 authorizing the Maryland Department of Health to provide certain services relating
10 to sickle cell disease in consultation with the Steering Committee; requiring the
11 Department to provide certain services through community-based organizations to
12 the extent practicable; ~~requiring a local health department to provide sickle cell~~
13 ~~disease testing and counseling at no cost to any individual referred by certain health~~
14 ~~care providers; requiring a local health department to notify an individual if certain~~
15 ~~testing is positive for sickle cell disease; requiring the Maryland Public Health~~
16 ~~Laboratory, under certain circumstances, to provide an individual's sickle cell~~
17 ~~screening test results to a local health department or entity contracting with the~~
18 ~~local health department providing certain services to the individual; and generally~~
19 relating to sickle cell disease.

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.



1 BY repealing and reenacting, with amendments,
2 Article – Health – General
3 Section 18–501 and 18–506
4 Annotated Code of Maryland
5 (2015 Replacement Volume and 2018 Supplement)

6 BY adding to
7 Article – Health – General
8 Section 18–507 ~~and 18–508~~
9 Annotated Code of Maryland
10 (2015 Replacement Volume and 2018 Supplement)

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

13 **Article – Health – General**

14 18–501.

15 The intent of this subtitle is:

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

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

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

21 18–506.

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

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

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

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

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

30 [(3) The Genetic Alliance;

- 1 (4) Faith-based organizations;]
- 2 [[5]] (3) Community and consumer groups;
- 3 [[6]] (4) Academic and private clinical settings with knowledge and
- 4 experience caring for adults with sickle cell disease;
- 5 [[7]] (5) Area hospitals caring for individuals with sickle cell disease; and
- 6 [[8]] (6) Pediatric clinics that care for children with sickle cell disease.

7 (d) The Steering Committee shall:

- 8 (1) Establish institution and community partnerships;
- 9 (2) Establish a statewide network of stakeholders who care for individuals
- 10 with sickle cell disease;
- 11 (3) Educate individuals with sickle cell disease, the public, and health care
- 12 providers about the State options for care of sickle cell disease; and
- 13 [[4]] Seek grant funding to:
 - 14 (i) Develop and establish a case management system for adults with
 - 15 sickle cell disease;
 - 16 (ii) Establish an adult sickle cell disease day infusion center;
 - 17 (iii) Develop, implement, and lead a State comprehensive education
 - 18 and treatment program for adults with sickle cell disease; and
 - 19 (iv) Develop and implement a health care provider awareness and
 - 20 education campaign to increase provider awareness of health disparities, community
 - 21 dynamics, cultural practice, behavioral and psychosocial issues, and the use of
 - 22 standardized treatment and emergency room protocols.]

23 **(4) IDENTIFY FUNDING SOURCES FOR IMPLEMENTING OR**

24 **SUPPORTING THE ACTIONS, STUDIES, POLICIES, REGULATIONS, OR LAWS**

25 **RECOMMENDED BY THE STEERING COMMITTEE, INCLUDING FUNDING FROM:**

- 26 **(I) STATE, FEDERAL, AND LOCAL GOVERNMENT SOURCES; AND**
- 27 **(II) PRIVATE SOURCES.**

1 (A) THE DEPARTMENT ~~SHALL~~ MAY, IN CONSULTATION WITH THE
2 STATEWIDE STEERING COMMITTEE ON SERVICES FOR ADULTS WITH SICKLE CELL
3 DISEASE, PROVIDE SERVICES RELATING TO SICKLE CELL DISEASE, INCLUDING:

4 (1) EDUCATIONAL PROGRAMS ON SICKLE CELL DISEASE FOR
5 INDIVIDUALS AFFECTED BY THE DISEASE, INCLUDING:

6 (I) INDIVIDUALS WITH SICKLE CELL DISEASE;

7 (II) FAMILIES OF INDIVIDUALS WITH SICKLE CELL DISEASE;

8 (III) CAREGIVERS OF INDIVIDUALS WITH SICKLE CELL DISEASE;

9 (IV) EMPLOYEES AT PRIMARY AND SECONDARY SCHOOLS; AND

10 (V) HEALTH CARE PROVIDERS;

11 (2) SOCIAL SERVICES SUPPORT TO INDIVIDUALS WITH SICKLE CELL
12 DISEASE, INCLUDING SUPPORT FROM SOCIAL WORKERS AND COMMUNITY HEALTH
13 WORKERS TO PROVIDE INFORMATION ON SERVICES THAT MAY BE AVAILABLE TO
14 THE INDIVIDUAL;

15 (3) TESTING;

16 (4) GENETIC COUNSELING;

17 ~~(5) BY ESTABLISHING SICKLE CELL DISEASE INFUSION CENTERS IN~~
18 ~~THE STATE;~~

19 ~~(6)~~ (5) ASSISTANCE WITH ANY AVAILABLE REIMBURSEMENT FOR
20 MEDICAL EXPENSES RELATED TO SICKLE CELL DISEASE;

21 ~~(7)~~ (6) EDUCATION AND COUNSELING SERVICES AFTER THE
22 RECEIPT OF SICKLE CELL TRAIT TEST RESULTS FROM THE STATE'S NEWBORN
23 SCREENING PROGRAM; AND

24 ~~(8)~~ (7) ANY OTHER PROGRAMS OR SERVICES THAT ARE NECESSARY
25 TO DECREASE THE USE OF ACUTE CARE SERVICES BY INDIVIDUALS WHO HAVE
26 SICKLE CELL DISEASE.

27 (B) THE DEPARTMENT SHALL PROVIDE THE SERVICES IN SUBSECTION (A)
28 OF THIS SECTION THROUGH COMMUNITY-BASED ORGANIZATIONS TO THE EXTENT
29 PRACTICABLE.

1 ~~18-508.~~

2 ~~(A) (1) A LOCAL HEALTH DEPARTMENT SHALL PROVIDE SICKLE CELL~~
3 ~~DISEASE TESTING AND COUNSELING AT NO COST TO ANY INDIVIDUAL WHO IS~~
4 ~~REFERRED BY:~~

5 ~~(I) A PHYSICIAN LICENSED TO PRACTICE MEDICINE IN THE~~
6 ~~STATE;~~

7 ~~(II) A PHYSICIAN ASSISTANT LICENSED UNDER TITLE 15 OF THE~~
8 ~~HEALTH OCCUPATIONS ARTICLE; OR~~

9 ~~(III) A NURSE PRACTITIONER LICENSED TO PRACTICE~~
10 ~~REGISTERED NURSING IN THE STATE WHO IS CERTIFIED AS A NURSE PRACTITIONER~~
11 ~~BY THE STATE BOARD OF NURSING UNDER TITLE 8 OF THE HEALTH OCCUPATIONS~~
12 ~~ARTICLE.~~

13 ~~(2) A LOCAL HEALTH DEPARTMENT SHALL NOTIFY AN INDIVIDUAL IF~~
14 ~~ANY TESTING CONDUCTED BY THE DEPARTMENT IS POSITIVE FOR SICKLE CELL~~
15 ~~DISEASE.~~

16 ~~(B) THE MARYLAND PUBLIC HEALTH LABORATORY SHALL PROVIDE AN~~
17 ~~INDIVIDUAL'S SICKLE CELL SCREENING TEST RESULTS TO ANY LOCAL HEALTH~~
18 ~~DEPARTMENT OR ENTITY CONTRACTING WITH THE LOCAL HEALTH DEPARTMENT~~
19 ~~THAT IS PROVIDING SICKLE CELL SERVICES TO THE INDIVIDUAL UNDER~~
20 ~~SUBSECTION (A) OF THIS SECTION:~~

21 ~~(1) ON REQUEST; AND~~

22 ~~(2) WITH THE INDIVIDUAL'S AUTHORIZATION.~~

23 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect June
24 1, 2019.

Approved:

Governor.

Speaker of the House of Delegates.

President of the Senate.