

HOUSE BILL 1188

J1

(2lr2064)

ENROLLED BILL

— Health and Government Operations/Finance —

Introduced by **Delegates Patterson, Crutchfield, Henson, Howell, R. Jones, Kaiser, and ~~McComas~~ McComas, Pendergrass, Pena-Melnyk, Bagnall, Belcastro, Bhandari, Carr, Chisholm, Cullison, Hill, Johnson, Kelly, Kerr, Kipke, Landis, R. Lewis, Morgan, Reilly, Rosenberg, Saab, Sample-Hughes, Szeliga, and K. Young**

Read and Examined by Proofreaders:

Proofreader.

Proofreader.

Sealed with the Great Seal and presented to the Governor, for his approval this _____ day of _____ at _____ o'clock, _____ M.

Speaker.

CHAPTER _____

1 AN ACT concerning

2 **Public Health – Sickle Cell Disease ~~and Trait – Information for Individuals and~~**
3 **~~Health Care Practitioners~~**

4 FOR the purpose of renaming the Statewide Steering Committee on Services for Adults
5 with Sickle Cell Disease to be the Statewide Steering Committee on Sickle Cell
6 Disease; requiring the Maryland Department of Health to establish and implement
7 a system of providing information on the sickle cell trait or the thalassemia trait to
8 certain individuals; requiring the Department to maintain on its website a certain
9 list of resources for health care practitioners and establish a plan for updating its
10 website to meet certain requirements; ~~requiring the State Board of Nursing and the~~
11 ~~State Board of Physicians to include certain information related to the list of~~

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.

Italics indicate opposite chamber/conference committee amendments.



~~resources in the renewal notices sent to licensees; and generally relating to information for individuals and health care practitioners on sickle cell disease and trait.~~

BY repealing and reenacting, with amendments,

Article – Health – General

Section 18–506 and 18–507

Annotated Code of Maryland

(2019 Replacement Volume and 2021 Supplement)

BY adding to

Article – Health – General

Section 18–508 and 18–509

Annotated Code of Maryland

(2019 Replacement Volume and 2021 Supplement)

~~BY repealing and reenacting, with amendments,~~

~~Article – Health Occupations~~

~~Section 8–312(b) and 14–316(b)~~

~~Annotated Code of Maryland~~

~~(2021 Replacement Volume)~~

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

Article – Health – General

18–506.

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

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

(c) The Steering Committee shall include representatives from:

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

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

(3) Community and consumer groups;

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

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

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

3 (d) The Steering Committee shall:

4 (1) Establish institution and community partnerships;

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

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

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

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

13 (ii) Private sources.

14 18-507.

15 (a) The Department may, in consultation with the Statewide Steering Committee
16 on [Services for Adults with] Sickle Cell Disease, provide services relating to sickle cell
17 disease, including:

18 (1) Educational programs on sickle cell disease for individuals affected by
19 the disease, including:

20 (i) Individuals with sickle cell disease;

21 (ii) Families of individuals with sickle cell disease;

22 (iii) Caregivers of individuals with sickle cell disease;

23 (iv) Employees at primary and secondary schools; and

24 (v) Health care providers;

25 (2) Social services support to individuals with sickle cell disease, including
26 support from social workers and community health workers to provide information on
27 services that may be available to the individual;

28 (3) Testing;

1 (4) Genetic counseling;

2 (5) Assistance with any available reimbursement for medical expenses
3 related to sickle cell disease;

4 (6) Education and counseling services after the receipt of sickle cell trait
5 test results from the State's Newborn Screening Program; and

6 (7) Any other programs or services that are necessary to decrease the use
7 of acute care services by individuals who have sickle cell disease.

8 (b) The Department shall provide the services in subsection (a) of this section
9 through community-based organizations to the extent practicable.

10 **18-508.**

11 **(A) THE DEPARTMENT, IN CONSULTATION WITH THE STATEWIDE**
12 **STEERING COMMITTEE ON SICKLE CELL DISEASE, SHALL ESTABLISH AND**
13 **IMPLEMENT A SYSTEM OF PROVIDING INFORMATION ON THE SICKLE CELL TRAIT OR**
14 **THE THALASSEMIA TRAIT TO:**

15 **(1) AN INDIVIDUAL WHO HAS THE SICKLE CELL TRAIT OR THE**
16 **THALASSEMIA TRAIT, INCLUDING AS DETERMINED THROUGH A NEWBORN**
17 **SCREENING UNDER § 18-502 OF THIS SUBTITLE; AND**

18 **(2) IF THE INDIVIDUAL IS A MINOR, THE INDIVIDUAL'S FAMILY.**

19 **(B) THE DEPARTMENT SHALL INCLUDE THE FOLLOWING IN THE**
20 **INFORMATION PROVIDED UNDER SUBSECTION (A) OF THIS SECTION:**

21 **(1) HOW THE SICKLE CELL TRAIT OR THE THALASSEMIA TRAIT**
22 **IMPACTS THE HEALTH OF AN INDIVIDUAL WITH THE TRAIT; AND**

23 **(2) HOW THE SICKLE CELL TRAIT OR THE THALASSEMIA TRAIT IS**
24 **PASSED FROM A PARENT TO A CHILD.**

25 **18-509.**

26 **THE DEPARTMENT SHALL MAINTAIN IN A CONSPICUOUS LOCATION ON ITS**
27 **WEBSITE A LIST OF RESOURCES FOR HEALTH CARE PRACTITIONERS TO USE TO**
28 **IMPROVE THEIR UNDERSTANDING AND CLINICAL TREATMENT OF INDIVIDUALS**
29 **WITH SICKLE CELL DISEASE OR THE SICKLE CELL TRAIT, INCLUDING INFORMATION**
30 **ON THE HEALTH IMPACTS OF CARRYING THE SICKLE CELL TRAIT.**

1 ~~§ 312.~~

2 ~~(b) (1) At least 3 months before a license expires, the Board shall send to the~~
3 ~~licensee a renewal notice by:~~

4 ~~(i) First class mail to the last known mailing address of the~~
5 ~~licensee; or~~

6 ~~(ii) Electronic means to the last known electronic address of the~~
7 ~~licensee.~~

8 ~~(2) THE RENEWAL NOTICE SENT UNDER PARAGRAPH (1) OF THIS~~
9 ~~SUBSECTION SHALL INCLUDE A NOTICE TO THE LICENSEE THAT:~~

10 ~~(I) THE DEPARTMENT MAINTAINS ON ITS WEBSITE~~
11 ~~INFORMATION ON SICKLE CELL DISEASE AND THE SICKLE CELL TRAIT; AND~~

12 ~~(II) INCLUDES THE ADDRESS OF THE WEBPAGE ON THE~~
13 ~~WEBSITE ON WHICH THE INFORMATION IS MAINTAINED IN ACCORDANCE WITH §~~
14 ~~18-509 OF THE HEALTH GENERAL ARTICLE.~~

15 ~~[(2)] (3) If a licensee is required to have a criminal history records check~~
16 ~~before a license may be renewed, the Board shall send the licensee the documents necessary~~
17 ~~for initiating the criminal history records check in conjunction with the renewal notice~~
18 ~~required under paragraph (1) of this subsection.~~

19 ~~14-316.~~

20 ~~(b) (1) Subject to paragraph (2) of this subsection, at least 1 month before the~~
21 ~~license expires, the Board shall send to the licensee, by electronic or first class mail to the~~
22 ~~last known electronic or physical address of the licensee:~~

23 ~~(i) A renewal notice that states:~~

24 ~~1. The date on which the current license expires;~~

25 ~~2. The date by which the renewal application must be~~
26 ~~received by the Board for the renewal to be issued and mailed before the license expires;~~
27 ~~and~~

28 ~~3. The amount of the renewal fee; [and]~~

29 ~~(ii) A blank panel data sheet supplied by the Health Care~~
30 ~~Alternative Dispute Resolution Office; AND~~

~~(H) A NOTICE TO THE LICENSEE THAT:~~

~~1. THE DEPARTMENT MAINTAINS ON ITS WEBSITE INFORMATION ON SICKLE CELL DISEASE AND THE SICKLE CELL TRAIT; AND~~

~~2. INCLUDES THE ADDRESS OF THE WEBPAGE ON THE WEBSITE ON WHICH THE INFORMATION IS MAINTAINED IN ACCORDANCE WITH § 18-509 OF THE HEALTH – GENERAL ARTICLE.~~

~~(2) If the Board chooses to send renewal notices exclusively by electronic mail under paragraph (1) of this subsection, the Board shall send a renewal notice by first class mail to a licensee on request of the licensee.~~

SECTION 2. AND BE IT FURTHER ENACTED, That, on or before April 1, 2023, the Maryland Department of Health shall establish a plan to update its website to reflect the information required under § 18-509 of the Health – General Article, as enacted by Section 1 of this Act, including a timeline for when the updates will be available on the website.

SECTION 3. AND BE IT FURTHER ENACTED, That:

(a) The Statewide Steering Committee on Sickle Cell Disease, in conjunction with the Maryland Department of Health and other relevant stakeholders, shall study and make recommendations on:

(1) how to enhance access to services for individuals with sickle cell disease with a focus on areas of the State where there is a statistically high number of individuals with sickle cell disease and areas where there is a lack of providers with expertise in treating sickle cell disease;

(2) whether to establish a sickle cell disease registry, and if recommended, the process and guidelines for establishing a registry, obtaining information, connecting with the State designated exchange, and protecting data privacy;

(3) how to enhance the coordination of health care services for individuals with sickle cell disease who are transitioning from pediatric to adult health care in the State including the identification of available resources for individuals who are transitioning; and

(4) how to engage with community-based health fairs and other community-sponsored events in areas with a statistically high number of individuals with sickle cell disease to provide outreach and education on living with sickle cell disease and how to access health care services.

1 (b) On or before December 1, 2022, the Statewide Committee on Sickle Cell
2 Disease shall report its findings and recommendations, in accordance with § 2-1257 of the
3 State Government Article, to the General Assembly ~~on or before December 1, 2022.~~

4 SECTION ~~3~~ 4. AND BE IT FURTHER ENACTED, That this Act shall take effect
5 ~~October~~ July 1, 2022.

Approved:

Governor.

Speaker of the House of Delegates.

President of the Senate.