

SENATE BILL 859

J1

(2lr2941)

ENROLLED BILL

— Finance/Health and Government Operations —

Introduced by **Senator Watson**

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.

President.

CHAPTER _____

1 AN ACT concerning

2 **Public Health – Sickle Cell Disease Registry – Establishment**

3 FOR the purpose of ~~requiring the Maryland Department of Health to establish and~~
4 ~~maintain a registry of individuals diagnosed with sickle cell disease for a certain~~
5 ~~purpose; requiring the Department to periodically publish information identifying~~
6 ~~areas with statistically high populations of individuals with sickle cell disease~~
7 *renaming the Statewide Steering Committee on Services for Adults with Sickle Cell*
8 *Disease to be the Statewide Steering Committee on Sickle Cell Disease; requiring the*
9 *Maryland Department of Health to establish and implement a system of providing*
10 *information on the sickle cell trait or the thalassemia trait to certain individuals;*
11 *requiring the Department to maintain on its website a certain list of resources for*
12 *health care practitioners and establish a plan for updating its website to meet certain*
13 *requirements; and generally relating to a sickle cell disease registry.*

14 *BY repealing and reenacting, with amendments,*

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.



1 Article – Health – General
 2 Section 18–506 and 18–507
 3 Annotated Code of Maryland
 4 (2019 Replacement Volume and 2021 Supplement)

5 BY adding to
 6 Article – Health – General
 7 Section 18–508 and 18–509
 8 Annotated Code of Maryland
 9 (2019 Replacement Volume and 2021 Supplement)

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

12 **Article – Health – General**

13 18–506.

14 (a) In this section, “Steering Committee” means the Statewide Steering Committee
 15 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) Community and consumer groups;

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

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

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

27 (d) The Steering Committee shall:

28 (1) Establish institution and community partnerships;

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

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

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

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

7 (ii) Private sources.

8 18-507.

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

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

14 (i) Individuals with sickle cell disease;

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

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

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

18 (v) Health care providers;

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

22 (3) Testing;

23 (4) Genetic counseling;

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

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

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

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

3 ~~18-508.~~

4 ~~(A) THE DEPARTMENT SHALL ESTABLISH AND MAINTAIN A REGISTRY OF~~
5 ~~INDIVIDUALS DIAGNOSED WITH SICKLE CELL DISEASE FOR USE AS A SINGLE~~
6 ~~REPOSITORY OF ACCURATE, COMPLETE RECORDS TO AID IN PROMOTING THE SITING~~
7 ~~OF THE FOLLOWING HEALTH CARE PROVIDERS IN AREAS WITH STATISTICALLY HIGH~~
8 ~~POPULATIONS OF INDIVIDUALS WITH SICKLE CELL DISEASE:~~

9 ~~(1) HEALTH CARE FACILITIES THAT PROVIDE INFUSION THERAPY;~~
10 ~~AND~~

11 ~~(2) HEMATOLOGIST OFFICES.~~

12 ~~(B) THE SICKLE CELL DISEASE REGISTRY ESTABLISHED UNDER~~
13 ~~SUBSECTION (A) OF THIS SECTION SHALL INCLUDE:~~

14 ~~(1) A RECORD OF INDIVIDUALS IN THE STATE WHO HAVE BEEN~~
15 ~~DIAGNOSED WITH SICKLE CELL DISEASE; AND~~

16 ~~(2) ANY OTHER INFORMATION REGARDING INDIVIDUALS WHO HAVE~~
17 ~~BEEN DIAGNOSED WITH SICKLE CELL DISEASE THAT THE DEPARTMENT CONSIDERS~~
18 ~~NECESSARY AND APPROPRIATE FOR INCLUSION ON THE REGISTRY.~~

19 ~~(C) (1) THE DEPARTMENT SHALL ESTABLISH A PROCESS AND~~
20 ~~GUIDELINES FOR:~~

21 ~~(I) OBTAINING INFORMATION REGARDING AN INDIVIDUAL~~
22 ~~DIAGNOSED WITH SICKLE CELL DISEASE FROM HEALTH CARE FACILITIES FOR USE~~
23 ~~IN THE REGISTRY; AND~~

24 ~~(II) ENSURING THAT THE REGISTRY AND THE PROCESS OF~~
25 ~~OBTAINING INFORMATION FOR THE REGISTRY COMPLY WITH THE REQUIREMENTS~~
26 ~~OF § 18-504 OF THIS SUBTITLE, § 13-109 OF THIS ARTICLE, THE HEALTH~~
27 ~~INSURANCE PORTABILITY AND ACCOUNTABILITY ACT OF 1996, AND ANY OTHER~~
28 ~~APPLICABLE PRIVACY LAW; AND~~

29 ~~(III) INTEGRATING THE REGISTRY WITH THE~~
30 ~~STATE DESIGNATED HEALTH INFORMATION EXCHANGE.~~

~~(2) THE DEPARTMENT MAY USE ANY AVAILABLE SOURCES OF DATA FOR THE REGISTRY OR AS PART OF THE PROCESS AND GUIDELINES ESTABLISHED UNDER PARAGRAPH (1) OF THIS SUBSECTION, INCLUDING:~~

~~(I) DATA FROM THE DESIGNATED HEALTH INFORMATION EXCHANGE IN THE STATE;~~

~~(II) CENSUS TRACT LEVEL DATA; AND~~

~~(III) INFORMATION COLLECTED FROM VITAL RECORDS.~~

~~(D) A HEALTH CARE PROVIDER WHO PROVIDES HEALTH CARE TO AN INDIVIDUAL WITH SICKLE CELL DISEASE SHALL PROVIDE TO THE DEPARTMENT ANY INFORMATION IN THE FORM AND MANNER REQUIRED BY THE GUIDELINES ESTABLISHED UNDER SUBSECTION (C) OF THIS SECTION.~~

~~(E) TO THE EXTENT AUTHORIZED BY LAW, THE DEPARTMENT SHALL PERIODICALLY PUBLISH INFORMATION IDENTIFYING AREAS WITH STATISTICALLY HIGH POPULATIONS OF INDIVIDUALS WITH SICKLE CELL DISEASE, WHICH MAY INCLUDE INFORMATION PUBLISHED IN A MAP.~~

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

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

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

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

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

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

18-509.

1 THE DEPARTMENT SHALL MAINTAIN IN A CONSPICUOUS LOCATION ON ITS
2 WEBSITE A LIST OF RESOURCES FOR HEALTH CARE PRACTITIONERS TO USE TO
3 IMPROVE THEIR UNDERSTANDING AND CLINICAL TREATMENT OF INDIVIDUALS WITH
4 SICKLE CELL DISEASE OR THE SICKLE CELL TRAIT, INCLUDING INFORMATION ON
5 THE HEALTH IMPACTS OF CARRYING THE SICKLE CELL TRAIT.

6 SECTION 2. AND BE IT FURTHER ENACTED, That, on or before April 1, 2023,
7 the Maryland Department of Health shall establish a plan to update its website to reflect the
8 information required under § 18-509 of the Health – General Article, as enacted by Section
9 1 of this Act, including a timeline for when the updates will be available on the website.

10 SECTION 3. AND BE IT FURTHER ENACTED, That:

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

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

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

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

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

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

31 SECTION ~~2~~ 4. AND BE IT FURTHER ENACTED, That this Act shall take effect
32 ~~October~~ July 1, 2022.