

**SB0859/893722/1**

BY: Health and Government Operations Committee

AMENDMENTS TO SENATE BILL 859  
(Third Reading File Bill)

AMENDMENT NO. 1

On page 1, in line 2, strike “**Registry – Establishment**”; strike beginning with “requiring” in line 3 down through “disease” in line 6 and substitute “renaming the Statewide Steering Committee on Services for Adults with Sickle Cell Disease to be the Statewide Steering Committee on Sickle Cell Disease; requiring the Maryland Department of Health to establish and implement a system of providing information on the sickle cell trait or the thalassemia trait to certain individuals; requiring the Department to maintain on its website a certain list of resources for health care practitioners and establish a plan for updating its website to meet certain requirements”; in line 7, strike “a”; in the same line, strike “registry”; after line 7, insert:

“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)”;

and in line 10, after “18–508” insert “and 18–509”.

AMENDMENT NO. 2

On page 1, after line 15, insert:

“18–506.

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

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(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;

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

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

(d) The Steering Committee shall:

(1) Establish institution and community partnerships;

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

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

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

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- (i) State, federal, and local government sources; and
- (ii) Private sources.

18-507.

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

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

- (i) Individuals with sickle cell disease;
- (ii) Families of individuals with sickle cell disease;
- (iii) Caregivers of individuals with sickle cell disease;
- (iv) Employees at primary and secondary schools; and
- (v) Health care providers;

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

- (3) Testing;
- (4) Genetic counseling;

(Over)

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

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

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

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

On pages 1 through 3, strike in their entirety the lines beginning with line 17 on page 1 through line 8 on page 3, inclusive, and substitute:

**“(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.**

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

On page 3, after line 8, insert:

“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;

(Over)

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(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.

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

in line 9, strike “2.” and substitute “4.”; and in line 10, strike “October” and substitute “July”.