

Chapter 280

(Senate Bill 859)

AN ACT concerning

Public Health – Sickle Cell Disease Registry – Establishment

FOR the purpose of ~~requiring the Maryland Department of Health to establish and maintain a registry of individuals diagnosed with sickle cell disease for a certain purpose; requiring the Department to periodically publish information identifying areas with statistically high populations of individuals with sickle cell disease~~ 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; and generally relating to ~~a sickle cell disease registry.~~

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)

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;
- (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:
- (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;

(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.

18-508.

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

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

~~(2) HEMATOLOGIST OFFICES.~~

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

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

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

~~(c) (1) THE DEPARTMENT SHALL ESTABLISH A PROCESS AND GUIDELINES FOR:~~

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

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

~~(iii) INTEGRATING THE REGISTRY WITH THE 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.

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.

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.

(b) On or before December 1, 2022, the Statewide Steering 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.

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

Approved by the Governor, May 12, 2022.