

Chapter 452

(Senate Bill 600)

AN ACT concerning

**Health – Sickle Cell Disease – Steering Committee, and Services, ~~Testing, and Funding~~
(~~Sickle Cell Treatment Act of 2019~~)**

FOR the purpose of altering the intent of certain provisions of law regarding sickle cell anemia to include the provision of certain resources; altering the representatives required to be included on the Statewide Steering Committee on Services for Adults with Sickle Cell Disease; altering the duties of the Steering Committee; ~~requiring~~ authorizing the Maryland Department of Health to provide certain services relating to sickle cell disease in consultation with the Steering Committee; requiring the Department to provide certain services through community-based organizations to the extent practicable; ~~requiring a local health department to provide sickle cell disease testing and counseling at no cost to any individual referred by certain health care providers; requiring a local health department to notify an individual if certain testing is positive for sickle cell disease; requiring the Maryland Public Health Laboratory, under certain circumstances, to provide an individual's sickle cell screening test results to a local health department or entity contracting with the local health department providing certain services to the individual;~~ and generally relating to sickle cell disease.

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

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

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

Article – Health – General

18–501.

The intent of this subtitle is:

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

(2) To monitor each affected infant's health in that regard; AND

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

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) The Genetic Alliance;

(4) Faith-based organizations;]

[(5)] **(3)** Community and consumer groups;

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

[(7)] **(5)** Area hospitals caring for individuals with sickle cell disease; and

[(8)] **(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) Seek grant funding to:

- (i) Develop and establish a case management system for adults with sickle cell disease;
- (ii) Establish an adult sickle cell disease day infusion center;
- (iii) Develop, implement, and lead a State comprehensive education and treatment program for adults with sickle cell disease; and
- (iv) Develop and implement a health care provider awareness and education campaign to increase provider awareness of health disparities, community dynamics, cultural practice, behavioral and psychosocial issues, and the use of standardized treatment and emergency room protocols.]

(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 ~~SHALL~~ 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) BY ESTABLISHING SICKLE CELL DISEASE INFUSION CENTERS IN THE STATE;~~

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

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

~~(8)~~ (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) (1) A LOCAL HEALTH DEPARTMENT SHALL PROVIDE SICKLE CELL DISEASE TESTING AND COUNSELING AT NO COST TO ANY INDIVIDUAL WHO IS REFERRED BY:~~

~~(i) A PHYSICIAN LICENSED TO PRACTICE MEDICINE IN THE STATE;~~

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

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

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

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

~~(1) ON REQUEST; AND~~

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

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

Approved by the Governor, May 13, 2019.