J1 9lr1496 CF 9lr2762

By: Senator Nathan-Pulliam

Introduced and read first time: February 4, 2019

Assigned to: Education, Health, and Environmental Affairs

A BILL ENTITLED

1 AN ACT concerning

Health – Sickle Cell Disease – Steering Committee, Services, Testing, and
Funding

(Sickle Cell Treatment Act of 2019)

(Sickle Cell Treatment Act of 2019)

5 FOR the purpose of altering the intent of certain provisions of law regarding sickle cell 6 anemia to include the provision of certain resources; altering the representatives 7 required to be included on the Statewide Steering Committee on Services for Adults 8 with Sickle Cell Disease; altering the duties of the Steering Committee; requiring 9 the Maryland Department of Health to provide certain services relating to sickle cell disease in consultation with the Steering Committee; requiring the Department to 10 11 provide certain services through community-based organizations to the extent 12 practicable; requiring a local health department to provide sickle cell disease testing 13 and counseling at no cost to any individual referred by certain health care providers; 14 requiring a local health department to notify an individual if certain testing is 15 positive for sickle cell disease; requiring the Maryland Public Health Laboratory, 16 under certain circumstances, to provide an individual's sickle cell screening test 17 results to a local health department or entity contracting with the local health department providing certain services to the individual; and generally relating to 18 19 sickle cell disease.

20 BY repealing and reenacting, with amendments,

Article – Health – General

22 Section 18–501 and 18–506

23 Annotated Code of Maryland

24 (2015 Replacement Volume and 2018 Supplement)

25 BY adding to

21

27

26 Article – Health – General

Section 18–507 and 18–508

28 Annotated Code of Maryland

29 (2015 Replacement Volume and 2018 Supplement)

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



$\frac{1}{2}$	SECTION 1. BE IT ENACTED BY THE GENERAL ASSEMBLY OF MARYLAND, That the Laws of Maryland read as follows:			
3	Article – Health – General			
4	18–501.			
5	The intent of this subtitle is:			
6 7	(1) To educate parents and physicians regarding homozygous sickle cell anemia; [and]			
8	(2) To monitor each affected infant's health in that regard; AND			
9 10	(3) TO PROVIDE RESOURCES FOR DETECTING SICKLE CELL DISEASE AND SUPPORTING INDIVIDUALS WITH SICKLE CELL DISEASE.			
11	18–506.			
12 13	(a) In this section, "Steering Committee" means the Statewide Steering Committee on Services for Adults with Sickle Cell Disease.			
14 15	(b) There is a Statewide Steering Committee on Services for Adults with Sickle Cell Disease.			
16	(c) The Steering Committee shall include representatives from:			
17 18	(1) Local and national groups that advocate for individuals with sickle cell disease;			
19	(2) Interest and support groups for individuals with sickle cell disease;			
20	[(3) The Genetic Alliance;			
21	(4) Faith-based organizations;]			
22	[(5)] (3) Community and consumer groups;			
23 24	[(6)] (4) Academic and private clinical settings with knowledge and experience caring for adults with sickle cell disease;			
25	[(7)] (5) Area hospitals caring for individuals with sickle cell disease; and			
26	[(8)] (6) Pediatric clinics that care for children with sickle cell disease.			

1	(d)	The S	teering Committee shall:
2		(1)	Establish institution and community partnerships;
3 4	with sickle co	(2) ell disc	Establish a statewide network of stakeholders who care for individuals ease;
5 6	providers abo	(3) out the	Educate individuals with sickle cell disease, the public, and health care e State options for care of sickle cell disease; and
7		[(4)	Seek grant funding to:
8 9	sickle cell dis	sease;	(i) Develop and establish a case management system for adults with
10			(ii) Establish an adult sickle cell disease day infusion center;
11 12	and treatmen	nt prog	(iii) Develop, implement, and lead a State comprehensive education gram for adults with sickle cell disease; and
13 14 15 16	dynamics, o	cultura	(iv) Develop and implement a health care provider awareness and on to increase provider awareness of health disparities, community all practice, behavioral and psychosocial issues, and the use of ment and emergency room protocols.]
17 18 19	SUPPORTIN RECOMMEN		IDENTIFY FUNDING SOURCES FOR IMPLEMENTING OR IE ACTIONS, STUDIES, POLICIES, REGULATIONS, OR LAWS BY THE STEERING COMMITTEE, INCLUDING FUNDING FROM:
20			(I) STATE, FEDERAL, AND LOCAL GOVERNMENT SOURCES; AND
21			(II) PRIVATE SOURCES.
22	18–507.		
23 24 25	STEERING	COMM	DEPARTMENT SHALL, IN CONSULTATION WITH THE STATEWIDE IITTEE ON SERVICES FOR ADULTS WITH SICKLE CELL DISEASE, ES RELATING TO SICKLE CELL DISEASE, INCLUDING:
26 27	INDIVIDUAL	(1) LS AFF	EDUCATIONAL PROGRAMS ON SICKLE CELL DISEASE FOR ECTED BY THE DISEASE, INCLUDING:
28			(I) INDIVIDUALS WITH SICKLE CELL DISEASE;

(II) FAMILIES OF INDIVIDUALS WITH SICKLE CELL DISEASE;

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1	(III) CAREGIVERS OF INDIVIDUALS WITH SICKLE CELL DISEASE;
2	(IV) EMPLOYEES AT PRIMARY AND SECONDARY SCHOOLS; AND
3	(V) HEALTH CARE PROVIDERS;
4	(2) SOCIAL SERVICES SUPPORT TO INDIVIDUALS WITH SICKLE CELL
5 c	DISEASE, INCLUDING SUPPORT FROM SOCIAL WORKERS AND COMMUNITY HEALTH
6	WORKERS TO PROVIDE INFORMATION ON SERVICES THAT MAY BE AVAILABLE TO
7	THE INDIVIDUAL;
8	(3) Testing;
9	(4) GENETIC COUNSELING;
0	(5) By establishing sickle cell disease infusion centers in
1	THE STATE;
LI	THE STATE,
2	(6) Assistance with any available reimbursement for
3	MEDICAL EXPENSES RELATED TO SICKLE CELL DISEASE;
	MIDIONE MILENEDE WEEKIND TO STORME OEDE DISEMBE,
4	(7) EDUCATION AND COUNSELING SERVICES AFTER THE RECEIPT OF
5	SICKLE CELL TRAIT TEST RESULTS FROM THE STATE'S NEWBORN SCREENING
6	PROGRAM; AND
7	(8) Any other programs or services that are necessary to
8	DECREASE THE USE OF ACUTE CARE SERVICES BY INDIVIDUALS WHO HAVE SICKLE
9	CELL DISEASE.
20	(B) THE DEPARTMENT SHALL PROVIDE THE SERVICES IN SUBSECTION (A)
21	OF THIS SECTION THROUGH COMMUNITY-BASED ORGANIZATIONS TO THE EXTENT
22	PRACTICABLE.
23	18–508.
24	(A) (1) A LOCAL HEALTH DEPARTMENT SHALL PROVIDE SICKLE CELL
25	DISEASE TESTING AND COUNSELING AT NO COST TO ANY INDIVIDUAL WHO IS
26	REFERRED BY:
27	(I) A PHYSICIAN LICENSED TO PRACTICE MEDICINE IN THE
Q	STATE.

- 1 (II) A PHYSICIAN ASSISTANT LICENSED UNDER TITLE 15 OF THE 2 HEALTH OCCUPATIONS ARTICLE; OR
- 3 (III) A NURSE PRACTITIONER LICENSED TO PRACTICE
- 4 REGISTERED NURSING IN THE STATE WHO IS CERTIFIED AS A NURSE PRACTITIONER
- 5 BY THE STATE BOARD OF NURSING UNDER TITLE 8 OF THE HEALTH OCCUPATIONS
- 6 ARTICLE.
- 7 (2) A LOCAL HEALTH DEPARTMENT SHALL NOTIFY AN INDIVIDUAL IF
- 8 ANY TESTING CONDUCTED BY THE DEPARTMENT IS POSITIVE FOR SICKLE CELL
- 9 DISEASE.
- 10 (B) THE MARYLAND PUBLIC HEALTH LABORATORY SHALL PROVIDE AN
- 11 INDIVIDUAL'S SICKLE CELL SCREENING TEST RESULTS TO ANY LOCAL HEALTH
- 12 DEPARTMENT OR ENTITY CONTRACTING WITH THE LOCAL HEALTH DEPARTMENT
- 13 THAT IS PROVIDING SICKLE CELL SERVICES TO THE INDIVIDUAL UNDER
- 14 SUBSECTION (A) OF THIS SECTION:
- 15 (1) ON REQUEST; AND
- 16 (2) WITH THE INDIVIDUAL'S AUTHORIZATION.
- 17 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect June
- 18 1, 2019.