

HOUSE BILL 793

J1

7lr1418

By: **Delegates Nathan-Pulliam, Benson, Braveboy, Cane, Conaway, Costa, Gaines, Glenn, Griffith, Gutierrez, Kipke, Lee, Montgomery, Oaks, Pena-Melnyk, ~~and Tarrant~~ Tarrant, Hammen, Morhaim, Bromwell, V. Turner, Donoghue, Elliott, Hubbard, Weldon, Riley, Kach, Kullen, McDonough, Mizeur, and Pendergrass**

Introduced and read first time: February 9, 2007

Assigned to: Health and Government Operations

Committee Report: Favorable with amendments

House action: Adopted

Read second time: March 20, 2007

CHAPTER _____

1 AN ACT concerning

2 **Sickle Cell Disease - ~~Adults - Best Practices Treatment and Awareness Act~~**
3 **Statewide Steering Committee on Services for Adults with Sickle Cell**
4 **Disease**

5 FOR the purpose of establishing a Statewide Steering Committee on ~~Service~~ Services
6 for Adults with Sickle Cell Disease; requiring the Steering Committee to include
7 representatives from certain groups and organizations; providing for the duties
8 of the Steering Committee; ~~requiring the Steering Committee to establish an~~
9 ~~Adult Sickle Cell Disease Day Infusion Center in the State; requiring the~~
10 ~~Center to be structured in a certain manner; requiring the Center to include~~
11 ~~certain services; requiring the Steering Committee to work to expand a certain~~
12 ~~Center to include certain services; requiring the Governor to include a certain~~
13 ~~appropriation of a certain amount in the State budget in certain fiscal years;~~
14 ~~requiring the Steering Committee to develop and implement a certain case~~
15 ~~management system; providing for services that a certain case management~~
16 ~~system may include; requiring the Governor to include a certain appropriation~~
17 ~~of a certain amount in the State budget in certain fiscal years; and generally~~

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.



1 relating to ~~State services for the treatment and management of sickle cell~~
 2 ~~disease in adults~~ the establishment of a Statewide Steering Committee on
 3 Services for Adults with Sickle Cell Disease.

4 ~~BY repealing and reenacting, with amendments,~~
 5 ~~Article – Health – General~~
 6 ~~Section 18-501~~
 7 ~~Annotated Code of Maryland~~
 8 ~~(2005 Replacement Volume and 2006 Supplement)~~

9 BY adding to
 10 Article – Health – General
 11 Section 18-506 ~~through 18-508~~
 12 Annotated Code of Maryland
 13 (2005 Replacement Volume and 2006 Supplement)

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

16 **Article – Health – General**

17 ~~18-501.~~

18 ~~The intent of this subtitle is:~~

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

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

22 ~~(3) ESTABLISH A COMPREHENSIVE EDUCATION, TREATMENT,~~
 23 ~~AND CASE MANAGEMENT NETWORK FOR ADULTS WITH SICKLE CELL ANEMIA.~~

24 **18-506.**

25 (A) **IN THIS ~~SUBTITLE~~ SECTION, "STEERING COMMITTEE" MEANS THE**
 26 **STATEWIDE STEERING COMMITTEE ON SERVICES FOR ADULTS WITH SICKLE**
 27 **CELL DISEASE.**

28 (B) **THERE IS A STATEWIDE STEERING COMMITTEE ON SERVICES FOR**
 29 **ADULTS WITH SICKLE CELL DISEASE.**

1 **(C) THE STEERING COMMITTEE SHALL INCLUDE REPRESENTATIVES**
2 **FROM:**

3 **(1) LOCAL AND NATIONAL GROUPS THAT ADVOCATE FOR**
4 **INDIVIDUALS WITH SICKLE CELL DISEASE;**

5 **(2) INTEREST AND SUPPORT GROUPS FOR INDIVIDUALS WITH**
6 **SICKLE CELL DISEASE;**

7 **(3) THE GENETIC ALLIANCE;**

8 **(4) FAITH-BASED ORGANIZATIONS;**

9 **(5) COMMUNITY AND CONSUMER GROUPS;**

10 **(6) ACADEMIC AND PRIVATE CLINICAL SETTINGS WITH**
11 **KNOWLEDGE AND EXPERIENCE CARING FOR ADULTS WITH SICKLE CELL**
12 **DISEASE;**

13 **(7) AREA HOSPITALS CARING FOR INDIVIDUALS WITH SICKLE**
14 **CELL DISEASE; AND**

15 **(8) PEDIATRIC CLINICS THAT CARE FOR CHILDREN WITH SICKLE**
16 **CELL DISEASE.**

17 **(D) THE STEERING COMMITTEE SHALL:**

18 **(1) ESTABLISH INSTITUTION AND COMMUNITY PARTNERSHIPS;**

19 **(2) ESTABLISH A STATEWIDE NETWORK OF STAKEHOLDERS WHO**
20 **CARE FOR INDIVIDUALS WITH SICKLE CELL DISEASE;**

21 **(3) DEVELOP, IMPLEMENT, AND LEAD A STATE COMPREHENSIVE**
22 **EDUCATION AND TREATMENT PROGRAM FOR ADULTS WITH SICKLE CELL**
23 **DISEASE;**

24 ~~**(4) DEVELOP AND IMPLEMENT A PUBLIC AWARENESS AND**~~
25 ~~**EDUCATION CAMPAIGN ABOUT SICKLE CELL DISEASE;**~~

1 ~~(5)~~ (4) DEVELOP AND IMPLEMENT A HEALTH CARE PROVIDER
2 AWARENESS AND EDUCATION CAMPAIGN TO INCREASE PROVIDER AWARENESS
3 OF HEALTH DISPARITIES, COMMUNITY DYNAMICS, CULTURAL PRACTICE,
4 BEHAVIORAL AND PSYCHOSOCIAL ISSUES, AND THE USE OF STANDARDIZED
5 TREATMENT AND EMERGENCY ROOM PROTOCOLS; ~~AND~~

6 ~~(6)~~ (5) EDUCATE INDIVIDUALS WITH SICKLE CELL DISEASE, THE
7 PUBLIC, AND HEALTH CARE PROVIDERS ABOUT THE STATE OPTIONS FOR CARE
8 OF SICKLE CELL DISEASE; AND

9 (6) SEEK GRANT FUNDING TO:

10 (I) DEVELOP AND ESTABLISH A CASE MANAGEMENT
11 SYSTEM FOR ADULTS WITH SICKLE CELL DISEASE; AND

12 (II) ESTABLISH AN ADULT SICKLE CELL DISEASE DAY
13 INFUSION CENTER.

14 ~~18-507.~~

15 ~~(A)~~ ~~IN THIS SECTION, "CENTER" MEANS THE ADULT SICKLE CELL~~
16 ~~DISEASE DAY INFUSION CENTER.~~

17 ~~(B)~~ ~~THE STEERING COMMITTEE SHALL ESTABLISH AN ADULT SICKLE~~
18 ~~CELL DISEASE DAY INFUSION CENTER IN THE STATE.~~

19 ~~(C)~~ ~~THE CENTER SHALL BE STRUCTURED TO MEET ALL OF A SICKLE~~
20 ~~CELL DISEASE PATIENT'S NEEDS IN A SINGLE TREATMENT AREA, INCLUDING:~~

21 ~~(1)~~ ~~THE RAPID ASSESSMENT AND TREATMENT OF PAIN;~~

22 ~~(2)~~ ~~MEDICAL CARE; AND~~

23 ~~(3)~~ ~~SOCIAL SUPPORT.~~

24 ~~(D)~~ ~~THE CENTER SHALL INCLUDE:~~

25 ~~(1)~~ ~~FACILITIES TO PROVIDE SERVICES FOR UP TO FOUR~~
26 ~~PATIENTS WHO ARE IN CRISIS; AND~~

1 ~~(2) THE APPROPRIATE NUMBER AND TYPES OF HEALTH CARE~~
2 ~~PROVIDERS TO PROVIDE PATIENTS WITH THE APPROPRIATE SERVICES,~~
3 ~~INCLUDING:~~

4 ~~(I) PAIN MANAGEMENT;~~

5 ~~(II) SOCIAL WORK SERVICES;~~

6 ~~(III) PSYCHOLOGY SERVICES;~~

7 ~~(IV) GENETIC COUNSELING;~~

8 ~~(V) HEALTH AND NUTRITION COUNSELING; AND~~

9 ~~(VI) COMMUNITY OUTREACH.~~

10 ~~(E) THE STEERING COMMITTEE SHALL WORK TO EXPAND THE CENTER~~
11 ~~TO INCLUDE:~~

12 ~~(1) REFERENCE AND RESEARCH LABORATORIES;~~

13 ~~(2) NUTRITION COUNSELING;~~

14 ~~(3) OUTREACH AND TELEMEDICINE CLINICS;~~

15 ~~(4) PATIENT AND PROVIDER EDUCATION PROGRAMS;~~

16 ~~(5) MENTAL HEALTH AND PSYCHOSOCIAL SUPPORT SERVICES;~~

17 ~~AND~~

18 ~~(6) SECONDARY EDUCATION AND JOB TRAINING PROGRAMS.~~

19 ~~(F) (1) IN FISCAL YEAR 2009, THE GOVERNOR SHALL INCLUDE AN~~
20 ~~APPROPRIATION OF AT LEAST \$1,900,000 IN THE STATE BUDGET FOR THE~~
21 ~~ESTABLISHMENT AND OPERATION OF THE CENTER.~~

22 ~~(2) IN EACH YEAR SUBSEQUENT TO 2009, THE GOVERNOR SHALL~~
23 ~~INCLUDE AN APPROPRIATION OF AT LEAST \$960,000 IN THE ANNUAL BUDGET~~
24 ~~FOR THE OPERATION OF THE CENTER.~~

1 ~~18-508.~~

2 ~~(A) THE STEERING COMMITTEE SHALL DEVELOP AND IMPLEMENT A~~
3 ~~CASE MANAGEMENT SYSTEM FOR ADULTS WITH SICKLE CELL DISEASE.~~

4 ~~(B) THE CASE MANAGEMENT SYSTEM MAY INCLUDE:~~

5 ~~(1) A CASE MANAGEMENT NETWORK THAT PROVIDES THE~~
6 ~~SERVICES OF HEALTH CARE PROFESSIONALS WHO HAVE EDUCATION, TRAINING,~~
7 ~~AND EXPERIENCE WITH SICKLE CELL DISEASE TO ASSIST INDIVIDUALS IN~~
8 ~~NAVIGATING THE HEALTH CARE AND SOCIAL WORK SYSTEM TO OBTAIN ALL THE~~
9 ~~NEEDED ELEMENTS OF CARE, INCLUDING:~~

10 ~~(I) PATIENT HOME VISITATION;~~

11 ~~(II) ATTENDING CLINICS WITH PATIENTS; AND~~

12 ~~(III) ON-SITE AND TELEPHONE CONSULTATION WITH A~~
13 ~~PATIENT'S PRIMARY CARE PROVIDER AND EMERGENCY ROOMS;~~

14 ~~(2) AN ON-CALL CONSULTATION SERVICE THAT OPERATES 24~~
15 ~~HOURS A DAY AND 7 DAYS A WEEK;~~

16 ~~(3) OUTREACH CLINICS AND TELEMEDICINE CLINICS;~~

17 ~~(4) A VOLUNTARY SICKLE CELL DISEASE PATIENT REGISTRY OR~~
18 ~~DATABASE; OR~~

19 ~~(5) A WEB-BASED REPOSITORY FOR ABBREVIATED ELECTRONIC~~
20 ~~MEDICAL RECORDS FOR SICKLE CELL DISEASE PATIENTS.~~

21 ~~(C) IN FISCAL YEAR 2009 AND EACH SUBSEQUENT YEAR, THE~~
22 ~~GOVERNOR SHALL INCLUDE AN APPROPRIATION OF AT LEAST \$1,000,000 IN~~
23 ~~THE ANNUAL BUDGET FOR THE OPERATION OF THE STEERING COMMITTEE AND~~
24 ~~THE STATE CASE MANAGEMENT SYSTEM FOR SICKLE CELL DISEASE.~~

25 SECTION 2. AND BE IT FURTHER ENACTED, That this Act shall take effect
26 October 1, 2007.