

HOUSE BILL 793

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By: **Delegates Nathan-Pulliam, Benson, Braveboy, Cane, Conaway, Costa, Gaines, Glenn, Griffith, Gutierrez, Kipke, Lee, Montgomery, Oaks, Pena-Melnyk, and Tarrant**

Introduced and read first time: February 9, 2007

Assigned to: Health and Government Operations

A BILL ENTITLED

1 AN ACT concerning

2 **Sickle Cell Disease – Adults – Best Practices Treatment and Awareness Act**

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

18 BY repealing and reenacting, with amendments,
19 Article – Health – General
20 Section 18–501
21 Annotated Code of Maryland
22 (2005 Replacement Volume and 2006 Supplement)

EXPLANATION: CAPITALS INDICATE MATTER ADDED TO EXISTING LAW.

[Brackets] indicate matter deleted from existing law.



1 BY adding to
2 Article – Health – General
3 Section 18–506 through 18–508
4 Annotated Code of Maryland
5 (2005 Replacement Volume and 2006 Supplement)

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

8 **Article – Health – General**

9 **18–501.**

10 The intent of this subtitle is:

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

13 (2) To monitor each affected infant’s health in that regard; **AND**

14 **(3) ESTABLISH A COMPREHENSIVE EDUCATION, TREATMENT,**
15 **AND CASE MANAGEMENT NETWORK FOR ADULTS WITH SICKLE CELL ANEMIA.**

16 **18–506.**

17 **(A) IN THIS SUBTITLE, “STEERING COMMITTEE” MEANS THE**
18 **STATEWIDE STEERING COMMITTEE ON SERVICES FOR ADULTS WITH SICKLE**
19 **CELL DISEASE.**

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

22 **(C) THE STEERING COMMITTEE SHALL INCLUDE REPRESENTATIVES**
23 **FROM:**

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

26 **(2) INTEREST AND SUPPORT GROUPS FOR INDIVIDUALS WITH**
27 **SICKLE CELL DISEASE;**

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

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

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

4 **(6) ACADEMIC AND PRIVATE CLINICAL SETTINGS WITH**
5 **KNOWLEDGE AND EXPERIENCE CARING FOR ADULTS WITH SICKLE CELL**
6 **DISEASE;**

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

9 **(8) PEDIATRIC CLINICS THAT CARE FOR CHILDREN WITH SICKLE**
10 **CELL DISEASE.**

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

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

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

15 **(3) DEVELOP, IMPLEMENT, AND LEAD A STATE COMPREHENSIVE**
16 **EDUCATION AND TREATMENT PROGRAM FOR ADULTS WITH SICKLE CELL**
17 **DISEASE;**

18 **(4) DEVELOP AND IMPLEMENT A PUBLIC AWARENESS AND**
19 **EDUCATION CAMPAIGN ABOUT SICKLE CELL DISEASE;**

20 **(5) DEVELOP AND IMPLEMENT A HEALTH CARE PROVIDER**
21 **AWARENESS AND EDUCATION CAMPAIGN TO INCREASE PROVIDER AWARENESS**
22 **OF HEALTH DISPARITIES, COMMUNITY DYNAMICS, CULTURAL PRACTICE,**
23 **BEHAVIORAL AND PSYCHOSOCIAL ISSUES, AND THE USE OF STANDARDIZED**
24 **TREATMENT AND EMERGENCY ROOM PROTOCOLS; AND**

25 **(6) EDUCATE INDIVIDUALS WITH SICKLE CELL DISEASE, THE**
26 **PUBLIC, AND HEALTH CARE PROVIDERS ABOUT THE STATE OPTIONS FOR CARE**
27 **OF SICKLE CELL DISEASE.**

1 **18-507.**

2 (A) IN THIS SECTION, "CENTER" MEANS THE ADULT SICKLE CELL
3 DISEASE DAY INFUSION CENTER.

4 (B) THE STEERING COMMITTEE SHALL ESTABLISH AN ADULT SICKLE
5 CELL DISEASE DAY INFUSION CENTER IN THE STATE.

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

8 (1) THE RAPID ASSESSMENT AND TREATMENT OF PAIN;

9 (2) MEDICAL CARE; AND

10 (3) SOCIAL SUPPORT.

11 (D) THE CENTER SHALL INCLUDE:

12 (1) FACILITIES TO PROVIDE SERVICES FOR UP TO FOUR
13 PATIENTS WHO ARE IN CRISIS; AND

14 (2) THE APPROPRIATE NUMBER AND TYPES OF HEALTH CARE
15 PROVIDERS TO PROVIDE PATIENTS WITH THE APPROPRIATE SERVICES,
16 INCLUDING:

17 (I) PAIN MANAGEMENT;

18 (II) SOCIAL WORK SERVICES;

19 (III) PSYCHOLOGY SERVICES;

20 (IV) GENETIC COUNSELING;

21 (V) HEALTH AND NUTRITION COUNSELING; AND

22 (VI) COMMUNITY OUTREACH.

1 **(E) THE STEERING COMMITTEE SHALL WORK TO EXPAND THE CENTER**
2 **TO INCLUDE:**

- 3 **(1) REFERENCE AND RESEARCH LABORATORIES;**
- 4 **(2) NUTRITION COUNSELING;**
- 5 **(3) OUTREACH AND TELEMEDICINE CLINICS;**
- 6 **(4) PATIENT AND PROVIDER EDUCATION PROGRAMS;**
- 7 **(5) MENTAL HEALTH AND PSYCHOSOCIAL SUPPORT SERVICES;**
8 **AND**
- 9 **(6) SECONDARY EDUCATION AND JOB TRAINING PROGRAMS.**

10 **(F) (1) IN FISCAL YEAR 2009, THE GOVERNOR SHALL INCLUDE AN**
11 **APPROPRIATION OF AT LEAST \$1,900,000 IN THE STATE BUDGET FOR THE**
12 **ESTABLISHMENT AND OPERATION OF THE CENTER.**

13 **(2) IN EACH YEAR SUBSEQUENT TO 2009, THE GOVERNOR SHALL**
14 **INCLUDE AN APPROPRIATION OF AT LEAST \$960,000 IN THE ANNUAL BUDGET**
15 **FOR THE OPERATION OF THE CENTER.**

16 **18-508.**

17 **(A) THE STEERING COMMITTEE SHALL DEVELOP AND IMPLEMENT A**
18 **CASE MANAGEMENT SYSTEM FOR ADULTS WITH SICKLE CELL DISEASE.**

19 **(B) THE CASE MANAGEMENT SYSTEM MAY INCLUDE:**

20 **(1) A CASE MANAGEMENT NETWORK THAT PROVIDES THE**
21 **SERVICES OF HEALTH CARE PROFESSIONALS WHO HAVE EDUCATION, TRAINING,**
22 **AND EXPERIENCE WITH SICKLE CELL DISEASE TO ASSIST INDIVIDUALS IN**
23 **NAVIGATING THE HEALTH CARE AND SOCIAL WORK SYSTEM TO OBTAIN ALL THE**
24 **NEEDED ELEMENTS OF CARE, INCLUDING:**

25 **(I) PATIENT HOME VISITATION;**

1 **(II) ATTENDING CLINICS WITH PATIENTS; AND**

2 **(III) ON-SITE AND TELEPHONE CONSULTATION WITH A**
3 **PATIENT'S PRIMARY CARE PROVIDER AND EMERGENCY ROOMS;**

4 **(2) AN ON-CALL CONSULTATION SERVICE THAT OPERATES 24**
5 **HOURS A DAY AND 7 DAYS A WEEK;**

6 **(3) OUTREACH CLINICS AND TELEMEDICINE CLINICS;**

7 **(4) A VOLUNTARY SICKLE CELL DISEASE PATIENT REGISTRY OR**
8 **DATABASE; OR**

9 **(5) A WEB-BASED REPOSITORY FOR ABBREVIATED ELECTRONIC**
10 **MEDICAL RECORDS FOR SICKLE CELL DISEASE PATIENTS.**

11 **(C) IN FISCAL YEAR 2009 AND EACH SUBSEQUENT YEAR, THE**
12 **GOVERNOR SHALL INCLUDE AN APPROPRIATION OF AT LEAST \$1,000,000 IN**
13 **THE ANNUAL BUDGET FOR THE OPERATION OF THE STEERING COMMITTEE AND**
14 **THE STATE CASE MANAGEMENT SYSTEM FOR SICKLE CELL DISEASE.**

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