

SECOND REGULAR SESSION

[PERFECTED]

HOUSE COMMITTEE SUBSTITUTE FOR

**HOUSE BILL NO. 1407**

**96TH GENERAL ASSEMBLY**

4905L.03P

D. ADAM CRUMBLISS, Chief Clerk

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**AN ACT**

To amend chapter 191, RSMo, by adding thereto one new section relating to a sickle cell standing committee.

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*Be it enacted by the General Assembly of the state of Missouri, as follows:*

Section A. Chapter 191, RSMo, is amended by adding thereto one new section, to be  
2 known as section 191.117, to read as follows:

**191.117. 1. There is hereby established in the department of health and senior  
2 services a "Sickle Cell Standing Committee" as a subcommittee of the Missouri genetic  
3 disease advisory committee. The committee shall consist of nineteen members, as follows:**

4 **(1) The lieutenant governor or his or her designee, who shall serve as chair of the  
5 committee;**

6 **(2) The director of the department of health and senior services, or the director's  
7 designee;**

8 **(3) One member of the house of representatives appointed by the speaker of the  
9 house;**

10 **(4) One member of the senate appointed by the president pro tem of the senate;**

11 **(5) Two members who have sickle cell disease or are family members of persons  
12 with sickle cell disease;**

13 **(6) Two members who are licensed physicians with experience in the diagnosis and  
14 treatment of sickle cell disease;**

15 **(7) Two members with expertise in sickle cell disease research;**

16 **(8) One member with expertise in minority health;**

17 **(9) Three members from leading sickle cell disease organizations; and**

EXPLANATION — Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

18           **(10) Five members representing urban community leaders and organizations.**

19           **2. The members of the committee, other than the lieutenant governor, members**  
20 **from the general assembly, and department director, shall be appointed by the governor**  
21 **with the advice and consent of the senate. Members shall serve on the committee without**  
22 **compensation or reimbursement for expenses incurred.**

23           **3. The committee shall:**

24           **(1) Assess the impact of sickle cell disease on urban communities in the state of**  
25 **Missouri;**

26           **(2) Examine the existing services and resources addressing the needs of persons**  
27 **with sickle cell disease; and**

28           **(3) Develop recommendations to provide educational services to schools on the**  
29 **traits of sickle cell disease and their effects.**

30           **4. The committee shall include an examination of the following in its assessment**  
31 **and recommendations required to be completed under subsection 3 of this section:**

32           **(1) Trends in state sickle cell disease populations and their needs, including but not**  
33 **limited to the state's role in providing assistance;**

34           **(2) Existing services and resources;**

35           **(3) Needed state policies or responses, including but not limited to directions for the**  
36 **provision of clear and coordinated services and supports to persons living with sickle cell**  
37 **disease and strategies to address any identified gaps in services; and**

38           **(4) Replacing the genetic testing and counseling program eliminated due to lack of**  
39 **funding. The program was an hour-long workshop provided to schools on the traits of**  
40 **sickle cell disease and the effects of such traits.**

41           **5. The committee shall hold a minimum of one meeting at three urban regions in**  
42 **the state of Missouri to seek public input.**

43           **6. The committee shall submit a report of its findings and any recommendations**  
44 **to the general assembly and the governor no later than December 31, 2012.**

45           **7. After December 31, 2012, the committee shall continue to meet at the request of**  
46 **the chair and at a minimum of one time annually for the purpose of continuing the study**  
47 **of sickle cell disease in this state, the impact of the committee recommendations, and to**  
48 **provide an annual supplemental report on the findings to the governor and the general**  
49 **assembly.**

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