

SECOND REGULAR SESSION

# HOUSE BILL NO. 2369

## 95TH GENERAL ASSEMBLY

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INTRODUCED BY REPRESENTATIVES WALTON GRAY (Sponsor), LeBLANC, PACE,  
JONES (63) AND MORRIS (Co-sponsors).

5357L.011

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 disease task force.

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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 known as section 191.117, to read as follows:

**191.117. 1. There is hereby established in the department of health and senior services a "Sickle Cell Disease Task Force". The task force shall consist of nineteen members, as follows:**

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

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

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

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

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

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

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

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

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.

- 17           **(9) Three members from leading sickle cell disease organizations; and**  
18           **(10) Five members representing urban community leaders and organizations.**  
19           **2. The members of the task force, 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 task force without**  
22 **compensation.**  
23           **3. The task force 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 task force shall include an examination of the following in its assessment and**  
31 **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 task force shall hold a minimum of one meeting at three urban regions in the**  
42 **state of Missouri to seek public input.**  
43           **6. The task force shall submit a report of its findings and any recommendations to**  
44 **the general assembly and the governor no later than December 31, 2010.**  
45           **7. Until December 31, 2012, the task force 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 task force recommendations, and to**  
48 **provide an annual supplemental report on the findings to the governor and the general**  
49 **assembly.**  
50           **8. The provisions of this section shall expire on December 31, 2012.**

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