

HOUSE _____ AMENDMENT NO. _____

Offered By _____

AMEND House Committee Substitute for Senate Substitute No. 2 for Senate Committee
Substitute for Senate Bill No. 62, Page 1, Section 190.839, Line 1, by inserting after all of said
line the following:

“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;

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

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

2. The members of the task force, other than the lieutenant governor, members from the
general assembly, and department director, shall be appointed by the governor with the advice and
consent of the senate. Members shall serve on the task force without compensation.

3. The task force shall:

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

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

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

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

1 (1) Trends in state sickle cell disease populations and their needs, including but not
2 limited to the state's role in providing assistance;
3 (2) Existing services and resources;
4 (3) Needed state policies or responses, including but not limited to directions for the
5 provision of clear and coordinated services and supports to persons living with sickle cell disease
6 and strategies to address any identified gaps in services; and
7 (4) Replacing the genetic testing and counseling program eliminated due to lack of
8 funding. The program was an hour-long workshop provided to schools on the traits of sickle cell
9 disease and the effects of such traits.
10 5. The task force shall hold a minimum of one meeting at three urban regions in the state
11 of Missouri to seek public input.
12 6. The task force shall submit a report of its findings and any recommendations to the
13 general assembly and the governor no later than December 31, 2011.
14 7. Until December 31, 2013, the task force shall continue to meet at the request of the
15 chair and at a minimum of one time annually for the purpose of continuing the study of sickle cell
16 disease in this state, the impact of the task force recommendations, and to provide an annual
17 supplemental report on the findings to the governor and the general assembly.
18 8. The provisions of this section shall expire on December 31, 2013.”; and

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20 Further amend said bill by amending the title, enacting clause, and intersectional references
21 accordingly.
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