

House _____ Amendment NO. _____

Offered By _____

1 AMEND House Bill No. 1994, Page 1, In the Title, Line 2, by deleting the words "palliative care"
2 and inserting in lieu thereof the words "health care"; and
3

4 Further amend said bill and page, Section A, Line 2, by inserting after all of said section and line
5 the following:
6

7 "191.117. 1. There is hereby established in the department of health and senior services a
8 "Sickle Cell Standing Committee" as a subcommittee of the Missouri genetic advisory committee.
9 The committee shall consist of the following members:

10 (1) One member who is a licensed physician with experience in the diagnosis and treatment
11 of sickle cell disease and who shall serve as chair of the committee;

12 (2) One member who has sickle cell disease or is a family member of a person with sickle
13 cell disease;

14 (3) One member with expertise in sickle cell disease research;

15 (4) One member from a leading sickle cell disease organization;

16 (5) One member with expertise in minority health; and

17 (6) One member from each of the hemoglobinopathy centers which contracts with the
18 department.

19 2. The members of the committee shall be appointed by the director of the department of
20 health and senior services. Members shall serve on the committee without compensation or
21 reimbursement for expenses incurred.

22 3. The committee shall:

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

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

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

28 4. The committee shall include an examination of the following in its assessment and
29 recommendations required under subsection 3 of this section:

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

32 (2) Existing services and resources;

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

36 (4) Replacing the hour-long genetic testing and counseling program workshop provided to

Standing Action Taken _____ Date _____

Select Action Taken _____ Date _____

1 schools on the traits of sickle cell disease and the effects of such traits, which was eliminated due to
2 lack of funding.

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

5 6. The committee shall submit a report of its findings and any recommendations to the
6 general assembly and the governor no later than December 31, 2017.

7 7. After December 31, 2017, the committee shall continue to meet at the request of the chair
8 and at a minimum of one time annually for the purpose of continuing the study of sickle cell disease
9 in this state, the impact of the committee recommendations, and to provide an annual supplemental
10 report on the findings to the governor and the general assembly."; and

11
12 Further amend said bill by amending the title, enacting clause, and intersectional references
13 accordingly.