

HOUSEAMENDMENT NO. ____Offered byof

1 AMEND Senate Substitute for Senate Committee Substitute for
 2 Senate Bill No. 129, Page 1, Section A, Line 3, by inserting
 3 after all of said line the following:

4 "191.117. 1. There is hereby established in the department
 5 of health and senior services a "Sickle Cell Standing Committee"
 6 as a subcommittee of the Missouri genetic disease advisory
 7 committee. The committee shall consist of the following members:

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

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

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

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

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

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

20 2. The members of the committee shall be appointed by the
 21 director of the department of health and senior services.

22 Members shall serve on the committee without compensation or
 23 reimbursement for expenses incurred.

24 3. The committee shall:

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

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

29 (3) Develop recommendations to provide educational services

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1 to schools on the traits of sickle cell disease and their
2 effects.

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

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

9 (2) Existing services and resources;

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

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

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

21 6. The committee shall submit a report of its findings and
22 any recommendations to the general assembly and the governor no
23 later than December 31, 2014.

24 7. After December 31, 2014, the committee shall continue to
25 meet at the request of the chair and at a minimum of one time
26 annually for the purpose of continuing the study of sickle cell
27 disease in this state, the impact of the committee
28 recommendations, and to provide an annual supplemental report on
29 the findings to the governor and the general assembly."; and

30
31 Further amend said title, enacting clause and intersectional
32 references accordingly.