

SECOND REGULAR SESSION

HOUSE BILL NO. 1483

98TH GENERAL ASSEMBLY

INTRODUCED BY REPRESENTATIVE WALTON GRAY.

4257H.011

D. ADAM CRUMBLISS, Chief Clerk

AN ACT

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

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 Standing Committee" as a subcommittee of the Missouri genetic advisory committee. The committee shall consist of the following members:

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

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

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

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

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

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

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

3. The committee shall:

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

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

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

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

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

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

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

31 **(4) Replacing the hour-long genetic testing and counseling program workshop**
32 **provided to schools on the traits of sickle cell disease and the effects of such traits, which**
33 **was eliminated due to lack of funding.**

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

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

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

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