

SENATE BILL NO. 1735

103RD GENERAL ASSEMBLY

INTRODUCED BY SENATOR WASHINGTON.

7233S.011

KRISTINA MARTIN, Secretary

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
2 one new section, to be known as section 191.117, to read as
3 follows:

191.117. 1. This section shall be known and may be
2 cited as the "Lori Zena Baker Act".

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

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

11 (2) One member who has sickle cell disease or is a
12 family member of a person 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
19 center that contracts with the department.

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

24 4. 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
28 addressing the needs of persons with sickle cell disease; and

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

32 5. The committee shall include an examination of the
33 following in its assessment and recommendations required
34 under subsection 4 of this section:

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

38 (2) Existing services and resources; and

39 (3) Needed state policies or responses, including, but
40 not limited to, directions for the provision of clear and
41 coordinated services and supports to persons living with
42 sickle cell disease and strategies to address any identified
43 gaps in services.

44 6. The committee shall hold a minimum of one meeting
45 at three urban regions in the state to seek public input.

46 7. The committee shall submit a report of its findings
47 and any recommendations to the general assembly and the
48 governor no later than December 31, 2027.

49 8. After December 31, 2027, the committee shall
50 continue to meet at the request of the chair and at a
51 minimum of one time annually for the purpose of continuing
52 the study of sickle cell disease in this state, the impact
53 of the committee recommendations, and to provide an annual
54 supplemental report on the findings to the governor and the
55 general assembly.

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