

SECOND REGULAR SESSION

[PERFECTED]

HOUSE COMMITTEE SUBSTITUTE FOR

HOUSE BILL NO. 1387

98TH GENERAL ASSEMBLY

4487H.02P

D. ADAM CRUMBLISS, Chief Clerk

AN ACT

To repeal section 191.332, RSMo, and to enact in lieu thereof two new sections relating to public health, with an emergency clause.

Be it enacted by the General Assembly of the state of Missouri, as follows:

Section A. Section 191.332, RSMo, is repealed and two new sections enacted in lieu thereof, to be known as sections 191.117 and 191.332, to read as follows: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.**

191.332. 1. By January 1, 2002, the department of health and senior services shall,
2 subject to appropriations, expand the newborn screening requirements in section 191.331 to
3 include potentially treatable or manageable disorders, which may include but are not limited to
4 cystic fibrosis, galactosemia, biotinidase deficiency, congenital adrenal hyperplasia, maple syrup
5 urine disease (MSUD) and other amino acid disorders, glucose-6-phosphate dehydrogenase
6 deficiency (G-6-PD), MCAD and other fatty acid oxidation disorders, methylmalonic acidemia,
7 propionic acidemia, isovaleric acidemia and glutaric acidemia Type I.

8 **2. By January 1, 2017, the department of health and senior services shall, subject**
9 **to appropriations, expand the newborn screening requirements in section 191.331 to**
10 **include severe combined immunodeficiency (SCID), also known as bubble boy disease. The**

11 **department may increase the fee authorized under subsection 6 of section 191.331 to cover**
12 **any additional costs of the expanded newborn screening requirements under this**
13 **subsection.**

14 **3.** The department of health and senior services may promulgate rules to implement the
15 provisions of this section. No rule or portion of a rule promulgated pursuant to the authority of
16 this section shall become effective unless it has been promulgated pursuant to chapter 536.

Section B. Because immediate action is necessary to ensure the health of newborn babies
2 in Missouri, the enactment of section 191.332 of section A of this act is deemed necessary for
3 the immediate preservation of the public health, welfare, peace, and safety, and is hereby
4 declared to be an emergency act within the meaning of the constitution, and the enactment of
5 section 191.332 of section A of this act shall be in full force and effect upon its passage and
6 approval.

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