

2024 Regular Session

SENATE BILL NO. 192

BY SENATOR BARROW

DISEASE CONTROL. Provides relative to the Louisiana Sickle Cell Commission. (gov sig)

1 AN ACT

2 To amend and reenact R.S. 40:1125.1, relative to the Louisiana Sickle Cell Commission; to
3 provide for membership of the commission; to provide for the duties and functions
4 of the commission; and to provide for related matters.

5 Be it enacted by the Legislature of Louisiana:

6 Section 1. R.S. 40:1125.1 is hereby amended and reenacted to read as follows:

7 §1125.1. Louisiana Sickle Cell Commission

8 A. There shall be established within the Louisiana Department of Health a
9 commission designated the "Louisiana Sickle Cell Commission", **which shall be**
10 composed of seventeen members as provided in Subsection B of this Section.

11 B.(1) Thirteen members shall be appointed by the governor, subject to Senate
12 confirmation, as follows:

13 (a) ~~One member from a list of nominees submitted by the Sickle Cell Center~~
14 ~~of Southern Louisiana, Tulane University School of Medicine~~ **Three medical**
15 **professionals actively engaged in the treatment and care of individuals living**
16 **with sickle cell disease.**

17 (b) ~~One member from a list of nominees submitted by Children's Hospital,~~

1 ~~New Orleans~~ **medical professional actively engaged in the practice of emergency**
2 **medicine or with oversight of emergency department care.**

3 (c) ~~One member from a list of nominees submitted by~~ **A representative of**
4 the Louisiana Primary Care Association.

5 (d) ~~One member from a list of nominees submitted by the Sickle Cell~~
6 ~~Association of South Louisiana~~ **Five representatives from five distinct service**
7 **organizations actively providing outreach, education, and case management**
8 **services for individuals living with sickle cell disease and their families.**

9 (e) ~~One member from a list of nominees submitted by the Northeast~~
10 ~~Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc~~ **Two individuals**
11 **living with sickle cell disease.**

12 (f) ~~One member from a list of nominees submitted by the Sickle Cell Disease~~
13 ~~Association of America, Inc., Northwest Louisiana Chapter~~ **One parent of a child**
14 **living with sickle cell disease.**

15 (g) ~~One member from a list of nominees submitted by the Sickle Cell Anemia~~
16 ~~Research Foundation, Alexandria.~~

17 (h) ~~One member from a list of nominees submitted by Southwest Louisiana~~
18 ~~Sickle Cell Anemia, Inc.~~

19 (i) ~~Five members from a list of nominees submitted by the Louisiana~~
20 ~~Department of Health; two of whom shall be persons diagnosed with sickle cell~~
21 ~~disease, one of whom shall be a parent of a person diagnosed with sickle cell disease,~~
22 ~~and two of whom shall be medical professionals who provide treatment and care to~~
23 ~~patients diagnosed with sickle cell disease.~~

24 (2) ~~Two of the~~ **Four** members shall be as follows:

25 (a) ~~The secretary of the Louisiana Department of Health or his designee.~~

26 (b) ~~The Medicaid director of the Louisiana Department of Health or his~~
27 ~~designee.~~

28 **(b) The Title V Maternal and Child Health Block Grant director of the**
29 **Louisiana Department of Health or his designee.**

1 ~~(3)~~ Two members shall be appointed as follows:

2 ~~(a)~~ One member of the Louisiana Senate appointed by the

3 **(c) The president of the Senate or his designee.**

4 ~~(b)~~ One member of the Louisiana House of Representatives appointed by the

5 **(d) The speaker of the House of Representatives or his designee.**

6 ~~(4)~~**(3)** Each appointment by the governor shall serve at his pleasure. The
7 legislative members shall serve at the pleasure of the presiding officer of the
8 respective legislative body.

9 ~~(5)~~**(4)** The term of an appointee shall be four years. Any vacancy occurring
10 in board membership shall be filled for the remainder of the unexpired term in the
11 same manner as the original appointment.

12 ~~(6)~~**(5)** Nonlegislative members of the commission shall not be entitled to a
13 per diem or any other compensation for their service but shall be entitled to
14 reimbursement of any necessary and reasonable expense incurred in the performance
15 of their duties on the panel, including travel expenses. Each legislative member of
16 the commission shall receive a per diem and travel expenses equal to the per diem
17 and travel expenses provided by law for members of the legislature.

18 ~~(7)~~ Meetings of the commission shall be held at the call of the chairman or
19 on a petition of at least five members of the commission.

20 ~~(8)~~**(6)** At the first meeting of the commission, each **Each** year after its
21 members assume their positions, the members shall select one of the commission
22 members to serve as chairman and one of the commission members to serve as vice
23 chairman, and each shall serve for a term of one year. The chairman shall preside at
24 meetings of the commission, and in his absence, the vice chairman shall preside.

25 ~~(9)~~**(7)** The commission shall hold at least four regular meetings each year.
26 **Additional meetings of the commission may be held at the call of the**
27 **chairperson or on petition of at least five members of the commission.** The
28 commission shall meet at locations that rotate throughout the state, as determined by
29 the chairman, to provide ease of travel for the members of the commission.

1 ~~(10) The appointment of the initial members of the commission shall take~~
2 ~~place no later than October 1, 2013, and the commission shall convene its first~~
3 ~~meeting no later than November 1, 2013.~~

4 C. The Louisiana Department of Health shall **serve as staff and** provide
5 administrative assistance to ~~and serve as staff~~ for the commission.

6 D. The functions of the commission shall be to:

7 (1) ~~Ensure the delivery of~~ **Assess the availability and quality of** sickle cell
8 services to affected persons in all parishes in Louisiana and assist in establishing
9 geographical service delivery boundaries.

10 (2) ~~Promulgate~~ **Review and promote** guidelines for creating uniformity in
11 the delivery of services and ~~the management of~~ statewide programs **for individuals**
12 **living with sickle cell disease, including the Sickle Cell Patient Navigator**
13 **Program as described in this Part.**

14 (3) ~~Submit budget recommendations to the legislature and the governor.~~
15 **Monitor national recommendations and guidelines for the management or**
16 **treatment of sickle cell disease.**

17 (4) Prepare and publish an annual report on sickle cell that includes:

18 (a) An assessment of the ~~programs and activities aimed at~~ **systems of care**
19 **and support for individuals living with** sickle cell **disease.**

20 (b) A description of the level of coordination ~~existing between the state and~~
21 ~~private stakeholders in~~ **entities integral to** the management and treatment of sickle
22 cell **disease.**

23 (c) ~~The development of a detailed action plan for battling~~ **Recommendations**
24 **to the secretary of the Louisiana Department of Health for providing a**
25 **continuum of high-quality medical care and supportive services for individuals**
26 **living with** sickle cell **disease.**

27 (5) ~~Direct the Sickle Cell Patient Navigator Program established by the~~
28 ~~provisions of R.S. 40:1125.21.~~ **Assist the Louisiana Department of Health with**
29 **the development and implementation of the Louisiana Sickle Cell Registry, also**

1 **known as the "Skylar-Cooper Database", as described in this Part.**

2 (6) ~~Apply for grants and donations from any public or private source to~~
3 ~~implement the provisions of this Subsection.~~ **Serve as an advocate for the needs**
4 **and rights of individuals living with sickle cell disease.**

5 Section 2. This Act shall become effective upon signature by the governor or, if not
6 signed by the governor, upon expiration of the time for bills to become law without signature
7 by the governor, as provided by Article III, Section 18 of the Constitution of Louisiana. If
8 vetoed by the governor and subsequently approved by the legislature, this Act shall become
9 effective on the day following such approval.

The original instrument and the following digest, which constitutes no part
of the legislative instrument, were prepared by Amanda Trapp.

DIGEST

SB 192 Original 2024 Regular Session Barrow

Present law establishes the Louisiana Sickle Cell Commission within the Louisiana Department of Health.

Present law provides for the membership, duties, and functions of the commission.

Proposed law updates the commission membership and expands the duties and functions of the commission.

Effective upon signature of the governor or lapse of time for gubernatorial action.

(Amends R.S. 40:1125.1)