2024 Regular Session

HOUSE BILL NO. 330

BY REPRESENTATIVE PHELPS

HEALTH/SICKLE CELL ANEM: Provides relative to the membership of the Louisiana Sickle Cell Commission

1	AN ACT
2	To amend and reenact R.S. 40:1125.1(A) and (B)(1), relative to the Louisiana Sickle Cell
3	Commission; to provide for the membership of the commission; to specifically limit
4	the membership 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(A) and (B)(1) are hereby amended and reenacted to read
7	as follows:
8	§1125.1. Louisiana Sickle Cell Commission
9	A. There shall be established within the Louisiana Department of Health a
10	commission designated the "Louisiana Sickle Cell Commission", composed of
11	seventeen members as provided in Subsection B of this Section. No organization,
12	entity, or individual shall be a member unless expressly provided for in Subsection
13	B of this Section.
14	B.(1) Thirteen members shall be appointed by the governor, subject to
15	Senate confirmation, as follows:
16	(a) One member from a list of nominees submitted by the Sickle Cell Center
17	of Southern Louisiana, Tulane University School of Medicine, which has provided
18	health care to patients with sickle cell disease since 1979 and houses the only life
19	span clinic, which provides care to patients from birth to death, and a transition
20	clinic, which provides a seamless transition during the high risk death gap period
21	from pediatric to adult care.

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CODING: Words in struck through type are deletions from existing law; words <u>underscored</u> are additions.

1	(b) One member from a list of nominees submitted by Children's Hospital,
2	New Orleans, which is the only hospital in this state to provide stem cell and gene
3	therapies to patients with sickle cell disease and focuses on sickle cell pediatric
4	hematology.
5	(c) One member from a list of nominees submitted by the Louisiana Primary
6	Care Association.
7	(d) One member from a list of nominees submitted by the Sickle Cell
8	Association of South Louisiana, which has served eleven parishes in south Louisiana
9	since 1974 and has the historical and institutional knowledge of patient care within
10	the community.
11	(e) One member from a list of nominees submitted by the Northeast
12	Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc, which has served
13	northeast Louisiana since 1979 and has the historical and institutional knowledge of
14	patient care within the community.
15	(f) One member from a list of nominees submitted by the Sickle Cell Disease
16	Association of America, Inc., Northwest Louisiana Chapter, which has served
17	northwest Louisiana since 1974 and has the historical and institutional knowledge
18	of patient care within the community.
19	(g) One member from a list of nominees submitted by the Sickle Cell
20	Anemia Research Foundation, Alexandria, which has served twelve parishes in
21	central Louisiana since 1974 and has the historical and institutional knowledge of
22	patient care within the community.
23	(h) One member from a list of nominees submitted by Southwest Louisiana
24	Sickle Cell Anemia, Inc., which has served southwest Louisiana and has the
25	historical and institutional knowledge of patient care within the community.
26	(i) Five members from a list of nominees submitted by the Louisiana
27	Department of Health; two of whom shall be persons diagnosed with sickle cell
28	disease, one of whom shall be a parent of a person diagnosed with sickle cell disease,

- 1 and two of whom shall be medical professionals who provide treatment and care to
- 2 patients diagnosed with sickle cell disease.
- 3 * *

DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

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Abstract: Limits the membership of the La. Sickle Cell Commission.

<u>Present law</u> provides for the organizations, entities, and individuals that make up the 13member La. Sickle Cell Commission (commission).

<u>Proposed law</u> retains <u>present law</u> and requires that the membership of the commission be comprised of only those members that are expressly provided for in <u>present law</u>.

<u>Proposed law</u> provides historical information to support and justify certain members of the commission.

(Amends R.S. 40:1125.1(A) and (B)(1))

Summary of Amendments Adopted by House

The Committee Amendments Proposed by <u>House Committee on Health and Welfare</u> to the <u>original</u> bill:

- 1. Add information to justify the membership of the La. Sickle Cell Commission.
- 2. Make technical changes.