

AN ACT

relating to the establishment of the sickle cell disease registry.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:

SECTION 1. Subtitle B, Title 2, Health and Safety Code, is amended by adding Chapter 52B to read as follows:

CHAPTER 52B. SICKLE CELL DISEASE REGISTRY

Sec. 52B.001. DEFINITION. In this chapter, "health care facility" means:

- (1) a hospital licensed under Chapter 241; or
- (2) any other facility that provides diagnostic or treatment services to patients with sickle cell disease.

Sec. 52B.002. REGISTRY; CONTENTS. (a) The department shall establish and maintain a sickle cell disease registry in accordance with this chapter for use as a single repository of accurate, complete records of sickle cell disease cases to aid in the cure and treatment of sickle cell disease in this state.

(b) The sickle cell disease registry must include:

- (1) a record of sickle cell disease cases that occur in this state; and
- (2) any other information concerning sickle cell disease cases the executive commissioner considers necessary and appropriate to assist with the cure or treatment of sickle cell disease.

Sec. 52B.003. DATA FROM HEALTH CARE FACILITIES. A health

care facility shall provide to the department, in the form and manner the department prescribes, data the department considers necessary and appropriate concerning sickle cell disease cases.

Sec. 52B.004. DEPARTMENT POWERS; RULES. (a) To implement this chapter, the department may:

(1) execute necessary contracts;

(2) receive data from health care facilities concerning sickle cell disease cases to record and analyze the data directly related to the disease; and

(3) compile and publish statistical and other studies derived from data obtained under this chapter to provide, in an accessible form, information useful to physicians, other medical personnel, and the public.

(b) The executive commissioner shall adopt rules to implement this chapter.

(c) The executive commissioner by rule shall develop guidelines to:

(1) obtain data from health care facilities regarding sickle cell disease cases;

(2) require consent of an individual or the individual's legally authorized representative before any information relating to the individual is included in the sickle cell disease registry;

(3) allow the individual or the individual's legally authorized representative to withdraw consent for inclusion of the individual's information in the registry;

(4) protect the confidentiality of individuals

1 diagnosed with sickle cell disease in accordance with Section
2 159.002, Occupations Code; and

3 (5) ensure the registry is developed in a manner
4 consistent with:

5 (A) the Health Insurance Portability and
6 Accountability Act of 1996 (Pub. L. No. 104-191) and regulations
7 adopted under that Act; and

8 (B) other applicable laws and rules governing the
9 disclosure of health information.

10 (d) The executive commissioner shall ensure the rules
11 adopted under this section provide protections to restrict the use
12 or disclosure of Medicaid information to purposes only directly
13 connected with the administration of the Medicaid program.

14 Sec. 52B.005. CONFIDENTIALITY. (a) Reports, records, and
15 information obtained under this chapter:

16 (1) are not public information;

17 (2) are not subject to the requirements of Chapter
18 552, Government Code;

19 (3) are not subject to subpoena; and

20 (4) may not otherwise be released or made public
21 except as provided by this section or Section 52B.004.

22 (b) The reports, records, and information obtained under
23 this chapter are for the confidential use of the department and the
24 persons or public or private entities the department determines are
25 necessary to carry out the purposes of this chapter.

26 (c) Medical or epidemiological information may be released:

27 (1) for statistical purposes in a manner that prevents

identification of individuals, health care facilities, clinical laboratories, or health care practitioners; or

(2) with the consent of each person identified in the information.

(d) A state employee may not testify in a civil, criminal, special, or other proceeding as to the existence or contents of records, reports, or information concerning an individual's medical records used in submitting information required under this chapter unless the individual consents in advance.

(e) Information furnished to a sickle cell disease registry or a sickle cell researcher under Subsection (c) is for the confidential use of the sickle cell disease registry or the sickle cell researcher, as applicable, and is subject to Subsection (a).

(f) The department's institutional review board established under Chapter 108 shall review and approve requests for access to information that identifies individuals in the sickle cell disease registry.

Sec. 52B.006. REPORTS. (a) The department shall submit an annual report to the legislature on the information obtained under this chapter.

(b) The department, in cooperation with other sickle cell disease reporting organizations and research institutions, may publish reports the department determines are necessary to carry out the purposes of this chapter.

SECTION 2. The Department of State Health Services is required to implement a provision of this Act only if the legislature appropriates money specifically for that purpose. If

1 the legislature does not appropriate money specifically for that
2 purpose, the department may, but is not required to, implement a
3 provision of this Act using other money available for that purpose.

4 SECTION 3. As soon as practicable after the effective date
5 of this Act, the executive commissioner of the Health and Human
6 Services Commission shall adopt rules necessary to implement
7 Chapter 52B, Health and Safety Code, as added by this Act.

8 SECTION 4. This Act takes effect September 1, 2025.

President of the Senate

Speaker of the House

I certify that H.B. No. 107 was passed by the House on April 28, 2025, by the following vote: Yeas 110, Nays 33, 1 present, not voting; and that the House concurred in Senate amendments to H.B. No. 107 on May 28, 2025, by the following vote: Yeas 96, Nays 31, 2 present, not voting.

Chief Clerk of the House

I certify that H.B. No. 107 was passed by the Senate, with amendments, on May 20, 2025, by the following vote: Yeas 25, Nays 6.

Secretary of the Senate

APPROVED: _____

Date

Governor