

By: Miles

S.B. No. 820

A BILL TO BE ENTITLED

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

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

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

6 (1) execute necessary contracts;

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

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

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

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

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

20 (2) protect the confidentiality of individuals
21 diagnosed with sickle cell disease in accordance with Section
22 [159.002](#), Occupations Code; and

23 (3) ensure the registry is developed in a manner
24 consistent with:

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

1 (B) other applicable laws and regulations
2 governing disclosure of health information.

3 Sec. 52B.005. REPORTS. (a) The department shall submit an
4 annual report to the legislature on the information obtained under
5 this chapter.

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

10 SECTION 2. As soon as practicable after the effective date
11 of this Act, the executive commissioner of the Health and Human
12 Services Commission shall adopt rules necessary to implement
13 Chapter 52B, Health and Safety Code, as added by this Act.

14 SECTION 3. This Act takes effect September 1, 2025.