

By: J. Johnson of Harris

H.B. No. 181

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 52A to read as follows:

CHAPTER 52A. SICKLE CELL DISEASE REGISTRY

Sec. 52A.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. 52A.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 cases of sickle cell disease 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 cases of sickle cell disease that occur in this state; and

(2) any other information concerning cases of sickle cell disease that the executive commissioner considers necessary and appropriate for the cure or treatment of sickle cell disease.

Sec. 52A.003. DATA FROM HEALTH CARE FACILITIES. A health care facility shall provide to the department, in the form and

1 manner prescribed by the department, data the department considers
2 necessary and appropriate concerning cases of sickle cell disease.

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

5 (1) execute necessary contracts;

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

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

13 (b) The executive commissioner shall adopt rules as
14 necessary to implement this chapter.

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

17 (1) obtain information from health care facilities
18 regarding cases of sickle cell disease;

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

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

24 (A) the Health Insurance Portability and
25 Accountability Act of 1996 (Pub. L. No. 104-191);

26 (B) regulations adopted under that Act; and

27 (C) other applicable laws and regulations

1 governing disclosure of health information.

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

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

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

13 SECTION 3. This Act takes effect September 1, 2023.