

By: J. Johnson of Harris

H.B. No. 3673

A BILL TO BE ENTITLED

AN ACT

relating to the establishment of a 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 registry of individuals diagnosed with sickle cell disease in accordance with this chapter for use as a single repository of accurate, complete records 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 individuals in this state who have been diagnosed with sickle cell disease; and

(2) any other information regarding individuals who have been diagnosed with sickle cell disease that the executive commissioner considers necessary and appropriate for inclusion on the registry.

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

1 care facility shall provide to the department, in the form and
2 manner prescribed by the department, data regarding individuals who
3 have been diagnosed with sickle cell disease.

4 Sec. 52A.004. RULES. The executive commissioner by rule
5 shall develop guidelines to:

6 (1) obtain information regarding individuals
7 diagnosed with sickle cell disease from health care facilities;

8 (2) protect the confidentiality of the individuals in
9 accordance with Section 159.002, Occupations Code; and

10 (3) ensure that the registry is developed in a manner
11 consistent with the Health Insurance Portability and
12 Accountability Act of 1996 (Pub. L. No. 104-191), regulations
13 adopted under that Act, and other applicable laws and regulations
14 governing disclosure of health information.

15 Sec. 52A.005. REPORTS. (a) The department shall publish an
16 annual report to the legislature of the information obtained under
17 this chapter.

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

22 SECTION 2. As soon as practicable after the effective date
23 of this act, the executive commissioner of the Health and Human
24 Services Commission shall adopt rules necessary to implement
25 Chapter 52A, Health and Safety Code, as added by this Act.

26 SECTION 3. This Act takes effect September 1, 2021.