

1-1 By: J. Johnson of Harris, et al. H.B. No. 181
 1-2 (Senate Sponsor - Miles)
 1-3 (In the Senate - Received from the House May 4, 2023;
 1-4 May 5, 2023, read first time and referred to Committee on Health &
 1-5 Human Services; May 21, 2023, reported favorably by the following
 1-6 vote: Yeas 8, Nays 0; May 21, 2023, sent to printer.)

1-7 COMMITTEE VOTE

	Yea	Nay	Absent	PNV
1-8				
1-9	X			
1-10	X			
1-11	X			
1-12	X			
1-13	X			
1-14			X	
1-15	X			
1-16	X			
1-17	X			

1-18 A BILL TO BE ENTITLED
 1-19 AN ACT

1-20 relating to the establishment of the sickle cell disease registry.
 1-21 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF TEXAS:
 1-22 SECTION 1. Subtitle B, Title 2, Health and Safety Code, is
 1-23 amended by adding Chapter 52A to read as follows:
 1-24 CHAPTER 52A. SICKLE CELL DISEASE REGISTRY
 1-25 Sec. 52A.001. DEFINITION. In this chapter, "health care
 1-26 facility" means:
 1-27 (1) a hospital licensed under Chapter 241; or
 1-28 (2) any other facility that provides diagnostic or
 1-29 treatment services to patients with sickle cell disease.
 1-30 Sec. 52A.002. REGISTRY; CONTENTS. (a) The department shall
 1-31 establish and maintain a sickle cell disease registry in accordance
 1-32 with this chapter for use as a single repository of accurate,
 1-33 complete records of cases of sickle cell disease to aid in the cure
 1-34 and treatment of sickle cell disease in this state.
 1-35 (b) The sickle cell disease registry must include:
 1-36 (1) a record of cases of sickle cell disease that occur
 1-37 in this state; and
 1-38 (2) any other information concerning cases of sickle
 1-39 cell disease that the executive commissioner considers necessary
 1-40 and appropriate for the cure or treatment of sickle cell disease.
 1-41 Sec. 52A.003. DATA FROM HEALTH CARE FACILITIES. A health
 1-42 care facility shall provide to the department, in the form and
 1-43 manner prescribed by the department, data the department considers
 1-44 necessary and appropriate concerning cases of sickle cell disease.
 1-45 Sec. 52A.004. DEPARTMENT POWERS; RULES. (a) To implement
 1-46 this chapter, the department may:
 1-47 (1) execute necessary contracts;
 1-48 (2) receive data from health care facilities
 1-49 concerning cases of sickle cell disease to record and analyze the
 1-50 data directly related to the disease; and
 1-51 (3) compile and publish statistical and other studies
 1-52 derived from data obtained under this chapter to provide, in an
 1-53 accessible form, information that is useful to physicians, other
 1-54 medical personnel, and the public.
 1-55 (b) The executive commissioner shall adopt rules as
 1-56 necessary to implement this chapter.
 1-57 (c) The executive commissioner by rule shall develop
 1-58 guidelines to:
 1-59 (1) obtain information from health care facilities
 1-60 regarding cases of sickle cell disease;
 1-61 (2) protect the confidentiality of individuals

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

2-3 (3) ensure that the registry is developed in a manner
2-4 consistent with:

2-5 (A) the Health Insurance Portability and
2-6 Accountability Act of 1996 (Pub. L. No. 104-191);

2-7 (B) regulations adopted under that Act; and

2-8 (C) other applicable laws and regulations
2-9 governing disclosure of health information.

2-10 Sec. 52A.005. REPORTS. (a) The department shall submit an
2-11 annual report to the legislature of the information obtained under
2-12 this chapter.

2-13 (b) The department, in cooperation with other sickle cell
2-14 disease reporting organizations and research institutions, may
2-15 publish reports the department determines are necessary to carry
2-16 out the purposes of this chapter.

2-17 SECTION 2. As soon as practicable after the effective date
2-18 of this Act, the executive commissioner of the Health and Human
2-19 Services Commission shall adopt rules necessary to implement
2-20 Chapter 52A, Health and Safety Code, as added by this Act.

2-21 SECTION 3. This Act takes effect September 1, 2023.

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