BILL ANALYSIS

Senate Research Center
89R6037 MCF-D

H.B. 107
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Health & Human Services
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Engrossed

AUTHOR'S / SPONSOR'S STATEMENT OF INTENT

Sickle cell disease (SCD) is a serious genetic disorder that affects a person's red blood cells, leading to lifelong health complications. In Texas, about 1 in every 2,000 newborns is born with SCD—primarily impacting African American communities. Despite this, many patients struggle to receive adequate care due limited provider awareness of appropriate diagnosis, and a lack of coordinated statewide data. Without accurate data, efforts to improve treatment, track outcomes, and secure research funding are severely limited.

Texas must establish a centralized, population-based system to collect and maintain accurate records of SCD cases. This registry must be designed to support improved healthcare access, promote early diagnosis, guide policymaking, and ensure medical professionals have the information they need to treat patients effectively. It must also meet strict privacy standards to protect individual health information.

H.B. 107 establishes and maintains a Sickle Cell Disease Registry. The registry will serve as a single, accurate source of information about SCD cases across Texas. It requires health care facilities to report data on SCD cases to the Department of State Health Services (DSHS), and it mandates that all data collection comply with HIPAA, the Occupations Code, and other privacy laws. The bill authorizes DSHS to publish reports, conduct analysis, and provide accessible information to healthcare providers and the public. It also requires DSHS to submit an annual report to the legislature. This bill addresses concerns raised in a prior vetoed version by explicitly ensuring strong data privacy protections.

H.B. 107 amends current law relating to the establishment of the sickle cell disease registry.

RULEMAKING AUTHORITY

Rulemaking authority is expressly granted to the executive commissioner of the Health and Human Services Commission in SECTION 1 (Section 52B.004, Health and Safety Code) of this bill.

SECTION BY SECTION ANALYSIS

SECTION 1. Amends Subtitle B, Title 2, Health and Safety Code, by adding Chapter 52B, as follows:

CHAPTER 52B. SICKLE CELL DISEASE REGISTRY

Sec. 52B.001. DEFINITION. Defines "health care facility."

Sec. 52B.002. REGISTRY; CONTENTS. (a) Requires the Department of State Health Services (DSHS) to 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) Requires that the sickle cell disease registry include a record of sickle cell disease cases that occur in this state and any other information concerning sickle cell disease cases the executive commissioner of the Health and Human Services

Commission (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. Requires a health care facility to provide to DSHS, in the form and manner DSHS prescribes, data DSHS considers necessary and appropriate concerning sickle cell disease cases.

Sec. 52B.004. DEPARTMENT POWERS; RULES. (a) Authorizes DSHS, to implement this chapter, to execute necessary contracts, receive data from health care facilities concerning sickle cell disease cases to record and analyze the data directly related to the disease, and 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) Requires the executive commissioner to adopt rules to implement this chapter.

(c) Requires the executive commissioner by rule to develop guidelines to:

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

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

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

Sec. 52B.005. REPORTS. (a) Requires DSHS to submit an annual report to the legislature on the information obtained under this chapter.

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

SECTION 2. Requires the executive commissioner, as soon as practicable after the effective date of this Act, to adopt rules necessary to implement Chapter 52B, Health and Safety Code, as added by this Act.

SECTION 3. Effective date: September 1, 2025.