SENATE AMENDMENTS

2nd Printing

By: Simmons, Rose, Collier, Jones of Dallas, Oliverson, et al. H.B. No. 107

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

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

(1) execute necessary contracts;

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

(3) 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) The executive commissioner shall adopt rules to implement this chapter.

(c) The executive commissioner by rule shall 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, Occupations Code; and

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

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

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

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

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

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

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

ADOPTED

MAY 20 2025

Patsy Spaw
Secretary of the Senate

FLOOR AMENDMENT NO. 1 BY:

Amend H.B. No. 107 (senate committee report) as follows:

(1) In SECTION 1 of the bill, in added Section 52B.004(c), Health and Safety Code (page 1, line 61, through page 2, line 9), strike Subdivisions (2) and (3) and substitute the following:

(2) require consent of an individual or the individual's legally authorized representative before any information relating to the individual is included in the sickle cell disease registry;

(3) allow the individual or the individual's legally authorized representative to withdraw consent for inclusion of the individual's information in the registry;

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

(5) ensure the registry is developed in a manner consistent with:

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

(B) other applicable laws and rules governing the disclosure of health information.

(d) The executive commissioner shall ensure the rules adopted under this section provide protections to restrict the use or disclosure of Medicaid information to purposes only directly connected with the administration of the Medicaid program.

Sec. 52B.005. CONFIDENTIALITY. (a) Reports, records, and information obtained under this chapter:

(1) are not public information;

(2) are not subject to the requirements of Chapter

552, Government Code;

(3) are not subject to subpoena; and

(4) may not otherwise be released or made public except as provided by this section or Section 52B.004.

(b) The reports, records, and information obtained under this chapter are for the confidential use of the department and the persons or public or private entities the department determines are necessary to carry out the purposes of this chapter.

(c) Medical or epidemiological information may be released:

(1) for statistical purposes in a manner that prevents identification of individuals, health care facilities, clinical laboratories, or health care practitioners; or

(2) with the consent of each person identified in the information.

(d) A state employee may not testify in a civil, criminal, special, or other proceeding as to the existence or contents of records, reports, or information concerning an individual's medical records used in submitting information required under this chapter unless the individual consents in advance.

(e) Information furnished to a sickle cell disease registry or a sickle cell researcher under Subsection (c) is for the confidential use of the sickle cell disease registry or the sickle cell researcher, as applicable, and is subject to Subsection (a).

(f) The department's institutional review board established under Chapter 108 shall review and approve requests for access to information that identifies individuals in the sickle cell disease registry.

(2) In SECTION 1 of the bill, in added Section 52B.005, Health and Safety Code (page 2, line 10), strike "52B.005" and substitute "52B.006".

(3) Immediately following SECTION 1 of the bill, adding

Chapter 52B, Health and Safety Code (page 2, between lines 16 and 17), add the following appropriately numbered SECTION to the bill and renumber subsequent SECTIONS of the bill accordingly:

SECTION ____. The Department of State Health Services is required to implement a provision of this Act only if the legislature appropriates money specifically for that purpose. If the legislature does not appropriate money specifically for that purpose, the department may, but is not required to, implement a provision of this Act using other money available for that purpose.

LEGISLATIVE BUDGET BOARD
Austin, Texas

FISCAL NOTE, 89TH LEGISLATIVE REGULAR SESSION

May 22, 2025

TO: Honorable Dustin Burrows, Speaker of the House, House of Representatives

FROM: Jerry McGinty, Director, Legislative Budget Board

IN RE: **HB107** by Simmons (Relating to the establishment of the sickle cell disease registry.), **As Passed 2nd House**

Estimated Two-year Net Impact to General Revenue Related Funds for HB107, As Passed 2nd House: a negative impact of ($4,795,371) through the biennium ending August 31, 2027.

The Department of State Health Services is required to implement a provision of the bill only if the legislature appropriates money specifically for that purpose. If the legislature does not appropriate money specifically for that purpose, the Department of State Health Services may, but is not required to, implement a provision of the bill using other appropriations available for that purpose.

The bill would make no appropriation but could provide the legal basis for an appropriation of funds to implement the provisions of the bill.

General Revenue-Related Funds, Five- Year Impact:

Fiscal Year	**Probable Net Positive/(Negative) Impact to** *General Revenue Related Funds*
2026	($3,346,894)
2027	($1,448,477)
2028	($747,954)
2029	($748,869)
2030	($749,804)

All Funds, Five-Year Impact:

Fiscal Year	**Probable Savings/(Cost) from** *General Revenue Fund* 1	*Change in Number of State Employees from FY 2025*
2026	($3,346,894)	4.5
2027	($1,448,477)	5.0
2028	($747,954)	5.0
2029	($748,869)	5.0
2030	($749,804)	5.0

Fiscal Analysis

The bill would authorize the Department of State Health Services (DSHS) to establish and maintain a registry of cases of sickle cell disease in the state. Health care facilities would provide data regarding individuals who have been diagnosed with sickle cell disease to DSHS. The Health and Human Services Commission (HHSC) shall adopt rules related to implementation of the registry including ensuring confidentiality and informed consent related to information obtained on individuals for the registry. The bill would require DSHS to submit an annual report on information in the registry to the legislature, and DSHS would be authorized to publish other reports in cooperation with other sickle cell disease reporting organizations and research institutions.

Methodology

The analysis assumes DSHS would require 5.0 additional full-time-equivalent positions (FTEs) to establish and maintain the registry. This includes 2.0 FTE Epidemiologist III positions to calculate appropriate statistics, to analyze data quality, and to create reports; a 1.0 FTE Information Specialist IV position to oversee the dissemination of data and reports from the Sickle Cell Registry and to conduct trainings and education for registry users; a 1.0 FTE Program Specialist V position to oversee the Sickle Cell Registry Program and serve as the subject matter expert; and a 1.0 FTE Systems Analyst V position for programming, quality assurance testing, managing system specifications and requirements, and security and updates on the new Sickle Cell Disease Registry system.

Salaries, benefits, and other related costs for the new FTEs total $531,242 in fiscal year 2026 and $746,854 in fiscal year 2027, all from the General Revenue Fund. The lower cost in fiscal year 2026 is attributable to a later start date for the new positions assumed in the first fiscal year and because the Systems Analyst V position would begin as a 0.5 FTE in fiscal year 2026.

Technology

DSHS would build a standalone registry system modeled off an existing system to receive lab and provider reports for sickle cell disease. The agency will utilize HHSC information technology (IT) staff augmentation to build the system estimated to total $1,151,652 in fiscal year 2026 and $287,623 in fiscal year 2027, all from the General Revenue Fund.

Other IT costs related to new requirements and components of the new registry include new hardware costs of $350,000 in fiscal year 2026; software licenses costs of $300,000 in fiscal year 2026 and $100,000 in fiscal year 2027; Identity Account Management development and integration costs of $350,000 in fiscal year 2026; Independent Validation and Verification requirement for new IT projects costs of $350,000 in fiscal year 2026; and State Health Analytics and Reporting Platform (SHARP) integration and report development costs of $314,000 in each fiscal year, all from the General Revenue Fund.

Local Government Impact

No significant fiscal implication to units of local government is anticipated.

Source Agencies: 529 Health and Human Services Commission, 537 State Health Services, Department of

LBB Staff: JMc, NPe, ER, APA, NV

LEGISLATIVE BUDGET BOARD
Austin, Texas

FISCAL NOTE, 89TH LEGISLATIVE REGULAR SESSION

May 13, 2025

TO: Honorable Lois W. Kolkhorst, Chair, Senate Committee on Health & Human Services

FROM: Jerry McGinty, Director, Legislative Budget Board

IN RE: HB107 by Simmons (Relating to the establishment of the sickle cell disease registry.), **As Engrossed**

Estimated Two-year Net Impact to General Revenue Related Funds for HB107, As Engrossed: a negative impact of ($4,795,371) through the biennium ending August 31, 2027.

The bill would make no appropriation but could provide the legal basis for an appropriation of funds to implement the provisions of the bill.

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Methodology

The analysis assumes DSHS would require 5.0 additional full-time-equivalent positions (FTEs) to establish and maintain the registry. This includes 2.0 FTE Epidemiologist III positions to calculate appropriate statistics, to analyze data quality, and to create reports; a 1.0 FTE Information Specialist IV position to oversee the dissemination of data and reports from the Sickle Cell Registry and to conduct trainings and education for registry users; a 1.0 FTE Program Specialist V position to oversee the Sickle Cell Registry Program and serve as the subject matter expert; and a 1.0 FTE Systems Analyst V position for programming, quality assurance testing, managing system specifications and requirements, and security and updates on the new Sickle Cell Disease Registry system.

Salaries, benefits, and other related costs for the new FTEs total $531,242 in fiscal year 2026 and $746,854 in fiscal year 2027, all from the General Revenue Fund. The lower cost in fiscal year 2026 is attributable to a later start date for the new positions assumed in the first fiscal year and because the Systems Analyst V position would begin as a 0.5 FTE in fiscal year 2026.

Technology

DSHS would build a standalone registry system modeled off an existing system to receive lab and provider reports for sickle cell disease. The agency will utilize HHSC information technology (IT) staff augmentation to build the system estimated to total $1,151,652 in fiscal year 2026 and $287,623 in fiscal year 2027, all from the General Revenue Fund.

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Source Agencies: 529 Health and Human Services Commission, 537 State Health Services, Department of
LBB Staff: JMc, NPe, ER, APA, NV

LEGISLATIVE BUDGET BOARD
Austin, Texas

FISCAL NOTE, 89TH LEGISLATIVE REGULAR SESSION

March 30, 2025

TO: Honorable Gary VanDeaver, Chair, House Committee on Public Health

FROM: Jerry McGinty, Director, Legislative Budget Board

IN RE: **HB107** by Simmons (Relating to the establishment of the sickle cell disease registry.), **As Introduced**

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