

**SUBJECT:** Creating a sickle cell disease registry

**COMMITTEE:** Public Health — favorable, without amendment

**VOTE:** 10 ayes — Klick, Campos, Jetton, A. Johnson, J. Jones, V. Jones, Oliverson, Price, Smith, Tinderholt

0 nays

1 absent — Collier

**WITNESSES:** For — Heather Avant; Titilope Fasipe; André Harris (*Registered, but did not testify*; Bill Kelly, Mayor’s Office, City of Houston; Eric Glenn, Superior Health Plan; Matt Abel, Texas Association of Business; Jessica Lynch, Texas Association of Health Plans; David Reynolds, Texas Chapter American College of Physicians; Matt Dowling, Texas Medical Association; Jill Sutton, Texas Osteopathic Medical Association; Krista DuRapau, Texas Pain Society; Clayton Travis, Texas Pediatric Society; Kyle Kamrath, Vertex Pharmaceuticals; Susan Stewart)

Against — None

On — (*Registered, but did not testify*: Dr. Manda Hall, Department of State Health Services)

**BACKGROUND:** Some have suggested that better data on sickle cell disease could improve health outcomes.

**DIGEST:** HB 181 would require the Department of State Health Services (DSHS) to establish and maintain a sickle cell disease registry for use as a repository of accurate, complete records of sickle cell disease cases. The registry also would include other information concerning sickle cell disease cases that the executive commissioner of the Health and Human Services Commission (HHSC) considered necessary and appropriate for the cure or treatment of sickle cell disease.

Health care facilities, including a licensed hospital or any other facility providing diagnostic or treatment services to sickle cell disease patients, would be required to provide any necessary and appropriate data to DSHS.

To implement the bill, DSHS could execute necessary contracts, receive and analyze sickle cell disease data from health care facilities, and compile and publish statistical and other studies. The HHSC executive commissioner would by rule establish certain guidelines relating to obtaining information from health care facilities, protecting the confidentiality of individuals diagnosed with sickle cell disease, and ensure that the registry was developed in a manner consistent with certain federal laws and regulations.

DSHS would submit an annual report to the Legislature with the information obtained under the bill. DSHS could publish reports necessary to carry out the purposes of the bill in cooperation with other sickle cell disease reporting organizations and research institutions.

HHSC would adopt necessary rules as soon as practicable after the effective date.

The bill would take effect September 1, 2023.

NOTES:

According to the Legislative Budget Board, HB 181 would have a negative impact of about \$2.5 million on general revenue related funds for fiscal 2024-25.