

SUBJECT: Requiring DSHS to establish and maintain a sickle cell disease registry

COMMITTEE: Public Health — favorable, without amendment

VOTE: 10 ayes — Klick, Guerra, Allison, Coleman, Collier, Jetton, Oliverson, Price, Smith, Zwiener

0 nays

1 absent — Campos

WITNESSES: For — Heather Avant, Carol's Promise; Tonya Prince, Sickle Cell Association of Houston, Inc.; Titilope Fasipe, Texas Children's Hospital; (*Registered, but did not testify:* Tim Schauer, Community Health Choice; Eric Woomer, Global Blood Therapeutics; Bill Kelly, Mayor's Office, City of Houston; André Harris, Sickle Cell Association of Houston; David Reynolds, Texas Chapter of the American College of Physicians; Dan Finch, Texas Medical Association; Clayton Travis, Texas Pediatric Society)

Against — None

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

BACKGROUND: Some have suggested the need to establish a sickle cell disease registry to aid in the cure and treatment of sickle cell disease in the state.

DIGEST: HB 3673 would require the Department of State Health Services (DSHS) to establish and maintain a sickle cell disease registry including a record of individuals in the state who have been diagnosed with sickle cell disease and any other information deemed necessary by the executive commissioner of the Health and Human Services Commission (HHSC).

**Data.** The bill would require a health care facility to provide to DSHS data regarding individuals who have been diagnosed with sickle cell

disease.

"Health care facility" would mean a licensed hospital or any other facility that provided diagnostic or treatment services to patients with sickle cell disease.

**Rules.** As soon as practicable after the bill's effective date, the executive commissioner of HHSC by rule would have to develop guidelines to:

- obtain information regarding individuals diagnosed with sickle cell disease from health care facilities;
- protect the confidentiality of the individuals under Occupations Code sec. 159.002, regarding the confidential communication in the physician-patient relationship; and
- ensure that the registry was developed in a manner consistent with the Health Insurance Portability and Accountability Act (HIPAA).

**Reports.** The bill would require DSHS to publish an annual report to the Legislature containing information obtained from health care facilities.

DSHS, in cooperation with other sickle cell disease reporting organizations and research institutions, could publish reports the department determined were necessary to create and maintain the sickle cell disease registry.

The bill would take effect September 1, 2021.

**NOTES:** According to the Legislative Budget Board, the bill would have a negative impact of about \$2 million to general revenue through fiscal 2022-23.