

- SUBJECT:** Creating a task force to raise awareness of sickle cell disease
- COMMITTEE:** Public Health — favorable, without amendment
- VOTE:** 8 ayes — S. Thompson, Wray, Frank, Guerra, Ortega, Price, Sheffield, Zedler
- 1 nay — Allison
- 2 absent — Coleman, Lucio
- WITNESSES:** For — Tonya Prince, Sickle Cell Association of Houston; Titilope Fasipe, Texas Children's Hospital Cancer and Hematology Center; Caitlin McNeil, Sickle Cell Association of Texas Marc Thomas Foundation; Phillip Okwo; (*Registered, but did not testify:* Jazmine Brown, As One Foundation; Will Francis, National Association of Social Workers-Texas Chapter; Amber Pearce, Pfizer; Yesica Martinez, Rae Navarro and DeAnna Navarro, Sickle Cell Association Of Texas Marc Thomas Foundation; Troy Alexander and Michelle Romero, Texas Medical Association; Shatia Bartlett; Sharolyn Browning)
- Against — None
- On — (*Registered, but did not testify:* Manda Hall, Department of State Health Services Community Health Improvement Division)
- BACKGROUND:** 25 TAC part 1, chap. 37, subch. R, sec. 37.420 created the Sickle Cell Advisory Committee to review and suggest methods for raising awareness of sickle cell disease and sickle cell trait in Texas. The committee was dissolved September 1, 2018, after issuing a report to the executive commissioner of the Health and Human Services Commission.
- DIGEST:** HB 3405 would require the executive commissioner of the Health and Human Services Commission (HHSC) to establish and maintain a task force to raise awareness of sickle cell disease and sickle cell trait. The executive commissioner would collaborate with the members appointed to

the Newborn Screening Advisory Committee representing the sickle cell community in creating the task force.

Duties. The task force would study and advise the Department of State Health Services on implementing the recommendations from the 2018 report from the Sickle Cell Advisory Committee, or any other report deemed appropriate by the executive commissioner of HHSC. The executive commissioner could assign tasks to the task force and would provide administrative support at the request of the task force.

Members. The task force would be appointed by the executive commissioner and would include:

- two members from community-based organizations experienced in addressing the needs of individuals with sickle cell disease;
- two physicians specializing in hematology;
- two members of the public, each of whom either had sickle cell disease or was the parent of a person with sickle cell disease or sickle cell trait; and
- one representative of a health-related institution.

The first meeting of the task force would be held no later than December 1, 2019.

Task force members would not be entitled to compensation for serving on the task force but would be entitled to reimbursement expenses incurred in performing task force duties. The task force could accept gifts, grants, and donations to pay for these expenses.

Report. The task force would submit a report to the governor and the Legislature no later than December 1 of each year summarizing the work of the task force and recommended actions or policy changes. The task force would submit its first report by December 1, 2020.

The bill would take effect September 1, 2019.