Sickle Cell Task Force

Approved Meeting Minutes

Thursday, June 26, 2025
1:00 p.m.

Virtual Site – Teams Meeting Platform
In Person Site – John H. Winters Building, Public Hearing Room 125, First Floor
125 West 51st Street, Austin, Texas 78751

Agenda Item 1. Call to order, roll call, and welcoming remarks

Titilope Fasipe, M.D., Ph.D., Chair, presided and called the Sickle Cell Task Force (SCTF) meeting to order at 1:09 p.m.

Dr. Fasipe provided welcoming remarks and turned the floor over to Jacqueline Thompson, Facilitator, Advisory Committee Coordination Office (ACCO), Texas Health and Human Services Commission (HHSC).

Ms. Thompson read the logistical announcements and stated the meeting was being conducted in compliance with the Texas Open Meetings Act. Ms. Thompson conducted the member roll call. With five members present and one absent, Ms. Thompson announced the presence of quorum.

Table 1. SCTF member attendance at the Thursday, June 26, 2025, meeting.

Member Name	Attended
Titilope Fasipe, M.D., Ph.D., Chair	Yes
Melissa Frei-Jones, M.D., M.S.C.I.	Yes
André Harris, M.S.W.	Yes
Alecia Nero, M.D.	No
Marqué Reed-Shackelford, Vice-Chair	Yes
Linda Thomas Wade	Yes
Vacant	No

Before moving to the next agenda item, Dr. Fasipe called for a moment of silence to reflect on those lost to sickle cell disease (SCD). Dr. Fasipe then announced Dr. Dawn Johnson recently resigned from the SCTF and thanked her for her service. Dr. Fasipe also thanked the representatives who championed sickle cell during the last legislative session.

Agenda Item 2. Consideration of December 10, 2024, draft meeting minutes

Dr. Fasipe, Chair, asked members to review the draft meeting minutes they received in their meeting packets and called for any edits or changes. Hearing none, Dr. Fasipe called for a motion to approve December 10, 2024, draft meeting minutes as presented.

Motion:

Dr. Frei-Jones moved to approve the draft minutes from the December 10, 2024, meeting as posted. Mr. Harris seconded the motion.

Dr. Fasipe, Chair, called for discussion on the motion. Hearing none, Dr. Fasipe, instructed Ms. Jacqueline Thompson, ACCO, HHSC, to conduct a roll call vote. Ms. Thompson conducted a roll call vote and announced the motion carried by a majority vote of five approves (Dr. Fasipe, Dr. Frei-Jones, Mr. Harris, Mrs. Reed-Shackelford, and Ms. Thomas Wade), zero disapproves, zero abstentions, and one absence (Dr. Nero).

Agenda Item 3. Legislative updates

Dr. Fasipe, Chair, introduced Ms. Alison Hern, Government Relations Specialist, Government Affairs, Texas Department of State Health Services (DSHS), to provide an update on DSHS-impacted legislative activities during the 89th Regular Session, 2025.

Update highlights included:

- Dates for the regular session, veto period, and upcoming special session.
- Statistics for bills filed, tracked by DSHS, sent to the Governor, signed into law, vetoed, and set to become law without the Governor's signature.
- Description, requirements, and status of House Bill (HB) 107, which concerns a sickle cell registry and annual report of SCD cases and takes effect September 1, 2025.
    - HB 107 includes a contingency requiring DSHS to implement a provision of the bill only if the legislature appropriates funds specifically for that purpose.
    - The Legislature appropriated $1 million in a contingency rider of Senate Bill 1, The General Appropriations Act, for the 2026-2027 biennium, to implement HB 107.

- Given that DSHS estimates a total cost for 2026-2027 of $6.1 million, DSHS does not have the resources and funding to implement the functions of HB 107 and will evaluate next steps for implementation.

Member discussion:

- DSHS response when what is appropriated does not match what it costs to implement a bill.
- Identifying the necessity of further legislative action to implement HB 107.
- Financial impact of not having funding needed for implementation.
- Precedents for working with other established sickle cell registries and possibility of collaboration with registries outside of DSHS, such as the national GRNDaD (Globin Regional Data and Discovery) registry to offset the costs of a Texas registry.

Action Item:

DSHS will provide an update on HB 107 implementation plans at the next SCTF meeting.

Agenda Item 4. DSHS Newborn Screening (NBS) Program updates and announcements

Dr. Fasipe, Chair, introduced Leslie McKenzie, B.S.N., R.N., Unit Director, NBS Unit, DSHS; and Jessica Brown, M.D., M.P.H., Medical Director, NBS Unit, DSHS, to present NBS Program updates and announcements. Ms. McKenzie and Dr. Brown referenced the PowerPoint and handout, *Newborn Screening Program Updates, June 26, 2025*.

Presentation highlights included:

- General NBS program updates, including NBS 2026 fee increases, United States Postal Service shipping delay courier hub improvements, and 2025 Texas NBS Summit overview.
- An annual update on NBS Hemoglobinopathies diagnosed cases, including data for dates of birth from 2020-2024.

Member discussion:

- Texas NBS Summit
- Availability of NBS results for learning about sickle cell trait status

- Interest in learning how sickle cell trait cases will or can factor into the sickle cell registry bill
- Accessibility to sickle cell trait testing, including types of tests, who can order tests, and options for patients without insurance

Action Items:

- Program will verify the date range of available newborn screening results and share with members.
- Sickle cell trait testing discussion as future agenda item

Agenda Item 5. Sickle Cell Data Collection Program update

Dr. Fasipe, Chair, introduced Heidi Bojes, Ph.D., Director, Environmental Epidemiology and Disease Registries Section, DSHS, and Principal Investigator, Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program grant, to provide a SCDC update.

Presentation highlights included:

- Progress toward goal of establishing of SCDC system core data set to match to other DSHS administrative data sets and conduct analyses on collected data with identifiable information
- Status of other data projects evaluating deidentified hospital discharge data from the Texas Health Care Information Collection to get a better idea of demographics and prevalence of individuals with SCD in Texas
- Contract in progress with UTHealth Houston to evaluate All Payor Claims Database for SCD and related visits in Texas from 2022-2024
- Contract in progress with University of Texas (UT) at Austin Moody School of Communication to develop an education module and handouts to increase awareness of SCD among university and college students and health care providers
- SCDC summer intern is working on an online survey to expand the photoblog project into a series
- Acknowledgement of other SCDC team members Victoria Salinas and Preciosa Martinez and summer intern, Mary Haynes

Member discussion:

- SCDC analysis of All Payor Claims Database will only be a one-time look at 2022-2024 data under the grant

- SCDC is working on dissemination plans for all colleges and requests SCTF member expertise in putting out the word
- DSHS approval for photoblog survey
- Usefulness of Texas Syndromic Surveillance data for SCDC reports

Action Item:

SCDC will provide report summaries at a future meeting once they receive approval for posting.

Agenda Item 6. SCTF subcommittee updates

Dr. Fasipe, Chair, announced they will not have a report from the Education Subcommittee. Dr. Fasipe asked for the Education Subcommittee to go on hiatus until HHSC appoints the member representing the Texas Education Agency to the SCTF. She also invited Mr. Harris to join the Medicaid Subcommittee in Dr. Johnson's place, and he accepted the invitation.

a. Medicaid Subcommittee (Dr. Fasipe, Dr. Frei-Jones and Dr. Johnson)

Dr. Frei-Jones, subcommittee member, provided the Medicaid Subcommittee update. The Medicaid Subcommittee met in January, March, and April 2025 and discussed the following:

- Implementation goals for House Bill 1488, 88th Legislature, Regular Session, 2023, including improving health outcomes, connecting patients with SCD experts, identifying high quality sickle cell programs, and directing patients to programs
- Role for SCTF to make recommendations to Medicaid to define what a sickle cell center should do in terms of care, such preventative stroke screening
- Quality care plans for patients under Medicaid and private plans
- Defining what an ideal sickle cell program would look like and making some actionable recommendations

b. Public Awareness Campaigns Subcommittee (Dr. Nero, Mrs. Reed-Shackelford, and Ms. Thomas Wade)

Ms. Thomas Wade, subcommittee member, provided the Public Awareness Campaigns Subcommittee update. The subcommittee met and discussed the following:

- Increase effectiveness of community engagement with public, community-based organizations (CBOs), and sickle cell community
- Role DSHS can play to bring CBOs together to collaborate and to perform sickle cell outreach

Member discussion:

- Role of subcommittee and task force as an advisory body
- Invite SCDC program to discuss UT Austin collaboration
- Invite UT Pharmacy students to discuss their work on enhancing resources and navigation for individuals living with sickle cell in central Texas

c. Education Subcommittee (Dr. Frei-Jones, Mr. Harris, and Ms. Thomas Wade)

The Education Subcommittee did not have an update for this meeting.

d. Legislatively Mandate Report Subcommittee (Dr. Fasipe, Dr. Frei-Jones, and Mrs. Reed-Shackelford)

Dr. Fasipe, SCTF Chair and subcommittee member, provided the Legislatively Mandated Report Subcommittee update. The subcommittee met and discussed the following:

- Goals for 2025 report, including how to make report be relevant but simple enough to be approachable for the community and legislators
- Using another DSHS advisory committee's report as an example

Agenda Item 7. 2025 SCTF annual report planning and discussion

Dr. Fasipe referenced the handout, *2024 Recommended Actions*, and reviewed each of 2024 SCTF Annual Report recommended actions and led members in a discussion on changes they would like to make for the 2025 SCTF Annual Report.

Member discussion:

- Health care coverage and access for individuals with sickle cell disease, especially after age 26, without Texas Medicaid expansion
- Ability of SCTF to convene legislators to share SCTF report

Action item:

Include sickle cell trait testing on a future meeting agenda.

Agenda Item 8. Public comment

Ms. Thompson, ACCO, HHSC, announced no one registered to provide public comment.

Agenda Item 9. Action items and future agenda items

Dr. Fasipe, Chair, announced the next meeting will be on Tuesday, August 19, 2025, and reviewed future agenda items. She then opened the floor for SCTF members to discuss and review future meeting topics and agenda items.

Future agenda items:

- Legislative update regarding House Bill 107 plans
- Standing agenda items
  - Program updates
  - Subcommittee updates
- Subject matter expert from another state with an innovative care or comprehensive coverage model for caring for people with SCD
- Vote to approve draft 2025 SCTF Annual Report

Member discussion:

- Presentation from University of Texas Pharmacy students
- Presentation on options for SCTF to engage with legislators and communicate information about the SCTF and their annual report
- Update on Texas' participation in the Centers for Medicare and Medicaid Services Cell and Gene Therapy Access Model

Agenda Item 10. Adjournment

Dr. Fasipe adjourned the meeting at 3:16 p.m.

Below is the link to the archived video recording of the June 26, 2025, SCTF meeting. The public may view and listen to this meeting recording for approximately two years from the date the meeting is posted, in accordance with the HHSC records retention schedule.

Sickle Cell Task Force – June 26, 2025 meeting