

Sickle Cell Task Force (SCTF)

Approved Meeting Minutes

Tuesday, August 19, 2025

1:00 p.m.

Virtual Site – Teams Meeting Platform

In Person Site – Robert Bernstein Building, Room K-100, First Floor

1100 W. 49th Street, Austin, Texas 78756

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

Ms. Linda Thomas Wade, Acting Chair, presided and called the Sickle Cell Task Force (SCTF) meeting to order at 1:01 p.m.

Ms. Thomas Wade turned the floor over to Ms. Jacqueline Thompson, Facilitator, Advisory Committee Coordination Office (ACCO), Texas Health and Human Services Commission (HHSC).

Ms. Thompson provided logistical announcements and conducted roll call. With four members present and two members absent, Ms. Thompson announced the presence of quorum.

Table 1. SCTF member attendance at the Tuesday, August 19, 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.	Yes ^a
Marqué Reed-Shackelford, Vice-Chair	Yes ^a
Linda Thomas Wade	Yes
Vacant	

^a Joined after Roll Call.

Ms. Thomas Wade announced Agenda Item #2, Consideration of the draft June 26, 2025, SCTF meeting minutes, is tabled and will be considered at the next meeting.

Ms. Thomas Wade then proceeded to Agenda Item #3.

Agenda Item 2. Consideration of June 26, 2025, draft meeting minutes – **TABLED**

Agenda Item 3. Consideration of draft 2025 SCTF Annual Report

Ms. Thomas Wade, Acting Chair, introduced Ms. Wendy Beathard, Manager, Special Projects, Newborn Screening Unit, Texas Department of State Health Services (DSHS), to present the draft 2025 SCTF Annual Report. Ms. Beathard referenced and reviewed the handout, *Sickle Cell Task Force 2024 Annual Report Recommendations*.

Ms. Beathard stated members will discuss the 2024 annual report recommendations. Ms. Beathard also stated the members will vote to adopt changes to the 2024 annual report recommendations for their 2025 annual report and to allow Dr. Fasipe, Chair, to edit the report on the members' behalf.

Member discussion:

Dr. Titilope Fasipe and Dr. Melissa Frei-Jones led a member discussion on the 2025 report's content and structure. Discussion included the changes members would like to make to the 2024 annual report recommendations. Dr. Fasipe and Dr. Frei-Jones asked for clarification if the task force members can edit the draft 2025 SCTF Annual Report after the SCTF votes to approve the report. Ms. Jacqueline Thompson, ACCO, HHSC, confirmed that SCTF members may vote to grant Dr. Fasipe, as subject matter expert, the authority to make substantive edits to the report. Ms. Thompson stated agency staff can only make non-substantive edits to the report.

Motion:

Ms. Thomas Wade, Acting Chair, requested a motion to approve the 2025 SCTF Annual Report recommendations with suggested changes, to authorize DSHS authority to make non-substantive edits to the 2025 SCTF Annual Report, and to authorize Dr. Fasipe, Chair, to make substantive edits to the 2025 SCTF Annual Report on the SCTF members' behalf. Mrs. Reed-Shackelford made the first motion. Mr. Harris seconded the motion.

Ms. Thomas Wade instructed Ms. Jacqueline Thompson, ACCO, HHSC, to conduct a roll call vote. Ms. Thompson conducted a roll call vote and announced the motion to approve the 2025 SCTF 2025 Recommendations carried by a majority vote of six approves (Dr. Fasipe, Dr. Frei-Jones, Mr. Harris, Dr. Nero, Mrs. Reed-Shackelford, and Ms. Thomas Wade), zero disapproves, zero abstentions, and zero absences.

Agenda Item 4. Medicaid Cell and Gene Therapy Access (CGT) Model

Ms. Thomas Wade, Acting Chair, introduced Aaliya Ahmad, Pharm.D., Pharmacist, Vendor Drug Program, HHSC. Dr. Ahmad referenced the presentation and handout, *Medicaid Cell & Gene Therapy Access Model*.

Presentation highlights included:

- CGT model is a Centers for Medicare and Medicaid Services (CMS) led initiative with state participation
- Focus is currently on sickle cell disease (SCD) gene therapies
- Treatment journey of sickle cell gene therapies
- Model framework
- Resources
 - CMS announcement (hhs.gov/press-room/cms-announces-participation-in-cell-and-gene-therapy-access-model.html)
 - CGT Model website (cms.gov/priorities/innovation/innovation-models/cgt)

Member discussion:

- Criteria to receive gene therapy under the model and where members may get more information.
- Clarifying the model start date in Texas.

Agenda Item 5. DSHS Newborn Screening (NBS) Program updates and announcements

Ms. Thomas Wade, Acting Chair, introduced Jessica Brown, M.D., M.P.H., Medical Director, NBS Unit, Ms. Leslie McKenzie, B.S.N., R.N., Unit Director, NBS Unit, DSHS, to provide program updates.

Presentation highlights included:

- Texas NBS Summit in Dallas, Texas – 80 attended in person and over 300 attended virtually.
- Dr. Brown presented NBS information at the Texas Sickle Cell Action Initiative in Houston, Texas.

Agenda Item 6. Sickie Cell Data Collection (SCDC) Program update

Ms. Thomas Wade, Acting Chair, introduced Ms. Preciosa Martinez, Epidemiologist, Texas SCDC Program and Environmental and Disease Registries (EEDRS) Section, DSHS, and Ms. Victoria Salinas, Texas SCDC Program and EEDRS Section, DSHS. Ms. Martinez and Ms. Salinas referenced the presentation and report, *Emergency Department Visits by Individuals with Sickie Cell Disease in Texas, 2023*.

Presentation highlights included:

- Purpose and background of the first Texas SCDC Program report, *Emergency Department Visits by Individuals with Sickie Cell Disease in Texas, 2023*
- Report utilizes deidentified and aggregate 2023 data from the DSHS Texas Health Care Information Collection (THCIC) System Hospital Emergency Department Public Use Data files.
- THCIC is responsible for collecting and reporting data on Texas health care activity and related claims.
- In 2023, a total of 19,109 Emergency Department (ED) visits by individuals with SCD were reported to the THCIC System.
- Most common diagnosis among ED visits by individuals with SCD was Hb-SS disease, or sickie cell anemia, with unspecified crisis.
- The highest rate of ED visits by individuals with SCD occurred in Public Health Regions (PHRs) 4 and 5.
- 2023 report includes ED visit rates of individuals with SCD broken down by race, ethnicity, SCD genotype, age group, sex, patient stay, discharge outcome, payer type (such as Medicaid or private insurance), and cost.
- Data limitations
- Next steps

Member discussion:

- Causes of death among individuals with that discharge outcome.
- Availability of county-level data for determining ED visits in rural areas
- Future analysis possibilities with identifiable data

Agenda Item 7: Sickie Cell Task Force Subcommittee updates

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

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

- Welcoming Mr. Harris, who joined after Dr. Dawn Johnson's departure from the SCTF.
- Dr. Frei-Jones and Mr. Harris will serve as co-chairs until new members join the subcommittee.
- Dr. Ryan Van Ramshorst, Chief Medical Director, Medicaid and CHIP Services, HHSC, will join the subcommittee meetings regularly to provide insight into Medicaid and Medicaid programs.
- Updating the Texas Health Steps Online Provider Education Module on SCD to make it more comprehensive and eligible for Continuing Education credit.
- Updating Texas Health Steps periodicity schedule to include counseling on sickle cell trait for teens diagnosed with sickle cell trait during newborn screening.
- Considering Managed Care Organization contract changes to include sickle cell as health inclusion criteria for members with special health care needs.
- Pursuing SCD-specific quality metrics through one or more preliminary discussions with external quality review organizations.

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

Dr. Nero, subcommittee member, provided the Public Awareness Campaigns Subcommittee update. The subcommittee met to regroup and discussed the following:

- Previous initiatives such as sickle cell education for schools.
- Ways to disseminate and make known sickle cell activities across the state to increase awareness, engagement, and involvement.

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

Since this agenda item was addressed earlier in the meeting, Ms. Thomas Wade, Acting Chair, hearing no questions or comments, proceeded to Agenda Item #8.

Agenda Item 8. Sickie Cell Outcomes Policy, and Excellence Conference

Dr. Fasipe, Chair, presented an update on the Sickie Cell Outcomes, Policy, and Excellence Conference and the Texas Sickie Cell Action Plan Initiative Meeting.

Presentation highlights included:

- Conference was held on Thursday, August 14, 2025 and was followed by the third Texas Sickie Cell Action Plan Initiative meeting.
- Ninety participants attended in person and some attended virtually.
- Conference focused on one of the biggest challenges of individuals with SCD face, which is care.
- Conference kicked off with a keynote speaker who reflected on the history and trajectory of how to improve health outcomes of sickie cell and challenges that persist.
- A panel session followed focusing on comprehensive care and transition.
- The last panel focused on transformative therapies, including transplant and gene therapies.
- Texas Sickie Cell Action Plan Initiative Meeting happened the second day and had several presentations, including one from Dr. Brown, NBS Unit Medical Director and one on educating emergency medicine professionals.
- After the presentations, three workgroups on Assurance, Assessment, and Policy Development met, shared notes, and made plans for future meetings.

Agenda Item 9. Texas Sickie Cell Action Plan Initiative Meeting

Since Dr. Fasipe shared information on the Texas Sickie Cell Action Plan Initiative Meeting during Agenda Item #8, Ms. Thomas Wade, Acting Chair, proceeded to Agenda Item #10.

Agenda Item 10. Public Comment

Ms. Thompson, ACCO, HHSC, stated, for the record, no one pre- registered for public comment and no one registered onsite for public comment.

Agenda Item 11. Action Items and future agenda items

Ms. Thomas Wade, Acting Chair, invited members to submit agenda topics for the next meeting. Ms. Thomas Wade then announced the next meeting will take place

on December 12, 2025, at 1:00 p.m. in the Moreton Building, Room M-100, and to notify the committee liaison, Ms. Aimee Millangue, of any scheduling conflicts.

Agenda Item 12. Adjournment

Ms. Thomas Wade, Acting Chair, adjourned the SCTF meeting at 2:12 p.m.

Below is the link to the archived video recording of the August 19, 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 – August 19, 2025, meeting](#)