Sickle Cell Task Force (SCTF)

FINAL Meeting Minutes

Monday, February 2, 2026
1:00 p.m.

Virtual Site – Teams Meeting Platform
In Person Site – Robert Bernsten Building, Room K-100, First Floor
1100 W. 49th Street, Austin, Texas 78756

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

Dr. Titilope Fasipe, Chair, presided over the Sickle Cell Task Force (SCTF) meeting and called the meeting to order at 1:02 p.m.

Dr. Fasipe introduced Ms. Christina Alaniz, Facilitator, Texas Health and Human Services Commission (HHSC) Advisory Committee Coordination Office (ACCO).

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

Table 1. SCTF member attendance at the Monday, February 2, 2026, 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
Justin Luong, Pharm.D.	Yes
Alecia Nero, M.D.	Yes
Marqué Reed-Shackelford, Vice-Chair	Yes
Linda Thomas Wade	No
Vacant	Not applicable

Dr. Fasipe welcomed everyone in attendance and acknowledged Texas Department of State Health Services (DSHS) staff. Dr. Fasipe then requested a moment of silence to reflect on those lost to sickle cell disease and goals for 2026. Dr. Fasipe also welcomed new member, Dr. Justin Luong, and gave him the opportunity to provide his background and additional remarks.

Agenda Item 2. Consideration of December 12, 2025, draft meeting minutes

Dr. Titilope Fasipe, Chair, reminded members they should have received a copy of the December 12, 2025, draft meeting minutes by email and called for any edits or changes. Hearing none, Dr, Fasipe called for a motion to approve December 12, 2025, draft meeting minutes.

Motion:

Mr. André Harris motioned to approve the December 12, 2025, draft meeting minutes. Dr. Melissa Frei-Jones seconded the motion.

Dr. Fasipe opened the floor for members to discuss the motion. Hearing no discussion, Dr. Fasipe turned the floor over to Ms. Christina Alaniz, Facilitator, HHSC ACCO. Ms. Alaniz conducted a roll call vote and announced the motion to approve the December 12, 2025, draft meeting minutes as written carried with six approves (Dr. Titilope Fasipe, Dr. Melissa Frei-Jones, Mr. André Harris, Dr. Justin Luong, Dr. Alecia Nero, and Mrs. Marqué Reed-Shackelford), zero disapproves, zero abstentions, and one absence (Ms. Linda Thomas Wade).

Agenda Item 3. Hemoglobinopathy testing methods and variant identification

Dr. Titilope Fasipe, Chair, introduced Omar Ordonez, B.S., Micr., Hemoglobinopathy Screening Group Manager, Hemoglobinopathy Screening Laboratory, DSHS Laboratory and Infectious Disease Services. Mr. Ordonez stated he will provide an update to his presentation at the previous meeting and referenced the PowerPoint and handout, *Methods and Variant Identification*.

Presentation highlights included:

- Hemoglobinopathy testing methods.
- Data table showing hemoglobin variants identified and the methods used for identification.

Member discussion:

- Complexities of the process looking at hemoglobinopathy testing methods.
- Timeline for transitioning to new testing methods.
- Opportunity for stakeholders to provide feedback.
- Projected future testing methods.

- Looking at other states' testing methods.
- Clarifying if some testing methods may miss specific hemoglobin variants and if further testing may identify those variants.
- Impact of switching order of testing methods on volume of retesting and cost.

Agenda Item 4. Medicaid Cell and Gene Therapy Access Model update

Dr. Titilope Fasipe, Chair, introduced Justin Luong, Pharm.D., HHSC representative SCTF member and Drug Utilization Review Formulary Management Director, Vendor Drug Program, HHSC Medicaid and Children's Health Insurance Program Services. Dr. Luong provided an update.

Presentation highlights included:

- Centers for Medicare and Medicaid Services implemented the Cell and Gene Therapy Access Model on September 1, 2025.
- Names and companies of two gene therapies.
- Model offers client access to fertility preservation services.
- High-level clinical criteria and where it can be found.

Member discussion:

- What informed eligibility criteria.
- Number of Texans who may be eligible for participation.

Agenda Item 5. DSHS Newborn Screening Program updates and announcements

Dr. Titilope Fasipe, Chair, introduced Jessica Brown, M.D., MPH, Medical Director, Newborn Screening Unit, DSHS, and Ms. Leslie McKenzie, BSN, RN, Unit Director, Newborn Screening Unit, DSHS, to provide program updates.

Presentation highlights included:

- Redesigned sickle cell trait brochure includes potential sickle cell trait symptoms.
- Virtual hematology specialist collaborating partnership annual meeting on March 27, 2026.

- Request to share Medicaid Cell and Gene Therapy model recruitment process during the March specialist meeting.

Member discussion:

- Sickle cell trait brochure:
  - Distribution and
  - Opportunity for SCTF member review and feedback.

Action item:

Program will email a copy of the sickle cell trait brochure to members.

Agenda Item 7. Sickle Cell Data Collection (SCDC) and House Bill (HB) 107, 89th Texas Legislature, Regular Session, 2025 update

Dr. Titilope Fasipe, Chair, introduced Heidi Bojes, Ph.D., MPH, Director, Environmental and Disease Registries (EEDRS) Section, DSHS, and Principal Investigator, Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) Program grant, to provide an update on recent sickle cell disease legislation and grant program activities.

Presentation highlights included:

- DSHS is conducting a registry assessment with consultants to outline how DSHS can establish the sickle cell disease registry required by HB 107 by the 89th Texas Legislature, Regular Session, 2025.
- Consultants are collecting stakeholder feedback.
- An overview of the third year of SCDC grant activities:
  - Status of establishing a SCDC core data set using administrative datasets such as identifiable hospital discharge information.
  - Collaboration on a multi-state sickle cell disease prevalence project with other grantees.
- Other projects in various states of completion:
  - Status of complementary data analysis projects using deidentified data.
  - Updates to existing state pediatric hematology consultants list, which will include practicing pediatric and adult hematologists.
  - Status of collaboration with University of Texas at Austin School of Communication to develop educational materials

- Completed reports and materials are posted to the DSHS SCDC website.
- Status of sickle cell disease reporting within Reportable Conditions Knowledge Management System disease surveillance system.
- Redesign of DSHS SCDC website based on stakeholder feedback.
- Acknowledgement of other SCDC team members Victoria Salinas and Preciosa Martinez and the work of the SCTF and stakeholders.

Member discussion:

- Hematology sickle cell providers list needed.
- Recruiting providers to care for people with sickle cell based on need in area.
- Identifying places needing more sickle cell providers based on prevalence data to find opportunities for intervention.
- Questions for potential sickle cell providers.
- National Alliance of Sickle Cell Centers annual program advocating for sickle cell care.
- If sickle cell providers list will include other subspecialties other than hematology and oncology.
- Providing feedback on sickle cell registry.
- Consent process for sickle cell registry.
- Timeline of summary documents for sickle cell data reports.

Agenda Item 7. SCTF subcommittee updates

a. Medicaid Subcommittee (Dr. Titilope Fasipe, Dr. Melissa Frei-Jones, and André Harris)

Mr. André Harris, Subcommittee Co-Chair, provided the Medicaid Subcommittee update and stated that more information is available in the subcommittee meeting minutes. The subcommittee met January 13, 2026, and discussed the following:

- Changing meeting frequency to quarterly.
- Dr. Justin Luong providing a Medicaid Cell and Gene Therapy model update at the next SCTF meeting.
- Recommended actions.
- Medicaid eligibility.

- Educating public about Medicaid eligibility and options to pursue coverage.
- Having ongoing discussion about the Qualified Medicare Beneficiary Program and how it can be helpful to people living with sickle cell in Texas.
- Texas Health Steps Education module.

Member discussion:

- National Academies of Science, Engineering, and Medicine Social Security assessment webinar recommendations on eligibility criteria.
- Recommending Social Security eligibility as a subcommittee or SCTF agenda item.

b. Public Awareness Campaigns Subcommittee (Dr. Alecia Nero, Marqué Reed-Shackelford, and Linda Thomas Wade)

Dr. Alecia Nero, subcommittee member, provided the Public Awareness Campaigns Subcommittee update. The subcommittee met January 16, 2026, joined by DSHS staff including Preciosa Martinez, EEDRS, SCDC Program, and discussed the following:

- Future goals.
- Creation of resources for the community, such as a community health worker one-pager, toolkits, and press releases.
- Prairie View A & M University initiative.
- Statewide sickle cell meetings.
- Sickle cell website events calendar.
- Meeting frequency.

Members discussed:

- SCDC collaboration.
- Historical DSHS-organized sickle cell meetings.
- Budget and funding barriers for public awareness activities.

Agenda Item 8. Sickle cell trait testing discussion - TABLED

Agenda Item 9. 2026 SCTF Annual Report development discussion

Dr. Titilope Fasipe, Chair, stated members received a copy of the 2025 recommended actions to use as a roadmap for subcommittee agenda items. Dr.

Fasipe led members in a discussion of any changes and updates members would like to make.

Member discussion:

- Ways to receive public input and interaction on SCTF recommendations outside current public comment avenues.
- Committing to place public comment topics on a SCTF or subcommittee agenda.

Agenda Item 10. Member reports

Dr. Titilope Fasipe, Chair, stated member reports is a new standing agenda item added at the December meeting. Dr. Fasipe called on each member to share any clinical partner, community-based organization, or advocacy or warrior activities.

Member reports included:

- Dr. Melissa Frei-Jones
- Program did not have a sickle cell nurse for a year after a long-time nurse retired.
  - Programs need more:
    - Sickle cell nurses, care team members, navigators, and coordinators and
    - Institutional administrative support to maintain staff needed for patient populations.
- Dr. Justin Luong
  - Under the Vendor Drug Program, the sickle cell drug class under the pharmacy benefit is a Preferred Drug List class that gets reviewed once a year.
  - Since the agents in the class are all preferred, they do not need prior authorization.
  - Next Drug Utilization Review Board meeting is on April 21, and they will take comment from the public and drug manufacturers.
- André Harris
- Representing community-based organizations along with thousands of advocates who are going to Washington, D.C. at the end of February to support Rare Disease Week and Rare Disease Day.

    - While 2026 is an off year for the legislature, rare disease stakeholders will also rally at the Austin capitol, various city halls, and other bodies.
    - Every Life Foundation has more information under "Rare Disease Week."
- Dr. Alecia Nero
    - Texas Association of Black Female Physicians Winter Symposium is February 28 in Frisco, and Dr. Nero will be organizing the education session with renal disease and sickle cell discussion and sickle cell treatment updates.
- Dr. Titilope Fasipe
    - National Academies of Science, Engineering, and Medicine has a webinar, "Sickle Cell Disease in Social Security Disability Evaluations" that discusses getting better access to sickle cell care.

Agenda Item 11. Public Comment

Ms. Christina Alaniz, ACCO, HHSC, stated, for the record, no one registered for public comment.

Agenda Item 12. Action Items and future agenda items

Dr. Titilope Fasipe, Chair, led members in a discussion of action items and future agenda items.

Member discussion:

- Continuing discussion on the future of hemoglobinopathy testing.
- Standing agenda items:
    - Subcommittee updates.
    - Member updates.
    - Program updates.
- Discuss feedback on sickle cell trait brochure updates.
- Executing public awareness subcommittee goals.
- Goals from past DSHS sickle cell state meetings.
- Membership updates.

Dr. Fasipe stated members should send other agenda items to Aimee Millangue, Advisory Committee Liaison, DSHS NBS Unit. She announced the next meeting is May 15, 2026, at 1 p.m.

Agenda Item 14. Adjournment

Dr. Titilope Fasipe, Chair, adjourned the Sickle Cell Task Force meeting at 3:13 p.m.

Below is the link to the archived video recording of the February 2, 2026, 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 – February 2, 2026 meeting