Sickle Cell Task Force (SCTF)

FINAL Meeting Minutes

Friday, December 12, 2025
1:00 p.m.

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

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

Mrs. Marqué Reed-Shackelford, Vice-Chair, presided over the Sickle Cell Task Force (SCTF) meeting and called the meeting to order at 1:03 p.m.

Mrs. Reed-Shackelford introduced 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 five members present and two absent, Ms. Thompson announced the presence of quorum.

Table 1. SCTF member attendance at the Friday, December 12, 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
Justin Luong, Pharm.D.	No
Alecia Nero, M.D.	Yes
Marqué Reed-Shackelford, Vice-Chair	Yes
Linda Thomas Wade	No
Vacant	Not applicable

Mrs. Reed-Shackelford announced Agenda Item #10, Sickle cell trait testing discussion, is tabled and will be discussed at a future meeting.

Agenda Item 2. Consideration of June 26, 2025, and August 19, 2025, draft meeting minutes

Ms. Jacqueline Thompson, Facilitator, ACCO, HHSC, reminded members they should have received a copy of the June 26, 2025, and August 19, 2025, draft meeting minutes and called for any edits or changes. Hearing none, Ms. Thompson asked members if there is a motion to approve the June 26, 2025, and August 19, 2025, draft meeting minutes.

Motion:

Mr. André Harris made a motion to approve the June 26, 2025, and August 19, 2025, draft meeting minutes. Dr. Melissa Frei-Jones seconded the motion.

Ms. Thompson conducted a roll call vote and announced the motion to approve the June 26, 2025, and August 19, 2025, draft meeting minutes carried with four approves (Dr. Titilope Fasipe, Dr. Melissa Frei-Jones, Mr. André Harris, and Mrs. Marqué Reed-Shackelford), zero disapproves, one abstention (Dr. Alecia Nero), and two absences (Dr. Justin Luong and Ms. Linda Thomas Wade).

Agenda Item 3. 2025 SCTF annual report status and recommendations discussion

Mrs. Marqué Reed-Shackelford, Vice-Chair, reviewed the 2025 SCTF annual report recommended actions with members and referenced the handout, *2025 Sickle Cell Task Force Annual Report.*

Member discussion:

- Dr. Titilope Fasipe, Chair, thanked members for their support in giving her the ability to approve edits made during the report's approval process and for fine-tuning the language for developing the recommended actions.
- If members notice changes from the report they approved of in August, Texas Department of State Health Services (DSHS) staff needed to make minor edits during the review and approval process.
- Dr. Fasipe stated they were able to build upon their previous recommended actions and word them more strategically.
- Members are optimistic about additional members joining the SCTF to help them move forward on their action items and create even more focused recommended actions in next year's report.

Agenda Item 4. Member reports

Mrs. Marqué Reed-Shackelford, Vice-Chair, introduced Jessica Brown, M.D., MPH, Medical Director, Newborn Screening Unit. Dr. Brown gave an overview and the context for member reports as a new standing agenda item. Member reports will be an opportunity for members to give updates about the sickle cell community. Mrs. Reed-Shackelford called on members to share any applicable updates.

a. Clinical partner activities

- Dr. Alecia Nero
  - Thanked members for their support, participation, and spreading the word of the September health expo and blood drive event for Sickle Cell Awareness month held in the Dallas area at Concord Church. She spearheaded the event with Dr. Clarissa Johnson at Cooks Fort Worth with support from the C.V. Roman Medical Society. She also called for support next year's event set for the last Sunday of September 2026 at Concord Church.
  - Through the Texas Association of Black Female Physicians, working on the challenge, particularly with adult sickle cell care, of having enough people experienced in competent and compassionate care of sickle cell patients. Planning to offer educational credit for people who can take care of people with sickle cell disease, tentatively for the end of February. The curriculum is intended for physicians and non-physician staff who can care for sickle cell patients and get them up to date with the guidelines and management of sickle cell disease. Asking for partnerships and promotion, especially in places where patients need access to sickle cell care and providers who have expertise with sickle cell care.
- Dr. Melissa Frei-Jones – Involved with the National Alliance of Sickle Cell Centers, who are working on consensus guidelines and just published consensus guidelines for pediatric patients from birth to 18 on their website, sicklecenters.org.

b. Community-based activities

- Mrs. Marqué Reed-Shackelford – Supporting our Sickle Cell Survivors is working on a spring workshop for caregivers at the end of April and will share information at the next meeting.
- Mr. André Harris

- The Sickle Cell Association of Houston will have some holiday activities, such as giveaways, for the local community.
- Recently attended sickle cell-related conferences from American Society of Hematology and Sickle Cell Disease Association of America and learned about new therapies and interventions from pharmaceutical partners.

c. Sickle cell warrior activities

- Mr. André Harris – Some in the sickle cell warrior community are partnering with pharmaceutical partners to help roll out launches of new therapies.

Member discussion:

Mr. André Harris requested clarification if members need to submit their reports ahead of time for approval.

Agenda Item 5. DSHS Newborn Screening Program updates and announcements

Mrs. Marqué Reed-Shackelford, Vice-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. Dr. Brown and Ms. McKenzie referenced the PowerPoint and handout, *Newborn Screening Program Updates*, *December 12, 2025.*

Presentation highlights included:

- New disorder implementation of lysosomal diseases on August 18, 2025
- New disorder implementation of guanidinoacetate methyltransferase deficiency expected in late Winter or Spring 2026
- Availability of the Clinical Care Coordination staff contacts list and 24-hour phone line
- Provider Survey Summary
- Texas Newborn Screening Summit
- Feedback from surveys

Agenda Item 6. Potential future of hemoglobinopathy newborn screening

Mrs. Marqué Reed-Shackelford, Vice-Chair, introduced Omar Ordonez, Hemoglobinopathy Screening Group Manager, Hemoglobinopathy Screening

Laboratory, Laboratory and Infectious Disease Services, DSHS. Mr. Ordonez referenced the PowerPoint and handout, *Potential Future of Hemoglobinopathy Newborn Screening*.

Presentation highlights included:

- Current Hemoglobinopathy Screening Lab workload and overview of the primary and secondary testing methods
- Isoelectric focusing (IEF) testing process, screen gel, and retest gel
- Current high-performance liquid chromatography (HPLC) testing
- Potential future of hemoglobinopathy newborn screening overview
- HPLC as a primary method
- HPLC missed variants
- HPLC benefits
- HPLC with two methods
- Capillary Electrophoresis (CE)
- CE variants
- CE Barts
- Summary
- Next steps
- Questions for members
- Contacts

Member discussion:

- Reviewing the options the Hemoglobinopathies Laboratory is considering for replacing their current primary and secondary testing methods.
- Changing the laboratory's hemoglobinopathy testing methods to options that require less manual labor will impact a small subset of variants.
- Clarifying what results would continue to be reported and what results would no longer be reported through each type of testing method.
- What would happen if the laboratory skips the IEF retest and uses HPLC after the initial IEF screen gel because HPLC is a less labor-intensive process.

Action Item:

Mr. Ordonez will circle back with the SCTF once the laboratory completes their cost analysis and include how the volume of specimens needing retesting changes with each level and method of testing.

Break

At Mrs. Marqué Reed-Shackelford, Vice-Chair, announced a 15-minute break at 2:37 p.m.

Mrs. Reed-Shackelford called the meeting to order at 2:53 p.m. and asked Ms. Jacqueline Thompson, Facilitator, ACCO, HHSC, to conduct a roll call.

Ms. Thompson conducted roll call. With five members present (Dr. Titilope Fasipe, Dr. Melissa Frei-Jones, Mr. André Harris, Dr. Alecia Nero, and Mrs. Marqué Reed-Shackelford) and two members absent (Dr. Justin Luong and Ms. Linda Thomas Wade), Ms. Thompson announced the presence of quorum.

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

Mrs. Marqué Reed-Shackelford, Vice-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:

- The passing of HB 107 by the 89th Texas Legislature, Regular Session, 2025, which requires DSHS to establish a sickle cell disease registry.
- The unique requirements of the registry under statute.
- DSHS using the funding awarded by the Texas legislature to conduct a registry assessment to outline how DSHS can establish the registry.
- How the assessment will help DSHS propose appropriate Information Technology solutions and costs during the next legislative session.
- Start date of the assessment.
- An overview of the third year of SCDC grant activities:

    - Status of establishing a SCDC core data set of individuals living with sickle cell disease by using newborn screening data as the base and linking that data to various administrative datasets available at DSHS, such as hospital discharge records and vital records.
    - They received Institutional Review Board approval to start obtaining data with identifiable information
    - What analyses they plan to conduct.
- Other projects in various states of completion:
    - Multi-state prevalence project to update a 2010 paper estimating the number of people with sickle cell disease in the United States.
    - A project using deidentified hospital discharge data from emergency department visits from individuals with sickle cell disease in Texas in 2023.
    - A complementary report evaluating non-emergency or hospital visits by individuals with sickle cell disease in 2023.
    - Collaboration with UTHealth Houston to evaluate 2022-2023 All Payor Claims data to describe the patterns in health care utilization among individuals with sickle cell disease identified in the health care claims database.
    - Collaboration with University of Texas at Austin School of Communication to develop educational materials for campus health care providers and students in Texas to inform them about sickle cell disease and the transition from pediatric to adult care.
- Completed reports and materials are posted to the SCDC website.
- Public Health Informatics Data team set up Reportable Conditions Knowledge Management System (RCKMS) for sickle disease reporting, and they are working on implementing this data source. RCKMS is a real-time portal to enhance disease surveillance, and very simply will help receive electronic case reports from health care facilities.
- Acknowledgement of other SCDC team members Victoria Salinas and Preciosa Martinez and the work of the SCTF and stakeholders.

Member discussion:

- Identifying barriers or issues that may prevent people from opting in to the sickle cell registry and circumventing the barriers or issues is a data gap that will be addressed during the IT assessment.

- One of the registry assessment deliverables for IT consultants is to get stakeholder input and SCTF member feedback is important for that phase of the project
- The hope that RCKMS will be a good source of information and how other DSHS programs with RCKMS experience may share lessons learned with EEDRS.

Action Item:

The SCDC Program will brainstorm ideas for other analyses, and they welcome suggestions from the SCTF.

Agenda Item 8. Newborn Screening Benefits Program presentation

Mrs. Marqué Reed-Shackelford, Vice-Chair, introduced Robyne Damond, Program Specialist, Newborn Screening Benefits Program, Newborn Screening Unit, DSHS. Ms. Damond referenced PowerPoint and Handout*, Newborn Screening Benefits Program*.

Presentation highlights included:

- Program history
- Overview
- Newborn Screening Benefits Lifecycle
- Eligibility requirements
- Priority populations
- Presumptive eligibility and standard application processes
- Fiscal year 2025 open enrollment
- Open enrollment contractor requirements
- Open enrollment resources
- Contact information for program partners

Dr. Jessica Brown, Medical Director, Newborn Screening Unit, DSHS, clarified that the Newborn Screening Benefits Program differs from traditional medical insurance or Children with Special Health Care Needs in that it does not cover well child exams, annual exams, emergency room visits, hospitalizations, or durable medical equipment. It is more designed for interaction with specialists. Dr. Brown also stated Benefits does not currently have any clinicians, hospitals, or clinics who are currently listed as vendors to care for people with hemoglobinopathies, including

sickle cell disease, so she asked for anyone interested in participating to please reach out. The Benefits Program can potentially help fill a gap in care for children up to 21 years and 364 days old.

Agenda Item 9: Sickle Cell Task Force Subcommittee updates

Mrs. Marqué Reed-Shackelford, Vice-Chair, stated the subcommittees did not meet this quarter, so the subcommittees do not have updates for this meeting.

Agenda Item 10. Sickle cell trait testing discussion - TABLED

Agenda Item 11. 2026 report development discussion

Mrs. Marqué Reed-Shackelford, Vice-Chair, opened the floor for members to discuss ideas for their 2026 annual report. Hearing no discussion, Mrs. Reed-Shackelford moved to Agenda Item #12.

Agenda Item 12. Public Comment

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

Agenda Item 13. Action Items and future agenda items

Mrs. Marqué Reed-Shackelford, Vice-Chair, announced the next meeting will take place on Monday, February 2, 2026, at 1:00 p.m. in the Moreton Building, Room M-100. Mrs. Reed-Shackelford then 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 reports
  - Program updates
- Update on Texas' participation in the Medicaid Cell and Gene Therapy Access Model
- Sickle cell trait testing discussion

Mrs. Reed-Shackelford stated if members have any scheduling conflicts, to please reach out to the committee liaison, Aimee Millangue, at the email address at listed on the posted public agenda.

Agenda Item 14. Adjournment

Mrs. Marqué Reed-Shackelford, Vice-Chair, adjourned the Sickle Cell Task Force meeting at 3:37 p.m.

Below is the link to the archived video recording of the December 12, 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 – December 12, 2025, meeting