

Sickle Cell Task Force

FINAL APPROVED

Meeting Minutes

Tuesday, December 10, 2024

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

Melissa Frei-Jones, M.D., M.S.C.I., Presiding Member, called the Sick Cell Task Force (SCTF) meeting to order at 1:04 p.m.

Dr. Frei-Jones provided welcoming remarks and turned the floor over to Jacqueline Thompson, Facilitator, Advisory Committee Coordination Office, 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 and announced the presence of quorum.

Table 1. SCTF member attendance at the Tuesday, December 10, 2024, 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
Dawn Johnson, M.D.	Yes
Alecia Nero, M.D.	Yes
Marqué Reed-Shackelford, Vice-Chair	No
Linda Wade	Yes

Agenda Item 2. Consideration of August 19, 2024, draft meeting minutes

Dr. Frei-Jones asked members to review the draft meeting minutes they received through email and called for any edits or changes. Hearing none, Dr. Frei-Jones

called for a motion to approve the August 19, 2024, draft meeting minutes as written.

Motion:

Ms. Linda Wade moved to approve the draft minutes from the August 19, 2024, meetings as written. Dr. Johnson seconded the motion. Ms. Thompson conducted a roll call vote and announced the motion carried by a majority vote with five approves (Dr. Fasipe, Dr. Frei-Jones, Dr. Johnson, Dr. Nero, and Ms. Wade), zero disapproves, and zero abstentions.

Agenda Item 3. Membership update

Dr. Frei-Jones provided an update regarding the solicitation for new members and membership status. Dr. Frei-Jones stated the membership applications are under review. The hope is to fill the new and other openings positions by the next meeting.

Member discussion:

Members did not have any questions or comments.

Agenda Item 4. Texas Department of State Health Services (DSHS) Newborn Screening (NBS) Program updates

Dr. Frei-Jones 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. Ms. McKenzie and Dr. Brown referenced the PowerPoint and handout, *Newborn Screening Program Updates, December 10, 2024*.

Presentation highlights included:

- Recap of August 23, 2024, NBS Education Conference
 - Outcome
 - Theme
 - Goal
 - Turnout
 - Continuing education credits offerings
 - Attendee feedback
- 2025 NBS Education Conference announcements

- Clinician Survey
 - Timeline
 - Purpose
 - Initial takeaways
 - Need for increased participation from physicians, midwives, and advanced practice providers.
 - Request for SCTF members' help to share survey link.
- Newborn Screening Awareness Month
 - September 2024 activities
 - Plans for 60th anniversary in September 2025
- SCTF and Newborn Screening Advisory Committee updates
 - New member solicitation timeline
 - Application deadlines

Member discussion:

Members did not have any questions or comments.

Agenda Item 5. Sickle Cell Data Collection Program update

Dr. Frei-Jones 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:

- Reviewing CDC cooperative agreement details and purpose.
- Progress toward:
 - Goal to develop a SCDC system and conduct analyses on collected data.
 - ◇ Institutional Review Board (IRB) application final approval is pending.
 - ◇ Need IRB approval to collect data with identifiable information.
 - ◇ Pending IRB approval, they will establish a core dataset of individuals with sickle cell disease (SCD) using NBS data as the base.
 - ◇ They will match or link NBS data to other DSHS administrative datasets to fill in missing or verify existing information.

- ▶ Other data projects using deidentified information to get a better idea of demographics and prevalence of individuals with SCD in Texas and developing reports on:
 - ◊ Texas Health Care Information Collection health care activity and hospital data.
 - ◊ Syndromic Surveillance System emergency department, clinical setting, and non-clinical setting data.
- CDC SCDC Program Annual Meeting and Sickle Cell Disease Summit November meeting recap:
 - ▶ DSHS and Multi-disciplinary Team attendees.
 - ▶ Central theme.
- Reformatting quarterly multi-disciplinary meetings to focus on the CDC Annual Meeting central theme of communities.
- Multi-Disciplinary Team quarterly recap:
 - ▶ Held on November 20, 2024.
 - ▶ Featured overviews of two community-based organizations.
- Photo blog:
 - ▶ Currently highlights a SCD patient advocate.
 - ▶ They have plans to build upon photo blog with a series of photo blogs on the sickle cell community.
 - ▶ They will continue to share on the program's website and with partners.

Member discussion:

Members did not have any questions or comments.

Agenda Item 6. SCTF subcommittee updates

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

Dr. Frei-Jones turned the floor over to Dr. Johnson to provide the Medicaid Subcommittee update.

Update highlights included:

- Reviewing asks in House Bill 1488, Texas Legislature, 88th Regular Session, 2023.

- Discussing how to work with Medicaid insurance plans to get data.
- Hopes to create quality efforts around the data.
- Progress made in looking at how many people with SCD on Medicaid have seen a hematologist in the past 12 months.
- Hopes to work with data to create a plan to present to insurance plans and government entities to help collaborate on ensuring people with SCD have access to a hematologist.
- Discussed proposals to create sickle cell centers of excellence to improve patient access to SCD experts and multidisciplinary care teams.

Member discussion:

Agency staff have helped members understand processes for when the subcommittee makes recommendations.

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

Dr. Frei-Jones announced the postponement of the Public Awareness Campaigns Subcommittee update.

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

Update highlights included:

- Final draft emailed to members.
- Appreciation for member feedback.
- Reviewing recommended actions in the final report.

Member discussion:

Members did not have any questions or comments.

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

Update highlights included:

- Continuing conversations started by the Medicaid Subcommittee on House Bill 1488 education recommendations focused on patients, caregivers, individuals with SCD, and providers focused on:

- Medical provider education.
- Public school education.
- Looked at options to engage with public schools, school nurses, and other groups who provide education in school districts.
- Looked at options and opportunities to make sure trainees in various medical specialties who interact with people with SCD have sickle cell education.

Member discussion:

Members did not have any questions or comments.

Agenda Item 7. Public engagement discussion

Dr. Frei-Jones stated the members will discuss ways to increase public awareness of the SCTF, and she opened the floor for discussion.

Member discussion:

- Past public comment received from patients, caregivers, or family members.
- Proposing the Education Subcommittee explores the issue.
- How to involve the community:
 - Social media where sickle cell community congregates virtually.
 - Community organization advertisement of messages suggested by Education Subcommittee.

Agenda Item 8. SCTF annual report

a. Status update

Dr. Frei-Jones stated the SCTF reviewed the report as part of the Legislatively Mandated Report Subcommittee update.

b. Recommended actions discussion

Dr. Frei-Jones opened the floor for members to discuss the report and recommended actions more specifically.

Member discussion:

- Identifying subcommittees to look at specific recommended actions.
- Not likely the Texas Legislature would change Medicaid enrollment eligibility.

- Continuing to look for ways for a Medicaid carve out for this population.
- Expanding the conditions the Children with Special Health Care Needs Program covers throughout the lifespan to include SCD.
- What advocacy would look like.
- Pushing for lifespan coverage.
- The possibility of making progress exists even if it is unlikely.
- Unsure how to get Texas Legislature to act on recommendations.
- Expand current Medicaid Subcommittee scope to include:
 - Access to care.
 - Sickle cell care models.
- A new subcommittee for:
 - Studying development of comprehensive medical home models.
 - Creating outcome measures.
 - Quality improvement projects.
 - Increasing access to care.
 - Lifespan care models.
 - Comprehensive sickle cell centers.
- Adding subcommittees:
 - Quality
 - Clinical
 - Care
- Continuing to think of ways to support patients without health care coverage.
- Addressing issues with adolescents' ability to access their sickle cell NBS results through a standard of care approach.

Agenda Item 9. Public comment

Ms. Thompson announced no one registered to provide public comment.

Action Item:

Mr. Harris will email comments for the NBS program to share with SCTF members.

Agenda Item 10. Action items and future agenda items

Dr. Frei-Jones opened the floor for SCTF members to discuss and review future meeting topics and agenda items and announced the next meeting will be on May 16, 2025.

Member discussion:

- SCTF usually has a February and May meeting.
- Postponing the next meeting may mean the SCTF will skip a meeting and meet only three times this year instead of four.
- New member orientation for new members.
- Identifying additional presenters for future meetings when new members can attend.

Future agenda items:

- Subcommittee updates
- NBS Program updates
- SCDC Program updates

Agenda Item 11. Adjournment

Dr. Frei-Jones adjourned the meeting at 2:27 p.m.

Below is the link to the archived video recording of the December 10, 2024, 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 10, 2024 meeting](#)