

# Sickle Cell Task Force

**FINAL APPROVED**

## Meeting Minutes

Monday, August 19, 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

Titilope Fasipe, M.D., Ph.D., Chair, called the Sickle Cell Task Force (SCTF) meeting to order at 1:00 p.m.

Dr. Fasipe 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. Dr. Fasipe thanked members and asked for a moment of silence to reflect on those they have lost and the work that they are doing. Dr. Fasipe then provided opening remarks.

**Table 1. SCTF member attendance at the Monday, August 19, 2024 meeting.**

Member Name	Attended
<b>Titilope Fasipe, M.D., Ph.D., Chair</b>	Yes
<b>Melissa Frei-Jones, M.D., M.S.C.I.</b>	Yes
<b>André Harris, M.S.W.</b>	Yes
<b>Dawn Johnson, M.D.</b>	Yes
<b>Alecia Nero, M.D.</b>	Yes
<b>Marqué Reed-Shackelford, Vice-Chair</b>	Yes
<b>Linda Wade</b>	Yes

## **Agenda Item 2. Consideration of August 18, 2023, December 1, 2023, and May 3, 2024, draft meeting minutes**

Dr. Fasipe, Chair, asked members to refer their email and meeting packets for three sets of draft meeting minutes and called for any edits. Hearing none, Dr. Fasipe called for a motion to approve the August 18, 2023, December 1, 2023, and May 3, 2024, draft meeting minutes.

### **Motion:**

Dr. Dawn Johnson moved to approve the draft minutes from the August 18, 2023, December 1, 2023, and May 3, 2024, meetings as presented. Ms. Linda Wade seconded the motion. Ms. Thompson conducted a roll call vote and announced the motion carried by a majority vote with seven yeas (Dr. Fasipe, Dr. Frei-Jones, Mr. Harris, Dr. Johnson, Dr. Nero, Ms. Reed-Shackelford, and Ms. Wade), zero disapproves, and zero abstentions. (Due to technical issues, Ms. Reed-Shackelford provided her vote in the meeting chat.)

Dr. Fasipe announced agenda item 3, Consideration of draft SCTF Bylaws Amendment, is tabled for a future meeting.

## **Agenda Item 3. Consideration of draft SCTF Bylaws Amendment – Tabled**

## **Agenda Item 4. Consideration of draft 2024 SCTF Annual Report**

Dr. Fasipe reminded members they received a copy of the draft report to review and led members in a discussion over draft edits.

### **Member discussion:**

- Updates to 2023 annual report recommendations
- Proposed edits to recommendation on adolescent routine care
  - ▶ Add reflex testing
  - ▶ Include language on availability of newborn screening results
  - ▶ Remove specifics to athletes

Dr. Fasipe called for a motion to approve the draft of the 2024 SCTF annual report with the suggested edits.

**Motion:**

Dr. Johnson moved to adopt the report with suggested edits. Mr. Harris seconded the motion. Ms. Thompson conducted a roll call vote and announced the motion carried by a majority vote with seven yeas (Dr. Fasipe, Dr. Frei-Jones, Mr. Harris, Dr. Johnson, Dr. Nero, Ms. Reed-Shackelford, and Ms. Wade), zero disapproves, and zero abstentions. Due to technical issues, Ms. Reed-Shackelford provided her vote during Agenda Item 5.

Dr. Fasipe then called for a second motion to allow the Chair, Dr. Fasipe, to make non-substantive edits to the report before submission.

**Motion:**

Dr. Johnson moved to allow the chair to make edits as necessary. Ms. Thompson conducted a roll call vote and announced the motion carried by a majority vote with seven yeas (Dr. Fasipe, Dr. Frei-Jones, Mr. Harris, Dr. Johnson, Dr. Nero, Ms. Reed-Shackelford, and Ms. Wade), zero disapproves, and zero abstentions. Due to technical issues, Ms. Reed-Shackelford provided her vote during Agenda Item 5.

**Agenda Item 5. Membership solicitation update**

Dr. Fasipe stated the member application solicitation deadline was August 12, 2024 and announced plans for a member orientation.

**Agenda Item 6. Texas Department of State Health Services (DSHS) program updates**

Dr. Fasipe introduced Leslie McKenzie, B.S.N., R.N., Director, Newborn Screening (NBS) Unit, DSHS; and Jessica Brown, M.D., M.P.H., Medical Director, NBS Unit, DSHS, to provide a NBS Program update.

**Presentation highlights included:**

- New disorder implementation
- NBS results report modifications
- Comparing the current format to the new results report format
- Laboratory-developed tests
- NBS Education Conference
- Data integration plan
- Texas NBS diagnosed hemoglobinopathies, 2019-2022

**Member discussion:**

- New report format
- Clarifying Federal Drug Administration laboratory-developed test policy
- Ways program shares conference announcements

**Action item:**

Program staff will share link for listserv subscription.

**Agenda Item 7. Sickle Cell Data Collection Program update**

Dr. Fasipe 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:**

- SCDC background and history review
- Grant activity progress
- Multi-disciplinary team meeting plans
- Institutional Review Board request status
- New staff epidemiologist announcement
- Educational outreach activities status
  - Photo blog completion
  - Progress on transition to care video project

**Member discussion:**

- Social vulnerability index concept
- If photo blog will be public-facing

**Agenda Item 8. SCTF Subcommittee updates****A. Medicaid Subcommittee – Dr. Frei-Jones, Dr. Johnson, and Dr. Fasipe****Update highlights included:**

- Dr. Frei-Jones joined the subcommittee and attended the last meeting

- Members continuing to discuss understanding how to meet requirements in Texas 88th Legislature, Regular Session, 2023, House Bill 1488
- Dr. Fasipe presented at a recent Medicaid Medical Directors meeting as part of their ongoing partnership

## **B. Public Awareness Campaigns Subcommittee – Dr. Nero**

### **Update highlights included:**

- Previous work with colleges and universities
- Ways to make opportunities actionable
- Proposed statewide presence information
- Proposed recommendation for 2024 annual report to share and organize information in a calendar for the statewide sickle cell community

## **C. Legislatively Mandated Report Subcommittee – Dr. Fasipe**

### **Update highlights included:**

- Discussed drafting of report

## **D. Education Subcommittee – Dr. Frei-Jones**

### **Update highlights included:**

- Need for new members, such as Texas Education Agency representative
- Options and opportunities for school nurses and education in public schools
- Options to increase opportunities for providers

### **Member discussion:**

- Clarifying Texas Medical Board requirements for opioid management
- Explore adding Continuing Medical Education on sickle cell for providers

## **Agenda Item 9. Sickle Cell Action Plan Initiative update**

Dr. Fasipe stated the Sickle Cell Action Plan Initiative will have their next meeting in late 2024 or early 2025.

## **Agenda Item 10. Public comment**

Ms. Thompson, ACCO Facilitator, read the public comment announcement and called on the individual registered on-site to provide public comment.

## **Oral public comment**

- **Mr. Adetimilehim Ariyo, representing self**
  - ▶ As a Ph.D. nursing student at University of Texas at Austin whose research is on sickle cell and health care accessibility, need for more awareness of the SCTF's work in Texas, especially among other Ph.D. students researching sickle cell.
  - ▶ Need for collaboration with colleges and universities, as the SCTF recommended in their annual report.

## **Agenda Item 11. Action items and future agenda items**

Dr. Fasipe opened the floor for SCTF members to discuss and review future meeting topics and agenda items and announced the next meeting will be on December 10, 2024.

### **Future agenda items:**

- Standing items:
  - ▶ Subcommittee reports
  - ▶ NBS Program and SCDC updates
  - ▶ Sickle Cell Action Plan Initiative update
- 2024 report status
- Membership update, including new member introductions
- Public awareness of what the SCTF does

### **Action item:**

- Public Awareness Subcommittee will discuss how to help the public more aware of what the SCTF does.

## **Agenda Item 12. Adjournment**

Dr. Fasipe gave closing remarks and adjourned the meeting at 2:52 p.m.

Below is the link to the archived video recording of the August 19, 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 – August 19, 2024 meeting](#)