

Sickle Cell Task Force

FINAL APPROVED

Meeting Minutes

Friday, December 1, 2023

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

Titilope Fasipe, M.D., Ph.D., Chair, called the Sickle Cell Task Force (SCTF) meeting to order at 1:11 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.

Table 1. SCTF member attendance at the Friday, December 1, 2023 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.	No
Dawn Johnson, M.D.	Yes
Alecia Nero, M.D.	No
Marqué Reed-Shackelford, Vice-Chair	No
Linda Wade	Yes

Dr. Fasipe thanked members and Texas Department of State Health Services (DSHS) staff for their work. Dr. Fasipe then asked for a moment to reflect on those lost due to sickle cell and for whom they continue to fight.

Dr. Fasipe announced they will table the next agenda item, the minutes, and proceed to agenda item 3.

Agenda Item 2. Consideration of August 18, 2023, draft meeting minutes – Tabled

Agenda Item 3. DSHS Newborn Screening (NBS) Unit program updates

Dr. Fasipe introduced Ms. Lori Gabbert Charney, Director, Maternal and Child Health Section, DSHS to provide NBS Unit program updates.

Presentation highlights included:

- Personnel changes;
- New staff introductions; and
- New NBS Unit structure.

Member discussion:

- Clarification on new structure; and
- Special Projects Team.

Dr. Fasipe announced they will table two items, agenda item 2 and agenda item 10, the mortality report discussion, for a future meeting.

Agenda Item 4. 2023 SCTF annual report status update

Dr. Fasipe announced DSHS posted the 2023 annual report on the DSHS website and referenced the slide with the link. She added program staff will add a link to the report on the SCTF website and share the link with members.

Agenda Item 5. SCTF membership update

Dr. Fasipe announced they have no SCTF membership updates.

Agenda Item 6. SCTF Bylaws Amendment review

Dr. Fasipe reminded members they discussed the bylaws and proposed updates in their past few meetings. Dr. Fasipe reviewed the previous bylaws discussions with members and called for proposed amendments.

Review highlights included:

- Texas Administrative Code, Title 25, Section 37/420 needs to be revised before the SCTF can amend the bylaws; and
- Proposed changes:
 - ▶ Term length;
 - ▶ Term limit; and
 - ▶ Presiding officer term expiration timeline.

Member discussion:

- Amendment approval process;
- SCTF member composition;
- Voting;
- Identifying confusing language;
- Presiding officers:
 - ▶ Selection processes;
 - ▶ Terms; and
 - ▶ Removal process.
- Knowledge loss from member turnover; and
- Expertise continuity plans after SCTF growth.

Action items

- Program will email members their membership details; and
- SCTF will include a term limit discussion on their next meeting agenda.

Agenda Item 7. Sickle cell emergency care

Dr. Fasipe introduced Jamie Barner, Ph.D., F.A.A.C.P., F.A.Ph.A., Professor and Division Head, Klinck Centennial Professor, Co-Director, Texas Center for Health Outcomes Research and Education, The University of Texas at Austin, College of Pharmacy, Health Outcomes Division, to present on sickle cell emergency care. Dr.

Barner referenced the PowerPoint and handout, *Patient Experience and Factors Influencing Willingness to Utilize the Emergency Department Among Individuals Living With Sickle Cell Disease: Mixed Methods Study*.

Presentation highlights included:

- Study background;
- Theory of planned behavior conceptual model;
- Methodology and approach;
- Qualitative and quantitative data analyses;
- Focus group results;
- Survey results;
- Summary of study findings; and
- Study limitations.

Member discussion:

- Study reflects what patients tell their doctors on a regular basis;
- Lack of objective research on patient experience causes frustration for patients and doctors;
- Once published, study will serve as a tool for the sickle cell community;
- Collaboration with Linda Wade;
- Linking study with Centers for Disease Control and Prevention (CDC) sickle cell work;
- Study publishing and presentation history; and
- Identifying conferences for a future presentation.

Agenda Item 8. House Bill 1488 presentation

Dr. Fasipe introduced Ms. Emily Stauffer Rocha, M.B.A., M.S.N., R.N., N.E.-B.C., C.H.C.Q.M, Director of Clinical Innovation, Office of the Medical Director, Medicaid & CHIP Services, HHSC, to provide an update on work to achieve Texas 88th Legislature, Regular Session, 2023, House Bill 1488 goals. Ms. Rocha referenced the handout, *Provider Education Resources*.

Presentation highlights included:

- HHSC, DSHS, and Medicaid Contract Subcommittee collaboration;

- Medicaid Contracts Subcommittee worked on a draft document to meet a House Bill 1488 ask to recommend and promote existing resources or facilitate the development of provider education resources.
- Medicaid Contracts Subcommittee will also draft a document to meet a House Bill 1488 ask related to school resources.
- The Medicaid Contracts Subcommittee will share the provider education and school resource draft documents with the SCTF to review and include in the 2024 SCTF annual report.

Member discussion:

- Other possible resources to include:
 - ▶ Additional Health Resources and Services Administration information;
 - ▶ Community arm of the American Society of Hematology Clinical Trials Network;
 - ▶ Sickle cell disease workshops for sickle cell center development; and
 - ▶ National Alliance of Sickle Cell Centers.

Action item

SCTF members will email additional Provider Education Resources feedback to program staff by December 31, 2023.

Agenda Item 9. SCTF Subcommittee updates

A. Sickle Cell Surveillance Subcommittee

Dr. Fasipe introduced Dr. Melissa Frei-Jones, Subcommittee Chair, to provide a subcommittee update. Dr. Frei-Jones announced the subcommittee did not meet.

Dr. Fasipe stated the Sickle Cell Surveillance Subcommittee is a reflection of efforts to collaborate with DSHS on the CDC sickle cell grant, and introduced Victoria Salinas, Medical Research Specialist, Environmental Epidemiology and Disease Registry Section, DSHS. Ms. Salinas presented an update on the new Texas Sickle Cell Data Collection (SCDC) Program.

Presentation highlights included:

- When DSHS received the notice of award;
- Program overview and purpose;

- November 2023 CDC reverse site visit recap;
- Institutional Review Board application status;
- Staffing update; and
- Scheduling of grant-required site visit.

Member discussion:

- Reverse site visit details;
- Highlighting the SCDC Program is not a registry; and
- The importance of requesting the need for a registry.

B. Medicaid Contracts Subcommittee

Dr. Fasipe introduced Dr. Dawn Johnson and Dr. Alecia Nero, subcommittee members, to present a Medicaid Contracts Subcommittee update.

Presentation highlights included:

- Subcommittee met a few times to discuss House Bill 1488;
- Meeting discussions included:
 - ▶ Reviewing educational content;
 - ▶ Reviewing available data on state websites; and
 - ▶ House Bill 1488 work breakdown; and
- Subcommittee will meet monthly;
- Subcommittee identified an issue with the lack of appropriate training and exposure on how to properly care for sickle cell disease;
- Women with sickle cell disease have unique issues to address; and
- The need to include training opportunities.

C. Public Awareness Campaigns Subcommittee

Dr. Fasipe announced the Public Awareness Campaigns Subcommittee did not have an update.

D. Legislatively Mandated Report Subcommittee

Dr. Fasipe announced the Legislatively Mandated Report Subcommittee did not have an update.

E. Sickle Cell Education Subcommittee

Dr. Fasipe announced the Sickle Cell Education Subcommittee did not have an update.

Agenda Item 10. Mortality data discussion - Tabled

Agenda Item 11. Public comment

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

Agenda Item 12. 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 February 16, 2024.

Member discussion:

- Bylaws Subcommittee formation;
- Bylaws Subcommittee membership:
 - ▶ Dr. Dawn Johnson; and
 - ▶ Dr. Melissa Frei-Jones.

Future agenda items:

- August 2023 meeting minutes;
- Chair election;
- Mortality data discussion;
- Standing items:
 - ▶ DSHS Newborn Screening Program update;
 - ▶ SCDC Program update;
 - ▶ Membership update; and
 - ▶ Subcommittee reports.
- Medicaid eligibility;
- Bylaws amendment; and
- Term update review.

Agenda Item 13. Adjournment

Dr. Fasipe adjourned the meeting at 4:09 p.m.

Below is the link to the archived video recording of the December 1, 2023 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 1, 2023 meeting](#)