

Sickle Cell Task Force (SCTF)

Meeting Minutes

FINAL APPROVED

Friday, August 18, 2023

1:00 p.m.

Hybrid Meeting:

Microsoft Teams Virtual Meeting

Robert D. Moreton Building

Public Hearing Room M-100 / K-100*

1100 W. 49th St, Austin, Texas 78756

**Note: Due to Technical Difficulties, the Sickle Cell Task Force Meeting was moved from M-100 to K-100*

Agenda Item 1: Welcome, introductions, and logistical announcements

Dr. Titilope Fasipe, Chair of the Sickle Cell Task Force (SCTF), called the meeting to order at 12:47 p.m. and welcomed everyone in attendance.

Dr. Fasipe introduced Ms. Jacqueline Thompson, Texas Health and Human Services Commission (HHSC), Policy & Rules, Advisory Committee Coordination Office (ACCO). Ms. Thompson reviewed logistical announcements, conducted a roll call, and announced the presence of a quorum.

Table 1. Sickle Cell Task Force member attendance at the Friday, August 18, 2023 meeting.^{1,2}

Member Name	In Attendance
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Mr. André Harris	No
Dr. Dawn Johnson	Yes
Dr. Alecia Nero	No
Ms. Marqué Reed-Shackelford	Yes
Ms. Linda Wade	Yes

¹ Yes – Indicates member attended the meeting.

² No – Indicates member did not attend the meeting.

Dr. Fasipe provided opening remarks and paused for a moment of silence to reflect on the important work that the members and staff do for those that have been lost to sickle cell disease.

Agenda Item 2: Consideration of February 24, 2023, and July 11, 2023, draft meeting minutes

Dr. Fasipe reminded members that program staff emailed members the February 24, 2023, and July 11, 2023, draft meeting minutes. Ms. Thompson, ACCO, stated the February 24, 2023, draft minutes were tabled from the last meeting. Dr. Fasipe acknowledged the change and asked if there were any edits or changes. Hearing none, the chair requested a motion to approve the February 24, 2023, and July 11, 2023, draft meeting minutes.

MOTION: Dr. Melissa Frei-Jones motioned to approve the February 24, 2023, and July 11, 2023, draft meeting minutes as presented. Ms. Linda Wade seconded the motion. Ms. Thompson conducted a roll call vote and announced the motion carried with five yeas (Dr. Fasipe, Dr. Frei-Jones, Dr. Johnson, Ms. Wade, and Ms. Reed-Shackelford), zero nays, and two abstentions.

Agenda Item 3: Consideration of draft SCTF Bylaws Amendment

Dr. Fasipe led the discussion on the recommended language for the SCTF Bylaws Amendment.

Member discussion:

- Dr. Fasipe recommended a change in the language under Section 5 to extend membership terms to three years.
- Ms. Walquiria Sanchez, Policy Attorney, HHSC, provided a brief overview to SCTF members to help them better understand the process for making changing to their bylaws. Ms. Sanchez confirmed submitting recommended changes to the HHSC and DSHS leadership for consideration is the correct course of action.
- Ms. Linda Wade expressed her support in proposed change to language extending membership terms to three years.
- Dr. Frei-Jones and Dr. Dawn Johnson expressed support of statements from Ms. Wade and Dr. Fasipe.
- Ms. Sanchez suggested members include their rationale to extend terms to resemble other advisory committees with a longer duration.

- The rules under Texas Administrative Code, Title 25, Section 37.420, state members serve two-year terms.
- The rules need to go through the rule review process before members can change their bylaws to extend term length.

Agenda Item 4: Consideration of draft 2023 legislatively mandated report

Dr. Fasipe led members in a discussion of the draft 2023 annual report. Dr. Fasipe reminded SCTF members the final report is due in December.

Member discussion:

- Emphasis on the new recommendations;
- Inclusion of language reflecting the 88th Texas Legislature, Regular Session, 2023, House Bill 1488 requirements;
- Updated some 2022 report recommended actions to include in the 2023 report;
- Changing recommendation on lifespan coverage to eligibility until age 26;
- Timeframe for recommendations to take effect; and
- Adding language on health care provider education.

Motion: Dr. Titilope Fasipe requested a motion to adopt the 2023 SCTF Report and allow non-substantive editing by the chair and DSHS staff. Dr. Melissa Frei-Jones motioned to adopt the 2023 SCTF Report and allow non-substantive editing by the chair and DSHS staff. Ms. Linda Wade seconded the motion. Ms. Thompson conducted a roll call vote and announced the motion carried with four yeas (Dr. Fasipe, Dr. Frei-Jones, Dr. Johnson, and Ms. Wade), zero nays, and three abstentions (Ms. Reed-Shackelford, Dr. Nero, and Mr. Harris).

Agenda Item 5: Texas Syndromic Surveillance (TxS2) Annual Report

Dr. Fasipe introduced Ms. Valerie Tewell Derosier, Analytics Group Manager, Division for Regional and Local Health Operations, DSHS. Ms. Tewell Derosier referenced the PowerPoint and handout, *Texas Syndromic Surveillance System (TxS2)*, and the handout, *Sickle Cell Disease in Texas Syndromic Surveillance Systems in 2022*.

Highlights of the presentation included:

- TxS2 background;
- Sick cell query and information; and
- Data overview:
 - ▶ Demographics;
 - ▶ Number of sickle cell disease (SCD) visits by patient; and
 - ▶ SCD visit length of stay.

Member discussion:

- Ways to track how individuals were treated as far as the level of care they received or if they returned to that same medical facility;
- The way individuals are treated in the emergency department is a chief complaint;
- Availability of data to show why patients only visited the hospital once:
 - ▶ Level of or lack of care they received; or
 - ▶ Patient went to another hospital because he or she did not like the previous one.
- Availability of data on the medications the patient received;
- TxS2 data is based on administrative claims data;
- Accessibility of data from the electronic health record;
- Data includes general provider notes;
- TxS2 data shows an unexpected number of patients seeking care for sickle cell disease compared to previously reported data;
- Other data sources;
- Data does not include sickle cell trait;
- Deduplicated datasets;
- Availability of pediatric data; and
- Demographics.

Agenda Item 6: Sickle Cell Emergency Care - Tabled

Agenda Item 7: Newborn Screening Unit Program Updates

There were no program updates.

Agenda Item 8: Newborn Screening Unit Program Updates

Dr. Fasipe introduced Ms. Karen Hess, Director, Newborn Screening Unit, DSHS, to present an update.

Presentation highlights included:

- Texas Newborn Screening (NBS) Program goals;
- Clinical Care Coordination (CCC) Genetics Branch organization;
- 2019-2022 NBS/Hemoglobin workload;
- Abnormal hemoglobin CCC notification process;
- 2017-2022 diagnosed hemoglobinopathies;
- Short-term follow up requirements;
- Long-term follow up requirements and goals;
- Follow up form sickle cell data overview;
- Sickle cell trait notification process;
- Sickle cell trait data overview; and
- NBS CCC contacts.

Member discussion:

- Reason for the differences between presumptive positive data and diagnosed case data;
- Presumptive positive data includes the first and second screen;
- Rate of sickle cell hemoglobin compared to conditions;
- Significant drop off in the number of follow forms DSHS receives after two years;
- Sickle cell trait follow up;
- Impact of Texas screening for sickle cell since 1983, long before the United States added sickle cell to universal sickle cell screening in 2006; and
- Number of primary care providers compared to specialists reporting data;

- Long-term follow-up data availability.

Agenda Item 9: Texas sickle cell mortality data

Dr. Fasipe turned the floor over to Dr. Frei-Jones to lead a discussion on Texas sickle cell mortality data.

Member discussion:

- Sickle Cell Surveillance Subcommittee requested 2009-2019 and 2020 data from DSHS Vital Statistics;
- Data includes deaths of Texas residents in which sickle cell was the underlying cause of death or contributing factor based on a specific set of International Classification of Diseases, Tenth Revision codes.

Action item:

The SCTF will include an agenda for Texas sickle cell mortality data discussion on the next meeting agenda.

Agenda Item 10: Subcommittee reporting

A. Sickle Cell Surveillance Subcommittee

B. Medicaid Contracts Subcommittee

C. Public Awareness Campaigns Subcommittee

D. Legislatively Mandated Report Subcommittee

Dr. Fasipe announced none of the subcommittees have reports and they will move to agenda item 11.

Agenda Item 12: Health care coverage and eligibility

Dr. Fasipe introduced Ms. Leticia Avery, L.C.S.W.-S., Social Worker, South Texas Comprehensive Sickle Cell and Thalassemia Program, Department of Pediatrics, Joe R. and Teresa Lozano-Long School of Hematology, UT Health-San Antonio to present on health care coverage and eligibility. Ms. Avery referenced the PowerPoint and handout, *Adolescents and Young Adults (AYAs) with Sickle Cell & Insurance Needs*.

Presentation highlights included:

- Coverage options;
- Coverage timeline;

- Anticipatory guidance for patients to transition from pediatric to adult care;
- Coverage options for patients 19 years old and older in Texas; and
- Resources.

Member discussion:

- Availability of an indigent health program in every county; and
- Medicaid Buy-In criteria.

Dr. Fasipe announced they will return to agenda item 11.

Agenda Item 11: Health care provider education

Dr. Fasipe turned the floor over to Dr. Frei-Jones to lead a discussion on health care provider education.

Member discussion:

- Texas Education Code, Section 58A.001, requirements for medical school education programs;
- Processes for incorporating sickle cell disease training in curriculum requirements;
- Family practice, emergency medicine, obstetrics, gynecology, pediatrics, and internal medicine board content curriculums include sickle cell disease;
- Challenge of putting legislation into practice;
- The way each residency program provides content is different;
- Number of Texas residency programs;
- Subcommittee formation;
- Member experiences learning about sickle cell disease in their medical school education; and
- Student group engagement opportunities.

Agenda Item 13: Public Comment

Ms. Thompson, ACCO Facilitator, announced no one onsite pre-registered for public comment and one individual representing the Texas Black Nurses Association requested to go on record.

Agenda Item 14: Future agenda items, next meeting date, and adjournment

Dr. Fasipe opened the floor for SCTF members to discuss and review future meeting topics and agenda items.

Future meeting topics and agenda items included:

- Standing items:
 - ▶ Newborn Screening Unit program update;
 - ▶ Subcommittee reports;
 - ▶ Meeting minutes;
- Tabled agenda items:
 - ▶ Emergency care presentation; and
 - ▶ Presentation from Gary Freed, M.D., M.P.H, author of the article, *Sickle Cell Disease: A National Shame*;
 - ▶ SCTF annual report update;
 - ▶ Bylaws amendment discussion;
 - ▶ SCTF rules update;
 - ▶ Medicaid presentation;
 - ▶ Mortality data discussion

Member discussion:

- Sickle Cell Education Subcommittee members:
 - ▶ Dr. Frei-Jones;
 - ▶ Ms. Wade; and
 - ▶ Dr. Fasipe (if someone not present wishes to join, Dr. Fasipe will remove herself from the subcommittee).

Dr. Fasipe announced the next SCTF meeting will take place on Friday, December 1, 2023. Dr. Fasipe, Chair, called the Sickle Cell Task Force meeting to an end at 4:06 p.m.

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Below is the link to the archived video of the August 18, 2023, Sickle Cell Task Force meeting to view and listen for approx., two years from date meeting is posted and in accordance with the DSHS records retention schedule.

(To view and listen to the entirety of the meeting click on the link below)

[Sickle Cell Task Force Meeting August 18, 2023](#)