

Sickle Cell Task Force

FINAL APPROVED

Meeting Minutes

Friday, May 3, 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 1:03 p.m.

Dr. Fasipe announced they will table the August 18, 2023, and December 1, 2023, draft meeting minutes and agenda item three, consideration of the draft bylaws, until the next meeting.

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, May 3, 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.	No
Alecia Nero, M.D.	Yes
Marqué Reed-Shackelford, Vice-Chair	Yes
Linda Wade	Yes

Dr. Fasipe shared news about the December approval of new sickle cell gene therapy products, reminded members of the importance of their work, and acknowledged the Texas Department of State Health Services (DSHS) team. She then asked for a moment of reflection for those who have passed away from sickle cell disease and the work that they do.

Agenda Item 2. Consideration of August 18, 2023, and December 1, 2023, draft meeting minutes - Tabled

Agenda Item 3. Consideration of draft SCTF Bylaws Amendment - Tabled

Agenda Item 4. Texas Department of State Health Services (DSHS) program updates

A. Newborn Screening Unit

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 Unit update.

Presentation highlights included:

- Progress made on addressing second newborn screen collection issues;
- Program ask for members to discuss with their respective organizations the need for second screens in Texas;
- Program support of Reportable Conditions Knowledge Management System efforts;
- An overview of recent Specialist Collaborating Partner meetings, formerly known as consultants meetings; and
- Social media outreach to parents and general public.

Member discussion:

- Second screen collection:
 - If the Program has noticed any regional disparities or gaps in second screen collection; and
 - What may help the gaps;
- New consultants meeting name; and
- Next hematologist meeting plans.

B. Sickle Cell Data Collection

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:

- CDC final budget approval status and funding details;
- Noting how a SCDC system differs from a sickle cell registry;
- Texas SCDC system goals;
- Grant activities overview:
 - SCDC multi-disciplinary subject matter expert team meetings; and
 - Data collection and analysis protocol submission to DSHS Institutional Review Board (IRB).
- IRB review and approval purpose;
- Aggregate data project exploration; and
- Educational outreach activities:
 - Photo blog; and
 - Collaborative video project.

Member discussion:

- IRB process barriers; and
- If SCDC needs SCTF support.

Agenda Item 5. Medicaid eligibility presentation

Dr. Fasipe introduced Ms. Kristi Brown, Lead Policy Analyst, Medicaid for the Elderly and People with Disabilities, HHSC, and Ms. Heather Kuhlman, STAR Kids Senior Policy Analyst, Medicaid and CHIP Services, HHSC. Ms. Brown and Ms. Kuhlman referenced the PowerPoint and handout, *Texas Medicaid Overview*.

Presentation highlights included:

- Medicaid, Children's Health Insurance Program (CHIP), and Medicare definitions;

- Medicaid coverage impact;
- Eligibility;
- Requirements;
- Medicaid Buy-In (MBI) programs;
- Applying for benefits;
- Managed care programs and waiver services overview; and
- Potentially Preventable Event data.

Member discussion:

- 2017 Medicaid and CHIP sickle cell report data;
- Comparison of MBI programs to marketplace plans;
- Clarifying how patients with sickle cell disease may qualify for MBI for Adults;
- Gap coverage during transition period for patients who have aged out of Medicaid;
- Disability requirements for MBI programs and Supplemental Security Income are the same;
- Waiver requirements; and
- Children with Special Health Care Needs.

Agenda Item 6. SCTF membership update

Dr. Fasipe gave an update on SCTF membership and the solicitation process.

Agenda Item 7. SCTF Subcommittee updates

A. Sickle Cell Surveillance Subcommittee

Dr. Fasipe announced the Sickle Cell Surveillance Subcommittee did not meet, and they will wind down the subcommittee since the SCDC Program will report data.

B. Medicaid Contracts Subcommittee

Dr. Fasipe gave a Medicaid Contracts Subcommittee update.

Presentation highlights included:

- Name change to the “Medicaid Subcommittee;”
- Overview of subcommittee work to meeting requirements in Texas 88th Legislature, Regular Session, 2023, House Bill 1488; and

- Annual sickle cell disease presentation at the last Medicaid Medical Directors meeting.

C. Public Awareness Campaigns Subcommittee

Dr. Fasipe announced the Public Awareness Campaigns Subcommittee did not meet.

D. Legislatively Mandated Report Subcommittee

Dr. Fasipe turned the floor over to Ms. Marqué Reed Shackelford, subcommittee member, to give a Legislatively Mandated Report Subcommittee update.

Presentation highlights included:

- April 23, 2024 meeting overview;
- 2023 report feedback; and
- 2024 report guidance.

Member discussion:

- Linking the 2024 report back to the original Sickle Cell Advisory Committee report recommendations;
- Plain language usage; and
- Report length.

E. Education Subcommittee

Dr. Fasipe announced the Education Subcommittee did not meet.

F. SCTF Bylaws Subcommittee

Dr. Fasipe announced they will wind down the SCTF Bylaws Subcommittee because it is not necessary. Dr. Fasipe stated DSHS will guide members on bylaws changes at a future meeting. Dr. Fasipe added if the SCTF needs the subcommittee later, they can bring it back.

Agenda Item 8. Sickle Cell Action Plan Initiative update

Dr. Fasipe gave a Sickle Cell Action Plan Initiative update.

Presentation highlights included:

- Health Resources and Services Administration grant background; and
- Meetings:

- ▶ September 2023;
- ▶ January 2024; and
- ▶ May 10, 2024.
- Purpose and goals.

Agenda Item 9. Public comment

Ms. Thompson, ACCO Facilitator, read the public comment announcement and stated one individual registered to provide public comment.

Written public comment

One individual registered to provide written public comment from the following organizations or associations:

- Brightstar Foundation

Agenda Item 10. 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 August 19, 2024.

Member discussion:

- SCTF members may give the SCDC Program feedback on datasets to capture;
- Impact of new gene therapies and medications; and
- Inviting the Medicaid Chief Medical Director to a future meeting to answer questions.

Future agenda items:

- Review ways to access health care in Texas and rank by affordability;
- Medicaid coverage;
- Marketplace insurance plan coverage;
- Commercial insurance coverage;
- Review legislatively mandated report;
- Membership update;
- Transformative therapy access;

- Gene therapy overview; and
- Standing items:
 - ▶ SCDC Program update;
 - ▶ Newborn Screening Program update; and
 - ▶ Subcommittee reports.

Action items:

- Subcommittees will work on recommendations for the annual report and report to the full task force at the August meeting; and
- Program staff will send members a copy of the 2023 annual report.

Agenda Item 11. Adjournment

Dr. Fasipe adjourned the meeting at 3:01 p.m.

Below is the link to the archived video recording of the May 3, 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 – May 3, 2024 meeting](#)