

**APPROVED Sickle Cell Task
Force Meeting Minutes
February 24, 2023
1:00 p.m.**

Hybrid Meeting:

Microsoft Teams Virtual Meeting
Robert D. Moreton Building
Public Hearing Room M-100
1100 W. 49th St, Austin, Texas 78756

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 1:05 p.m. and welcomed everyone in attendance.

Dr. Fasipe introduced Ms. Tessa Buck-Ragland, Texas Health and Human Services Commission (HHSC), Policy & Rules, Advisory Committee Coordination Office (ACCO), and announced a change in the order of agenda items. Agenda item 2, Consideration of August 19, 2022, and December 1, 2022, draft meeting minutes, would be tabled and presented at the next meeting.

Ms. Buck-Ragland reviewed logistical announcements, conducted a roll call, and announced that with only two members present, the Task Force did not meet quorum.

Table 1. Sickle Cell Task Force member attendance at the Friday, February 24, 2023 meeting.

Member Name	In Attendance
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Dr. Dawn Johnson	No
Dr. Alecia Nero	No
Ms. Marqué Reed-Shackelford joined at 2:16 p.m.	Yes
Vacant	
Vacant	

Yes: Indicates attended the meeting

No: Indicates did not attend the meeting

Ms. Karen Hess, Director, Texas Department of State Health Services (DSHS), Newborn Screening (NBS) Unit, introduced herself, and she called on program staff members Dr. Debra Freedenberg, Laura Arellano, Aimee Millangue, and Kerrie Sheedy and asked that they provide a brief introduction.

Dr. Fasipe offered opening remarks. She requested a moment of reflection to honor reflect on the work that they are doing as well as individuals with sickle cell disease and those that they continue to fight for.

Agenda Item 2: Consideration of August 19, 2022, and December 1, 2022, draft meeting minutes

Minutes were tabled until the next meeting.

Agenda Item 3: Membership updates

Dr. Fasipe introduced Ms. Aimee Millangue, Advisory Committee Coordinator, DSHS, Newborn Screening Unit, to give an update on membership.

Highlights of the update included:

- Three members had their terms expire on August 31, 2022 – two physicians specializing in hematology and a member of a community-based organization.
- Another member, who represented a community-based organization, resigned.
- The solicitation was opened in the summer to fill the three positions for members whose terms were to end on August 31, 2022 and closed on September 1, 2022.
- An application review team met to review the applications and make recommendations on candidates to fill the positions.
- Since the member who left the community-based organization category was appointed in the last year, the review team also recommended a candidate from 2021 solicitation for appointment.
- The application review team's recommendations have been going through the approval process for appointment by the Executive Commissioner and the program is hoping that the positions will be filled by the next meeting.

Member discussion:

- Members expressed concerns that the solicitation for applications closed on September 1, and it is February 23, and they have a minimum number of people on the task force to meet the requirements set forth by legislature. They are disheartened by the amount of time that has gone by and they have not been able to have additional membership identified for this task force.
- When members were developing the legislatively mandated report for the 2022 season, they saw how much work the task force needs to do, and it made them include language in the report to add additional members in addition to the ones they already started with, so they hope that the processes of adding members will continue to be optimized so they can reach their goals.

Ms. Millangue reminded members that it is an unusual circumstance that two members resigned. Usually, when membership terms are over, members are asked to serve until their replacements are appointed, and it is just an extenuating circumstance in which two members were not able to continue their service to the task force.

Agenda Item 4: Legislative update

Dr. Fasipe introduced Ms. Karen Hess, Unit Director, DSHS, Newborn Screening Unit to provide a legislative update.

Highlights of the update included:

- Newborn screening received several bills, and some of them directly impact sickle cell and the Sickle Cell Task Force.

- How to access the Texas Legislature Online, where you can look up bill text, proceedings and community hearings, House and Senate members, and bills.
- House Bill 181 from Jarvis Johnson directs DSHS to create and maintain a sickle cell disease registry. The bill also directs DSHS to publish an annual report to the Legislature of information regarding cases of sickle cell disease.
- Two additional bills related to sickle cell were drafted by Representative Rose, House Bill 1481 and House Bill 1488, are almost identical and include the following main points:
 - Requires HHSC collaboration with the task force to expand managed care plan features and improve quality of care for individuals with sickle cell disease.
 - Changes the composition of the task force by adding two members to include representatives from the Texas Education Agency (TEA) and HHSC.
 - Impacts multiple agencies – Health and Human Services, DSHS, TEA, graduate medical education programs, and Texas Health Services Authority.
 - Requires the task force to include in their annual report recommendations for improving sickle cell disease, education, or health care providers.
 - Includes that medical schools in the state that offer emergency medicine, family medicine or internal medicine in their residency programs try to incorporate in the curriculum education focused on sickle cell disease and sickle cell trait.
 - Requires HHSC, in collaboration with the Sickle Cell Task Force, to explore methods for improving sickle cell disease education and awareness within the public school system and provide recommendations to the TEA.
 - To the extent possible, requires TEA to collaborate with sickle cell disease community-based organizations to provide information on sickle cell disease and sickle cell trait to public school districts.
- One piece unique to House Bill 1481 directs DSHS to establish and maintain a voluntary sickle cell disease surveillance system using grant money awarded by the Centers for Disease Control and Prevention Sickle Cell Data Collection Program.
- Senate Bill 704, Section 14, by Paxton impacts Chapter 33 of the Texas Health and Safety Code, which scratches the language “on the grounds that conflict with religious tenants or practices of an organized church, of which they are adherent,” so it now reads, “screening tests may not be administered to a newborn child whose parent, managing conservator, or guardian, objects to the tests.” This introduces an opt out for newborn screening for any reason.

Member discussion:

- Clarifying whether there is already an opt-out option.
- The meeting would not be the appropriate forum for some discussion.
- Whether bills go back to the program for review during the bill life cycle.

Dr. Fasipe announced a 10-minute break.

Agenda Item 5: Sickle Cell Surveillance Subcommittee reporting

Dr. Fasipe reconvened the meeting at 1:42 p.m. She introduced Dr. Melissa Frei-Jones, Subcommittee Chair. Dr. Frei-Jones referenced the handout, *Sickle Cell Surveillance Subcommittee meeting minutes*.

Highlights of the presentation included:

- Met on Tuesday, February 21.
- Joined by guest Dr. Heidi Bojes, Director, DSHS Environmental Epidemiology and Disease Registry Section (EEDRS)
- Subcommittee was focused on task given by the advisory committee and Sickle Cell Task Force to determine how to provide disease surveillance and identify the number of people in the state of Texas with sickle cell disease.
- There is legislation again trying to establish a disease registry for sickle cell disease.
- Other pieces of legislation included information about participating in the Centers for Disease Control and Prevention (CDC) Sickle Cell Data Collection (SCDC) consortium.
- Subcommittee has been working to identify sources of data within the state of Texas and collaborations with individuals who might be able to help them realize goal of sickle cell disease surveillance.
- Most of meeting centered the status of the Request for Applications (RFA) for grant funding to add members to the CDC SCDC project, due in May.
- How the EEDRS Section could be a key player in DSHS participating and applying for the CDC grant due to their experience with data use agreements and memorandums of understanding, related to other registries - the cancer registry and birth defects registry.
- Some of the bills, if passed, would make it easier to have some public health ability to access information instead of going through the Institutional Review Board.
- Since the grant is not competitive and subcommittee's understanding is that only one grant accepted from each state, the hope is there is going to be conversations with other entities exploring in submitting the grant application so Texas can submit one cohesive grant by May 11.
- Being able to submit a grant would be a huge success for the advisory committee, task force, DSHS, and everyone.
- Next steps:
 - Meet with Dr. Kelly Fegan-Bohm, Medical Director, DSHS Community Health Improvement Division.
 - Work with EEDRS, since their limitation is they do not have sickle cell expertise.
 - Have conversations with the Center for Healthcare Data, who is looking to participate in the grant application.

Member discussion:

- Commending Dr. Frei-Jones and the subcommittee for their work on sickle cell surveillance.
- The data in the Texas Syndromic Surveillance Report and what role the report may have along with the other surveillance efforts.
- The All-Payer Claims Database may have some of the same data.
- The Texas Syndromic Surveillance reports were part of the preliminary work of any surveillance the subcommittee could get, but the power of a more comprehensive surveillance structure would incorporate the data they already have and go even further.
- How to collate all the pieces of sickle cell data in Texas.

- The nine states who currently participate in the SCDC do not all have the same data sources, so that shows the different number of ways to get the same information.

Agenda Item 6: Medicaid Contracts Subcommittee reporting

Dr. Fasipe presented an update of the Medicaid Contracts Subcommittee and referenced the handout, *Medicaid Contracts Subcommittee meeting minutes*.

Highlights of the presentation included:

- Met on February 17 and reviewed progress so far.
- Dr. Fasipe met with the state Medicaid Managed Care Advisory Committee on August 25, which led to the committee wanting to learn more and assigning task force discussion into further subcommittee components.
 - The Clinical Oversight and Administrative Simplification Subcommittee works on prior authorizations, which is an issue with sickle cell disease care.
 - The Network Adequacy and Access to Care Subcommittee focuses on telemedicine and transition.
 - The Service and Care Coordination Subcommittee focuses on how to improve care, coordination, and case management.
- Discussed if there is a way for more individuals with sickle cell disease to be covered by managed care and what it would entail and understanding the options available, ways that care can be expanded, and what type of Medicaid option makes sense.
- Defined goals for 2023 which included continuing to work with the Medicaid Medical Directors Office team, educate various Medicaid medical directors on sickle cell disease and how to optimize the care that they are offering for children and any of the adults they care for with sickle cell disease.
- A few bills were discussed, which included mention of the managed care component.
- Action items
 - Follow-up with subcommittees
 - Follow-up with Dr. Van Ramshorst, Chief Medical Director, Office of the Medical Director, HHSC, Medicaid and Children's Health Insurance Program to understand how 340B programs work and make sure they have not left anything off the table in regards to Medicaid services.
 - Follow up with Dr. Glenn, Senior Associate Medical Director, to understand various waiver interest lists.
 - Dr. Johnson will follow up with the author of an article, *A Missed Opportunity to Address a National Shame: The Case Of Sickle Cell Disease in the United States*, Dr. Gary Freed, whose perspective might be helpful for their subcommittee and to understand how to address inadequate coverage for sickle cell disease.

Member discussion:

- Whether the subcommittee has any meetings planned with the Medicaid directors or discussing with them if they have implemented any of the things the subcommittee talked to them about.
- How regional Medicaid plans impacts the plans the doctors work within their individual institutions, and if each plan utilized expertise, since Dr. Frei-Jones has recently

experienced receiving a few standardized form notifications from one health plan with specific recommendations for care that could be problematic.

- If Dr. Frei-Jones could communicate feedback to the health plan about their inconsistent messages through Dr. Van Ramshorst.
- Comparing health plan care guidelines for other chronic diseases, which may have a very guided structure, since certain children may not fit into all buckets.
- Having health plans carve out space for sickle cell disease and whether they have gap areas.

Dr. Fasipe announced a 5-minute break.

Agenda Item 7: Public Awareness Campaigns Subcommittee reporting

Dr. Fasipe reconvened the meeting at 2:28 p.m. and turned the floor over to Ms. Marqué Reed-Shackelford, Subcommittee Chair. Ms. Reed-Shackelford referenced the handout, *Public Awareness Campaigns Subcommittee meeting minutes*.

Highlights of the presentation included:

- Met last week for the first time since August of last year.
- Discussed how to make Community Health Workers (CHWs) aware of the sickle cell pathway.
- Joining and working with Community-Based Organizations (CBOs) and how to advertise among individual communities.
- Consider reviewing the CBOs list on the DSHS website for updates.
- CHWs have grassroots education in Texas since it is not required.
- CHWs not specifically required to learn about sickle cell and not governed by the same hierarchy as doctors and nurses.
- Dr. Fasipe previously shared CHW education with the CHW program to forward to their distribution list.
- Sharing information with student organizations at medical schools and undergraduate colleges and universities.
- Subcommittees cannot seek funding and sponsorship for activities such as Grand Rounds.
- Leverage CBOs who receive grants or have funding available.
- Action items:
 - Program will follow up with their Section on the approval of the Human Dimensions of Organizations (HDO) report to have at a meeting and share with outside groups, such as student groups at universities and CBOs.
 - Working with student groups to increase ability to access bone marrow donation.
 - Update CBO list.
 - Organizing a Grand Rounds, which could be available to all the pediatricians that participate in newborn screening.
 - 2023 World Sickle Cell Day campaign.

- Program will investigate feasibility of sharing how to request newborn screening results.
- Looking into how sickle cell education can be shared with CHWs specializing in reproductive health.
- Organizing CBO stakeholder meetings.
- Checking with the Board of Nursing, Coaches Association, and other associations about school education.

Member discussion:

- If the program has mechanisms for organizing Grand Rounds.
- Submitting sickle cell as a topic to the Texas Pediatric Society for consideration for their annual education meeting and possible presenters.
- Whether the transition to adult care for patients with sickle cell or long term follow up could be a possible topic for Grand Rounds.
- Identifying the top three priority subcommittee action items and dividing assignments among members.

ACTION ITEMS:

- Dr. Frei-Jones will share HDO report recommendations with the student group at her institution once program staff share guidance on how to proceed from agency leadership.
- Dr. Frei-Jones will work on organizing a Grand Rounds at DSHS.
- Ms. Reed-Shackelford will work with program staff to discuss meeting with CBOs and updating the CBO list on the DSHS Newborn Screening website.

Agenda Item 8: 2023 legislatively mandated report planning

Dr. Fasipe led a discussion of the 2023 legislatively mandated report (LMR).

Highlights of the presentation included:

- Incorporating the 2023 LMR into their planning for each of the subcommittees.
- Reforming the Legislatively Mandated Report Subcommittee to work on the 2023 report and for the subcommittee to include the same members who worked on the 2022 report, Dr. Frei-Jones and Ms. Reed-Shackelford.
- 2023 Task Force priorities for each subcommittee:
 - The Sickle Cell Surveillance Subcommittee should continue to have a Syndromic Surveillance report for 2023 regardless of what happens with the Centers for Disease Control and Prevention (CDC) grant.
 - The Medicaid Contracts Subcommittee should continue to engage with Dr. Van Ramshorst and the Medicaid Medical Directors and prioritize education of the Medicaid Medical Directors and various plans.
 - The Public Awareness Campaigns Subcommittee should have the goal of having a campaign for World Sickle Cell Day on June 19, which will emphasize that there is an opportunity for everyone born in Texas to know their sickle cell status through the DSHS website instead of being retested, and they will prioritize CBO outreach.

Member discussion:

- Whether Dr. Frei-Jones and Ms. Reed-Shackelford were willing to continue to serve on the reformed Legislatively Mandated Report Subcommittee to develop the 2023 draft report.
- It may be too much to ask future new committee members to draft the report, since they will only have managed to make it to one meeting.
- Clarifying when the SCTF will end and if new members will get to work on a future report.
- The Sickle Cell Surveillance Subcommittee originally had the plan to continue to work with the individuals within the state to move towards a surveillance or registry system development in Texas and had discussions with the Center for Health Data on the All-Payer Claims database.
- The Sickle Cell Surveillance Subcommittee next steps depends on whether the state participates in the Centers for Disease Control and Prevention grant.
- Clarifying what collaborating or working with the task force means in one of the bills.
- How one of the bills includes that HHSC would collaborate with the Sickle Cell Task Force regarding education and awareness within public schools and being creative about figuring out how to collaborate.
- Needing more guidance on what collaboration would mean if the bill became law.
- The Sickle Cell Surveillance Subcommittee direction changed when they received the grant update, and their intention was to have updated data set reports from Vital Statistics, Medicaid, and Syndromic Surveillance every year.
- The availability of each dataset the Sickle Cell Surveillance Subcommittee would like to include in the 2023 LMR and whether anyone agreed to present the data in a report to the SCTF.
- Knowing that the Sickle Cell Surveillance Subcommittee will navigate continuation of their previous work and the potential the CDC grant opportunity appropriately.
- Clarifying if the World Sickle Cell Day campaign is related to the HDO report versus doing something they have already been successful in doing with DSHS staff and the You Tube social media campaign.
- One question from the last Public Awareness Campaigns Subcommittee meeting was whether they could continue to work with the HDO program at the University of Texas because they have not gotten the initial report approved by DSHS, so the subcommittee is still waiting to determine how they will move forward with that.

Agenda Item 9: Public Comment

No public comment was received for this meeting.

Agenda Item 10: Future agenda items, next meeting date, and adjournment

Dr. Fasipe stated the next meeting is to be determined due to a scheduling conflict with a conference on May 12, and Ms. Aimee Millangue, Advisory Committee Coordinator and Ombudsman, DSHS Newborn Screening Unit, will notify members once a date has been set. She then opened the floor for discussion of future agenda items and requested Ms. Millangue provide a recap of the action items and topics they listed

Member discussion:

- Agenda items should include subcommittee reports from the Sickle Cell Surveillance Subcommittee, Public Awareness Campaigns Subcommittee, Medicaid Contracts Subcommittee, and Legislatively Mandated Report Subcommittee.
- The Sickle Cell Surveillance Subcommittee will report if they met with the individuals looking at the grant and provide an update on that process.
- Membership update
- If new members are anticipated to at the next SCTF meeting, including an agenda item for introduction and history information to catch them up on what has been going on.
- Since Dr. Fasipe, as Chair, can appoint new members to subcommittees, new members may show up to the next subcommittee meetings before they participate in their first SCTF meeting.
- Clarifying the status of new member appointments.
- Potentially include an agenda item if a CDC grant application is submitted and invite the individuals who submitted the grant application to have a discussion with the SCTF.
- Providing clarification on how DSHS would know if someone from Texas applied for the CDC grant.
- If including an agenda item for World Sickle Cell Day separately from the Public Awareness Campaigns Subcommittee report is redundant.
- Having the Public Awareness Campaigns Subcommittee incorporate HDO report guidance into their next meeting along with World Sickle Cell Day or have the HDO report as its own agenda item.
- Including an agenda item for a Bylaws review and whether the Bylaws could be amended to increase subcommittee membership.
- Clarifying that since membership is written into statute, Bylaws changes would have to be in statute.
- Not discussing the topic of the Bylaws attendance requirement since it is not included on the posted agenda, but Bylaws requirements could be discussed further by adding the agenda item to the next meeting.
- Have a member expectations discussion as part of the membership update, including what the Bylaws say about participation, and calling the agenda item "Membership updates and requirements."
- Legislative update

ACTION ITEMS:

- Recruit new members to the subcommittees and give them opportunities to serve.
- If they can do so and time allows, program staff will send out appointment letters to new members prior to the next meeting and have a non-public orientation with just the new members or include an orientation on the next meeting agenda.
- Follow up with Ken Fraser, Outreach Manager at Project Extension for Community Healthcare Outcomes (Project ECHO) to see if he could share his contacts for regional Project ECHOs so they could discuss their experiences with setting up their programs.
- Follow up with the Heartland Southwest Conference, Child Psychiatry Action Network, or other state ECHOs to identify someone to present on Project ECHO topics, such as funding structures.

- Follow up on having Community Health Worker presentation or discussion at the next meeting.
- Program staff will follow up with the DSHS Communications Office about the World Sickle Cell Day campaign.

With no further discussion, Dr. Fasipe, Chair, provided closing remarks and called the Sickle Cell Task Force meeting to an end at 3:43 p.m.

Below is the link to the archived video of the February 24, 2023 Sickle Cell Task Force meeting to view and listen for approximately 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)

Webcast recording link: [Sickle Cell Task Force Meeting February 24, 2023](#)