

**Sickle Cell Task Force  
Meeting Minutes  
April 1, 2022  
12:00 p.m.**

**Microsoft Teams Live Event**

Table 1: Sickle Cell Task Force member attendance at the Friday, April 01, 2022 meeting.

MEMBER NAME	IN ATTENDANCE
Dr. Titilope Fasipe	Yes, joined late
Dr. Melissa Frei-Jones	Yes
Ms. Priscilla Hill-Ardoin	Yes
Dr. Dawn Johnson	Yes
Dr. Alecia Nero	Yes
Mrs. Marqué Reed-Shackelford	Yes
Ms. Alysian Thomas, J.D.	Yes, joined late

**Agenda Item 1: Welcome, introductions and logistical announcements**

Mrs. Marqué Reed-Shackelford, acting Presiding Officer of the Sickle Cell Task Force (SCTF), called the meeting to order at 12:02 p.m. and welcomed everyone in attendance.

Mrs. Reed-Shackelford provided opening remarks then introduced and turned the floor over to Ms. Sallie Allen, Health and Human Services Commission (HHSC), Policy & Rules, Advisory Committee Coordination Office (ACCO). Ms. Allen reviewed logistical announcements, conducted a roll call, and announced the presence of a quorum.

Mrs. Reed-Shackelford recognized two new SCTF members, Ms. Priscilla Hill-Ardoin and Dr. Dawn Johnson, and the reappointment of Dr. Titilope Fasipe and herself. She called on members to introduce themselves and provide their background and affiliation. She then welcomed Karen Hess, Director, DSHS Newborn Screening Unit, asked her to introduce herself, and that she call on program staff members Dr. Debra Freedenberg, Aimee Millangue, Laura Arellano, Gwen Hanley and Julianna Ybarbo to provide brief introductions.

**Agenda Item 2: Consideration of November 10, 2021 meeting minutes**

Mrs. Reed-Shackelford reminded members that the November 10, 2021 draft meeting minutes were sent to them via email and asked if there were any edits or changes. Mrs. Reed-Shackelford stated that her name was misspelled in the motion for Agenda item #3. Hearing no additional edits, she requested a motion to approve the draft November 10, 2021 meeting minutes.

**MOTION:** Dr. Melissa Frei-Jones motioned to approve the November 10, 2021, meeting minutes with the edit presented. Ms. Alysian Thomas seconded the motion. Ms. Allen conducted a roll call vote, and the motion carried unanimously with no objections or abstentions.

### **Agenda Item 3: Presiding Officer Election**

Mrs. Reed-Shackelford introduced and turned the floor over to Ms. Allen and she read aloud the Adoption of Procedure for Election of Officers and Officer Election Process in its entirety to members. She proceeded and called for a motion to adopt the officer election procedure and process.

**MOTION:** Ms. Priscilla Hill-Ardoin motioned to adopt the Procedure for Election of Officers. Mrs. Marqué Reed-Shackelford seconded the motion. Ms. Allen conducted a roll call vote, and the motion carried unanimously with no objections or abstentions.

After the adoption of the Procedure for Election of Officers, Ms. Allen read for the record members who were nominated and accepted their nomination through email prior to the meeting.

Nominees for Chair:

- Dr. Titilope Fasipe
- Dr. Melissa Frei-Jones
- Dr. Alecia Nero

Ms. Allen called on nominees to inform members of their qualifications for the presiding office. When called, Dr. Nero announced that she would like to retract and decline the nomination for Chair. Ms. Allen proceeded and opened the floor to nominations for Chair.

No other nominations were received, thus the nominations were closed. Ms. Allen conducted a roll call vote of members to cast the vote for Chair. The tally of the votes resulted with Dr. Fasipe receiving three votes, Dr. Frei-Jones receiving two votes, and two members abstaining. Dr. Fasipe was elected as the new Chair.

Ms. Allen proceeded with the election for Vice Chair and read for the record members who were nominated and accepted their nomination for Vice Chair.

Nominees for Vice Chair:

- Dr. Titilope Fasipe
- Mrs. Marqué Reed-Shackelford

Ms. Allen stated that since Dr. Fasipe was appointed the new Chair, she is removed as a nominee for Vice Chair, and opened the floor for nominations. Receiving no other nominations from the floor, Ms. Allen acknowledged that Mrs. Reed-Shackelford was the single nominee and called for a motion to elect her by acclamation.

**MOTION:** Dr. Frei-Jones motioned to elect by acclamation, Mrs. Marqué Reed-Shackelford for Vice Chair. Ms. Alysian Thomas seconded the motion. Ms. Allen

conducted a roll call vote, and the motion carried unanimously with no objections or abstentions.

Ms. Allen announced Mrs. Marqué Reed-Shackelford as the new Vice Chair and congratulated her on her appointment. Ms. Allen advised that Dr. Fasipe and Mrs. Reed-Shackelford will assume their new roles at the next meeting and turned the floor over to Mrs. Reed-Shackelford.

#### **Agenda Item 4: Sickle Cell Surveillance Subcommittee Reporting**

Mrs. Reed-Shackelford introduced and turned the floor over to Ms. Aimee Millangue to provide a brief overview of the subcommittee's role and the members. She then introduced and turned the floor over to Dr. Melissa Frei-Jones, subcommittee member, to provide the Sickle Cell Surveillance Subcommittee report.

#### **Highlights of the report included:**

- An overview of the subcommittee's background and previous activities for the new SCTF members:
  - One of the things lacking for sickle cell disease (SCD) in the United States is a surveillance system for quantifying the number of individuals living with SCD and understanding their morbidity, mortality, and health outcomes
  - The subcommittee has benefitted from reports from Georgia, California and Michigan, who have participated in the Centers for Disease Control and Prevention's (CDC's) efforts to create a national surveillance system
    - Additional grant funding has allowed the CDC to expand participation to additional states
    - Subcommittee has been brainstorming on how Texas can participate and if there is the possibility of creating a state surveillance system
  - Met or worked with various groups to learn about the types of data currently available in Texas:
    - Syndromic Surveillance – put together a report about individuals with SCD
    - Medicaid & Children's Health Insurance Program (CHIP) – put together a report about individuals with SCD in the Medicaid system
    - Vital Statistics – provided mortality data tables and maps
  - Learned about legislation passed that has authorized the creation of a statewide claims database, which will include both private and public insurance
- Extending an invite for a third member to join the subcommittee
- Last met in January and invited Dr. Sarah Reeves to walk the through the steps of how Michigan joined the CDC Surveillance program and the pieces they already had in place
  - Conceptualizing what Texas needs
    - State data
    - Clinical data from centers
    - Coordinating getting data, putting it together, and submitting it to be a part of the surveillance information

- Logistics of applying for a grant with competing university/academic sickle cell programs in Texas
- While Michigan is able to get clinical data through a grant of public authority, question is how to get clinical data in Texas?
- Goal of subcommittee is to come up with a plan to either participate in the CDC's next round of funding for surveillance programs or to start to build the infrastructure to have the data sources to get to that point
  - Setting up data use agreements
  - Making sure different data sources are available
  - Taking information that is already available to the legislature to ask additional support for surveillance, if needed

Mrs. Reed-Shackelford asked if members had any questions. Hearing none, Mrs. Shackelford then opened the floor for volunteers to serve on the subcommittee with Ms. Thomas and Dr. Frei-Jones.

Dr. Dawn Johnson volunteered. Ms. Priscilla Hill-Ardoin also volunteered if there is additional need. Mrs. Reed-Shackelford advised there is a maximum of 3 members for each of the subcommittees.

**ACTION ITEM:** Members will share ideas for future presenters on sickle cell surveillance with program staff.

### **Agenda Item 5: Public Awareness Campaigns Subcommittee Reporting**

Mrs. Reed-Shackelford introduced and turned the floor over to Ms. Millangue to provide a brief overview of the subcommittee. She then introduced Dr. Alecia Nero, subcommittee member, and they provided the Public Awareness Campaigns Subcommittee report.

#### **Highlights of the report included:**

- A summary of recent efforts
  - Met to discuss a project with students from the University of Texas Human Dimensions of Organizations (HDO) program
    - Students take on projects to identify needs and help with things like marketing and research, then they will develop formal recommendations on how to implement things based of their research and work
    - Had meetings with the professor from the program
    - At their most recent meeting in January, subcommittee members worked on a questionnaire for the HDO program that included:
      - Defining the audience and ask
      - Identifying more specifically what the SCTF is looking for and hoping to gain from their work with the students, particularly with zero budget
      - Listing contacts
      - Agreeing to attend meetings with students
      - Describing the SCTF and key issues, using information from the annual report

- Possible references and sources for the project
- Priorities and expectations for deliverables

Mrs. Reed-Shackelford then turned the floor over to Ms. Millangue for a status update on the HDO project. Ms. Millangue reminded members that program staff were going email the professor after the last SCTF meeting to confirm the SCTF's willingness to participate in a project for the Spring 2022 semester. Ms. Millangue stated that unfortunately, the HDO program could not accommodate a SCTF project for the Spring 2022 semester, but there may be time to continue work toward participation in another semester.

**Members discussed:**

- Trying to participate during the Fall 2022 semester, which will give the SCTF time to include the new SCTF members in thinking about their focus
- Continuing efforts for September awareness
- The lead time needed to have a concrete ask and have the survey completed and submitted
- The subcommittee's recommendations for an ask
  - Researching successful awareness campaigns for rare diseases and how it could be applied to SCD
  - Capturing broader audiences to become allies, supporters, and champions
    - Medical professionals beyond those who care for people with SCD
    - General public, such as how to appeal to those who could donate blood and unaware of the needs of the SCD population
  - Maintaining engagement with existing SCD population
- How to incorporate community organizations who could have a wider reach throughout Texas without having a deliverable limited to a list of groups

After discussion concluded, Mrs. Reed-Shackelford opened the floor for a volunteer to join the Public Awareness Campaigns Subcommittee.

Ms. Hill-Ardoin volunteered to join the subcommittee.

**ACTION ITEMS:**

- Program staff will invite Dr. Wright back to a future subcommittee meeting to get her input on developing a concrete ask.
- Subcommittee will continue their study of the Sickle Cell Advisory Committee's (SCAC's) recommendation on collaborating Community Health Workers (CHWs) by working on some tangible asks.
- Program staff will ask for a timeline on when a concrete ask is needed.
- Subcommittee will complete ask and survey.

**Agenda Item 6: Medicaid Contracts Subcommittee Reporting**

Mrs. Reed-Shackelford introduced and turned the floor over to Ms. Millangue to provide a brief overview of the subcommittee's role and its members. Mrs. Reed-Shackelford then introduced Dr. Titilope Fasipe and Dr. Alecia Nero, subcommittee members, to provide the Medicaid Contracts Subcommittee report.

### **Highlights of the report included:**

- Recap of the subcommittee's work
  - Working on making sure that Managed Care Organizations (MCOs) and Accountable Care Organizations (ACOs) improved what they offer for the SCD population
  - Getting a baseline understanding of each of the groups
    - Saw there was variability with most of the groups not really identifying SCD as a unique population
    - Found that some groups have had prioritized SCD
  - Earlier discussions were about finding out who the audience was and what Medicaid Medical Directors knew about SCD
    - Tried to give tangible examples of how some of the policies might create barriers unintentionally for SCD
    - Members were able to bring both a pediatric lens and adult lens to the issues
  - Because of education gaps, found ways to be more productive
    - Meeting with core groups that have already had success, such as with a different disease population
  - HHSC staff with the Office of the Medical Director, Medicaid & CHIP Services shared opportunities for subcommittee to pursue
  - Met most recently in January and discussed:
    - Action items from prior meetings with Dr. Lisa Glenn, Senior Associate Medical Director, Medicaid & CHIP, HHSC
    - Medical home model for sickle cell
    - Medications that are considered non-formulary versus medications being on the preferred list
    - Existence of pharmacy benefit management component
    - Need for value-based models for care of diseases like SCD
    - Next steps:
      - Getting on the agenda of the STAR Kids Managed Care Advisory Committee and applicable subcommittees
      - Continuing mentorship relationship with Dr. Rahel Berhane, who started a pilot medical home program for children with complex care needs
  - Subcommittee also wanted to ask Medicaid groups to change their policies for sickle cell, for example, made a recommended action to bundle care resources for SCD

Dr. Fasipe added that the subcommittee is also just her herself and Dr. Nero and offered an opening to an additional member.

Dr. Johnson replied that she would love to be a part of the subcommittee, as her primary care clinic is already a patient-centered medical home for several other diseases.

**Members discussed:**

- Dr. Johnson's background and expertise with the medical home model will be helpful for the subcommittee
- Importance of addressing patient transition from pediatric to adult care and the gaps in care during that period
- Care and insurance coverage of the adult population with SCD
  - Lack of Medicaid expansion in Texas
  - No advisory committee on adult issues related to Medicaid
- Possibility of a bill or policy that helps bring more coverage options for adults with SCD
- Linking transition with medical home to improve outcomes
- Having each subcommittee select a chair instead of having the SCTF chair serve as chair of each subcommittee
  - The previous chair was a member and chair of each subcommittee, which lead to each subcommittee only having 2 members when she left the SCTF
  - The new SCTF chair will not be a member of each subcommittee

**ACTION ITEM:** Each subcommittee will designate a subcommittee chair at their next meeting.

**Agenda Item 7: 2021 Sickle Task Force Annual Report**

Mrs. Reed-Shackelford introduced Ms. Karen Hess, DSHS Newborn Screening Unit Director, to provide an overview of the *2021 Sickle Cell Task Force Annual Report*. Ms. Hess led the discussion with members and responded to member's questions.

**Highlights of the presentation included:**

- SCTF's responsibilities per the statute
  - Raising awareness of sickle cell and sickle cell trait
  - Studying and advising DSHS on implementing the 5 recommendations made in the 2018 report by the SCAC
    - Establish a SCTF – done
    - Develop statewide sickle cell awareness campaign
    - Begin statewide sickle cell surveillance throughout the lifespan
    - Partner with Medicaid and Medicare MCOs and ACOs
    - Utilize CHWs to improve care for those with SCD and sickle cell trait
  - SCTF is required to submit an annual report to the Governor and Legislature by December 1 each year that summarizes the SCTF's work and include any recommended actions or policy changes endorsed by the SCTF and outline the SCTF's proposed actions for implementing the SCAC's original recommendations
- Since it goes to the Governor and Legislature, approval of the report is routed through a department chain of command
- Government Affairs (GA) made adjustments to comply with

- protocols on how reports are designed for submission to legislators
- As a result, the report looks different
  - GA removed information such as data and charts from the body and appendices
  - Web links replaced removed information in the narrative of the report
- An overview of the contents of each section of the report
  - Acknowledgement of Dr. Frei-Jones, Dr. Fasipe, and Dr. Michelle Mackey for their work on writing the report

**Members discussed:**

- Not being able to share the surveillance components in the report
- Instead including Syndromic Surveillance data or a direct link to the handout that was provided at a previous SCTF meeting in the report, it was provided as a link to the full webcast of that meeting
- Program staff are trying to figure out how to share the newborn screening data and the data from the Center for Health Statistics on sickle cell-related deaths
- Sharing the amount of data the SCTF wanted to share in the report is not part of the report procedure
- Possibility of sharing the data as reports on the DSHS website, and linking to them in the report

**ACTION ITEMS:**

- Program staff will find out if sharing data from the other programs such as Syndromic Surveillance and Center for Health Statistics is allowed and can be posted on the DSHS website.
- Program staff will contact GA to find out if they could attend one of the subcommittee meetings to get their input on including data in the report and challenges with linking to the data directly and if they could offer some ideas.

**Agenda Item 8: 2022 Sickle Cell Task Force Annual Report Planning**

Mrs. Reed-Shackelford introduced Ms. Millangue to provide points of interests related to the preparing of the 2022 report.

**Highlights of the presentation included:**

- The agency provides a template that requires sections much like those in the 2021 report
- The 2022 report will follow the template and include highlights of the SCTF recommended actions for 2022 and any activities and tasks the SCTF completed
- In previous years, writing of the report was delegated to a subcommittee
  - Members included Dr. Fasipe, Dr. Frei-Jones, and previous chair, Dr. Mackey
  - Each member had sections to write
  - Ms. Millangue compiled the sections into a draft report that was presented to the full Task Force at their August meetings
- The last 2 years, SCTF members voted to approve the draft with a motion for the Chair to have final review and approval



- Dr. Mackey had opportunities to review and approve the draft of the 2021 report

Mrs. Reed-Shackelford then opened the floor up for members to discuss the SCTF's 2022 Legislatively Mandated Report (LMR) and called for volunteers to serve on a subcommittee to develop the 2022 report.

Dr. Frei-Jones and Dr. Fasipe expressed their interest in continuing to serve on the subcommittee.

**Members discussed:**

- While working on the report may seem daunting, the subcommittee receives support from the program staff with the template and guidance
- Much of the report stays the same and the subcommittee updates a lot of the sickle cell information
- The timeline for writing the report is between the current meeting and August
- Members review drafts of the report through email and provide feedback to program staff
- Members discuss the final draft of the report at their August meeting

Mrs. Reed-Shackelford added that she volunteers to support the subcommittee.

**Agenda Item 9: Sickle Cell Task Force Rules**

Mrs. Reed-Shackelford introduced Ms. Laura Arellano and she provided an overview of repealed SCAC rules and replacement with new SCTF Rules. Ms. Arellano led the discussion with members and responded to questions.

**Highlights of the presentation included:**

- The SCAC was abolished in 2019 per Texas Government Code, Section 2110
- The SCTF was established in accordance with House Bill 3405 in the 86<sup>th</sup> Legislature.
- The statute resides in Texas Health and Safety Code Chapter 52.
- The purpose of the rules is to repeal Texas Administrative Code Title 25, Subchapter R, Section 27, the old SCAC rules, which are no longer in effect
- The agency will repeal and replace the old rules with new rules governing the SCTF operations
- The proposed new rule establishes the SCTF and describes the SCTF composition, roles, responsibilities, and, for now, perspective sunset date of September 1, 2025
- The proposed rules were posted on the HHS and DSHS websites from December 15, 2021 – January 3, 2022.
- SCTF members received a link, and the agency did not receive any public informal comments
- While a draft of the proposed rules is not available, they will be presented to the Executive Council on May 18, 2021
- The proposed rules are expected to be published in the Texas Register around mid-June with a 30-day formal comment period
- Everyone has the ability to comment on the rules as an individual
- By September 2022, the finalized rules are expected to be published in the

Texas Register and will become effective

**Members discussed:**

- If there are substantial differences between the rules being repealed and the proposed rules
- If there will be an opportunity to review the proposed rules before May
- Commenting on rules is not something that is generally within an advisory committee's purview, unless it is specified in statute

**ACTION ITEMS:**

- Program staff will send links to the draft rules once they're posted in case members want to provide comments.
- Program will check with the Division if it is possible for the SCTF to review and comment on the proposed rules as a committee

**Agenda Item 10: Public Comment**

No public comment was received for this meeting.

**Agenda Item 10: Future Agenda Items/Next Meeting Date/Adjournment**

Mrs. Reed-Shackelford opened the floor for discussion of future agenda items and stated the next meeting is scheduled May 27, 2022. Mrs. Reed-Shackelford turned the floor over to Ms. Millangue to recap action items and topics for a future meeting.

**Ms. Millangue stated:**

- She will check if Dr. Jamie Barner and Dr. Kang from the College of Pharmacy at the University of Texas, who were unable to join the current meeting, are available to present their SCD research and work with the Marc Thomas Foundation at the next meeting.
- She will follow up with Dr. Amy Nathan Wright if she could join a Public Awareness Campaigns subcommittee meeting.
- She will follow up on a previous action item to contact Brett Spencer and Frank Luera with the CHW program and also ask the Public Awareness Subcommittee if they are ready to share a tangible ask of the Community Health Workers Program.
- Asked for members to share thoughts on presenters and subject matter experts to invite to the next subcommittee meetings.
- Subcommittee reports on:
  - Sickle Cell Surveillance
  - Public Awareness Campaigns
  - Medicaid Contracts
  - LMR
- Dr. Fasipe, as the new chair, will need to be available when the SCTF's recommended actions from their 2021 report are presented at an Executive Council meeting in May or August

**Members discussed:**

- Action items for the LMR and Medicaid Contracts subcommittees
- Members needing to submit their signed Statement by Members for the bylaws passed at the November meeting

- Providing a more thorough introduction to the new members
- Going over the proposed SCTF rules
- Timeline for submitting agenda items for the next SCTF meeting
- If every subcommittee will meet before the next SCTF meeting
- Possibility of program staff polling on other dates to reschedule the next meeting since it falls before Memorial Day weekend

Ms. Millangue also reminded new members of the training information that was emailed to them.

Mrs. Reed-Shackelford thanked everyone and adjourned the meeting at 2:24 p.m.

Below is the link to the archived video of the April 1, 2022 SCTF meeting that will be available for viewing approximately two years from the date the meeting was posted on the website and based on the DSHS records retention schedule:

<https://texashhsc.new.swagit.com/videos/157931>