

**Sickle Cell Task Force
Meeting Minutes
November 10, 2021
12:00 p.m.**

Microsoft Teams Live Event

Table 1: Sickle Cell Task Force member attendance at the Wednesday, November 10, 2021 meeting.

| MEMBER NAME | IN ATTENDANCE |
|------------------------------|-------------------------------|
| Dr. Titilope Fasipe | Yes |
| Dr. Melissa Frei-Jones | Yes |
| Dr. Alecia Nero | Yes (Joined at Agenda Item 4) |
| Mrs. Marqué Reed-Shackelford | Yes |
| Ms. Alysian Thomas, J.D. | Yes |

Agenda Item 1: Welcome & Introductions and logistical announcements

Dr. Titilope Fasipe, acting Presiding Officer of the Sickle Cell Task Force (SCTF), called the meeting to order at 12:01 p.m. and welcomed everyone in attendance.

Dr. Fasipe provided opening remarks then introduced and turned the floor over to Eric Owens, Health and Human Services Commission (HHSC), Policy & Rules, Advisory Committee Coordination Office (ACCO). Mr. Owens reviewed logistical announcements, conducted a roll call, asked members to introduce themselves, and announced the presence of a quorum.

Dr. Fasipe took a moment to recognize and thank Dr. Michelle Mackey, former SCTF Chair, and Mr. David Martinez, outgoing Director, Department of State Health Services (DSHS) Newborn Screening Unit. Dr. Fasipe then welcomed Karen Hess, Interim Director, DSHS Newborn Screening Unit, asked her to introduce herself, and that she call on program staff members Dr. Debra Freedenberg, Aimee Millangué, Laura Arellano, and Christy Ryman to provide brief introductions.

Agenda Item 2: Consideration of August 20, 2021 meeting minutes

Dr. Fasipe reminded members that the August 20, 2021 draft meeting minutes were sent to members via email for review and asked if they had any edits or changes. Dr. Fasipe requested a motion to approve the August 20, 2021 meeting minutes.

MOTION: Dr. Melissa Frei-Jones motioned to approve the August 20, 2021 meeting minutes. Ms. Alysian Thomas seconded the motion. Mr. Owens conducted a roll call vote, and the motion was majorly carried with four “for” votes, no objections, and no abstentions.

Agenda Item 3: Consideration of Bylaws

Dr. Fasipe reminded members that the draft Bylaws were sent to members via email for review and asked if they had any edits or changes. Dr. Fasipe requested that Ms. Aimee Millangue, Advisory Committee Liaison, DSHS Newborn Screening Unit, review major changes to the bylaws. Dr. Fasipe then requested a motion to approve the Sickle Cell Task Force Bylaws.

MOTION: Dr. Melissa Frei-Jones motioned to approve the Sickle Cell Task Force Bylaws. Mrs. Marqué Reed-Shackelford seconded the motion. Mr. Owens conducted a roll call vote, and the motion was majorly carried with four “for” votes, no objections, and no abstentions.

Agenda Item 4: Collaborating with Community Health Workers

Dr. Fasipe introduced and turned the floor over to Dr. Melissa Frei-Jones, Task Force member. Dr. Frei-Jones lead discussion related to collaborating with community health workers (CHWs).

Dr. Frei- Jones stated:

- She was invited to present at a recent Promotor(a) or Community Health Worker Training and Certification Advisory Committee (CHWAC) meeting.
- She gave them information about sickle cell disease (SCD) and discussed background of the advisory committee and SCTF.
- She presented information on how other programs are using CHWs, how the Sickle Cell Association of America has a CHWs training program, some active research studies which were comparing the use of CHWs versus other items for individuals with SCD who may be transitioning care or as navigators through the adult health care system.
- She answered a few questions and received comments.
- She was not sure if she conveyed that there were patients in other pockets of the state who need to have someone advocate for them because comments from the advisory committee members gave the perception that the CHWs at hospital systems in large urban areas should be the ones addressing SCD.
- She mentioned the availability of the Texas Health Steps module online.

Members discussed:

- Dr. Frei-Jones’ understanding of who the audience was
- Next steps
 - Engage their leadership if they want to continue or options for working together
 - If there was a way to optimize recommending CHWs take Texas Health Steps training
 - How often the advisory committee has meetings
 - Forming a CHWs subcommittee or adding CHW discussion to an existing subcommittee

ACTION ITEMS:

- Program staff will follow up with Brett Spencer and Frank Luera about other connections can be made with the CHW community.
- The Public Awareness Subcommittee will explore CHW outreach.

Agenda Item 5: Sickle Cell Surveillance Subcommittee Reporting

Dr. Fasipe introduced and turned the floor over to Dr. Melissa Frei-Jones, subcommittee member. Dr. Frei-Jones referenced the handouts, *Sickle Cell Surveillance Subcommittee Meeting Minutes*.

Highlights of the presentation included:

- Met on October 21, 2021 with staff from the Texas Medicaid and the Children's Health Insurance Program (CHIP).
 - They presented 2019 Texas data they pulled based on the 2017 national data highlighted in the recent Medicaid report on the state of SCD care.
 - They created 14 data tables that showed:
 - Number of Medicaid and CHIP members
 - Number of patients with SCD that received services in 2019
 - Percentage of patients under 21
 - Areas where most patients lived
 - Measures on transcranial doppler ultrasounds, hydroxyurea prescriptions, vaccinations, antibiotic prophylaxis, emergency department use, inpatient hospitalization, and outpatient visits, and preventative care
- Subcommittee requested a report be generated for 2020 data
- Possibly including 2019 and 2020 data in the SCTF's 2022 legislative report to show gaps in care
- Data was for patients on only continuous Medicaid, so subcommittee requested data on gap population of patients who had interrupted coverage
- Passing of House Bill 1907 to establish a statewide all payor claims database, and future possibility of using database to link to clinical data
- Still needing to figure out logistics of setting up a sickle cell data collection system (SCDC) and surveillance in Texas
 - Texas already has many core data sets
 - Missing connection to clinical case reports

Members discussed:

- Which data was available to be included in the 2021 SCTF legislative report
- Submitting annual requests for Medicaid and CHIP data

ACTION ITEMS:

- Program will invite Dr. Sarah Reeves with Michigan's SCDC to present to the subcommittee.
- Request that Medicaid and CHIP present 2020 data to the subcommittee when it is available.

Agenda Item 6: Public Awareness Campaigns Subcommittee Reporting

Dr Fasipe introduced Mrs. Marqué Reed-Shackelford, subcommittee member. Mrs. Reed-Shackelford referenced the handout, *Public Awareness Campaigns Subcommittee Meeting Minutes*.

Highlights of the presentation included:

- Met with Dr. Amy Nathan Wright, Assistant Professor of Instruction for the Human Dimensions of Organizations (HDO), College of Liberal Arts at University of Texas – Austin (UT)
- Subcommittee discussed with Dr. Wright the background of the HDO program and what the HDO program offers with students finding solutions to people-centered problems
- Teams of HDO students work with businesses, non-profits, or other organizations on an “ask” as part of their practicum projects each semester
- HDO’s previous projects have included marketing campaigns
- Students present their formal recommendations and a report with documented research to address the “ask” at the end of each semester
- Deliverables could include things such as manuals and toolkits
- Subcommittee discussed possible SCTF asks:
 - Sickle cell awareness through marketing and public campaigns
 - Partnering with community organizations related to health
 - Producing a resource list or directory of organizations within major cities across Texas
 - How to overcome pitfalls of raising awareness
 - Raising awareness among different audiences, such as medical professionals or college students
- No cost or formal arrangements required
- SCTF could email Dr. Wright by mid-December to start a Spring 2022 project

Members discussed:

- Students can take on multiple projects each semester
- Opportunity for an ongoing collaboration HDO over multiple semesters
- Whether SCTF would like to participate during Spring 2022 semester
- Students could provide new ideas in terms of social media
- Pairing possible asks with SCTF’s charge
- Having a definitive ask by mid-January
- Subcommittee members will meet with students throughout the semester on behalf of the SCTF
- A spring 2022 semester project could be beneficial for June World Sickle Cell Day and September Sickle Cell Awareness month
- What the ask needs to look like
- When ask needs to be finalized
- When considering an ask of overcoming pitfalls of spreading awareness and raising awareness among different audiences, including transition
- Projects can benefit students academically and professionally, since they may be able to present research at meetings about SCD or hematology disorders.

ACTION ITEMS:

- Program staff will email Dr. Wright to confirm commitment to spring project.
- Subcommittee will present their recommended asks for SCTF to vote upon and finalize at their next meeting.

Agenda Item 7: Medicaid Contracts Subcommittee Reporting

Dr. Titilope Fasipe, acting presiding officer, referenced the handout, *Public Awareness Campaigns Subcommittee Meeting Minutes*.

Highlights of the presentation included:

- Since first presenting at the Medicaid Directors meeting last year, the subcommittee has had a champion, Dr. Van Ramshorst
- Having a champion has allowed the subcommittee to keep in close communication with the Medicaid directors through their meetings and also be introduced to others through the process
- Subcommittee had learned in the last year that there was less education about sickle cell, the disease.
- Dr. Fasipe presented at the Medicaid directors meeting on October 18 and focused on education, laying the foundation for understanding the disease and why, as a chronic disease, it needs more support at the payor level.
- At the meeting, there was another presentation on a pilot project for complex medical needs that showed a possible model of how to work with the Medicaid moving forward
- Subcommittee met and reviewed previous discussion on having “care packages” of certain resources for individuals with SCD that Subcommittee members considered essential based on recommendations from national guidelines or reports from patients on what has helped them
- Subcommittee learned from Dr. Van Ramshorst and his team which resources Medicaid payors already covered versus which resources were not covered but could be incorporated into care packages later
- Subcommittee defined asks for Medicaid and CHIP:
 - Continuation of SCD education
 - Concept of medical home and who should make up medical home
 - Identifying what essentials are needed under guideline-based care and making recommendations on what should be covered by Medicaid
- There are waiver programs and processes available that can facilitate coverage of some resources that are not already covered by Medicaid

Members discussed:

- Doctors could get some resources covered by using different diagnosis codes
- Supporting idea of requesting coverage of resources based on evidence
- Care resources that are not evidence-based could be developed by community-based organizations
- Importance of co-management of the medical home to improve patient care
- Needing to address issues with prior authorization process

ACTION ITEM: Program staff will contact the STAR Kids Advisory Committee about the subcommittee presenting at one of their meetings.

Agenda Item 8: Review of Task Force recommended actions

Dr. Fasipe led a discussion to provide members an opportunity to review and discuss the Task Force’s recommended actions.

Highlights of the presentation included:

- Utilize existing agency framework to promote annual sickle cell awareness campaigns
- Design an awareness campaign on SCD and SCT education in collaboration with Texas colleges and universities.
- Publish an annual Texas sickle cell report based on data from the DSHS Newborn Screening Unit, DSHS Texas Syndromic Surveillance System, and the DSHS Center for Health Statistics.
- Establish and maintain a universal sickle cell data collection system
- Partner with the HHSC Office of the Medical Director, Medicaid and Children’s Health Insurance Program (Medicaid & CHIP) Services to provide current sickle cell clinical care guidelines.
- Collaborate with the HHSC Office of the Medical Director, Medicaid & CHIP Services to integrate non-pharmacological alternatives into care packages for patients with SCD

Members discussed:

- Public awareness campaigns
 - The progress that has been made with a \$0 budget
 - Possibility of accessing television and radio
 - Spreading message throughout the month
 - Sickle Cell Surveillance
- Sickle cell annual report
 - Adding Medicaid claims data to recommendation
 - Adding an educational component along with data

Agenda Item 9: Public Comment

No public comment was received for this meeting.

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

Dr. Fasipe opened the floor for discussion of future agenda items and stated the next meeting is scheduled in February 2022. Dr. Fasipe turned the floor over to Ms. Millangue to recap action items and topics for a future meeting.

Ms. Millangue stated:

- Subcommittee reports
- Program will invite Dr. Rahel Berhane to the Medicaid Contracts Subcommittee meeting
- Program staff will follow up with Dr. Amy Nathan Wright to confirm commitment to working with their senior HDO project and for the spring 2022 semester
- Contact Brett Spencer and Frank Luera with the Community Health Workers program
- Program staff will reach out to Dr. Sarah Reeves from the Michigan Sickle Cell Data Collection program for more information about data linking with the clinical side of the surveillance data
- Have a Chair and Vice Chair election
- Review 2021 annual report
- Program staff will develop a draft of the 2022 annual report for the SCTF to review
- Program staff will invite Dr. Jamie Barner and Dr. Hyeun Ah Kang with the College of Pharmacy at UT to present their research on SCD and their work with the Sickle Cell Association of Texas Marc Thomas Foundation

Members discussed:

- Status of 2021 annual report
- Checking with agency legal counsel to make sure there are no conflicts of interest with Dr. Barner and Dr. Kang presenting to the SCTF
- Status of new member appointments

Dr. Fasipe thanked everyone and adjourned the meeting at 2:20 p.m.

Below is the link to the archived video of the November 10, 2021 Sickle Cell Task Force (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://texashsc.swagit.com/play/11102021-1140/2/>