

**Sickle Cell Task Force
Meeting Minutes
February 27, 2020
12:00 p.m.**

**Brown-Heatly Building, Public Hearing Room
4900 N. Lamar Blvd, Austin, TX 78751**

Table 1: Sickle Cell Task Force attendance at the Thursday, February 27, 2020 meeting.

MEMBER NAME	IN ATTENDANCE
Dr. Titilope Fasipe	Yes
Dr. Melissa Frei-Jones	Yes
Dr. Michelle Mackey	Yes
Dr. Alecia Nero	Yes
Ms. Tonya Prince	Yes
Ms. Marque Reed-Shackelford	Yes
Ms. Alysian Thomas	Yes

Table 2: Sickle Cell Task Force attendance at the Thursday, February 27, 2020 meeting.

GUEST NAME and Organization	IN ATTENDANCE
Clarence Mackey	Yes

Agenda Item 1: Welcome and Introductions

Mr. David Martinez, Unit Director, DSHS, Newborn Screening, convened the meeting of the Sickle Cell Task Force at 12:01 p.m. Mr. Martinez introduced himself and requested members introduce themselves.

Agenda Item 2: Task Force Logistical Announcements

Mr. Martinez turned the floor over to Ms. Stephanie Gutierrez, HHSC, Advisory Committee Coordination Office, to read logistical announcements and announce a quorum.

Agenda Item 3: Review and approval of meeting minutes from November 26, 2019

Ms. Gutierrez requested a motion to approve the November 26, 2019 meeting minutes.

MOTION: Dr. Melissa Frei-Jones made a motion to approve the November 26, 2019 meeting minutes. Dr. Michelle Mackey seconded. A voice vote was taken. The motion carried with no objections and no abstentions.

Agenda Item 4: Review and adoption of Sickle Cell Task Force Bylaws

Ms. Gutierrez reminded members at the November 26, 2019 meeting, the Task Force reviewed the bylaws and requested more time for review before adoption.

Ms. Gutierrez noted for the record that the bylaws will need to be amended at a future meeting to update the abolishment date and term durations. Ms. Gutierrez also noted for the record that members will draw staggered terms at the next meeting.

Mr. Martinez provided explanation regarding the abolishment date being under review and that the Task Force could potentially extend beyond two years.

Ms. Gutierrez requested a motion to adopt the Sickle Cell Task Force Bylaws.

MOTION: Ms. Marque Reed-Shackelford made a motion to adopt the Sickle Cell Task Force Bylaws. Ms. Alysian Thomas seconded the motion. A voice vote was taken. The motion carried unanimously with no objections and no abstentions.

Agenda Item 5: Presiding Officer Election

Ms. Gutierrez reminded members that the Officer Election Process was adopted at the November 26, 2019 meeting.

Ms. Gutierrez noted for the record that members will vote for Chair during the current meeting. The chair will charge the next meeting, May 29, 2020 and all meetings thereafter.

Ms. Gutierrez read the role of the Chair from the adopted bylaws. Ms. Aimee Millangue, DSHS, Newborn Screening Unit, noted for the record that the Chair will also need to attend conference calls with the program.

Ms. Gutierrez opened the floor for nominations and informed members of persons whom have already been nominated and whom have accepted their nominations:

1. Dr. Melissa Frei-Jones = Accepted
2. Dr. Michelle Mackey = Accepted
3. Dr. Titilope Fasipe = Declined
4. Dr. Alecia Nero = Accepted
5. Ms. Tonya Prince = Accepted

No other nominations were made. The floor was closed for nominations.

Ms. Gutierrez gave each member who accepted their nomination the opportunity to give a two-minute qualification speech.

Ms. Gutierrez stated for the record that each member's name and the person whom they are voting for will be read out loud.

Ms. Gutierrez requested a motion as to which method the election will be handled. Members had a brief discussion.

MOTION: Dr. Melissa Frei-Jones made a motion to vote by ballot. Ms. Marque Reed-Shackelford seconded the motion. A voice vote was taken. The motion carried with no objections and no abstentions.

Ms. Gutierrez requested members cast their vote by ballot. Ms. Gutierrez and Ms. Millangue collected ballots. Ms. Gutierrez tallied the votes, and read each members' vote out loud for the record. Dr. Frei-Jones received two votes, Dr. Nero received two votes, and Dr. Mackey received three votes. Ms. Gutierrez announced the new chair of the Sickie Cell Task Force, Dr. Michelle Mackey.

Dr. Mackey extended her appreciation to the Task Force.

Agenda Item 6: Agency Overview of Statewide Public Awareness Campaigns

Mr. Martinez introduced Ms. Lisa Cazacu, DSHS, Center for External Relations, Communications Specialist. Ms. Cazacu referenced the handout and PowerPoint, *Sickle Cell Awareness Campaigns: Marketing Communications*.

Members discussed:

- Statewide campaigns of varying budgets
- The budget is determined internally through program
 - The Task Force has no funding attached to it
 - Funding through partner organizations and scholarship grants are allowable
 - The task force's legislatively mandated report can include recommendations for funding public awareness campaigns
- \$400-thousand is on the lower end of the budget range
- Blanket contract marketing vendors have not bid on contracts with lower budgets
- Market research is a great way to start with a lower budget
- Campaigns being created with \$0 budgets
 - Agency Social Media posts
 - Agency Homepage notices
 - DSHS Communications office can assist with creating flyers and letters
- Geofencing
- Thinking outside of the box and not being limited by having no funding with stop-gap measures
- Challenge of program budgets being siloed within the agency
- Influencers marketing through social media
- Marketing vendor contracts provide specifics of what needs to be accomplished with each campaign, which limits the ability to piggy back messaging of related topics

Agenda Item 7: Texas Syndromic Surveillance (TxS2) System

Mr. Martinez introduced and turned the floor over to Mr. Linc Allen, DSHS, Texas Syndromic Surveillance Coordinator, Division for Regional and Local Health Operations. Mr. Allen referenced the handout and PowerPoint, *Texas Syndromic Surveillance System (TxS2)*.

Members discussed:

- System contains emergency disease data from voluntary reporting sites including hospitals, urgent care clinics and freestanding emergency rooms with emergency disease data, but no inpatient data
- Sickle Cell data is available for query within the existing TxS2 dataset and does not require sickle cell data to be submitted separately for input
- No cost to run a query for Sickle Cell data, but results include Personal Health Information (PHI), so only aggregate data in the form of graphs and maps can be shared publicly
- The TxS2 system is tied into the Centers for Disease Control and Prevention (CDC)
- Hospitals are not rolled into the system automatically
- Need to maximize potential for collecting sickle cell data within the system for collaborating with CDC
- Data sharing of hospital/hospital system level data is not available to other hospitals/hospital systems
- Reaching out to smaller unaffiliated hospitals
- Lack of data verification is the strength and weakness of TxS2 because of a fast turnaround from data collection to query results
- Using NVivo software for program queries
- Hospitals in the system can only compare patient-level data from within own network or their own hospital
- The data is delayed by days
- Task force members can submit their ideas for refining a sickle cell data query by emailing Ms. Millangue to forward to Mr. Allen
- Reviewing the data elements and refined queries at a future meeting

Agenda Item 8: Break

Mr. Martinez announced a 13-minute break.

Agenda Item 9: Medicaid Managed Care

Mr. Martinez reconvened the meeting at 2:05 p.m.

Mr. Martinez introduced and turned the floor over to Ms. Laura Jourdan, HHSC, Office of Policy, Medicaid and CHIP. Ms. Jourdan referenced the handout and PowerPoint, *Overview of Medicaid Managed Care*.

Members discussed:

- Recommendations provided to medical providers are determined by the Managed Care Organizations (MCOs)

- Efficiency of communication between specialists and MCO Service Coordinators
- Current evidence-based standards on treatment and current workflow needs to be revisited with the MCO Service Coordination and Management in collaboration with disease-specific teams caring for patients and familiar with their complications
- Improved training of Sickle Cell disease for individual health plans
- Opportunities to share feedback with MCOs
- The federal Centers for Medicare & Medicaid Services (CMS) education should be the standard for all regions
- The long-term care component guides service care coordination
- Concerns with the appeals process for service denials

ACTION ITEM: Ms. Jourdan will send Ms. Millangue the links to the Texas Medicaid and MCO contracts for members to review.

Agenda Item 10: Newborn Screening Advisory Committee

Mr. Martinez introduced and turned the floor over to Dr. Melissa Frei-Jones, Sickle Cell Task Force and Newborn Screening Advisory Committee member. Dr. Frei-Jones referenced the handout and PowerPoint, *Newborn Screening Advisory Committee*.

Members discussed:

- General overview of the Newborn Screening Advisory Committee and its membership
- Overview of the Sickle Cell Subcommittee
 - Current activities and next steps
 - Other issues that subcommittee can investigate
 - Missing newborn screening sickle cell results for parents of current sickle cell patients
 - The Newborn Screening laboratory can give this type of information for individuals born in 1984 and later

Agenda Item 11: Community Health Workers

Mr. Martinez introduced and turned the floor over to Mr. Brett Spencer, DSHS, Community Health and Wellness Branch Manager, Health Promotion and Chronic Disease Prevention Section. Mr. Spencer referenced the handout and PowerPoint, *Overview of Promotor(a) or Community Health Worker (CHW) Certification in Texas*.

Members discussed:

- Background information on individuals who take the training program
- Reimbursements for CHWs
- Requirements and certification
- Sickle Cell Disease Association of American has a CHW training
- Variance in salary ranges for CHWs

ACTION ITEM: Mr. Spencer will send members follow-up information regarding the Statewide Online Survey.

Agenda Item 12: Legislative Report

Mr. Martinez introduced and turned the floor over to Ms. Karin Hopkins, DSHS, System Coordination, Center for External Relations. Ms. Hopkins referenced the handout and PowerPoint, *Legislative Reports*.

Members discussed:

- Report timeline
 - Forming a subcommittee to draft the report
 - Have draft to vote on by mid-summer

Agenda Item 13: Public Comment

No public comment was made.

Agenda Item 14: Future Agenda Items/Next Meeting Date/Adjournment

Mr. Martinez stated the next meeting dates, May 29, 2020 and August 31, 2020 located in M-100.

Mr. Martinez opened the floor for discussion of agenda items for the next meeting.

Members discussed:

- Ideas for public awareness campaigns
 - \$0 budget
 - Targeted audiences
- Newborn Screening program's follow up process for children identified with sickle cell
- Medicaid contracts
- Subcommittee development
- Extending the meeting duration
- Working on milestones and goals
- Legislatively Mandated report

Mr. Martinez adjourned the meeting at 3:59 p.m.

Webcast: <https://texashhsc.swagit.com/play/02272020-1158>