

**Sickle Cell Task Force
Meeting Minutes
August 31, 2020
1:00 p.m.**

Microsoft Teams Live Event

Table 1: Sickle Cell Task Force member attendance at the Monday, August 31, 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. Marqué Reed-Shackelford	Yes
Ms. Alysian Thomas, J.D.	Yes

Agenda Item 1: Welcome and Introductions

Dr. Michelle Mackey, Chair of the Sickle Cell Task Force (SCTF), called the meeting to order at 1:02 p.m. and welcomed everyone in attendance. Dr. Mackey asked for agency staff to introduce themselves and provided opening remarks.

Agenda Item 2: Task Force Logistical Announcements

Dr. Mackey introduced Ms. Sallie Allen, HHSC, Policy & Rules, Advisory Committee Coordination Office. Ms. Allen reviewed logistical announcements, conducted a roll call and announced the presence of a quorum.

Agenda Item 3: Review and Approval of Meeting Minutes from June 12, 2020

Dr. Mackey requested a motion to approve the June 12, 2020 meeting minutes.

MOTION: Dr. Melissa Frei-Jones motioned to approve the June 12, 2020 meeting minutes. Ms. Alysian Thomas seconded the motion. Ms. Allen conducted a roll call vote, and the motion carried with no objections and no abstentions. Ms. Tonya Prince and Ms. Marqué Reed-Shackelford were not present at the time of approval.

Agenda Item 4: Task Force Milestone Development Subcommittee Reporting

Dr. Mackey referenced the handout, *Task Force Milestone Development Subcommittee Meeting Minutes*, and opened the floor for comments and questions.

Members discussed:

- Including COVID-19 messaging in the Public Awareness Campaigns
 - Information will be posted on the Newborn Screening Program website linking to the Centers for Disease Control (CDC) website.
- Milestones were well-developed and thanked the subcommittee for their work

Agenda Item 5: Public Awareness Campaigns Subcommittee Reporting

Dr. Mackey referenced the handout, *Public Awareness Campaigns Subcommittee Meeting Minutes*, and opened the floor for discussion.

Mr. David R. Martinez, DSHS, Director, Newborn Screening Unit, gave an update on the Public Awareness Campaign for Sickle Cell Awareness Month, September 2020:

- Subcommittee's ideas included sharing links, such as for awareness and blood donation, which will be posted on the Newborn Screening website.
- Program is working closely with DSHS and HHS Communications and social media messages will be sent out.

Members discussed:

- Exploring sponsorship from pharmaceutical companies
 - Dr. Alecia Nero contacted some companies to gauge willingness and experience working with other state agencies
 - Found there was an interest
 - Did not find that companies had experience working with state agencies
 - Working with Legal departments (pharmaceutical company, state)
 - How funds would be used
- How information about Blood centers for different regions will be shared
- Working with Communications to review all messaging
- Partnering with universities, explore marketing public awareness
- Not limiting ideas for making a recommendation for Public Awareness campaigns based on cost
- Targeting health care professionals down the line

Agenda Item 6: Medicaid Contracts Subcommittee Reporting

Dr. Mackey referenced the handout, *Medicaid Contracts Subcommittee Meeting Minutes*, and opened the floor for discussion.

Members discussed:

- Subcommittee action item follow up with Ms. Laura Jourdan, HHSC, Office of Policy, Medicaid and CHIP
 - Opportunities to join Medicaid Managed Care Organization stakeholder meetings
 - Presentation on Medicaid Medical Home at next meeting
 - Guidance on how to review contracts since there is no specific sickle cell language in the contracts
- Difficulties for specialists providing care under Medicaid/CHIP

- Delay in care for patients due to the referral process from primary care provider
- Current sickle cell medical home model has limitations on specialists to provide care in a more timely fashion
- Working with Medicaid/CHIP to broaden definition of medical home
 - Whether to include Centers for Excellence
 - Integrating specialists in medical home model, such as in Missouri, for example
 - Hematologists cover most of the care, not PCPs
 - Referrals go through PCPs, complicates access to care and consistency
 - Different Medicaid programs offer different levels of support

Agenda Item 7: Legislatively Mandated Report

Dr. Mackey referenced the handouts, Legislatively Mandated Report Subcommittee Meeting Minutes and the Legislatively Mandated Report. Dr. Mackey stated members will have a discussion over the draft of the report.

Ms. Aimee Millangue, DSHS, Newborn Screening Unit, Advisory Committee Support, reviewed the draft Legislative Report with the Task Force and members' suggested edits.

Members discussed:

- Report should be limited to 10 pages
- Keeping the Background section short
- Timeline of legislation to bring history of sickle cell current
- Therapies approved by the Federal Drug Administration

MOTION: Dr. Melissa Frei-Jones motioned to approve the Legislative Mandated Report with edits and revisions presented and to grant authority to Dr. Mackey, Chair, to incorporate the changes, finalize the report and submit to DSHS for review. Ms. Marque Reed-Shackelford seconded the motion. Ms. Allen conducted a roll call vote, and the motion carried with no objections and no abstentions.

Agenda Item 8: Public Comment

Ms. Allen read the public comment logistical announcements and called on those registered for public comment.

Written public comment was received from:

Mrs. Tanya Ardoin, a private citizen. Her document addressed collection of surveillance information related to individual diagnosed with sickle cell.

Oral and written public comment was received from:

Ms. Cierra King, a graduate student at University of Southern California Sol Price School of Public Policy and has sickle cell disease. She represented an initiative she developed that explores the data of the medical treatment of sickle cell disease.

Agenda Item 9: Future Agenda Items/Next Meeting Date/Adjournment

Dr. Mackey opened the floor for discussion of future agenda items and stated the next meeting will be on November 20, 2020.

Members discussed:

- Invite Medicaid SME, Laura Jordan to next meeting
- Syndromic Surveillance System and Community Health Workers
- Public Awareness Subcommittee and Medicaid Contracts Subcommittee reports
- Overview of newborn screening for sickle cell
- Update on Pharma sponsorships

Dr. Mackey adjourned the meeting at 4:25 p.m.

To listen to the webcast recording of the August 31, 2020 meeting, go to:
<http://texashsc.swagit.com/play/09012020-596/>