Sickle Cell Task Force Meeting Minutes June 12, 2020 1:00 p.m.

Microsoft Teams Live Event

Table 1: Sickle Cell Task Force member attendance at the Friday, June 12, 2020 meeting.

MEMBER NAME	IN ATTENDANCE
Dr. Titilope Fasipe	By Phone/Microsoft Teams
Dr. Melissa Frei-Jones	By Phone/Microsoft Teams
Dr. Michelle Mackey	By Phone/Microsoft Teams
Dr. Alecia Nero	By Phone/Microsoft Teams
Ms. Tonya Prince	By Phone/Microsoft Teams
Ms. Marqué Reed-Shackelford	By Phone/Microsoft Teams
Ms. Alysian Thomas	By Phone/Microsoft Teams

Agenda Item 1: Welcome and Introductions

Dr. Michelle Mackey, Chair of the Sickle Cell Task Force (SCTF) called the meeting of the Sickle Cell Task Force to order at 1:06 p.m. and welcomed everyone in attendance.

Agenda Item 2: Task Force Logistical Announcements

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

Dr. Mackey provided opening remarks, introduced agency staff and asked members for introductions.

Agenda Item 3: Review and approval of meeting minutes from February 27, 2020

Dr. Mackey requested a motion to approve the February 27, 2020 meeting minutes.

MOTION: Ms. Alysian Thomas made a motion to approve the February 27, 2020 meeting minutes. Dr. Melissa Frei-Jones seconded. Ms. Allen called for a roll call vote, and the motion carried with no objections and no abstentions.

Agenda Item 4: Drawing of Member Terms

Ms. Allen reviewed how members terms will be drawn. Ms. Allen noted that four, 3year terms will be drawn and three, 2-year terms will be drawn. Ms. Aimee Millangue, DSHS, Newborn Screening Unit, assisted in the process for term selection. Ms. Millangue displayed on the video screen a container which held individual slips of paper with the number 2 or 3 on it. Ms. Allen announced each member's name, and Ms. Millangue drew a slip of paper, displayed it on the video screen and announced the number. The number announced represented that member's term.

Following is a summary of the membership terms:

- 1. Dr. Titilope Fasipe = 2 years
- 2. Dr. Melissa Frei-Jones = 3 years
- 3. Dr. Michelle Mackey = 2 years
- 4. Dr. Alecia Nero = 3 years
- 5. Ms. Tonya Prince = 3 years
- 6. Ms. Alysian Thomas = 3 years
- 7. Ms. Marqué Reed-Shackelford = 2 years

For the record, Ms. Millangue announced each member's name and the term each member will serve. Members with a 2-year term will serve from September 1, 2019 through August 31, 2021, and members with a 3-year term will serve from September 1, 2019 through August 31, 2022.

Agenda Item 5: Task Force Milestone Development

Dr. Mackey opened the floor for member discussion of Task Force Milestone Development.

Members discussed:

- Developing a framework, outlining a workplan as to how the task force could collectively work together to develop the milestones for the recommendations
- Appointing subcommittees to develop milestones for the three recommendations, and provide the task force with a report
- Developing milestones for the first recommendation; the public awareness campaigns, would help develop the strategy to serve as a foundation and sounding board to segue into the other topics for establishing partnerships, and working with community stakeholders
- Considering healthcare access, and tracking from a provider's level, an important issue as work moves forward
- Establishing obtainable milestone goals on a quarterly or yearly basis
- Milestones can give a framework for the content of the Legislatively Mandated Report
- Taking into consideration the flexibility of what milestones are to be included in the August legislative report and the possibility of revisions being made is of importance to the task force

Dr. Mackey called for the establishment of a Task Force Milestone Subcommittee and appointed subcommittee members.

Subcommittee members include:

- Dr. Michelle Mackey
- Ms. Tonya Prince
- Ms. Alysian Thomas

Agenda Item 6: Public Awareness Campaigns

Dr. Mackey opened the floor for member discussion of Public Awareness Campaigns.

Members discussed:

- Developing \$0 campaigns and methods of messaging without any cost
- How members may be able to engage with the legislature, stakeholders and outside entities via grants and sponsorships to establish campaigns
 - Request letters
 - Feasibility of collaborating on events such as a benefit concert
 - Logistics of getting stakeholders involved
- DSHS does have a Twitter, Facebook, and other social media outlets for broadcasting awareness
- Members should not feel limited by funding in proposing campaigns
- Maximizing efforts for 2020
 - \$0 ways to promote Sickle Cell Awareness month in September 2020
 - Looking for a sister/cousin message that correlates with other existing state messaging.
- Messaging
 - Foundational concept of awareness
 - Campaign throughout lifespan
 - For parents Are you a carrier, get tested?
 - For patients with sickle cell disease maybe where to go for help online if you need a doctor?
 - Information for providers, patients, and families on COVID-19 and sickle cell, and its effects on things such as work and school
- Creating a subcommittee that can work on ideas for messaging

Dr. Mackey called for the establishment of a Public Awareness Campaigns Subcommittee and appointed subcommittee members.

Subcommittee members include:

- Dr. Michelle Mackey
- Dr. Alecia Nero
- Ms. Marqué Reed-Shackelford

ACTION ITEMS:

• Members requested samples of \$0 campaigns from the state for ideas that the program can email to them

- Program will investigate how funding from stakeholders may work, including processes such as contracting
- The program can facilitate the posting on the Newborn Screening and Sickle Cell websites messages that the subcommittee develops

Agenda Item 7: Medicaid Contracts

Dr. Mackey opened the floor for member discussion of Medicaid Contracts.

Members discussed:

- Task force members, especially those who are physicians, expressed concerns about the contract processes and how contractors communicate with patients
- Creating a subcommittee to engage more in depth
- Having further conversations on understanding their current approach versus areas of potential recommendations and growth regarding evidence-based standards, training for sickle disease, and ways to help them improve their sickle cell framework
- Reach an understanding on what the task force can give insights and perspective over

Dr. Mackey called for the establishment of Medicaid Contracts Subcommittee and appointed subcommittee members.

Subcommittee members include:

- Dr. Michelle Mackey
- Dr. Titilope Fasipe
- Dr. Alecia Nero

Agenda Item 8: Legislatively Mandated Report

Dr. Mackey opened the floor for member discussion of the Legislatively Mandated Report.

Members discussed:

- Needing to finalize and approve the report at the Sickle Cell Task Force meeting tentatively scheduled August 31, 2020
- Reviewing what content needs to be included in the report
- Program needs to begin routing the final version for approval by September 2, 2020

Dr. Mackey called for the establishment of a Legislatively Mandated Report Subcommittee and appointed subcommittee members.

Subcommittee members include:

- Dr. Michelle Mackey
- Dr. Titilope Fasipe
- Dr. Melissa Frei-Jones

Agenda I tem 9: Public Comment

No public comment was made.

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

Dr. Mackey opened the floor for discussion of agenda items for the next meeting.

Members discussed:

- Subcommittee reporting
- Finalizing and approving the Legislative Report
- Next meeting is tentatively scheduled for August 31, 2020 and will most likely be held virtually

Dr. Mackey adjourned the meeting at 3:03 p.m.

Webcast link: http://texashhsc.swagit.com/play/06132020-503/12/