

**Sickle Cell Advisory Committee
Meeting Minutes
March 30, 2018
9:00 a.m.**

**Moreton Building, Board Room M-100
1100 W. 49th Street
Austin, TX 78756**

Table 1: Sickle Cell Advisory Committee member attendance at the March 30, 2018 meeting.

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
Titilope Fasipe, MD	X		Marque Reed-Shackelford	X	
Melissa Frei-Jones, MD	X		Toni Tennent	X	
Clarissa Johnson, MD	X		Alysian Thomas	X	
Harinder Juneja, MD	X				

P: Indicates participated by phone

Table 2: Sickle Cell Advisory staff member attendance at the March 30, 2018 meeting.

DSHS STAFF NAME	YES	NO	DSHS STAFF NAME	YES	NO
Beth Rider	X		Debra Freedenberg, MD	X	
David Martinez	X		Lorene Nealy	X	
Karen Hess	X		Patricia Lanfranco	X	
Michelle Shaffer	X		Julianna Ybarbo	X	
Mackenzie Spahn	X		Adriana Flores	X	
Debra Freedenberg	X		Katlyn Le	X	
Eugenia Dunham	X				

Agenda Item 1: Welcome and Introductions

Dr. Harinder Juneja, Chair, opened the meeting and requested that members introduce themselves.

Agenda Item 2: Committee Business Logistics

Ms. Stephanie Gutierrez, HHSC Advisory Committee Coordination Office, provided committee logistics, called roll, and noted quorum.

Agenda Item 3: Review and Approval of Minutes for November 03, 2017

Ms. Gutierrez requested a motion to approve the November 03, 2017 meeting minutes. Dr. Melissa Frei-Jones motioned to approve the November 03, 2017 meeting minutes. Dr. Clarissa Johnson seconded the motion. A roll call vote was taken. The motion carried.

Agenda Item 4: Sickle Cell Advisory Committee Bylaws: Review/Discuss/Adopt

Ms. Gutierrez reviewed the draft bylaws with the Committee. Ms. Gutierrez requested a motion to approve the Sickle Cell Draft Bylaws. Dr. Harinder Juneja motioned to approve the Sickle Cell Draft Bylaws. Dr. Melissa Frei-Jones seconded the motion. A roll call vote was taken. The motion carried.

Agenda Item 5: Surveillance Project: Sickle Cell Data Collection

Dr. Juneja introduced and turned the floor over to Dr. Mary Hulihan. Dr. Hulihan referenced the PowerPoint and handout titled, *CDC's Sickle Cell Disease Surveillance: Overview*.

The Committee discussed entities that are responsible for conducting training and housing data. The Committee also discussed funding for the project in addition to working with the Health Resources and Services Administration (HRSA).

Agenda Item 6: Legislative Report Process Q&A

Dr. Juneja introduced Ms. Rachael Hendrickson, DSHS Government Affairs. Ms. Hendrickson greeted the Committee and stated she is available for questions regarding the legislative process or about the recommendations that will go in the report to the DSHS Commissioner.

The Committee discussed what happens after the report has been written as well as the responsibilities of Committee members when speaking to a member of the legislature.

The Committee asked Ms. Hendrickson questions regarding budget and how it is administered by the agency.

Mr. David Martinez, Newborn Screening, stated to the Committee that at the next Sickle Cell meeting the expectation is the Committee members will vote on the final recommendations. Mr. Martinez informed the Committee of two possible positions opening up on the Newborn Screening Advisory Committee to continue the work that the Sickle Cell Advisory Committee has started. The two positions are:

1. Healthcare Professional that provides services for Sickle Cell disease and trait services.
2. A parent representative that has Sickle Cell disease or has a child that has Sickle Cell disease.

Agenda Item 7: Community Health Workers

Dr. Juneja introduced Ms. Adriana Flores, DSHS Promotor(a)/CHW Training and Certification Program. Ms. Flores referenced the PowerPoint and handout titled, *Community Health Workers*.

The Committee discussed mandating Managed Care Organizations (MCO) to use Community Health Workers (CHW) when creating and utilizing a navigation system with all Sickle Cell patients. The Committee also discussed training modules for CHWs regarding Sickle Cell disease and trait.

Agenda Item 8: Break

Dr. Juneja announced a 15-minute break.

Agenda Item 9: Working Lunch: Toolkit and discussion of Promoting Awareness of Sickle Cell

Dr. Juneja reconvened the meeting.

Dr. Juneja stated that the Committee will focus on the recommendations rather than how the recommendations will be implemented. Dr. Juneja stated it can be suggested how the recommendations will be implemented but no other discussion about the details is necessary for the current meeting. Dr. Juneja turned the floor over to Dr. Titilope Fasipe.

Dr. Fasipe gave an overview of the PowerPoint and handout titled, *Texas Sickle Cell Advisory Committee- Promoting Awareness of Sickle Cell Discussion Points*.

The Committee discussed:

1. Ways to promote Sickle Cell education to the community.
2. Using the Hemoglobinopathy Consultant Committee as a way to track Sickle Cell services.
3. Web access to the toolkit, toolkit revisions, and website revisions.
4. The inclusion, on the SCAC website, of all entities dealing with Sickle Cell Disease.

Dr. Juneja made a motion that DSHS will compile a list of physicians in Texas, by region, that treat adult patients with Sickle Cell Disease and include that information in the toolkit located on the website. Dr. Fasipe seconded the motion. A roll call vote was taken. The motion carried. The physicians on the Committee will assist by including physicians in their city.

Dr. Fasipe made a motion to add a transition-focused component to the toolkit and website modifications. Ms. Alysian Thomas seconded the motion. A roll call vote was taken. The motion carried.

Agenda Item 10: Discuss Recommendations to Executive Commissioner/Legislative Report

1. Dr. Juneja reviewed the proposed recommendations for the Committee members to consider before making the final report recommendations. The Committee referenced the handout and PowerPoint titled, *Texas Sickle Cell Advisory Committee -Promoting Awareness of Sickle Cell Discussion Points March 30, 2018*. The Committee asked that updates be made to the toolkit and disseminated using electronic or hard copies to various stakeholders associated with Sickle Cell Disease.
 - a. Discussion regarding the report:
 - i. Including the accomplishments of year one with year two's report.
 - ii. Budget line items.

The Committee decided on the final report recommendations to include the following:

1. Establish a statewide Sickle Cell Task Force to be supported by the legislature to carry out current Committee recommendations.
2. Initiate State-wide Sickle Cell Surveillance.
3. Partner with current CHW Network to improve healthcare access.
 - a. Discussion regarding this recommendation:
 - i. MCOs and Accountable Care Organizations (ACO) use CHWs as a resource to improve patient care, navigation, and education.
4. Develop a state-wide Sickle Cell campaign and organize an education forum.
 - a. Discussion regarding this recommendation:
 - i. Assign this task to the Task Force.
 - ii. Adding an awareness component.
 - iii. A statewide annual conference for credit hosted by the state.
5. Expand outreach of current Texas health Steps (THSteps) Sickle Cell Module.
 - a. Incorporate into mandated training for government-funded healthcare entities (specified personnel) and public school district personnel (nurses/coaches/counselors/teachers)
 - b. Encourage Community Health Workers to take module if working in areas that intersect with sickle cell population.

Dr. Juneja volunteered three members to form a subcommittee charged with drafting a report:

1. Dr. Titilope Fasipe
2. Dr. Melissa Frei-Jones
3. Ms. Toni Tennent

Ms. Rider stated by June 1 a draft copy of the report needs to be submitted to DSHS so it can be reviewed internally, then disseminated by Ms. Rider or Mr. Martinez to the full Committee for their review prior to the July Sickle Cell meeting, which is the last meeting for the Committee.

Agenda Item 11: Public Comment

Ms. Gutierrez read the Public Comment Logistical Announcements.

Ms. Gutierrez called Ms. Emily O'Shea to address the Committee.

Ms. O'Shea stated she would like to assist the Committee with their charge.

Agenda Item 12: Future Agenda Items, Confirm Next Meeting Date

The Committee discussed the next meeting date. The Committee agreed on July 6. This date is pending room availability. The Committee also discussed a meeting start time beginning at 9:30 a.m.

The Committee discussed the agenda for the next meeting:

1. Finalizing the report.
2. Invite the DSHS Commissioner.
3. Invite a member of different medical boards.
4. Health policy discussion.
5. Discussion of the legislative process.
6. Invite Rachael Hendrickson.
7. Refine the list of physicians.
8. Present the updated website.

Action Item: Dr. Fasipe will send an addition for the Toolkit transition component to the program.

Agenda Item 11: Adjournment

Dr. Juneja adjourned the meeting at 2:43 p.m.