

**Sickle Cell Advisory Committee
Meeting Minutes
November 03, 2017
1:00 p.m.**

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

Table 1: Sickie Cell Advisory Committee member attendance at the November 03, 2017 meeting.

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

P: Indicates participated by phone

Table 2: Sickie Cell Advisory staff member attendance at the November 03, 2017 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	
Carolyn Pittman	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. Francesca Kupper, HHSC Stakeholder Relations, provided committee logistics, called roll, and noted quorum. The Committee held a moment of silence for deceased Committee member, Mr. LeDarrin Taite.

Agenda Item 3: Review and Approval of Minutes for July 21, 2017

Ms. Kupper requested a motion to approve the July 21, 2017 meeting minutes. Dr. Titilope Fasipe motioned to approve the July 21, 2017 meeting minutes. Dr. Clarissa Johnson seconded the motion. A roll call vote was taken. The motion carried.

Agenda Item 4: Raising Awareness on Sickie Cell Disease and Trait in Louisiana

Dr. Juneja introduced and turned the floor over to Mr. Jantz Malbrue, Program Manager, Genetics Disease, Louisiana Department of Health. Mr. Malbrue works in the Genetic Diseases program that handles all newborn screening in the state of Louisiana. Mr. Malbrue manages the follow up

coordination for sickle cell disease and trait and serves as the administrative support for the Louisiana Sickle Cell Commission. Mr. Malbrue referenced the handout and PowerPoint titled, *Raising Awareness on Sickle Cell Disease and Trait in Louisiana*.

Mr. Malbrue discussed their strategic plan to improve sickle cell disease health care coordination to include data and surveillance, medical services workgroups, patient navigation systems, education and advocacy.

The Committee had questions regarding consent mechanisms for the program as well as the sources of funding. Mr. Malbrue stated that consent was handled through the Department of Health contracts in terms of sharing information. Currently, Mr. Malbrue stated that individual consent is being worked out. Funding has come through the Genetic Disease program budget which receives a majority of funds through reimbursement by lab forms in addition to searching for public funds. The Committee also asked if physicians contribute their expertise, and if so, how much. Mr. Malbrue stated that physicians are involved often and contribute a fair amount of work. Regarding Medicaid expansion, the Committee asked if there is current coverage being offered for people over 18 years of age. Mr. Malbrue stated that under the current Medicaid expansion, for the past year and a half coverage has been offered for people over 18 years of age which has opened enrollment for those individuals.

Agenda Item 5: Follow up on Training for Sickle Cell - Community Health Workers Presentation and Texas Health Steps (THSteps)

Dr. Juneja introduced and turned the floor over to Mr. David Martinez. Mr. Martinez discussed the process of having Community Health Workers deliver training on sickle cell disease and trait. Mr. Martinez referenced a handout titled, *2017 Texas DSHS-Certified Training Programs for Community Health Workers (CHWs) and CHW Instructors* for a listing of approved DSHS Community Health Worker Training Programs.

Mr. Martinez explained to the Committee the process to approve training materials for CHWs. Any training in development needs to be in collaboration with a DSHS approved Community Health Worker Training Program. Materials used for training need to be submitted to the Training and Certification program. The organization that creates the materials must provide written approval for the CHWs to use the materials for training.

The Committee discussed the option of utilizing CHWs to train in sickle cell disease and trait.

The Committee discussed the results/statistics of the Sickle Cell Disease module on the Texas Provider website. Mr. Martinez reviewed the handout titled, *THSteps Sickle Cell Module*. Mr. Martinez stated the module has not been online since April 2017. Dr. Melissa Frei-Jones, who served as a consultant with the module revision for recertification, stated the module was down due to an update based on the 2014 guidelines. The module will go live at the end of November 2017 as an interactive module to include Sickle Cell Disease, Sickle Cell Trait, Sickle Cell Genetic Counseling, and Culturally Sensitive Communication.

The Committee had a discussion regarding how to encourage other organizations to use their CHWs to provide education on sickle cell disease and trait to the community.

ACTION ITEM: Mr. Martinez will follow up with the Committee after meeting with the CHW program to inquire how they share information by way of materials to the community, specifically.

The Committee also discussed developing a toolkit and using that as a basis for training as part of a CHW training program.

Agenda Item 6: Update on Marketing Strategies - Academic and Professional Organizations

Dr. Juneja provided an update to the Committee regarding marketing strategies. Dr. Juneja stated he met with Dr. Utpal Dholakia at the Rice University Business School. Dr. Juneja shared that, during the meeting with Dr. Dholakia, it was determined that the Toolkit would be a challenge to relay messages to the community. His suggestion was to use newer electronic media such as Facebook, Twitter, or SnapChat. Another point of discussion between Dr. Juneja and Dr. Dholakia was the lack of public inquiry regarding sickle cell disease and trait. Dr. Juneja referenced the handout titled, *Marketing Strategies for Academic and Professional Organizations*.

Dr. Juneja opened up discussion to the Committee asking input on how to share information with professionals and the community regarding sickle cell disease and trait. The Committee discussed a possible marketing campaign, and request that the Texas Department of State Health Services Commissioner consider including monies in the budget for sickle cell awareness.

Dr. Juneja requested Mr. Martinez restate the charge of the Sickle Cell Advisory Committee. Mr. Martinez stated it is the responsibility of the Committee to provide two strategies or recommendations to raise awareness

of sickle cell disease and trait in Texas. Ms. Beth Rider confirmed this statement according to the bylaws. Ms. Rider stated two tasks. One is to review and suggest methods for raising public awareness and is included in the template for the annual report. The second is that the Committee needs to recommend two specific strategies to raise public awareness by the end of their tenure. Dr. Fasipe made the suggestion that the team who worked on the annual report discuss the charge to see if strategies can be infused in the annual report.

Agenda Item 7: Committee Assignment Status: DSHS Website Revision and Toolkit

Dr. Juneja turned the floor over to Dr. Fasipe and Ms. Toni Tennent. Ms. Tennent informed the Committee of her suggestion of developing a research booklet with different resources across the state and what each will offer in regard to the Toolkit.

Dr. Fasipe referenced the handout and PowerPoint, *Suggested Website Revisions/Review of Resources*. The Committee discussed specific changes and whether it was appropriate to remove them. Mr. Martinez brought Dr. Fasipe's attention to areas of the website that housed specific information.

ACTION ITEM: Ms. Rider requested Dr. Fasipe send her an updated version of the revisions document to disseminate to the Committee.

The Committee suggested developing a list of physicians that provide medical care to adults with sickle cell disease. The list would include their location and contact information.

ACTION ITEM: The state will communicate with the program, Children with Special Health Care Needs, regarding a transition program from childhood to adult. The state will inquire if there is a list of adult providers that already exists.

Agenda Item 8: Committee DRAFT Annual Report Review and Discussion

Dr. Juneja referenced the handout and PowerPoint titled, *Sickle Cell Advisory Committee*.

ACTION ITEM: The state will provide the Committee with data of demographics, disease, and region.

The Committee discussed changes that could be made to the report as well as next steps toward recommending strategies. Dr. Juneja made a motion to have the Sickle Cell Advisory Committee report be modified and reviewed by

members. The Committee chair will then submit an approval on behalf of the Committee. The report will be reviewed and edited as appropriate, and routed to the Executive Commissioner. Dr. Clarissa Johnson seconded the motion. A roll call vote was taken. The motion carried.

ACTION ITEM: Ms. Rider will make the changes to the report and disseminate to the committee and the Chair will approve the changes.

Agenda Item 9: Public Comment

There was no public comment.

Agenda Item 10: Future Agenda Items and Confirm Next Meeting Date

Dr. Juneja asked Ms. Rider to recap future agenda items:

1. Dr. Fasipe to request a presentation on the Project ECHO through the Health Resources and Services Administration (HRSA).
2. Dr. Fasipe suggested a presentation on surveillance and a sickle cell registry demonstration program.
3. Website revision and toolkit updates.
4. Discuss funding for a marketing project.
5. Include a member brainstorm or break-out session at the next in-person meeting.

Action Item Recap:

1. Mr. Martinez will follow up with the Community Health Worker program to find out what materials are used to educate the community and if there is a way to develop a training module as a basis for the training program.
2. Mr. Martinez will liaison with other programs to inquire whether there is a list of adult providers for each region.

The next meeting will be in March 2018 and Ms. Rider will poll the Committee members for the best date. Dr. Juneja and the members agreed to hold the meeting as an in-person meeting.

Agenda Item 11: Adjournment

Dr. Juneja adjourned the meeting at 5:08 pm.