

**Sickle Cell Advisory Committee
Meeting Minutes
November 4, 2016
12:30 p.m. – 3:00 p.m.**

**Tower Building, Conference Room T-609
1100 W. 49th Street
Austin, TX 78756**

Table 1: Sickle Cell Advisory Committee member attendance at the November 4, 2016 meeting.

MEMBER NAME	YES	NO	PHONE	MEMBER NAME	YES	NO	PHONE
Dr. Titilope Fasipe			X	Mr. LeDarrin Taite			X
Dr. Melissa Frei-Jones			X	Ms. Toni Tennent			X
Dr. Clarissa Johnson		X		Ms. Alysian Thomas			X
Dr. Harinder Juneja			X				

Table 2: Sickle Cell Advisory staff member attendance at the November 4, 2016 meeting.

DSHS STAFF NAME	YES	NO	DSHS STAFF NAME	YES	NO
Beth Rider	X		Kurt Wolf	X	
Eugenia Dunham	X		Lori Fitzgerald	X	
Karen Hess	X		Patti Lanfranco	X	
Dr. Debbie Freedenberg	X		Cheryl Florida	X	
Xuejing Bai	X		Christie Moore	X	
Lorene Nealy	X		Felipe Rocha	X	
Julianna Ybarbo	X		Michael Brown	X	

Table 3: Sickle Cell Advisory Committee guest attendance at the November 4, 2016 meeting.

GUEST NAME/ORG.	YES	NO
Shauna Williams, Consultant, DK Pierce	X	

Agenda Item 1: Welcome and Introductions

Mr. Felipe Rocha opened the meeting and requested that guests in the room and members on the webinar introduce themselves.

Mr. Rocha turned the floor over to Ms. Stephanie Gutierrez to cover logistics.

Agenda Item 2: Nominate/Elect new Chairperson & Vice Chairperson

Ms. Gutierrez read the Officer Election Process to the Committee. Ms. Gutierrez requested nominations for Chair. Dr. Harinder Juneja self-nominated for Chair. A request was made for a formal motion for Committee Chair. Dr. Melissa Frei-Jones made a motion for Dr. Harinder Juneja to be Chair. The motion was seconded by Dr. Titilope Fasipe. A vote was taken and the motion carries by unanimous vote for Dr. Juneja to be Chair of the Sickle Cell Advisory Committee.

MOTION: Dr. Melissa Frei-Jones

SECONDED: Dr. Titilope Fasipe

Motion carries for Dr. Harinder Juneja to be Chair of the Sickle Cell Advisory Committee.

Ms. Gutierrez requested nominations for Vice Chair. Mr. LeDarrin Taite self-nominated for Vice Chair. A request was made for a formal motion for Committee Vice Chair. Ms. Alysian Thomas made a motion for Mr. LeDarrin Taite to be Vice Chair. The motion was seconded by Ms. Toni Tennent. A vote was taken and the motion carries by unanimous vote for Mr. LeDarrin Taite to be Vice Chair of the Sickle Cell Advisory Committee.

MOTION: Ms. Alysian Thomas

SECONDED: Ms. Toni Tennent

Motion carries for Mr. LeDarrin Taite to be Vice Chair of the Sickle Cell Advisory Committee.

Agenda Item 3: Call to Order

Mr. Rocha turned the meeting over to the Chair, Dr. Juneja. Dr. Juneja thanked the members for electing the Chair and Vice Chair.

Agenda Item 4: Review and Approval of Minutes for August 26, 2016

Ms. Beth Rider asked the Committee if there was a motion to approve the minutes for August 26, 2016. A motion was made by Dr. Frei-Jones to approve the August 26, 2016 minutes. The motion was seconded by Dr. Fasipe. A vote was taken and the motion carries by unanimous vote for approval of the August 26, 2016 minutes.

MOTION: Dr. Melissa Frei-Jones

SECONDED: Dr. Titilope Fasipe

Motion carries for approval of the August 26, 2016 minutes.

Agenda Item 5: Approve Committee Bylaws

Dr. Juneja asked the Committee if everyone had read the bylaws. There were members that had questions. The Department of State Health Services (DSHS) staff in support of the Committee, also known as Committee Staff, were able to answer these questions regarding Committee term, Committee appointments, the amendment of Committee bylaws, and when the Committee report is due.

Mr. Taite made a formal motion to adopt the bylaws for the Sickle Cell Advisory Committee as is. The motion was seconded by Ms. Thomas. A vote was taken and the motion carries by unanimous vote for the adoption of the bylaws for the Sickle Cell Advisory Committee as is.

MOTION: Mr. LeDarrin Taite

SECONDED: Ms. Alysian Thomas

Motion carries for the adoption of the bylaws for the Sickle Cell Advisory Committee as is.

Agenda Item 6: Discussion and Strategies on Raising Public Awareness of Sickle Cell Disease and Sickle Cell Trait

Dr. Juneja requested that members discuss their ideas on raising public awareness at the state level for Sickle Cell Disease and Sickle Cell Trait. Dr. Fasipe shared her thoughts regarding improving the state literature on informing the public of Sickle Cell Trait, and how Sickle Cell Trait is represented (e.g. disease or risk factor). Dr. Fasipe asked if there is a way to offer Trait testing aside from Newborn Screening that could be assisted by the state. Dr. Fasipe also mentioned how education can be improved and the possibility of targeting the younger population within the schools.

Mr. Taite agreed that improving literature is important and the responsibility of the state, especially in the absence of available literature produced by non-profit organizations and the hospitals. Ms. Thomas recommended looking at Sickle Cell Trait as a risk factor rather than a disease.

The Committee discussed the focus for the two recommendations the Committee must make to the state. The Committee is in agreement of the focus of the issues, which is education and Sickle Cell Trait. The Committee also discussed the importance of educating the health care and medical providers on the Sickle Cell Disease, especially with respect to treatment.

ACTION ITEM: Committee staff will send the Act and Fact Sheets to Committee members, and a link to the DSHS website which includes those sheets as well as the brochures on Sickle Cell Disease and Trait.

The Committee shared their experience with not being able to locate resources for Sickle Cell online. Dr. Juneja summarized the need to create a consolidated website for Sickle Cell that would be available for family, patients, and clinicians.

Mr. Rocha asked the Committee if members are familiar with any initiatives that are creating awareness in schools currently. Ms. Thomas stated that the nonprofit Sickle Cell Association of Texas assists with schools and families to provide support. A few members have conducted educational sessions at schools.

ACTION ITEM: The Committee staff will share the webinar information about Sickle Cell hosted by the Centers for Disease Control.

Mr. Taite summarized the Committee's discussion by saying there are two focuses: a Sickle Cell tool kit for patients, families, and general health care providers as well as Sickle Cell screenings for adolescents and adults.

Mr. Rocha read to the Committee from the Texas Administrative Code, that the task of the Committee is to raise awareness of Sickle Cell Disease and Trait in Texas by recommending two specific strategies in the two year duration of the Committee to raise public awareness.

Committee staff recommended to the Committee to have one recommendation for the state ready by the next in-person meeting. Mr. Taite asked Committee staff how the recommendations are presented to the state. Mr. Rocha confirmed that they would be identified in the report to the Commissioner. Committee staff read the Committee Bylaws to the Committee regarding this matter.

Dr. Juneja suggested that the DSHS website be updated and made more accessible, and discuss additional improvements at the first in-person meeting.

ACTION ITEM: The state will send a link to the website to the Committee as well as a link to the CDC Grand Rounds for Committee feedback.

Dr. Juneja asked the Committee staff what the rules and guidelines are for Committee members to talk about business outside of a formal meeting. Ms. Rider replied that all Committee business must be discussed in a meeting with a quorum. Ms. Gutierrez also explained the Open Meetings Act and

what would be in violation. Dr. Juneja asked Committee staff of the possible creation of a Subcommittee. Ms. Gutierrez explained what the subcommittee would need to comprise of and how business would be conducted by the subcommittee in relation to the full Committee. The State brought up the proposal of adding an agenda item named, "New Business" as stated in the bylaws. A motion was made by Mr. Taite and seconded by Ms. Tennent to add the agenda item, "New Business" to each agenda going forward. A vote was taken and the motion carries by unanimous vote to add, "New Business" to the next and each subsequent Committee meeting agenda.

MOTION: Mr. LeDarrin Taite

SECONDED: Ms. Toni Tennent

Motion carries to add, "New Business" to the agenda for all future meetings. The Committee and Committee staff discussed the number of meetings per year. The Committee discussed the possibility of having Subcommittees meet during a full Committee meeting.

ACTION ITEM: Dr. Juneja requested that the State do research of what other states are doing in terms of consolidating ideas for implementation of this legislation.

The Committee discussed and agreed on having individual committee members do research to gather information to bring to the full Committee rather than having Subcommittees.

Agenda Item 7: Public Comment

No public comment was made.

Agenda Item 8: Future Agenda Items/Confirm Next Meeting Date

The State will report on any findings they have based on the request made by the Committee Chair. Dr. Juneja determined who the individual committee members are to present information for both sickle cell disease and sickle cell trait at the next meeting.

1. Dr. Frei-Jones: Medical information that should be shared with health care professionals.
2. Dr. Fasipe & Ms. Tennent: Medical information that should be shared with patients and families.
3. Mr. Taite & Ms. Thomas: Medical information that should be shared with the general public such as schools, universities, legislators, and insurance companies.

4. Add "New Business" to the next and all following committee meeting agendas.
5. The DSHS staff will present information/activities from other states as requested.

The next meeting date was not stated.

Agenda Item 9: Adjourn

Dr. Juneja adjourned the meeting at 3:00 p.m.