

**Sickle Cell Advisory Committee
Meeting Minutes
March 24, 2017
10:00 a.m. – 4:00 p.m.**

**Moreton Building, Conference Room M-653
1100 W. 49th Street
Austin, TX 78756**

Table 1: Sickle Cell Advisory Committee member attendance at the March 24, 2017 meeting.

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
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				

P: Indicates participated by phone

Table 2: Sickle Cell Advisory staff member attendance at the March 24, 2017 meeting.

HHS STAFF NAME	YES	NO	HHS STAFF NAME	YES	NO
Beth Rider	X		Patricia Lanfranco	X	
David Martinez	X		Katlyn Le	X	
Lynette Borgfeld	X		Lorene Nealy	X	
Dawn Ferriter	X		Felipe Rocha	X	
Karen Hess	X		Michelle Shaffer	X	
Cassandra Marx	X				

Table 3: Sickle Cell Advisory Committee guest attendance at the March 24, 2017 meeting.

GUEST NAME/ORGANIZATION	YES	NO
Itzel Joy, CHS/Red Cross	X	

Agenda Item 1: Welcome and Introductions

Dr. Harinder Juneja, Chair, opened the meeting and requested that guests in the room introduce themselves.

Agenda Item 2: Committee Business Logistics

Ms. Cassandra Marx provided committee logistics and provided information to members on factors that guide Health and Human Services committees.

Agenda Item 3: Review and Approval of Minutes for November 4, 2016

Dr. Juneja called for any changes to the November 4, 2016 meeting minutes. Hearing none, he called for a motion to approve the minutes.

MOTION: Dr. Melissa Frei-Jones moved to approve the November 4, 2016 meeting minutes as written. Mr. LeDarrin Taite seconded the motion. The Committee members unanimously approved the minutes by voice vote, with no nays and no abstentions.

Agenda Item 4: DSHS Presentation on Other States' Activities for Public Outreach

Mr. David Martinez, Newborn Screening Unit Manager, DSHS, referenced a PowerPoint handout entitled, *Sickle Cell Awareness*, and provided a presentation on what other states are doing to promote Sickle Cell awareness.

Ms. Patti Lanfranco, Texas Department of State Health Services (DSHS), conducted the research by sending out a request for information utilizing a nationwide listserv which has 161 members covering all 50 states. Three states responded to the request: Virginia, Alabama, and Iowa. That request is still open. Members discussed the results and discussed possible new ideas.

ACTION:

- Staff will send out another request to ask what other state advisory committees are doing, and research any other states that have Sickle Cell committees.
- Staff will also ask if events conducted are done regionally, or in just one specific location.
- Staff will research legislation in other states regarding Sickle Cell Awareness.
- Staff will invite Mr. Dave Gruber to discuss Syndromic Surveillance.
- Staff will invite someone from the Title V Program to discuss information on transitional programs.

Agenda Item 5: Breakout Sessions - Discussion and Strategies on Raising Public Awareness of Sickle Cell Disease and Sickle Cell Trait

NOTE: Members discussed information as one group, therefore, a Summarization of Strategies from the Breakout Sessions was not needed.

Dr. Juneja requested that members discuss their ideas on raising public awareness at the state level for Sickle Cell Disease and Sickle Cell Trait. Highlights of the discussion were:

- There are currently resources available on the DSHS Newborn Screening (NBS) website, but awareness needs to be increased and methods determined to direct traffic to those resources.

ACTION:

- Staff will get analytics on NBS and Sickle Cell websites.
- Dr. Fasipe noted that getting to the Sickle Cell website is not easy and changes need to be made.
 - The graphics and aesthetics should be updated as well;
 - Use real people, not caricatures on web and brochures, as well as reflecting diversity; and
 - Add link on the NBS homepage for Sickle Cell or drop down on the left menu to include a “Sickle Cell Toolkit”
- Pocket toolkits already exist (a copy is provided in the packet and is available online), but the links need to be pulled together so they are easy to find.

- Treating centers need to help get information out.

ACTION:

- Staff will research what other outreach has been done that was successful (media blasts, etc.).
- On the Sickle Cell Advisory Committee page, it says Sickle Cell at the top, but bullet points include other diseases which may be confusing. It was suggested to remove these or at least identify disease categories.
- Training for committee members to share information on Sickle Cell.
- Have each agency focus on ways they can promote awareness (e.g. TEA - schools, students, school nurses, etc.)
- Explore Community Health Workers/Promotores as a way to help raise awareness.

ACTION:

- Staff will contact the Community Health Workers staff at DSHS to explore this and possibly invite a staff member to present at the next meeting if appropriate.
- DSHS could create public service announcements on sickle cell awareness.
- Possibly seek to have mayor-to-mayor statewide communications in areas. Could see if this could get started in Houston.
- Could DSHS instruct local health departments, community-based organizations, etc. to become a task force for this?
- The UK and Jamaica are already doing some things successfully (refer to handout, “SCD Outreach Ideas” in packet.)
- Encourage Sickle Cell Sabbath where after the sermon at church, a health care worker would talk about sickle cell. St. Louis combined this with a blood drive.

- Have family-to-family contact to help break the stigma.
- Some resources to explore:
 - <https://www.navigatelifetexas.org/en>
 - <https://www.txp2p.org/>
 - Network of community-based organizations
- Review current DSHS website resources and receive input from committee members to create a Sickle Cell Toolkit - setup for Caregivers and Families, Healthcare Providers, and Schools. For the general public, address how to treat a crisis.

Agenda Item 6: Summarization of Strategies from Breakout Sessions

Members discussed information as one group, therefore, a Summarization of Strategies from the Breakout Sessions was not needed.

Agenda Item 7: Potential Action: Recommendation on Strategies to Raise Public Awareness

Members discussed taking action on the following items:

- Work on creating a toolkit with committee members' input
- Update Sickle Cell website
- Twitter feed on Sickle Cell Awareness activities
- Dr. Fasipe will share information from the Houston Sickle Cell Task Force.

Agenda Item 8: New Business

- Dr. Fasipe noted that a sickle cell awareness event would occur June 19th since so much happens in September. It was agreed that this was a good day to reach out and connect with the African American community.
- The Houston Sickle Cell Task Force started with a group meeting with the Houston Health Department. They had a great turnout and are working towards identifying health gaps and putting initiatives in place for better treatment.
- Members will send information for the toolkit to Ms. Tennent to compile and send to Mr. Martinez/Ms. Rider. Ms. Rider will send information to members.
- Dr. Frei-Jones will send new content to Ms. Tennent.
- Dr. Fasipe will look at the webpage content and offer input there.

Agenda Item 9: Public Comment

No public comment was made.

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

Members discussed topics for the next meeting.

- Dissemination of information.
- Invite Community Health Workers staff to present.
- Invite someone to discuss Syndromic Surveillance to present.
- Invite someone from Title V Program to present.
- Staff will find out if sponsors can assist with events.
- Mr. Martinez will check what authority the DSHS commissioner, or another, has regarding committee recommendations.

The next meeting date was identified as July 21, 2017 from 1:00 pm – 5:00 pm.

Agenda Item 9: Adjourn

Dr. Juneja adjourned the meeting.