

**Sickle Cell Advisory Committee  
Meeting Minutes  
August 26, 2016 via Conference Call  
10:00 a.m. – 12:30 p.m.**

**Texas Department of State Health Services  
1100 W. 49<sup>th</sup>, Austin, Texas 78756  
Moreton Building, Conference Room M-204**

Table 1: Sickie Cell Advisory Committee member attendance at the Friday, August 26, 2016 meeting.

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

**Yes:** Indicates attended the meeting   **No:** Indicates did not attend the meeting   **P:** Indicates participated by phone

Table 2: Sickie Cell Advisory Committee staff attendance at the Friday, August 26, 2016 meeting.

| STAFF NAME      | YES | NO | STAFF NAME            | YES | NO |
|-----------------|-----|----|-----------------------|-----|----|
| David Martinez  | X   |    | Elizabeth Fitzgerald  | X   |    |
| Beth Rider      | X   |    | Dr. Debra Freedenberg | X   |    |
| Kurt Wolf       | X   |    | Karen Hess            | X   |    |
| Patti Lanfranco | X   |    | Eugenia Dunham        | X   |    |
| Olivia Walker   | X   |    | Monica Molina         | X   |    |
| Lorene Nealy    | X   |    | Sam Cooper            | X   |    |
| Rachel Lee      | X   |    |                       |     |    |

**Yes:** Indicates attended the meeting   **No:** Indicates did not attend the meeting

There were no Sickie Cell Advisory Committee guests who attended the Friday, August 26, 2016 meeting.

## **Welcome and Introductions:**

Mr. David R. Martinez, Newborn Screening Unit Manager, welcomed the committee members to this first Sickie Cell Advisory Committee meeting. The committee participated via conference call.

## **Agenda Item 1: Committee Member Handbook**

Ms. Beth Rider, DSHS Committee Support, reviewed the sections of the member handbook with the committee. The committee was reminded to complete the mandatory training: the Open Meetings Act and Public Information Act via the Office of Attorney General's website.

## **Agenda Item 2: Committee Member Orientation (Statute, Lobbying, Ethics)**

Ms. Elizabeth Fitzgerald, DSHS attorney, discussed the committee responsibilities: attendance, participation as committee members during the meetings; open meetings; public information; and ethics, including standards of conduct and conflict of interest. Ms. Fitzgerald discussed committee meetings following proper procedures and bylaws to conduct committee business with a quorum. The committee was also provided an overview of the DSHS rulemaking process.

## **Agenda Item 3: Newborn Screening in Texas**

Ms. Karen Hess, Newborn Screening Branch Manager, provided an overview of the newborn screening program in a PowerPoint presentation. Ms. Hess discussed the goals of the program including testing, short-term, and long-term follow-up protocols. Texas newborns are screened for 53 blood spot conditions including Metabolic; Pulmonary (Cystic Fibrosis); Immunologic (SCID); Endocrine; and Hemoglobinopathies (Sickle Cell Anemia, Sickle Beta Thalassemia, Sickle-Hemoglobin C Disease, and various other Hemoglobinopathies). The Newborn Screening Unit staff also oversees the newborn hearing screening program, and supports facilities with conducting point-of-care screening for Critical Congenital Heart Disease (CCHD). Ms. Lorene Nealy, RN, Hemoglobin Team Lead, provided an overview of how clinical care coordination staff perform specific tasks related to Hemoglobinopathies such as Sickle Cell Disease and Sickle Cell Trait. The staff contact the primary care physician and the specialists, and provide education to the parents.

## **Agenda Item 4: Appoint Temporary Presiding Officers**

**MOTION:** Mr. LeDarrin (Darrin) Taite volunteered as a Temporary Presiding Officer

**SECOND:** Dr. Melissa Frei-Jones

**MOTION:** Ms. Alysian Thomas volunteered as a secondary Temporary Presiding Officer in the absence of Mr. Taite

**SECOND:** Mr. Darrin Taite

Motion carries to appoint the above temporary presiding officers.

**CALL TO ORDER:** The meeting was called to order by Mr. Taite at 11:40 AM on August 26, 2016.

### **Agenda Item 5: Committee Bylaws**

The committee was given a copy of the Draft Sickle Cell Advisory Committee Bylaws to review and provide written recommendations if any. The members were reminded of the statute and rules governing the Sickle Cell Advisory Committee. The purpose of the committee is to raise awareness of Sickle Cell Disease and Sickle Cell Trait in the state of Texas. The tasks are to review and suggest methods for raising public awareness, and recommend two specific strategies in the two-year term to raise public awareness.

### **Agenda Item 6: Public Comment**

There was no public comment.

### **Agenda Item 7: Future Agenda Items**

1. Elect Committee Chair and Vice-Chair
2. Approve Committee Bylaws
3. Define target population and discuss strategies on raising public awareness of Sickle Cell Disease and Sickle Cell Trait

The next meeting will be conducted via conference call. Ms. Beth Rider will send out a poll of dates.

### **Agenda Item 8: Adjourn**

Mr. Taite adjourned the meeting at 12:23 p.m.