ALABAMA SICKLE CELL OVERSIGHT AND REGULATORY COMMISSION

2777 Zelda Road • Montgomery, AL 36106 Phone: (334) 420-7238 • Fax: (334) 263-6115 • Email: alsicklecell@alstateboard.com

MINUTES December 17, 2024

Presiding: Katherine Long, Commission Vice President Called to Order: 11:09 A.M. Adjourned: 12:27 P.M.

Members Participating

Ms. Katherine Long

Ms. Linda Garrett

Mr. James Belton

Dr. Julie Kanter

Dr. Jacqueline Williams (virtual)

Dr. Lee M. Hilliard

Dr. Ardie Pack-Mabien

Ms. Leah J. Wiggins (virtual)

Ms. Tokie Dunn (virtual)

Members Absent

Dr. Felicia Wilson, President

Ms. Janet Martin

Others Present

Mr. Keith Warren, Executive Director

Ms. Sara Rogan, Assistant Attorney General and Commission's Legal Counsel

Mr. James Arrington, Southeast Alabama Sickle Cell Chapter

Ms. Monica Van Diver, Greater Montgomery Sickle Cell Chapter

Mr. Gerald Alfred, Mobile Sickle Cell Chapter

Ms. Sophia Leverson, Central Alabama Sickle Cell Chapter

Ms. La'Quisha Moore Banks, ADPH Newborn Screening Program

Ms. Veronica Thompson, ADPH Newborn Screening Program

Ms. Renee' Reames (recording secretary)

I. Call to Order and Roll Call

The Sickle Cell Oversight and Regulatory Commission met on Tuesday, December 17, 2024. The meeting was held at the Commission's office located at 2777 Zelda Road in Montgomery, AL. The meeting was called to order at 11:09 a.m. by Ms. Katherine Long, Commission Vice President. Mr. Warren conducted the roll call of members and indicated that a quorum of the Commissioners was present to conduct business.

Chairperson Long welcomed all present at the meeting, with guest Ms. Banks and Ms. Thompson with the Department of Public Health and Mr. Alfred, the new Executive Director of the Mobile Sickle Cell Chapter.

II. Approval of Agenda

Chairperson Long presented the agenda for the December 17, 2024, meeting for the Commissioners' approval. Dr. Kanter inquired about the agenda item concerning Advocacy Committee report and Mr. Warren explained that committee chairperson, Ms. Wiggins, may have a report later in the meeting.

<u>MOTION</u>: Ms. Garrett made the motion to approve the agenda for the December meeting. The motion was seconded by Dr. Kanter and following a roll call vote, the motion was unanimously approved by the Commission.

III. Review and Approval of Meeting Minutes

Chairperson Long presented the minutes from the September 24, 2024 meeting for the Commissioners' approval.

<u>MOTION</u>: Mr. Belton made the motion to accept the September meeting minutes with the correction of Ms. Wiggins serving as chairperson of the Advocacy Committee. The motion was seconded by Ms. Garrett, and following a roll call vote, the motion was approved by the Commission, with Dr. Kanter abstaining from voting (copy of minutes available in official Book of Minutes).

IV. Executive Director Report

Mr. Warren reported that he had received the Proclamation from the Governor's office concerning Ms. Barnes and he recommended that a more descriptive Proclamation covering the work and achievements by Ms. Barnes in the sickle cell profession be prepared. Ms. Wiggins recommended that Representative Hollis or Representative Coleman-Madison be contacted about assisting with a legislative resolution of commendation concerning Ms. Barnes. Mr. Warren indicated that he would proceed with obtaining a legislative commendation.

Mr. Warren reported that the allocation budget for FY 2025 had been updated and a copy was distributed at the meeting (copy available in official Book of Minutes). Ms. Garrett reported that monthly allocations continued to be received late and Mr. Warren indicated that he would check with the Comptroller's office about the reason for the delays. Dr. Hilliard inquired about the allocation to the inactive Chapter previously located in Selma that was currently being served by two existing sickle cell chapters and removing the inactive Chapter from the Commission's statute. Mr. Warren reported that he would contact Senator Stewart in Selma about the status of the inactive chapter and will have a follow-up report.

Mr. Warren reported that the Sunset Audit was underway by the Examiners of Public Accounts and he asked the Commissioners to respond to the audit survey notices they would be receiving, wish would be included in the report. He reported that the Commissioners would be notified when the audit exit meeting was scheduled, and he encouraged the members to attend, which could be virtual attendance.

V. Legal Counsel Report

<u>Update on Administrative Services Contract and Contract Review Committee Meeting:</u> Mr. Warren reported that a copy of the Administrative Services Contract had been delivered to the Contract Review Committee for its January meeting, and he asked the Commission members to attend. Mr. Belton indicated that he could attend the Contract Review Committee meeting on January 2, 2025 to represent the Commission, and Dr. Kanter agreed to serve as back-up should Mr. Belton not be able to attend.

VI. CBO Reports

Chairperson Long called for reports from the CBOs about activities. Mr. Arrington reported that Ms. Thompson was not feeling well and was unable to attend.

Southeast Alabama Chapter: Mr. Arrington reported on year-end celebrations of activities that occurred through the year, along with the partnership with Pfizer Pharmaceutical in sponsoring some of the Chapter's activities.

Greater Montgomery Chapter: Ms. Van Diver reported that a year-end financial audit was underway at the Chapter, and she reported on holiday activities held in the Chapter office for children. She thanked the Commissioners for their time and service provided voluntarily and without compensation.

Mobile Chapter: Mr. Alfred introduced himself as the new Executive Director of the Mobile Chapter. He reported on the number of clients being services and making strategic plans in 2025 for professional development, managing client transportation demands and rebranding the Chapter.

West Alabama Chapter: Dr. Williams reported that she had not had an opportunity to receive an update from Ms. McCoy about activities at the West Alabama Chapter.

Central Alabama Chapter: Ms. Leverson reported that the Chapter had been busy with toy drives in partnering with the United Way, and Ms. Wiggins was recently elected as chairperson of the Chapter's Board of Directors.

Newborn Screening Program: Chairperson Long asked Ms. Banks with the Alabama Newborn Screening program of the Department of Public Health (DPH) if she had any announcements. Ms. Banks introduced Ms. Veronica Thompson, nurse supervisor with DPH and an alternate contact person within the Newborn Screening program. Ms. Banks reported that she had sent sickle cell and newborn screening promotional and educational material to the CBOs. Dr. Kanter reported that she had promotional material in other languages that could be added to the CBOs websites, etc., and Mr. Arrington reported that he had contact information on translators, and Dr. Kanter reported that an i-pad translation service was also available.

The Commission discussed trait testing by the chapters. Dr. Kanter cautioned about errors in inconclusive readings of blood tests and indicated that she would provide additional information with resources on the matter in a separate email to the CBOs, etc.

VII Committee Reports

<u>CBO Standardized Core Education Committee</u>: Mr. Arrington reported that he had received information from the CBO directors about Chapters' educational programs and planned to incorporate into one report. He reminded the committee members, Dr. Kanter and Dr. Wilson, that the committee would meet after January 2025.

<u>Performance Goals Committee:</u> Dr. Kanter, chairperson of the Performance Goals Committee, reported that she had no report at this time.

Advocacy Committee: Ms. Wiggins, chairperson of the Advocacy Committee, reported that the committee was conducting a survey of the CBO and would have a report at the next Commission meeting.

<u>Blood Utilization Committee:</u> Dr. Pack-Mabien, chairperson of the Blood Utilization Committee, asked the CBOs for printed materials they were using as educational and resource material on blood transfusions, etc. She indicated that Dr. Mohammad Barouqa, director of the blood bank at USA Health University Hospital, was a resource for the committee.

VIII. Old Business

<u>Proclamations Honoring Ms. Eleanor Barnes and Ms. Lynne Eskridge</u>: Chairperson Long indicated that pursuing a proclamation from the Legislature concerning Ms. Barnes was discussed earlier in the meeting.

IX. New Business

<u>Proposed FY 2025 Meeting Schedule:</u> Chairperson Long presented a list of proposed dates in 2025 for the Commission to meet. Several Commissioners reported a conflict with the meeting dates and Chairperson Long asked the Executive Director to poll the Commissioners about identifying meeting dates in 2025. She recommended that he solicit responses from the Commissioners concerning several dates in each of the proposed months.

X. Announcements

<u>Contract Review Committee Meeting:</u> Ms. Rogan indicated that she would follow-up with the Commissioners about attending the January Contract Review Committee meeting and send a reminder to Mr. Belton about the January 2, 2025 meeting date.

<u>Database Surveillance Meeting</u>: Dr. Kanter reported that a meeting was scheduled January 31, 2025 to discuss the database surveillance program and all were invited to participate.

<u>Next Commission Meeting:</u> Mr. Warren reported that he would send a doodle poll to the Commissioners about meeting in February and identifying other dates in 2025 to conduct meetings.

XI. Adjournment

There was no further business and Chairperson Long called for a motion to adjourn. MOTION: Dr. Pack-Mabien made the motion to adjourn the meeting. The motion was seconded by Ms. Garrett and, following a roll call vote, the motion was unanimously approved by the Commission. Chairperson Long adjourned the meeting at 12:27 p.m.

Respectfully Submitted,

Linda C. Garrett

Commission Secretary

Keith E. Warren

Executive Director

Minutes Approved by the Commission on _

Jehruary 25, 2025 /rr (20)