

ALABAMA SICKLE CELL OVERSIGHT AND REGULATORY COMMISSION

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MINUTES February 20, 2024

Presiding: Dr. Felicia Wilson Called to Order: 11:11 A.M. Adjourned: 12:52 P.M.

Members Participating

Dr. Felicia Wilson, President

Ms. Katherine Long

Dr. Julie Kanter

Dr. Jacqueline Williams

Ms. Linda Garrett (arrived 11:20 a.m.)

Dr. Ardie Pack-Mabien (virtual)

Dr. Lee M. Hilliard (virtual)

Ms. Leah J. Wiggins (virtual)

Ms. Janet Martin (virtual)

Members Absent

Mr. James Belton

Mr. Larry Moorer

Others Present

Mr. Keith Warren, Executive Director

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

Ms. Renee' Reames, Recording Secretary

Mr. James Arrington, Southeast Alabama Sickle Cell Chapter

Ms. Pam Thompson, North Alabama Sickle Cell Chapter

Dr. LaMonica Herron-McCoy, West Alabama Sickle Cell Chapter (virtual)

Ms. Monica Van Diver, Greater Montgomery Sickle Cell Chapter

Ms. Aleida Johnson Ponquinette, Mobile Sickle Cell Chapter

Ms. Sophia Leverson, Central Alabama Sickle Cell Chapter

Ms. Sonja Smith, UAB Comprehensive Sickle Cell Center (virtual)

Ms. LaQuisha Banks, ADPH Newborn Screening

Mr. Pat McWhorter, SW Legislative Consultant

I. Call to Order and Roll Call

The Sickle Cell Oversight and Regulatory Commission met on Tuesday, February 20, 2024. The meeting was held at the Commission's office located at 2777 Zelda Road in Montgomery. The meeting was called to order at 11:10 a.m. by Dr. Felicia Wilson, Commission President. Mr. Warren conducted the roll call of members and indicated that a quorum of the Commissioners was present to conduct business and Commissioners' travel expense forms were accepted by the Commission. The Commissioners and guests were introduced.

II. Approval of Agenda

President Wilson presented the agenda for February 20, 2024, meeting for the Commissioners' approval. Ms. Wiggins recommended an update on the Proclamation regarding Ms. Eleanor Barnes be added to the agenda.

<u>MOTION 2024.09</u>: Dr. Kanter made the motion to accept the meeting agenda as amended. The motion was seconded by Dr. Williams and, following a roll call vote, the motion was unanimously approved by the Commission, with President Wilson voting on matters to break a tie-vote.

III. Review and Approval of Meeting Minutes

President Wilson presented the minutes from the October 24, 2023, meeting for the Commissioners' approval. A copy of the minutes was provided to the Commissioners for their review prior to the meeting.

MOTION 2024.10: Ms. Long made the motion that the minutes be amended on page 3, Site Visits and Reports, to indicate that the North Alabama Chapter site visit report had been submitted, and spelling of Dr. Pack-Mabien. The motion was seconded by Dr. Williams and, following a roll call vote, the motion was unanimously approved by the Commission.

MOTION 2024.11: Dr. Kanter made the motion to approve the October minutes as amended. The motion was seconded by Dr. Williams and, following a roll call vote, the motion was approved by the Commission.

IV. Executive Director Report

- **A.** Update on Commission Website: Mr. Warren reported that the Commission's website would soon launch (https://sicklecell.alabama.gov) and encouraged the Commissioners to submit recommendations regarding contents.
- **B.** Commission Funding: Mr. Warren explained that he was working with Senator Coleman-Madison who supported the work of the Sickle Cell Centers and Chapters, and efforts to schedule a meeting with her to discuss Sickle Cell funding. Mr. McWhorter reported on working with member(s) in the Legislative House Chamber and similar efforts to schedule a meeting.
- C. Commissioner Terms: Mr. Warren reported that the appointment of Ms. Tokie Dunn, representative of the Mobile Chapter, was pending confirmation by the Senate in the current Legislative session, and other appointments were pending Governor Ivey's approval.

V. Legal Counsel Report

- A. Report of Governor's Executive Order 735: Ms. Rogan reported that Phase 1 of the Governor's Executive Order #735 has been completed that required the analysis of discrepancies between the Commission's rules and statute. Phase 2 had been postponed indefinitely. She reviewed some of the areas of discrepancy and some rule changes. Mr. Warren reported the after WestLaw had incorporated the recent rule changes, the Commission's rules would be updated on the Commission's website and the meeting notebooks.
- **B.** Board Training: Ms. Rogan reported that online Board training through the Department of Public Examiners and completion of Statement of Economic Interest on the Ethics Commission websites were due. Mr. Warren reminded the Commissioners that emails had been sent to them about this process. He explained that no certificate of completion would be evident on the Board training website, but internal records were being maintained through the Public Examiners' weblink.

C. RFP Specifications for Administrative Services: Ms. Rogan reported that Request for Proposals Specifications for Administrative Services would be presented later in the meeting under New Business.

VI. CBO Reports

Montgomery Chapter: Ms. Van Diver commented on delays with the ADPH Memorandum of Understanding for Newborn Screening. She reported that her staff were working with the local Wellness Commission in having health fairs in each of the counties served by the Montgomery Chapter and efforts in targeting more minority groups, along with offering some publications in Spanish. She thanked the Mobile Chapter for their work with the Counselor Certification program.

West Alabama Chapter: Dr. McCoy reported on efforts to contact sickle cell-affected families in each of the counties served by the West Alabama Chapter, along with conducting blood drives and health fairs, etc.

Mobile Chapter: Ms. Ponquinette reported on efforts to coordinate speakers for the upcoming Counselor Certification program. She commented on the difficulty in reaching clients and receiving responses to mail and email communications. She reported that her staff were working on identifying other media platforms to notify clients, and there had been indications that the population was migrating away and other obstacles the staff faced in contacting clients.

Dr. Kanter encouraged the Chapters to follow-up with clients about seeing the Centers' clinics after being referred by the Chapters to the Centers.

Southeast Alabama Chapter: Mr. Arrington commented on preparation toward awareness and celebration of the 50th anniversary of Sickle Cell Chapters. He also commented on the difficulty in contacting clients and the high volume of returned mail. He commented on the rising expense in his Chapter offering transportation to clients and families to healthcare and similar appointments, etc.

North Alabama Chapter: Ms. Thompson commented on efforts for awareness and celebration of Black History month and fund-raising activities by the Chapter.

Central Alabama Chapter: Ms. Leverson reported on efforts to grow the Chapter's staff, continuing the NBS program and fund-raising activities by the Chapter.

President Wilson recognized guest, Ms. LaQuisha Banks, with the ADPH Newborn Screening Program. She reported on the process of NB screening from hospital to Public Health to physicians and sickle cell chapters. She asked for assistance from the Chapters in following up with client/patient about seeing a hematologist.

<u>Tracking</u>: The Commission discussed coordinating a meeting with ADPH NBS to meet with Chapters to further discussion coordination, referral and follow-up efforts.

The Commission also discussed the problem with pediatric age clients not continuing with medical care and tracking of their care may have been dropped before the client was transferred into adult care.

VII. Committee Reports

MOTION 2024.12: Dr. Kanter made the motion to table to the next Commission meeting the discussion of Committee Reports and Old Business and move to New Business. The motion was seconded by Dr. Williams and, following a roll call vote, the motion was unanimously approved by the Commission.

VIII. **Old Business**

IX. **New Business**

A. Proposed Request for Proposal Specifications for Administrative Services: Ms. Rogan presented a draft of the Request for Proposals Specifications for Administrative Services in advance of the contract expiring in its fifth year as of September 2024.

Mr. Warren and staff left the meeting at 12:40 p.m. Ms. Reames continued to record the minutes.

Following a review of the proposed specifications, the Commission agreed to require a minimum of three (3) years' experience in licensing, regulatory or similar agency.

MOTION: 2024-13: Dr. Kanter made the motion to approve the RFP Specifications as amended. The motion was seconded by Ms. Garrett and, following a roll call vote by President Wilson, the motion was unanimously approved by the Commission.

MOTION: 2024-14: Dr. Kanter made the motion to send the amended RFP to State Procurement to solicit and collect proposals for administrative services. The motion was seconded by Dr. Williams and, following a roll call vote by President Wilson, the motion was unanimously approved by the Commission.

Mr. Warren and staff joined the meeting at 12:50 p.m.

Ms. Rogan reported that the proposal responding to the RFP would be presented for the Commissioners consideration at the next meeting scheduled June 18, 2024.

X. Other Business and Announcements

MOTION 2024-15: Dr. Kanter made the motion to table the remainder of the meeting agenda to the next Commission meeting. The motion was seconded by Ms. Garrett and, following a roll call vote by Mr. Warren, the motion was unanimously approved by the Commission.

Dr. Kanter reminded the Commission and Chapter members about the Sickle Cell disease and surveillance data share program scheduled February 22, 2024, at the UAB-Hilton.

IX. Adjournment

There was no further business and President Wilson called for a motion to adjourn.

MOTION 2024-16: Dr. Kanter made the motion to adjourn the meeting. The motion was seconded by Ms. Garrett and, following a roll call vote, unanimously approved by the Commission. President Wilson adjourned the meeting at 12:52 p.m.

Respectfully Submitted,

Felicia L. Wilson, M.D.

Commission President

Keith E. Warren Executive Director

Minutes Approved by the Commission on June 18, 2024