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ALABAMA SICKLE CELL OVERSIGHT AND REGULATORY COMMISSION

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MINUTES October 24, 2023

Presiding: Dr. Felicia Wilson Called to Order: 11:12 A.M. Adjourned: 12:35 P.M.

Members Participating

Dr. Felicia Wilson, President

Mr. James Belton

Ms. Linda Garrett

Dr. Jacqueline Williams (virtual)

Dr. Ardie Pack-Mabien

Ms. Leah J. Wiggins

Ms. Janet Martin (virtual)

Members Absent

Ms. Katherine Long

Dr. Julie Kanter

Mr. Larry Moorer

Dr. Lee M. Hilliard

Others Present

Mr. Keith Warren, Executive Director

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

Ms. Renee' Reames, Recorder

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)

Mr. Anthony Wright, Central Alabama Chapter

Ms. Monique Hopkins, Greater Montgomery Sickle Cell Chapter

Ms. Monica Van Diver, Greater Montgomery Sickle Cell Chapter

Ms. Sonya Smith, UAB Comprehensive Sickle Cell Center

I. Call to Order and Roll Call

The Sickle Cell Oversight and Regulatory Commission met on Tuesday, October 24, 2023. The meeting was held at the Commission's office located at 2777 Zelda Road in Montgomery. The meeting was called to order at 11:12 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.

II. Approval of Agenda

President Wilson presented the agenda for October 24, 2023 meeting for the Commissioners' approval. The agenda was accepted by consensus of the members.

III. Review and Approval of Meeting Minutes

President Wilson presented the minutes from the August 29, 2023 meeting for the Commissioners' approval. A copy of the minutes was provided to the Commissioners for their review prior to the meeting.

MOTION 2024.01: Ms. Wiggins made the motion to approve the August meeting minutes as presented. The motion was seconded by Dr. Pack-Mabien. The following members vote in favor of the motion: Mr. Belton, Ms. Garrett, Dr. Pack-Mabien, Ms. Wiggins, Dr. Williams and Ms. Martin. With no opposing votes, the motion was unanimously approved by the Commission and the Commissioners' roll call vote was established, with President Wilson voting on matters to break a tievote.

IV. Executive Director Report

- A. Update on Commission Website: Mr. Warren reported that plans were to launch the Commission's website soon and encouraged the Commissioners to submit recommendations regarding contents.
- **B.** Allocation of Funds Process: Mr. Warren explained that he had contacted the State Comptroller's office about steps to improve delays in the monthly allocation of funds. He reported that the Comptroller's office was working on establishing the electronic transfer of funds, and he indicated that he would notify the Chapters and Centers about registering as a vendor to receive funds electronically (EFT).

V. Legal Counsel Report

Ms. Rogan reported that Request for Proposals specifications for Administrative Services would be discussed in calendar year 2024 in advance of the contract expiring in its fifth year.

VI. CBO Reports

Southeast Alabama Chapter: Mr. Arrington commented on the current shortage of funds to meet the communities' service needs and the compounded problems when state-allocated funds were delayed. He asked the Commission's assistance in arranging timely receipt of funds and advocating for additional funds.

North Alabama Chapter: Ms. Thompson supported the need for additional funding.

Central Alabama Chapter: Mr. Wright reported that a new Executive Director had been hired starting in November and two new staff members were hired to provide services. The Commissioners thanked Mr. Wright for stepping up to provide leadership, assist with the staffing transition, and participation in the Chapter's site visit.

West Alabama Chapter: Dr. Williams reported that the walk-a-thon sponsored by the West Alabama Chapter was a success and well-attended.

VII. Committee Reports

- A. CBO Standardized Core Educational Committee: In the absence of Dr. Kanter, Mr. Arrington reported that Dr. Kanter would be submitting a written report on the activities of the Standardized Core Educational Committee.
- B. Performance Goals Committee: Mr. Arrington reported that he had solicited comments from other Chapters about changes to the performance goals and he planned to provide a report of the Performance Goals Committee at the next Commission meeting.
- C. Funding Discussion: Ms. Sonya Smith, with Dr. Kanter's office at the UAB Comprehensive Sickle Cell Center, commented on discussion with UAB's fiscal director and recommended that a letter be sent from the Commission's Governor appointee to the State's Finance Director, Mr. Poole, requesting a meeting to discuss the Commission's funding needs for CBOs and Centers, and to follow-up with a telephone call to Mr. Poole to schedule the meeting.

VIII. Old Business

- A. Proclamation honoring Lynne Eskridge: Mr. Warren reported that there has been no progress on obtaining Lynne Eskridge's professional work history for the Governor's Proclamation honoring Mrs. Eskridge.
- **B.** Site Visits and Reports: President Wilson reviewed the status of written site visit reports to be submitted to the Commission:

Johnson Haynes, Jr. MD Comprehensive Sickle Cell Center to be submitted by Dr. Kanter and Mr. Arrington.

Mobile Alabama Chapter to be submitted by Ms. Thompson.

Central Alabama Chapter to be submitted by Mr. Arrington.

Southeast Alabama Chapter to be submitted by Mr. Belton.

UAB/Childrens to be submitted by Dr. Wilson.

West Alabama Chapter to be submitted by Ms. Thompson.

Greater Montgomery report had been submitted by Ms. Barnes, who previously served on the Commission.

North Alabama Chapter report had been submitted by Ms. Long.

The Commission discussed the site visits conducted prior to COVID interrupting the 2020 cycle of site visits. The Commission reviewed the written site visit reports submitted for the North Alabama Chapter and the Greater Montgomery Chapter (copies available in the Commission's official Book of Minutes).

Mr. Belton and Mr. Arrington reported that they were impressed with the liability coverage, the organization of documents reviewed by the team, and the good job the staff were doing at the North Alabama Chapter.

Mr. Belton and Mr. Arrington commented on the good job the staff were doing at the Greater Montgomery Chapter and availability of substantial office space.

Motion 2024-02: Mr. Belton made the motion to accept the site visit final reports for the North Alabama Chapter and the Greater Montgomery Chapter as submitted. The motion was seconded by Dr. Pack-Mabien and, following a roll call vote, the motion was unanimously approved by the Commission.

The Commission discussed resuming the 5-year cycle to conduct site visits.

Motion 2024-03: Ms. Garrett made the motion to conduct future site visits in March 2025. The motion was seconded by Mr. Belton and, following a roll call vote, the motion was unanimously approved by the Commission.

C. Proclamation for Eleanor Barnes: It was the consensus of the Commission to request a proclamation from the Governor thanking Ms. Barnes for her service on the Commission.

IX. New Business

A. Proposed 2024 Meeting Calendar: President Wilson presented a list of proposed dates in 2024 for the Commission to conduct meetings.

Motion 2024-04: Ms. Wiggins made the motion to approve February 20, June 18 and August 20, 2024, as meeting dates. The motion was seconded by Mr. Belton and, following a roll call vote, the motion was unanimously approved by the Commission.

B. Election of Officers: President Wilson reminded the members that Commission officers were elected every four (4) years, and she called for nominations from the members. Ms. Garrett nominated Dr. Wilson as Commission President.

Motion 2024-05: Mr. Belton made the motion that nominations be closed for the office of Commission President. The motion was seconded by Ms. Wiggins and Dr. Wilson was elected as Commission President by acclamation.

Mr. Belton nominated Ms. Long as Commission Vice President.

Motion 2024-06: Ms. Wiggins made the motion that nominations be closed for the office of Commission Vice President. The motion was seconded by Dr. Pack-Mabien and Ms. Long was elected as Commission Vice President by acclamation.

Dr. Wilson nominated Ms. Garrett as Commission Secretary/Treasurer.

Motion 2024-07: Mr. Belton made the motion that nominations be closed for the office of Commission Secretary/Treasurer. The motion was seconded by Dr. Williams and Ms. Garrett was elected as Commission Secretary/Treasurer by acclamation.

X. Other Business and Announcements

UAB Open House: Ms. Smith, with Dr. Kanter's office at the UAB Comprehensive Sickle Cell Center, announced the Adult Sickle Cell Clinic Open House scheduled for January 25, 2024 and Holiday Open House for December 5, 2023.

Sickle Cell Awareness Proclamation: Mr. Arrington commented on the Sickle Cell Awareness Proclamation signed in September by Governor Ivey. He reported that the signing included the representative of Vertex Pharmaceutical. Dr. Wilson asked that the photograph from the official Proclamation signing be posted to the Commission's website. Mr. Arrington also expressed his appreciation to the City of Birmingham for including the Sickle Cell Chapters in their Sickle Cell Month Awareness activities.

Sickle Cell Educator/Counselor Certification: Dr. Wilson reported that Ms. Johnson, with the Mobile Sickle Cell Chapter, had been involved with hosting the Sickle Cell Educator/Counselor Certification program and was unable to attend the Commission meeting.

Deadline for Quarterly Performance Goals Reports: Ms. Reames reminded the CBOs' and Centers' staff that the fiscal year 2023 4th quarter performance goals reports were due. She reported that this was the final report for fiscal year 2023 to summarize services for the prior twelve (12) months.

Sickle Cell as a Chronic Illness: Dr. Pack-Mabien responded to questions about adult patients having to document sickle cell treatment and health management as a chronic illness to qualify for disability and explained that sickle cell had been declared as a chronic illness in pediatrics. The Commission discussed creating statistical documentation to present to the Legislature for advocacy of patient and family needs and funding services.

Awareness and Advocacy Committee: President Wilson established an ad hoc committee on Sickle Cell Awareness and Advocacy and appointed Ms. Wiggins, Mr. Arrington and Dr. Pack-Mabien to the committee.

Letter to the State Finance Director: President Wilson reported that she would contact Ms. Long about writing a letter to State Finance Director, as discussed earlier in the meeting, and would collaborate with Dr. Kanter and Ms. Sonya Smith regarding content of the letter. Dr. Pack-Mabien suggested that a form letter campaign could be developed simultaneously to support the Commission's efforts.

IX. Adjournment

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

Wilson, MO

MOTION 2024-08: Ms. Garrett made the motion to adjourn the meeting. The motion was seconded by Ms. Wiggins and unanimously approved by the Commission. President Wilson adjourned the meeting at 12:35 p.m.

Respectfully Submitted,

Felicia L. Wilson, M.D.

Commission President

Keith E. Warren Executive Director

Minutes Approved by the Commission on Jebruary 20, 3024 /rr