ALABAMA SICKLE CELL OVERSIGHT AND REGULATORY COMMISSION

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MINUTES June 18, 2024

Presiding: Dr. Felicia Wilson Called to Order: 11:19 A.M. Adjourned: 1:50 P.M.

Members Participating

Dr. Felicia Wilson, President

Ms. Katherine Long

Dr. Julie Kanter

Ms. Leah J. Wiggins

Dr. Ardie Pack-Mabien

Mr. James Belton

Dr. Lee M. Hilliard (virtual)

Ms. Janet Martin (virtual)

Ms. Tokie Dunn

Members Absent

Dr. Jacqueline Williams

Ms. Linda Garrett

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

Mr. Anthony Wright, Central Alabama Sickle Cell Chapter

Ms. LaQuisha Banks, ADPH Newborn Screening

I. Call to Order and Roll Call

The Sickle Cell Oversight and Regulatory Commission met on Tuesday, June 18, 2024. The meeting was held at the Commission's office located at 2777 Zelda Road in Montgomery. The meeting was called to order at 11:19 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 and Commissioners' travel expense forms were accepted by the Commission. The Commissioners and guests were welcomed by President Wilson.

II. Approval of Agenda

President Wilson presented the agenda for February 20, 2024, meeting for the Commissioners' approval and indicated that this was the third meeting in FY 2024.

MOTION 2024.17: Dr. Kanter made the motion to accept the meeting agenda as presented. The motion was seconded by Mr. Belton 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.

Dr. Martin joined the meeting virtually at 11:33 a.m.

III. Review and Approval of Meeting Minutes

President Wilson presented the minutes from the February 20, 2024, meeting for the Commissioners' approval. A copy of the minutes was provided to the Commissioners for their review prior to the meeting.

MOTION 2024.18: Ms. Long made the motion that the minutes as presented. The motion was seconded by Ms. Wiggins and, following a roll call vote, the motion was unanimously approved by the Commission.

IV. CBO Reports

North Alabama Chapter: Ms. Thompson commented on the chapter's successful walkathon and logistical challenges.

Southeast Alabama Chapter: Mr. Arrington commented on plans to hold the 17th annual golf tournament and preparation for celebrating the 50th anniversary of Sickle Cell Chapters. He also commented on the high volume in requests for assistance and the cost associated with transportation services.

Mobile Chapter: Ms. Ponquinette reported on coordinating the meeting in Mobile with Representative Drummond and attending the meeting in Birmingham with Senator Coleman-Madison. She also remarked on the Chapter's plans to have a blood drive in June on the World Sickle Cell Day and the chapter celebrating its 50th anniversary in 2026.

Montgomery Chapter: Ms. Van Diver commented on working with the local Wellness Coalition to conduct health fairs and partnering with Alabama State University, along with the chapter's plans to raise capital development funds for a new building. She indicated that the chapter was planning its annual radiothon in September – Sickle Cell month.

Central Alabama Chapter: Mr. Wright reported on efforts to submit data in building a new case worker database and having held a successful walkathon fundraiser and efforts to provide services to outer counties, along with recent employment of a social worker.

Ms. Banks with the Alabama Newborn Screen program commented on providing data to the Chapters. Also discussed were the trait testing programs in the chapters and the chapters reported on various laboratories utilized for these services. Dr. Kanter commented on interpretation of tests and errors in inconclusive readings. Dr. Kanter indicated that she would provide more information via email on this matter.

V. Legal Counsel Report

Ms. Rogan reported that specifications for Requests for Proposals (RFP) for Administrative Services were released and a proposal received. Mr. Warren and staff left the meeting at 12:02 p.m. Ms. Rogan explained the State's RFP process. The Commission reviewed and discussed the proposal submitted by Smith Warren Management Services.

Dr. Kanter left the meeting at 12:19 p.m. to take a telephone call and returned at 12:24 p.m.

The Commission had questions for the Legal Counsel to respond to before the meeting tentatively planned in July to discuss the matter further. The Commission did not reach a decision nor vote on the proposal. Mr. Warren and staff returned to the meeting at 1:05 p.m.

Legal Counsel left the meeting at 1:07 p.m. due to a conflict in her schedule.

VI. OLD BUSINESS

MOTION 2024-19: Ms. Wiggins made the motion to remove from the agenda items under Old Business concerning Report by the Awareness and Advocacy Committee, Update on Proclamation Honoring Lynne Eskridge, and Status of Letter to State Finance Director. The motion was seconded by Dr. Kanter and, following a roll call vote, the motion was unanimously approved.

Update on Proclamation Honoring Eleanor Barnes: President Wilson reviewed some achievements and work history of Ms. Eleanor Barnes and service on the Central Alabama Chapter and the Sickle Cell Commission in advocating for sickle cell services. Mr. Warren indicated that he would request a Proclamation from the Governor's Office, and he would coordinate with Ms. Barnes about presenting the Proclamation. Dr. Kanter offered to host the Sickle Cell Commission meeting at UAB and provide lunch when presenting the Proclamation to Ms. Barnes.

Site Visit Reports: Ms. Thompson presented the Mobile Chapter site visit report and commented on the organization of documentation. She reported that the site visit team found the Mobile Chapter to be in compliance (copy of report in official Book of Minutes).

MOTION 2024-20: Dr. Kanter made the motion to accept the final site visit report concerning Mobile Chapter. The motion was seconded by Mr. Belton and, following a roll call vote, the motion was unanimously approved.

Ms. Thompson presented the West Alabama Chapter site visit report and reported on the two recommendations for improvements by the site visit team (copy of report in official Book of Minutes). MOTION 2024-21: Dr. Pack-Mabien made the motion to accept the final site visit report concerning West Alabama Chapter. The motion was seconded by Ms. Long and, following a roll call vote, the motion was unanimously approved.

Mr. Arrington presented the Johnson Haynes, Jr., MD Comprehensive Sickle Cell Center site visit report (copy of report in official Book of Minutes). He reported that the center's documentation satisfied the requirements and were in compliance, and the services were of the highest quality. MOTION 2024-22: Dr. Kanter made the motion to accept the final site visit report concerning the

<u>MOTION 2024-22:</u> Dr. Kanter made the motion to accept the final site visit report concerning the Johnson Haynes, Jr., MD Comprehensive Sickle Cell Center. The motion was seconded by Mr. Belton and, following a roll call vote, the motion was unanimously approved.

Mr. Arrington presented the Greater Montgomery Chapter site visit report (copy of report in official Book of Minutes) and reported that the chapter's documentation met the requirements and were in compliance.

MOTION 2024-23: Dr. Kanter made the motion to accept the final site visit report concerning Greater Montgomery Chapter. The motion was seconded by Mr. Belton and, following a roll call vote, the motion was unanimously approved.

Dr. Wilson presented the UAB Comprehensive Sickle Cell Center and Children's Hospital site visit report (copy of report in official Book of Minutes). She reported that the documentation was in compliance and complimented the organizations on the service components of the program.

MOTION 2024-24: Ms. Long made the motion to accept the final site visit report concerning UAB Comprehensive Sickle Cell Center and Children's Hospital. The motion was seconded by Dr. Pack-Mabien and, following a roll call vote, the motion was unanimously approved.

Mr. Arrington presented the site visit report prepared by Mr. Belton concerning Southeast Sickle Cell Chapter. The site visit team reviewed the documentation, and the Chapter was in compliance. The site visit team had recommendations regarding transportation liability (copy of report in official Book of Minutes).

<u>MOTION 2024-25</u>: Ms. Wiggins made the motion to accept the final site visit report concerning Southeast Sickle Cell Chapter. The motion was seconded by Dr. Pack-Mabien and, following a roll call vote, the motion was unanimously approved.

VII. NEW BUSINESS

Report on Meetings with Legislators: Mr. Warren reported on the funding acquired in the 2025 fiscal year budget for Sickle Cell chapters and centers. He thanked the chapters in Birmingham and Mobile for their efforts to coordinate meetings with Senator Coleman-Madison in Birmingham and Representative Drummond in Mobile.

Dr. Pack-Mabien recommended that a committee be appointed to develop data for future presentations. Dr. Kanter recommended that this data also be posted on the Commission's website. <u>COMMITTEE</u>: Three Commissioners volunteered to serve on the committee: Ms. Wiggins, Dr. Pack-Mabien and Ms. Dunn and President Wilson appointed Ms. Wiggins as Committee chairperson of the Advocacy Committee.

Mr. Warren requested that the chapters and centers submit a list of special events to be held in September – Sickle Cell Awareness month and he would request that the Governor's office feature the events on the Governor's website.

Adoption of FY 2025 Allocation of Funds: Mr. Warren presented the FY 2025 allocation of funds to chapters and centers, along with the administrative services funding, as approved in the State Budget.

MOTION 2024-26: Ms. Wiggins made the motion to accept the FY 2025 budget for the allocation of funds as presented (copy in the official Book of Minutes). The motion was seconded by Ms. Long and, following a roll call vote, the motion was unanimously approved.

VIII. ANNOUNCEMENTS AND OTHER BUSINESS

Mr. Arrington reminded the members about World Sickle Cell Day and invited everyone to participate in the annual W.L. Strain Sickle Cell Chairty golf tournament.

Special/Called meeting: President Wilson announced the special/called meeting of the Commission to be held July 16, 2024 in Mobile.

Next Regular Commission meeting: President Wilson reminded the Commission about the next scheduled regular business meeting of the Commission on August 20, 2024 in Montgomery.

IX. Adjournment

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

MOTION 2024-27: Mr. Belton made the motion to adjourn the meeting. The motion was seconded by Ms. Dunn and, following a roll call vote, unanimously approved by the Commission. President Wilson adjourned the meeting at 1:50 p.m.

Respectfully Submitted,

Felicia L. Wilson, M.D.

Commission President

Keith E. Warren
Executive Director

Minutes Approved by the Commission on Spotential) 24, 2024 /rr