



State of Louisiana

Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION Meeting Minutes

January 30, 2024 | 2:00pm | Bienville Building

COMMISSIONER ATTENDANCE

Present: DeJean, Fulbright, Gardner, Goldsmith (Proxy), Hardison, Hebert-Magee, Henry, Jeroudi, Phelps, Robertson, Spain, & Thaxton.

Absent: Barrow, Campbell, Harris, & Warriier

CALL TO ORDER

Erin Fulbright called the meeting to order at 2:00 pm.

ROLL CALL

Erin Fulbright called the roll, and a quorum was established.

APPROVAL OF PREVIOUS MEETING MINUTES

Hebert-Magee motioned to approve the minutes from the August and November 2023 meetings, Spain seconded and the motion passed unanimously.

REVIEW OF DRAFT OF LSCC BY-LAWS

Fulbright opened the floor to discuss the draft of the by-laws. The discussion focused on the Committee Operations & Meetings section and clarifying the difference between a majority and a simple majority. Spain motioned to amend by laws to reflect the attendance requirements adopted by Louisiana Commission on HIV and Hepatitis C Education, Prevention, and Treatment; Thaxton seconded and the motion passed unanimously.

ELECTION OF 2024 CHAIR & VICE-CHAIR

Spain motioned to reelect Erin Fulbright as Chair and Donna Thaxton as Vice Chair, Hebert-Magee seconded and the motion passed unanimously.

REPORT: DATA & SURVEILLANCE

Skylar-Cooper Database- Goldsmith reported that there are bi-weekly meetings with BHI & DAT. A dashboard has been developed and there are discussions about hiring an epidemiologist and additional personnel to clean the data collected for SCD patients. He listed the data elements being collected and stored in ETO currently. The registry will be implemented in a phased approach. Commissioners inquired if the registry will track hematologists and include data for patients that are currently incarcerated or in homecare

facilities. Additional patient data will be monitored as the registry continues to be developed. Commissioners stated that they would like to invite Amy Zapata to attend the next meeting to address delays in the development of the registry.

REPORT: MEDICAL SERVICE/DELIVERY

Telehealth Access Presentation- Dr. Karen Wyble, Vice President of Regional Community Affairs at Ochsner Lafayette General, discussed the importance of telehealth access for SCD patients in Louisiana. She stated a taskforce was created to look at healthcare disparities and they composed a playbook to report findings to the state legislature. Commissioners expressed concerns that using telehealth as a primary method of treating patients diagnosed with SCD, especially children, may not be as effective as in-person care. Dr. Wyble acknowledged these concerns and stated she would like to collaborate with the LSCC to continue focusing on filling in the gaps in care for SCD patients living in Louisiana.

Medicaid Updates- Dr. Shantel Hebert-Magee stated that Medicaid is currently working with TOP\$, a Medicaid contractor with a multi-state pharmaceutical purchasing pool to provide supplemental rebates for Casgevy and Lyfgenia, the two new gene therapy treatments for SCD. They have completed mandated reports on drug access and gene therapies coming to market.

REPORT: PATIENT NAVIGATION

Medical ID Bracelet Pilot Project- Pauline Clark, a representative from the Northeast Louisiana Sickle Cell Anemia Foundation, briefly spoke about the MedicAlert/SCDAA Medical ID Pilot Program and NELASCAF Medical ID Bracelet Pilot Program. The purpose of the program is to improve access to timely, effective emergency care for people experiencing a sickle cell crisis. Individuals with SCD over the age of 18 can submit an application to participate.

NELASCAF developed a pilot program for children (age 4 – 17) is set to launch on April 1, 2024. The pilot will last for one year.

ANNOUNCEMENTS

Fulbright announced that the next Commission meeting is tentatively set for Tuesday, May 14, 2024, at 2:00 pm in Shreveport, Louisiana. Additional details will be emailed at a later time.

ADJOURN

The meeting adjourned at approximately 3:39 pm.

Note: The order of the agenda may not be followed exactly, to accommodate presenter schedules.

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In lieu of verbal public comment, individuals may submit a prepared statement in accordance with Senate Rule 13.79. Statements should be emailed to lsccl@la.gov and must be received at least 24 hours prior to the meeting to be included in the record for the meeting.