



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Date: Monday, March 17, 2025 **Time:** 1:00 pm – 2:30 pm

Location: 628 North 4th Street, Room 173, Baton Rouge, La 70802

Zoom: zoom.us/j/94373015676 **Meeting ID:** 943 7301 5676 **Code:** gZW9G3

MEETING MINUTES

- I. **Call to Order** – The meeting was called to order at 1:05 pm by the Chair, Erin Fulbright.
- II. **Roll Call** – A quorum was established.
 - a. **Present:** Ernest DeJean, Erin Fulbright, Cheryl Harris, Shantel Hebert-Magee, Majed Jeroudi, Dana LeBlanc, Simone Martin*, Tammy Phelps, Rosalyn Spain*, & Donna Thaxton.
 - b. **Absent:** Regina Barrow, Twarnette Hardison, & Shannon Robertson.
- III. **Public Comments** – None submitted.
- IV. **Approval of Minutes**
 - a. Martin motioned to approve the minutes from the January 2024 meeting, LeBlanc seconded, and the motion passed unanimously.
 - b. Hebert-Magee motioned to approve the minutes from the May 2024 meeting, Harris seconded, and the motion passed unanimously.
 - c. DeJean motioned to approve the minutes from the August 2024 meeting, Hebert-Magee seconded, and the motion passed unanimously.
 - d. Phelps motioned to approve the minutes from the November 2024 meeting, Hebert-Magee seconded, and the motion passed unanimously.
- V. **Mandate Review** – The BFH Facilitator reviewed Revised Statute 40:1125.1 (see agenda).
- VI. **Vacancy Announcements** – The following vacancies were announced:
 - a. One parent of a person diagnosed with SCD, one person diagnosed with SCD, & one medical professional caring for persons diagnosed with SCD.
 - b. Members were informed of the application process and the new requirements established by the Governor's office.
- VII. **Old Business**
 - a. **Status Report | SCD Registry:** Rebecca Majdloch introduced Ashlyn Pinkins, the newly hired SCD Registry Epidemiologist. Ashlyn is currently reviewing reports and legislation to become familiar with the SCD registry and researching best practices used by the CDC and other states to develop the registries. Majdloch shared the following updates from the Registry Development Team:

- i. Currently reviewing and verifying data obtained from available health information systems to learn more about the state's current SCD population and identify methods to improve access to services and resources available to them.
 - ii. Plans to develop a HIPAA compliant reporting system for providers to report data on people who have been newly diagnosed or identified with SCD. Will also identify providers most likely to encounter patients newly diagnosed with SCD that are not included in the newborn screening program.
- b. Status Report | Transcranial Doppler Access: Heiki Griffin, OPH-BFH Statewide Pediatric Nurse Consultant, reported that the landscape assessment is still on-going. The team recently reviewed data and learned that only 2 of the 12 requests have been completed in the last two years. They will continue foundational research to identify physicians and learn more about their processes. The team will meet with a hematologist in April. Griffin also shared that members interested in participating in the landscape assessment should contact her.
- c. Status Report | SCD Training for School Nurses: Ernest DeJean reported that the training module will include components to help school nurses identify appropriate medical and academic accommodations for students diagnosed with SCD to share with school staff and parents. The team has met with several stakeholders to obtain input, and plans to get additional guidance from the Louisiana State Nurses' Association. DeJean anticipates the final version of the training module will be available before the beginning of the 2025-26 school year.

VIII. 2025 Chair & Co-Chair Elections

- a. Nominations were accepted via email and from members present.
- b. Nominee for Chair: Donna Thaxton. Nomination accepted by Thaxton. Donna Thaxton elected as 2025 – 2026 Chair by a unanimous vote.
- c. Nominee for Co-Chair: Ernest DeJean. Nomination accepted by DeJean. Ernest DeJean elected as 2025 – 2026 Co-Chair by a unanimous vote.

IX. Public Comments – None submitted.

X. Adjournment – Meeting was adjourned at 2:45 pm.

Next Meeting | Thursday, April 3 at 1:30 pm Location: TBA

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

Presenters, members, and guests may submit requests for accessibility and accommodations prior to a scheduled meeting. Please submit a request to lsccl@la.gov at least 2 weeks prior to the meeting with details of the required accommodations.

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.