

Louisiana Department of Health Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Date: Thursday, July 24, 2025 **Time:** 1:30 pm – 3:00 pm **Location:** 628 North 4th Street, Room 118, 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 1:33 pm by the Chair, Donna Thaxton.
- II. Roll Call A quorum was established. (*virtual)
 - a. **Present:** Jacqueline Cummings, Ernest DeJean, Erin Fulbright, Twarnette Hardison, Cheryl Harris*, Majed Jeroudi, Dana LeBlanc*, Simone Martin*, Tammy Phelps, & Donna Thaxton.
 - b. Absent: Regina Barrow, Shannon Robertson, & Rosalyn Spain.

III. Approval of Minutes

- a. Fulbright motioned to approve the minutes from the March 2025 meeting, DeJean seconded, and the motion passed unanimously.
- b. Hardison motioned to approve the minutes from the April 2025 meeting, DeJean seconded, and the motion passed unanimously.
- IV. Mandate Review The BFH Facilitator reviewed Revised Statute 40:1125.1 (see agenda).
- V. Vacancy Announcements The following positions are currently vacant: one (1) parent of a person diagnosed with SCD, one (1) person diagnosed with SCD, and one (1) medical professional caring for persons diagnosed with SCD. The Facilitator asked members to share these vacancies within their networks and to have interested candidates email LSCC@LA.Gov. He also informed members of the application process and requirements established by the Governor's office.

VI. Old Business

- a. **Status Report | SCD Registry:** Rebecca Majdoch & Ashlyn Pinkins provided the following update on the Sickle Cell Disease Registry.
 - i. Data visualizations were developed using data from the newborn screening program.
 - ii. Coverage includes births from 2021 to 2024.
 - iii. Visuals highlight babies born with sickle cell disease in Louisiana during this timeframe.
 - iv. A webpage featuring this data is in development and pending approval.

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b. **Status Report | Transcranial Doppler Landscape Assessment:** Michelle Duplantier, CSHS Statewide Social Work Consultant shared the following update:

- Assessment efforts are ongoing. The team has been meeting with various institutions, including Tulane and LSU. A survey is in development and expected to be distributed by early August.
- ii. DeJean motioned for the LSCC (DeJean & Thaxton) to contact the LSU/Ochsner Hospital System in New Orleans to request an official Transcranial Doppler training for physicians in the Ochsner Hospital System in Monroe; Hardison seconded, and the motion passed unanimously.
- c. Status Report | SCD Training for School Nurses: DeJean updated members on the status of the training module for school nurses.
 - i. Group is collaborating with the Tulane University, School of Performance Advancement, to include more interactive components and quizzes. Tulane is providing this service inkind to the LSCC. The Louisiana State Nursing Board is working to get the module accredited so that nurses receive CEU credit upon completing the module. The module is still in development and is expected to be completed before the start of the 2025-26 school year.
 - ii. Shane Bates, BFH Legislative & Policy Lead, expressed concerns that school nurses might be out of compliance because the training is not ready. Phelps responded that nurses would not be out of compliance since the training will be available to them via the LSNB's website. She continued that they are working to ensure they have a stellar training program that is beneficial for nurses and addresses the concerns of parents and other stakeholders throughout the state. DeJean added that it is a collaborative effort, and they have encountered barriers outside of their control (the LSNB and the accreditation process, etc.).
- d. **Status Report | 2025 SCD Symposium:** DeJean updated members on the status of the 2025 Sickle Cell Disease Symposium.
 - i. Planning is underway for the SCD Symposium on Friday, November 7 and Saturday, November 8 in Region 1. The Save the Date will be sent as soon as possible. Friday will focus on providers and Saturday will focus on patients. The plan is to have a variety of discussions about patient care, treatment, and breakout sessions for patients and families to learn more about transitional care and advocacy.
- VII. Adjournment The meeting was adjourned at 2:15 pm.

Next Meeting: Wednesday, October 8 | 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 <u>LSCC@LA.GOV</u> 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 <u>Senate Rule 13.79</u>. Statements should be emailed to <u>LSCC@LA.GOV</u> and must be received at least 24 hours prior to the meeting to be included in the record for the meeting.