



State of Louisiana

Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Thursday, April 3, 2025

1:30 pm – 3:00 pm

LOCATION

628 North 4th Street, Room 118, Baton Rouge, La 70802

ZOOM DETAILS

zoom.us/j/94373015676

Meeting ID: 943 7301 5676 Code: gZW9G3

MEETING MINUTES

- I. **Call to Order** – The meeting was called to order at 1:40 pm by the Vice Chair, Ernest DeJean.
- II. **Roll Call** – A quorum was established.
 - a. **Present:** Ernest DeJean, Erin Fulbright, Twarnette Hardison, Cheryl Harris, Shantel Hebert-Magee*, Majed Jeroudi, Dana LeBlanc, Simone Martin*, & Tammy Phelps.
 - b. **Absent:** Regina Barrow, Shannon Robertson, Rosalyn Spain, & Donna Thaxton.
- III. **Public Comments** – Tyler Craddock, Bluebird Bio Account Executive, shared that Louisiana has elected to enter the Centers for Medicare & Medicaid Innovation (CMMI) Reimbursement Model for sickle cell disease as of the end of March. CMMI directed the states to provide a published set of clinical criteria for physicians to use as a roadmap toward approval of reimbursement for gene therapies. LDH will review the criteria developed by Medicaid to determine if any adjustments are needed. The criteria will be shared with the Commission when it becomes available.
- 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. Members were encouraged to share these vacancies with their networks and to have interested candidates email lsccl@la.gov. The application process and requirements established by the Governor's office were also shared.
- VI. **New Business**
 - a. **Status Report | Transcranial Doppler Access:** Dr. Dana LeBlanc and Michelle Duplantier briefly discussed the status of the landscape assessment and addressed concerns about the standardization across the state. The workgroup is meeting on Friday, April 4 to discuss action items and next steps. An update will be shared at the next meeting.

- b. **Status Report | SCD Training for School Nurses:** DeJean announced that the workgroup plans to meet with the Louisiana State Nurses Association director soon and aims to complete the training module by the fall.
- c. **2025 SCD Symposium Planning:** DeJean led the discussion about planning the 2025 SCD Symposium. He emphasized the importance of equitable representation for all organizations and increasing community participation. A subcommittee for planning the event consists of the following individuals: DeJean, Harris, Jeroudi, Hardison, LeBlanc, and Michelle Duplantier. The subcommittee will share a status report at the next meeting.
- d. **LSCC Bylaws:** Members discussed potential changes to the bylaws, specifically regarding the number of meetings held annually. The statute mandates at least four regular meetings per year, with a rotation of locations throughout the state. However, members considered extending this to six meetings, allowing for two virtual meetings. Members also debated proxy voting and clarified that the Opens Meeting Law allows members to participate in public meetings virtually, and voting by proxy is permitted. Jeroudi expressed concerns about the potential misuse of proxy voting. Others specified that proxies must represent the same organization as the absent member.

Fulbright motioned to amend Section 3: Commission Meeting Procedures of the bylaws to increase the number of regular meetings from four (4) to six (6) per year, and LeBlanc seconded. LeBlanc motioned to amend Section 3, subsection C-3 to allow proxy voting and include the stipulation that the proxy must represent the member's organization, and Phelps seconded.

Members voted unanimously to pass both amendments with the understanding that the motion to increase the number of annual meetings and the allowance for two virtual meetings will not take effect until January 1, 2026.

- VII. **Public Comments** – Karen Gant from Emmaus Medical spoke about their medication for sickle cell disease. The medication is for pediatric patients starting at age five and for adult patients. She encouraged continued use of their product. She also suggested that Medicaid/Medicare's policy for L-glutamine should be analyzed to ensure it is up to date.
- VIII. **Adjournment** – Harris motioned to adjourn the meeting, Hardison seconded, and the motion passed unanimously. The meeting was adjourned at 3:07 pm.

<p>Next Meeting Thursday, July 24 1:30 pm Location: TBA</p>

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 LSCC@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 LSCC@LA.GOV and must be received at least 24 hours prior to the meeting to be included in the record for the meeting.