



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Date: Thursday, July 30, 2026

Zoom: ldhophbfhgenetics.zoom.us/j/95573653337

Time: 02:00 PM – 03:30 PM

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

The Bureau of Family Health is committed to promoting transparency, accessibility, and public engagement in all board, council, & commission meetings. As part of that commitment and for the convenience of members of the public, access the meeting online using the provided link.

MEETING MINUTES

- I) Call to Order** – The Commission Chair, Donna Thaxton, called the meeting to order at 2:05 pm.
- II) Roll Call/Introductions** – A quorum was not present. (**Virtual*)
- Members Present: Jacqueline Cummings*, Ernest DeJean*, Cheryl Harris*, Dr. Majed Jeroudi*, Dr. Dana LeBlanc*, and Donna Thaxton.
 - Members Absent: Senator Regina Barrow, Erin Coleman, Twarnette Hardison, Simone Martin, Representative Tammy Phelps, Shannon Robertson, and Rosalind Spain.
- III) Public Comments**
- Karen Gant, the Community Engagement Director for Neo Immune Tech Pharmaceuticals, spoke about the importance of equitable access to evidence-based treatments for sickle cell disease and highlighted the benefits of Endari. This prescription medication reduces acute complications of sickle cell disease. Gant asked the Commission to support efforts to make Endari more accessible to people living with sickle cell disease.
- IV) Mandate Review and Announcements**
- The Bureau of Family Health facilitator reviewed the Commission's mandate.
 - Vacancy Announcements – The following positions are currently vacant: one parent of a person diagnosed with sickle cell disease; one person diagnosed with sickle cell disease; and one representative from Southwest Louisiana Sickle Cell Anemia, Inc. Members were informed of the application process established by the Governor's office and were encouraged to share these vacancies with potential members and have them email LSCC@LA.Gov. The facilitator also shared the Governor's office is currently reviewing previous applicants.
 - Donna Thaxton announced that the Northeast Sickle Cell Anemia Foundation is seeking alternative funding due to the expiration of a grant. She invited the executive directors of other sickle cell foundations in the state to join her in developing a budget request to submit to the Louisiana Department of Health.
- V) Old Business** – The Chair announced that there was no old business to discuss.

VI) New Business – There was no new business conducted because a quorum was not present. The Chair announced that the item listed on the agenda under New Business (Revisions to LSCC Bylaws) will be tabled until the next meeting.

VII) Reports

- Report | Sickle Cell Disease Registry: Christian Beauchamp, Quality Improvement and Data Registry Manager for the Bureau of Family Health, announced that the new Sickle Cell Disease Registry epidemiologist will join the Bureau of Family Health on August 24. In this role, the epidemiologist will manage and analyze registry data, ensure data quality, conduct statistical analyses, support data linkages, and develop reports to inform sickle cell disease surveillance, research, and policy decisions. He also mentioned ongoing work with the Bureau of Health Informatics to complete quality-assurance checks for the 2025 analysis of Louisiana Newborn Screening data.
- Legislation | 2024 Regular Session: Acts 375 & 748: Ernest DeJean shared that the training module for school nurses and emergency personnel mandated by Acts 375 and 748 has been completed and is awaiting approval from the Louisiana Department of Education (LDOE) to ensure compliance. Susan Dubon works at the LDOE and offered to assist with facilitating the process.
- Legislation | 2026 Regular Session: Act 533: The Bureau of Family Health facilitator briefly summarized Act 533 and stated that the sickle cell foundation executive directors must submit documentation to LSCC@La.gov for a healthcare professional on their respective foundation's governance board by Friday, July 31 at noon.
- Report | Data and Surveillance Workgroup: Cheryl Harris reported that the workgroup worked closely with the Bureau of Family Health's Data to Action team on data collection for the sickle cell registry and that they are open to receiving new data requests.
- Report | Medical Services Workgroup: Dr. Dana LeBlanc discussed the ongoing work to develop processes for gene therapy and curative therapies and plans to meet with the Louisiana Primary Care Association to improve education and support for primary care providers. She also announced that there are two clinical trials open for sickle cell disease treatment at Manning Family Children's.
- Report | Patient Navigation Workgroup: Donna Thaxton reported on ongoing issues with referrals for clients' needs, particularly transportation, food, and housing benefits. She shared that the foundations are making progress with the data sharing agreement with health clinics to provide necessary information for clients. Lastly, she highlighted their efforts to develop a transition program for people diagnosed with sickle cell disease now that the Med Alert bracelet program has concluded.
- Report | Education and Advocacy Workgroup: Dr. Majed Jeroudi discussed the fever protocol for treating people with sickle cell disease in emergency rooms. He requested that Commission members review the fever protocol and send him feedback by Friday, August 15, 2026.

VIII) Public Comments – No additional public comments.

IX) Adjournment – The Chair adjourned the meeting at 3:18 pm.

NEXT MEETING: Thursday, October 1 | 2:00 PM | 628 N. Fourth St. Room 118 | Baton Rouge, LA 70802

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.