



State of Louisiana

Louisiana Department of Health Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Date: Wednesday, October 8, 2025 **Time:** 1:30 pm – 3:00 pm

Location: State Library of Louisiana 701 North 4th Street, Baton Rouge, La 70802

Zoom: ldhophbfhgenetics.zoom.us/j/96740616054

Webinar ID: 967 4061 6054

MEETING MINUTES

- I. **Call to Order** – LSCC Chair, Donna Thaxton called the meeting to order at 1:35 pm.
- II. **Roll Call – No quorum present. (*virtual)**
 - a. Present: Cummings, DeJean, Hardison, Harris*, LeBlanc, Spain* & Thaxton.
 - b. Absent: Barrow, Fulbright, Jeroudi, Martin, Phelps, & Robertson.
- III. **Approval of Minutes** – No vote on the July meeting minutes due to no quorum.
- IV. **Mandate Review & Membership Updates** – BFH facilitator reviewed R.S. 40:1125.1 (see agenda).
 - a. 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. Members were informed of the application process and requirements established by the Governor's office.
 - b. Expiring Appointments: BFH facilitator shared a list of current members' appointments that are expiring in 2026. Members were informed of the reappointment process and that Jasmine Thomas, BFH Boards, Commissions, & Councils Strategy and Operations Lead, will contact them to obtain a resume and short bio.
- V. **Old Business**
 - a. Status Report | SCD Registry: Rebecca Majdoch & Ashlyn Pinkins provided the following update on the Sickle Cell Disease Registry. The Notice of Intent for the Louisiana Sickle Cell Registry rule will be published in the October 2025 edition of the Louisiana Register and open for public comment. The final rule is issued 90 days following the Notice of Intent or longer if revisions are required due to the time of public comment. In October 2025, the Office of Public Health team developing the Louisiana Sickle Cell Disease Registry continued to receive daily data feeds from the Louisiana Hospital Association (LHA) on patient admissions, discharges, and transfers (ADT) to Louisiana hospitals and emergency departments. As of September 17, 2025, the daily feed will include anyone who has sickle cell illness in his or her data. Based on the data feed assessment, the Bureau of Family Health is creating a data brief to document the use cases for the ADT data, as well as recommendations for links and analyses once enough data is received to conduct valid studies. The Bureau of Family Health continued work on the data dictionary to define variables across data sources, which will allow for data linkages in the future as more data sets are

connected to the registry. The Louisiana Sickle Cell Disease Registry will publish the data brief that outlines the methodology used to assess and prepare the newborn screening data for the data visualization upon review and approval. This brief documents how to identify missing data and how to use data linkage to fill in missing variables with reliability.

- b. Status Report | 2025 SCD Symposium: DeJean announced that planning is underway for the SCD Symposium on Friday, November 7 and Saturday, November 8 in Region 1. The workgroup will share a finalized budget with members via email. They are planning 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.
- c. Status Report | Transcranial Doppler Landscape Assessment: Michelle Duplantier, CSHS Statewide Social Work Consultant, shared that the team is currently working through suggested revisions to the survey from the BFH Communications team.
- d. Status Report | SCD Training for School Nurses: DeJean stated that the Tulane University, School of Performance Advancement, donated their services in-kind to the LSCC. They are still searching for a learning management system that is publicly accessible to host the training for nurses to easily access.
- e. Legislative Update | House Bill 883: State legislator and LSCC member, Representative Tammy Phelps, authored this bill in 2024. It mandates the Louisiana Department of Health to “facilitate an agreement between sickle cell clinics as provided for in R.S. 40:1125.31 et seq, and an association (foundation) that is part of the Louisiana Sickle Cell Commission that provides information and assistance to individuals diagnosed with sickle cell disease. The data sharing agreement template was shared with the LSCC and the hospitals in the Louisiana Hospital Association network in January 2025. After a brief discussion, DeJean and Thaxton stated they would send an email to the BFH director to request Newborn Screening data be shared with the sickle cell disease foundations associated with the LSCC.

VI. New Business

2026 Meeting Schedule: Members were asked to complete a brief Meeting Availability Survey by close of business on Friday, November 14. The meeting schedule will be shared once dates are finalized.

VII. Public Comments

Genetix Biotherapeutics, (formerly bluebird bio, Inc.) account executive, Tyler Craddock, announced that the Centers for Medicare and Medicaid Innovation Reimbursement Model, specifically the Cell and Gene Therapy Access Model, can now assist individuals diagnosed with sickle cell disease with travel and lodging when participating in gene therapy treatment program. He also asked SCD foundations to encourage their clients to participate.

VIII. Adjournment – The meeting adjourned at 2:57 pm.

Next Meeting: TBD | 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 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.