



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION
Meeting Minutes

Tues, August 13, 2024 | 2:00 pm | Benson Tower, Room 1801-B, 1450 Poydras St. New Orleans, La

COMMISSIONER ATTENDANCE **via Zoom*

Present: DeJean, Fulbright, Hardison, Harris, Jeroudi*, Phelps, Spain, Thaxton, & Warrier*.

Absent: Barrow, Hebert-Magee, & Robertson.

CALL TO ORDER

The meeting was called to order at 2:02 pm.

ROLL CALL

Fulbright took attendance and announced that a quorum was not present.

REPORT: DATA & SURVEILLANCE

Skylar Cooper Database- Rebecca Majdoch, BFH Data to Action (DAT) Team Lead, updated everyone on the status of the development of the SCD registry.

What's Been Accomplished to Date?

- Multidisciplinary Steering Committee and LDH Internal Guidance Team convened – October 2022 through February 2023
 - Created preliminary criteria for the data to be included in the registry
 - Identified potential uses of the data
 - Determined data sharing needs
 - Determined availability and scope of existing data sources
 - Identified additional data sources necessary to meet preliminary purpose of the registry
- Outreach to providers on the development of guidelines and standard operating procedures for obtaining data – January 2023 through September 2023
 - LDH Guidance Team convened
 - Development of partnership between BFH & Bureau of Health Informatics

What's in Progress?

- Create standards ensuring registry complies with HIPAA – ECD- Sept 2024
- Negotiating MOU between LDH bureaus outlining allowable uses
- Draft language for rulemaking process –anticipating NOI publication in Fall 2024
- Data Sharing Agreements from HB 883 are contingent on rule promulgation
- Develop the SCD Registry Infrastructure – August 2024 through December 2024
- Clean existing data sets to comply with standards
- Hire SCD Registry Epidemiologist – recruitment beginning August 2024

Name: Louisiana Sickle Cell Commission Meeting

Date: Tuesday, August 13, 2024

Page: 2

Upcoming Next Steps

- Anticipate publishing the Notice of Intent for the SCD Registry Rule in October 2024
- Develop SCD Registry Technical Manual with policies and procedures
- Complete clean-up of data by November 2024
- Begin connecting data sources to the OPH Data Warehouse, establishing linkages, and automating processes – ongoing
- Hire and onboard SCD Epidemiologist by November 2024
- Develop job description and selection criteria to implement a Multi-Disciplinary SCD
- Registry Guidance Team – October – December 2024

REPORT: MEDICAL SERVICE & DELIVERY

Medicaid Updates- Dr. Hebert-Magee was not present, but provided a written report (attached) for members to review. Tyler Craddock, Bluebird Bio representative, announced that hospitals are permitted to administer gene therapy to Medicaid patients.

REPORT: PATIENT NAVIGATION

Medical ID Bracelet Pilot Project Update- Pauline Clark, a representative from the Northeast Louisiana Sickle Cell Anemia Foundation, briefly updated everyone on the current success of this initiative launched on April 1, 2024. She mentioned that clients in the region are very enthusiastic and physicians are also very supportive of the project.

REPORT: DATA & SURVEILLANCE

Skylar-Cooper Database- Rebecca Majdoch, BFH Data to Action (DAT) Team Lead, updated everyone on the status of the development of the SCD registry.

REPORT: EDUCATION & ADVOCACY

Symposium & Education Meeting- Fulbright announced that the LSCC is hosting a Sickle Cell Symposium: State of the Union on September 19 in Lafayette, LA. It is a full day event with a small roundtable conversation for speakers & commission members on September 20.

SCD Legislation Update- Ayesha Umrigar, BFH Legislative Coordinator, shared a presentation recapping the 2024 Regular Session Sickle Cell Legislation and BFH Legislative Implementation Tasks (attached).

OTHER BUSINESS & ANNOUNCEMENTS

Membership Applications- Current applications are being reviewed by the Governor soon. The chair will be notified as soon as a decision is made.

ADJOURNMENT

The meeting adjourned at approximately 3:36 pm.

Next Meeting | Tuesday, November 12 at 2:00 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.