



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION
Meeting Minutes

Tuesday, May 14, 2024 | 2:00 pm | 5340 Jewella Ave. Shreveport, La 71109

COMMISSIONER ATTENDANCE **via Zoom*

Present: DeJean, Fulbright, Hardison, Harris*, Henry*, Jeroudi, Spain, Thaxton, and Warrier*.

Absent: Barrow, Campbell, Hebert-Magee, Phelps, and Robertson.

CALL TO ORDER

Erin Fulbright called the meeting to order at 2:02 pm.

ROLL CALL

Erin Fulbright called the roll, and a quorum was not present.

REPORT: DATA & SURVEILLANCE

Skylar Cooper Database- BFH Director, Amy Zapata, shared updates on the current status of the legislative mandate to establish a sickle cell disease registry. She gave a detailed presentation describing elements of a public health surveillance system as well as a recap of previous reports about the registry. Zapata shared a tentative timeline for developing the registry (below)

- **Summer 2024-** Hire SCD Registry Epidemiologist; Establish data sharing/use agreements
- **Fall/Winter 2024-** Establish data linkage algorithms; Build registry infrastructure; Reestablish internal and external advisory bodies; Publish preliminary progress report
- **Winter/Spring 2025-** Prepare data for linkage; Develop data analysis plan; Test the registry
- **Summer 2025-** Launch the public-facing SCD Registry with baseline data about the population
- **Ongoing-** Assess for rulemaking needs and promulgate rules as identified
- **Future-** Analyze data in the registry to assess how the population is doing

The primary contact person for the registry, OPH-BFH Data to Action Team Lead, Rebecca Majdoch will attend future meetings to continue providing status updates.

REPORT: PATIENT NAVIGATION

Sickle Cell Follow-up Monitor Update- Cheryl Harris shared a presentation about sickle cell trait and the current efforts being made to improve awareness. SC trait follow up was recommended by the BFH SCD Registry Steering Committee in spring 2023 and implemented in August 2023. The process is as follows: 1) Trait results reported from labs to NBS Follow up and automatically uploaded into ETO; 2) Letters informing parents of status and local foundations are batched weekly and mailed to parents of children with trait; 3) Follow up coordinator contacts parents 2 weeks after mailing to discuss trait implications; and 4) Result of encounter or no contact is recorded in ETO. As of March 2024, 1,126 cases have been reported. The coordinator sent letters/called all parents/guardians, and spoke with 586 parents/guardians.

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REPORT: EDUCATION & ADVOCACY

Webinar Series, Symposium & Education Meeting- Fulbright announced that the Sickle Cell Disease State Pathology Webinar is scheduled on Wednesday, May 15, 2024, at 5:30 pm. The webinar is a one-hour webinar tailored for healthcare providers to elevate the understanding of sickle cell disease (SCD) and enhance their ability to support patients living with SCD. Another webinar for patients will take place on June 20. She also asked for members interested in planning a symposium scheduled in October to email suggestions/recommendations to her.

SCD Legislation Update- Zapata informed everyone about legislation related to the LSCC being reviewed during the current regular legislative session. A resolution was shared with Senator Barrow. This study resolution will request the Louisiana Department of Health to conduct a comprehensive review of all current Louisiana legislation pertaining to sickle cell disease to evaluate if the legislation aligns with current conditions and meets the demands of service delivery and systems of care in Louisiana.

OTHER BUSINESS

SCD Provider (Absolute Care) Discussion- DeJean informed everyone about Absolute Care, a primary care medical home in New Orleans, partnering with Louisiana Health Connection serving patients with SCD. He shared that Louisiana Healthcare Connections (LHC) are referring high utilizers to Absolute Care and the treatment patients receive there is underlying the treatment of other hematologists. He also shared that several patients that go to the emergency room for care are being referred to primary care providers instead of hematologists. He inquired if this is happening in other regions and if LHC is the only Medicare provider participating. Amy Zapata stated that she would reach out to the director of LHC/Medicare to get clarity on the matter.

ANNOUNCEMENTS

Fulbright announced that the next Commission meeting is scheduled on Tuesday, August 13, 2024, at 2:00 pm at Benson Tower in New Orleans, Louisiana.

ADJOURNMENT

The meeting adjourned at approximately 3:36 pm.

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.