



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Tuesday, November 12, 2024
2:00 pm – 3:30 pm

Location

Rapides Parish Health Unit
5604 Coliseum Blvd. Suite A,
Alexandria, La 71303

Meeting Minutes

I. Call to Order

A. The meeting was called to order at 2:00 pm by Chair Erin Fulbright.

II. Roll Call – A quorum was not present.

A. The following members were present:

1. Erin Fulbright (Chair)
2. Ernest DeJean
3. Twarnette Hardison
4. Cheryl Harris (virtual)
5. Majed Jeroudi, MD
6. Rajasekharan Warriar, MD (virtual)

B. **Absent:** Barrow, Hebert-Magee, Phelps, Spain, Thaxton, & Robertson

III. Report: Data & Surveillance

A. Rebecca Majdoch, BFH Data to Action (DAT) Team Lead, and Lee Mendoza, Bureau of Health Informatics Director, presented a dashboard of preliminary data collected from various data sources showing the distribution of sickle cell disease cases across parishes and demographic breakdowns. None of the data sources give a comprehensive picture of service delivery in the state. However, the team plans to link different data sources, including vital records, hospital discharge data, and Medicaid claims data, to create a more comprehensive list of individuals with sickle cell disease in Louisiana.

B. The website for the registry is expected to launch on January 1, 2025. In addition to the registry, infographics displaying the data collected and instructions for submitting a data request will be available.

IV. Transcranial Doppler Access

A. Fulbright facilitated a discussion about the need for SCD patients in the northern/central regions of the state to have more access. The previous contractor was no longer available, and members discussed ways to ensure this service becomes available for patients in these regions. Harris suggested conducting a landscape assessment to identify who provides these services. Dr. Jeroudi, Dr. Warrior, and Michelle Duplantier will assist with completing the assessment and determining training needs. The group will present the findings at the first LSCC meeting in 2025.

V. Legislative Updates

A. **HR 275 | SCD Resolution** – Harris shared that all the SCD-related legislation has been collected, and a report is being drafted. The team overseeing this project will contact commission members and other stakeholders soon to obtain feedback and recommendations. The final report will be available to the public.

B. **HB 883 & HB 363 | Develop Training for School Nurses** – Majdoch shared that the Data to Action team is collaborating with LDH Legal to develop a data-sharing agreement template that providers and CBOs can use. After reviewing the template to ensure it complies with all HIPAA regulations, it will be available on the LDH website. The SCD foundations and clinics currently under contract will also receive an email with instructions once the template is finalized.

1. Goldsmith stated that HB 883 and HB 363 require the LSCC to develop SCD training/instructional materials for school nurses. HB 363 mandates that the training materials must be provided to the Louisiana Department of Education. HB 883 says materials must be available on the Louisiana State Board of Nursing's website.

2. After a brief discussion, Fulbright stated that the commission would review two training presentations, one currently used for school nurses in Rapides parish and the other developed by Tulane, and meet with Representative Phelps, the author of the bill, to confirm both satisfy the mandate of both bills.

VI. Membership Updates

A. The Governor's Office of Boards & Commissions has selected two candidates to join the Commission (a representative from Children's Hospital & an individual diagnosed with SCD). Both candidates are currently in the final stages of being appointed. There are 3 three remaining vacancies. The Chair emphasized the importance of having members present at meetings to push the agenda forward and encouraged members to continue recruiting efforts.

VII. Other Announcements

- A. Elections for the 2025-26 LSCC Chair and Co-Chair will occur at the first meeting next year. Interested members should submit nominations to the Chair or email LSCC@LA.GOV to nominate a fellow commissioner.
- B. Dr. Warrior announced his retirement and will be stepping down from the Commission.

VIII. Public Comments

- A. Karen Gant, representing Emmaus Life Sciences- Shared link with group. Please visit EndariRx.com or EmmausMedical.com for more information on Endari, a medication for the acute complications of Sickle Cell Disease in adults and children ages 5 years and older. Shared statement of support on behalf of Emmaus Life Sciences. Steve Frankowitz & Patrick Price also shared support for SCD advocates. Medication has been FDA approved.

IX. Adjournment

- A. The meeting was adjourned at 3:40 PM.

Next Meeting | TBA

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