



State of Louisiana

Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION MEETING MINUTES

Date: August 8, 2023	Zoom
Time: 2:00 pm – 3:30 pm	Link: zoom.us/j/97729233858
Location: Bienville Building 628 N. 4th St. Room 118 Baton Rouge, La 70802	Meeting ID: 97729233858 Access Code: 532143 Phone: 669-444-9171

ATTENDANCE CHART		P PRESENT; A ABSENT; V VIRTUAL			
Hon. Regina Barrow LA SENATE	A	Twarnette (Shay) Hardison SICKLE CELL ANEMIA RESEARCH FOUNDATION	P	Shannon Robertson, RN, BSN LA PRIMARY CARE ASSOC.	P
Shaleathia Campbell PARENT OF A PERSON W/SCD	A	Cheryl Harris, MPH DESIGNEE OF DEPT. OF HEALTH SECRETARY	P	Rosalind Spain SICKLE CELL DISEASE ASSOC., NW LA CHAPTER	P
Ernest DeJean, MSW TULANE UNIV, SCHOOL OF MEDICINE	P	Chantel Hebert-Magee, M.D. MPH DESIGNEE OF MEDICAID DIRECTOR	P	Donna Thaxton SICKLE CELL ANEMIA FOUNDATION, NE LA	P
Erin Fulbright SICKLE CELL ASSOC. OF SOUTH LA	P	Majed Jeroudi, M.D. OCHSNER LSU HEALTH SHREVEPORT	A	Rajasekharan Warriar, M.D. OCHSNER HEALTH CENTER FOR CHILDREN	A
Renee Gardner, M.D. CHILDREN'S HOSPITAL OF NEW ORLEANS	P	Hon. Tammy Phelps LA HOUSE OF REPRESENTATIVES	V	Quorum Present?	Y

CALL TO ORDER

Fulbright called the meeting to order at 2:10 pm. A quorum was present.

ROLL CALL & INTRODUCTIONS

Fulbright took attendance and introduced new members, DeJean & Hebert-Magee.

REVIEW & APPROVAL OF PREVIOUS MEETING MINUTES

The previous meeting minutes were approved unanimously.

LSCC COMMISSIONER VACANCIES

It was announced that the representative for the SW La Sickle Cell Anemia had resigned. Vacancy announcements have been shared with the public for a replacement in addition to the two vacant seats representing individuals living with sickle cell disease.

2024 MEETING SCHEDULE

The 2024 meeting schedule was announced. Additional details will be shared as they become available. The dates & locations are January 9 at 2:00 pm in Alexandria; April 9 at 2:00 pm in Baton Rouge; July 16 at 2:00 pm in Monroe; and October 8 at 2:00 pm in New Orleans.

REPORT: DATA & SURVEILLANCE

ETO- ETO is the data management system that will be used by the foundations for case management. More information regarding ETO will be presented at the upcoming Sickle Cell Foundation Quarterly Meeting.

Update on the CDC Funding Opportunity- The Sickle Cell Data Collection (SCDC) Program is a grant funded by the CDC for five years to inform decisions and policies that may lead to significant improvements in the sickle cell disease (SCD) community. Recipients will be announced on August 31.

Update on the Skyler Cooper Database- A work plan based on the action items listed in the Sickle Cell Steering Committee Report is currently in development. Additional research is being conducted to see how other agencies developed similar registries & surveillance systems.

REPORT: MEDICAL SERVICE/DELIVERY

There was a discussion about data reports and care gaps identified in the LDH Business Plan that could possibly be addressed through Medicaid. A report will be disseminated when the data is verified.

Bluebird Gene Therapy Presentation- Tyler Craddock, an account executive, from Bluebird Gene Therapy gave a brief presentation explaining some of the work his team does in Louisiana, and that they are looking for opportunities to collaborate with the Commission.

REPORT: PATIENT NAVIGATION

Sickle Cell Follow-up Monitor- A follow-up monitor has been hired by the Genetic Diseases program to report sickle cell results from Newborn Screening Program. As a new initiative, the monitor will also contact parents of children with sickle cell trait to ensure that they are aware of their trait status.

REPORT: EDUCATION & ADVOCACY

Emergency Provider Toolkit- the Sickle Cell Disease Pain Management Toolkit for Emergency Providers is available to the public on the LDH Sickle Cell Disease website.

SCD Awareness/Education Campaign- the BFH Communications team is launching an awareness campaign for Sickle Cell Awareness month in September.

SCD Webinars- A second webinar is in development and more details will be announced soon.

ADJOURN

The meeting was adjourned at 3:53 pm.