



State of Louisiana

Louisiana Department of Health
Office of Public Health

Louisiana Sickle Cell Commission Meeting Minutes

November 7, 2023 | 2:00pm | Bienville Building | View Zoom Recording

Attendance Chart		P Present; A Absent; V Virtual			
Regina Barrow	A	Twarnette Hardison	P	Tammy Phelps	P
Shaleathia Campbell	A	Cheryl Harris	P	Shannon Robertson	P
Ernest DeJean	V	Shantel Hebert-Magee	V	Rosalind Spain	P
Erin Fulbright	P	Alvin Henry Jr.	P	Donna Thaxton	P
Renee Gardner	P	Majed Jeroudi	V	Rajasekharan Warriier	A

I. Call to Order

Erin Fulbright, commission chair, called the meeting to order at 2:07 pm and took attendance. Fulbright announced that a quorum was not present and also welcomed Alvin Henry to the commission.

II. Current Vacancies

There are currently 2 vacant seats: a representative from Southwest Louisiana Sickle Cell Anemia, Inc., and one for an individual diagnosed with sickle cell disease. Both are under review and will be filled as soon as possible.

III. Report: Data & Surveillance

a. Sickle Cell Data Collection (SCDC) Funding Opportunity (Update)

The Sickle Cell Data Collection (SCDC) Program grant provides funding for states to gather vital health information about people living with sickle cell disease (SCD). The goal is to study long-term trends in diagnosis, treatment, and healthcare access. No notification was received when recipients were announced on August 31.

b. Skylar-Cooper Database (Update)

Developed an implementation proposal, instead of a work plan, based on action items in the Steering Committee's report and data presented at the SCDC Summit in September. The basic functions of the ETO platform will be expanded to for the initial phase of implementation to identify all individuals in the state diagnosed with SCD.

IV. Report: Medical Service/Delivery

a. Telehealth Access [Nola.com Article](#)

Fulbright summarized the article and mentioned that she invited the chair of the Louisiana Health Disparities in Rural Areas task force to discuss the work highlighted in the article at the next LSCC meeting.

b. Adult Care

There was discussion among members about CBOs getting better access to patient data, how to ensure the shared data is within the guidelines of HIPPA regulations, and identify barriers to patients receiving care. It was suggested that members submit a formal request to the department asking for access to data for adult SCD patients.

c. Medicaid Updates

Dr. Hebert-Magee stated that the department has participated in a consortium with several other states and they recognize these states have higher percentages of individuals with sickle cell disease. These states wrote a paper that will be published and made public in hopes of covering new treatments for individuals with SCD.

V. Report: Patient Navigation**a. Update on Sickle Cell Follow-Up Monitor**

Harris reported that follow-up program monitor has been hired by the Genetic Diseases program to report sickle cell results from Newborn Screening Program. The program monitor will also contact parents of children with sickle cell disease as well as parents of infants with sickle cell trait to ensure that they are aware of the infant's trait status. Data will be provided at the next meeting.

VI. Report: Education & Advocacy**a. Care Coordination [Toolkit](#)**

Fulbright announced that a care coordination toolkit is being developed for individuals with sickle cell disease and members were contacted to provide feedback.

b. Developing a Webinar Series & Symposium

Fulbright asked for volunteers to join a newly formed committee to organize a webinar series and symposium for next year.

c. Proposed Revisions to Sickle Cell Laws

There were revisions submitted to update the language in the laws pertaining to SCD. These changes include updating the language and active foundations. Members were informed that they are permitted to review the current laws and submit any changes to the department, Representative Phelps, or Senator Barrow.

VII. Other Business**a. Proposed LSCC By-Laws**

Fulbright asked members to review the proposed by-laws and submit feedback before the next meeting.

VIII. Announcements**a. Upcoming Retirements**

Fulbright announced that Dr. Renee Gardner and Dr. Majed Jeroudi are retiring this year. She thanked them both for their service & commitment.

IX. Public Comments

Members provided clarification on what type of follow up information that CBOs would like to receive from emergency providers when individuals diagnosed with SCD are discharged to ensure services are not being duplicated.

X. Adjourn

The meeting was adjourned at 3:37 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.

DRAFT