Jeff Landry
GOVERNOR

Bruce D. Greenstein
SECRETARY

State of Louisiana

Louisiana Department of Health

Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Date: Thursday, April 2, 2026
Time: 02:00 PM – 03:30 PM
Zoom: ldhophbfhgenetics.zoom.us/j/94922414794
Location: 628 North 4th Street, Room 173
Baton Rouge, LA 70802

MEETING MINUTES

I) Call to Order – Donna Thaxton called the meeting to order at 2:04 pm.

II) Roll Call & Introductions – A quorum was established.

- **Members Present:** Jacqueline Cummings; Ernest DeJean; Twarnette Hardison; Cheryl Harris (virtual); Dr. Majed Jeroudi; Dr. Dana LeBlanc; Representative Tammy Phelps; Aaron Ruffin (proxy for Erin Coleman – Sickle Cell Association of South Louisiana); Lucretia Stewart (proxy for Shannon Robertson – Louisiana Primary Care Association); & Donna Thaxton.
- **Members Absent:** Senator Regina Barrow, Simone Martin, & Rosalind Spain.

III) Approval of Minutes – February 5, 2026

- Dr. Jeroudi motioned to approve the minutes as written, Twarnette Hardison seconded, and the motion passed unanimously with no abstentions.

IV) Mandate Review & Announcements

- The Bureau of Family Health facilitator reviewed the Commission's mandate (agenda attachment). Vacancy Announcements – The following positions are currently vacant: one parent of a person diagnosed with sickle cell disease; one person diagnosed with sickle cell disease; and one representative from Southwest Louisiana Sickle Cell Anemia, Inc. The facilitator asked members to share these vacancies within their networks and to have interested candidates email LSCC@LA.Gov. He also informed members of the application process and requirements established by the Governor's office.
- The Statewide Sickle Cell Disease Symposium is scheduled to take place on May 15 & 16 at the New Orleans Marriott Metairie at Lakeway in Metairie, LA. Registration is required for all attendees.
- Representative Tammy Phelps discussed House Bill 193. The proposed legislation seeks to amend R.S. 40:1125.1 to revise the membership of the Louisiana Sickle Cell Commission by naming executive directors of designated Louisiana sickle cell disease organizations as members of the Commission.

V) Old Business

- **Report | Sickle Cell Disease Registry:** Rebecca Majdoch shared the link to the job announcement for the Sickle Cell Disease Epidemiologist position, and that a candidate has been hired for the Quality Improvement and Data Registry Manager position. Her team is continuing to sanitize the admissions transfer/discharge data.

- **Report | Sickle Cell Disease Symposium:** Ernest DeJean informed members that registration is open and shared the link. The event will take place on May 15 -16 in Metairie, Louisiana. He shared a tentative agenda and encouraged members to participate. Cheryl Harris stated she would submit a request to the Bureau of Family Health Communications Team to develop and a flyer and registration link on all Office of Family Health/Bureau of Family Health platforms. Ernest DeJean stated that vendors seeking to sponsor the event should contact him or the Chair directly.

  Members also discussed creating a new Louisiana Sickle Cell Commission logo for the event, sponsorship requirements, and receiving support from Bureau of Family Health. These discussions will be shared with the Bureau of Family Health senior management team and additional updates will be shared at a future meeting.

VI) Workgroup Reports

- **Report | Data and Surveillance:** Cheryl Harris informed members of recent updates to the case management software for the sickle cell disease foundations. The foundations were asked to continue using the system to ensure accurate data is used for quarterly reports.
- **Report | Medical Services:** Dr. Dana LeBlanc shared that the workgroup will discuss patient access to care and developing a workflow to share with clinics statewide. Ernest DeJean added that the group is also contacting medical providers to participate in the ongoing transcranial Doppler landscape assessment. They have requested providers complete survey and will share the results at a future meeting.
- **Report | Patient Navigation:** Report attached.
- **Report | Education and Advocacy:** Report attached.

VII) New Business – No new business was raised.

VIII) Public Comments – No public comments.

IX) Adjournment – A quorum was no longer present and the meeting was adjourned at 3:42 p.m.

NEXT MEETING: Thursday, June 4, 2026 at 2:00 PM
Bienville Building | 628 North 4th St., Room 118 | Baton Rouge, LA 70802

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 LSCC@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 LSCC@LA.GOV and must be received at least 24 hours prior to the meeting to be included in the record for the meeting.

Report | Patient Navigation Workgroup

Suggested workgroup recommendation to leverage existing infrastructure comprehensive support:
Develop a coordinated statewide referral with:

- Medical home establishment and hematology care connecting
- Insurance/medication access support
- Social needs screening (transportation, food, housing, benefits)
  *Foundation is conducting a needs assessment at the time of intake and as needs arise for those patients known by the foundations. Medical providers seldom make referrals to the foundation for patient needs. Training is needed in this area. Foundation is not equipped with man-hours to adequately address this area.
- Transition support (pediatric to adult care)
  *Some areas of the state have formal transition programs while other areas are severely lacking. All areas of the state need transition support.
- Shared contacts and follow-up protocols across clinics, foundations, Medicaid MCOs.
  *The HIPAA Business Associate Agreement has been signed by Health Units and Foundations in regions 6 and 8. It is unclear if other regions are using this document for hospital-based clinics or some other agreement that is in place. Barriers continue to exist, as clinic staff do not have a clear understanding of their role as it relates to making referrals and the sharing of information. Continued efforts are being made to address this issue.
- Medic Alert ID Bracelets: This pilot program was established at NELASCAF to help clients diagnosed with sickle cell navigate through the ER more effectively. This program was well accepted by patients and the medical professionals. Success has been noted; a patient reported she had the best experience ever after having used the bracelet. However, overall, more usage of bracelets is desired. Due to the known success of the medic alert bracelet, the program continues with a smaller sample size to assess and address areas of need improvement. Other outcome measures are being requested from Medic Alert pertaining to the adult pilot program.
- Nutritional Program: The foundation addresses the nutritional needs of clients in various ways. This includes educational information and monetary support as well.

Barriers:
State contract agreements with foundations cover many of these items to a certain extent. However, the foundations alone have limited staff, resources and funds, to adequately address the needs of patients diagnosed with sickle cell. This is evident by the many documented disparities and gaps in services across the state. The efforts of the workgroup performed as part of the Commission are paramount in addressing this need from a holistic standpoint.

Report | Education and Advocacy Workgroup

1. **Main Focus**
   - Improve access to care for patients with sickle cell disease
   - Develop and implement a standardized fever protocol aligned with national guidelines

2. **Fever Protocol (Sickle Cell)**
   - Agreement on importance of adopting a standard fever protocol
   - Determine if a similar protocol was previously distributed in Louisiana
   - Obtain prior materials from the state sickle cell commission

3. **Protocol Review & Approval**
   - Protocol to be reviewed by Dr. LeBlanc and Tulane's group
   - Clarify submission process and responsible parties
   - Decision requires discussion with a larger group

4. **Distribution & Implementation**
   - Determine how protocol will be distributed across hospitals and ERs
   - Identify leadership for implementation
   - Plan larger multidisciplinary meeting for rollout strategy

5. **Monitoring & Data Collection**
   - Establish monitoring system for compliance and outcomes
   - Coordinate with state data collection group

6. **Legal & Regulatory Considerations**
   - Ensure no legal barriers or liability concerns
   - Confirm no restrictions on submission or implementation

7. **Strategic Approach**
   - Start with one focused project (fever protocol)
   - Expand to additional initiatives in future

8. **Next Steps**
   - Retrieve prior Louisiana fever protocol
   - Review protocol with Dr. LeBlanc and Tulane's group
   - Clarify submission and approval pathway
   - Engage data team for monitoring framework
   - Plan larger stakeholder meeting
   - Assess legal considerations before rollout

Fever in Pediatric Sickle Cell Disease – Protocol Summary (next page)

Fever in Pediatric Sickle Cell Disease – Protocol Summary

1. **Definition of Fever: include history of fever with antipyretics.**
   - ≥ 38.5 °C (101.3 °F) once, (oral/rectal, Adjust Axillary temperature),
   - OR ≥ 38.0 °C (100.4 °F) on two readings.

2. **Immediate ER Actions**
   - Triage as high priority
   - Full vitals + SpO_2 monitoring
   - IV access
   - Labs: CBC, reticulocyte count, CMP, CRP, blood cultures (before antibiotics), urine culture, Respiratory panel, and COVID. Strep Screen/throat culture if indicated.
   - Do not delay antibiotics for tests or imaging
   - CXR

3. **Empiric Antibiotics (within 60 min of arrival)**
   - Ceftriaxone 50 mg/kg IV (max 2 g)
     - Cefotaxime if < 2 months old
   - Add vancomycin if:
     - Central line present
     - Concern for MRSA
     - Septic/toxic-appearing
   - Add azithromycin if CXR suggests acute chest syndrome, or cough

4. **Admission Criteria -Admit if any of the following:**
   - High-Risk Clinical Features
   - Ill or toxic appearance
   - Hypotension, tachycardia, poor perfusion
   - SpO_2 < 94% on room air
   - Age < 12 months (especially < 6 months)
   - WBC < 5 × 10^9/L or > 30 × 10^9/L or significant increase in WBC
   - Hemoglobin drop ≥ 1 g/dL from baseline
   - Platelets < 120 × 10^9/L
   - Reticulocyte count very low
   - Positive blood culture or rapid bacterial test
   - Incomplete immunization or known poor vaccine response
   - Poor compliance with Pen VK
   - Complications
   - Acute chest syndrome/pneumonia
   - Splenic/hepatic sequestration
   - Meningitis, osteomyelitis, septic arthritis
   - Stroke symptoms or altered mental status
   - Social / Follow-Up Risks
   - Unreliable follow-up or inability to return if worsens

5. **Discharge Criteria (only if all met)**
   - Well-appearing, stable vitals, SpO_2 ≥ 94% RA
   - Reliable caregiver & transportation
   - Access to follow-up within 24 hours
   - Fully immunized + on penicillin prophylaxis
   - Labs reassuring, CXR clear
   - First antibiotic dose given in ER. Follow up daily until no fever and cultures are negative for 48-72 hours.