



State of Louisiana
Louisiana Department of Health
Office of Public Health

LOUISIANA SICKLE CELL COMMISSION

Date: Thursday, June 4, 2026

Zoom: <https://zoom.us/j/99734618657>

Time: 02:00 PM – 03:30 PM

Location: 628 North 4th Street, Room 118
Baton Rouge, LA 70802

The Bureau of Family Health is committed to promoting transparency, accessibility, and public engagement in all board, commission, and council meetings. The link to access the meeting online is provided for convenience for members of the public as a part of that commitment.

AGENDA

- I) Call to Order
- II) Roll Call
- III) Public Comments
- IV) Approval of Minutes – April 2, 2026
- V) Mandate Review & Announcements
 - A. Revised Statute 40:1125.1
 - B. Current Vacancies
 - One parent of a person diagnosed with sickle cell disease
 - One person diagnosed with sickle cell disease
 - One medical professional caring for persons diagnosed with sickle cell disease
 - One representative from Southwest Louisiana Sickle Cell Anemia, Inc.
- VI) Old Business
- VII) New Business
 - A. Southwest Louisiana Sickle Cell Anemia, Inc. & Etta Pete Sickle Cell Anemia Foundation
- VIII) Reports
 - A. Sickle Cell Disease Registry
 - B. Data & Surveillance Workgroup
 - C. Medical Services Workgroup
 - D. Patient Navigation Workgroup
 - E. Education & Advocacy Workgroup
- IX) Public Comments
- X) Adjournment

NEXT MEETING: Thursday, July 30, 2026 at 2:00 PM | **Virtual Meeting.** Will share Zoom details soon.

Note: 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.

REVISED STATUTE 40:1125.1 | LOUISIANA SICKLE CELL COMMISSION

- A) There shall be established within the Louisiana Department of Health a commission designated the "Louisiana Sickle Cell Commission", composed of seventeen members as provided in Subsection B of this Section. No organization, entity, or individual shall be a member unless expressly provided for in Subsection B of this Section.
- B) 1. Thirteen members shall be appointed by the governor, subject to Senate confirmation, as follows:
- a) One member from a list of nominees submitted by the Sickle Cell Center of Southern Louisiana, Tulane University School of Medicine, which has provided health care to patients with sickle cell disease since 1979 and houses the only life span clinic, which provides care to patients from birth to death, and a transition clinic, which provides a seamless transition during the high risk death gap period from pediatric to adult care.
 - b) One member from a list of nominees submitted by Children's Hospital, New Orleans, which is the only hospital in this state to provide stem cell and gene therapies to patients with sickle cell disease and focuses on sickle cell pediatric hematology.
 - c) One member from a list of nominees submitted by the Louisiana Primary Care Association.
 - d) One member from a list of nominees submitted by the Sickle Cell Association of South Louisiana, which has served eleven parishes in south Louisiana since 1974 and has the historical and institutional knowledge of patient care within the community.
 - e) One member from a list of nominees submitted by the Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc., which has served northeast Louisiana since 1979 and has the historical and institutional knowledge of patient care within the community.
 - f) One member from a list of nominees submitted by the Sickle Cell Disease Association of America, Inc., Northwest Louisiana Chapter, which has served northwest Louisiana since 1974 and has the historical and institutional knowledge of patient care within the community.
 - g) One member from a list of nominees submitted by the Sickle Cell Anemia Research Foundation, Alexandria, which has served twelve parishes in central Louisiana since 1974 and has the historical and institutional knowledge of patient care within the community.
 - h) One member from a list of nominees submitted by Southwest Louisiana Sickle Cell Anemia, Inc., which has served southwest Louisiana and has the historical and institutional knowledge of patient care within the community.
 - i) Five members from a list of nominees submitted by the Louisiana Department of Health, two of whom shall be persons diagnosed with sickle cell disease, one of whom shall be a parent of a person diagnosed with sickle cell disease, and two of whom shall be medical professionals who provide treatment and care to patients diagnosed with sickle cell disease.
2. Two of the members shall be as follows:
- a) The secretary of the Louisiana Department of Health or his designee.
 - b) The Medicaid director of the Louisiana Department of Health or his designee.
3. Two members shall be appointed as follows:
- a) One member of the Louisiana Senate appointed by the president of the Senate.
 - b) One member of the Louisiana House of Representatives appointed by the speaker of the House of Representatives.

4. Each appointment by the governor shall serve at his pleasure. The legislative members shall serve at the pleasure of the presiding officer of the respective legislative body.
 5. The term of an appointee shall be four years. Any vacancy occurring in board membership shall be filled for the remainder of the unexpired term in the same manner as the original appointment.
 6. Nonlegislative members of the commission shall not be entitled to a per diem or any other compensation for their service but shall be entitled to reimbursement of any necessary and reasonable expense incurred in the performance of their duties on the panel, including travel expenses. Each legislative member of the commission shall receive a per diem and travel expenses equal to the per diem and travel expenses provided by law for members of the legislature.
 7. Meetings of the commission shall be held at the call of the chairman or on a petition of at least five members of the commission.
 8. At the first meeting of the commission, each year after its members assume their positions, the members shall select one of the commission members to serve as chairman and one of the commission members to serve as vice chairman, and each shall serve for a term of one year. The chairman shall preside at meetings of the commission, and in his absence, the vice chairman shall preside.
 9. The commission shall hold at least four regular meetings each year. The commission shall meet at locations that rotate throughout the state, as determined by the chairman, to provide ease of travel for the members of the commission.
 10. The appointment of the initial members of the commission shall take place no later than October 1, 2013, and the commission shall convene its first meeting no later than November 1, 2013.
- C) The Louisiana Department of Health shall provide administrative assistance to and serve as staff for the commission.
- D) The functions of the commission shall be to:
1. Ensure the delivery of sickle cell services to affected persons in all parishes in Louisiana and assist in establishing geographical service delivery boundaries.
 2. Promulgate guidelines for creating uniformity in the delivery of services and the management of statewide programs.
 3. Submit budget recommendations to the legislature and the governor.
 4. Prepare and publish an annual report on sickle cell that includes:
 - a) An assessment of the programs and activities aimed at sickle cell.
 - b) A description of the level of coordination existing between the state and private stakeholders in the management and treatment of sickle cell.
 - c) The development of a detailed action plan for battling sickle cell.
 5. Direct the Sickle Cell Patient Navigator Program established by the provisions of R.S. 40:1125.21.
 6. Apply for grants and donations from any public or private source to implement the provisions of this Subsection.