

# Louisiana Sickle Cell Commission

*2024 Annual Legislative Report*

*Prepared by:*

**Bureau of Family Health**

*Office of Public Health*

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**Submitted to:**

Jeff Landry, Governor, State of Louisiana

Health and Welfare Committee, Louisiana Senate

Health and Welfare Committee, Louisiana House of Representatives

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This report was compiled and written by the Louisiana Department of Health, Office of Public Health, Bureau of Family Health staff responsible for supporting the Louisiana Sickle Cell Commission. Amy Zapata, MPH, serves as the director of the Bureau of Family Health. Key Bureau of Family Health contributors include Children's Special Healthcare Services Program Manager Cheryl Harris and Genetic Diseases Strategy Manager Rodney Goldsmith.

We recognize the members of the Louisiana Sickle Cell Commission and the team at the Bureau of Family Health whose dedication and hard work made this report possible, including the clinical systems team program manager and the communication staff who edited and designed the report.

Lastly, we honor the people living with sickle cell disease represented in this report. It is our sincere hope that the activities of the Louisiana Sickle Cell Commission will make progress in addressing the needs of the sickle cell community and working toward a more informed and supportive environment for all those impacted by sickle cell disease in Louisiana.

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## Introduction

The Louisiana Department of Health, Office of Public Health, Bureau of Family Health is responsible for supporting the Louisiana Sickle Cell Commission in its mission to improve clinical care and the systems of support for individuals living with sickle cell disease. The Bureau's broader mission is to promote the health of Louisiana families throughout their lifetime through programs and initiatives that support pregnant women, babies, children, teens, adults and youth with special health care needs.

Our vision is for Louisiana to be a state where all people are valued and can reach their full potential, from birth through the next generation. Our mission is to elevate the strengths and voices of individuals, families and communities to catalyze transformational change to improve population health and achieve equity. The Louisiana Sickle Cell Commission and this report reflect the Bureau of Family Health's efforts to advance health outcomes for women, children, families and individuals with special health care needs.

In accordance with its authorizing statute ([Louisiana R.S. 40:1125](#)), the Louisiana Sickle Cell Commission exists to:

- Ensure the delivery of sickle cell services to affected persons in all parishes in Louisiana and assist in establishing geographical service delivery boundaries.
- Promulgate guidelines for creating uniformity in the delivery of services and the management of statewide programs.
- Prepare an annual report that includes information on programs, activities and the coordination of services relative to sickle cell disease and an action plan to address sickle cell disease.
- Direct the Sickle Cell Patient Navigator Program established by [R.S. 40:1125.21](#).

The Commission is comprised of 17 members representing clinical care systems, supportive services, advocates, and individuals with lived experience (see Appendix A for a list of Commission members).

This report reflects the accomplishments and activities of the Louisiana Sickle Cell Commission during State Fiscal Year (SFY) 2024 (July 1, 2023, to June 30, 2024).

## Sickle Cell Disease in Louisiana

Sickle cell disease, also known as sickle cell anemia, is a collection of genetic illnesses that affect hemoglobin, the primary protein that transports oxygen in red blood cells. Normally, red blood cells are disc-shaped and flexible, allowing them to travel freely through blood channels. Red blood cells in sickle cell disease are misshaped, often crescent or sickle-shaped, because of a gene mutation affecting the hemoglobin molecule. When red blood cells sickle, they become stiff and difficult to move, preventing blood flow to the rest of the body.<sup>1</sup> This can cause pain and other serious complications such as infection, acute chest syndrome and stroke.<sup>2</sup> Sickle cell disease occurs when a person inherits two sickle cell genes, leading to abnormal red blood cells. Individuals living with the sickle cell trait inherit one sickle cell gene and one normal gene, usually resulting in no symptoms and a generally healthy life.<sup>3</sup>

Approximately 80 infants are born each year in Louisiana with sickle cell disease. Louisiana Medicaid provides health care coverage to approximately 3,000 individuals living with the condition annually. The number of

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<sup>1</sup> (What is Sickle Cell Disease?, 2024)

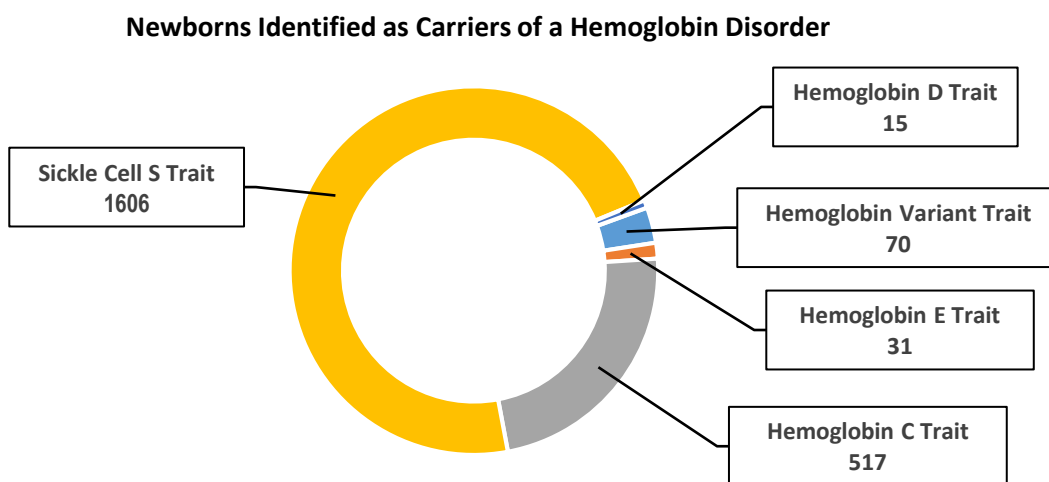
<sup>2</sup> (About Sickle Cell Disease, 2024)

<sup>3</sup> (What Is Sickle Cell Trait?, 2024)

individuals living with sickle cell disease in Louisiana is currently unknown, as the state—like most others—has not implemented a comprehensive population-level public health monitoring system for sickle cell disease. However, in 2022, the Louisiana Legislature created the legal authorities to establish the Louisiana Sickle Cell Disease Registry (also known as the “Skylar-Cooper Database”). This system is now in development. Over the next year, Louisiana will make its first summary data collection available to the public. Over time, this system will be able to produce comprehensive population estimates and illustrate long-term trends in diagnosis, treatment and health care access. This data is integral to informing state policy, resource allocation and efforts to improve the quality and accessibility of care for individuals living with sickle cell disease and their families.

## Sickle Cell Disease Programs and Activities

The Bureau of Family Health administers the state’s newborn heel stick screening program and is responsible for ensuring access to sickle cell genetic evaluation and counseling for Louisiana residents. In SFY 2024, the newborn screening program identified 79 newborns born with a hemoglobin disorder; 54 were diagnosed with the most severe variant, Hemoglobin S. Additionally, 2,239 newborns were identified as carriers of a hemoglobin disorder and 1,606 were diagnosed with sickle cell S trait. The program also reported that 98.7%\* of infants born in Louisiana were screened for sickle cell disease, with 100% of infants receiving a positive screen being linked to follow-up care by a hematologist.



The Office of Public Health’s Bureau of Family Health Genetic Diseases Program oversees sickle cell clinics through its parish health units in Alexandria and Monroe. These clinics provide access to hematologists and other specialist providers for individuals with sickle cell disease living in parts of the state that otherwise might not have local access. The program also contracts with sickle cell clinics in New Orleans, Lake Charles, Shreveport, Alexandria and Monroe and works closely with the sickle cell clinics in Baton Rouge, Lafayette and New Orleans to ensure access to care throughout the state.

In addition to the Bureau of Family Health’s work with clinical systems, the Bureau also provides support to sickle cell foundations statewide. Sickle cell foundations are community-based organizations that assist individuals living with sickle cell disease and their families. The Bureau of Family Health provides funding for five sickle cell

\* Please note that a small number of families declined the screening test.

foundations, which are located in Baton Rouge, Lake Charles, Alexandria, Shreveport and Monroe. Sickle cell foundations have programs that link individuals and families affected by sickle cell disease with medical and non-medical resources needed to manage this complex disease. The foundations also help to ensure all infants diagnosed with sickle cell disease through the newborn screening program are linked to appropriate care upon diagnosis. In SFY 2023, the Bureau of Family Health's contracts with the sickle cell foundations aligned the foundations' activities and reporting with the key functions outlined in Act 387 of the 2015 Regular Session of the Louisiana Legislature that outlined the parameters for patient navigation services for individuals with sickle cell disease. This alignment aims to improve coordination among foundations, insurers and health care delivery systems.

To improve access to sickle cell services, the Healthy Louisiana Medicaid managed care organizations (MCOs) introduced sickle cell care management programs in 2015 as a concerted effort to integrate sickle cell specialty care into their clinical guidelines for individuals living with sickle cell disease. While the services offered vary between MCOs, all utilize telephonic case management, focusing primarily on members in their networks who experience frequent and unpredictable episodes of pain and other serious health problems.

Despite ongoing efforts of the Bureau of Family Health, sickle cell foundations and the Medicaid MCOs, people living with sickle cell disease continue to experience barriers in accessing and retaining specialized care. In general, children with sickle cell disease can access services more readily. However, significant gaps in service access and care coordination persist for the adult population and those transitioning from pediatric to adult care. Adverse health outcomes related to sickle cell disease can lead to infection, acute chest syndrome and stroke, as indicated by numerous emergency room visits and hospitalizations.

A new activity initiated over the past two years is the foundational work to establish the state's sickle cell registry. In SFY 2023, the Bureau of Family Health worked with the Louisiana Sickle Cell Commission, public health experts and other constituencies to identify the steps needed to establish the registry. The Bureau published two reports from the first year of planning for the registry: [Establishment of a Sickle Cell Registry in Louisiana: Preliminary Research, Findings and Recommendations—February 2023](#) and [Establishment of a Sickle Cell Registry in Louisiana: Feedback on Preliminary Recommendations—June 2023](#). Over SFY 2024, the Bureau of Family Health and the Office of Public Health, Bureau of Health Informatics initiated the technical development of the registry. The first analyses from the newly developing registry will be published in January 2025 and will focus on data from newborn screening and hospital-related care episodes. To improve the registry's completeness and comprehensiveness, the Bureau plans to integrate data from other sources by the end of SFY 2025.

## Louisiana Sickle Cell Commission Activities

The Louisiana Sickle Cell Commission is charged with making recommendations to improve clinical care and the systems of support for individuals living with sickle cell disease. The Bureau of Family Health is responsible for providing staff and policy expertise to assist the Louisiana Sickle Cell Commission with carrying out its charge. In May 2023, the Bureau hired public health's first dedicated role to support the Louisiana Sickle Cell Commission and another commission charged with advancing the systems of care for individuals with rare and heritable conditions. This position serves as a single point of contact for commissioners and is responsible for providing assistance to advance the work of the Louisiana Sickle Cell Commission. The Commission is led by a chair and co-chair, and the work of the commission is guided by four workgroups, with topics directed by the Commission overall: Medical Services, Patient Navigation, Education and Advocacy, and Data and Surveillance.

Over the course of SFY 2024, the Louisiana Sickle Cell Commission held four regular meetings (see Commission membership in [Appendix A](#) and SFY 2024 meeting dates in [Appendix B](#)). The Commission focused particularly on

elevating the work of partners in the state who are working to advance care and support for individuals living with sickle cell disease. These partner efforts are described below, followed by an overview of the activities of the commission's workgroups.

### Partners Efforts to Advance Care and Supports for Individuals with Sickle Cell Disease

In SFY 2024, the work of the Louisiana Sickle Cell Commission included a particular focus on understanding the changing landscape for care, care access and other supports for individuals living with sickle cell disease. Featured presenters included the following:

- **Gene Therapy:** In March 2024, [Children's Hospital New Orleans](#) announced it had been authorized to provide two novel gene therapies recently approved by the [Food and Drug Administration \(FDA\)](#) to treat sickle cell disease: Lyfgenia (BlueBird Bio) and Casgevy (Vertex Pharmaceuticals). In SFY 2024, the Louisiana Sickle Cell Commission heard a presentation from Tyler Craddock, an account executive from [Bluebird Gene Therapy](#), who provided an overview of his team's work in Louisiana. He emphasized Bluebird's interest in collaborating with the Commission to explore opportunities for advancing gene therapy and improving sickle cell disease care. Bluebird is looking to expand its efforts in the state and forge partnerships that can contribute to the betterment of patient outcomes.
- **Telehealth Access for Individuals Living with Sickle Cell Disease:** Dr. Karen Wyble, vice president of regional community affairs at Ochsner Lafayette General, [discussed the critical role of telehealth](#) in expanding access to care for individuals living with sickle cell disease in Louisiana. She highlighted the creation of a taskforce that focused on health care disparities in rural areas, which produced a playbook to report findings to the state Legislature.
- **Medical ID Bracelet Pilot Program:** Pauline Clark, a representative of the Northeast Louisiana Sickle Cell Anemia Foundation, introduced the MedicAlert/Sickle Cell Disease Association of America Medical ID Pilot Program and the Northeast Louisiana Sickle Cell Anemia Foundation Medical ID Bracelet Pilot Program. The goal of these initiatives is to improve access to timely and effective emergency care for individuals experiencing sickle cell crises. First, participants complete their MedicAlert digital health profile, which includes their vital health data, a physician-approved pain plan and contact information for their hematologist. Next, participants receive a customized Smart Medical ID Card with a QR code that links to their health information and pain plan. Lastly, in the event of an acute need, participants present their Smart Medical ID Card to emergency room staff who can easily scan the card to obtain the patient's history and treatment plan. The programs are open to children ages 4 to 17 and individuals over the age of 18.
- **Sickle Cell Disease State Pathology Webinar:** The Sickle Cell Disease State Pathology Webinar took place in May 2024, focused on the latest advancements in treatment and care for individuals with sickle cell disease. The keynote speaker, Bridgette Pierre, APRN, MSN, FNP-BC, field medical director at Pfizer, Inc., discussed the complexities of sickle cell disease, shared the latest research on treatments and provided strategies for delivering compassionate care to patients.

### Medical Services Workgroup

The Medical Services Workgroup is charged with improving medical access and care for patients with sickle cell disease in Louisiana while reducing health care costs. Objectives include improving access to acute pain treatment related to sickle cell disease crisis, improving management of chronic pain caused by sickle cell disease, creating a patient-centered medical home and improving access to specialized sickle cell outpatient care.

[R.S. 40:1125.41](#), also known as the Lorri Burgess Law, requires the Louisiana Department of Health to conduct an annual review of all medications and forms of treatment for sickle cell disease and services for enrollees with a

diagnosis of sickle cell disease who are eligible for coverage under the Louisiana Medicaid Program. The review is intended to assess if the available covered medications, treatments and services are adequate to meet the needs of enrollees with a diagnosis of sickle cell disease and whether the Louisiana Department of Health should seek to add additional medications, treatments or services. Since 2023, the Louisiana Department of Health has been required to submit an annual report detailing findings from the yearly review as well as recommendations to select committees of the Legislature.

This workgroup previously examined the findings shared by a medical leadership representative from Louisiana Medicaid. The findings included all current medications and evidence-based treatments available for patients diagnosed with sickle cell disease who are eligible for coverage under the Louisiana Medicaid program. Treatment services addressed sickling prevention, crises reduction, complication reduction and emerging treatments related to sickle cell disease. Data showed that 63 percent of children and 27 percent of adults with sickle cell disease had a visit with a hematologist during the reporting period. These findings indicate a need for increased emphasis on preventive care within primary care settings, coupled with improved access to subspecialty care, particularly for adult patients. Commissioners continued discussions with the Medicaid representative about the report findings and identified care gaps outlined in the [Louisiana Department of Health Business Plan](#). Medicaid will share a formal report with the Louisiana Sickle Cell Commission once the data verification process is completed.

Other notable activities of the workgroup included:

- Advocating for new treatment coverage for individuals diagnosed with sickle cell disease.
- Assisting Medicaid in their efforts to collaborate with contractors to provide supplemental rebates for the new gene therapy treatments for residents in Louisiana living with sickle cell disease.
- Discussing the pros and cons of using telehealth as a primary care method for children diagnosed with sickle cell disease.

### Patient Navigation Workgroup

Sickle cell disease is a chronic, complex disease that can be overwhelming for patients to manage; therefore, the Patient Navigation Workgroup aims to build patient self-efficacy to manage their condition and thrive. Charged with providing education and guidance to improve physical health care, mental health care, social services and public education for a person living with sickle cell disease, the workgroup's objectives include establishing confidence and trust with clients and families, partnerships with agencies and medical professionals, and advocacy and support groups for clients.

One long-standing reported barrier to patient navigation of care and coordinated care has been a lack of integrated information or exchange of information across services. While health systems, payors and foundations may coordinate support individuals with sickle cell disease, the roles of each in addressing health and health-related social needs are not clear and the exchange of information between the entities is not optimal. Over the course of SFY 2025, Bureau of Family Health staff with care coordination expertise will work with the sickle cell foundations to review each foundation's approaches to care coordination and their relationships with local health care delivery systems. This work will help identify opportunities to strengthen relationships, referral pathways and ongoing coordination of care.

### Education and Advocacy Workgroup

The goal of the Education and Advocacy Workgroup is to educate citizens and stakeholders on sickle cell disease. During SFY 2024, members of the Education and Advocacy workgroup supported the Bureau of Family Health by contributing to the development of a [care coordination toolkit](#) designed to support health care providers in



improving or expanding care coordination services at the clinic level. In addition, a subcommittee was formed to plan for the statewide sickle cell disease symposium took place in September 2024.

### Data and Surveillance Workgroup

The Data and Surveillance Workgroup is responsible informing the development of the state’s capacity to monitor the health of individuals with sickle cell disease and strengthen care systems to help them reach their fullest health potential. The Louisiana Sickle Cell Commission has been integral to the development of the sickle cell disease registry, with legislative designee Rep. Tammy Phelps authoring legislation that required the Louisiana Department of Health (through the Bureau of Family Health) to create the Sickle Cell Disease Registry and to facilitate access to its data.<sup>4</sup> At the request of the Commission, Bureau staff attended commission meetings to report the status of the registry and community-based organizations’ access to patient data. As a result, legislation establishing a timeline for the Bureau to launch the Sickle Cell Disease Registry and create data-sharing agreements was introduced and passed during the 2024 Regular Session of the Louisiana Legislature.

### Legislation Related to Sickle Cell Disease Passed in 2024

Every legislative session, the Bureau of Family Health monitors and tracks legislation that has the potential to impact service delivery for patients living with sickle cell disease and this information is shared with Commission. In addition, members may attend legislative committee hearings to stay informed and even testify on the impacts of pending legislation on individuals living with sickle cell disease or the sickle cell disease systems of care in this state.

During the 2024 Regular Session of the Louisiana Legislature, a number of legislative instruments related to sickle cell disease were filed. Below is a listing of the passed legislation and the corresponding implementation activities to be completed by the Louisiana Sickle Cell Commission:

- [SR 131](#) – Requests that the Louisiana Department of Health meet certain benchmarks toward establishing the Sickle Cell Disease Registry. It also requires the Louisiana Department of Health to execute a memorandum of understanding or a data use agreement with health care providers and sickle cell associations to govern the transfer of patient contact information by July 1, 2024; to develop necessary administrative rules by August 1, 2024; and to complete data analysis and data de-duplication by November 1, 2024, with registry launch by January 1, 2025.
- [HR 275](#) – Requests that the Louisiana Department of Health complete a comprehensive review of all current Louisiana legislation related to sickle cell disease and assessment of clinical quality outcomes and the current system of care in Louisiana. It calls for the Louisiana Department of Health to collaborate with the Louisiana Sickle Cell Commission, individuals with sickle cell disease and other external parties (i.e., other state agencies, non-governmental entities and professionals who work with individuals living with sickle cell disease) to review current Louisiana legislation related to sickle cell disease and to obtain recommendations in conducting the review and assessment. The Louisiana Department of Health is required to make recommendations to the Governor and Legislature to strengthen current statutes related to health care access, quality and supportive services in order to address current demands, align with national standards for best practices and increase accessibility to high-quality care for individuals living with sickle cell disease. Lastly, it requires the submission of a written report summarizing the findings and

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<sup>4</sup> (Act No. 647, 2024)

recommendations of the comprehensive review on how to improve sickle cell disease legislation in this state to the Governor, the members of the Commission and the House and Senate Committees on Health and Welfare no later than February 14, 2025.

- [SR 134](#) – The resolution has the same directive as [HR 275](#), but no due date.
- [HR 320](#) – Recognizes gene editing as a significant advancement in the treatment of sickle cell disease.
- [HB 330 | Act 608](#) – Amends language in Louisiana [R.S. 40:1125.1\(A\)](#), by limiting the membership to the organizations, entities and individuals listed in [R.S. 40:1125.1\(B\)](#). The bill does not add or remove any members.
- [HB 363 | Act 375](#) – Mandates that public school boards require school nurses to complete one hour of training on sickle cell disease. The training must cover the medical needs of students with sickle cell disease, possible accommodations and communication strategies with parents and school staff. The Louisiana Sickle Cell Commission is charged with developing and providing instructional materials to the Louisiana Department of Education, which will provide the materials to school boards.
- [HB 883 | Act 748](#) – This act entails two directives. The first is the same as that described in [HB 363 | Act 375](#). However, the educational materials are to be posted on the Louisiana State Board of Nursing website. The second directive states that the Louisiana Department of Health is to facilitate agreements that allow for the transfer of patient contact information between sickle cell clinics and associations that are part of the Louisiana Sickle Cell Commission.
- [HB 421 | Act 616](#) – Allows the parent or guardian of a student with sickle cell disease to submit a management and treatment plan to the student's school. Treatment plans must be developed with the student's physician and must include necessary health care accommodations, such as unrestricted restroom access, adequate hydration and limitations on required physical activity. The treatment plan must be signed by the student's parent or guardian and by the treating physician.
- [HB 869 | Act 744](#) – Requires physicians and physician assistants working in emergency medicine to complete an initial one-hour training on sickle cell disease and a one-hour refresher course every three years. The course must be approved by the Louisiana State Board of Medical Examiners and be made available on the board's website.
- [HB 896 | Act 749](#) – Requires Medicaid coverage for remote patient monitoring services, which includes tracking clinical data, medication adherence and providing interactive video conferencing. Patients with chronic conditions, including sickle cell disease, are eligible for these services.

## Conclusion

In SFY 2024, the Louisiana Sickle Cell Commission continued its work to improve the systems of care to support the health and quality of life for individuals with sickle cell disease in the state. Over the past several years, the Commission has ensured sustained attention on sickle cell disease, the issues and opportunities in the systems of care and the experiences of individuals living with sickle cell disease. With advancements in data and innovative treatments for sickle cell disease, the Commission continues to have important work ahead to ensure that all

people in Louisiana diagnosed with sickle cell disease have access to specialized health care and community services across the state.

## Appendix A: Louisiana Sickle Cell Commission Membership Roster

<b>Member's Name</b>	<b>Role</b>	<b>Appointed By</b>
<b>Erin Fulbright, Chair</b>	Sickle Cell Association of South Louisiana	Governor
<b>Donna Thaxton, Vice-Chair</b>	Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.	Governor
<b>Sen. Regina Barrow</b>	Louisiana Senate	President of the Senate
<b>Ernest DeJean</b>	Sickle Cell Center of Southern Louisiana, Tulane University School of Medicine	Governor
<b>Renee Gardner, M.D.</b>	Children's Hospital, New Orleans	Governor
<b>Twarnette Hardison</b>	Sickle Cell Anemia Research Foundation, Alexandria	Governor
<b>Cheryl Harris, MPH</b>	Secretary of the Louisiana Department of Health designee	Governor
<b>Shantel Hébert-Magee, Ph.D.</b>	Medicaid Director of the Louisiana Department of Health or Designee	Governor
<b>Majed Jeroudi, M.D.</b>	Medical Professional Who Provide Treatment & Care to Patients Diagnosed with Sickle Cell Disease	Governor
<b>Alvin Henry Jr.</b>	Person Diagnosed with Sickle Cell Disease	Governor
<b>Rep. Tammy Phelps</b>	Louisiana House of Representatives	Speaker of the House of Representatives
<b>Shannon Robertson</b>	Louisiana Primary Care Association	Governor
<b>Rosalind Spain</b>	Sickle Cell Disease Association of America, Inc., Northwest Louisiana Chapter	Governor
<b>Rajasekharan Warriier, M.D.</b>	Medical Professional Who Provide Treatment & Care to Patients Diagnosed with Sickle Cell Disease	Governor
<b>Vacant</b>	Parent of a Person Diagnosed with Sickle Cell Disease	Governor
<b>Vacant</b>	Person Diagnosed with Sickle Cell Disease	Governor
<b>Vacant</b>	Southwest Louisiana Sickle Cell Anemia, Inc.	Governor

## Appendix B: Louisiana Sickle Cell Commission Meeting Schedule

The SFY 2024 Louisiana Sickle Cell Commission meeting schedule is listed below, with links to each meeting's agenda and minutes. The agendas and minutes for prior meetings are located on the Bureau of Family Health [Boards and Commissions webpage](#) in the [Louisiana Sickle Cell Commission](#) section.

- August 8, 2023: [Agenda](#) | [Minutes](#)
- November 7, 2023: [Agenda](#) | [Minutes](#)
- January 30, 2024: [Agenda](#) | [Minutes](#)
- May 14, 2024: [Agenda](#) | [Minutes](#)

## Appendix C: Revised Statute 40:1125.1

### §1125.1. Louisiana Sickle Cell Commission<sup>5</sup>

- 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.
- 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.
  - b. One member from a list of nominees submitted by Children's Hospital, New Orleans.
  - 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.
  - e. One member from a list of nominees submitted by the Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.
  - f. One member from a list of nominees submitted by the Sickle Cell Disease Association of America, Inc., Northwest Louisiana Chapter.
  - g. One member from a list of nominees submitted by the Sickle Cell Anemia Research Foundation, Alexandria.
  - h. One member from a list of nominees submitted by Southwest Louisiana Sickle Cell Anemia, Inc.
  - 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) Non-legislative 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

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<sup>5</sup> (Louisiana Revised Statute 40:1125.1. Acts 2013, No. 117, §2; Acts 2015, No. 387, §1; Acts 2020, No. 280, §1, eff. June 11, 2020; Acts 2022, No. 271, §4; Acts 2022, No. 647, §§2, 4A; Redesignated from R.S. 40:2018.3., 2024)

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.

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