

Legislative Report on the Louisiana Sickle Cell Commission

*Report Prepared in Response to ACT 117 (SB 57)
of the 2013 Regular Legislative Session*

Reflects activities of State Fiscal Year (SFY) 2023

Prepared by:

Office of Public Health – Bureau of Family Health

Genetic Diseases Program

Cheryl Harris, MPH

Rodney Goldsmith, MPA



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Introduction

The Louisiana Sickle Cell Commission (LSCC) is a statutorily established advisory body that works to improve the delivery of sickle cell services in Louisiana. The LSCC comprises 17 members representing clinical care systems, supportive services, advocates, and individuals with lived experience. As defined in Louisiana [R.S. 40:1125.1](#), the charges of the LSCC are 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 disease and services that includes:
 - a. An assessment of the programs and activities aimed at sickle cell disease and services
 - b. A description of the level of coordination existing between the state and private stakeholders in the management and treatment of sickle cell disease
 - c. The development of a detailed action plan for battling sickle cell disease
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 the statute

This report reflects the accomplishments and activities of the LSCC during State Fiscal Year (SFY) 2023 (July 1, 2022 to June 30, 2023).

Sickle Cell Disease in Louisiana

Sickle cell disease (SCD) is an inherited disorder of a protein called hemoglobin in red blood cells. Red blood cells are responsible for carrying oxygen in the blood to the body's tissues. Normal red blood cells contain Hemoglobin A and are round-shaped. However, the presence of Hemoglobin S causes red blood cells to become sickle-shaped, and this change in shape can cause the red blood cells to block off blood vessels and impede the delivery of oxygen. The effects of this can be severe pain (also known as sickle cell crisis) and can lead to permanent damage to the brain, liver, kidneys, bones, and spleen. Consequently, individuals with SCD are at increased risk for infections, stroke, heart disease, and renal failure. In addition, the signs and symptoms of SCD vary from person to person, and pain episodes occur without warning. The complexity and variability in symptoms demand specialized clinical guidance and advanced care coordination regarding counseling and education. In the past, SCD was considered "a disease of childhood," with few patients surviving to adulthood.¹ However, healthcare reform efforts have greatly improved the identification of SCD, leading to advancements in treatment and significantly improving patients' life expectancy well into their 60s with the proper resources.²

According to data from the [Louisiana Newborn Screening Program](#), 73 infants were born with a hemoglobin disorder in SFY 2023. Of that total number, 56 newborns were diagnosed with the presence of Hemoglobin S, the most serious variant, during this period. In addition, 2,385 infants were born as carriers of a hemoglobin disorder in SFY 2023. A majority of the infants identified as carriers (n=1,744) were diagnosed with sickle cell S trait. The remaining infants identified as carriers included 527 infants

¹ Dacie, J. V. (1960). *The haemolytic anaemias: congenital and acquired* (Vol. 2). Grune & Stratton.

² Platt, O. S., et. al. (1994). Mortality in sickle cell disease. *N Engl J Med*, 1994(331), 1022-1023.

with hemoglobin C trait, 69 with hemoglobin variant trait, 20 with hemoglobin D trait, and 45 with hemoglobin E trait.

The number of individuals living with SCD in Louisiana is currently unknown because there was no comprehensive population-level public health monitoring system in the state until recently. In the 2022 Regular Session of the Louisiana Legislature, a bill was introduced that has now authorized the [establishment of a sickle cell disease registry](#) (the “Skylar-Cooper Database”). Per Act 647, the registry is “...to function as a single repository of accurate, complete records to aid in the cure and treatment of sickle cell disease in this state.” Public health registries provide important information about the prevalence of certain conditions and the health of individuals with that condition. As has been demonstrated in [other states that have established similar registries](#), data from such systems are integral to efforts that inform policy and improve care.

Sickle Cell Programs and Activities

The Office of Public Health’s (OPH) Bureau of Family Health (BFH) Genetic Diseases Program 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 2023, 99% of infants born in Louisiana were screened* for SCD, and 100% of infants with a positive screen were linked to follow-up care by a hematologist (*please note that a small number of families declined the screening test). The Genetic Diseases Program oversees sickle cell clinics through the OPH Parish Health Units (PHUs) in Alexandria and Monroe. These clinics provide access to hematologists and other specialist providers for individuals with SCD living in parts of the state that otherwise might not have local access. The program also has contractual relationships 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 in an effort to ensure access to care throughout the state.

In addition to the program’s work with clinical systems, the Genetic Diseases Program supports Sickle Cell Foundations statewide. Sickle Cell Foundations are community-based organizations that assist individuals living with SCD and their families. The Genetic Diseases Program provides funding for five Sickle Cell Foundations that are located in Baton Rouge, Lake Charles, Alexandria, Shreveport, and Monroe. Sickle Cell Foundations have programs that link individuals and families affected by SCD with medical and non-medical resources needed to manage this complex disease. The foundations also help ensure all infants diagnosed with SCD through the newborn screening program are linked to appropriate care upon diagnosis. In SFY 2023, the Genetic Diseases Program’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, which outlined the parameters for patient navigation services for individuals with SCD. This should help facilitate improved coordination between the foundations, insurers, and healthcare 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 SCD. While the services offered vary between MCOs, all utilize telephonic case management and focus primarily on members in their networks who experience frequent and unpredictable episodes of pain and other serious health problems.

Despite ongoing efforts of the Genetic Diseases Program, Sickle Cell Foundations, and the Medicaid MCOs, people living with SCD continue to experience barriers with access to and retention of specialized care. In general, children with SCD 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 SCD can lead to infection, acute chest syndrome, and stroke, as evidenced by emergency room visits and hospitalizations.

LDH's Business Plan SFY 2023 [*Invest: Teaming up for a Stronger LDH and a Healthier Louisiana made developing and implementing the registry a department priority.*](#) Over the past year, BFH worked with the LSCC, 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*](#).

Louisiana Sickle Cell Commission

As described in the introduction, the LSCC makes recommendations to improve clinical care and the systems of support for individuals living with SCD. The Genetic Diseases Program is responsible for providing staff and policy expertise to assist the LSCC with carrying out its charge. In May 2023, BFH hired public health's first-ever dedicated role to support key commissions 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 LSCC.

Over the course of SFY 2023, the LSCC held four regular meetings (see Appendix A for the list of members and Appendix B for the meeting notes). The activities of the commission's workgroups are described below, along with plans for SFY 2024.

Strategic Plan Update, Workgroup Activities and Recommendations

In 2014, the LSCC developed a strategic plan to fulfill legislative mandates and improve the health outcomes of individuals living with SCD in Louisiana. Four workgroups with topics directed by the Commission: Medical Services, Patient Navigation, Education and Advocacy, and Data and Surveillance help implement activities outlined in the strategic plan. This fiscal year, the LSCC initiated the development of a new two-year strategic plan to address new and ongoing challenges that affect service delivery across the state.

Medical Services Workgroup

The goal of the Medical Services Workgroup is to improve medical access and care for patients with sickle cell disease while reducing health care costs in Louisiana. Objectives for this workgroup include:

1. Improve access to acute pain treatment related to SCD crisis
2. Improve management of chronic pain caused by SCD
3. Create a patient-centered medical home
4. Improve access to specialized sickle cell outpatient care

One of the activities of this workgroup was to review data from Louisiana Medicaid. [Act No. 670 of the 2022 Regular Session of the Louisiana Legislature](#) directed LDH to assess critical aspects of care for

individuals with SCD and secure public input. Specifically this act 1) requires an annual review of available treatments for sickle cell disease and 2) requires an assessment of Medicaid coverage for sickle cell treatments. In February 2023, medical leadership from Louisiana Medicaid presented the findings from this review, which included all current medications and evidence-based treatments available for patients diagnosed with sickle cell disease eligible for coverage under the Louisiana Medicaid program. Treatment services addressed sickling prevention, crises reduction, complication reductions, and emerging treatments related to SCD. Data showed that 63% of children and 27% of adults with SCD had a visit with a hematologist during the reporting period. This suggests that more preventive care should be directed by the primary care provider and/or that access to subspecialty care should be improved, particularly for adult patients.

The Medical Services Workgroup strategies for SFY 2024 are:

1. To identify hematologists/oncologists throughout the state with the capacity to provide treatment for youth and adults with SCD
2. To collaborate with emergency departments and emergency medical services on pain management protocols to improve treatment outcomes for individuals with SCD experiencing a pain crisis
3. To establish appropriate access to transcranial Doppler ultrasound (TCD) screenings for early detection of the risk of strokes in children with SCD

Patient Navigation Workgroup

SDC is a chronic, complex disease that can be overwhelming for patients to manage. The Patient Navigation Workgroup aims to build patient self-efficacy to manage their condition and thrive. The goal of the workgroup is to provide education and guidance to improve physical health care, mental health care, social services, and public education for a person living with sickle cell disease. Objectives include:

1. Establishing confidence and trust with clients and families
2. Establishing partnerships with agencies and medical professionals
3. Establishing 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 the readily exchange of information across services. While health systems, payers, and the Foundations all may be working to support individuals with SCD, the roles of each in addressing health and health-related social needs is not clear and the exchange of information between the entities is not optimal. The establishment of the state sickle cell registry may be useful in the future to identify care needs and/or to facilitate care coordination. Generally, public health registries do not serve as real-time health information exchange systems. However, when designed with the right legal authorities, public input, and ethics reviews, registries can sometimes become tools to facilitate information exchange needed to support effective coordination of services.

The Patient Navigation Workgroup strategies for SFY 2024 are:

1. To expand community-based supportive services to regions without an established foundation
2. To strengthen transition services for young adults with SCD transitioning to the adult medical home model
3. To increase access to medical homes for all individuals living with SCD throughout the state

Education and Advocacy Workgroup

The goal of the Education and Advocacy Workgroup is to educate residents and stakeholders on sickle cell disease. Objectives for this workgroup include:

1. Establishing statewide print and media campaign to be inclusive of all activities
2. Coordinating with the Louisiana Sickle Cell Association (LASCA) for the Annual Sickle Cell Disease State Conference
3. Establishing a Community-Based Organization (CBO) section on the LDH website
4. Assembling a statewide informational publication that will include public service announcements (video/audio) and a directory of each state agency/organization that provides services and resources to patients with sickle cell disease

In SFY 2023, members of the Education and Advocacy Workgroup were instrumental in helping the Genetic Diseases Program with fulfilling two deliverables in the SFY 2023 LDH Business Plan: the development of a toolkit for school providers to support children living with SCD and a pain management toolkit for emergency providers. Both toolkits are available on the [LDH Sickle Cell Program website](#).

The Education and Advocacy Workgroup strategies for SFY 2024 are:

1. To increase the frequency of regional engagement activities to educate providers and community agencies on SCD
2. To expand printed educational materials for statewide dissemination
3. To improve online presence with the dedicated website highlighting public service announcements and a directory of organizations providing sickle cell related services

Data and Surveillance Workgroup

The goal of the Data and Surveillance Workgroup is to build and maintain the state's capacity to monitor the health of individuals with SCD and strengthen the ability of our care systems to support every person living with SCD to achieve their fullest health potential. Objectives for this workgroup include the development of a surveillance system/registry for the tracking of SCD in Louisiana with the following information:

- Demographics characteristics and geographic distribution of patients with sickle cell in Louisiana
- Health care utilization, costs of care, and the geographic variation of specific services
- Mortality rates, including case fatality rates for individuals with SCD

The primary activities of this workgroup in SFY 2023 aimed to inform the development of the sickle cell registry. Additional information about the registry is available on the [LDH Sickle Cell Program website](#).

The Data and Surveillance Workgroup strategies for SFY 2024 are:

1. To increase access to Medicaid claims level surveillance data to monitor utilization rates
2. To establish data sharing agreements with the Sickle Cell Foundations
3. To expand statewide data reporting requirements of clinical health outcomes in the development of a comprehensive data repository for SCD
4. To identify other statewide health information exchanges for population-level monitoring and data-informed trends for system of care improvements

2023 Legislation Related to Sickle Cell Disease

In every legislative session, the LSCC and BFH track legislation that has the potential to impact service delivery for patients with sickle cell diseases. During the 2023 Regular Session of the Louisiana Legislature, the following bills were passed:

[HCR 92](#) – Requested that LDH “...ensure timely patient access to gene therapies utilizing any and all available, innovative payment arrangements and methodologies for the Medicaid program to study the feasibility of funding gene therapy for all sickle cell patients via Medicaid” and issue a report with findings and recommendations no later than 30 days prior to the convening of the 2024 Regular Session.

[HR 201](#) - Requests the chairman of the House Committee on Health and Welfare to create a subcommittee to study the effectiveness of sickle cell healthcare treatment practices in this state. Requests the subcommittee to submit its findings in the form of a written report by February 1, 2024.

[HR 289](#) - Requests that LDH Medicaid review prior authorization criteria for L-glutamine which is used to treat acute complications caused by sickle cell disease. Requests a report of findings be submitted by February 1, 2024.

Conclusion

In SFY 2023, the LSCC continued its important work to improve the systems of care to support the health and quality of life for individuals with SCD in the state. Over the past several years, the work of the LSCC and the commissioners ensured sustained attention on SCD, on the issues and opportunities in the systems of care, and on the experiences of individuals living with SCD. With the advancements in data and innovative treatments of sickle cell disease, the LSCC has important work ahead to ensure that all people in Louisiana diagnosed with SCD have access to specialized health care and community services across the state.

Appendix A: LSCC Membership List & Meeting Attendees

LSCC Membership List

Membership is by appointment of the Governor, subject to Senate confirmation and is inclusive of a representative from each of the following:

- The Sickle Cell Center of Southern Louisiana, Tulane University School of Medicine
- Children’s Hospital, New Orleans
- The Louisiana Primary Care Association
- The Baton Rouge Sickle Cell Anemia Foundation, Inc.
- The Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.
- The Sickle Cell Disease Association of America, Inc., Northwest Louisiana Chapter
- The Sickle Cell Anemia Research Foundation, Alexandria
- The Southwest Louisiana Sickle Cell Anemia, Inc.
- The Secretary of the Department of Health or a designee
- One member of the Louisiana Senate appointed by the President of the Senate
- One member of the Louisiana House of Representatives appointed by the speaker of the House of Representatives
- A person diagnosed with sickle cell disease
- A parent of a person diagnosed with sickle cell disease
- Two medical professionals who provide treatment and care to patients diagnosed with sickle cell disease
- The Medicaid director of the Louisiana Department of Health or a designee

Attendees and Participants at the Louisiana Sickle Cell Commission Meetings

SFY 2023 Appointed Members

Renee Gardner, M.D., Children’s Hospital-New Orleans

Amina Rafique, M.D., Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine

Shannon Robertson, RN, BSN, Louisiana Primary Care Association

Donna Thaxton, Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.

Rosalind Spain, Sickle Cell Diseases Association, Northwest Louisiana Chapter

Chris Archinard, Southwest Louisiana Sickle Cell Anemia, Inc.

Erin Fulbright, Sickle Cell Association of South Louisiana

Twinett “Shay” Hardison, Sickle Cell Anemia Research Foundation, Inc.

Cheryl Harris, MPH, Secretary of the Department of Health Designee

Regina Barrow, Louisiana Senate

Tammy Phelps, Louisiana House of Representatives

Vacant, Person Diagnosed with Sickle Cell Disease

Shaleathia Campbell, Parent Advocate

Rajasekharan Warriar, M.D., Ochsner Health Center for Children, medical professional who provides treatment and care to patients diagnosed with sickle cell disease

Majed Jeroudi, M.D., Ochsner LSU Health Shreveport, medical professional who provides treatment and care to patients diagnosed with sickle cell disease

Partners and Stakeholders

Pamela Saulsberry, PhD, LCSW, Northeast Louisiana Sickle Cell Anemia Tech. Resource Foundation, Inc.
Medria Taylor-Buford, Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.
Sharon Price, Sickle Cell Anemia Research Foundation, Inc.
Jerry Paige, Sickle Cell Disease Association of America, Inc.-Northwest Louisiana Chapter
Melody Benton, Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine
Ernest DeJean, Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine
Rihanna Galloway-Dawkins, Sickle Cell Center of Southern Louisiana-Tulane Univ. School of Medicine
Karen Odoms Johnson, Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine
Rachelle Defillo, NOLA Sickle Cell Awareness, LLC
Kathy Williams, Sickle Cell Association of South Louisiana
Alishia Vallien, Southwest Louisiana Sickle Cell Anemia, Inc.
Jasmine Mosley, Southwest Louisiana Sickle Cell Anemia, Inc.
Marquita Brown, Southwest Louisiana Sickle Cell Anemia, Inc.
Cassandra Norman, Sickle Cell Association of America, Inc.
Dana LeBlanc, M.D., Children's Hospital, New Orleans
Cherie Hadley, RN, Children's Hospital, New Orleans
Jessica Templet, PA-C, St. Jude Affiliate Clinic, Baton Rouge
Erica Rose-Crawford, Louisiana Primary Care Association
Courtney Sanford, Louisiana Primary Care Association
Raymond Poliquit, M.D., Healthy Blue
LaTarsha Carter, RN, BSN, Healthy Blue
Karen Grevemberg, MBA, BSN, RN, UnitedHealthcare
Kelly Hess, Global Blood Therapeutics, Inc.
Horatio Handy, Global Blood Therapeutics, Inc.
Shawn Henderson, Global Blood Therapeutics, Inc.
Brent Young, Global Blood Therapeutics, Inc.
Bridgette Pierre, Global Blood Therapeutics, Inc.
Lisa Tracz, Global Blood Therapeutics, Inc.
Maurice Garland, Global Blood Therapeutics, Inc.
Tyler Craddock, Bluebird Bio
April Dickerson, Bluebird Bio
Amanda Dumas, M.D., Louisiana Medicaid
Amy Zapata, MPH, LDH OPH Bureau of Family Health
Amanda Perry, LDH OPH Bureau of Family Health
Patti Barovechio, DNP, MN, LDH OPH BFH Children Special Health Services Program
Michelle Duplantier, LCSW-BACS, LDH OPH-BFH Children Special Health Services Program
Sharonda Smith, LDH OPH Bureau of Family Health
Cynthia Suire, DNP, MSN, RN, LDH OPH Bureau of Family Health
Rachelle Boudreaux, MA, LDH OPH Bureau of Family Health
Jantz Malbrue, MSPH, LDH OPH Bureau of Regional and Clinical Operations

Appendix B: LSCC Meeting Schedule & Minutes

The LSCC meetings were held on the dates below. Minutes are available on the [Division of Administration website](#).

August 15, 2022

December 6, 2022

February 7, 2023

March 2, 2023

May 9, 2023

Appendix C: RS 40:1125.1

§2018.3. 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 eleven members as provided in Subsection B of this Section.

B. (1) Eight members shall be appointed by the governor, subject to Senate confirmation, from a list submitted by each of the following organizations:

- (a) A representative from the Sickle Cell Center of Southern Louisiana, Tulane University School of Medicine.
 - (b) A representative from Children's Hospital, New Orleans.
 - (c) A representative from the Louisiana Primary Care Association.
 - (d) A representative from The Baton Rouge Sickle Cell Anemia Foundation, Inc.
 - (e) A representative from the Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.
 - (f) A representative from the Sickle Cell Disease Association of America, Inc., Northwest Louisiana Chapter.
 - (g) A representative from the Sickle Cell Anemia Research Foundation, Alexandria.
 - (h) A representative from the Southwest Louisiana Sickle Cell Anemia, Inc.
- (2) The secretary 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 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 at the Louisiana Department of Health headquarters in Baton Rouge.

(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.

40:1081.8.

(6) Apply for grants and donations from any public or private source to implement the provisions of this Subsection.

Acts 2013, No. 117, §2; Acts 2015, No. 387, §1.

Appendix D: Act No. 280 (House Bill No. 591) of the 2020 Regular Session

AN ACT

To amend and reenact R.S. 40:2018.3(A) and (B)(1), (2), and (9), relative to the composition of the Louisiana Sickle Cell Commission; to provide for appointments for members to the commission; to provide for additional members to serve on the commission; to provide a meeting location for the commission meetings to take place; to provide for an effective date; and to provide for related matters.

Be it enacted by the Legislature of Louisiana:

Section 1. R.S. 40:2018.3(A) and (B)(1), (2), and (9) are hereby amended and reenacted to read as follows:

§2018.3. 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.

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 the 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.

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.

Louisiana Department of Health

628 North Fourth Street, Baton Rouge, Louisiana 70802

(225) 342-9500

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