

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 Years (SFYs) 2021 and 2022

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Executive Summary

The mandate of the Louisiana Sickle Cell Commission (LSCC) is to improve the delivery of sickle cell services in Louisiana. Under the guidelines established in [RS 40:2018.3](#), these are the charges of the LSCC:

- 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 with these details:
 - 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](#).

This Legislative Report on the LSCC reflects accomplishments from activities of State Fiscal Year 2021 and 2022 (SFY 2021 & 2022), from July 1, 2020 to June 30, 2022. The report highlights the impact of sickle cell disease throughout the state and care coordination efforts among the LSCC, Medicaid, Office of Public Health (OPH), stakeholder partners.

The effects of COVID-19 and strategies deployed to minimize interruptions in care and negative impacts on health outcomes are detailed below. The updates to the strategic plan and designated activities of the different workgroups are described within the report.

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 distortion 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. In the past, SCD was considered "a disease of childhood," with few patients surviving to adulthood.¹ However, healthcare reform has greatly improved the identification of SCD, leading to advancements in treatment that significantly improve patients' life expectancies well into their sixties with the proper resources.²

According to SFY 2021 data from the [Louisiana Newborn Screening Program](#), 70 infants were born with a hemoglobin disorder and 61 of those newborns were diagnosed with the presence of Hemoglobin S, the most serious variant. During SFY 2022, the numbers were slightly lower - 68 infants were born with a hemoglobin disorder, and 55 of them were diagnosed with the presence of Hemoglobin S. In addition to these diagnoses, 1,972 and 1,902 infants were born as carriers of a hemoglobin gene mutation in SFY 2021 and SFY 2022 respectively. See the table below for a more detailed look at the numbers.

Year	Born with hemoglobin diseases	Diagnosed with hemoglobin S disease	Born as carrier of abnormal hemoglobin gene mutation	Carrier of hemoglobin C	Carrier of hemoglobin D	Carrier of hemoglobin E	Carrier of hemoglobin S	Has a hemoglobin variant
SFY 2021	70	61	1,972	464	17	38	1,386	67
SFY 2022	68	55	1,902	388	15	29	1,411	59

Hemoglobin disorder is the larger group of affected red blood cell disorders that includes sickling diseases like sickle cell. Only the sickling diseases/traits are associated and there are other variations which are included in those diagnosed with hemoglobin S disease. These numbers are helpful in that the chances of a child being diagnosed with sickle cell or another sickling disease increases if one parent has a sickling disease and the other parent has one of these traits

Sickle Cell Programs and Activities

The Office of Public Health (OPH), Bureau of Family Health (BFH), Genetic Diseases Program provides two core functions related to SCD:

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.

- Newborn genetic screening
- Oversight of the safety-net, state-assisted Sickle Cell Clinics in New Orleans, Lake Charles, Shreveport, Alexandria, and Monroe. The program also works closely with private-funded sickle cell clinics in Baton Rouge, Lafayette, and New Orleans.

As the federally mandated newborn heel stick screening program administrator, the Genetic Diseases Program ensures access to sickle cell genetic evaluation and counseling to Louisiana residents. In SFYs 2021 and 2022, 99%* of infants born in Louisiana were screened for SCD, and 100% of infants with a positive screen were linked to care (*please note that a small number of families refused the screening test). The Genetic Diseases Program also operates safety-net Sickle Cell Clinics through the OPH Parish Health Units (PHUs) in Alexandria and Monroe. The Sickle Cell Clinics provide access to hematologists and other specialist providers for individuals with SCD living in urban and rural parts of the state.

Sickle Cell Foundations are community-based organizations that assist individuals with SCD throughout the state with navigating services and care coordination. The Genetic Diseases Program funds five Sickle Cell 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 SCD with medical and non-medical resources needed to manage this complex disease. The Genetic Diseases Program subcontracts with these five Sickle Cell Foundations to help ensure all infants diagnosed with SCD through the newborn screening program are linked to appropriate care upon diagnosis.

To improve access to sickle cell-designated services, the Healthy Louisiana Medicaid Managed Care Organizations (MCOs) introduced their sickle cell care management programs in 2015 as a concerted effort to integrate sickle cell specialty care into their clinical guidelines. While the details of the services offered vary between organizations, 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 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 exist for the adult population and those transitioning from pediatric to adult care.

Coordination of Care

Coordination of care for individuals with SCD in Louisiana continues to be a key challenge for service providers and a priority area for SCD stakeholders. The Sickle Cell Foundations work closely with the regional Sickle Cell Clinics to conduct outreach activities and assess patients between their clinic appointments to improve care coordination. The Sickle Cell Foundations and Sickle Cell Clinics continue efforts to collaborate with Medicaid MCOs to provide existing enrollees with support and education on available resources. Over the last several years, pharmaceutical and biotechnology companies have expanded their efforts to educate healthcare providers within the state by collaborating with the Sickle Cell Clinics and Foundations in educating patients on current and emerging therapies along with clinical trial opportunities.

One barrier to coordinated care has been a lack of integrated health information exchange across services. Each private health care provider and insurance company, including Medicaid and Medicaid

MCOs, operate a case management system. However, there was not a mechanism to monitor the efficacy of community support services. The Genetic Diseases Program implemented a case management data system in SFY 2021 for the services provided through Sickle Cell Foundations. The system aims to reduce service duplication, disruption in the continuum of care, and loss of patients to follow-up, potentially facilitating an integrated health information exchange in the future. However, the case management system lacks the ability to exchange clinical indicators with other electronic medical records to assess the effectiveness of medical services throughout the state.

Louisiana Sickle Cell Commission

Act No. 117 of the 2013 Regular Legislative Session of the Louisiana Legislature mandated LDH to create the Louisiana Sickle Cell Commission (LSCC) to ensure adequate services to all persons living with SCD and formulate new actions to reduce the burden of SCD in Louisiana. Appendix A lists the commission members appointed by the Governor and attendees of meetings held throughout SFYs 2021 and 2022.

In 2014, the LSCC developed a strategic plan to fulfill legislative mandates and improve the health outcomes of individuals living with SCD in Louisiana. The LSCC implements initiatives through four workgroups: Medical Services, Patient Navigation, Education & Advocacy, and Data & Surveillance. The LSCC initiated a new two-year strategic plan to address new and ongoing challenges that hinder service delivery that are included in this report for SFY 2021 and SFY 2022.

The LSCC's annual activities, future directions, and recommendations to the legislature are outlined in the section below.

Strategic Plan Update and Workgroup Activities

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:

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

Telehealth

To limit the risk of severe illness, telehealth services continued to be utilized by regional pediatric and adult sickle cell clinics as well as the Medicaid MCOs due to the COVID-19 pandemic. Telehealth services remain vital for people living with SCD in areas without a dedicated sickle cell clinic. Although this model has been instrumental to increasing access to services, additional specialists and regional, sickle cell clinical services are needed to reduce the dependence on emergency departments.

Prior Authorization

Despite ongoing efforts, people living with SCD continue to experience barriers with access to and retention of specialized care and medications. Hydroxyurea is therapy beneficial for increasing blood flow and reducing pain crises for individuals with SCD that prevents hospital admission. Depending on the phenotype of sickle cell, some individuals may receive a prescription as early as 9 months of age. Changes to the prior authorization process in SFY 2021 created a barrier to hematologists and

healthcare providers prescribing the medication for patients with SCD. Providers detailed their difficulties with the prior authorization process in a letter to Louisiana Medicaid. Because of their advocacy, the prior authorization process for hydroxyurea changed to accommodate the flexibility needed in prescribing this medication.

The Medical Services Workgroup strategies for SFY 2023 are to:

- Identify hematologists/oncologists throughout the state with the capacity to provide treatment for youth and adults with SCD.
- Collaborate with emergency departments and emergency medical services on pain management protocols to improve treatment outcomes for individuals with SCD experiencing a pain crisis.
- 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 establishing:

- Confidence and trust with clients and families.
- Partnerships with agencies and medical professionals.
- Advocacy and support groups for clients.

Act No. 387: Patient Navigator Program

In 2015, [Act 387](#) was signed into law, officially launching the Sickle Cell Patient Navigation Program in Louisiana. While there has been no specific appropriation by the legislature to support these services to date, OPH contracts with the regional Sickle Cell Foundations for care navigation services, in particular for children and young adults. According to the legislation, the Sickle Cell Patient Navigator Program was intended to "increase statewide access to the types of specialty care that are critical to the health and well-being of sickle cell patients."

The mandated functions of the program include to:

- Train patient navigators to serve as outreach coordinators, coordinators of family educational sessions, and patient case managers.
- Establish and strengthen care continuum for sickle cell patients served by the program and for the families of those patients.
- Identify and contact sickle cell patients, conducting home visits with patients and their family members, and coordinating patient care as needed.
- Facilitate collaboration among healthcare providers that serve sickle cell patients.
- Deliver public health education on sickle cell disease and treatment.

The SFY 23 contracts between OPH and the Sickle Cell Foundations seek to align the foundations' activities and reporting with the key functions outlined in Act 387. Doing so is intended to facilitate improved coordination between the foundations, insurers, and healthcare delivery systems.

Coordination with State Medicaid

The OPH Bureau of Family Health collaborated with State Medicaid in the assessment of care management services to identify issues and areas of improvement. All five Healthy Louisiana MCOs provide chronic care management programs for their members diagnosed with SCD. However, activities vary across the plans. By working together to assess care management services available through the MCOs, OPH and Medicaid aim to determine how the MCOs can work most effectively with the Sickle Cell Foundations, and to ensure that services are provided to all patients with SCD. Each MCO shared a summary of the services they offered which were then compared to the contracted services of the Sickle Cell Foundations. Next steps include ensuring there are not any duplication of services and utilizing the expertise of all entities to provide comprehensive care management through an optimal system of care.

The Patient Navigation Workgroup strategies for SFY 2023 are to:

- Expand community-based supportive services to regions without an established foundation.
- Strengthen transition services for young adults with SCD transitioning to the adult medical home model.
- Increase access to transformative and curative therapies for all individuals living with SCD throughout the state.

Education and Advocacy Workgroup

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

- Establishing statewide print and media campaign to be inclusive of all activities.
- Coordinating with Louisiana Sickle Cell Association (LASCA) for Annual Sickle Cell Disease State Conference.
- Establishing a Community Based Organization (CBO) section on the LDH website.
- 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.

Financial Management Webinar

As a capacity building training, the Sickle Cell Foundations participated in a leadership training with the Chief Financial Officer, Cassandra Norman, of the Sickle Cell Disease Association of America, Inc. on June 10, 2021. The webinar provided strategic initiatives on financial reporting, grant allocation, operational funding, and human resources.

Awareness Events

Over the past two years, the Sickle Cell Foundations and Sickle Cell Clinics continued their efforts to increase awareness and engage stakeholders for World Sickle Cell Awareness day on June 19 and during National Sickle Cell Awareness Month in September each year. Several cities across the state participated in the “Let Your Light Shine” campaign promoting awareness for SCD by shining a red light on public buildings. Yearly runs, galas, and radiothons were held as virtual events on social media platforms like Facebook live. More events are schedule for the upcoming SFY 2023 as local COVID-19 restrictions are removed to accommodate larger in-person gatherings.

The Education and Advocacy Workgroup strategies for SFY 2023 are to:

- Increase frequency of regional engagement activities to educate providers and community agencies on SCD.

- Expand printed educational materials for statewide dissemination.
- Improve online presence with the dedicated website highlighting public service announcements and a directory of organizations providing sickle cell related services.

Data & Surveillance Workgroup

The goal of the Data and Surveillance Workgroup is to establish and maintain an active surveillance system for patients with sickle cell disease in Louisiana. The main objective for this workgroup is to contribute to 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.

Case Management Data System

The Genetic Diseases Program implemented a case management data platform to be utilized by the OPH Sickle Cell Program and the Sickle Cell Foundations to record individual-level services. The platform is expected to eliminate the need for data entry into multiple systems and will facilitate tracking and monitoring service provision, client needs, and caseloads. The system will also help the state and foundations understand and quantify needs for services and support overall.

The Data and Surveillance Workgroup strategies for SFY 2023 are to:

1. Analyze Medicaid claims-level data to assess utilization and gaps.
2. Assess possible data reporting needs related to clinical outcomes as a part of the development of the SCD registry.
3. Identify other data reported to or collected by the state and existing health information exchanges that may be useful for monitoring and addressing population-level health, the quality and accessibility of healthcare services, and individual-level needs.

2021 & 2022 Legislative Actions

2021 Regular Session of the Louisiana Legislature

[Senate Concurrent Resolution No. 66](#)

The resolution urges and requests LDH to address regulatory barriers that impede patient access to novel therapies for SCD, and to work to ensure that sickle cell patients in the Louisiana Medicaid program have access to potentially curatives therapies. (Bill author: Senator Regina Barrow)

2022 Regular Session of the Louisiana Legislature

[House Bill No. 163](#)

The bill creates the “Sickle Cell Disease Association” special prestige license plate. (Bill author: Representative Tammy Phelps)

[Senate Bill No. 298](#)

This act, also known as the “Lorri Burgess’ Law”, requires LDH 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 that are eligible for coverage under the Louisiana Medicaid program. It requires LDH

to determine if the available covered medications, treatments, and services are adequate to meet the needs of enrollees or whether LDH should seek to add additional medications, treatments, or services. (Bill author: Senator Regina Barrow)

[House Bill No. 968](#)

The bill requires LDH to establish and maintain a sickle cell disease registry to be known as the “Skylar-Cooper Database” which shall function as a repository of accurate, complete records to aid in the cure and treatment of sickle cell disease. (Bill author: Representative Tammy Phelps)

[House Concurrent Resolution No. 76](#)

The resolution expresses the support of the legislature for equitable access to transformative therapies for SCD. (Bill author: Representative Tammy Phelps)

Conclusion

With the improvements implemented and the legislative actions in SFY 2021 and 2022, Louisiana is poised for significant change in the systems that are charged with helping to ensure that individuals diagnosed with sickle cell disease live long, productive lives. The LSCC continues to improve the quality of life for individuals with sickle cell through improvements in medical care coordination, surveillance, patient navigation, advocacy, and education on enhancing the delivery of sickle cell services in Louisiana. This report summarizes the Louisiana Sickle Cell Commission's SFY 2021 and 2022 activities and outlines strategies the LSCC will undertake in SFY 2023 to strengthen the systems of care and support for individuals living with sickle cell disease in Louisiana.

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

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

Chauncey Hardy, 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

Torris Johnson, 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, Ph.D., LCSW, Northeast Louisiana Sickle Cell Anemia Technical 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 University 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
Nora McCarstle, RN, BSN, LDH OPH Bureau of Family Health
Gail Gibson, RN, BSN, MN, CPM, FABC, LDH OPH Bureau of Family Health
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
Chelsea Carter, MPH, LDH OPH BFH Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program
Albaney Gray, LDH OPH-BFH Genetic Diseases Program MCH Scholar
Caroline Werenskjold, LDH OPH BFH Genetic Diseases Program MCH Scholar
Kera Simmons, MPH, LDH OPH BFH Genetic Diseases Program
Jantz Malbrue, MSPH, LDH OPH BFH Genetic Diseases Program

Appendix B: LSCC Meeting Schedule & Minutes

The dates below link to the LSCC's published agendas and minutes, featuring attending members and guests:

[July 29, 2020](#)

[October 27, 2020](#)

[December 8, 2020](#)

[June 10, 2021](#)

[May 24, 2022](#)

Appendix C: [Revised Statute 40:2018.3](#)

§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

www.ldh.la.gov



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