SFY 2020 Legislative Report on the Louisiana Sickle Cell Commission

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

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LOUISIANA
DEPARTMENT OF HEALTH

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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.

This Legislative Report on the LSCC reflects accomplishments from activities of State Fiscal Year 2020 (SFY 2020), from July 1, 2019 to June 30, 2020. The report emphasizes the impact of sickle cell disease throughout the state and care coordination efforts amongst the LSCC, Office of Public Health (OPH), stakeholders, and 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.

In Memoriam

The OPH-Bureau of Family Health (OPH-BFH) Genetic Diseases Program and the LSCC would like to commemorate and honor the lives of three pioneer members of the LSCC and influential advocates who passed away during this SFY. Ms. Lorri Burgess was the Executive Director of the Sickle Cell Association of South Louisiana in Baton Rouge and served as the Chair of the LSCC since its inception in 2013. Ms. Burgess was an integral voice in the sickle cell community, as indicated by the annual Ryan's Run's event. Ms. Etta Pete was the Executive Director of the Southwest Sickle Cell Anemia, Inc. for over 14 years. Ms. Pete's advocacy led to supportive community services throughout the Lake Charles and Lafayette areas. Ms. Lillie Bradford was the Executive Director of the Sickle Cell Disease Association of America, Northwest Louisiana Chapter in Shreveport, for 23 years. Ms. Bradford was a leader in her community and previously served as Chair of the Louisiana Association of Sickle Cell (LASCA).

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. Also, 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 efforts have greatly improved the identification of SCD, leading to advancements in treatment, significantly improving patients' life expectancy well into their sixties with the proper resources.[2]

According to data from the Louisiana Sickle Cell Registry created by the Louisiana Newborn Screening Program, 77 infants were born with a hemoglobin disorder in SFY 2020. Of that total number, 70 newborns were diagnosed with the presence of Hemoglobin S, the most serious variant, during this period. Also, 1,934 infants were born as carriers of a hemoglobin disorder in SFY 2020. A majority of the infants identified as carriers (n=1,434) were diagnosed with sickle cell trait. The remaining infants identified as carriers included 413 hemoglobin C trait, 65 hemoglobin variant trait, 10 hemoglobin D trait, and 33 hemoglobin E trait. Although previous initiatives coordinated through the LSCC gradually improved medical services throughout the state, the care system for individuals with SCD needs further support, especially from Medicaid. The "Geography of Sickle Cell Disease within Louisiana Medicaid" was a report produced in 2014 that indicated that the average cost of care for individuals with SCD with Medicaid in 2013 was nearly three times as much as the overall average cost of care for all individuals with Medicaid.[3] The document detailed the average cost of Medicaid per person without a SCD diagnosis, the average cost of SCD related claims, and the average cost of SCD related emergency room claims per member in the calendar year 2013. Additional data analysis of SCD related claims is being conducted by the LDH OPH Bureau of Health Informatics to determine the overall cost of care between 2014 and 2020.

Sickle Cell Programs and Activities

The OPH-BFH Genetic Diseases Program, provides two core functions related to SCD: newborn genetic screening and oversight of the safety-net, state-assisted Sickle Cell Clinics in New Orleans, Lake Charles, Shreveport, Alexandria, and Monroe. Also, the program works closely with private-funded sickle cell clinics in Baton Rouge, Lafayette, Lake Charles, and Alexandria. As the federally mandated newborn heel stick screening program administrator, the OPH-BFH Genetic Diseases Program ensures access to sickle cell genetic evaluation and counseling to Louisiana residents. In SFY 2020, 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 amount of families refused the screening test). The OPH-BFH Genetic

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[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.

[3] Bilbo, R., & Baifu, X. (2014). The Geography of Sickle Cell Disease within Louisiana Medicaid: Population, Claims, and Costs (CY 2013).

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 rural parts of the state.

Sickle Cell Foundations are community-based organizations that assist individuals throughout the state with SCD. The OPH-BFH Genetic Diseases Program funds five Sickle Cell Foundations 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 OPH-BFH Genetic Diseases Program subcontracts with these five Sickle Cell Foundations to ensure all infants diagnosed with SCD through the newborn screening program are linked to appropriate care upon diagnosis.

In order 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. Adverse health outcomes could lead to infection, acute chest syndrome, and stroke, as indicated by numerous emergency room visits and hospitalizations.

Despite ongoing efforts of the OPH-BFH 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 continue to send part-time community health workers to 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 increased their collaboration with Medicaid MCOs to provide existing enrollees with support and education on available resources. Pharmaceutical companies expanded their efforts to educate healthcare providers to connect patients with current and developing therapies.

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 wasn't a mechanism to monitor the efficacy of community support services. The OPH-BFH Genetic Diseases Program secured funding for a case management data system in SFY 2020 to be used by the Sickle Cell Foundations and gradually integrate with other case management systems. User training has begun, and full implementation of the Sickle Cell Foundations system will start in SFY 2021. Other case management systems are scheduled for integration in SFY 2022. The case management system will integrate the Louisiana Sickle Cell Registry, monitor clinical indicators, and assess medical services' effectiveness throughout the state. The system aims to reduce service duplication, disruption in the continuum of care, and loss of patients to follow-up, ultimately leading to an integrated health information exchange.

Louisiana Sickle Cell Commission

Act No. 117 (Senate Bill 57) of the 2013 Regular Legislative Session 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.

The eleven members of the LSCC includes representatives from LDH, Louisiana Primary Care Association (LPCA), Children's Hospital of New Orleans, Tulane University School of Medicine, and each of the five regional Sickle Cell Foundations. Key partners and stakeholders attended the LSCC meetings and provided expertise to strengthen care for the SCD community in Louisiana. Under the legislative mandate, the Commission held quarterly meetings at the LDH headquarters in Baton Rouge throughout SFY 2020 (for a list, see Appendix A).

In 2014, the LSCC developed a strategic plan to fulfill legislative mandates and improve the health outcomes of individuals living with SCD in Louisiana. This plan continues to be implemented 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 which will be included in the report for SFY 2021.

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:

1. Improve access to acute pain treatment;
2. Improve chronic pain management;
3. Create a patient-centered medical home; and
4. Improve access to specialized sickle cell outpatient care.

Provider Education

In efforts to improve care quality, several educational events for providers were conducted to disseminate current best practices for medical protocols and pain management techniques. These events included:

- Hematologists at the Children's Hospital in New Orleans coordinated oncology and sickle cell seminars for providers to interact and learn from hematologists and individuals with SCD.
- In New Orleans, Ochsner Health Center hosted guest lecturer, Dr. Lakshmanan Krishnamurti, from the Children's Hospital and Aflac Cancer Center in Atlanta to discuss current clinical trials in bone marrow transplant and gene therapy for sickle cell during pediatric grand rounds.

- Ochsner Health Center collaborated with the OPH-BFH Genetic Diseases Program in identifying the adherence rate to the recommended immunization schedule for children diagnosed with SCD compared to children without in the New Orleans metro region.
- The team of physicians, nurse practitioners, nurses, and social workers at Our Lady of the Lake and St. Jude held an event in Baton Rouge for other providers to learn about their pediatric and adult sickle cell programs and their methods for treating patients.
- Hematologists at the LSU Health Sciences Center Shreveport conducted a symposium on updated medical protocols and pain management techniques for treating adults with SCD.
- Telehealth practices were initiated and utilized by all regional pediatric and adult sickle cell clinics and Medicaid MCOs to sustain continuity of care during statewide restrictions in response to COVID-19.

The Medical Services Workgroup strategies for SFY 2021 are:

1. To implement monthly video conferencing seminars to increase multidisciplinary learning regarding treatment options for providers, youth, and adults with SCD;
2. To investigate the emergency department protocols to determine the average wait time before the initiation of treatment for individuals with SCD experiencing a pain crisis; and
3. To establish pain management and medication subscription protocols for youth and adults with SCD based on national standards.

Patient Navigation Workgroup

The goal of the Patient Navigation 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 for this workgroup include:

1. Establish confidence and trust with clients and families;
2. Establish partnerships with agencies and medical professionals; and
3. Establish advocacy and support groups for clients.

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.

Act No. 387: Patient Navigator Program

In 2015, Act 387 was signed into law, officially launching the Sickle Cell Patient Navigation Program with implementation contingent upon appropriated funds. According to the legislation, the Sickle Cell Patient Navigator Program will "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:

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

Patient Navigator Program-Implementation

Currently, the program is not operational as funds have not been appropriated by the Legislature. The budget for the implementation of the program is estimated to be $440,000, which includes personnel, training, and administrative costs. The program can be enacted as outlined in statute once funds are appropriated. Members of the LSCC continued to promote the Patient Navigator Program to State Legislators in Districts 2, 15, 16, 17, 26 and 34 and encouraged them to appropriate funds as part of their legislative agendas. The absence of adequate patient navigation increases the number of health inequities and disparities encountered by individuals living with SCD. Implementation of the program would enhance the ability of the current Sickle Cell Clinics and Sickle Cell Foundations to successfully engage and provide sustainable medical and supportive care to patients and families who are not being served through the Medicaid MCO programs.

The program would require: 1) training patient navigators to serve as outreach coordinators, coordinators of family educational sessions, and patient case managers; 2) establishing and strengthening a continuum of care for each sickle cell patient served by the program and for those patients' families; 3) identifying and contacting sickle cell patients, conducting home visits with patients and their family members and coordinating patient care; and 4) facilitating collaboration among healthcare providers that serve sickle cell patients. The OPH-BFH Genetic Diseases Program and LSCC plan to request funding through the department's annual budget process for new and expanded funding in order to implement the Sickle Cell Patient Navigator Program as mandated in HB 260 of the 2015 Legislative Session.

The Patient Navigation Workgroup strategies for SFY 2021 are:

1. To secure funding in the OPH-BFH Genetic Diseases Program to support contracts with the Sickle Cell Foundations to implement patient navigators;
2. To expand navigation resources to regions without an established foundation; and
3. To identify and outreach to providers delivering SCD services to strengthen the medical home model within all state regions.

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:

1. Establish statewide print and media campaign to be inclusive of all activities;
2. Coordinate with Louisiana Sickle Cell Association (LASCA) for Annual Sickle Cell Disease State Conference;
3. Establish a Community Based Organization (CBO) section on the LDH website; and
4. Assemble 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.

Governor's Spotlight

The ninth anniversary of World Sickle Cell Awareness Day was June 19, 2019. The Sickle Cell Disease Association of America, Inc. established the 'Shine the Light on Sickle Cell" as a national initiative to bring attention to the disease. Governor Jon Bel Edwards commemorated the day by shining red lights on the Governor's Mansion. The tradition was on schedule to continue in June 2020; however, restrictions due to COVID-19 caused the event's postponement.

Awareness Events

Since Congress designated September as National Sickle Cell Awareness Month, the Sickle Cell Foundations have dedicated their efforts to increasing awareness and engaging stakeholders on research and treatment. The Sickle Cell Association of South Louisiana hosted its annual Ryan's Run and gala in Baton Rouge. The Southwest Sickle Anemia, Inc. showcased a documentary at the public library in Lake Charles on a local individual who recently lost his battle with SCD. The Sickle Cell Anemia Research Foundation, Inc. held its annual black-tie fundraiser for the Alexandria region. The Sickle Cell Disease Association of American Northwest Louisiana Chapter organized its yearly awareness radiothon and charity softball game in Shreveport. The Northeast Sickle Cell Anemia Foundation hosted its annual banquet to raise funds to support SCD initiatives in the Monroe area.

COVID-19 Awareness

As the increase of COVID-19 cases impacted the state, the OPH-BFH Genetic Diseases Program disseminated national resources for providers, families, and schools. Sickle Cell Disease Association of America distributed an outline to decrease the burden and minimize morbidity due to COVID-19 for providers. The tool highlighted treatment options for individuals with SCD who tested positive for COVID-19 and strategies to improve clinic flow to meet transfusion demands. An additional resource highlighting preparedness recommendations was created for patients and caregivers and distributed by partners throughout the state.

The Education and Advocacy Workgroup strategies for SFY 2021 are:

1. To increase the frequency of statewide educational campaigns outside of national sickle cell awareness month to enlighten the legislature and communities;
2. To expand participation in grand rounds to educate healthcare professionals and highlight solutions to overcome challenges within the system of care;
3. To research the effectiveness of emerging gene therapies and prescription options available through MCOs, pharmaceutical companies, and biotechnology companies to educate the legislature and stakeholders on behalf of youth and adults living with SCD.

Data & Surveillance Workgroup

The goal of the Data and Surveillance Workgroup is to maintain an active surveillance system for patients with sickle cell disease in Louisiana. Objectives for this workgroup include:

1. Develop surveillance system/registry for the tracking of SCD in Louisiana with the following info:
    - 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; and
    - Mortality rates, including case fatality rates for individuals with SCD.

A registry of all persons with an abnormal hemoglobin result for SCD on their newborn screen over the past 20 years was a collaborative effort between the OPH-BFH Genetic Diseases Program and the LSCC. At the end of SFY 2020, the Sickle Cell Registry contained 2,451 total SCD cases, reflecting all cases detected through newborn screening between 1978 and 2020.

Case Management Data System

The Sickle Cell Registry provides a comprehensive inventory of SCD in the state; however, a more robust data system is needed to increase client-level data reporting to support more coordinated care as well as to inform policy and decision-making. As noted in the Care Coordination section, OPH BFH has been working with a vendor to establish a client-level data system. In addition to enhancing statewide monitoring and surveillance efforts, the case management system will be used to record care coordination activities and track outcomes. The anticipated implementation of the case management system is SFY 2021.

Medicaid Surveillance System

The registry and upcoming case management system provide a snapshot of the population diagnosed with SCD and services provided through sickle cell providers; however, they do not incorporate healthcare utilization or costs of care. The OPH-BFH Genetic Diseases Program collaborated with the LDH Bureau of Health Informatics to analyze population-level trends in patient care and clinical utilization costs through a surveillance system designed to identify IC9 & ICD10 codes associated with SCD in Medicaid. The LDH Bureau of Health Informatics generated a list of individuals with a sickle cell diagnosis and related Medicaid claims. The client-level data contain demographic information and the funding spent on each sickle cell-related and non-sickle cell-related claims for calendar years 2014 through 2017. The surveillance system was created utilizing parameters from the 2014 report titled "Geography of Sickle Cell Disease within Louisiana Medicaid". Starting in SFY 2021, client-level data will be reviewed quarterly by the OPH-BFH Genetic Diseases Program to monitor utilization trends and costs associated with inpatient, outpatient, home health, transportation, dental, and pharmacy claims. By the end of SFY 2021, the OPH-BFH Genetic Diseases Program anticipates producing summary reports with policy recommendations by July 1 each year to support budget needs for the following fiscal year.

Sickle Cell Trait Registry

The Sickle Cell Trait Registry has expanded since its creation in 2017. The identification of individuals diagnosed as sickle cell trait carriers has assisted with care coordination and community outreach. These efforts have fostered a movement to increase the awareness of individuals' statuses and educating parents about the importance of family testing.

SECURE-SCD Registry

The Medical College of Wisconsin created a registry to track all cases of COVID-19 for patients with sickle cell disease throughout the United States and the world. Clinicians were encouraged to report all cases of COVID-19 in their patients with SCD, regardless of severity (including asymptomatic patients detected through public health screening), to the Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE)-SCD registry. The project website provided frequently updated summary information about reported cases, including numbers of patients by state, the number of cases by treatment, and more. The entire SCD community had access to the data indicators. The project reported 9 cases of COVID-19 among the SCD population in Louisiana during the SFY 2020.

The Data and Surveillance Workgroup strategies for SFY 2021 are:

1. To launch the new case management system to monitor care coordination, health outcomes, and utilization trends;
2. To analyze client-level Medicaid surveillance data to determine clinical utilization costs for sickle cell-related claims throughout the state; and
3. To research the impact of the LSCC's strategies on the patient retention rate for clinical appointments and emergency department usage.

Legislative Proposals

In the fall of 2019, LSCC recommended updates to the original LSCC legislation for the 2020 Regular Session of the Louisiana Legislature. Act 117, establishing LSCC, requires the LSCC to hold its meetings at the Bienville Building in Baton Rouge. Since the LSCC is a statewide collaborative with members from all regions, the lack of flexibility in meeting location has made it difficult for all members to attend in-person. Removing the LSCC's meeting requirement at the Bienville Building would allow members to be more productive and collaborative in performing the legislatively mandated work while rotating the meeting location. In addition, changes were proposed to update the membership to include the addition of hospital and patient representatives as members. These changes would increase the expertise on the Commission and help LSCC meet the charges of the workgroups.

Representatives Larvadain, Carter, and Cox introduced House Bill No. 591, and it passed with amendments detailed in Appendix D within the report. Under HB 591, LSCC may now hold its public meetings in other locations. The legislation added five additional members, including a person diagnosed with SCD, a parent of a person diagnosed with SCD, two medical professionals who treat SCD, and a Medicaid representative while removing appointed nominees from the Senate and House of Representatives. The total number of appointed members for the LSCC increased to 17. The amendments will go into effect in SFY 2021.

Conclusion

With the improvements implemented in SFY 2020, individuals diagnosed with sickle cell disease are living longer productive lives, and reducing the medical costs on the state's medical infrastructure due to better management of their care. LSCC continued to improve the quality of life for individuals with sickle cell through medical care coordination, surveillance, patient navigation, advocacy, and education on enhancing the delivery of sickle cell services in Louisiana. This report summarized the Louisiana Sickle Cell Commission's SFY 2020 activities and outlines strategies the LSCC will undertake in SFY 2021 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

Attendees and Participants at the Louisiana Sickle Cell Commission Meetings

Appointed Members

Chair, Lorri Burgess, Sickle Cell Association of South Louisiana
Vice-Chair, Pamela Saulsberry, Ph.D., LCSW, Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.
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
Jerry Paige, Sickle Cell Disease Association of America, Inc.-Northwest Louisiana Chapter
Etta Pete, Southwest Louisiana Sickle Cell Anemia, Inc.
Chauncey Hardy, Sickle Cell Anemia Research Foundation, Inc.
Cheryl Harris, MPH, Secretary of the Department of Health Designee
Vacant, One member of the Louisiana Senate
Vacant, One member of the Louisiana House of Representatives

Partners and Stakeholders

Lillie Bradford, Sickle Cell Disease Association, Northwest Louisiana Chapter
Donna Thaxton, Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.
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
Karen Odoms Johnson, Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine
Kathy Williams, Sickle Cell Association of South Louisiana
Torris Johnson, Sickle Cell Association of South Louisiana
Rajasekharan Warrier, M.D., Ochsner Health Center for Children
Jensine Speed, LMSW, Our Lady of the Lake Physician Group
Courtney Sanford, Louisiana Primary Care Association
Raymond Poliquit, M.D., Healthy Blue

Annie Garnier, MBA, Healthy Blue
Latarsha Carter, RN, BSN, Healthy Blue
Ginny Martinez, Novartis
Karen Grevemberg, MBA, BSN, RN, UnitedHealthcare
Sylvia Rugg, 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.
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, OPH Bureau of Family Health
Gail Gibson, RN, BSN, MN, CPM, FABC, OPH Bureau of Family Health
Rachelle Boudreaux, MA, OPH Bureau of Family Health
Chelsea Carter, MPH, LDH OPH-BFH Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program
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:

June 11, 2019

September 10, 2019

December 10, 2019

March 25, 2020

Appendix C: RS 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.

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