DEPARTMENT OF HEALTH AND HOSPITALS

THE LOUISIANA SICKLE CELL COMMISSION

REPORT PREPARED IN RESPONSE TO ACT 117 (SB57) OF THE 2013 REGULAR LEGISLATIVE SESSION

JANUARY 2016

Contact:
Louisiana Department of Health and Hospitals
Matthew Valliere, MPA
Office of Public Health
628 North Fourth St., 3rd Floor Baton Rouge, LA 70802
225.342.2655
Matthew.Valliere@la.gov

EXECUTIVE SUMMARY

Act 117 (SB57) of the 2013 Regular Legislative Session requires the Department of Health and Hospital to form the Louisiana Sickle Cell Commission. Act 117 outlines membership on the commission and the function of the committee. 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.
- Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.
- 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 and Hospitals or a Designee
- One member of the Louisiana Senate
- One member of the Louisiana House of Representatives

The functions of the committee are to: 1) Ensure delivery of sickle cell services to affected person in all parishes in Louisiana and assist in establishing geographical service delivery boundaries, 2) Promulgate guidelines for creating uniformity of service delivery to sickle cell patients, 3) Submit budget recommendations to the legislature and the governor, prepare and publish an annual report on sickle cell.

The commission has formed the following workgroups that will focus on the mandates outlined in the Act: Medical Services, Patient Navigation, Education & Advocacy, Data & Surveillance and Budget. The report below details the membership of the commission and the activities undertaken by the workgroups in the second year of the commission.

THE LOUISIANA SICKLE CELL COMMISSION

INTRODUCTION

Each year, approximately 80 infants are born with Sickle Cell Disease (SCD) in Louisiana. It is estimated that there are approximately 3000 children and adults living with SCD in the state.

In the past, the life expectancy for patients living with SCD was not much past the twenties. However, with improved identification and treatment, the life expectancy has greatly improved and patients can live well into their 60s with the proper resources. However, the provision of the proper resources for patients with sickle cell disease is limited.

Because of unstructured service delivery, Sickle Cell Disease has placed a tremendous burden on medical services, especially with Medicaid. Sickle Cell Disease (SCD) was the top diagnosis category with readmissions for Louisiana Medicaid patients in 2011 – of 1,630 Medicaid discharges, 313 (19.2%) resulted in readmissions. 77.7% of readmissions were for adult patients over the age of 18. Of the 1,630 Medicaid SCD discharges from inpatient settings, 17.25% of the SCD discharges involved behavioral health co-morbidities.

Due to the increase in SCD life expectancy, the adult SCD population is considered a relatively new population and is growing. Currently, there are very few resources and a lack of access to care for adult SCD patients in Louisiana:

- Few adult hematologists specialize in the care of SCD patients.
- Preventive and specialized acute and non-acute services for SCD patients are limited due to low Medicaid reimbursement rates.
- Adult patients experience difficulty obtaining insurance coverage once they turn 18 due to the gap in time before they are covered by Medicaid.
- There are almost no programs geared toward individuals who are transitioning from the pediatric to the adult SCD treatment arena.

While access to care for SCD is typically not an issue for pediatric patients, the following additional opportunities for intervention have been identified for the pediatric and adult SCD populations as a whole:

- Currently no registry/database or program exists to track SCD patients throughout their lifetime to ensure that they are not lost to follow-up.
- There are deficits in SCD patient and family education and engagement in both the pediatric and adult populations.

The overall goal of the Louisiana Sickle Cell Commission (LSCC) is to address these concerns and formulate actions to reduce the burden of SCD in Louisiana.

Commission Members

The following individuals have been appointed by the Governor to represent the organizations outlined in the Act:

Organization	Representative
• The Sickle Cell Center of Southern Louisiana – Tulane University School of Medicine	Dr. Tamuella Singleton
• Children's Hospital – New Orleans	Dr. Renee Gardner, ***Co-Chair***
• The Louisiana Primary Care Association	Tonia Canale
• The Baton Rouge Sickle Cell Anemia Foundation, Inc.	Lorri Burgess, ***Chair***
• Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.	Dr. Pamela Saulsberry
• Sickle Cell Disease Association of America, Inc.- Northwest Louisiana Chapter	Jerry Paige
• The Sickle Cell Anemia Research Foundation, Alexandria	Rosia Metoyer
• The Southwest Louisiana Sickle Cell Anemia, Inc.	Etta Pete
• The Secretary of the Department of Health and Hospitals or a Designee	Hugh Eley
• Louisiana Senate	Senator Yvonne Dorsey-Colomb
• Louisiana House of Representatives	Awaiting new appointee

Partnerships

Along with the organizations and individuals appointed by the Governor, other state agencies and stakeholders have attended the commission's public meetings. Partnerships include Louisiana Medicaid, Bayou Health Plans, Genetic Diseases Program, Title V Children and Youth with Special Health Care Needs Program, LSU Medical Centers (New Orleans and Shreveport) and private citizens affected by SCD.

Meetings

Meetings during year two of the Sickle Cell Commission were all held at the Department of Health and Hospitals' Bienville Building. Meeting dates for year two were:

- December 9, 2014
- February 10, 2015
- May 12, 2015
- August 11, 2015

Workgroup Activities

The workgroups within the LSCC has implemented ideas and initiatives designed to improve the health outcomes of people living with SCD in Louisiana during the past year. Below are the workgroups and a brief description of the activities which have been conducted to meet the goals/objectives established for the 2015 calendar year:

1. **Medical Services**

   Goal: to improve medical access and care for people with sickle cell disease while reducing health care cost in Louisiana

   Objectives:

   a) improve access to acute pain treatment
   b) improve chronic pain management
   c) create a patient centered medical home
   d) improve access to specialized sickle cell outpatient care

   Year Two Activities:

   a) Dr. Renee Gardner developed a Standards of Care toolkit for physicians across the state to follow as best practices for treating patients with SCD. Dr. Gardner is implementing final touches and the toolkit will be submitted to DHH's Bureau of Media and Communication (BMAC) for review. Once approved, the toolkit will be distributed to pediatricians, family practitioners and other primary care providers who might treat patients with SCD.
   b) The LSCC is working with medical facilities in each region to perform transcranial dopplers (TCDs). TCD is a non-invasive ultra sound that detects stroke risk which is higher in children with SCD.
   c) Dr. Gardner provided information on SCD service delivery in Louisiana. Over 50% of the physicians who responded indicated that they not want to provide care for patients with SCD.
   d) Bayou Health Plans

      (1). Aetna Better Health

      Aetna Better Health of Louisiana implemented a program of Case Management for Sickle Cell Disease in May of 2015. The program identifies adult member's ages 18 through 65 years through referrals from providers, community agencies, members, internal staff and our HRQ/HRA tools as well as through Medical and Pharmacy Claims for Sickle Cell disorders and treatments. Case Management outreach is then undertaken and, depending on member knowledge about the condition and about treating provider access and also depending on the availability of support structures, the member is enrolled in Intensive or Supportive Case Management. The Individualized Care Plan is constructed to ensure that the member is availing themselves of appropriate standards of care as documented in NHLBI Guidelines.

(2). AmeriHealth Caritas

ACLA's 2015 Sickle Cell initiatives: ACLA organized a Regional Sickle Cell Readmission Task Force, comprised of Regional Medical Directors, Pharmacy and Director of Integrated Health Care Management (IHCM), with the objective to reduce preventative hospital readmissions.

1. ACLA IHCM conducted targeted monthly outreach to high-risk Sickle Cell members utilizing medical informatics reporting.
2. Hydroxyurea initiative – ACLA provided physicians with updated evidenced-based clinical guidelines on the management of Sickle Cell Disease based on Expert Panel Reports released by the NIH. ACLA also provided providers with a list of their members who were potential candidates for Hydroxyurea and/or penicillin prophylaxis.
3. ACLA IHCM collaborated with Our Lady of the Lake Regional Medical Center to gain knowledgeable regarding their Sickle Cell Transition Program Services.
4. ACLA developed and implemented a Sickle Cell Hydroxyurea screening survey tool to identify members found non-compliant with their Hydroxyurea medication regimen.
5. ACLA IHCM and Community Education teams issued educational items, including magnets, water bottles, and medication bags, to members with sickle cell diagnosis to promote treatment compliance.
6. ACLA posted a Sickle Cell Disease webpage including member educational materials.
7. ACLA referred members to and coordinated care with the LSU Tele-Health program to provide Sickle Cell specialists.

(3). Amerigroup Real Solutions

Amerigroup Louisiana's Sickle Cell Management Program was developed to provide secondary and tertiary crisis prevention interventions and condition specific management, based on a comprehensive, multidisciplinary, system-wide approach that encompasses evidence-based guidelines, provider practice, and member empowerment strategies all in an effort to improve members' health outcomes. Amerigroup's complex case and disease managers provide active care coordination to all identified members with Sickle Cell Disease who have consented to services.

The objectives fulfilled through the program are as follows:

- Improve the understanding of the disease process
- Improve member quality of life
- Collaborate to develop member-centered goals and interventions
- Support relationships between members and network providers
- Reduce acute episodes requiring emergent or inpatient care

(4). Louisiana Healthcare Connections:

Louisiana Healthcare Connections (LHC) utilizes a formalized, evidence-based program to address quality of life issues for members with sickle cell disease. LHC's Sickle Cell program provides health education, engages members in care management and offers care coordination services. Additionally, the program promotes the

appropriate use of Hydroxyurea (a medication used to reduce sickle cell crisis) and on-going medication adherence.

LHC has seen significant, meaningful improvement for members participating in care management:

- 155% increase in Hydroxyurea use among members in care management for sickle cell, from 2014 to 2015.
  - 40.4% of these members filled scripts for Hydroxyurea in 2015, compared to only 15.79% in 2014.
- 31% of members (187 members) with sickle cell have participated in care management.

(5). UnitedHealthcare (See attached Exhibit 1 – Optum Sickle Cell Program)
Sickle Cell Disease (SCD) Model:

1. Identification of all the members living with SCD, both pediatric and adults
2. Provide longitudinal telephonic and face to face care management support to address medical, behavioral, and socio-economic needs of SCD members
   a. Trained specialized nurses and SCD Medical Director for program development and clinical support
3. Medical Home Model
   a. Strong member and provider partnerships on a longitudinal basis to improve outcomes
   b. Develop networks of hematologists and primary providers, community based organizations, with utilization of community health workers for face to face engagement
   c. Focus is on care management to help SCD members live a quality life by
      i. Medication Adherence - Immunizations, Penicillin, Hydroxyurea, Transfusions
      ii. Transition Management
      iii. Pain Management - Reduced episodes of pain crisis, iron overload, strokes
      iv. Reduced ER visits and inpatient stays
      v. Address barriers to care
         1. Transportation, housing, getting recommended tests and medication, compliance with follow-up visits, and decreasing avoidable ED, inpatient visits
4. Analytic support to measure program success
   a. % of members engaged in program
   b. Hydroxyurea use and adherence
   c. Decrease in ED and inpatient stays and costs

2. Patient Navigation

Goal: 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:

a) Establish confidence and trust with clients and families
b) Establish partnerships with agencies and medical professionals
c) Establish advocacy and support groups for clients

Year Two Activities:

a) HB 260 (2015 Regular Session) Establishment of the Sickle Cell Patient Navigator Program – At the request of the LSCC, the late Rep. Alfred Williams proposed legislation to provide for the program and the functions of the program which include:
   - Training of patient navigators to serve as outreach coordinators, coordinators of family educational sessions and patient case managers
   - Establishing and strengthening a continuum of care for each sickle cell patient served by the program and for the families of those patients
   - Identifying and contacting sickle cell patients, conducting homes visits with patients and their family members and coordinating patient care
   - Facilitating collaboration among healthcare providers that serve sickle cell patients
   - Delivering public health education on sickle cell disease and treatment

b) Development of Sickle Cell Apps – LSCC is looking into phone apps that would help patients with SCD manage their condition. The apps would be beneficial in tracking important health measures for SCD patients such as hydration, compliance, physical activities, ER protocols and sleep. The apps would also be designed so that health providers, social workers and the SCD foundations can access patient information.

3. Education & Advocacy

Goal: To educate citizens and other stakeholders on Sickle Cell Disease

Objectives:

a) Establish statewide print and media campaign to be inclusive of all activities.
b) Coordinate with Louisiana Sickle Cell Association (LASCA) for Annual Sickle Cell Disease State Conference.
c) Establish a Community Based Organization (CBO) section on DHH website.
d) Assemble a sickle cell disease state-wide informational publication, to include PSAs (video/audio) and directory, featuring each state agency/organization.

Year Two Activities:

a) The LSCC partnered with the Louisiana Primary Care Association (LPCA) to present topics relevant to SCD at LPCA's Medical Summit. The summit was held May 29-30, 2015. Over 100 medical providers, clinicians and those affected by SCD were presented with material regarding understanding the disease, transitional services for youth and standards of care.
b) LSCC Brochure: a brochure is being developed that outlines the purpose of the commission and provides more information on the SCD foundations located throughout the state. Once approved by BMAC, this information will be presented to Bayou Health Plans, clinicians and families affected by SCD to garner greater public input to the commission.

4. Data & Surveillance

Goal: To maintain an active surveillance system for Sickle Cell Disease patients in Louisiana.

Objectives:

Develop surveillance system/registry for the tracking of sickle cell disease in Louisiana with the following info:

a. Demographics characteristics and geographic distribution of sickle cell patients in Louisiana
b. Health care utilization, costs of care, and the geographic variation of specific services
c. Mortality rates, including case fatality rates for individuals with sickle cell disease;

Year 2 Activities:

Sickle Cell Registry – The LSCC worked with the Office of Public Health's Genetic Diseases Program to develop a registry of all persons who had a newborn screen for SCD over the past 20 years. The registry lists the names and addresses for each person screened. This information will be matched with Medicaid data to see which patients are in care and with Vital Records to determine which patients are deceased. The registry will be broken into regions and provided to the foundations so that patient navigators can determine what services are needed for each patient.

5. Budget Recommendation

Goal: The Sickle Cell Commission would like to recommend the development of a Statewide Case Management Platform that will be able to be utilized by all Sickle Cell Foundations to track the care of current Sickle Cell patients. The Commission has researched and received a quote for system development in the amount of twenty-seven thousand dollars ($27,000).

Objectives:

To strategize and successfully implement the creation of a new website; to produce a clean and professional user-friendly experience, that is both easily manageable and built to expand. The initial project will feature an intake management tool for new applicants, provide a streamlined process for cross-referencing applicants on a local and statewide basis, and render report data into a CVS file for comparative research and grant support.

Features:

- Data Entry Components
- Searchable Data Retrieval Database
- Reporting
- Multi-Level Management Controls
- SSL Security Encryption
- Mobile Compatibility

CONCLUSION

If managed properly, patients with Sickle Cell Disease can live longer, productive lives and reduce the burden of medical costs on the medical infrastructure of the state. The Louisiana Sickle Cell Commission has made strides during the past year to appropriately address the goals established in the annual work plan for the Commission. It is recommended that funds be made available to the Louisiana Sickle Cell Commission to carry out the activities outlined in the work plan.

Acknowledgments

Authors:
Matthew Valliere, Deputy Director
Office of Public Health
Center for Community and Preventive Health (CCPH)

Cheryl Harris, Administrator
Office of Public Health
CCPH – Genetic Diseases Program

Louisiana Department of Health and Hospitals
Rebekah E. Gee MD, MPH, Secretary
Michelle Alletto, Deputy Secretary
Jeff Reynolds, Undersecretary
Dr. David Holcombe, Assistant Secretary – Office of Public Health

Optum Sickle Cell Program

Our sickle cell program is an integrated model to identify and engage sickle cell disease (SCD) members for appropriate guidance on medical, behavioral, and socio-economic needs. This is a lifelong condition the members are born with so the program focuses on increased engagement by field based approach (Community Health Workers) and continued case management interventions for life. This will help members with SCD manage their illness leading to an improved quality of life. Early identification of these members when they are young and successful management of the condition will reduce likelihood that members will seek health care services in an inappropriate setting, such as ER and inpatient hospitalization.

Our national clinical team has significant experience managing the care of members with SCD so they understand the unique needs of these members. We have leveraged the team's expertise to develop a comprehensive SCD program that enhances the care coordination by collaborating with Person Centered Clinical Model (PCCM), Behavioral Health team, Accountable Care Communities, Medical Mall, Health Homes to offer timely SCD specific interventions tailored to individual member needs. Our SCD program addresses the challenges unique to each stage of life, from newborn through adulthood, to mitigate disease progression and complications and improve the quality of life for members with SCD.

Our SCD expertise includes:

- Associate medical director Dr. Lanetta Jordan, who is a world-renowned expert in SCD, has helped develop our national SCD clinical model. She also participated in the development of national SCD evidence-based guidelines sponsored by the National Institutes of Health (NIH)
- National clinical team has Medicaid experience and hands-on experience in the management of patients with SCD.
- SCD medical director Dr. Paul Monte is American Board of Internal Medicine-certified and has significant experience managing patients with SCD in a hospital setting. Dr. Monte and Dr. Jordan will oversee our national SCD clinical model.
- National SCD expert panel, comprising board-certified experts in treating members with SCD, reviews and updates all clinical components of our model under the oversight of Dr. Monte.
- Our national clinical quality team is adopting SCD evidence-based guidelines tailored to the needs of our members, based upon the NIH guidelines (e.g., clinical trials or managing transplants for members with SCD). The team has also developed a pain management process to help SCD members manage their daily pain levels so they are not visiting the ER or being admitted to the hospital. We further discuss this process in our response to RFP question N.6.

SCD program goals include:

- Early Identification - This is a lifelong condition so it's extremely important to identify these members when they are young to manage their clinical, behavioral, and socio-economic needs for life
- Increased engagement of SCD members through collaboration with PCCM Community Health Workers, Accountable Care Communities, Medical Mall, PCP and Provider Networks
- Successful management of SCD condition will help members live a quality life without many ER visits and hospitalizations
- Successful transition from pediatric to adolescent and adult condition management
- Measurable decreases in ER visits, inpatient admissions and readmission rates

- Measurable decrease in the overall cost of care for members with SCD
- Improved hydroxyurea adherence
- Reduced episodes of pain crisis and iron overload
- Reduction in ischemic stroke and transient ischemic attacks
- Delayed disease progression

The Process for an Integrated SCD Program:

- Perform an initial risk stratification and identification of high-utilizers by a non-clinical team.
- Telephonic and Field Based approach to engage and manage the members.
- Case managers with SCD experience to manage the clinical, behavioral, and socio-economic needs of SCD members for life.
- Develop job aids, procedures and processes for SCD case managers.
- Develop referral procedures for SCD case managers to refer high-risk members to specialized programs (e.g., behavioral health providers, kidney specialists or transplant specialists). For example, for high-risk pregnant members, the SCD case manager coordinates with the Healthy First Steps case manager to collaboratively manage the member's SCD and their high-risk pregnancy.
- Focus on collaboration other community-based resources (e.g., hospitals, universities and community- based organizations) throughout the state, Accountable Care Communities, Medical Mall, Health Homes, Provider and Specialist networks.

In addition to these efforts, we are:

- Identifying gaps in our provider network so that we can develop an interconnected network of physicians who are experienced in treating SCD.
- Identifying educational opportunities for PCPs that includes information on how to manage members with SCD (e.g., use of hydroxyurea and penicillin and Transcranial Doppler [TCD] screening). This PCP education is critical to providing PCPs the knowledge to successfully manage the care of members with SCD. For example, TCD screening is a covered benefit that screens for the risk of a stroke. The results of the screening allow the provider to conduct interventions, such as regular blood transfusions, to minimize the stroke risk to the member.
- Develop a state specific advisory panel that will be made up of non-clinical members, such as community organizations and caregivers, to understand the unique needs of the members
- Working to establish Programs or Centers of Excellence consisting of local providers and specialists with expertise managing SCD patients. This center of excellence will work to improve the care and management of all SCD patients in the State.

Sickle cell program interventions are designed to achieve:

- Early identification and engagement in the program when the members are young
- Controlled and delayed disease progression
- Pain and symptom management
- Prevention of iron overload, stroke, infections, acute chest syndrome, organ failure and other complications
- Identification and treatment of depression

Once implemented in the State, our SCD program will enhance our person-centered model of care by:

- Identifying all members with SCD to assess and risk stratify those members, enabling prospective outreach and education to the appropriate population. We identify members through:
  - Analysis of claims and clinical data and risk stratification
  - The new member welcome call and health risk assessment (HRA).
- For members identified with SCD, we refer them to our SCD non-clinical team for initial outreach
- Collaborate with PCCM Community Health Workers for field based visits to engage those members who are unable to reach or lost contact
- The cases get referred back to the case manager for future interventions
- Clinical team focuses on a comprehensive sickle cell assessment that will identify member needs and their risk levels.
- Engaging low or moderate risk members in care management services that help them manage their illness leading to improved quality of life and reduced likelihood that members will seek health care services in an inappropriate setting, such as inpatient hospitalization or ER.
- Engaging high-risk members (e.g., members experiencing recurring pain crises) in case management through collaboration between a member's PCP and a case manager with expertise in managing patients with SCD or enrollment in an ACC practice with SCD expertise. For practices without this expertise, our SCD case manager will partner with the practice to manage the member's care.
- Engaging providers and members at practices, hospitals, schools and community events to provide education, develop relationships and connect members to community resources.
- Implementing local, field-based SCD experts, supported by telephonic experts who help find members, conduct the sickle cell assessment, identify gaps in care, and resolve barriers to care (e.g., transportation issues, member not knowing their PCP, member perception about cost).
- Coordinating with behavioral, pharmacy and other services, such as Healthy First Steps. Ensuring development of an effective, individualized plan of care to reduce pain and manage symptoms, including short- and long-term pain management goals.
- Ensuring members have a pain management plan in order to manage their daily pain levels so they are not visiting the ER or being admitted to the hospital.
- Providing patient/caregiver education and support, such as use of hydroxyurea; managing daily life functioning; coping with cognitive functioning issues; understanding how to speak with providers; transitioning to adult condition management, including managing their own care; and empowering members to get what they need to manage their condition from their provider.

Lifelong sickle cell program interventions to help members live an improved quality of life:

- Ongoing evaluation and risk stratification
- Monitoring and managing ER and inpatient admissions and readmissions
- Creating, updating, communicating and managing an individualized plan of care
- Coordinating access to appropriate support services both inside and outside of our provider network
- Periodic member assessment
- Patient, caregiver and physician education
- Patient advocacy throughout all stages of the care continuum