2018 Legislative Report on the Louisiana Sickle Cell Commission

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

Prepared by:

Office of Public Health – Bureau of Family Health

Genetic Diseases Program

Jantz Malbrue, MSPH

Cheryl Harris, MPH

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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 Act 117 (SB57), 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 29 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.

The LSCC consists of eight Governor-appointed voting members, as well as three additional members (see Appendix A). It fulfills its mandate by providing policy guidance and expertise, as well as by conducting effective oversight relating to Medical Services, Patient Navigation, Education & Advocacy, and Data & Surveillance. Administration of the LSCC is coordinated through the Louisiana Department of Health (LDH), Office of Public Health (OPH), Bureau of Family Health (BFH) Genetic Diseases Program.

Notable accomplishments during 2018 include education of providers throughout the state with the Standards for Care of Patients with a Sickle Cell Disease Toolkit, the second annual Sickle Cell Statewide Conference in partnership with Ochsner Medical Center and Louisiana Sickle Cell Association (LASCA), and the development of the Sickle Cell Medicaid Surveillance System.

Key challenges LSCC continues to address include identifying medical homes for youth and adults with sickle cell disease (SCD) in areas of the state with limited resources, establishing patient navigation and expanding care coordination, and monitoring and surveillance of clinical and cost indicators.

The LSCC recommendations to the Legislature include appropriation of funds to implement the Patient Navigator Program as established through Act No. 117, and the appropriation of funds for the development and implementation of a centralized case management system in order to decrease data management barriers, improve health care management and enhance monitoring and surveillance of SCD in Louisiana.

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. This results in severe pain (also known as sickle cell crisis) and can lead to permanent damage of 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, with advancements in SCD identification and treatment, the life expectancy has greatly improved, and patients can live well into their 60s with the proper resources.[2]

According to the Louisiana Sickle Cell Registry, approximately 80 infants are born with SCD in Louisiana every year. Seventy-seven newborns were diagnosed with SCD in 2017, and sixty newborns were diagnosed in 2018. SCD has placed a significant burden on medical services, especially with Medicaid. According to the Geography of Sickle Cell Disease within Louisiana Medicaid, 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 individuals with Medicaid.[3] The report, last published in 2014, summarized the Medicaid claims associated with a SCD diagnosis in calendar year 2013. The narrative 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.

Sickle Cell Programs and Activities

A majority of specialized sickle cell programs and activities are administered by the Genetic Diseases Program, community-based sickle cell foundations, regional sickle cell clinics and the Healthy Louisiana Medicaid managed care organizations.

The Genetic Diseases Program provides two core functions related to SCD: newborn genetic screening and oversight of the safety-net sickle cell clinics throughout the state. As the administrator of the federally mandated newborn heel stick screening program, the Genetic Diseases Program ensures access to sickle cell genetic evaluation and counseling to residents in all areas of Louisiana. In 2018, the program screened 99% of infants born in Louisiana, and 100% of infants with a positive screen were linked to care. The Genetic Diseases Program also operates safety-net sickle cell clinics through the OPH Parish Health Units (PHUs). 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. Sickle cell foundations have programs that link individuals and families affected by SCD with medical and non-medical resources needed to manage the disease. The Genetic Diseases Program works closely with the sickle cell foundations to ensure all of the infants diagnosed with SCD through the newborn screening program are linked to appropriate care upon diagnosis.

In 2015, each Medicaid MCOs introduced its own sickle cell case management program in a concerted effort to incorporate sickle cell specialty care in their clinical guidelines. While the details of the services offered vary between programs, all of the programs utilize telephonic case management and focus primarily on high-risk, high-usage members in their networks.

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 are able to access services more readily, but major gaps in service access and care coordination exist for the adult population and for those transitioning from pediatric to adult care.

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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).

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 the major SCD stakeholders.

In an effort to improve coordination of care, the sickle cell foundations have begun to send part-time community health workers to regional sickle cell clinics to conduct outreach activities and assess patients in between their clinic appointments. The sickle cell foundations and sickle cell clinics are also collaborating with the Medicaid MCOs to provide existing enrollees with support and education on available resources and to support eligible individuals with enrollment. Although SCD stakeholders are committed to working toward improved care coordination, restrictions on resources have made collaborative efforts difficult to sustain or scale to an impactful level.

The primary barrier to effective care coordination is the lack of a centralized case management mechanism. Each sickle cell foundation, private health care provider and insurance company, including Medicaid and Medicaid MCOs, maintains its own case management system. This results in service duplication, breaks in the continuum of care and patient loss to follow-up. Additionally, the lack of a centralized data system makes it virtually impossible to track clinical indicators in a meaningful way or evaluate the effectiveness of medical services provided throughout the state.

Louisiana Sickle Cell Commission

Act 117 (SB57) of the 2013 regular legislative session mandated LDH to create the Louisiana Sickle Cell Commission (LSCC) to ensure the adequate delivery of services to all persons living with SCD and to formulate new actions to reduce the burden of SCD in Louisiana.

The 11 members of the LSCC consist of representatives from LDH, Louisiana Primary Care Association (LPCA), Children's Hospital of New Orleans, Tulane University School of Medicine and each of the 5 regional sickle cell foundations. Key partners and stakeholders attended the LSCC meetings and provided expertise to strengthen care for the SCD community in Louisiana. In accordance with legislative mandate, the Commission held quarterly meetings at the LDH headquarters in Baton Rouge throughout SFY 2018 (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. It continues to be implemented through four workgroups: Medical Services, Patient Navigation, Education & Advocacy, and Data & Surveillance.

The LSCC's annual updates to the strategic plan and workgroup activities are outlined in the following section.

Strategic Plan Update and Workgroup Activities

Medical Services Workgroup

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

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.

Standards for Care Implementation-Provider Education
At the 2018 Sickle Cell Statewide Conference, Dr. Rene Gardner lectured on current medical protocols related to the care of SCD. The goal in 2019 is to revise the Standards for Care to include the updated medical protocols and pain management techniques for treating SCD.

The Medical Services Workgroup strategies for 2019 and 2020 include identifying new providers treating youth and adult patients with SCD, collaborating with Medicaid MCO primary care providers (PCPs) to improve referrals for SCD services, educating Emergency Department Personnel to improve acute pain treatment, and establishing statewide pain management protocols.

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:

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 self-efficacy within the patient so they are able to manage their disease and thrive.

ACT No. 387: Patient Navigator Program
Since 2014, the LSCC has submitted recommendations to the Legislature for the establishment of and funding for a Patient Navigator Program. In 2015, Act 387 was signed into law, officially establishing 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:

1. Train patient navigators to serve as outreach coordinators, coordinators of family educational sessions and patient case managers;
2. Establish and strengthen a continuum of care for each sickle cell patient 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
To date, the program is not operational, as funds have not been appropriated by the Legislature. The budget for the program is estimated to be $440,000, which includes salaries, benefits, training costs, travel costs and equipment/supplies administrative costs. When monies are appropriated, the program can be implemented as outlined in statute. Members of LSCC promoted the Patient Navigator Program to state representatives in Districts 2, 16 and 17 and encouraged them to add the appropriation of funds to their legislative agendas.

With the implementation of the program, the eight patient navigators would conduct outreach, provide patient education, and coordinate case management services to patients and families who are not being served through the Medicaid MCO programs. The Patient Navigator Program would complement the existing care coordination resources available through MCOs and sickle cell foundations. Patient navigators would be able to facilitate patient care within the sickle cell clinics and conduct home visits to educate patients and family members regarding medication adherence, pain management, transition and other barriers to care. The Patient Navigator Program will serve as the bridge between all services for individuals and families affected by SCD, equity in access to medical care and supportive services that improve health outcomes of patients.

The Patient Navigation Workgroup strategies for 2019 and 2020 include establishing parameters in the sickle cell foundation contracts to include funding for the Patient Navigator Program, incorporating SCD within the Louisiana Chronic Pain Guidelines, investigating the use of medical marijuana with chronic pain management, launching the Know Your Sickle Cell Status Campaign at universities and schools statewide, and establishing sickle cell status ID cards.

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:

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.

Annual Sickle Cell Conference

The second annual Sickle Cell Statewide Conference was held in June 2018 at the Ochsner Medical Center Campus in New Orleans. The conference was co-hosted by LSCC and the Ochsner Medical Foundation. Subject matter experts presented on the role of the healthcare professional, pain management, advocacy, youth health transition, bone marrow transplant and support services. In addition, the conference attendees learned about clinical trials, participated in interactive panel discussions, and received and shared resources. Attending the event were 105 individuals living with sickle cell, family members, community advocates, physicians, nurses, mental health providers and healthcare providers. Exhibitors distributing resources included the Medicaid MCO plans and pharmaceutical companies. Parham Jaberi, MD, MPH, Assistant State Health Officer, attended the conference on behalf of the Louisiana Department of Health and discussed the opioid crisis in relation to pain management for SCD.

Print and Media Activities

A webpage was created for the Sickle Cell Commission (http://ldh.la.gov/index.cfm/page/2900). The webpage highlights the functions of the Commission and provides information on the LSCC guidelines, membership and workgroups. The Bureau of Family Health is providing ongoing website development support and design upgrades to make the website user friendly.

The Education and Advocacy Workgroup strategies for 2019 and 2020 include increasing statewide print and media campaigns to be inclusive of all activities, launching the Know Your Sickle Cell Status Campaign at universities and schools statewide, establishing sickle cell status ID cards, and assembling a statewide informational publication that will include public service announcements and a directory of events for sickle cell disease.

Data & Surveillance Workgroup

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

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.

In 2015, the LSCC worked with the OPH Genetic Diseases Program to develop a registry of all persons who had a positive newborn screen for SCD over the past 20 years. At the end of 2018, the Sickle Cell Registry contained 2,365 total SCD cases, which reflects all cases detected through newborn screening between 1978 and 2018.

According to the Louisiana State Sanitary Code,[3] only SCD cases identified through newborn screening are required to be reported. Therefore, the current registry is limited to those cases. In contrast to the 2,365 total cases in the registry, there were 9,951 Medicaid-eligible individuals who filed a SCD-related Medicaid claim between January 2014 and October 2017, signifying a major reporting gap.

The LSCC is proposing an expansion of the state reporting requirements so that all cases of SCD must be reported. By expanding the reporting requirement to all ages, the Genetic Diseases Program would be able to capture all cases of SCD that have not been identified through newborn screening. Moreover, the increase in reporting of acute and chronic SCD pain crises would allow for better monitoring and coordination of medical services among healthcare providers.

Case Management Data System

The Sickle Cell Registry has provided a more comprehensive view of SCD in the state. However, the picture is still highly fragmented. The current registry platform functions like a standard inventory, and a more robust data system is needed to collect and report on data that can effectively drive policy and decision-making.

The LSCC is developing a comprehensive case management system that will streamline data entry statewide and improve reporting quality. With this case management system, the sickle cell foundations will be able to capture client-level data, which would then be managed through a secure central server within the Genetic Diseases Program. In addition to enhancing statewide monitoring and surveillance efforts, the case management system will facilitate client-level care coordination and improve health outcomes.

The centralized case management system will decrease data management barriers, improve health care management, and significantly enhance monitoring and surveillance efforts. The case management

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[3] LAC 51:II.105.D.4.a.xvi

system will also be beneficial in evaluating and improving quality management indicators. In addition to serving as a uniform intake and case management tool, the data platform will provide a streamlined process for cross-referencing applicants on a local and statewide basis, and it would produce exportable reports for comparative research and grant support.

The Bureau of Family Health is working with Social Solutions, a software company that provides comprehensive case management tools for nonprofits and public sector agencies, to develop this case management system. Social Solutions develops software for other programs within the Bureau of Family Health and has many years of experience developing software to meet the needs of populations. The software packages created by Social Solutions deliver infrastructure and scalability needed to manage data, share information and track progress. The company will develop a data system scaled to the needs of the Sickle Cell Program and the number of users statewide.

Medicaid Surveillance System

Additionally, the current registry does not allow for monitoring of health care utilization and costs of care. The OPH Genetic Diseases Program collaborated with the LDH Bureau of Health Informatics to develop a surveillance system that utilizes ICD9 and ICD10 codes associated with SCD in Medicaid to monitor population-level trends in patient care and clinical utilization costs.

The LDH Bureau of Health Informatics generated a list of individuals with a sickle cell diagnosis and a related Medicaid claim. The client-level data contains demographic information as well as the funding spent for each sickle cell related and non-sickle cell related claim. The surveillance system was created around the parameters used for the 2013 Geography of Sickle Cell Disease within Louisiana Medicaid report.

The goal will be to review the report on a quarterly basis to monitor utilization and costs. Eventually, more indicators will be added to monitor trends.

Sickle Cell Trait Registry

Although the Sickle Cell Registry developed in 2015 provided a more comprehensive view of SCD throughout the state, the total number of individuals diagnosed as sickle cell carriers is still unknown. An additional registry known as the Sickle Cell Trait Registry was created in 2017 to identify individuals diagnosed as a sickle cell trait carrier through the newborn screening program. The combination of these two registries will assist care coordination, community outreach and data reporting that can effectively drive decision-making.

The Data and Surveillance Workgroup strategies for 2019 and 2020:

1. Improve registry of sickle cell patients by monitoring patients visits to the sickle cell foundations to provide a more comprehensive view of SCD in the state;
2. Expand Medicaid surveillance systems by including additional demographic information, healthcare services accessed, medication rates and immunization utilization; and
3. Increase the distribution and visual representation of data.

Conclusion

If managed properly, patients with a diagnosis of sickle cell can live longer, productive lives and reduce the burden of medical costs on the medical infrastructure of the state. LSCC is working hard to improve the lives of patients with sickle cell through education, advocacy, surveillance, patient navigation, and as charged by legislation, LSCC is improving the delivery of sickle cell services in Louisiana. This report provided a summarization of the 2018 activities of the Sickle Cell Commission to combat sickle cell in Louisiana. Also included, as an appendix to this report, is a list of Governor-appointed agency representatives, stakeholders and partners that attended a commission meeting during the reporting period. Within the next year, the Louisiana Sickle Cell Commission will continue its efforts as the commission works to implement the new case management system.

Appendix A: LSCC Membership List and 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, Baton Rouge Sickle Cell Anemia Foundation, Inc.
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
Melody Benton, Sickle Cell Center of Southern Louisiana-Tulane University School of Medicine (proxy for Tammuella Singleton, M.D.)
Shannon Robertson, 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.
Rajasekharan Warrier, M.D., Ochsner Health Center for Children

Tanisha Smith, ANP-BC, Our Lady of the Lake Physician Group
Bridgette Pierre, NP, Our Lady of the Lake Physician Group
Jensine Speed, LMSW, Our Lady of the Lake Physician Group
Jessica Templet, PA-C, St. Jude Baton Rouge Affiliate
Raymond Poliquit, M.D., Healthy Blue
David Hall, Louisiana Healthcare Connections
Steve Higgs, MBA, Louisiana Healthcare Connections
Dana LeBlanc, M.D., Children's Hospital New Orleans
Cherie Hadley, RN, Children's Hospital New Orleans
Marcus Wallace, M.D., Louisiana Healthcare Connections
Shelly Krawchuck, RN, Aetna
Rachel Smith, Aetna
Paula Morris, UnitedHealthcare
Karen Grevemberg, MBA, BSN, RN, UnitedHealthcare
Patti Barovechio, DNP, MN, LDH OPH Children Special Health Services Program
Michelle Duplantier, LCSW-BACS, LDH OPH Children Special Health Services Program
Chelsea Carter, LDH OPH Louisiana Healthy Homes and Childhood Lead Poisoning PreventionProgram
Kera Simmons, LDH OPH Genetic Diseases Program
Jantz Malbrue, LDH OPH Genetic Diseases Program

Presenters
Brent Young, Global Blood Therapeutics, Inc.
Heidi Wagner, J.D., Global Blood Therapeutics, Inc.
Irene Agodoa, M.D., Global Blood Therapeutics, Inc.

The link below links to LSCC's published minutes, featuring additional members and guests:

https://wwwcfprd.doa.louisiana.gov/boardsandcommissions/viewMeetingMinutes.cfm?board=606

Appendix B: 2018 Sickle Cell Statewide Conference Agenda- June 8-9, 2019

2018 Sickle Cell Statewide Conference June 8-9, 2018

Sponsored by the Louisiana Department of Health & Sickle Cell Commission

Co-sponsor – Ochsner Children's Center

Program Director: Rajasekharan Warrier, MD

Co-directors: Samira Brown, MD and Angela Delsa RN, BSN

Schedule

Friday, June 8, 2018

1.00 PM – 1.45 PM Registration

1.45 PM – 1.50 PM Introductory Remarks

1.50 PM – 2.10 PM Role of LDH/OPH in Sickle Cell Program
Cheryl Harris, MPH and Jantz Malbrue, MSPH

2.10 PM - 2.30 PM Role of PCP in Sickle Cell Anemia
Samira Brown, MD

2.30 PM – 2.55 PM Guidelines (NHLB) for Care of Sickle Cell Anemia
Matthew Fletcher, MD

2.55 PM – 3.15 PM Renal Manifestations of Sickle Cell
Radhakrishna Baliga, MD

3.15PM – 3.20 PM Inauguration and Remarks by the Assistant Health Officer of LDH
Parham Jaberi, MD, MPH

3.25 PM – 3.35 PM Coffee Break

3.35 PM – 3.55 PM Advocacy Issues in Sickle Cell Anemia
Pamela Saulsberry, PhD, LCSW-BACS

3. 55 PM – 4.10 PM Transition and Rights: A Patient Perspective
Michelle Duplantier, LCSW-BACS

4. 10 PM - 4.50 PM Panel discussion/Round table:
Panel: *Matthew Fletcher, MD; Ernest DeJean, MSW; Chanel Holt, RN; Susan Serio, RN; Parent; and Michelle Duplantier, LCSW-BACS*
Moderator – *Craig Lotterman, MD & Rajasekharan Warrier, MD*

4. 50 PM Summary and Concluding Remarks

Saturday June 9, 2018

7.00 AM – 8.00 AM Registration and Continental Breakfast

8.00 AM – 8.20 AM Case Presentations by Students
1) Fever and hypoxia /ACS – *Alexander Redman, Medical Student*
2) An unusual case of meningitis in sickle cell –*Lesley N Desmond, Medical Student*

8.20 AM – 8.40 AM Prevention of Infections in Sickle Cell Anemia
Russell Steele, MD

8.40 AM – 9.00 AM Infections in Sickle Cell Anemia
Craig Lotterman, MD

9.00 AM – 9.20 AM Pulmonary Complications in Sickle Cell Anemia
Fernando Urrego, MD

9.20 AM – 9.45 AM Pain Management in Sickle Cell Anemia
Sonia Malhotra, MD

9.45 AM – 9.55 AM Question and Answer

9.55 AM –10.10 AM Coffee break

10.10 AM – 10.30 AM Nursing Perspectives in Sickle Cell Anemia
Angela Delsa, RN, BSN

10.30 AM – 10.55 AM Sickle Cell Anemia: Yesterday, Today and Tomorrow
Rajasekharan Warrier, MD

10.55 AM – 11.25 AM Case Presentations
Priapism - *Jeffery Coote, Medical Student*
Urological Problems in Sickle Cell - *Frank Cerniglia, MD*

11.25AM – 11.50 AM Bone Marrow Transplant
Robert Vasquez, MD, PhD

11.50 AM – 12.00 PM Question and Answer

12.00 PM – 1.00 PM Lunch (provided)

1.00 PM – 1.25 PM Transfusion and Iron Overload
Matthew Fletcher, MD

1.25 PM– 1.35 PM “Model Chelation” – Personal Experience
Timothy Ngyuen, BS, Medical Student

1.35 PM – 1.45 PM “My Child is Not Walking” Case Presentation
Jai Patel, BS Medical Student

1.45 PM – 2.10 PM CNS Complications of Sickle Cell Anemia
Rajasekharan Warrier, MD

2.10 PM – 2.35 PM Sickle Cell and the Skeletal System
Sean Waldron, MD

2.35 PM – 2.45 PM “Hematuria in a Child with Sickle Cell Trait” Case Presentation
Stefanie K. Ward, BS Medical Student

2.45 PM - 3.10 PM Sickle Cell Anemia and the Emergency Room (*Megan Marino, MD*)

3.10 PM – 3.20 PM Question and Answer

3.20 PM – 3.40 PM Insurance, Health Care Economics and Sickle Cell (*Raymond Poliquit, MD*)

3.40 PM – 4.00 PM Newer Modalities of Therapy for Sickle Cell (*Renee Gardner, MD*)

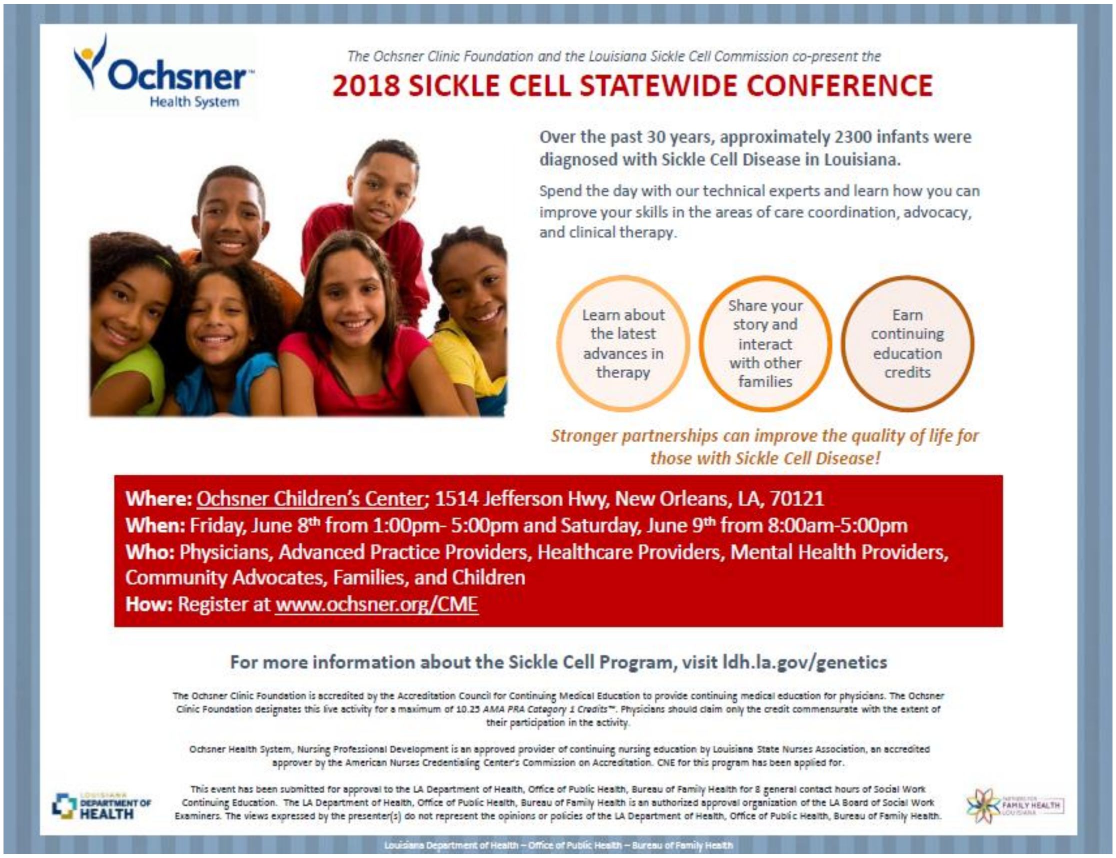
4.00 PM – 4.45 PM Panel Discussion: Transition Clinic, Barriers to Care, Complimentary Therapy, Look to the Future

Panel Members: *Renee Gardner, MD; Robert Vasquez, MD, PhD; Michelle DeFrisco, RN; Parent; and Patient*

4.45 PM Concluding Remarks and vote of thanks

Bone Marrow Transplant Registry drive sponsored by the Ochsner Clinical School of University of Queensland and Be a Donor – Saturday, June 9, 2018

Appendix C: 2018 Sickle Cell Statewide Conference Flyer-June 8-9, 2019



The Ochsner Clinic Foundation and the Louisiana Sickle Cell Commission co-present the

2018 SICKLE CELL STATEWIDE CONFERENCE

Over the past 30 years, approximately 2300 infants were diagnosed with Sickle Cell Disease in Louisiana.

Spend the day with our technical experts and learn how you can improve your skills in the areas of care coordination, advocacy, and clinical therapy.

Learn about the latest advances in therapy

Share your story and interact with other families

Earn continuing education credits

Stronger partnerships can improve the quality of life for those with Sickle Cell Disease!

Where: Ochsner Children’s Center; 1514 Jefferson Hwy, New Orleans, LA, 70121
When: Friday, June 8th from 1:00pm- 5:00pm and Saturday, June 9th from 8:00am-5:00pm
Who: Physicians, Advanced Practice Providers, Healthcare Providers, Mental Health Providers, Community Advocates, Families, and Children
How: Register at www.ochsner.org/CME

For more information about the Sickle Cell Program, visit ldh.la.gov/genetics

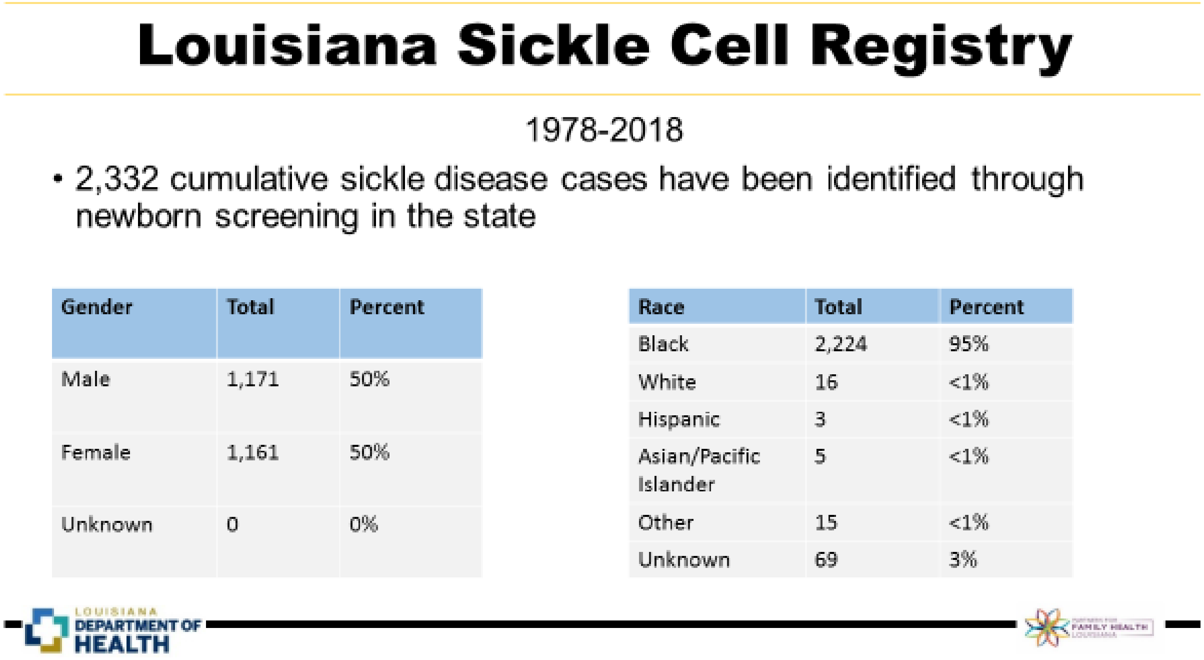
The Ochsner Clinic Foundation is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians. The Ochsner Clinic Foundation designates this live activity for a maximum of 10.25 *AMA PRA Category 1 Credits™*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Ochsner Health System, Nursing Professional Development is an approved provider of continuing nursing education by Louisiana State Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation. CNE for this program has been applied for.

This event has been submitted for approval to the LA Department of Health, Office of Public Health, Bureau of Family Health for 8 general contact hours of Social Work Continuing Education. The LA Department of Health, Office of Public Health, Bureau of Family Health is an authorized approval organization of the LA Board of Social Work Examiners. The views expressed by the presenter(s) do not represent the opinions or policies of the LA Department of Health, Office of Public Health, Bureau of Family Health.

Louisiana Department of Health – Office of Public Health – Bureau of Family Health

Appendix D: LSCC Meeting Data & Surveillance- September 18, 2018



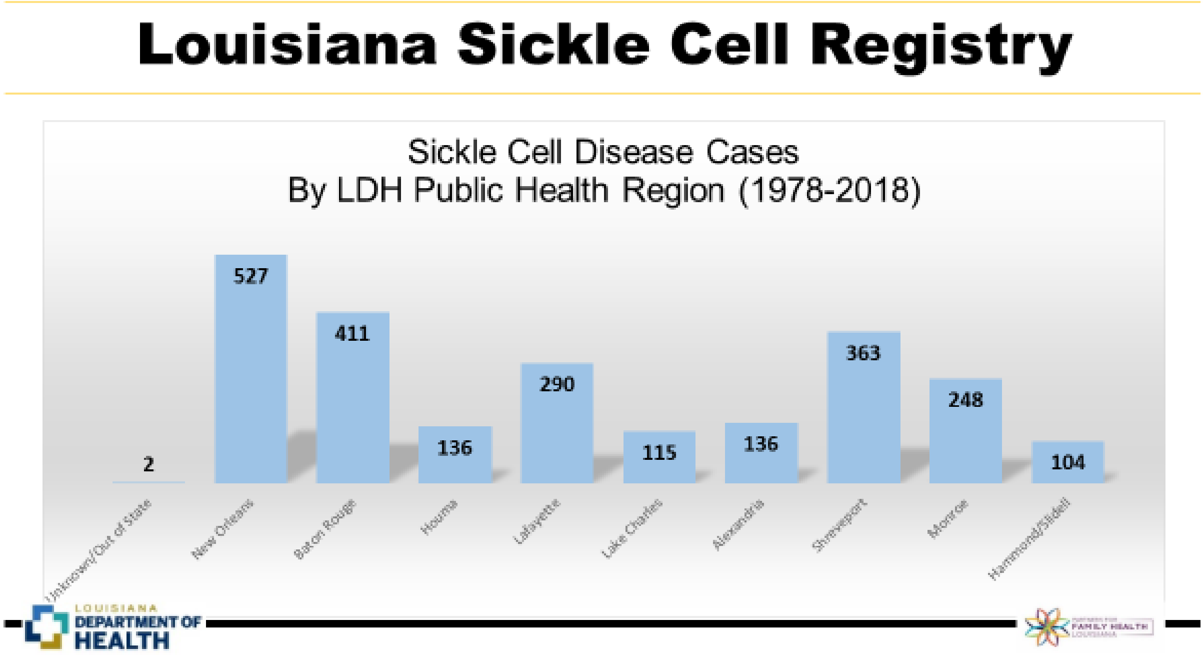
Louisiana Sickle Cell Registry

1978-2018

- 2,332 cumulative sickle disease cases have been identified through newborn screening in the state

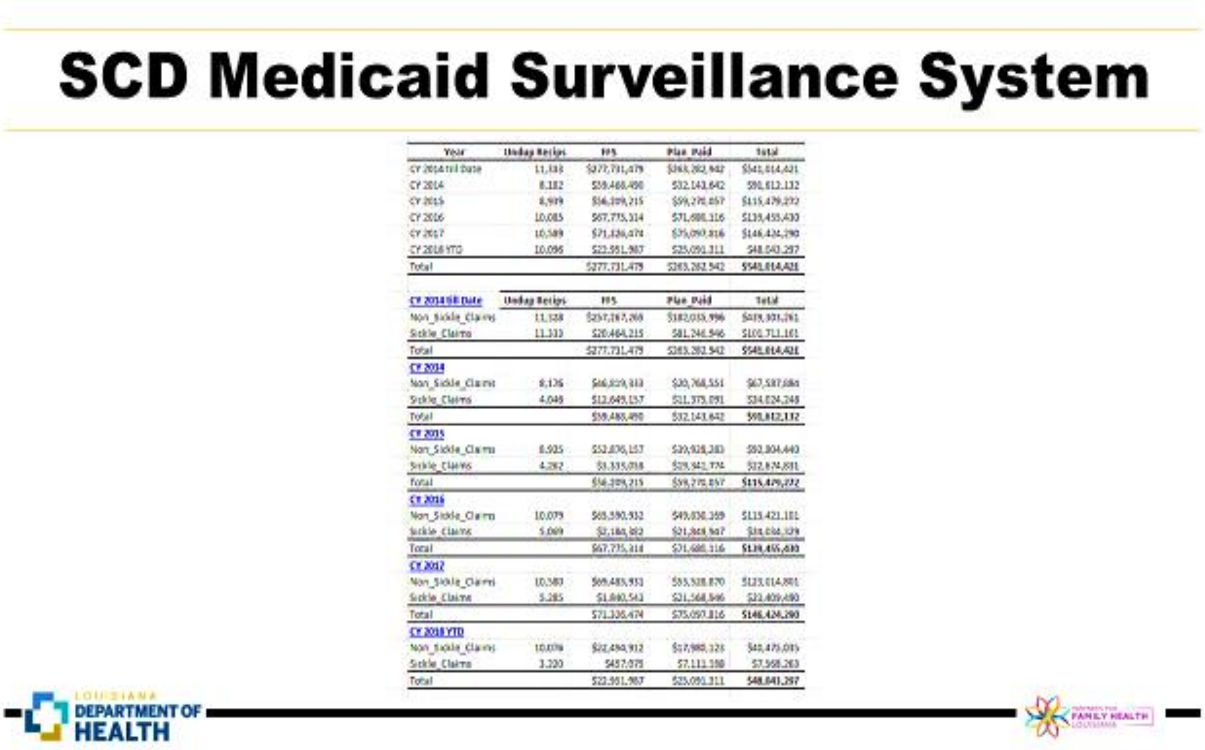
Gender	Total	Percent
Male	1,171	50%
Female	1,161	50%
Unknown	0	0%

Race	Total	Percent
Black	2,224	95%
White	16	<1%
Hispanic	3	<1%
Asian/Pacific Islander	5	<1%
Other	15	<1%
Unknown	69	3%



Louisiana Sickle Cell Registry

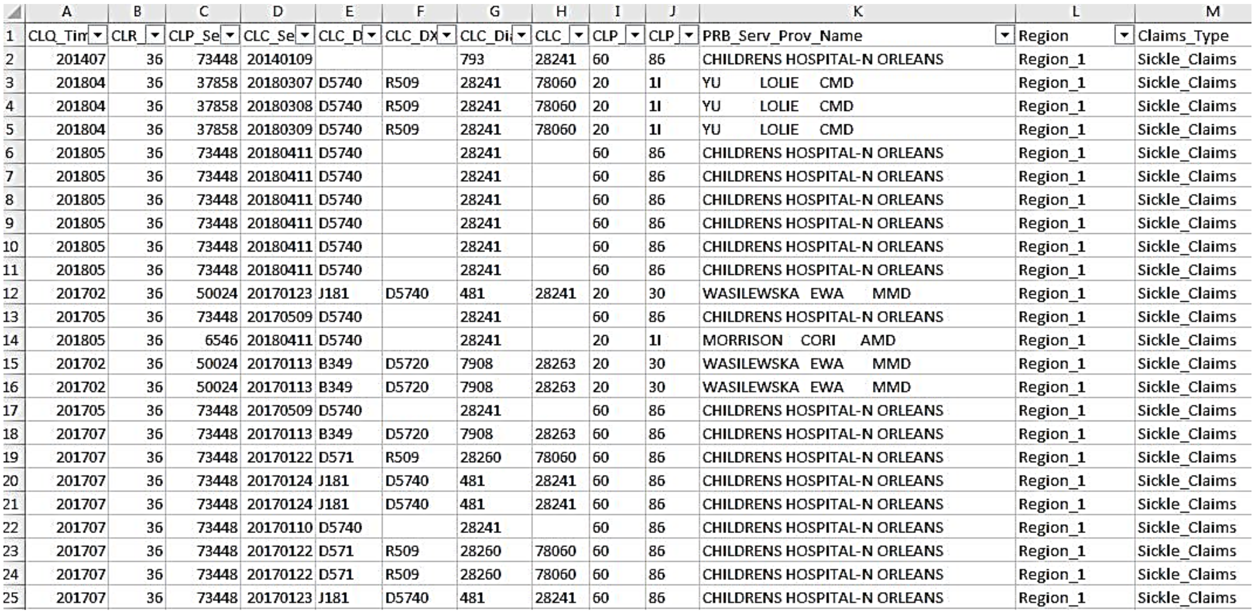
Sickle Cell Disease Cases
By LDH Public Health Region (1978-2018)



SCD Medicaid Surveillance System

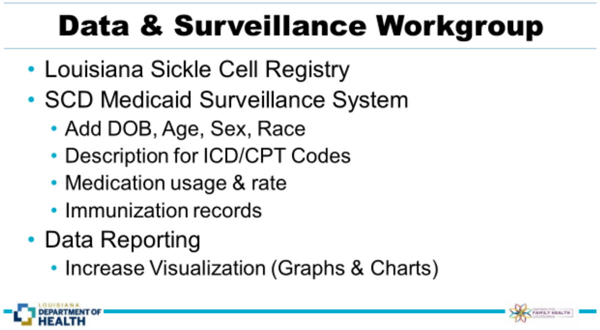
Year	Undup Recips	FFS	Plan_Paid	Total
CY 2014 till Date	11,333	$277,731,479	$263,282,942	$541,014,421
CY 2014	8,182	$59,468,490	$32,143,642	$91,612,132
CY 2015	8,909	$56,209,215	$59,270,057	$115,479,272
CY 2016	10,085	$67,775,314	$71,680,116	$139,455,430
CY 2017	10,589	$71,326,474	$75,097,816	$146,424,290
CY 2018 YTD	10,096	$22,951,987	$25,091,311	$48,043,297
Total		$277,731,479	$263,282,942	$541,014,421

CY 2014 till Date	Undup Recips	FFS	Plan_Paid	Total
Non_Sickle_Claims	11,328	$257,267,268	$182,035,996	$439,303,261
Sickle_Claims	11,333	$20,464,215	$81,246,946	$101,711,161
Total		$277,731,479	$263,282,942	$541,014,421
CY 2014				
Non_Sickle_Claims	8,176	$46,819,333	$20,768,551	$67,587,884
Sickle_Claims	4,048	$12,649,157	$11,375,091	$24,024,248
Total		$59,468,490	$32,143,642	$91,612,132
CY 2015				
Non_Sickle_Claims	8,925	$52,876,157	$39,928,283	$92,804,440
Sickle_Claims	4,282	$3,333,058	$19,341,774	$22,674,831
Total		$56,209,215	$59,270,057	$115,479,272
CY 2016				
Non_Sickle_Claims	10,079	$65,590,932	$49,830,169	$115,421,101
Sickle_Claims	5,069	$2,184,382	$21,849,947	$24,034,329
Total		$67,775,314	$71,680,116	$139,455,430
CY 2017				
Non_Sickle_Claims	10,580	$69,485,931	$53,528,870	$123,014,801
Sickle_Claims	5,285	$1,840,543	$21,568,946	$23,409,490
Total		$71,326,474	$75,097,816	$146,424,290
CY 2018 YTD				
Non_Sickle_Claims	10,076	$22,494,912	$17,980,123	$40,475,035
Sickle_Claims	3,220	$457,075	$7,111,188	$7,568,263
Total		$22,951,987	$25,091,311	$48,043,297



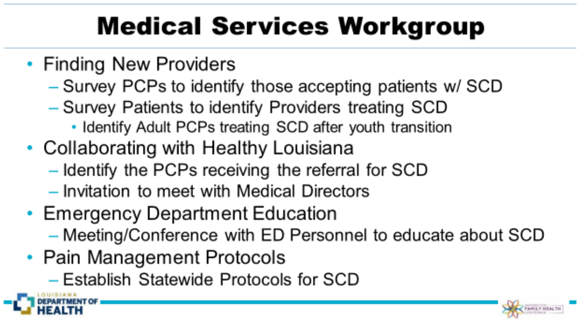
	A	B	C	D	E	F	G	H	I	J	K	L	M
1	CLQ_Tim	CLR_	CLP_Se	CLC_Se	CLC_D	CLC_DX	CLC_Di	CLC_	CLP_	CLP_	PRB_Serv_Prov_Name	Region	Claims_Type
2	201407	36	73448	20140109			793	28241	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
3	201804	36	37858	20180307	D5740	R509	28241	78060	20	1I	YU LOLIE CMD	Region_1	Sickle_Claims
4	201804	36	37858	20180308	D5740	R509	28241	78060	20	1I	YU LOLIE CMD	Region_1	Sickle_Claims
5	201804	36	37858	20180309	D5740	R509	28241	78060	20	1I	YU LOLIE CMD	Region_1	Sickle_Claims
6	201805	36	73448	20180411	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
7	201805	36	73448	20180411	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
8	201805	36	73448	20180411	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
9	201805	36	73448	20180411	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
10	201805	36	73448	20180411	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
11	201805	36	73448	20180411	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
12	201702	36	50024	20170123	J181	D5740	481	28241	20	30	WASILEWSKA EWA MMD	Region_1	Sickle_Claims
13	201705	36	73448	20170509	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
14	201805	36	6546	20180411	D5740		28241		20	1I	MORRISON CORI AMD	Region_1	Sickle_Claims
15	201702	36	50024	20170113	B349	D5720	7908	28263	20	30	WASILEWSKA EWA MMD	Region_1	Sickle_Claims
16	201702	36	50024	20170113	B349	D5720	7908	28263	20	30	WASILEWSKA EWA MMD	Region_1	Sickle_Claims
17	201705	36	73448	20170509	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
18	201707	36	73448	20170113	B349	D5720	7908	28263	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
19	201707	36	73448	20170122	D571	R509	28260	78060	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
20	201707	36	73448	20170124	J181	D5740	481	28241	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
21	201707	36	73448	20170124	J181	D5740	481	28241	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
22	201707	36	73448	20170110	D5740		28241		60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
23	201707	36	73448	20170122	D571	R509	28260	78060	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
24	201707	36	73448	20170122	D571	R509	28260	78060	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims
25	201707	36	73448	20170123	J181	D5740	481	28241	60	86	CHILDRENS HOSPITAL-N ORLEANS	Region_1	Sickle_Claims

Appendix E: LSCC Meeting Workgroup Summary-September 18, 2018



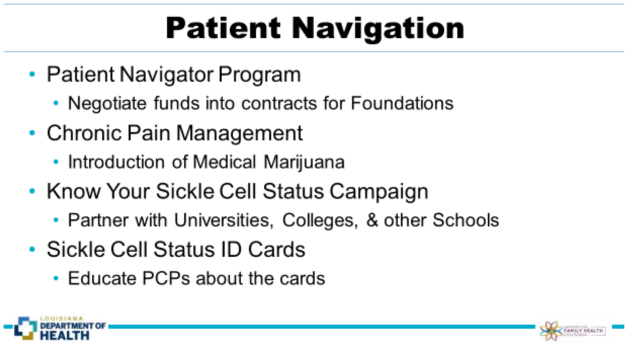
Data & Surveillance Workgroup

- Louisiana Sickle Cell Registry
- SCD Medicaid Surveillance System
  - Add DOB, Age, Sex, Race
  - Description for ICD/CPT Codes
  - Medication usage & rate
  - Immunization records
- Data Reporting
  - Increase Visualization (Graphs & Charts)



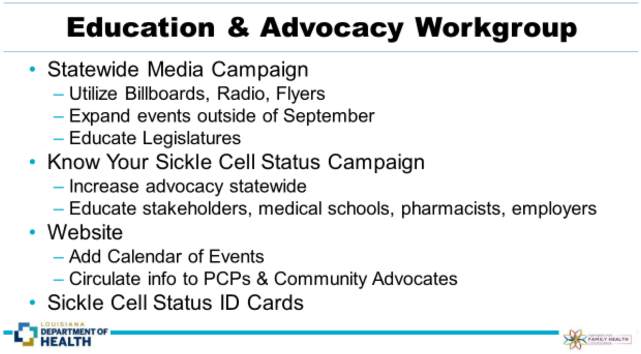
Medical Services Workgroup

- Finding New Providers
  - Survey PCPs to identify those accepting patients w/ SCD
  - Survey Patients to identify Providers treating SCD
    - Identify Adult PCPs treating SCD after youth transition
- Collaborating with Healthy Louisiana
  - Identify the PCPs receiving the referral for SCD
  - Invitation to meet with Medical Directors
- Emergency Department Education
  - Meeting/Conference with ED Personnel to educate about SCD
- Pain Management Protocols
  - Establish Statewide Protocols for SCD



Patient Navigation

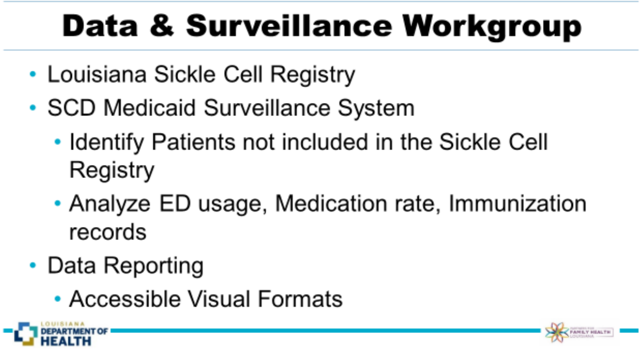
- Patient Navigator Program
  - Negotiate funds into contracts for Foundations
- Chronic Pain Management
  - Introduction of Medical Marijuana
- Know Your Sickle Cell Status Campaign
  - Partner with Universities, Colleges, & other Schools
- Sickle Cell Status ID Cards
  - Educate PCPs about the cards



Education & Advocacy Workgroup

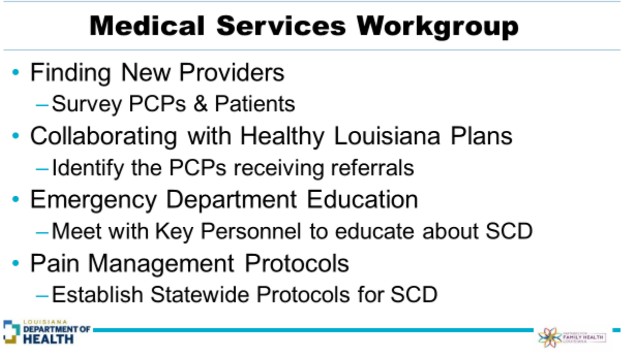
- Statewide Media Campaign
  - Utilize Billboards, Radio, Flyers
  - Expand events outside of September
  - Educate Legislatures
- Know Your Sickle Cell Status Campaign
  - Increase advocacy statewide
  - Educate stakeholders, medical schools, pharmacists, employers
- Website
  - Add Calendar of Events
  - Circulate info to PCPs & Community Advocates
- Sickle Cell Status ID Cards

Appendix F: LSCC Meeting Data & Surveillance-December 11, 2018



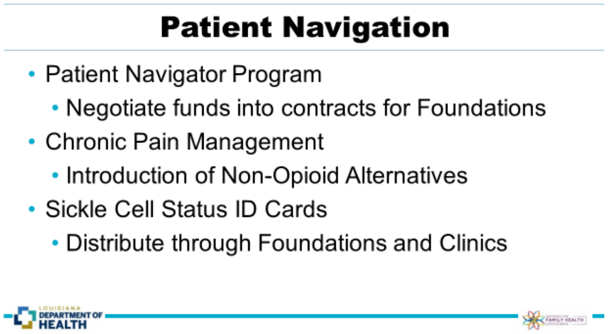
Data & Surveillance Workgroup

- Louisiana Sickle Cell Registry
- SCD Medicaid Surveillance System
  - Identify Patients not included in the Sickle Cell Registry
  - Analyze ED usage, Medication rate, Immunization records
- Data Reporting
  - Accessible Visual Formats



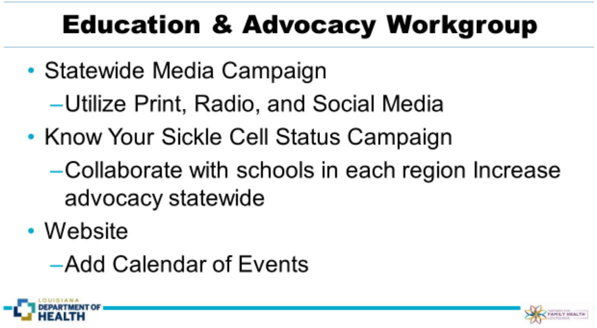
Medical Services Workgroup

- Finding New Providers
  - –Survey PCPs & Patients
- Collaborating with Healthy Louisiana Plans
  - –Identify the PCPs receiving referrals
- Emergency Department Education
  - –Meet with Key Personnel to educate about SCD
- Pain Management Protocols
  - –Establish Statewide Protocols for SCD



Patient Navigation

- Patient Navigator Program
  - Negotiate funds into contracts for Foundations
- Chronic Pain Management
  - Introduction of Non-Opioid Alternatives
- Sickle Cell Status ID Cards
  - Distribute through Foundations and Clinics



Education & Advocacy Workgroup

- Statewide Media Campaign
  - –Utilize Print, Radio, and Social Media
- Know Your Sickle Cell Status Campaign
  - –Collaborate with schools in each region Increase advocacy statewide
- Website
  - –Add Calendar of Events

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.

Louisiana Department of Health
628 North Fourth Street, Baton Rouge, Louisiana 70802
(225) 342-9500
www.ldh.la.gov

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