Raising Awareness on Sickle Cell Disease and Trait in Louisiana

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Louisiana Genetic Diseases Program
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The Louisiana Genetic Diseases Program was established in 1981 through a federal grant from the Health Resources and Services Administration (HRSA). The purpose of the program continues to be the operation of a comprehensive newborn heel stick screening program meeting national standards as well as to ensure access to genetic evaluation and counseling to residents in all areas of Louisiana.

http://ldh.la.gov/Genetics
Landscape of Sickle Cell Disease in Louisiana

• Approximately 80 infants are born with sickle cell disease (SCD) and 1400 infants are born with sickle cell trait (SCT) in Louisiana each year.

• Estimated that there are approximately 3000 children and adults living with SCD in the state.
Limited Resources for Adult SCD Patients

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

- No registry/database or program existed to track SCD patients throughout their lifetime to ensure that they were not lost to follow-up.
- There were deficits in SCD patient and family education and engagement in both the pediatric and adult populations.
Geography of Sickle Cell Disease within Louisiana Medicaid: Population, Claims, and Costs (CY2013)

- Prepared by the Center for Population Health Informatics and Bureau of Health Services Financing

- Between January 2009 and May 2014, there were 5,749 people in Louisiana who were eligible for Medicaid and incurred a sickle cell disease related Medicaid claim.

- 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.

- This Medicaid sub-population had an average cost of $11,720 per person, while the overall per member cost of Medicaid was $4,511 according to the FY13 Medicaid report.
Geography of Sickle Cell Disease within Louisiana Medicaid: Population, Claims, and Costs (CY2013)
Louisiana Sickle Cell Commission (LSCC)

Act No. 117 (Senate Bill 57) of the 2013 Regular Legislative Session mandated the Louisiana Department of Health (LDH) to create the Louisiana Sickle Cell Commission (LSCC) to ensure the adequate delivery of services to all persons and formulate new actions to reduce the burden of SCD in Louisiana.
LSCC Members

Organizations appointed by the Governor:

- 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.
- 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 Senate
- One member of the Louisiana House of Representatives appointed by the speaker of the House of Representatives
LSCC Partners & Stakeholders

- Department of Health
  - Genetic Diseases Program
  - Children’s Special Health Services Program
  - Bureau of Family Health
  - Bureau of Health Informatics
- Louisiana Sickle Cell Foundations (Community Based Organizations)
- Louisiana Sickle Cell Clinics
- Louisiana State University Health Sciences Centers (New Orleans & Shreveport)
- Ochsner Health Center for Children
- Our Lady of the Lake Physician Group
- Louisiana Public Health Institute
  - Research Action for Health Network (REACHnet)
- Healthy Louisiana (Medicaid Managed Care Organizations-MCOs)
- Private citizens affected by SCD
Strategic Plan to Improve Sickle Cell Disease Health Care Coordination

In 2014, the LSCC developed a strategic plan to improve the health outcomes of individuals living with SCD in Louisiana, and it continues to be implemented through four workgroups:

- Data & Surveillance
- Medical Services Workgroup
- Patient Navigation
- Education and Advocacy
Data & Surveillance

**Goal:** to maintain an active surveillance system for Sickle Cell Disease patients in Louisiana
Louisiana Sickle Cell Registry

- Newborn screening data was monitored for individuals identified with a SCD and SCT diagnosis then documented in the Louisiana Sickle Cell Registry.
- The registry data was divided by LDH Regions and provided to the Sickle Cell Foundations in order to decrease gaps in medical care and provide supportive sickle cell services for patients in their region.
- The caseloads of the Sickle Cell Foundations were crossed checked with the names in the registry and the unmatched individuals were added.
- The Genetic Diseases Program monitors the registry and established a process for sharing Protected Health information (PHI) in a confidential environment that complies with all LDH Policies and the Privacy Regulations of the Health Insurance Portability and Accountability Act (HIPAA).
Sickle Cell Disease Cases
Development of Sickle Cell Surveillance System utilizing Medicaid Data

The Genetic Disease Program has been collaborating with the Bureau of Health Informatics in developing a surveillance system that will use ICD9 & ICD10 codes associated with SCD and SCT in Medicaid to monitor patient care and clinical utilization costs.

- Modified the Geography of Sickle Cell Disease within Louisiana Medicaid Report
- Data for all sickle cell patients (CY 2014 till date) were broken down by each calendar year and payments made by Medicaid for their claims (sickle cell related claims, non sickle cell related claims and total payments).

Subsets include:
- Age Group, i.e., Children (less than 21 years) and Adult (21 years and above)
- Gender
- Race
- LDH Regions and Parishes
- Claim Type
- ER Claims and non ER Claims
- Diagnosis Code
Medical Services Workgroup

**Goal:** to improve medical access and care for people with sickle cell disease while reducing health care cost in Louisiana
Standards for Care of Patients with SCD Toolkit

- This toolkit was developed to be informative to the healthcare professional who has no familiarity with SCD populations, the community liaison who has moderate knowledge and experience, and the professional with considerable knowledge who can benefit from a refresher.

- 1000 copies of the toolkits were printed and an electronic version was created.
Statewide Distribution of Standards for Care

344 toolkits were mailed to Medical Centers and Healthcare Providers throughout the state.

**Healthcare Facilities**
- Federally Qualified Health Centers 172 (50 %)
- Hospitals/Emergency Departments 109 (32 %)
- School-Based Health Center Sponsors 63 (18 %)
Healthy Louisiana (Medicaid MCOs)

- Implemented case management programs targeting the clinical management of SCD.
- Engaged and invited representatives to attend LSCC meetings.
- Connected the five plans with the sickle cell clinics and foundations.
- Matched the Sickle Cell Registry data with Medicaid data to identify the Healthy Louisiana plan patients are enrolled.
  - Subset is included among the registry data provided to the Sickle Cell Foundations.
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
Establishment of the Sickle Cell Patient Navigator Program

- Act No. 387 (House Bill 260) of the 2015 Regular Legislative Session mandated the Louisiana Department of Health (LDH) under the direction of the Louisiana Sickle Cell Commission (LSCC) to create the Sickle Cell Patient Navigator Program to increase statewide access to the types of specialty care that are critical to the health and well-being of sickle cell patients in Louisiana.

- Due to State Budget reductions, funding has not been granted to implement the Program.

- The Genetic Diseases Program and the LSCC have applied for funds and continue to search for alternative funding opportunities:
  - LDH
  - State Legislatures
  - HRSA
  - Louisiana Health Works Commission
Developed Partnerships with State Agencies and Healthcare Organizations

- Children Special Health Services Program
  - National Performance Measure 11-12
    - Collaborating with CYSHCH around care coordination initiatives
    - Participating at Resource Information Workshop
    - Included sickle cell contacts in the regional resource guides
    - Identifying subspecialty providers willing to accept new sickle cell patients
- Louisiana Public Health Institute- Research Action for Health Network (REACHnet)
  - Sickle Cell Advisory Group
- Emergency Preparedness and Response Program
- Louisiana Health Insurance Premium Payment Program (LaHIPP)
Education and Advocacy

**Goal:** to educate citizens and stakeholders on Sickle Cell Disease
Emphasized Sickle Cell Disease at Medical Symposium

2015 Louisiana Primary Care Association Medical Summit

- Devoted a day to SCD
- National and local speakers discussed several topics related to Primary and Behavioral Health
Launched Sickle Cell Statewide Conference

- The objective for the 2017 inaugural conference was to bring all stakeholders together in the fight against sickle cell disease to build on the achievements of the LSCC.
- The group of well known experts that participated in the conference included Professors, Educators, Doctors, Nurses, Social workers, Directors, Researchers, Members of Boards and other authorities.
- Breakout sessions focused on the state of Sickle Cell Adult Care in Louisiana, Patient Advocacy, Youth Health Transition, Patient Rights, Clinical Trials, Disability and more.
Established Statewide Sickle Cell Awareness Campaign

- Developed web content highlighting sickle cell related resources and activities around the State.
  - Louisiana Sickle Cell Disease Web Page
    - Educational Materials and Regional Resource Guides
    - Regional Sickle Cell Events during National Sickle Cell Awareness Month
  - Louisiana Sickle Cell Commission Web Page

- Disseminated articles through the Department of Health
  - Louisiana Department of Health (LDH) Today Electronic Newsletter
  - LA Morbidity Report
Louisiana Sickle Cell Disease Webpage

September is National Sickle Cell Awareness Month, which calls attention to Sickle Cell Disease (SCD), a genetic disorder that affects about 100,000 Americans according to the National Heart, Lung, and Blood Institute.

Each year, approximately 80 infants are born with 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.

Through the Genetic Diseases Program, the Louisiana Department of Health provides resources and information on how individuals diagnosed with sickle cell can receive assistance and care through the Sickle Cell Foundations and Clinics around the state.

http://ldh.la.gov/Genetics

Louisiana Department of Health
Educational Materials on Sickle Cell Disease and Sickle Cell Trait

Sickle Cell Anemia
(Hemoglobin SS Disease)

What Every Parent Should Know

Sickle Cell Trait - What Does It Mean?

Hemoglobin SC Disease

What Every Parent Should Know

Louisiana Department of Health
Genetic Diseases Program
1450 Poydras St., Suite 2046
New Orleans, LA 70112
(504) 568-8254
www.idh.la.gov/genetics

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Regional Resource Guides for Sickle Cell Clinics and Foundations

Louisiana Sickle Cell Clinics

New Orleans, Houma, Slidell
Children’s Hospital
200 Hospital Dr
New Orleans, LA 70119
504-713-1504
Renee Gautier, MD
Maeve Vary, MD
Franky Fontenot, MD

Baton Rouge
2400 Louisiana State University Health Complex
Baton Rouge, LA 70808
225-388-6000
Tameny Winyard, MD

Lake Charles
200 Lake Street
Lake Charles, LA 70601
318-442-3250
Annette Young, MD

Sickle Cell Centers of Southern Louisiana - Tulane University
150 South Liberty Street
New Orleans, LA 70113
504-945-5000

Tulane Laminar Flow Laboratory
4201 Tulane Avenue, New Orleans, LA 70118
504-945-5000

Louisiana Sickle Cell Centers

New Orleans, Houma, Slidell
Sickle Cell Center of Southern Louisiana - Tulane University
150 South Liberty Street
New Orleans, LA 70113
504-945-6200
Melody Boynton, Administrative Director

Alexandria
Sickle Cell Anemia Research Foundation
2023 Third Street
Alexandria, LA 71302
318-487-8019
Ronis Mossey, Executive Director

Shreveport
Sickle Cell Disease Association of America, Northwest Louisiana
1313 Judson Street
Shreveport, LA 71109
318-429-5300
Lindle Bradford, Executive Director

Lake Charles
Sickle Cell Anemia, Inc.
1901 Hadley Street
Lake Charles, LA 70601
337-433-2402
Elena Petre, Executive Director

For additional information, please contact the Genetic Diseases Program at (504) 568-8234 or visit http://dhhs.la.gov/Genetics

Louisiana Department of Health
Regional Sickle Cell Events and Health Fairs
The mandate of the Louisiana Sickle Cell Commission (LSCC) is to improve the delivery of sickle cell services to affected people in all parishes of Louisiana.

Under the guidelines set out in Act 117 (SB 57) R.S. 40:2018.3, the charge of the LSCC is 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 28 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.

Membership is by appointment of the Governor, subject to Senate confirmation and is inclusive of a representative from each of the following:
What's next for the LSCC in 2018?

Data & Surveillance
Funding and Development of a Case Management System.

Medical Services Workgroup
- Implementing Sickle Cell Triage Procedures for Emergency Departments.

Patient Navigation
Funding and Implementation of the Sickle Cell Patient Navigator Program.

Education and Advocacy
- 2018 Statewide Sickle Cell Disease Conference in New Orleans.
- Authorization and Print of the LSCC Brochure
Thank You!

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