

Raising Awareness on Sickle Cell Disease and Trait in Louisiana

Presented By: Jantz Malbrue, MSPH

Sickle Cell Program Manager

Louisiana Genetic Diseases Program

Louisiana Genetic Diseases Program

The screenshot shows the Louisiana Department of Health website. At the top left is the state seal and the text "LOUISIANA DEPARTMENT OF HEALTH". At the top right, it says "Secretary REBEKAH E. GEE, MD, MPH" and a teal button with a left arrow and "BACK TO LDH". The main header area is dark blue with the text "COMMUNITY & PREVENTIVE HEALTH" in large white letters. Below this is a teal bar with the breadcrumb "Louisiana.gov > LDH > Community and Preventive Health". On the left side, there is a vertical menu with three items: "OPH HOME", "ABOUT COMMUNITY AND PREVENTIVE HEALTH", and "FOR SPECIAL HEALTH NEEDS". The main content area has the title "Genetic Diseases and Lead Poisoning Prevention" followed by a paragraph: "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.

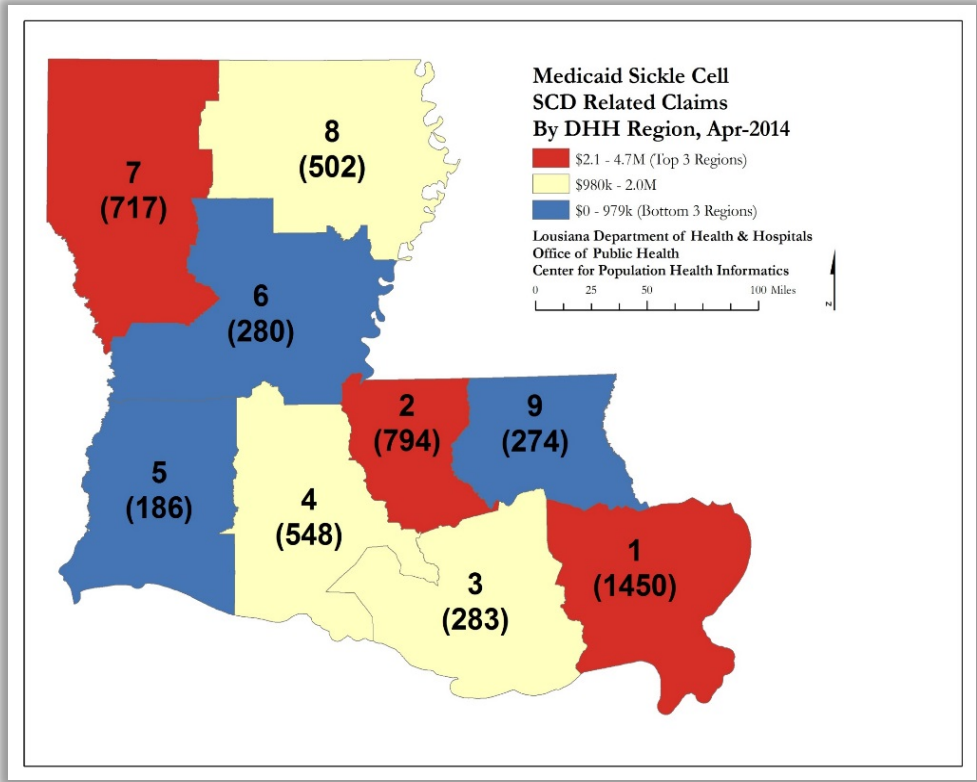
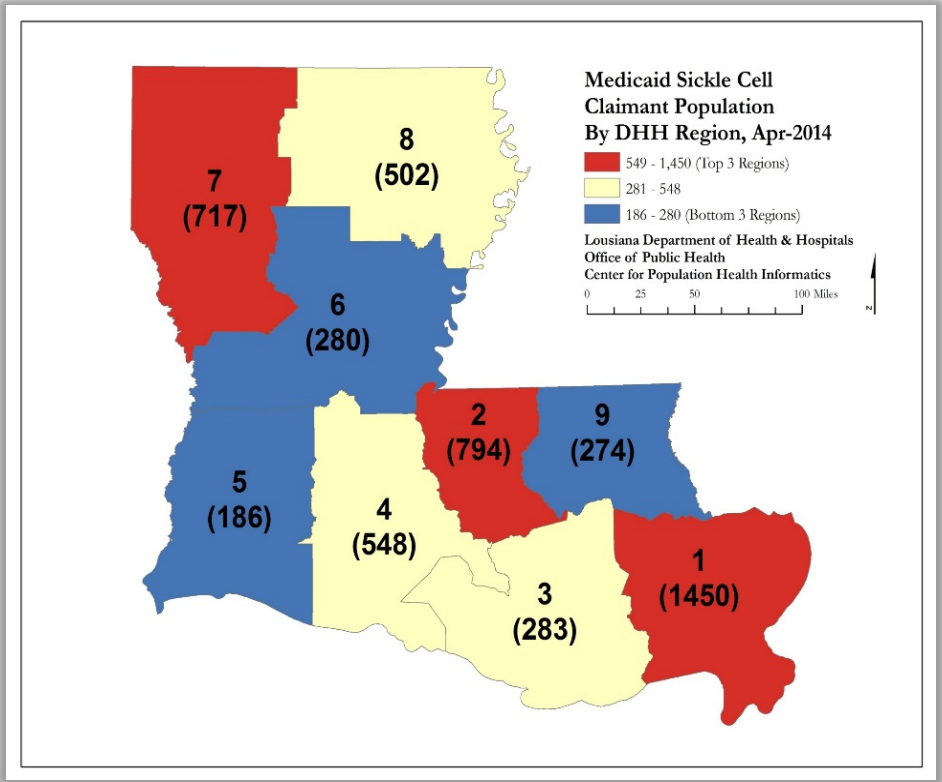
Additional Opportunities for Intervention

- 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.
- 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 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**

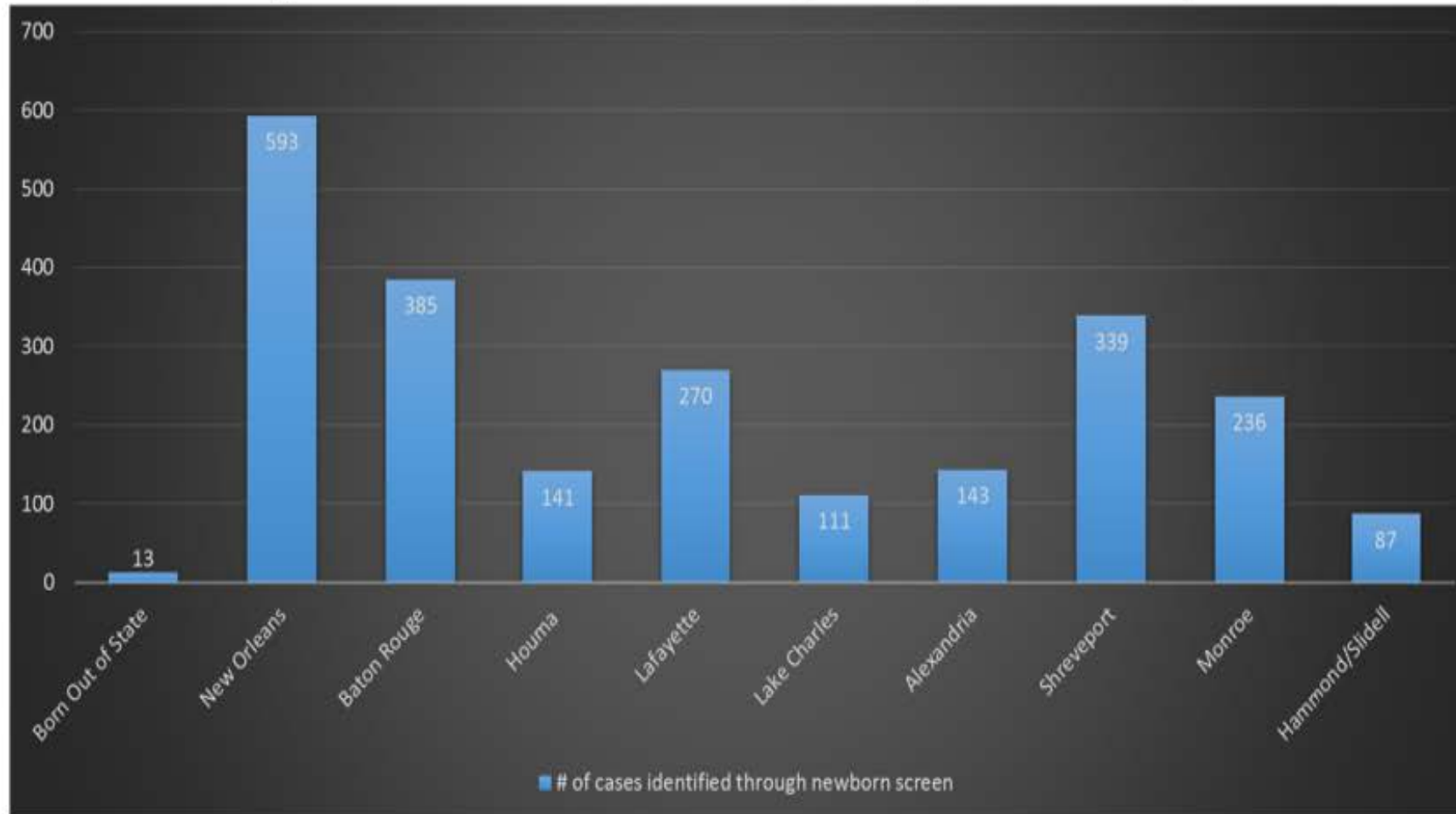
Data & Surveillance

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

Louisiana Sickle Cell Registry

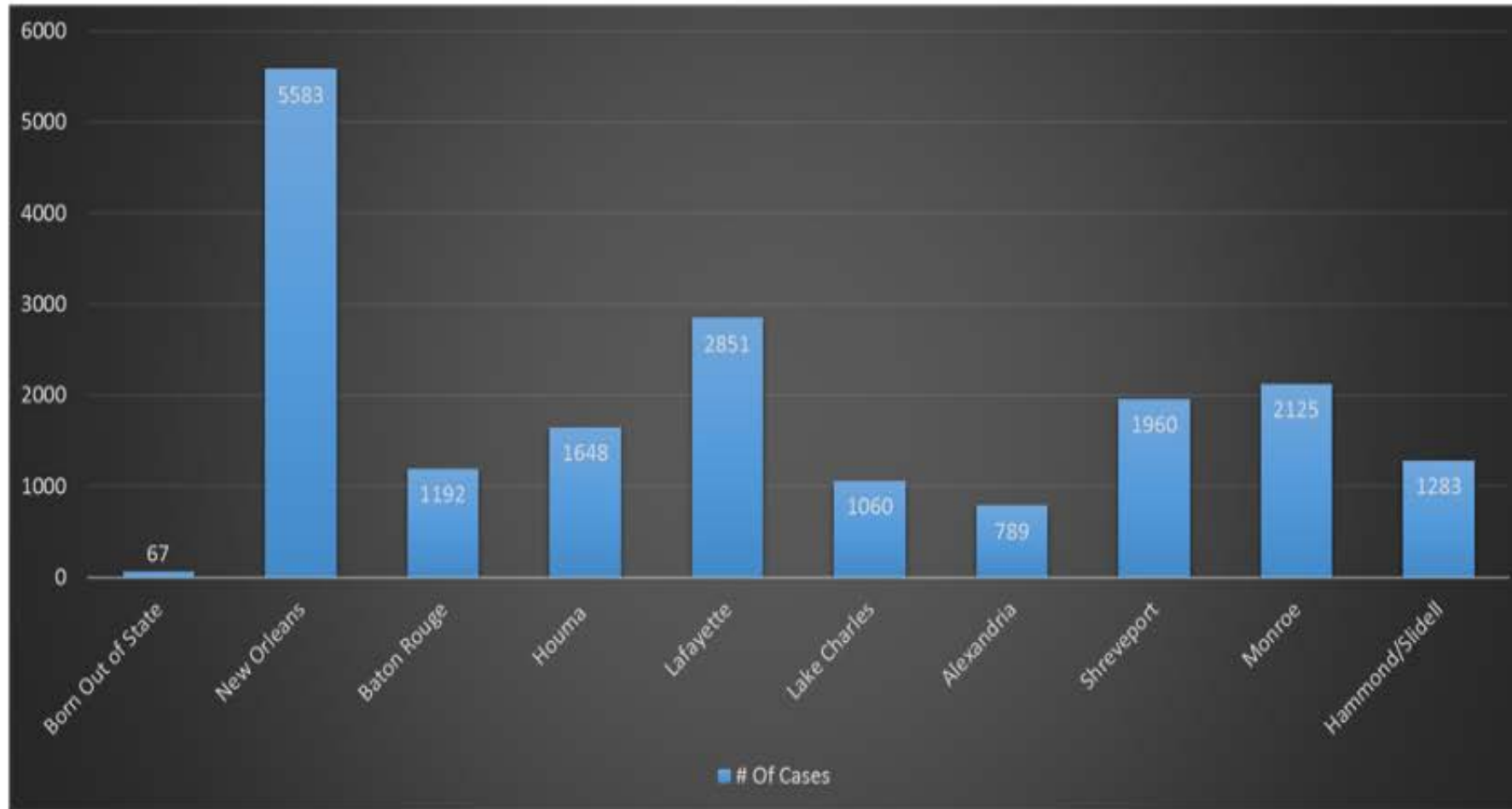
- Newborn screening data was monitored for individuals identified with a SCD and SCT diagnosis then documented in the Louisiana Sickle Cell Registry.
- The registry data was divided by LDH Regions and provided to the Sickle Cell Foundations in order to decrease gaps in medical care and provide supportive 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 the all LDH Policies and the Privacy Regulations of the Health Insurance Portability and Accountability Act (HIPAA).

Sickle Cell Disease Cases by LDH Public Health Region (1988-2017)



Sickle Cell Trait Cases

by LDH Public Health Region (2003-2017)



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.

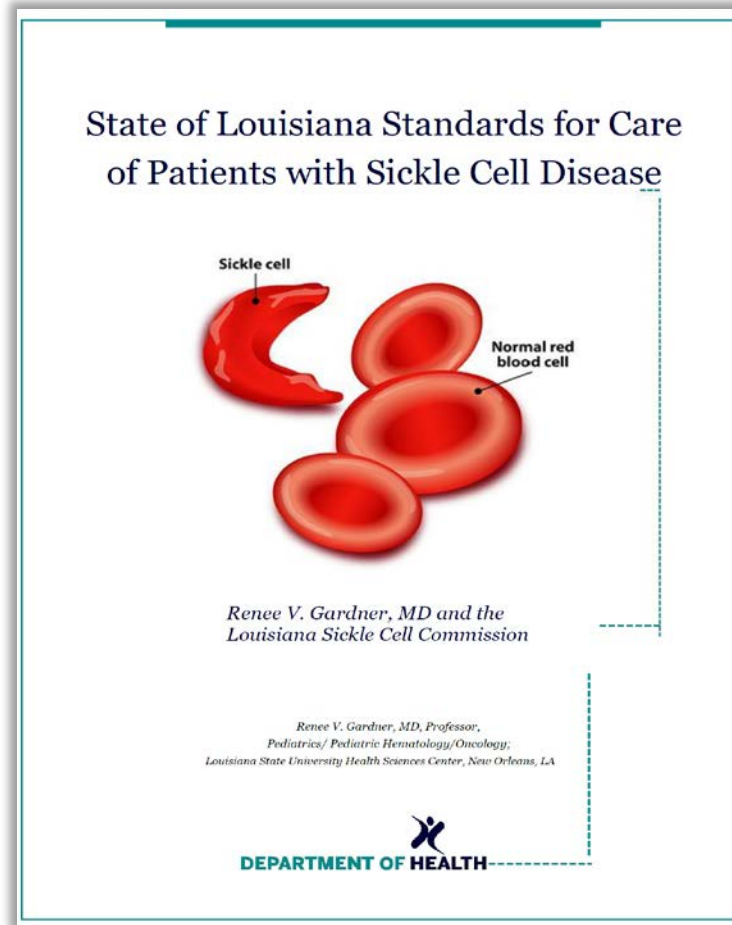
- Modified the Geography of Sickle Cell Disease within Louisiana Medicaid Report
- Data for all sickle cell patients (CY 2014 till date) were broken down by each calendar year and payments made by Medicaid for their claims (sickle cell related claims, non sickle cell related claims and total payments).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

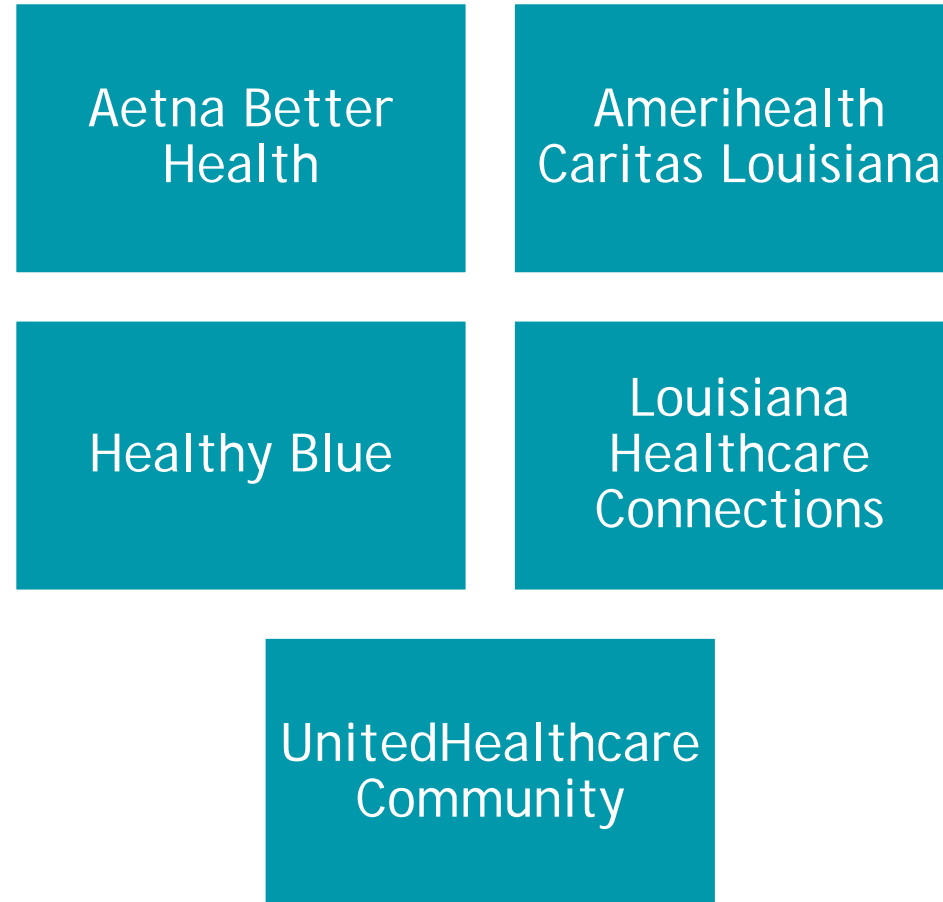
344 toolkits were mailed to Medical Centers and Healthcare Providers throughout the state.

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

COMMUNITY & PREVENTIVE HEALTH

Louisiana.gov > LDH > Community and Preventive Health

OPH HOME

ABOUT COMMUNITY
AND PREVENTIVE
HEALTH

FOR SPECIAL
HEALTH NEEDS

FOR WOMEN &
CHILDREN

FOR PUBLIC HEALTH
PROFESSIONALS

LABORATORY
SERVICES

REPORTING
INFECTIOUS
DISEASES

NUTRITION
PROGRAMS



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

 **LOUISIANA DEPARTMENT OF HEALTH**
Public Health

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

Hemoglobin SC Disease




What Every Parent Should Know


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**Sickle Cell Trait -
What Does It Mean?**



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Regional Resource Guides for Sickle Cell Clinics and Foundations


LOUISIANA DEPARTMENT OF HEALTH
Public Health

Louisiana Sickle Cell Clinics

New Orleans, Houma, Slidell
 Children's Hospital
 200 Henry Clay Avenue
 New Orleans, LA 70118
 504.896.9740
 Renee Gardner, MD
 Maria Velez MD
 Pinky Prasad, MD

Ochsner Foundation Hospital
 1315 Jefferson Highway
 New Orleans, LA 70121
 504.842.3900
 Raj Warner, MD
 Craig Lotterman, MD
 Matthew Fletcher, MD
 Robert Vasquez, MD

Sickle Cell Center of Southern Louisiana- Tulane University
 150 South Liberty Street (Adult & Transitional Clinic)
 New Orleans, LA 70112
 504.988.5413
 Cindy Leissing, MD (Adult Clinic)

Tulane Lakeside Hospital for Women and Children
 4th Floor (Pediatric Clinic)
 4700 S. Interstate 10 Service Road West
 Metairie, LA 70001
 504.988.6253
 Tammuela Singleton, MD

Baton Rouge
 St. Jude Children's Hospital Baton Rouge Affiliate Clinic (Pediatric Clinic)
 7777 Hennessy Boulevard Suite 312
 Baton Rouge, LA 70808
 225.763.6337
 Sheila Moore, MD
 Jeffrey Deyo, MD
 Catherine Boston, MD
 Kacie Sims, MD

Our Lady of the Lake Adult Sickle Cell Clinic
 4950 Essen Lane Suite 300
 Baton Rouge, LA 70809
 225.757-0343
 J. Ryan Shows, MD
 Siva Yadlapati, MD

For additional information, please contact the Genetic Diseases Program at (504) 568-8254 or visit <http://ldh.la.gov/Genetics>.

Lafayette
 Women's & Children's Kids Specialty Center
 4704 Ambassador Caffery Parkway
 Lafayette, LA 70508
 337.521.9500
 Ammar Morad, MD

Lake Charles
 Women's & Children's
 1890 W. Gauthier Road Suite 115
 Lake Charles, LA 70605
 337.371.3107
 Ammar Morad, MD


Moss Memorial Health Clinic Sickle Cell Clinic
 1000 Walters Street
 Lake Charles, LA 70607
 337.480.8066
 Renee Gardner, MD

Alexandria
 Alexandria Sickle Cell Clinic
 Rapides Parish Health Unit
 5604-A Coliseum Boulevard
 Alexandria, LA 71303
 318.487.5282
 Majed Jeroudi, MD

Rapides Women's & Children's Hospital
 501 Medical Center Drive #4C
 Alexandria, LA 71301
 318.442.5800
 Ammar Morad, MD

Shreveport
 Sickle Cell Center of Northern Louisiana
 LSUHSC Shreveport Feist-Weiller Cancer Center
 St. Jude Affiliate Clinic
 1405 Kings Highway
 Shreveport, LA 71104
 318.813.1000
 Richard Mansour, MD (Adult Clinic-Director)
 Srinivas Devarakonda, MD (Adult Clinic)
 Majed Jeroudi, MD (Pediatric Clinic)

Monroe
 Monroe Sickle Cell Center
 Ouachita Parish Health Unit
 1650 Desiard Street
 Monroe, LA 71201
 318.361.7282
 Majed Jeroudi, MD


LOUISIANA DEPARTMENT OF HEALTH
Public Health

Louisiana Sickle Cell Foundations

New Orleans, Houma, Slidell
 Sickle Cell Center of Southern Louisiana- Tulane University
 150 South Liberty Street
 New Orleans, LA 70112
 504.988.6300
 Melody Benton, Administrative Director

Alexandria
 Sickle Cell Anemia Research Foundation, Inc.
 2625 Third Street
 Alexandria, LA 71302
 318.487.8019
 Rosia Metoyer, Executive Director

Baton Rouge
 Baton Rouge Sickle Cell Anemia Foundation
 2301 North Boulevard
 Baton Rouge, LA 70806
 225.346.8434
 Lorri Burgess, Executive Director

Lake Charles
 Southwest Sickle Cell Anemia, Inc.
 1901 Harless Street
 Lake Charles, LA 70601
 337.433.2602
 Etta Pete, Executive Director


Shreveport
 Sickle Cell Disease Association of America, Northwest Louisiana Chapter
 3658 Judson Street
 Shreveport, LA 71109
 318.636.5300
 Lillie Bradford, Executive Director

Monroe
 Northeast Sickle Cell Anemia Foundation
 1604 Winnsboro Road
 Monroe, LA 71202
 318.322.0896
 Donna Thaxton, Executive Director

For additional information, please contact the Genetic Diseases Program at (504) 568-8254 or visit <http://ldh.la.gov/Genetics>.

Regional Sickle Cell Events and Health Fairs

Educating, Advocating, Caring, and Promoting a Healthier Way to Live!



Adult Sickle Cell Anemia Symposium

A CONTINUING MEDICAL EDUCATION ACTIVITY

August 19, 2017
LSU Health Shreveport
Main Auditorium

For more information:
J. Walton
Feist-Weiller Cancer Center
(318) 813-1405
jwalto@lsuhsc.edu

LSU Health SHREVEPORT Feist-Weiller Cancer Center University Health



RYAN'S RUN 2017

For Sickle Cell Anemia

SATURDAY	AUGUST 26
<i>Downtown Baton Rouge</i>	TOWN SQUARE
RYAN CLARK HONORARY CHAIRPERSON SUPER BOWL CHAMPION SICKLE CELL CHAMPION 	6:30AM REGISTRATION 7:30AM 5K RUN 7:45AM OPENING CEREMONY 8:00 AM 5K WALK 8:15 AM 1 MILE FUN FOR KIDS EARLY REGISTRATION PICK-UP DATES: AUGUST 23-24 8AM-4:30PM AUGUST 25 8AM-2:30PM <i>Pick-up location:</i> 2301 NORTH BOULEVARD, BATON ROUGE, LA 70806
KHLOE NOELLE CUSHENBERRY 2017-2018 SICKLE CELL AMBASSADOR 	For more information, call 225.346.6434 To register online, visit www.brscaf.org/walkrun












SEPTEMBER
Is Sickle Cell Awareness Month

"THE RED RUN"

SEPTEMBER 09, 2017

Where: City Park Festival Grounds
Time: Registration 7:00 am | Run 8:00 am
Cost: \$25 for individuals and group 10 or more \$20
Register: www.nolascaawareness.com
All proceeds will benefit the Sickle Cell Center of Southern Louisiana

The RED Run
The RED Run will be a way to bring awareness, provide medical research for a cure, and to bring HOPE to those individuals who's in the fight everyday.

Prepare your teams for the 2 mile run. WE will run and fight together.

Who Does It Benefit?
The Sickle Cell Center of Southern Louisiana.


because it matters...
SICKLE CELL anemia
Awareness

For Questions Contact: Rachele DeFillo at 504.307.8876

September is Sickle Cell Awareness Month

Save the Date

Children's Hospital SATURDAY, SEPT 23, 2017 at 10AM-2PM in the Auditorium




Calling all Sickle Cell Heroes and their Families to attend our **Inaugural Sickle Cell Resource Fair**

Featuring:
Educational Guest Speakers, Informational Booths, Blood Drive, Door Prizes, Food, Children's Activities and more!

More information flying your way soon!

LSU Health NEW ORLEANS "Heroes... Ordinary People Doing Extraordinary Things"



Louisiana Sickle Cell Commission Webpage

COMMUNITY & PREVENTIVE HEALTH

Louisiana.gov > LDH > Community and Preventive Health

OPH HOME

Louisiana Sickle Cell Commission

ABOUT COMMUNITY
AND PREVENTIVE
HEALTH

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.

FOR SPECIAL
HEALTH NEEDS

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

FOR WOMEN &
CHILDREN

1. Ensure the delivery of sickle cell services to affected persons in all parishes in Louisiana and assist in establishing geographical service delivery boundaries.

FOR PUBLIC HEALTH
PROFESSIONALS

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.

LABORATORY
SERVICES

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.

REPORTING
INFECTIOUS
DISEASES

NUTRITION
PROGRAMS

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.
- Development of Sickle Cell Pain Management Protocols.

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!

Jantz Malbrue, MSPH
Genetic Diseases Program
Sickle Cell Program Manager

Jantz.Malbrue@la.gov

504-568-8254

<http://ldh.la.gov/Genetics>