



## State of Louisiana

Louisiana Department of Health  
Office of Public Health

Louisiana Sickle Cell Commission

June 10, 2021

1:00 p.m.-2:30 p.m.

<https://ldhophbfhgenetics.zoom.us/j/89191129003>

Conference Call info: (602) 333-0032

Access Code: 532143#

Roll Call taken; members present at the meeting were as follows:

- Pamela Saulsberry, Ph.D., LCSW, Northeast Sickle Cell Anemia Foundation
- Shannon Robertson, RN, BSN, Louisiana Primary Care Association
- Chauncey Hardy, Sickle Cell Anemia Research Foundation, Alexandria
- Erin Fulbright, Sickle Cell Association of South Louisiana
- Rosalind Spain, Sickle Cell Disease Association, Northwest Louisiana Chapter
- Cheryl Harris, MPH, OPH Genetic Diseases Program (LDH Designee)

Additional meeting attendees:

- Cassandra Norman, Sickle Cell Disease Association of America Inc.
- Donna Thaxton, Northeast Sickle Cell Anemia Foundation
- Medria Taylor-Buford, Northeast Sickle Cell Anemia Foundation
- Sharon Price, Sickle Cell Anemia Research Foundation, Alexandria
- Ernest DeJean- Sickle Cell Center-Tulane University
- Rihanna Galloway-Dawkins- Sickle Cell Center-Tulane University
- Dana LeBlanc, MD., Children's Hospital, New Orleans
- Majed Jeroudi, MD., Ochsner LSU Health Shreveport
- Kathy Williams, Sickle Cell Association of South Louisiana
- Torris Johnson, Sickle Cell Association of South Louisiana
- Courtney Sanford, Louisiana Primary Care Association
- Kelly Hess, Global Blood Therapeutics, Inc.
- Maurice Garland, Global Blood Therapeutics, Inc.
- Gail Gibson, RN, BSN, MN, CPM, FABC, OPH Bureau of Family Health
- Jantz Malbrue, OPH Genetic Diseases Program

Call to Order

Jantz Malbrue called the meeting to order at 1:15 p.m.

Welcome

OFFICE OF PUBLIC HEALTH  
Genetic Diseases Program

1450 Poydras St Suite 2046 • P.O. Box 60630 • New Orleans, Louisiana 70160-0630  
Phone #: 504/568-8254 • Fax #: 504/568-8253 • [www.ldh.la.gov/genetics](http://www.ldh.la.gov/genetics)

"An Equal Opportunity Employer"

1. Care Coordination
  - a. Issues and Barrier

Rosalind Spain discussed the lack of insurance coverage for clients with sickle cell and asked how to use more data to illustrate the problem. Kathy Williams mentioned the trouble of clients being able to find or purchase insurance. In addition, Ms. Williams discussed bringing this issue to the legislators for advice and support. Cheryl Harris mentioned the lack of knowledge on the true cost of providing services for sickle cell clients. Ms. Harris proposed a thorough review of sickle cell-related emergency department usage, care coordination, and patient navigation services.

2. Medication Therapies
  - b. Access to Curative Therapies

Dr. Majed Jeroudi discussed the barriers he has been encountering with the prior authorization process when prescribing Hydroxyurea. Kathy Williams is experiencing similar barriers with the Endari prescriptions. Dr. Pamela Saulsberry asked if meds were distributed everywhere. Horatio Handy mentioned that Oxbryta was not available at all pharmacies, but it is available for dispense at specialty pharmacies.

3. Patient Advocacy

Rosalind Spain discussed advocating with legislators at the state capital. Ms. Spain mentioned Representative Tammy Phelps as a contact for support on sickle cell initiatives. Medria Taylor-Buford stated that Representative Frederick Jones was another legislator to direct concerns. Chauncey Hardy discussed the idea of using a legislative designee from each region. Ms. Taylor-Buford discussed tapping into the resources of Together Louisiana that is a statewide network of faith and community based organizations to assist with affecting change on a larger scale.

4. Other Business

The Sickle Cell Disease Association Northwest LA Chapter discussed the upcoming Shine the Light awareness event with a red spotlight on the courthouse in Shreveport for July 9 to 11. In addition, Ms. Spain discussed the upcoming annual softball tournament. The Northeast Sickle Cell Anemia Foundation is hosting an all-white gala awareness event on August 31. The Sickle Cell Association of South Louisiana is hosting a blood drive on Juneteenth in New Orleans. The Southwest Sickle Cell Anemia is hosting an upcoming sickle cell awareness and Juneteenth event in Lake Charles.

Adjournment 2:35 PM

---

# Louisiana Genetic Disease Program

An Introduction Into Our Work

---

# Program History

---

- Established in 1981
- Purpose was fourfold:
  - (1) Make genetic evaluation and counseling accessible
  - (2) Improve the coordination of the newborn screening program
  - (3) Increase community awareness of genetic services
  - (4) Strengthen linkages between genetic services providers

---

# Funding Structure

---

Funding was secured through the Maternal and Child Health (MCH) Block Grant Program, administered by the Health Resources and Services Administration (HRSA).

A mix of self-generated, Medicaid and state funding was added. The Hemophilia Program (in 1986) and the Lead Screening Program (in 1990) became units under the LaGDP

---

# Services

---

- Newborn Screening Follow-up
- Clinical Genetics Services
- Metabolic Formula Distribution
- Genetics Advisory Committee
- Sickle Cell Disease Program
- Cystic Fibrosis Advisory Committee
- Pediatric Endocrinology Advisory Committee (PEAC)

# Newborn Screening

GDP tests for 29 genetic disorders

\*Required by Louisiana Law (R.S. 40:1299.1.2.3)

- Metabolic Disorders
  - Amino Acid Disorders
  - Organic Acid Disorders
  - Fatty Acid Disorder
  - Galactosemia
  - Biotinidase Deficiency
- Hemoglobin disorders
  - SS Disease
  - SC disease
  - S/Beta Thalassemia
- Endocrine Disorders
  - Congenital Hypothyroidism
  - Congenital Adrenal Hyperplasia
- Pulmonary Disorders
  - Cystic Fibrosis
- Other Disorders\*
  - Severe Combined Immunodeficiency
  - Spinal Muscular Atrophy\*
  - X-Adrenoleukodystrophy\*
  - Mucopolysaccharidosis Type I\*
  - Pompe Disease\*

---

# Newborn Screening Follow-up

---

The following phenotypes identified from newborn screening in Louisiana:

- Sickle Cell Disorders  
FS, FSA, FSC, FCS, FSD, FSE, FSV
- Other Hemoglobin Disorders  
FC, FD, FE, FV
- Hemoglobin Traits  
FAS, FAC, FAD, FAE, FAV



---

# Legislation for Sickle Cell

---

## Four Statutes

- LA Rev Stat §40:1081.5 (2015) Sickle cell anemia clinic
- LA Rev Stat §40:1081.7 (2016) Sickle cell anemia local programs
- LA Rev Stat §40:2018.3 (2013) Louisiana Sickle Cell Commission
- LA Rev Stat §40:1081.8 (2016) Sickle cell patient navigator program

---

# LA Rev Stat §40:1081.5 (2015)

---

## Sickle Cell Anemia clinic

- Authorized LDH to establish and operate clinics in cooperation with medical schools at LSU and Tulane to treat those with sickle cell anemia
- Clinics shall be maintained for the treatment of victims of sickle cell anemia regardless of geographic and economic family situation without regard to the standard eligibility requirements of charity hospitals and for the training of physicians and medical students in methods of treatment and for research into the causes of the disease and its cure
- Originally promulgated by Acts 1972, No. 27, §1. and amended by Acts 1978, No. 786, §5, eff. July 17, 1978; Acts 1984, No. 265, §2; Acts 1984, No. 859, §1; Acts 1993, No. 604, §2; The act was redesignated from R.S. 40:1299.4 by HCR 84 of 2015 R.S.

---

# Clinical Sickle Cell Services

---

## Region 1, 3, 9 (New Orleans, Houma, Slidell)

- Children's Hospital
- Ochsner Foundation Hospital
- Sickle Cell Center of Southern Louisiana-Tulane University  
(Adult & Transitional Clinic)
- Tulane Lakeside Hospital for Women and Children  
(Pediatric Clinic)

## Region 2 (Baton Rouge)

- St. Jude Children's Hospital Baton Rouge Affiliate Clinic (Pediatric Clinic)
- Our Lady of the Lake Adult Sickle Cell Clinic

## Region 4 (Lafayette)

- Women's & Children's Kids Specialty Center

## Region 5 (Lake Charles)

- Moss Memorial Health Clinic Sickle Cell Clinic

## Region 6 (Alexandria)

- Alexandria Sickle Cell Clinic Rapides Parish Health Unit

## Region 7 (Shreveport)

- Sickle Cell Center of Northern Louisiana LSUHSC Shreveport Feist-Weiller Cancer Center St. Jude Affiliate Clinic

## Region 8 (Monroe)

- Monroe Sickle Cell Center Ouachita Parish Health Unit

---

# LA Rev Stat §40:1081.7 (2016)

---

## Sickle Cell Anemia Local Programs

- Shall be maintained for the treatment of victims of sickle cell anemia regardless of geographic and economic family situation and the program shall provide holistic care, which shall include but not be limited to educational literature, screening, testing, treatment, and referrals:
  - (1) Provide a physician or nurse to provide proper health care.
  - (2) Provide a hematologist to provide proper testing to sickle cell anemia patients.
  - (3) Provide counseling for families of those who are affected by sickle cell anemia and which fatality appears imminent.
  - (4) The executive director of each regional sickle cell anemia clinic shall possess the minimum qualifications established by rules promulgated by the Louisiana Department of Health.
- The statute was originally promulgated under Acts 1993, No. 605, §1 and was redesignated from R.S. 40:1299.4.2 by HCR 84 of 2015 R.S.

---

# Community-Based Sickle Cell Services

---

## Region 2 (Baton Rouge)

- Sickle Cell Association of South Louisiana

## Region 5 (Lake Charles)

- Southwest Sickle Cell Anemia, Inc.

## Region 6 (Alexandria)

- Sickle Cell Anemia Research Foundation, Inc.

## Region 7 (Shreveport)

- Sickle Cell Disease Association of America, Northwest Louisiana Chapter

## Region 8 (Monroe)

- Northeast Sickle Cell Anemia Foundation

---

# LA Rev Stat §40:2018.3 (2013)

---

## Louisiana Sickle Cell Commission

- Ensure the delivery of sickle cell services to affected persons in all parishes in Louisiana
- Promulgate guidelines for creating uniformity in the delivery of services and the management of statewide programs
- Submit budget recommendations to the legislature and the governor
- 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
- Apply for grants and donations from any public or private source to implement the provisions of this Subsection.

---

# LA Rev Stat §40:2018.3 (2013)

---

## Louisiana Sickle Cell Commission

- LDH to establish and maintain the commission following statute as regards to:
  1. Membership, terms, chairman and vice chairman selection
  2. Meeting frequency
  3. Facilitation and administrative assistance for meetings
  4. Function and duties
- Developed a strategic plan to improve the health outcomes of individuals living with SCD
  - Four workgroups:
    - Data & Surveillance
    - Medical Services
    - Patient Navigation
    - Education and Advocacy

---

# Louisiana Sickle Cell Commission

---

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



---

# Louisiana Sickle Cell Commission

---

## Partners and Stakeholders:

- Department of Health
  - Genetic Diseases Program
  - Children’s Special Health Services Program
  - Bureau of Family Health
  - Bureau of Health Informatics
- Ochsner Health Center for Children
- Our Lady of the Lake Physician Group
- Private citizens affected by SCD
- Health Care Providers and Organizations
- Louisiana Public Health Institute
- Healthy Louisiana (Medicaid Managed Care Organizations-MCOs)
- Pharmaceutical and Biotechnology Companies

---

# Louisiana Sickle Cell Commission

---

Revised in 2020 to include five additional members appointed by the Governor:

- A person diagnosed with sickle cell disease
- A parent of a person diagnosed with sickle cell disease
- Two medical providers who provide treatment and care for patients diagnosed with sickle cell disease
- Medicaid Director for the Louisiana Department of Health or designee

---

# Louisiana Sickle Cell Commission

---

## Key Accomplishments

- Sickle Cell Registry
- Case Management Software
- Standards for Care Toolkit
- Educational Resources/Pamphlets
- Statewide Sickle Cell Conference

---

# LA Rev Stat §40:1081.8 (2016)

---

## Sickle Cell Patient Navigator Program

- Administered by LDH under direction of Sickle Cell Commission; implemented upon appropriated funding (no funding at date)
- Purpose will be to increase statewide access to the types of specialty care that are critical to the health and well-being of sickle cell patients
- Functions of the program include:
  - Train patient navigators to serve as outreach coordinators, coordinators of family educational sessions, and patient case managers
  - Establish and strengthen care continuum for sickle cell patients served by the program and for the families of those patients
  - Identify and contact sickle cell patients, conducting home visits with patients and their family members, and coordinating patient care as needed
  - Facilitate collaboration among healthcare providers that serve sickle cell patients
  - Deliver public health education on sickle cell disease and treatment.

---

# Future Legislation

---

## Louisiana Senate Concurrent Resolution No. 66 (2021)

- Requests the Department of Health to provide for equitable access to transformative therapies for sickle cell disease
- Urge and request the Louisiana Department of Health to address regulatory barriers that impede patient access to novel therapies for sickle cell disease, and to work to ensure that sickle cell patients in the Louisiana Medicaid program have access to potentially curative therapies