



State of Louisiana

Louisiana Department of Health
Office of Public Health

Louisiana Sickle Cell Commission Meeting

December 8, 2020

10:00 a.m.-12:00 p.m.

<https://ldhophbfhgenetics.zoom.us/j/87951800540>

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
- 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:

- Donna Thaxton, Northeast Sickle Cell Anemia Foundation
- Dana LeBlanc, MD., Children's Hospital, New Orleans
- Cherie Hadley, RN, Children's Hospital, New Orleans
- Majed Jeroudi, MD., Ochsner LSU Health Shreveport
- Karen Grevemberg, MBA, BSN, RN, United Healthcare
- Kathy Williams, Sickle Cell Association of South Louisiana
- Marquette Brown, Southwest Louisiana Sickle Cell Anemia, Inc.
- Kelly Hess, Global Blood Therapeutics, Inc.
- Tyler Craddock, Bluebird Bio
- April Dickerson, Bluebird Bio
- Gail Gibson, RN, BSN, MN, CPM, FABC, OPH Bureau of Family Health
- Sharonda Smith, OPH Bureau of Family Health
- Michelle Duplantier, LCSW-BACS, OPH Bureau of Family Health
- Nora McCarstle, RN, BSN, OPH Bureau of Family Health
- Chelsea Carter, MPH, OPH Louisiana Healthy Homes and Childhood Lead Poisoning Prevention Program
- Jantz Malbrue, OPH Genetic Diseases Program

Call to Order

Jantz Malbrue called the meeting to order at 10:05 a.m.

Welcome

Approval of meeting minutes – October 27, 2020

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

“An Equal Opportunity Employer”

1. Work Group Updates
 - a. New Strategic Plan Development

Medical Services & Delivery

Dr. Pamela Saulsberry recommended additional educational services due to the impact of COVID-19 on disparities. Donna Thaxton discussed the foundation's recent meetings with Ochsner LSU Monroe and other local providers on the treatment of patients with sickle cell entering their clinics. The Northeast Sickle Cell Anemia Foundation continues to use the educate the educators training method. Ms. Thaxton has encountered providers who are not knowledgeable on the treatment options for sickle cell. Rosalind Spain and Dr. Majed Jeroudi have met to discuss treatment protocols for emergency departments to use when treat patients with sickle cell. Dr. Jeroudi proposed a study to review the emergency room wait time for patients with a sickle cell pain crisis and establish guidelines for the appropriate triage period. Dr. Saulsberry stated the importance of conducting a needs assessment and collecting qualitative data. Chauncey Hardy suggested developing an instrument to monitor and track emergency department utilization. Cheryl Harris agreed with improving access to care and stated that recommendations should include a data element.

Patient Navigation

Ms. Thaxton discussed the importance of building trust with healthcare providers. She added that the foundations is having more success building trust with youth and young adults transitioning to adult providers. Dr. Saulsberry stated the importance of families as advocates. She added that the commission should develop a resource on advocacy and other resources that would be beneficial for teachers. Michelle Duplantier mentioned that the Bureau of Family Health continues to work on a transition toolkit that should be ready for distribution by early 2021.

Education & Advocacy

Mr. Hardy proposed educational training and resources for hospitals and providers to help eliminate the drug-seeking stigma towards patients with sickle cell. Ms. Harris suggested coordination with medical and allied health schools to participate in grand rounds and discuss challenges with providers. Dr. Saulsberry added the use of equity and inclusion training similar to what is occurring at the University of Louisiana Monroe.

2. 2021 Statewide Conference Planning

The potential target audience should include providers, nurses, social workers, and pharmacists. The potential learning objectives will focus on reshaping their thinking on sickle cell and the tools needed to provide adequate care and support.

Ms. Duplantier suggested the inclusion of youth health transition as a topic and inviting hematologists that treat adult patients to learn more about therapies and technology that could benefit the aging sickle cell population.

3. 2021 Regular Legislative Session

A scheduled of the upcoming legislative session will be shared with the commission.

4. 2021 Election of Officials

Members of the commission are asked to submit their nominations for the seats of chair and vice-chair.

5. 2021 Meeting Schedule

The quarterly meetings are tentatively scheduled for the 4th Tuesday in March, June, September, and December of 2021. A calendar invite will be sent vial email for all attendees.

6. Other Business

Tyler Craddock and April Dickerson provided an overview on Bluebird Bio that is a biotechnology company focusing on investigational gene therapies for severe genetic diseases.

Adjournment at 11:24 AM

LSCC Strategic Plan

Medical Services

Goal is to improve medical access and care for sickle cell disease patients while reducing health care costs in Louisiana.

Objectives for this workgroup include:

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.

Patient Navigation

Goal 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 include:

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.

Education and Advocacy

Goal is to educate citizens and stakeholders on Sickle Cell Disease. Objectives for this workgroup include:

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.
-

Data and Surveillance

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

Objectives for this workgroup include:

1. Develop surveillance system/registry for the tracking of SCD in Louisiana with the following info:
2. Demographics characteristics and geographic distribution of patients with sickle cell in Louisiana;
3. Health care utilization, costs of care, and the geographic variation of specific services; and
4. Mortality rates, including case fatality rates for individuals with SCD.