



## State of Louisiana

Louisiana Department of Health  
Office of Public Health  
Louisiana Sickle Cell Commission Meeting  
October 27, 2020  
10:00 a.m.-12:00 p.m.  
<https://ldhophbfhgenetics.zoom.us/j/96230075206>  
Conference Call info: (602) 333-0032  
Access Code: 532143#

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

- Renee Gardner, MD, Children's Hospital, New Orleans
- 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:

- Dana LeBlanc, MD., Children's Hospital, New Orleans
- LaTarsha Carter, Healthy Blue
- Karen Grevemberg, MBA, BSN, RN, United Healthcare
- Kathy Williams, Sickle Cell Association of South Louisiana
- Torris Johnson, Sickle Cell Association of South Louisiana
- Shaleathia Campbell, Sickle Cell Association of South Louisiana (Parent Advocate)
- Marquita Brown, Southwest Louisiana Sickle Cell Anemia, Inc.
- Courtney Sanford, Louisiana Primary Care Association
- Erica Rose-Crawford, Louisiana Primary Care Association
- Raymond Poliquit, MD., Healthy Blue
- Kelly Hess, Global Blood Therapeutics, Inc.
- Horatio Handy, Global Blood Therapeutics, Inc.
- Shawn Henderson, Global Blood Therapeutics, Inc.
- Brent Young, Global Blood Therapeutics, Inc.
- Tyler Craddock, Bluebird Bio
- April Dickerson, Bluebird Bio
- Patti Barovechio, DNP, MN, OPH Bureau of Family Health
- Gail Gibson, RN, BSN, MN, CPM, FABC, OPH Bureau of Family Health
- Cynthia Suire, DNP, MSN, RN, OPH Bureau of Family Health
- Sharonda Smith, OPH Bureau of Family Health
- Rachelle Boudreaux, MA, OPH Bureau of Family Health

- Michelle Duplantier, LCSW-BACS, OPH Bureau of Family Health
- Nora McCarstle, RN, BSN, OPH Bureau of Family Health
- Kera Simmons, MPH, OPH Genetic Diseases Program
- 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 – July 29, 2020

1. Data and Surveillance- Jantz Malbrue
  - a. Surveillance System/Registry Model

COVID-19 Impact on Sickle Cell in Louisiana

Louisiana leads the country for COVID-19 cases per capita (111,038 reported cases in Louisiana). The Medical College of Wisconsin created a registry to track all cases of COVID-19 for sickle cell disease patients. Clinicians are encouraged to report ALL cases of COVID-19 in their sickle cell diseases (SCD) patients, regardless of severity (including asymptomatic patients detected through public health screening), to the Surveillance Epidemiology of Coronavirus) Under Research Exclusion (SECURE)-SCD registry. The project website, <https://covidsicklecell.org/>, provides regularly updated summary information about reported cases, including numbers of cases by country, number of cases by treatment, etc. so the entire SCD community has access to these data. As of October 16, 371 cases across the US. There are a total of 9 cases reported from Louisiana (3% of total numbers). The SECURE-SCD Registry tracks the reported symptoms, experience during COVID infection, treatments, and interventions for individuals with SCD.

Social Solutions Case Management Software

Developed a case management system to track sickle cell services through the Social Solutions platform. The system has real time monitoring and tracking capabilities for monitoring clinical and supportive services statewide. It has data reporting capabilities that can be accessed by all users. Ms. Grevemberg asked who has access to the system. Now, the Office of Public Health (OPH) and the Sickle Cell Foundations, but the future goal is to expand the system for other organizations to access and integrate data. Currently, the Bureau of Health Informatics utilizes clinical and Medicaid data for hospital utilizations, emergency department visits, outpatient encounters, and medication prescriptions for individuals with SCD. Social Solutions will provide more preliminary insight into this level of data.

Dr. Gardner asked when the system would be functioning. The creation of the system is complete and the next will include the import of patient information. Dr. Gardner also asked if healthcare providers will have access at some point. The goal is for

healthcare providers to have access to the system. The next step is determining the number of users who would need licensing privileges to access the system.

Ms. Grevemberg also asked if she could send a request to OPH if she was interested in the number of patients visiting the emergency room. Mr. Malbrue responded yes that she could send the request to him to collect the information. Ms. Williams asked if the system would include from the provider regarding patients' emergency department visits. At the moment, the system does not automatically import emergency room visits. The next step will be integrating that feature. The primary care provider or hematologist should be contacted to get the most accurate information regarding emergency room encounters.

## 2. Medical Service/Delivery

### Project ECHO

Project ECHO (Extension for Community Healthcare Outcomes) is a potential tool for engaging physicians, emergency departments, patients and families across the state. Project ECHO would increase the sharing of knowledge and skill sets of providers and patients by connecting virtually with experts on sickle cell. Possible topics could include treatment for adult patients, emergency department protocols, psychosocial interventions, immunization screenings, new therapies and treatments. Ms. Grevemberg asked if the affects of COVID on sickle cell be included as a future topic and if the topics would be directed towards providers or patients. The goal of the sessions would be interactive for providers and patients to ask questions. Participants will be targeted from different parts of the state in efforts to receive different perspectives. Marketing and media information is being developed to share electronically. Mr. Malbrue questioned if a mid-week or early morning schedule be beneficial not to conflict with clinic and meeting schedules. Ms. Campbell and Ms. Spain asked that media information is shared with the group to familiarize themselves with the system.

### New Therapies & Treatments

Barriers are continuing to limit and reduce access patients have to newer therapies and treatments. Dr. Gardner stated that the link between Medicaid and insurance companies has been an issue. She received information from one healthcare provider stating they would no longer approve treatment, but there wasn't an alternative. Dr. Gardner suggested working with insurance companies as a way to be make treatment more accessible. Ms. Williams stated that clients are experiencing barriers and having to travel from Baton Rouge to New Orleans for hematology care. She also added that local providers may not accept their insurance and their travel may only be covered up to 60 miles round trip. Courtney Sanford indicated that there was a way for providers to eliminate the 60 miles' limit. She suggested completing and submitting a document 24 to 48 hours prior to trip to override limit. Horatio Handy stated that there was a gap with providers and insurance that needed to be addressed. LaTarsha Carter stated that the lack of providers and linking patients to providers were barriers. Cheryl Harris stated that mission of OPH is to make sure all patients

with sickle cell have a medical home and access to specialist. Ms. Harris recommended a statewide assessment of these issues including transportation. Michelle Duplantier stated that OPH has a standing order to assist with medication and may be able to help. She encouraged patients to try their insurance plan first and that Families Helping Families could be another avenue if patients continue to encounter roadblocks. Ms. Duplantier also mentioned the Parish Public Health Units as options and discussing telehealth options for visits with specialists.

### 3. Report: Education and Advocacy

Educational materials and resources are being developed to inform providers and patients. However, more education and outreach is needed to state legislators and stakeholders. Mr. Hardy agrees with the statement and expresses that emergency department personnel do not want to hear from sickle cell patients and it is up to us speak on their behalf. He added that the wait time for a patient with sickle cell can be 50% longer than an individual with a bone fracture. Ms. Williams and Dr. Gardner discussed the need to talk with legislators about reimbursement. Dr. Gardner added that need to educate providers that patients with sickle cell deserve adequate access to treatment. Ms. Duplantier stated that many providers do not accept Medicaid patients or limit the amount of services they receive. She added that the Bureau of Family health is conducting a landscape assessment and they are having a hard time collecting data on which providers accept patients with Medicaid. Mr. Handy indicated that a big challenge was the Integrated Delivery Networks. He added that they are not accepting new Medicaid patients and referring them out. Dr. Saulsberry stated that they are combating the stigma that people without insurance or on Medicaid are not considered good people in Northeast Louisiana. She is working with hematologist, Dr. Majed Jeroudi, to educate emergency department personnel. Mr. Handy reiterated the importance of the advocacy by the commission during legislative sessions. Ms. Harris suggested that the commission develop a formal plan with requests or changes that would like to see that can be supported by legislation through OPH.

### 4. Other Business

The next meeting is scheduled for Tuesday, December 8, 2020.

Adjournment 11:45 AM