



State of Louisiana

Louisiana Department of Health
Office of Public Health
Louisiana Sickle Cell Commission Meeting
March 25, 2020
10:00 a.m.-12:00 p.m.
<https://ldhophbfhgenetics.zoom.us/j/979695783>
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
- Renee Gardner, MD, Children's Hospital, New Orleans
- Shannon Robertson, RN, BSN, Louisiana Primary Care Association
- Chauncey Hardy, Sickle Cell Anemia Research Foundation, Alexandria
- Jerry Page, Sickle Cell Disease Association, NW Louisiana

Additional meeting attendees:

- Melody Benton, Sickle Cell Center-Tulane University
- Ernest DeJean, Sickle Cell Center-Tulane University
- Karen Odoms Johnson, Sickle Cell Center-Tulane University
- Jensine Speed, LMSW., Our Lady of the Lake
- Raymond Poliquit, MD, Healthy Blue
- Sylvia Rogue, UnitedHealthcare
- Kathy Williams, Sickle Cell Association of South Louisiana
- Torris Johnson, Sickle Cell Association of South Louisiana
- Rajasekharan Warriar, MD., Ochsner Health Center for Children
- Courtney Sanford, Louisiana Primary Care Association
- Kelly Hess, Global Blood Therapeutics, Inc.
- Horatio Handy, Global Blood Therapeutics, Inc.
- Shawn Henderson, Global Blood Therapeutics, Inc.
- Brent Young, Global Blood Therapeutics, Inc.
- Nora McCarstle, RN, BSN, OPH Bureau of Family Health
- Patti Barovechio, DNP, MN, OPH Bureau of Family Health
- Gail Gibson, RN, BSN, MN, CPM, FABC, OPH Bureau of Family Health
- Rachelle Boudreaux, MA, OPH Bureau of Family Health
- Michelle Duplantier, LCSW-BACS, 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 – September 10, 2019 and December 10, 2019

Mr. Malbrue discussed available resources regarding the coronavirus (COVID-19) and the sickle cell community. The Sickle Cell Disease Association of America has several resources for providers and families.

- Sickle Cell Disease and COVID-19: An Outline to Decrease Burden and Minimize Morbidity Medical and Research Advisory Committee Sickle Cell Disease Association of America
www.sicklecelldisease.org
- For families: <https://www.sicklecelldisease.org/files/sites/181/2020/03/SCDAA-MARAC-COVID-19-Patient-Caregiver-Advisory-3-17-20-FINAL4.docx.pdf>
- For providers: <https://www.sicklecelldisease.org/files/sites/181/2020/03/FINAL-SCDAA-PROVIDER-ADVISORY7.pdf>

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. To report a case of coronavirus, please visit <https://covidsicklecell.org/>. If you have any questions, please reach out to Covid.sicklecell@mcw.edu.

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

The aim is to determine how to increase data capacity. Proposed solutions included expansion of data monitoring and data sets. Through the expansion of data monitoring, the commission improved the monitoring of people living with SCD in the state. Surveillance will need to be expanded to accurately detect the number of providers (pediatric and adult) treating SCD, the available treatment options along with the number of patients receiving them, and the percentage of emergency room visits along with inpatient stays. Also, the type of data sets included in surveillance will be expanded to monitor on a monthly basis. This method will assist in determining data points within parishes around the state. Also, categorizing the data sets by pediatric patients versus adult patients to determine where services should be directed.

Dr. Warriar discussed a study Ochsner Health Center is collaborating with the Department of Health researching the immunization status of individuals with SCD compared to individuals without in the New Orleans metro region. Previous studies have shown that immunizations can reduce infections in individuals with sickle cell disease, but adherence to the schedule is a concern.

2. Medical Service/Delivery

The aim is to determine how to improve the treatment of care. Proposed solutions included increasing the number of providers treating patients with sickle cell and increasing collaboration with Medicaid managed care organizations (MCOs). The expansion of providers will be assisted through increased telehealth, telementoring through provider to provider education, and exploring inclusivity to incorporate nurse practitioners, physician assistants, and other health care professionals in treating SCD. The collaboration with the MCOs would provide annual data for each plan illustrating the number of in-network providers and the percentages of pediatric and adult patients. Also, the collaboration would provide an opportunity to align pain management protocols and incorporate a mechanism to educate providers.

Project ECHO

Dr. Warriar discussed the utilization of Project ECHO (Extension for Community Healthcare Outcomes) as an educational tool to engage 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 with experts from sickle cell centers through telementoring.

Pain Management Protocols

Dr. Gardener discussed the important of reimbursement rates and receiving further guidance from Medicaid regarding the feasibility. She also discussed scheduling a meeting among all sickle cell experts to initiate development of protocols. Mr. Hardy explained his trouble connecting emergency room providers with SCD protocols. Ms. Kathy is experiencing the same problem with clients in the Baton Rouge area. Dr. Saulsberry discussed her conversation with an emergency room nurse and the insight that workers are not knowledgeable about SCD. She stressed the need for more training and educational information for providers. Mr. Hardy discussed the troubles of triage levels with an emergency room and the perception that sickle cell patients are at the lowest level. Dr. Gardner proposed supplying patients with SCD protocols that can be taken with them to emergency rooms. The protocols could indicate the level of medication needed for resolution of pain.

3. Patient Navigation

The aim is to determine how to improve access to care. The proposed solution was increasing the number of patients who have access to quality care. More emphasis on the medical home model and care coordination will ensure patients are not getting lost within the system of care. Improved tracking of health maintenance will

determine the levels of diagnosis counseling and therapy adherence throughout all regions of the state. Also, the increased emphasis on transition programs and resources will assist in overcoming the disruption of services due to a lack of adult providers.

Dr. Gardner discussed having Patient Navigators in place to help desensitize providers and emergency rooms. She emphasized that all patients are not able to advocate for themselves. Dr. Warrier discussed that newly graduated medical residents are learning more about SCD than medical graduates of the past. Dr. Saulsberry iterated engaging the hospital social workers to reeducate and reengage providers and patients. Mr. Horatio discussed his experience in regards to the lack of knowledge among emergency room providers around the state and he expressed the need to include more emergency room physicians, nurses, and social workers in future educational trainings. Mr. Henderson offered to partner with community advocates to promote educational sessions for emergency room providers. Ms. Kathy mentioned that clients are directed to certain emergency departments that may not be the closest to their homes. Ms. Rogue currently works for UnitedHealthcare, and previously spent years working in the sickle cell clinic in Monroe. She discussed the backlash patients received while seeking medication and help since many providers assumed they were drug seeking.

4. Report: Education and Advocacy

The aim is to determine how to improve community and provider knowledge. The objective is to provide multilevel education toward the patient, family, provider and system. One avenue is to increase engagement with government, private, and community partners. Another opportunity is to expand outreach and awareness campaigns outside of the month of September to improve public visibility. Also, the increase of web presence through tools, resources, and best practices. These avenues will assist in recruitment and reengagement utilizing social media, circulating print and electronic media to highlight the voices of the community, and a centralized location for patient and provider educational materials.

Ms. Speed discussed the importance of working with patients in efforts to continue empowering them. She expressed the need to create resources that will educate patients on how to engage with their legislatures within the capital. Dr. Saulsberry discussed the educate the educator resources and training guides on advocacy for patients and parents.

5. Other Business

a. Announcements

Ms. Speed discussed possible participation in Rare Disease Day events hosted by the National Organization of Rare Disorders. Dr. Poliquit stated that Healthy

Blue incorporated telehealth practices for patients to have access to providers virtually in response to COVID-19. Ms. Williams talked about a proposed sickle cell march scheduled for June in Lafayette. Mr. Malbrue discussed the HHS Office of Minority scheduling a sickle cell event in June in New Orleans. Mr. Hardy discussed a recent health disparity training held in Alexandria and contacting the facilitators from the Department of Health for future collaborations.

Adjournment 11:44 AM