



State of Louisiana

Louisiana Department of Health
Office of Public Health

Sickle Cell Commission Meeting

September 10, 2019

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

LDH Bienville Building, Room 118

628 North 4th Street, Baton Rouge, LA 70802

<https://ldhophbfhgenetics.zoom.us/j/576066458>

Conference Call info: (602) 333-0032 or (888) 270-9936

Access Code: 532143#

Roll Call taken by Ms. Burgess; members present at the meeting were as follows:

- Lorri Burgess, Baton Rouge Sickle Cell Disease Foundation – **Commission Chair**
- Pamela Saulsberry, Ph.D., LCSW, Northeast Sickle Cell Anemia Foundation – **Commission Vice Chair** (via phone)
- Renee Gardner, MD, Children’s Hospital, New Orleans
- Courtney Sanford, Louisiana Primary Care Association (proxy on behalf of Shannon Robertson, RN, BSN)
- Chauncey Hardy, Sickle Cell Anemia Research Foundation, Alexandria (via phone)
- Cheryl Harris, MPH, OPH Genetic Diseases Program (LDH Designee) (via phone)

Additional meeting attendees:

- Jensine Speed, LMSW., Our Lady of the Lake (via phone)
- Karen Grevemberg, MBA, BSN, RN, United HealthCare (via phone)
- Raymond Poliquit, MD, Healthy Blue (via phone)
- LaTarsha Carter, RN, BSN, Healthy Blue
- Ginny Martinez, Novartis
- Rachelle Boudreaux, MA, OPH Bureau of Family Health
- Michelle Duplantier, LCSW, OPH CYSHCN Program (via phone)
- Kera Simmons, OPH Genetic Diseases Program
- Jantz Malbrue, OPH Genetic Diseases Program

Call to Order

Lorri Burgess called the meeting to order at 10:04 a.m.

Welcome

Approval of meeting minutes – March 26, 2019 and June 11, 2019

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Genetic Diseases Program

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Dr. Renee Gardner motioned, second by Dr. Pamela Saulsberry

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

Since the beginning of 2019, newborn screening identified 52 newborns with a sickle cell disease diagnosis and 893 newborns were identified with a sickle cell trait diagnosis. The newly identified cases were distributed by regions to the sickle cell foundations and clinics. The Sickle Cell Disease Registry has 2,418 individuals identified through the newborn screening program. The Sickle Cell Trait Registry was created and there are 22,914 individuals identified through newborn screening program with a sickle cell trait diagnosis.

Work Group Summary

Data reporting will be expanded to monitor the populations of adults and transition age youth. The new case management software by Social Solutions will integrate service planning, measure and manage outcomes, and display comprehensive reporting formats. The Medicaid Surveillance System reporting sickle cell disease related data will expand to evaluate medication usage and rate. Also, the surveillance system will monitor emergency department usage and rates related to sickle cell disease.

Lorri Burgess and Dr. Renee Gardner questioned policy change regarding the particular ICD codes for sickle cell. Dr. Gardner and Dr. Raymond Poliquit offered to review the codes the list of codes. Dr. Pamela Saulsberry asked if the Sickle Cell Foundations would have access to the Social Solutions software. Jantz Malbrue stated that the Foundations would be users of the software. Dr. Raymond Poliquit suggested the idea of allowing MCO case managers to access the software. He stated that finding members and engaging them where they are being a challenge for MCOs. Jensine Speed asked when the software would be developed and Jantz Malbrue stated that the software is in the development phase. Lorri Burgess mentioned the inclusion of a data sharing agreement to dictate the information that will documented and shared. Dr. Pamela Saulsberry stressed the importance of medication adherence and documenting that information. Dr. Renee Gardner discussed the importance of medication review and utilizing patient advocates to increase the discussion. Dr. Gardner mentioned the introduction of new drugs and the financial benefits they presented for MCOs.

2. Report: Medical Service/Delivery

Work Group Summary

New providers and methods of care will be indemnified by exploring the usage of nurse practitioners and integration of telemedicine. Emergency Department education will increase with updated protocols for personnel treating sickle cell disease. Transcranial Doppler Ultrasound Screening (TCD) will be reviewed to ensure accessibility and trainings for providers. The Prescription Drug Prior

Authorization Protocols needs to be revised to decrease the limitations on medications for sickle cell disease. Also, the collaboration with Louisiana Medicaid and the MCOs will increase to expand medication protocols.

3. Report: Patient/Navigation

Work Group Summary

The Patient Navigator Program will be implemented through the Sickle Cell Foundations to increase capacity and ensure accessibility in all regions. The Families Helping Families Networks model will be explored for research resources, support systems, and trainings. The Children Special Health Services Parent Liaisons would serve as great partners in regions with limited sickle cell services.

Dr. Pamela Saulsberry discussed reviewing the model for Families Helping Families and studying proposals from other advocacy organizations.

4. Report: Education and Advocacy

Work Group Summary

The Statewide Education Campaign will be expanded to reinforce education to the state Legislature, providers, and schools. As part of the campaign, educational resources for adults and transitioning youth need to be strengthened. The collaboration with sickle cell related services within MCOs will be improved. The Statewide Media Campaign will increase print distribution, internet access, and media exposure. Medication and treatment options will be explored by reviewing prescription drug formularies for pharmacies and MCOs. New Medications and treatments being studied will be shared with the network.

Jensine Speed asked about the launch of the statewide campaigns. Etta Pete stated that the 2020 campaigns should launch now on a larger scale.

Dr. Pamela Saulsberry motioned to accept items 1-4, second by Etta Pete

5. Other Business

a. 2019 Meeting Schedule

The remaining in-person meeting is scheduled for December 10, 2019.

b. Announcements

The Northeast Sickle Cell Anemia Foundation will host a banquet on September 12. Etta Pete informed the group about an upcoming documentary on a patient living with sickle cell disease who recently passed away. The documentary will air on September 23 and a showing of the film will occur at the library in Lake Charles. Lorri Burgess suggested sharing copies of the

documentary with other libraries and organizations as well as archiving it for sickle cell history.

Dr. Pamela Saulsberry motioned, second by Etta Pete

Adjournment 11:25 AM