

Sickle Cell Commission Meeting

March 23, 2016

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

DHH Bienville Building-Room 173

Conference Call info: 888-278-0296

Access Code: 8965636#

Meeting minutes – March 23, 2016

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

* Lorri Burgess, Baton Rouge Sickle Cell Disease Foundation – **Commission Chair**
* Etta Pete, Southwest Louisiana Sickle Cell Disease Foundation (via phone)
* Rosia Metoyer, Sickle Cell Anemia Research Foundation
* Jerry Paige, Sickle Cell Disease Association, NW Louisiana Chapter
* Dr. Pamela Saulsberry, Northeast Sickle Cell Anemia Foundation (via phone)

Additional meeting attendees:

* Shannon Robertson, Louisiana Primary Care Association
* Patti Barovechio, OPH CSHS Program (via phone)
* Cheryl Harris , OPH Genetic Diseases Program (via phone)
* Jantz Malbrue, OPH Genetic Diseases Program

Call to Order

Lorri Burgess called the meeting to order at 10:28 a.m.

Welcome

Approval of meeting minutes – December 16, 2015

Minutes were reviewed and an error was noticed that Rosia Metoyer was not included in the meeting attendees. The change was adopted, motion for approval by Etta Pete and seconded by Rosia Metoyer.

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

Currently, the Sickle Cell Registry has a total of 2142 individuals. Approximately 381 names were listed in the registry with incomplete data such as name and physical address. 250 of those clients have been identified and their information updated. The other incomplete records will be matched against data in LINKS (Louisiana Immunization Network for Kids Statewide) & the Louisiana Medicaid

Systems for current information. Lorri Burgess asked Etta Pete if our model was similar to the national registry model and Ms. Pete confirmed that it is.

* 1. Sickle Cell Tracking Data Plan

There was a total of 77 newborns identified with sickle cell in 2015. So far in 2016, a total of 14 newborns have been identified with sickle cell. The newly identified cases have been distributed by regions to the sickle cell foundations and clinics. All of the Foundations provided a list of their current client registries. The lists of clients were matched against those already identified in the state registry and the rest were added to the total number of cases. Also, Cheryl Harris met with the Director of the Bureau of Family Health, Amy Zapata. Ms. Zapata mentioned a data system that’s being used by her programs for monitoring client level data. The case management software is developed by Social Solutions and I plan to meet with the Data/Quality Manager soon to discuss the software’s capability. Ms. Burgess asked how the system would work with employing Patient Navigators and having a Licensed Clinical Social Worker for reimbursement. Also, she asked if we could design the software in a way to where the LCSW guides the Foundations on the proper way to bill the State for case management. Cheryl Harris stated that each foundation could use a portion of their Patient Navigator funds to support the LCSW. Ms. Burgess and Ms. Pete agreed that it would be in the best interest of the Foundations to have a Patient Navigator and a new software would allow everyone to access the same information. Also, an idea was presented to the Commission in which one LCSW is hired to monitor all of the foundations in the state. The budget will be reviewed to determine financial viability of regionals LCSWs versus one LCSW for the entire state. Cheryl Harris mentioned that the Bayou Health plans may be good resources for identifying models that work.

Jerry Paige motioned to approve, second by Rosia Metoyer

1. Report: Medical Service/Delivery
   1. 2016 Standards of Care- Renee Gardner

Dr. Gardner wasn’t able to attend the meeting, but the draft standards of care was sent to Cheryl Harris and Jantz Malbrue. Lorri Burgess asked if the Standards of Care would be ready for implementation by the 2017 Conference. Ms. Harris stated that the material could be printed and launched at the Conference.

Dr. Pamela Saulsberry motioned to approve, second by Jerry Paige

1. Report: Patient/Navigation
   1. Report Health Navigator Legislation- Lorri Burgess

Lorri Burgess and Jerry Paige have been strategizing on the Health Navigator Legislation. The Commission isn’t able to discuss political activities, but they plan to follow up with specific individuals soon. The goal is to receive $100,000 in funding and Mr. Paige has a specific legislature in mind for assistance.

Dr. Pamela Saulsberry motioned, second by Jerry Paige

1. Report: Education and Advocacy
   1. Sickle Cell Statewide Conference (Summer 2017)- Lorri Burgess

Lorri Burgess met with the Renaissance Baton Rouge Hotel staff to discuss the availability for June 16 & 17, 2017. Ms. Burgess has been researching past LPCA Conferences as well as others to assist in creating the conference structure. One topic for consideration is Integrative Health Medicine. Ms. Burgess mentioned that Tamika Moseley has helpful book (Sickle Cell Natural Healing: A Mother’s Journey) and she will extend an invitation for her to attend. The goal is to focus on healthy living and nutrition for individual living with sickle cell. Ms. Pete mentioned that she attended an event where Tamika Moseley presented and she enjoyed it. Other important topics for consideration include pediatric and adult hematology along with eye care. Dr. Saulsberry stated that their agency has been receiving a great response from their Educate the Educator/Train the Trainor initiative. Ms. Burgess asked if this component would be directed towards provider, patients or parents. Dr. Saulsberry stated that it would benefit everyone since it’s difficult to find information and disseminate it to school counselors, social workers and parents. Also, CEUs could offered which would be essential for professionals needing to gain a minimum number of training hours. The idea received a great response from the commission and Shannon Robertson would like to include it in future LPCA summits. The next LPCA Summit scheduled for June 3 & 4, 2016. They received glowing reviews about the sickle cell related sessions offered during the last summit. Ms. Robinson offered to provide guidance with organizing abstracts and other accreditations for the Sickle Cell Conference. The goal is to have the conference framework set by September 2016 to ensure that the planning remains on track with abstractors and presenters for June 2017.

* 1. Update on proposed statewide brochures- Etta Pete

Etta Pete developed a template of the statewide brochure and presented it to the commission. Ms. Pete asked the commission for their thoughts on whether a larger document that detailed more about the foundations was needed. Ms. Burgess mentioned that a profile sheet could be added to the digital presence that would allow the community to learn more about the sickle commission and the agencies providing services throughout the state. Cheryl Harris stated that the brochure would have to be reviewed by the Bureau of Media and Communications (BMAC) for approval before it can be uploaded onto the Department of Health and Hospitals website.

Jerry Paige motioned, second by Dr. Pamela Saulsberry

1. 2016 Newly Elected Officers

The electronic ballots determined that the newly appointed Commission Co-Chair will be Dr. Pamela Saulsberry and Ms. Lorri Burgess will remain in the role as Commission Chair.

1. 2016 Meeting Schedule

During the December 2015 meeting, the upcoming commission meeting schedule was discussed. Although availabilities vary on Wednesdays throughout the month, the commission has decided that future meetings will remain on the second Wednesday of every quarter. The future meetings have been confirmed for June 8th, September 7th and December 14th, 2016.

1. Other Business

Replacement members are needed for DHH, the Louisiana Senate, and the Louisiana House of Representatives. The commission is awaiting a response from DHH’s Legislative and Governmental Relations (LGR) section within the Office of the Secretary on the new designees. The newly appointed Secretary of DHH is Dr. Rebekah Gee and Michelle Alletto has been appointed as Deputy Secretary.

The meeting was adjourned at 11:45 am.