

Sickle Cell Commission Meeting

December 16, 2015

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

DHH Bienville Building-Room 372

Conference Call info: 605-475-3235

Access Code: 998791#

Meeting minutes – December 16, 2015

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 (via phone)

Additional meeting attendees:

* Matthew Valliere, DHH Office of Public Health
* Cheryl Harris , OPH Genetic Diseases Program
* Jantz Malbrue, OPH Genetic Diseases Program
* Shannon Robertson, Louisiana Primary Care Association
* Dr. Rishikesh Chavan, Sickle Cell Center of Southern Louisiana (via phone)
* Ernest DeJean, Sickle Cell Center of Southern Louisiana (via phone)
* Chanel Holt, Sickle Cell Center of Southern Louisiana (via phone)

Call to Order

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

Welcome

Approval of August 11, 2015 meeting minutes

Minutes were adopted with no changes; motion for approval of minutes by Etta Pete and seconded by Jerry Paige.

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

Currently, the Sickle Cell Registry has a total of 2120 individuals. Lorri Burgess asked if the registry list was matched against other systems to identify individuals who may have expired. Also, Cheryl Harris asked about matching the list against Medicaid claims for sickle cell services and Matthew Valliere suggested that we contact Joe Foxhood, Center for Population Health Informatics Director, to determine the process. The current newborn screening process was implemented in 1992 and data prior to that needs to be validated. The plan is match data against other systems (Medicaid, Vital Records, etc.) to ensure all individuals living with sickle cell in Louisiana are identified and that older data is verified.

* 1. Sickle Cell Tracking Data Plan- Jantz Malbrue

Once data has been verified, the plan is to distribute the list by regions to the sickle cell foundations and clinics. The goal is to have the data registry complete by the end of January 2016. As the program receives notification of new heelstick screens identified with Hemoglobinopathy, a list will be generated and sent monthly to the prospective foundations and clinics.

Jerry Paige motioned to approve, second by Lorri Burgess.

1. Report: Medical Service/Delivery
   1. Update on Standards of Care- Dr. Renee Gardner

Dr. Gardner was absent from the meeting and the commission did not have any updates.

* 1. Work Group Report:
     1. Bayou Health Plans: Sickle Cell Care- Sue Berry

Dr. Berry was absent from the meeting and the commission did not have any updates.

* + 1. Report on Transcranial Doppler Screening Training- Etta Pete

Etta Pete has been collaborating with Dr. Gardner on this topic, however they did not have any new updates regarding the subject.

* 1. Pain Management protocol For Doctors

Dr. Gardner was absent from the meeting and the commission did not have any updates.

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

Lorri Burgess stated that the legislation was approved during the last legislative session. Ms. Burgess asked the commission if they could recommend a legislature who would be willing to push the legislation. Jerry Paige and Etta Pete stated that they would reach out to people. Cheryl Harris mentioned that Senator Wesley Bishop would be a great resource. Ms. Burgess will reach out to Senator Bishop since he is in the Baton Rouge Area. Also, Ms. Burgess asked the commission to review the approved amendments for any changes that may need to be addressed.

* 1. Proposed 2016 CBO Education and Training- Lorri Burgess

The Genetics Program (Cheryl Harris and Jantz Malbrue) visited all of the agencies providing sickle cell support services throughout the state. The visits focused on the current array of services being provided and changes that could be made to enhance those agencies in order to reach more individuals living with sickle cell in those regions. Lorri Burgess proposed more educational trainings for the Foundation staff in order to increase knowledge and capacity. Matthew Valliere asked the attendees if the series of trainings should be spearheaded by the commission or the Genetics Program. Ms. Burgess stated that it’s essential for the foundations to have curriculum for continuing education that would require a number of annual trainings and encounters. Etta Pete asked if the trainings would follow the national agenda. Ms. Burgess stated that trainings would follow the national agenda and that the foundations currently submit quarterly reports, but the intention will be to include more teeth in the quarterly reports. The commission attendees agreed that the Genetics Program will lead the development of trainings and the item will be taken off of the commission agenda. Also, Ms. Burgess stated that it would be helpful to include the Bayou Health Managed Care Organizations in order to gain a better understanding of the services offered.

Ms. Harris agreed with extended a hand with the Bayou Health Organizations is order to improve the wrap around services for sickle cell and the Bayou Health Organizations will be contacted to schedule meeting. Etta Pete attended a training in Alabama that gave great information regarding new changes in sickle cell care. It’s a training that other committee organizations have attended in the past and are familiar with.

Jerry Paige motioned to approve, second by Etta Pete.

1. Report: Education and Advocacy
   1. 2016 Sickle Cell Statewide Conference- Lorri Burgess

Lorri Burgess has been communicating with the Baton Rouge Convention & Visitor Bureaus regarding the proposed dates for the Statewide Sickle Cell Conference. Unfortunately, the proposed dates are not available. Also, Ms. Burgess inquired about the prior weekend of National Sickle Cell Day, however there has been difficulty in securing a location for that weekend as well. She feels that time may be running out for a conference in 2016 and that project of this size would need a year of preparation. Etta Pete offered to contact locations in the Lake Charles area for a possible space to hold a retreat for those interested in meeting in 2016. Ms. Burgess will continue to work with Visitor & Convention Bureaus to secure dates for a conference in 2017.

* 1. Update on proposed statewide brochures- Etta Pete

Etta Pete has been working on the statewide brochure and she plans to seek feedback from all of the foundations and commission members to confirm that the information is sufficient. The purpose of the brochure is to include the commission’s mission, vision and goals along with sickle information for individuals living with sickle cell in Louisiana. The brochure along with the links to each foundation’s website will be incorporated on the DHH’s Genetics Program website. Matthew Valliere asked if there was template for the brochure. Ms. Pete stated that the previous template that was sent to the commission focused primarily on the community, but it was updated to include the committee members along with the contact information for the foundations. Also, she stated that including services provided by each foundation would expand the brochure past the one page size. Ms. Pete plans to resend the brochure template to the commission members. Lorri Burgess reiterated that the brochure will give the commission a digital presence along with providing an option for members to share the brochure with community groups and individuals to educate about the statewide sickle cell commission and the agencies providing services throughout the state.

Advocacy- Matthew Valliere

Matthew Valliere mentioned that the original proposal for the sickle cell commission included a three year plan for operation. Next year, 2016, would be the final year in the three year plan causing the commission to end. Mr. Valliere asked if the members would be interested in continuing the commission and if there were any sponsors who may be interested in extending the lifespan. Lorri Burgess asked Etta Pete if she could consult with Representative Albert B. Franklin about extending the commission and Ms. Pete agreed to follow up with him.

Jerry Paige motioned to approve, second by Lorri Burgess.

1. 2015 Annual Report- Matthew Valliere

Matthew Valliere acknowledged Cheryl Harris and Lorri Burgess for their roles in leading and reviewing the annual report. The reports details the commission’s plan, collaborating with the Louisiana Primary Care Association, the updated Standards for Care of Patients with Sickle Cell Disease, the proposed case management system and much more. Mr. Valliere stated that the 2015 report is shorter than last year’s report since statistical data wasn’t included unlike the 2014 report. With the updates of the Sickle Cell Registry, the plan will be to include this data along with updated Medicaid statistics in the 2016 report. The 2015 report was emailed to all of the commission members today for review. Lorri Burgess stated that an estimate of $27,000 was detailed for the development of a data management system.

Dr. Rishikesh Chavan was given a few minutes to discuss his patient navigation sickle cell app with the commission. He expressed his willingness to work with DHH and the commission on the app. Matthew Valliere stated that the development of mobile apps were included in the 2015 Report as Year Two Activities for Patient Navigation.

1. 2016 Election of Officers

Matthew Valliere recommended sending electronic ballots to the commission members since the current meeting didn’t have the minimum number of members needed to satisfy a quorum. The email will be delivered shortly and the results of the newly appointed commission chair and vice chair will be announced to the commission in the upcoming weeks.

1. 2016 Meeting Schedule

Matthew Valliere discussed the past schedule of quarterly meetings and he proposed that future meeting remain on Wednesdays at 10 am. The meeting attendees agreed with scheduling the meetings on the second Wednesday of every third month. The upcoming meeting dates have been confirmed for March 9th, June 8th, September 7th and December 14th. Mr. Valliere will schedule the future reservations and display on the DHH website.

Lorri Burgess motioned to approve.

1. Other Business

a. Update on DHH Website Linkage

Cheryl Harris reminded the foundations to send the links for their websites so it can be included on DHH’s Genetics Programs website. The information can be sent to either Cheryl Harris or Jantz Malbrue.

b. Note

Matthew Valliere informed the attendees about his resignation with DHH. His last day in his current role will be January 22nd. Mr. Valliere plans to continue building relationships and remain involved with the sickle cell commission as he transitions into his new role as CEO of Capital City Family Health Center in Baton Rouge. He plans to continue working with the Louisiana Primacy Care Association along with other physicians to improve the services for sickle cell statewide. Mr. Valliere will transfer the commission’s contacts to Cheryl Harris and Jantz Malbrue.

c. Upcoming Clinical Summit

Shannon Robertson stated that the Louisiana Primary Care Association will host the 3rd Annual Clinical Summit on June 3-4, 2016. LPCA is willing to partner with the commission to include speakers and presenters to discuss sickle cell.

The meeting was adjourned at 11:10 am.