

Louisiana Sickle Cell Commission Meeting

Tuesday, May 12, 2015

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

DHH Bienville Building-Room 371

Meeting minutes – May 12, 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**
* Hugh Eley, DHH Deputy Secretary (DHH Designee)
* Rosia Metoyer, Sickle Cell Anemia Research Foundation
* Etta Pete, Southwest Louisiana Sickle Cell Disease Foundation (via phone)
* Jerry Paige, Sickle Cell Disease Association, NW Louisiana Chapter
* Dr. Pamela Saulsberry, Northeast Louisiana Sickle Anemia Technical Resource Foundation, Inc. - Monroe (via phone)
* Tonia Canale, Louisiana Primary Care Association

Additional meeting attendees:

* Matthew Valliere, DHH Office of Public Health (via phone)
* Cheryl Harris , OPH Genetic Diseases Program
* Dana Randall, DHH Office of the Secretary
* Susan Berry, M.D., OPH CSHS Program
* Patti Barovechio, OPH CSHS Program
* Marcus Wallace, M.D., Amerigroup

Call to Order

Lorri called the meeting to order at 10:11 a.m.

Approval of February 10, 2015 meeting minutes

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

Report: Data and Surveillance – Cheryl Harris

* 1. Update on Surveillance System/Registry Model

Cheryl informed the commission that he sickle cell registry is complete. The Genetic Diseases Program is in the final stages of hiring a new Program Manager to oversee Sickle Cell Disease. Once that person’s hiring is complete, he will be responsible for working with the foundations to see which patients are in their care. Dr. Wallace asked if Amerigroup can have access to the data as this will help them get patients into care. This will require approval from OPH administrators.

* 1. Presentation of Sickle Cell Health Navigator Application – James Davis

James Davis presented an app designed for IPhones. The purpose of the app is to allow patients with Sickle Cell Disease to monitor certain metrics such as sleep, hydration, and medication in order to improve health outcomes. Patients are able to earn badges for meeting goals and medical providers are able to use the software to determine when a patient has had a crisis, has been seen in the ED, had transfusions, etc. The benefits of the app include increased compliance, better patient education and helps navigators engage with patients better. Although the app is geared more for young adults, parents can use it for young children. The app also contains an educational model that addresses what sickle cell is and provides information on diet, hydration, etc. Providers are not able to link to the patient data currently but navigators will be able to access information providers need.

Report: Medical Service Delivery

1. Standards of Care

Dr. Gardner was absent from this meeting.

1. Work Group Report

i. Bayou Health Plans: Sickle Cell Care – Sue Berry

Dr. Berry and Lorri held a conference call with Dr. Rebecca Gee in Medicaid to discuss plans for Sickle Cell healthcare navigation and help in identifying specialists such as hematologists and Ophthalmologists who can be added as providers in Medicaid. Dr. Gee asked the group to defer any upcoming plans until the new governor is in office.

ii. Report on Transdoppler Screening Training – Etta Pete

Mrs. Pete tried to contact staff from Lake Charles Memorial Hospital to obtain information on TCDs being done at their hospital. She is still waiting on a response from them.

iii. Pain Management Protocol for Doctors – Jamie Alexander

Jamie was not present at the meeting to provide an update.

Report: Patient Navigation – Lorri Burgess

a. Health Navigator Legislation

Rep. Alfred Lewis sponsored House Bill 260 which supports Patient Navigators for the sickle cell foundations. The bill went before the Committee on Health and Welfare and passed. The next hurdle to pass is the Committee on Finance. Lorri mentioned that the Appropriations Committee would like the maps for sickle cell Medicaid usage broken down by district.

Report: Education and Advocacy – Etta Pete

1. 2015 LPCA Medical Summit

Summit will be held on May 29-30, 2015 at the Hyatt Regency (French Quarter). Speakers include Dr. Edward Ivy and Dr. Julie Kanter. The seminars related to Sickle Cell Disease will be held on the first day. Fees are reduced for foundation directions. The link for registration is [www.lpca.net](http://www.lpca.net). Lorri thanked Tonia and LPCA for allowing topics related to Sickle Cell Disease to be presented. Dr. Wallace offered that the foundations can contact Amerigroup to see if Amerigroup can sponsor clients to attend. He also agreed to check with other Bayou Health CMOs to see if they would sponsor patients.

1. 2016 Sickle Cell Statewide Conference

The date for the conference is June 24-25, 2016. A location is to be determined. The Baton Rouge Foundation has agreed to host the conference. The foundations in Alexandria and Monroe have agreed to assist. Mrs. Pete said that she will reach out to Dr. Wallace for the 2016 conference.

1. Update on proposed statewide brochures

Mrs. Pete would like information in the brochures to reflect the commission and a separate brochure for each foundation. Lorri thought that the brochure should reflect both. Dr. Saulsberry recommended that the cities in which the foundations are located should be added to the brochure.

Report: Other Business – Cheryl Harris

1. Update on DHH Website Linkage

All foundations were asked to send their link to Cheryl Harris for inclusion on the DHH website.

1. Replacement of Commission Members – Commission members from Tulane, Rep. Dixon’s Office, and Northeast Sickle Cell are needed.

The Genetics Program is in the process of hiring a Program Manger 1A to replace Connie Simonson. Once the new individual is hired, the incumbent will continue site visits with the foundations.

The meeting was adjourned at 11:32.