

Sickle Cell Commission Meeting

Tuesday, August 11, 2015

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

DHH Bienville Building-Room 173

Conference Call info: 605-475-3235

Access Code: 998791#

Meeting minutes – August 11, 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 (via phone)
* Renee Gardner, M.D., Children’s Hospital New Orleans

Additional meeting attendees:

* Cheryl Harris , OPH Genetic Diseases Program
* Jantz Malbrue, OPH Genetic Diseases Program
* Shannon Robertson, Louisiana Primary Care Association
* Retana Comeaux, Southwest Louisiana Sickle Cell Disease Foundation (via phone)
* Denise Brewer, UnitedHealthcare
* Karen Grevemberg, UnitedHealthcare

Call to Order

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

Welcome

Introduction of new members

Approval of May 12, 2015 meeting minutes

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

1. Report: Data and Surveillance- Cheryl Harris

Cheryl Harris announced the hiring of Jantz Malbrue who will serve as the Program Manager over the Sickle Cell Disease Program. The plan is for him to meet with the foundations to gain more knowledge about their procedures and assist in determining which patients are in their care.

* 1. Update on Surveillance System/Registry Model- Jantz Malbrue

Data continues to be imported into the registry and the verification process is almost complete. The registry consists of clients from 1992 to present and the goal is to share the list with the community based organizations.

Dr. Saulsberry motioned to approve, second by Rosie Metoyer.

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

The clinical standards of care are going through the editing process. The new standards are modeled after evidence based national practices. Lorri Burgess asked how the resources would be distributed to physicians. Cheryl Harris stated that she would ask the State Bureau of Media and Communications about the best method for distributing materials to partners. Dr. Gardner expressed the importance of adult conditions in the standards of care and the request for additional physicians to review.

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

Dr. Susan Berry was absent from the meeting because of jury duty. Karen Brewer provided the commission with a quick update about UnitedHealthcare (UHC). The agency offers case management services for individuals diagnosed with sickle cell. UHC is working with clients without a primary care physician and each individual is referred to a case manager and hematologist. UHC has two nurses in New Orleans and one in Baton Rouge. The case managers visit hospitals included in the Our Lady of the Lake, Tulane and Ochsner networks. To date, UHC has signed up around 150 members diagnosed with sickle cell. The biggest struggle has been finding hematologists for adults since a large number of young adults continue to visit pediatricians. Lorri Burgess asked if there were any incentives the commission could offer to new hematologists. Dr. Gardner stated that the Chair of LSU Hematology expressed that fewer people are pursuing benign hematology since oncology offers a higher salary. Hugh Eley mentioned that the Bayou Health Plans have the flexibility to pay for a variety of quality improvement indicators and sickle cell could be included. Retana Comeaux stated that Howard University would be a great resource due to their medical center dedicated to sickle cell training and knowledge. Dr. Gardner stated that it would be best to speak with hospital administration about increasing funds for an adult hematologist. Lorri Burgess brought up the idea of offering tuition incentives for upcoming doctors.

* + 1. Report on Transcranial Doppler Screening Training

Retana Comeaux is still waiting on a response from Lake Charles Memorial. She plans to reach out to Moss Memorial Clinic on TCDS being done at their hospital. Dr. Gardner spoke with Dr. Martinez, head of Radiology at Moss Memorial, about sending someone for training and he supports the idea as long as there’s adequate reimbursement from Medicaid. Dr. Gardner explained that transcranial dopplers are able to determine someone’s risk for stroke. The procedure has been mandated to be performed on children ages two to sixteen years of age. Facilities are able to provide the service in New Orleans, Baton Rouge and Lafayette, but there aren’t any facilities providing this service in Lake Charles. Cheryl Harris stated that DHH is working on expanding the capabilities to other regions in the state.

* 1. Pain Management protocol For Doctors

Dr. Gardner has a graduate student who is interested in sickle cell. The student has a strategy for pain management and Dr. Garner would like to add it to the next meeting agenda.

Lorri Burgess motioned to approves 2a and 2b; moved by Jerry Page and second by Dr. Saulsberry.

1. Report: Patient/Navigation
   1. Report Health Navigator Legislation

Lorri Burgess delivered the sad news that Rep. Williams passed away recently. The Health Navigator Legislation went through entire legislative process without any objections. The commission was able to provide legislators with data from DHH to show the number of individuals diagnosed with sickle cell in each region. The commission has the framework to show total costs and how sickle cell patients affect the state budget. Lorri noted that Rep. Williams’s district had the highest number of individuals living with sickle cell. There’s a possibility for designated funds and a renewal process. The bill has been signed, but the exact bill number is unknown.

Lorri Burgess motioned to approve, second by Jerry Paige and Hugh Eley.

1. Report: Education and Advocacy
   1. 2015 LPCA Medical Summit

The Summit was held on May 29-30, 2015 at the Hyatt Regency (French Quarter). Tonia Canale confirmed that there were over 100 participants at the summit. The LPCA agreed to devote a day to sickle cell at the summit and several sickle cell related courses were offered in the Primary and Behavioral Health tracks. The participants and speakers left excellent reviews in their evaluations of the sickle cell courses. Commission members who attended the summit expressed their enjoyment and gratitude. Currently, the 2016 LPCA Conference is scheduled to occur a month before the statewide sickle cell conference.

* 1. 2016 Sickle Cell Statewide Conference

The date for the Statewide Sickle Cell Conference is June 24-26, 2016. The conference will be located in Baton Rouge. The Baton Rouge Foundation will host the conference and Ms. Lorri Burgess will be the chair.

* 1. Update on proposed statewide brochures

Etta Pete stated that the brochures will be featured on the state website. Also, the website will include a web link to each of the foundations’ websites along with their staff directory. Lorri Burgess recommended the creation of a uniformed data sheet on the foundations that highlights their services to provide to the community.

Dr. Gardner motioned to approve, second by Hugh Eley.

1. Other Business

a. Preparation of annual report

Lorri Burgess stated that Matthew Valliere praised the great work of the commission. He proposed extending the commission sunset in order to address more statewide issues. Also, Lorri encouraged commission members to think about new ways to reach the sickle cell population such as billboard campaigns. Cheryl Harris reminded the commission that annual election for a new chair and co-chair would occur at the next meeting.

The meeting was adjourned at 11:30 pm.