Sickle Cell Commission Meeting

Tuesday, April, 2014

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

DHH Bienville Building-Room 671

Minutes

Roll Call

In Person:

* Tonia Canale (member), Louisiana Primary Care Association
* Jerry Paige (member), Sickle Cell Disease Association of America, Inc. – Northwest Louisiana Chapter
* Dr. Renee Gardner (member), Children’s Hospital New Orleans
* Matthew Valliere, Deputy Director – Office of Public Health, Center for Community and Preventive Health
* Cheryl Harris, Administrator – Office of Public Health Genetic Diseases Program
* Connie Simonson, Program Manager – Office of Public Health, Genetic Diseases Program

Via Conference Call:

* Lorri Burgess (Chair), Baton Rouge Sickle Cell Anemia Foundation, Inc.
* Etta Pete (member), Southwest Louisiana Sickle Cell Anemia, Inc.
* Dr. Rebecca Kruse-Jarres (member), Sickle Cell Center of Southern Louisiana – Tulane University School of Medicine
* Dr. Pamela Saulsberry (member) – Northeast Louisiana Sickle Cell Anemia Technical Resource Foundation, Inc.

Absent:

* Rosia Metoyer (member), Sickle Cell Anemia Research Foundation, Alexandria
* Courtney Phillips (member), Department of Health and Hospitals
* Sen. Yvonne Dorsey-Colomb, Louisiana Senate
* Rep. Herbert Dixon, Louisiana Legislature

Welcome – Matt welcomed everyone to the meeting and explained that he was facilitating the meeting as the chairperson would be joining the meeting later. Matt mentioned that all commission members were officially approved as of March 14, 2014.

1. Discussion, strategies, and proposed budget of work groups:
2. Medical Service Delivery (Dr. Rebecca Kruse-Jarres)

Dr. Kruse-Jarres announced to the group that she has resigned her position as Director of the Sickle Cell Center of Southern Louisiana as she is moving out of state. The members of the commission thanked her for her dedication and service.

Dr. Tammuela Singleton has been appointed the new director and Dr. Kruse-Jarres has updated her on the work of the commission. Matt will look into the process of resignation and a nomination form will be sent to Tulane to replace Dr. Kruse-Jarres.

Dr. Kruse-Jarres reiterated that there are not enough hematologist and other service providers for patients with Sickle Cell Disease. A focus of the commission needs to be to find enough funding to provide necessary medical as well as wrap around services.

Dr. Kruse-Jarres has recently written a grant to obtain additional funding. Dr. Singleton will monitor the grant’s process once she leaves.

b. Education and Advocacy (Etta Pete)

Ideas for education activities include a statewide media campaign for World Sickle Cell Day, information posted to the DHH website, an ID card for SCD patients to present to the ER. (Connie will try to locate an old copy of the card.)

Matt advised that the workgroup propose a budget for the activities.

1. Data and Surveillance (Matthew Valliere)

Matt is working with OPH Informatics to develop data to provide an overall picture of Sickle Cell Disease in the state and to provide the legislature with the cost burden of the disease.

1. Patient Navigation (Lorri Burgess) – Lorri is researching all opportunities for clients with Sickle Cell patients (ex. Housing). Lorri inquired about ways to identify providers who are interested in treating patients. Dr. Gardner suggested a survey to ascertain this information and to find out what the barriers are.

Matt asked Tonia if the LPCA is willing to work with Sickle Cell patients if DHH provided training. Tonia said that there is definitely an opportunity for education and growth. She will work to identify interested providers and work on a formal agreement.

Lorri mentioned that her foundation pays part of some clients services through monies obtained from fundraising and explained how the Voucher Program operates. Ms. Pete would like to see it implemented in the Lake Charles area.

2. Discussion of proposed:

a. Standard Care Plan for Sickle Cell Disease (Dr. Renee Gardner) – Dr. Gardner provided a report on the patients who have received transcranial dopplers (TCDs) on the patients seen by LSU clinics in New Orleans, Baton Rouge and Lake Charles (attachment 1). .

There is still a need for technicians to perform TCDs. Dr. Kruse-Jarres suggested that the commission can help in providing training to ultrasound technicians to perform TCDs.

Dr. Gardner is working on a standardized care plan and will make it available in the next few months

1. Statewide Conference (Etta Pete) – The workgroup is in the process of developing a budget and locating a venue for the conference. Ms. Pete is asking everyone to send in potential topics and presenters for the conference. She is also asking for help to provide CEUs for the medical professionals. It was decided that all commission members will serve on the planning commission.

Tonia Canale proposed that the Sickle Cell Statewide Conference is planned as pre-conference to the LPCA Medical Services conference next spring. The group was in agreement.

1. Discussion of Genetics Program Expectations of Grantee (Cheryl Harris/Matt Valliere)

Cheryl mentioned that she and Connie will be conducting site visits to the foundations before the end of the fiscal year to review the caseload, policies and procedures for each. After the visits, Cheryl and Connie will establish a more cohesive set of deliverables for each foundation to follow.

1. Genetic Diseases Program Funding for SCD (Mathew Valliere and Cheryl Harris)

Cheryl presented a spreadsheet that contained the amount of funding each contractor associated with the program receives (attachment 2). Of the $1,230,698 the program disburses in contracts, the foundations received $155,000 in disbursements and the clinics received $441,675 for a total of $596,675 in Sickle Cell services. Matt said that he will look at the possibility of having some funding restored to these contracts.

5. Annual Report (Matthew Valliere) – Matt distributed a draft copy of the annual report (attachment 3). The commission was asked to review the report, make additions and changes and work on adding a budget to the report. The report needs line item appropriations to provide wrap around services. The report will be finalized by the fall.

6. Other items (Matthew Valliere) –

The commission voted to replace Dr. Kruse-Jarress with Dr. Gardner as the vice-chair.

It was suggested that the foundations have a meeting with their legislatures and hold a community event in September in accordance with Sickle Cell Disease Awareness Month.

The group is encouraged to invite stakeholders and other interested parties to the meetings and to provide notice of important activities well in advance of the commission meetings.

1. Next Meeting Date

Future meeting dates are June 24th, August 26th and November 14th. Workgroups are asked to meet in between meetings.

Adjournment