Sickle Cell Commission Meeting

Tuesday, June 24, 2014

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

DHH Bienville Building-Room 371

**Meeting Minutes**

**Attendance:**

* Members
	+ Jerry Paige – Sickle Cell Disease Association of America, NW Louisiana Chapter
	+ Lorri Burgess – Baton Rouge Sickle Cell Foundation
	+ Courtney Phillips – Department of Health and Hospitals (via conference call)
	+ Etta Pete – Southwest Louisiana Sickle Cell Foundation (via conference call)
	+ Renee Gardner, M.D. – LSU Children’s Hospital
	+ Pamela Saulsberry, Ph.D. – Northeast Louisiana Sickle Cell Foundation
	+ Rosia Metoyer – Sickle Cell Anemia Research Foundation (via conference call)
	+ Tonia Canale – Louisiana Primary Care Association
* Others
	+ Connie Simonson – DHH OPH Genetic Diseases Program
	+ Matthew Valliere – DHH OPH Center for Community and Preventive Health
	+ Susan Berry, M.D. – DHH OPH Children & Youth with Special Health Care Needs
	+ Cheryl Harris – DHH OPH Genetic Diseases Program
	+ Jamie Alexander – DHH Medicaid

**Welcome** – Lorrie welcomed everyone and the participants introduced themselves.

1. **Discussion of proposed budget and justification of work groups:**

*a.* *Medical Service Delivery (Tammuela Singleton)* – Dr. Singleton was absent therefore no update was given.

*b.* *Patient Navigation (Lorri Burgess)* – Lorri mentioned to the group that a patient navigator at each foundation will be a real coup for the program. The navigator could provide coordination of community partners and medical providers. The navigator would need to be trained and certified. Lorri mentioned that an organization in Mobile, Al has a good training program.

Dr. Berry asked where the navigators would be located and Lorri suggested two per foundation. Matt asked if the patient would be connected to a medical home. Lorri answered that if the patients aren’t insured with Medicaid or private insurance, the navigator could help them tie into a medical home. The navigator can also help access federally qualified health centers, workforce sources and social security.

Dr. Saulsberry suggested use of the Older Worker Program to use older workers to answer phones, organizing, setting appointments, etc. Lorri stated that there are challenges with older workers with the complexity of the social work and health issues with Sickle Cell Disease.

Dr. Saulsberry and Lorri agreed that the use of student interns might be beneficial to the foundations under certain situations. Lorri has used the Southern University Extern Program to assist with foundation activities.

Cheryl proposed also having outreach people to do work more on a community level as well as a higher level navigator. Dr. Berry mentioned that Families Helping Families has a training program for parents for the Children Special Health Services Program to help parents link to resources.

The cost for this activity is $50,000 for an educated, higher level navigator, $30,000 for an outreach person and $10,000 for travel and other expense per foundation per year. Lorri will work on job descriptions, benefits, and training requirements.

*c. Education and Advocacy (Etta Pete)* – Ms. Pete mentioned that this workgroup met on June 19, 2014 to discuss activities. Before proceeding with the workgroup report, Ms. Pete asked Matt where the finances for the activities, particularly the conference, will come from. Matt said that all monies will be requested through the annual report.

Ms. Pete mentioned that she is working with Tonia Canale to work out the details of the conference.

The group is also pursuing a method of providing identification for sickle cell patients to carry to medical providers for treatment, emergencies, etc. Cheryl suggested a toolkit similar to the Lead Program toolkit for providers and patients.

Ms. Metoyer volunteered to work with Ms. Pete and the workgroup will have more information and a budget by July 25th.

*d. Data and Surveillance (Matthew Valliere & Courtney Phillips)* - Connie is working on a list of sickle cell patients to help establish a registry. The registry will allow foundations to access client information in their regions.

Matt is working with OPH Center for Public Health Informatics (Ryan Bilbo) to look at medical data and the cost benefit of the commission’s proposed activities. Matt will have a data presentation at the next meeting.

Lorri mentioned that the foundations would like data sharing agreements with DHH and hospitals.

2. **Discussion of proposed Standard Care Plan and budget for SCD (Rene Gardner) –** Dr. Gardner presented an excellent draft of a Standard of Care Plan (see attachment) for the care of patients with SCD. Dr. Saulsberry mentioned that the document fits with the “educate the educator” model. She also mentioned that the book *Hope and Destiny* is a good resource for parents and that Dr. Betty Lo is interested in taking care of patients with SCD.

3. **Discussion of proposed 2015 Statewide Conference (Etta Pete**) – Ms. Pete reported that the SCD Conference will be a pre-conference as part of the LPCA conference. The committee would like to provide scholarships to clients of each foundation. LPCA will be responsible for advertising the conference .

Tonia Canale will be responsible for securing sponsorships and the committee would like DHH to provide payment for speakers (travel, room, meals, etc.).

List of topics for the conference include:

* Educate the educators
* Know your SCD status – includes knowing one’s trait status
* Psychological plans
* Statewide standard of care plan (Dr. Gardner)

4. **Update from Genetics Division (Cheryl Harris**) – Matt has requested that DHH put additional monies into each foundation. Cheryl and Connie are planning site visits in FY 15 to standardize foundation deliverables.

Matt will speak to Rudy Macklin of the Office of Minority Health to obtain suggestions on how to provide training to sickle cell patients on Community Readiness in case of a disaster.

5. **Discussion of statewide Voucher Program through LPCA (Tonia Canale)** – Tonia mentioned that LPCA would be interested in expanding the voucher program if there can be an assurance of participation.

Lorri will contact LPCA to determine how the foundations can apply for the voucher program.

6. **Discussion of Proposed Funding for Media Consultant** for Public Relations, World Sickle Cell Day, Sickle Cell Awareness Month, Annual Report/September Press Conference (Cheryl Harris) – Public relation activities and materials must be cleared through the DHH Bureau of Media and Communications (BMAC). BMAC needs at least a four to six week turnaround time.

 7. **Suggestions for 2015 legislation and authors Assignments (**Commission Members)

 a. Medicaid exception

 b. Day hospital(s)

 c. Patient navigation

 d. Other suggestions – Another suggestion was to provide telemedicine for SCD patients

8. Annual Report (Matthew Valliere) – July 25th is the due date for budgets. Lorri will construct a timeline for submission.

9. Other Matters – Lorri will contact Sen. Dorsey and Mrs. Metoyer will contact Rep. Dixon to ensure their representation at the next meeting.

Agenda items must be submitted two week before the next meeting.

Save the Date!

Next Meeting Date

Tuesday, August 26, 2014