

Sickle Cell Commission Meeting

June 8, 2016

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

DHH Bienville Building-Room 132

Conference Call info: 888-278-0296

Access Code: 8965636#

Meeting minutes – June 8, 2016

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)
* Dr. Pamela Saulsberry, Northeast Sickle Cell Anemia Foundation – **Commission Vice Chair** (via phone)
* Tonia Canale, Louisiana Primary Care Association
* Rene Gardner, M.D., Children’s Hospital New Orleans (via phone)

Additional meeting attendees:

* Patti Barovechio, OPH CSHS Program (via phone)
* David Schuster, Tulane University School of Medicine Fourth Year Student
* Harrison Martin, Tulane University School of Medicine Fourth Year Student
* Anh Pham, OPH Emergency Preparedness and Response Program (via phone)
* Cheryl Harris , OPH Genetic Diseases Program (via phone)
* Jantz Malbrue, OPH Genetic Diseases Program

Call to Order

Lorri Burgess called the meeting to order at 10:16 a.m.

Welcome

Approval of meeting minutes – March 23, 2016

Minutes were reviewed and Tonia Canale asked that those not in attendance be included in the minutes if they have a proxy filling in for them.

Tonia Canale motioned to approve, second by Rosia Metoyer.

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

Currently, the Sickle Cell Registry has a total of 2166 individuals. Approximately 381 names were listed in the registry with incomplete data such as name and physical address. 234 of those clients have been identified and their information updated. The other incomplete records will be matched against data in LINKS (Louisiana Immunization Network for Kids Statewide) & the Louisiana Medicaid Systems for current information. In preparation for Medicaid expansion, recipient ID and managed care plan will be added to the registry for those individuals enrolled in a Healthy Louisiana Plan. Lorri Burgess asked if the total number highlighted for the registry included individuals 30 years of age and older. Also, Ms. Burgess asked how the total number of individuals in the Sickle Cell Registry related to the approximately 3000 individuals cited with sickle cell disease Medicaid claims in the 2014 report. Cheryl Harris stated that the newborn screening was universally instated across the state and monitored by the Office of Public Health Genetics Program during the early 1990s. As the active client lists of the Foundations are added to the registry, the total number should match the total number of claims highlighted in the Medicaid report. Dr. Renee Gardner asked if the registry included sickle cell individuals attending emergency rooms and if there was a way to access other systems for more information. Ms. Harris stated that the goal is to work closer with the Office of Public Health Bureau of Informatics to access meaningful related data.

* 1. Sickle Cell Tracking Data Plan

There was a total of 77 newborns identified with sickle cell in 2015. So far in 2016, a total of 21 newborns have been identified with sickle cell. The newly identified cases have been distributed by regions to the sickle cell foundations and clinics. All of the Foundations provided a list of their current client registries. The lists of clients were matched against those already identified in the state registry and the rest are being added to the total number of cases. A demonstration of the Social Solutions-ETO Case Management software occurred with the Data/Quality Manager of the Bureau of Family Health. Since the software requires a custom production, the next step will be to meet with the Bureau of Family Health’s Data Action Team Lead to discuss the possibility of adding sickle cell data into their software for us to access and monitor. Tonia Canale inquired about the time frame for the number of new cases. The newly identified cases have been monitored through the Office of Public Health Newborn Heelstick Screen from January 1st to June 8th of 2016. Ms. Canale asked the commission for its essentials in a data system. She’s been working closely with the LSU Health Sciences Center to build a system and she is willing to share her contacts and suggestions. The next step will be to get input from the Bureau of Health Informatics on the possibility of data compatibility and integration of case management software.

1. Report: Medical Service/Delivery
	1. 2016 Standards of Care- Renee Gardner

Dr. Renee Gardner submitted a revised draft of the Standards for Care of Patients with Sickle Cell Disease. The draft will be submitted to the Bureau of Media & Communications (BMAC) for final approval. Tonia Canale asked if there was a deadline for approval and distribution. Cheryl Harris stated that the goal for approval is July in order to be able to distribute the document in September during National Sickle Cell Awareness Month.

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

Lorri Burgess and Jerry Paige continue to strategize on the Health Navigator Legislation. Dr. Gardner asked how the state budget crisis would hinder the navigator proposal. Ms. Harris stated that DHH has funds to support the navigators, but authority needs to be granted by a legislature and approved by Dr. Rebekah Gee. Dr. Gardner stressed the importance of having supporters contact legislatures to promote the proposal. The Office of Public Health has undergone organizational changes merging the Genetics Program under the Bureau of Family Health. The Bureau of Family Health has Maternal Child Health and Title V funds that could be used to support Health Navigators.

* 1. 2017 Legislative Session and Proposals

Dr. Pamela Saulsberry discussed the “Know Your Status Campaign” that the Northeast Sickle Cell Anemia Foundation has been conducting in their region of the state. The Foundation has attended health fairs along with schools while partnering with primary care providers as referral sources. Dr. Saulsberry stated that the campaign attracted individuals who did not know their status or the differences between sickle cell disease and trait. Cheryl Harris asked if it would be beneficial to include sickle cell as a reportable condition under the Louisiana Sanitary Code in order for follow up to be relayed to the Foundations. Etta Pete mentioned that that the message during the last National Sickle Cell Meeting was for agencies not to overshadow sickle cell disease with trait in order not to confuse funders. Lorri Burgess asked if legislation could be created to improve the triage of individuals living with sickle cell during admission. David Schuster highlighted the variables related to sickle cell disease and the idea of using triage nurses. Dr. Renee Gardner stated that a pain management protocol would be useful. Although patients present with other critical problems, something has to be done to help medical professionals understand sickle cell pain protocols. Dr. Gardner stated that it would be necessary to meet with Department Heads to discuss protocols. Tonia Canale explained that triage discussions occurred

regarding asthma patients. Emphasis was placed on educating nurses as well as patients to improve triage strategies. The same protocols and procedures could be used triaging sickle cell patients. Dr. Rene Gardner explained the struggles of seeing kids with symptoms who aren’t able to access pain medications. Dr. Gardner is open to working with other medical professionals like Dr. Singleton to address a triage strategy. Lorri Burgess asked if pain management protocols would be developed externally from the standards for care. Dr. Gardner stated that pain management is discussed in the standards for care, but she envisions the protocols becoming a standard item. Also, she will collaborate with other physicians in the field. Ms. Burgess asked if the development of a work group was needed. Dr. Gardner noted that the discussion on triage would occur amongst sickle cell physicians and emergency room doctors. Ms. Burgess stated that a pain management training could be offered at the 2017 conference. Dr. Gardner mentioned that offering CEUs for nursing professionals would be beneficial. Mr. Schuster stated that nurses could play a vital role by administering medicine to subdue pain until the patients are able to be seen by the physician. Ms. Burgess asked if pain management and triage protocols could be included in legislation. Tonia Canale wasn’t sure that the procedure could be written into legislation, but the belief is that the protocol for acute care for sickle cell patients could become legislation. Dr. Saulsberry reminded the commission to view the potential protocols from an ethical perspective as well as a beneficial policy. Dr. Gardner stated that the protocols should not be rigid and would need flexibility before becoming legislation. Dr. Saulsberry explained the issue of diversity and providing the medical community with enough information to address the different sickle cell conditions.

2017 Proposal suggestions:

1. *Establish Sickle Cell Protocols*
2. *Ethical Protocols, Policies and Procedures*
3. *Expanding Pain Management Protocol*
4. *Education of Medical Professionals on Triaging Sickle Cell Patients (CEU credit)*
5. *Sickle Cell as a Reportable Condition Through the Office of Public Health*
6. *Campaign on Sickle Cell Trait Awareness*
7. Report: Education and Advocacy
	1. Sickle Cell Awareness Month- Lorri Burgess

Lorri Burgess proposed an idea for Sickle Cell Awareness Month in September. Ms. Burgess proposed the Commission unveiling the new sickle cell standards for care with Dr. Rebekah Gee, Secretary of the Louisiana Department of Health. Cheryl Harris stated that the Bureau of Media & Communications review of the standards for care may take time, but the document should be ready to distribute by September. Ms. Harris proposed having the event at the Governor’s Mansion. Tonia Canale stated that this would be a great event to invite a speaker and media outlets.

* 1. Update on Sickle Cell Statewide Conference- Etta Pete

The 2017 Sickle Cell Statewide Conference is scheduled for June 16-18, 2017. A deposit was made to reserve twenty rooms at the Renaissance Baton Rouge Hotel for those dates. The list of potential speakers and agenda are becoming more refined. The goal is to open registration for the conference on January 1, 2017. Ms. Burgess has created a list of sponsors and she plans to update the commission on changes periodically. Her staff has been researching what sponsors have paid at past events in order to determine a reasonable package. Tonia Canale offered to provide insight from past LPCA conferences. Ms. Canale mentioned that the commission could sell lanyards and name tags as part of sponsorship. Also, she stated that the speaker abstract could include whether travel is required. Ms. Burgess moved to forward electronic information. Once a website is created for the Statewide Conference, DHH and the Foundations will add web links to their websites to direct potential attendees.

Tonia Canale motioned, second by Ms. Rosia Metoyer.

1. Other Business

Etta Pete reminded the commission about the Louisiana Association for Sickle Cell Anemia, Inc. Conference on June 24-26, 2016 in Lake Charles. Lorri Burgess stated that Ryan’s Walk/Run is scheduled for August 27, 2016 in Baton Rouge. Jerry Paige mentioned that the Northwest Louisiana Chapter’s Sickle Cell Softball Tournament was cancelled due to construction occurring at the park. Cheryl Harris stated that the program was notified by the Division of Administration detailing that the commission is in compliance by completing the necessary documents and meetings required by Act 814 of 2013.

The meeting was adjourned at 11:50 am.