**Sickle Cell Commission Meeting**

**January 14, 2014**

**10a-12p**

**DHH Bienville Building – Room 371**

**Minutes**

**Attendees:**

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| --- | --- |
| ***In Person:***  **Lorri Burgess, Director**  **Baton Rouge Sickle Cell Disease Foundation**  **Rebecca Kruse-Jarres, M.D., Director**  **Southeast Louisiana Sickle Cell Center**  **Tulane University**  **Renee Gardner, M.D., Pediatric Hematologist**  **Children’s Hospital**  **LSU Medical Center**  **Tonia Canale**  **Louisiana Primary Care Association**  **Courtney Phillips**  **Deputy Secretary**  **Department of Health and Hospitals**  **Matthew Valliere, Deputy Director**  **OPH, Center for Community & Preventive Health**  **Cheryl Harris, Administrator**  **OPH, Genetic Diseases Program**  **Connie Simonson, Program Manager**  **OPH, Genetic Diseases Program** | ***Via Conference Line:***  **Etta Pete, Director**  **Southwest Louisiana Sickle Cell Disease Foundation**  **Pamela Saulsberry, Ph.D.**  **University of Louisiana-Monroe**  **Representative, Northeast Sickle Cell Foundation**  **Dwana Green**  **Program Analyst**  **MVA, Bayou Health** |

**A copy of the agenda is attached (Attachment 1).**

1. **Welcome/Introductions**

**The meeting was called to order by M. Valliere who thanked everyone for their participation and introductions were made. Mr. Valliere issued a list of the appointed members of the commission (Attachment 2).**

1. **Voting on Commission Leadership**

**Nominations were made on for chair and vice chair of the commission. Members voted Lorri Burgess as chair and Dr. Rebecca Kruse-Jarres as vice chair. Mr. Valliere handed charge of the meeting over to Ms. Burgess.**

1. **Workgroup Updates – each workgroup presented their members, objectives, expected outcomes, activities and performance measures. See the attached workplans.**
2. **Medical Service Delivery (Attachment 3) –**

* **Members- Dr. Kruse-Jarres noted that Dr. Gardner has been added to the workgroup so that there can be representation from the pediatric perspective.**
* **Objectives**
  + **Improve access to acute pain treatment– It was noted that this is the number 1 reason for ER use among patients. This workgroup is proposing to seek funding to train teams across the state that can care for the patients and proposes that funding is procured for day hospitals, particularly in areas with high volumes of ER use.**
  + **Increase chronic pain management – Dr. Kruse-Jarres informed the group that sickle cell pain is much different from other chronic pain and providers are often reluctant to administer certain medications because of substance abuse. Resources are needed for more of a team approach for pain management which can include a psychologist, an addiction specialist, social worker and chronic pain specialist.**

**Dwana Green noted that she is working with Catholic Charities to obtain information on patients’ Medicaid plans and to determine what plan best suits them.**

* + **Create a patient centered medical home – Dr. Kruse-Jarres stated that it would be ideal to have hematologists or other physicians trained in sickle cell disease management to be at the center of the medical home. This is would be based on Project ECHO which helps provide best practice in underserved populations.**

**Dr. Gardner mentioned that the National Sickle Cell Disease Association proposed that organizations need to add financial incentives to persuade specialists in hematology/oncology to treat sickle cell patients. She emphasized that is difficult to find providers who will take sickle cell patients, especially because of Medicaid.**

**Typically, interns do not receive training on treatment of patients. Both LSU and Tulane have expressed interest in training physicians who are interested in the treatment of patients with sickle cell disease.**

**Dr. Saulsberry suggested that the commission contact the Delta Regional Authority Leadership Institute in order to help provide incentive to medical providers to practice in this underserved population, especially in rural areas.**

**Mr. Valliere indicated that the workgroup should tie in the cost of training to the annual legislative report and see if the Legislature or Senate takes it on.**

**Ms. Phillips inquired about the role of Bayou Health plans and Ms. Green said that her group will be able to run better data of the use of the plans for 2013 since 2012 was a transition year. Ms. Green stated that she also participates in weekly calls with the plans but there are no indicators centered on sickle cell disease.**

**Dr. Kruse-Jarres and the workgroup will continue to tweak the workplan and Tonia Canale will be added to the workgroup.**

1. **Patient Navigation (Attachment 4)**
   1. **One aim of this workgroup is to encourage patients to become more involved in their care and in policy and legislation that affect their condition. Another goal is to help social service entities become more familiar with patients with sickle cell and connect patients to their services.**
   2. **Cheryl Harris indicated that having standards of care guidelines to use on patients will be beneficial in help planning for sickle cell funding to foundations. Dr. Gardner replied that the NIH will be providing a new set of guidelines for care of pediatric and adult patients and she will provide these when they are released.**
2. **Education and Advocacy (Attachment 5)** 
   1. **One of the main objectives of the workgroup is to educate the general public on various aspects of sickle cell disease since there is a lot of misinformation on the condition.**
   2. **Dr. Kruse-Jarres and Ms. Phillips suggested that the workgroup include outreach to medical providers as well.**
   3. **Ms. Phillips also suggested that the group reach out to entities such as pharmaceutical companies to encourage education and advocacy.**
   4. **The workgroup will look at developing a Sickle Cell conference that can possibly offer continuing education to providers. The group is also looking into developing booklets, training courses and webcasts.**
   5. **Dr. Saulsberry and Ms. Harris will work with Ms. Pete in organizing the conference.**
3. **Data & Surveillance (Attachment 6)**

* **Ms. Phillips will chair this workgroup for now. The main aim of this workgroup is to show DHH administration and state legislators how implementation of commission activities can result in cost savings.**

1. **Budget and Financing**

* **Each workgroup will develop a budget based on their workplan.**
* **Each workgroup should have a proposed budget for the next meeting.**

1. **Next Meeting**

**The next meeting is scheduled for February 18, 2014 at 10a.m. The room number will be sent out at a later date.**

1. **Adjournment**