**Sickle Cell Commission Meeting**

**October 15, 2013**

**9:30a-12p**

**DHH Bienville Building – Room 671 & 673**

**Minutes**

**Attendees:**

**Matthew Valliere, Deputy Director**

**OPH, Center for Community & Preventive Health**

**Susan Berry, M.D., Director**

**Title V: Children & Youth with Special Health Care Needs Programs**

**Cheryl Harris, Administrator**

**Genetic Diseases Program**

**Connie Simonson, Program Monitor**

**Genetic Diseases Program**

**Etta Pete, Director**

**Southwest Louisiana Sickle Cell Disease Foundation**

**Lorri Burgess, Director**

**Baton Rouge Sickle Cell Disease Foundation**

**Rebecca Kruse-Jarres, M.D., Director**

**Southeast Louisiana Sickle Cell Center**

**Tulane University**

**A copy of the agenda is attached.**

1. **Welcome/Introductions**

**The meeting was called to order by M. Valliere who thanked everyone for their participation and introductions were made.**

1. **Purpose of the Commission**

**The group discussed the purpose of the commission which is to promulgate the guidelines set forth in Acts 2013, No. 117 (Not sure if notation is correct), to procure funding tied to Sickle Cell activities and to review policies, legislation, etc. relative treatment of Sickle Cell Disease.**

**The commission is required to meet four times per year.**

1. **OPH Sickle Cell Program Overview**

**Cheryl Harris presented an overview of the OPH Sickle Cell Program. Highlights of the presentation included the revised statutes pertaining to Sickle Cell Disease, the programmatic budget and noteworthy topics. Effective 10/01/2013, Connie Simonson will be serving as the Program Manager for the Sickle Cell Unit of the Genetic Diseases Program. A copy of the presentation is attached.**

**After the presentation, Dr. Kruse-Jarres stressed that legislators will want to know how costs are being reduced, especially through decreased ER visits, decreased disease complications, decreased hospitalizations and increased compliance. She distributed a map of areas of the state with highest costs related to Sickle Cell Disease.**

1. **Commission Action Plan/Focus Areas/Workgroups**

**The commission decided on the following workgroups and various members volunteered to chair the workgroups.**

* **Medical Service Delivery – Dr. Rebecca Kruse-Jarres**
* **Patient Navigation – Lorri Burgess**
* **Education & Advocacy – Etta Pete**
* **Data/Surveillance – Matthew Valliere**
* **Budget/Funding – Commission**
1. **Voting on Commission Leadership**

**Matthew is working with Carol Lee to get the final names of commission members.**

**Once all members are confirmed, Matthew will send out an election ballot so that members can vote on a chair and vice-chair.**

1. **Possible Ancillary Members**

**In addition to the members approved by the Governor, the group discussed inviting ancillary members who will not be voting members but may have input into Sickle Cell topics. Possible ancillary members include:**

* **Dr. Rebecca Gee, Medicaid**
* **Bayou Health Plans**
* **Hematologists**
* **Mental Health Specialists**
* **Pain Specialists**

**Other suggestions can be emailed to Matthew.**

1. **Meeting Dates**

**The group decided that Tuesdays from 10:30 to 12 noon are good meeting dates. Locations will be announced.**

**Proposed future meeting dates are:**

* **December 3, 2013**
* **January 2, 2014**
* **February 18, 2013**
1. **Adjournment**