

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

**Meeting Notes
May 28, 2009**

Members Present

Shawn Bediako, PhD
Lizzie Johnson
Soula Lambropoulos, MS
Caterina Minniti, MD
Efa Ahmed Williams, MA

Carlton Haywood Jr., PhD
Malcolm Joseph III, MD
Sophie Lanzkron, MD
Larry Lee Thomas, DDiv

DHMH Staff

Donna Harris, BS
Susan Panny, MD
David Mann, MD

Carlessia Hussein, D.r.P.H.
Mary Russell, PhD

Welcome and Introductions

Dr. Susan R. Panny called the meeting to order at 8:30 a.m.

Old Business. Potential partners for data are Medicaid, Vital Statistics.

CDC/CCHP/NCBDDD Sickle Cell Registry Project Proposal

Dr. Carlessia Hussein gave an overview of the CDC/CCHP/NCBDDD Sickle Cell Registry Project Proposal. The letter of intent has been sent. The application principals are Dr. Allan Noonan at Morgan State University, Dr. Carlessia Hussein and Dr. Susan Panny. Dr. Hussein's focus at this point is to find out what exists that's similar and what lessons we can learn from it. Dr. Hussein had an opportunity to meet with the Cancer Registry staff who outlined how the registry is organized. In her conversations with Dr. Noonan, they discussed the possibility of Morgan hosting a website specifically to educate students, providers, minority groups and organizations about sickle cell. Dr. Hussein also plans to form a small advisory group and she wants representation from the Steering committee as well as others who are not part of the State. More information will be forthcoming as we move further along in the process.

Sickle Cell Disease Awareness Month Committee Activities

The committee is working on a press conference with the Mayor to kick off Sickle Cell Disease Awareness Month in September. Ms. Soula Lambropoulos has submitted a request to the Mayor's office and is waiting for their response and confirmation of a date. The press conference will be held at the Sickle Cell Day Infusion Center at Johns Hopkins. Events for the day are still in the planning stage. In addition, the committee is working on developing a list of activities that

can be promoted by the committee for Sickle Cell Awareness Month Members will receive notification as details materialize.

Directory of Services for Adults with Sickle Cell Disease

Ms. Soula Lambropoulos distributed the Inventory of Sickle Cell Services in Maryland form for discussion. The inventory form attempts to solicit information on the organization, name and type of program, number of persons served, source of funding, and program evaluation. Suggestions were noted and Ms. Lambropoulos will make the recommended changes. Ms. Lambropoulos will also write the first draft of the cover letter and circulate it to sub-committee members for editing along with the revised version of the inventory form.

United Nations First Annual World Sickle Cell Day

Dr. Carlton Haywood announced that citizens around the world will participate in the first annual event recognizing sickle cell disease as an international health dilemma. The General Assembly of the United Nations recently adopted a resolution that recognizes sickle cell disease as a global public health priority, and designates June 19th of each year as World Sickle Cell Day. The committee recommends that the Department do a press release announcing this momentous occasion. Drs. Haywood, Lanzkron and Bediako will write the draft and circulate it for comments. Once finalized, Ms. Donna Harris will initiate contact with the Department's Public Relations Office and follow-up as needed.

Sickle Cell Day Infusion Center

Dr. Lanzkron shared overall summary statistics from the sickle cell day infusion clinic from February 2008 to March 2009. She distributed charts on: the number of patients seen in the Day Infusion Center and the number of visits per patient; the percentage of patients admitted into the hospital from the clinic; and the number of discharges per local hospitals. There have been well over a thousand visits to the infusion clinic. The overall admission rates before they opened through the emergency room 50%. The admission rate from the infusion clinic is 20%, cutting the admission rate by 30%. Admission rates from the emergency room have dropped to about an average of 38 % during the week when the infusion clinic is open. Patients are sent to the infusion clinic instead of admitting them. Admission still remains at 50% when the clinic is closed, so the infusion center is clearly making an impact. In the 3rd quarter 2007 compared to the 3rd quarter 2008, there were 60 fewer hospitalizations or hospital discharges for sickle cell in the city of Baltimore. In the next quarter, there were 24 fewer admissions, so it appears that the infusion clinic is having some impact on the number of hospital discharges for the entire community.

Next Meeting

The next meeting is tentatively scheduled for July.