

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

Meeting Notes November 20, 2008

Members Present

Shawn Bediako, PhD
Willarda Edwards, MD
Lizzie Johnson
Sophie Lanzkron, MD
Caterina Minniti, MD
Larry Lee Thomas, DDiv
Donald Shell, MD
Efa Ahmed Williams, MA

C. Christine Corbin, BSN
Carlton Haywood Jr., PhD
Soula Lambropoulos, MS
Sherell Mason, MD
Karen Proudford, PhD
Allen Tien, MD
Anika Wilkerson

Members Absent

Natasha Bonhomme, BA
George Dover, MD
Victor R. Gordeuk, MD
Ross Heffer
Reddix Irance, MD
Marie Y. Mann, MPH
Sohail Rana, MD

James Casella, MD
Ronald T. Evans, MDiv
Neil J. Grossman, MD
Betty Johnson, MED
Malcolm Joseph III, MD
Patricia O'Neal, MD
Kimberly Whitehead, PhD

DHMH Staff

Donna Harris, BS
Carlessia Hussein, PhD
Susan Panny, MD
Mary Russell, PhD

Welcome and Introductions

Dr. Donald Shell called the meeting to order at 8:30 a.m. New member, Dr. Caterina Minniti, Director, Clinical Services for the Vascular Disease Unit, National Heart, Lung, and Blood Institute, National Institute of Health was introduced and welcomed. Dr. Minniti is replacing Dr. Gregory Kato on the committee.

Old Business

Committee Report - Recommendations to Secretary Colmers

Dr. Shell opened the discussion on the Secretary's report, Expanding Comprehensive Services for Adults with Sickle Cell Disease. This report makes recommendations on how to increase public awareness and coordinate services to improve health care delivery to adults diagnosed with sickle cell disease. Following a lengthy discussion, Dr. Bediako agreed to incorporate the changes discussed into the document. Any additional comments should be sent to Dr, Bediako by December.

The summary of the report recommendations are:

- Develop a statewide patient registry to facilitate continuity of care across health care systems and providers
- Ensure the provision of *both* Medicaid-covered, preventative primary care and comprehensive specialty care to adults with SCD
- Educate physicians and other health care professionals on best practices in the management and treatment of SCD
- Use the range of services provided by the Sickle Cell Infusion Center at Johns Hopkins (i.e., continuity of care and access to psychiatric/social services) as a model to be implemented in other regions of the state
- Develop a standard protocol for SCD treatment in emergency department and other urgent care settings
- Enhance patient education to include appropriate pain self-management and information about the range of evidence-based treatment options
- Increase the availability of educational and employment counseling services for adults with SCD

New Business

Sickle Cell Anemia Treatment Act of 2003

Dr. Haywood led the discussion on the Sickle Cell Anemia Treatment Act of 2003. This new optional Medicaid benefit provides States with additional flexibility to provide sickle cell services. It guarantees a 50 % federal match for services and education and other services related to the prevention and treatment of sickle cell disease, but States have to seek reimbursement on their own. It's a perfect opportunity to have the State of Maryland explore how it can use the flexibility provided by this treatment act to help enact some of the services we are discussing. Dr. Haywood will write a paragraph on the treatment act to include in the Secretary's report. For a summary of the provision of the Act, link to

http://www.cms.hhs.gov/MedicaidSpecialCovCond/03_SickleCellAnemia.asp#TopOfPage

Sickle Cell Disease Awareness Month 2009

The committee unanimously decided to organize one or more special events during Sickle Cell Disease Awareness Month in September. Volunteers are asked to join this sub-committee to make recommendations on what activities/events could be realistically accomplished.

Possibility of Developing a Multimedia PSA

Following a discussion on developing a media campaign to increase awareness of sickle cell disease and to improve access to information about educational, social, and health care resources, members agreed to establish a list of potential media outlets in the Baltimore-Washington area that could broadcast PSA on services for adults with sickle cell

disease. The Media/Public Awareness Sub-committee has a public outreach plan and has developed specific strategies for reaching targeted groups. The committee will be asked to present its proposed plan of action at a future meeting.

Next Meeting - Please Note Room Change

The next meeting will be held on Thursday, December 18, 8:00–11:00 a.m. in lobby room L-4, 201 West Preston Street.