

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

February 28, 2008
Meeting Notes

Committee Member Attendees

Shawn Bediako	Natasha Bonhomme
Lizzie Johnson	Malcolm Joseph
Gregory J. Kato	Anastasia Lambropoulos
Sophie Lanzkron	Sherell Mason
Karen Proudford	Iranice Reddix
Donald Shell	Allen Tien
Kimberly Whitehead	Anika Wilkerson
Efa Ahmed Williams	Donna Harris
Carlessia Hussein	Ilana Mittman

Welcome and Introductions

The meeting was called to order at 8:30 a.m. by Dr. Carlessia Hussein.

Steering Committee Co-Chairs

Dr. Hussein announced that Dr. Donald Shell, Dr. Shawn Bediako and Ms. Anika Wilkerson have volunteered to co-chair the steering committee. Dr. Shell will have lead responsibility. The co-chairs discussed the direction of the steering committee and its challenges to accomplish and succeed in improving the quality of health care and health care delivery for adult patients with sickle cell disease. Dr. Shell also emphasized the importance of prioritizing our priorities and asked the sub-committee co-chairs to submit three attainable goals after meeting with their respective committee.

January 31, 2008 Meeting Notes

The meeting notes were reviewed and approved as written.

Sickle Cell Conference Update

Dr. Shell led the discussion on the recent NIH Consensus Development Conference: Hydroxyurea Treatment for Sickle Cell Disease, February 25–27, 2008. According to the report the independent panel concluded that the use of hydroxyurea for sickle cell patients should be increased in adolescents and adults. Patients who use this drug experience fewer pain crises and hospital admissions and the side effects of hydroxyurea are low in adults. The panel recognized the importance of patients having one primary healthcare provider who is in frequent contact with the hematologist to manage their sickle cell disease. It further recognizes that providers need additional knowledge to effectively manage adults with sickle cell disease. A copy of the draft report can be found on the NIH website:
<http://consensus.nih.gov/2008/2008SickleCellCDC119main.htm>.

As follow-up to the NIH Consensus Development Conference, Dr. Lanzkron and Dr. Tien will draft a letter to Dr. Otis Brawley and Dr. Ellen Werner, Chairs, outlining the benefit of the conference and recommend next steps. The draft letter will be circulated to the membership for comments.

Sub-committee Reports

Sub-Specialist/PCP Education Awareness Campaign Sub-Committee - Dr. Irance Riddix, chairperson and members Dr. Gregory Kato, Dr. Sherell Mason and Dr. George Dover. This committee plans to recommend a protocol or checklist to educate primary care physicians on health maintenance and hydroxyurea therapy for adult sickle cell disease patients. In addition, recommendations for emergency room physicians to follow for patients in a sickle cell disease acute crisis will be developed. Of equal importance to this committee is to raise the level of awareness and prioritization in emergency rooms so patients can move quickly through the system.

Dr. Sophie Lanzkron said that the Crisis Center at Johns Hopkins Hospital does have protocols for patients in acute crisis that can be used for emergency rooms/hospitals, however she will have a better idea in the next six months on their effectiveness. The forms are with the IRB and are being tested. Dr. Lanzkron also posed the question, what would be the committee's recommendation as to who should distribute hydroxyurea therapy, the primary care provider or the hematologist?

This committee also wants to develop identification cards for patients. The card would identify what medications work for the patient and what does not. It was recommended to explore what California and Pittsburg are using because they have something similar.

Public Awareness Campaign Sub-Committee - Dr. Shawn Bediako, chairperson, Ms. Betty Johnson, Dr. Karen Proudford, Ms. Soula Lambropoulos, and Ms. Natasha Bonhomme referred to their previous report that outlined its scope and proposed activities. The committee is working on developing specific objectives and a time line to achieve its goals.

Grant Sub-Committee – Dr. Donald Shell welcomed Dr. Allen Tien who volunteered to chair this committee. Other members of this committee are Ms. Anika Wilkerson, Dr. Kimberly Whitehead and Dr. Sophie Lanzkron. Dr. Tien said his committee will develop a mechanism to get grant funds. He also volunteered to host the adult sickle cell steering committee website.

Community Based Support Group Activities Sub-Committee - Ms. Christin Corbin, chairperson was absent and no report available.

Patient Registry Sub-Committee - Dr. Willarda Edwards, chairperson was absent and no report available. Other committee members include Dr. Sophie Lanzkron and Dr. Kimberly Whitehead.

Announcements

The Lauren D. Beck Sickle Cell Foundation in affiliation with DC-Greater Access to Pediatric Services for Sickle Cell Disease is sponsoring a Sickle Cell Disease Walk-a-thon on May 17, 2008 at 8:30 a.m. Walkers will begin at the Stanton Community Center, 92 W. Washington Street, Annapolis, MD 21401 and walk to the Governor's Mansion. Registration fee is \$5.00. Log onto www.laurenbeckscfoundation.org for more information and to pre-register or call (443) 618-3812. All participants receive a discount parking voucher for the Clay St. garage. Donations are being accepted.

Dr. Shawn Bediako discussed the National Transition Symposium he attended in Florida. Of particular interest was Connecticut's Department of Public Health major initiative to provide comprehensive care for children, adolescence and adults with sickle cell disease. The press release can be found at <http://www.uchc.edu/ocomm/newsarchive/news08/jan08/sicklecell.html> and the plan at http://www.ct.gov/dph/lib/dph/sickle_cell_plan-final_12-28-07.pdf.

Next Meeting - Please Note Room Change

The next meeting will be held on **Thursday, March 27, 8:00–11:00 a.m. in room L-1**, 201 West Preston Street. The L-1 conference is across the isle from L-3 conference room.