

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

January 31, 2008
Meeting Notes

Committee Member Attendees

Shawn Bediako	Natasha Bonhomme
James Casella	George Dover
Willarda V. Edwards	Reddix Irance
Betty Johnson	Lizzie Johnson
Malcolm Joseph	Gregory J. Kato
Anastasia Lambropoulos	Sophie Lanzkron
Sherell Mason	Karen Proudford
Donald Shell	Allen Tien
Kimberly Whitehead	Anika Wilkerson
Adi Bello	Donna Harris
Carlessia Hussein	Ilana Mittman
Susan Panny	David Mann

Welcome and Introductions

The meeting was called to order at 8:15 a.m. by Dr. Carlessia Hussein who led the welcome and introductions.

November 27, 2007 Meeting Notes

The meeting notes were reviewed, amended and approved. The notes will be amended to include a fifth sub-committee that will research funding opportunities to develop and establish a case management system for adults with sickle cell disease. There was some discussion about the mission of this sub-committee but no chair has yet been identified.

Sickle Cell Day with Legislators

Ms. Anika Wilkerson was commended for her leadership in organizing The Sickle Cell Day with Legislators in Annapolis. The event was held on January 22 at the House Office Building, Room 302 from 9:00 a.m.-11:00 a.m. There was a good showing from legislators as well as community groups, families and friends. Attendees had the opportunity to meet with their legislators to discuss sickle cell disease and the continuum of care.

State Ethics Commission

The State Ethics Commission is requesting committee members to complete a financial disclosure form. Dr. Susan Panny spoke to Robert A. Hahn, Executive

Director and explained that the committee is an advisory body that does not receive and manage funds. The commissioner expressed the opinion that the authorizing statute appeared to give the committee the power to handle funds and manage programs. It was agreed that Dr. Panny will contact the Department's Attorney General, David Morgan Esq. for guidance.

Sub-committee Reports

Dr. Shawn Bediako, **Public Awareness Campaign** sub-committee co-chair distributed their report that outlined its scope and proposed activities. The sub-committee activities include establishing relationships with local media outlets, increasing community awareness and knowledge of sickle cell, reducing disease-specific stigma experienced by patients, challenging perceptions of patient stereotypes by medical professionals, and developing and training a "spokesperson corps" to interface with the media. Clarification of the authority of the public relations sub-committee is requested to determine what, if any, items should be approved by the Department's Public Relations Committee prior to action by the steering committee.

Dr. Donald Shell recommended that the committee should have a chairperson and co-chairperson to speak for the committee so issues remain clear. Dr. Carlessia Hussein again asked for volunteers and said that in the interim she and Dr. Susan Panny will lead the meetings.

Dr. Iranice Riddix, **Sub-Specialist/PCP Education Awareness Campaign** sub-committee chairperson said they have not met.

Ms. Christin Corbin, **Community Based Support Group Activities** sub-committee chairperson said they have not met, but did report that a local Maryland Division of Sickle Cell Disease of America has been established. Johns Hopkins Hospital is providing support groups for adults.

Dr. Willarda Edwards, **Patient Registry** sub-committee chairperson reported that they have not met. Dr. Edwards did state that The Sickle Cell Disease Association of America, Inc. is submitting an application to the Agency for Healthcare Research and Quality, Ambulatory Safety and Quality Program: Improving Management of Individuals with Complex Healthcare Needs through Health IT 2008. The Office for Genetics and Children with Special Health Care Needs is one of its partners. The pilot Sickle Cell Disease Patient Registry will model the autism registry designed by Dr. Allen Tien.

Announcements

Dr. Sophie Lanzkron announced that the Sickle Cell Infusion Center at Johns Hopkins will have its grand opening on February 18, 2008. The center is located at 600 N. Wolfe Street, Carnegie Building. The Infusion Center provides treatment of sickle cell disease crisis in a dedicated center where each patient is known to

the staff. Other services provided by the Center include a monthly support group, transition services for teenagers, outpatient sickle cell clinics that meet twice a week, a dedicated team that evaluates all sickle cell patients admitted to the hospital and 24/7 consultative service to doctors throughout the state.

Next Meeting

The next meeting will be held on Thursday, February 28, 8:00–11:00 a.m. in room L-1, 201 West Preston Street.