

Statewide Steering Committee on Services for Adults with Sickle Cell Disease

November 27, 2007
Meeting Notes

Committee Member Attendees

Shawn Bediako	Natasha Bonhomme
James Casella	C. Christine Corbin
George Dover	Willarda V. Edwards
Victor R. Gordeuk	Carlton Haywood
Betty Johnson	Lizzie Johnson
Gregory J. Kato	Anastasia Lambropoulos
Sophie Lanzkron	Marie Y. Mann
Sherell Mason	Shirley Nathan-Pulliam
Karen Proudford	Reddix Irance
Bishop Larry Lee Thomas, Sr.	Kimberly Whitehead
Efa Ahmed-Williams	Anika Wilkerson
Donna Harris	Carlessia Hussein
Ilana Mittman	Susan Panny

Guests

Secretary John Colmers
Christi Megna
Barbara DiPetro

The meeting was called to order at 8:15 a.m. by Dr. Carlessia Hussein who led the welcome and introductions. Delegate Shirley Nathan-Pulliam and Secretary John M. Colmers addressed the group. Secretary Colmers commended the "citizen volunteers" that have come around the table to address many of the health care inequities that exist in our healthcare system. He stated that when committed collaborative endeavors between the government and the private sector occur, improvements in healthcare can happen.

Dr. Susan Panny gave an overview of the history of the initiative on the Services for Adults with Sickle Cell Disease. House Bill 851 (2006), House Bill 793 (2007) and the 2006 Legislative Report Recommendations were discussed.

Dr. Carlessia Hussein spoke about the charge to the steering committee which includes: 1) establishing institution and community partnerships, and a network of stakeholders who care for individuals with sickle cell disease; 2) developing and implementing a State comprehensive education and treatment program for adults with sickle cell disease; 3) developing and implementing a health care provider awareness and education campaign; 4) educating individuals with sickle cell disease, the public, and health care providers about the State options for care of adults with sickle cell disease; and 5) seeking grant funding to develop and establish a case management system for adults with sickle cell disease and a day infusion center.

Dr. Sophie Lanzkron provided an update on the progress toward State's only Day Infusion Center at Johns Hopkins Hospital. The Johns Hopkins Medical Institutions are contributing space and the renovation of that space and a capitated arrangement with several major managed health systems will contribute to the ongoing operation of the Center. Renovations have begun. It is hoped that the Center can open in the spring of 2008.

Dr. Sophie Lanzkron also discussed the NIH Comprehensive Sickle Cell Disease Center Grant application and the Maryland Community Health Resources Grant application. Dr. James Casella reported that the NIH Comprehensive Sickle Cell Disease Center application received a favorable review and that the NIH will be making funding decisions in February 2008.

Dr. Willarda Edwards gave a brief progress report on the Electronic Record/Voluntary Registry project of the Sickle Cell Disease Association of America (SCDAA). At their last meeting, stakeholders continued the dialog on establishing a national Sickle Cell Disease Registry, developing an action plan for implementing a pilot project. Dr. Greg Kato of the NIH commented that there was a group at NIH working on developing a registry, primarily targeted toward research. A third group, MDLogix, associated with the Johns Hopkins University School of Public Health, has been working on the development of electronic medical records to guide patient care and has, in the past, obtained grant funding from the NIH Institute of Nursing to develop the concept of electronic information exchange between Maryland hospitals and the newborn screening program and then back to the pediatric specialty clinics at the State's hematology centers. This proposal used Johns Hopkins as a prototype hospital and the Johns Hopkins Pediatric SCD Clinic as a prototype specialty clinic.

Dr. Edwards also described the SCDAA's proposed approach to the development of a Maryland Chapter of the Sickle Cell Disease Association of America (SCDAA). The proposal addresses the establishment of a Maryland division of SCDAA, rather than a Chapter, whose primary focus will be to educate the community about Sickle Cell Disease by offering a variety of services and programs statewide.

Committee members made recommendations that the Committee expand its membership to include representation from community health centers, insurers, MCO's, nurses, emergency room doctors, additional clergy, business community, Care First/United, and the NIH SCD patient registry project.

Workgroups were created to begin addressing the issues involved in improving the quality of health care and health care delivery for adult patients with sickle cell disease: public awareness campaign committee; community based support group activities committee; sub-specialist/PCP education awareness campaign committee; and a patient registry committee. All workgroups plan to meet prior to the next meeting of the full steering committee. The following suggestions were made for sub-committee consideration:

The Public Awareness Campaign Sub-Committee will suggest recommendations for promoting the use of standardized treatment guidelines, emergency room

protocols and hydroxyurea monitoring protocols, and publicizing Medicaid's Employed Individuals with Disabilities Program to promote opportunities for health coverage; The Community Based Support Group Activities Sub-Committee will make recommendations for establishing an effective SCD self-help support group;

The Sub-Specialist/PCP Education Awareness Campaign Sub-Committee will put forward recommendations for ensuring the availability of primary care by supporting primary care providers in their efforts to care for adult SCD patients, establishing an ongoing educational program for providers, establishing a 24/7 on-call consultant service, educating providers about the use of hydroxyurea, establishing a case management network to assist patients and support primary care physicians, and establishing a network of outreach and telemedicine clinics to complement the outreach case management network.

The Patient Registry Sub-committee will offer recommendations for developing a web-based repository for an abbreviated electronic medical record, and using a confidential patient registry to ensure that all patients are receiving care consistent with established standardized guidelines. The sub-committee will contact and involve the several "registry projects" already underway at SCDA, the NIH and MDLogix.

Our next meeting will be held on Thursday, January 31 at 8:00 in room L-3, 201 West Preston Street.

At the January 31, 2008 Steering Committee Meeting the meeting notes were reviewed and amended to add: the fifth sub-committee will research funding opportunities to develop and establish a case management system for adults with sickle cell disease. A chairperson for this sub-committee has not yet been identified.