STATE OF MARYLAND
DHMH
Maryland Department of Health and Mental Hygiene
201 W. Preston Street • Baltimore, Maryland 21201
Robert L. Ehrlich, Jr., Governor – Michael S. Steele, Lt. Governor – S. Anthony McCann, Secretary

JAN 1 5 2007

The Honorable Joan Carter Conway
Senate Education, Health, and Environmental Affairs Committee
2 West Miller Senate Building
Annapolis, MD 21401

The Honorable Peter A. Hammen
House Health and Government Operations Committee
Room 241 House Office Building
Annapolis, MD 21401

RE: HB 851 (Ch. 358) of the Acts of 2006 -
2006 Legislative Report on Adult Sickle Cell Disease

Dear Chairmen Conway and Hammen:

Pursuant to House Bill 851-2006, the Department of Health and Mental Hygiene (the Department) respectfully submits this legislative report on recommendations to improve the quality of health care delivery and reduce the mortality rate in the State with respect to adults who are diagnosed with sickle cell disease. The report also makes recommendations on funding amounts and potential funding sources to improve the quality of health care for these adults.

If you have questions or wish to discuss this report, please contact me or Dr. Susan Panny, Director, Office for Genetics & Children with Special Health Care Needs at (410) 767-1362.

Sincerely,

S. Anthony McCann
Secretary

Enclosure

cc: Senate Education, Health, and Environmental Affairs Committee
House Health and Government Operations Committee
Michelle A. Gourdine, M.D.
Russell Moy, M.D., M.P.H.
Susan Panny, M.D.
Ms. Anne Hubbard

Department of Health and Mental Hygiene

2006 Legislative Report

The Study of Adult Sickle Cell Disease in Maryland

Executive Summary

Sickle cell disease (SCD) is an inherited blood disorder characterized by anemia, increased susceptibility to infection, progressive organ damage, and a shortened life span. There is currently no cure for most people with SCD, but treatment is improving. Maryland has an excellent SCD program for children, with the lowest mortality among young children with SCD in the U.S. However, the same level of care does not exist for adults with SCD, and therefore, many adults do not receive the comprehensive medical care that they need.

There are approximately 1,700 adult patients with SCD in Maryland. African-Americans are the largest high-risk group in Maryland, with approximately 1 in 400 African-Americans having SCD, and 1 in 10 being carriers. African-Americans make up almost 30% of the population of Maryland, which has the third largest percentage of African-Americans in the U.S. The geographical distribution of SCD patients living in the State is consistent with the distribution of the African-American population, with most patients living in the two major urban areas of the State.

There is indisputable evidence that ethnic and racial minorities in the U.S. experience disparate health care encounters and health outcomes. These disparities seem to persist regardless of insurance, income, and other access-related factors as the result of biases in the health care system. African-Americans have particular issues related to health disparities due to having experienced a long history of significant social injustices. These circumstances pose special challenges to providing culturally competent state-of-the-art care to adults with SCD, the majority of whom are African-American.

There were 772 adults with SCD enrolled in Medicaid in FY 2005. Sixty eight percent (68%) were enrolled in HealthChoice and 32% received Fee For Service (FFS) Medicaid. Expenditures for FFS enrollees who were not also eligible for Medicare were $5,886 per member per month. Approximately 42% of the expenditures were for inpatient hospital care. The total Medicaid expenditures for the entire FFS cohort were approximately $5.9 million in 2005. In-patient hospital admissions accounted for 41.7% of the expenditure. Encounter data for the 523 patients enrolled in HealthChoice shows that 56% had an inpatient admission.

The Hospital Discharge Database of the Maryland Health Care Commission, which includes data covering all hospital admissions for SCD, shows that over the period 2000-2005 there were 13,724 hospital admissions for adults with SCD, with an average length of stay of 4.94 days, and a total cost of $97 million. Approximately 26% of the admissions were covered by private insurance, 44% were covered by Medicaid (HMO and FFS), and 25% were covered by Medicare.

Published studies have shown that comprehensive care is more cost-effective than episodic care. Patients using a comprehensive clinic have fewer emergency room visits, fewer hospital admissions, shorter lengths of stay, and lower annual costs per patient.

House Bill 851 (2006) required the Department of Health and Mental Hygiene to consult with its Office of Minority Health and Health Disparities and interested stakeholders to formulate recommendations to: 1) improve the quality of health care delivery to adults with SCD; 2) reduce the mortality rate of adults with SCD; 3) assist health care institutions in the State that have clinics for adults with SCD; 4) estimate the amount of State general fund support required to address the above-described recommendations; and 5) identify any additional available funding sources. The Department's full recommendations are as follows:

1. The most promising opportunities for improving the quality of health care and health care delivery for adult patients with SCD are to:

    - Establish a Statewide SCD Steering Committee of all stakeholders to ensure that services for adults with SCD and their families are developed in such a way that they effectively serve the community.
    - Further develop the State's only comprehensive SCD treatment center, the Sickle Cell Center for Adults at Johns Hopkins. The first enhancement for this Center should be a day infusion center, because day infusion programs result in significant cost savings and provide better care. Day centers have been shown to decrease hospital admissions by 43%, decrease length of stay by 49%, and save money. Future enhancements should include expansion of mental health services, nutrition counseling, and the establishment of secondary education and job training programs for patients.
    - Promote the use of standardized treatment guidelines, emergency room protocols and hydroxyurea monitoring protocols
    - Ensure the availability of primary care by supporting primary care providers in their efforts to care for adult SCD patients.
    - Establish an ongoing educational program for providers, including the use of web-based tutorials to provide cultural competence training to increase provider awareness of health disparities, the needs and cultural beliefs of SCD patients, their families and communities as well as education about state-of-the-art medical care for SCD patients.
    - Establish an effective SCD self-help support group.
    - Establish a case management network to assist patients and support primary care physicians.
    - Establish a 24/7 on-call consultant service.
    - Establish a network of outreach and telemedicine clinics to complement the outreach case management network, to enable the Center at Johns Hopkins to provide specialty care to adult patients with SCD living in the outlying areas of the State, and to support local primary care providers.
    - Develop a web-based repository for an abbreviated electronic medical record for each patient so patients can be more rapidly treated where they are not known.

- Publicize Medicaid's Employed Individuals with Disabilities Program to promote opportunities for health coverage.

2. The most promising opportunities to reduce mortality among adults with SCD include:

- Improve the quality of care as a whole, using the above-noted recommendations.
- Educate providers about the use of hydroxyurea, which has been shown to reduce mortality by approximately 40%, the frequency of painful crises by almost 50%, and hospitalizations by 44%.
- Use a confidential patient registry to ensure that all patients are receiving care consistent with established standardized guidelines.

3. The most promising opportunities to assist health care institutions in the State that have clinics for adults with sickle cell disease would be to further develop the only institution in the State that provides comprehensive services for adults with SCD, the Johns Hopkins Sickle Cell Center for Adults. Recommendations for improving and enhancing this Center are outlined above.

4. The State funding needed to improve the quality of health care and reduce mortality rates for adults diagnosed with SCD would total approximately $2.2 million in the first year, and approximately $1.9 million per year thereafter. This estimate is derived from the following approximations:

- $100,000 per year would be required to establish and operate the Statewide SCD Steering Committee
- $1,006,000 would be needed to establish the recommended day infusion center and approximately $960,000 per year would be required to operate it.
- $730,000 per year would be required to operate the case management network and the outreach/telemedicine clinics. This includes the funding required to establish and facilitate the SCD self-help support group.
- $100,000 would be required to establish the web-based provider education program and informational web site and a lesser amount would be required to manage it each year. This includes the cultural competency training and education about health disparities as well as education about the medical aspects of caring for patients with SCD.
- $250,000 initially and $50,000 per year would be required to implement both the patient registry and the remote access medical record repository.

Sources of funding for these recommendations include: the National Institutes of Health (NIH) (multiple grants), Health Services and Resources Administration (HRSA), the Commonwealth Fund, the Robert Wood Johnson Foundation, the Kellogg Foundation, and the Maryland Community Health Resources Commission.

I. Introduction

This report is the result of House Bill 851 (2006), which requires the Department of Health and Mental Hygiene (the Department) to study the status of care for adults with sickle cell disease in Maryland and to submit a one-time legislative report that includes the following:

(1) Recommendations to improve the quality of health care delivery to adults in the State who are diagnosed with sickle cell disease;

(2) Recommendations to reduce the mortality rate of adults in the State who are diagnosed with sickle cell disease;

(3) Recommendations to assist health care institutions in the State that have clinics for adults with sickle cell disease;

(4) The amount of general fund State support required to address the above-described recommendations; and

(5) Any available funding sources to improve the quality of health care delivered to adults diagnosed with sickle cell disease.

To address the above tasks, a workgroup was formed to develop this report. The workgroup included SCD patients, SCD support groups, State legislators, physicians, health department professional staff, and representatives from the Genetics Branch of the federal Maternal and Child Health Bureau. The members of the workgroup are listed in Appendix A. The workgroup held three meetings to gather information develop ideas and formulate the plan. All meetings were open to the public but the second meeting, held at Johns Hopkins, was designed to be a forum for SCD patients to express their views. The report was prepared by the Department's Office for Genetics and Children with Special Health Care Needs and the Office of Minority Health and Health Disparities.

II. Overview of Sickle Cell Disease

Description of the Disorder

Sickle cell disease (SCD) is an inherited blood disorder characterized by anemia, increased susceptibility to infection in childhood, episodes of painful blockage of the small blood vessels causing progressive organ damage, and a shortened life span. SCD is a disorder of hemoglobin, the red pigment in red blood cells. Patients with SCD make an abnormal hemoglobin (hemoglobin S). Under low oxygen conditions, the abnormal hemoglobin forms fibers within the red blood cells, distorting their shape. The deformed cells take on a crescent or "sickle" shape, and are rigid and fragile. These deformed red blood cells break easily causing anemia and they get stuck in narrow blood vessels

blocking those blood vessels. The tissues that depend on the blocked blood vessels do not get the oxygen and nutrients they need and their waste products are not removed. This causes intense pain (the painful or vaso-occlusive crisis of SCD) and tissue damage. Any organ or tissue can be affected. If a blood vessel supplying the brain is blocked, the patient may suffer a stroke. The lungs, kidneys, heart, liver, spleen, bones, eyes, and the skin in dependent parts of the body are frequent sites of damage. Chest syndrome, a vicious cycle of infection and vaso-occlusive crisis in the lung, is a frequent serious complication that can be lethal. Additional frequent serious complications include life-threatening anemia, renal insufficiency, congestive heart failure, gallstones, blindness, bone and joint damage and skin ulcers.

The course of SCD is quite variable with the most severely affected 5% of adult patients having one-third of all the painful crises. Some patients have a mild form of SCD. Over time, however, damage from repeated painful episodes accumulates. The average life span is shortened. The mean age at death for those with SCD is 42 years for men and 48 years for women, but treatment and survival are constantly improving. Patients with a mild form of SCD may have normal life spans.[1]

Treatment

There is currently no cure for most people with SCD. Bone marrow transplantation may essentially cure a fortunate few who have matched donors. However, bone marrow transplantation is not always successful and is associated with a significant risk of mortality. Fortunately, treatment can help to manage the disease by relieving pain and preventing complications. Treatment for SCD patients often includes hydration, pain management, drugs like hydroxyurea that reduce the frequency of painful episodes, antibiotics for infections and blood transfusions.

There have been dramatic advances in the treatment of SCD in children. Young children with SCD are much more susceptible to infection than children who do not have SCD. Before current treatments were in use, 5% of babies with SCD died from infection before age two years and another 5% died between ages two and 10 years. Fortunately, taking penicillin daily can prevent 84% of these infections and dramatically improve survival. New vaccines that immunize babies with SCD against the most troublesome germs further reduce the risk of life threatening infections. Babies with SCD are identified through newborn screening and receive comprehensive care from the beginning of their lives. Care is provided according to regional standardized guidelines to assure that all children receive all the essential elements of care and that the most up-to-date treatments are used. The guidelines used for children in Maryland are the *Pediatric Sickle Cell Disease Management Guidelines of the Mid-Atlantic Sickle Cell Disease Consortium* (MASCC). These guidelines are available on the Internet at www.pitt.edu/~marhgn/guide.pdf. The children are followed to age six years by the newborn screening follow-up program to assure that they are, in fact, receiving appropriate care. Third party coverage is not a major problem for young children. Approximately 80% of children from birth to age six years receive care through some form of medical assistance. Mortality among young children with SCD in Maryland is now lower than

1%. Most years there are no deaths among young children with SCD (ages one to four years) in Maryland. Maryland has the lowest mortality among young children with SCD of any state in the U.S. [2]

Unfortunately, there is no organized system of services in Maryland for adults with SCD. Many adults do not receive comprehensive care and may not be receiving the most advanced drugs or optimal management. An average of 22 adults died each year between 1999 and 2005, from causes related to SCD, a total of 155 deaths for the seven-year period. The most significant recent improvement in adult SCD management is the use of hydroxyurea. On average, hydroxyurea reduces the number of pain crises by a factor of two. Hydroxyurea also reduces the incidence of chest syndrome by approximately the same factor of two and reduces the need for transfusion by about 35%. Nonetheless, this drug is underutilized. In contrast to children, adults with SCD face major problems in obtaining and keeping third party health care coverage. Mortality among adults has not declined in the same dramatic way as has mortality among children.

Social work interventions provided by full-time certified individual, genetic counselors and psychological counselors can be key components of treating adults with SCD, as the disease is a chronic illness that can be debilitating. Vocational counseling and assistance is important because absenteeism can be related to complications in some patients. The frequent painful episodes related to vaso-occlusive crises may be associated with depression necessitating management for this condition.

III. Demographics and Characteristics of SCD Population

The State of Maryland has the sixth most diverse population in the U.S., and ethnic minorities are expected to make up the majority of the Maryland population in 2010. Moreover, according to 2005 data from the American Community Survey, Maryland ranks fourth in the nation (after Mississippi, Louisiana and Georgia) with respect to percentage of African-Americans, who are closely approaching 30% of the State's population.

High-Risk Population

SCD can affect people of any ethnic background. However, it is more common in people of African, Mediterranean, Hispanic, and Southeast Asian ancestry. African-Americans are the largest high-risk group in Maryland. Approximately 1 in 400 African-American babies is born with some form of SCD. Approximately 1 in 10 African-Americans is a carrier for an abnormal hemoglobin that could lead to some form of SCD in his or her children, if the other parent were a carrier for hemoglobin S. In Maryland, one in every 385 babies born (2000 to 2004) was affected by some form of SCD.

Number of Sickle Cell Disease Patients in Maryland

The number of adults with SCD in Maryland is difficult to ascertain. Approximately 80 babies with SCD are born in Maryland each year. Between July 1,

1985 and June 20, 2006, a total of 1,680 babies were identified through newborn screening with a sickling disorder requiring follow-up. If all patients survived to age 65 years, there would be 3,520 SCD patients over 21 years of age. However, SCD has been, and still is, associated with significant mortality in childhood and throughout adulthood. As treatment has improved, survival has also improved, so older mortality curves are not applicable. The longitudinal study of survival in SCD published in 1994 estimated that approximately one-half of the patients with SCD would survive to the age of 50 years.[3] This would suggest that 1,760 Maryland SCD patients could be expected to reach age 50 years. The Center for Health Program Development and Management (CHPDM) at the University of Maryland, Baltimore County has identified 772 adult SCD Medicaid patients in CY 2005 data.

Geographical Distribution of Maryland Sickle Cell Disease Patients

The geographical distribution of SCD patients living in the State is consistent with the distribution of the African-American population (see Appendix C). Most patients are concentrated in the two major urban areas of the State. Approximately 47.5% of the children identified through newborn screening with SCD live in the Baltimore Metro area, 47% live in the Washington Metro area, 3% live on the Eastern Shore, 2% live in Southern Maryland and 0.5% live in Western Maryland. Population distribution studies of the Maryland African-American population show a higher proportion of young children and elderly living in the Baltimore Metro area and a higher proportion of young adults and middle aged adults living in the Prince George's County-Washington Metro areas. Of those adult SCD patients enrolled in Medicaid, 42.5% live in Baltimore City, 28.1% live in the Washington Metro area, 19.3% live in Central Maryland, 5.3% live on the Eastern Shore, 3.4% live in Southern Maryland, and 1.4% live in Western Maryland (details in Appendix B).

Age and Racial Characteristics of Adult Sickle Cell Disease Patients

The Department is conducting a needs assessment through an anonymous survey of adult SCD patients and their providers in an effort to further describe this patient population and identify their needs (see Appendices D and E). However, issues related to confidentiality, HIPAA and Institutional Review Board (IRB) approval initially delayed that project. The data, therefore, will not be available in time for this report, but the data will follow when available. Aggregate data on the adult SCD patients receiving care through Medicaid are in Appendix B. Individuals who meet the income or disability requirements for Medicaid may not be representative of the general population of adults with SCD. For example, the gender distribution of adults with SCD on Medicaid appears to reflect the overall gender distribution of adults in the Medicaid program. There were approximately twice as many women (68.3%) as men (31.7%) among the SCD patients enrolled in Medicaid. As expected, the overwhelming majority the patients (90.9%) were African-American. The average age of the SCD patients was 34.9 years.

IV. Health Care Utilization and Cost Profile of Maryland Adult Sickle Cell Disease Patients

A. The Medicaid Population

Of the 772 adult patients enrolled in Medicaid, 68% (523 patients) were enrolled in HealthChoice, Maryland's Medicaid Managed Care Program, and the remaining 32% (249 patients) received Fee For Service (FFS) Medicaid. The FFS enrollees were older on the average (average age of 42.1 years) than the HealthChoice enrollees (average age of 31.4 years) (details in Appendix B). It is important to consider the differences between the FFS and HealthChoice populations. The population of patients receiving FFS Medicaid is largely composed of individuals who spend down to Medicaid because of high health care costs and individuals dually eligible for Medicaid and Medicare. Individuals in the FFS population tend to be sicker than the HealthChoice population.

HealthChoice Utilization

Managed Care Organization encounter data were used to analyze service utilization for the HealthChoice population.[4] In CY 2005, 85% of adult Medicaid SCD patients had at least one ambulatory visit. Of those patients who had an ambulatory visit, the average number was 10.5 ambulatory visits per year. Forty-six percent (46%) of HealthChoice patients had an ED visit. Of those patients who had an emergency department (ED) visit, the average number was 5.6 ED visits per year. Fifty-six percent (56%) of the HealthChoice patients had an in-patient hospital admission. Of those who had an in-patient admission, the average number of in-patient admissions was 4.5 admissions per year. The HealthChoice SCD patients had the following frequency of visits in CY 2005: 1,328 in-patient hospital admissions, 4,679 ambulatory visits, and 1,349 ED visits.

Fee For Service Expenditures

Claims data were analyzed for the FFS population. The Medicaid expenditure for the FFS cohort in CY 2005 was approximately $6 million (total funds). This does not include Medicare expenditures for dually eligible individuals. If dually eligible individuals are excluded, Medicaid expenditures per FFS patient per month were $5,886 (total funds) or $41,513 per year. Not surprisingly, in-patient hospital admissions accounted for the bulk of the expenditures, accounting for 41.7% of Medicaid FFS expenditures. Other expenditures were as follows: 16.8% for long-term care; 14.2% were for pharmacy; 11.8% were for physician services; 7.6% were for outpatient care; 5.7% were for home health services; and 2.1% were for special services.

B. The General Population

The Hospital Discharge Database of the Maryland Health Care Commission provides complementary data covering all hospital admissions for SCD, Medicaid and non-Medicaid, but it cannot distinguish individual patients, only admissions. Thus, the

data cannot distinguish between those patients who have multiple admissions in a given year and those with one.

Over the five-year period 2001 to 2005, there were 13,724 hospital admissions for SCD, with an average length of stay of 4.94 days, and a total cost of $97 million. The average cost of a hospital admission was $7,080. The average age of the patient was 34 years of age. Approximately 46% of the admissions were for patients receiving some form of managed care. Over the five year period the number of admissions increased from 2,258 in 2001 to 3,202 in 2005. The average length of stay decreased slightly from 5.5 days in 2001 to 4.9 days in 2005. The total cost of all the admissions each year increased from almost $14 million in 2001 to over $26 million in 2005.

Over the five-year period 26% of the admissions were covered by private insurance, 43.8% were covered by Medicaid (MCO and FFS), 24.7% were covered by Medicare, and 4.4% were self pay. Government insurance of some type paid for 69.1% of admissions (details in Appendix F).

Over fifty percent (52.6%) of the admissions were for patients from the Baltimore Metro area. Baltimore City and Baltimore County accounted for the largest share of admissions, with 49.2% of admissions being for patients residing in Baltimore City or Baltimore County. Approximately 30% of the admissions were for patients from the Washington DC Metro area. Twenty-one percent of the admissions were for patients residing in Prince George's County and 8% for patients residing in Montgomery County. Just over 6% of the admissions were for patients residing on the Eastern Shore, almost 3% were for patients from Southern Maryland but only 1% were patients residing in Western Maryland.

The overwhelming majority of admissions were for SCD with vaso-occlusive pain crisis. Pneumonia, hypovolemia, asthma, anemia and congestive heart failure were the next most common diagnoses, and many patients had one of these conditions in addition to SCD with crisis (details in Appendix G).

V. Requirements for Optimal Outcome in Adult Sickle Cell Disease Patients

Adults with SCD have the same requirements for a successful life as people without SCD. Most people want a decent place to live, nutritious food and adequate clothing, access to appropriate health care including necessary drugs, an opportunity to pursue personal interests, and a supportive social network. Most people need a measure of economic security through employment to achieve these things. Adults with SCD also have the additional needs that would be related to any chronic debilitating illness and some specific needs related to their diagnosis.

Adults with SCD, or any other chronic disease, need comprehensive medical care. For SCD patients this includes accessible primary care, state-of-the-art multidisciplinary specialty care, an easily accessible site with knowledgeable staff for urgent and emergency care, access to appropriate inpatient care, expert pain management,

psychosocial support, and access to other health maintenance services, such as vision, dental, and mental health services. Transportation to needed care may be an issue. Standardized treatment guidelines can help ensure that all patients receive all the needed elements of care and that the most up-to-date treatment modalities are used. Medical records need to be readily accessible to providers caring for the patient. Case management can assist the patient in navigating the system. Third party health insurance removes many economic barriers to care. Peer support groups can provide the framework for patient education and social activities. Some voluntary groups associated with some other disorders such as cystic fibrosis have started patient registries to facilitate needs assessment, provide clinical data to enhance understanding of the disorder, and to prevent patients from "falling through the cracks." Although this population has historical cause to fear discrimination and unethical research, establishing a patient registry should receive serious consideration.

In addition, there is indisputable evidence that ethnic and racial minorities in the U.S. experience disparate health care encounters and health outcomes compared to majority groups. These disparities seem to persist even when insurance, income, and other access-related factors are controlled for, as a result of prejudices and biases in the health care system.[5] African-Americans and persons from the African Diaspora have particular issues related to health disparities. Past encounters with unethical medical experimentation, such as the Tuskegee Syphilis study in which adequate treatment was withheld from poor African-Americans men with syphilis, causing needless pain and suffering, may contribute to a lack of trust in the medical system for many African-Americans.[6] Further, the Sickle Cell Anemia Control Act of 1972 was fraught with problems. It led to a flurry of states legislating sickle cell screening, some mandating screening among preschool children, those seeking marriage licenses, army recruits, job applicants, and mental and correctional institutions' inmates, leading to discrimination and stigmatization of African-Americans. Misguided, mass-screening programs took place, ignoring the family dynamics and cultural needs of African-Americans, and propagating misinformation regarding the trait and the disease.[7] Thus certain issues in particular influence health seeking behaviors of African-Americans, including socio-cultural (poverty, racism, prejudice and discrimination) and psychosocial factors (perceived health status, the lack of personal efficacy in decision-making about health care, and the lack of trust in health care providers).[8]

The above-described circumstances pose special challenges to providing culturally competent state-of-the-art care to adults with SCD. Therefore, the optimal delivery of care to SCD patients must include mechanisms such as cultural competency training for providers and SCD self-support groups designed to assist these patients in overcoming historic ethnic and racial barriers.

VI. Current Health Care Services for Adults with Sickle Cell Disease in Maryland

While Maryland has advanced the care of infants and children with SCD by supporting programs providing comprehensive care and case management, similar services are lacking for adults with SCD. The growing number of adult patients with

SCD is a natural consequence of increased survival in childhood. As young patients identified through newborn screening approach adulthood, they are referred to the Transition Clinic, which is partially supported by the Department, at Johns Hopkins Hospital to assist them in transitioning from the pediatric health care delivery system to the adult health care delivery system. However, the adult health care delivery system has few options for SCD patients.

Many qualitative studies have found that adult patients with SCD experience a lack of respect in their relations with health professionals, particularly when seeking care for vaso-occlusive pain crisis.[9] Patients have reported that they are often in conflict with providers,[10] that providers respond negatively to patients' queries about their care,[11] and that they experience long delays in being treated.[12] Some patients with SCD describe providers as being suspicious of the legitimacy of their pain and unwilling to give control over to patients. Patients with SCD also report feeling that they are treated differently than other patients, and feel neglected.[13] Perhaps as a result, one study found that behaviors such as tampering with analgesic delivery systems and disputes with hospital staff over pain medications were more likely to be associated with 'pseudo-addiction' (as a result of inadequate pain control) than actual narcotic addition.[14] Some literature suggests that when the negative factors are adequately addressed, the health seeking behavior of African-Americans mirrors that of the majority population.[15]

Because patients with SCD are mostly African-Americans, their experience may be seen in the larger context of how racial and ethnic minorities are treated in the health care system. Several studies[16] have used direct observation to examine how patient race and ethnicity influence physician interpersonal behaviors. In their interactions with African-American patients, physicians have been shown to exhibit less nonverbal attention, empathy, courtesy, and information giving[9], adopt a more "narrowly biomedical" communication style[10], and spend less time providing health education, conversing, and answering questions.[17] Physicians have also been found to be more verbally dominant and exhibit a more negative emotional tone than with Caucasian patients.[18] Education to increase awareness among health care providers caring for patients with SCD and their families about health and health care disparities, and providing culturally competent training to make them aware of patients' needs and issues pertaining to patients' cultural beliefs and community life is needed to improve care at all levels.

The unpredictable, recurrent, intense, and persistent pain associated with SCD presents difficult challenges for both patients and provider.[19] A study at Johns Hopkins Hospital (JHH) examined SCD patient's perceptions regarding levels of respect experienced in the ED when they presented for treatment of vaso-occlusive crises. In a survey of 54 adult patients upon discharge from the ED, patients generally reported receiving low levels of respect and poor pain management. A small proportion of patients reported ('all of the time') that physicians and nurses seemed to care about them as a person (19%), listened carefully to what they had to say (17%), and took their concerns seriously (13%). A substantial proportion reported ('all, 'most' or 'some of the time') that their physicians and nurses had a negative attitude towards them (63%), made

them feel inferior (74%), made them feel as if they were not welcome (65%), and behaved rudely towards them (50%). Only 34% of patients reported timely receipt of pain medication and 48% reported that ineffective medication was changed.

Patient experience of respect and pain management quality were not significantly related to patient age, sex, or employment status; however, patients seen more frequently in the ED reported less respect (mean respect scores 74.1, 62.7, and 54.6 for patients seen <5 times/year, 5-15 times/year, and >15 times per year respectively, p=0.04). Patients who experienced lower respect also reported poorer pain management quality. Compared to patients who reported timely receipt of and changes in ineffective medication, patients who reported delays in receipt and no change in ineffective medication had lower respect scores (mean 71.9 vs. 53.9, p=0.001 for timely vs. delayed; 65.6 vs. 53.7 for change vs. no change). Given the prior published data the experiences of patients seen in JHH ED are unlikely to be isolated, and probably reflect the care that patients receive in most of the EDs that they visit. This study demonstrates that interventions are needed to improve the experiences of adult patients with SCD who present with vaso-occlusive crises.

In the last decade the number of hospital admissions and the cost of care for adults with SCD have increased significantly in Maryland. The cost of care for adults with SCD in Fiscal Year 2003 was 60% higher than Fiscal Year 1995 costs even after adjusting for inflation. It is likely that this cost has increased due to the lack of availability of specialty care for adults with SCD. Model programs in other states have seen the rate of hospitalization decrease over the last decade, due to the development of day infusion centers that treat patients with crises as outpatients.[20] In Maryland, no such day infusion center exists.

Health Care Institutions in the State that Have Clinics for Adults Diagnosed with Sickle Cell Disease

The Sickle Cell Center for Adults at Johns Hopkins is the only facility in the State of Maryland dedicated to providing comprehensive services for adults with SCD. The Center serves those who live in the greater metropolitan Baltimore and Washington, D.C. areas. However, it is clearly more easily accessed by patients in the greater Baltimore Metro area. Approximately 40% of SCD patients reside in the Washington DC Metro area. Howard University Hospital provides care for some adult SCD patients in that area and could be a future potential partner. At present, however, SCD patients at Howard are cared for under the auspices of Medical Oncology. Some patients with SCD are served by other institutions such as the University of Maryland Medical Center, Sinai Hospital of Baltimore and the Life Bridge Health System, as well as some private providers. However, none of these institutions has a clinic, unit, or program specifically devoted to adult patients with SCD.

Sickle Cell Center for Adults at Johns Hopkins

The Sickle Cell Center for Adults at Johns Hopkins is solely dedicated to providing comprehensive services for adults with SCD. The Center seeks to improve the

lives of patients by providing specialized care and patient education, and by supporting research on the best treatment options.

The goal of the Center's multidisciplinary staff, which includes a full-time hematologist, a full-time physician's assistant and a part-time social work student, is to provide care for patients at multiple levels. The Center provides comprehensive outpatient services for adults twice per week, including screening for the appropriateness of hydroxyurea therapy, genetic counseling, pain management, education, wound care, and social services. Each patient is provided with a copy of Hope and Destiny: A Patient's and Parent's Guide to Sickle Cell Disease and Sickle Cell Trait by Allen Platt, Jr., PA-C and Alan Sacerdote, MD. Hope and Destiny is considered the definitive layman's guide to SCD and is the only in-depth resource written specifically for patients and their families. Monthly patient support groups and a quarterly newsletter for all patients provide additional opportunities for patient education. Patients admitted to the JHH are followed by Center staff for continuity of care. The Center collaborates with the ED so that patients in sickle crisis are seen and treated promptly.

This comprehensive approach has led to a decrease in length of stay for patients with SCD at JHH and decreased waiting times in the ED. The Center serves approximately 250 patients. The Center hosts the Transition Clinic for young adults moving from pediatric to adult providers. The Transition Clinic is staffed by both pediatric and adult providers to provide continuity and insure a medical home. In 2005, the Transition Clinic provided 75 visits to 34 patients between the ages of 19 and 25 years, and welcomed 13 new patients.

Studies have shown that comprehensive care is more cost effective than episodic care. One study in particular showed that patients using a comprehensive clinic had fewer emergency room visits, fewer hospital admissions, shorter lengths of stay and lower annual costs per patient. The cost per patient for comprehensive clinic patients was $5,315, compared to $12,431 for patients not using the comprehensive clinic.[21] The Sickle Cell Center for Adults at Johns Hopkins has made an excellent start. There are a number of well-established comprehensive Sickle Cell Disease Centers in the United States that could serve as models for the further development of the Center at Johns Hopkins. These centers are at Emory University/Grady Hospital, Medical College of Georgia, Montefiore Hospital/Albert Einstein, University of Illinois at Chicago, University of South Alabama, University of Cincinnati, and Truman Medical Center at Kansas City. Some, but not all, of these centers are part of an NIH funded Comprehensive Sickle Cell Disease Center. There are currently 10 such centers and in the past the NIH considered research to be the major emphasis of the centers. However, each of these federally funded Centers has a clinical component. These centers have a variety of services not yet available at the Johns Hopkins Center. These services include sophisticated reference and research laboratories, extensive professional and public education programs, secondary education and job training programs for patients, expanded psychosocial support services, outreach and telemedicine clinics, and most importantly a day hospital/day management center/infusion center. (See Appendix H for more information on adult SCD model programs.)

The day infusion center concept was developed to provide timely and appropriate treatment of pain crises in a comfortable setting without the need to admit the patient to the hospital. Care in this setting is delivered by staff knowledgeable about SCD and is instituted more quickly than in the ED. Treatment with IV hydration and analgesia is instituted in this setting when homecare with oral hydration and medications had not been effective. Day infusion centers have been very successful at providing effective treatment of uncomplicated pain crises, averting hospital admissions, decreasing length of stay for patients who are admitted, and saving money. In the U.S and U.K., painful crises account for 80-90% of hospital admissions for SCD and the average length of stay is 5-11 days. Approximately 43% of patients presenting to the ED with uncomplicated pain crises are admitted from the ED. When patients are treated in a day center, only 8.3% to 16% are admitted to the hospital (8.3% at Montifiore Hospital in the Bronx, NY, 8.8% in Kingston, Jamaica, and 16% at Birmingham, UK). Birmingham reports an overall decrease in hospital admissions for SCD of approximately 43% and a 49% decrease in length of stay. Montifiore Hospital reports a 40% decrease in admissions from both the ED and day center combined, over the prior ED admission rate. Length of stay at Montifiore Hospital decreased by 1.5 days. The reduction of admissions and decrease in length of stay at Montefiore represented a savings of approximately $1.7 million. [22] The Sickle Cell Center for Adults at Johns Hopkins does not have a day center.

Carrier Screening

Hemoglobin screening to identify carriers of SCD and other hemoglobin disorders is available free of charge from the State Public Health Laboratory. Occasionally individuals with SCD are identified in the course of carrier screening. Any person desiring carrier screening should ask his physician or local health department to send a specimen to the Public Health Laboratory. Approximately 12,000 individuals receive screening each year. (The Department also provides newborn screening and six years of follow-up case management for children with SCD.)

Genetic Counseling

Genetic counseling for any disorder, for individuals of any age, is available through the Maryland Genetics Network, which is partially supported by the Department. The Genetic Centers in the network include Johns Hopkins, the University of Maryland and Children's National Medical Center. Together the Genetics Centers provide outreach clinics at 14 sites around the State (list in Appendix I).

Support Groups

Unfortunately, Maryland currently does not have any Statewide, independent, community-based SCD organizations providing support groups and education. Maryland has had a number of such groups in the past (The Central Committee for Sickle Cell Anemia, ASSERT, the Maryland Chapter of the Sickle Cell Disease Association of America, the Sickle Cell Connection operating from Bon Secours Hospital, and the

Chesapeake Family Sickle Cell Support Group sponsored by the Baltimore Rh Testing Laboratory-BRT); however, none are active at present.

There are support groups sponsored by Johns Hopkins for adults and children with SCD and their families. Children's National Medical Center in Washington, DC also has an active support group for pediatric patients and many Maryland families of young children living in the Washington, DC metro area belong to this group.

There are two small local support groups operating in Maryland—one serving Harford and Cecil Counties and one in Howard County. There is a Harford/Cecil County Chapter for Sickle Cell Anemia America. Their major events are a yearly proclamation of a Sickle Cell Day in Aberdeen in May, and a Walk-A-Thon and Golf Tournament to raise funds. The Lauren D. Beck Foundation operates in Howard County and concentrates on public education about SCD and providing screening at local events. (See Appendix J for contact information).

Although the headquarters of the Sickle Cell Disease Association of America is in Baltimore, there is no Maryland chapter of this national organization. Mr. Benjamin Joseph and Mr. Derek Robertson are currently trying to start a new chapter of the Sickle Cell Disease Association of America (see Appendix J for contact information). Mr. Joseph has made a presentation to the Adult Sickle Cell Support Group at Johns Hopkins and both Mr. Joseph and Mr. Robertson attended the Annual Sickle Cell Disease Picnic, co-sponsored by the Department and the Johns Hopkins Division of Pediatric Hematology, on September16, 2006. The picnic was originally organized for children with SCD and their families, but it is open to patients of any age.

VII. Recommendations

A. Recommendations on Health Care Quality and Delivery, Mortality Rate Reductions, and Adult Sickle Cell Clinic Assistance

The strategies in this section focus on addressing the unmet needs of the SCD community with a comprehensive, multi-disciplinary approach. These strategies reflect recommendations for: (1) improving the quality of health care and health care delivery; (2) reducing the mortality rate; and (3) assisting health care institutions that have clinics for adults with SCD.

One promising opportunity for improving the quality of health care and health care delivery for adult patients with SCD is to establish a Statewide Steering Committee of all stakeholders to assure that services are developed in such a way that they truly serve the community and are used in the following ways:

- To promote a patient-centered service model.
- To foster community and institutional partnerships.
- To increase the cultural competence of providers.

- To increase provider awareness of health disparities, community dynamics, cultural practices and behavioral and psychosocial issues.
- To promote public and consumer education about SCD.
- To ensure that patients and the community know about the opportunities for care.

The clinical medical strategies most likely to improve the quality of health care and health care delivery for adult patients with SCD are to further develop the State's only comprehensive SCD treatment center, to promote the use of standardized treatment guidelines, hydroxyurea monitoring protocols, and emergency room protocols, to provide SCD specific education and support to the State's primary care providers, and to pursue strategies to bring the benefits of the comprehensive treatment center to patients and physicians in other areas of the State.

The most promising opportunities to reduce mortality among adults with SCD include improving the quality of care as a whole, educating providers about the use of hydroxyurea, and using a patient registry to assure that all patients are receiving care consistent with established standardized guidelines.

1. Establish a Statewide Steering Committee on Services for Adults with SCD.

Recommendation

Create a Statewide Steering Committee to engage all stakeholders in SCD management to include the following: local and national SCD advocates, interest and support groups such as the Sickle Cell Disease Association of America; the Genetic Alliance; faith-based organizations; community and consumer groups; and representatives from academic and private clinical settings caring for adults with SCD. Moreover, since 40% of SCD patients reside in the Washington DC Metro area, it is imperative that providers for SCD patients at Howard University Hospital (now under the auspices of Medical Oncology) be involved in the Steering Committee, as well as other area hospitals caring for patients with SCD including the University of Maryland in Baltimore, Sinai Hospital of Baltimore, Bon Secours Hospital and the LifeBridge Health System. Pediatric clinics will also be included because of the need to assure smooth patient transition to adult care.

The Steering Committee would foster institution and community partnerships as well as establish a Statewide network of stakeholders in caring for adults with SCD. The Steering Committee would develop a client-centered interventions model taking into account the experience, preferences, and needs of patients to be served.

Rationale

The Institute of Medicine publication *Crossing the Quality Chasm: a New Health System for the 21st Century* reaffirms that patient-centeredness is a crucial component of medical quality and must be based on patients' preferences, needs, and values.[23] Further, the best medical services will not benefit patients if they do not use them. Services are more likely to be used if the community takes ownership of them, if the services are

physically and culturally accessible, and if the patients feel valued and empowered to direct their own care. In addition, the patients and community must know about the services available.

2. Further Develop Maryland's Only Adult Sickle Cell Disease Treatment Center

Recommendation

Further developing the Sickle Cell Center for Adults at Johns Hopkins would improve the quality of health care and health care delivery. The first enhancement for the Sickle Cell Center for Adults at Johns Hopkins should be a day infusion center. Patients will receive better care when the Center meets its long-term goal of modeling the Center after those in Atlanta and the Bronx. These model centers have day infusion centers in addition to sophisticated reference and research laboratories, extensive professional and public education programs, nutrition counseling, expanded mental health and psychosocial support services, outreach and telemedicine clinics, and secondary education and job training programs for patients. A dedicated SCD day infusion center meets patients' needs in a single treatment area that offers rapid assessment and treatment of pain, medical care and social support. These centers circumvent the ED and employ full-time social workers and counselors to help patients deal with and learn about their chronic illness. The appropriate use of a day infusion center reduces hospital admissions by 43% and reduces length of stay by 49%. In addition, patients much prefer the supportive atmosphere of the day center to the ED where they must wait much longer for treatment. These programs have demonstrated significant cost savings (for example, $1.7 million for the program in the Bronx).

The use of a day center does not reduce the number of patients presenting for evaluation and treatment of acute pain crisis. (However, it is hoped that increased utilization of hydroxyurea will decrease the number and frequency of pain crises and thus both day center and ED visits.) The patients merely present to the day center instead of the ED. However, the cost per visit to the day center is lower than the cost per visit to the ED. It should be noted that the cost of hospital admissions and any projected savings from reduced hospital admissions do not include the ED or day center costs for patients not admitted.

The proposed sickle day infusion center would provide services for up to four patients who are suffering from a vaso-occlusive pain crisis. Patients would be able to present to the center when having a crisis, and be quickly triaged and evaluated by a nurse and a physician's assistant. They would then receive hydration, oxygen, narcotic therapy, and careful monitoring. Patients would be re-evaluated for response to treatment every 15-30 minutes. In order to staff the day center adequately, Johns Hopkins would need to hire an additional physician experienced in pain management, a physician extender (nurse practitioner or physician's assistant), a full-time registered nurse, a full-time licensed social worker and a clinic coordinator/data manager. A licensed clinical psychologist, a board-eligible/certified genetic counselor, a health educator and a

community outreach worker would be shared with the outreach network (see Recommendation 11).

Back-up genetic counseling services at the center are available from the McKusick/Nathans Institute. Back-up genetic counseling services for the outreach network are available through the outreach genetics clinics of the Maryland Genetics Network. (The Department already provides grant funding to partially support these genetic services.) Since some patients with SCD have increased energy requirements and frequently have gallbladder disease, achieving optimal nutrition is a challenge. A part-time nutritionist is needed for inpatients, outpatients, and for consultation with patients and providers in the community. One physician's assistant, a part-time resource/social worker, and some faculty support are already available.

Future enhancements should include expansion of mental health services, nutrition counseling, expansion of the program for patient and family education about SCD (see recommendation 8), and the establishment of secondary education and job training programs for patients. As funding becomes available the center's hours should be extended to include weekend operation. When funding becomes available, child care services, transportation vouchers, and nutritional meals should be provided on site. These service enhancements would complement the establishment of the day infusion center as described above. The Center should also coordinate with the self-help support group described in recommendation 7.

It should be noted that all of the model centers began with support from State funds, in the amount of approximately $1.5 million.

Rationale

The Sickle Cell Center for Adults at Johns Hopkins has long hoped to establish a sickle cell day infusion center to offer their adult patients more rapid, standardized treatment for their crises, in an effort to resolve pain faster and decrease admissions to the hospital. Currently, the waiting time for patients with SCD in the Johns Hopkins ED is on average 2.5 hours, and patients suffer while waiting for therapy. At Johns Hopkins over 50% of the patients seen in the ED are admitted to the hospital.

Other adult sickle cell programs (Bronx, NY, Atlanta, GA, Birmingham-UK) have documented that a day infusion center can decrease hospital admissions by approximately 40% and reduce length of stay for those patients that are admitted. The best and most detailed data comes from Montefiore Hospital in the Bronx, N.Y. If Maryland experiences a similar decrease in hospital admissions and length of stay, there could be significant savings to Medicaid. Since Medicaid expenditure for inpatient care for FFS SCD patients in CY 2005 was almost $2.5 million, a day infusion center could potentially save Medicaid as much as $996,847 in inpatient costs. However, it should be noted that Maryland already has a shorter length of stay than Montefiore (4.94 days vs. 7.80 days) and a lower cost per hospital admission due to Maryland's unique all payer system. In addition, the data from Montefiore and Maryland do not reflect the same

years. These factors make it difficult to more exactly calculate the potential savings for Maryland.

A proposed budget for setting up a day infusion center is in Appendix L. The projected cost of setting up the infusion center is $1 million. Since the Hospital Cost Review Commission (HSCRC) fixes the hospital outpatient facility rates and allows hospitals to include start up costs for new services, some start up costs may be recovered by the institution. This would allow for some cost sharing by payers other than the State. This possibility should be explored with HSCRC.

Since some costs are one-time and some equipment will last for a number of years, the cost to maintain the center in the second year is projected to be approximately $960,000, although the cost of operating the center will increase over time with inflation. The day center at Montefiore, once established, was able to bill enough to cover approximately 86% of their costs. The rates set by the HSCRC may allow the proposed center at Johns Hopkins to also eventually cover a significant fraction of ongoing operating costs.

The State has limited assistance to offer to Johns Hopkins. The most direct assistance would be financial. As noted all the model centers in other states receive financial support from state government. When interviewed all centers indicate that they could never have gotten started and could not continue operating without some state support. State support is required to apply for funds from some grant makers and state funding makes it easier to get grants from others. Many of the model centers now bring in significant grant support. The average state grant received by the model centers is approximately $1.5 million. A State grant may, in part, be offset if the expected savings from decreasing hospital admissions and length of stay are realized.

3. Educating Providers about Hydroxyurea

Recommendation

Providers should be educated about the use of hydroxyurea to treat SCD patients. While hydroxyurea therapy is not appropriate for every patient, clearly the education of community-based hematologists and primary care providers about the appropriate use of hydroxyurea would help decrease mortality and morbidity and save money. There is little cost associated with promoting the appropriate use of hydroxyurea once a provider education program has been established.

Rationale

The use of hydroxyurea has been shown to reduce mortality by approximately 40%, the frequency of painful crises by almost 50%, the frequency of chest syndrome by approximately 50%, the need for transfusion by approximately 35%, hospitalizations by 44%, and it probably also reduces the occurrence and/or recurrence of stroke (at least in children).[24] The use of hydroxyurea is also cost-effective despite the expenses of closely monitoring the patients because decreasing pain crises decreases ED use and hospital admissions. A study by Johns Hopkins investigators showed that the mean annual cost

per patient on hydroxyurea was $12,160 compared to $17,290 for patients not on hydroxyurea, a savings of $5,130 per patient per year, yet this drug is underutilized.[25] In one hospital, 70% of the patients eligible for hydroxyurea therapy were not receiving the drug and studies have shown that hematologists not practicing in the academic setting did not know the indications for hydroxyurea use.[26] The indications for the use of hydroxyurea and standard protocols to monitor patients on hydroxyurea should be put on an educational web site to be downloaded by providers as needed.

4. Promote the Use of Standardized Treatment Guidelines and Emergency Room Protocols.

Recommendation

Standardized treatment guidelines should be used to manage patients with SCD. The use of standardized protocols, such as those available from the Sickle Cell Disease Branch, National Heart, Lung and Blood Institute at NIH and the Agency for Health Care Policy and Research at the U.S. Department of Health and Human Services (HSS), will not only contribute to the confidence with which primary care providers approach SCD patients, but will also improve the quality of care. The use of standardized guidelines will also help to ensure that all patients receive all the needed elements of care and that the most up-to-date treatment methods are used.

Rationale

The use of standardized ED assessment and treatment protocols should allow SCD patients presenting to the ED to be rapidly assessed and have appropriate treatment started quickly. Proper use of the ED protocols should increase the confidence level with which EDs utilize narcotics for pain control and decrease the percentage of patients admitted to the hospital.

The use of standardized guidelines has been very helpful in ensuring the quality of care for children with SCD in Maryland. Several national agencies (the Sickle Cell Disease Branch, National Heart, Lung and Blood Institute at NIH and the Agency for Health Care Policy and Research at HSS) have issued treatment guidelines for adult patients. The Sickle Cell Adult Provider Network (SCAPN) was formed in 2002 by a group of experienced providers of SCD care to adults, to share information on difficult clinical issues, research priorities, and advocacy. SCAPN is also working on guidelines for care (see Appendix J for their contact information). Using one of these sets of guidelines and educating primary care providers about the use of the guidelines in managing their patients can help to assure that all patients receive the necessary elements of care and that the most up-to-date treatment modalities are available to all patients. Guidelines and ED protocols should be easily accessible on the Internet.

5. Ensure the Availability of Primary Care by Supporting Primary Care Providers

Recommendation

Supporting primary care providers would ensure the availability of primary care, because SCD patients have the same needs regardless of where they live. SCD patients

need both primary and specialty care, as well as a place where they are known, with knowledgeable staff for urgent and emergency care, where they can receive the type of care delivered in a day infusion center, as well as access to appropriate inpatient care. However, many primary care providers are reluctant to take patients with SCD into their practices.

Rationale

Finding primary care providers willing to take SCD patients into their practices is a challenge. The American Jobs Creation Act, PL108-357, which passed in 2004, authorized a Sickle Cell Treatment Demonstration Program (SCTDP). Consequently, the Genetic Services Branch, Maternal and Child Health Bureau, HRSA, issued a Request For Applications (RFA) for Sickle Cell Treatment Demonstration Programs in the spring of 2006. Eligible applicants were required to be Federally Qualified Health Centers (FQHCs), non-profit hospitals, clinics, or university health centers that provide primary care for patients with SCD. Furthermore, these FQHCs or "FQHC look alikes" are required to have partnerships with a community-based SCD organization, various State public health agencies, and a comprehensive SCD treatment center that is not funded by the NIH. Dr. Sophie Lanzkron (JHH) and Dr. Susan Panny (the Department) attempted to identify an FQHC that would partner with JHH and the Department to apply for funding.

Although every FQHC in Maryland and many "FQHC look-alikes" were approached, none were willing to take on the responsibility for providing primary care for a significant population of SCD patients. Although individual physicians from the FQHCs were interested, the administrative officers were unwilling to participate due to fiscal concerns. They stated that the FQHCs could not afford to take on additional SCD patients because they are too expensive and that the proper care of such patients is so labor intensive that they require too large a commitment of health professional time. In addition, they were concerned about possible issues with narcotics, the burden of providing acute care 24/7 for patients with frequent pain crises, and with issues relating to non-compliance on the part of patients. Many adults with SCD report that they have difficulty finding knowledgeable primary care providers. The Department sent a needs assessment to providers, which may identify additional barriers that prevent providers from being willing to accept more patients with SCD.

Several strategies were considered for supporting primary care providers. These strategies included establishing a physician education program, providing ED assessment and treatment protocols, establishing a 24/7 on-call consultant service that a community provider can call for a telephone consult about a difficult clinical situation, establishing a network of physician's assistants and nurse practitioners to provide case management, enhancing the support available from home health agencies, establishing a confidential patient registry with a secure but centrally accessible repository for an abbreviated medical record for each patient, providing patients with an abbreviated medical record "passport" to carry with them, establishing outreach clinics to provide hands-on subspecialty consultation in the community, and partnering with local community hospital EDs to create mini-day infusion sites around the State.

6. Establish an Educational Program for Providers

Recommendation

It is strongly recommended that an ongoing educational program be established for providers. This program should encompass clinical medical education as well as cultural competence and health disparities education. Providers who are confident that they have the knowledge needed to properly manage adult patients with SCD will be more willing to accept additional SCD patients. The Department further recommends the development of Web-based tutorials that can be studied at the individual provider's pace and convenience for Continuing Medical Education (CME) credit. Standardized treatment guidelines, including guidelines for hydroxyurea use, and emergency protocols should be easily accessible on the web site. Services available for providers and their patients should also be publicized on the web site.

The provider education program should also include education to increase awareness among health care providers caring for patients with SCD and their families about health and health care disparities, and provide culturally competent training to promote provider awareness of patients' needs and issues pertaining to patients' cultural beliefs and community life.

Rationale

A clinical provider education program is needed to inform community providers of the availability of standardized treatment guidelines and emergency treatment protocols, about the appropriate use of hydroxyurea, and about the services available to them and their SCD patients. The educational program must include the ability to award CME credits. Web-based tutorials are likely to be well accepted (most medical specialties offer CME credits on the Internet). Emergency department physicians, nurses, and other staff should also be included with tutorials on rapid assessment of the SCD patient and optimal ED protocols.

The standardized management guidelines, standard ED protocols, and other educational materials should be posted on an easily accessible and well-publicized web site. The Sickle Cell Center for Adults at Johns Hopkins should manage the web site and post its newsletter on the site.

A cultural competence, health disparities awareness program is needed to ensure that services provided are culturally appropriate and acceptable to patients and the community. As stated earlier, in Maryland, the vast majority of patients with SCD are African-American, and a large proportion of them are Medicaid recipients. The medical literature illustrates that African-American patients are more likely than other patients to be discriminated against and stereotyped during the medical encounter and thus not have their needs fully met. The nature of SCD further compounds this situation. For example, SCD complications include unpredictable and extremely painful episodes related to vaso-occlusive crisis. It is well documented that providers tend to view patients, especially those with repeated episodes, as exhibiting "drug-seeking" behavior,

or being aggressive and manipulative.[27] Thus increasing the understanding among providers of patients' needs and preferences is key to improving the quality of care for these patients.

Lastly, a study done in 1994 ascertained that materials about patient behavior and psychosocial issues as opposed to those about the disease and treatment tend to either be unavailable, or not as well sought after as materials about disease and treatment.[28] Education to providers about social and behavioral issues pertaining to SCD is therefore paramount.

7. Develop a Self-Help Support Group for Adults with SCD

Recommendation

As noted, Maryland does not currently have a Statewide independent community-based support group for adults with SCD, although there are several individuals working to start such a group. The support group should be developed in consultation with the Genetic Alliance based in Washington, DC. The support group should be run by a certified psychologist knowledgeable about the needs of SCD patients, and the operations of patient support group. The support group should also be staffed by a full-time certified social worker and a board-certified genetic counselor. Such a group should deal with life skills, self-sufficiency and independent living as well as mental health wellness issues.

Rationale

SCD is a chronic disorder that can be debilitating for patients and their family members. Affected individuals may have issues related to depression, reduced sense of self-worth, lack of personal efficacy in medical decision making, issues related to employment stability, family dynamics, and stressed financial resources.

8. Provide Outreach Education to Patients, Family Members, and Community Groups about SCD

Recommendation

Provide outreach education to consumers, family members, and community groups about SCD, its significance, logistics, and intervention opportunities. Engage in marketing efforts and community education to advertise State initiatives in SCD through Public Service Announcements (PSAs) and other advertisement campaigns.

Rationale

Educational initiatives are paramount for a successful health promotion program for SCD patients. Many educational materials have already been developed for SCD and are available through national repositories such as the federal Maternal and Child Health Educational Clearing House, the March of Dimes, the Sickle Cell Association of America, and others. An evaluation of existing materials and a needs assessment for new materials should take place. Repositories of materials for different audiences, with age, linguistic, and literacy needs should be searched. Educational materials such as brochures, flyers, and interactive audiovisual media should be made available to patients

and their family members. Education should include issues pertaining to testing, diagnosis, and treatment, social and physical aspects of the disease, interventions, and resources available.

9. Establish a Case Management Network

Recommendation

A case management network should be established to assist patients and support primary care physicians Statewide, in order to navigate the system and obtain all the needed elements of care. A staff of several physician's assistants or nurse practitioners, stationed around the State, and able to travel within their catchment areas, would assist patients in navigating the system and accessing recommended care, and address issues of compliance. The adequacy of care will be measured against the standardized treatment guidelines. The case management staff would also provide phone and on-site consultation to primary care providers and EDs. In time, the case management staff could form partnerships with local community hospitals to establish a series of mini day infusion centers that would operate only when a patient presented. The case management network would also staff the self-help support group described in recommendation 7. Costs associated with this recommendation are primarily staff salaries and travel expenses.

Rationale

Standardized case management and home visiting have been extremely helpful in ensuring the adequacy of care for children with SCD in Maryland. Approximately 25 years ago, there was a system of nurse practitioner case management for adult SCD patients in the Baltimore area. This was directed by Dr. Samuel Charache of Johns Hopkins Hospital. At that time there were a significant number of adult SCD patients being managed at several facilities, including Johns Hopkins, the University of Maryland, Provident Hospital, Lutheran Hospital, Bon Secours, Sinai Hospital, and the Garwin Medical Center. A single full-time nurse practitioner and a part-time social worker provided case management, conducted home visiting, and attended clinics with patients being followed at all these institutions. The nurse practitioner worked closely with the voluntary support groups active at that time (ASSERT and the Central Committee for Sickle Cell Anemia). The loss of this program, when grant funding ended, was a significant loss to patients.

Since approximately 40% of the population of patients with SCD now resides in the Washington, DC Metro area and almost 10% of the population resides on the Eastern Shore or Southern Maryland, a case management network must serve these areas as well as the Baltimore Metro area. A network of three physician's assistants or specialized nurse practitioners, a licensed social worker, and a licensed clinical psychologist/drug counselor operating in the community with the support of the staff of the Johns Hopkins Center (expert hematologist, pain management specialist, pharmacist, nutritionist) could provide case management for patients not residing within practical reach of the Center at Johns Hopkins. A board-certified/eligible genetic counselor, a health educator and a community outreach worker would be shared with the Center. The case management

team could form partnerships with the Mental Hygiene Administration within the Department, and the Maryland Genetics Network supported by the Office for Genetics and Children with Special Health Care Needs in the Department's Family Health Administration. Back-up genetic counseling could be provided at the 14 existing genetics outreach clinic sites to augment the efforts of the single genetic counselor attached to the outreach case management team. In addition, the case management network could partner with home health agencies. Eastern Virginia has found such a partnership to be cost effective.

10. Establish an On-Call Consultant Service

Recommendation

A 24/7 on-call consultant service should be established. A provider knowledgeable about the acute management of SCD should always be available by phone for consultation. This would be a two-tiered system with the first on-call provider being a case management network nurse practitioner, physician's assistant, or the hematology fellow on-call at a university teaching hospital. An attending hematologist would provide back-up and expert consultation to the first-tier respondent at need. There is little or no extra cost associated with this service.

Rationale

Several of the model programs have on-call consultant services, and it has been very successful in supporting pediatric SCD management in Maryland. A provider knowledgeable about the acute management of SCD is always available by telephone. Knowing that there is always an expert available for a consult often gives primary care providers the confidence to manage difficult patients. Furthermore, the two-tiered system expands the ability of a very small number of expert adult hematologists to serve the entire state 24/7.

11. Establish Outreach Clinics and Telemedicine Clinics

Recommendation

Establishing a network of outreach and telemedicine clinics would complement the outreach case management network and enable the Center at Johns Hopkins to provide specialty care to adult patients with SCD living in the outlying areas of the State and support local primary care providers. Outreach clinics require a host site and a team of providers who travel from the Center to the outreach site. In other outreach clinic networks in the State, the outreach clinics have been hosted by local health departments, community hospitals, and private practice offices. Host sites are not compensated for the use of their space. The costs associated with outreach clinics are primarily staff time and travel expenses. Telemedicine clinics will be used to supplement, not replace, in-person, patient and provider encounters in the community.

Rationale

Telemedicine clinics have been used to supplement on-site outreach clinics in other States. The use of telemedicine saves staff travel time and increases the

productivity of the consultants. Many local health departments and community hospitals already have facilities for telemedicine. Partnership with other State entities already operating a telemedicine system would also conserve costs. While the infrastructure for telemedicine exists and the outreach network staff would be available at no additional cost, the actual impact of professional fees charged for the telemedicine clinic visits on third party payers needs further analysis.

An outreach clinic network has been extremely helpful in providing genetic services to the outlying areas of the State. Those same clinic sites were used to host outreach SCD clinics for infants and children when they were needed at the inception of newborn screening for SCD. As the pediatric provider community became more comfortable in managing these patients, the demand for those particular clinics declined. A network of outreach clinics could make it possible for the Center to provide specialty care to adult patients with SCD living in the outlying areas of the State. This would be a support to local primary care providers. As noted, SCD patients in the outlying areas of the State could receive genetic counseling at the outreach genetics clinics.

Outreach clinics require a host site and a team of providers who travel from the Center to the outreach site. Local specialty providers, if any, are always invited to participate in the outreach clinics. For example, the neonatal geneticist at Frederick Memorial Hospital regularly participates in the outreach genetics clinic in Frederick, staffed by the University of Maryland. The outreach clinics of the Maryland Genetics Network have been hosted by local health departments, community hospitals, and the offices of private practices. No host site has been compensated for the use of their space. Depending on the local resources, some host sites have been able to provide nursing assistance, scheduling, clinic coordination, transportation for patients, and recruitment of patients. Others have only been able to provide a contact person, while all the other arrangements have to be handled by the Center (coordinating a clinic remotely from a central location is labor intensive). The outreach clinics utilize local laboratory, imaging, and other available services on a fee for service basis. When a patient requires a trip to the Center for special studies or an in-patient stay, the outreach clinic team coordinates the work-up or admission.

All of the model programs in other states serve a catchment area surrounding their centers. None are able to provide services on the same scale to an entire state. Several of the model programs, notably the Medical College of Georgia, utilize outreach clinics to provide services to SCD patients who do not live close to the centers. Recently, telemedicine has enhanced the ability of centers to provide services to outlying areas. The Medical College of Georgia has had considerable success with telemedicine clinics. The telemedicine clinics were used to supplement on-site outreach clinics. The Medical College of Georgia Sickle Cell Center serves 1,200 SCD patients in central and southern Georgia, including 533 patients in the Augusta metropolitan area. Patient satisfaction with telemedicine clinics was high as demonstrated using standardized Client Satisfaction Questionnaires. Patients utilizing telemedicine tended to be younger and to be on hydroxyurea. Their only concern was confidentiality. The use of telemedicine increased the Medical College of Georgia adult SCD clinic's capacity to serve SCD patients by

34%, from 1413 encounters per year to 1889 encounters per year. Rural outreach contacts increased 2.75 fold, from 271 to 745. This expansion of service required the addition of only a single physician's assistant to the Center staff. [29]

The needs of patients not residing near the Johns Hopkins Center can be met in part through outreach clinics, telemedicine, and primary care physician and local ED education. However, these patients would not have the advantage of the day infusion center. If the outreach clinic network were to seek community hospitals as host sites, some of them might be willing to work with the physician's assistants of the case management network to use space at their EDs or other facilities as a day infusion center. The local ED could be well prepared in advance with standardized protocols. The ED staff could be relieved of much of the management of the patient in pain crisis by the physician assistants, and if necessary, be in frequent telephone contact with the physician assistant for further pain management consultation. The result would be a network of mini-day infusion centers that only operate when there is a patient in need. This would obviously require a great deal of negotiation with the Maryland Hospital Association, accrediting bodies, individual local hospitals, and the development of an atmosphere of professional trust and collaboration between the Center, the case management network personnel, and the hospitals.

12. Assure Access to the Medical Record

Recommendation

Access to medical records could be supported by the development of a Web-based repository for an abbreviated electronic medical record for each patient. The repository should also provide laboratory information on the patient.

Rationale

This would simplify providing care, no matter where the patient presented. This would be especially helpful for those patients who seek services at a number of different facilities. Any verifiable provider treating the patient could access the patient's medical record. Improvements in encryption technology and increasing experience with electronic medical records should make a secure Web-based system possible. In addition, many patients have stated that they would find a letter, ID card, or a "medical passport" containing some core information from their medical record helpful in introducing themselves to the providers at whatever facility they may access. This would save time in verifying that the patient does indeed have SCD and help avoid the unpleasantness of being suspected of being a drug addict seeking drugs under false pretenses. Providing laboratory information on usual laboratory values would also be very helpful in assessing the patient and identifying the analgesics that have been the most successful for the individual patient facilitates rapid treatment.

In the mid-1990s, North Carolina developed a central computerized system to maintain an abbreviated medical record on all SCD patients to simplify care, no matter where the patient presented. Both providers and patients found it extremely helpful.

13. Promote Access to Existing Third Party Health Care Coverage

Recommendation

Maryland Medicaid has a program which could be helpful in breaking the cycle of patients who work, thereby losing eligibility for State or federal health care coverage, having their health deteriorate because of inability to pay for care, and then losing their jobs. The Employed Individuals with Disabilities (EID) Program allows employed individuals with disabilities to "buy in" to FFS Medicaid for a premium of $75 for six full months of coverage. Efforts should be made to publicize this program to SCD patients and the social work professionals who work with these patients.

Rationale

Third party coverage for health care is necessary but not sufficient to assure access to needed care. As mentioned, one of the most distressing phenomena in this population is a cycle in which patients gain and lose health care coverage. When patients have good health care, many do extremely well and are able to seek and find appropriate employment. Unfortunately, this often results in making them ineligible for State or federal assistance due to their income level. Without health care overage, they cannot access needed care and become ill and unable to work. They then become financially eligible for health care coverage through State or federal programs again. Their health then improves, as they are receiving adequate care, and they seek employment. The cycle thus begins again.

14. Use of a Patient Registry to Assure that All Patients Receive Care

Recommendation

Development of a confidential patient registry would ensure that all patients receive care.

Rationale

One of the important factors in the success of a population based program is knowing who all the patients are. This way the patients can be provided with case management and monitored and retrieved, if they fall through the cracks. In this way it is possible to assure that each patient receives all the needed elements of care according to the standardized guidelines, to make referrals for the resolution of special problems and to target provider education. It also makes it possible to collect statistical data on the entire cohort to track outcomes, assess the need for additional services, project costs and refine management pediatric guidelines.

One of the important factors in the success of the program for infants and children with SCD is that the case management staff in the Office for Genetics and Children with Special Health Care Needs at the Department knows who all the patients are. The patients are identified through newborn screening and entered directly into the case management program. This way the patients can be provided with follow-up care, and monitored and retrieved if need be. In this way it is possible to assure that each child receives all the necessary elements of care according to the MASCC guidelines, to make

appropriate referrals and to target provider education. It has made it possible to collect statistical data, track outcomes, assess the need for additional services, project costs, and continually refine management guidelines.

A number of other disorders utilize a registry or patient database, for instance cystic fibrosis and hemophilia. Such registries have been very helpful in improving care for those disorders. These patient databases are usually in the custody of voluntary organizations like the Cystic Fibrosis Foundation or federal agencies like the Centers for Disease Control and Prevention. The NIH is interested in such a registry of SCD patients for research purposes, and some of the NIH-funded SCD Centers have extensive patient databases for this purpose.

The question of a registry for SCD patients is a sensitive one. Because of stigmatization and discrimination experienced by persons with SCD as well as by carriers of sickle cell trait, careful consultation should take place with community health advocates, SCD interest groups, civil rights advocates and other interested stakeholders to prevent the misuse of the patient registry prior to establishing a Patient Registry of persons with SCD. This population has historical cause to fear discrimination and unethical research; nonetheless, establishing a patient registry should receive serious consideration.

B. Funding Recommendations

Compared to other chronic disorders federal and private funds for SCD are inadequate to address the multiple needs of patients and their families.[30] Since Maryland ranks among the top states nationally for the percentage of African-Americans in its population, State funding is recommended to establish patient-centered, culturally competent care of patients with SCD using state-of-the-art medical technology. It is hoped that such a model program could provide necessary data for increasing federal appropriations for SCD treatment and management.

The funding discussion in this section: (1) addresses the amount of State general fund support that would be needed to improve the quality of health care and reduce mortality rates for adults diagnosed with sickle cell disease; and (2) identifies available funding sources that currently exist for this purpose.

1. State General Funds

Approximately $2.2 million of State general funds would be required in the first year and approximately $1.9 million per year thereafter in order to administer an effective SCD program for adults.

<u>Statewide Steering Committee on Services for Adults with SCD</u>

Approximately $100,000 per year will be requested for establishing and maintaining the Steering Committee. These costs are for staffing, supplies, and travel reimbursement for the Committee members (see Appendix K for budget).

Day Infusion Center at Johns Hopkins

Approximately $1 million would be needed to establish the recommended day infusion center and approximately $960,000 per year would be required to administer it. Most of these costs are for professional staff. The details are in Appendix L. It is extremely unlikely that grant funding could be obtained to support the day center, so State general funds would be required. Day infusion centers at model programs in other states have eventually been able to bill enough to cover approximately 86% of their costs.[15] This expenditure of State general funds may be partially offset if the anticipated savings from decreased hospital admissions and decreased length of stay are realized.

Case Management Network, Outreach/Telemedicine Clinics, Telephone Consultation Service and Support Group

Approximately $730,000 per year would be required to operate the case management network and the outreach/telemedicine clinics. Most of these costs are for professional staff, cell phones with Internet and data storage capability, and travel (see Appendix M for further detail). Once the professional staff is in place, there is little additional cost for the 24/7 phone consultation service or the outreach clinics. The staff of the case management network will provide this service with back-up from the Center. The professional staff of the outreach network will staff the self-help support group described in recommendation 7. The professional staff of the outreach network will also provide the outreach clinics with back up from the Center. The outreach host sites for the genetics outreach clinics historically have not asked for compensation for the use of their space. Most of the host sites are local health departments, and many local health departments and community hospitals already have the facilities for telemedicine. Partnership with other State entities already operating a telemedicine system would conserve costs. The staff of the outreach system would also staff the patient and community outreach education described in recommendation 8. It is extremely unlikely that grant support for the case management network could be found, thus State general funds would be required.

Physician Education Program

Approximately $100,000 would be required to establish the Web-based provider education program and informational Web site and a lesser amount would be required to manage it each year. The Distance Learning Center at the Johns Hopkins School of Public Health has a great deal of experience with similar projects and provided the cost estimates. The modules of the tutorial and the protocols and list of services available could reside on the either the Open Courseware (OCW) site or the public health workforce training management (TRAMS) site. The cost to maintain the Web site and

update the tutorial modules, guidelines, and list of services depends on the amount of revision and the Web site, but should be less than $10,000. There is no additional cost for promoting the use of standardized guidelines and emergency room protocols, for promoting the appropriate use of hydroxyurea, or for publicizing available services once the educational program is established.

Patient Registry and Remote Access Electronic Medical Record Repository

Approximately $250,000 initially and $50,000 each year would be required to implement both the patient registry and the remote access medical record repository. The patient registry and remote access electronic medical record repository could be developed separately or together. MDLogix, a software development group that started at the Johns Hopkins University School of Public Health, has developed a similar application for autism (see Appendix J for MDLogix contact information). MDLogix maintains a HIPAA compliant secure data center. It is estimated that the registry and the protected remotely accessible electronic medical record repository could be developed for approximately $250,000 and maintained at $50,000 a year under an application service provider model. In this model, MDLogix would develop the application, the registry and record repository, and maintain it in their data center. The $50,000 consists of an annual licensing fee of $35,000 and an annual fee of $15,000 to maintain the application in their secure data center. Service comes with the licensing fee. Individual medical records would have to be updated by the patients' provider.

2. Potential Available Funding Sources

The Sickle Cell Disease Treatment Act of 2004:

The best opportunities for substantial grant funding to support the Sickle Cell Center for Adults is for Johns Hopkins to apply to become an NIH funded Comprehensive Sickle Cell Disease Center. Some, but not all, of the centers cited as models in this report are part of an NIH funded Comprehensive Sickle Cell Disease Center. There are currently 10 such centers and in the past the NIH considered research to be the major emphasis of the centers. However, each has a clinical component. Johns Hopkins had applied, unsuccessfully, to become one of these NIH-funded comprehensive centers in the early 1990s.

Awards from this program have been approximately $500,000 for both adult and pediatric care. Support from this source would not be sufficient to establish a day center but could be helpful for other enhancements. It should also be emphasized that grant funding from any source lasts only a limited number of years and so cannot be used for ongoing support of clinical services.

Clearly 10 centers could not adequately serve the entire population of the United States. The Sickle Cell Disease Treatment Act was passed by Congress and signed into law in October 2004 in order to expand specialized SCD treatment programs. Funding is to be used to establish 40 additional Sickle Cell Disease Treatment Centers.[31] The first round of this funding was the Sickle Cell Treatment Demonstration Program grant

described below. However, as noted, the RFA required SCD centers to partner with FQHCs or similar organizations that provide primary care to SCD patients, and solicitation of such a partner was unsuccessful. A better response in the future is hoped for as a result of the efforts to support primary care providers outlined in this report.

Patient Navigator, Outreach, and Chronic Disease Prevention Act of 2002:

In 2002, the federal government passed a bill to establish a patient navigation program *"Patient Navigator, Outreach, and Chronic Disease Prevention Act"* (HR 5187). However, appropriations for its implementation have not been made available yet and are not planned in the coming federal Fiscal Year. This again reinforces the need to establish State funding for the plethora of care areas generated by SCD.

The Commonwealth Fund:

The Commonwealth Fund offers grants to improve the quality of health care for underserved populations. Established in 2000, the Program on Quality of Care for Underserved Populations aims to improve quality and reduce disparities in health care for low-income and racial/ethnic minority patients. For more information, see: http://www.cmwf.org/index.htm

The Robert Wood Johnson Foundation:

The Robert Wood Johnson Foundation (RWJF) funded *The Local Initiative Funding Partners* (LIFP) program. This grant opportunity is now closed, but is offered annually. *Local Initiative Funding Partners* is a partnership program between the Robert Wood Johnson Foundation and local grantmakers that supports innovative, community-based projects to improve health and health care for vulnerable populations. *Local Initiative Funding Partners* provides grants of $200,000 to $500,000 per project, which must be matched dollar for dollar by local grantmakers such as community foundations, family foundations, corporate grantmakers, and others. The total award is paid out over a three-year or four-year period. Grants are awarded after a competitive process that begins when a project is nominated by a local funder according to the guidelines specified in the Request for Proposals. In 2007, up to $6 million will be awarded under the program. Existing programs are not eligible for this grant, with the exception of those undergoing extensive expansion. More information at: http://www.lifp.org

RWJF also offers *Unsolicted Grants*. The Foundation currently awards approximately 25 percent of its grantmaking funds to unsolicited proposals developed by people and organizations outside of RWJF that help to address one or more of the Foundation's 11 key interest areas but do not fit within the specific strategy outlined in a Request for Proposals. Specifically, RWJF is committed to a series of targeted investments to help reduce racial and ethnic disparities in care. These investments will focus on improving the treatment for particular conditions, such as cardiac care and diabetes, which have a particularly large impact on certain racial and ethnic groups, and where experts and research agree on a recommended standard of care for all patients.

Kellogg Foundation:

Health programming at the Kellogg Foundation focuses explicitly on improving individual and community health, and improving access to and the quality of health care. The Kellogg Foundation's current goal is to promote health among vulnerable individuals and communities through programming that empowers individuals, mobilizes communities, engages institutions, improves health care quality and access, and informs public and marketplace policy. Grantmaking takes into account the social and economic determinants of health within a person's community, the quality of health institutions within that community, and the policies that determine how health services are organized, provided, and financed. Grantmaking also targets communities, health care systems, and public health as centers of change. For more information on applying for a Kellogg Foundation grant, see:
http://www.wkkf.org/default.aspx?tabid=63&ItemID=6&NID=41&LanguageID=0

HRSA:

HRSA funded a Sickle Cell Treatment Demonstration Program, although this grant opportunity closed in June 2006. The Sickle Cell Treatment Demonstration Program's purpose is to develop and establish systemic mechanisms to enhance the prevention and treatment of SCD through the coordination of service delivery; genetic counseling and testing; bundling of technical services; training of health professionals; and other related efforts. Up to four regional Sickle Cell Disease Collaborative Networks will be funded for a period of four years, subject to availability of funding, satisfactory grantee performance, and a determination that continued funding is in the best interest of the government.

National Institutes of Health:

NIH offers a number of different grants each year. Many of these grants specifically cite SCD, while others are broader in scope and include stem cell research and health disparities. Specifically, NIH offered the two following grant opportunities in 2006:

- The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) seeks research to understand and mitigate issues of health disparities in high priority diseases within its scope, including diabetes, obesity, nutrition-related disorders, hepatitis C, gallbladder disease, H. Pylori infection, SCD, kidney diseases, and metabolic, gastrointestinal, hepatic, and renal complications from infection with HIV. Because the nature and scope of the proposed research will vary from application to application, it is anticipated that the size and duration of each award will also vary. The total amount awarded and the number of awards will depend upon the numbers, quality, duration, and costs of the applications received. Application due dates run in cycles, see below link for specifics: http://grants.nih.gov/grants/guide/pa-files/PA-06-182.html

- The National Heart, Lung, and Blood Institute (NHLBI) invites applications for the renewal of the Comprehensive Sickle Cell Center Program, whose purpose is to conduct comprehensive research, training, and education efforts related to SCD. Up to $118.4 million (total costs) will be awarded over five years. Letters

of Intent Receipt Date: Due December 22, 2006; Application Receipt Date: Due January 24, 2007 http://grants.nih.gov/grants/guide/rfa-files/RFA-HL-06-008.html

Maryland Community Health Resources Commission Grants:

On May 10, 2005, Governor Robert L. Ehrlich, Jr. signed into law the Community Health Care Access and Safety Net Act of 2005. This legislation authorized the creation of the Maryland Community Health Resources Commission. Through grants, community assessments, and technical assistance, the Commission is working to increase access to care for low-income families and under- and uninsured individuals. The Commission will help communities develop more coordinated, integrated systems of community-based care, redirect non-emergency care from hospital emergency rooms to other providers in the community, and assist individuals in establishing a medical home. The cornerstone of these efforts will be community-based health care centers and programs.

Grantmakers in Health:

Grantmakers in Health is an excellent resource to locate funding. Located in Baltimore, their staff works one-on-one with health care professionals to help them locate funding opportunities.

VIII. Conclusion

Maryland is a national leader in the diagnosis and treatment of infants and children with SCD, but the same cannot be said for the adult population. Given the expertise and resources in this State, Maryland has the necessary ingredients to improve the care of the adult SCD population. The recommendations outlined in this report represent the ideas and experiences of the foremost SCD experts in the State. These recommendations, if implemented and funded with substantial State support, have the potential to transform the lives of many adult SCD patients, to extend Maryland's national leadership for children and infants with SCD to adults, and to result in significant cost savings to the State.

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APPENDIX A: ADULT SICKLE CELL DISEASE CARE WORKING GROUP

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APPENDIX B

CENTER FOR HEALTH PROGRAM DEVELOPMENT AND MANAGEMENT

University of Maryland, Baltimore County
1000 Hilltop Circle
Baltimore, Maryland 21250

PHONE: 410-455-6854
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M e m o r a n d u m

To: Alycia Steinburg

Through: Ann Volpel, John O'Brien

From: David Idala

Date: September 13, 2006

Re: Sickle Cell Analysis

The Maryland General Assembly passed House Bill 851 which requires the Department of Health and Mental Hygiene (The Department) to provide a report on adults with sickle cell to the legislature by December 1, 2006. At the request of The Department, the Center for Health Program Development and Management (The Center) has prepared data on the adult sickle cell population enrolled in Medicaid in calendar years 2004 (CY 2004) and 2005 (CY 2005). The findings in the two years are consistent; therefore, this memo will discuss data from CY 2005.

The sickle cell cohort was composed of any Medicaid recipient who received services in an inpatient, physician or outpatient setting anytime during the year, and had a sickle cell diagnosis in any diagnosis field. The following diagnosis codes were used to identify adults with sickle cell -282.60, 282.61, 282.62, 282.63, 282.64, 282.68, 282.69, 282.41, 282.42.

In CY 2005, we identified 772 adults in Medicaid with sickle cell, which accounts for 0.44% of adults in the Medicaid program. This number was slightly higher than the 733 (0.42 %) identified in CY 2004. Tables 1 (a) and (b) below show the breakdown of Medicaid enrollees with a sickle cell diagnosis by sex and race respectively. The data show that there were twice as many women as men with the disease. It is likely that the gender difference is due to the overall gender distribution of adults in the Medicaid program.[1] Ninety percent of the enrollees with the disease are Black.

[1] Our analysis of children with sickle cell revealed no gender difference in the prevalence of the disease.

Table 1

(a) Enrollee Distribution by Sex (CY 2005)

Sex	Enrollees	Percentage
Male	245	31.7%
Female	527	68.3%
Total	**772**	**100.0%**

(b) Enrollee Distribution by Race (CY 2005)

Race	Enrollees	Percentage
Black	702	90.9%
All Other Races	70	9.1%
Total	**772**	**100.0%**

We divided the sickle cell cohort into two sub-groups: HealthChoice and fee-for-service (FFS). The HealthChoice sub-group was comprised of any enrollee who was in a managed care health plan at any time during the year. On the other hand, the FFS sub-group was comprised of any enrollee whose expenditures were paid for exclusively on a fee-for-service basis for the entire calendar year. For this analysis, all members of the cohort fell into either the HealthChoice sub-cohort or the FFS sub-cohort. Sixty-eight percent of the cohort (523 enrollees) were in the HealthChoice sub-cohort and 32 percent (249 enrollees) were in the FFS sub-cohort.

For those enrolled in HealthChoice, the distribution of enrollees with sickle cell varied across the seven health plans. Americaid and Priority, the two largest HealthChoice plans, combined to house about 60 percent of the cohort. In order to observe whether certain health plans had a disproportionate share of enrollees with sickle cell, we included overall HealthChoice adult enrollee distribution data in Table 2. We find that Americaid and Priority had a slightly greater proportion of adults with sickle cell compared to their ratio of adult HealthChoice enrollees. The other health plans had a slightly lower adult sickle cell distribution compared to their overall HealthChoice enrollment.

Table 2 Sickle Cell and HealthChoice Enrollee Distribution by Health Plan – Adults only (CY05)

Health Plan	Sickle Cell	% Sickle Cell	HealthChoice	% HealthChoice
MPC	75	14.3%	34,953	20.0%
Coventry	—[2]	—[2]	3,386	1.9%
Americaid	175	33.5%	45,889	26.2%
JAI	—[2]	—[2]	5,335	3.0%
United	92	17.6%	36,930	21.1%
Helix	22	4.2%	9,158	5.2%
Priority	145	27.7%	39,276	22.5%
TOTAL	**523**	**100.0%**	**174,927**	**100.0%**

HealthChoice	523	67.7%
Fee-For-Service	249	32.3%
TOTAL	**772**	**100.0%**

The average age of the 772 adults with sickle cell was 34.9 years. The 523 HealthChoice enrollees averaged 31.4 years, while their fee-for-service counterparts had an average age of 42.1.

Table 3 provides a breakdown of enrollee distribution by region. We find that enrollees with sickle cell are more likely to live in urban areas. The majority of the enrollees resided in Baltimore City (42.5%) and the Washington DC suburbs (28.1%). The Western and Southern Regions of Maryland as well as

[2] Data withheld to protect enrollee privacy (small cell size).

the Eastern Shore had the fewest number of sickle cell enrollees in Medicaid, combining to account for about 10 percent of the cohort.

Table 3 Enrollee Distribution by Region (CY05)

Region	HealthChoice	FFS	Total	Total (%)
Western MD	—[3]	—[3]	**11**	1.4%
Central MD	99	50	**149**	19.3%
Baltimore City	230	98	**328**	42.5%
Washington DC Area	140	77	**217**	28.1%
Southern MD	—[3]	—[3]	**26**	3.4%
Eastern Shore	27	14	**41**	5.3%
TOTAL	**523**	**249**	**772**	**100.0%**

Table 4 shows the Medicaid expenditures for members with a sickle cell diagnosis in the FFS sub-cohort. As expected, the bulk of the expenditures for the FFS sub-cohort were for inpatient services which accounted for 41.7 percent of the total fee-for-service expenditures. The expenditures for long-term care, physician, and pharmacy fell in the 11 to 17 percent range, while expenditures for special services, outpatient, and home-health care were each under 10 percent.

Table 4 Expenditures for Adults with Sickle Cell in the FFS Sub-cohort by Service Type (CY 2005)

Service	FFS	FFS (%)
RX	$846,481	14.20%
Dental	$1,369	0.02%
LTC	$1,002,860	16.80%
Inpatient	$2,492,117	41.70%
Outpatient	$456,061	7.60%
Physician	$701,605	11.80%
Home Health	$342,104	5.70%
Special Services	$126,806	2.10%
Total FFS Sub-cohorts' Expenditures	**$5,969,401**	**100.00%**

	FFS
Recipients	249
Total Number of Member Months	2,441
Average Member Months	9.8
Expenditures per Member per Year	$23,973
Expenditures per Member per Month	**$2,445**

The average monthly expenditures for members of the FFS sub-cohort were $2,445 per member per month (PMPM), which equates to an average annual expenditure of $23,973 per member per year. It is important to remember that the FFS population is largely composed of dual eligibles and individuals who spend down to Medicaid because of high health care expenditures. There were 198 dual eligibles in the sickle cell cohort. Twenty-five of the dual eligibles spent some time in a HealthChoice managed care plan, while the other 173 had their services provided only on a fee-for-service basis. Total

[3] Data withheld to protect enrollee privacy (small cell size).

Medicaid expenditures for services rendered to the fee-for-service cohort were about $5.9 million in CY 2005. The cost of Medicare funded services to dual eligible enrollees is not included in this analysis.

Table 5 presents utilization data for the 523 enrollees in the HealthChoice sub-cohort. As presented in the table, these enrollees had a combined total of 4,679 ambulatory care visits, 1,349 emergency room visits[4] and 1,328 inpatient admissions in CY2005. Eighty-five percent (444) of the 523 adults with sickle cell in HealthChoice had at least one ambulatory care visit. The average number of visits for enrollees who had at least one ambulatory care visit was 10.5 visits per person per year. However, the average number of ambulatory visits for the entire cohort was 8.9 visits per person per year.

Forty-six percent (239) of the 523 adults with sickle cell in HealthChoice had at least one ER visit, while 56 percent of enrollees had at least one inpatient admission. The average number of visits for members with at least one ER visit was 5.6, while the average number of admissions for members who had at least one admission was 4.5 hospitalizations. This analysis considers only utilization of MCO-funded services. It does not include services accessed on a FFS basis by the HealthChoice sub-cohort.

Table 5. Ambulatory Care Visits, Inpatient Admissions and ER Visits for Sickle Cell Enrollees in a HealthChoice MCO (CY 2005)

Type of Service	Frequency of Visits	Number of Enrollees who had a Visit	Average Visits per Enrollee for Enrollees who had a Visit	Average Visits per Enrollee for all Enrollees in the Cohort	Visits per thousand Member Months
Ambulatory Visits	4,679	444	10.5	8.9	10,605
ER Visits	1,349	239	5.6	2.6	3,057
Inpatient Admissions	1,328	292	4.5	2.5	3,010
Number of Enrollees	523				

Some Notes of Caution

The per member per month expenditure data should be interpreted with caution. These data are affected by a number of the decisions that were made in conducting the analysis.

- Including duals in the FFS cohort lowers the PMPM expenditures for the FFS population

  As noted in Table 6, by including dual eligibles in the cohort, the average FFS expenditures per member per month decrease from $5,886 to $2,445. It is likely that Medicare pays for much of the care to the dual eligible population and those expenditures are not included in these data. Any application of these data should note the absence of Medicare expenditure data.

[4] Emergency room visits exclude ER visits that resulted in an inpatient admission.

Table 6 Comparison of Expenditure on Duals vs. the FFS Cohort (CY 2005)

	Duals Only	FFS Subset (Including Duals)	FFS Subset (Excluding Duals)
Recipients	173	249	76
Total Member Months	1,905	2,441	536
Average Member Months	11.0	9.8	7.1
Total Expenditures	**$2,814,378**	**$5,969,401**	**$3,155,023**
Expenditures per Member per Year	$16,268	$23,973	$41,513
Expenditures per Member per Month	**$1,477**	**$2,445**	**$5,886**

- Limiting the Threshold Number of Sickle Cell Diagnoses Substantially Increases the Cohort Size

  With the definition we applied, individuals who only had one sickle cell diagnosis appear on a claim during the entire year were included in the cohort. As Table 7 demonstrates, almost 27 percent of the cohort had only one diagnosis for sickle cell during the year. Additional analysis would be necessary to better understand whether a diagnosis threshold of one is appropriate.

Table 7 Frequency of Enrollees with a Specified Number of Sickle Cell Diagnoses Codes in any Medical Setting (CY05)

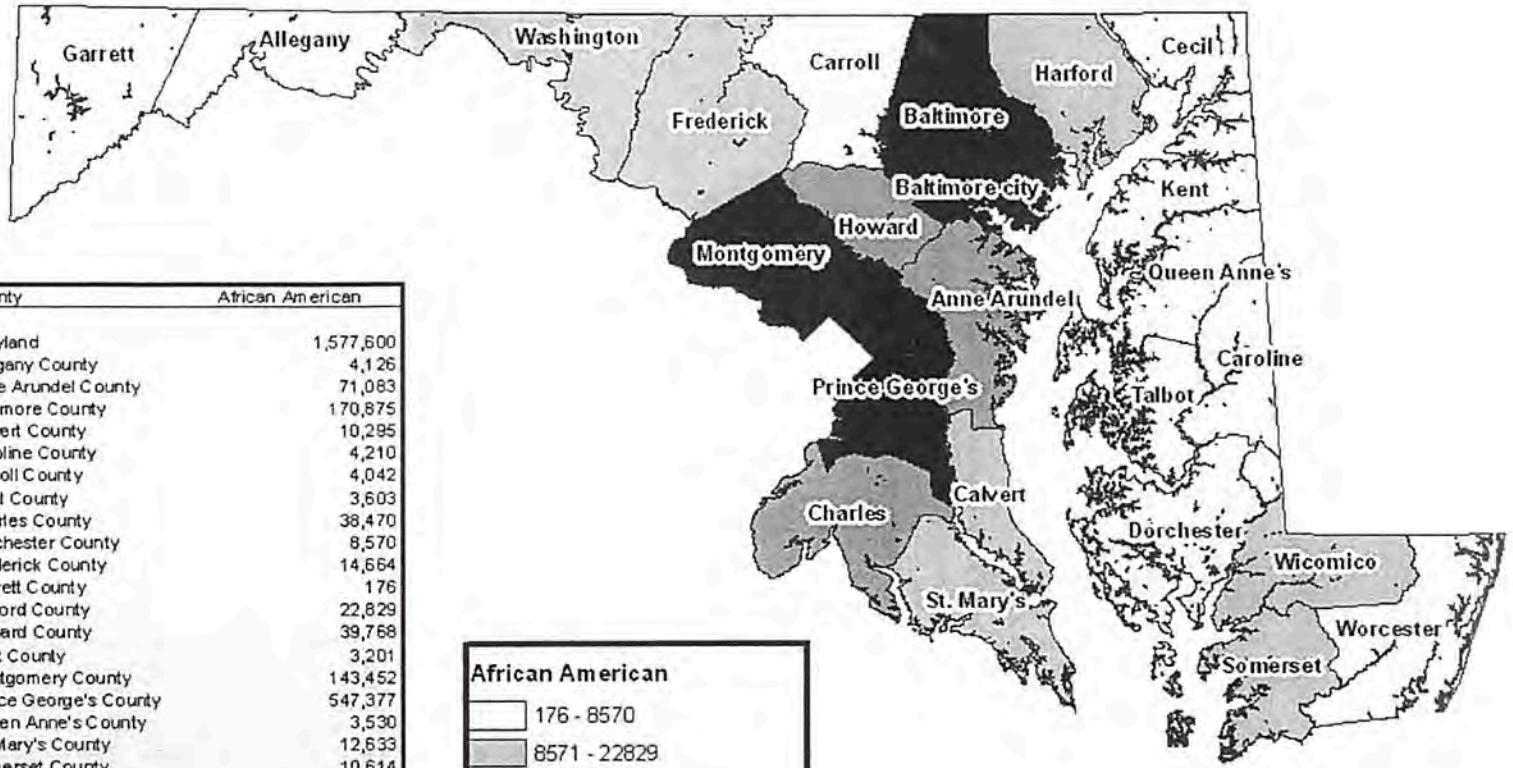
Number of Diagnoses	Enrollees	Percentage
1	208	26.9%
2	59	7.6%
3	35	4.5%
4+	470	60.9%
Total	**772**	**100.0%**

Next Steps

We would welcome the opportunity to further discuss with you your plans for applying these data to determine whether additional analysis is warranted. In addition to the issues raised above, analysis of the Medicare expenditure data could provide a more complete picture of expenditures for dual eligibles.

APPENDIX C

African American Population alone or in combination in Maryland



County	African American
Maryland	1,577,600
Allegany County	4,126
Anne Arundel County	71,083
Baltimore County	170,875
Calvert County	10,295
Caroline County	4,210
Carroll County	4,042
Cecil County	3,603
Charles County	38,470
Dorchester County	8,570
Frederick County	14,664
Garrett County	176
Harford County	22,829
Howard County	39,768
Kent County	3,201
Montgomery County	143,452
Prince George's County	547,377
Queen Anne's County	3,530
St. Mary's County	12,633
Somerset County	10,614
Talbot County	5,174
Washington County	11,128
Wicomico County	20,460
Worcester County	7,539
Baltimore City	419,761

Source: Population Division, U.S Census Bureau
Release Date: September 18, 2003

APPENDIX D:
Adult Sickle Cell Disease Questionnaire

A committee, made up of sickle cell disease patients, sickle cell disease support groups, State legislators, doctors, and health department staff, is working to improve care for adult patients with sickle cell disease. We are trying to find out what patients need? Would you be willing to help us by answering these questions? Filling out the questionnaire is entirely voluntary. The questionnaire is anonymous. Your name will not be on this questionnaire. All answers will be kept confidential. We will include a summary of all the answers we receive in our report which will go to the State Legislature, the Governor, the Lieutenant Governor and the State health department. Please send the completed questionnaire to the Office for Genetics and CSHCN at the Maryland Department of Health and Mental Hygiene in the stamped self addressed envelope provided.

About You

What type of sickle cell disease do you have?

_____SS disease
_____SC disease
_____Sickle β-thalassemia
_____Other

What is your ethnic origin?

_____African American
_____African
_____African Caribbean
_____Central American
_____Other

How old are you? _____

What is your sex? Male_____ Female_____

What is the zip code where you live? _____

Health Care

Do you have a primary care physician (PCP) that you see for general medical care, not just sickle cell disease?

Yes_____ No_____

What kind of doctor is your primary care doctor?

_____An Internal medicine doctor
_____A Family Medicine doctor
_____A General Practitioner
_____Other (specify)

Which, if any, of the following treatments, are you on?

_____Transfusions
_____Hydroxyurea
_____Other drugs

How many pain episodes have you had in the last year (pain in any part of your body lasting at least 2 hours)? _____

How many pain episodes were managed at home? _____

How many pain episodes were managed in the ER/hospital?_____

Do you have difficulty getting lab tests done? Yes _____ No _____
If so, why?

Too hard to get to lab _____
No lab near my home _____
Lack of transportation _____
Cost of lab work _____
Other reason _____

Of the following medical specialists, which do you see and how often do you see them?

	Do not see	Less than once a year	Once a year	Two or three times a year	More than three times a year
Case manager					
Medication manager					
Pain management doctor					
Orthopedic doctor					
Ophthalmologist					
Pulmonologist					
Cardiologist					
Nephrologist					
Urologist					
Neurologist					
Gastroenterologist					
Endocrinologist					
Physical Therapist					
OB/Gynecologist					
Psychiatrist/Psychologist					
Social worker					
Dentist					
Geneticist					

Do you receive:

_____Supplemental Security Income (SSI)
_____Social Security Disability Income (SSDI)

How are your medical bills paid?

_____Insurance pays in full
_____Insurance pays most/I pay remainder
_____Insurance pays some/I pay remainder
_____I pay in full

Are there services you need that your insurance does not cover?
If so, what services?

Do you receive any services from your local health department? Yes_____ No_____
If so, what services?

Your Education and Employment

What is the highest level of education you have completed?

_____Completed elementary school
_____Some high school
_____Graduated from high school
_____Completed trade school
_____Some college
_____Graduated from college

Were you involved in vocational training in school? Yes_____ No_____

Were you involved in vocational training after leaving school? Yes_____ No_____

Describe your employment situation: (Please check all that apply.)

_____GED program	_____Work in full time paid job
_____Other pre- college program	_____Work in part time paid job
_____Full time college student	_____Full time homemaker
_____Part time college student	_____Sheltered workshop
_____Vocational training center	_____Volunteer
_____Not employed	_____Other

Public ignorance about sickle cell disease				

Which of these issues pose the greatest problems for you?

Largest problem:
Second largest problem:
Third largest problem:

How would you describe your quality of life?

_____Excellent
_____Good
_____Fair
_____Poor

How often does sickle cell disease affect your life?

_____Every day
_____Most days
_____Half the time
_____Few days
_____Never

Are you involved in a sickle cell disease support group? Yes____ No____

If so, do you find it helpful?

If not, why not?

What services do you need that you are not receiving?

If there was one thing that the State health department could do to help you, what would you like that to be?

APPENDIX E

Physician Survey on the Needs of Adult Sickle Cell Disease Patients in Maryland

A committee, made up of sickle cell disease patients, sickle cell disease support groups, State legislators, doctors, and health department staff, is working to improve care for adult patients with sickle cell disease. We are trying to identify the needs of adult patients with sickle cell disease. Would you be willing to help us by answering these questions? Filling out the questionnaire is entirely voluntary. The questionnaire is anonymous. Your name will not be included on this questionnaire. All answers will be kept confidential. We will include a summary of all the answers that we receive in our report which will go to the State Legislature, the Governor, the Lieutenant Governor, and the State Health Department.

This survey is available online. If at all possible, we would prefer that you use the online survey. You may access it here:

http://www.surveymonkey.com/s.asp?u=606122720027

Alternatively, you may complete the survey on the following pages and use the self-addressed stamped envelope provided to send your completed survey to:

Sophie Lanzkron, MD
Sickle Cell Disease Project
Johns Hopkins University
1830 E. Monument Street
Suite 7300
Baltimore, Maryland 21205

THANK YOU FOR YOUR PARTICIPATION!

1	O
2 to 3	O
4 to 9	O
10-30	O
31+	O

Q11. How many adults with sickle cell disease have you treated as an inpatient over the last 12 months?

0	O
1	O
2 to 3	O
4 to 9	O
10-30	O
31+	O

Q12. What percentage of your adult patients with sickle cell disease are male? _____

Q13. What percentage of your adult patients with sickle cell disease have the following:

SS disease	_____%
SC disease	_____%
Sickle β-thalassemia	_____%
Other	_____%

Q14. What percentage of your adults patients with sickle cell disease are covered by:

Medicaid	_____%
Medicaid MCO	_____%
Medicare	_____%
Private Insurance	_____%
SSI	_____%
SSDI	_____%

Q15. What percentage of your adult sickle cell patients are:

African American	_____%
Hispanic	_____%
Other	_____%
If "Other", please specify:	_____

Q16. What percentage of your sickle cell patients live in the following settings:

Rural	_____%
Urban	_____%

Q17. Do your patients with sickle cell disease participate in support groups?

Yes	O
No	O
Not Sure	O

Q18. Do you provide your patients with an ID card or bracelet explaining their medical condition and medications?

Unique ID#_____

No O

IF YOU RESPONDED "NO", SKIP TO Q29

Q27. When you refer your patients, where do you send them? (Mark all that apply)

Academic center for hematology O
Community hematologist O

Q28. How useful have you found these referrals to be in helping you manage your adult patients with sickle cell disease?

Not at all useful	O	Somewhat Useful	O	Useful	O	Very Useful	O

Q29. How comfortable are you in managing pain in adults with sickle cell disease?

Very Uncomfortable	O	Somewhat Uncomfortable	O	Somewhat Comfortable	O	Very Comfortable	O

Q30. What percentage of your adult patients with sickle cell disease are on chronic pain medications?

0 to 10% O
11 to 19% O
20 to 29% O
30 to 39% O
40 to 49% O
50% or more O

Q31. What percentage of your adult patients with sickle cell disease do you refer to a pain specialist?

0 to 10% O
11 to 19% O
20 to 29% O
30 to 39% O
40 to 49% O
50% or more O

Q32. How useful have you found these referrals to pain specialist?

Not at all useful	O	Somewhat Useful	O	Useful	O	Very Useful	O

Q33. How often do you see your adult patients with sickle cell disease?

Every month O
Every 3 months O
Every 6 months O
Once a year O
As needed O

Q34. Do you routinely screen your patients for the following? (Mark all that apply)

Renal disease O

Unique ID#_____

Yes O No O

Q45. What do you think the State Health Department could do to improve these patients' quality of life?

_____

_____

IV. FACILITATORS IN CARING FOR ADULTS WITH SICKLE CELL DISEASE

Q46. What would it take for you to see patients (or to see more patients if you already see patients) with sickle cell? (Mark all that apply)

Higher reimbursement?	O
Case management services available without charge?	O
More continuing medical education?	O
A more comprehensive sickle cell center within reach?	O
A day hospital within reach?	O
A roster of sickle cell disease specialists/consultants on call to answer questions 24/7?	O
A pain management specialist on call to answer questions?	O
A better relationship/ communications with specialists?	O
A formal agreement with a local emergency room for back up?	O
Centralized brief electronic medical records?	O
Transportation for the patients?	O
Other?	O
I don't want to see patients with sickle cell disease	O

Q47. If there are other ways to facilitate your seeing patients, or seeing more patients, with sickle cell, please provide them below:

_____

_____

V. CONTACT INFORMATION AND QUESTIONNAIRE DISSEMINATION

Q48. Would be willing to distribute copies of our Patient Questionnaire to your adult sickle cell patients? If so, please write-in how many to provide to you, and include the address to send them to you in Q50 below.

Yes O No O

Q49. Please include any additional comments here:

_____

_____

Q50. Voluntary Contact information:

_____

_____

_____

Q51. May we contact you about future studies?

Yes O

No O

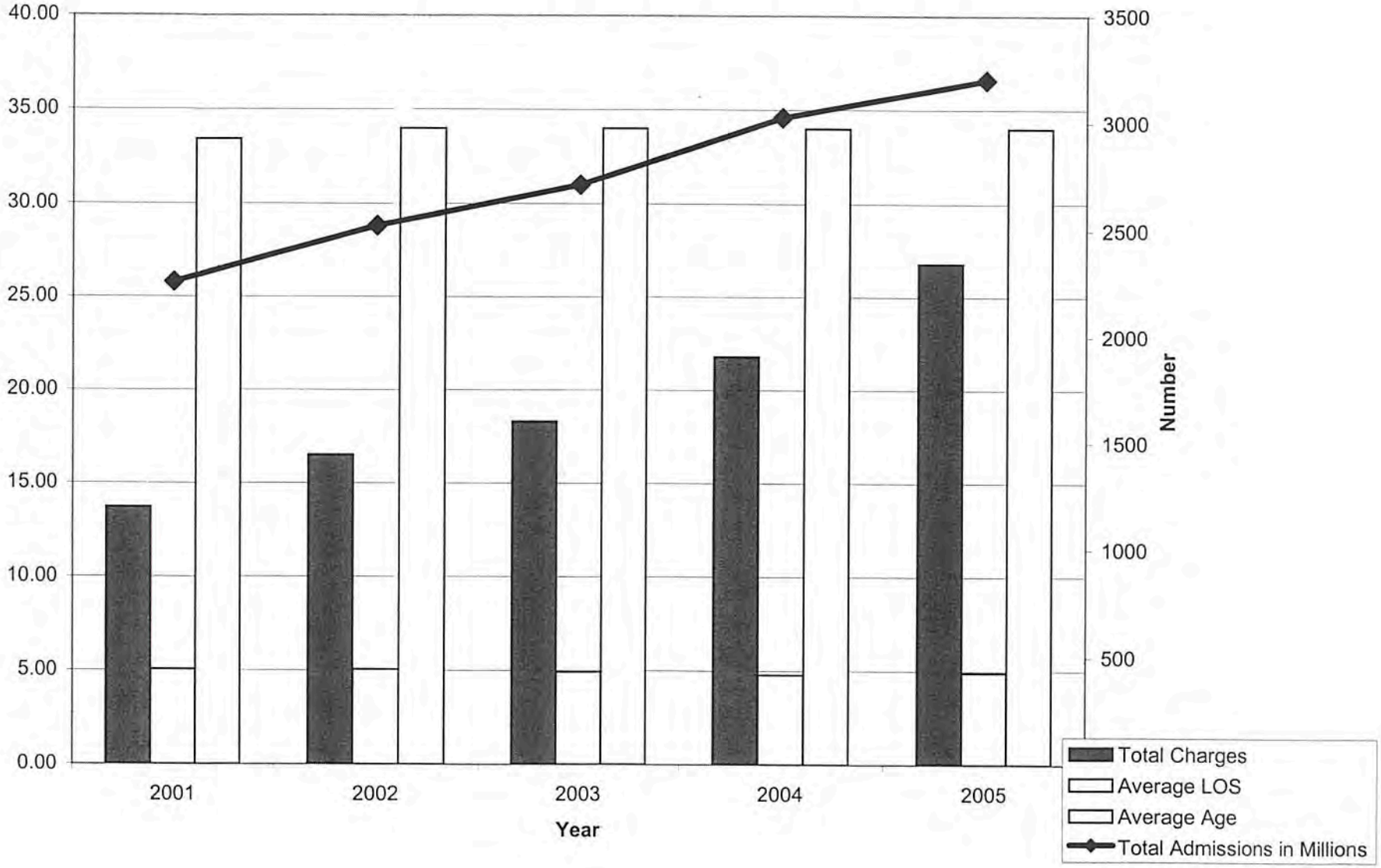
PLEASE RETURN THIS QUESTIONNAIRE IN THE SELF ADDRESSED STAMPED ENVELOPE PROVIDED

THANK YOU FOR YOUR PARTICIPATION!!

Sickle Cell Disease Admissions 2001-2005

Appendix F: Sickel Cell Admissions 2001-2005						
CY	2001	2001 % of total admits	2002	2002 % of total admits	2003	2003 % of total admits
Total Admissions	2258		2523		2715	
Total Charges	$13,720,722.00		$16,533,847.00		$18,279,083.00	
Average LOS	5.05		5.05		4.93	
Average Age	33		34		34	
Payor						
Blue Cross MD	146	6.47	160	6.34	196	7.22
Blue Cross Nationa	31	1.37	35	1.39	45	1.66
Blue Cross Other	13	0.58	18	0.71	44	1.62
Commercial	144	6.38	117	4.64	155	5.71
HMO	309	13.68	300	11.89	274	10.09
HMO- Medicaid	759	33.61	852	33.77	889	32.74
HMO- Medicare	5	0.22	2	0.08	5	0.18
Medicaid	200	8.86	227	9.00	262	9.65
Medicare	505	22.36	648	25.68	705	25.97
Other Govt	12	0.53	10	0.40	7	0.26
Other	5	0.66	6	0.70	7	0.79
Self Pay	120	5.31	138	5.47	115	4.24
Worker's Comp	0	0.00	1	0.44	2	0.76
Title V	0	0.00	1	0.15	2	0.28
Unknown	8	0.35	4	0.16	3	0.11
County of Residence						
Alleghany	2	0.09	3	0.12	1	0.04
Anne Arundel	85	3.76	82	3.25	67	2.47
Baltimore City	852	37.73	973	38.57	994	36.61
Baltimore County	295	13.06	302	11.97	304	11.20
Calvert County	3	0.13	6	0.24	3	0.11
Caroline County	18	0.80	11	0.44	4	0.15
Carroll County	3	0.13	1	0.04	1	0.04
Cecil County	1	0.04	1	0.04	1	0.04
Charles County	37	1.64	49	1.94	45	1.66
Dorchester County	24	1.06	45	1.78	38	1.40
Frederick County	10	0.44	13	0.52	16	0.59
Harford County	23	1.02	37	1.47	48	1.77
Howard county	77	3.41	55	2.18	73	2.69
Kent County	7	0.31	8	0.32	11	0.41
Montgomery County	200	8.86	224	8.88	263	9.69
Prince George's County	431	19.09	475	18.83	641	23.61
Queen Anne's County	2	0.09	0	0.00	0	0.00
Somerset County	23	1.02	24	0.95	26	0.96
St. Mary's County	18	0.80	27	1.07	30	1.10
Talbot County	4	0.18	1	0.04	5	0.18
Washington County	9	0.40	9	0.36	7	0.26
Worchester County	6	0.27	5	0.20	11	0.41
Wicomico County	55	2.44	60	2.38	56	2.06
Delaware	5	0.22	8	0.32	1	0.04
Pennsylvania	3	0.13	2	0.08	3	0.11
Washington DC	34	1.51	56	2.22	32	1.18
West Virginia	1	0.04	0	0.00	1	0.04
Virginia	1	0.04	3	0.12	8	0.29
Other States	21	0.93	24	0.95	16	0.59
Foreign	2	0.09	1	0.04	1	0.04
Unknown	5	0.22	13	0.52	8	0.29

Appendix F: Sickle Cell Admissions in MD 2001-2005



APPENDIX G
First Five Diagnoses 2001- 2005

APPENDIX G: First Five Diagnoses					
Admission Year	**2001**	**2002**	**2003**	**2004**	**2005**
Total Number of admissions	**2258**	**2523**	**2715**	**3026**	**3202**
The first 5 diagnoses were coded as follows:					
SS with Crisis	2301	2525	2658	2595	2789
SCD unspecified	508	493	571	670	471
SS without Crisis	145	109	155	155	487
Pneumonia	355	325	351	404	478
Hypovolemia	292	420	406	431	434
Asthma	242	273	269	354	471
Anemia	207	155	176	176	161
Smoking	75	116	152	192	250
CHF	162	238	204	220	256
HTN	106	156	198	211	231
Delivery	111	133	146	133	127
CKD	52	75	85	115	132
UTI	133	115	116	149	170
AVN	92	89	119	145	159
Fever	113	147	143	184	185
Drug/ETOH use	103	67	84	104	122
Depression	68	101	127	108	126
Opioid Dependence	42	80	86	136	124
Sickle Thal	NA	NA	NA	55	146

APPENDIX H:
EXISTING MODELS OF SERVICE DELIVERY FOR ADULTS WITH SICKLE CELL DISEASE

Ngozi A. Nwokoro, M.D., Ph.D.
FHA
Office for Genetics and Children with Special Health Care Needs

Comprehensive Adult Sickle Cell Disease Care Centers

- The Georgia Comprehensive Sickle Cell Center – Emory; 700 patients
- Medical College of Georgia, Augusta; 533 patients
- University of Illinois at Chicago; 485 patients
- The University of South Alabama, Mobile; 300 patients
- University of Cincinnati College of Medicine; 200 patients
- Johns Hopkins University; 250 patients
- Truman Medical Center Sickle Cell Disease Clinic Kansas City, MO; 100 patients

The 24 Hour Acute Care Center

- Designated Service Area
- Urgent Care for Adults over 16 years old
- Full evaluation of Sickle Cell Emergencies by Dedicated Staff Rapidly and Efficiently
- If Adequate Pain Relief in < 8 Hours, Patient Discharged Home (80% of the Patients)
- If Inadequate Pain Relief After 8 Hours of Treatment or if Patient has more Severe complications, he ro she is Admitted for Inpatient Treatment (20% of the Emergency Patients)
- Average Length of Hospitalization is 5 Days
- Inpatient Consultations

Other Services Provided by the Center

- Pain Management Program
- Chronic Transfusion Services
- Transcranial Doppler (TCD) ultrasound Testing for Stroke Prevention
- Stroke Rehabilitation
- Leg Ulcer Clinic and Hydrea Clinic
- Psychiatric and Psychological Services
- Research Center

Interim Outcome Measures

	1985	1992
Emergency room visits/year	17.9/year	3.5/year
Admission rate/patient	2.1/year	0.8/year
Outpatient charges/patient	$16,800.00/year	$4,700.00/year

Benefits from the Existence of the Center

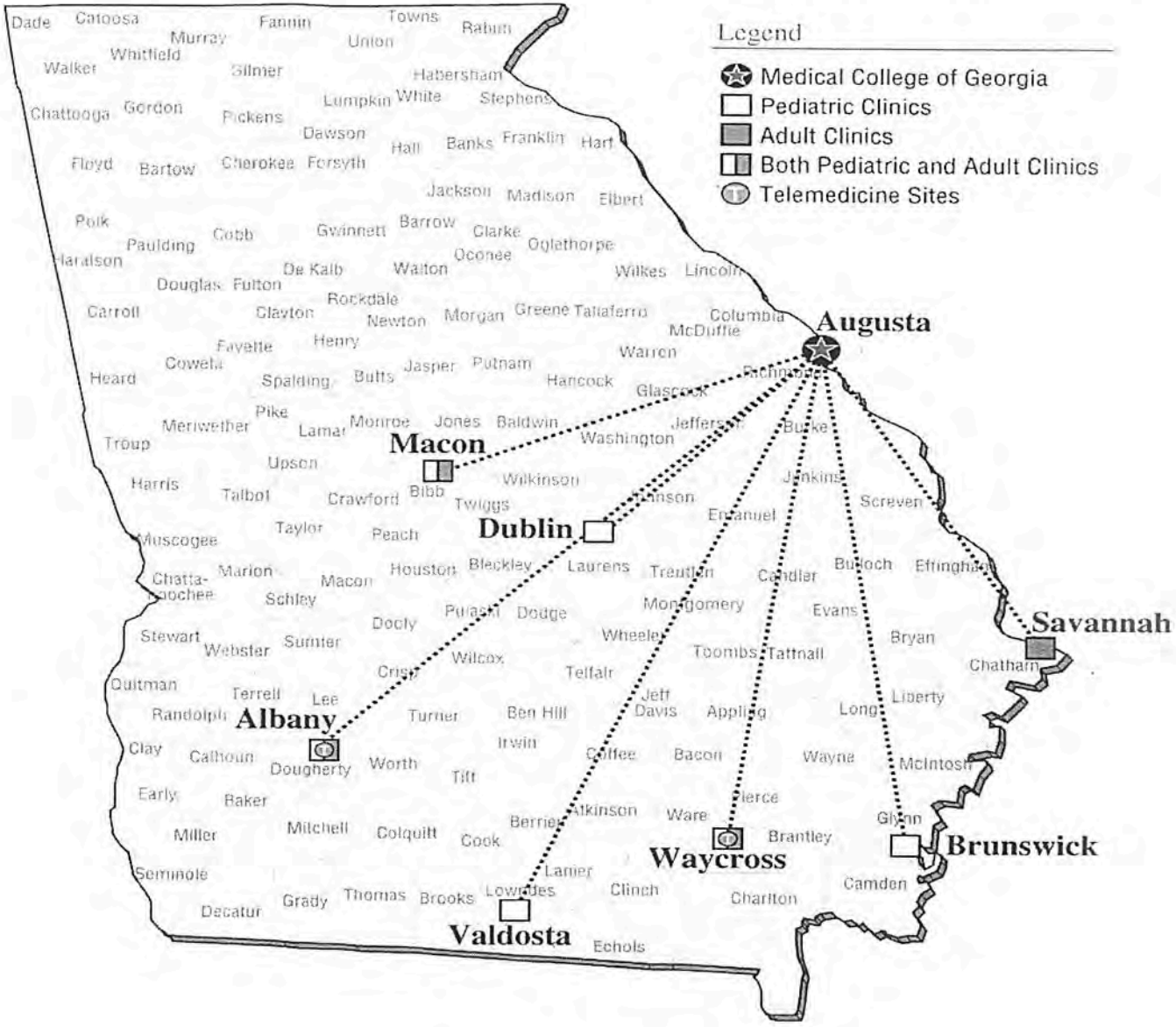
- Greater than Two-Thirds Reduction of the Annual Cost of Treating Adult Patients
- Reduced Number of Hospitalizations
- Cost Effectiveness of Care
- Improvement in the Quality of Life for Adult SCD Patients Through Health Maintenance and Education
- Cost Savings for Patients and the State

MCG SICKLE CELL CENTER

- CLINICAL
  - Pediatric
  - Adult
- LABORATORY
  - Titus HJ Huisman Hemoglobin Laboratory
  - DNA Laboratory
- RESEARCH
- EDUCATIONAL PROGRAM

Medical College of Georgia

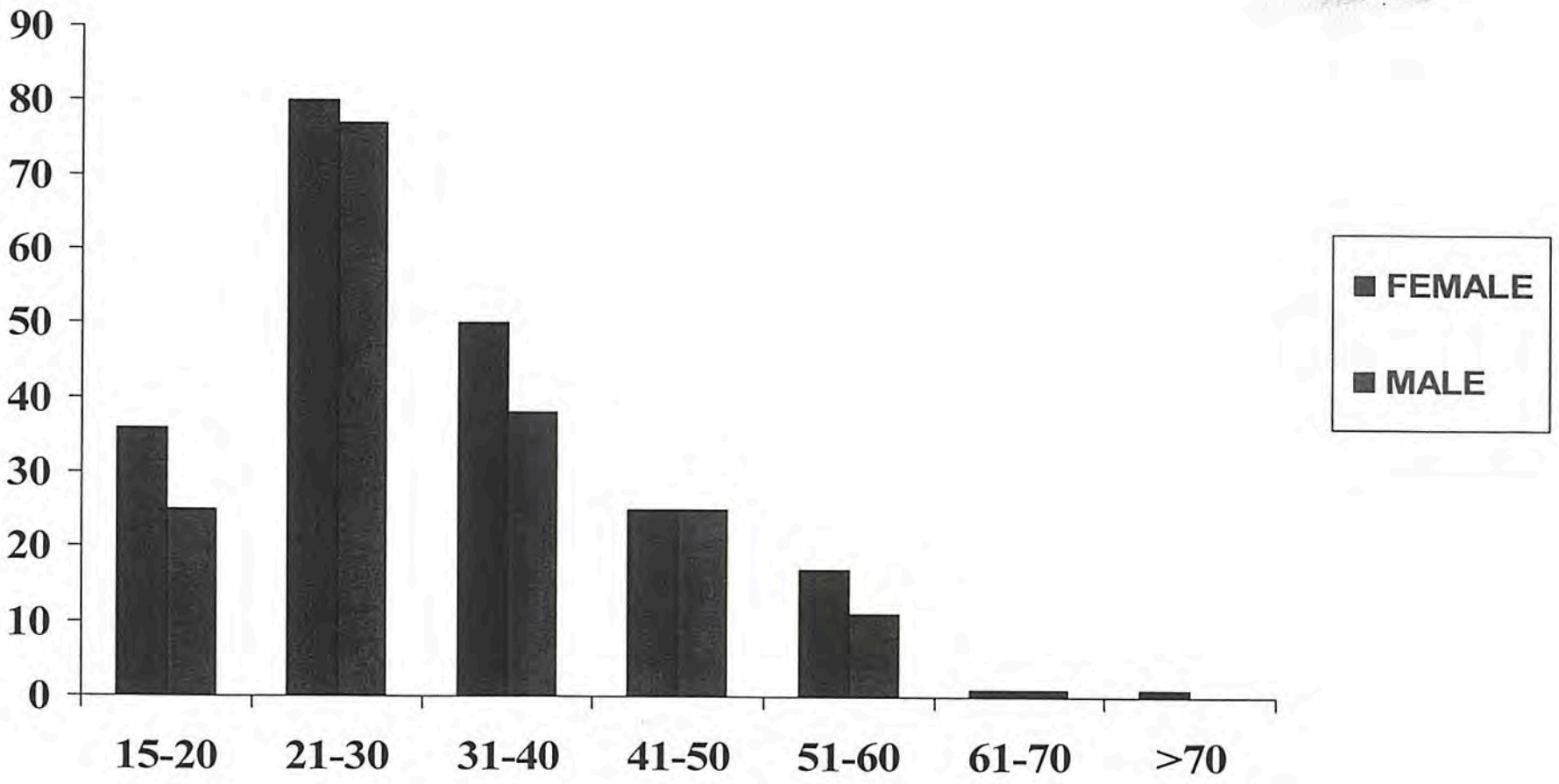
Sickle Cell Center Clinical Activities



ADULT SICKLE CELL CLINIC POPULATION

- Total number = 533
- Mean age = 31.3 $\pm$ 11.1
- Median age = 28
- 56.3% of patients < 30 years of age
- 79% of patients < 40 years of age
- Gender
  - Male = 246
  - Female = 287

Age Distribution of Adult SS Patients



MCG SICKLE CELL CENTER EDUCATION PROGRAM

- Courses for healthcare providers throughout the state
- Colleges and technical schools
- High School and Secondary Schools
- Community based programs
- Patient education and counseling

MCG SICKLE CELL CENTER RESEARCH ACTIVITIES

Industry Sponsored Studies:

- ICL670 (oral iron chelator)
- ICA17043 (Gardos channel inhibitor)
- Aranesp (long-acting erythropoeitin)

MCG Sponsored Study:

- Exercise Study in sickle cell trait (Bergeron, PI)

APPENDIX I:
SATELLITE GENETIC CLINICS
MARYLAND DEPARTMENT OF HEALTH AND MENTAL HYGIENE

Location	Address	Contact Person	Consultant
ALLEGANY COUNTY			
(CUMBERLAND)	Allegany County Health Department Willowbrook Rd, Box 1745	Michelle Green, R. N. (301) 777-5696	University of Maryland Hospital, Division of Human Genetics – Carol Greene, M.D. Stephanie Ashley Meredith Weaver Genetic Counselors (410) 328-3335
ANNE ARUNDEL COUNTY			
(ANNAPOLIS)	Anne Arundel County Health Department 3 Harry S. Truman Pkwy Annapolis, MD 21401	Sue Crosby, R.N. Children's Health Services (410) 222-7004	Children's National Medical Ctr., Clinical Genetics Cynthia Tifft, M.D., Ph.D Genetic Counselor Amy Fuller, M.S. (202) 884-2187
(MILLERSVILLE)	Shipley's Choice Medical Park 8601 Veteran's Highway Suite 110 Millersville, MD 21108	Cornelia Szmajda (Cookie) (410) 328-3335	University of Maryland Hospital, Division of Human Genetics – Carol Greene, M.D. Stephanie Ashley Meredith Weaver Genetic Counselors (410) 328-3335

Location	Address	Contact Person	Consultants
CHARLES COUNTY (WHITE PLAINS)	Charles County Health Department 4545 Crain Highway (Route 301) White Plains, MD 20695	Lucy Richmond, R.N. (301) 609-6852	Children's National Medical Ctr., Clinical Genetics Cynthia Tifft, M.D., Ph.D. Deborah Hung-Copenheaver, M.S. Genetic Counselor Amy Fuller, MS (202) 884-2187
FREDERICK COUNTY (FREDERICK)	Frederick County Health Department 350 Montevue Lane Frederick, MD 21702	Cornelia Szmajda (Cookie) (410) 328-3335	University of Maryland Hospital, Division of Human Genetics – Carol Greene, M.D. Stephanie Ashley Meredith Weaver Genetic Counselors (410) 328-3335
HARFORD COUNTY (BEL AIR)	University Pediatric Specialty 4 C North Avenue Suite 423 Bel Air, MD 21014	Pam Wiechiech (410) 879-7730	University of Maryland Hospital, Division of Human Genetics – Carol Greene, M.D. Stephanie Ashley Meredith Weaver Genetic Counselors (410) 328-3335

Location	Address	Contact Person	Consultant
TALBOT COUNTY (EASTON)	Talbot County Health Department 100 S. Hanson Street Easton, MD 21601	CorneliaSzmajda (Cookie) (410) 328-3335	University of Maryland Hospital, Division of Human Genetics – Carol Greene, M.D. Stephanie Ashley Meredith Weaver Genetic Counselors (410) 328-3335
WASHINGTON COUNTY (HAGERSTOWN)	Washington County Health Department 1302 Pennsylvania Ave. Hagerstown, MD 21740	Gretchen Oswald (410) 955-3071	Johns Hopkins Hospital, Division of Human Genetics Emily Crocker Ada Hamosh, M.D. Gretchen Oswald Amanda Gergner Genetic Counselors (410) 955-3071
WICOMICO COUNTY (SALISBURY)	Baker's Women's Clinic 207 W. Vine Street Salisbury, MD 21801	Cornelia Szmajda (Cookie) (410) 328-3335	University of Maryland Hospital, Division of Human Genetics – Carol Greene, M.D. Stephanie Ashley Meredith Weaver Genetic Counselors (410) 328-3335

Rev. 07/14/2006

APPENDIX J:
SCD Contact information cited in report:

Harford/Cecil County Chapter for Sickle Cell Anemia America
Phone: (410)-272-5471

The Lauren D. Beck Foundation
Howard County
Ms Anika Wilkerson
anikadownswilkerson@hotmail.com

Sickle Cell Disease Association of America
Baltimore, Maryland
Sonya Ross
siross@sicklecelldisease.net

Mr. Benjamin Joseph bjoseph06@yahoo.com
Mr. Derek Robertson drobby1@aol.com
(trying to start a new chapter of the Sickle Cell Disease Association of America)

The Sickle Cell Adult Provider Network (SCAPN)
www.uchsc.edu/scapn/index.htm.

MDLogix
Website: http://www.mdlogix.com

Dr Allen Tien, MD,MHS, President
Phone: (410)-828-8948 or (410)-821-5618
Fax: (410)-828-8948
E-mail: allen@mdlogix.com

The Distance Learning Center at the Johns Hopkins School of Public Health
Phone: (410)-223-1844

Appendix K: Proposed Annual Budget for Statewide SCD Steering Committee

Personnel: Director Assistant	$91,800.00
Supplies	$1,000.00
Equipment	$2,500.00
Travel	$2,000.00
Mailing	$600.00
Meeting Support	$1,200.00
Conference Calls	$900.00
TOTAL	$100,000.00

Appendix E.

Proposed Budget for Sickle Cell Day Infusion Center at Johns Hopkins

One Time Start-Up Cost

	Year 1
Space/Operating Expenses	
Moving Costs	$ 10,000
Infusion Chair (4 at $1,185)	$ 4,740
Subtotal	**$ 14,740**
Office Operating Needs	
Adjust walls and doors	$ 3,000
Painting	$ 2,000
Cabinetry	$ 2,000
Flooring updates	$ 1,000
Office Furniture	$ 20,000
Pyxsis System	$ 10,000
Copier	$ 8,000
PC's, printers, PC stand	$ 15,700
Fax	$ 1,000
Subtotal	**$ 62,700**
Ammenities	
Paintings	$ 500
Rugs	$ 700
Audio Visual	$ 5,800
Subtotal	**$ 7,000**
TOTAL	**$ 84,440**

On Going Operating Cost

Personnel

Name	Role on Project	% Effort	Salary	Fringe	Total Year 1	Total Year 2	Total Year 3
Sophie Lanzkron, MD	Principal Investigator	50%	$ 62,135	$ 20,505	$ 82,640	$ 85,946	$ 89,384
TBN	Physician	50%	$ 62,135	$ 20,505	$ 82,640	$ 85,946	$ 89,384
Mandy Davis	Physician Assistant	100%	$ 72,527	$ 23,934	$ 96,461	$ 100,319	$ 104,332
TBN	Physician Assistant	100%	$ 70,000	$ 23,100	$ 93,100	$ 96,824	$ 100,697
TBN	Nurse	100%	$ 68,250	$ 22,523	$ 90,773	$ 94,404	$ 98,180
TBN	Clinic / Data Coordinator	100%	$ 39,600	$ 13,068	$ 52,668	$ 54,775	$ 56,966
TBN	Social Worker	100%	$ 51,915	$ 17,132	$ 69,047	$ 71,809	$ 74,681
Brian Estes	Drug Counselor	50%	$ 24,200	$ 7,986	$ 32,186	$ 33,473	$ 34,812
TBN	Clinical Psychologist	50%	$ 35,000	$ 11,550	$ 46,550	$ 48,412	$ 50,348
TBN	Health Educator	50%	$ 16,750	$ 5,528	$ 22,278	$ 23,169	$ 24,096
TBN	Outreach Worker	50%	$ 13,750	$ 4,538	$ 18,288	$ 19,020	$ 19,781
TBN	Gentetic Counselor	50%	$ 18,150	$ 5,990	$ 24,140	$ 25,106	$ 26,110
Subtotal			**$ 534,412**	**$ 176,359**	**$ 710,771**	**$ 739,203**	**$ 768,771**
Space/Operating Expenses							
JHOC Swing Space ($28/sq ft, 2000 sq ft)					$ 56,000	$ 59,360	$ 62,922
Office space for employees					$ 24,775	$ 26,261	$ 27,837
Billing Support					$ 17,000	$ 17,510	$ 18,035
Subtotal					**$ 97,775**	**$ 103,131**	**$ 108,794**
Office Operating Needs							
Office Furniture					$ -	$ -	$ 5,000
PC's, printers, PC stand					$ -	$ -	$ 5,600
Oxygen (H cylinder @ $14.50 a tank, 10 tanks a week)					$ 7,540	$ 7,540	$ 7,540
Disposable supplies					$ 9,075	$ 9,347	$ 9,628
Telephones					$ 9,000	$ 9,270	$ 9,548
Service contracts (incl. LAN support)					$ 7,300	$ 7,519	$ 7,745
Subtotal					**$ 32,915**	**$ 33,676**	**$ 45,060**
Ammenities							
Audio Visual					$ -	$ 1,220	$ 1,220
Subtotal					$ -	**$ 1,220**	**$ 1,220**
Information							
Brochure/Education Materials					$ 6,000	$ 2,500	$ 2,500
Subtotal					**$ 6,000**	**$ 2,500**	**$ 2,500**
Other Charges							
Malpractice Insurance					$ 17,745	$ 20,407	$ 23,468
Subtotal					**$ 17,745**	**$ 20,407**	**$ 23,468**
TOTAL Direct Costs					**$ 865,206**	**$ 900,137**	**$ 949,813**
	grant support/billing revenue						
	IDC @ 8% (salary & benefits only)				$ 56,862	$ 59,136	$ 61,502
	Total Budget				**$ 1,006,508**	**$ 959,273**	**$ 1,011,315**

Appendix M: Budget for Outreach

Personnel							
Name	Role on Project	% Effort	Salary	Fringe	Total Year 1	Total Year 2	Total Year 3
TBN	Physician	20%	$ 23,671	$ 7,811	$ 31,482	$ 32,741	$ 34,051
TBN	PA	100%	$ 72,527	$ 23,934	$ 96,461	$ 100,319	$ 104,332
TBN	PA	100%	$ 72,527	$ 23,934	$ 96,461	$ 100,319	$ 104,332
TBN	PA	100%	$ 72,527	$ 23,934	$ 96,461	$ 100,319	$ 104,332
TBN	Clinic / Data Coordinator	100%	$ 39,600	$ 13,068	$ 52,668	$ 54,775	$ 56,966
TBN	Clinical Psychologist	50%	$ 35,000	$ 11,550	$ 46,550	$ 48,412	$ 50,348
TBN	Social Worker	100%	$ 51,915	$ 17,132	$ 69,047	$ 71,809	$ 74,681
TBN	Health Educator	50%	$ 16,750	$ 5,528	$ 22,278	$ 23,169	$ 24,096
TBN	Outreach Worker	50%	$ 13,750	$ 4,538	$ 18,288	$ 19,020	$ 19,781
TBN	Genetic Counselor	50%	$ 18,150	$ 5,990	$ 24,140	$ 25,106	$ 26,110
TBN	Drug Counselor	50%	$ 24,200	$ 7,986	$ 32,186	$ 33,473	$ 34,812
Subtotal			**$ 440,617**	**$ 145,405**	**$ 586,022**	**$ 609,462**	**$ 633,841**
Malpractice Insurance*					$ 22,714	$ 26,121	$ 30,039
Cell phone service-(Blackberry level) 11@$70/mth					$ 9,240	$ 9,240	$ 9,240
Travel-in State**					$ 45,613	$ 45,613	$ 45,613
Lap top computers					$ 9,900	0	0
Supplies					$ 10,000	$ 10,000	$ 10,000
Total Direct Costs					**$ 683,489**	**$ 700,436**	**$ 728,733**
Indirect Costs @ 8% (salary and benefits only)					$ 46,882	$ 48,757	$ 50,707
Total Budget					**$ 730,371**	**$ 749,193**	**$ 779,440**

* $7,098 JHH malpractice for non-invasive physician or PA x 3.2 FTE

** 300mi/wk x 6 people x 50wks @$.445/mi plus 50mi/wk x 5 people X 50wks @$.445/mi