



March 1, 2010

Delegate Peter Hammen, Chairman
Delegate Shane Pendergrass, Vice Chairman
House Health & Government Operations (HGO) Committee
241 Lowe House Office Building
Annapolis, MD 21401-1991

RE: House Bill 333—Support

Dear Chairman Hammen and Vice Chairman Pendergrass:

On behalf of Children's National Medical Center (Children's National,) I am pleased to support House Bill (HB) 333, "State Government - Sickle Cell Anemia Awareness Month." Children's National commends Delegates Jay Walker and Nathaniel Oaks for their leadership in introducing this bill, which would require the Governor to proclaim annually the month of September to be "Sickle Cell Anemia Awareness Month".

Children's National Medical Center, a 283 bed not-for-profit academic medical center, is located in Washington, DC, but serves the pediatric health care needs of the broader Washington metropolitan region. Located just three miles from the Maryland border, Children's National annually devotes nearly 60% of its inpatient care to children from Maryland. With five outpatient centers in Maryland and specialty care services provided in eight Maryland locations, Children's National is proud to be one of the largest providers of high quality pediatric primary, specialty and emergency care to Maryland's children and families.

The Sickle Cell program at Children's National is one of the busiest in the country, treating more than 1,400 patients each year. Advocating for patients with sickle cell is a key initiative at Children's Child Health Advocacy Institute where we are collaborating with a number of national organizations to bring awareness of the disease to the forefront, and work to improve the lives of pediatric patients who suffer from the debilitating symptoms associated with the disease.

We work closely with The Bobby Engram Foundation; we participate annually in the Sickle Cell Walk; and Children's National hosted a celebration in honor of the first annual United Nations Sickle Cell Awareness Day in April, 2009.

Sickle Cell Disease (SCD) is a global health problem impacting over 30 million individuals worldwide. In the United States, it is the most common inherited blood disorder, with more than 70,000 Americans with SCD and over 2 million genetic carriers. The 2,200 children born each year with the condition makes SCD the most common

disorder detected by neonatal blood screening. The incidence of SCD exceeds that of most other serious genetic disorders, including cystic fibrosis and hemophilia.

SCD occurs in 1 of every 500 African-American births and 1 of every 1,000-1,400 Hispanic-American births. One of every 12 African-Americans and 1 of every 100 Hispanic-Americans are carriers of the sickle cell trait. It is a common misperception that SCD affects only people of African ancestry. SCD also occurs in persons with Greek, Italian, Turkish, Asian Indian, Saudi Arabian, Central and South American and Caribbean ancestries. There are no reliable statistics on the exact incidence and prevalence in these populations.

In Maryland, there were 1,680 children born between 7/1/1985 and 12/31/2007 identified through newborn screening with some sickling disorder requiring follow-up. There are also 275 children with other hemoglobin disorders who receive services through the Maryland Sickle Cell Disease Program.

The number of older children and adults with sickle cell disease in Maryland is difficult to ascertain. However, the best estimate from the Maryland Department of Health and Mental Hygiene is that there are 1,760 adult patients with sickle cell disease in Maryland. The best estimate of the total number of patients with sickle cell disease in Maryland is 3,543 patients. While there is an effective case management program through the Department of Health and Mental Hygiene for children with sickle cell disease, there is currently no case management service for adult sickle cell disease patients.

Approximately 47.5% of the children identified through newborn screening with sickle cell disease live in the Baltimore 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.

Estimated Incidence and Prevalence of SCD in the Washington, D.C. Metropolitan Area of Maryland

	# of Carriers	Incidence - # of Newborns/yr w/SCD	Prevalence - # children 0-17 yrs w/SCD
Calvert County	912		7
Charles County	4,277		35
Frederick County	1,649		16
Montgomery County	14,006		122
Prince George's County	46,243		352
St. Mary's County	1,166		9
		Total # in 6 counties = 44	Total # in 6 counties = 541

SCD occurs when recessive genes are combined from two carriers. Sickle Cell Disease is a group of complex inherited genetic disorders in which the red blood cells contain

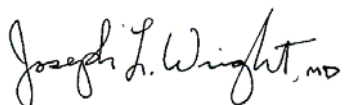
abnormal hemoglobin, the molecule that transports oxygen throughout the body. The abnormal hemoglobin, hemoglobin S, causes some red blood cells to distort into a sickle or crescent shape and become stiff. The sickle cells stick to each other and block the flow of blood through the vessels, which can result in tissue and organ damage, pain, stroke and other serious complications including death. Sickle cells also break down more rapidly than normal blood cells resulting in anemia and jaundice. The three most common types of the disease are sickle cell anemia (HbSS), sickle-hemoglobin C disease (HbSC) and sickle β -thalassemia.

Because of the complexity of the disease and the potential for life threatening complications from a very early age, specialized comprehensive medical care, including counseling and education for the patient and family, has become the standard of care, and has been shown to decrease mortality and morbidity during childhood.

Marylanders with sickle cell in clinical trials have been in the vanguard of improving lifespan and quality of life for sickle cell patients through treatment with hydroxyurea, bone marrow transplantation, pain centers, and expert management of medical complications like stroke and pulmonary hypertension. The national headquarters of the Sickle Cell Disease Association of America is in Maryland. The Maryland Department of Health and Mental Hygiene's newborn screening and follow-up for sickle cell is considered a model program for other states. Medical centers in Maryland (the National Institute of Health, Johns Hopkins Medical Institutions) and adjacent centers employing Marylanders (Howard University Hospital, Children's National) continue to lead the fight against sickle cell disease.

Children's National Medical Center is committed to policies that improve the health and well-being of the children we serve. In fact, it is part of Children's National's mission to improve health outcomes for children regionally, nationally and internationally. As such, Children's National Medical Center respectfully urges the Committee to give a favorable report to HB 333. The declaration of September as Sickle Cell Disease Month would facilitate the education of Marylanders about this disease and increase their understanding about its diagnosis and treatment.

Sincerely,

A handwritten signature in black ink that reads "Joseph L. Wright, MD". The signature is written in a cursive style with a clear, legible font.

Joseph L. Wright, MD, MPH
Senior Vice President, Child Health Advocacy Institute
Children's National Medical Center

CC: Members of the House HGO Committee
Delegate Jay Walker