



## Legislation Details (With Text)

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**Title:** Authorizing Council's Committees on the Public Safety and Public Health and Human Services to conduct joint public hearings to investigate funding opportunities for the research towards the cure of Sickle Cell disease underway at the Children's Hospital of Philadelphia.

**Sponsors:** Councilmember Jones, Councilmember Tasco

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6/4/2015	0	CITY COUNCIL	Introduced and Ordered Placed on This Week's Final Passage Calendar	Pass	
6/4/2015	0	CITY COUNCIL	ADOPTED		

Authorizing Council's Committees on the Public Safety and Public Health and Human Services to conduct joint public hearings to investigate funding opportunities for the research towards the cure of Sickle Cell disease underway at the Children's Hospital of Philadelphia.

WHEREAS, Sickle cell disease is the most common inherited disorder among African-Americans. Roughly, 1 in 12 African-Americans is a silent carrier of the disease and it affects 1 in 375 births. It is also common in those of Caribbean Ancestry. It has also been found in Latin America, the Mediterranean, the Middle East and India; and

WHEREAS, There are currently 100,000 individuals with sickle cell disease in the United States alone and many millions worldwide; and

WHEREAS, Sickle cell disease is caused by a mutation of the beta-globin gene which turns a normally soft, round red blood cell into a stiff, sickle-shaped one. These sickle cells tend to get stuck in and block small blood vessels, leading to debilitating pain crises. These blockages, which over time will damage body organs, can also cause fatal strokes and heart attacks. About 15% of children with sickle cell require frequent blood transfusions to prevent stroke. With few normal red blood cells to carry oxygen to the body, people with the disease are easily fatigued. This oxygen deprivation can also damage organs; and

WHEREAS, Living with sickle cell disease is a constant struggle and the burden on children is particularly heavy. In addition to living with extreme pain, affected children are prone to chronic infections, which can be life threatening; and

WHEREAS, It requires constant vigilance to keep children with sickle cell disease healthy. Often these children live with the difficult knowledge that their lives may be cut short: although research efforts are underway to develop new treatments that we hope will extend their lives significantly, the disease is often fatal in one's 40s; and

WHEREAS, Children's Hospital of Philadelphia (CHOP) makes it a priority to push forward with sickle cell research and enhance clinical care for those deserving children; and

WHEREAS, With more than 1000 families under its care, the comprehensive sickle cell center at CHOP is one of the largest, more renowned centers for children and adolescents living with sickle cell anemia; and

WHEREAS, The center is staffed by a multidisciplinary team of pediatric hematologist, hematology nurse-specialists, and social workers. Each patient is assigned a physician who managed his or her outpatient care. Patient and family education is incorporated into all clinic visits as part of comprehensive care; and

WHEREAS, Their patients have access to pediatric general surgeons, orthopedic surgeons, ophthalmologists, neurologists and pulmonologists with expertise in sickle cell disease; and

WHEREAS, The Children Hospital of Philadelphia is making progress with finding a cure for the sickle cell disease under the leadership of Alan Flake, MD who has dedicated nearly 30 years toward developing a pioneering procedure that promises to be an actual cure for all children who inherit the genes that cause sickle cell disease; now, therefore, be it

RESOLVED, BY THE COUNCIL OF THE CITY OF PHILADELPHIA, That the Committee on Public Safety and Public Health and Human Services is hereby authorized to hold public hearings to investigate funding opportunities for the research towards the cure of Sickle Cell disease underway at the Children's Hospital of Philadelphia.