

Legislation Text

File #: 210554, **Version:** 0

Urging the Pennsylvania Department of Public Health to restore funding to the Philadelphia/Delaware Valley Chapter of the Sickle Cell Disease Association of America, and recognizing the SCDAА/PDVC's nearly 39-year dedication to providing culturally competent services and to raising awareness of the serious condition of sickle cell disease.

WHEREAS, The Philadelphia/Delaware Valley Chapter of the Sickle Cell Disease Association of America (SCDAА/PDVC) has been serving people living with sickle cell disease in Montgomery, Delaware, Bucks, Chester, and Philadelphia counties since the chapter's inception in July 1982; and

WHEREAS, Sickle cell disease is a hereditary red blood cell disorder affecting approximately 100,000 individuals in the United States and over 4,000 residents served by the SCDAА/PDVC. Sickle cell disease disproportionately affects people of African descent, occurring in 1 out of every 500 Black Americans. 1 in every 12 Black Americans is a carrier of the sickle cell trait; and

WHEREAS, Individuals affected by sickle cell disease experience debilitating symptoms including chronic pain, anemia-induced fatigue, frequent infections, and severe swelling of the hands and feet. These symptoms can have severe effects on the employment and mental health of people living with sickle cell disease, making community-based support services particularly vital for both those affected by the disease, as well as their family and loved ones; and

WHEREAS, Culturally competent outreach and care is particularly crucial to effectively address sickle cell disease, due to persistent racism and racial health disparities that prevent many Black Americans from getting the medical care and treatment they need. Data shows that people living with sickle cell disease too often receive poor care or are not given needed pain relief or preventative treatments that may limit serious complications due to racist stereotypes; and

WHEREAS, The SCDAА/PDVC has provided community-based psychosocial and social services to children, adolescents, adults, and families living with sickle cell disease and the sickle cell trait in the Philadelphia area for the last 39 years. These services include case management, single gene genetic counseling, hospital, clinic, and home visitation, advocacy support, newborn screening follow-ups, round-trip transportation for pediatric families, patient/parent support groups, community outreach & education, resources and referrals for housing, food, clothing, and utility assistance; and

WHEREAS, The SCDAА/PDVC had received the majority of its funding from the Pennsylvania Department of Public Health for twenty years as the only organization in the area that provides community-based services and support for the sickle cell community; and

WHEREAS, During the Covid-19 crisis last year, the PA Department of Public Health unexpectedly did not fund the SCDAА/PDVC and then put out its longstanding contract for bidding, ultimately awarding the funding to an out of state for-profit corporation that does not specialize in sickle cell; and

WHEREAS, The SCDA/PDVC will not be able to continue operations without the reinstatement of its longstanding funding. This would be an enormous loss for the Philadelphia area sickle cell community, which relies on the extensive and capable services that the SCDA/PDVC has provided for the last 39 years. The closure of the Philadelphia and Delaware Valley Chapter of the Sickle Cell Disease Association of America would do irreparable harm to residents of the region who trust the organization's commitment to their community and rely on their services; now, therefore, be it

RESOLVED, THAT THE COUNCIL OF THE CITY OF PHILADELPHIA, Urges the Pennsylvania Department of Public Health to restore funding to the Philadelphia/Delaware Valley Chapter of the Sickle Cell Disease Association of America, and recognizes the SCDA/PDVC's nearly 39-year dedication to providing culturally competent services and to raising awareness of the serious condition of sickle cell disease.