

THE PRINCE GEORGE'S COUNTY GOVERNMENT

(301) 952-3700 County Council

POSITION STATEMENT

SB 859

Public Health – Sickle Cell Disease Registry - Establishment

Senator Watson (FIN Committee)

POSITION: SUPPORT

SB 859 – Public Health – Sickle Cell Disease Registry - Establishment – This bill requires the Maryland Department of Health (MDH) to establish a registry of individuals diagnosed with sickle cell disease (SCD). The purpose of the registry is to serve as a single repository of accurate, complete records to aid in promoting the siting of hematologist offices and health care facilities that provide "Infusion Therapy" in areas of the State with high populations of individuals with SCD. The registry must include any other information regarding individuals diagnosed with SCD necessary and appropriate. A health care provider who serves individuals with SCD must provide specified information, such as data from the designated health information exchange in the state, census-tract level data and information collected from vital records. To the extent authorized by law, MDH must periodically publish information identifying areas with high populations of individuals with SCD, which may include information published in a map.

The Prince George's County Council recognizes the following estimates as reported by the U.S. Centers for Disease Control (CDC):

- SCD affects approximately 100,000 Americans.
- SCD occurs among about 1 out of every 365 Black or African-American births.
- SCD occurs among about 1 out of every 16,230 Hispanic-American births.
- About 1 in 13 Black of African-American babies are born with the sickle cell trait.

The Council has concerns regarding the security of personal, confidential, and sensitive medical records in light of the reported cyberattacks at the MDH. It is imperative that MDH protect the privacy of medical records and adherence to the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

For the foregoing reasons, the Prince George's County Council **SUPPORTS SB 859** and respectfully requests your favorable consideration of its position.

Prepared by: Carrington & Associates, LLC

On behalf of the Prince George's County Council

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