Kennedy Krieger Institute

DATE: **March 7, 2022** **COMMITTEE: House Health and Government Operations**
BILL NO: **House Bill 1188**
BILL TITLE: **Public Health - Sickle Cell Disease and Trait - Information for Individuals and Health Care Practitioners**
POSITION: **Support**

Kennedy Krieger Institute supports House Bill 1188 - Public Health - Sickle Cell Disease and Trait - Information for Individuals and Health Care Practitioners.

Bill Summary:
House Bill 1188 requires the Maryland Department of Health (MDH) to establish and implement a system of providing information on the sickle cell trait or the thalassemia trait to the parent or guardian of an infant who is found to have the trait as determined through a newborn screening. MDH will also maintain on its website a list of resources for healthcare practitioners o use to improve their understanding and clinical treatment of individuals with sickle cell disease, or the sickle cell trait.

Background:
Kennedy Krieger Institute is dedicated to improving the lives of children and young adults with developmental, behavioral, cognitive and physical challenges. Kennedy Krieger's services include inpatient, outpatient, school-based and community-based programs. Over 25,000 individuals receive services annually at Kennedy Krieger.

The Kennedy Krieger Institute Sickle Cell Neurodevelopmental Clinic provides neurological, developmental, neuropsychological, and behavioral psychology services in a comprehensive, multi-disciplinary outpatient clinic. We also see the siblings of these children who have neurodevelopmental disorders, many of whom have sickle cell trait, both in the Sickle Cell Neurodevelopmental Clinic and other Kennedy Krieger outpatient clinics.

Rationale:
While identification of sickle cell disease is part of the newborn screen testing, people with sickle cell trait may not reliably know their trait status. Per the CDC, sickle cell trait is present in 1 out of 60 babies in the US, and disproportionately affects Black babies for whom it is present in 1 out of 13.[1] Specific information on Maryland sickle cell trait numbers is not available; a recent study noted a frequency of 9.8% of individuals with sickle cell trait in metropolitan Washington D.C.[2] While sickle cell trait can protect affected individuals from infection with malaria, this population can also have severe complications including exercise-related rhabdomyolysis and sudden death, renal complications like hematuria, renal papillary necrosis, hyposthenuria, renal medullary cancer, and venous thromboembolism.[3,4,5,6] Awareness about the risks associated with sickle cell trait would empower people to seek information regarding their own trait status, medical risk, and preventative healthcare needs.

In addition, awareness of sickle cell trait status along with genetic counseling will allow individuals to carefully weigh their reproductive decisions with regards to their risk of having a child with sickle cell trait as well as sickle cell disease. Genetic counseling may be particularly helpful for families with no prior knowledge of sickle cell trait or sickle cell disease and may also inform them regarding future consideration of prenatal genetic testing.[7,8] Given the high rates of sickle cell trait, increased public awareness of these issues can allow families to better prepare themselves, emotionally, physically, and financially for these considerations.

Kennedy Krieger Institute requests a favorable report on House Bill 1188.

References

[1] https://www.cdc.gov/ncbddd/sicklecell/data.html
[2] Niu X, Parry CS, Mason A, et al. Prevalence of Sickle Cell Trait and Rare Hemoglobin Variants in the Metropolitan Washington DC Area. J Hematol. 2020;9(3):93-95. doi:10.14740/jh603
[3] Naik RP, Haywood C Jr. Sickle cell trait diagnosis: clinical and social implications. Hematology Am Soc Hematol Educ Program. 2015;2015(1):160-7.
[4] Tsaras G, Owusu-Ansah A, Boateng FO, Amoateng-Adjepong Y. Complications associated with sickle cell trait: a brief narrative review. Am J Med. 2009 Jun;122(6):507-12.
[5] Pecker LH, Naik RP. The current state of sickle cell trait: implications for reproductive and genetic counseling. Blood. 2018 Nov 29;132(22):2331-2338.
[6] Liem RI. Balancing exercise risk and benefits: lessons learned from sickle cell trait and sickle cell anemia. Hematology Am Soc Hematol Educ Program. 2018 Nov 30;2018(1):418-425.
[7] Grossman LK, Holtzman NA, Charney E, Schwartz AD. Neonatal screening and genetic counseling for sickle cell trait. Am J Dis Child. 1985 Mar;139(3):241-4.
[8]Stevens EM, Patterson CA, Tchume-Johnson T, Antiel RM, Flake A, Smith-Whitley K, Barakat LP. Parental Attitudes Towards Prenatal Genetic Testing For Sickle Cell Disease. J Pediatr Hematol Oncol. 2019 Nov;41(8):579-585.