



DATE: March 7, 2022 **COMMITTEE:** House Health and Government Operations
BILL NO: House Bill 1192
BILL TITLE: Maryland Health Care Commission - Studies of Issues Affecting Individuals With Sickle Cell Disease
POSITION: Support

Kennedy Krieger Institute supports House Bill 1192 - Maryland Health Care Commission - Studies of Issues Affecting Individuals with Sickle Cell Disease

Bill Summary:

House Bill 1192 the Maryland Health Care Commission (MHCC), in consultation with the Maryland Department of Health, experts and stakeholders, to conduct a study on individuals who provide medical services and their knowledge of sickle cell disease. On or before July 1, 2023, MHCC will report its findings and recommendations from this study to the Maryland General Assembly.

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:

As children living with sickle cell disease transition to adult health care, coordination of services between hematology and primary care clinicians is paramount. Given the high rates of neurological and neurodevelopmental complications in these patients, similar provisions are necessary for specialty providers in these areas. While few neurodevelopmental clinicians have been trained to provide medical care for pediatric patients with developmental and cognitive difficulties, even fewer clinicians are available for transition of care when pediatric sickle cell disease patients become adults. Information regarding transitions in primary care, hematological, and other subspecialty care for these patients will help inform the complex healthcare needs of these patients as adults, improve the care coordination process, and increase the quality of care these vulnerable patients receive.

Kennedy Krieger Institute requests a favorable report on House Bill 1192.