

DATE: March 15, 2022 COMMITTEE: House Health and Government Operations

BILL NO: House Bill 987

BILL TITLE: General Provisions - Sickle Cell Anemia Awareness Month

POSITION: Support

Kennedy Krieger Institute supports House Bill 987 - General Provisions - Sickle Cell Anemia Awareness Month

Bill Summary:

House Bill 987 requires the Governor to annually proclaim the month of September as Sickle Cell Anemia Awareness month. The proclamation will urge educational and public health organizations to observe Sickle Cell Anemia Awareness month with appropriate programs, events and activities.

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:

Sickle cell disease is an inherited hemoglobinopathy affecting approximately 100,000 Americans¹. People living with sickle cell disease suffer from a variety of systemic complications, including, but not limited to, pain crises, neurodevelopmental disabilities, severe infections, and stroke. These issues have a high likelihood of impacting their educational attainment, employment options, quality of life, and life expectancy. Increased awareness about sickle cell disease through the proposed legislation is an effective approach to educating others in the broader community about the real world experiences of patients living with sickle cell disease and their families. This approach will also help to educate the sickle cell disease community about services and resources available to them.

Kennedy Krieger Institute requests a favorable report on House Bill 987.

References

¹ https://www.cdc.gov/ncbddd/sicklecell/data.html