



Kennedy Krieger Institute

**Bradley L. Schlaggar, MD, PhD**

President and CEO

Zanvyl Krieger Faculty Endowed Chair

*A comprehensive resource  
for children with disabilities*

March 7, 2022

The Honorable Shane Pendergrass  
Chair, House Health and Government Operations Committee  
Room 241 House Office Building  
Annapolis, MD 21401

**Re: Letter of Information on House Bill 1176 - Public Health - Sickle Cell Disease Registry - Establishment**

Dear Chair Pendergrass:

Kennedy Krieger Institute applauds Delegate McComas for her sponsorship of House Bill 1176 and for advocating for individuals with sickle cell disease.

At Kennedy Krieger Institute, we have a Sickle Cell Neurodevelopmental Clinic. This clinic provides neurological, developmental, neuropsychological, and behavioral psychology services in a comprehensive, multi-disciplinary outpatient clinic.

This legislation would allow identification of communities that have statistically high populations of individuals with sickle cell disease. This information would facilitate Maryland's ability to implement needed improvements in regional services for these patients and significantly broaden knowledge of extant local resources in these areas. The clear objective is to empower people to access specialty healthcare services.

While Kennedy Krieger agrees with the excellent intentions of this proposed legislation, we have concern for the privacy of the individuals living with sickle cell disease. Given the critical obligation to protect the privacy of registrants, we recommend that the General Assembly outlines specifically how the Department of Health will utilize and protect the data collected.

Additionally, to effectively disseminate information to high-risk communities, Kennedy Krieger recommends that the Department engage with people living with sickle cell disease, with sickle cell disease community organization leaders, and with clinical providers all to ensure successful communication campaigns and engender trust with this vulnerable population.

We deeply appreciate the efforts of the Committee.

Respectfully,

Bradley L. Schlaggar, MD, PhD  
President and CEO  
Kennedy Krieger Institute

Eboni Lance, MD, PhD  
Medical Director, Sickle Cell Neurodevelopmental Clinic  
Kennedy Krieger Institute