

Testimony of Derek Robertson, MBA, JD, CHC
President, The Maryland Sickle Cell Disease Association
Before the Health and Government Operations Committee
Maryland House of Delegates
March 7, 2022

House Bill 1185 - Public Health – Sickle Cell Disease – Referral for Transcranial Doppler Ultrasound

Good afternoon, my name is Derek Robertson. I am the President and co-founder, along with my wife Shantá, of the Maryland Sickle Cell Disease Association (MSCDA) based in Columbia, MD. My wife and I have three sons, two of whom have Sickle Cell Disease (SCD).

Chairperson Pendergrass thank you or the opportunity to talk with your committee today about sickle cell disease. Delegate Patterson, thank you for tireless efforts to improve the lives of persons affected by of sickle cell disease and for sponsoring this Bill. MSCDA is in favor of House Bill 1185 because it will help reduce the likelihood of children in Maryland who have SCD from having a stroke.

According to a 2010 study, there are approximately 4,000 people in Maryland living with SCD.¹ It is estimated that about half the population are children.

As many, if not all, of you are aware, SCD is an inherited blood disorder where some of the patient’s red blood cells are shaped like a sickle instead of being donut shaped. Red blood cells carry life sustaining oxygen to all of organs and must flow smoothly through our blood system. With SCD, the red blood cells that are sickled shaped are sticky and don’t carry oxygen effectively. The stickiness of the cells cause the cells to clump together and block the flow of blood. This “clumping” known as a vaso-occlusive crisis is the cause for extreme pain that characterizes SCD. As bad as it is, the excruciating pain faced by SCD patients is not the only complication of SCD. “Sickling” of red blood cells takes place in every organ leading to the breaking down of organs such as the eyes, kidneys, joint damage and even stroke.

This bill is needed for the following reasons:

- **Without effective screening and treatment to prevent stroke, about 1 in 10 children with Sickle Cell Disease experience a stroke by 18**
- A transcranial doppler ultrasound (TCD) can be used to detect whether a child with SCD is likely to have a stroke
- Only 33% of children with stroke complete high school in four years because of the significant physical and neurocognitive impairment caused by stroke and school failure is common
- The cost for a single child who develops stroke and requires rehabilitation and regular monthly transfusion is approximately \$80,000/year

¹ Hassell, *Am J Prev Med* 2010;38(4S):S512–S521. Table 3, Using CDC Data corrected for early mortality in HbSS.

- With 75% of SCD patients on Medicaid, the State will likely bear the brunt of such costs

HB 1185 can set the stage for a comprehensive TCD screening program to prevent children with SCD having to endure the lifelong consequences of a devastating stroke. It is for these reasons MSCDA is in favor of House Bill 1185.

Thank you Chairperson Pendergrass for allowing my testimony, and thank you Del. Patterson for sponsoring this Bill.

If you have any questions, I can be reached at 240-447-8728 or at mscdainfo@verizon.net.