Testimony of Derek Robertson, MBA, JD, CHC
President, The Maryland Sickle Cell Disease Association
Before the Finance Committee
Maryland Senate
March 31, 2022
Position: Favorable

House Bill 1188 - Public Health – Sickle Cell Disease

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 Kelley thank you or the opportunity to provide your committee with this testimony 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 1188 because it will bring much needed awareness and education about SCD and sickle cell trait (SCT).

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.

The need for a Bill such as this was identified Maryland Statewide Steering Committee on Services for Adults with Sickle Cell Disease in their report to the legislature over ten years ago in 2008. In that report, the Committee recommended significant improvements in the quality of life for adults living with SCD, "along with significant savings for the state of Maryland" could be achieved by doing the following:

- Enhance patient education to include appropriate pain self-management and information about the range of evidence-based treatment options
- Increase public awareness and education about sickle cell disease and sickle cell trait

This bill is still today needed for the following reasons:

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

- Some individuals with SCT are at risk for certain conditions, including hematuria (blood in the urine), renal medullary carcinoma (a rare kidney cancer), complications with trauma to the eye, spleen tissue death at high altitudes, and false positives on A1C type 2 diabetes tests.
- Knowing their status is important for carriers of SCT to have discussions with their health care provider;
- Given that SCD occurs when both parents have SCT, it is important for individuals with SCT to know their status so they can make informed reproductive decisions;
- There is a general lack of awareness and education about SCD and SCT among many health care practitioners leading to less than optimal interactions between patients and providers.
- By providing educational resources for health care practitioners, this Bill will lead to improved clinical outcomes for individuals with SCD and SCT.

HB 1188 can play a critical role in enhancing the health of individuals with SCD and SCT by ensuring there is system to provide education to patients and providers. It is for these reasons MSCDA is in favor of House Bill 1188.

Thank you Chairperson Kelley for accepting my testimony into the record of this hearing, 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.