Testimony of Derek Robertson, MBA, JD, CHC
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Before the Health and Government Operations Committee
Maryland House of Delegates
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House Bill 1306 - Public Health - Sickle Cell Disease Registry - Establishment

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 Peña-Melnyk thank you or the opportunity to talk with your committee today about sickle cell disease. Delegate Patterson, thank you for sponsoring this Bill. MSCDA is in favor of House Bill 1306 because it is critical to ensuring appropriate care reaches persons in Maryland who are living with this devastating disorder.

According to a 2010 study, there are approximately 5,000 people in Maryland living with SCD.[1] This bill will have a direct impact on these 5,000 individuals, their families and their providers.

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 and joint damage.

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 almost fifteen years ago in 2008. In that report, the Committee recommended significant improvements in the quality of life for adults living with SCD including, "(S)hifting resources toward comprehensive specialty care and preventive care models such as regional infusion centers".

This Bill is needed for the following reasons:

- Care for individuals with SCD living in MD is concentrated in Baltimore City. As a result, individuals have to travel far distances, upwards of two hours in some instances, to obtain appropriate care. This travel is often done when these individuals are in excruciating pain;

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

- Individuals with SCD should not have to leave the county in which they live to seek care. In 2006, my family relocated from Germantown in Montgomery County to Ellicott City, in Howard County so our children could have easier access to Johns Hopkins. Today, nineteen years later, there are families in Montgomery County considering this same choice and that should not be the case. There are many families where relocating is not an option;
- Having care close to where one lives improves health outcomes and saves costs. The state funded Community Health Resources Commission has supported a model in Prince George's County that established a local SCD clinic that partners with SCD experts in Baltimore City and community-based organizations. **This model has resulted in a 63% reduction in emergency room visits and a 41% reduction in hospital admissions** (see poster below);
- This Bill would replicate the successful Prince George's County model to the counties most in need;
- Most importantly, the Bill will result in focused efforts to provide expert care to this vulnerable, underserved population which will lead to improvement in health care outcomes, including better access to new treatments or cures.
- Improved access to care has also been demonstrated to decrease costs of care.

HB 1306 can address these needs immediately and will move Maryland in the direction of having a comprehensive approach to the delivery of healthcare services to person living with sickle cell disease. It is for these reasons MSCDA is in favor of House Bill 1306.

Thank you Chairperson Peña-Melnyk 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.