

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
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House Bill 1176 - 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 Pendergrass thank you for the opportunity to talk with your committee today about sickle cell disease. Delegate McComas, thank you for sponsoring this Bill. MSCDA is in favor of House Bill 1176 because it is an important first step in ensuring appropriate care reaches persons in Maryland who are living with this devastating disorder.

According to a 2010 study, there are approximately 4,000 people in Maryland living with SCD.¹ This bill will have a direct impact on these 4,000 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, "along with significant savings for the state of Maryland" could be achieved by, "develop(ing) a statewide patient registry to facilitate continuity of care across health care systems and providers".

This Bill is needed for the following reasons:

- There is no accurate count of the number of patients with SCD living in MD. As a result, we do not have comprehensive data on patient outcomes or where patients receive care;
- Newborn screening only captures babies born in Maryland and its data skews to youth, while hospitalization data skews to those who are more ill;

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

- While there are four high quality pediatric comprehensive centers in Maryland there is only one adult program. To drive effective public health policy for SCD and understand where people with SCD live and receive care, the state needs a dedicated surveillance program;
- With an effective registry and surveillance program healthcare providers can understand how people interact with the healthcare system and can help identify people with SCD who may be receiving the majority of their care in the emergency department and are unaffiliated with high quality sickle expert care;
- An effective registry and surveillance program provides needed information that will allow researchers and public health professionals to know where to target activities and programs;
- 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 1176 can address these needs immediately and 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 1176.

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

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