

**Testimony of
Derek Robertson, MBA, JD, CHC
President, The Maryland Sickle Cell Disease Association
8775 Centre Park Drive, #701, Columbia, MD 21045
Before the Health and Government Operations Committee
Maryland House of Delegates
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SUPPORT

House Bill 987 - General Provisions – Sickle Cell Anemia Awareness Month

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 Walker, thank you for longstanding support of sickle cell disease and for sponsoring this Bill. MSCDA is in support of House Bill 987 because it will help raise awareness about the many needs of persons in Maryland affected by SCD.

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 tag line for MSCDA is, "Awareness. Knowledge, Cure". We chose this tag line because we believe that the journey to a cure for SCD starts with awareness. As more people are made aware of SCD and its impact on the lives of those affected, knowledge will grow, leading to a cure. We can see how other diseases have benefitted from the focus a dedicated month of activity. Perhaps most notable is the focus Breast Cancer Awareness Month brings in October.

There is a general lack of awareness and education about SCD and sickle cell trait (SCT) among many health care practitioners leading to less than optimal interactions between patients and providers.

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

Sickle cell has benefitted from September being designated Sickle Cell Disease Awareness month on the federal level. Several activities are planned during that month across the country. Having an official designation in Maryland would certainly help to focus attention on SCD and highlight the needs of the community.

HB 987 can be the catalyst for increased awareness of SCD which can lead to more resources being dedicated to SCD and sickle cell trait (SCT). Raising awareness is a critical component of improving care for persons in Maryland affected by SCD. It is for these reasons MSCDA is in support of House Bill 1185.

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

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