

Testimony of Derek Robertson, MBA, JD, CHC
President, The Maryland Sickle Cell Disease Association
Before the Senate Finance Committee
Maryland Senate
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FAVORABLE

Senate Bill 883 - Public Health – Sickle Cell Disease – Testing at a Community–Based Health Fair

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 talk with your committee today about sickle cell disease. Senator Watson, thank you for sponsoring this Bill. MSCDA is in favor of Senate Bill 883 because it will allow for the identification of individuals, particularly those with sickle cell trait (SCT), and help raise awareness about SCD and SCT.

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.

This Bill is needed for the following reasons:

- Most parents do not remember their child’s or, children’s, newborn screening (NBS) results and most teenagers do not know their SCT status.
- NBS only captures babies born in Maryland.
- With migration and immigration testing of teens and adults is necessary. Maryland does not do any follow up on children who test positive for SCT.
- Testing will help identify persons with SCT and they need to be identified for two main reasons:
 1. Knowing their status is important for carriers of SCT to have discussions with their health care provider. Certain 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.

2. 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. Testing will help raise awareness in the community.

SB 883 can address these needs immediately by increasing awareness and knowledge of sickle cell trait and disease. It is for these reasons MSCDA is in favor of Senate Bill 883.

Thank you, Chairperson Kelley, for allowing my testimony, and thank you Sen. Watson for sponsoring this Bill.

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