

SB_883_Maryland Sickle Cell Disease Association_FA

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Testimony of Derek Robertson, MBA, JD, CHC
President, The Maryland Sickle Cell Disease Association
Before the Senate Finance Committee
Maryland Senate
March 16, 2022

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.

Public Health - Sickle Cell Disease - Testing at a

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**Written Testimony Submitted for the Record to the
Maryland Senate
Finance Committee
For the Hearing on
Public Health - Sickle Cell Disease - Testing at a Community-Based Health Fair (SB 883)
March 16, 2022**

SUPPORT

Free State PTA represents over 40,000 volunteer members and families in over 500 public schools. Free State PTA is comprised of families, students, teachers, administrators, and business as well as community leaders devoted to the educational success of children and family engagement in Maryland. As the state's premier and largest child advocacy organization, Free State PTA is a powerful voice for all children, a relevant resource for families, schools and communities and a strong advocate for public education.

Free State PTA submits this testimony enthusiastically *in support* of Senate Bill 883 – Public Health - Sickle Cell Disease - Testing at a Community-Based Health Fair. This is a very simple bill that broadens the opportunity to test individuals for the sickle-cell disease by allowing professionals the opportunity to test for this disease at a community-based health fair.

A community health fair is defined as an event that offers health care services to an individual for free or using a sliding fee scale that is sponsored by the three core levels of government, a 501c (3) nonprofit or a nonprofit community organization whose purpose is providing health care services to low-income individuals.

For years now, the PTA supports guidelines that highlight the need to address the health care concerns of children who have the sickle-cell disease. In particular, Chapter 385 of Acts of 2018, Public Schools – Students With Sickle Cell Disease – Guidelines required public schools to establish guidelines on the [administration](#) of health care services to students with sickle cell disease. The sickle-cell disease can be painful and oftentimes parents and children themselves are not aware that they may have the disease. Broadening the opportunity for testing of sickle-cell disease in the community increases the chances of addressing health ailments among youth much sooner and can possibly save their lives and that of their family members.

Free State PTA supports health services that appropriately reflect the community's commitment to address identified health problems that limit students' abilities to learn. The core way that sickle-cell disease limits a student's opportunity to learn is when they confront a health crisis that results in absenteeism from school and perhaps homecare. Indirectly, if their parents undergo a health crisis, then they aren't available for students at home because they are hospitalized. Community testing is a way to mitigate potential problems and begin to develop a network of [resources](#) to help families and communities live with sickle-cell in a manageable fashion. As the PTA is a 501c (3) nonprofit our local constituent units can be involved by using their parent members who may be health care professionals.

To allow testing for sickle-cell at a community health fair is in direct alignment of the Free State PTA's support for parent, family and community education that includes research and awareness of issues that affect children's

health and welfare. With the passage of such a bill, it will help our Association continue our advocacy for health and safety campaigns to properly identify, treat, and resolve those having a sickle-cell disease crisis.

It is for these reasons that Free State PTA urges you to support SB 883.

Testimony is presented on the behalf of

Marla Posey-Moss

Marla Posey-Moss, President

Free State Parent Teacher Association

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SB 883 Senator Watson FAV.pdf

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RON WATSON, PH.D
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The Senate of Maryland

ANNAPOLIS, MARYLAND 21401

March 16, 2022

To Chair Kelley, Vice-Chair Feldman, and the members of the Finance Committee:

Thank you for the opportunity to present this legislation before you today.

Dr. Sophie Lanzkron is the Director of the Adult Sickle Cell Clinic at John Hopkins and Co-Chair of the Maryland Statewide Steering Committee on Services to Adults with Sickle Cell Disease. In December 2008, the committee issued its report advising the public and its officials of the situation in Maryland: Expanding Comprehensive Services for Adults with Sickle Cell Disease. After the report was issued, the Committee went dormant until it was reactivated in 2019. However, Dr. Lanzkron, would be quick to tell you there is no funding for the committee to support any needed sickle cell outreach programs or to expand the services to those suffering the devastating effects of Sickle Cell Disease. There is a need to inform the public through testing and counseling upon a positive diagnosis of Sickle Cell Disease and to inform the public through testing and counseling upon a Sickle Cell Trait positive test.

Although testing for SCD is done at birth in Maryland, many mothers do not remember the results of such tests. This is somewhat underscored by the lack of counseling that should be provided at the time that such test results are disclosed. Counseling is in fact an important component of treatment. Health care fairs are an excellent way of providing information about the available resources for treatment and counseling and the psychosocial issues and genetic considerations related to a positive test for Sickle Cell Disease or Trait.

Health Care Fairs are not the fix-all solution to the medical needs of the SCD Warriors. However, this is a step in the right direction in an effort to test and treat those afflicted, and to distribute information in areas underserved by service providers that are trained in the diagnosis and treatment of the chronic conditions suffered as a result of the disease. Testing and subsequent counseling will aid those in the future to make decisions about family planning and Testing at health fairs could be conducted at the outset in those areas that have a concentration of SCD cases, and later expanded as the results and concentration of patients are determined. Testing provides the information needed to make sound decisions, and local health fairs provide a perfect venue for this testing. **For these reasons, I respectfully urge a favorable vote for SB 883.**

Sincerely,

A handwritten signature in blue ink that reads "Ron L. Watson".

Senator Ron Watson

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Position: INFO



Larry Hogan, Governor · Boyd K. Rutherford, Lt. Governor · Dennis R. Schrader, Secretary

March 16, 2022

The Honorable Delores G. Kelley
Chair, Senate Finance Committee
3 East Miller Office Building
Annapolis, MD 21401-1991

Re: SB 883 – Public Health – Sickle Cell Disease – Testing at a Community-Based Health Fair - Letter of Information

Dear Chair Kelley and Committee Members:

The Maryland Department of Health (MDH) respectfully submits this letter of information for Senate Bill (SB) 883 - Public Health – Sickle Cell Disease – Testing at a Community-Based Health Fair. SB 883 requires MDH to authorize qualified individuals to offer and perform laboratory testing for detecting sickle cell disease at community-based health fairs.

Under Md. Code Ann. Health-General, § 13-111, MDH’s Laboratories Administration Division of Newborn and Childhood Screening is mandated to conduct hereditary and congenital screening for all infants born in the State of Maryland. Infants are screened for approximately 61 primary and secondary known disorders to determine those at risk for particular disorders and those who may need additional diagnostic testing. This screening includes sickle cell trait and disease testing.

Additionally, MDH provided testing services for sickle cell in adults through 2019. However, the testing services stopped because MDH only received a few specimens per year. In fact, only eight (8) specimens were received for testing in 2018 and three (3) were received in 2019. Therefore, the cost to maintain the equipment/instruments, reagents, and supplies was considerable in comparison to the total number of specimens received for adult sickle cell testing.

Lastly, MDH is not aware of any U.S. Food and Drug Administration (FDA) approved Clinical Laboratory Improvement Amendments (CLIA) waived tests for sickle cell that can be used at community-based health fairs.¹ Screening for sickle cell has been designated by the FDA as a high complexity test and as such, Maryland cannot waive the federal requirement for this level of testing to be performed in a CLIA certified high complexity lab. If SB 883 is enacted, samples

¹ The Centers for Medicare & Medicaid Services (CMS) regulates all laboratory testing (except research) performed on humans in the U.S. through the Clinical Laboratory Improvement Amendments (CLIA). In total, CLIA covers approximately 260,000 laboratory entities.

will need to be collected at community-based health fairs in compliance with CLIA regulations and forwarded to MDH for testing. In order to reinstate adult sickle cell testing in the MDH lab, additional staff, equipment, reagents and supplies for testing and follow-up services on positive screening results will be required.

If you have any questions or need additional information, please feel free to contact Ms. Heather Shek, Director of the Office of Governmental Affairs at heather.shek@maryland.gov or (410) 260-3190.

Sincerely,

A handwritten signature in cursive script that reads "Dennis R. Schrader". The signature is written in black ink and is positioned above the typed name.

Dennis R. Schrader
Secretary