HB 1188 - Public Health – Sickle Cell Disease and
Uploaded by: Brian Sims
Position: FAV

Maryland
Hospital Association

March 31, 2022

To: The Honorable Delores G. Kelley, Chair, Senate Finance Committee

Re: Letter of Support- House Bill 1188 - Public Health - Sickle Cell Disease and Trait - Information for Individuals and Health Care Practitioners

Dear Chair Kelley:

On behalf of the Maryland Hospital Association's (MHA) 60 member hospitals and health systems, we appreciate the opportunity to comment in support of House Bill 1188.

As part of MHA's commitment to racial equity, Maryland hospitals are evaluating factors inside and outside of their organizations to promote racial equity and opportunities to address social determinants impacting Marylanders' health. We are working with members of our Diversity, Equity & Inclusion Advisory Group and Health Equity Task Force to identify partners and external opportunities to support these efforts. Hospitals are committed to embracing culturally responsive strategies to address disparities in health outcomes to ensure all Marylanders can be as healthy as possible.

HB 1188 requires the Maryland Department of Health to establish and implement a system to provide information on the sickle cell trait (SCT) or the thalassemia trait to certain individuals. SCT impacts one in 12 Blacks or African Americans in the United States—almost three times that of their white counterparts.[1,2] The thalassemia trait, while rarer, occurs most often in African Americans and in people of Mediterranean and Southeast Asian descent.[3]

Sickle cell disease (SCD) is a genetic condition that is present at birth. It is inherited when a child receives two sickle cell genes—one from each parent. A person with SCD can pass the disease or SCT on to their children. SCD can cause a constant shortage of red blood cells. Due to the mutation of the red blood cells, when they travel through small blood vessels, they get stuck and clog the blood flow.[1] This can cause pain and other serious problems.

It is important for individuals to know what SCT is, how it can affect them, and if and how SCD runs in their family. If left undetected and untreated, SCD can lead to severe health problems and even death, early in childhood. Addressing the underlying causes contributing to the racial

[1] *What you should know about sickle cell trait*. (n.d.). Retrieved March 3, 2022, from https://www.cdc.gov/ncbddd/sicklecell/documents/SCD%20factsheet_Sickle%20Cell%20Trait.pdf

[2] MediLexicon International. (n.d.). *Sickle cell anemia in African Americans: Symptoms, causes, and more*. Medical News Today. Retrieved March 3, 2022, from https://www.medicalnewstoday.com/articles/african-american-anemia#causes

[3] Mayo Foundation for Medical Education and Research. (2021, November 17). *Thalassemia*. Mayo Clinic. Retrieved March 3, 2022, from https://www.mayoclinic.org/diseases-conditions/thalassemia/symptoms-causes/syc-20354995

disparities in health outcomes and meeting the unique needs of individuals predisposed to genetic conditions will promote increased health equity and ensure progress on the state's population health goals.

For these reasons, we urge a **favorable** report on HB 1188.

For more information, please contact:
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HB 1188_MSCDA_FAV.pdf
Uploaded by: Derek Robertson
Position: FAV

Testimony of Derek Robertson, MBA, JD, CHC
President, The Maryland Sickle Cell Disease Association
Before the Finance Committee
Maryland Senate
March 31, 2022
Position: Favorable

House Bill 1188 - Public Health – Sickle Cell Disease

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 provide your committee with this testimony about sickle cell disease. Delegate Patterson, thank you for tireless efforts to improve the lives of persons affected by of sickle cell disease and for sponsoring this Bill. MSCDA is in favor of House Bill 1188 because it will bring much needed awareness and education about SCD and sickle cell trait (SCT).

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 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 over ten 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 doing the following:

- Enhance patient education to include appropriate pain self-management and information about the range of evidence-based treatment options
- Increase public awareness and education about sickle cell disease and sickle cell trait

This bill is still today needed for the following reasons:

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

- Some 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.
- Knowing their status is important for carriers of SCT to have discussions with their health care provider;
- 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 among many health care practitioners leading to less than optimal interactions between patients and providers.
- By providing educational resources for health care practitioners, this Bill will lead to improved clinical outcomes for individuals with SCD and SCT.

HB 1188 can play a critical role in enhancing the health of individuals with SCD and SCT by ensuring there is system to provide education to patients and providers. It is for these reasons MSCDA is in favor of House Bill 1188.

Thank you Chairperson Kelley for accepting my testimony into the record of this hearing, 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.

E. Patterson HB 1188 Final LOS.pdf
Uploaded by: Edith Patterson
Position: FAV

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March 31, 2022

Delegate Shane Pendergrass
Chair, HGO

Delegate Joseline Pena-Melnyk
Vice Chair, HGO

Dear Chair Pendergrass and Members of the Committee:

The Legislative Black Caucus of Maryland (LBCM) has voted to offer **favorable** support for HB1188- Sickle Cell Disease. This legislation requires the Maryland Health Care Commission to conduct studies: on individuals who provide medical services in emergency departments and their knowledge of SCD.

In addition the bill requires the Maryland Department of Health to establish and implement a system of providing information on the Sickle Cell Trait to certain individuals; the Department to maintain a website of resources and update the resources; requires the State Board to include certain information and resources in the renewal notices sent to licensees; and general information for individuals and health care practitioners on SCD and trait. It also requires physicians/medical providers to refer minor patients who has SCD to a hematologist for a transcranial doppler ultrasound to monitor the effect of the lack of blood flow to the brain and allow hematologists to initiate therapies to negate strokes.

Sickle Cell Disease (SCD) is one of the world's foremost, potential lethal, genetic diseases that has severe physical, psychological and social consequences for those affected and their families. Sick Cell Disease is largely found in the African American communities. It occurs among about 1 out of 365 African-American births. About 1 in 13 African American babies is born with the Sickle Cell Trait. SCD can be treated but not easily cured so lifelong care to prevent or treat problems from SCD is critical. For these reasons, the Legislative Black Caucus of Maryland, Inc. supports HB 1188.
Respectfully,

Darryl Barnes

Darryl Barnes
Chair, Legislative Black Caucus of Maryland

Melissa Wells

Melissa Wells
1st Vice Chair, Legislative Black Caucus of Maryland

HB 1188 Senate 03312022 Finance.pdf
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Position: FAV

EDITH J. PATTERSON, ED.D.
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THE MARYLAND HOUSE OF DELEGATES
ANNAPOLIS, MARYLAND 21401

Testimony in Support of HB 1188:
Public Health - Sickle Cell Disease

April 1, 2022

Dear Chairwoman Kelley, Vice-Chairman Feldman and Committee Members of Finance Committee:

Sickle Cell Disease (SCD) is one of the world's foremost potentially lethal, genetic diseases, that has severe physical, psychological and social consequences for those affected and their families. SCD can be treated but not easily cured, so lifelong care to prevent or treat problems from SCD is critical. Data show it occurs among approximately 1 out of every 767 births in Maryland and 1 out of every 256 African American births in Maryland. The estimated number of patients in MD include: 2880 adults and 1920 pediatrics with a total of 4800.

House Bill 1188 - Public Health - Sickle Cell Disease (SCD) is a compilation of ideas presented in four Sickle Cell bills – HB1188, HB1170, HB1176 and HB1192. The bill asks the Maryland Department of Health (MDH) to:

- establish and implement a system of providing information on the sickle cell trait or the thalassemia trait to individuals diagnosed with those traits;
- requires MDH to enhance access to online resources and community events for individuals with SCD as well as health care practitioners;
- study and make recommendations on the idea of a registry;
- enhance services for individuals transitioning from pediatric to adult care;
- and, identify a timeline for the submission of the report and recommendations.

All of the stakeholders worked carefully to ensure that HB1188 is a strong bill that will increase awareness, provide critical resources and bolster our abilities to advocate for Sickle Cell services.

I am seeking favorable report for this proposed legislation.

Sincerely,

Edith Patterson

HB1188_MDHSickleCellInfo_KennedyKrieger_Support_SE
Uploaded by: Emily Arneson
Position: FAV

Kennedy Krieger Institute

DATE: **March 31, 2022** **COMMITTEE: Senate Finance**
BILL NO: **House Bill 1188**
BILL TITLE: **Public Health - Sickle Cell Disease and Trait - Information for Individuals and Health Care Practitioners**
POSITION: **Support**

Kennedy Krieger Institute supports House Bill 1188 - Public Health - Sickle Cell Disease and Trait - Information for Individuals and Health Care Practitioners.

Bill Summary:
House Bill 1188 requires the Maryland Department of Health (MDH) to establish and implement a system of providing information on the sickle cell trait or the thalassemia trait to the parent or guardian of an infant who is found to have the trait as determined through a newborn screening. MDH will also maintain on its website a list of resources for healthcare practitioners to use to improve their understanding and clinical treatment of individuals with sickle cell disease, or the sickle cell trait.

Background:
Kennedy Krieger Institute is dedicated to improving the lives of children and young adults with developmental, behavioral, cognitive and physical challenges. Kennedy Krieger's services include inpatient, outpatient, school-based and community-based programs. Over 25,000 individuals receive services annually at Kennedy Krieger.

The Kennedy Krieger Institute Sickle Cell Neurodevelopmental Clinic provides neurological, developmental, neuropsychological, and behavioral psychology services in a comprehensive, multi-disciplinary outpatient clinic. We also see the siblings of these children who have neurodevelopmental disorders, many of whom have sickle cell trait, both in the Sickle Cell Neurodevelopmental Clinic and other Kennedy Krieger outpatient clinics.

Rationale:
While identification of sickle cell disease is part of the newborn screen testing, people with sickle cell trait may not reliably know their trait status. Per the CDC, sickle cell trait is present in 1 out of 60 babies in the US, and disproportionately affects Black babies for whom it is present in 1 out of 13.[1] Specific information on Maryland sickle cell trait numbers is not available; a recent study noted a frequency of 9.8% of individuals with sickle cell trait in metropolitan Washington D.C.[2] While sickle cell trait can protect affected individuals from infection with malaria, this population can also have severe complications including exercise-related rhabdomyolysis and sudden death, renal complications like hematuria, renal papillary necrosis, hyposthenuria, renal medullary cancer, and venous thromboembolism.[3,4,5,6] Awareness about the risks associated with sickle cell trait would empower people to seek information regarding their own trait status, medical risk, and preventative healthcare needs.

In addition, awareness of sickle cell trait status along with genetic counseling will allow individuals to carefully weigh their reproductive decisions with regards to their risk of having a child with sickle cell trait as well as sickle cell disease. Genetic counseling may be particularly helpful for families with no prior knowledge of sickle cell trait or sickle cell disease and may also inform them regarding future consideration of prenatal genetic testing.[7,8] Given the high rates of sickle cell trait, increased public awareness of these issues can allow families to better prepare themselves, emotionally, physically, and financially for these considerations.

Kennedy Krieger Institute requests a favorable report on House Bill 1188.

References

[1] https://www.cdc.gov/ncbddd/sicklecell/data.html
[2] Niu X, Parry CS, Mason A, et al. Prevalence of Sickle Cell Trait and Rare Hemoglobin Variants in the Metropolitan Washington DC Area. J Hematol. 2020;9(3):93-95. doi:10.14740/jh603
[3] Naik RP, Haywood C Jr. Sickle cell trait diagnosis: clinical and social implications. Hematology Am Soc Hematol Educ Program. 2015;2015(1):160-7.
[4] Tsaras G, Owusu-Ansah A, Boateng FO, Amoateng-Adjepong Y. Complications associated with sickle cell trait: a brief narrative review. Am J Med. 2009 Jun;122(6):507-12.
[5] Pecker LH, Naik RP. The current state of sickle cell trait: implications for reproductive and genetic counseling. Blood. 2018 Nov 29;132(22):2331-2338.
[6] Liem RI. Balancing exercise risk and benefits: lessons learned from sickle cell trait and sickle cell anemia. Hematology Am Soc Hematol Educ Program. 2018 Nov 30;2018(1):418-425.
[7] Grossman LK, Holtzman NA, Charney E, Schwartz AD. Neonatal screening and genetic counseling for sickle cell trait. Am J Dis Child. 1985 Mar;139(3):241-4.
[8]Stevens EM, Patterson CA, Tchume-Johnson T, Antiel RM, Flake A, Smith-Whitley K, Barakat LP. Parental Attitudes Towards Prenatal Genetic Testing For Sickle Cell Disease. J Pediatr Hematol Oncol. 2019 Nov;41(8):579-585.

HB1188 - Senate_FAV_MedChi, MDAAP_PH - Sickle Cell

Uploaded by: Pam Kasemeyer

Position: FAV

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Maryland Chapter
American Academy of Pediatrics
Speaking for Maryland Kids!

TO: The Honorable Delores G. Kelley, Chair
Members, Senate Finance Committee
The Honorable Edith J. Patterson

FROM: Pamela Metz Kasemeyer
J. Steven Wise
Danna L. Kauffman
Christine K. Krone

DATE: March 31, 2022

RE: **SUPPORT** – House Bill 1188 – *Public Health – Sickle Cell Disease*

On behalf of the Maryland State Medical Society and the Maryland Chapter of the American Academy of Pediatrics, we submit this letter of **support** for House Bill 1188 as amended.

House Bill 1188 requires the Maryland Department of Health (MDH), in consultation with the Statewide Committee on Sickle Cell Disease to establish and implement a system of providing information on the sickle cell trait or thalassemia trait to individuals diagnosed with the sickle cell trait or the thalassemia trait or an individual's family if the individual is a minor. It also requires MDH to maintain on its website a list of resources for health care practitioners to use to improve their understanding and clinical treatment of individuals with sickle cell or the sickle cell trait.

As amended House Bill 1188 also requires the Statewide Committee on Sickle Cell Disease, in conjunction with MDH and other relevant stakeholders, to study and make recommendations by December 1, 2022 on a number of avenues to enhance sickle cell trait and disease awareness as well as improve access to necessary medical services including:

- How to enhance access to services for individuals with a focus on areas of the State where there is a statistically high number of individuals with sickle cell disease and areas where there is a lack of providers with expertise in treating sickle cell disease;
- Whether to establish a sickle cell disease registry, and if recommended the process and guidelines for establishing a registry; obtaining information, connecting with the State designated exchange; and protecting data privacy;
- How to enhance the coordination of health care services for individuals with sickle cell disease who are transitioning from pediatric to adult health care in the State including the identification of available resources for individuals who are transitioning; and

- How to engage with community-based health fairs and other community sponsored events in areas with statistically high number of individuals with sickle cell disease to provide outreach and education on living with sickle cell disease and how to access health care services.

MedChi and MDAAP recognize the ongoing challenges in addressing health outcomes among people with the sickle cell trait and sickle cell disease. As noted in testimony on Senate Bill 859, which was passed by this Committee, the development of a registry has merit. However, MedChi and MDAAP believe the structure reflected in House Bill 1188 will ensure a better product if the development of a registry is recommended after further evaluation by the Statewide Committee on Sickle Cell Disease. MedChi and MDAAP strongly urge a favorable report on House Bill 1188 as amended.

For more information call:
Pamela Metz Kasemeyer
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SCCM Testimony - SB 1188.pdf
Uploaded by: Teanika Hoffman
Position: FAV

WRITTEN TESTIMONY ON SENATE BILL 1188

Testimony offered on behalf of: Sickle Cell Coalition of Maryland in support of SENATE BILL 1188

March 31, 2022

RE: Services to Treat and Educate Marylanders with Sickle Cell Disease

Dear Senate Finance Committee Chair;

On behalf of the southern Maryland sickle cell population, their families, and the Sickle Cell Coalition of Maryland, we respectfully ask the members of the Maryland State Assembly to vote favorably on bill SB 1188. If bill SB 1188 passes it would mean SCD warriors such as myself would be afforded the necessary services and resources to live a healthy life. The narrative of the SCD Warrior is often one of despair and silence, nationally and in our great state of Maryland. However, the approval of Bill SB 1188 could begin a change in the narrative; we can begin to chip away at the stigmatization that constantly remains loud and unabated in the community.

Maryland sickle cell warriors like myself have access to little or no hematologists in our home counties. The resources available to support treatment of care inpatient and outpatient, are often limited to scarce. In addition to the minimum assistance available for SCD warriors, social health determinants are aggravated. It is very unfortunate because the sickle cell disease population in Maryland is one of the highest SCD populations in the nation with few resources compared to other states.

Sickle cell disease is a debilitating blood disorder that devastates the body and places a massive financial burden on the state coffers and patients' wallets. A favorable vote for bill SB 1188 would help lessen the financial burden on the state approving preventive protocols to be implemented for the betterment of young SCD warriors. For example, a simple Transcranial Doppler (TCD) scan, when done yearly, can identify children who are at risk for stroke. When a child with SCD suffers a stroke, it can cost the system $80,000 a year; the requirement for this scan could 1. save a life and 2. save money.

Furthermore, the education of the Maryland population on the dangers of SCD through community health fairs and a Sickle Cell Awareness Month, would help to

begin to educate the population on SCD where the knowledge barrier is great. Currently, Marylanders have little to no access to relatable information on the disease and the trait. I believe our state can help warn the population through community education on the dangers of inheriting such a disease. I write to ask for you to vote favorably to change the reality of misinformation that runs rampant through our communities.

We are in the age of the CRISPR Cure for SCD and the creation of the first two sickle cell medications, SCD since the year 1910, sickle cell awareness is finally entering the mainstream and I believe our time is now! Your favorable vote for SB 1188 will help affirm sickle cell warriors, the community, and newly formed organizations like the Sickle Cell Coalition of Maryland in the fight to combat health disparities and change the needle and narrative for SCD warriors in our beautiful state.

We respectfully urge a favorable report.

Teanika Hoffman

Teanika Hoffman, MA
Executive Director
Sickle Cell Coalition of Maryland
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