

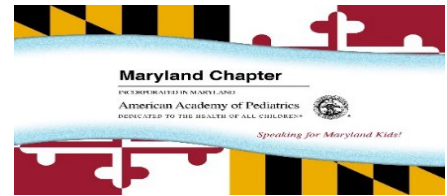


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TO: The Honorable Delores G. Kelley, Chair
Members, Senate Finance Committee
The Honorable Edith J. Patterson

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:

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