

Maryland Department of Health Rare Disease Advisory Council

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The Honorable Heather Bagnall, Chair
The Honorable Bonnie Cullison, Vice Chair
Maryland House of Delegates
Health Committee
120 Taylor House Office Building
Annapolis, Maryland 21401

Re: HB0178
Information

Dear Delegates Bagnall and Cullison and members of the Health Committee,

I am writing on behalf of the Maryland Rare Disease Advisory Council (RDAC) to provide information regarding House Bill 178. The RDAC is a legislated Governor's Advisory Council tasked with improving access to care and outcomes for people in Maryland living with Rare Disease. Sickle Cell Disease is a relatively common rare disease in Maryland. It, like many others, waxes and wanes with periods of good health and periods of severe pain and/or chest syndrome and an increased risk of strokes.

We support the essence of this legislation but recommend extensive revision to make its intent feasible in Maryland. First, while we are certain that background data on prevalence of sickle cell disease by county or region in Maryland exists, it is not shared here. We need that data to support the locations listed in the bill. Furthermore, MDH does not hire physicians or personnel to staff outreach clinics. This is generally accomplished by grants through the Maryland Department of Health. For example, grants to the UMMS and/or JHUSOM Hematology divisions could enable them to expand their services to additional locations by hiring advanced practice providers and sending attending hematologists and fellows to these outreach locations as part of their job and training, in addition to using telemedicine to provide outstanding remote care. The hub and spoke model is correct. This mechanism of its implementation is just not feasible.

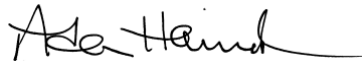
As to section 18-511, the council concurs with the need to incentivize sickle cell care, but direct payments in the form of stipends or grants cannot be made for residents (who are already receiving a salary). Instead, we recommend directly incentivizing this care by either supporting hematology fellowships with a focus on sickle cell or a loan repayment program (as the average medical student graduates with over \$200,000 in student loans).

We strongly support expanding access to state-of-the-art care for sickle cell disease. We recommend rewriting this bill for reconsideration.

Sincerely,

Council Coordinator

Lauren Whiteman, MPH,



Ada Hamosh, MD, MPH, Chair