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TESTIMONY IN SUPPORT OF HB 1176/SB 859 Sickle Cell Disease Registry

Dr. Sophie Lanzkron is Director of the Sickle Cell Center at Johns Hopkins and Co-Chairman of the Maryland Statewide Steering Committee on Services to Adults with Sickle Cell Disease. This Committee was established with statutory authority in October 2007. *See Health General Md. Ann. Code §18-507.* 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 by Governor Hogan. However, Dr. Lanzkron, would be quick to tell you there is no funding for the Committee to support any needed sickle cell outreach programs to expand the services to those suffering the devastating effects of Sickle Cell Disease or inform the public through testing and counseling upon a Sickle Cell Trait positive test.

There are few trained hematologists in Maryland that are well versed in the treatment of SCD and NONE in Harford and Cecil counties or the rural counties of the Eastern Shore. The Eastern Shore has more than double the population of SCD patients than Harford/Cecil combined, despite the overwhelming numbers of those individuals with positive Sickle Cell Trait tests.

SCD patients are forced to travel to Baltimore, Delaware, Washington, DC and Virginia for expert health care. A Sickle Cell Registry would provide the demographic information needed to identify where SCD health care providers are needed and the facilities in those areas that are required.

SCD is the root cause of catastrophic illnesses. Chronic Organ Damage with the related complications that may go unreported. SCD can affect the brain, eyes, heart, lungs, liver, gallbladder, spleen, kidneys, and bones. This is not an exhaustive list. There are fellow Marylanders that are suffering without the access to the knowledge and health care a Sickle Cell Registry would support to aid in determining where the needs are greatest and what needs cannot be met due to inadequate health care facilities.

PLEASE ENTER A FAVORABLE REPORT FOR HB 1176. The bill is also cross filed as SB859.